



Indigenous Research Principles: Contributions to Public Health Collaborations

STATE OF KNOWLEDGE

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KNOWLEDGE SYNTHESIS

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FOREWORD

The Institut national de santé publique du Québec (INSPQ) is the public health expertise and reference centre for Québec. Our mission is to support Québec's Minister of Health and Social Services, regional public health authorities, and local, regional, and national institutions in carrying out their duties and responsibilities.

Our *State of Knowledge* collection brings together a variety of scientific publications that summarize and relay what the science has to say about a given issue; it uses rigorous methods to review and analyze the scientific literature and other relevant information.

This knowledge synthesis focuses on Indigenous research principles. It aims to identify research principles put forward by Indigenous communities and organizations in Canada.

It was developed at the request of the Ministère de la Santé et des Services sociaux (MSSS) as part of the Entente spécifique en santé des Autochtones (specific agreement on Indigenous health).

This document is intended for public health professionals and anyone who, whatever their discipline, conducts research in an Indigenous setting or wants to contribute to the improvement of Indigenous health and well-being.

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GLOSSARY

Indigenous

The United Nations Permanent Forum on Indigenous Issues has determined that no formal, universal definition of Indigenous Peoples is necessary, as such a definition would emphasize some characteristics of Indigenous Peoples and thus not be representative of their diversity (1). In Canada, the term “Indigenous” (or “Aboriginal”) is used to define the original peoples who inhabited the land before the arrival of European colonizers and their descendants. The *Constitution Act, 1982* recognizes three distinct Indigenous Peoples: First Nations (Status and Non-Status), Inuit, and Métis.

In Québec, the term “Indigenous” generally encompasses ten First Nations and Inuit, as no legally and politically recognized, historic Métis community exists in the province. These ten First Nations are the Wabanaki (Abenaki), Anishnaabe, Atikamekw Nehirowisiwok, Eeyou (Cree), Huron-Wendat, Innu, Wolastoqiyik Wahsipekuk (Maliseet), Mi’kmaq (Micmac), Kanyen’kehà:ka (Mohawk), and Naskapi. Inuit in Québec live in the territory of Nunavik, mainly in one of 14 communities along the shores of the Hudson and Ungava bays.

Indigenous communities

The term “Indigenous community” is commonly used to designate a place inhabited by a group of Indigenous people who recognize their family, cultural, and historical ties. Culturally, linguistically, and geographically diverse, these communities also exhibit political and administrative diversity due to jurisdictional issues (2). Federal authorities have legally established several communities as reserves under the *Indian Act* (3).

In Québec, growing numbers of Indigenous people live in cities for various reasons, and this urban presence is characterized by increased travel between the city and rural communities. Individuals may belong to both an urban Indigenous community and an Indigenous community on Indigenous territory (4).

Inuit Nunangat

Inuit Nunangat is the territory—including the land, water, and ice—inhabited by Inuit in Canada; in 2022, the federal government recognized it as a distinct region (5). Inuit Nunangat includes four territories: the Inuvialuit Settlement Region, Nunavut, Nunavik, and Nunatsiavut. Nunavik is in the Arctic region of Québec and comprises 14 villages located along the shores of the Hudson and Ungava bays (6).

Indigenous organizations

In this synthesis, “Indigenous organization” refers to a variety of Indigenous groups, including non-profit organizations, ethics committees, political representative bodies, and band councils. These organizations self-identify as Indigenous and may act at national, regional, or local levels. They may, for example, provide services to Indigenous people or promote Indigenous peoples’ cultures, interests, or rights. The mandates of each Indigenous organization that published a document included in this synthesis are detailed in Appendix 3.

HIGHLIGHTS

Indigenous organizations and communities have developed research principles to raise researchers' awareness of ethical issues in research involving Indigenous populations, with the aim of decolonizing practices and knowledge.

These principles and their usefulness in supporting public health actions appear to be of interest to the Québec public health network. This synthesis aims to identify, through a systematized review of the grey literature, the research principles put forth by Indigenous organizations in Canada.

Nineteen documents were analysed. The identified principles have been grouped into eight categories for ease of comprehension:

- Self-determination
- Relationship building
- Respect for local needs and priorities
- Positive impacts and capacity building
- Respect for culture and values
- Recognition of Indigenous knowledge
- Respect for consent and confidentiality
- Data governance

These categories are not presented in order of priority. They are also porous: for instance, self-determination cuts across all eight categories. There is consensus on these principles among the documents analyzed, and the principles are consistent with the findings of other similar reviews conducted in Canada.

Reviewing Indigenous research principles can deepen knowledge of Indigenous peoples' cultural realities, strengthen dialogue, and support discussion of parameters for collaboration that respect Indigenous communities' autonomy, to ultimately improve health and well-being.

None of the principles identified were developed specifically for public health. However, they echo key public health values, including equity and collaboration, and can contribute to ethical analyses of public health issues.

SUMMARY

Background

For the past twenty years, Indigenous organizations and communities have put forward research principles to raise researchers' awareness of ethical issues in research involving Indigenous populations and to redress power imbalances. In Canada, non-compliance with ethical rules in research involving Indigenous people and populations has been reported through the work of commissions of inquiry, including the Truth and Reconciliation Commission, and ensuing studies. Links between research and colonialism have also been established. Principles made and determined by Indigenous Peoples are thus in line with aims to decolonize practice and knowledge not just in research, but also in science more generally.

Knowledge of these principles and their usefulness in supporting public health actions are of interest for improving health and well-being. Increasing numbers of health actors are keen to improve their skills in working appropriately with First Nations and Inuit on factors that influence their health at the population level.

To our knowledge, no review of Indigenous research principles has been carried out in Québec, in contrast to elsewhere in Canada. The Ministère de la Santé et des Services sociaux (MSSS) therefore mandated the INSPQ to carry out a knowledge synthesis addressing the following question: what research principles have been put forward by Indigenous organizations in Canada? The aim is to build a picture of the factors likely to foster respectful collaborations with First Nations and Inuit in public health actions.

Methodology

A systematized narrative review of the grey literature was conducted to identify documents that were produced by Indigenous organizations or communities and contain research principles. Expert keyword searches were carried out with the Google search engine. An advisory committee made up of representatives from Indigenous organizations in Québec contributed to the project.

Principles identified

Some 19 documents published by 17 organizations were analyzed. The principles identified in these documents were grouped into eight categories:

- **Self-determination:** Indigenous Peoples have the right to self-determination, including in research activities. Self-determination is a cross-cutting principle linked to all other categories.
- **Relationship building:** Relationship building is characterized by respect, reciprocity, honesty, fairness, and humility. It is important that researchers adopt a reflexive approach, respect communities' and organizations' protocols, and provide written research agreements.

- **Respect for local needs and priorities:** This category encompasses the usefulness and relevance of the research, which is ensured by respecting local priorities and meeting the needs of communities and organizations, involving all groups concerned, and cultivating egalitarian power relations to foster autonomy.
- **Positive impacts and capacity building:** Research should have meaningful benefits and foster capacity building, should contribute to the common good and improving living conditions, and protect participants.
- **Respect for culture and values:** includes principles such as respect for Indigenous Peoples' holistic perspectives and preserving knowledge, languages, and practices. Research must be relevant to the local social realities and take Indigenous cultural realities into account.
- **Recognition of Indigenous knowledge:** This includes respect for intellectual property rights, recognizing Indigenous knowledge, and recognizing the expertise of Indigenous communities and organizations. Cultural knowledge and practices must be considered equal to scientific knowledge.
- **Respect for consent and confidentiality:** Consent must be given ongoingly throughout the project, and participants can withdraw their consent at any time. Equity and respect for privacy, dignity, and rights are also included in this category.
- **Data governance:** Data governance mainly encompasses the OCAP® (ownership, control, access, and possession) principles. These principles are widely used by Indigenous organizations and communities as data governance guidelines for data affecting them.

Avenues for further reflection in public health

Indigenous research principles overlap with the principles of public health action, including collaboration, taking populations' needs into account, and respect for people's autonomy.

Reviewing Indigenous research principles aids in introducing public health actors to some fundamental principles of collaborating with Indigenous communities and organizations. These principles encourage public health actors to deepen their understanding of Indigenous populations' and communities' cultural realities, to strengthen their dialogue with these populations and communities, and to agree on the parameters of collaboration. This review also provides a snapshot of research priorities and requirements promoted by Indigenous Peoples in Canada.

This knowledge synthesis neither supplants nor replaces documents produced by Indigenous organizations and communities. Professionals and managers wishing to initiate collaborations, partnerships, or research with First Nations and Inuit have every advantage in learning from their Indigenous counterparts about their research requirements and principles.

1 INTRODUCTION

For the past 20 years, Indigenous organizations and communities have put forward research principles to raise the scientific community's awareness of ethical issues in research involving Indigenous populations (7, 8); these efforts have sometimes been assisted by university researchers. Their principles aim to redress imbalances in research, addressing the tendency for research, most often conducted by non-Indigenous individuals, to benefit researchers more than the participating populations (9).

