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Patient Reported Outcome (PROMs) and Experience Measures (PREMs) for Indigenous Peoples: A Literature Exploration

Shabnam Ziabakhsh
BC Women's Hospital + Health Centre, Canada, sziabakhsh@cw.bc.ca

Lori d'Agincourt-Canning
University of British Columbia, Canada, ldagincourt@telus.net

Soudabeh Joolaee
Fraser Health Authority, Canada, soudabeh.jolaei@fraserhealth.ca

Julia Hwang
University of British Columbia, Canada, jhwang@cmmt.ubc.ca

Elder Sharon Jinkerson-Brass
University of Saskatchewan, Canada, sharonbrass@gmail.com

Jenny Morgan
University of Victoria, Canada, jenny32@uvic.ca

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Patient Reported Outcome (PROMs) and Experience Measures (PREMs) for Indigenous Peoples: A Literature Exploration

Abstract

Documenting Indigenous patient voices through safe and culturally appropriate patient-reported outcome (PROMs) and experience measures (PREMs) is essential for monitoring impacts of health care programming and policies. We explored the literature in order to understand the current landscape of PROMs and PREMs that have been developed for and with Indigenous Peoples in Canada, United States, Australia and New Zealand. From our exploration a number of key themes regarding the development of PROMs and PREMs emerged including, applying a wholistic perspective, a relational framework with an emphasis on the role of the family, ensuring cultural fit (reflecting a resilience, strength-based and cultural approach to health), being sensitive to the ethics of survey tools, and ensuring decolonizing approaches in their development. In addition, the scarcity and the need for developing Indigenous-specific PREMs are highlighted.

Keywords

Indigenous healthcare, patient-reported outcome measures, patient-reported experience measures, cultural safety, measurement tools

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Engagement of patients and families is considered integral to improving health care delivery and patient-centered outcomes (Frampton et al., 2017). Patients offer critical perspectives based on their knowledge of living with a condition or illness, as well as their experiences with treatments and the health care system. As such, there is a long-standing shift in focus from biomedical disease-focused model of health towards patient-centered care that focuses on the patient voice in informing care delivery (Austin et al., 2020; Perfetto & Pomerantz, 2021). One way to document the patient voice is through patient-reported outcome (PROMs) and patient-reported experience measures (PREMs). PROMs and PREMs are standardized, validated survey instruments that measure patients' views of their health status and experience while receiving care, respectively. PROMs assess elements of patients' self-reported health, function, and quality of life, while PREMs measure quality of care by assessing patients' experience with care delivery (Kingsley & Patel, 2017). Information gathered from PROMs and PREMs have been used for a variety of reasons: To audit health care services (Devlin et al., 2010; Jensen, 2014); inform changes to clinical management, care planning, and shared decision making with patients (Damman et al., 2020; Santana et al., 2015); evaluate new service delivery and models of care (Fiedeldey-Van Dijk et al., 2017; McCalman et al., 2017); and assess health and quality of care services at the population level (Feng et al., 2015; Hadibhai et al., 2018). However, despite the value of PROMs and PREMs in helping organizations improve the health care delivery in a way that is meaningful to non-Indigenous patients and their families, these instruments have mainly fallen short in adequately documenting the voices of Indigenous Peoples, due to the prevalence of the dominant western colonial lens and the scarcity of culturally appropriate PROMs and PREMs.

Documenting patient voices is crucial when it comes to providing care and services to Indigenous patients and families. The enduring impact of colonization and racist policies within colonized societies such as Canada, United States, Australia, and New Zealand has systematically eroded the traditional ways of life for Indigenous Peoples across generations. Physical and cultural genocide, together with intergenerational trauma and grief, enacted a devastating toll on the wellbeing of individuals, their families, communities and the very fabric of their lands (Allan & Smylie, 2015; Dwyer et al., 2014; Mitchell & Maracle, 2005). Therefore, to understand whether current health care systems and structures meet the needs of Indigenous Peoples, it is pertinent to seek self-reported outcomes and experiences using culturally appropriate methods (Ryder et al., 2022; Smylie et al., 2006).

Although measuring outcomes and experiences through qualitative and Indigenous methods, such as gathering stories via sharing circles and yarning, has been successfully used in Indigenous communities, (Butten et al., 2021; Goodman et al., 2017; Kennedy, 2022; Lavalee, 2009; Ziabakhsh et al., 2016) there is still a need to measure voices in a more systematic way via patient-reported survey instruments (Hayward et al., 2021). An emergent yet limited body of studies using culturally-appropriate PROMs and PREMs within Indigenous health contexts have shown that these measures can provide evidence to support concerns in Indigenous communities, allow for feedback from a larger number of individuals in order to assess unmet needs, measure cultural or community-specific aspects of health, monitor care performance in meeting Indigenous needs, and address disparities between Indigenous and non-

Indigenous service provisions across time (BC Association of Aboriginal Friendship Centres [BACCAFC], 2010; Drawson, 2018; Elvidge et al., 2019; First Nations Information Governance Centre [FNIGC], 2018; Fiedeldey-Van Dijk et al., 2017; Kitching et al., 2020; O'Gorman et al., 2021;). PROMs and PREMs also allow analysis between components that impact wellbeing. For example, O'Gorman et al. (2021) recently examined the relationship between mental and physical health and water/sanitation infrastructure among First Nations communities in British Columbia using the Regional Health Survey.

In order for the health status of Indigenous Peoples in Canada (and internationally) to improve, there must be first an understanding of their health status and experience through accurate and culturally meaningful health assessment and experience measures (Aboriginal Health Policy Directorate, 2018, Fiedeldey-Van Dijk et al., 2017; Smylie et al., 2006). To ensure that self-reported outcome and experience measures are meaningful, safe, and culturally appropriate, it is crucial that they are developed using Indigenous lenses and knowledges. Culturally safe and appropriate self-reported measures can be achieved by consulting with Indigenous communities, grounding them in Indigenous knowledges, histories and experiences, resulting in measures that accurately reflect the aspects of health and experience that hold the most significance for Indigenous Peoples (d'Agincourt-Canning et al., 2024a; Angell et al., 2016; Canadian Institute of Health Research [CIHR], 2010; Smylie et al., 2006). These practices align with ethical research and engagement guidelines and recommendations concerning Indigenous Peoples (Australian Institute of Aboriginal and Torres Strait Islander Studies [AIATSIS], 2020; CIHR, 2010; Government of Canada, 2019)—namely recognition, respect and engagement with Indigenous people's worldviews, knowledges, and ways of being—and can be extended to the development of Indigenous-specific PROMs and PREMs. Furthermore, having meaningful and culturally appropriate PROMs and PREMs is in line with Indigenous Peoples' right to self-determination (AIATSIS, 2020; FNIGC, 2014), since it empowers them to define, measure and address their own health needs on their own terms.

However, the development of Indigenous-specific PROMs and PREMs is a relatively new field of study, with a limited number of survey instruments that have been developed or adapted for and with Indigenous Peoples. For example, Angell et al.'s (2016) systematic review of health-related quality-of-life (HRQoL) instruments used with Indigenous Peoples 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 in different studies (Aboriginal Health Policy Directorate, 2018; Green et al, 2018). This gap is due to the continued predominance of the Western colonial paradigm and perspectives that discount Indigenous worldviews and knowledges (Durey & Thompson, 2012; Hyett et al., 2018; Rieger et al., 2020). The prevalence of this approach has resulted in measurement tools that are mainly developed from a colonial Western lens and tailored-made for non-Indigenous patients and communities, in turn disregarding or failing to document the voices of Indigenous Peoples in health care.

An important first step in addressing this gap and moving forward with the development of meaningful and culturally safe PROMs and PREMs for and with Indigenous Peoples, is to review and analyze the research previously done. Our literature exploration is part of a larger study that aimed to develop a

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framework for supporting researchers, practitioners and other decision makers in the development of Indigenous-specific PROMs and PREMs (d'Agincourt-Canning et al., 2024a). The purpose of our exploration was three-fold: (1) to identify PROMS and PREMS that have been specifically developed or adapted for Indigenous Peoples; (2) to inform the guiding questions for qualitative interviews conducted in our larger study; and (3) to identify key themes and apply the knowledge gained to developing a framework for creating Indigenous-specific PREMs and PROMs. In this paper, we describe themes that emerged from the literature exploration – as well as gaps in the research - and their relevance for developing PROMS and PREMs with Indigenous Peoples.

Methods

We conducted a review of both published and grey literature in March 2020 to identify PROMs and PREMs that were developed or adapted for use with Indigenous Peoples. This search was updated in February 2024 using the same search strategy and processes. The identified PROMs and PREMs were mainly assessed on the integration of Indigenous lenses and knowledges in their development.

We attempted to take a decolonizing approach in our literature exploration (Rieger et al., 2020). Our work, which was part of the larger study (see d'Agincourt-Canning et al., 2024b), was grounded in Indigenous knowledges and practices. Here are some examples of the decolonizing research processes we undertook: We established an advisory committee, which included two Indigenous health care providers and planners, as well as two Indigenous patient representatives—the patient representatives were provided with honorariums as a sign of respect for their time and contribution; we had a project Elder and Elder-in-Training as research team members; we applied Indigenous lenses in defining concepts of health and wellbeing, which informed our inclusion/exclusion criteria in our exploration; we also identified information about governance and attribution of the survey instruments—in alignment with the First Nations principles of ownership, control, access and possession (OCAP) (FNIGC, 2014); and we engaged in collaborative interpretation and critical reflection of our study findings, often in a Talking circle format, with the presence of our Elder and Elder-in-Training, while incorporating ceremonial elements (e.g., opening and closing prayers).

Inclusion/Exclusion Criteria

The search included studies in peer-reviewed journals and grey literature published in English and Indigenous related websites—see Table 1 for inclusion criteria and search strategy. All Indigenous population related terms (e.g., Aboriginal, Native American, etc.) were used to search for studies on the study population. We also defined "health outcome" using a social determinant lens and consistent with how health/wellbeing is conceptualized in Indigenous cultures (Allen et al., 2019; Richmond et al., 2009; Smylie & Anderson, 2006;). As such, many studies related to survey instruments that at first glance may not have been viewed as PROMs (such as survey instruments that measure identity and cultural engagement) were included in the review.

Table 1: Inclusion Criteria and Search Strategy

Inclusion Criteria	1) Studies from Australia, Canada, New Zealand or the United States (CANZUS nations) – in English language; **AND** 2) Studies that included PROMs or PREMs that were developed for and with Indigenous Peoples or adapted (modified for use with Indigenous Peoples). The United Nations' (UN) definition of Indigenous Peoples was used to guide this review (https://www.un.org/development/desa/indigenouspeoples/about-us.html).
Search Concepts:	3) Indigenous/Aboriginal Population. The search terms included: Aboriginal, Indigenous, "First Nation" /," Torres Strait Island"/, Māori/, Inuit/Metis/, "Native American*", "American Indian*"/" Native Hawaiian"/" Thangata Whenua" **AND** 4) Patient Reported Outcome Measures/ Patient Reported Experience Measures. The search terms included: "Patient Reported Outcome Measures"/PROMs/ "Patient Reported Experience Measures"/PREMs/ Survey/ Instrument/ Scale/ Tool/ Questionnaire/ Measure/ Assessment / "Quality of Life"/ Satisfaction
Search sources:	A) **Electronic Databases search:** MEDLINE(OVID), CINAHL, Google- Google Scholar B) **Websites manually searched**: **Australia**: Indigenous Health Infonet; Australia Bureau of Statistics **Canada:** The National Collaborating Center for Aboriginal Health; First Nations Health Authority; Statistics Canada **New Zealand**: Māori Health **USA**: American Indian Health
Years of search:	Initial search: From inception to March 2020 Updated search: March 2020 to February 29, 2024.

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Our exploration 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 search terms were selected after reviewing the Medical Subject Headings (MeSH) from the US National Library of Medicine. Keywords were also identified by hand searching references in journals. This was essential, as some items of interest may not be indexed as subject terms in the MeSH. The "Indigenous Peoples" health sciences search filer was also used to retrieve studies on the University of Alberta (UA) library's website (Available at: https://guides.library.ualberta.ca/health-sciences-search-filters/indigenous-peoples).

The search results and their full texts were imported into the citation management software Zotero as well as Excel. All articles were reviewed by Shabnam Ziabakhsh and Soudabeh Joolaee. In the first round, the titles and abstracts were reviewed based on the eligibility criteria. In the second round, the full texts of the included articles were assessed to ensure relevancy based on criteria. Any inconsistencies in viewer assessment (in round one or two) were resolved through discussion and reaching consensus (see figure 1).

Data Abstraction and Analysis

Articles that met the inclusion criteria were examined by three reviewers, Shabnam Ziabakhsh, Soudabeh Joolaee, and Julia Hwang. Abstraction and analysis were done in an iterative fashion, with multiple rounds of assessment and re-assessment by the reviewers. Numerical analysis was conducted to describe the nature of studies. Descriptive information from the articles were analyzed using conventional content analysis to perform a narrative synthesis (Arksey & O'Malley, 2005).

