INPLASY

Indigenous quality of life measurement for health and social services: A systematic review protocol following a hermeneutic approach

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ADMINISTRATIVE INFORMATION

INTRODUCTION

Review question / Objective 1) What are the relevant domains, indicators, and measures of quality of life (QOL) to inform culturally affirming health and social services in Indigenous communities?
2) What are recommended practices for use and digital integration of QOL data to inform policy, investment, clinical, and service actions in Indigenous communities?

Rationale There is increasing recognition of the importance of integrating information about quality of life (QOL) into digital health systems (Craig et al., 2021). Incorporating information about QOL may help empower individuals and communities to monitor their perceived wellbeing in a way that is culturally safe, meaningful, and appropriate for them. This is particularly important for addressing health inequities experienced by Indigenous communities, who have endured historical and ongoing colonization and research atrocities (Hyett et al, 2019). This systematic review will contribute to the development of a QOL measurement framework and offer guidance and strategies for digital collection, reporting, and interpretation of QOL measures to inform policy, investment, clinical, and service actions.

Our Indigenous-initiated review builds upon three systematic reviews on related topics. The first two reviews by Butler et al. (2019) and Gall et al. (2021) describe QOL domains o for Indigenous populations in Australia and the Torres Strait, Canada, New Zealand, and the United States. The third by Angell et al. (2016) examines health-related QOL instruments administered in Indigenous populations. These reviews highlight a current dearth of Indigenous-specific indicators and

measures for quality of life (Angell et al., 2016; Butler et al, 2019; Gall et al, 2021).

As part of the overarching Indigenous Digital Health Ecosystem (IDHE) project, the results from this review will be used to develop an Indigenous QOL measurement framework for integration into a culturally supportive digital platform for health and social services in Indigenous communities. Further information on the IDHE can be found on the Digital website (Digital, 2022). The IDHE project is informed by the principles of OCAP® (First Nations Information Governance Centre, 2022), Calls to Action 18-24 of the Truth and Reconciliation Commission of Canada (2015), Section 3 of the Calls for Justice by the National Inquiry into Missing and Murdered Indigenous Women and Girls (2019), and the In Plain Sight report (2020).

Condition being studied The World Health Organization (WHO) defines QOL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 2012). The concept of "quality of life" has several synonyms, including "wellbeing." Indigenous concepts of QOL tend to emphasize holistic and spiritual approaches (Butler et al., 2019; Gall et al., 2021). Many Indigenous nations have words or concepts in their own languages that are not directly analogous to the term "quality of life," but rather emulate the particular land base and worldview of each nation. One example in Canada is "mino-bimaadiziwin," loosely translated as "the good life," in the Ojibwe language (Ojibwe People's Dictionary, 2021). An example from the US is the Navajo/Diné term "hózhó" as a concept of beauty, wellness, and balance in the Navajo language (Kahn-John & Koithan, 2015). In this review, such words and phrases as they arise will be considered analogue terms to "quality of life."

METHODS

Search strategy The search strategy is iterative and will be guided by the hermeneutic literature review approach described by Boell and Cecez-Kecmanovic (2014). The emerging body of knowledge will be considered and the original search strategy reviewed and refined on an ongoing basis following the "analysis and interpretation" and "search and acquisition" phases of the hermeneutic circle.

Preliminary searches occurred from November 21-28, 2022. Search strategies and key terms have been developed in conjunction with our inclusion criteria. For preliminary searching, keywords and standardized search terms for the three concepts

(a) "Indigenous" (b) "quality of life" (which includes "wellbeing") and (c) "indicators or measures" were compiled and applied to the following library databases: PSYCHINFO, CINAHL, PubMed (with MEDLINE content included), and Social Science Citation Index (using the Web of Science interface). The search string for the "Indigenous" concept was adapted from Rieger et al. (2023). For QOL, the keywords ("quality of life" OR "spirituality" OR "well being" OR "well-being" OR "wellbeing" OR "holistic wellness" OR "wholistic wellness" OR "health balance") were used. For "indicators or measures," the keywords ("indicator*" OR "measure*" OR "evaluat*" OR "assess*") were used. Standardized search terms for "Indigenous" and "quality of life" differed slightly depending on the database. No filters were applied in any of the database searches. Hand searching of Indigenous academic journals not captured in database searching will be conducted for articles relevant to QOL.

Grey literature will be identified by searching relevant individual First Nations and Indigenous organizations in Canada (e.g., websites) for content relevant to Indigenous quality of life, as well as Google Scholar. Other search strategies will include literature recommended by team members and stakeholders, as well as select documents found by general browsing . The grey literature search aims to fill epistemic gaps in knowledge due to colonial structures that privilege academic, Westernized bodies of knowledge over Indigenous bodies of knowledge (Sinclaire et al., 2021). It is crucial that Indigenous bodies of knowledge are equally and respectfully used to inform the IDHE measurement framework. Gall et al. (2021) mention that no grey literature review was conducted in their study, and this review will expand upon their work by synthesizing grey literature from Canada.