In Canada, historical events illustrating this imbalance were outlined in the Truth and Reconciliation Commission's reports, which documented the mistreatment of children in residential schools (10). Recent data have shown that these abuses included medical experiments on children (11). These historical events have undermined studies with Indigenous Peoples, who may view research as "an instrument of oppression, imperialism, and colonization" (12) ^[p.1].

The academic community has also examined the issues surrounding research in an Indigenous context (8, 9, 13, 14). Likewise, Indigenous organizations and communities have identified challenges for researchers (7–9, 12, 15–21), including the following:

- Initiating collaboration prior to the project development phase
- Ensuring mutual benefits for all groups involved
- Adopting a flexible stance conducive to collaboration
- Fostering the meaningful participation of Indigenous organizations and communities, including their access to funding and involvement in decision-making
- Including and respecting Indigenous knowledge

As such, research has not always been ethically conducted nor has it always met needs of the communities involved (8, 14, 21). To rectify the situation, Indigenous organizations increasingly require that close collaboration between the parties be established right from the project development phase, so that their rights and interests are taken into account (14).

1.1 Collaboration: A fundamental of public health action

Public health research in Québec aims to advance knowledge on the factors influencing health and well-being, to inform decision-making, and to develop health-friendly public policies (22). This research is conducted by professionals and experts in the public health network, as well as by academic researchers from various fields who may be associated with organizations or institutes with research mandates (22).

In research and other activities supporting public health action, our population health approach emphasizes collaboration, partnerships, and capacity building as central concepts (23). These concepts support evidence-based decision-making in implementing interventions (24) in order

to better inform populations about their health status, provide feedback on public policy effects, and empower populations in making health-related decisions (25). They also help ensure interventions are consistent.

In Indigenous health, greater collaboration improves consideration of the determinants influencing Indigenous health (2), helps identify Indigenous people's needs while acknowledging their cultural diversity (26), and promotes better consultation between Indigenous and non-Indigenous public health actors. Reconciliation processes are fundamental to reducing social inequalities in health (27).

Increasingly, public health actors are committed to improving their practices to enhance collaboration with Indigenous Peoples by strengthening protective factors and reducing social health inequalities (15, 28–31). In Ontario, regional public health units conducted research to identify principles and practices for better collaboration with First Nations. Four fundamental principles emerged from their knowledge synthesis: respect, trust, self-determination, and commitment (29). A parallel consultation showed that the vast majority of public health unit respondents felt ill-equipped to effectively engage with Indigenous communities (30). To our knowledge, no similar investigation has been carried out in Québec.

Finally, the Truth and Reconciliation Commission of Canada's calls to action (10), the Viens Commission's recommendations, the Laurent Commission, and the tragic death of Joyce Echaquan have marked our current context and call on us to reconsider our approaches and practices. The Québec government is also committed to establishing cultural safety in the health and social services network (réseau de la santé et des services sociaux [RSSS]), through implementing culturally safe services and programs in public institutions and in RSSS employee training (32). A bill to establish cultural safety in the RSSS was introduced in the National Assembly in the spring of 2023. This approach aims to "transform health care and social services towards a better consideration of the needs, expectations, rights, and identities of Indigenous patients" (33). Collaborating with First Nations and Inuit fosters cultural safety (32).

1.2 Research question and target audience

To support public health actors in building and sustaining respectful collaborations with First Nations and Inuit, the MSSS gave the INSPQ a mandate to compile a knowledge synthesis on the following question: what research principles have been put forward by Indigenous organizations in Canada?

This document is intended for public health professionals and anyone who, whatever their discipline, conducts research in an Indigenous setting or who wants to contribute to the improvement of Indigenous health and well-being.

2 METHODOLOGY

A systematized narrative review of the grey literature (36) was carried out to identify principles recommended by Indigenous organizations in Québec and elsewhere in Canada. Grey literature, which is literature published by institutions and not controlled by commercial publishing (37), was favoured over scientific literature to allow for faster identification of documents produced by recognized, credible Indigenous organizations, regardless of the Indigenous or non-Indigenous status of the authors. The principles identified were therefore formulated *by and for* Indigenous organizations and *for* non-Indigenous researchers.

2.1 Literature search strategy

To identify relevant grey literature, a keyword search was conducted using Google's search engine. This strategy involved two stages: first, Indigenous organizations in Canada were identified; second, we confirmed whether they had published documents presenting research principles. The literature search strategy was developed in partnership with an INSPQ librarian. The selected publications include the following three concepts: "Indigenous," "research," and "principles." These concepts were then itemized into keywords, such as "First Nations" and "Inuit;" these keywords are presented in Appendix 1.

The search was conducted in French and English in May 2022. A list of websites of Indigenous organizations in Canada was created based on the results of this query. The keywords were searched via the sites' search engines or with the Google Boolean operator "site:". To increase the comprehensiveness of the results, no time restrictions were applied. When two versions of the same document were identified, the most recent was retained.

In addition, some documents were identified using the snowball method by consulting bibliographies and on the recommendations of experts and advisory committee members.

2.2 Selection criteria

For the expert Google search, the results were limited to Canada, and a maximum of 100 results were viewed in each language (step 1). For the searches of the websites of the identified organizations carried out with the Google operator "site:" (step 2), the first 10 results obtained were downloaded. The 1,433 documents identified through this strategy were evaluated by reading the title and summary (where available) to identify whether they included a detailed description of principles that should be respected in an Indigenous context. The documents were included if they had the following characteristics:

- Published by an Indigenous organization, community, or political body located in Canada
- Published in French or English
- Published in PDF format (due to the Google search strategy, which is able to search this format)

Documents were excluded if they were:

- Sample agreements between two partners
- Forms for submitting a project application
- Published by non-Indigenous organizations
- Generated through collaborations with non-Indigenous governments or collaborations with the academic or philanthropic sectors
- A review, analysis, or discussion of existing research principles (excluded to prioritize organizations that present their own principles)
- Scientific articles, books, masters' theses, PhD dissertations, presentations, or posters
- Letters to the editor, commentaries, or editorials

This first screening made it possible to select documents identified through the expert Google search (n = 75), the snowball method (n = 28), and the recommendations of experts and advisory committee members (n = 19).

A second screening was then carried out with the same criteria by two members of the team, following an independent intercoder agreement process. At the end of this step, a total of 19 documents were retained for analysis (the PRISMA flowchart for publication selection and list of documents are available in Appendix 2).

2.3 Quality assessment

Document quality was assessed using the AACODS (Authority, Accuracy, Coverage, Objectivity, Date, Significance) grey literature checklist (34); this checklist is generally used to assess the value of a document in a given field of research. It helps determine whether the document is useful and relevant, enriches the research, strengthens a position, is representative or unique, and has an influence. The analysis showed that the selected documents were published by credible Indigenous organizations and that they are representative of work on research principles in an Indigenous context.

2.4 Data extraction and analysis

A grid was used to extract the data from each of the documents using the following categories: the name of the organization, the scope of its mandate (community, province, or territory), the objective of the document, and the principles presented therein. The authors may have described these principles as skills, values, best practices, research principles, or ethical principles.

Next, an inductive, iterative approach was used to identify categories to classify the principles. The chosen analytical approach was mainly descriptive. The categorization of the principles was intended to facilitate their analysis, not to establish their order of importance or reflect the number of documents that mention them.

2.5 Advisory committee support

The full synthesis process received support from an advisory committee made up of representatives from three First Nations organizations and one Inuit organization, all based in Québec. The committee provided feedback on the project's approach, contributed to identifying existing documents, discussed preliminary findings in relation to the project's objectives, and reviewed a preliminary version of the knowledge synthesis.

The committee's suggestions helped identify documents of interest, such as the First Nations of Quebec and Labrador Health and Social Services Commission's *Toolbox of Research Principles in an Aboriginal Context* (7). This document was not included in the corpus since it did not meet the selection criteria. However, it remains a tool that can be useful in guiding collaborative research efforts.

2.6 Peer review

In accordance with the INSPQ's framework for peer review, two reviewers evaluated a pre-final version of this synthesis. The authors and external revisers have completed their declarations of interests. No real, apparent, or potential conflict of interest was found.

3 RESULTS

This results section is divided into three parts. First, the selected documents and their publishing organizations are briefly described. Then, the categories of principles are detailed. Finally, the explicitly health-related principles are presented.

3.1 Description of organizations and publications

3.1.1 Overview of publishing organizations

A total of 19 documents, published by 17 different organizations, were selected. The list of documents is presented in Table 1.

The majority of the documents come from organizations that offer pan-Canadian services (n = 7). The others are from Québec (n = 4), Ontario (n = 3), Manitoba (n = 1), Prince Edward Island (n = 1), British Columbia (n = 1), and Inuit Nunangat (n = 2). The organizations' mandates are presented in Appendix 3. The target audience and the objectives of each selected document are presented in Appendix 4.