An abstraction form was developed to document the following information from each study: Construct(s) measured; description of the survey instrument; target population; governance; application; Indigenous lenses/knowledges or theoretical framework applied to content development (the primary area of interest in this study); processes employed (including survey administration); along with information on psychometric properties. Information on governance considered whether Indigenous agencies or authors were involved in the development of PROMs/PREMs. This data was primarily sourced from the articles by examining the authors' affiliations and the acknowledgment section. When such information was absent in the articles, we searched the authors' biographies online.

Although psychometric properties were documented, wherever available, standardized assessment tools to evaluate the quality of PROMs and PREMs on these dimensions were not utilized. Given the scarcity of Indigenous-specific survey instruments and because this field is relatively new, it was deemed inappropriate to rank these surveys. Rather, the value of each study was seen as demonstrating possibilities and providing lessons on how to develop PROMs and PREMs with and for Indigenous Peoples. Key themes identified from our search were shared with our broader research team for discussion, informing our thinking and interpretations as presented herein. These feedback gathering sessions mainly occurred through Talking Circles (via Zoom meetings), where all members of the research team (including our Elder and Elder-in-Training) participated.

Findings

Our initial search in March 2020 resulted in 295 abstracts for review. An updated search in February 2024 added another 266 abstracts, bringing the total to 561 abstracts (see Figure 1). Once duplicates were removed, 535 unique abstracts remained for further assessment, and 201 were deemed relevant for full- text review. Ultimately, 81 articles/documents were included in this literature exploration, relating to 48 PROMs and PREMs, including 8 survey tools suggested by reviewers during the journal publication peer review process. The instruments and their summary are presented in Tables 2 to 6.

Among these PROMs and PREMs, 37 were developed specifically for Indigenous Peoples, and 11 were adapted (general self-reported PROMs/PREMs that were modified and validated). In total, 38 were PROMs and 9 were PREMs– including 4 survey instruments that had elements of both PROMs and PREMs (FNIGC, 2018; Garvey et al., 2012; Howard et al., 2024; Ingham et al., 2023).

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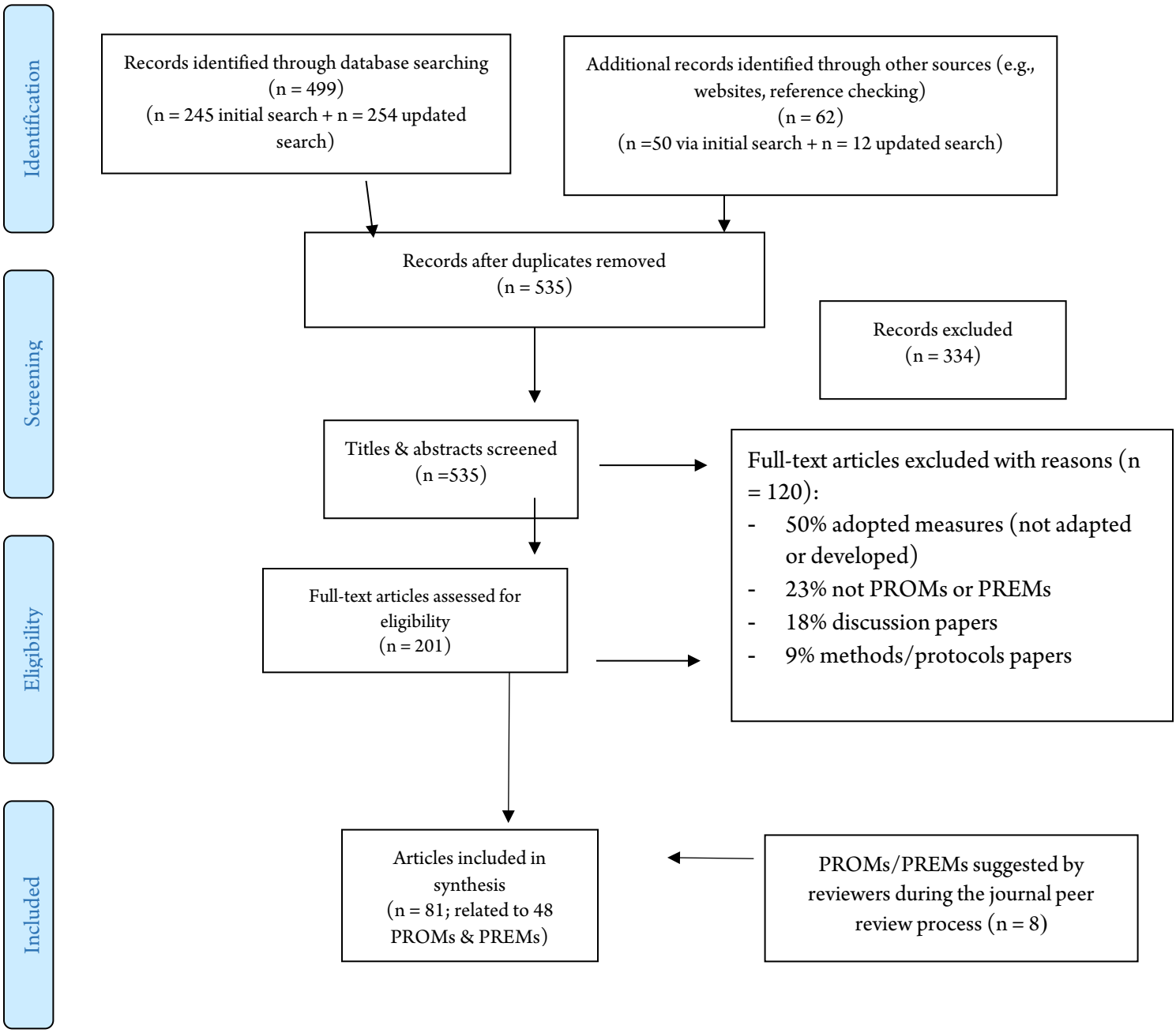
Figure 1: PRISMA Flow Diagram*



*Note: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097.

Target Population

Twenty four patient-reported survey instruments were developed or adapted for Aboriginal and Torres Strait Islanders in Australia (Australia Bureau of Statistics [ABS], 2002, 2018; Bourke et al., 2022; Brown et al., 2013, 2015; Bureau of Health Information, 2020; Butten et al., 2021; Cairney et al., 2017; De Maio et al., 2005; Elvidge et al., 2019; Gartland et al., 2021; Garvey et al., 2012; Gee et al., 2023; Gilchrist et al., 2023; Gould et al., 2014; Haswell et al., 2010; Howard et al., 2024; Kickett-Tucker et al., 2015; Langham et al., 2018; McCalman et al., 2017; Paradies & Cunningham, 2008; Schlesinger et al., 2007; Thomas et al., 2010; Westerman, 2003). Eleven PROMs/PREMs were developed or adapted for First Nations, Métis, and/or Inuit in Canada (Ayotee et al., 2024; BC Ministry of Health, 2020; Drawson, 2018; Fiedeldey-Van Dijik et al., 2017; FNIGC, 2018; Ford-Gilboe et al., 2018; Roach et al., 2023; Snowshoe et al., 2015; Statistics Canada, 2006; Worthington et al., 2010; Young et al., 2013). Another 11 PROMs/PREMs were developed or adapted for Native Americans in the United States (Allen et al., 2006, 2012, 2019; Fok et al., 2012; Gupchup et al., 2001; Kaholokula et al., 2008; Lowe, 2003; Mohatt et al., 2011; Peters et al., 2019; Venner et al., 2006; Winderowd et al., 2008). Two PROMs/PREMs were developed in New Zealand, for Māori and Pacific Islanders (Harwood et al., 2012; Ingham et al., 2023).

Twenty six PROMs/PREMs were developed or adapted for adults (ABS, 2002, 2018; Allen et al., 2006; BC Ministry of Health, 2020; Bourke et al., 2022; Brown et al., 2013, 2015; Bureau of Health Information, 2020; Elvidge et al., 2019; Fiedeldey-Van Dijk et al., 2017; FNIGC, 2018; Ford-Gilboe et al., 2018; Garvey et al., 2012; Gee et al., 2023; Gould et al.,2014; Gupchup et al., 2001; Harwood et al., 2012; Haswell et al., 2010; Howard et al., 2024; Ingham et al., 2023; Kaholokula et al., 2008; Paradies & Cunningham, 2008; Roach et al., 2023; Schlesinger et al., 2007; Venner et al., 2006; Winderowd et al., 2008). Another 22 of the PROMs/PREMs were developed or adapted for Indigenous children/youth (Allen et al., 2012, 2019; Butten et al., 2021; Cairney et al., 2017; De Maio et al., 2005; Drawson, 2018; FNIGC, 2018; Fok et al., 2012; Gartland et al., 2021; Kickett-Tucker et al., 2015; Langham et al., 2018; Lowe, 2003; Mohatt et al., 2011; Moran et al., 1999; Snowshoe et al., 2015; Statistics Canada, 2006; Thomas et al., 2010; Westerman, 2003; Worthington et al., 2010; Young et al., 2013). Six survey instruments were developed for both adults and youth (Allen et al., 2006, 2012; Ayottee et al., 2024; Cairney et al., 2017; FNIGC, 2018; Moran et al., 1999; Peters et al., 2019; Venner et al., 2006). Two PROMs were specifically developed for men (Brown et al., 2015; Lowe, 2003), and one was developed for older adults Gilchrist et al., 2023).

Governance

All of the non-population based PROMs and PREMs (n = 40) were developed with both Indigenous and non-Indigenous (general) agencies/institutions listed as the authors' affiliation and/or had Indigenous researchers listed as authors (Tables 2 to 6). Almost all of the population-based surveys (n = 7) were developed by general agencies/institutions in collaboration with Indigenous researchers or agencies (ABS, 2002, 2018; Ayottee et al., 2024; BC Ministry of Health, 2020; Bourke et al., 2022; Ingham et al., 2023; Statistics Canada, 2006), with the exception of the Regional Health Survey (FNIGC, 2018), the only national survey in Canada that was developed solely by Indigenous

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organization(s) and communities, fully under Indigenous control and in alignment with the First Nations principles of OCAP (FNIGC, 2014).

Processes of Survey Development

All of the PROMs and PREMs (n =48) were developed using collaborative approaches with involvement of community members as either co-researchers or consultants. For example, in developing the Yup'ik Protective Factor Scale, Alaska Natives joined the research project as co-researchers due to their rich knowledge of their culture and sobriety process (Allen et al. ,2006). They served on the research council, worked collaboratively alongside university researchers co-directing the project and took on roles such as research staff, field workers and cultural consultants and translators. In a number of the studies (n = 15) involvement of Elders was mentioned (Allen et al., 2012, 2019; Brown et al, 2013; Fiedeldey-Van Dijk et al., 2017; Fok et al., 2012; Gee et al., 2023; Gilchrist et al., 2023; Gould et al., 2014; Lowe, 2003; Peters et al., 2019; Roache et al., 2023; Snowshoe et al., 2015; Westerman, 2003; Worthington et al., 2010; Young et al., 2013). In some of the studies (n = 13) Advisory group members informed their work (ABS, 2018; Allen et al., 2006, 2012; Ayottee et al., 2024; Drawson, 2018; Gartland et al., 2021; Howard et al., 2024; Ingham et al., 2023; Langham et al., 2018; Oliver et al., 2009; Roach et al., 2023; Westerman, 2003; Worthington et al., 2010; Young et al., 2013). In a few instances (n =3) the development of PROMs/PREMs was driven by personal experiences of the authors/research team members (Mohatt et al., 2011; Paradies & Cunningham, 2008; Winderowd et al., 2008)– illustrating the very personal nature of doing research, and that research questions often begin with personal stories (McIvor, 2010). For example, the development of the Measure of Indigenous Racism Experience (Paradies & Cunningham, 2008) was partly driven by the first author's experiences of racism as an Indigenous Australian as well as self-reported racism of others in their community.

Constructs Measured

The most common constructs measured through these survey instruments were wholistic wellness and quality of life (n = 14) (Table 2), mental health, including protective factors and risk for alcohol/drug/tobacco use and suicide (n = 10) (see Table 3), and cultural identity and engagement (n = 9) (Table 4). Other constructs measured were related to self-reliance, empowerment, self-resilience or mastery (n = 7) (Table 5). Some measures solely focused on the experiences and needs of Indigenous Peoples in the health care system, by measuring cultural safety, racism and equitable and tailored access to health care (n = 8) (Table 6).

