

Indigenous Data and Evaluation Framework

ABORIGINAL HOUSING
MANAGEMENT ASSOCIATION

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List of Acronyms

CARE: Collective Benefit, Authority to Control, Responsibility, and Ethics

CIPA: Common or Integrated Program Agreement

DRIPA: Declaration of the Rights of Indigenous Peoples Act

FIBI: For Indigenous, By Indigenous

FIPPA: Freedom of Information and Protection of Privacy Act

ICES: Institute for Clinical Evaluative Sciences

IDAC: Indigenous Data Advisory Committee

MMHA: Ministry of Mental Health and Addictions

MMIWG: Missing and Murdered Indigenous Women and Girls in Canada

NICHI: National Indigenous Collaborative Housing Inc.

OCAP: Ownership, Control, Access, and Possession

OCAS: Ownership, Control, Access, and Stewardship

OFIFC: Ontario Federation of Indigenous Friendship Centres

OIPC: Office of the Information and Privacy Officer

PIA: Privacy Impact Assessment

PIPA: Personal Information and Protection Act

SUILC: Surrey Urban Indigenous Leadership Committee

TCPS2: Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans

TRC: Truth and Reconciliation Commission

UNDRIP: United Nations Declaration on the Rights of Indigenous Peoples

About AHMA

The Aboriginal Housing Management Association (AHMA) was established in 1996 with a mission to "lead and advance housing rights for all Indigenous Peoples in British Columbia." AHMA is comprised of 58 Indigenous housing and service providers located all across BC. These members manage more than 95% of all Indigenous housing units in urban, rural, and northern areas of the province (off reserve).

AHMA administers funds – in partnership with BC Housing – for almost 6,400 units that house First Nations, Métis, Inuit, and self-identified Indigenous families living off reserve. AHMA will also administer funds for approximately 1,653 units that are currently in development.

The programs and services that AHMA members provide include affordable housing units, shelters, transition homes, supportive housing, and assisted living facilities. Many of AHMA's members also offer support services including homelessness prevention, parenting supports, and mental health and addictions programs. AHMA members make up over one third of Indigenous housing providers in Canada.



Section 1: Why is AHMA developing an Indigenous Data & Evaluation Framework?

Purpose and Background

"All Indigenous people in urban, rural, and northern communities in BC will have an affordable, culturally supportive, and safe place to call home."

AHMA's Urban, Rural and Northern Indigenous Housing Strategy (2022)

The Indigenous Data and Evaluation Framework supports AHMA's long-term goal of For Indigenous, By Indigenous (FIBI) housing in four ways:

- 1. Improve awareness, capacity, and knowledge of Indigenous data governance and evaluation practices.
- 2. Advocate for the data sovereignty of Indigenous people living off-reserve in urban, rural, and northern communities.
- 3. Develop Indigenous-led approaches to data, research, and evaluation.
- 4. Develop best practices for data governance and management of Indigenous data.

This framework supports any individual or organization that engages with issues relevant to Indigenous data governance, such as:

- Culturally safe data collection with vulnerable populations.
- Including people with lived or living experience in knowledge gathering.
- Designing and conducting research, evaluation, monitoring, and assessment activities.
- Navigating data requests, access, and sharing with other agencies and government.
- Safeguarding the privacy and security of clients.

Target Audience

Our target audience is people involved in Indigenous housing and homelessness services, including AHMA members and external partners (e.g., BC Housing). However, agencies involved in other related activities (e.g., drug poisoning, healthcare) may also find this document useful. Our framework provides an overview of recommended processes and principles that AHMA is using to access, collect, use, and share Indigenous data in a good way.



The Framework is a Toolkit

The framework is *not* prescriptive. There is no checklist or 'one size fits all' list of rules to follow. Rather, the purpose of this document is to improve capacity and knowledge around key topics in data relevant to AHMA's mandate (urban, rural, and northern Indigenous people). The use and applicability of this framework vary for different roles and organizations.

You should approach this document as a *toolbox*. It is not necessary to become an expert on everything. Pick and choose the right tools (section or topic) for the job. The document is meant to spur further thought and questions.

For a follow-up with AHMA's Training and Evaluation Team, contact:

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www.ahma-bc.org

Section 2: Privacy and Ethical Considerations

Privacy Legislation

In BC, the *Personal Information and Protection Act* (PIPA) regulates the use, collection, and disclosure of personal information by private (non-governmental) agencies, such as AHMA. PIPA defines personal information as information that could identify an individual (e.g., birth date), but it does not include contact information and work product information.¹

People from smaller communities or population groups are at greater risk of identification from demographic information (e.g., gender, location, ethnicity). For example, you will often see data suppression in smaller Indigenous communities to ensure anonymity. A key consideration when collecting information from Indigenous people (about 6% of the BC population) is that they are more at risk of identification from demographic and aggregate data.

While there is different legislation and privacy contexts with their own unique guidelines (e.g., health information), proper management of personal information typically includes:

- Informed consent making sure people have sufficient information to make a free and informed choice about their participation.
- Transparency about how you will use and share personal data once it's collected.
- Only personal information that is relevant to business operations should be collected.
- Organizations should have established processes, policies, and infrastructure (e.g., IT, security, software solutions) to safely secure and store personal information, including procedures in the event of privacy breaches.
- Review and assess privacy and security issues at your organization. For example, if a new program or software system is being used.

