INDIGENOUS
PRIMARY
HEALTH CARE
COUNCIL

May 10, 2023
12:00 pm – 1:00 pm

Empowering Indigenous Communities through Data Governance, Sovereignty, and Protection

FNIM Data & Indigenous Data Sovereignty Webinar – Part 2

This is part of a series on Equity, Diversity, Inclusion, Indigeneity, and Accessibility in Research hosted by the Primary Care of Ontario Learning and Research (POPLAR) Network, in collaboration with the Alliance for Healthier Communities.

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Indigenous Primary Health Care Council

Chief Executive Officer

Learning Objectives

Defining Indigenous Health Data in Ontario

Data Principles and Concepts

Indigenous Data types and usage

Privacy and Data Protection

Model of Wholistic Health and Wellbeing

Inter-generational Transfer of Data

Ethical and Cultural Considerations

Data Governance and Sovereignty

About the IPHCC

The Indigenous Primary Health Care Council (IPHCC) is an Indigenous-governed and culture-based organization.

It was established to support the advancement and evolution of Indigenous primary health care service provisions and planning in Ontario, through partnerships, education and advocacy.

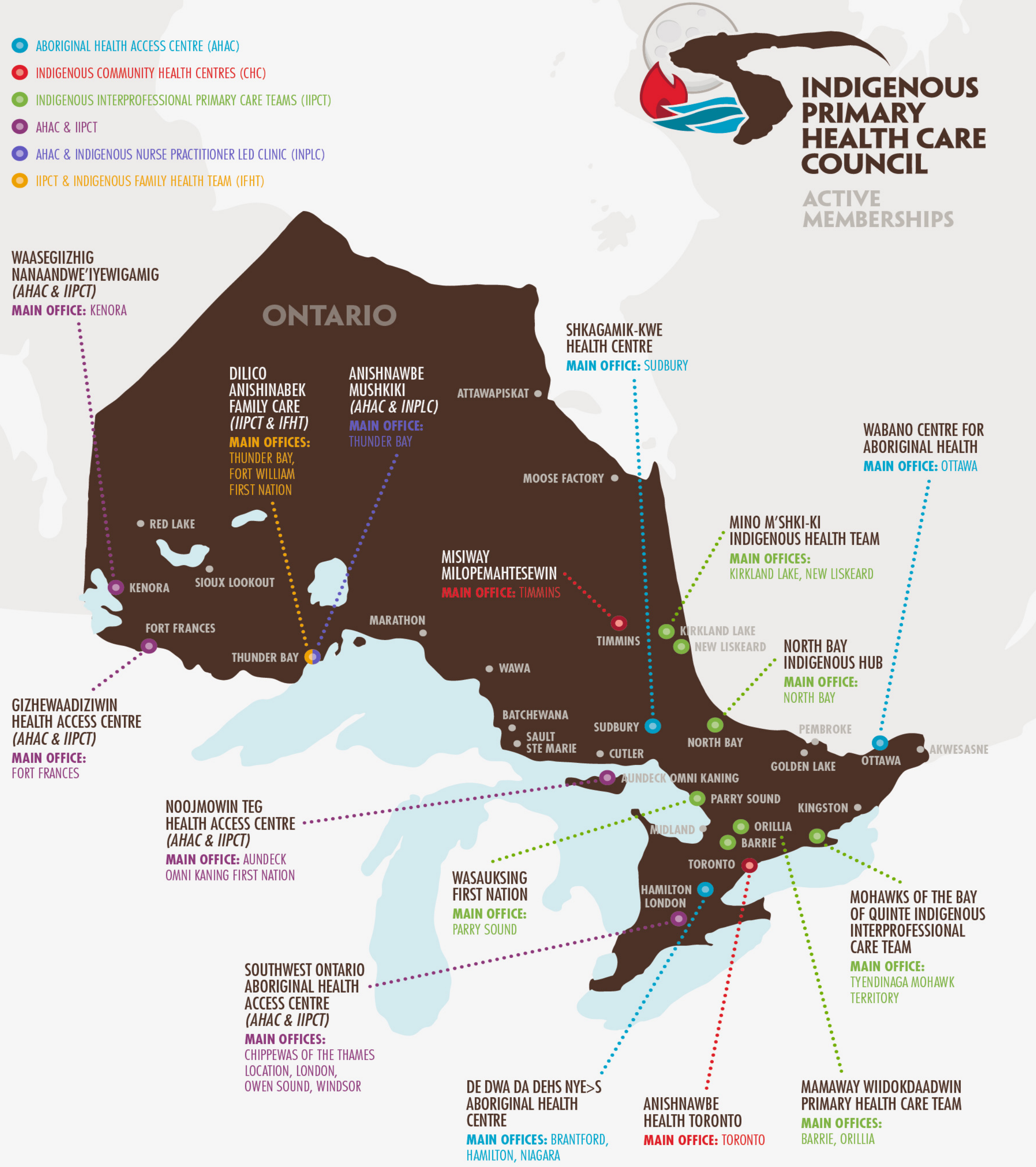
The IPHCC uses Indigenous solutions to transform Indigenous health outcomes and decolonize health systems by:

- ***Empowering*** the voices of Indigenous peoples and communities to effect change.
- ***Partnering*** with Indigenous communities, mainstream health organizations and government agencies.
- ***Gathering*** and sharing data about the health status of Indigenous peoples in Ontario and inequitable service gaps.
- ***Equipping*** IPHCC members with the tools, training and networks to provide quality health care.

IPHCC Members (21 members)

Indigenous Primary Health Care Organizations (IPHCOs):

- Indigenous Community Health Centres (ICHCs)
- Aboriginal Health Access Centres (AHACs)
- Family Health Teams (FHTs)
- Nurse Practitioner-Led Clinics (INPLCs)
- Indigenous Interprofessional Primary Care Teams (IIPCTs)



Membership has grown since infographic created to 21 IPHCO members and a new version is being created.

Part 1 - Recap

Impact of past research practices

Acknowledge the impact of past research practices on Indigenous populations.

Building and Maintaining Trust

Understand the importance of building trust with Indigenous communities.

Engagement and Collaboration

Discover what meaningful engagement and collaboration from an Indigenous perspective.

Impact and application to practice

Consider the impact and application of knowledge shared today within your own practice.

