Indigenous Population Health Our Data, Our Stories

Data Governance
Practical Application Guide

2025

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CONTENTS

ACKNOWLEDGEMENTS

The Indigenous Primary Health Care Council (IPHCC) gratefully acknowledges the contributions of the following partners to the development of this guide:

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The invaluable input of the following IPHCC staff is also very much appreciated:

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In many Indigenous cultures, the crow is seen as cunning and intelligent and considered to be an old spirit carrying with it knowledge from past lifetimes.

INTRODUCTION

Indigenous communities worldwide possess a rich repository of traditional knowledge, cultural practices, and historical data that can significantly contribute to public health initiatives and approaches. However, the use of Indigenous data in public health surveillance, research and policymaking has been fraught with challenges, including ethical concerns, data sovereignty issues, and cultural safety considerations related to how the data is used.

This Guide aims to provide guidance for public health agencies on how to utilize Indigenous data ethically and effectively in public health efforts, respecting the rights and perspectives of Indigenous Peoples[1]. It may also be useful to First Nations, Métis, and Inuit (FNIM) organizations partnering with public health agencies to help guide data discussions. It incorporates elements from the Indigenous Primary Health Care Council's Data Governance Framework that are important for those working in public health to reflect on when making decisions regarding collection and reporting of Indigenous health information.

Indigenous Primary Health Care Council

The Indigenous Primary Health Care Council (IPHCC) is an Indigenous governed, culture-based, and Indigenous-informed organization with the key mandate to support the advancement and evolution of Indigenous primary health care service provision and planning throughout Ontario. IPHCC is a member-based organization consisting of 25 Indigenous Primary Health Care Organizations (IPHCOs) located in 108 different locations across the province. Members provide care in urban, rural, remote and on-territory (reserve) settings. The combined membership provides care to almost 100,000 FNIM clients.

IPHCC is a provincial leader in the areas of Indigenous cultural safety, Indigenous data governance, traditional healing and wellness approaches, health system transformation, as well as FNIM engagement and relationship development.

Model of Wholistic Health & Wellbeing

North: Spiritual, Reclamation, Generosity

West: Physical, Teaching, Interdependence

East: Emotional, Healing, Belonging

South: Learning, Language, Mental

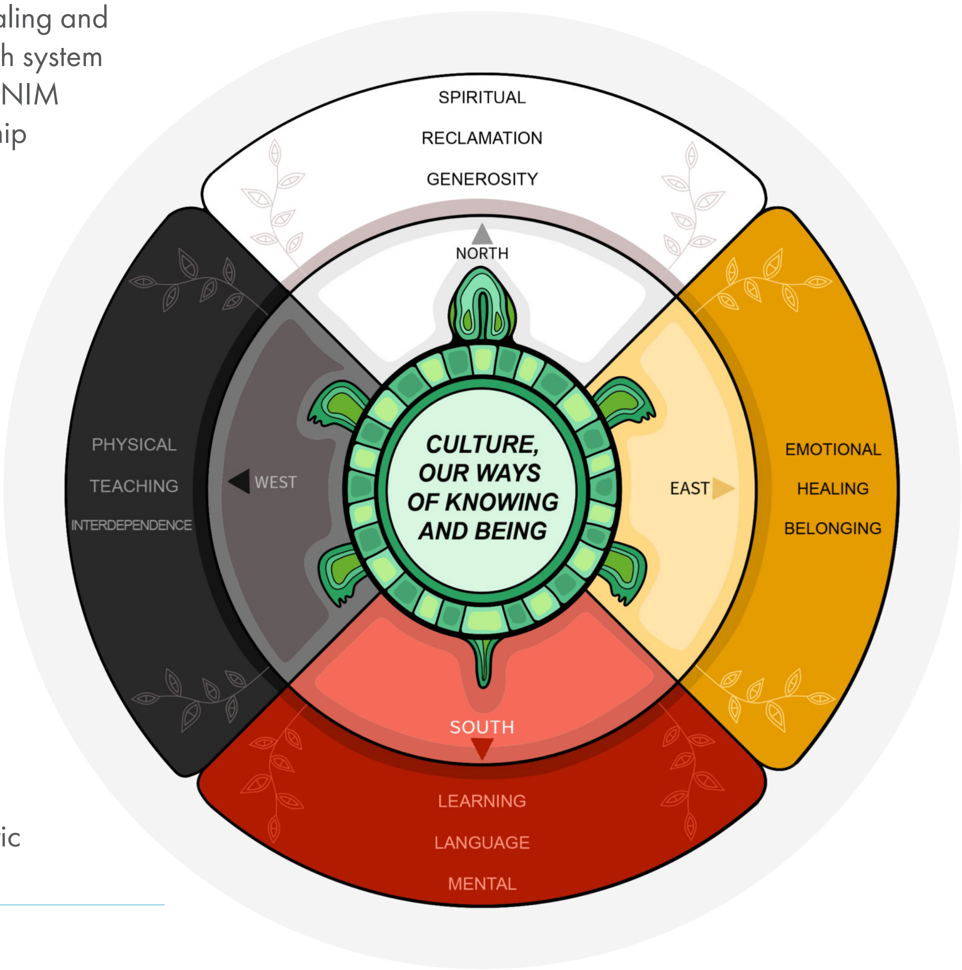


Figure 1: Model of Wholistic Health & Wellbeing

Indigenous Primary Health Care Organizations

IPHCOs are unique in Canada and made in Ontario. They were birthed through the Indigenous Healing and Wellness Strategy. IPHCOs are community-governed, community-led, Indigenous informed primary health care organizations.

IPHCOs take an Indigenous-led and community-centered wholistic approach to improve the mental, emotional, physical, and spiritual health and wellbeing of Indigenous Peoples. They operate from the community-endorsed Model of Wholistic Health and Wellbeing (MWHW), which is rooted in a population needs-based approach to health care planning and delivery for FNIM. Indigenous primary health care encompasses distinct Indigenous models of care while at the same time incorporates western practices to delivery. These adaptations and blending of approaches are referred to as Two-Eyed Seeing[2] and is supported within a traditional healing and wellness framework (Bartlett, Marshall, & Marshall, 2012, p. 335). Indigenous Peoples are free to choose traditional methods and medicines, westernized methods and medicines or a combination of both.

IPHCOs provide a comprehensive array of culturally safe and appropriate health and social services to FNIM communities across the province. Services include but are not limited to primary care, family-focused maternal/child health care, traditional healing and medicines, mental health and wellness, cultural programs, health promotion programs, community development initiatives, youth empowerment programs, and social support services. IPHCOs continue to serve as a key entry point to overall family and community health and development.

IPHCC Data Governance Framework & Resources

Indigenous data governance refers to the principles, processes, and mechanisms by which Indigenous communities exercise their right to data sovereignty, namely the right to govern the entire life cycle of their information and data.