Our intent with this section is to highlight that privacy legislation is an important consideration when thinking about data collection, use and sharing; and to briefly discuss some of the common high-level considerations. For more resources, we recommend the <u>Office of the Information and Privacy</u> <u>Commissioner</u> website, which provides independent oversight and enforcement of BC's access and privacy laws. The OIPC website has many good resources, such as guidance documents, training materials, reports, and judicial rulings.

Please note: this information is *not* legal advice. Consult your legal counsel to discuss specifics related to your organization's privacy practices.



Research Ethics

Research activities that involve data collection with people in Canada must comply with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2) (Government of Canada, 2022). However, Article 2.5 in TCPS2 notes that "quality assurance and quality improvement studies, program evaluation activities, and performance reviews" fall outside the scope of the guidelines. Key ethical principles for research involving people include (a) informed consent, (b) inclusion in research is fair and equitable, (c) benefits of research equitable, (d) identifiable personal information is safeguarded, and (e) approval from a Research Ethics Board.

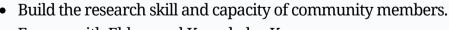
Chapter 9, titled "Research Involving the First Nations, Inuit and Métis Peoples of Canada", further outlines the unique ethical requirements when research is conducted with Indigenous peoples. When a research project impacts an Indigenous community, the TCPS2 requires community engagement with relevant Indigenous groups, including governing authorities (First Nation, Metis, or Inuit), Indigenous organizations, and communities of interest. Guiding principles include:



- Respect community customs and codes of practice.
- Use collaborative and participatory approaches to the community.

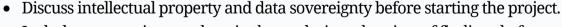


Develop research that benefits community needs and priorities.





• Engage with Elders and Knowledge Keepers.





 Include community members in the analysis and review of findings before publication.

If you are involved as a collaborator on research projects, organizations should consider how they will apply the community engagement principles outlined in Chapter 9 of the TCPS2.

Evaluation and Information Gathering Activities

Information collected during program evaluations, quality improvement, needs assessment, environmental scans, and consultations fall outside the scope of research (where TCPS2 formally applies). There are no well-established protocols or best practices for ethical guidance with community data gathering across Canada. While the TCPS2 provides good ethical guidance, in practice, it would be overly cumbersome, expensive, and time-consuming for community-based projects.



So how might community organizations collect data in a good way? One way would be to align with and adapt the principles of the TCPS2 for community situations, where and when appropriate. Within this vacuum, Alberta Innovates has developed (to our knowledge) the only tool in Canada that addresses this gap.³ AHMA recommends using the freely available *ARECCI Screening Tool* when a (non-research) project involves potential ethical risks.⁴ The screening tool helps identify the level and types of risk involved in a project. A higher risk level may warrant further consultation and discussion before proceeding with data gathering.

Resources

Office of the Information and Privacy Commissioner

Provides information and resources about BC's access and privacy laws.

<u>Tri-Council Policy Statement: Ethical Conduct</u> <u>for Research Involving Humans (TCPS2 2022)</u> This is a PDF link to the TCPS2 document.

<u>CIPA (Common or Integrated Program Agreement)</u>

This is a link to the CIPA guidelines developed by the OIPC.

Privacy Impact Assessment

This is the BC government website that guides PIA applications.

ARECCI Screening Tool

This links to the Alberta Innovates website with the ethics screening tool and resources.

Ontario Federation of Indigenous Friendship Centres (OFIFC)

This links to the OFIFC ethics application page, which describes their innovative approach to community research with Indigenous people.

Section 3: Indigenous Data Sovereignty

Introduction

Indigenous data sovereignty refers to the inherent right of Indigenous peoples to determine the **use**, **access, interpretation, management, and sharing** of data that impacts their lives and communities (Carroll et al., 2019; First Nations Information Governance Centre, 2019; Indigenous Innovation Initiative, 2021; Inuit Tapiriit Kanatami, 2018; Kukutia & Taylor, 2016).

More simply, Indigenous people have constitutional rights to self-determination, and this formally recognizes that Indigenous people should be in control of their own data and knowledge generation. Such a right is *not* a broad, pan-Indigenous one for any Indigenous peoples or groups, in all situations. Rather, it is a *specific* collective and shared concept that is tied to peoples, territories, laws, and governance.

Indigenous knowledge differs from the western tradition, which only codifies *individual* knowledge acquisition through consent processes, because "Indigenous data systems rely on shared responsibilities to ensure that Indigenous ways of knowing, being, and doing are transmitted from one generation to the next" (Carroll et al., 2019, p. 2). Indigenous knowledge is a collective right. We define Indigenous data as any knowledge or experience about Indigenous people and their nation, land, culture, and community (Indigenous Innovation Initiative, 2021). Indigenous data sovereignty recognizes both the (a) inherent individual right to informed consent and (b) broader collective rights of Indigenous communities to govern their knowledge.

Assertion of Indigenous data sovereignty did not emerge in a vacuum. It emerged in response to barriers that prevented ownership of primary Indigenous data, resulting in colonial dependence on secondary sources and/or data sets with poor data quality (First Nations Information Governance Centre, 2022). The First Nation principles of OCAP® (Ownership, Control, Access, and Possession) declare that nations have "control over data collection processes and that they own and control how this information can be used." ⁵

The OCAP principles sparked a catalyst for Indigenous data governance and stewardship across Canada and the globe. Examples include the Inuit Qaujimajatuqangit ("traditional knowledge") principles and the Manitoba Métis principles of OCAS (Ownership, Control, Access and Stewardship), which outline guidelines for Indigenous governance. Many partner agencies, like the Canadian Institute for Health Information, are developing data governance partnerships with Indigenous peoples as part of their Reconciliation commitments. Outside Canada, Indigenous data sovereignty groups are well established in New Zealand (Maori Data Sovereignty Network), Australia (Maiam Nayri Wingara), and the United States (U.S. Indigenous Data Sovereignty Network).