Table 2: Summary of PROMs Measuring Wholistic Wellness and Quality of Life

Author(s) & Instrument	Type & Construct Measured	Target Population	Governance* & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties** & Administration
Australian Bureau of Statistics, 2018 **National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) - 2018**	Population-based/ developed PROM: Health status with focus on health conditions, lifestyle factors, health service use, social and emotional wellbeing, and physical measurements	Australia: Aboriginal and Torres Strait Islander population	Governance: General agency; in collaboration with Indigenous researchers Application: To better understand the health and wellbeing of Aboriginal and Torres Strait Islander Peoples; To assist in improving services and health programs; To monitor health status across time and populations	- Social-determinant approach to health. Process: Collaborative process: Advisory guided the research; Extensive engagement with community members.	- List of topics covered in the survey is available at: https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4715.0Appendix62018%E2%80%9319 - Information on psychometric testing is not available Administration: Verbally administered (interview)
Ayottee et al., 2024 **Qanuilirpitaa? 2017 Nunavik Health Survey**	Population-based/ developed PROM: Wellbeing	Canada: Nunavik Inuit (Northern Quebec) youth and adults (16+)	Governance: Indigenous & general agencies Application: To monitor and update health services and inform policies and programming	- Social-determinant approach. Process: Participatory approach; Principles of Ownership, Control, Access and Possession (OCAP); Steering committee guided the research; Extensive community and expert consultation.	- List of topics covered in the survey is available at: https://numerique.banq.qc.ca/patrimoine/details/52327/4234697?docref=zKkf8Wxi5O7ug-Lgy3r_jw - √ Content and face validity Administration: Verbally administered (computer-assisted interview), or self-completion via paper survey

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Author(s) & Instrument	Type & Construct Measured	Target Population	Governance* & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties** & Administration
Butten et al., 2021 **Parent-Proxy Health-Related Quality of Life Survey**	Developed PROM: Quality of life	Australia: Aboriginal and Torres Strait Islander children (up to 12 years)	Governance: General agencies; includes Indigenous authorship Application: To monitor and assess patient outcomes	Process: Extensive consultation; Yarning circles used for item development.	- 21-item questionnaire - Structure: 3 factors: Quality of life; Patient experience; Patient support - √ Construct validity (via EFA) - √ Convergent validity - √ Test-retest reliability - √ Internal consistency: Acceptable to good Administration: Self-completed via paper or online survey
Cairney et al., 2017 **Interplay Survey**	Developed PROM: Wellbeing	Australia: Aboriginal and Torres Strait Islander people (aged 15-34)	Governance: General agencies; includes Indigenous authorship Application: To inform policy and practice	- Interplay Wellbeing framework: Wholistic and interconnected. - Strength-based approach. Process: Shared-space approach to working collaboratively; Involvement of a large number of Aboriginal community researchers; Extensive grass-roots community consultation.	- 40-item questionnaire - Structure: 12 subscales/factors: Importance of culture; Practice of culture; Culture in school; Aboriginal literacy; Empowerment; Community; Motivation for Education; English literacy and numeracy; Work; General health; Social and emotional wellbeing; Substances. - √ Construct validity (via EFA) - √ Content and face validity - Internal consistency: Good to excellent Administration: Verbally administered (interview)
Drawson, 2018 **First Nations Children Wellbeing**	Developed PROM:	Canada: First Nations children in the Robinson Superior Treaty	Governance: Indigenous & general agencies	- Importance of engagement in traditional activities and the role of culture.	- 51- item questionnaire - Structure: 3 subscale/factors: General well-being; Traditional activities; Social engagement

Author(s) & Instrument	Type & Construct Measured	Target Population	Governance* & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties** & Administration
Measure (FNCWM)	Wellbeing of First Nations Children	Area; Anishinabek children	Application: Assess wellness in Anishinabek children to determine when children are thriving or need additional supports	- Importance of relational wellbeing (as opposed to autonomy). - Balanced view: Medicine wheel as framework for wellbeing; Being unwell means being out of balance. - First Nations Mental Wellness Continuum Framework - Strength-based: Focused on stories of success when developing indicators of wellness. Process: Community-based participatory approach; Advisory Committee; Research driven by community needs.	- √ Construct validity (via PCA) - √ Content validity - √ Convergent validity - Internal consistency: Excellent to acceptable Administration: Unclear
FNIGC, 2018; Harvard Project on American Indian Economic Development, 2006 **Regional Health Survey (RHS)**- (with Adult, Youth and Child versions)	Population-based/ developed PROM and PREM: Health and wellness	Canada: First Nations and Inuit adults, children (0-11) and youth (12-17) living on reserves	Governance: Indigenous agencies Application: A national health survey conducted *by* & *for* First Nations, documents a snapshot of the health and wellness of First Nations peoples living on reserves across Canada	- Two-eye seeing: Embraced both western and traditional understanding of health. - RHS Cultural Framework: "Total health of the total person within the total environment". - The concept of "total person": Includes all dimensions of personhood including body, mind, heart and spirit. - "Total environment": "Healthy connection and relationship with the living environment (i.e., land, culture, community, family).	- Core questions plus region specific questions; Each year new themes/indicators are introduced - List of full indicators: https://fnigc.ca/sites/default/files/docs/fnigc_rhs_phase_3_national_report_vol_1_rev_july_2018.pdf. - √ Content and face validity - RHS has gone through an independent review by Harvard University in 2006 Administration: Self-completed or verbally administered (interview) via laptops

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Author(s) & Instrument	Type & Construct Measured	Target Population	Governance* & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties** & Administration
				Process: Indigenous led and participatory research process; Extensive community consultation.	
Gilchrist et al., 2023; Smith et al., 2021 **Good Sprit, Good Life Quality-of-Life tool**	Developed PROM: Quality of life	Australia: Older Aboriginal people (45+) living in Perth and Melbourne	Governance: Indigenous & general agencies Application: Identify and address quality of life needs of older Aboriginal people	- Wholistic lens: based on 12 factors that protect or enhance inner spirit: basic needs, family and friends, country, community, culture, health, respect, Elder role, support and services, safety and security, spirituality and future planning. Process: Participatory action research approach; Advisory Elders groups established; Extensive consultation; Yarning groups.	- 12-item questionnaire - Two versions self-rated and caregiver rated (as proxy) - Structure: 2 subscales: Foundation and external - √ Construct validity (via PCA and EFA) - √ Face and content validity - √ Convergent validity - √ Internal consistency: Acceptable Administration: Unclear
Gupchup et al., 2001 **Asthma-Specific Quality of Life Questionnaire for Native American Adults (AQLQ-NAA)**	Adapted PROM: Quality of life	United States: Native American adults in Albuquerque, New Mexico	Governance: Indigenous & general agencies Application: Measure patient outcomes in clinical settings	- AQLQ-NAA has more emphasis on social, community, and cultural activities. Process: Community engagement.	- 19- item questionnaire - Structure: -3 subscales/ factors: Community and social restrictions; Psychological impact; Symptoms - √ Construct validity (via PCA) - √ Content validity - √ Convergent validity - √ Internal consistency: Excellent to good Administration: Verbally administered (interview)
Harwood et al., 2012; Kingi & Durie, 2000; McClintock et al., 2011	Developed PROM: Wholistic Māori	New Zealand: Māori and Pacific People; Administered to	Governance: Indigenous & general agencies	Māori Mental Health Framework.	- 20- item questionnaire - Structure: 2 subscales/ factors: Physical-mental; Spiritual-family

Author(s) & Instrument	Type & Construct Measured	Target Population	Governance* & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties** & Administration
Hua Oranga (Fruits of Health)	and Pacific People wellness	patients, health care providers and family/care givers	Application: Determine improvements in physical, mental, spiritual, and family domains of health for Māoris with mental illness (McClintock, 2011) Validated for use with Māori and Pacific People with stroke (Harwood et al., 2012)	Wholistic Māori model/perspective of wellbeing (Whare tapawha), with four pillars: - Physical: Health is related to unseen and unspoken energies. - Mental: Mind and body are inseparable. - Physical: Good physical health is required for optimal development. - Family: Individuals are part of a larger social system. Process: Community-based with extensive engagement with community using Māori principles of engagement.	- √ Construct validity (via PCA) - √ Content validity - √ Convergent validity Administration: Verbally administered (interview)
Howard et al., 2024; 2020 **What Matters 2 Adults (WM2A) Wellbeing Measure**	Developed PROM & PREM: Wellbeing	Australia: Aboriginal and Torres Strait Islander adults	Governance: Indigenous & general agencies Application: Implement in routine patient reporting to improve patient outcomes.	- Wholistic conceptualization of wellbeing. - Grounded in culture. - Strength-based. Process: Collaborative approach; Indigenous project advisory group; Yarning circle methodology; Research team using reflexivity.	- 32 item questionnaire - Structure: 10 domains: Balance & Control; Hope; Resilience; Caring for others; Culture & country; Spirit & identity; Feeling valued; Connection with others; Access; Racism & worries; Pride & strength. - √ Content and face validity - √ Construct validity (via EFA, CFA and item response theory (IRT) Administration: Self completed via online survey
Ingham et al., 2023	Adapted Population-based PROM & PREM:	New Zealand: Māori adults	Governance: Indigenous & general agencies. Application:	- "Karanga rua, karanga maha" (multiple identities). - Strength-based approach.	- 153-item questionnaire - Structure: Domains Māori identity; Inclusion and discrimination; Health and

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Author(s) & Instrument	Type & Construct Measured	Target Population	Governance* & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties** & Administration
Māori Health, Wellbeing and Disability	Wellbeing and disability		Understand the impact of wellbeing and disability at the population level.	- Māori wholistic perspective on disability that is based on spiritual, collective and relational values. Process: Indigenous co-design; Māori steering group; Whakawhiti korero (traditional process of discussion and negotiation) was used.	wellbeing; Access to health services; Economics. - √ Content and face validity Administration: Self completed via online or mail survey, or verbally administered (via telephone interview)
Peters et al., 2019 **Wicozani Instrument**	Developed PROM: Overall health (Mental, physical and spiritual health)	United States: Dakota Wicohan native youth and adults	Governance: Indigenous & general agencies Application: Assess impact of programing	- Wholistic perspective. - Strength-based: focusing on strength, self-knowledge and overall health and wellbeing. Process: Collaborative research partnership; Community based participatory action research; Elder advisors; Focus on capacity building.	- 9-item questionnaire - Structure: Two subscales: Self-knowledge; Quality of life. - √ Face validity - √ Convergent and discriminant validity - √ Internal consistency: From acceptable to excellent. Administration: Self-completed via paper survey, with assistance provided if needed.
Statistics Canada, 2006; Oliver et al., 2009 **Aboriginal Children's Survey (ACS) – 2006**	Population-based/ developed PROM: Wellbeing: Measured via a wide range of topics	Canada: Aboriginal children under 6 years of age (First Nations children living off reserve, Métis children and Inuit children) living in urban, rural and northern regions throughout Canada	Governance: General agency - in collaboration with Indigenous researchers Application: To assess health, development and needs; To inform decision making and support academic research	- Wholistic conceptualization of health. Process: Collaborative approach; Advisory informed the process; Engagement with parents, frontline workers, child educators, researchers and Indigenous organizations.	- Questions cover: Child's health, sleep, nutrition, motor, social, and cognitive development, nurturing, childcare, school, language, behavior, and activities, and demographics and socioeconomic data - Includes the Strengths and Difficulties questionnaire (Goodman, 2001) - √ Content validity Administration: Verbally administered to parents/caregivers (interview)

Author(s) & Instrument	Type & Construct Measured	Target Population	Governance* & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties** & Administration
Young et al., 2013, 2015, 2016, 2017 **Aboriginal Children's Health and Well-being Measure, (ACHWM)**	Developed PROM: Wholistic health of Aboriginal children	Canada: Aboriginal Anishinaabek children/youth (8 to 18 years of age) in Northeastern Ontario	Governance: Indigenous & general agencies Application: Assess health of children and evaluate improvements over time; To assist in the planning and evaluation of health services	- Anishinaabek conceptualization of health: Medicine Wheel framework with domains of spiritual, emotional, physical and mental. - Full spectrum of health from wellness to illness/Anishinaabek view of balance. Process: Collaborative community-based; Aboriginal children involved in content creation; Elder involvement; Advisory group.	- 62 –item questionnaire (latest version) - √ Face and content validity - √ Convergent validity - √ Test-retest reliability - √ Internal consistency: Excellent Administration: Self-completed via tablet

* Governance = Agencies or institutions involved in the development of the survey tools—whether agencies were solely targeting Indigenous communities or patient groups or were they serving general populations (e.g., universities); Whether any Indigenous authors were listed—as identified in the article and/or by searching online biographies.
** Results on internal consistency (reliability) are reported based on Nunally (1978)'s Cronbach's coefficient alpha ranges of acceptability: $\alpha \geq 0.9$ = Excellent; $0.8 \leq \alpha < 0.9$ = Good; $0.7 \leq \alpha < 0.8$ = Acceptable; $0.6 \leq \alpha < 0.7$ = Questionable; $0.5 \leq \alpha < 0.6$ = Poor; $\alpha < 0.5$ = unacceptable

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Table 3: Summary of PROMs Measuring Mental Health, Suicide Risk, Substance and Tobacco Use

