National Métis Health Data Strategy & Principles

A REPORT PREPARED FOR MÉTIS NATIONAL COUNCIL
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EXECUTIVE SUMMARY

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Background

This report establishes guiding principles for Métis-specific health research and data governance. Drawing upon existing frameworks on Métis research governance, these principles offer conceptual direction to uphold Métis sovereignty in research development, methodologies, data sharing, storage, and knowledge mobilization. They serve as a resource for the Métis National Council (MNC), provincial governing bodies, Métis communities, organizations, researchers, universities, ethics boards, and relevant stakeholders to streamline research and data sharing processes. By adhering to these principles, researchers, policymakers, and decision-makers can ensure they respect Métis research protocols and address the health and wellbeing priorities identified by Métis people.

In Canada, a comprehensive understanding of Métis population health and wellbeing has been lacking due to insufficient, inaccurate, and inaccessible data and information. With these principles in place, Métis organizations and communities will be better equipped to engage in research and data partnerships that directly explore their health and wellbeing needs, distinct from other Indigenous populations in Canada and globally. Access to reliable data and evidence is essential for developing effective health systems tailored to Métis communities nationwide.

COMMUNITY-ENGAGEMENT

Guided by a community-engaged research (CER) paradigm, our approach to the project included in-person and online meetings with the National Métis Council, each of the governing bodies as well as local employment and capacity building. Preliminary results of the report were presented at the Métis Nation Technical Health Committee Meeting on November 9th, 2023 and at the National Métis Health Pre-Forum Data Workshop on February 6th and the National Métis Health Forum on February 8th, 2024.

Feedback was provided by Métis governing bodies at every stage of the process, including thorough review of its recommendations and next steps.

OUTCOMES

The National Métis Health Data Principles are designed for utilization by the Métis National Council (MNC), Métis governing bodies and other Métis stakeholders in their collaborative efforts with researchers, governmental, and non-governmental organizations regarding research and data sharing. These principles affirm the authority of Métis governing entities over health research and data governance specific to their communities and constituents. Beyond health-focused inquiries, these principles can extend their application to various research and knowledge dissemination realms, encompassing domains like education, justice, housing, social welfare, agriculture, environment, and natural resources.

The National Métis Health Data Principles accommodate the diversity among Métis populations (including those residing in rural, urban, and remote areas), organizations, and communities. They allow for adaptable implementation at local, regional, provincial, and national levels concerning research endeavors and data sharing arrangements. Drawing upon established frameworks on Métis research governance, these principles offer conceptual guidance that upholds Métis sovereignty in the realm of research development, methodologies, data sharing, storage, and knowledge mobilization. Serving as a practical resource, these principles aid the MNC, Métis communities, organizations, and affiliated groups in streamlining research processes, thus attracting researchers and resources to areas of health and wellbeing research prioritized by Métis individuals.

The following recommendations and next steps guide the establishment and implementation of the National Métis Health Data Principles:

RECOMMENDATIONS

1. Dissemination of this report.

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2. The development and implementation of an ongoing, comprehensive Canada-wide Métis health survey.

3. Create an arms-length centre to manage Métis data.

4. Training of Métis Data Principles through the Saskatchewan Network Environments for Indigenous Health Research (NEIHR) for Governing Member Health Teams, Métis communities, university ethics boards, and all researchers who wish to work with Métis health data.

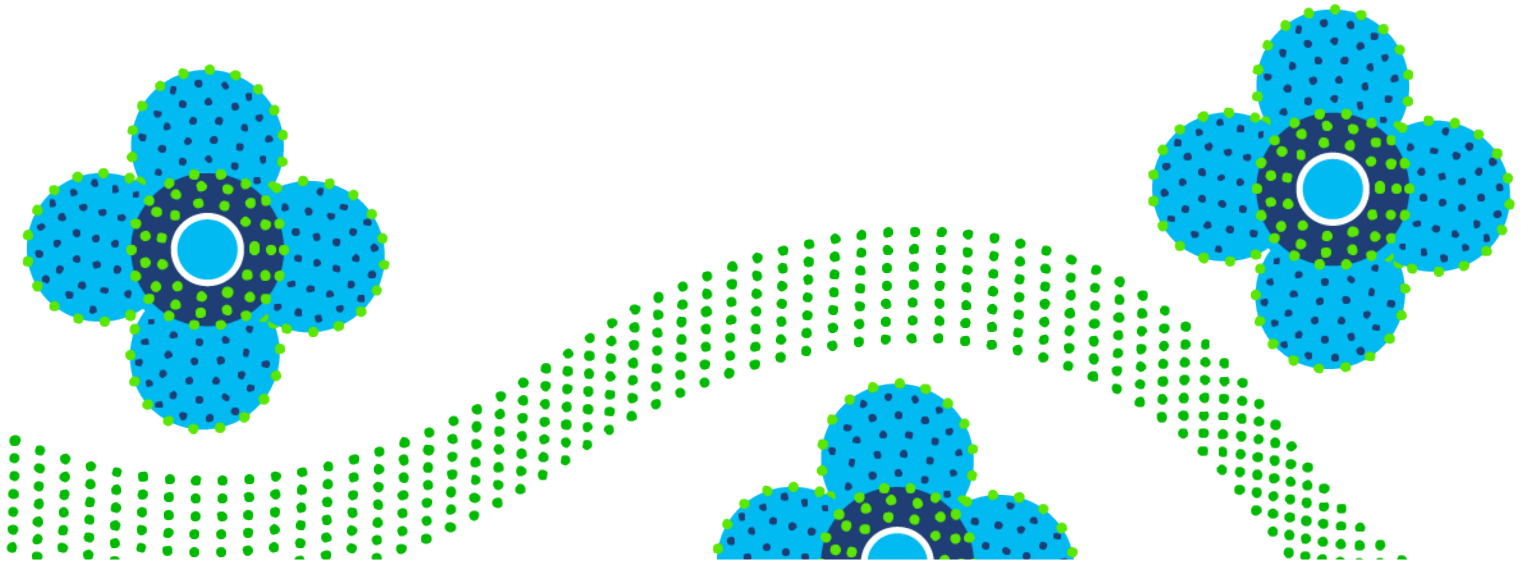
5. Update the Tri-Council Policy Statement for Ethical Conduct for Research involving Humans Chapter 9 to incorporate Métis data principles.

NEXT STEPS

1. A key priority is to ensure the implementation of this report, promote community validation and ownership of recommendations, and maintain momentum and leadership around key recommendations outlined above. We propose that the Métis National Council fund and coordinate additional meetings that bring together the Métis governing bodies, other interested communities, Indigenous organizations, academics, governments, and leaders to discuss the report and prioritize recommendations.

2. The National Métis Health Data Strategy should be implemented into the larger National Métis Data Strategy to frame the process of how research and data is to be collected with and for Métis Peoples, communities, and governments.

3. Present the National Métis Health Data Principles to the Canadian Institutes of Health Research Science Council (SC).



INTRODUCTION AND CONTEXT

The purpose of this report is to establish Métis-specific health research and data governance principles. Drawing from existing work on Métis research governance, the principles provide conceptual guidance to support Métis sovereignty regarding research development, methodologies, data sharing, data storage and knowledge mobilization. The principles are intended to act as a tool for the Métis National Council (MNC), Métis provincial governing bodies, Métis communities, Métis peoples, organizations, researchers, universities, ethics boards and other relevant groups to facilitate research and data sharing processes more effectively and efficiently, ensuring researchers, policy-makers and decision-makers are respecting Métis research protocols and the health and well-being research priorities identified by Métis people. For Métis in Canada, a true picture of population health and well-being has been missing, the predominant reason being the lack of adequate, accurate and accessible data and information on Métis health and well-being (Gmitroski, Hastings, Lagualt & Barbic, 2023; Tait & Henry, 2023). With the principles in place, Métis organizations and communities will be better situated to partner in research and data partnerships that directly investigates their health and well-being as distinct from other Indigenous populations in Canada and internationally. We simply can't build our own health systems (whatever those may look like across the country) if we don't have the data, appropriate evidence base and understanding of our communities.

