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Searching for Indigenous Health Information and Knowledges

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Key Messages

What Was the Question?

- How can we work toward reconciliation by improving search methods for CADTH projects on Indigenous health topics?

What Did We Do?

- We scanned the library and information science literature to find mention of searching for Indigenous topics.
- We examined a list of key journals to determine their inclusion in bibliographic databases.
- We analyzed a set of evidence reviews to assess their search methods.
- We expanded the library collection to include Indigenous research methodologies.

What Did We Find?

- Standard biomedical sources for literature searching do not include the full spectrum of Indigenous health information and Indigenous Knowledges.
- Development of research and literature searching methodology for Indigenous health topics must ensure Indigenous Knowledges are respected and Indigenous communities are consulted.

What Does This Mean?

- Current search methods may not adequately retrieve relevant sources of Indigenous health information.
- CADTH is taking steps to expand literature search methods to retrieve sources of Indigenous information.
- This work aligns with CADTH's commitment to reconciliation as outlined in our Strategic Plan and Statement of Reconciliation.
- Further engagement with Indigenous communities is needed to help ensure respect is maintained in CADTH's reconciliation work moving forward.

What Was the Question?

CADTH defines equity as a state in which “everyone is treated according to their diverse needs in a way that enables all people to participate, perform, and engage.”¹ Equity is an important consideration in health technology assessment (HTA), which applies not only to the topics and conclusions of HTA work but also to the methods used. Equity considerations in the evidence used to assess health technologies can enhance decision-making, optimize resource allocation, improve patient trust, prevent unintended consequences, address disparities, and promote social justice.¹ As a guiding principle of its Strategic Plan, CADTH has focused attention on the ways in which Indigenous Peoples experience inequity in the health care system, and on how CADTH can work toward reconciliation with Indigenous Peoples in its work,² including in its Statement of Reconciliation, which calls on CADTH to “explore how Indigenous Knowledge Systems can inform how CADTH operates and strategizes, which could include [...] incorporating Indigenous research methodologies within operations of the organization.”³

CADTH’S Research Information Services (RIS) team conducts complex literature searches to identify the evidence used for HTA reports. The RIS team also provides access to various information resources (print collection, electronic journals, e-books, biomedical databases, and so on). Appropriate engagement with Indigenous information and Indigenous Knowledges is also a professional obligation for the RIS team. As stewards of knowledge, librarians and information specialists are at the centre of discussions about how to store, share, and use knowledge; therefore, it is important to thoughtfully consider and address how professional obligations prompt the RIS team to act with humility, integrity, and transparency when engaging with Indigenous information and Knowledges. This lens of librarianship or information science, specifically stewardship of knowledge, positions the profession to both provide access to information as well as respect the origin of that information.⁴⁻⁸ In this case, librarianship principles of good stewardship include adherence to the Canadian Federation of Library Associations’ *Truth and Reconciliation Report and Recommendations*, which provides some guidance on reconciliation and decolonization for Canadian librarians.⁹

To contribute toward CADTH’s reconciliation goal, the RIS team addressed the following questions:

- What sources of information can be used to find or engage with Indigenous health information?
- What are the information retrieval methods used to locate this information?
- What are ways to support respectful engagement with Indigenous Knowledges and Ways of Knowing?

The purpose of this article is not to draw definitive conclusions and recommendations; instead, it is meant to demonstrate how a library science framework can help to uncover the gaps in finding and accessing this type of information to inform a sensible and respectful approach to searching for Indigenous health information and engaging with Indigenous Knowledges.

This project began with a reconciliatory mindset, which includes acknowledging the limits of one’s understanding of Indigenous Knowledges and Ways of Knowing, respecting data Sovereignty, and attempting to push back against one’s own biases. “Reconciliation” has many definitions, and this project follows the definition put forward by the Truth and Reconciliation Commission.¹⁰ The first 2 authors, both members of

the RIS team, are settlers. They engaged an Indigenous-led public relations group on the initial project plan, followed by in-depth conversations with the third author, a Strategic Partner for Indigenous Engagement and Partnerships at CADTH during the project's later stages. CADTH itself is a "settler organization," an organization that was created by and for Canadian settler governments and has since been guided by the goals, beliefs, and ways of thinking of settler Canada.