The vast majority of selected documents were produced by First Nations organizations. Two documents were published by a single Inuit organization and one document was published by a Métis organization. The documents were published between 2003 and 2021. The activities of these organizations are mainly aimed at the following:

- Protecting and advocating for Indigenous interests and rights, including through political representation (35–39), in some cases specifically for urban Indigenous populations (40–42)
- Representing and advocating for the well-being and interests of certain subgroups of populations (e.g., women, children) (43–46)
- Providing services in health and social services (47) or education (48, 49)
- Representing a population as a Band Council (50, 51)
- Acting as an ethics committee for a community (52)

Table 1 Selected documents

Mandate scope	Organization	Year	Title	Reference
Canada	Native Women's Association of Canada	2021	<i>Native Women's Association of Canada Research Toolkit</i>	(44)
Canada	First Nation Child and Family Caring Society & Indigenous Youth Voices	2019	<i>Indigenous Youth Voices: A Way Forward in Conducting Research With and by Indigenous Youth</i>	(45)
Canada	Urban Aboriginal Knowledge Network	2016	<i>Urban Aboriginal Research Charter Template: A Guide to Building Research Relationships</i>	(53)
Canada	Urban Aboriginal Knowledge Network	2015	<i>Cadre Éthique du RCAU</i>	(42)
Canada	First Nation Information Governance Centre	2014	<i>Ownership, Control, Access and Possession (OCAP™): The Path to First Nations Information Governance</i>	(39)
Canada	Métis Centre, National Aboriginal Health Organization	2011	<i>Principles of Ethical Métis Research</i>	(46)
Canada	Assembly of First Nations	2009	<i>Ethics in First Nations Research</i>	(36)
Québec	Regroupement des centres d'amitié autochtones du Québec	2021	<i>Cadre de référence en recherche par et pour les Autochtones en milieu urbain au Québec</i>	(40)
Québec (Kahnawà:ke)	Kahnawà:ke Education Center	2021	<i>Principles, Protocols & Procedures for Conducting Education Research in Kahnawà:ke</i>	(49)
Québec and Labrador	Assembly of First Nations Quebec-Labrador	2014	<i>First Nations in Quebec and Labrador's Research Protocol</i>	(35)
Québec	Quebec Native Women	2012	<i>Guidelines for Research with Aboriginal Women</i>	(43)
Ontario	Ontario Federation of Indigenous Friendship Centres	2016	<i>USAI Research Framework</i>	(41)
Ontario (Aundeck mni Kaning First Nation)	Noojmowin Teg Health Centre	2003	<i>Guidelines for Ethical Aboriginal Research</i>	(47)
Ontario (Six Nations First Nation)	Six Nations Elected Council	2014	<i>Conducting Research At Six Nations</i>	(50)
Inuit Nunangat	Inuit Tapiriit Kanatami	2006	<i>Negotiating Research Relationships with Inuit Communities: A Guide for Researchers</i>	(37)
Inuit Nunangat	Inuit Tapiriit Kanatami	2018	<i>National Inuit Strategy on Research</i>	(38)

Table 1 Selected documents (continued)

Mandate scope	Organization	Year	Title	Reference
Manitoba	Manitoba First Nations Education Resource Centre	2014	Guidelines for Ethical Research in Manitoba First Nations	(48)
Prince Edward Island	Native Council of Prince Edward Island	2016	Research Advisory Committee: Guidance for Researchers	(51)
British Columbia	Nuu-chah-nulth Tribal Council Research Ethics Committee	2008	Protocols and Principles for Conducting Research in a Nuu-Chah-Nulth Context	(52)

3.1.2 Objectives, target audience, and methodology of the selected documents

In general, the objective of these documents is to foster more collaborative practices between Indigenous organizations, Indigenous communities, and external researchers (35, 37, 38, 40, 41, 44, 45, 48, 53), and to address ethical issues (36, 47, 49, 52).

There are three types of target audiences for these publications: both Indigenous organizations and communities and researchers outside the community (35, 40, 47); primarily Indigenous organizations and communities (43, 44); and primarily researchers outside the community (37, 42, 48, 53). Almost half of the documents do not explicitly specify who their target audience is (36, 38, 39, 45, 46, 49–52). None of the selected documents presents the methodology used to identify the research principles in a detailed manner. This observation is not surprising, since this is the case for general principles used in research.

3.2 Principles identified

The principles have been grouped into eight non-hierarchical categories (Figure 1): self-determination, relationship building, taking local needs and priorities into account, benefits and capacity building, respect for culture and values, respect for consent and confidentiality, recognition of Indigenous knowledge, and data governance. It should be noted that self-determination cuts across all the results and is linked to all identified principles. A diagram in Appendix 5 presents the eight categories and the principles (keywords) associated with each of them.

These principles are named in the majority of documents, though often using different terms. They are sometimes presented as values or position statements. All publications explicitly present principles, except for the two documents prepared by Inuit Tapiriit Kanatami (37, 38), which instead present practices to adopt or priority areas for action.

Out of a total of 19 documents, 16 include content that either is directly or indirectly related to all eight themes below. Two documents include content related to six out of eight themes. One document includes detailed content on just one of the eight themes. Thus, the selected publications largely converge around the principles found in Figure 1.

Figure 1 Categories of Indigenous research principles



The following sections describe the eight categories, including the main elements of each, as identified in the corpus.

3.2.1 Self-determination

Recognizing Indigenous Peoples' right to self-determination is a principle that cuts across all others found in the corpus. It is described as follows: "First Nations [...] have the right to self-government and self-determination, including the right to manage themselves their communities and traditional territories" (35). Several documents cite the importance of transferring skills and knowledge to communities to strengthen their research autonomy (35, 40, 42, 43, 48, 49, 52).

Several documents mention that Indigenous groups should be included in decision-making at each stage of the project to foster self-determination (35, 38, 40, 43, 47). Collaborations should be developed from the early stages of conceptualization and grant application preparation, to ensure that each partner's research priorities are well established (35, 38). To facilitate Indigenous-led research and the development of Indigenous-specific methodology, modifications that improve Indigenous access should be made to funding criteria (35, 38).

3.2.2 Relationship building

Building meaningful relationships between the research team, Indigenous organizations, and the Indigenous populations concerned appears to be a fundamental starting point for improving research practices and making them more collaborative. The corpus highlights the importance that these relationships be characterized by respect (35, 42, 43, 46, 47, 50, 51, 53), reciprocity (35, 40, 45, 46, 51, 53), honesty (35, 37, 42, 47), fairness (35, 42), and humility (35, 37, 43, 47). It is necessary for the team conducting the research to identify, in collaboration with those concerned, the individuals with whom they should make initial contact and discuss the research.

Fostering dialogue and respect

Dialogue is considered a means of exchange and collaboration that allows parties to share their perspectives (35, 45, 46). Establishing a relationship of trust is necessary for this dialogue to occur (46). Oral communication remains a favoured means of knowledge transmission today (35, 49). Meaningful relationships bring mutual benefits to all parties involved (44). Respect is important both to individuals and communities (46). Transparency is also important throughout this process (36).

Fostering reflexivity and the coexistence of knowledges

Reciprocity refers to egalitarian relationships between Indigenous communities and researchers (35, 40, 43, 45, 46, 51, 53). Reciprocity can be incorporated through the adoption of a Two-Eyed Seeing approach, which promotes the coexistence of Indigenous and non-Indigenous knowledges and practices (35, 51). Several organizations emphasize the importance of adopting a reflexive research approach to identify the perspectives (Indigenous or non-Indigenous) from which new knowledge is generated (40–42, 49). This involves examining and observing oneself in order to become aware of one's own biases or prejudices, among other things (35, 44).

Participatory action research approaches have also been deemed relevant, as they challenge the power relations between researchers and the individuals affected by research, by recognizing the expertise of the latter (41, 43). This is essential for respecting the autonomy of Indigenous communities and organizations (41, 43). Some documents remind us that these relationships are often marked by a power imbalance stemming from colonial history (36, 42).

Respecting local protocols

For collaboration to be respectful, the research process must be transparent and local protocols, where they exist, should be taken into account (36). These protocols could include such things as guidelines from a community's band council regarding the process for project evaluation. Flexibility is important for facilitating collaborations (40). When a project is presented to a community early—for example, during the preparation of the research proposal—it can help develop an approach that's relevant to Indigenous realities (35, 42). The importance of adhering to timelines is mentioned in one document (36). Collaborating with the groups concerned from the beginning of a project facilitates community participation (35–37, 43, 49).

3.2.3 Taking local needs and priorities into account

This category includes various principles related to one of the objectives of research, which is to meet the needs of the populations studied (35, 37, 40–44, 48–50). The principles of usefulness (41) and relevance (40, 51) have been included in this category. Documents also present principles that emphasize the importance of knowing the community's context (46) and adapting funding to needs (38). One principle also links the participants' needs to their involvement: "Nothing about us without us" (42).

Respecting Indigenous research priorities

The corpus recommends that the research team hold discussions on the needs of the participating Indigenous population prior to the project's implementation (35, 38, 42). In this respect, it appears important that the people concerned are able to actively participate, according to their capacity, in each stage of the research project (45). Research projects require time and energy from organizations and communities, so they expect "the research [to] be useful, culturally relevant, and meaningful" (40). Project leaders could collaborate with a committee made up of Indigenous representatives, for example, to ensure these expectations are met (47).

