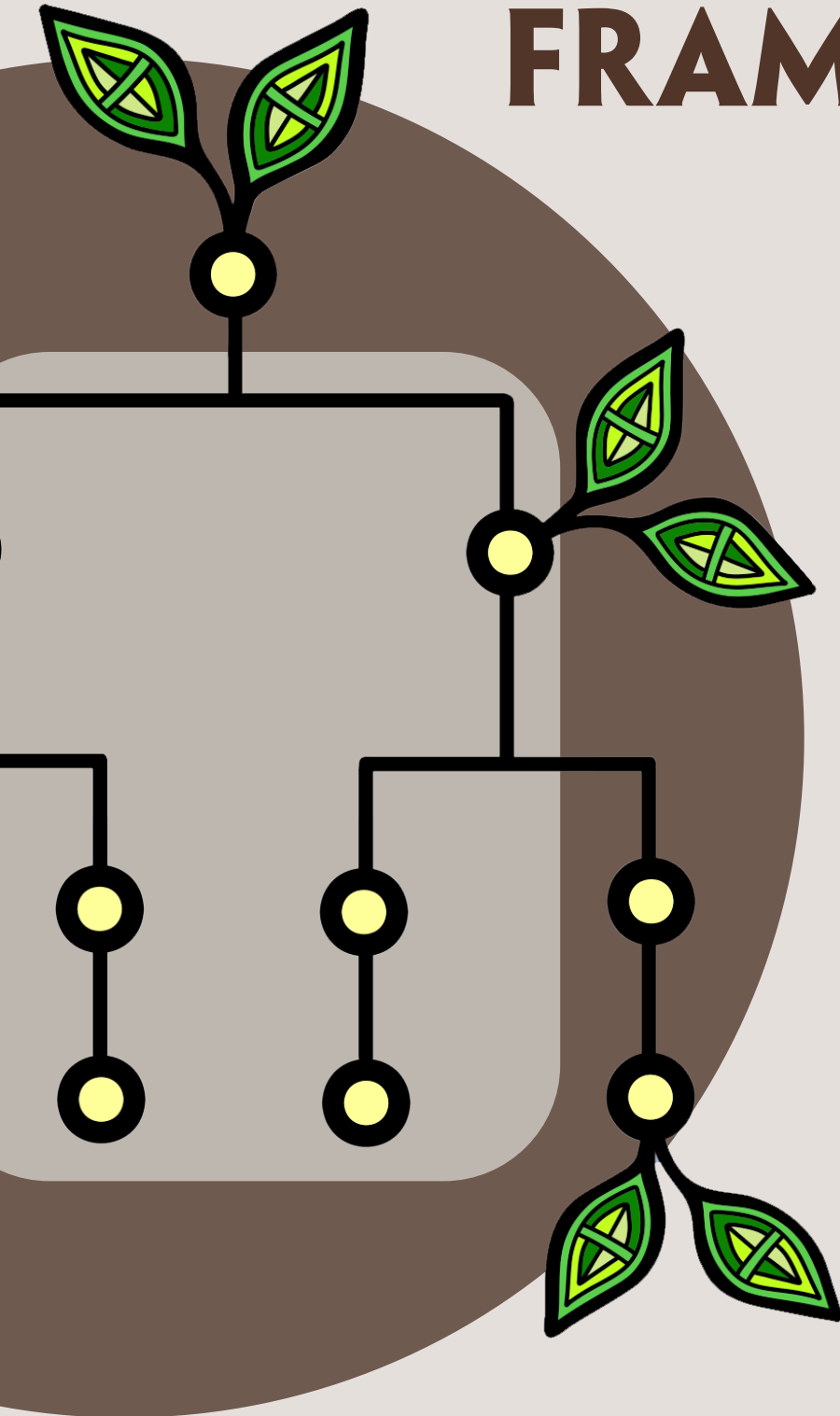


INDIGENOUS PRIMARY HEALTH CARE COUNCIL  
DATA GOVERNANCE  
**FRAMEWORK**



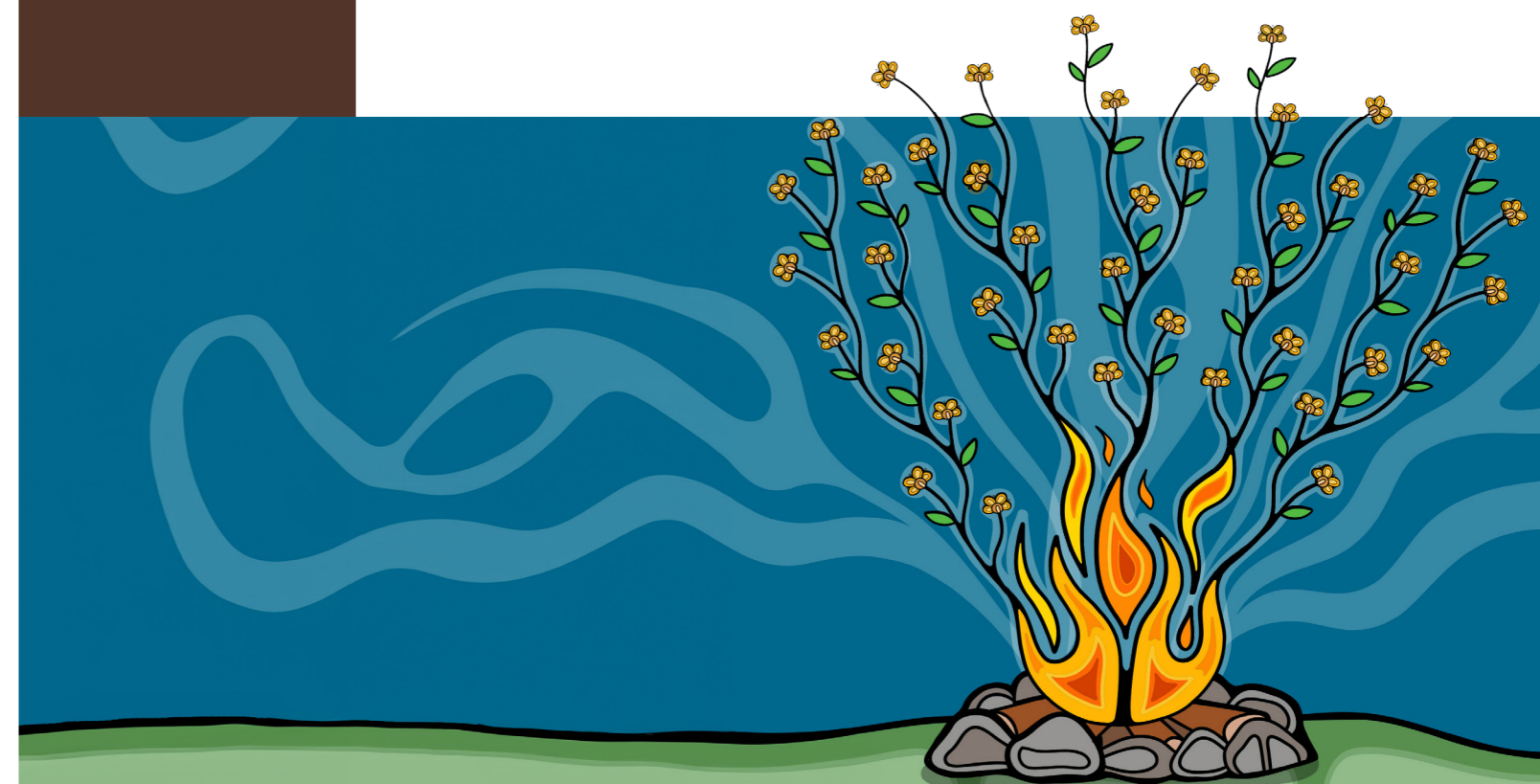
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## 1.0 INTRODUCTION

The Indigenous Primary Health Care Council (IPHCC) was incorporated on November 20th, 2019, although it has been operating informally for many years. It 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 services provision and planning throughout Ontario. Since its establishment, the IPHCC has expanded its membership and worked collaboratively with its members and the Alliance for Healthier Communities to develop and enhance data governance and management practices specific to the primary healthcare sector.

Membership currently includes 23 Indigenous Primary Health Care Organizations (IPHCOs) located in 44 different locations from across the province. IPHCOs developed at different times, as provincial funding opportunities and support became available. Former names include Aboriginal Health Access Centres (AHACs), Indigenous Community Health Centres (IHCs), Indigenous Interprofessional Primary Care Teams (IIPCTs), Indigenous Nurse-Practitioner-Led Clinic (INPLC), and Indigenous Family Health Teams (IFHTs). IPHCC is currently in discussions with several additional Indigenous-led health organizations regarding their interest in membership. IPHCOs provide care in urban, rural, and remote areas, both on and off territory (reserve). They are status blind, and service First Nation, Inuit, and Métis (FNIM), with 50% having Inuit clients, 88% having Métis clients, and 100% having First Nations clients. Service delivery is based on self-selection and availability of providers.