Throughout this article, the terms *Indigenous (health) information* and *Indigenous Knowledges* are used. Information regarding Indigenous health is available in many formats, including print formats (e.g., books, articles, and reports), as well as oral formats (such as lived experiences, teachings, ceremonies, and personal conversations). Some information on Indigenous health is held within Indigenous Knowledges. These Knowledges are often contrasted with western, Eurocentric biomedical knowledge as being *dynamic* and *action-oriented*, but also based on *traditions* sustained over thousands of years;¹¹⁻¹⁵ necessarily *shared*;¹⁵ frequently found in *oral* rather than written forms;^{12-14,16} focused on relationships and the *interrelationality* of all things;^{12-15,17} *specific* to distinct Indigenous groups and places;^{15,17} and part of a cultural and/or spiritual *system*.^{11,13,17} The plural "Indigenous Knowledges" is used to acknowledge that there is more than 1 such Knowledge and that Indigenous Peoples are not a homogeneous group.^{13,18} Indigenous Peoples alone hold direct access to and ownership of Indigenous Knowledges, because Indigenous Knowledges are inherently associated with their ways of life. Indigenous Knowledges are described as the intellectual property of Indigenous communities in sources such as the United Nations Declaration on the Rights of Indigenous Peoples Act and the Inuit Circumpolar Council's research protocols,^{19,20} and guidance and protocols on good research emphasize that Indigenous communities control the use of these Knowledges (refer to, for instance, the OCAP [ownership, control, access, and possession] principles designed for First Nations research and the research protocols developed by the Inuit Circumpolar Council).^{12,20-22} Therefore, non-Indigenous people cannot take ownership of Indigenous Knowledges.¹¹ For this reason, this project – as the work of a settler organization – can engage with Indigenous Knowledges in limited ways; it is imperative not to misinterpret or misuse these Knowledges. As a result, throughout this project, Eurocentric rather than Indigenous methods have been used.

What Did We Do?

The authors conducted 2 exploratory scans, a journal analysis, and collection development activities.

Initial Exploratory Scan

To assess the literature on searching for Indigenous information, a focused search was conducted in Library, Information Science and Technology Abstracts (LISTA) and MEDLINE for the concepts "Indigenous" and "literature searching." Guidance produced by medical library associations related to Indigenous information or sources was also informally searched, but no additional material was identified this way.

Based on the small set of results, it appears that no widely agreed-upon guidance exists on this topic in the public academic sphere. Preliminary conclusions can be drawn – first, that some search tools do exist. For instance, there are several publicly available search filters (sets of search terms pre-emptively designed

by experts to be used in multiple reviews), including 1 widely known set produced by University of Alberta librarians.^{23,24} However, Indigenous health literature is poorly indexed in biomedical databases and often difficult to retrieve.²⁵⁻²⁸ It is also frequently found outside of the published literature and therefore must be searched for outside of databases that capture only published journal articles and books.^{26,29,30} It is also important to consider the implications of search terms for Indigenous Peoples, such as the impacts of including outdated or offensive terminology.^{25,26} Finally, information specialists must reflect and self-locate when working on Indigenous-focused projects and use this reflection process to determine how to conduct this work in a respectful way.^{31,32} This can affect everything from which search terms are chosen, to how the entire review is conducted.