OVERVIEW

This report includes an overview of the current data governance environment and a summary of the existing research governance guidelines for Métis communities in Canada. The report also provides an overview of health and data priorities across the Métis Nations of British Columbia, Alberta, Saskatchewan, and Ontario. Importantly, the Métis health data principles derived from this report are adapted from the Métis Data Principles created by Drs. Caroline Tait and Robert Henry (2023). Specific attention is paid to the importance of research partnership agreements, data sovereignty, and introduces the mamawiikikayaahk Health and Wellness Research Network, part of the Saskatchewan Network Environments for Indigenous Health Research (NEIHR), funded by the Canadian Institutes of Health Research (CIHR) with an emphasis on the importance of data stewardship. The principles are intended to guide the inclusion of Métis peoples in data processes that strengthen Métis control for improved discovery, access, use, reuse, and attribution in contemporary data landscapes. These principles will aim to contribute to evidence-based and informed community, regional, provincial and national-level planning regarding Métis-specific health research and data governance principles.

This report concludes by offering a number of recommendations and next steps for MNC to move forward in implementing health research and health data governance principles. Ultimately, this report is as much about process as outcome, and a primary objective is to support planning and discussion that is already taking place within and across the Métis nation.

This report undertook a 3-phase approach that included the following:

MILESTONE	START DATE	END DATE
PHASE ONE		
PRELIMINARY MEEING & RELATIONSHIP-BUILDING ACTIVITIES WITH THE GMS DIRECTORS OF HEALTH	15-AUG-23	15-DEC-23
PHASE 2A		
SUBMISSION OF DRAFT REPORT	15-JAN-24	15-MAR-24
1. INVENTORY AND ASSESSMENT OF CURRENT MÉTIS HEALTH DATA GOVERNANCE	15-JAN-24	15-MAR-24
2. NATIONAL HEALTH DATA GOVERNANCE PRINCIPLES	15-JAN-24	15-MAR-24
3. ENGAGEMENT STRATEGY	15-JAN-24	15-MAR-24
PHASE 2B		
SUBMISSION OF FINAL REPORT		31-MAR-24

RELATIONSHIP-BUILDING ACTIVITIES

An accurate assessment of Métis health status is critical and will allow for the development of distinctions-based, Métis policies and programs. Because most Métis health data in Canada exists in federal and provincial databases, death and birth registries, health survey databases, and disease registries, limitations inherent to each source have led to poor data quality development as well as inadequate and non-existent data (National Collaborating Centre for Aboriginal Health, 2011). As a result, Métis governments, communities and individuals across the country share a deep interest and concern about data governance and the ways in which data can be used to better inform their health and well-being. This makes a community-engaged approach the right one for this initiative. A community-engaged approach ensures that the project goals reflect a wide range of perspectives, across diverse Métis communities through a ground up approach. A collaborative approach also ensures that project outcomes will be accessible to all audiences, and promises health, social, cultural and intellectual benefits to a wide range of stakeholders. These benefits transcend what could be delivered by any one individual, consultant, or partner.

Overall the National Métis Health Data Strategy and Principles brings together academics, the National Métis Council, and the Governing Members of the Métis Nation British Columbia, the Métis Nation of Alberta, Métis Nation-Saskatchewan, and the Métis Nation of Ontario. All partners have provided input into the National Métis Health Data Principles and have worked together to refine the project questions, methods, principles, recommendations, knowledge outcomes, dissemination and engagement strategies.

Support from academic institutions have played a pivotal role in the strategy and development of the Principles. McMaster University, the University of Saskatchewan and the University of Calgary have provided financial and in-kind contributions supporting the development of the National Métis Health Data Strategy and Principles, specifically with regards to research design and analysis, researcher time, plus facilities for meetings and daily work on the strategy.

INDIGENOUS DATA GOVERNANCE INITIATIVES

Background

In today's world, data is considered one of the most valuable resources across both private and public sectors. Leveraging data creates opportunities for groups, companies, and nations to advocate for their needs and participate in decision-making which can ignite innovation (Caroll et al., 2020). However, quantity and "newness" are often seen as the metrics that determine the value of data which can create an environment that breeds inaccuracy and misrepresentation (Andersen, Walter, Kukutai, Gabel, 2025, Forthcoming). This is particularly true for Indigenous[1] Peoples globally, as a scarce number of statistical agencies, researchers and other data collectors respect the intersections of Indigenous rights within the data collection process (Davis, 2016; Rainie et al., 2019). Indigenous Peoples and nations remain on the outside of population-level data collection processes which not only determines what is collected but how it is collected (Kukutai & Walter, 2015; Rainie et al., 2019; Carroll, et al. 2019). This is particularly true in the case of the Métis specific data. Between the 2006 and 2016 Canadian National censuses, the Canadian Federal Government laid claim that the Métis are one of the fastest growing populations in Canada, despite Métis citizenship registries showing otherwise (Andersen, 2016). Métis governmental bodies have called into question the accuracy of these findings and pointed to the significant increase in individuals who self-identified as Métis without citizenship as a factor that has caused inaccuracy across census data (O'Donnell & LaPointe, 2019). The 2021 Census made an attempt to rectify this by reframing the survey question to ask respondents whether they are members of a Métis organization or a citizen of a Métis government (Statistics Canada, 2022). The data revealed that only one third of the individuals who self-identified as Métis reported having citizenship or membership with a Métis organization or settlement (Statistics Canada, 2022). This affirmed previous concerns regarding accuracy of Métis population level data.

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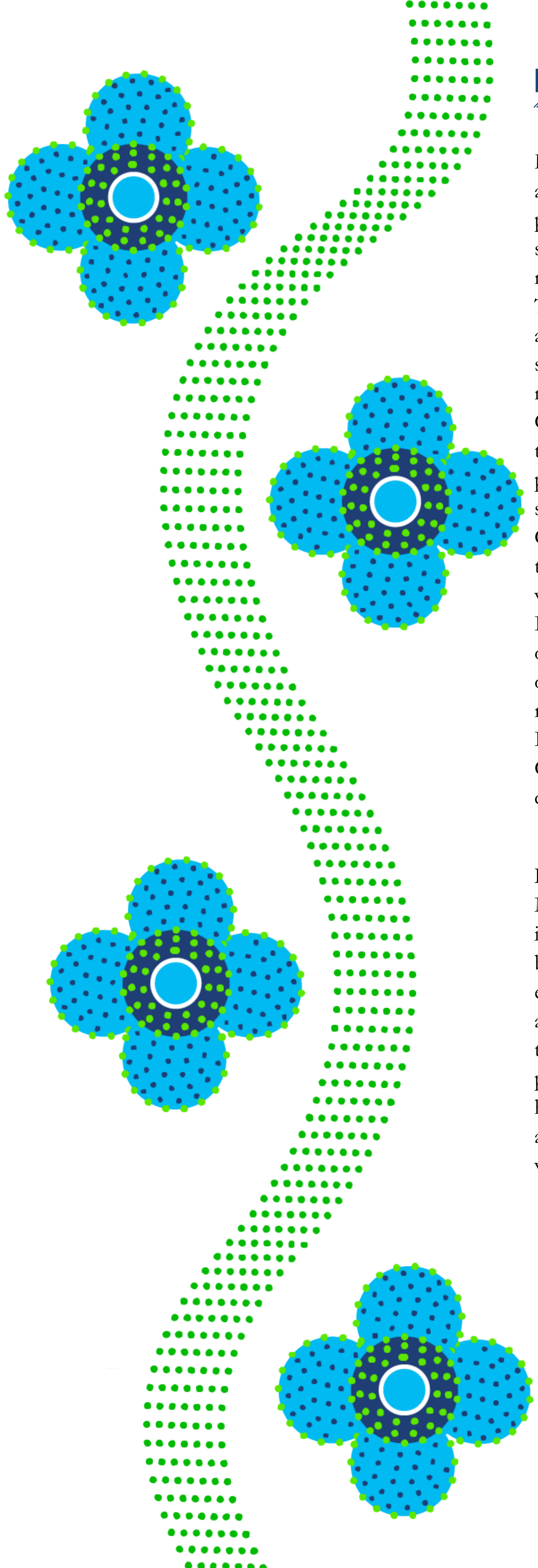
[1] For the purpose of this report, Indigenous Peoples refers to the international context, whereas the term First Nations, Inuit and Métis (FNIM) refers specifically to Indigenous peoples in the Canadian context.