Other Indigenous data governance protocols include:

- Nindokiikayencikewin: Indigenous Knowledges & Data Governance Protocol (2021) provides a guide for how to collect and use Indigenous knowledge.
- Grandmother Perspective on disaggregated demographic data collection in British Columbia
- (British Columbia's Office of the Human Rights Commissioner, 2020), which develops principles for addressing gaps in disaggregated data in BC to reduce discrimination and injustice.
- CARE Principles (Collective Benefit, Authority to Control, Responsibility, and Ethics) for Indigenous Data Governance (Research Data Alliance International Indigenous Data Sovereignty Interest Group, 2019), which is a global movement to adopt Indigenous-led open data principles that are grounded in Indigenous rights and benefits.

But why does data sovereignty matter for Indigenous communities? It's the law. Section 35 of the Constitution and the *Declaration of the Rights of Indigenous Peoples Act* (DRIPA) legislation in BC clearly outlines a distinction-based right to data sovereignty for First Nation, Metis, and Inuit nations. In addition to legal rights, data sovereignty is a solution to racism and discrimination that is rooted in a lack of self-determination, such as:

- Ongoing theft, appropriation, misrepresentation, and colonization of Indigenous-owned data and wisdom.
- Data gaps in how Indigenous people experience housing and homelessness, making it impossible to understand what is happening, or if policy interventions are fair and effective.
- Lack of self-determination, transparency, and informed consent for Indigenous people to determine the terms and conditions of how data is collected, used, shared, and stored.
- Lack of reciprocity. Data collected from Indigenous communities is not shared back, or when it is, not in a useful way.
- Program reporting is imposed on Indigenous communities in funding agreements, without considering the needs and values of impacted communities.
- Limited data stewardship. Indigenous data critical to service provision and planning is stored in databases that communities can't access and don't control.

As this list indicates, asserting Indigenous data sovereignty is a journey, with many steps and pitfalls along the way. For (non-distinction based) Indigenous-led collectives that advocate for the shared principles of members, such as AHMA, there are headwinds. AHMA is not a nation or distinction-based authority, which faces barriers in BC because new legislation (DRIPA) is founded on Charter rights (First Nation, Metis, and Inuit). This section outlines the main legislation in Canada governing Indigenous data sovereignty. The focus is on seeing where non-distinction based Indigenous agencies like AHMA fit within the data sovereignty conversation.

To date, we have not found an established framework that recognizes the fourth stream of Indigenous data sovereignty rights of people living in and using (non-distinction based) services in off-reserve locations. This has real-world consequences for advocacy and service delivery. Consider this statement from a working group of the Missing and Murdered Indigenous Women and Girls in Canada (MMIWG):

These begin with the inclusion of Urban Indigenous people in codevelopment, and a necessary re-establishment of the relationship between data and urban Indigenous people, to ensure adequate provision of programs and services based on residency as understood in the urban lens. As related, Indigenous Data Sovereignty means, in part, supporting urban Indigenous organizations in their efforts to collect, analyze and protect data and protecting the rights of those who contribute data to informed consent and for ethical and authentic data collection and protection. Communities should be able to lead research into basic demographics to fill existing data gaps. Supporting urban codevelopment, Indigenous Data Sovereignty, and informed consent also emphasizes the importance of culturally appropriate lenses, including the importance of supporting strength and resiliency in data analysis and performance measurement. In other words, understanding the complexity of urban Indigenous identities requires different lenses that take these into account (Data Strategy for the National Action Plan Working Group, 2021, p. 74).

This next section identifies emerging practices across Canada that point toward pathways to data sovereignty for (non-distinction) Indigenous services and peoples. It first outlines the context of the off-reserve Indigenous population in BC and then discusses the fourth stream of Indigenous data sovereignty.

Context of the Indigenous Population in BC

According to the 2021 Census (Statistics Canada, 2022a), 5.9% (or 290,210) of people living in BC identified as Indigenous. Of those who identified as Indigenous, 62% were First Nation, 34% were Metis, 0.6% were Inuit, 2% had multiple Indigenous identities, and 1.5% reported other Indigenous identity responses.

Table 1. BC Indigenous Identity in the 2021 Census

Status	First Nation	Metis	Inuit	Other Indigenous Identities ⁷	TOTALS
Total Population (Census)	180,085	97,860	1,720	10,540	290,210
Registered or Treaty Status	125,105	6,585	105	5,085	136,880 (47%)
Not Registered or Treaty Status	54,975	91,280	1,620	5,460	153,335 (53%)
Living on reserve	50,810	1,210	50	1,005	53,075 (18%)
Living off- reserve	129,280	96,655	1,670	9,530	237,135 (82%)

Indigenous identity is complex and fluid (e.g., people routinely move on and off reserve). The Census, by its nature, is only a snapshot in time and therefore can't tell the full story. There are also incomplete records that undercount the number of people living on reserves and settlements (Statistics Canada, 2022b). That said, with those limitations in mind, the Census still provides a useful picture of the population-level landscape.