Journal Analysis

To address the question of how to improve retrieval of Indigenous health information, an analysis of journals and databases was conducted. A list of 32 key journals in Indigenous health was generated using multiple sources: studies from past CADTH reports focused on Indigenous health; bibliographies of key papers previously identified for this project; a list compiled by an RIS team member with previous experience in publishing; and a number of research guides on Indigenous health from university libraries in Canada, including the Xwi7xwa Library at the University of British Columbia, the only Indigenous branch of an academic library in Canada. Each journal was checked to determine if it was indexed in the following databases: PubMed, Embase, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, PsycInfo, the Social Sciences Citation Index through Web of Science (SSCI), the Bibliography of Indigenous Peoples in North America (BIPNA), and the Informit Indigenous Collection.

This analysis found that the biomedical databases did not index most of the key journals; both PubMed and Embase indexed only 3 (less than 10%) of the journals. This exclusion might be due to the interdisciplinary scope of the journals, and some are also smaller journals that may not have the resources to seek inclusion in such databases. This finding suggests that standard guidance on searching for evidence synthesis (which generally recommends both PubMed or MEDLINE and Embase)³³⁻³⁵ may not be appropriate for Indigenous health topics. In contrast, both SSCI and BIPNA included either full or partial indexing of a significant number of key journals (21 [66%] for BIPNA and 12 [38%] for SSCI), suggesting that it is worthwhile to expand searching to nonmedical databases.

For several key journals not indexed in any of the databases, a Google custom search was created to search the root of each journal website URL. Based on initial tests, this Google custom search may be useful to retrieve nonindexed articles. However, 2 journals do not have dedicated title-based URLs and therefore need to be handsearched.

Subsequent Scan: Decolonizing Methods

As a complementary approach to the journal analysis, a sample set of evidence reviews on health topics about Indigenous communities was analyzed for commonly used sources. This exercise also identified examples of questions or issues raised about search terms, and examples of how and whether a review

might respectfully engage with Indigenous Knowledges or use decolonizing approaches (refer to McGregor et al. [2018]³⁶ for a definition of *decolonizing research*).

To create the sample set, MEDLINE was searched for evidence reviews (systematic, scoping, integrative, and so on) combined with CADTH's Canada filter;³⁷ terms for Indigenous Peoples; and a set of terms designed to retrieve articles that may have engaged more thoughtfully with the potential harms of Eurocentric methods, such as decolonizing, indigenizing, co-design, and cultural sensitivity or humility. This set of terms was included to capture reviews that took a decolonizing approach to their search methods; however, in limiting the search this way, it is likely that other reviews of potential interest were missed. In addition, a targeted Google search was conducted for reviews available in the grey literature.

The searches retrieved a total of 86 reviews. The literature sources used by the reviews (databases, grey literature sources, and specific journals) were aligned with the initial findings of the exploratory scan and journal analysis. Eighteen of the reviews incorporated some decolonizing approaches in their search methods. Examples included: receiving input from Indigenous advisors or Elders on search terms; deliberately including a wider range of grey literature; acknowledging the difficulties with search terms, such as whether to use outdated and offensive terminology; and reaching out directly to Indigenous partners to identify sources of information. If determined to be appropriate and of value by the HTA producer and Indigenous community partners, methods such as these examples could be incorporated into HTA projects.

Library Resource Acquisition

In tandem with analyzing methods used in literature searching, collection development activities were undertaken to expand content focusing on Indigenous health topics, Indigenous research methodology, and Indigenous Knowledges in the CADTH collection. These works were selected from library guides from Canadian universities; bibliographies of Indigenous Knowledges; online library catalogues; discussions with internal colleagues; and browsing Indigenous-owned bookstores, such as GoodMinds, Strong Nations, and Iron Dog Books. To ensure Indigenous perspectives were honoured, many purchased works were authored by Indigenous community members, centring lived experiences of these communities. When feasible, physical books were purchased from Indigenous-owned bookstores. As well, CADTH's library catalogue was updated with a progressive and reconciliatory system, based in nonharmful nomenclature and standardized vocabulary to remove potentially harmful language.^{9,38-43}

External Conversations

To build a community of practice and not rely solely on quantitative methods, the authors held informal conversations with colleagues working in evidence synthesis to gather common practices in searching for Indigenous health information. The authors are continuing to reach out to librarian colleagues in evidence synthesis and are also planning meetings with colleagues who identify as Indigenous to learn directly from them, since Indigenous people's own perspectives and experiences must be centred in this work as much as possible.