Author(s) & Instrument	Type & Construct Measured	Target Population	Governance & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties & Administration
ABS, 2002; Kowal et al., 2007 **Negative Life Events**	Population-based/ developed PROM: Stressful life events	Australia: Aboriginal and Torres Strait Islander population	Governance: General agencies in collaboration with Indigenous researchers Application: Assess and monitor social and emotional wellbeing in order to improve psychosocial determinants of health	- Social determinants of health. Process: Extensive community and expert consultation.	- 16- item questionnaire - √ Discriminant validity - Internal consistency: Good Administration: Unclear
Allen et al., 2006 **Yup'ik Protective Factor Scale** *Later adapted for Youth:* Allen et al., 2012 **Reflective Processes Scale** (RPS)	Developed PROM: Protective factors of sobriety (Adult scale) Awareness of the consequences of alcohol use (Youth scale)	United States: Alaska native - Yup'ik adults; later adapted for Yup'ik youth	Governance: Yup'ik Protective Factor Scale: General agencies; includes Indigenous authorship RPS: Indigenous & general agencies Application: Assessment of risk of alcohol use	- Ethical concerns over directly asking about alcohol use; Focus on protective factors; Focus on reflections on negative consequences of alcohol use. - Heuristic model of protective factors of sobriety; with elements of individual, family, community, social characteristics, and trauma. Process: Collaborative research process, had community members as co-researchers; translated survey into Yup'ik language; Research Advisory.	Yup'ik Protective Factor Scale: - 21-item-questionnaire - Structure: 4 subscales/ factors: Things I want for… (1) myself, (2) family, (3) body/wellbeing, (4) way of life - √ Construct validity (via FA) - √ Content validity - Internal consistency: Good to acceptable Reflective Processes Scale (adapted for youth): - 10-item questionnaire - Structure: 3 subscales/ factors: Things I want for… (1) myself, (2) family, (3) way of life

Author(s) & Instrument	Type & Construct Measured	Target Population	Governance & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties & Administration
					- √ Construct validity (via CFA) - √ Content and face validity - √ Convergent and discriminant validity Administration: Verbally administered (interview); provided honorarium
Allen et al., 2019 **Reasons for Life (RFL)** *Alternative Name: Yuuyaraqegtaa = A Way to Live a Very Good, Beautiful Life*	Adapted PROM: Culturally-based Protective factors from suicide risk; beliefs and experiences that contribute to making life enjoyable, worthwhile, and meaningful for youth as protective factors for suicide.	United States: Rural Alaska, Yup'ik Native Adolescents	Governance: Indigenous & general agencies Application: To assess outcomes from strengths-based, culturally grounded suicide prevention efforts – to address concerns regarding direct assessment of suicide risk (as direct assessment can be viewed as stigmatizing, triggering and traumatizing in at risk communities)	- Indigenous wellbeing frameworks. - Strength-based: Focus on strengths and positive attributes, rather than risks. - Culturally-based protective factors. - Trauma-informed. Process: Collaborative approach; engaged with Elders, youth and leaders.	- 11-item questionnaire (latest version) - Structure: 3 subscales/factors: Efficacy over life problems; Cultural and spiritual beliefs; Others assessment of me - √ Construct validity (via CFA) - √ Content & face validity - √ Convergent validity - Internal consistency: Acceptable Administration: Self-completed individually or in groups via online survey
Brown et al., 2013; Hackett et al., 2016; Getting it Right Collaborative Group, 2019 **Adapted Patient Health**	Adapted PROM: Depression	Australia: Aboriginal and Torres Strait Island men (Brown et al., 2013) Aboriginal and Torres Strait Island individuals	Governance: General agencies; includes Indigenous authorship Application: Screening tool for depression and assessing symptom severity; outcome assessment	- Cultural-specificity: Different cultural groups experience and express psychological distress differently. Process: Extensive community consultation; Elder involvement; Translated survey in Aboriginal languages.	- 9- item questionnaire - √ Content and Face validity - √ Criterion validity - Internal consistency: Good Administration: Self-completed via paper/online surveys, or verbally administered via telephone/in-person interviews

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Author(s) & Instrument	Type & Construct Measured	Target Population	Governance & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties & Administration
Questionnaire – 9 (aPHQ-9)		(men and women) (Hackett et al., 2019)			
Brown et al., 2015 **Men, Hearts & Mind (MHM) Psychosocial Questionnaire**	Developed PROM: Psychosocial stress and depression	Australia: Aboriginal and Torres Strait Islander Australian men	Governance: General agencies; includes Indigenous authorship Application: Screening tool in clinical practice and research	- Wholistic: Kurunpa (spirit) is seen as the foundation of vitality and central to physical, emotional and spiritual wellbeing. - Strength-based: Importance of community and family. Process: Multi-stage and iterative; extensive community consultation and pilot testing.	- 28-item questionnaire - Structure: 4 scales: Sense of injury; Chronic stress; Deprivation; Social support. - √ Construct validity (via EFA) - √ Content and face validity - √ Predictive validity - Internal consistency: Acceptable to good Administration: Unclear
De Maio et al., 2005; Zubrick et al., 2005; Blair et al., 2006 **Strengths and Difficulties Questionnaire (SDQ)** (Adapted in Australia as part of the Western Australian Aboriginal Child Health Survey (WAACHS)	Adapted PROM: Mental health - strengths and difficulties over the last 6 months	Australia: Aboriginal children between 4-17 years of age in urban New South Wales (Williamson et al., 2014) and Western Australia (WAACHS-Youth)	Governance: Indigenous & general agencies Application: To assess psychological adjustments of children and youth; screening tool in medical practice and research; to assess treatment outcomes	Content: Not reported. Process: Community engagement.	- 25-item questionnaire; focusing on strengths (10 items) and difficulties (15 items) - Structure: 5 subscales/ factors: Emotional symptom; Conduct problems; Hyperactivity; Peer problems; Pro-social skills – variability seen for the Peer-problems subscale - √ Construct validity (via CFA) - √ Content and face validity - √ Convergent validity - Internal consistency: Good, with the exception of Peer problems subscale; reliability

Author(s) & Instrument	Type & Construct Measured	Target Population	Governance & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties & Administration
					declines as the child resides in more remote locality Administration: Verbally administered (interview)
Gould et al., 2014) **Smoking Risk Assessment Target (SRAT)**	Adapted PROM: Assessment of tobacco smoking risks	Australia: Aboriginal and Torres Strait Islanders	Governance: General agencies; includes Indigenous authorship Application: Assess the risk of tobacco smoking	Content: Not reported. Process: Community consultation, inclusion of Elder.	- 7-item questionnaire - √ Face and content validity Administration: Verbally administered (interview)
Schlesinger et al., 2007 **Indigenous Risk Impact Screen (IRIS)**	Developed PROM: Presence of alcohol, drug and mental health risks	Australia: Aboriginal or Torres Strait Islander background; both patient and non-patient groups	Governance: General agencies; includes Indigenous authorship Application: Screening tool for determining the presence of alcohol, drug and mental health risks	Content: Not reported. Process: Research driven by identified needs in the community; Consultation with community members.	- 13-item questionnaire - Structure: 2 sub scales/ factors: Alcohol/drugs; Mental health - √ Construct validity (via EFA) - √ Content and face validity - √ Convergent validity - Internal consistency: Good Administration: Verbally administered (interview); honorarium provided
Thomas et al., 2010 **Strong Souls**	Developed PROM: Social and emotional wellbeing in Indigenous youths	Australia: Indigenous Youth (ages 16-20) from rural and urban Northern regions	Governance: General agencies; includes Indigenous authorship Application: Screening tool to assess wellness; potential to be used as health outcome measure	- Wholistic: Health is defined in terms of the physical, emotional, cultural and spiritual wellbeing, not only for the individual but also of the whole community. - Indigenous perspectives of mental health, which include being in harmony with country, lawfulness, and social and kinship relationships.	- 25-item questionnaire - Structure: 4 subscales/ factors: Anxiety; Resilience; Depression; Suicide risk - √ Construct validity (via EFA) - √ Face validity - Internal consistency: Acceptable Administration: Verbally administered (interview)

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Author(s) & Instrument	Type & Construct Measured	Target Population	Governance & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties & Administration
				Process: Extensive engagement with community members.	
Westerman, 2003 **Westerman Aboriginal Symptom Checklist- Youth (WASC-Y)**	Developed PROM: Mental health: Depression, suicidal behaviour, alcohol/drug use, impulsivity, anxiety, and cultural resilience	Australia: Western Australia (rural and urban regions) Aboriginal youth (13- 17 years)	Governance: General agency; includes Indigenous authorship Application: Use in clinical practice as part of mental health assessment	- Wholistic lens. - Resilience approach – focus on protective factors. Process: Extensive consultation with communities and Elders; Steering committee; Developed a model for culturally safe consultation process.	- 53-item scale - Structure: sub-scales: Depression; Suicidal behaviours; Alcohol and drug usage; Impulsivity; Anxiety; Cultural resilience - √ Construct validity (via EFA) - √ Content validity - √ Internal consistency: Acceptable to good Administration: Self-completed individually or in groups via paper survey or verbally administered (interview)

Table 4: Summary of PROMs Measuring Cultural Identity and Engagement

Author(s) & Instrument	Type & Construct Measured	Target Population	Governance & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties & Administration
Allen et al., 2012; Fok et al., 2012 **Alaska Native Cultural Identification (ANCI)**	Adapted PROM: Cultural identification; Bicultural identification	United States: Rural Alaska Yup'ik Native youth	Governance: Indigenous & general agencies Application: To assess culture as protective factor in health promoting behaviour	- Culture as protective factor. - Orthogonal Cultural Identification Theory: Identification with one culture is separate from one's identification with another culture. Process: Collaborative approach; Elder involvement; Community engagement.	- 8-item questionnaire - Structure: 2 subscales/ factors: Alaska Native cultural identification; White American cultural identification - √ Construct validity (via CFA) - √ Content and face validity - √ Internal consistency: Acceptable, but questionable for the White American cultural identification subscale Administration: Self-completed via online survey; Honorarium provided
Bourke et al., 2022 **Mayi Kuwayu, the National Study of Aboriginal and Torres Strait Islander Wellbeing**	Population-based/ Developed PROM: Wellbeing through culture	Australia: Aboriginal and Torres Strait Islanders adults	Governance: Indigenous & general agencies Application: Monitoring trends and evaluation	- Importance of culture in wellbeing. - Resilience lens. Process: Collaborative approach; Extensive community consultation.	- 41-item questionnaire - Structure: six cultural domains: Connection to country; Beliefs and knowledge; Language; Family, kinship and community; Cultural expression and continuity; Self-determination and leadership - √ Content and face validity Administration: Self completed via online survey, or verbally administered (interview)
Fiedeldey-Van Dijk et al., 2017 **Native Wellness Assessment (NWA)**	Developed PROM: Culturally-embedded wellness	Canada: Indigenous peoples (First Nations, Métis, and Inuit) in	Governance: Indigenous & general agencies Application: To assess the effectives of culture-as-	- Culture is protective and vital for healing. - Medicine Wheel/wholistic approach to wellness: Native wellness was defined as enablement	- NWA includes: 66- cultural statements plus 39 cultural intervention practices (CIP) - NWA has two versions: Self-report form (S version) and a

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		treatment centers for addiction	intervention, among those in alcohol and drug treatment programs	of individuals and communities to actualize their potential emotionally, spiritually, mentally and physically. - Strength-based: Resilience perspective on alcohol and drug addiction (not just focus on risks, disease and socioeconomic problems). Process: Two-eye seeing approach; Elder involvement; Engagement with community to understand success stories (strength-based).	parallel observer form (O version) - Structure: One scale/ factor– "wellness" - √ Construct validity (via PCA) - √ Content and face validity - √ Convergent validity - √ Predictive validity - √ Internal consistency: Acceptable for S-version and good for the O-version Administration: Self /observer completed via paper surveys
Kaholokula et al., 2008; Antonio et al., 2020 **Native Hawaiian Cultural Identity Scale (NHCIS)**	Developed PROM: Cultural identity	United States: Native Hawaiians adults	Governance: Indigenous & general agencies Application: Outcome measure	Not reported.	- 4-item questionnaire - Structure: One scale/ "cultural identity" - √ Convergent and discriminant validity Administration: Self completed via mail survey; Honorarium provided (Antonio et al., 2020)
Kickett-Tucker et al., 2015 **Racial Identity & Self-Esteem Inventory (IRISE-C)**	Developed PROM: Racial identity and self-esteem	Australia: Urban and rural Aboriginal children (8-12 yrs)	Governance: Indigenous & general agencies Application: Screening tool and outcome measure in research.	- Culture-strength-based lens: Culture being protective factor. - Collectivism: Focus on community and family. Process: Community consultation; Involvement of Aboriginal community-based research assistants; Local Aboriginal protocols were employed.	- 40-item questionnaire - Structure: 2 scales: Knowledge of Aboriginal culture; Knowledge of racial/cultural identity - √ Construct validity (via EFA) - √ Face and content validity - √ Construct validity - √ Internal consistency: Good Administration: Verbally administered (interview)