Participant or population The population of interest in this study comprises Indigenous peoples from four geographical regions: Turtle Island (limited to Canada and the USA), Australia and the Torres Strait, and Aotearoa (New Zealand), which have similar experiences of British colonization. The United Nations Permanent Forum on Indigenous Issues (n.d.) notes that Indigenous peoples: self-identify as distinct peoples individually and at the community level; have historical continuity with certain lands, territories and natural resources before colonization of those lands by any other people group; have distinct social, economic, and political systems; have distinct languages, cultures, and beliefs; are non-dominant groups of society; and maintain ancestral environments and systems that are distinct to them. Cherokee scholar Adrienne Keene provides

an eloquent definition that "[t]o be Indigenous is to be of a place, to have creation stories of how your people emerged from the land, and to be connected to a community from that place" (2021, p. 11).Terminology and discourse surrounding the word "Indigenous" is nuanced and varied (Younging, 2018). For the purposes of this review protocol, we use the word "Indigenous" as a respectful umbrella term that encompasses other regional terms including but not limited to Aboriginal, First Nations, Métis, Inuit, Native American, Torres Strait Islander, and Māori.

Intervention This study does not investigate a specific intervention.

Comparator This review does not include a comparator.

Study designs to be included COMMERCIAL OR ACADEMIC LITERATURE: We will include qualitative, quantitative, and mixed methods studies and systematic reviews, as well as book chapters, discussion papers and opinion papers. GREY LITERATURE: We include health department reports, annual reports, strategic plans, community newsletters, community constitutions, nation-specific legal documents and ERIC documents. We will include select masters and PhD theses found by general browsing if they meet the inclusion criteria and are considered to have notable contributions to address the research questions.

Eligibility criteria INCLUSION CRITERIA: 1) PARTICIPANTS. Included literature must involve Indigenous peoples as the primary focus and/or primary population. Various terms for Indigenous people groups will be accepted as noted in Item 12. 2) GEOGRAPHICAL CONTEXT. The document must focus on one or more of the following geographical regions: Turtle Island (Canada and the USA), Australia and the Torres Strait, and Aotearoa (New Zealand). 3) CONCEPT. Selected literature will focus on the concept of QOL (including "wellbeing" and other analogue concepts, e.g. mino-bimaadiziwin, hózhó) or indicators and measures of QOL/wellbeing/ analogue concepts in relation to Indigenous populations. INCLUSION CATEGORIES: Included literature will be sorted into three categories: 1) Include as Relevant for QOL data extraction, where identifying domains, measures, or indicators of QOL is the central focus of the document; 2) Include as Related, where the document identifies domains, measures, or indicators of QOL but it is not the main focus of the document; and 3) Unsure for QOL data extraction, where after eight minutes

of reading the document, the reader is still unsure whether it identifies domains, measures, or indicators of QOL. Items in the first and then the second category will be prioritized for data extraction. EXCLUSION CRITERIA: Documents will be excluded if: 1) they are not written in English; 2) the focus is on non-Indigenous peoples, a particular disease or health condition, or a particular healthcare service (e.g., dental care, maternity care, prison health).

Information sources The included databases for this systematic review are described in item 11. Hand searching for the search term "quality of life" and analogue terms (e.g. mino-bimaadiziwin, hózhó) will be conducted in several Indigenous academic journals relevant to our study.
For the grey literature search, digital publications of the following Nations and Indigenous organizations will be searched: Cowichan tribes, Cowessess First Nation and Chief Red Bear Children's Lodge, Sioux Lookout First Nations Health Authority, First Nations Health and Social Secretariat of Manitoba, and First Nations Digital Health Ontario. These are the six entities officially partnered with the IDHE project (Digital, 2022). Additional grey literature searching will be conducted in websites of Indigenous organizations spread geographically across Canada and Google Scholar. Any resources recommended by project team members and stakeholders will be included if they meet the inclusion criteria.

Main outcome(s) This review is not an interventional study and does not focus on any particular outcomes.

Additional outcome(s) Not applicable.

Data management Available abstracts of the initial results will be randomly sorted into batches for screening from all search results, using EPPI Reviewer software (Thomas et al., 2022). The titles and abstracts of each citation will be randomly assigned for independent screening against our inclusion criteria by two reviewers using EPPI Reviewer software tools and an artificial intelligence-facilitated approach. Disagreements will be resolved by consensus. Inclusion status not discernible by abstract will be advanced to full text screening by two research team members. Other uncertain results may require input from additional members of the research team for include/exclude decisions. The same method will then be used for full text screening to confirm eligibility. Document screening is designated for the period March 2023-July 2023, and machine learning will be utilized to

assist with screening. A PRISMA flowchart will be used to report the search and screening results.

All documents that have been screened and included will undergo data extraction using the EPPI Reviewer platform. Detailed study-level information will be included in a final report. Initial QOL domains included for data extraction have been adapted from the WHO (2012). Other preliminary data extraction categories include QOL measures used, type of literature (qualitative study, quantitative study, discussion paper, etc.), and location (which geographical region and/or specific Indigenous Nation named in the document). Full data extraction will also include categories for digital and practical implications and applications to health and social services for Indigenous peoples.