In 2023, IPHCC published a Data Governance Framework to serve as a guide for IPHCOs. The Framework is both inclusive of and responsive to the distinct approaches to data governance and sovereignty upheld by or emerging among Indigenous governments as the restoration of rights evolves within the Canadian context[3]. The Framework was developed to help address the following gaps in understanding and practice by health organizations and present systems:

- Non-Indigenous organizations may collect and hold a significant amount of information on Indigenous people, contributing to the deficiencies in the data quality, relevance and infrastructure. This information and data are often not shared with FNIM communities.
- Indigenous health information often lacks inclusive and reliable information on Indigenous identity. This leads to an inability to link information across multiple datasets, limiting the ability to fully analyze information on Indigenous health, determinants of health, and health service utilization.
- Present systems do not have adequate safeguards in place to help ensure the protection of Indigenous data that is collected outside of Indigenous communities and organizations[4].
- There is a focus on quantitative data and numbers that could be more effectively coupled with qualitative data and stories.
- There is limited formal systems in place to validate the data collected to ensure accuracy and understanding of Indigenous story.

IPHCC has developed documents to support implementation of their Data Governance Framework. Table 1 provides an overview of these documents, which offer additional detail and guidance in specific areas of data governance. Most are focused on health care services and can aid as a complementary perspective or resource to this Guide. Please refer to these documents for additional details:

Table 1 – IPHCC Indigenous Data Resources*

Document	Key points on content / Resources
Data Governance Framework Appendix	Appendices include: • Indigenous data governance environmental scan (including case studies and models) • Detail on the Secure, Govern, Act, Report (SGAR) framework • Data Sharing Agreement template • Relationship Agreement template
Indigenous Data Governance Indicator Framework	Includes suggested measures that can be used to evaluate, monitor and further the implementation of Indigenous data governance practices, under the categories of Partnerships, Policies, Personal Experiences and Processes.
Indigenous Data Governance Draft Policy Handbook	Contains a list and description of suggested data governance policies. The vision is to ultimately include sample policies that organizations can customize.
Indigenous Data Governance Privacy and Security Handbook *(draft)*	Contains sample privacy policies, privacy breach procedures, a public privacy notice, safeguard guidelines for patient information, access and correction procedures related to the release of patient information, and lockbox procedures. Resources are intended to be customized and by Health Information Custodians (HICs) and adopted by organizations to ensure the overall privacy and security of Indigenous data.
Indigenous Population Health Indicators	Contains wholistic, strength-based population health indicators that align with the Public Health Ontario (PHO) population health indicators. The current PHO indicators were reviewed with specific domains and/or indicators identified where opportunity existed to develop or reframe using a wholistic, strength-based lens. Several PHO indicators were reworded using this lens, while other indicators were created anew to incorporate FNIM perspectives.
FNIM Community Engagement Guide	Includes principles for engagement, protocols, and tools that can be used to partner with FNIM communities and organizations to ensure public health programs and services are designed by, with and for FNIM.

**Note: the documents above were all released in 2023/2024.*

Data Governance Practical Application

Implementation Strategy One:
Align with Indigenous Values

Public health agencies should ensure that data collection processes are culturally appropriate and inclusive of traditional knowledge and oral histories. The IPHCC's Indigenous self-identification toolkit is an essential resource that includes training modules, cheat sheets for staff, communication templates, and posters. Collaboration with Indigenous organizations and other intermediary bodies is crucial to facilitate culturally appropriate data collection that respects traditional knowledge and practices. By establishing relationships with Indigenous Elders and community leaders, public health agencies can gain valuable insights into culturally appropriate methods of data collection and analysis. Regular reviews and updates of data collection tools and processes, in consultation with Indigenous representatives, will ensure these methods remain culturally relevant and respectful. Be mindful that these approaches may change over time as you learn more about wise practices.

Implementation Strategy Two:
Enhance Data Integrity

Maintaining high standards of data integrity is essential for effective data governance. Public health agencies should conduct regular data quality assessments using templates provided in the Data Governance Policy Manual. Establishing a centralized data quality team can help ensure that these assessments are thorough and consistent. This team should be responsible for developing a comprehensive data inventory that includes detailed descriptions, sensitivity classifications, and storage information for all datasets. This inventory helps maintain an organized record of data holdings as well as supports transparency and accountability. Utilizing the Data Flow Index to document and review data flows can further ensure consistency in data handling processes. Collaboration with Indigenous communities can identify and address data quality issues, ensuring that the data remains accurate and relevant.

Implementation Strategy Three:
Data Access and Usage

Implementing strict data access policies is critical to protect Indigenous data. Public health agencies must ensure that all staff and contractors complete Indigenous Data Governance and Privacy Awareness Training before accessing any data. This training should be updated regularly to reflect new policies and community feedback. Data holdings should be classified by sensitivity, with appropriate access levels assigned based on these classifications. Access to sensitive data should be restricted until the necessary training is completed. Regular audits and reviews of compliance with data access and usage policies are essential to reinforce the importance of data integrity and privacy. This approach not only protects the data but also builds trust with Indigenous communities by demonstrating a commitment to ethical data handling.

Implementation Strategy Four:
Community Engagement

Effective community engagement is fundamental to successful data governance. Public health agencies should use the FNIM Community Engagement Guide (for public health) to develop strategies that build and maintain trust through transparent communication and reciprocal learning. Engaging community members at all stages of research and data governance—from design to dissemination—ensures that initiatives are designed by, with, and for Indigenous Peoples. Using a readiness scale to assess the public health agency's readiness for meaningful engagement helps tailor strategies to community needs. Establishing continuous dialogue with intermediary bodies such as Tribal Councils, local friendship centres, Métis offices, ONWA chapters, and Inuit associations will help to facilitate effective community engagement and uphold data sovereignty principles. Formalizing these partnerships through Relationship Agreements can provide structure and clarity, ensuring mutual understanding and respect.

Implementation Strategy Five:
Data Sharing Agreements

Customizable data sharing agreements that reflect the values and interests of Indigenous communities are essential for ethical data governance. Public health agencies should prioritize mutual benefit and reciprocity in these agreements and ensure continuous communication between all parties involved. Collaborating with Indigenous legal advisors helps ensure that agreements align with cultural values and legal requirements. These agreements should be regularly reviewed and updated to reflect changes in community needs and organizational policies. Establishing data sharing agreements that support inter-agency collaboration respects the data sovereignty of multiple Indigenous communities, ensuring that shared data is used ethically and benefits all parties involved.

By adopting these detailed guidelines, public health agencies can integrate and uphold Indigenous data governance principles effectively. This approach ensures culturally sensitive, ethical, and transparent practices that honor Indigenous data sovereignty, fostering trust and collaboration with Indigenous communities.

Public Health Approaches

Mainstream Public Health

Public health is an upstream approach that focuses on a population approach to preventing illness and promoting well-being. In Canada, it is often defined with six core functions: population health assessment, health surveillance, health protection, disease and injury prevention, health promotion, and emergency preparedness and response. In Ontario, public health functions are implemented by approximately 34 public health units (Governed by Boards of Health), which serve the whole population within their respective jurisdictions according to best practices and standards set by the provincial government. As of 2024, some of the public health units (PHUs) may be combined in the coming years but the overall structure is remaining similar. PHUs are also supported by Public Health Ontario, a crown corporation that provides scientific evidence and expert guidance that shapes policies and practices.