We pride ourselves in being a status-blind organization, committed to promoting health equity for **First Nations, Inuit, and Métis** communities, guided by the principles of the Model of Wholistic Health and Well-being.

In recognition of the importance of Indigenous Peoples' data rights and autonomy, IPHCC respects and adheres to the established data principles of Ownership, Control, Access, and Possession (OCAP), Ownership, Control, Access, and Stewardship (OCAS), and Inuit Qaujimajatuqangit Principles (IQ). Our Data Governance Framework will incorporate and expand upon these principles to ensure responsible and ethical data management practices that prioritize Indigenous perspectives and voices. Recognizing that each of the three nations has developed data principles tailored to their specific needs, lived experiences and culture. IPHCC has developed a set of data principles that are inclusive of all three groups, known as the **STORIES OF STRENGTH** data principles.

We are the voice of the collective sector (Indigenous Primary Health Care Organizations).



Our members are diverse and may or may not be directly affiliated with an Indigenous government. As such, our approach needs to be 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.

**Our Data Governance Framework is informed by this context in the following ways:**

- 1** Our principles honour the Indigenous data sovereignty of individuals, member sites, communities, and Nations.
- 2** Our principles align with the shared principles and teachings articulated within existing Indigenous data governance frameworks and approaches.
- 3** Our approach is guided and informed by all our members via the **IPHCC Planning & Evaluation Committee (IPEC)** and respects our role as personal health information holders under privacy and confidentiality legislation.



# 1.1 INDIGENOUS DATA GOVERNANCE

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

Indigenous data governance ensures that the individual and collective rights of First Nations, Inuit, and Métis receiving care at our member sites are respected, by establishing a cohesive set of principles, objectives, roles, and responsibilities to govern Data. For the IPHCC, data governance ensures that those principles, objectives, roles, and responsibilities are upheld for the collective information generated by the sector, as well as for the data produced through our day-to-day activities.

Good data governance practices are vital for the IPHCC and our sector because they set the stage for how we collectively work to tell our stories in a respectful and safe way. Data Governance structures need to be in place to ensure that the data, stories, knowledge, and insights that we create, collect, hold, handle, and share help us to appropriately interpret and disseminate our stories. Coupled with that it is vital that we validate those stories by the Indigenous Peoples who are affected by its outcomes through our members and the communities they serve.

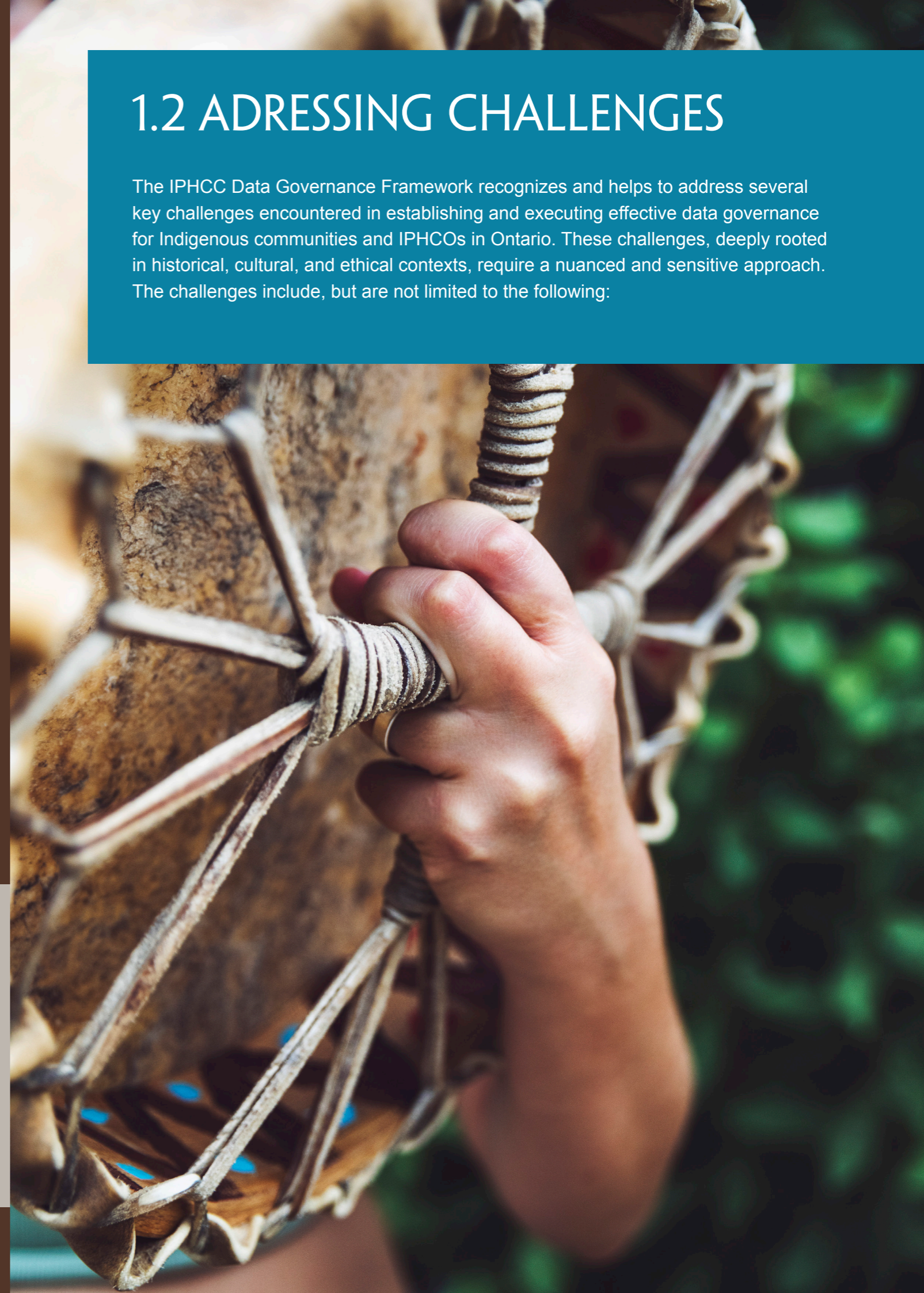
In addition, it enables us to reliably advocate for change and properly identify actions that cultivate positive health outcomes for Indigenous Peoples and communities in Ontario. This information helps to set the stage for working with both Indigenous and non-Indigenous health systems and research partners.

**United Nations  
Declaration on the Rights  
of Indigenous Peoples**  
*Article 31*

Indigenous Peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge, and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.

# 1.2 ADDRESSING CHALLENGES

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. The challenges include, but are not limited to the following:



Challenges	Descriptor
<b>Historical Trauma</b>	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. At one point in time, Indigenous Peoples were experimented on to test the impacts of new health procedures and methods. These experiences leave lasting generational impacts and must be navigated with sensitivity and empathy.
<b>Data Sovereignty</b>	Indigenous communities have their own concepts and understandings of data ownership and sovereignty. They may be hesitant to share their data with external organizations, especially government bodies, due to concerns about misuse or exploitation.
<b>Cultural Sensitivity</b>	Healthcare data governance frameworks need to be culturally sensitive to the unique needs and preferences of Indigenous communities. This may require a more holistic approach (physical, spiritual, mental and emotional wellbeing) that includes traditional healing methods and medicines while at the same time respecting Indigenous knowledge and practices.
<b>Community Engagement</b>	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 consultation with Indigenous leaders and stakeholders. This may include several interactions to establish the relationship.
<b>Ethical Considerations</b>	Data governance frameworks for Indigenous Peoples must address ethical issues, 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.
<b>Jurisdictional Challenges</b>	The Non-Insured Health Benefits (NIHB) program is a health benefits program that provides eligible First Nations and Inuit clients with coverage for a range of health benefits that are not covered through other social programs, private insurance plans, or provincial or territorial health insurance. This is a federal responsibility. The information collected for this program is managed in separate systems and databases. In some cases, this information is collected via paper-based systems at the community-level due to technology and connectivity accessibility issues. This causes huge challenges when accessing data. Databases and information is disconnected and does not show the complete health picture for First Nation and Inuit populations. In addition, NIHB is not available to Métis individuals.
<b>Resource Constraints</b>	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.
<b>Traditional Insights/ Knowledge</b>	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. Compounding the issue, inadequate systems and fund-ing hinder the acknowledgment of traditional approaches as a fundamental pillar of healing within Indigenous communities.

IPHCC not only recognizes the challenges posed by safeguarding Indigenous data but actively endeavors to tackle them through a comprehensive approach encompassing six strategic areas.

### THESE AREAS ARE AS FOLLOWS:

1. **DATA SOVEREIGNTY**
2. **GOVERNANCE STRUCTURE**
3. **ACCOUNTABILITY**
4. **POLICY**
5. **PARTNERSHIPS AND MEANINGFUL ENGAGEMENT**
6. **RESEARCH & ETHICS**

Collectively these six strategic areas help to ensure that data governance is not only efficient but also characterized by a deep respect and responsiveness to the distinctive needs and histories of Indigenous communities in Ontario.