Including the various groups concerned

To highlight the heterogeneity of Indigenous communities, organizations emphasize the importance of fostering the participation and inclusion of a greater diversity of subgroups of people (42, 45). For example, women possess knowledge distinct from that of men and their voices are often excluded from research (36, 43). Yet, they "hold specific knowledge and must have equitable representation in discussions and decision-making" (43). Several organizations also cite the inclusion of youth, Elders, and people of diverse genders and sexualities (45, 46). Research with youth can support capacity development while promoting Indigenous languages and cultures (45).

Ensuring funding

Most research projects are initiated, funded, and led by non-Indigenous people (39). To reverse this trend and respect the autonomy of communities and organizations, Indigenous access to funding agencies must be improved (38). Also, translation services and consulting fees should be provided to facilitate the participation of various community members, including Elders (36).

3.2.4 Positive research impacts, capacity building, and participant protection

Indigenous organizations call for research to provide benefits (35, 47), contribute to capacity building (40, 48), protect participants, and be useful (42, 46, 52).

Creating positive impacts

Research must generate positive impacts for communities (35, 37, 45), including Indigenous populations in urban areas (40–42). Organizations want the time and energy that communities

invest in projects to help improve people's lives, promote reconciliation, and support Indigenous aspirations (40). More broadly, they emphasize that research must serve the common good (42). To achieve this, the expected benefits for each of the parties should be specified at the beginning of the project (40). According to a community health centre, research should collectively and directly focus on the health benefits for communities (47).

Supporting capacity building

The vast majority of organizations emphasize that research can contribute to capacity building and empowerment (35–38, 40, 42, 44–46, 48–50, 53) for both individuals and groups (40). To do so, one organization recommends offering workshops, training, or internships and ensuring that a budget is earmarked for this purpose (40). Funding to support participation in projects is cited as a way to promote capacity building (38). At the socio-community level, research activities can, for example, be used to promote knowledge, language, well-being, and self-esteem (45, 49).

Participant protection

The protection of research participants emerges as an essential element (40, 42, 46, 50). One document mentions that research activities must “protect the well-being of individuals and communities, minimize side effects, and ensure that research serves the common good of society” (42). The importance of creating “safe and inclusive environments” (46) is also highlighted (45). In addition, as Indigenous populations continue to cope with the effects of historical trauma on their health and well-being, researchers must collaborate with the community at the beginning of the project to ensure that participants will have immediate access to support and healing services if the planned activities are likely to trigger traumas. These services will be chosen by the Indigenous respondent or in collaboration with the researcher (40). Participant protection also extends to the dissemination of knowledge, because inadequately presenting certain results can lead to stigmatization (48).

3.2.5 Respect for cultural realities

Respect for cultural realities and Indigenous values is an important element in the corpus. A number of principles are involved, such as “respecting the holistic vision of Indigenous Peoples” (35, 43, 45) and contributing to “the preservation of traditional knowledge, languages, and practices” (48). Achieving this requires the researchers to prepare prior to collaborations and show sensitivity to the context.

Respecting Indigenous worldviews

The importance of recognizing that participants have “a diverse set of ways of knowing, lenses, or worldviews” (46) is described as a principle, as is the importance that research respect Indigenous worldviews (44). Several principles require researchers to adopt an approach and methodology that respect Indigenous values, cultural realities, and worldviews (42, 46, 47, 49). Some principles suggest promoting the preservation of knowledge, languages, and practices, especially to improve participants' research experiences (45, 48). Within a group, participants may have diverse ways of knowing or worldviews (46).

Be prepared and sensitive to the context

The importance of following a community's protocols and being culturally sensitive is emphasized (36, 49). Authors note that good intentions are not enough and that preparation is required (49), including researchers understanding the impacts of colonization on communities before undertaking projects (35, 44, 49). They have a responsibility to "people's lives, stories, communities, and the land" (44).

3.2.6 Respect for consent and confidentiality as well as ethics review

All documents include the principles of respect for free and informed consent and for confidentiality. Consent can be obtained on an individual level, as is generally required in research, but also on a collective level (46). The notion of consent is "negotiated throughout the project" and "at any time participants can choose the option to withdraw their consent" (42). In terms of ethics, documents also mention the importance of "privacy, dignity, cultures, traditions, and rights" (35).

When research is conducted within a community, organizations recommend obtaining consent in a contract written, negotiated, and approved by the community (36), in which the right of withdrawal is clearly stated (40). It is suggested that documentation be presented in plain, easy-to-understand language and that local customs and protocols be taken into account in obtaining consent (36). For children and youth participants, consent must be obtained from a parent or guardian (49). Researchers must also ensure the confidentiality and anonymity of participants, organizations, and communities, unless the participants have opted to have certain information disclosed when the results are reported (49).

Ethics reviews of projects

Organizations ask that, in addition to conducting the necessary ethics reviews at universities and research institutions, community-specific ethics review processes be followed and respected (35, 38, 47–52). Some Indigenous communities, nations, and organizations have their own review committees, and their approval is required before starting research (48, 50–52). One community, for example, states that its ethics committee aims to protect the integrity of Indigenous knowledge, culture, and community members as well as to prevent any kind of abuse (50).

3.2.7 Contributions of Indigenous knowledge

This category includes principles such as respect for intellectual property rights (36), respect for Indigenous knowledge (43), recognition of Indigenous knowledge (53), and inclusion of cultural knowledge and practices (53). First Nations are "the guardians, interpreters, and collective owners of their cultures and [...] knowledge systems" (35). The importance of recognizing "the strengths, knowledge, experiences, and culture" (49) of communities is cited. Specifically, it is crucial to "recogniz[e] communities and Indigenous people as experts in the research process," including in authorship (42).

Protecting and respecting Indigenous knowledge

Indigenous knowledge can be defined as a “cumulative body of knowledge, practices and beliefs, evolving by adaptive processes and handed down through generations” (54)^[p.7] (35). The active participation of Indigenous people in data interpretation fosters the inclusion of Indigenous knowledge (35). The principles state that this knowledge must be respected in the same way as peer-reviewed scientific knowledge (37, 43). The corpus highlights the importance of respecting and recognizing Indigenous knowledge in its diversity (40), including Oral Traditions (51). Indigenous groups may inform researchers of what information must be protected in a project (48). Indigenous expertise, experiences, values, know-how, and life skills must be respected and valued (40, 41).

The intellectual property of Indigenous knowledge is also mentioned in the corpus (35, 36, 41). The Assembly of First Nations Quebec-Labrador notes challenges in protecting this knowledge as intellectual property: according to the Canadian legal framework, copyrights, research, discoveries, etc., must be attributed to identifiable individuals and apply only to new data (35). It is therefore important, given the nature of Indigenous knowledge, that explicit agreements be made between Indigenous people and researchers to protect the disclosure and use of their knowledge (35). That said, two international documents give special attention to Indigenous Peoples’ intellectual property rights: the *United Nations Declaration on the Rights of Indigenous Peoples* (35) and the *Universal Declaration of Human Rights* (36, 41).

Recognizing contributions of Indigenous partners

Several organizations emphasize the importance of formally recognizing the contributions of Indigenous partners in research publications. This acknowledgement could take the form of a co-author status for the community members who have actively participated in the co-construction of knowledge and in the publications (35, 37). Another document mentions the importance of fully recognizing communities as the authors and guardians of the knowledge (self-voicing) (41).

Some documents indicate that research must not only promote inclusion and participation, but also recognize Indigenous people as Knowledge Keepers with the ability to define their own practices for the production and transmission of knowledge (41). Indigenous participation in knowledge production and dissemination, along with author status, constitute a political process to decolonize research (41). Observance of Indigenous principles makes it possible to adopt a decolonial stance in research activities, while non-observance results in a colonial stance that undermines Indigenous knowledge (44). One document mentions that local knowledge, experiences, and narratives are reliable and valid forms of knowledge (41). Another cites the importance of recognizing that Indigenous people are collective bearers of knowledge and practices, and that they act as the guardians of this knowledge (41).

Supporting participation in results interpretation

Indigenous organizations advise against taking Indigenous knowledge out of its context, especially since seeking its scientific validation can be considered offensive (35). Several documents stressed the importance of allowing communities to participate in data interpretation (35, 43, 44, 46) and returning the results to them (35, 37, 39, 41, 43, 45, 48). Organizations emphasize the importance of “valuing the unique knowledge, skills, and expertise of Elders and Knowledge Keepers” (40), including in interpreting data. Others emphasize the importance of women’s participation in interpreting and validating results (43, 44). Matters of knowledge, such as its protection and interpretation, must be discussed prior to research activities (47).

3.2.8 Data governance

This category covers principles for data governance, including the OCAP® principles for data: ownership, control, access, and possession. This section also describes the importance of producing a research agreement.

Compliance with OCAP® principles

The OCAP® principles are widely used by Indigenous organizations and communities as a framework for data governance (39). These principles assert that First Nations have control over data collection processes and how this data can be used (39). They are shared by all the organizations that produced documents in this corpus.

Some components of data governance are detailed in the following principles: “Research must be accessible, from the initial stages of the project to the dissemination of results” (45), “no research data is to be sold, transferred or reused without the prior approval of the Research Ethics Committee” (50), and “all partners [...] must be involved in making decisions and collectively sharing knowledge about [...] research, including the publication and dissemination of research outcomes” (49). Data ownership issues should be clarified at the start of the activities (37), particularly in the initial research agreement (35). The documents analyzed argue that communities’ control over data representing them is fundamental to developing their autonomy (39).