Public health agencies use population health data to monitor the health of communities and to understand the needs and risks that can be addressed by public health programs. Some examples of population health data are:

- Demographic data
- Communicable disease data
- Data on determinants of health (e.g. health behaviours, income, education, etc.)
- Chronic disease and injury data
- Environmental hazards
- Immunization data

Public Health Legislation, Regulations, and Standards

Legislative considerations include those relevant to communicable disease, environmental health, health emergencies, and schools. Some of these data are collected by Public Health agencies under federal, provincial and territorial legislation. For example, the Health Protection and Promotion Act (HPPA), Communicable Disease Regulation outlines the communicable diseases that are designated reportable in the province of Ontario. Under the authority of the HPPA, these conditions must be reported to the local Medical Officer of Health by healthcare providers, schools, and institutions. The public health system depends upon these reports of communicable diseases to monitor the health of the community and to provide the basis for preventive action. Personal Health Information is collected so that these cases, and any close contacts, can be followed up and treated if needed.

Other regulations under the HPPA include those related to food premises and small drinking water systems. In addition, PHUs in Ontario are required to collect immunization information on school-aged children under the Immunization of School Pupils Act.

In addition to legislation and regulation, Ontario boards of health are accountable for implementing the provincial government's Ontario Public Health Standards, including the Standards' associated guidelines. The Relationship with Indigenous Communities Guideline includes a section on use of Indigenous health information.

Public Health from an Indigenous Perspective

Indigenous health systems follow a natural continuum of care that is based on the cycle of life – from pre-conception to death of the physical body and understanding the impact of the internal spirit and fire. There is a shared understanding among Indigenous groups of the interconnectedness between the physical, mental, emotional, and spiritual realms of being that are shaped by the environment in which we live (NCCIH, 2021). In many publications, Indigenous health is presented through a deficit-based lens and synonymous with poor mental health and high addiction rates, intergenerational trauma, greater incidence of communicable diseases, lower life expectancy, and greater rates of chronic conditions. Indigenous health is further compromised by continuing deficits across the social determinants of health; namely, poverty, overcrowded housing, food insecurity, and inadequate access to health services from either a physical or culturally appropriate perspective, or both. These disparities and inequities were magnified and heightened during the COVID-19 pandemic, requiring many Indigenous communities and organizations to lead work to protect those for whom they provide care.

Improving the health of Indigenous people is a shared responsibility between Indigenous, federal, and provincial/territorial partners. To move the dial on Indigenous health outcomes, it is imperative that sustainable, long-term, integrated solutions are developed through dedicated and collaborative efforts at all levels. Government entities can not only support but also enable Indigenous people to address their own health needs by increasing their control over health program design and delivery through **Indigenous Health in Indigenous Hands**.

Blending some health care and public health components, the Primary Health Care (PHC) approach used by the First Nation Inuit Health Branch (Figure 2) of the federal government encompasses (Government of Canada, 2020):

- **Health promotion and disease prevention programs** – to improve health outcomes and reduce health risks.
- **Public health protection, including surveillance** – to prevent and/or mitigate human health risks associated with communicable diseases and exposure to environmental hazards.
- **Primary care** – where individuals are provided diagnostic, curative, rehabilitative, supportive, palliative/end-of-life care, and referral services.

Indigenous primary health care (IPHC) takes an Indigenous-led and community-centred wholistic approach to improve the mental, emotional, physical, and spiritual health and wellbeing of Indigenous Peoples. Traditional knowledge, traditional healing practices, and self-determination underpin IPHC and are central to restoring balance at the individual, familial, community, and nation levels.

For many IPHCOs, IPHC services are provided to FNIM people and their families, living on and off territory, in rural areas, and the urban Indigenous population across the province.

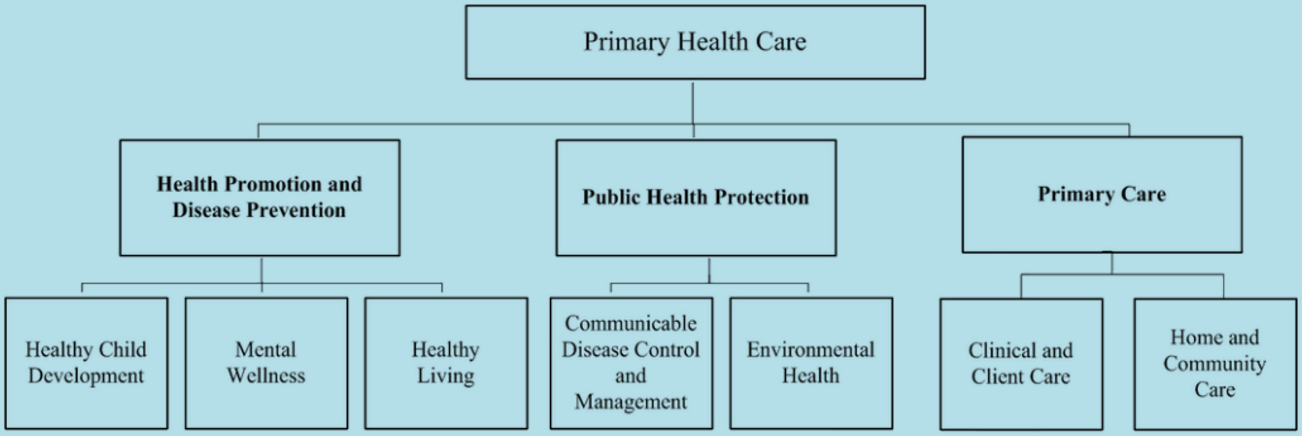


Figure 2: Primary Health Care

Indigenous Considerations

While public health agencies are highly trained in epidemiology, and other disciplines, they typically do not have strong expertise in Indigenous knowledge and ways of knowing. Public health agencies recognize that the data they work with contain sensitive information and are bound by privacy and confidentiality policies within each jurisdiction, for the duration of the data life cycle. When reporting data, they often employ various parameters to avoid a possible breach on privacy and confidentiality. Data usually are not broken down to small categories and are kept at the highest level that will not allow any of the individuals to become identifiable. Public health leaders also acknowledge there are significant gaps in existing Indigenous-specific data, and recognize the importance of respecting and prioritizing Indigenous data sovereignty[5] and governance. Many are looking for ways to work with partners to do this, within their organizational mandates, legal constraints and parameters in the Relationship with Indigenous Communities Guideline.