In BC, 47% of all people who identify as Indigenous are registered or have treaty status, although First Nation peoples (69%) are much more likely to claim status compared to Metis (7%) and Inuit peoples (6%). The Census also found that 82% of Indigenous peoples reported living off-reserve and settlement. As such, a significant number of Indigenous people in BC either (a) live off reserve (82%) and/or (b) do not have formal distinction-based status (53%). Census data suggests that many of Indigenous people living in urban, rural, and northern locations do not have a clear mechanism to assert their data sovereignty rights.

AHMA is an umbrella organization that supports 58 Indigenous housing and service providers across BC. Despite managing 95% of off-reserve Indigenous social housing, AHMA and our members have limited data access and stewardship. Much of the data about Indigenous people in AHMA-administered housing is held by BC Housing. As the recent Ernst & Young report (2022, p. 25) details, however, there are major data quality issues at BC Housing:

At the time of this review, there was no centralized data function within BC Housing that assists with providing clear documentation or interpretation of data across the organization, despite the large number of reports produced... Data validation activities are largely manual and performed on an informal basis. Interviews revealed there are instances where the same data is inputted and stored in multiple systems, creating 'multiple versions of the truth'. Further, it was shared that to produce a list of BC Housing development projects for new housing stock, it required two individuals manually reconciling over 600 reports, taking three weeks to prepare. Interviewees also noted that there is not a singular definition of Building BC within the organization, resulting in discrepancies in unit counts depending on when the report is run and by which group.

As such, even the limited access to data that AHMA does have from BC Housing is low quality, and not of high enough quality to implement FIBI housing. Indigenous data sovereignty is the solution. In their report, "A For Indigenous, By Indigenous National Housing Strategy" (Indigenous Housing Caucus Working Group, 2018, p. 20), the Canadian Housing and Renewal Association working group argues that data gaps need to be overcome through self-determination: "An increased and Indigenous-led focus will allow for enhanced evidence-based decision making on program design, service planning and the provision of housing and services." While a pathway to data sovereignty exists through the nation-to-nation process, there are no established protocols for the data sovereignty rights of Indigenous people in urban, rural, and northern (off-reserve) settings.

Our framework does *not* propose a one size fits all solution to the complex question of data sovereignty. Instead, our framework outlines emerging practices and policies across Canada that could be used to advocate for a FIBI approach within this context. The long-term goal is to build and expand on these practices by establishing a fourth stream of Indigenous data sovereignty.

Legislative Context

This section outlines the main legislation in Canada governing Indigenous data sovereignty. The focus is on seeing where non-distinction based Indigenous agencies, such as AHMA, fit within the legislation.

UNDRIP - International Context

Indigenous peoples have an inherent right to data sovereignty – to determine how, who, when, and where knowledge is used. Although such rights have always existed, they have only recently been recognized in law. In 2007, the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP) was endorsed by 148 countries, including Canada, using a human rights approach (United Nations, 2007).

UNDRIP re-affirms the inherent rights of Indigenous peoples to self-determination, as stated in Article 4: "right to autonomy or self-government in matters relating to their internal and local affairs, as well as ways and means for financing their autonomous functions." Although data governance is not explicitly mentioned, it falls under Articles 18, 23, and 33:

Article 18: "Indigenous peoples have the right to participate in decision-making in matters which would affect their rights, through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own indigenous decision-making institutions."

Article 23: "Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programs affecting them and, as far as possible, to administer such programs through their own institutions."

Article 33: "Indigenous peoples have the right to determine their own identity or membership in accordance with their customs and traditions... Indigenous peoples have the right to determine the structures and to select the membership of their institutions in accordance with their own procedures."

UNDRIP sets the framework for Indigenous peoples across Canada to self-govern and control their own institutions. It also establishes that Indigenous communities and institutions will determine their own development, strategies, identity, and membership.

Truth and Reconciliation - Federal Context

The *Truth and Reconciliation Commission* (TRC) was formed in 2008 to document the impacts and experiences of Canada's residential school system on Indigenous peoples. In 2015, the TRC released 94 calls to action, including the recognition that UNDRIP was the "framework for reconciliation" between Indigenous and non-Indigenous communities (Truth and Reconciliation Commission of Canada, 2015).

DRIPA - BC Context

In 2019, BC passed the *Declaration of the Rights of Indigenous Peoples Act* (DRIPA) becoming the first province to legislate all 46 articles of UNDRIP, as called for in the TRC. Under DRIPA the BC government must create an Action Plan (and report annually on progress) to implement UNDRIP. In 2022, the BC Ministry of Indigenous Relations and Reconciliation published the DRIPA Action Plan for 2022-2027 with 89 actions, organized around four key themes:

- Self-determination and inherent right of self-government
- Title and rights of Indigenous Peoples
- Ending Indigenous-specific racism and discrimination
- Social, Cultural and Economic Well-Being

How does the fourth stream (non-distinction based Indigenous groups) fit into the DRIPA legislation? On the surface, DRIPA appears to only apply to nations and distinctions-based representation. For example, AHMA is *not* an Indigenous governing body, which refers to an "entity that is authorized to act on behalf of Indigenous peoples that hold rights recognized and affirmed by section 35" in DRIPA.