Indigenous Health Data

Defining Indigenous Health Data

- **Indigenous communities in Ontario, include FNIM populations**
  - face unique health challenges stemming from complex interplays of historical, social, and cultural factors (Allan & Smylie, 2015).
- These **challenges** include:
  - higher rates of chronic and infectious diseases, mental health and health disparities resulting from social determinants such as poverty, housing, and access to education (Reading & Wien, 2009; Smylie & Firestone, 2015).
- To **address these challenges** effectively:
  - develop culturally appropriate and relevant health data that inform services and policies tailored to Ontario Indigenous needs.
- **Health data is considered Indigenous:**
  - when it is derived from **Indigenous peoples**, **communities**, or **organizations**
  - reflects their **unique historical, cultural**, and social contexts (Kukutai & Taylor, 2016).

Challenges with Indigenous Health Data

- Indigenous health is frequently reported as **solely a problem**, with excessive emphasis on **negative outcomes**
  - rather than recognizing advancements in certain areas, such as decreased smoking rates, cardiovascular deaths, and improved vaccine coverage.
- To **monitor progress**, Indigenous communities require precise data to:
  - assess health determinants, healthcare access, and the impact of significant illnesses and their complications.
- Significant deficiencies persist in the **accessibility** and **quality** of data on Indigenous health

Data Gaps in the Sector

Despite efforts to improve Indigenous health data collection, there are still significant gaps in data for several key areas:

IPHCO Represented Population

~78,000

Indigenous people in Ontario served by IPHCOs

Healthcare Access Barriers

21%

First Nations people living off reserve experienced unmet needs for health care services during the first year of the pandemic

Children in Care Population

52.2%

of children in foster care under the age of 15 are Indigenous, despite only representing 7.7% of the child population in Canada

Incarcerated Population

28%

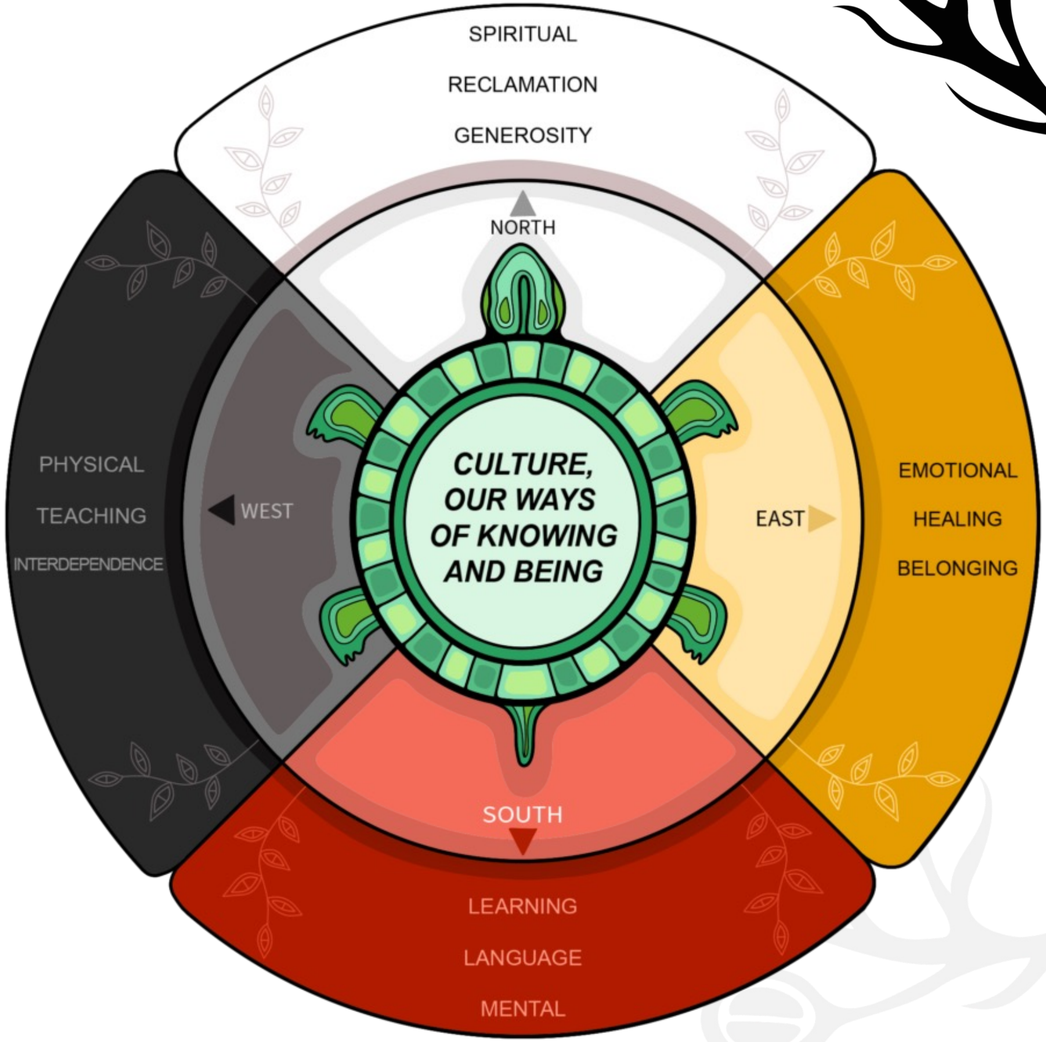
of admissions to provincial/territorial correctional services in Ontario are Indigenous people, despite being only 4.1% of the general population

Model of Wholistic Health and Wellbeing

Our Model

Indigenous Health in Indigenous Hands

- Integrated care that is inclusive of the Model of Wholistic Health and Wellbeing
- Speaks to the value and necessity of incorporating Traditional Healing in service delivery, promoting health and wellbeing across all aspects of the self–spiritual, emotional, physical, and mental.
- Culture-as-Healing and treatment provides inter-professional, team-based primary healthcare that is grounded in Indigenous traditions and ways of knowing.