Mohatt et al., 2011 **Awareness of Connectedness Scale (ACS)**	Developed PROM: Awareness of connectedness	United States: Alaska Native (mainly Yup'ik) Youth	Governance: Indigenous & general agencies Application: Outcome measure for behavioral health programs	- Connectedness: Interrelated welfare of the individual, one's family, one's community and one's natural environment – "all of my relatives". - Wholistic: "Life-world". - Medicine wheel: Balance between the domains of wellbeing. - Strength-based: Focus on sobriety, wellness and resilience. - Connectedness: Culturally-based protective factor against substance abuse and suicide. Process: Personal experiences drove work; Community consultation.	- 12-item questionnaire (final version) - Structure: 4 subscales/ factors: Individual; Family; Community; Natural Environment - √ Construct validity (via CFA) - √ Convergent validity - √ Internal consistency: Good for overall scale; Good to poor for subscales Administration: Self-completed in small groups via online survey; Honorarium provided
Snowshoe et al., 2015 **Cultural Connectedness Scale (CCS)**	Developed PROM: Cultural Connectedness: The extent to which an Indigenous youth is integrated within their culture	Canada: First Nations, Métis and Inuit youth (grades 8 to 12) from urban and rural Saskatchewan and Southwestern Ontario	Governance: Indigenous & general agencies Application: Assess the impact of cultural preservation programming	- Strength-based approach: Culture as having protective factors. - Resilience framework: Natural human capacity to live life well. Process: Community-based collaboration and engagement with youth and cultural experts/Elders.	- 29-item questionnaire - Structure: 3 subscales/ factors: Cultural Identity; Traditions; Spirituality - √ Construct validity (via EFA/CFA) - √ Content and face validity - √ Predictive validity - √ Internal consistency: Good to acceptable Administration: Unclear
Venner et al., 2006 **Orthogonal Cultural Identification Scale (OCIS)** (Validated for adults) Moran et al., 1999	Adapted PROM: Strength of one's identification with each cultural way of life—American Indian identity and White identity	United States: American Mission Indian adults (Venner et al., 2006); and American Indian youth between ages 14 to 19 years representing	Governance: General agencies; includes Indigenous authorship Application: Asses the impact of cultural interventions that promote psychological wellbeing	- The Orthogonal Cultural Identification: Identification with one culture is separate from one's identification with another culture. - Culture as protective factor: Strong identification with one or more Indian cultural groups serve as protective factors for a	Adult scale (Vernner et al., 2006): - 12-item questionnaire - Structure: 2 subscales/ factors: Native American identification; Anglo identification - √ Construct validity (via CFA) - √ Convergent validity

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Bicultural Ethnic Identity Scale (Adapted for youth)		cultural groups from the South-Central, Northern Plains, and two distinct areas of the Southwestern United States (Moran et al., 1999)		host of undesirable outcomes, such as addiction. Process: Community engagement.	- √ Discriminant validity - √ Internal consistency: Excellent to good Youth Scale (Moran et al., 1999): - 16-item questionnaire - Structure: 2 subscales/ factors: Native American identification; Anglo identification - √ Construct validity (via EFA and CFA) - √ Content and face validity - √ Internal consistency: Excellent Administration: Self-completed via paper survey; Honorarium provided
Winderowd et al., 2008 **American Indian Enculturation Scale (AIES)**	Developed PROM: Enculturation: Process by which one learns about and identifies with one's cultural roots particularly tribal activities and spiritual practices	United States: American Indians from Oklahoma and Southwestern tribes; both patient and non-patient groups	Governance*:* General agencies; includes Indigenous authorship Application: Used in counseling practice to assess the enculturation of American Indian (AI) people; To assess cultural engagement in community	- Wholism: Relates to harmony, balance, connectedness, and wellness. - Traditional ways of knowing and being (culture) have protective factors and promotes resilience. Process: Personal experiences drove work; Extensive community consultation.	- 17- item questionnaire - Structure: 1 scale/factor - √ Construct validity (via CPA) - √ Content validity - √ Convergent and discriminant validity - √ Internal consistency: Excellent Administration: Unclear

Table 5: Summary of PROMs Measuring Resilience and Empowerment

Author(s) & Instrument	Type & Construct Measured	Target Population	Governance & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties & Administration
Fok et al., 2012 **Multicultural Mastery Scale (MMS) for Youth**	Adapted PROM: Mastery: Problem-focused coping styles	United States: 12 to 18-year-old predominately Yup'ik Eskimo Alaska Native adolescents	Governance: Indigenous & general agencies Application: To assess youth coping, resiliency and health outcomes	- Collectivism, in contrast to mainstream western individualistic orientations. - Belief that one can overcome stress by tapping the social/family/friends resources. - Interconnectedness and expanded sense of self-resilience focused. Process: Collaborative process with extensive community engagement; Involvement of Elders.	- 13-item questionnaire (final version) - Structure: 3 sub-scales/ factors: Mastery-Friends; Mastery-Family; Mastery-Self - √ Construct validity (via CFA) - √ Content and face validity - √ Convergent and discriminant validity - √ Internal consistency: Acceptable Administration: Self-completed via online survey in small groups
Gartland et al., 2021; 2022; **Resilience Questionnaire-Child (CRQ-C)**	Developed PROM: Resilience	Australia: Aboriginal children aged 7-12 years	Governance: Indigenous & general agencies Application: Assessment, program evaluation and research	- Ecological-transactional model of resilience: Child is at the center, surrounded by their family, community and social factors. Process: Participatory research methods; Extensive consultation with community members and experts; Aboriginal working group established.	- 104- item questionnaire - Structure: 10 scales and 4 domains: Individual; family; school; and community - √ Construct validity (via CFA) - √ Face and content validity - Convergent validity moderately supported - √ Internal consistency: Acceptable to good Administration: Verbally administered (interview) with visual aid (response options were measured by a pictogram of glass empty or full), or self-completed via iPad

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Gee et al., 2023 **Aboriginal Resilience and Recovery Questionnaire (ARRQ)**	Developed PROM: Resilience	Australia: Urban Aboriginals (Victoria) adults	Governance: Indigenous & general agencies Application: Investigate resilience, healing and recovery of patients from trauma in family counselling services	- Protective effects of cultural determinants of wellbeing; resilience is contextual and shaped by culture. - Socioecological model – whole-system approach to understanding resilience. Process: Extensive consultation with community members and providers; Elder involvement; Study grounded in Indigenous research methodology.	- 60-item questionnaire - Structure: 2 components (personal strength; relational-community-cultural strengths - √ Construct validity (PCA) - √ Convergent and discriminant validity - √ Internal consistency: Adequate Administration: Verbally administered (interview)
Haswell et al., 2010 **Growth + Empowerment Measure (GME)**	Developed PROM: Emotional and functional aspects of Empowerment	Australia: Aboriginal, Torres Strait Islander	Governance: Indigenous & general agencies Application: To measure outcomes of a family wellness workshop	- Wholistic: Measure from the individual family, organization and structural levels. - Adoption of "tree" as a metaphor for growth and empowerment. - Strength-based. Process: Community-based; Extensive community consultation.	GME consists of two measures: 1. 14-item Emotional Empowerment Scale (EES-14): - Structure: 2 subscales/ factors: Inner Peace; Self-Capacity 2. 12-item Empowerment Scenarios (12S): - Structure: 2 subscales/ factors: Healing; Connection - √ Construct validity (via EFA) - √ Content validity - √ Convergent validity - √ Internal consistency: Good Administration: Unclear
Langham et al., 2018 **Child and Youth Resilience Measure (CYRM-28)**	Adapted PROM: Youth resilience	Australia: Indigenous youth/ secondary students	Governance: Indigenous & general agencies Application: Assess the resilience of Indigenous youth out of home care settings	- Strength-based. Process: Six-phase participatory action research process; Establishment of a community advisory committee.	- 28-item questionnaire - Structure: 2 subscales/ factors: Sources of resilience; Expression of resilience - √ Construct validity (via CFA) - √ Face and content validity - √ Internal consistency: Good Administration: Self-completed via iPads individually or in groups

Lowe, 2003, 2008; Lowe et al., 2009 **Cherokee Self-Reliance Questionnaire**	Developed PROM: Self-reliance	United States: Cherokee adolescents (developed for males, but used on females in other studies)	Governance: General agencies; includes Indigenous authorship Application: Assess impact of interventions	- Cherokee's concept of self-reliance: Wholistic worldview where all things are believed to come together to form a whole. - Self-reliance as mainstay and way of life to keep Cherokees in balance. - Cultural themes of being true to oneself and being connected cut across all three qualities of self-reliance (being responsible, being disciplined and being confident). Process: Community engagement; Elder involvement in research.	- 24-item questionnaire - Structure: 3 subscales/ factors: Being responsible; Being disciplined; Being confident - √ Construct validity (via FA) - √ Content validity - √ Internal consistency: Good Administration: Self-completed via paper survey
McCalman et al., 2017 **Transition Support Service Student Survey (T4S)**	Developed PROM: Resilience and risk for self-harm	Australia: Aboriginal, Torres Strait Islander; Adolescents/ secondary students	Governance: Indigenous & general agencies Application: Assess resilience and risk factors of secondary students; To assess outcomes after a resilience- based support program	- Strength-based, as opposed to deficit-based (focus on resiliency). - Cultural and wholistic definition of resilience used. Process: Collaborative and community-based; Indigenous voices central to the process.	- 59-item questionnaire - Includes the following sections: Ability to cope with stress; Feeling supported; Family, community and culture engagement; Personal and social skills/leadership; Enhanced learning; Post-school aspiration; Safe environment and ability to deal with crisis; Access to and satisfaction with health services - √ Content and face validity Administration: Self-completed via paper, online survey or iPads, individually or in groups; or verbally administered (interviews)

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Table 6: Summary of PREMs

Author(s) & Instrument	Construct measured	Target Population	Governance & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties & Administration
BC Ministry of Health, 2020 (In Plain Sight report) **Indigenous Peoples' Survey (IPS)**	Population-based/ developed PREM: Racism in the health care system	Canada: Indigenous peoples in British Columbia	Governance: General agency - in collaboration with Indigenous researchers Application: Measure experiences of racism and discrimination in the health care system to inform policy and practice changes	- Survey was developed as part of an independent review of Indigenous-specific racism in British Columbia's health care system. - No information is available regarding lens/framework. Process: Indigenous led process; Extensive engagement with key stakeholders.	- 44-item questionnaire - Questions centered around the following topics: Feeling of safety; Interaction with health care providers; Care outcomes; Perception of racism and equity; Making complaints; Perceived benefits of strategies to improve care experiences - √ Content validity Administration: Self-completed via online survey
Bureau of Health Information, 2020 **Aboriginal Patient Experience Questionnaire**	Developed PREM: Experience with hospital stay	Australia: Aboriginal and Torres Strait Islanders	Governance: Indigenous and general agencies Application: Quality improvement and accountability	- Cultural safety. Process: Developed with the guidance and input of community members and stakeholders.	- 31-item questionnaire - Domains: Access; Family; Welcoming environment; Communication and information; culturally appropriate care/safe care; and Perceived discrimination. - √ Content and face validity Administration: Unclear
Elvidge et al., 2019 **Cultural Safety Survey**	Developed PREM: Cultural safety in hospitals	Australia: Aboriginal and Torres Strait Islander in North South Wales	Governance: General agencies; includes Indigenous authorship Application: To measure cultural safety in hospitals from an Aboriginal patient perspective; Accountability	- Cultural safety: Centers around the subjective experiences of the recipient of care and health care providers' responsiveness to different cultural needs, and how their values can impact the care they provide. Process: consultation with Indigenous academics, health care providers,	- 23-item questionnaire - Measuring five domains of cultural safety: (1) Positive communication between patients and hospital staff; (2) Negative communication between patients and hospital staff; (3) Trust between patients and hospital staff; (4)

Author(s) & Instrument	Construct measured	Target Population	Governance & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties & Administration
				community organizers and community members.	Hospital environment; (5) Support for Aboriginal families and culture - Structure: 4 subscales/ factors- labels for factors not provided - √ Construct validity (via EFA) - √ Content and face validity - √ Internal consistency: Excellent to acceptable Administration: Self-completed via paper or online, or verbally administered (interview)
Ford-Gilboe et al., 2018 **Equity Oriented Health Care Scale (EHoCS)***	Developed PREM: Equity oriented health care—whether care is equitable and tailored	Canada: Marginalized groups (although not solely developed for Indigenous Peoples, their main target was Indigenous Peoples)	Governance: Indigenous & general agencies Application: Assess degree of equity oriented care in order to enhance capacity at the staff and organizational levels	- Equity-oriented primary health care. - Conceptual grounding: (1) Trauma-and violence informed care; (2) Culturally safe care; (3) Contextually-tailored care. Process: Consultation with patient groups.	12-item questionnaire (final version) - √ Convergent validity 24-item version: - Structure: Uni-dimensional with 5 domains loading on a single factor; Domains: Promote accessibility and reduce barriers; Welcoming comfortable milieu; Emotional safety and trust; Non-discriminatory posture; Tailoring to context, history and experience - √ Construct validity (via CFA) - √ Face & content validity - √ Internal consistency: Excellent for the overall scale and questionable to good for each domain