That said, several sections outline the explicit role of agencies like AHMA. First, Section 3 of DRIPA formally aligns the provincial legislation with UNDRIP, which means that Articles 18, 23, and 33 (and all the other sections) must also be followed. Furthermore, Section 4 of DRIPA requires the province to develop an action plan to meet the objectives of UNDRIP and consult broadly with Indigenous peoples. The action plan *explicitly* outlines a role for (non-distinction) Indigenous organizations – such as AHMA and Friendship Centres – in self-governance (BC Ministry of Indigenous Relations and Reconciliation, 2022). Consider the following sections, which are most relevant to Indigenous housing and homeless (AHMA's mandate):

4.21 – Bring together **key Indigenous urban leaders to create a provincial urban Indigenous advisory table** to develop and implement a five-year plan to address the priorities of urban Indigenous Peoples, including a focus on Elders, youth, children, women, men, 2SLGBTQQIA+ and persons with disabilities.

4.23 – Undertake a cross-government review of provincial supports and services for **Indigenous Peoples in urban settings** and develop a plan with clear timelines that will provide greater collaboration and coordination to meet needs.

4.25 – Work with **Indigenous Peoples to build more on- and off-reserve housing** and pursue new federal contributions.

While DRIPA is founded on the legal rights of nations to create pathways to self-determination, the legislation also recognizes that in off-reserve locations, Indigenous organizations also play a key role in the governance process. Given the demographic reality (82% of the Indigenous population living off reserve), there is no way to address the priorities in DRIPA without the involvement of non-distinction based Indigenous urban, rural, and northern organizations. This does *not* replace or usurp First Nation, Metis, and Inuit rights, but rather charts a path for the integration and collaboration of (non-distinction based) Indigenous groups that support the majority of Indigenous people in BC.

Urban Indigenous Organizations

Against this challenging backdrop, Indigenous non-government organizations have developed creative and innovative responses to the data sovereignty issue. A description of some different models and approaches used in urban contexts is discussed.

Surrey Urban Indigenous Leadership Committee

Over the last 20 years, Surrey has seen a more than 20% growth in the urban Indigenous population. Many Indigenous groups recognized the need for more involvement and visibility in decision making. In 2015, the Surrey Urban Indigenous Leadership Committee (SUILC) formed to better understand how the more than 13,000 Indigenous people living in the city were doing. The group includes (a) all Indigenous organizations operating in Surrey (including several AHMA members), (b) non-Indigenous agencies with significant connection to the population (e.g., Surrey School District, Fraser Health), and (c) standing invitations to land-based First Nations.

A key finding from the initial work was that 45% of Indigenous youth and children were living in poverty in Surrey. The SUILC has undertaken two major initiatives in response:

- A comprehensive social innovation strategy, called "All Our Relations Strategy."
- Implementation of the Skookum Lab, a social innovation hub, to reduce urban Indigenous youth poverty. The lab collaborates with lived experience groups from Land Based Nations, Elders, youth, caregivers, and support workers.

As part of this work, the SUILC has developed a response to UNDRIP, called "Implementing UNDRIP in B.C.: Perspectives of the Urban Indigenous Community in Surrey" (Surrey Urban Indigenous Leadership Committee, 2021). The document outlines the role within UNDRIP for a "coalition of organizations that are working hard to give voice to the more than 13,000 Indigenous people that live and work in Surrey" (ibid, p. 3). Similar to AHMA's situation, this coalition is explicitly not an Indigenous nation, government, or distinction-based group. The SUILC statement on UNDRIP attempts to chart a pathway forward for the participation of all Indigenous people that respects the land-based rights of the territorial Coast Salish First Nations:

Our group, the SUILC, does not represent these land based First Nations, and we are careful not to speak on their behalf. Instead, we represent urban Indigenous people that have moved here from all over BC and in fact, from all over Canada to make Surrey their home. Our focus is on making Surrey a great place for Indigenous people living in the city, regardless of where they come from, their legal status, or their particular cultural heritage. As we do this, we endeavour to live in a good way with the land based First Nations that have called this land their home since time immemorial (ibid, p. 4).

The Skookum Lab has developed an innovative and thoughtful model for data governance that creates a platform for many diverse urban Indigenous peoples in Surrey, while acknowledging the sovereignty of Coast Salish First Nations.

Montréal Indigenous Community Network (NETWORK)

The NETWORK project collects data to understand the experience of First Nations people living in Montreal. The goal is to create opportunities for First Nations people to set their priorities. One partner notes that data sovereignty is central to the project:

The most important impact of this project is to increase sovereignty and data management. The concept of sovereignty is well known when it applies to territory, governments, and other forms of self-determination for Indigenous people. However, these rights have not yet been extended to data collection and management. That is what this project seeks to do (Montréal Indigenous Community Network, 2021).

Currently, the project has two active committees with Indigenous-led partners: the Covid-19 and Primary Needs Committee and the Montreal Indigenous Health Advisory Circle, which are working towards transforming decision-making through an Indigenous approach to collective governance.

Ontario Federation of Indigenous Friendship Centres (OFIFC)

The OFIFC is an umbrella agency that supports the collective interests of 29 Friendship Centres in Ontario. As part of that work, the OFIFC has established a comprehensive Research Framework that is based on a community-driven process:

We start with community project visions. Where a nonindigenous evaluation begins at the end of a project with the intention to measure, assess, and/or evaluate its efficacy once it is completed, the USAI Evaluation Path examines the utility of a project to the community throughout the project – from beginning to end – to reflect on all project components and produce change as needed to best serve community visions in real time (Ontario Federation of Indigenous Friendship Centres, 2016, p. 10).