What Did We Find?

Several conclusions can be drawn from this initial work. First, there are a number of different sources for finding Indigenous health information. Second, standard approaches to information retrieval in HTA will not reach some of these sources, so it is important to employ creative search approaches, such as handsearching relevant journals and thorough grey literature searching. Third, Indigenous Knowledges and Ways of Knowing go beyond Indigenous information contained in Eurocentric biomedical types of publications, although the 2 can and do intersect. Fourth, based on the limited evidence retrieved in the scans conducted for this project, discussions of methodology regarding literature searching on topics related to Indigenous Peoples are limited in published literature. This is especially true for questions of how and whether to search for Indigenous Knowledges, although the authors do not know whether such discussion is taking place in other environments, such as within Indigenous communities and between Indigenous researchers.

Finally, the authors learned that while it is important to improve methods for information retrieval relating to Indigenous health information, development of research methods on the use of Indigenous *Knowledges*, as a type of intellectual property, must be led by Indigenous people, with settler organizations supporting that work where appropriate.^{11-13,16,17,21}

What Does This Mean?

This project has revealed that searching for Indigenous health information requires engaging with the complexities of Eurocentric research and its impacts on underrepresented communities, particularly when interacting with Indigenous Knowledges. As a result of this work, CADTH's RIS team has included new sources of Indigenous information and Indigenous Knowledges that are available in the literature, whether published in journals or in the grey literature. Searching for Indigenous health information at this time is uncertain and fluid, and therefore requires a nimble and adaptive approach. This work will contribute to broadening the evidence base that CADTH uses for its reports, providing a foundation for equity-focused HTA.

This project is an ongoing process, and we expect that our internal approach to searching on Indigenous topics will regularly be updated as our own awareness evolves. One future action the RIS team intends to take is a review of CADTH's *Indigenous Peoples – Canada* filter. The authors also intend to reach out to international colleagues in future stages of this project. Respectful engagement with Indigenous information and Indigenous Knowledges is an area of growing interest, not only in Canada, but also in other countries with significant Indigenous populations and similar experiences of colonization (refer to, for example, the Lt.Search project at the Lowitja Institute⁴⁴ and the recently published *Indigenous Referencing Guidance for Indigenous Knowledges* produced by CAVAL).⁴⁵ Although there are important differences between Indigenous Peoples across the world, work done in other countries can provide valuable learnings.



We recommend that those participating in literature searches on Indigenous topics thoughtfully consider the limitations of their perspectives as they conduct this work. If you would like more details about this work, please contact requests@cadth.ca.

CADTH's RIS team has applied librarianship principles as guideposts for providing library services for the organization,⁴⁻⁸ identifying gaps in information access and providing that information where appropriate. Adhering to evolving librarianship principles requires CADTH to balance both the equity consideration of providing information from all voices, especially underrepresented ones, and respecting Indigenous ownership of data and Knowledges. CADTH must respond to Canada's commitments to reconciliation with First Nations, Métis, and Inuit Peoples, in particular in alignment with article 31.1 of the United Nations Declaration on the Rights of Indigenous Peoples Act, which states in part that "Indigenous peoples have the right to maintain, control, protect and develop their [...] traditional knowledge. [...] They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions."¹⁹ These efforts require listening in new ways, forming meaningful partnerships, and acting with humility, integrity, and transparency.²

For CADTH, this project represents a significant first step in fulfilling its commitment to reconciliation. This work also serves as an example of the organization acknowledging its limitations, the harms it has caused and continues to cause within its work, and its proactive move to begin to address them. As organizations work toward reconciliation, avoiding harms and respecting Indigenous authority requires this type of proactive thought and deliberate action to address.

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