## 1.3 WHY ARE WE EMBARKING ON THIS?

There are several reasons why we are collectively embarking on this journey together including:

- Canadian governments collect and hold a significant amount of information on Indigenous people, contributing to deficiencies in the data quality, data relevance, data infrastructure and access to data of Indigenous-led organizations.
- Second, Indigenous health information often lacks inclusive and reliable information on Indigenous identity. This leads to an inability to link information across multiple datasets that contain vital data about Indigenous identity, health services and determinants of health, which presents further challenges to the quality of Indigenous health data ecosystems.
- Third, the present systems do not have adequate safeguards in place to help ensure the protection of Indigenous data that is collected outside of Indigenous communities. Governments and institutions have multiple First Nation, Métis and Inuit players to navigate, and many times fail to move forward because of the complexities attached.
- Finally, our IPHCO's are collectors and owners of First Nation, Métis and Inuit personal health information. Access to this information is based on these individuals self-selecting to receive primary health care within our member sites. Responsible analysis of this collective information will help inform overall Indigenous population health outcomes in Ontario.

## 2.0 OVERVIEW OF THE FRAMEWORK

In August 2021, the IPHCC began the development of its Data Governance Framework and associated policies, as well as accompanying data governance resources and tools for our members. The purpose of the framework is to establish a coherent set of principles, objectives, roles, and responsibilities to govern the data, stories, knowledge, and insights that the collective Indigenous Primary Health Care Organizations (IPHCOs) creates, collects, holds, handles, and shares. The framework will provide an approach to share individual and collective stories on behalf of the sector, and support advocacy for change that will improve the mental, physical, spiritual, and emotional wellbeing for Indigenous people and communities across Ontario.

### This framework is divided into six strategic areas of focus as follows:

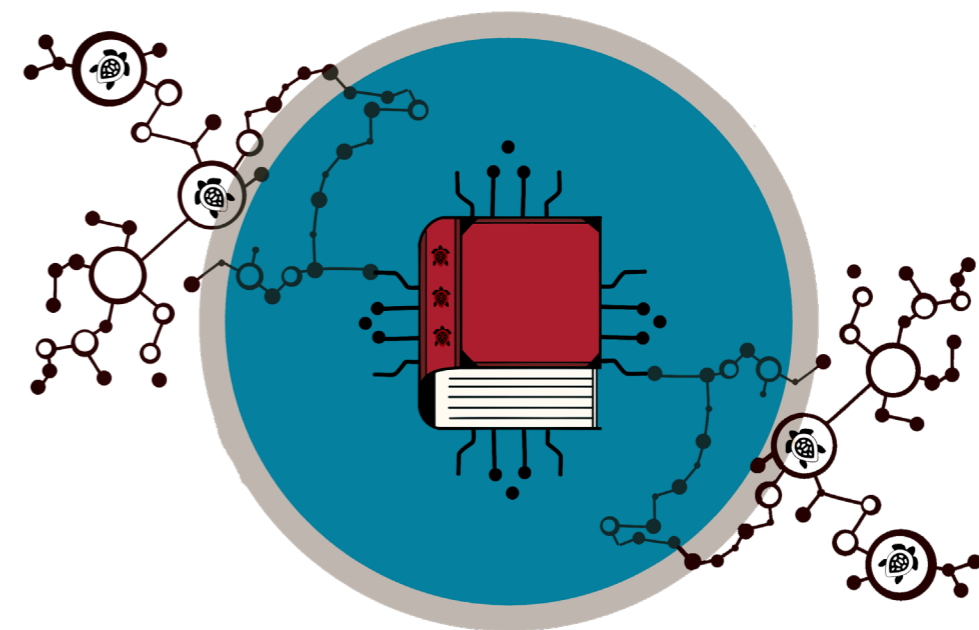
- 1. Data Sovereignty:** This area focuses on the principles guiding the framework's implementation, emphasizing data sovereignty, the narrative power of stories of strength (SOS), the application of the '4 Ps' known as Policy, Process, Partnerships and Personal Experience, the approach of Two-eyed Seeing, and the SGAR known as Secure, Govern, Act, Report foundations model.
- 2. Governance Structure:** This area outlines the types of stakeholders and suggests an organizational structure for Indigenous data stewardship. The approach includes the Micro/local level, Meso/provincial level, and Macro/Federal level involvement. In addition, it highlights various organizing structures, ensuring effective data governance at different system levels.
- 3. Accountability:** This area delineates clear accountability requirements and mechanisms from an Indigenous perspective. It encompasses legal instruments, data sharing protocols and agreement templates, and recommendations for the establishment of an Indigenous Governance Body (IGB) to oversee data governance.
- 4. Policy:** This area highlights policies, procedures, and tools for data governance, alongside privacy and security policies. These actions will help ensure data management and protection align with privacy compliance standards.
- 5. Partnerships and Meaningful Engagement:** This area stresses the importance of developing partnerships, completion of an organizational self-identification Maturity Model assessment, fostering meaningful engagement, and formalizing relationships via agreements, ensuring that partnerships are deeply rooted, respectful, and reciprocal.
- 6. Research & Ethics:** The final area of focus addresses ethical considerations in research related to data governance and sovereignty. It covers research ethics, sector research management and processes, data integrity and confidentiality, participant and community empowerment, and the role of the Research and Ethics Committee.

## 3.0 DATA SOVEREIGNTY

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 our distinct societies, including our languages, cultures, worldviews, histories, and land stewardship.<sup>1</sup> For our members, the people they serve, the communities and Nations they represent, data sovereignty is embedded within sovereignty more generally, meaning that it involves title, ownership, rights, and responsibilities.

In the context of Ontario, upholding Indigenous data sovereignty necessitates acknowledging the collective rights of Indigenous communities over their data, narratives, knowledge, insights, and traditional teachings. IPHCC encompasses a diverse membership across the province, which implies that this right is not vested in a single nation, community, or member site. Instead, it resides collectively within the sector through legislation, granting the sector the inherent authority to govern the data gathered by the Indigenous Primary Health Care Organizations (IPHCOs) on behalf of their respective patients and clients. As a full sector we safeguard the data in addition to being self-regulated entities under the legislation. This gatekeeping function helps to ensure meaningful engagement and collective input is given prior to utilizing the data for any health planning or research agendas and helps to validate the information we are sharing. This recognition values the urgency of evidence-based, data-driven decision-making requirements to enhance primary health care provision so that we can collectively advance the health and well-being of Indigenous individuals.

The sector acknowledges that 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. The evolution of the Provincial Indigenous Integrated Health Hub (PIIHH) allows system users to centralize discussions on Indigenous population health models and outcomes so that information is targeted and informed.



<sup>1</sup> Harmony Johnson, sełakəs, of the Tla'amin Nation

# 3.1 IPHCC DATA GOVERNANCE PRINCIPLES

IPHCC Data Governance Principles are the specific values we hold when it comes to all aspects of data governance and management, this is how we work to create, collect, hold, handle, or share data, in addition to how we interact with and set up the systems, processes, and people necessary to manage our Data.

IPHCC recognizes that the data held by our members speaks to the unique identity of the peoples, communities, nations, and cultures of the clients they serve across Ontario. It is a known tradition that Indigenous cultures have historically shared sacred information to upcoming generations by virtue of oral **storytelling**. It is with this recognition that stories were historically seen as valuable data and with this intent in mind we continue to represent and honour our cultural ways in the promotion of Indigenous Data Sovereignty for our sector.

**“ Stories are also important because they make us act. ”**

“Stories not only teach us how to act – they inspire us to act. Stories communicate our values through the language of the heart, our emotions. And it is what we feel – our hopes, our cares, our obligations – not simply what we know that can inspire us with the courage to act”

- Telling your Public Story, Marshall Ganz

The IPHCC has developed the STORIES of STRENGTH (SOS) values and principles through an extensive engagement process with our members to help ensure that no one is left behind and we are respectful of stories we hold.