A unique feature of the OFIFC approach is the creation of their own research ethics process that guides collaboration, data collection, intellectual property, and authorship. Community research projects are guided by Elders and Traditional Knowledge Keepers, who oversee the project and ensure a safe space for high quality Indigenous research.

Our Health Counts Project (Well Living House, St. Michael's Hospital)

The goal of this project is to create an urban Indigenous health database project that uses a "Two Eye Seeing" model of rigorous epidemiological data with an Indigenous approach to physical, mental, emotional, and spiritual health domains (Rotondi et al., 2017). The project addresses a gap in Census data, which underreports urban Indigenous peoples. Data is used by six participating Indigenous urban communities (Hamilton, Kenora, Toronto, London, Ottawa, and Thunder Bay) to understand the health needs and develop better solutions within each community. For example, when the pandemic started, the project team in Toronto started an Indigenous-led testing centre in Toronto, alongside the "We Count COVID-19" Indigenous database (Seventh Generation Midwives Toronto, 2021).

An innovative part of the project is a partnership based on a data sharing agreement with a nonprofit called the Institute for Clinical Evaluative Sciences (ICES). ICES has created an anonymous data linkage (with client consent) using their health cards to understand key health metrics. It is the only non-governmental, non-nation data set with administrative data linkages we have found in Canada. The project is run by Well Living House (out of St. Michael's Hospital), which is led by a group of Indigenous health researchers, practitioners, and community grandparents. Local Indigenous groups partner with the project in each community. A Governing Council includes the Ontario Federation of Indian Friendship Centres, Métis Nation of Ontario, Ontario Native Women's Association, Tungasuvvingat Inuit, and the Centre for Research on Inner City Health.

Resources

<u>Disaggregated demographic data collection in British</u>
<u>Columbia: The grandmother perspective</u>
This links to the report on the BC Office of the Human Rights
Commissioner website.

<u>Nindokiikayencikewin: to seek learning or Knowledges – Indigenous Knowledges & Data Governance Protocol</u>

This is the link to the report by the Indigenous Innovation Initiative, which supports Indigenous governance of data collection, sharing, interpretation, and storage.

<u>UN Declaration on the Rights of Indigenous Peoples (UNDRIP)</u> This is the link to the UNDRIP declaration.

<u>Declaration on the Rights of Indigenous Peoples Act (DRIPA)</u> This is a link to DRIPA resources, including the Legislation, Action Plan, and Annual Reports.

Truth and Reconciliation Commission of Canada (TRC) This is a link to the TRC website with resources, such as reports, records, research, and education.

Skookum Lab

Link to the Skookum Lab website, which outlines their work, who they are, and resources.

<u>Implementing UNDRIP in B.C.: Perspectives of the Urban</u> <u>Indigenous Community in Surrey</u>

Link to the report that outlines the unique approach taken by the SUILC coalition to UNDRIP.

<u>"Our Health Counts" Urban Aboriginal Health Database</u> <u>Project</u>

Link to the "Our Health Counts" projects, including Ottawa, Hamilton, Toronto, London, Kenora, and Thunder Bay.

<u>Indigenous Community NETWORK in Montreal</u>
Link to website, describing who the Montreal NETWORK is, their actions, and resources.

Ontario Federation of Indigenous Friendship Centres Link to the OFIFC website with resources, including policy, programs, training, and research.

Section 4: Indigenous led Evaluation

Why Indigenous Evaluation?

Why is AMHA developing Indigenous-led evaluation methods? Because as part of reconciliation and decolonization, Indigenous organizations should be leading their own evaluations to advance their needs and priorities. As Gloshay et al. (2020) put it: "Externally-imposed impact measurement requirements do not enable different ideas of what success, impact and return on investment mean, or for Indigenous Peoples to define, measure and report on impact in ways that are meaningful to them." Indigenous-led evaluation empowers Indigenous communities to determine their own journey, such as the objectives, what knowledge is valued, what methods are used to gather information, and how knowledge is shared (Smith, 1999).

We do not see Indigenous evaluation in conflict with or replacing mainstream program reporting. Even though program evaluation has flaws and limitations, it has a role to play for Indigenous organizations, including with:

- Fidelity to intended program goals.
- Tracking client outcomes and how they feel about the program.
- Assessment of program effectiveness.
- Understanding system-level impacts like barriers, facilitators, and unintended consequences.
- Information that supports program improvement and expansion.
- Advocating for more resources.

Our approach is pragmatic and strategic. That said, there are significant limitations to mainstream program evaluation for Indigenous communities, including that it often lacks utility and buy-in from communities, may cause harm and trauma, imposes demands on people without reciprocity, and focuses on short-term and linear program impacts (Johnston, 2016). Indigenous-led evaluation is a solution to these methodological issues that creates space for holistic, innovative, and relevant knowledge creation.

What is Indigenous-led Evaluation?