HEALTH DATA

Health data can be used to better understand how health systems and processes are performing, identify risk factors, and improve diagnosis and treatments for patients (Institute for Circumpolar Health Research, 2022). For Indigenous Peoples specifically, health data can help advocate for community specific health care needs, including strengthening culturally specific health programs and services. There are two types of health data - quantitative which includes the numerical and statistical methods this includes epidemiological data (such as seroprevalence studies, bench data), and drug trials, and qualitative which encompasses non-numerical data that is observed through stories and experiences (Institute for Circumpolar Health Research, 2022). Both types of data can be used in tandem to describe health experiences and phenomena; however, qualitative data is often preferred by Indigenous groups because it better captures community member's stories and experiences navigating their health and health care systems (Institute for Circumpolar Health Research, 2022). Historically, Indigenous Peoples have been the objects of health studies and not partners throughout the research process, which has created conflict over the storage, stewardship, and interpretation of Indigenous health data. More specifically, clinical researchers have been called out by Indigenous communities for storing Indigenous data and using it outside of its intended purposes,, including biological samples, which many nations want repatriated (Garrison & Cho, 2014; Hyett, Gabel, Marjerrison, Schwartz, 2019). As Indigenous nations and communities move towards self-determination across the Canadian research environment, there is an increased demand for governance over data across the research life span.

Despite an increase and focus on Indigenous health data governance and research, Métis specific data is lacking. Data that is used to describe Métis health or wellbeing is often conflated within Indigenous data collection, and therefore caution should be used. The Canadian Institutes of Health Research provided an overview of estimated investments in Indigenous health research. Through a distinctions-based analysis, Métis health research received less than 5% of the total dollars awarded to Indigenous health research, despite constituting over 31.5% of the Indigenous population in Canada. As such, there are large gaps in the understanding of Métis health and wellbeing, as well as how to develop ethical research partnerships and agreements to ensure data sovereignty and governance over Métis health and wellbeing research information.[2]

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[2] Canadian Institutes of Health Research, Institute of Indigenous Peoples Health, Investments in Indigenous Health Research, Presentation & Forthcoming Results, 2024.

INDIGENOUS DATA SOVEREIGNTY AND GOVERNANCE

Indigenous Data Sovereignty

Within the United Nations Declaration of Indigenous Peoples (UNDRIP), Indigenous Nations possess specific rights to data in ways that do not apply to other racial and ethnic groups (Banerjee 2003, United Nations 2018, Rainie et al. 2019). Indigenous data is defined as "data generated by Indigenous Peoples, as well as by governments and other institutions, on and about Indigenous Peoples and territories, as well as information about Indigenous communities and the individuals, Indigenous and non-Indigenous, that live within" (Carroll et al. , 2020, p.3). Within this purview, Indigenous data sovereignty challenges colonial nations' paternalistic data agendas by shifting data control and ownership back to Indigenous nations (Kukutai and Taylor, 2016). Indigenous nations then must shift their approach from a scarcity mindset that is limited by "what are we able to collect?" to that of abundance by asking "what do we want or need to know?" (Andersen, Walter, Kukutai, & Gabel, 2025, Forthcoming).

Indigenous data sovereignty is defined as "the right of each [Indigenous Nation] to control the collection, ownership, and application of its own data" (Rainie et al., 2017). The path to Indigenous data sovereignty requires that nations view data as a valued cultural resource rather than a means to government programming or funding, by focusing on collective data rights and ensuring that the nation's values are embedded in good data governance. The pursuit of Indigenous data sovereignty is the antithesis of data dependency and supports Indigenous nation rebuilding through data governance.

While many Indigenous Nations' ultimate goal is Indigenous Data Sovereignty, they remain stuck within data dependency (see Figure 1)

In today's world, data is considered one of the most valuable resources across both private and pub(Carroll, Rodeiguez-Lonebear, & Martinez, 2019). Data dependency occurs when there is either 1) an abundance of data about Indigenous Peoples and nations, or 2) a lack of data conducted for or by Indigenous Peoples or nations (Carroll, Rodeiguez-Lonebear, & Martinez, 2019). Examples of scenarios that perpetuate data dependency include inconsistent and inaccurate data about Indigenous Peoples, control and ownership of data by external bodies, exploitative research protocols and policies, using a deficit based lens to describe Indigenous Peoples, and the lack of external support for Indigenous specific data infrastructure (Carroll, Rodeiguez-Lonebear, & Martinez, 2019). For Métis people, data dependency currently relies on inaccurate and inconsistent data sets, with limited control and access to said data sets (Gmitroski, Hastings, Lagualt & Barbic, 2023; Tait & Henry, 2023).

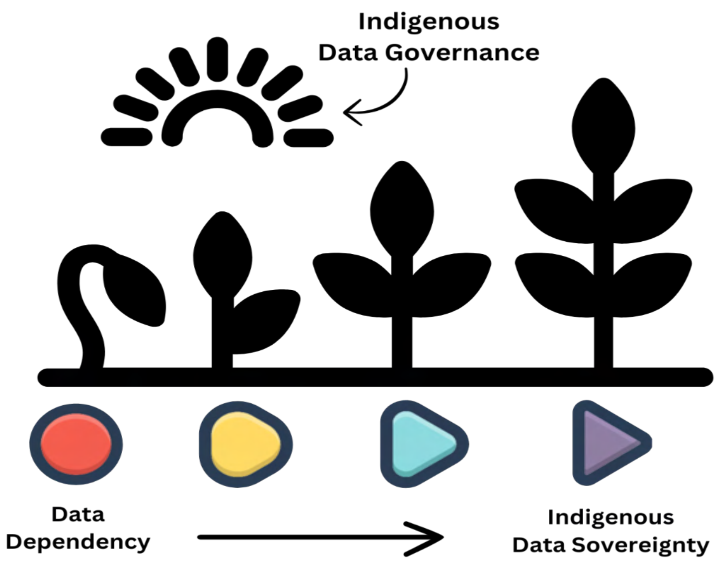


Figure 1. Relationship between Indigenous Data Dependency, Indigenous Data Sovereignty and Indigenous Data Governance.