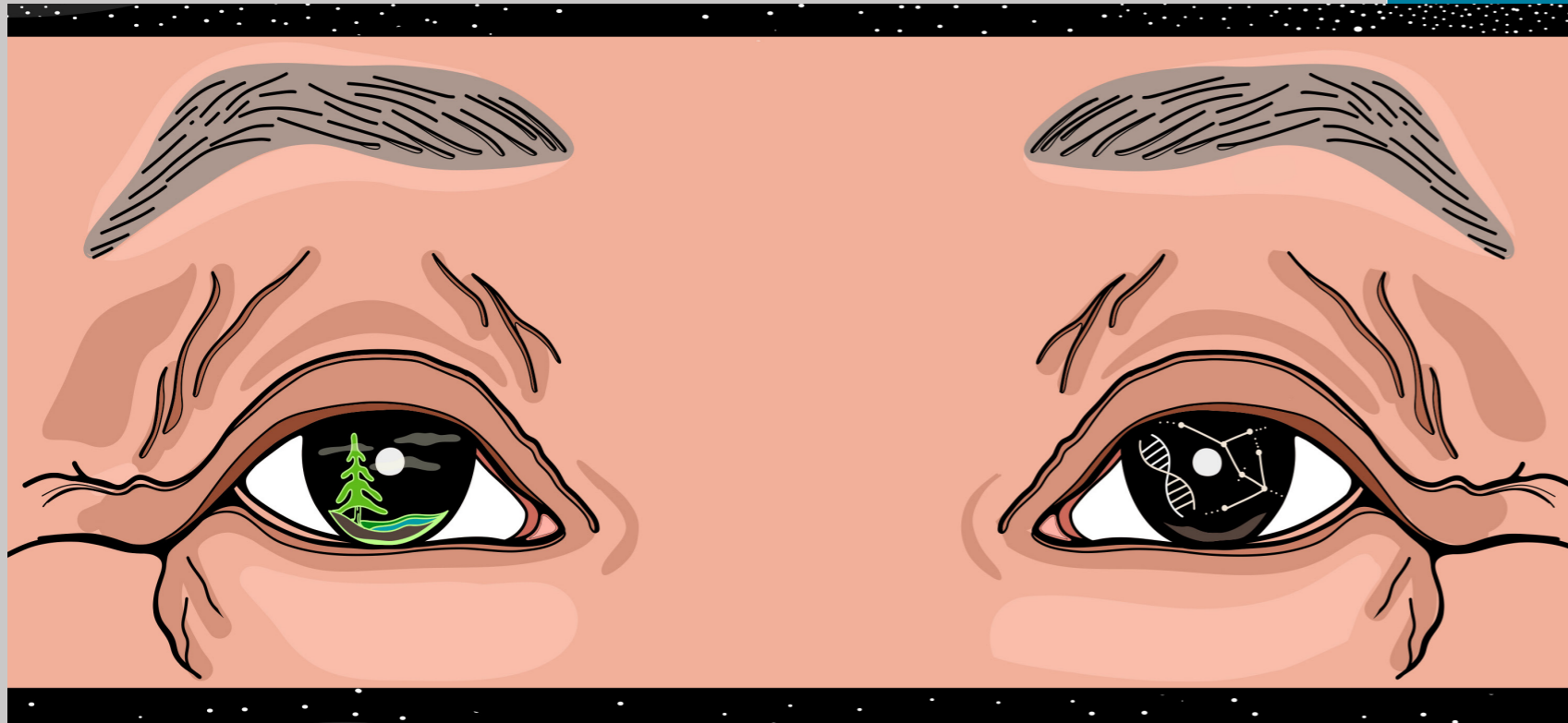
The following guiding principles outline the expectations for decision-making and behaviours relevant to IPHCC members and their communities. These principles will serve as a benchmark for application and will be maintained as part of the expanding and evolving implementation of the Data Governance Framework.

# 3.2 STORIES OF STRENGTH - SOS

Guiding principles that outline the expectations for decision-making and behaviours relevant to data governance represented by the STORIES OF STRENGTH acronym. The principles were designed through a series of consultative processes with IPHCC members and other key stakeholders starting in 2021.

Principle	Applicability to Data Governance
<b>Safety</b>	Members must feel <b>safe</b> 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.
<b>Trust</b>	Frameworks, policies and processes will be established on a foundation of <b>trust</b> so that all can speak freely, and the information is reflective of each party's experiences.
<b>Ownership</b>	Members will be supported to claim and <b>own</b> their truth when sharing data and information.
<b>Relationship-centrism</b>	Systems, policies and processes will be designed to build and maintain respectful reciprocal <b>relationships</b> with members and partners.
<b>Impact-awareness</b>	Data governance will create processes that support and strengthen our members, whose communities can be <b>impacted</b> by the words and actions of others.
<b>Excellence</b>	The data system will be designed to achieve <b>excellence</b> in all aspects so that information is shared respectfully, and our knowledge is celebrated.
<b>Strength-building</b>	Data and information will nurture and build <b>strength</b> in our future knowledge keepers.
<b>Optimism</b>	The IPHCC will strive to share stories of <b>optimism</b> for First Nations, Métis, and Inuit Peoples.
<b>Framing</b>	Data will <b>frame</b> opportunities for learning and ongoing advancement, including appropriately identifying actions that cultivate positive health outcomes for Indigenous people and communities in Ontario.
<b>Supportiveness</b>	Data will be used to <b>support</b> 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.
<b>Truthfulness</b>	Data will be reflective of individual <b>truths</b> as they are seen and experienced by First Nation, Métis 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.
<b>Respectfulness</b>	The governance approach will embody the principle of <b>respect</b> , recognizing that no person or entity is more valuable or important, but rather are accountable to each other.
<b>Expression-upholding</b>	The framework will support members to <b>express</b> individual truths by ensuring that data, stories, and information are validated by those involved.
<b>Narrator-focused</b>	The data system will respect members as <b>narrators</b> of their stories and support the sharing of knowledge that is meaningful to them.
<b>Gift-valuing</b>	Data governance will honor the unique <b>gifts</b> and contributions of our partners and members to the data system.
<b>Traditionally based</b>	The data system will honor <b>traditional</b> 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.
<b>Honour</b>	We <b>honour</b> Indigenous data sovereignty for individuals, member sites, communities, and Nations. Data and information will meet legal and regulatory requirements while maintaining cultural integrity.

## 3.3 TWO-EYED SEEING APPROACH



“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”

- Bartlett, Marshall, & Marshall, 2012, p. 335<sup>2</sup>

Two-Eyed Seeing requires leaders in health to reflect on their limited perspectives and personal experiences to provide wholistic health system delivery, which is extremely important when working with our Indigenous people, communities, and nations. We live in a world with multiple diversities, and it is understood that we recognize and embrace these differences in the stories we share and communicate with others.

As a sector, we are open to seeing all possibilities with both eyes open. This is vitally important because we hold personal health information for First Nation, Métis, and Inuit peoples. Each of these groups have multiple diversities, languages, cultural practices, and ways that we must respect. The interpretation of data cannot be seen with one lens, and this is why validation is part of the process.

We respect mainstream systems of data collection and realize the importance of the information contained within those systems. Structures to safeguard the information are designed with a westernized lens and focus on differing aspects of importance than what Indigenous communities typically view as significant. As valued partners we need to work together to develop and design systems that are workable with the parties involved so that the stories that are told make sense to the individuals they are about.

<sup>2</sup> Peltier, C. (2018). An Application of Two-Eyed Seeing: Indigenous Research Methods with Participatory Action Research. *International Journal of Qualitative Methods*, 17(1). <https://doi.org/10.1177/1609406918812346>

## 3.4 UNDERSTANDING THE FOUR (4) P'S APPROACH

The 4 P's to data governance are referred to as partnerships, policy, personal experiences and processes. Below provides an overview of the significance of each of these areas.

### Indigenous Approaches

#### Partnerships

Indigenous data governance requires extensive engagement with the communities served to ensure that their interests are prioritized. The existence of formal partnership agreements helps guide the relationship and enhances commitment. The partnership is evaluated according to the satisfaction of parties involved and is an important indication of success.

#### Personal Experiences

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

### Western Approaches

#### Policy

Speaks to the policies and/or strategies in place to ensure appropriate governance of the data collected. This approach is inclusive of privacy and confidentiality principles. Policies relate to the full data cycle.

#### Process

Reflects on the mechanisms and tools used to ensure that responsible and respectable data governance is upheld. Process indicators are often used to ensure that policies are being implemented as designed.



The IPHCC Data Governance Framework stands as a vital instrument, guaranteeing the effective, ethical, and culturally secure management of data belonging to both IPHCOs and the Indigenous Communities they serve. This framework underscores IPHCC's dedication to Indigenous data sovereignty, emphasizing the safeguarding of members' data privacy and protection. Moreover, it signifies a commitment to our collective efforts for the responsible utilization of data, directed towards enhancing the health outcomes and overall well-being of Indigenous individuals and communities in Ontario.



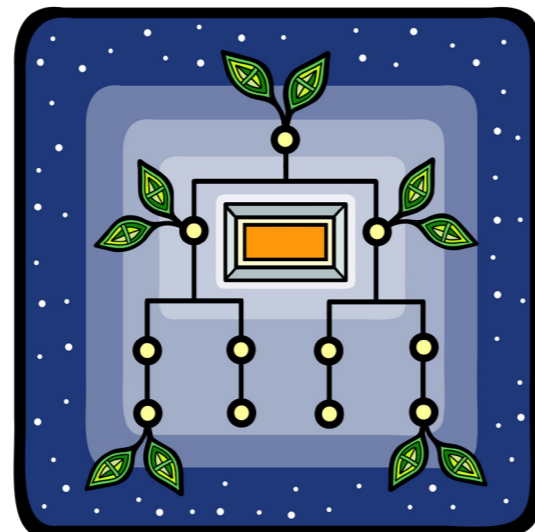
“It’s important to recognize that the sector’s data represents a **moment in a client’s health journey** and does not capture their entire life story. We must remember that **behind every data point is a person with a unique story**, experiences, and perspectives. By acknowledging the importance of these stories and working to centre them in our data governance practices, we can better understand the context and complexities of the health issues facing Indigenous Peoples and communities. Our data governance framework strives to collect, manage, and share data in a way that respects the individuality of our clients and promotes a wholistic approach to health and wellbeing.”