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Author(s) & Instrument	Construct measured	Target Population	Governance & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties & Administration
					Administration: Verbally administered (interview)
Garvey et al., 2012, 2015 **Supportive Care Need Assessment Tool-Indigenous Population (SCNAT-IP)**	Adapted PROM and PREM: Supportive care needs of Indigenous people with cancer as well as their experience with cancer care	Australia: Aboriginal and Torres Strait Islanders with cancer	Governance: General agencies- includes Indigenous authorship Application: To assess support needs during cancer care; To understand gaps in care; To assess the impact of interventions	- "Living in now" perspective versus focus on "uncertainty about future". - Elimination of "culturally-loaded terms", such as 'cancer' and 'death'. - Wholistic definition of wellbeing– e.g., "pain" needs to be described (physical pain vs. emotional). - Importance of culture and family/community support in wellbeing. Process: Community engagement and consultation.	- 26- item questionnaire - Structure: 4 sub-scales/ factors: Physical and psychological; Hospital care; Information and communication; Practical and cultural needs - √ Construct validity (via EFA) - √ Content and face validity - √ Convergent validity - √ Internal consistency: Good to acceptable Administration: Verbally administered (interview)
Paradies & Cunningham, 2008 **Measure of Indigenous Racism Experiences (MIRE)**	Developed PREM: Self-reported racism	Australia: Aboriginal, and/or Torres Strait Islander people	Governance: Indigenous & general agencies Application: Assess self-reported racism	- Lived-experiences of Indigenous residents. Process: Personal experiences/stories informed research; Engagement with community members	- 31-item questionnaire - Consists of 6 multi-item scales: Assessing exposure to inter-personal racism; Response and reactions to racism; Internalized racism; Recognition of systemic racism; Race-consciousness; Salience of Indigeneity within social group and among strangers - Structure: Some scales were uni-dimensional, and some had two subscales/factors - √ Construct validity (via PCA)

Author(s) & Instrument	Construct measured	Target Population	Governance & Application	Indigenous Lenses/ Knowledges or Cultural/Theoretical Frameworks Used in Content Development & Processes	Description, Psychometric Properties & Administration
					- √ Content and face validity - √ Convergent validity - √ Internal consistency: Good to unacceptable Administration: Unclear
Roach et al., 2023 **Access, Relationships, Quality and Safety (ARQS)**	Developed PREM: Assess virtual primary care experience	Canada: Indigenous peoples in Alberta	Governance: General agencies with Indigenous authorship Application: Gauge and support improvements in the quality of care.	-Social determinant of health Process: Patient-oriented and community-based research; OCAP principles; Indigenous advisory group; Elder involvement.	- 12-item questionnaire - Domains: Access, relationships, quality and safety - √ Face and content validity Administration: Verbally administered (telephone interview).
Worthington et al., 2010 **HIV testing experiences of Aboriginal youth in Canada**	Developed PREM: HIV testing experience	Canada: Aboriginal youth (15-30 yrs. of age) from 10 Canadian provinces and one territory (largely urban centers)	Governance: Indigenous & general agencies Application: Assess HIV testing experiences among Aboriginal Youth	- Principles of respect. - Cultural responsiveness: Importance of cultural practices in health care and the cultural competency of health care staff. Process: Community-based approach; Advisory group with youth and Elders guiding research; Shared results with community.	- 49-item questionnaire - Themes: Decision to test; Testing experience; Experiences of HIV care for those with HIV - √ Face & content validity Administration: Self-completed via paper survey

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Lenses & Frameworks Used in Content Development

PROMs and PREMs were mainly developed using Indigenous lenses and/or knowledges congruent with Indigenous worldviews—however, for certain survey instruments (n = 7), information regarding the specific lenses or frameworks used was not provided (BC Ministry of Health , 2020; Bureau of Health Information, 2020; Butten et al., 2023; De Maio et al., 2005; Gould et al., 2014; Kaholokula et al., 2008; Schlesinger et al., 2007). Some of the surveys were developed or adapted using the Medicine Wheel as framework (n = 4) (Drawson, 2018; Fiedeldey-Van Dijk et al., 2017; Mohatt et al., 2011; Young et al, 2013), or by applying a wholistic lens (n = 15), acknowledging different dimension of health, including physical, emotional, mental and spiritual wellbeing (Allen et al., 2006, 2012; Brown et al., 2015; Cairney et al., 2017; FNIGC, 2018; Garvey et al., 2012; Gilchrist et al., 2023; Harwood et al., 2012; Howard et al., 2024; Ingham et al., 2023; McCalman et al, 2017; Oliver et al., 2009; Peters et al., 2019; Thomas et al., 2010; Westerman, 2003; Winderowd et al., 2008). Several of the survey instruments also revealed the inter-connectedness of social systems and land in wellness (n = 12), centering around the Indigenous knowledge that being in harmony with one's greater social network and environment leads to wellness (Allen et al., 2006, 2012; Bourke et al., 2022; Cairney et al., 2017; FNIGC, 2018; Gartland et al., 2021; Gee et al., 2023; Gilchrist et al., 2023; Harwood et al., 2012; Haswell et al., 2010; Howard et al., 2024; Mohatt et al., 2011; Thomas et al., 2010). For example, the development of the Regional Health Survey (RHS) was based on a cultural framework, summarized by the phrase, "total health of the total person within the total environment" (FNIGC, 2018, p. 8). RHS covers a wide range of topics including self-reported physical and mental health status, involvement in traditional activities and language, health of the community and land, and their access to and experience with receiving care, along with other health determinants (e.g., education, employment) (FNIGC, 2018). Similarly, the Interplay Survey (Cairney et al., 2017) was developed utilizing the Interplay Wellbeing Framework, which centers on the interrelationships (interplay) of culture, empowerment and community with education, employment and health, constituting a wholistic and measurable wellbeing framework. The Interplay survey covers a wide range of domains, including questions on the importance and practice of culture, Aboriginal and English literacy, empowerment, community, work, culture in school, general health, social and emotional wellbeing as well as substance usage.

Consistent with a wholistic approach to wellness, some of these PROMs and PREMs were grounded in the "collective" and "relational" orientation to wellness (n = 19), emphasizing the role of the collective in supporting individual's wellbeing (Allen et al, 2006, 2012; Bourke et al., 2022; Brown et al., 2015; Bureau of Health Information, 2020; Butten et al., 2021; Cairney et al., 2017; Drawson, 2018; FNIGC, 2018; Fok et al., 2012; Gartland et al., 2021; Garvey et al., 2012, 2015; Gee et al., 2023; Gilchrist et al., 2023; Harwood et al., 2012; Haswell et al., 2010; Howard et al., 2024; Kickett-Tucker et al., 2015; Mohatt et al., 2011; Thomas et al., 2010). For example, the adaption of the Multicultural Mastery Scale for Youth (Fok et al., 2012), a tool measuring problem-focused coping, was guided by the concept of "communal mastery" (as opposed to self-mastery)—the concept that individuals can overcome stress by tapping into one's interwoven social networks, as opposed to resorting to one's sense of personal control and agency alone. As such, many questions on the survey centered around the person's access and willingness to access friends and family support in coping with stress. Similarly, the Resilience Questionnaire (Gartland et al., 2021; 2022) developed for youth was based on the ecological-

transactional model of resilience. This model positions the youth at the centre of a network consisting of family, community and social factors, with the measure including questions that focus on deriving strength from these connected social sources.

Many of the survey instruments were also developed or adapted using a resilience or strength-based approach (n = 17). The latter focused on wellness and measuring constructs such as empowerment, resilience and protective factors, as opposed to a deficit-based approach, measuring illness, risks, and social disparities (Allen et al., 2006, 2012, 2019; Bourke et al., 2022; Cairney et al., 2017; Drawson, 2018; Gartland et al., 2021; Gee et al., 2023; Gilchrist et al., 2023; Haswell et al., 2010; Howard et al., 2024; Kickett-Tucker et al., 2015; Langham et al., 2018; McCalman et al., 2017; Mohatt et al., 2011; Peters et al., 2019; Snowshoe et al., 2015; Westerman, 2003). This approach is consistent with the Indigenous concept of the "natural human capacity to navigate life well" (Fleming & Ledogar, 2008, p. 7). For example, in assessing the outcomes of a wellness workshop, the Growth and Empowerment Scale (Haswell et al., 2010) was developed with subscales on inner peace, self-capacity, healing and connection. Similarly, the Child and Youth Resilience Measure (Langham et al., 2018) covers questions on sources of resilience (e.g., "I have chances to learn skills"; "I talk to my family about how I feel") and expressions of resilience (e.g., "I know where to go to get help"; "When things don't go my way I can fix it").

In addition to a strength-based approach, Indigenous understandings of respect and ethics were seen as integral to designing appropriate survey instruments. Although most survey developers were likely cognizant of this through content development and pretesting, a few of the studies (n = 2) explicitly incorporated the principle of respect by tailoring questions to avoid harm (Allen et al., 2012; Worthington et al., 2010). For example, in the Reflective Processes Scale (Allen et al., 2012), the Yup'ik Protective Factor Scale adapted for youth, the concept of "reflection" was used, with questions focusing on youth's awareness of the consequences of alcohol use for themselves, their families and their way of life as opposed to posing direct questions on alcohol consumption. It was considered disrespectful and/or unethical to directly inquire about sensitive topics such as alcohol/drug use or suicide, since it was deemed as leading to perpetuation of dominant racist attitudes towards Indigenous Peoples. This, in turn, could lead to re-traumatization of Indigenous individuals and communities, and/or stigmatization of communities or regions once results are disseminated.

Congruent with a strength-based approach, several of the instruments developed or adapted were grounded in the "culture-as-prevention" lens (n = 18), with the premise and knowledge that culture has protective factors for the wellness of Indigenous Peoples (Allen et al., 2012, 2019; Bourke et al., 2022; Cairney et al., 2017; Fiedeldey-Van Dijk et al., Gilchrist et al., 2023; Kickett-Tucker et al., 2015; Fok et al., 2012; 2017; Garvey et al., 2012, 2019; Gee et al., 2023; Howard et al., 2024; Kaholokula et al., 2008; Langham et al., 2018; Mohatt et al., 2011; Snowshoe et al., 2015; Westerman, 2003; Winderowd et al., 2008). For example, the Native Wellness Assessment tool (Fiedeldey-Van Dijk et al., 2017) was developed to assess the effectiveness of cultural intervention on individuals' wellbeing. The survey instrument includes series of cultural statements and cultural practices to be rated on an agreement scale. Similarly, the Reason for Life scale (Allen et al., 2019), adapted for Yup'ik Natives in the United

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States assessed risk of suicide by focusing on protective factors, including questions on cultural and spiritual beliefs.

Additionally, the theoretical frameworks of cultural safety and cultural responsiveness were employed for the development of four PREMs (Bureau of Health Information, 2020; Elvidge et al., 2019; Roach et al., 2023; Worthington et al., 2010). An equity-oriented primary health care model informed the development of another PREM, grounded in trauma- and violence-informed care, and culturally safe and contextually-tailored care (Ford-Gilboe et al., 2018). For example, in the Cultural Safety Survey (Elvidge et al, 2019) cultural safety was defined as a multifaceted construct, covering areas related to patient-provider relationship and communication, sense of trust, the hospital environment being welcoming and the patients' access to culturally appropriate care and support. The development of this PREM was driven by the predominance of Aboriginal Australians' experiences with racism and discrimination in the health care system, highlighting the importance of cultural safety and racism as core factors in the Indigenous patient experience.

Application

Many of the PROMs and PREMs were employed to assess outcomes or experiences (n = 30), as part of evaluation, quality improvement and/or planning (ABS, 2002; Allen et al., 2012, 2019; Ayottee et al., 2024; BC Ministry of Health, 2020; Bourke et al., 2022; Bureau of Information, 2020; Cairney et al., 2017; De Maio et al., 2005; Elvidge et al., 2019; Fiedeldey-Van Dijk et al., 2017; Fok et al., 2012; Ford-Gilboe et al., 2018; Gartland et al., 2021; Garvey et al., 2012, 2015; Gupchup et al., 2001; Harwood et al., 2012; Haswell et al., 2010; Kickett-Tucker et al., 2015; Kowal et al., 2007; Langham et al., 2018;Lowe, 2003; McCalman et al., 2017; Mohatt et al., 2011; Moran et al., 1999; Paradise & Cunningham, 2008; Peters et al., 2019; Roach et al., 2023; Snowshoe et al, 2015; Venner et al., 2006; Worthington et al., 2010; Young et al, 2013). Some of the survey instruments were used as part of clinical intervention (n = 16), in order to assess wellness (protective factors) and risks in therapeutic settings (Allen et al., 2006, 2012; Brown et al., 2013, 2015; Butten et al., 2021; De Maio et al., 2005; Drawson, 2018; Gee et al., 2023; Gould et al., 2014; Howard et al., 2024; Kaholokula et al., 2008; Langham et al., 2018; McCalman et al., 2017; Schlesinger et al., 2007; Thomas et al., 2010; Westerman, 2003; Winderowd et al., 2008). A few of the instruments (n = 8) were used primarily to assess health needs and service gaps in communities or among patient groups (ABS, 2002, 2018; Cairney et al., 2017; FNIGC, 2018; Garvey et al., 2012, 2015; Gilchrist et al., 2023; Ingham et al., 2023; Kowal et al., 2007; Oliver et al., 2009).