The development of UNDRIP in 2007 (United Nations, 2007) has provided Indigenous nations around the globe a collective rights based framework that supports their rights to self-determination within their nation-states. Though UNDRIP (2007) itself did not explicitly reference data sovereignty as an inherent right, three years prior, the United Nations Permanent Forum on Indigenous Issues (UNPFII) highlighted the need for Indigenous social statistics to support governance and self-determination (Davis, 2016). UNDRIP does however discuss the concept of Free Prior and Informed Consent (FPIC) which supports Indigenous Peoples right to withhold or withdraw consent in all projects or initiatives on or impacting their communities and land, including research projects (United Nations, 2013).

The concept of collective consent upheld by FPIC is fundamental in ensuring that Indigenous Peoples and nations are fully informed regarding the purpose and methods of data collection in addition to how the data will be used corresponding to nation-specific Indigenous data sovereignty principles (Kukutai, 2023). The specific articles in the UNDRIP that incorporate FPIC include 1) Article 19 - the adoption of legislation or administrative policies that affect Indigenous peoples, and 2) Article 32 - the undertaking of projects that affect Indigenous peoples' rights to land, territory and resources, including mining and other utilization or exploitation of resources.

FPIC and Indigenous self-determination are reiterated and expanded upon in the 2018 United Nations Report of the special rapporteur on the right to privacy. The report stated:
" Governments and corporations recognise the sovereignty of Indigenous peoples over data that are about them or collected from them, and which pertain to Indigenous peoples, knowledge systems, customs or territories, by always including formalised Indigenous developed principles, a focus on Indigenous leadership and mechanisms of accountability" (United Nations, 2018, para 11).

INDIGENOUS DATA GOVERNANCE

If Indigenous data sovereignty is the destination, data governance is seen as the vehicle required to achieve the destination. Principles of data governance exist out of the Indigenous contexts however the concept of Indigenous data governance is often divided into two interdependent components including 1) Data for Governance and 2) Governance of Data (Smith, 2016; Carroll, Rodriguez-Lonebear, & Martinez, 2019):

> Data for Governance refers to the data needed to make evidence-based decisions and develop responsive and proactive policies by considering data's accessibility, accuracy, relevancy, and timeliness. Indigenous nations considering data for governance must be strategic by asking themselves what data they want to govern.

Governance of Data refers to the management of data including the policies and procedures put in place to protect and control data. These policies and procedures extend beyond the data a nation holds, to the data repositories held by other nations and organizations. Therefore, data managers possess the power to inform how other agencies, governments, institutions engage with an Indigenous nation's data.

INDIGENOUS NATION RE-BUILDING THROUGH INDIGENOUS DATA SOVEREIGNTY

Globally, Indigenous nations are undergoing nation re-building processes based on their interactions and relationships within settler colonialism (Carroll, Rodriguez-Lonebear, & Martinez, 2019; Rowe, 2023). Data plays a significant role in the ability for Indigenous nations to make strategic decisions throughout their nation re-building processes, including through aspiration and big picture planning (Indigenous Data Sovereignty) and short term policy and law considerations (Indigenous Data Governance).

Within the context of Canada, Drake & Gaudry (2016) suggest that Métis rights are often 10 to 15 years behind First Nations. In the case of data sovereignty and governance one could assert that the Métis are over 25 years behind due to a historic lack of recognition as a distinct people and jurisdictional ambiguity between federal and provincial responsibility to the Métis. This means that the Métis are often lacking both data for governance and governance of data (Andersen, 2014, Tait & Henry, 2023). As Métis continue to gain recognition and therefore self-determination, there is a need for strategic planning that ensures proportional capability and capacity building towards a robust and Métis distinct data strategy.

Population level data, such as census data, is often described as a critical component of effective nation building. Census data provides nations with in-depth knowledge about a nation's collective characteristics is vital in informing government decisions (Statistics Canada, 2021). Other administrative data collected via voting, citizenship registries, taxes, and service access can be used equally if not hold more power and accuracy for Indigenous governments (Carroll, Rodriguez-Lonebear, & Martinez, 2019). However, it requires the establishment of strategic linkages with other governmental bodies or agencies who currently hold the data (Tait & Henry, 2023). Recognition from federal and provincial governments has been the forefront of Métis political agendas. As recognition begins to be reached, focus needs to be directed to the establishment of strategic data linkages between healthcare systems and agencies with citizenship registries. As with other Indigenous nations, Métis governments recognize that data is the currency of the future. In the interest of Métis nation re-building, data can no longer be an afterthought, and must be embedded in future strategic planning.

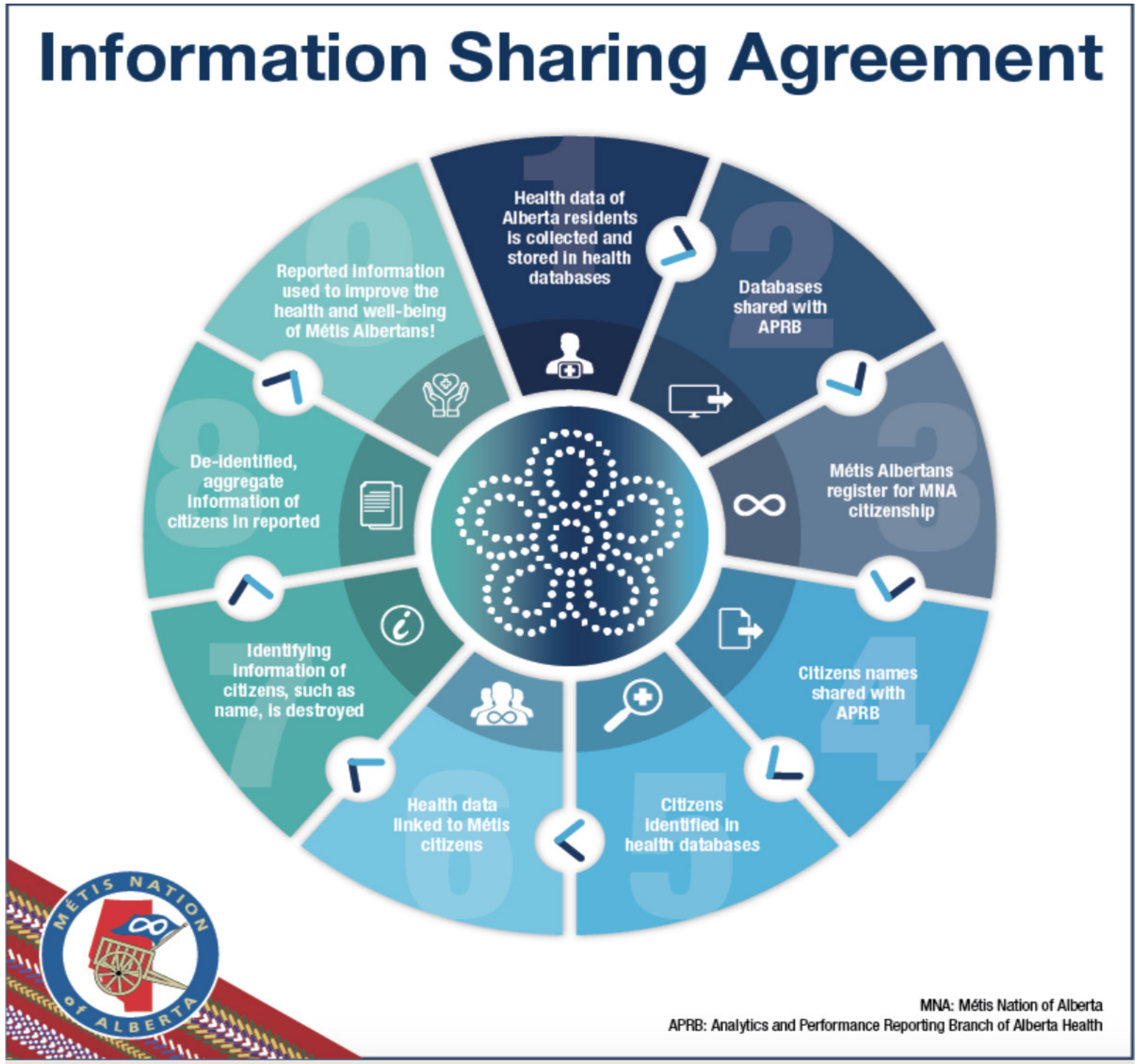
The COVID-19 pandemic has provided a notable example of the importance of data for the purpose of decision making in health contexts. During the early months of the pandemic, nearly every person's life in Canada became dependent on daily updates that included case numbers, deaths, and hospitalizations rates. These numbers determined public policy in real time, such as the number of people permitted to sit in a particular room and who was eligible for limited vaccines (Keshteli et al., 2021). These are but two examples of data for governance. During the pandemic the First Nations and Inuit Health Branch (FNIHB) was responsible for reporting on the COVID-19 status for FNIM Peoples in Canada. However, because Métis are not a priority under FNIHB, they were not captured by Indigenous Services Canada (Hahmann & Kumar, 2022; Richmond, Castleden, & Gabel, 2020). With the absence of data linkages to health authorities, Métis governments were making critical decisions pertaining to the health of their citizens without accurate data. Data about Métis individuals was being collected within federal and provincial data sets; however, there was no marker to separate Métis as a people which rendered them invisible within the data. This demonstrates the respective Métis Nations' inability to govern their data.