- Marlon Cole, Director of IT/IM and Communications, IPHCC

## 3.5 SGAR (SECURE, GOVERN, ACT, REPORT)

The SGAR model, as part of the Indigenous Primary Health Care Council’s (IPHCC) Data Sovereignty strategies, provides a comprehensive framework for the respectful and sensitive handling of Indigenous Data. This model addresses the unique considerations of Indigenous data, which includes personal, cultural, and traditional knowledge, and is a critical element in respecting and upholding the sovereignty of Indigenous communities over their data.



### 1. Secure

The ‘Secure’ phase emphasizes the importance of protecting Indigenous data through robust privacy and security guidelines. This involves applying encryption and secure storage methods, establishing strict access controls, and conducting regular security audits to safeguard the data throughout its lifecycle. Informed consent is a crucial component in this phase, necessitating that consent is not only obtained but also that it aligns with cultural protocols and respects Indigenous sovereignty. Furthermore, anonymization and de-identification techniques are prioritized to ensure the privacy of individuals and communities, especially when sharing or analyzing data.

### 2. Govern

Governance of Indigenous data under the SGAR model involves understanding and respecting Indigenous data sovereignty. This means developing an organizational culture that supports the safe and respectful handling of Indigenous data. It is essential to identify who owns the data and the rights associated with it. The implementation of data management procedures is key in this phase, including guidelines for data storage, retention, and disposal, which should be in harmony with Indigenous values, cultural norms, and legal requirements. Monitoring and reviewing the governance framework regularly is crucial to ensure its effectiveness and responsiveness to the needs of Indigenous communities.

### 3. Act

In the ‘Act’ phase, the focus is on addressing ethical considerations and ensuring that the actions taken benefit the Indigenous communities. This involves being mindful of potential ethical challenges such as lack of meaningful engagement, cultural misrepresentation, or violation of intellectual property and data sovereignty rights. Balancing Indigenous and Western knowledge systems is critical in this phase, calling for collaborative research and respectful data-sharing agreements that are trauma-informed and prioritize community benefits.

### 4. Report

Reporting 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. The Supportive Operational Team plays a vital role in this phase, responsible for reviewing and analyzing reports, investigating incidents, enforcing policies, and providing timely summaries to the Indigenous Governance Body. The frequency and meticulousness of reporting, ranging from urgent to annual reports, ensure that all aspects of data governance are continually assessed and improved upon.

Incorporating the SGAR model into the data governance framework reflects IPHCC’s commitment to upholding the rights and self-determination of Indigenous Peoples regarding their data. By implementing these strategies, organizations can foster trust, respect, and meaningful relationships with Indigenous communities, ensuring that data management is conducted in an ethical, responsible, and culturally sensitive and safe manner.

# 4.0 GOVERNANCE STRUCTURE

## 4.1 Micro-Meso-Macro Framework

The Micro-Meso-Macro Framework offers a comprehensive structure for organizations, both Indigenous and non-Indigenous, to establish and refine their data governance systems. This structure is exemplified by the IPHCC but extends its utility as a model for other organizations to identify their roles and responsibilities within the spectrum of data governance, enabling them to locate where they and their stakeholders fall within the framework.

The conceptualization of Indigenous governance of data within the framework of the IPHCC involves delineating three principal action pillars, namely reflective

of the IPHCC's membership, provincial partners, and federal collaborators. These pillars are intricately interconnected and function cohesively within the broader context of the IPHCC's overarching mission and vision. Moreover, they are firmly grounded in the principles and values that govern and steer the organization's endeavors.

The framework outlines the key principles and objectives that underpin each pillar of governance, as well as the roles and responsibilities of each stakeholder group in relation to the data held by the IPHCC.



### Structure Types

The delineated structure types have been specifically crafted to acknowledge the distinct roles each structure assumes within the broader landscape of Indigenous Data. Each stakeholder enumerated below has, at various stages of the Indigenous data lifecycle, engaged with, stored, or generated Indigenous forms of Data.

#### 1. Macro Governance | Federal

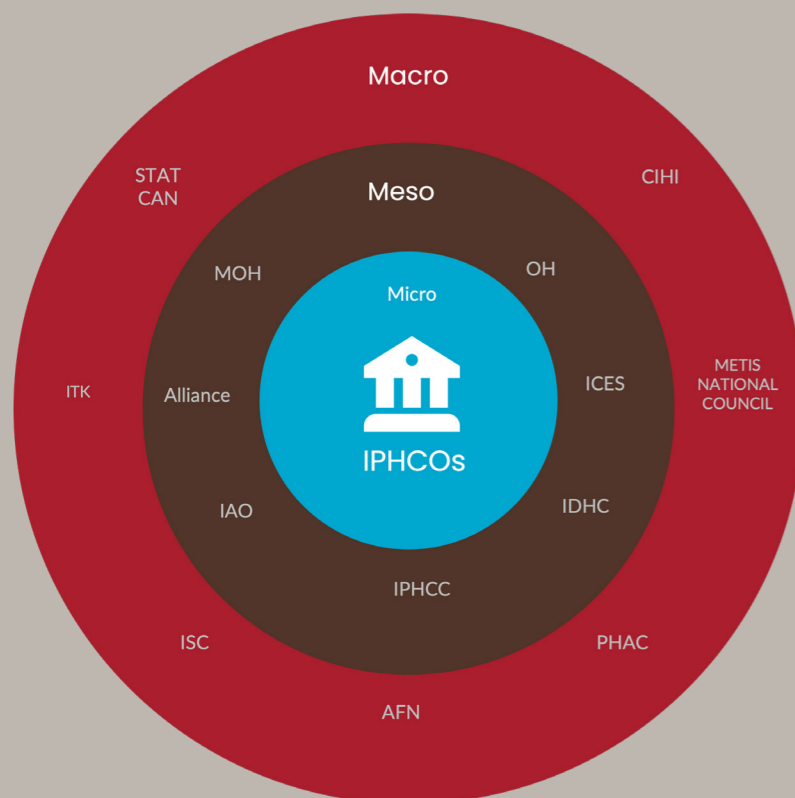
This refers to the overarching principles and policies that guide the management and use of Indigenous data at the pan Canadian or federal level. Our primary strategy underpinning governance at the macro level is to ensure that our federal partners understand and support through legislation the rights of Indigenous people and the sovereignty of their Data.

#### Federal and Pan Canadian Jurisdictions:

The establishment of a legislative framework/approach is imperative to acknowledge and honor Indigenous data sovereignty. This necessitates collaborative efforts with Indigenous nations to actively participate in the co-development of policies governing the collection, storage, and sharing of Indigenous Data. Central to this initiative is the recognition of the pivotal role legislation and our federal partners play in shaping the adherence of legal frameworks. It is essential to ensure a harmonious alignment between **federal laws** and **Indigenous rights**, particularly those intricately linked to data sovereignty and the right to self-determination. This collaborative and legally sound approach serve as a foundation for ethical and equitable practices in the realm of Indigenous data governance.

#### Responsibilities:

- Clearly define the roles and responsibilities of federal agencies, Indigenous organizations, and other stakeholders in managing and safeguarding Indigenous Data on this federal level.
- Establish mechanisms for transparent communication and collaboration between federal entities and IPHCOs/Indigenous Nations at the federal level.



- 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

## 2. Meso Governance | Provincial

As a facilitator in the Indigenous-governed primary healthcare sector, the IPHCC plays a pivotal role in supporting its members with shared resources and advocating with partners on their behalf to shape the data landscape which enables improved Indigenous-governed primary health care delivery. In this role, the IPHCC collects aggregate data (excluding PHI and/or health records), knowledge, stories, and insights from partner organizations whose work is connected to the Indigenous-governed primary health care sector. Our partners may also work directly with our member sites, sharing, collecting, or creating data, stories, knowledge, and insights, which may be shared back with the IPHCC through our members or the sector in summary form.

Provincial governance pertains to intermediate structures such as organizations or consortia, exemplified by the IPHCC. Key considerations include but not limited to three key areas:

### Data Sharing Protocols

- Formulation and implementation of data sharing protocols detailing the types of data shared, objectives, and conditions for access or utilization from an Indigenous Perspective.
- Integration of the SOS principles of reciprocity and benefit-sharing within data sharing agreements with IPHCOs.

### Security Measures

- Implementation of security measures to safeguard the confidentiality and integrity of shared data, particularly given the sensitive nature of health records.
- Periodic audits and updates to security protocols to address evolving threats.
- Understanding the value of conducting the privacy impact assessments to support Indigenous data sovereignty.

### Third-Party Involvement

- Clarification of the role of third-party systems or service providers in the data-sharing process.
- Establishment of stringent criteria for selecting and vetting third-party entities, ensuring adherence to Indigenous data governance principles.