SPIRITUAL

RECLAMATION

GENEROSITY

NORTH

PHYSICAL

TEACHING

INTERDEPENDENCE

WEST

CULTURE, OUR WAYS OF KNOWING AND BEING

EAST

EMOTIONAL

HEALING

BELONGING

SOUTH

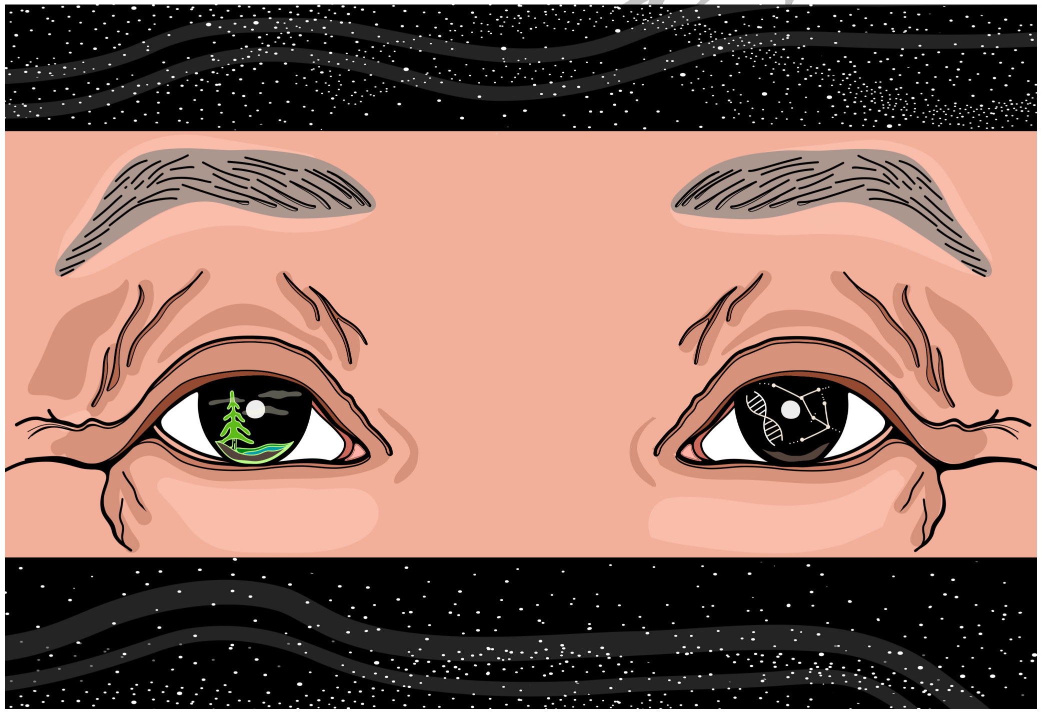
LEARNING

LANGUAGE

MENTAL

Bridging the gap

Understanding the value of data and the people to whom it most affects. We must look at frameworks which protects Indigenous FNIMUI data sovereignty on every level across the health system, peoples, communities and nationhood.



Two eyed seeing approach to data.

- We look at data from both traditional and western lens.
- We can also look at data from a local governance and provincial oversight approach (Ownership vs stewardship)

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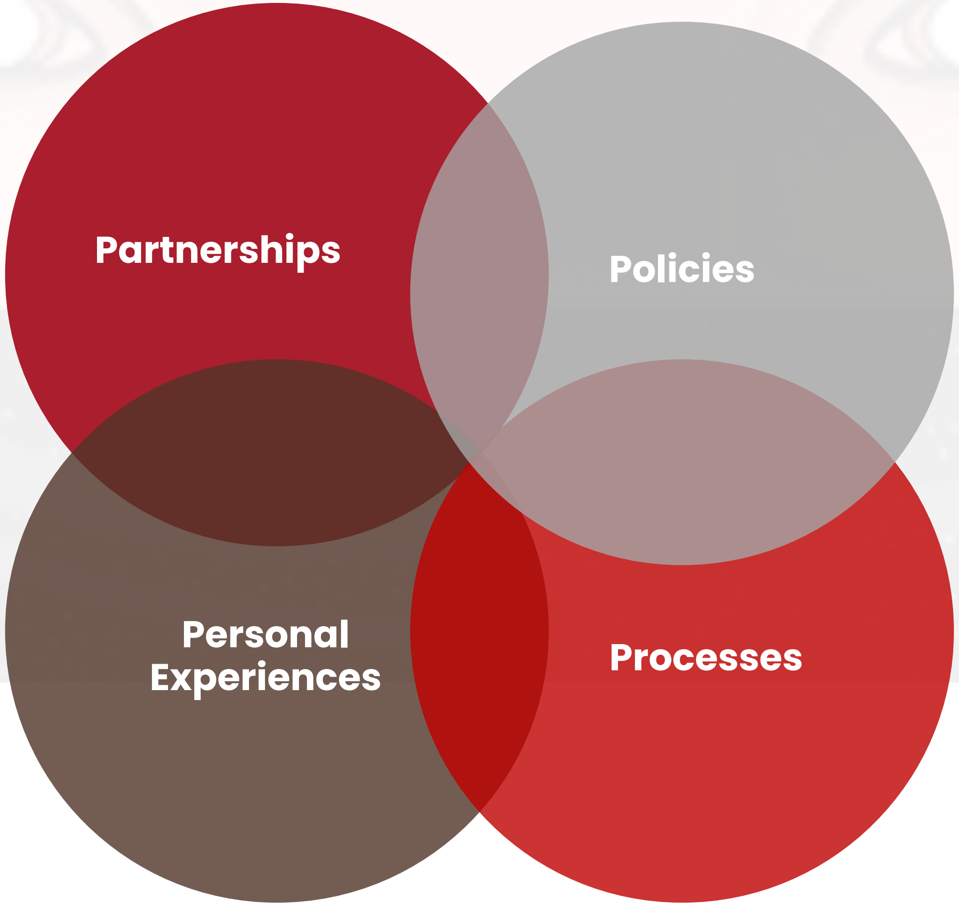
Data Sovereignty Rights

Data Sovereignty

We define data sovereignty using the four P's methodology in alignment with the two eyed seeing approach

Extensive **engagement** is required with communities to ensure their interests are prioritized. Formal **partnership agreements** are needed to evaluate the satisfaction of parties.

Speaks to the **policies** and/or strategies in place to ensure accountable governance of Indigenous data.