BARRIERS FOR INDIGENOUS NATIONS TO INDIGENOUS DATA GOVERNANCE

While control of data is often cited as the primary barrier to Indigenous data governance other considerations such as the capability to build capacity equally contribute (Ruckstuhl, 2022) . For example, limitations pertaining to sustainable funding models and infrastructure also serve as barriers for Indigenous nations (Ruckstuhl, 2022). This is heightened with data security, as protocols are constantly being updated that require new expertise, expensive technology and software to ensure data safety. While data security drives these conversations forward they give little space for the authority of Indigenous nations to manage, protect and control their data that aligns with their collective rights and values. Beyond this there can also be conflicts between Indigenous Peoples collective and individual rights pertaining to data.

HEALTH-SPECIFIC CONSIDERATIONS

Figure 2: The MNA and Alberta Health's Information Sharing Agreement process



MNA: Métis Nation of Alberta
APRB: Analytics and Performance Reporting Branch of Alberta Health

The concept of Indigenous data sovereignty is closely related to concepts of self-determination and intergenerational health and wellbeing (Cormack, Reid, Kukutai, 2019, Kukutai, 2023). Healthcare broadly has moved towards implementing a social determinants of health framework which acknowledges the existence of health inequities. However, implementing a SDOH framework is not enough to address inequities, as high quality and rigorously designed data collection is needed to collect accurate data fill these gaps (Wright et al., 2022). However, Indigenous health data is often interpreted broadly, perpetuating stereotypes rooted in ethnicity. This is problematic for two reasons 1) ethnicity and race have been rejected as a biological determinant of health (Wright et al. 2022) and 2) Indigenous citizenship/membership is not synonymous with race or ethnicity (Cormack, Reid, & Kukutai, 2019). From a solely genetic perspective, this creates the perception that being Indigenous is synonymous with being "unhealthy" (ie. the creation of the thrifty gene theory) rather than contextualizing Indigenous health within broader systems of oppression such as colonialism and white supremacy (Trudgett, Griffiths, Farnbach, & Shakeshaft, 2022; Hyett, Gabel, Marjerrison, & Schwartz, 2019). This further establishes the need for Indigenous nations across the globe to protect Indigenous data from misuse through data sovereignty principles (Trudgett, Griffiths, Farnbach, & Shakeshaft, 2022).

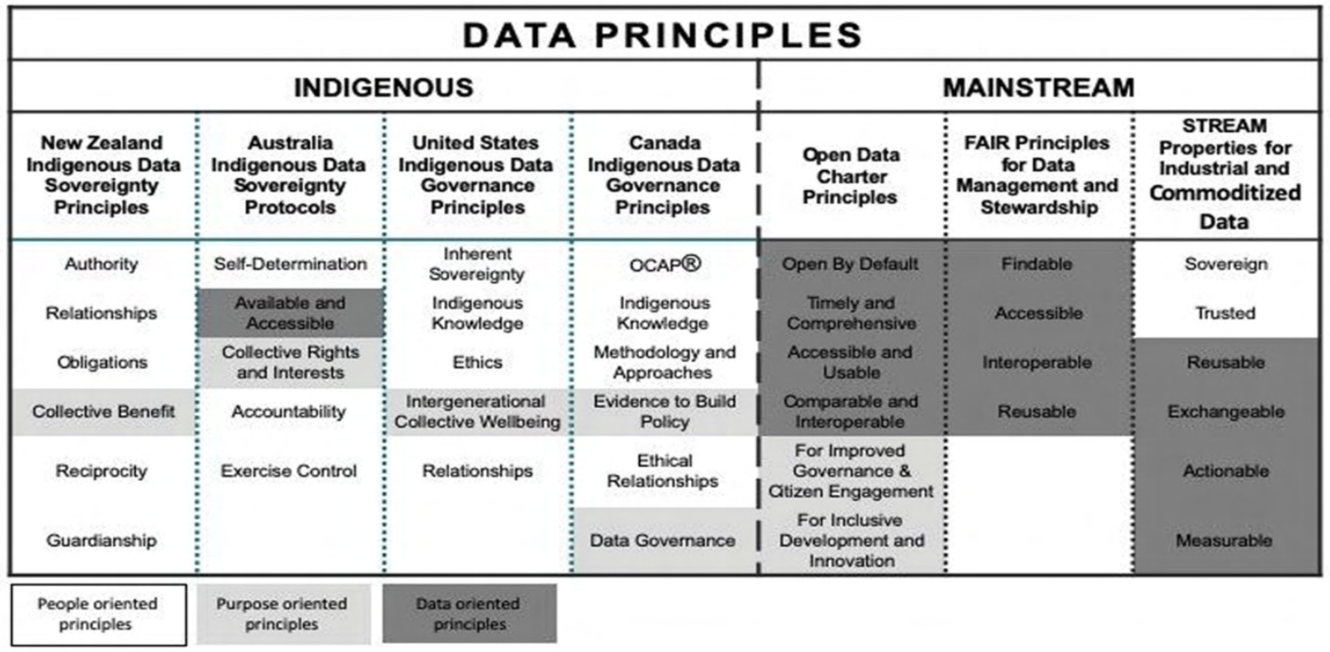
Historically, epidemiological data has been collected and utilized in ways that directly violate Indigenous peoples/nations rights and interests (Caroll et al., 2022; Boyer et al., 2007; Shaw et al., 2013; Trinidad et al., 2015; Haring et al., 2018; Chadwick et al., 2019; Dirks et al., 2019). Misuse of data continues to be perpetuated under the auspices of big data where disaggregated epidemiologicaldata can be accessed by researchers worldwide (National Collaborating Centre for Indigenous Health, 2021). In the Canadian context, federal and provincial governments and their corresponding health authorities that host health data (genetic and biomedical data in particular) continue to subject Métis to data dependency by 1) not aggregating data beyond "Indigenous" or "Aboriginal" markers and, 2) not implementing comprehensive verification processes that are separate from self-identification (Tait & Henry, 2023). Identity verification processes are particularly important for the Métis, due to the pervasive volume of identity fraud through race shifting which often renders Métis dataset as inaccurate.