Unlike mainstream program evaluation, there is no universal set of rules, protocols, and best practices guiding Indigenous evaluation. That is by design. Indigenous evaluation, at its heart, is focused on self-determination and reconciliation (Johnston, 2016; Smith, 1999). It does not strive for objective facts, removed from the meaning and context of everyday life, but rather embeds knowledge generation within Indigenous culture and worldviews. For Linda Tuhiwai Smith (1999, p. ix), a pioneering Māori scholar in this area, Indigenous research is less about the exact tool or method selection, and more about the "context in which research problems are conceptualized and designed, and with the implications of research for its participants and their communities." Indigenous scholar Gladys Rowe notes that each evaluation becomes as much about the *relationship* as methodology:

Recognition must be made that there is no one Indigenous culture or worldview; that Canada has many Indigenous languages; and that First Nation, Métis, and Inuit communities have greatly varied Indigenous cultures. The foundation of each of these cultures is relational and is in direct connection to the lands and the waters originally home to the different groups. This relationality across varied landscapes means that culture, ceremonies, language – each components of worldview that must be taken into consideration in so many cases when Indigenous cultures are being used to inform the development of programs, policies, and evaluations (Bremner et al., 2020, p. 52).

Given the diversity in worldviews, Indigenous evaluation means taking each situation on a case-by-case basis and grounding everything in relationships and self-determination. There is no pre-determined template to follow.

AHMA's Approach to Indigenous Evaluation

AHMA's approach to Indigenous evaluation is three-fold:

- 1. **Principles-based approach** that provides an ethical foundation and set of expectations to do the Indigenous evaluation in a good way.
- 2. **Action-oriented focus** that seeks to develop solutions by listening, pilot testing, innovation, creativity, adaptation, and sharing promising solutions.
- 3. **Collaborative learning approach** that seeks to grow and learn with our members and external partners.

Ultimately, we are developing Indigenous evaluation methods because we want to prioritize the needs and voices of urban, rural, and northern Indigenous people. A principles-based approach provides a set of expectations and boundaries that we think set the foundation for our evaluations to be done in a good way.

However, it is important to note that this is a set of values and aspirations for our approach, and that there are inevitable limitations (e.g., time, budget) when this is brought into practice. A practical 'how to guide' is in development with tools, workshops, and recommendations for implementing these principles. For now, this section is focused on spurring further reflection about how to engage in ethical and appropriate Indigenous evaluation.

Key principles guiding AHMA's Indigenous evaluation:

Self-Determination: Indigenous people and agencies have the ultimate authority to determine how, when, where, and why knowledge generation takes place. Indigenous people impacted by data collection set the terms and conditions of evaluation. This is a key part of Reconciliation and Decolonization.

Cultural safety: Honour AHMA's cultural safety framework, which includes four core Pillars: Reciprocity, Relationship, Trauma-Informed, and Self-Agency.

Holistic – Indigenous knowledge and wisdom come from a specific group of people, in a particular location, who then apply those learnings in that place. To understand a project or program, one must locate it within the relationships in the community. Knowledge is relative and context dependent.

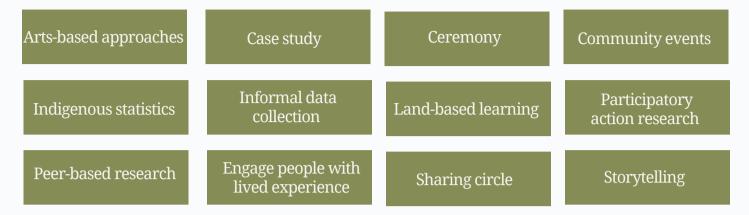
Spirit and Ceremony: Bringing spirit and ceremony into everyday practice, including project design, activities, and budgets. Not only a one-time or special feature but celebrating with ceremony throughout the evaluation processes (e.g., a ceremony to start each sharing circle).

Skills and Capacity Building: Support the development of skills and capacity building so that people and communities have the capacities they need for their autonomy and self-determination.

Person-centered: Focus on people and building authentic relationships as the priority. Situational awareness around things like trauma and cultural appropriateness. Never treat people as data points.

Strengths-based: Focus on building a person or communities' strengths, such as their knowledge, skills, resourcefulness, self-determination, or resiliency when in challenging situations.

What does Indigenous-led evaluation look like in practice? While there is no one-size fits all approach, some methodologies align well or can be adapted using Indigenous principles, including:





AHMA Protocols for Collecting and Using Indigenous Data

A protocol is a set of terms and conditions for the collection, interpretation, use, and sharing of Indigenous data. At its core, such protocols ultimately depend on the shared acceptance and self-determination of the people and communities involved. This section draws heavily from the collective knowledge shared in the "Nindokiikayencikewin: Indigenous Knowledges & Data Governance Protocol" (Indigenous Innovation Initiative, 2021) document. As the Indigenous Innovation Initiative (2021, p. 14) states, "protocols ensure the right people receive the right Knowledges, and that sacred information is cared for in the right way." Protocols do not supersede and/or replace other legal and ethical responsibilities, such as privacy legislation (PIPA), research ethics (TCPS2), information sharing agreements, and local protocols.

It is important to remember that these protocols are aspirational and value-based. Much like the principles-based approach above, there are practical limitations when we start to use these in the real world. For example, contractual obligations, limited budgets, time constraints, and disinterest from participants all impact how the protocols are implemented. A 'how to guide' for these protocols is in development, which will provide more tangible tools. At this point, we want the protocols to generate staff reflection and thoughtfulness about how we approach the collecting and using of Indigenous data.