Partnerships

Policies

Personal Experiences

Processes

Traditional Approaches

Western Approaches

This speaks to the **lived experiences** of Indigenous peoples and provides a 360° view of whether policies, processes and partnerships are **supporting their intended outcomes**.

The mechanisms used for data governance **accountability**. Process **indicators** are often used to ensure that policies are being implemented as designed.

Intergenerational Transfer of Data

- Traditional Indigenous knowledge plays a vital role in promoting health and well-being within Indigenous communities, including First Nations, Inuit, and Métis peoples.
- Intergenerational transfer of knowledge is essential for preserving and promoting Indigenous ways of knowing and understanding health.

FNIM Communities and Intergenerational Transfer of Data

First Nations

- Storytelling as a significant way of transmitting knowledge, values, and beliefs
- Preservation of cultural identity and integrity of traditional knowledge through storytelling

Inuit

- Inuit Qaujimajatuqangit (IQ) as a framework for traditional knowledge, values, and worldview
- Role of Inuit Elders in passing on knowledge, including teachings on hunting, fishing, subsistence practices, health, well-being, and environmental stewardship

Métis

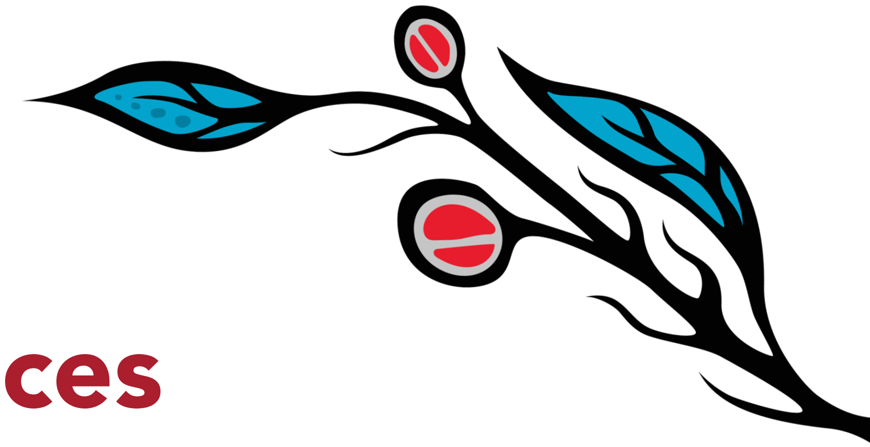
- Unique practices for intergenerational knowledge transfer: Michif language, beadwork, traditional dances (Teillet, 2018)
- Importance of Métis Elders and knowledge keepers in preserving and sharing traditional knowledge and wisdom

Ethical and Cultural Considerations for Present Day

Empowerment through Ethical Research – Best Practices

1. Engaging with and utilizing community-based participatory research
    - ❖ Ensure the community has capacity and resources to participate
2. Adhering to:
    - ❖ Ownership, Control, Access, and Possession (OCAP);
    - ❖ Inuit Qaujimajatuqangit (IQ) and
    - ❖ Ownership Control Access Stewardship (OCAS)
3. Collaborating with Indigenous researchers and organizations to align research with community priorities and values
    - ❖ Take the lead from the communities you're working with
4. Recognizing and incorporating Indigenous knowledge systems and methodologies
    - ❖ story telling, sharing circles, sacredness of ceremony

Empowerment through Ethical Research – Best Practices



5. Ensuring informed consent and ongoing consultation throughout the research process
    - ❖ Keep communities informed, sharing information and understanding
6. Building capacity within Indigenous communities through research partnerships and training opportunities
7. Practicing cultural humility and respect for Indigenous cultural protocols
    - ❖ How to approach Traditional People and Elders
    - ❖ How to engage leadership
8. Sharing research outcomes and benefits with Indigenous communities in a transparent and accessible manner
    - ❖ Validate your understanding of the research (does it make sense)

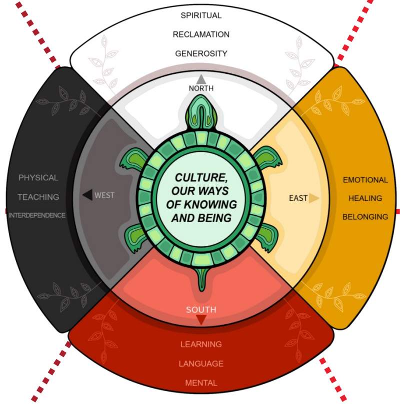
Data Types and Usage

> “…Indigenous people are often categorized into the “Other” category and thus not represented in the data. This junk data category tells us nothing; why is it still included in standard data collection nationwide?”

ABIGAIL ECHO-HAWK

Seattle Indian Health Board

How we use Data



Improved Population Health Outcomes

We collect, monitor, track, and analyze key performance Indicators

Evaluation & QI

We collect data to inform programs and operation

Research

We evaluate and conduct Indigenous research

Administrative Data

We use evidence-based approaches to addressing Indigenous health inequities. e.g. SAMI, Practice Profiles, etc.

Advocacy

We use Indigenous data to inform policy and funding proposals.

Story Telling

We tell stories with our data.
STORIES OF STRENGTH

National Administrative Data

Census Data:

- What: A comprehensive count of the population, typically conducted every five years, which collects demographic, social, and economic information on individuals and households.
- Downfalls: Incomplete or inaccurate data, undercounting of Indigenous populations, and limited consideration of Indigenous perspectives and priorities.
- **Recommendations:** Improve enumeration strategies in FNIM communities, ensure data is disaggregated (broken down) by Indigenous identity, and engage Indigenous communities in the design and governance of census data collection.

National Household Survey (NHS):

- What: A voluntary survey that complements the Census, providing additional information on social, economic, and housing characteristics of the population.
- Downfalls: Voluntary nature can lead to lower response rates in FNIM communities, potential for misreporting of Indigenous identity, and lack of data on important social determinants of health.
- **Recommendations:** Increase efforts to encourage participation in FNIM communities, incorporate culturally relevant questions and indicators, and collaborate with Indigenous organizations to ensure data relevance and accuracy.