In 2010 the Métis Nation of Alberta (MNA) and Alberta Health signed an Information Sharing Agreement which allowed for MNA to gain a greater understanding of their citizen's health and wellbeing (MNA, n.d.). This process uses citizenship verification rather than self-identification providing MNA with anonymous data that then can be used in a program and services development.

FROM F.A.I.R. TO C.A.R.E. PRINCIPLES

The Fair Guiding Principles for scientific data management and stewardship were published in 2016 in an attempt to improve the findability, accessibility, interoperability and reuse of digital data. (Go Fair, nd). The principles argue that data should be easy to find and access for both humans and computers, especially as data sets become larger and more complex, and that data should be integrated with other data so that it can be reused/replicated. While the big data movement supports these principles as a way to build capacity for large data sets to support innovation, discovery and decision-making, they have been critiqued by Indigenous scholars who point to the limitations of exercising their rights to control and access their data within this framework (Carroll et al., 2021).

Born out of response to the F.A.I.R. principles, the C.A.R.E. principles reflect the crucial role of data in advancing Indigenous innovation and self-determination through collective benefit, authority to control, responsibility and ethics. The C.A.R.E. principles highlight the importance of recognizing Indigenous rights to data as well as the power differentials and historical contexts that Indigenous people are subjected to, which limits Indigenous peoples ability to control and access their data within big data, open data and open science environments (Carroll et al., 2021). This is especially true in the context of genetic research, where Indigenous peoples have been unethically exploited throughout the data collection process (Caroll et al., 2022a; Caroll et al., 2022b). Therefore, the C.A.R.E. Principles are designed to complement the existing F.A.I.R. principles by encouraging open data movements to consider the people and purpose in their advocacy and pursuits (Global Indigenous Data Alliance, n.d.; Global Indigenous Data Alliance, 2019). This includes creating data ecosystems that are designed to function in ways that enable Indigenous People to derive benefit from data, including for improved governance and citizen engagement, as well as equitable outcomes.



DATA PRINCIPLES

INDIGENOUS				MAINSTREAM		
New Zealand Indigenous Data Sovereignty Principles	Australia Indigenous Data Sovereignty Protocols	United States Indigenous Data Governance Principles	Canada Indigenous Data Governance Principles	Open Data Charter Principles	FAIR Principles for Data Management and Stewardship	STREAM Properties for Industrial and Commoditized Data
Authority	Self-Determination	Inherent Sovereignty	OCAP®	Open By Default	Findable	Sovereign
Relationships	Available and Accessible	Indigenous Knowledge	Indigenous Knowledge	Timely and Comprehensive	Accessible	Trusted
Obligations	Collective Rights and Interests	Ethics	Methodology and Approaches	Accessible and Usable	Interoperable	Reusable
Collective Benefit	Accountability	Intergenerational Collective Wellbeing	Evidence to Build Policy	Comparable and Interoperable	Reusable	Exchangeable
Reciprocity	Exercise Control	Relationships	Ethical Relationships	For Improved Governance & Citizen Engagement		Actionable
Guardianship			Data Governance	For Inclusive Development and Innovation		Measurable

People oriented principles | Purpose oriented principles | Data oriented principles

Figure 3

Indigenous and Mainstream Data Principles, and Orientation toward Data, People, and Purpose.

CONTENTIONS BETWEEN OPEN DATA AND INDIGENOUS DATA SOVEREIGNTY

Open data is defined as "data" that can be freely used and shared by anyone for any purpose, under strict principles of privacy and confidentiality, when appropriate" (D'Agostino et al., 2018). The open data movement is often framed as a means to promote innovation, support evidence-based research, increase accountability, and streamline the development of consumer and commercial products (Government of Canada, 2022). The emergence of machine learning and Artificial Intelligence (AI) rely on open and accessible data (Russo Caroll et al., 2020). Advancements in open data and AI have created opportunities for Indigenous peoples to preserve the past (UNESCO, 2023) in addition to creating potential to predict future trends which has built capacity for informed decision making for nations and communities (Gurevich, El Hassean, and El Morr, 2023). Despite these technological advancements and their potential, Indigenous peoples must also consider the potential for the misuse of Indigenous knowledge, and data within these contexts (UNESCO, 2023; Carroll, Rodeiguez-Lonebear, & Martinez, 2019). The power of machine learning and AI can serve as a powerful resource, but also carry the potential to violate Indigenous data sovereignty and perpetuate inequities across the research environment (Gurevich, El Hassean, & El Morr, 2023, Rainie et al., 2019, UNESCO, 2023).

Furthermore, Indigenous peoples and Nations need to be cognizant that by not being included in large datasets, such as genomics metadata, they may be rendered "invisible and may not realize the benefits of emerging health technologies and advances" (Carroll, Rodeiguez-Lonebear, & Martinez, 2019, p.8).

Within health systems, AI and machine learning have already shown to improve patient health outcomes (Gurevich, El Hassean, & El Morr, 2023). There is evidence that AI may also be particularly helpful in optimizing rural and remote healthcare delivery See Case Study (MacKay, 2023) where many Métis citizens continue to reside. While AI can streamline access to health care services, Indigenous peoples need to be cautious as poorly collected data or inaccurate data used in these algorithms has the potential to replicate and perpetuate health inequities (Gurevich, El Hassean, El Morr, 2023). In the case of the Métis, these considerations are particularly critical; as there is a current gap pertaining to Métis-specific health research and grave concerns about the accuracy of data due to limitations in population level (i.e. census) data, and data linkages with healthcare systems and authorities (Gmitroski, Hastings, Lagualt, & Barbic, 2023).

CASE STUDY: DRUMBEAT.AI

Currently, AI is being used by Aboriginal and Torres Strait Islander people in rural and remote areas in Australia with children who have hearing and speech impairments to streamline diagnosis. Ear disease diagnosis usually requires the expertise of an Ear Nose and Throat (ENT) specialist, however there is limited access to ENTs in rural and remote communities. In response to this need, an app called DrumBeat.ai was created which uses a special algorithm based on previous ear scans to help the health care aides in the community determine the severity of a patient's disease and if a referral is required without the help of a specialist.

RESEARCH ETHICS PROTOCOLS AND BOARDS

Research ethics are general principles that guide the conduct of research projects. They are both the inherent principles that individual researchers carry that guide their ethical conduct, and also the external ethical values, processes and procedures that are pre-determined by different institutions, communities and organizations with stakes in research processes. Stakeholders can have competing interests in the research, especially in the context of Indigenous research as ethics protocols often prioritizes the institution and researcher over the community and participants. All universities in Canada are governed by a research ethics board (REB) that ensures compliance to internal institutional ethics protocols. Some universities may have multiple REBs that correspond to different departments or faculties. Other organizations and communities outside the university also host REBs including some FNIM communities, nations and organizations who have begun to develop their own research ethics frameworks that researchers must comply with if they want to engage in a collaborative relationship (Hayward, Sjoblom & Cidro, 2021). For example, the Manitoulin Anishinaabek Research Review Committee (MARRC) is one of the longest standing Indigenous Research Ethics Boards in the country. Other federal government agencies such as Health Canada, the Public Health Agency of Canada which also fund health care systems and health related research in Canada, have collectively operated an REB since 2010. According to the Inuit Tapiriit Kanatami (2018) a comprehensive list of operating REBs in Canada does not exist (p. 24).