Entering into a research agreement

A signed research agreement, preferably in writing, has been identified as an important basis for governing the relationship and helps protect each party. This agreement can be used to clarify roles, expectations, responsibilities, and funding sources (35). Several documents in the corpus contain model agreements that can be adapted to different research contexts (35). The responsibilities of all actors and their accountability beyond the conclusion of a project are also put forward. Organizations also highlight the importance of providing fair compensation for participation in research (37).

3.3 Indigenous research principles and health

Few documents explicitly describe the links between adherence to these principles and the improved health and well-being of Indigenous populations. Only one document was published by a health centre of a First Nation community (47). A few documents briefly mention that collaborative research activities can contribute to the well-being (35, 38, 42, 43, 47) or improved socio-community conditions of Indigenous populations (38, 42). Documents also mention that protecting participants from potential stigma caused by disseminating results that neglect Indigenous determinants of health, among other protections, can contribute to wellness (40, 48).

4 DISCUSSION

This synthesis identifies and describes the principles presented by diverse Indigenous organizations and communities in Canada with various mandates. It appears that similar principles are valued across these documents and that these principles are consistent with the conclusions of other similar reviews (7, 29). These principles mainly aim to support collaborations with researchers so that research and outcomes benefit the populations concerned.

4.1 Avenues for further reflection for public health action

As evidenced by the results, the principles are set out to guide research with Indigenous people. With the exception of one document written by a health centre, the documents do not seem to have been written with the specific intention of guiding health research. Few explicit links are thus made between the principles and the health and well-being of Indigenous populations. However, they provide a glimpse into spaces where respect for these principles would benefit public health actions involving First Nations and Inuit in Québec. The actions included in the Programme national de santé publique (Québec's public health program) (55), the Plan d'action interministériel 2022-2025 de la Politique gouvernementale de prévention en santé (Québec's 2022-2025 interdepartmental action plan for the government's preventative health policy) (56), and the 2022-2027 Government Action Plan for the Social and Cultural Wellness of the First Nations and Inuit (57), provide examples. The involvement and collaboration of multiple partners and population groups, including First Nations and Inuit, are included as guiding principles for planning, implementing, and evaluating approaches and interventions for reducing social inequalities in health.

Self-determination: Guiding decision-making to better meet Indigenous Peoples' needs

The principle of self-determination could have been included in each of the categories as it supports the efforts of Indigenous organizations and communities to reclaim power, including over their knowledge and know-how. The ability to accept or refuse to participate in research and to exercise free and informed consent are basic components of self-determination (5, 42, 43). In addition, Indigenous people uphold their holistic vision, cultures, languages, and ways of doing and being, and this experiential knowledge should be considered on an equal plane as scientific knowledge (37, 43). Indigenous people invite researchers to participate in this process by challenging their own work.

Even if self-determination is not presented as such in the documents analyzed, it is worth recalling that it is an important determinant of the health and well-being of Indigenous populations (58). As indicated by the World Health Organization (WHO), governance processes have an impact on living conditions and "on the 'causes of the causes'" of health inequalities (59). Self-determination is associated with access to care that respects holistic health (60) and with better representation of Indigenous perspectives in public health interventions (61). Indigenous experts and representatives, invited by Canada's Chief Public Health Officer (CPHO)

to imagine the future of public health, have provided some avenues for reflection to public health organizations wishing to better respect Indigenous rights (62). These include the participation of Indigenous organizations, the relationships between these organizations and non-Indigenous public health organizations, community expertise, information sharing agreements, and data governance protocols. Similarly, the CPHO Health Professional Forum agreed on four principles of engagement with Indigenous people to address social inequalities in health: advancing reconciliation; respecting Indigenous cultures, knowledge, and history; building relationships and demonstrating humility and openness; and improving health equity and social justice (63). These elements seem consistent with the principles that have been categorized in this synthesis.

Cultural safety in health: Improving the health and well-being of Indigenous populations

Emphasized by several Indigenous organizations and communities, the recognition of Indigenous cultural realities also appears relevant to public health, particularly from a cultural safety perspective (63). Cultural safety actions involve establishing relationships and partnerships with Indigenous populations and their representative organizations (64). For public health actors, recognition may involve better knowledge of the wide diversity of Indigenous realities as well as critical reflection on their own culture, their prejudices, and power relations (33, 63). Reflexivity is recognized as important for creating culturally safe environments (32, 33). To this effect, implementing cultural safety in services and public policy development is one of the aims of the 2022-2027 Government Action Plan for the Social and Cultural Wellness of the First Nations and Inuit (57). It also includes a measure targeting health promotion and prevention, including suicide prevention, among First Nations and Inuit.

The importance of respecting Indigenous research principles for essential data collection

Still today, known data access issues limit our ability to obtain a full picture of the health and well-being of Indigenous populations across Canada (65). As a result, it is difficult even for public health actors, both non-Indigenous and Indigenous, to assess what is going well in these populations, identify priority needs, and implement consistent actions to improve their health status (14, 17, 21, 26, 66). By setting out research principles, Indigenous organizations and communities provide guidelines for ethically and respectfully collecting data about them.

In Québec, in addition to data collected by organizations and communities on the state of populations, two major surveys provide an overview of the health and well-being of First Nations and Inuit: the First Nations Regional Health Survey for Québec and Labrador (67) and Qanuilirpitaa? 2017 (68). These two surveys are overseen by Indigenous organizations and demonstrate the potential of adopting a different approach that respects Indigenous research principles. The data obtained with the full collaboration of Indigenous people generally highlight the strengths of Indigenous Peoples and the uniqueness of each Nation, community, and living environment. The data also reflect Indigenous views of health and well-being, and generally attribute equal value to ancestral, experiential, and scientific knowledge (62). Finally, these data collection methods are consistent with some of the key values in public health, such as equity, the common good, beneficence, responsibility, and accountability (69).

4.2 Strengths and limitations

4.2.1 Strengths

This synthesis is based on documents published by Indigenous organizations located in Québec and elsewhere in Canada who have an excellent knowledge of research ethics issues and of developing collaborations with Indigenous people. It is an introductory document intended for a broad audience unfamiliar with research conducted with Indigenous populations. Its drafting process also benefited from the expertise of an advisory committee made up of representatives of Indigenous organizations.

The methodological decision to exclude scientific articles in favour of grey literature may have an impact on the results, as several Indigenous experts and researchers contribute to discussions on how to improve research practices. However, the use of grey literature makes it possible to highlight documents that have been approved by Indigenous communities and organizations. Moreover, Indigenous organizations' guidelines or main research principles are generally more often stated in grey literature than in scientific literature. Finally, the range of documents identified suggests that the results obtained are broadly representative of Indigenous research principles.

4.2.2 Limitations

Among other methodological limitations, it should be noted that grey literature searches using the Google search engine could only retrieve documents publicly available on the Internet. This is a considerable limitation, as many communities likely do not publish their principles online. Additionally, organizations may have put forward illuminating content without using the term "principle," which would have resulted in the exclusion of such relevant documents from this synthesis. Added to all this are the limitations inherent to the Google search engine, such as search history and the user's geographical location.

5 CONCLUSION

This knowledge synthesis identifies research principles formulated by Indigenous organizations and communities located in Canada. These principles fall under the broader context of decolonizing knowledge and practices. In becoming familiar with these principles, public health actors can deepen their understanding of the cultural realities of Indigenous populations and communities, strengthen their dialogue with these populations and communities, and agree on the parameters of collaboration.

Grouped into eight categories, the principles are consistent with those put forward in other work. While the results are useful in providing a clear picture of Indigenous communities' and organizations' research requirements, this synthesis does not take precedence over documents produced by Indigenous organizations and communities. For public health actors, this synthesis should therefore not replace further examination of the principles proposed by the Indigenous communities and organizations they wish to collaborate with. The principles may have different meanings in different contexts.

Although they have not been developed specifically for public health, these principles appear relevant to public health action, especially in fostering collaboration with First Nations and Inuit. The collaborative approach, which is fundamental to public health, appears essential to redress the social inequalities in health that these populations face.