Healthcare Data

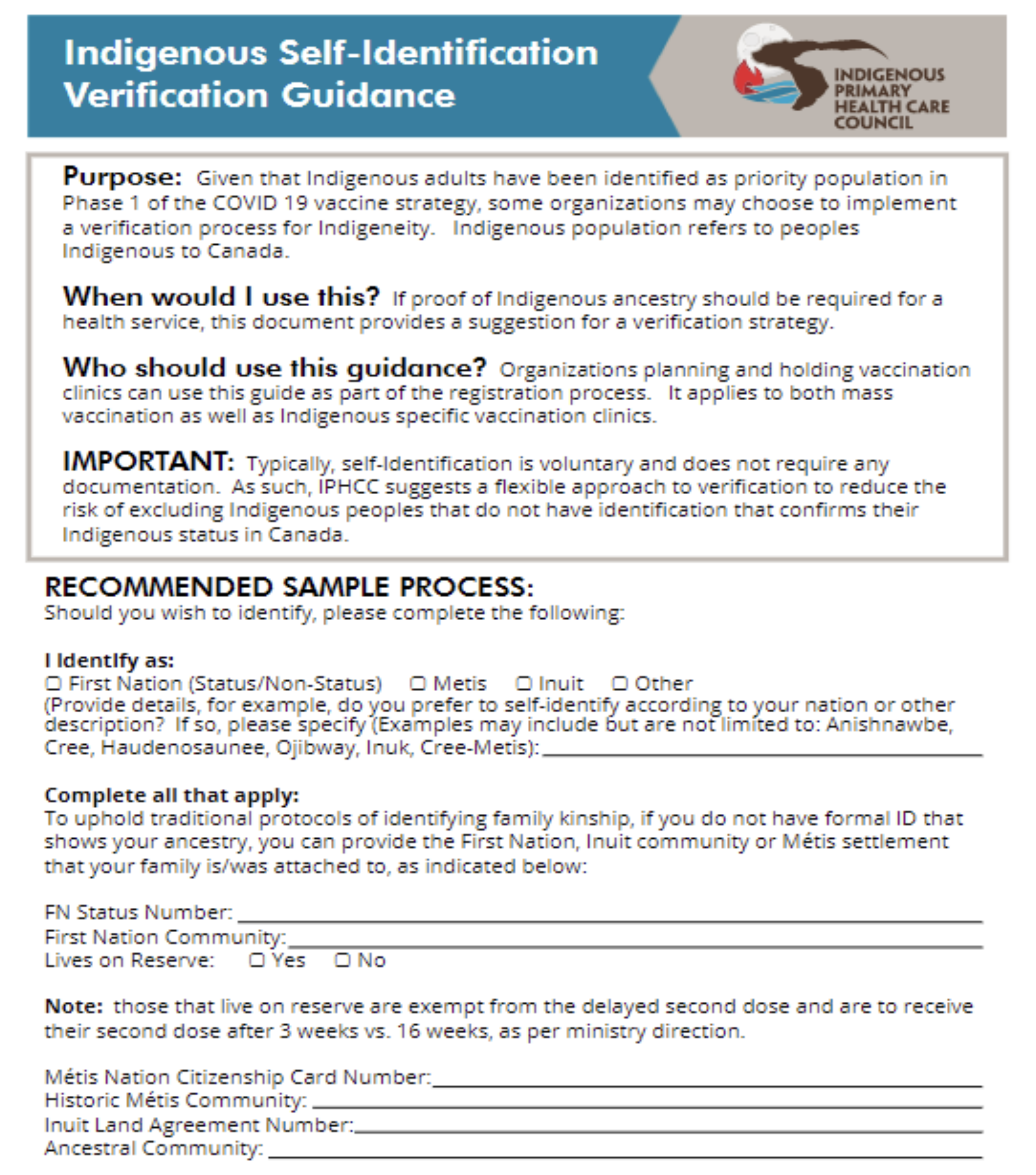
- What: Data collected from healthcare providers, institutions, and systems, which can be used to monitor health status, service utilization, and outcomes in the population.

- Downfalls: Limited disaggregation (breakdown) of data by Indigenous identity, potential for misclassification of Indigenous status, and lack of culturally appropriate and relevant health indicators.

- Recommendations: Implement consistent identification and reporting of Indigenous identity in healthcare data, incorporate Indigenous-specific health indicators, and engage Indigenous healthcare providers and organizations in the design and analysis of healthcare data systems.

Indigenous Self-Identification Tool

- Provide a means for individuals to **self-identify** as Indigenous, including specifying their **Nation or Tribal affiliation**.
- Allow Indigenous people to assert their rights to land, resources, and self-determination **without fear of discrimination**.
- Foster a sense of **community and connection** among Indigenous people who share common cultural and historical experiences.
- Acknowledge and honor the **diversity** of Indigenous nations and communities, and their unique cultural practices and traditions.
- Facilitate **access** to Indigenous-specific programs and services, such as education, health care, and cultural resources



Indigenous Self-Identification Verification Guidance

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Purpose: Given that Indigenous adults have been identified as priority population in Phase 1 of the COVID 19 vaccine strategy, some organizations may choose to implement a verification process for Indigeneity. Indigenous population refers to peoples Indigenous to Canada.

When would I use this? If proof of Indigenous ancestry should be required for a health service, this document provides a suggestion for a verification strategy.

Who should use this guidance? Organizations planning and holding vaccination clinics can use this guide as part of the registration process. It applies to both mass vaccination as well as Indigenous specific vaccination clinics.

IMPORTANT: Typically, self-Identification is voluntary and does not require any documentation. As such, IPHCC suggests a flexible approach to verification to reduce the risk of excluding Indigenous peoples that do not have identification that confirms their Indigenous status in Canada.