> ***It is crucial to recognize that Indigenous data is more than just numbers; it embodies the lived experiences, values, and worldview of Indigenous peoples.***

Addressing Challenges and Considering Strength-Based Approaches to Indigenous Public Health Data

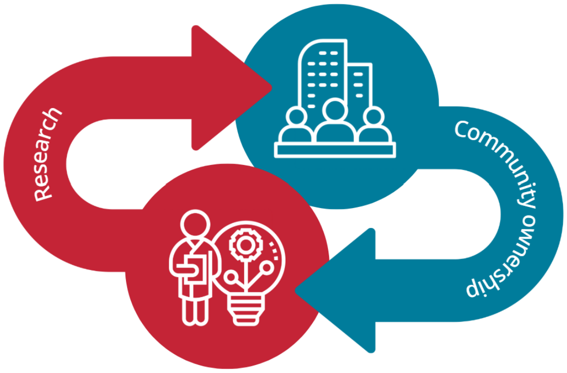
Indigenous data refers to information collected from or about Indigenous people and communities, often concerning their health, culture, environment, and socioeconomic conditions. These data may include traditional knowledge, oral histories, community surveys, health records, and other forms of information. It is **crucial to recognize that Indigenous data is more than just numbers; it embodies the lived experiences, values, and worldview of Indigenous Peoples**. There are effective and valid ways to incorporate this knowledge into public health information systems. IPHCC's resources on strengths-based indicators may be helpful to look to for examples.

The IPHCC Data Governance Framework recognizes and helps to address several key challenges encountered in establishing and executing effective data governance for Indigenous communities and IPHCOs in Ontario. These challenges, deeply rooted in historical, cultural, and ethical contexts, require a nuanced and sensitive approach.

Historical Trauma

Indigenous communities in Canada have a history of colonization, forced removal from their traditional lands, disintegration of family units and cultural suppression. This history has left a legacy of mistrust between Indigenous communities and government institutions, including those related to healthcare. These experiences leave lasting generational impacts and must be navigated with sensitivity and empathy. This also may to communities not consenting to data being collected or wanting to participate. It is important it is considered for data collection and reporting.

Data Sovereignty



Indigenous communities have the right to control their data and determine how it is collected, used, and shared. However, historical exploitation and colonization have undermined this sovereignty, leading to distrust and reluctance to engage with external researchers or institutions. As such, Indigenous data sovereignty addresses the misuse, adaptation, and stealing of Indigenous traditional knowledge, ways of knowing, and cultural practices.

Indigenous data sovereignty involves the inherent rights as Indigenous Peoples to be self-governed with data, including the collective ownership of the data and intellectual property that relates to their distinct societies, including languages, cultures, worldviews, histories, and land stewardship.

Engaging with a diverse and occasionally undefined array of data rights holders is essential as we move towards Indigenous Data Sovereignty. The IPHCC is seen as an enabler and facilitator to multiple health system entities, ensuring that systems are interoperable.

Although public health and privacy legislation governs how data are collected, used, and disclosed, there also needs to be consideration about how to appropriately obtain and provide some of the data back to communities without compromising privacy and confidentiality.

There can also be limited capturing of Indigenous identity in many quantitative data sets, which can limit opportunities for shared work in this area. IPHCC has developed an Indigenous self-identification toolkit to help address this challenge. Resources within the toolkit contain:

- **Draft Questionnaire:** A tool designed to accurately capture FNIM self-identification data.
- **Cheat Sheet:** Guidance for staff on how to ask Self-ID questions and handle common reactions and responses to the questions.
- **Communication Templates:** Ready-to-use templates for informing the community about the Self-ID process and guidance as to how to work with them upon implementation.
- **Posters:** Informational posters to notify clients about the new self-ID process.
- **Comprehensive Modules**:
  - Module 1: Technical training for data administrators on data collection and management.
  - Module 2: Training for organization-level staff on the importance of FNIM self-identification, the SGAR model, and data sovereignty strategies to respect Indigenous data sovereignty.

Traditional Ways of Knowing

Indigenous data sovereignty is intimately tied to Traditional Knowledge, a vital aspect of healing for Indigenous Peoples. However, challenges emerge in recognizing and incorporating these traditional insights due to a lack of awareness and educational resources. Non-Indigenous organizations can work harder at practicing cultural humility and incorporating the Two-Eyed Seeing Approach to collaboration and public health service delivery for FNIM. This requires meaningful engagement and input from both public health agency and Indigenous partners. The resulting analysis format and sharing would look markedly different to the current typical public health agency reporting format. It is as equally important for public health agencies to validate Indigenous data through community validation processes, acknowledge the importance of oral histories, traditional knowledge, and cultural practices in understanding health outcomes, and consider combining Indigenous and mainstream scientific approaches to enhance data validity and relevance.

Public health approaches to population health tend to be deficit-based, with a focus on rates of disease and illness. There are significant opportunities to be more strengths-based and acknowledge the wisdom, expertise, resilience, culture, and other elements within Indigenous communities. To advance FNIM self-determination in the health system, it is essential for FNIM narratives and knowledge to thrive in population health data and reporting. To support this shift in focus, IPHCC created and in some places reframed, existing population health indicators using the five promising practices highlighted below:

1. Be culturally relevant and centre on health and wellness.
2. Honour Indigenous ways of knowing and being.
3. Involve respectful relationships and meaningful engagement with FNIM communities so that co-creation is a regular process.
4. Ensure Indigenous leadership and self-determination – ***nothing about us, without us***.
5. Fully embrace a strength-based approach and contextualize indicators within historical, sociopolitical contexts.

Incorporating qualitative methods (including storytelling) alongside quantitative data (such as numbers and graphs) can be helpful to these shifts in approaches.

There should be cultural safety training for practitioners and public health staff working with Indigenous data.

Cultural Safety

The COVID-19 pandemic spotlighted the gap in comprehensive, quality Indigenous data, heightening the need for accurate, timely, relevant, comprehensive, and trustworthy Indigenous health data, which is a welcome shift for many data practitioners. Yet little remains understood regarding cultural safety and the important relationship between data and the communities who share the information.

Among FNIM, knowledge acquisition can occur in three main ways: from teachings of Elders (Traditional Knowledge), from dreams or visions (Revealed, Spiritual or Ancestral Knowledge), and by observation and experience (Empirical Knowledge) (Hill & Wolfe, 2020). Researchers and agencies take a more westernized approach and do not consider the Indigenous views and knowledge. This has resulted in culturally unsafe data collection from FNIM communities, attributing to appropriation and misuse of these data.

Indigenous data often contains sensitive information related to spirituality, family dynamics, and traditional practices. Public health agencies must approach data collection and analysis with cultural humility and respect for Indigenous protocols and customs. Collection and reporting of health data needs to be culturally sensitive to the unique needs and preferences of Indigenous communities. This may require a more wholistic approach.

There should be cultural safety training for practitioners and public health staff working with Indigenous data that fosters understanding of Indigenous worldviews, languages, and protocols to ensure respectful and culturally appropriate interactions.