Indigenous nations around the world and FNIM communities and nations in Canada are beginning to demand control over research pertaining to their communities and lands amongst an industry that has historically been dominated by non-FNIM people conducting research on, with, or on behalf of FNIM communities and nations. Research ethics boards have a responsibility to engage with FNIM peoples/nations about their respective data governance principles and protocols, specifically the movement away from mere “consultation” with FNIM people on projects to control of research agendas, data and outcomes. The following section is intended to highlight the various research ethics processes that currently oversee and inform institutional research within Canada.

UNIVERSITY ETHICS

The Tri-agencies which include the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC), are federal government agencies responsible for the management of public funds that support Canada’s research environment (Government of Canada, 2023). In 2001, the Tri-Agencies were brought together to strike the Interagency Advisory Panel on Research Ethics, whose mandate is to ensure that research using federal funds that is conducted with human participants remains ethical (Government of Canada, 2023). The Panel’s primary responsibility was the development, interpretation and implementation of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2) (Government of Canada, 2023). In 2010, Chapter 9 titled Research Involving the First Nations, Inuit and Métis Peoples of Canada was added to the TCPS 2, and has become the standard ethics protocol for research involving FNIM peoples within the Canadian research environment.

Predating the TCPS 2 Chapter 9 is CIHR’s Guidelines for Health Research Involving Aboriginal People which were developed in 2007 in collaboration with the Institutes of Aboriginal Peoples’ Health (now referred to as the Institute of Indigenous Peoples Health) to ensure research was aligned with Indigenous values and traditions to facilitate mutually beneficial and culturally competent research (Government of Canada, nd). Researchers who accessed funding through CIHR for projects involving FNIM people were required to follow the principles to receive their funding in addition to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2). The Guidelines include 15 articles which governed FNIM research conducted through CIHR until 2010 when Chapter 9 was added. CIHR’s Guidelines for Health Research Involving Aboriginal People still exist as a resource, and SSHRC and NSERC have since developed their own program guidelines for research involving FNIM people. Currently, Chapter 9 is being updated as it has not had a substantive revision since 2010 (Secretariat on Responsible Conduct of Research, 2024). As the Chapter is mainly focused on guidance for researchers engaging with Indigenous Peoples, the revision aims to include guidelines for REBs and institutions (Secretariat on Responsible Conduct of Research, 2024)

While all of these protocols have involved FNIM peoples in their development, many FNIM nations and communities have become critical of them and are working towards implementing their own community-based ethics protocols and frameworks. TCPS 2 in particular is limited despite the existence of Chapter 9, and arguably functions primarily as a tool for non-indigenous peoples to utilize when they want to conduct research involving FNIM people. Further, Chapter 9 is marketed as being applicable to research with “other distinct communities” (p. 108) which contradicts its distinctness as responsive to FNIM research needs.

Similarly, many REBs integrate safety measures to promote ethical research conducted with FNIM participants, however there are several limitations to their application. ITK (2018) has outlined several limitations and conflicts to both the TCPS2 and REBs generally in their National Inuit Research Strategy. They include:

1. The existence of REBs does not ensure actual compliance with the TCPS 2, as ethics applications occur prior to research being conducted. This puts the researcher’s level of compliance with TCPS2 primarily in the hands of the participants as they are responsible for reporting unethical conduct to the REB (Tait and Henry, 2023).

2. TCPS 2 was created specifically for institutions that receive federal funding from the Tri-Agencies.

3. The institution hosting the REB often has a vested financial, political and social interest in the research project.

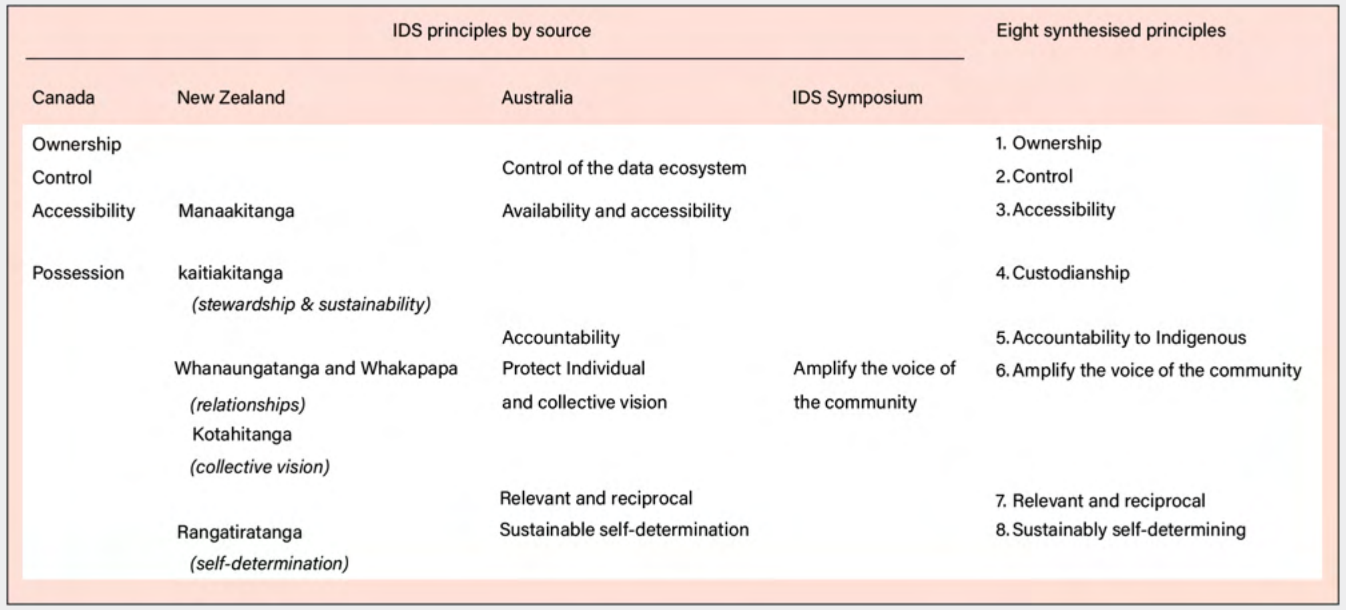
4. Members of the REB might be colleagues of the applicant imposing bias instead of protecting collective FNIM rights.

5. There is a general underrepresentation of FNIM people on REBs which impedes a nuanced consideration of each group’s distinct research realities and needs in the reviewal process.

INTERNATIONAL INDIGENOUS DATA SOVEREIGNTY PRINCIPLES

Similar to FNIM groups in Canada, international Indigenous communities experience inequities and barriers to data governance. Indigenous Data Sovereignty (IDS) networks exist within Canada, Australia, New Zealand and the United States (known collectively as the CANZUS countries) (U.S Indigenous Data Sovereignty Network, nd). Most Indigenous nations within the CANZUS countries have published their own data charters, principles or guidelines which are shaped by their unique relationships to the settler colonial governments. Andersen, Walter, Kukutai, and Gabel (2025, Forthcoming) summarizes common features that the CANZUS IDS networks all share. They include 1) a focus on self-determination and intergenerational wellbeing, 2) recognizing data as a valued cultural resource, 3) an emphasis on collective data rights and 4) prioritizing Indigenous values as the basis for good data governance.

Similarly, a systematic literature review by Trudgett et al. (2022) identified characteristics of Indigenous Data Sovereignty principles across Canada, Australia and New Zealand. The similarities were summarized into eight principles including 1) ownership, 2) control, 3) accessibility, 4) custodianship, 5) Accountability to Indigenous communities, 6) Amplify the voice of the community, 7) relevant and reciprocal, and 8) sustainability self-determining.