RECOMMENDED SAMPLE PROCESS:
Should you wish to identify, please complete the following:

I Identify as:
☐ First Nation (Status/Non-Status) ☐ Metis ☐ Inuit ☐ Other
(Provide details, for example, do you prefer to self-identify according to your nation or other description? If so, please specify (Examples may include but are not limited to: Anishnawbe, Cree, Haudenosaunee, Ojibway, Inuk, Cree-Metis):____________________

Complete all that apply:
To uphold traditional protocols of identifying family kinship, if you do not have formal ID that shows your ancestry, you can provide the First Nation, Inuit community or Métis settlement that your family is/was attached to, as indicated below:

FN Status Number: ____________________
First Nation Community:____________________
Lives on Reserve: ☐ Yes ☐ No

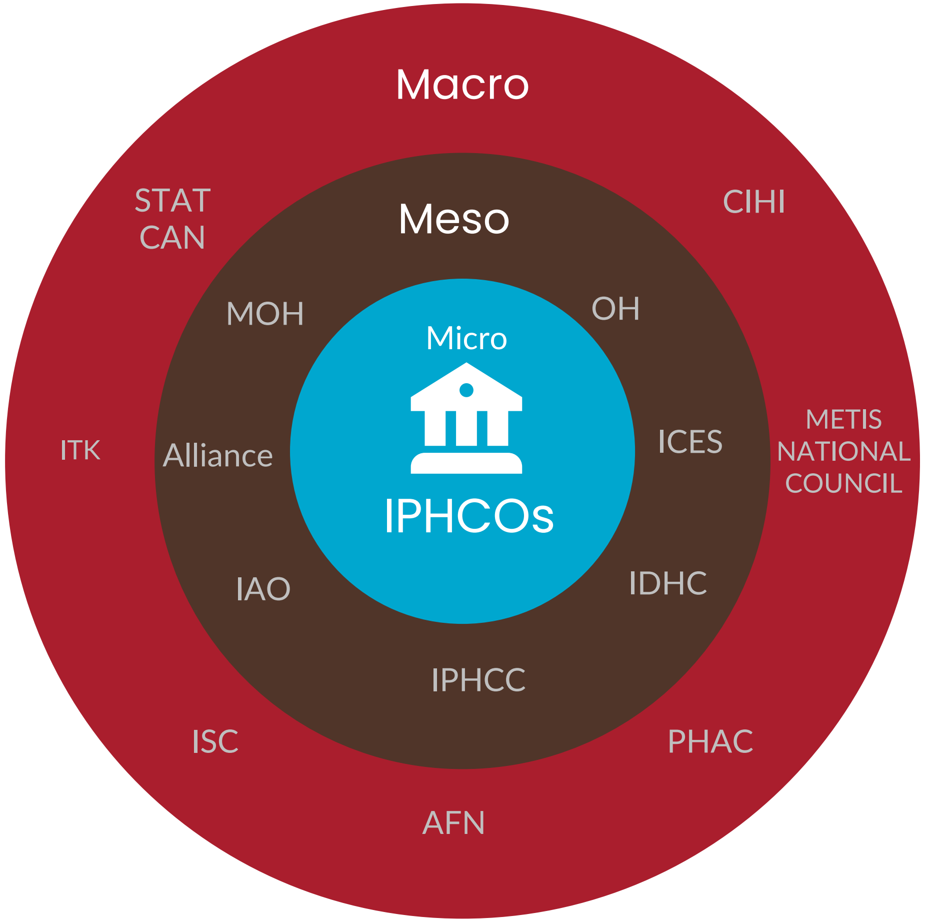
Note: those that live on reserve are exempt from the delayed second dose and are to receive their second dose after 3 weeks vs. 16 weeks, as per ministry direction.

Métis Nation Citizenship Card Number:____________________
Historic Métis Community: ____________________
Inuit Land Agreement Number:____________________
Ancestral Community: ____________________

Data Principles & Governance

Three Pillars to Governance

Providing guidelines to federal, provincial, and local parties are crucial for effective governance, given the complex nature of Indigenous data and recognized gaps in primary health care coverage.



01

Macro Governance

Organizations with federal or Canada-wide jurisdictions that have responsibilities related to ensuring appropriate governance of Indigenous-owned data

02

Meso Governance

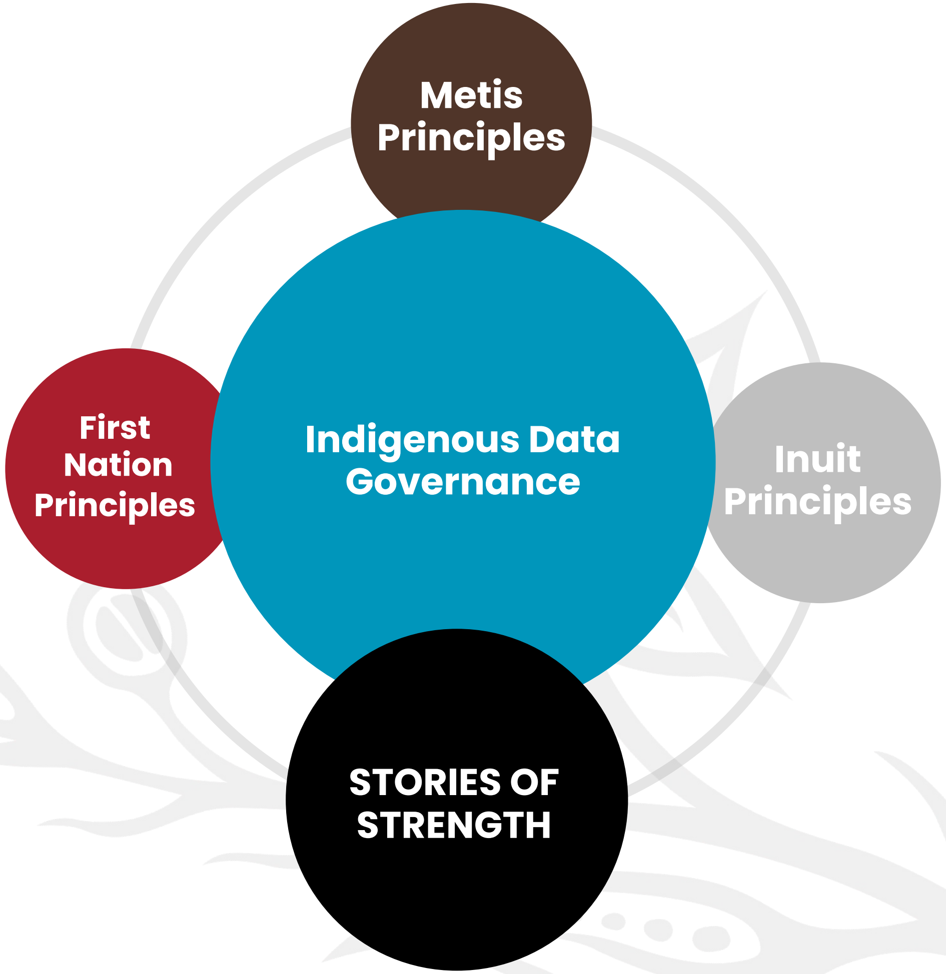
Provincial-level organizations who bear responsibility to ensure appropriate governance of Indigenous data

03

Micro Governance

Our members are at the heart of our governance approach. IPHCO's are the only Identifiable HICs for the Indigenous Primary Health Care Data in Ontario

Why are the Principles Important?