Community Engagement

Establishing data governance for Indigenous communities must involve the active participation and consent of the communities themselves. This requires building trust and engaging in meaningful collaboration with Indigenous communities and organizations – ***"nothing about us, without us."***

Collaborate with Indigenous communities and organizations from the outset of research projects and preparation of public reports, respecting their self-determination and priorities. Build trust through transparent communication, mutual respect, and equitable partnerships.

Prioritize community-driven research agendas that address the unique health needs and priorities of Indigenous populations. Involve community members in all stages of the research process, from study design to dissemination of findings. This can be very applied and pragmatic. As a public health professional, reflect on what's included in the last three reports your public health agency produced, asking the following questions:

- Were the questions/analysis decided based on what had been done before?
- Epidemiological data through a public health provider lens?
- Questions drawn from community leadership?

IPHCC emphasizes meaningful engagement and robust relationship agreements as cornerstones of effective partnerships in Indigenous health and data governance. This focus is not merely procedural but is rooted in a deep understanding of the complexities and nuances of working within Indigenous contexts.

The FNIM community engagement guide (specific to public health) includes a self- assessment to determine current state of engagement efforts. Public health agencies can consider reviewing and reflecting on how it may apply to their own organization.

Relationship Agreements are formal documents that outline the terms and expectations of the partnership. They provide structure and clarity, ensuring that both parties are aware of their roles, responsibilities, and the goals of the partnership. They also include dispute resolution mechanisms as well as accountability and enforcement measures.

These agreements are not static documents but evolve along with the relationship, reflecting changes in understanding, objectives, and the broader context of the partnership. IPHCC has included a template example in the Indigenous Data Governance Framework that public health agencies are welcome to use and adapt.

In many Indigenous cultures, the Beaver is a symbol of perseverance, resourcefulness, and hard work.

Meaningful Engagement Aspects	Description	Examples/ Wise Practices
Reciprocal Learning and Sharing	Both parties engage in a process of learning from and sharing with each other, fostering a deeper understanding and respect.	Holding joint workshops where both parties can present and discuss their perspectives; Collaborative research projects where knowledge is co-created.
Empowerment and Support for Self-Determination	Prioritizing the voices and choices of Indigenous communities, thereby supporting their right to self-determination.	Involving Indigenous communities in decision-making processes; Respecting and implementing the community's decisions regarding their data and resources.
Sustainability of Relationships	Building partnerships that are durable and adaptable to changing needs and circumstances.	Establishing long-term goals and commitments; Regularly revisiting and adjusting the partnership terms to accommodate evolving needs.

Ethical Considerations

Informed Consent

Data governance for Indigenous Peoples must address ethical considerations, such as informed consent and the protection of sensitive information. Researchers and institutions must be aware of the potential for harm when working with Indigenous data. They should prioritize understanding and valuing the shared values and customs, and connect with the Elders and leaders before collecting data and to determine when it is appropriate to collect data. Colonialism and its historical systems have caused deep trauma and loss amongst Indigenous Peoples, and data collection has the potential to be triggering and damaging. As such, it needs to be well planned and thought out.

Prioritize understanding and valuing shared values and customs.

Connect with the Elders and leaders

Determine when it is appropriate to collect data.

If data are collected but never reported, indicators need to be refined to justify the collection of data and minimize the potential harms in doing so. There are pre-determined life cycles for data in Public Health to ensure that retention policies are being followed as legislated.

Cultural Sensitivity

Culturally sensitive and clear informed consent procedures are essential. Throughout Canada, including in Ontario, health research has historically lacked appropriate consent or cultural sensitivity.

In the context of Ontario's Indigenous sector, the framework advocates for collaborative research models. Such models position Indigenous communities not as mere subjects of research but as equal partners in the creation of knowledge. This approach is crucial in a province with a rich and diverse Indigenous history, ensuring that research outputs are reflective of and beneficial to these communities. Plain language information available to communities, prior to any conference presentations or publications, is crucial. There is also an opportunity for internal (non-public) interim summaries that can be shared with Indigenous and public health partners on a regular basis to learn from and act on the findings from their respective roles.

Knowledge Translation and Capacity Strengthening

Knowledge translation practices should be accessible and beneficial to Indigenous communities, while also respecting their intellectual property rights. In Ontario, with its diverse Indigenous communities, this means creating research outputs that are not only academically rigorous but also accessible and useful to community members.

Capacity strengthening within Indigenous communities is another key aspect. The framework emphasizes the need for Indigenous communities in Ontario to develop the capability to lead and conduct their own research projects. This empowers communities, fosters self-reliance, and ensures that research is grounded in the lived experiences and perspectives of Indigenous Peoples.

Jurisdictional Challenges

PHUs provide public health functions, including population health assessment, for defined geographical areas. However, PHU boundaries may not coincide with those of municipalities or First Nations' territories and treaties. In addition, health for First Nations on territory (reserve) is typically more under the jurisdiction of Indigenous Services Canada (ISC) rather than Ontario provincial organizations, thus health service utilization data for on-reserve populations is not integrated with provincial information systems. Under the [Health Protection and Promotion Act](#) (section 50) formal agreements regarding public health services may be negotiated between First Nations communities and boards of health. Such agreements could cover all public health services or only a specific service such as data collection, use and disclosure. However, these agreements would not cover the off-reserve population, so would not necessarily address all the jurisdictional challenges in data governance. Appendix A provides specific examples of these agreements in Ontario.

Resource Constraints

Many Indigenous communities face resource constraints, which can hinder their ability to establish and maintain robust data governance structures. Support and resources are essential to address these challenges so that they can be actively and respectfully engaged. One action public health agencies can take is fostering Indigenous-led data initiatives that empower communities to address their own health challenges and leverage their strengths. They can also partner to invest in reciprocal building capacity for both Indigenous communities and public health. Through this approach, practitioners on both sides will have the opportunity to learn about the different techniques for data collection, analysis, and interpretation.

IPHCC Data Governance Principles

IPHCC's Data Governance Framework provides a detailed description of three important approaches to Indigenous Data Governance. These approaches, which are detailed more in the appendices, consist of:

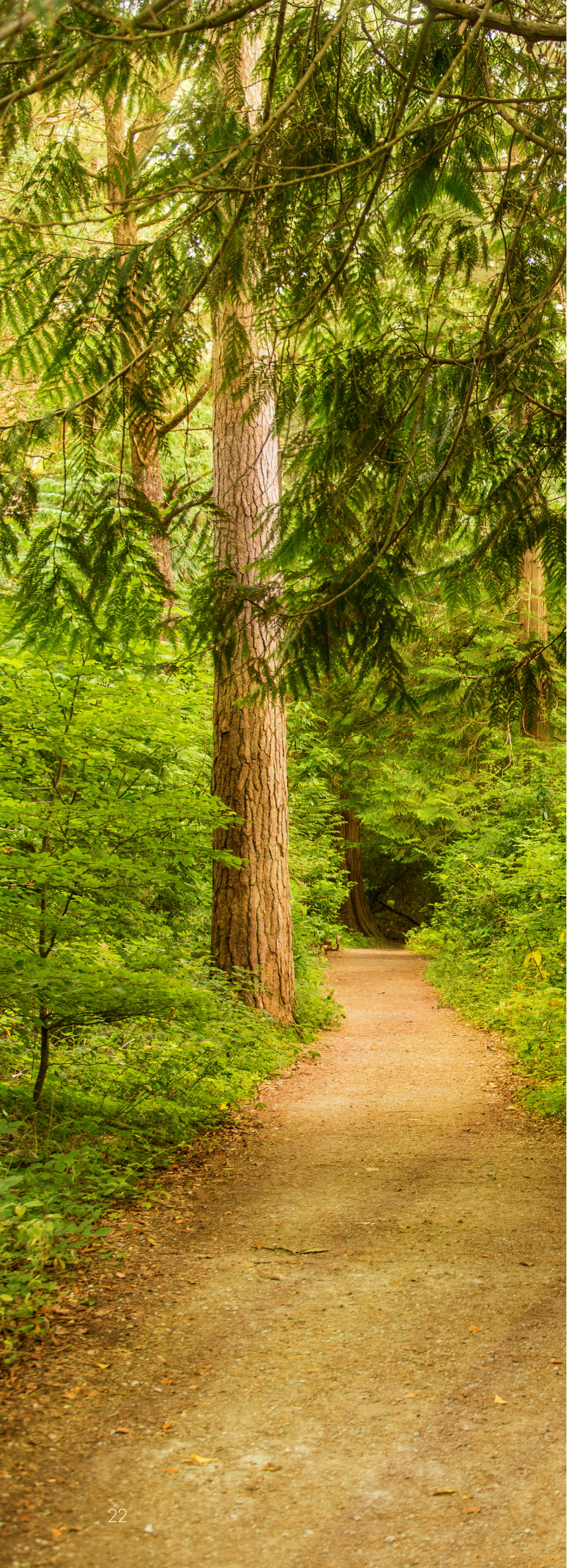
- **Stories of Strength (Appendix B):** Principles guiding decision-making and behaviour in data governance, developed with IPHCC members and stakeholders since 2021. These principles, foundational to all data processes, emphasize respectful management, creation, and sharing of data, extending to non-Indigenous partners like public health agencies.
- **4 Ps Approach:** Combines Indigenous (Partnerships, Personal Experiences) and Western (Policy, Process) perspectives, recognizing the importance of both in data governance.
- **SGAR Model (Appendix C):** A framework supporting respectful, culturally sensitive Indigenous Data management. The model includes:
  - **Secure:** Prioritizing data privacy and security.
  - **Govern:** Respecting Indigenous data sovereignty.
  - **Act:** Ensuring ethical practices that benefit Indigenous communities.
  - **Report:** Maintaining accountability and transparency through regular reporting.

Data Sources and Quality of Data

Information on Indigenous health may come from various sources such as public health practitioners, public health agencies, community organizations, laboratories, surveys, vital statistics, environmental monitoring, and sources monitoring social determinants of health (such as income, housing and education). The calculation of many indicators necessitates accurate population estimates to have appropriate denominators.

SGAR Model

Secure	The 'Secure' phase emphasizes the importance of protecting Indigenous data through robust privacy and security guidelines.
Govern	The 'Govern' phase involves understanding and respecting Indigenous data sovereignty.
Act	In the 'Act' phase, the focus is on addressing ethical considerations and ensuring that the actions taken benefit the Indigenous communities.
Report	The 'Report' phase is a critical component of the SGAR model, ensuring accountability and transparency in the management of Indigenous data. This phase involves establishing regular reporting schedules to monitor and evaluate the data governance practices.



Serious concerns have been raised about the quality of existing data reflecting Indigenous population counts, attributable populations and health status (Rotondi 2017; Anderson 2006; Smylie 2018; 2015). For example, there are differing population estimates for Registered (Status) First Nations people depending on whether the Indian Register, the Census, or band lists are used.

The absence of appropriate ethnic identification on health records, which is perpetuated by the lack of opportunity to self-identify, contributes to the ongoing oversight of non-registered (non-status) First Nations, Métis and many Inuit, particularly in urban communities. As a result of this lack of self-identification, the only source of Indigenous-specific health information is periodic surveys, which rely on self-reported health status, only occur every few years, and have insufficient sampling.

These factors contribute to the inadequacy of surveys in serving as the bases for regional or community level planning and surveillance (Anderson 2006; Smylie 2015; 2018). Currently, the most feasible way of obtaining Indigenous-specific data, is by linking the Indian Register with health care databases. It is important to note that such databases generate data that is reflective of federal priorities, categorized by externally imposed political definitions of who "Indigenous" people are, and allows for a coverage of less than 60% the population. In addition, Census data provides an inaccurate depiction of the Indigenous as they are grossly underestimated for the following reasons:

1. Due to a history of mistrust, many Indigenous people are hesitant to participate in a government data collection tool.
2. The Indigenous identity question is only asked on the long-form census which only goes to 25% of Canadian households.

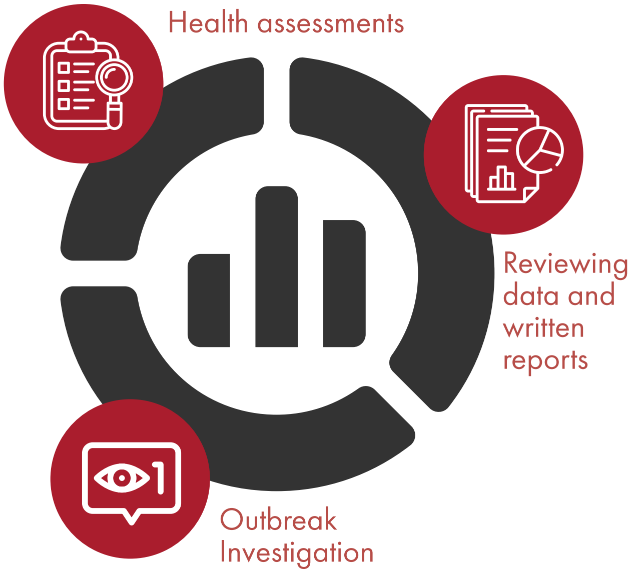
3. Statistics Canada does not collect data from the following groups:
    a. Those residing on territory (reserves)
    b. Those experiencing homelessness or unhoused (overrepresentation among FNIM)
    c. Those within correctional settings (overrepresentation among FNIM)

Key improvements are immediately required that include Indigenous self-identification and the right to be counted (Smylie 2015). Until this is done, using the usual data sources will undercount Indigenous populations up to 40%.

One strategy for consideration that will provide more accurate data is use of respondent-driven sampling to reach and include Indigenous people more effectively[6]. Community-driven data collection approaches have shown effectiveness in reaching Indigenous Peoples commonly excluded, unidentifiable or underrepresented in health information systems.