## Responsibilities

We see this approach as not only supporting Indigenous but non-Indigenous partners on a provincial level. In addition it can be further expanded on by mobilizing the Provincial Indigenous Integrated Health Hub (PIIHH) which will play a pivotal role by shouldering a range of responsibilities aimed at advancing the governance and delivery of Indigenous-governed primary health care services to our members. The hub, as part of its multifaceted duties, provides crucial data support to member sites within the Indigenous-governed primary healthcare sector. This information will help facilitate effective health planning, establish benchmarks for health system performance, create culturally relevant indicators, solicit and participate in meaningful research and help the overall health system appropriately interpret and validate Indigenous health data. Additionally, the information shared will aid advocacy efforts because it can be more directed towards health system gaps.

Non-Indigenous partners, through the hub, will also have a place to direct Indigenous-related data questions pertaining to Indigenous sovereignty and responsible management.

The PIIHH assumes a central role in data governance by aggregating non-Personally Identifiable Information (PII), knowledge, stories, and insights from partner organizations associated with the Indigenous-governed primary health care sector. Moreover, the hub facilitates collaborations, overseeing partnerships involving the sharing, collection, creation and analysis of data, stories, knowledge, and insights to inform quality improvement with a specific focus on improved Indigenous-governed primary healthcare across the sector. In ensuring the dissemination of valuable information, often presented in summarized form, the PIIHH serves as a conduit for sharing insights, contributing to the broader sector's understanding and advancement in Indigenous health care at the provincial level.

### 3. Micro Governance | Local

The IPHCC engages in the collection, storage, creation, and sharing of operational data from IPHCOs. This data is derived from various sources, including program delivery, resource development, governance processes, and day-to-day operations, all aligned with fulfilling our mandate. Operational data encompasses a spectrum, ranging from human resources, payroll, and finance data to program and project data for instance, it includes information generated through cultural safety training programs, resource development initiatives for our members, and projects aimed at identifying and addressing sector-specific needs.

Through the hub, we facilitate the analysis of de-identified health data. This support empowers and educates at the local level, fostering awareness of emerging Indigenous quality Key Performance Indicators (KPIs) and building data capacity across the sector. Additionally, we contribute to resource development to assist IPHCOs in implementing these KPIs within their unique local contexts.

Importantly, it should be clarified that member sites do not share Personal Health Information (PHI) with the IPHCC. Instead, de-identified data is shared directly with the IPHCC and indirectly through third-party systems or service providers (Business Intelligence Reporting Tool (B.I.R.T)/ Alliance/ICES), all governed by specific data sharing protocols.

## 4.2 ORGANIZING STRUCTURE

Considering the IPHCC's role as a network of providers and a facilitator within the Indigenous-governed primary healthcare sector, the Data Governance Framework strategically establishes linkages with the Macro, Meso, and Micro governance levels. This framework serves the purpose of elucidating the roles and responsibilities associated with the data held by the IPHCC on behalf of its members, from external partners, and internally. Importantly, it delineates data governance policies that align with and reinforce the operationalization of data governance principles and obligations across the entire data management lifecycle.



The ultimate custodianship of this Data Governance Framework rests with the **IPHCC Board of Directors**, who, within their broader governance roles, are entrusted with upholding its integrity. Concurrently, the organization's CEO assumes a pivotal role in overseeing the development and maintenance of policies, processes, and frameworks that not only align with but also champion the data governance vision and principles sanctioned by IPHCC's board. This collaborative governance structure extends further to involve the **IPHCC Planning and Evaluation Committee (IPEC)** and **IPHCC Research and Ethics Committee (IREC)**. These entities work in tandem to ensure a comprehensive understanding and adherence to the data governance vision, principles, and associated policies throughout the data management lifecycle. By facilitating this synergy, the IPHCC endeavors to guide its interactions with member organizations (IPHCOs), federal and provincial partners in a manner that adheres to the highest standards of data governance and privacy across Ontario.

## 5.0 ACCOUNTABILITY MECHANISMS

We understand that developing an Indigenous focused accountability mechanism demonstrates an ongoing commitment to ensuring appropriate governance of Indigenous Data which goes a long way with affirming and supporting Indigenous Sovereignty of Data. They can include budget allocations, committee representation, audits, and records of decision-making, cultural training and/or professional development.

### 5.1 LEGAL INSTRUMENTS

In Ontario, legal considerations related to Indigenous data governance are grounded in treaties, and constitutional rights that recognize and protect the rights of Indigenous Peoples. The legal landscape includes both Indigenous-specific rights and broader privacy and data protection laws that apply to everyone. Below are key legal considerations.

## Key Legal Considerations

### Constitutional Recognition

The Canadian Constitution, including Section 35 of the Constitution Act, 1982, recognizes and affirms the existing Aboriginal and treaty rights of Indigenous Peoples. This constitutional recognition sets the foundation for the legal recognition of Indigenous data governance rights.

### Treaty Rights

Treaties between Indigenous nations and the Crown in Canada often include provisions related to the use and management of land and resources. These agreements may have implications for data governance, especially when data is tied to aspects covered by the treaties, such as resource development.

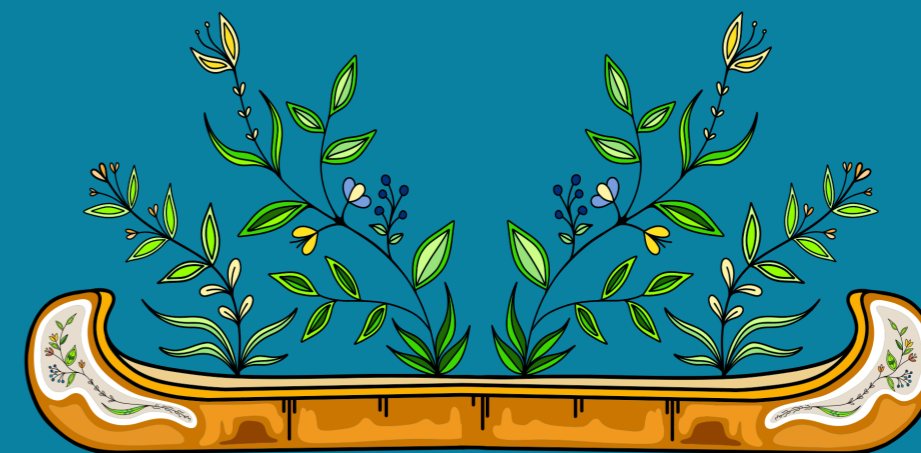
### Access to Information and Protection of Privacy Act (AIPPA)

This governs the collection, use, and disclosure of personal information by provincial public bodies. However, based on the historical challenges faced by Indigenous Peoples, this approach does not work and thus, the development of the Indigenous Privacy Framework (IPF) directly addresses privacy and access concerns from an Indigenous lens.

## 5.2 DATA SHARING PROTOCOLS & AGREEMENTS

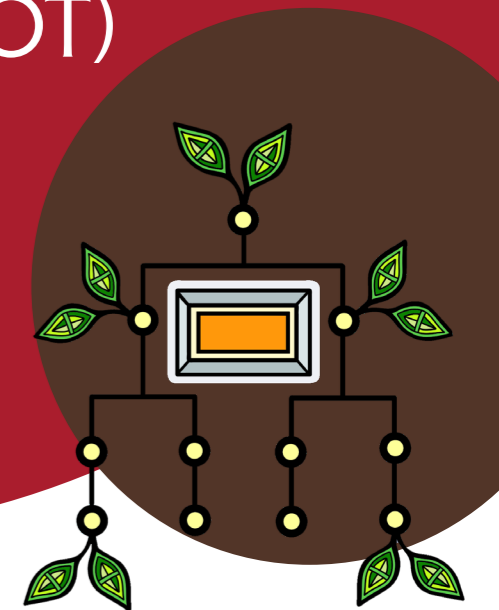
Ensuring the protection and thoughtful representation of data from our Sector is crucial, especially in upholding Indigenous data sovereignty principles. Recognizing this, IPHCC has actively collaborated with Indigenous legal advisors to create a set of sector-specific Data Sharing Agreements (DSAs), a key component of IPHCC's comprehensive data governance strategy. Historically, IPHCC has encountered standardized western DSAs from non-Indigenous organizations, such as funders and researchers, which did not align with the values and collective interests of Indigenous Peoples.

In collaboration with Olthuis, Kleer, Townshend LLP (OKT LLP), IPHCC has crafted detailed DSAs that address these concerns. These templates are integral to securely and ethically facilitating the exchange of information among the entity responsible for collecting Indigenous data, external collaborators, and First Nations, Inuit, and Métis (FNIM) communities. 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.