Metis Principles

First Nation Principles

Indigenous Data Governance

Inuit Principles

STORIES OF STRENGTH

- It helps us keep an eye on the bigger picture.
- It allows us the ability to tell indigenous stories through **meaningful engagement.**
- Data is the **building block** for the stories we share on behalf of our members.
- Data principles will enable us to **tell our stories with Integrity** while maintaining the sovereignty of the data/stories shared.
- The principles provide a **pathway** and **accountability** for the sector. Protector of data.
- It gives way to **access** and **control** and provides visibility on what the data is used for.
- Aligning the principles of the **data lifecycle** in a more culturally appropriate way.
- Allows us the ability to benchmark performance across the sector by utilizing meaningful metrics against **Quality Improvement standards.**

S.T.O.R.I.E.S | SOS (safeguarding our stories)

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.

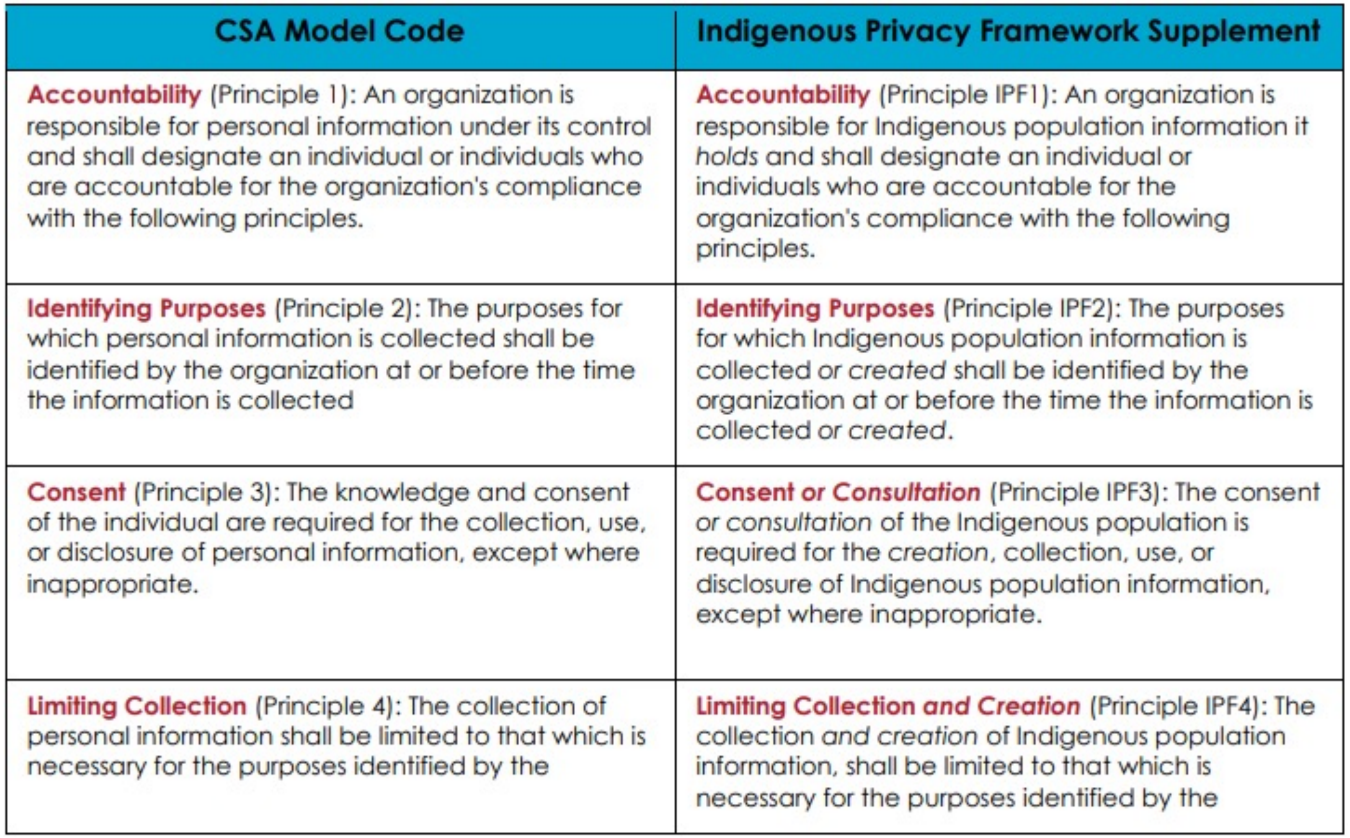
O.F S.T.R.E.N.GT.H

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 them so that all First Nation, Metis and Inuit people can learn and benefit. Information will reflect a wholistic and accurate view of Indigenous realities and 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.

Privacy and Data Protection

Indigenous Privacy Framework

- Most Privacy Impact Assessments to date have not approached Indigenous perspectives and considerations in any structured, repeatable way.
- To fill this gap, the Indigenous Primary Health Care Council (IPHCC) has drafted an "Indigenous Privacy Framework" against which Privacy Impact Assessments can be conducted.
- This framework builds off of the CSA Model Code (CSA Q830:03 (R2019)) principles.