Public Health Sources of Data

From a Western perspective, public health often has typical approaches /steps /expertise in responding to public health issues across a range of public health services and activities. For example, population health assessments can consider dozens or hundreds of variables relating to demographics, health status, behavioural factors, and social/cultural/environmental factors (Ontario Ministry of Health, 2018). For outbreak investigation and management, the well-established public health response includes collection and analysis of detailed outbreak-specific data to identify transmission patterns and risk factors as well as evaluate interventions aimed at mitigating the health impacts (Health Knowledge, n.d.).



Because it happens at group/community/population levels, much or most of public health action involves interacting with health data. There are opportunities to incorporate more Two-Eyed Seeing and not only value but embed Indigenous expertise in partnership with approaches like these.

> ***… many Indigenous people are hesitant to participate in a government data collection tool.***

The table below includes examples and questions for public health unit epidemiologists, Medical Officers of Health, and other team members to consider when working with Indigenous population health data.

Task	Key Questions
Decision-making	• Who asked for or decided to do this public health activity at this time (e.g. community members, public health, Indigenous leadership, etc.)? • Are there constraints related to data collection, use and disclosure that would limit flexibility in responding to partners' perspectives (e.g. legal requirements to collect data, limitations in current information systems)? • Who makes the decision about the direction of the activity and how related funds/staff time are spent? • If in partnership with Indigenous communities, does the public health organization know the contacts or have relationships developed with Indigenous partners? • Has there been an opportunity to have a relationship agreement in place?
Data Access, Collection, Management	• What questions are being answered by the activity? • Who is asking these? • How can a Two-Eyed Seeing approach (i.e. both Western and Indigenous perspectives and methods) using both qualitative and quantitative information be incorporated? • Has a strengths-based lens been considered for the work? • Who will "own" the data? • Who will determine who has access to the data?
Data Analysis and Interpretation	• Does the analysis consider cultural contexts and lived experiences to avoid misrepresentation or misinterpretation? • Is there a process to ensure that data sovereignty principles are upheld throughout the analysis? • Have Indigenous knowledge holders, Elders, or community representatives been engaged in interpreting the data? • Are the findings being validated with Indigenous communities before dissemination?
Reporting and Knowledge Exchange	• Who would benefit from release of data? What are potential harms? • How will the subjects of the data be informed ('nothing about us, without us')? • If complete public release of the information is not felt to be possible, have alternatives been considered (e.g. sharing with community leadership directly for them to share onwards as seen fit)? • Is data available in plain language? • Has information been translated?

**Note - this is not an exhaustive list but is meant instead to prompt ideas. All these things may not always be possible but should be considered when planning and conducting public health activities such as outbreak response, investigating a health hazard, health assessments, emergency responses, and other public health action. but should be considered on planning and conducting public health activities such as outbreak response, investigating a health hazard, health assessments, emergency responses, and other public health action).*

Protecting Indigenous Data

Constitutional recognition, treaty rights and the Access to Information and Protect of Privacy Act all need to be considered. Alongside relationship agreements discussed above, data sharing agreements and appropriate governing bodies are important mechanisms.

Indigenous Data Sharing Agreements

When a public health agency is going to be sharing Indigenous health data outside of the organization or to another department within the organization, strong established relationships are important. A data sharing agreement can ensure that the use of data and further sharing of data better aligns with Indigenous data governance protocols and policies as originally intended.

Some key elements of standard data sharing agreements include:

1. Limitations on data usage/ third party involvement
2. Data Privacy Measures
3. Data Security Measures

However, historically standardized western DSAs from non-Indigenous organizations, such as funders and researchers, did not align with the values and collective interests of Indigenous Peoples. When Indigenous data is involved, data sharing protocols need to incorporate the Indigenous perspective, including the types of data shared, objectives and conditions for access or utilization. IPHCC has actively collaborated with Indigenous legal advisors to create a set of sector-specific Data Sharing Agreements (DSAs). For access to templates, connect with relations@iphcc.ca

These templates are integral to facilitate the exchange of information securely and ethically among the entity responsible for collecting Indigenous data, external collaborators, and FNIM communities and organizations. This strategic approach ensures that the DSAs authentically represent the cultural context and priorities of Indigenous communities, marking a significant departure from historically imposed western-centric agreements.

Key features of data sharing agreements related to Indigenous data include:

- Prioritize mutual benefit and reciprocity, outlining community benefits.
- Allow for customization of protocols to suit the unique contexts of each community, ensuring flexibility.
- Foster continuous communication between data collectors, partners, and Indigenous communities.
- Include a mechanism for fair and culturally appropriate dispute resolution related to data sharing.

Establishing an Indigenous Governing Body

In line with Ontario Health's Indigenous Data Governance Matters initiative, organizations handling Indigenous data should establish a governance body accountable to their local FNIM communities. This governance body plays a crucial role in overseeing the collection, use, interpretation, and dissemination of Indigenous data. It should be comprised of representatives from FNIM communities and/or organizations, such as local IPHCOs, First Nation entities, MNO offices, ONWA chapters, Inuit associations, and local Indigenous advisory groups.

FNIM representatives participate on a voluntary basis; however, best practice includes providing honorariums as forms of appreciation to acknowledge their feedback and guidance. Often these individuals are working in settings where human resource capacity at the best of times is a challenge. Remember without them you have no informed process and limited ways to address data gaps.

It is recommended that public health agencies provide secretariat capacity for the Indigenous Governance Body that will support the review/approval process for requested data activities. The team should include staff who can provide advice related to

- Privacy and security
- Ethics
- Information Management
- Epidemiology, and research
- Legal and policy issues

Conclusion

The IPHCC Data Governance Framework underscores the importance of respecting and integrating traditional knowledge systems in all aspects of data governance. Emphasizing high-quality data sources and protecting Indigenous data through tailored Data Sharing Agreements (DSAs) ensures that data collection, management, and dissemination align with community values and standards. By fostering strong community engagement and navigating jurisdictional complexities, public health agencies can work alongside Indigenous communities in a way that honors Indigenous data sovereignty, upholds ethical standards, and contributes to improved health outcomes. This collaborative approach is foundational to building trust and achieving a data governance model that genuinely serves and empowers Indigenous communities.

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End Notes

1 The term Indigenous refers to First Nation, Inuit, and Métis, regardless of where they live.

2 "Two-Eyed Seeing refers to learning to see from one eye with the strengths of Indigenous ways of knowing and from the other eye with the strengths of Western ways of knowing and to using both of these eyes together"

3 Each of the three distinct Indigenous groups in Canada (First Nations, Metis and Inuit) has developed data principles tailored to their specific needs, lived experiences and culture. In recognition of the importance of Indigenous Peoples' data rights and autonomy, IPHCC respects and adheres to the established principles of First Nations' Ownership, Control, Access, and Possession (OCAP), Metis Ownership, Control, Access, and Stewardship (OCAS), and Inuit Qaujimajatuqangit Principles (IQ). The Data Governance Framework incorporates and expands upon these principles to ensure responsible and ethical data management practices that prioritize Indigenous perspectives and voices.