At the macro level, all of the PROMs and PREMs (n = 48) were produced in order to address the impact of intersectional factors or Indigenous determinants of health such as colonialism, intergenerational trauma, socioeconomic status, and/or marginalization. For example, the Indigenous Risk Impact Screen (Schlesinger et al., 2007) was developed based on reports, such as the Royal Commission into Aboriginal Deaths in Custody and the National and the Aboriginal Health Strategy in Australia. As part of an independent review of Indigenous-specific racism in Canada's health care system, the Indigenous Peoples' Survey was developed (BC Ministry of Health, 2020). The creation of the Native Wellness Assessment (Fiedeldey-Van Dijk et al. 2017) was driven by health data showing the need to support wellness for Indigenous Peoples in Canada through culturally appropriate initiatives that reflect their

unique lived experiences. The Cherokee Self-Reliance Questionnaire (Lowe, 2003, 2008) was developed to assess culturally appropriate interventions, against the backdrop of forced removal of Native Americans from their ancestral lands, forced assimilation practices, and social disenfranchisement spanning over generations.

Administration

More than one-third of the PROMs/PREMs (n = 16) were administered solely through verbal interviewers (ABS, 2018; Allen et al., 2006, 2012; Cairney et al., 2017; Ford-Gilboe et al., 2018; Garvey et al., 2015; Gee et al., 2023; Gould et al., 2014; Gupchup et al., 2001; Hackett et al., 2016; Kickett-Tucker et al., 2015; McClintock et al., 2011; Oliver et al., 2009; Roach et al., 2023; Schlesinger et al., 2007; Thomas et al., 2010; Zubrick et al., 2005). For seven of the PROMs/PREMs it was explicitly stated that Indigenous interviewers conducted these interviews (Allen et al., 2006; Cairney et al., 2017; FNIGC, 2018; Gee et al., 2023; Kickett-Tucker et al., 2015; McClintock et al., 2011; Roach et al., 2023). Other PROMs/PREMs were self-completed (n = 14) (Allen et al., 2012, 2019; BC Ministry of Health, 2020; Butten et al., 2021; Fiedeldey-Van Dijk et al., 2017; Fok et al., 2012; Howard et al., 2024; Venner et al., 2006; Worthington et al., 2010; Young 2015). For some of the survey instruments (n = 10), participants were given the choice to complete them either through self-completion or by interview (Elvidge et al., 2019; FNIGC, 2018; Hackett et al., 2016; McCalman et al., 2017; Westerman, 2003). When the option of self-completion was provided, in many of the studies (n = 16) the participants were given the opportunity to complete the survey electronically using iPad, tablet or computer (Allen et al., 2012, 2019; BC Ministry of Health, 2020; Bourke et al., 2022; Butten et al., 2021; Elvidge et al., 2019; Fok et al., 2012; FNIGC, 2018; Gartland et al., 2021; Hackett et al., 2016; Howard et al., 2024; Langham et al., 2018; Ingham et al., 2023; McCalman et al., 2017; Mohatt et al., 2011; Young et al., 2013). The option to self-complete the surveys individually or in a group was provided to youth in some studies (n =6) (Allen et al., 2019; Fok et al., 2012; Langham et al., 2018; McCalman et al., 2017; Mohatt et al., 2011; Westerman, 2003). Honorariums for the completion of PROMs/PREMs were also provided in a few studies (n = 6) (Allen et al., 2006, 2012; Antonio et al., 2020; Mohatt et al., 2011; Schlesigner et al., 2007; Venner et al., 2006).

Psychometric Properties

Methods used for the psychometric assessment of PROMs/PREMs varied across studies. In almost all of the studies qualitative methods were employed to assess either content or face validity. Content validity was established for PROMs and PREMs in a variety of ways, including through expert interviews/panels (n = 15) (Allen et al., 2006, 2012; BC Ministry of Health, 2020; Bourke et al., 2022; De Maoi et al, 2005; Drawson, 2018; Elvidge et al., 2019; Fiedeldey-Van Dijk et al., 2017; FNIGC, 2018; Gould et al., 2014; Lowe, 2003; Oliver et al., 2009; Schlesinger et al., 2007; Snowshoe et al, 2015; Windeorwd et al., 2008; Young et al., 2013), focus groups (n = 11) (Allen et al., 2012, 2019; Brown et al., 2013; Drawson, 2018; Fok et al., 2012; Garvey et al., 2012, 2015; Gee et al., 2023; Gupchup et al., 2001; Moran et al., 1999; Paradies & Cunningham, 2008; Venner et al., 2006; Westerman, 2003), workshops/consultations (n = 13) (Brown et al., 2015; Cairney et al., 2017; Ford-Gilboe et al., 2018; Gartland et al., 2022; Harwood et al., 2012; Haswell et al., 2010; Ingham et al., 2023; Kickett-Tucker et al., 2015; McCalman et al., 2017; Peters et al., 2019; Roach et al., 2023; Smith et al., 2021), and in one case ethnographic interviews and

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observations (Lowe, 2003). Face validity was established through pilot testing (n = 15) (Allen et al., 2012, 2029; Brown et al., 2015; De Maio et al., 2005; Elvidge et al., 2019; Fiedeldey-Van Dijk et al., 2017; Ford-Gilboe et al., 2018; FNIGC, 2018; Fok et al., 2012; Kickett-Tucker et al., 2015; McCalman et al., 2017; Moran et al., 1999; Smith et al., 2021; Thomas et al., 2010; Venner et al., 2006; Worthington et al., 2010), focus groups, yarning groups and/or interviews (n = 12) (Bourke et al., 2022; Brown et al., 2013; Butten et al., 2021; Cairney et al., 2017; Gartland et al., 2022; Garvey et al., 2012, 2015; Gee et al., 2023; Gould et al., 2014; Howard et al., 2024; Paradies & Cunningham, 2008; Schlesinger et al., 2007; Snowshoe et al., 2015), and in 4 cases the cognitive interview technique was utilized (Allen et al., 2012; Ford-Gilboe et al., 2018; Howard et al., 2024; Roach et al., 2023).

Exploratory factor analysis (EFA) was employed to establish construct validity for close to one-third of the PROMs/PREMs (n = 14) (Brown et al., 2015; Butten et al., 2021; Cairney et al., 2017; Elvidge et al., 2019; Garvey et al., 2015; Gilchrist et al., 2023; Haswell et al., 2010; Howard et al., 2024; Kickett-Tucker et al., 2015; Moran et al., 1999; Schlesinger et al., 2007; Snowshoe et al., 2015; Thomas et al., 2010; Westerman, 2003). In some studies Principal Component Analysis (PCA) was conducted as means to establish construct validity (n = 7) (Drawson, 2018; Gee et al., 2023; Gilchrist et al., 2023; Gupchup et al., 2001; Harwood et al., 2012; Paradies & Cunningham, 2008; Winderowd et al., 2008). Validation of factor structure from predetermined model, theory or established variables was conducted in a number of studies (n = 12) using confirmatory factor analysis (CFA) (Allen et al., 2012, 2019; De Maio et al., 2005; Fok et al., 2012; Ford-Gilboe et al., 2018; Gartland et al., 2022; Howard et al., 2024; Langham et al., 2018; Mohatt et al., 2011; Moran et al., 1999; Snowshoe et al., 2015; Venner et al., 2006). Item response theory (IRT) was used in one study to establish construct validity (Howard et al., 2024).

A number of studies also reported establishing convergent validity by demonstrating strong correlations between their PROM/PREM and other measures, which should theoretically be related (n = 23) (Allen et al., 2012, 2019; Antonio et al., 2020; Butten et al., 2021; Drawson, 2018; Fiedeldey-Van Dijk et al., 2017; Fok et al., 2012; Ford-Gilboe et al., 2018; Gartland et al., 2022; Gee et al., 2023; Gilchrist et al., 2023; Gupchup et al., 2001; Harwood et al., 2012; Haswell et al., 2010; Mohatt et al., 2011; Paradies & Cunningham, 2008; Peters et al., 2019; Schlesinger et al., 2007; Venner et al., 2006; Winderowd et al., 2008; Young et al., 2015; Zubrick et al., 2006). Similarly, a few studies established discriminant validity (n = 7), aiming to demonstrate that measures of constructs that theoretically should not be related are, in fact, not related (Antonio et al., 2020; Fok et al., 2012; Gee et al., 2023; Kowal et al., 2007; Peters et al., 2019; Venner et al., 2006; Winderowd et al., 2008). Criterion validity was established in one study, which demonstrated agreement between the adapted PHQ-9 and the outcomes of a well-established Neuropsychiatric interview (Hacket et al., 2016).

Internal consistency (reliability) was established for many of the PROMs/PREMs (n = 33) using Cronbach's alpha, as shown in Tables 2-6. Only two studies (Butten et al., 2021; Young et al., 2016) reported establishing test-retest reliability for their PROM.

Discussion

Through our literature exploration, we identified 48 PROMs and PREMs specifically developed or adapted for use with Indigenous Peoples. These survey instruments aim to measure wholistic wellness,

quality of life, mental wellbeing, cultural identity and engagement, resilience and empowerment, and the experience of safety in health care settings. Having a solid understanding of the current landscape of Indigenous-specific PROMs and PREMs provides insights into potential measurement options for assessing wellness and health care experiences. It also yields insight into developing survey instruments meaningful to Indigenous Peoples and respectful of Indigenous worldviews. Having culturally appropriate PROMs and PREMs also aligns with existing policies and principles that foster Indigenous self-determination and ethical research practices with Indigenous Peoples (American Indian Health Commission [AIHC], 2020; AIATSIS, 2020; CIHR, 2010; FNIGC, 2014; Government of Canada, 2019; Health Research Council of New Zealand [HRCNZ], 2010; National Health and Medical Research Council [NHMRC], 2018). As development of culturally appropriate PROMs and PREMs necessitates Indigenous leadership, a commitment to respecting cultural values, meaningful consultation with Indigenous communities, centering Indigenous voices, and measuring what truly matters to them in a respectful and culturally safe manner.

During our exploration of the literature, we identified several key themes that can help guide the development of Indigenous-specific PROMs and PREMs, ensuring they are respectful of Indigenous knowledges and worldviews.

A Wholistic Worldview

A critical lesson garnered from the current list of PROMs and PREMs is the importance of recognizing and incorporating a wholistic worldview into survey content development. Results indicate that balance between the mind, body, emotions and spirit is central to Indigenous understandings of health and wellness. Measuring the separate aspects of wellness in isolation can misrepresent and miss the critical interconnectedness and interdependence of wellness (Fiedeldey-Van Dijk et al., 2017; Peters et al., 2019). Indigenous wellness is broader than the absence of disease and is closely linked to community, culture, language, land and one's relationship to these interconnected systems. This multilayer approach to wellness sheds light on why questions that may be perceived outside of the realm of health (e.g., language, culture, spirituality, racism) are included in the context of health surveys. As such, PROMs and PREMs developed from a colonial lens require reframing, as wellness must be defined and measured using a wholistic lens. Wholistic frameworks, such as the Medicine Wheel and others that are specific to different communities and culture, can serve as valuable guides in the development of PROMs and PREMs. In particular, the RHS' cultural framework, summarized by the phrase, "total health of the total person within the total environment" (FNIGC, 2011) serves as a promising framework to measure wellness in totality. Likewise, the Interplay Wellbeing Framework (Cairney et al., 2017) is another valuable framework that recognizes that essentially everything is interrelated and must be considered as part of a wholistic measure of wellness.

These wholistic approaches are also congruent with a social and cultural health determinants approach to patient measurement (Marmot, 2005; Khurana et al., 2022), which considers factors such as housing, education, cultural and social relations as contributors to health and access to health care and are viewed as areas of inquiry in PROMs. Furthermore, a social and cultural health determinants approach to 'good' health can be positioned as a strength for Indigenous individuals and communities, countering

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negative stereotypes, and shifting the dialogue from a deficit-based discourse to a strength-based one (Fogarty et al., 2018), with culture as a focal point of strength (Fiedeldey-Van Dijk et al, 2017).

Resilience/ Strength-Based Framework and Culture as Prevention

Another key finding from the literature exploration was that many of the PROMs and PREMs were grounded in a resilience or strength-based framework. These approaches align with a wholistic view of well-being, seeking harmony and balance (Fleming & Ledogar, 2008) and being linked to culture. Survey instruments should emphasize strengths over risks, illness and social disparities, positioning 'culture at the apex of an Indigenous assessment' as fundamental to Indigenous health and wellbeing (Fiedeldey-Van Dijk et al, 2017; Bourke et al., 2022). Strength- and culture-based approaches are particularly central because they empower Indigenous Peoples to reclaim and reaffirm Indigenous ways of knowing and being (Snowshoe et al., 2015). In fact, there is a movement towards cultural revitalization, with strengthening of connection or re-connection to culture being viewed as a valuable health program objective and outcome measure for Indigenous Peoples (Massotti et al., 2020).