6 REFERENCES

1. Department of Economic and Social Affairs of the United Nations Secretariat. State of the world's Indigenous peoples. United Nations Publications; 2009.
2. Bergeron O. Cadres des déterminants de la santé : caractéristiques et spécificités en contexte autochtone. 2022; Disponible : <https://www.inspq.qc.ca/sites/default/files/publications/2888-determinants-sante-caracteristiques-autochtone.pdf>
3. Lepage P. Mythes et réalités sur les peuples autochtones. 3^{ème} édition mise à jour et augmentée [Internet]. Commission des droits de la personne et des droits de la jeunesse et Institut Tshakapesh; 2019. Disponible : <https://www.cdpdj.qc.ca/storage/app/media/publications/Mythes-Realites.pdf>
4. Lévesque C. La présence autochtone dans les villes du Québec: tendances, enjeux et actions [Internet]. Montréal: Alliance de recherche ODENA, Réseau de recherche et de connaissances relatives aux peuples autochtones (DIALOG) et Regroupement des centres d'amitié autochtones du Québec; 2016 [cité 15 août 2023]. (ODENA). Report No.: 2016-01. Disponible : <https://reseaudialog.ca/wp-content/uploads/2020/05/CahierODENA-2016-01.pdf>
5. Relations Couronne-Autochtones et Affaires du Nord Canada. Politique sur l'Inuit Nunangat [Internet]. 2022. Disponible : <https://www.rcaanc-cirnac.gc.ca/fra/1650556354784/1650556491509>
6. Inuit Tapiriit Kanatami. About Canadian Inuit [Internet]. Disponible : <https://www.itk.ca/about-canadian-inuit/>
7. Commission de la santé et des services sociaux des Premières Nations du Québec et du Labrador (CSSSPNQL), Université du Québec en Abitibi-Témiscamingue (UQAT), Université du Québec en Outaouais (UQO), Réseau DIALOG. Boîte à outils des principes de la recherche en contexte autochtone : éthique, respect, équité, réciprocité, collaboration et culture. 3^e édition. [Internet]. 2021. Disponible : https://reseaudialog.ca/wp-content/uploads/2022/02/Boite_Outils_Principe_Recherche_Contexte_Autochtone_2021.pdf
8. Smith LT. Decolonizing methodologies : research and Indigenous peoples. Bloomsbury Publishing; 2021.
9. Gentelet K. Les conditions d'une collaboration éthique entre chercheurs autochtones et non autochtones. Cahiers de recherche sociologique. 2009; (48):143-53.
10. Commission de vérité et réconciliation du Canada. Appels à l'action [Internet]. 2012. Disponible : https://ehprnh2mwo3.exactdn.com/wp-content/uploads/2021/04/4-Appels_a_l-Action_French.pdf
11. Mosby I. Administering Colonial science : nutrition research and human biomedical experimentation in Aboriginal Communities and residential schools, 1942–1952. Histoire sociale/Social History. 2013;46(91):145-72.
12. Durst D. Partnerships with Aboriginal researchers: hidden pitfalls and cultural pressures. Saskatchewan Institute of Public Policy; 2004.
13. Asselin H, Basile SI. Concrete ways to decolonize research. ACME : An International Journal for Critical Geographies. 2018;17(3):643-50.

14. Kovach M. Indigenous methodologies : characteristics, conversations, and contexts. University of Toronto press; 2021.
15. Saini M. Revue systématique des modèles de recherche occidentaux et autochtones : évaluation de la validation croisée pour l'exploration de la compatibilité et de la convergence [Internet]. Centre de collaboration nationale de la santé autochtone; 2012. Disponible : <https://www.ccsa.ca/docs/context/RPT-ReviewResearchDesigns-Saini-FR.pdf>
16. Ellison C. Savoir autochtone et synthèse, application et partage des connaissances (SAPC) [Internet]. Prince George (C.-B.): Centre de collaboration nationale de la santé autochtone; 2014. Disponible : <https://www.ccsa-nccah.ca/docs/context/RPT-IndigenousKnowledgeKSTE-Ellison-FR.pdf>
17. Hayward A, Wodtke L, Craft A, Robin T, Smylie J, McConkey S, *et al.* Addressing the need for indigenous and decolonized quantitative research methods in Canada. *SSM-Population Health*. 2021;15:100899.
18. Flicker S, Worthington CA. Public health research involving aboriginal peoples : research ethics board stakeholders' reflections on ethics principles and research processes. *Canadian Journal of Public Health*. 2012;103(1):19-22.
19. Vukic A, Gregory D, Martin-Misener R. Indigenous health research: theoretical and methodological perspectives. *Canadian Journal of Nursing Research Archive*. 2012;146-62.
20. Institut de développement durable des Premières Nations du Québec et du Labrador. Guide de bonnes pratiques pour l'inclusion des savoirs autochtones à l'intention des Ministères fédéraux [Internet]. 2022. Disponible : https://iddpnql.ca/wp-content/uploads/2022/04/2022_02_22_Guide_FR_finale.pdf
21. Quinless JM. Decolonizing Data: unsettling conversations about social research methods. University of Toronto Press; 2022.
22. Pouliot S, Bernier NicoleF, Chapados M, Paradis. La recherche en santé publique: pour une société plus prospère, bienveillante et durable: mémoire déposé au Ministère de l'Économie et de l'Innovation dans le cadre de la consultation sur la Stratégie québécoise de la recherche et de l'innovation 2022. Québec: Institut national de santé publique du Québec; 2021.
23. Loignon C, Baptiste G, Dupéré S, Gervais L. Recherches participatives et équité en santé. Presses de l'Université Laval; 2022.
24. Centre de collaboration nationale des méthodes et des outils. La prise de décisions fondée sur des données probantes [Internet]. 2018. Disponible : <https://www.nccmt.ca/uploads/media/media/0001/02/0831bd5a03bdeda528b8c9b9d94f9cb7c2ca3d54.pdf>
25. Orielle S, Irwin A. A conceptual framework for action on the social determinants of health. *Social Determinants of Health Discussion Paper 2* [Internet]. 2010. Disponible : http://apps.who.int/iris/bitstream/10665/44489/1/9789241500852_eng.pdf
26. Commission de la santé et des services sociaux des Premières Nations du Québec et du Labrador. La santé publique chez les Premières Nations au Québec Une responsabilité partagée pour une action concertée [Internet]. 2018. Disponible : <https://files.ccsspnql.com/index.php/s/29zsJlBpszZ8KM>

27. Richmond CAM, Cook C. Creating conditions for Canadian aboriginal health equity : the promise of healthy public policy. *Public Health Reviews*. 2016;37(1):2.
28. Talking Together To Improve Health Research Team. Talking together to improve health : gathering and sharing learning [Internet]. 2020. Disponible : https://www.publichealthontario.ca/-/media/Documents/G/2020/gathering-sharing-learning-first-nations-communities-report.pdf?sc_lang=en
29. Talking together to improve health: Gathering and sharing learning. Relationship building with First Nations and public health: exploring principles and practices for engagement to improve community health – Review of the Literature [Internet]. Locally Driven Collaborative Projects; 2017. Disponible : <https://www.phsd.ca/resources/research-statistics/research-evaluation/reports-knowledge-products/relationship-building-first-nations-public-health-exploring-principles-practices-engagement-improve-community-health-review-literature/>
30. Talking Together to Improve Health Project Team. Talking together to improve health : Ontario Public Health unit survey [Internet]. Locally Driven Collaborative Projects; 2018. Disponible : <https://www.publichealthontario.ca/-/media/documents/L/2018/ldcp-firstnations-engagement-survey-report.pdf>
31. Hunt S. Revue des compétences essentielles pour la santé publique : une perspective de santé publique Autochtone [Internet]. Centre de collaboration nationale de la santé autochtone.; 2015. Disponible : <https://www.cnsa.ca/docs/context/RPT-CoreCompentenciesHealth-Hunt-FR.pdf>
32. Ministère de la Santé et des Services sociaux. La sécurisation culturelle en santé et en services sociaux – Vers des soins et des services culturellement sécurisants pour les Premières Nations et les Inuit. 2021; Disponible : <https://publications.msss.gouv.qc.ca/msss/fichiers/2020/20-613-02W.pdf>
33. Désilets G. Conditions de succès et limites des formations en sécurisation culturelle pour le personnel de santé et services sociaux [Internet]. Institut national de santé publique du Québec; 2022. Disponible : <https://www.inspq.qc.ca/sites/default/files/publications/2870-formations-securisation-culturelle-sante-services-sociaux.pdf>
34. Tyndall J. How low can you go? Towards a hierarchy of grey literature. In Alice Springs Convention Centre, Alice Springs, NT Australia: ALIA; 2008. Disponible : https://www.researchgate.net/publication/236461971_How_low_can_you_go_Toward_a_hierarchy_of_grey_literature
35. Assemblée des Premières Nations du Québec et du Labrador. Protocole de recherche des Premières Nations au Québec et au Labrador [Internet]. 2014. Disponible : <https://files.cssspnql.com/index.php/s/ksbfKhjhfcc7hTl>
36. Assemblée des Premières Nations. Éthique de la recherche sur les autochtones [Internet]. 2009.
37. Inuit Tapiriit Kanatami, Nunavut Research Institute. Negotiating research relationships with Inuit communities [Internet]. 2006. Disponible : <https://ethicshub.ca/wp-content/uploads/2020/05/23-Negotiating-Research-Relationships-with-Inuit-Communities-a-guide-for-researchers.pdf>
38. Inuit Tapiriit Kanatami. National Inuit strategy on research [Internet]. 2018. Disponible : https://www.itk.ca/wp-content/uploads/2018/04/ITK_NISR-Report_English_low_res.pdf