Protocol Action	Description
<b>Community Engagement and Consent</b>	Prioritize community engagement; obtain free, prior, and informed consent for data-sharing activities.
<b>Cultural Protocols</b>	Develop and adhere to protocols respecting Indigenous knowledge and values, including cultural considerations.
<b>Data Ownership and Control</b>	Clearly define mechanisms for data ownership and control, with community decision-making authority.
<b>Reciprocity and Benefit-Sharing</b>	Prioritize mutual benefit and reciprocity in data-sharing agreements, outlining community benefits.
<b>Data Security and Privacy</b>	Implement robust data security measures to protect privacy and confidentiality throughout the process.
<b>Capacity Building</b>	Prioritize capacity building within Indigenous communities regarding data governance and privacy principles.
<b>Customization and Flexibility</b>	Allow for customization of protocols to suit the unique contexts of each community; ensure flexibility.
<b>Data Sharing Agreements (DSAs)</b>	Develop comprehensive DSAs aligning with community values, legal considerations, and ethical principles.
<b>Ongoing Communication</b>	Foster continuous communication between data collectors, partners, and Indigenous communities.
<b>Ethical Review</b>	Establish an ethical review process, potentially involving an Indigenous-led review board.
<b>Dispute Resolution Mechanism</b>	Include a mechanism for fair and culturally appropriate dispute resolution related to data sharing.
<b>Continuous Evaluation</b>	Implement continuous evaluation to assess the effectiveness of the protocol, considering feedback and changes.

## 5.3 INDIGENOUS GOVERNANCE BODY (IGB) AND SUPPORTIVE OPERATIONAL TEAM (SOT)



### Establishing an Indigenous Governance Body (IGB)

In line with Ontario Health's Indigenous Data Governance Matters initiative, organizations handling Indigenous data must establish a governance body accountable to their local First Nations, Inuit, Métis, and Indigenous (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 First Nation entities, Métis Nation of Ontario (MNO) chapters, Indigenous Primary Health Care Organizations (IPHCOs), Inuit associations, and local Indigenous advisory groups.

FNIM representatives participate on a voluntary basis; however, best practice includes providing honorariums as forms of appreciation for time spent on Body activities.

### Establishing a Supportive Operational Team

It is recommended that the organization provide an operational support team for the Indigenous Governance Body that will support the review/approval process for requested data activities. Roles may include:

1. Privacy and Security Officer
2. Ethics Review Officer
3. Information Management Specialist Researcher/epidemiologist
4. Legal and Policy Advisor

### Key Features of the Templates

- Template Language and Discussion Points
- Flexibility and Contextual Relevance
- Negotiation Framework

**The DSA templates are included in the Appendix supplement for reference.**

### The responsibilities of the Supportive Operational Team (SOT) will include:

- Develop a process to receive Indigenous data requests, both internally and externally to the organization.
- Conduct preliminary review of Data Engagement Request forms to vet and ensure appropriateness.
- Once established criteria has been met, forward request form to Indigenous Governance Body for review. If questions are raised, further clarification is needed, or changes are required, the form will be returned to the Support Operational Team for management of requested information.
- The Supportive Operational Team will connect with the requester, instructing them to update the request form accordingly. Once changes are made, the SOT will resubmit to the IGB for final review and decision-making. All data decisions will lie with the IGB, who will have final say if the request is rejected or approved.

## 6.0 POLICY

### 6.1 Data Governance Policy

PHCC's data governance policies describe specific requirements necessary to govern Data. They are used to inform and guide the implementation of the Data Governance Framework and the fulfillment of any related roles, responsibilities, and accountabilities; and provide our partners with a common understanding of our requirements. Each policy considers the vision and principles of our Data Governance Framework, and collectively adds strength to our protective blanketing of Data.

The goal of the Data Governance policies is to help prevent issues from developing by providing a common understanding of the application of data governance. Applying the policies will result in having a detailed understanding of data by:

- Maintaining an inventory of all data and describing where it resides, including understanding how it is collected, used, and disclosed.
- Classifying the sensitivity level of the data; defining data quality and data standard requirements
- Defining data disclosure, data sharing, and data linking requirements.
- Outlining how we will monitor and assess compliance with the Data Governance Framework and manage incidents.
- Describing the approach to raising awareness of the Data Governance Framework.
- Describing how changes can be supported; and
- Providing a common set of definitions.

The Data Governance policies are contained in a separate Data Governance Policy Manual that can be more easily updated over time. Each policy describes the applicability, related factors, date approved, approver title and name, purpose, policy details, roles and responsibilities, and where applicable supporting procedures. As/when a new policy is approved the manual will be updated to include the approved changes.

## 6.2 PRIVACY AND SECURITY POLICIES

IPHCC's privacy and security policies have been developed and will describe how data will be protected, and how security measures and processes that will be maintained to prevent privacy violations and inappropriate access to information. It considers applicable privacy legislation, integration with federal and provincial partners, and the unique needs of the IPHCC, its partners and member organizations. They are used to inform and guide our leadership, staff, members, and partners in the fulfillment of related roles, responsibilities and accountabilities; and provide stakeholders with an understanding of how data is protected by the organization. Combined with the other elements of the framework these Privacy and Security Policies provide more strength to the fibers of our protective blanket for our Data.

The goal of the Privacy and Security Policy manual will be to help prevent issues from developing by providing a common understanding of how data is to be protected. The policies will describe at a minimum:

- How access to data is provided and managed; how to prevent unauthorized access; and how to monitor compliance.
- How to protect against data loss or corruption.
- Data retention and disposal requirements; and
- Clients/customers and partners awareness programs, including the consent model for collecting, using, and disclosing information.

The Privacy and Security Policy Manual is a stand-alone document that can be accessed by relevant parties as needed. Each policy will describe its applicability, related factors, date approved, approver title and name, purpose, policy details, roles and responsibilities and, where applicable, supporting procedures. As/when a new policy is approved the manual will be updated to include the approved changes.

As the sector has grown and evolved, it has increasingly received research requests and collaborations from various institutions and organizations. Recognizing the importance of ethical considerations and the need to safeguard the interests of Indigenous communities, IPHCC has established the Research and Ethics Committee (REC). This committee is responsible for ensuring that research initiatives align with the values, vision, and mission of IPHCC, and that they are conducted in a manner that respects and responds to the needs and priorities of the Indigenous communities that we serve.

# 7.0 PARTNERSHIPS & MEANINGFUL ENGAGEMENT

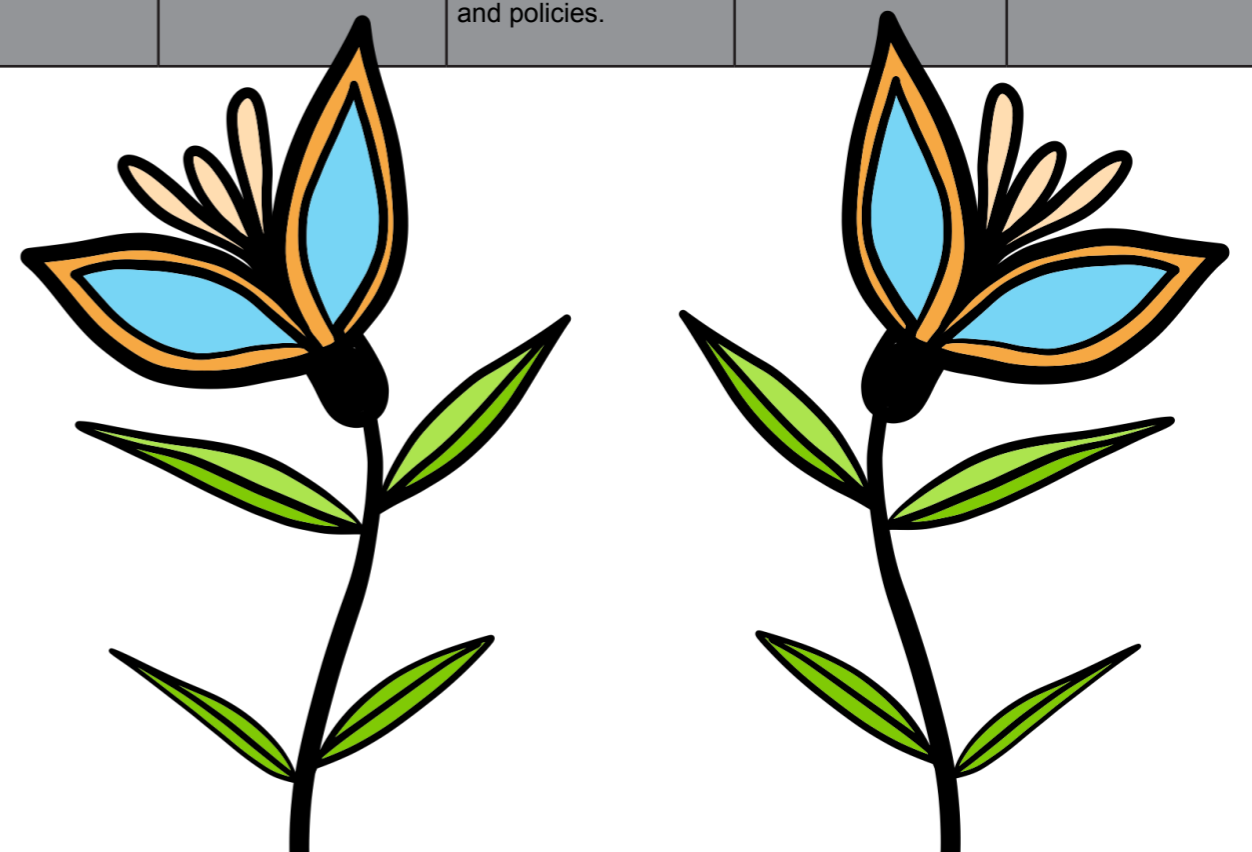
## 7.1 Maturity Model

The Maturity Model serves as a self-assessment tool for organizations, enabling them to identify their current stage in implementing the Indigenous data governance framework. This model delineates a phased journey, with each phase representing a progressive step towards achieving cultural safety, effective governance of Indigenous data, and ensuring health equity for Indigenous Peoples. The model is crafted to guide organizations through various stages of engagement, starting from an initial awareness phase and progressing towards the optimization of sustainable practices.