4 Indigenous communities and organizations refer to First Nations territories (reserves), Indigenous Primary Health Care Organizations, Métis Nation of Ontario chapters, Ontario Federation of Friendship Centres, Ontario Native Women Association, Inuit associations, local Indigenous entities, etc.

5 Indigenous data sovereignty is the ability for Indigenous peoples, communities, and Nations to participate, steward, and control data that is created with or about themselves.

6 Respondent driven sampling is a chain-referral technique recognized as valuable in gathering information from hard-to-reach populations. Recruitment begins with individuals termed "seeds" who receive a coupon to participate, give informed consent, and complete the survey. "Seeds" then receive coupons to refer people from their social networks to participate.

APPENDIX A
Existing Formal Relationships

Under section 50 of Ontario's Health Protection and Promotion Act (HPPA), First Nation communities can establish a formal agreement with public health units (PHUs). Within this agreement, PHUs agree to provide public health programs and services to the First Nations communities, and the First Nations community agrees to accept responsibilities within the health unit.

Twenty-one PHUs intersect with the boundaries of 133 First Nations communities. A 2017 survey of 14 public health units that intersect with First Nations communities found that seven had formal written agreements for certain public health programs and services, with memoranda of understanding as the most common. Agreements included needle syringe programs, nutrition, physical activity, dental screening, vaccines, and animal bite investigations. Below are some examples of PHUs who have or are seeking formal and collaborative agreements as of 2024.

- Peterborough Public Health: Peterborough Public Health has formal agreements to provide public health services to two local First Nations communities - Hiawatha First Nation and Curve Lake First Nation. They offer all programs and services to these communities, and the administration determines whether they want the health unit or Health Canada to provide services. In 2014, the Chief of Curve Lake First Nation was chair of the Board of Health.
- Eastern Ontario Health Unit: A 2015 report cites that Eastern Ontario Health Unit has an agreement with local First Nations communities.
- Algoma Public Health: In 2024, Algoma Public Health signed a collaboration agreement with Maamwesying Ontario Health Team.
- Northwestern Health Unit: A 2018 report references a formal agreement between Northwestern Health Unit and the Kenora Chiefs Association in the final stages.
- Thunder Bay District Health Unit: Minutes from a 2018 Thunder Bay District Board of Health meeting suggest that: 1) the Board of Health enter into agreements with Sioux Lookout First Nations Health Authority to support them in governing, managing, and delivering programs; and 2) the Medical Officer of Health explore options for formal agreements including a Section 50 agreement.
- Grey Bruce Public Health: A 2023 online news article notes that Grey-Bruce Board of Health is working towards a Section 50 formal agreement with Chippewas of Nawash Unceded First Nation. Prior to this, agreements have been on a mutually voluntary basis.
- Public Health Sudbury & Districts: A 2018 report highlights specific agreements with First Nations communities including an Indigenous diabetes prevention strategy, culturally appropriate tobacco resources, dental screening, harm reduction, mental health promotion, and Northern Fruit and Vegetable Program in First Nations schools.

It is important to note that an exhaustive search was not carried out for all 21 PHUs and their agreements with local First Nations communities. This information was gathered from publicly available sources, and more examples likely exist. It is also important to highlight that administrative agreements often do not recognize First Nations governance systems and Indigenous Services Canada's role in providing public health services.

APPENDIX B

IPHCC's Stories of Strength Principles

Principle	Applicability to data governance
Safety	Members must feel safe and secure in all interactions within the data system, including those with other members, communities and the nations they represent, service partners, government, and the health care system overall.
Trust	Frameworks, policies and processes will be established on a foundation of trust so that all can speak freely, and the information is reflective of each party's experiences.
Ownership	Members will be supported to claim and own their truth when sharing data and information.
Relationship-centrism	Systems, policies and processes will be designed to build and maintain respectful reciprocal relationships with members and partners.
Impact-awareness	Data governance will create processes that support and strengthen our members, whose communities can be impacted by the words and actions of others.
Excellence	The data system will be designed to achieve excellence in all aspects so that information is shared respectfully, and our knowledge is celebrated.
Strength-building	Data and information will nurture and build strength in our future knowledge keepers.
Optimism	The IPHCC will strive to share stories of optimism for First Nations, Metis, and Inuit Peoples.
Framing	Data will frame opportunities for learning and ongoing advancement, including appropriately identifying actions that cultivate positive health outcomes for Indigenous people and communities in Ontario.
Supportiveness	Data will be used to support and improve the wholistic health and wellbeing of individuals, their families, and their communities. They will also support our knowledge keepers so that they can continue educating and building capacity for future generations.
Truthfulness	Data will be reflective of individual truths as they are seen and experienced by First Nation, Metis and Inuit people so that we can all learn and benefit. Information will reflect a wholistic and accurate view of Indigenous realities as it applies to integrated Indigenous primary health care in Ontario.
Respectfulness	The governance approach will embody the principle of respect, recognizing that no person or entity is more valuable or important, but rather are accountable to each other.
Expression-upholding	The framework will support members to express individual truths by ensuring that data, stories, and information are validated by those involved.
Narrator-focused	The data system will respect members as narrators of their stories and support the sharing of knowledge that is meaningful to them.
Gift-valuing	Data governance will honor the unique gifts and contributions of our partners and members to the data system.
Traditionally based	The data system will honor traditional approaches to gathering and sharing knowledge such as storytelling, sharing circles, and word of mouth, which are important ways for sharing collective knowledge with new generations.
Honour	We honour Indigenous data sovereignty for individuals, member sites, communities, and Nations. Data and information will meet legal and regulatory requirements while maintaining cultural integrity.

APPENDIX C
Best Practices and Models

Best Practice/Model	Description	Application Example
Respect for Indigenous Values	Indigenous research ethics that respect leadership and foster trusting relationships, based on values like honor, trust, honesty, and humility.	Engaging with community leaders in a respectful manner, honoring their guidance and decisions.
Storytelling and Ethical Thinking	Storytelling as a primary learning process in Indigenous communities, guiding behavior, and solidifying belonging, crucial for ethical thinking in research.	Incorporating storytelling methods in research design, allowing narratives to shape the research context.
The Seven Sacred Teachings	These teachings include respect, bravery, honesty, humility, truth, wisdom, and love, represented by sacred animals, and are integral to Indigenous cultures.	Integrating these teachings into research practices, ensuring that each aspect is considered and respected.
Understanding Indigenous Shared Values	Taking time to learn the ways of the Indigenous community, including the roles and responsibilities of Elders and leaders.	Building relationships with Elders and knowledge keepers, understanding community-specific protocols.
Recognizing Historical Contexts	Awareness of the impacts of residential schools and colonization, being cautious with topics that might trigger trauma.	Approaching sensitive subjects with care and in consultation with community representatives.
Difference in Indigenous and Western Research Philosophy	Indigenous concepts of freedom focus on how people convey stories or data, differing from Western notions of freedom in inquiry.	Balancing Indigenous storytelling methods with Western research practices, respecting both perspectives.

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