39. First Nations Information Governance Centre. Ownership, Control, Access and Possession (OCAP™): the path to First Nations information governance [Internet]. 2014. Disponible : https://achh.ca/wp-content/uploads/2018/07/OCAP_FNIGC.pdf
40. Regroupement des centres d'amitié autochtones du Québec. Cadre de référence en recherche par et pour les Autochtones en milieu urbain au Québec [Internet]. 2021. Disponible : https://consultation.quebec.ca/uploads/decidim/attachment/file/102/Cadre_r%C3%A9f%C3%A9rence_recherche_final_cahier.pdf
41. Ontario Federation of Indigenous Friendship Centres. USAI research framework [Internet]. 2016. Disponible : <https://ofifc.org/wp-content/uploads/2020/03/USAI-Research-Framework-Second-Edition.pdf>
42. Réseau de connaissances des autochtones en milieu urbain. Cadre Éthique [Internet]. 2015. Disponible : <https://uakn.org/fr/uakn-guiding-ethical-principles/>
43. Femmes Autochtones du Québec inc. Lignes directrices en matière de recherche avec les femmes autochtones [Internet]. 2012. Disponible : https://www.faq-qnw.org/wp-content/uploads/2016/11/FAQ-2012-Lignes_directrices_recherche.pdf
44. Native Women's Association of Canada. Native women's association of Canada research toolkit [Internet]. 2021. Disponible : <https://www.nwac.ca/assets-knowledge-centre/SPARK-NWAC-CRGBA-TOOLKIT-2022-EN1-3-Feb-15-2022.pdf>
45. Indigenous Youth Voices and the First Nations Child & Family Caring Society. A way forward in conducting research with and by Indigenous youth [Internet]. First Nations Child & Family Caring Society; 2019. Disponible : <https://fncaringociety.com/publications/indigenous-youth-voices-way-forward-conducting-research-and-indigenous-youth>
46. Métis Center, National Aboriginal Health Organization. Principles of ethical Métis research [Internet]. 2011. Disponible : https://achh.ca/wp-content/uploads/2018/07/Guide_Ethics_NAHOMetisCentre.pdf
47. Noojmowin Teg Health Centre. Guidelines for ethical Aboriginal research [Internet]. 2003. Disponible : <https://www.noojmowin-teg.ca/images/GEAR - FINAL.pdf>
48. Manitoba First Nations Education Ressource Center. Guidelines for ethical research in Manitoba First Nations [Internet]. 2014. Guidelines for Ethical Research in Manitoba First Nations. Disponible : https://mfnerc.org/wp-content/uploads/2022/09/Ethics_Full.pdf
49. Kahnawà:ke Education Center. Principles, protocols & procedures for conducting education research in Kahnawà:ke [Internet]. 2021. Disponible : https://campussuite-storage.s3.amazonaws.com/prod/1071440/916e95dd-3436-11e7-9e05-124f7febbf4a/2309974/78b872f8-0c19-11ec-bc59-0e0f3950a543/file/KEC%20EducationResearchPolicyCodeofResearchEthics_ApprovedFeb2021.pdf
50. Six Nations Elected Council. Conducting reseach at Six Nation [Internet]. 2014. Disponible : https://achh.ca/wp-content/uploads/2018/07/Protocol_Ethics_Six-Nations.pdf
51. Native Council of Prince Edward Island. Research advisory committee: guidance for researchers [Internet]. 2016. Disponible : <https://ethicshub.ca/tool/research-advisory-committee-guidance-for-researchers/>

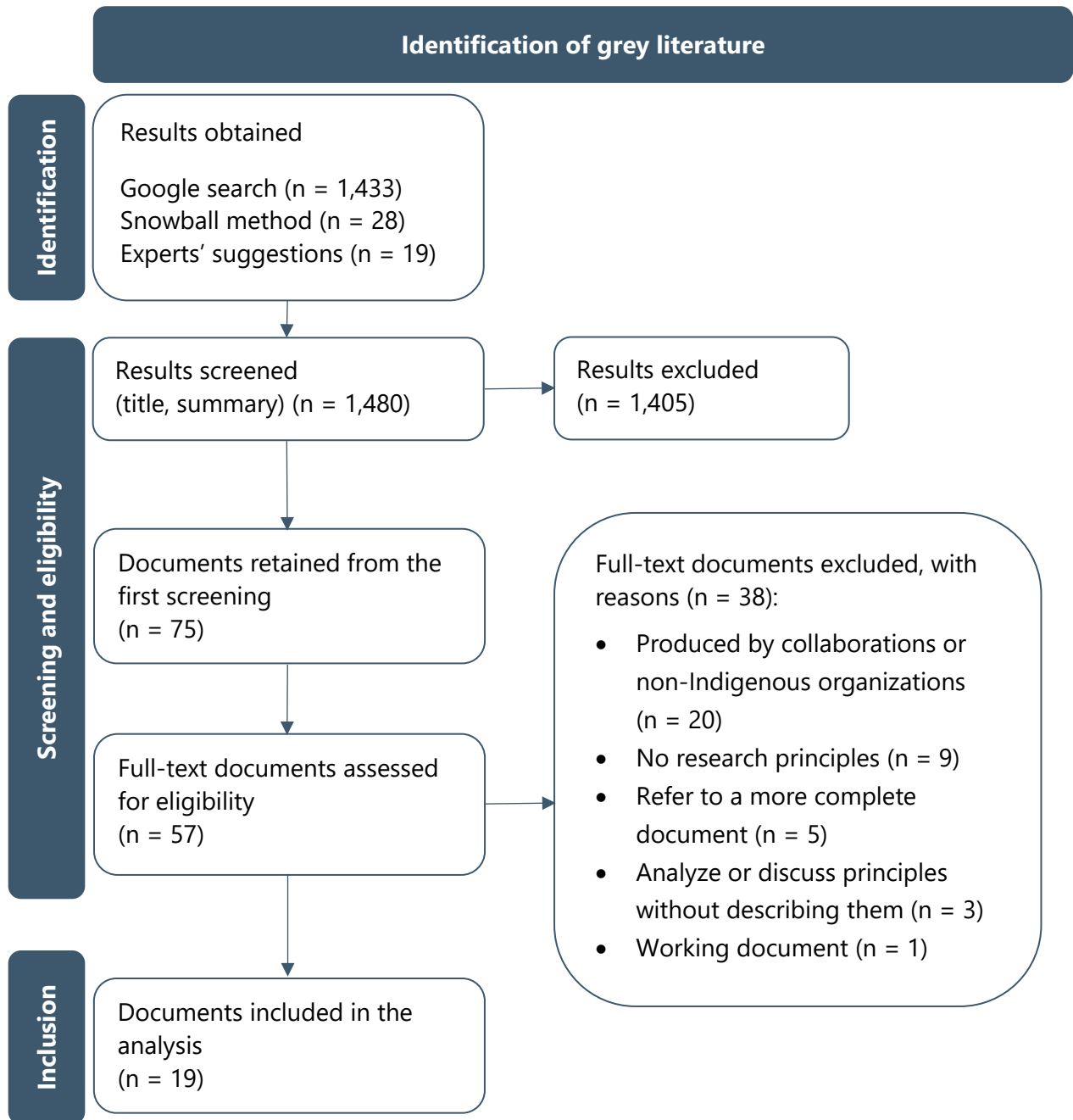
52. Nuu-chah-nulth Tribal Council Research Ethics Committee. Protocols and principles for conducting research in a conducting research in a Nuu-Chach-Nulth context [Internet]. 2008.
Disponible : <https://icwrn.uvic.ca/wp-content/uploads/2013/08/NTC-Protocols-and-Principles.pdf>
53. Urban Aboriginal Knowledge Network. Urban Aboriginal research charter template : a guide to building research relationship [Internet]. 2016.
Disponible : https://achh.ca/wp-content/uploads/2018/07/Guide_UAKN.pdf
54. Berkes F. Sacred ecology. Routledge; 2017.
55. Ministère de la Santé et des Services sociaux. Programme national de santé publique 2015-2025 [Internet]. 2015.
Disponible : <https://publications.msss.gouv.qc.ca/msss/fichiers/2015/15-216-01W.pdf>
56. Ministère de la Santé et des Services sociaux. Plan d'action interministériel 2022-2025 de la Politique gouvernementale de prévention en santé [Internet]. 2022.
Disponible : <https://publications.msss.gouv.qc.ca/msss/fichiers/2022/22-297-05W.pdf>
57. Secrétariat aux relations avec les Premières Nations et les Inuit. Plan d'action gouvernemental pour le mieux-être social et culturel des Premières Nations et des Inuit 2022-2027 [Internet]. Gouvernement du Québec; 2022. Disponible : https://cdn-contenu.quebec.ca/cdn-contenu/adm/min/conseil-executif/publications-adm/saa/administratives/plan_action/2022-2027/resume_mesures_plan_action.pdf?1655476397
58. Ng JYY, Ntoumanis N, Thøgersen-Ntoumani C, Deci EL, Ryan RM, Duda JL, *et al.* Self-determination theory applied to health contexts : a meta-analysis. *Perspect Psychol Sci.* 2012;7(4):325-40.
59. Organisation mondiale de la santé, Commission des déterminants sociaux de la santé. Comblent le fossé en une génération: instaurer l'équité en santé en agissant sur les déterminants sociaux de la santé: rapport final. [Internet]. 2009. Disponible : <https://apps.who.int/iris/handle/10665/44083>
60. Auger M, Howell T, Gomes T. Moving toward holistic wellness, empowerment and self-determination for Indigenous peoples in Canada : can traditional Indigenous health care practices increase ownership over health and health care decisions? *Can J Public Health.* 2016;107(4-5):e393-8.
61. Rasmus SM, Whitesell NR, Mousseau A, Allen J. An intervention science to advance underrepresented perspectives and indigenous self-determination in health. *Prev Sci.* 2020;21(Suppl 1):83-92.
62. National Collaborating Centre for Indigenous Health. Visioning the future: First Nations, Inuit, & Métis population and public health [Internet]. 2021.
Disponible : https://www.nccih.ca/Publications/Lists/Publications/Attachments/10351/Visioning-the-Future_EN_Web_2021-12-14.pdf
63. Agence de la santé publique du Canada. Principes de dialogue avec les Premières Nations, les Inuits et les Métis [Internet]. 2023. Disponible : <https://www.canada.ca/content/dam/hc-sc/documents/services/publications/health-system-services/chief-public-health-officer-health-professional-forum-principles-engaging-first-nations-inuit-metis/principles-engagement-fr2.pdf>