To facilitate this process, the model employs implementation tools such as the Indicator Framework (*Refer to Indicator Framework supplement document*), which associates specific indicators with each level of maturity. These indicators help organizations to gauge their progress quantitatively and qualitatively in implementing the framework, offering a clear view of where they stand and what steps are needed to advance to the next level. By using these tools, organizations can effectively measure and monitor their journey through the full spectrum of maturity phases, ensuring a comprehensive and structured approach to enhancing their cultural safety practices and data governance policies.



	Phase 1	Phase 2	Phase 3	Phase 4
	Awareness	Planning	Implementation	Optimization
Phase Description	Organization recognizes the importance of cultural safety and is working to develop and implement policies and procedures aimed at addressing health equity considerations for Indigenous people.	Organization has made a commitment to providing culturally safe care to Indigenous persons, and is beginning to engage in specific discussions with Indigenous communities about appropriate governance of Indigenous data.	Organization is actively ensuring ongoing cultural safety, and is equipped to ensure appropriate governance of Indigenous data.	Organization has fully implemented and is continuously improving its culturally safe care and Indigenous data governance practices.
Key characteristics	<p>Organization displays a commitment to engaging with communities represented by clients to understand strengths and needs</p> <p>Organization is creating a cultural safety strategy in collaboration with Indigenous clients and communities.</p>	<p>Organization has a developed cultural safety strategy.</p> <p>Organization is developing relationship template agreements with communities.</p> <p>Discussions regarding data governance/sovereignty are occurring</p> <p>Organization is working on creating Indigenous data governance structures, processes and policies.</p>	<p>Data sharing agreements in place with partners and Indigenous communities.</p> <p>Data governance policies and processes implemented.</p>	<p>Data governance policies and processes fully implemented.</p> <p>Organization actively monitors and refines its cultural safety and data governance Practices.</p> <p>Consistent engagement with Indigenous communities to adapt and evolve the practices.</p>





## 7.2 MEANINGFUL ENGAGEMENT



The Indigenous Primary Health Care Council (IPHCC) emphasizes meaningful engagement and robust relationship agreements as cornerstones of effective partnerships in Indigenous health care 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.

Meaningful Engagement Aspects	Description	Examples/Wise Practices
<b>Reciprocal Learning and Sharing</b>	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.
<b>Cultural Sensitivity and Competency</b>	Recognizing and integrating the cultural nuances and values of Indigenous communities into all aspects of the partnership.	Providing cultural competency training for staff; Consulting with Indigenous leaders to ensure practices and policies are culturally appropriate.
<b>Empowerment and Support for Self-Determination</b>	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.
<b>Sustainability of Relationships</b>	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.
<b>Building Trust</b>	Trust is the foundation of any meaningful relationship. Establishing trust involves consistent, transparent, and respectful interactions over time.	Maintaining open and honest communication; Demonstrating reliability and integrity in all interactions; Acknowledging and learning from past mistakes. Create a safe space to engage in difficult discussions when needed.

## 7.3 RELATIONSHIP AGREEMENTS

Relationship Agreements are formal documents that outline the terms and expectations of the partnership. They are essential for providing structure and clarity, ensuring that both parties are aware of their roles, responsibilities, and the goals of the partnership. These agreements are not static documents but evolve along with the relationship, reflecting changes in understanding, objectives, and the broader context of the partnership.

In the Indigenous Data Governance framework, Relationship Agreements are crucial for establishing clear, effective partnerships. These agreements explicitly outline each party's expectations and commitments, providing a clear roadmap for the partnership. They include dispute resolution mechanisms to efficiently address and resolve any disagreements, ensuring the partnership's smooth functioning. The agreements are designed to be adaptable and are periodically reviewed to reflect the evolving nature of the partnership and changing needs. Furthermore, they detail enforcement and accountability measures, ensuring all parties adhere to their commitments. Templates for these agreements can be found in the appendix of the document, offering a practical resource for formalizing such partnerships.

# 8.0 RESEARCH & ETHICS

Research and Ethics play a pivotal role in the comprehensive strategy to safeguard Indigenous data, stories, knowledge, and insights in Ontario. In the context of ethical research within Indigenous communities, it is imperative to integrate Indigenous values and principles, respecting knowledge systems and cultural protocols. Researchers must recognize Indigenous communities' sovereignty over their data, ensuring community consent is obtained in a culturally appropriate manner. Active involvement of Indigenous communities throughout the research process, aligned with principles of self-determination and community control, is crucial.

## 8.1 Participant and Community Consent

Culturally sensitive and clear informed consent procedures are essential, especially in Ontario, where historical research lacked proper consent or cultural sensitivity. This emphasis on informed consent is critical to respecting the rights and sovereignty of Indigenous communities.

**1. Transparent Communication:** Researchers must clearly explain the purpose, scope, and potential impacts of the research to participants, avoiding technical jargon and using plain language. This includes a detailed description of the study's objectives, the methods to be used, and the anticipated outcomes.

**2. Culturally Appropriate Engagement:** The consent process should be aligned with community-specific cultural practices and languages. This includes being sensitive to the historical context of Indigenous communities in Ontario, where past research practices have been lacking in cultural sensitivity and proper consent.

**3. Informed Decision-Making:** Participants should be fully informed about what participation in the study entails, including any activities or interventions they may be asked to partake in, such as surveys, focus groups, or providing biological samples. Special consideration should be given to research methods that align with Indigenous principles, like the use of talking circles, listening circles, and storytelling for instance.

**4. Consent for Future Use of Data:** Researchers should address the possibility of future use of participants' data or biological materials, being specific about potential uses and allowing participants to opt out if they wish. This foresight prevents the need for re-consenting individuals in the future, which can be challenging and impractical.

**5. Continual Consent and Withdrawal Rights:** Participants should be assured that consent is an ongoing process and that they have the right to withdraw their consent at any time, without any negative repercussions. Researchers must commit to informing participants of any new findings that might affect their willingness to continue participating in the study.

**6. Additional Considerations for Vulnerable Populations:** Special attention must be given to obtaining consent from vulnerable populations, including minors and adults with diminished decision-making capacity. In these cases, assent from the individual and consent from a legal guardian or authorized third party may be necessary.

## 8.2 Collaborative Research & Capacity Building

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.

Capacity building 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.

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.

## 8.3 Managing and Processing Research Requests in the Indigenous Sector

The Research & Ethics Committee (REC) of the Indigenous Primary Health Care Council (IPHCC) is integral to managing and protecting sector specific Indigenous data, stories, knowledge, and insights. This committee ensures that research conducted by or on behalf of IPHCC is ethical, respectful, and responsive to the needs of Indigenous communities.

The REC functions within the framework of the Government of Canada's Tri-Council Policy Statement: **Ethical Conduct for Research Involving Humans – TCPS 2 (2018)**, which includes respect for persons, concern for welfare, and justice. It plays a key role in reviewing research proposals, educating on ethical issues, promoting ethical conduct, and maintaining a library of research. The committee also takes into consideration provincial and federal legislation affecting Indigenous healthcare.

This framework and set of practices ensure that research conducted under the auspices of the IPHCC is not only rigorous but also deeply respectful of and responsive to the values, needs, and priorities of the diverse Indigenous communities in Ontario that we serve.

## 8.4 Best Practices and Models

Best Practice/Model	Description	Application Example
<b>Respect for Indigenous Values</b>	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.
<b>Storytelling and Ethical Thinking</b>	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.
<b>The Seven Sacred Teachings</b>	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.
<b>Understanding Indigenous Shared Values</b>	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.
<b>Recognizing Historical Contexts</b>	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.
<b>Difference in Indigenous and Western Research Philosophy</b>	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.

## 9.0 CONCLUSION

In summary, this Indigenous Data Governance Framework provides a holistic and culturally sensitive guide for organizations involved in Indigenous healthcare and data management. It not only addresses the technical aspects of data governance but, more importantly, centers on ethical considerations, community engagement, and a commitment to advancing the well-being of Indigenous communities in Ontario.

IPHCC's Data Governance Framework presented six strategic areas providing a comprehensive and nuanced approach to safeguarding Indigenous data, ensuring cultural safety, and promoting health equity for Indigenous communities in Ontario served by our members. The framework is designed to be adaptable, reflecting the unique needs and contexts of Indigenous communities and emphasizing collaboration, respect for Indigenous values, and the principles of self-determination.