When AHMA collects Indigenous data, we will:

- Discuss data governance with those responsible for its stewardship.
- Ensure informed consent from all impacted people before data collection.
- Ensure fair and equitable access to opportunities, including space for Elders, Knowledge Keepers, and people with lived/living experience.
- Collect data that is relevant to and benefits communities, using approaches that are grounded in local values and protocols.
- Provide food, honoraria, and/or financial support in recognition of people's time and contributions.
- Establish expectations, reciprocity, and terms of the engagement before data collection.
- Offer skill and capacity building opportunities.
- Engage people using culturally safe, trauma informed practices. This includes providing access to aftercare resources, such as debriefing or mental health support.
- Use participatory methods when feasible and appropriate, which involve participants in the project design and development of the data collection plan.
- Meet people and communities where they are at, including community readiness before proceeding with data collection.

When AHMA interprets Indigenous data, we will:

- Use participatory methods when feasible and appropriate, including opportunities for Elders, Knowledge Keepers, and people with lived experience, to understand the interpretations of impacted communities.
- Accept multiple interpretations and that not all differences can or need to be resolved.

When AHMA uses Indigenous data to create products, we will:

- Communicate and listen to our partners' feedback, to reach a consensus.
- When appropriate and feasible, co-create knowledge products with our partners.
- Prioritize useful and relevant knowledge based on our partner's needs and priorities that mutually support AHMA.
- Share information in a useful format that is most relevant to stakeholders.
- Recognize contributors and communities based on their wishes.
- Where and when appropriate, present First Nation, Metis, and Inuit information as unique and separate (e.g., don't automatically collapse everything into a pan-Indigenous finding).
- If a community or contributor voices disagreement with the analysis, then work collaboratively with the partner to resolve the issue by consensus.

When AHMA shares Indigenous data, we will:

- Honour our agreed upon data management protocols for sharing Indigenous data.
- Follow the lead of our participants and impacted communities, including consent and data sharing protocols.
- Request ongoing consent if any new ways to use or share this information emerges.

When AHMA stores Indigenous data, we will:

- Align with the five safes model, a globally recognized best practice approach for managing safe
 access to confidential data across five domains: people (authorized access only), projects (community
 interest), data (de-identified), settings (secure technology), and outputs (anonymous).
- Honour requests (when possible) to change where and how this information is being used or stored, including making it confidential, deleting it from our databases, or sharing and/or interpreting it in different ways.
- Support the autonomy and ownership of our partners, which could include storing it within their communities or within AHMA's database while they maintain ownership.

When collaborating with member societies about data, we will:

- Engage members in consultation using multiple opportunities and formats.
- Support and advocate for our member needs and priorities.
- Be accountable and transparent.
- Respect member autonomy and self-determination.
- When advocating for members, represent the shared values and principles of our members, not the members themselves.
- Advocate for the direct involvement and voice of members at the table (if that is their wish).

Resources

<u>Indigenous Innovation Initiative</u>

A link to their website, which has resources on Indigenous data and evaluation.

Johnston Research

A link to Andrea Johnston's website, which has more information about Indigenous evaluation services and workshops.

Privacy, security and the Five Safes model
A link to more information on the Five Safes model from BC's
Data Innovation Program website.

Ontario Federation of Indigenous Friendship Centres

A link to their website, which has a link to their Indigenous-led research framework.

Endnotes

- 1.PIPA defines work product information as "information prepared or collected by an individual or group of individuals as a part of the individual's or group's responsibilities or activities related to the individual's or group's employment or business but does not include personal information about an individual who did not prepare or collect the personal information."
- 2. Research is "defined as an undertaking intended to extend knowledge through a disciplined inquiry or systematic investigation" (ibid: 4).
- 3. To date, the Ontario Federation of Indigenous Friendship Centres (OFIFC) has created the only Indigenous-specific community research process in Canada that we know about, which includes an ethics board with Elders and Knowledge Keepers. However, this model is not an accessible resource for AHMA, and our agency is not ready to implement such an approach.
- 4. Examples of community data gathering with potential risk include engaging with vulnerable populations and situations where the public release of sensitive information would cause harm.
- 5. For more information about OCAP, visit the First Nations Information Governance Centre website: https://fnigc.ca/ocap-training/
- 6. Developments in Indigenous data sovereignty from other contexts, such as the Māori, were out of scope for this section. Canada's legal and governance structure (Section 35 of the Charter) makes it challenging for AHMA to apply other Indigenous experiences from different nations.
- 7. This includes (a) multiple Indigenous identities and (b) other Indigenous identity responses.
- 8. Due to incomplete records, the Census undercounts the number of Indigenous people, especially those living on reserves or settlements: "In 2021, a total of 63 census subdivisions defined as reserves and settlements were incompletely enumerated. For these reserves and settlements, dwelling enumeration was either not permitted or could not be completed because of the various reasons below" (Statistics Canada, 2022b). A total of 23 reserves/settlements in BC were excluded (missing data) from the 2021 Census. Other reserves and settlements had non-responses that limited the accuracy of the Census.
- 9. In 2011, the First Nations Health Authority (FNHA) and BC government signed a historic agreement (BC Tripartite Framework Agreement on First Nation Health Governance) to transfer health governance to nations.
- 10. AHMA developed its approach through several processes, including consultation with our members; engagement with Elders and Knowledge Keepers; literature review of academic research; scoping review of the grey literature in Canada, United States, Australia, and New Zealand (Chandna et al., 2019); and participating in Andrea Johnston's "Honouring Reconciliation in Evaluation" workshop.

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