64. Institut canadien d'information sur la santé. Santé des Premières Nations, des Inuits et des Métis [Internet]. 2023. Disponible : <https://www.cihi.ca/fr/a-propos-de-licis/sante-des-premieres-nations-des-inuits-et-des-metis>
65. Smylie J, Firestone M. Back to the basics : identifying and addressing underlying challenges in achieving high quality and relevant health statistics for indigenous populations in Canada. *Stat J IAOS*. 2015;31(1):67-87.
66. Laird P, Chang AB, Jacky J, Lane M, Schultz A, Walker R. Conducting decolonizing research and practice with Australian First Nations to close the health gap. *Health Research Policy and Systems*. 2021;19(1):127.
67. Commission de la santé et des services sociaux des Premières Nations du Québec et du Labrador. L'Enquête régionale sur la santé des Premières Nations (ERS) [Internet]. 2023. Disponible : <https://cssspnql.com/enquete-regionale-sante/>
68. Régie régionale de la santé et des services sociaux du Nunavik. QANUILIRPITAA? 2017 [Internet]. Disponible : <http://nrbhss.ca/fr/la-rrsssn/sant%C3%A9-publique/enqu%C3%AAtes-de-sant%C3%A9-au-nunavik/qanuilirpitaa-2017>
69. Filiatrault F, Désy M, Bruno L. Référentiel de valeurs pour soutenir l'analyse éthique des actions en santé publique [Internet]. Institut national de santé publique du Québec; 2015. Disponible : <https://www.inspq.qc.ca/publications/2010>

APPENDIX 1 LITERATURE SEARCH STRATEGY

Language	Literature search strategy using the Google search engine
French	ext:pdf Autochtone " premières nations" inuit métis "recherche AROUND(20) protocole "lignes directrices" méthode méthodologie principe Décolonisation"
English	ext:pdf Indigenous "First Nations" Inuit Metis Aboriginal maori "research AROUND(20) guideline ethic protocol method methodology Principle Decolonization"

APPENDIX 2 PRISMA FLOWCHART



APPENDIX 3 MANDATES OF THE ORGANIZATIONS INVOLVED

Organization	Mandate
Assembly of First Nations	National political representation body of First Nations in Canada.
Assembly of First Nations Quebec-Labrador	Regional political representation body of First Nations in Québec and Labrador.
First Nations Child and Family Caring Society & Indigenous Youth Voices	Organization that aims to support the health and education of First Nations children, youth, and families to ensure access to equal opportunities. Helps network Indigenous youth and their associations and support Indigenous youths' priorities as defined by Indigenous youth.
First Nations Information Governance Centre	Non-profit that develops and administers Canada-wide First Nations surveys in collaboration with regional partners.
Inuit Tapiriit Kanatami	National Inuit organization that represents the four Inuit regions in Canada and protects the rights and interests of these populations.
Kahnawà:ke Education Center (KEC)	Kahnawà:ke community organization that administers programs and services for students in Kahnawà:ke.
Manitoba First Nations Education Resource Centre	Organization that provides specialized education services to First Nations schools in Manitoba and supports the implementation of programs designed for these communities.
Métis Centre, National Aboriginal Health Organization	National Métis non-profit associated with the National Aboriginal Health Organization (NAHO). Dedicated to improving the mental, physical, spiritual, emotional, and social health of all Métis in Canada.
Native Council of Prince Edward Island	A community of people living off-reserve in traditional Mi'kmaq territory.
Native Women's Association of Canada	National organization that represents the political voices of Indigenous women, girls, and gender-diverse people in Canada, with the aim of enhancing, promoting, and fostering their well-being.
Noojmowin Teg Health Centre	Organization based in the Aundeck Omni Kaning community that promotes wellness through Anishinabek healing practices, holistic health care, and community programs.
Nuu-chah-nulth Tribal Council Research Ethics Committee	Nuu-chah-nulth Tribal Council Ethics Committee.
Ontario Federation of Indigenous Friendship Centres	Organization that aims to improve the quality of life for Indigenous Peoples in Ontario by supporting equity and self-determination.
Quebec Native Women	Organization that represents Indigenous women in Québec, including those living in urban areas.
Regroupement des centres d'amitié autochtones du Québec	Provincial association that campaigns for the rights and interests of Indigenous people living in cities in Québec.
Six Nations Elected Council	Band Council of the Six Nations community.
Urban Aboriginal Knowledge Network	National organization that aims to contribute to a better quality of life for urban Aboriginal people.

APPENDIX 4 TARGET AUDIENCE AND DOCUMENT OBJECTIVES

Organization	Target group	Document objectives
Assembly of First Nations	n/a	Help fill gaps in research ethics and highlight the problems faced by potential researchers and First Nations wishing to promote ethics.
Assembly of First Nations Quebec-Labrador	Community leaders and managers, scientific community	Support First Nations solicited to participate in research or in conducting their own research activities. Encourage the scientific community to give this protocol the same consideration as other documents used in research institutions.
First Nations Child and Family Caring Society & Indigenous Youth Voices	n/a	Provide a tool to rethink and reshape research so that it is meaningful, inclusive, and respectful of all Indigenous youth.
First Nations Information Governance Centre	n/a	Describe the origin and relevance of the OCAP® principles, as well as case studies, challenges, and future prospects.
Inuit Tapiriit Kanatami	n/a	Describe the actions needed to improve how research in Inuit Nunangat is governed, funded, conducted, and disseminated.
Inuit Tapiriit Kanatami	Researchers	Improve research collaborations in Canada's Inuit communities, including by identifying the roles and responsibilities, mutual benefits, and expectations of each party.
Kahnawà:ke Education Center	n/a	Describe the KEC Research Policy & Code of Ethics on all research partnerships and activities. Detail the principles, protocols, and procedures to follow for conducting educational research in partnership with the KEC.
Manitoba First Nations Education Resource Center	Individuals, organizations, and communities interested in conducting research with First Nations in Manitoba	Provide a framework for First Nations and researchers considering conducting research in First Nations communities in Manitoba.
Métis Center, National Aboriginal Health Organization	n/a	n/a
Native Council of Prince Edward Island	n/a	Present principles and guidelines to protect individual and community data and information and the intellectual and cultural knowledge of Indigenous people living in urban areas and off-reserve.
Native Women's Association of Canada	Association health team members	Provide guidance on how to collaborate with the Association in research activities.
Noojmowin Teg Health Centre	Local and external health agencies and researchers	Promote ethically conducted health research in First Nations communities in the Manitoulin District. Present tools and strategies designed to help organizations and communities make informed decisions on health research development and management in their communities.

Appendix 4 Target audience and document objectives (continued)

Organization	Target group	Document objectives
Nuu-chah-nulth Tribal Council Research Ethics Committee	n/a	Present the protocols and principles to respect in research in a Nuu-chah-nulth context.
Ontario Federation of Indigenous Friendship Centres	n/a	Guide all research projects conducted by the Federation in Indigenous contexts and in urban Indigenous communities in which the Federation is involved.
Quebec Native Women	Indigenous women, Indigenous women in Québec, community decision-makers and managers	Equip Indigenous women and Indigenous organizations to make informed decisions regarding the many research project proposals they receive and to establish egalitarian, transparent and mutually respectful relationships.
Regroupement des centres d'amitié autochtones du Québec	Indigenous people participating in a research project in one of the Native Friendship Centres of Québec; urban Indigenous organizations; researchers, students, academic or private sector research groups or ethics committees; other actors affected by Indigenous research in urban areas	Provide guidelines for organizations outside the Friendship Centre Movement to support research based on equitable collaboration and real co-construction. Additionally, support urban Indigenous organizations solicited to participate in research and evaluation projects.
Six Nations Elected Council	n/a	n/a
Urban Aboriginal Knowledge Network	Researchers, academics, communities, partners, and organizations	Complement the core principles of the Tri-Council Policy Statement 2 and present the most common research ethics considerations of Indigenous communities.
Urban Aboriginal Knowledge Network	Researchers	Support the development of research protocols that facilitate meaningful dialogue and partnerships between urban Indigenous organizations and researchers. Specifically designed for those who wish to foster collaborations to meaningfully contribute to the well-being of urban Indigenous people and the common good of our communities.

APPENDIX 5 CATEGORIES AND RELATED PRINCIPLES



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