CSA Model Code	Indigenous Privacy Framework Supplement
Accountability (Principle 1): An organization is responsible for personal information under its control and shall designate an individual or individuals who are accountable for the organization's compliance with the following principles.	**Accountability** (Principle IPF1): An organization is responsible for Indigenous population information it *holds* and shall designate an individual or individuals who are accountable for the organization's compliance with the following principles.
Identifying Purposes (Principle 2): The purposes for which personal information is collected shall be identified by the organization at or before the time the information is collected	**Identifying Purposes** (Principle IPF2): The purposes for which Indigenous population information is collected *or created* shall be identified by the organization at or before the time the information is collected *or created*.
Consent (Principle 3): The knowledge and consent of the individual are required for the collection, use, or disclosure of personal information, except where inappropriate.	**Consent *or Consultation*** (Principle IPF3): The consent *or consultation* of the Indigenous population is required for the *creation*, collection, use, or disclosure of Indigenous population information, except where inappropriate.
Limiting Collection (Principle 4): The collection of personal information shall be limited to that which is necessary for the purposes identified by the	**Limiting Collection *and Creation*** (Principle IPF4): The collection *and creation* of Indigenous population information, shall be limited to that which is necessary for the purposes identified by the

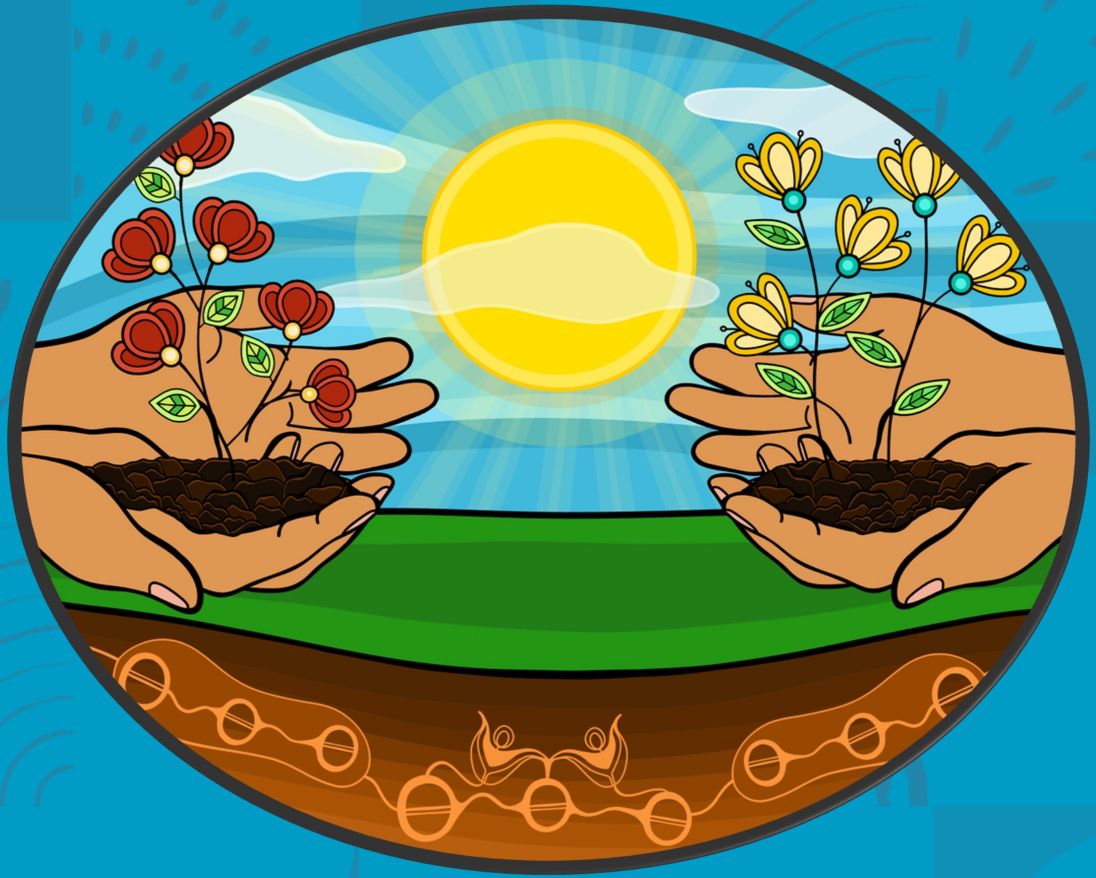
Table 1: Examples of Indigenous Privacy Framework supplemental principles arising from the CSA Model Code principles.

Indigenous Data Privacy

- Mainstream privacy frameworks have limitations in addressing unique Indigenous contexts
- **Recommendations for enhancing Indigenous data privacy:**
  - Engage Indigenous communities in the development of privacy policies and legislation
  - Ensure privacy frameworks are culturally appropriate and respect Indigenous perspectives
  - Incorporate principles like OCAP, IQ, OCAS, STORIES OF STRENGTH into privacy legislation
  - Don't allow legislation to promote structural racism within our health system fabric

Data Sharing and Protection

- We are encouraging communities to **develop Indigenous data sharing agreements** that recognizes the **unique rights**, values, and interests of Indigenous Peoples in the collection, use, and dissemination of data related to their peoples and territories.
    - *Historically, data about Indigenous peoples has been collected, owned, and controlled by non-Indigenous entities, often without the informed consent or involvement of Indigenous communities.*
- Indigenous data sharing agreements establish **collaborative relationships** between Indigenous communities and those who seek to collect, use, or share data related to them.
    - These agreements promote more ethical and respectful practices that respect Indigenous knowledge, sovereignty, and self-determination.
- Data sharing agreements that work from an Indigenous perspective can acknowledge and honor these connections, while also **promoting more equitable** and **inclusive approaches** to data collection, analysis, and dissemination that benefit both Indigenous and non-Indigenous peoples alike.



Conclusions

Empowering Indigenous communities through data governance, sovereignty, and protection is critical for addressing the **unique health challenges** faced by Indigenous populations in Ontario, Canada.

How do we do this?

- Focusing on culturally appropriate and relevant data, intergenerational transfer of knowledge, culturally safe collection methods, privacy and data protection
- Utilizing FNIMUI data governance and principles, and a wholistic approach to health and well-being that is **inclusive** respecting and resourcing the needs of Indigenous communities
- It is essential for stakeholders to support these efforts and work collaboratively with Indigenous communities to ensure their health data is managed in a manner that empowers them and promotes well-being and overall population health.

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- Work together on a collective and comprehensive data governance agreement which is consistent with principles
- Consider opportunities to collaborate on data collection and management infrastructure and technical expertise – e.g. regional data and governance centre
- Undertake review of & standardize data held by communities (e.g. on a Nation basis)

Meegwetch
Miigwetch
Maarsii
Nakurmiik
Nia:wen!