Since Indigenous-specific PROMs and PREMs need to be grounded in resilience and culture, this may require approaching self-reported measurements from a different perspective and paradigm all together. Rather than measuring depression, for instance, the focus could shift to assessing hope, resilience and protective factors. Gomez Cardona et al. (2021) recently showed that Mohawk and Inuit communities in Quebec favoured the Growth and Empowerment Measure (Haswell et al., 2010), due to its empowering approach over other scales that focus heavily on depressive symptoms and illness. The participants in their study felt that an overemphasis on negative symptoms hinders community members' quest for healing. In contrast, measures focusing on positive and protective factors were seen as promoting resilience and empowerment.

Relational Orientation

Several articles emphasized the value of a relational lens, which focuses on the role and the health of family and community in wellbeing. According to Wilson (2008), the relational way of being is "at the heart of what it means to be Indigenous" (p. 80). This perspective acknowledges that human beings are part of interwoven relationships with all things that promote good health, including the cosmos, the earth, the waters, all living things, and spiritual relatives (King, 2007). In particular, Indigenous wellbeing is closely linked to the role of family and community as nurturers of health promoting relationships (Gee et al., 2023; Hovey et al., 2014; Wilson et al., 2021). Furthermore, "networks of care", referring to the interrelated cultural and social systems provided by the extended family and friends, have shown to be a source of support to Indigenous families (Quinless, 2013). A relational stance, like one that focuses on resilience, promotes a different view of health and suggests different areas of inquiry for developing Indigenous-specific PROMs and PREMs. As such, individuals' engagement with their community and family for wellbeing and support should be reflected in self-reported survey instruments. For example, when measuring function (as an outcome), questions might focus on the ability to perform tasks with the help of family members, rather than solely focusing on

autonomous task completion. Exploring individuals' connections with their family and larger community should also be considered as part of PROMs, as lack of such connections can indicate potential risks (Hovey et al., 2014). Likewise, the role of the family and the experience of family members with care provision need to be explored in PREMs.

Respect and Ethics

The literature highlights the need for respect and ethical responsibility in designing questions when survey developers address sensitive subjects such as substance use and suicide. Allen et al. (2012), in the development of the Reflective Process Scale, tackled ethical implications of inquiring directly about alcohol misuse and opted to focus on resilience—versus deficit—as both a more respectful and ethical approach to addressing this sensitive subject. Likewise, Allen et al. emphasized the ethical responsibility of survey developers to be cognizant of the potential risks and harms their surveys could cause. Stigmatization and perpetuation of racist stereotypes remain serious obstacles for Indigenous Peoples and communities and need to be considered in relation to PROMs and PREMs used. These considerations align with calls for decolonizing and ethical research practices, where the benefit of research to the community is rigorously questioned and given careful consideration (AIATSIS, 2020; Government of Canada, 2019). These also support the Indigenous data sovereignty movement (Walter & Suina, 2019; Water et al., 2020), which recognizes Indigenous Peoples as rightsholders with authority to determine what information will be collected, how it will be collected, interpreted, disseminated and managed.

Cultural Safety

Among the 48 survey instruments identified in the literature exploration, only 9 were developed to measure health care experiences, highlighting the need for more Indigenous-specific PREMs. Of these, existing literature has identified cultural safety and racism as being core to the Indigenous patient experience. This is consistent with other research that has demonstrated how past experiences with health care and trust in health care system are contributing factors to Indigenous patient experience and engagement with care (Jones et al., 2020). Cultural safety emphasizes the power imbalances between the health care provider and a person (patient), while maintaining it is the Indigenous person who determines if the care being delivered to them is "safe" or not (Oetter & Johansen, 2017). Likewise, Curtis et al. (2019) argue that a shift towards cultural safety, characterized by critiquing power imbalances and power structures within organizations, along with engaging in critical self-reflection and dialogue, is warranted. Current evidence underscores the need for increased focus on cultural safety in relation to its impact on Indigenous patient experiences and health outcomes. As noted by Green et al. (2018, 2021), Indigenous-specific PREMs are particularly important since Indigenous patients' and families' sense of safety in the health care system could impede access, successful engagement with care and in turn negatively impact health outcomes.

As previously mentioned, Indigenous-specific PREMs remain sparse. The intersection of systemic and structural racism is a salient theme that requires further understanding in relation to access/barriers to health care, wellness and lived experience. In order to combat Indigenous-specific racism and foster cultural safety in health care, with the aim of establishing a decolonized, patient-centered and equitable

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health care system (Curtis et al., 2019), measurement and monitoring of progress of Indigenous Peoples' experiences with services are critically needed. Quality data can reveal whether system-level changes or service improvements have been beneficial, and whether expected responsibilities and accountabilities have been met (BC Ministry of Health, 2020). Organizations should ultimately use the data measured to facilitate critical self-reflection and address systematic power imbalances towards cultural safety (Curtis et al., 2019).

Decolonizing Research Approaches

Another key lesson from the literature exploration is that development of PROMs and PREMs need to be guided by decolonizing research approaches (Hayward et al., 2021). The survey instruments identified in our exploration were developed using community-based and collaborative processes. Indigenous community members were involved as experts, cultural consultants, and/or research staff. As part of the psychometric assessment, qualitative methods were employed to gather comprehensive feedback on survey content from Indigenous community members and cultural experts. The PROMs and PREMs were created to improve health outcomes and experiences, and considered systematic racism, disfranchisement and trauma in the Indigenous communities. A few of the survey instruments were born out of personal stories and experiences of the authors. Stories being the driving mechanism for research is indeed congruent with Indigenous research methodologies (McIvor, 2010). According to Absolon and Willett (2005), "the only thing we can write with authority about is ourselves" (p. 97).

Regarding governance, we identified that Indigenous researchers grounded and directed the development of PROMs and PREMs identified in our literature exploration. However, we feel that attribution of work need to be made more transparent, since at times we had to resort to online searches in order to gather background information on the authors. It is important for the work to be grounded in Indigenous leadership, and this must be made more transparent. Although objectivity and the notion of "researcher as blank slate" are very much ingrained in the Western science tradition, a decolonizing research approach calls for positioning of the researcher (Datta, 2018). Wilson (2003) remarks that researchers need to locate themselves and their work firmly in a relational context. The issue of governance in relation to PROMs and PREMs also ties in with the Indigenous data sovereignty movement. Indigenous decision making, from data conception to control, is essential for ensuring that the collected data aligns with Indigenous priorities, values, cultures, and worldviews (Walter & Suina, 2019; Water et al., 2020). Therefore, it is essential that the development of PROMs and PREMs be grounded in Indigenous leadership.

While standard PROMs and PREMs reflect a Western or colonial perspective, exploring their potential in Indigenous health research and their ability to contribute to solutions that improve outcomes and experiences for Indigenous Peoples are welcomed (Hayward et al., 2021). It is imperative to "decolonize and Indigenize" quantitative research methods by grounding the work in Indigenous leadership, engaging in community-based participatory approaches, and fostering opportunities for research training and capacity bridging (Loppie, 2022) within Indigenous communities. This includes developing culturally appropriate data collection instruments and administrative methods that align with Indigenous knowledges, ensuring Indigenous data sovereignty, and practicing positionality and reflexivity (Hayward et al., 2021). Additionally, incorporating decolonizing research methodologies in

development of PROMs and PREMs further supports Indigenous self-determination and leads to survey instruments that are congruent with their specific cultures, value systems and ways of knowing (Kite & Davy, 2015).

Limitations

In this literature exploration we used rigorous and transparent methods, with guidance from those with expertise in knowledge synthesis and literature reviews. However, we may not have identified all published and grey literature, despite attempts to be as comprehensive as possible. In particular, some grey literature may have been missed, as only certain websites were screened for inclusion.

Furthermore, some authors did not fully articulate on the Indigenous lenses or worldviews guiding the development of their surveys. As such, there may be more lessons that need to be uncovered and told regarding the development of PROMs and PREMs. Moreover, our search only included articles in the English language. Consequently, survey instruments and corresponding articles developed in other languages (including Indigenous languages) in Canada, United States, Australia and New Zealand, may have been excluded from our search.

In addition, we did not conduct a critical appraisal of the PROMs and PREMs identified in our search, including a thorough assessment of their psychometric properties, as our aim was to describe and provide examples of how Indigenous knowledges can potentially be used in the development of these survey instruments. However, it is important to note the existence of the Aboriginal and Torres Strait Islander Quality Appraisal Tool (Harfield et al., 2020), which serves as a framework for assessing research. This tool has the potential to be utilized in the appraisal of PROMs and PREMs from an Indigenous perspective. Additionally, this tool can guide research planning and ensure that researchers understand which crucial information to include in their publications regarding the development of PROMs and PREMs. We would also like to highlight that the end product of our larger study, Pathways (d'Agincourt-Canning et al., 2024a), offers similar guidance and can be used in planning and selecting PROMs and PREMs.

Although we provided descriptive information on the administration of PROMs and PREMs, further exploration is needed to identify survey distribution methods that are culturally acceptable and appropriate at the community level, and to assess the impact of these methods on survey findings. For instance, the use of honorariums is one potential area of further inquiry. Honorariums were used in the administration of several PROMs and PREMs (Allen et al., 2006, 2012; Antonio et al., 2020; Mohatt et al., 2011; Schlesigner et al., 2007; Venner et al., 2006), and their usage has been recommended as a way to foster reciprocal relationships between survey participants and survey administrators (d'Agincourt-Canning et al., 2024a). The use of electronic platforms in the administration of PROMs and PREMs is also on the rise (O'Connell et al., 2018), and their appropriateness needs to be further investigated. The PROMs and PREMs identified in our search were administered through various channels, including electronic platforms. However, it is important to recognize that Indigenous communities often prioritize oral knowledge sharing (Stevens, 2008). Therefore, further exploration of the appropriateness of electronic methods at the community level is necessary. This should include considering the option of

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conducting surveys through interviews if that approach better aligns with community preferences (d'Agincourt-Canning et al., 2024a).

Furthermore, we did not report on the results and outcomes of PROMs and PREMs. Understanding the implications of these measures for planning and quality improvement was beyond the scope of our study but needs to be considered in future research. However, reporting on changes and improvements resulting from the application of PROMs and PREMs is essential and aligns with ethical research practices and principles involving Indigenous Peoples (AIHC, 2020; AIATSIS, 2020; FNIGC, 2014; Government of Canada, 2019; HRCNZ, 2010; NHMRC, 2018).

Although in this paper we categorized people broadly using the term "Indigenous," it is important to recognize the vast diversity of Indigenous communities and cultures. Despite the limitations of these blanket terms, this study aims to provide a glimpse into the current state of Indigenous-specific PROMs and PREMs. Although there are similarities among the various Indigenous groups due to the legacy of colonization (Hayward et al., 2020), each survey instrument needs to be examined in context and validated when used in each respective community.

Regarding the strengths of our research, collaboration with a project Elder and Elders-in-training resulted in a nuanced and rich understanding of generated themes, supporting a decolonizing research process (d'Agincourt-Canning et al., 2024b). We also view our approach of primarily focusing on Indigenous knowledges and lenses in the development of PROMs and PREMs as a strength. The lessons garnered from these knowledges are invaluable and essential in supporting the development of future Indigenous-specific PROMs and PREMs.

Conclusion

Our study encompassed a literature exploration of the published and grey literature to gain an understanding of the work done on Indigenous-specific PROMs and PREMs. The implication of having appropriate PROMs and PREMs for Indigenous Peoples are substantial in terms of monitoring impacts of programming and policies, as well as supporting Indigenous self-determination and data sovereignty. Yet, the majority of work in this area privileges colonial worldviews that frequently conflict with Indigenous concepts of health and well-being. Thus, new PROMs and PREMs safe for and respectful of Indigenous cultures are urgently needed.

We identified five overarching themes that are relevant to future research and policy. First, a wholistic view—that is connectedness between mind, body and spirit with community and environment—is central to Indigenous peoples' concept of health and wellness and should be reflected in the survey instruments used. Secondly, PROMs and PREMS must have a cultural fit, reflecting a resilience, strength-based and cultural approach to health that is meaningful to the particular community. Third, relations between family are seen as integral to wellness and should be included in indicators that measure health experiences and outcomes. Fourth, survey developers should approach sensitive subjects with respect, as well as consider potential harms and the ethics of using PROMs and PREMs. Lastly, decolonizing research approaches need to be used in the survey development processes. Furthermore, this exploration has revealed significant gaps in the literature related to PREMs and Indigenous Peoples.

Addressing these gaps and further exploring these aspects should pave the way for the development of more appropriate Indigenous-specific PROMS and PREMS.

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