Quality assessment / Risk of bias analysis
Quality assessment will cover Indigenous engagement in creating each piece of literature. We adapted the Aboriginal and Torres Strait Islander Quality Appraisal Tool (ATSIQAT) by Harfield et al. (2020) and use the word "Indigenous" in the place of "Aboriginal and Torres Strait Islander" for terminology inclusive of our four geographical regions. This tool assesses several focused areas relevant for Indigenous peoples such as respect for community cultural contexts and protocols, use of Indigenous research paradigms, and safeguarding of intellectual and cultural property rights (Harfield et al., 2020).

Strategy of data synthesis Guided by the hermeneutic literature review approach (Boell & Cecez-Kecmanovic, 2014), analysis and synthesis will be an iterative and participatory process with input on emerging results sought through ongoing group meetings and interviews with Learning Alliance members, which has representation from various Indigenous organizations and communities in Canada. The Learning Alliance will directly engage Indigenous Elders, knowledge holders, and health care professionals in Canada who have lived experience that is applicable to development of a QOL measurement framework (see Item 27). The data analysis codebook will include the extraction categories from Item 20 and a section to identify visual representations of QOL frameworks, measurements, and indicators so that these can be more easily accessed during synthesis of the final QOL measurement framework. Information extracted will be combined into categories using content analysis, to address the review questions, each with descriptions and representative examples. A summary of relevant QOL domains, indicators and measures will be generated with a strengths-based approach, supported by tools

from EPPI Reviewer software. The synthesized findings will be reviewed and discussed with the Learning Alliance members. The main result of our collaborative synthesis will be an Indigenous QOL measurement framework of culturally relevant domains, indicators and measures (see Review Question One). The measurement framework will include strategies for collecting, reporting, and interpreting QOL information for health and social services in Indigenous communities (see Review Question Two).

Subgroup analysis Not applicable.

Sensitivity analysis Not applicable.

Language restriction Only documents written in English will be included in the synthesis due to feasibility, as comprehensive language translation services are not currently available to the research team.

Country(ies) involved Canada (School of Nursing, Trinity Western University, Langley, BC, Canada).

Other relevant information STAKEHOLDER ENGAGEMENT AND PARTICIPATORY ACTION RESEARCH, Mustimuhw Information Solutions (MIS) is a Nation-based company that is fully owned by Cowichan Tribes and the lead partner organization for the Mitacs accelerate application (which provided additional funding). Plans for Indigenous communities' access, use, and governance of resulting knowledge/data will be managed by MIS. The research was launched in response to an invitation from MIS for Trinity Western University (TWU) to join as a research partner with the overarching Indigenous Digital Health Ecosystem project. The research will include collaboration throughout the project with a Learning Alliance including representatives from MIS customers Cowichan Tribes (British Columbia), Cowessess First Nation (Saskatchewan), Sioux Outlook First Nations Health Authority (Ontario), and First Nations Health and Social Secretariat of Manitoba (Manitoba). We will engage with the Learning Alliance table to facilitate iKT focused on the initial phases of the Knowledge-to-Action Cycle (Gagliardi et al., 2016; Graham and Tetroe, 2010). The Learning Alliance will include two separate tables comprised of (a) people who can represent the perspectives of Indigenous communities in their geographic locations such as Elders and knowledge keepers, and (b) a range of health and social service providers who use MIS products. Via focus groups and interviews, the members of the Learning Alliance will be invited to provide their own

perspectives regarding collection, reporting, and use of QOL data. This information will help to contextualize and adapt research findings on QOL as they relate to Indigenous communities.

Keywords Indigenous health; digital health; Indigenous wellbeing; Indigenous quality of life.

Dissemination plans Results will be made freely available online via the http://www.healthyqol.com website. Dissemination of the results of this systematic review will occur collaboratively with MIS and the Learning Alliance tables. A variety of online and in-person dissemination modalities will be considered, depending on what best suits the Indigenous communities that are interested in the results of this research. The results will also be disseminated via conference presentations and a peer-reviewed manuscript.

Contributions of each author
Author 1 - Monica Friesen - Designing the review, preliminary analysis to inform development of the protocol, writing the protocol, data collection and management, data analysis and interpretation, writing the review manuscript.
Author 2 - Kathleen Lounsbury - Preliminary analysis to inform development of the protocol, editing the protocol, data collection and management, critical revision of data analysis and interpretation, editing the review manuscript.
Author 3 - Ayumi Sasaki - Editing the protocol, data collection and management, critical revision of data analysis and interpretation, editing the review manuscript.
Author 4 - Reilly Baldwin - MIS and Learning Alliance liaison, editing the review protocol, editing the review manuscript.
Author 5 - Paul Foth - Coordinating review planning, liaison for all IDHE project partners, editing the protocol, editing the review manuscript.
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Author 7 - Rick Sawatzky - Research lead, liaison for all IDHE project partners, coordinating the review, editing the protocol, editing the review manuscript.

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