IDS principles by source				Eight synthesised principles
Canada	New Zealand	Australia	IDS Symposium	
Ownership				1. Ownership
Control		Control of the data ecosystem		2. Control
Accessibility	Manaakitanga	Availability and accessibility		3. Accessibility
Possession	kaitiakitanga *(stewardship & sustainability)*			4. Custodianship
		Accountability		5. Accountability to Indigenous
	Whanaungatanga and Whakapapa *(relationships)* Kotahitanga *(collective vision)*	Protect Individual and collective vision	Amplify the voice of the community	6. Amplify the voice of the community
		Relevant and reciprocal		7. Relevant and reciprocal
	Rangatiratanga *(self-determination)*	Sustainable self-determination		8. Sustainably self-determining

Figure 4 Synthesis of eight Indigenous Data Sovereignty (IDS) principles from Canada, New Zealand, Australia and the 2017 IDS Symposium Table from: Trudgett, S., Griffiths, K., Farnbach, S., & Shakeshaft, A. (2022). A framework for operationalising Aboriginal and Torres Strait Islander data sovereignty in Australia: Results of a systematic literature review of published studies. EClinicalMedicine, 45, 101302–101302. https://doi.org/10.1016/j.eclinm.2022.101302

While the IDS networks share similar principles as described by Trudgett et al. (2022) and Andersen, Walter, Kukutai, and Gabel (2025, Forthcoming), it is also important to note their diversity, specifically how they have been informed by their local contexts and knowledge. The following sections provide an overview of the IDS principles that have emerged from Aerotera, Australia, and the United States.

AOTEAROA/NEW ZEALAND

Similar to Métis in Canada, Maori in Aotearoa disproportionately contribute to public sector and government data sets but do not receive the full benefits of the data, especially as it pertains to constructing their own narratives and answering their own questions (Kukutai et al., 2023a). In 2020, Maori data experts developed a Maori Data Governance model for use across the Aotearoa public service in partnership with Data Iwi Leaders Group (Data ILG) a data advocacy body for 80 tribes involved in the National Iwi Chairs Forum, and Stats NZ. The Model sets clear expectations for the system-wide governance of Maori data held by public service agencies and provides direction on the actions, process and activities that are needed to meet Maori data goals (Kukutai et al, 2023a).

The model is guided by five overarching values including nurture data as a taonga, put iwi-Maori data in iwi-Maori hands, use data for good, decolonize data ecosystems, and be accountable.

The model is also composed of eight data governance pillars which represent priority areas of data governance that organizations can implement practically Andersen, Walter, Kukutai, and Gabel (2025, Forthcoming).

1. Data capacities and workforce development
2. Data infrastructure
3. Data collection
4. Data protection
5. Data access, sharing and repatriation
6. Data use and reuse
7. Data quality and system integration
8. Data classification

The report highlights the strategic partnerships that have been facilitated to leverage specific outcomes from the Maori Data Governance Model. For example, the partnership with Stats NZ was created to ensure proper implementation of the model, unlike other models, frameworks and strategies that have been created and subsequently shelved as a result of the implementation gap Andersen, Walter, Kukutai, & Gabel (2025, Forthcoming).

AUSTRALIA

In 2018 the Maiam nayri Wingara Indigenous Data Sovereignty Collective and the Australian Indigenous Governance Institute came together to develop a set of Australian Indigenous Data Governance Protocols at an Data Sovereignty Summit in Canberra (Maiam nayri Wingara, 2018). Through the Summit the participants developed a set of Indigenous Sovereignty Principles. The principles assert that in Australia, Indigenous peoples have the right to:

1. Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.
2. Data that are contextual and disaggregated (available and accessible at individual, community and First Nations levels).
3. Data that are relevant and empowers sustainable self-determination and effective self-governance.
4. Data structures that are accountable to Indigenous peoples and First Nations.
5. Data that are protective and respects our individual and collective interests.

The communique that was developed from the summit also describes that enacting Indigenous Data Governance requires Indigenous leaders, practitioners and community members with the skills and infrastructure to advocate and participate across all sectors and jurisdictions. Indigenous communities retain the right to decide which sets of data require active governance and maintain the right to not participate in data processes inconsistent with the principles (Maiam nayri Wingara, 2018).

Trudget et al. (2022) build off of the principles that emerged from the Data Sovereignty Summit through a systematic literature review of published studies in Australia that discuss Indigenous Data Sovereignty Principles. Their search resulted in 34 articles of which the authors summarized six principles that emerged across the literature. They include: 1) control of the data ecosystem, 2) availability and accessibility, 3) accountability, 4) protect individual and collective vision, 5) relevant and reciprocal, and 6) sustainable self-determination.

Previous to the development of these principles, other protocols have been utilized across the Australian research environment to connect Indigenous peoples to their data. For example, the Aboriginal and Torres Strait Islander Data Archive (ATSIDA) was created as a specialist section of the Australian Data Archive to manage the collection and storage of Australia Indigenous data (Gardiner & Thorpe, 2014). The main goal of the ATSIDA is to connect Indigenous communities with research data that they have been historically dislocated from, particularly data pertaining to language, culture and heritage, through digital repatriation (Gardiner & Thorpe, 2014).

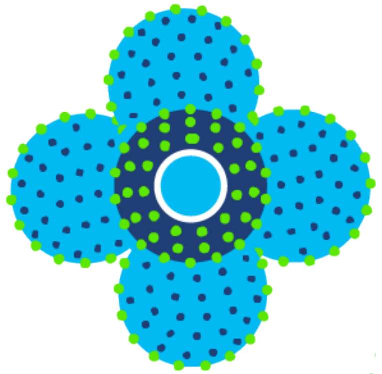
The ATSIDA Protocols are guided by three overarching principles to assist best practice in managing the data archive. They include 1) respect, 2) trust and 3) engagement (ATSIDA, nd). The archive and protocol creation was overseen by the ATSIDA Reference Group which was composed of "internationally recognized experts" in Australian Indigenous Research. Namely, representatives from library, archive museum, government and higher education sectors (Gardiner & Thorpe, 2014, p. 106). It is unclear if this group included Australian Indigenous Peoples, despite its main goal being to build relationships with Indigenous communities, researchers and curatorial institutions.

THE UNITED STATES

The Indigenous Data Sovereignty Network in the United States includes federally, state, un-recognized tribes, and peoples of Hawaii, Guam, Puerto Rico, northern Mariana Islands, American Samoa, and US Virgin Islands (U.S. Indigenous Data Sovereignty Network, n.d.). This April they are convening in Arizona to begin preliminary conversations around appropriate data governance structures that support Indigenous peoples data sovereignty initiatives as no national policies currently exist that address the data rights and needs of Indigenous Peoples in the U.S (U.S. Indigenous Data Sovereignty Network, n.d.). Specifically they want to 1) establish a national standard in the U.S. for Indigenous Data Governance, 2) create an Indigenous data standard via nation-to-nation partnerships between Indigenous peoples and the American federal government and 3) enhance Indigenous Peoples laws, policies and systems for Indigenous data sovereignty (U.S. Indigenous Data Sovereignty Network, n.d.).

Despite not having national policies on data governance, many tribes across the United States have successfully adapted data governance mechanisms to protect data, specifically as it pertains to health and wellness data (Carroll et al, 2019). For example, the Navajo Nation has been able to control data collection in their community through the establishment of a Navajo Nation Human Research Ethics Board (NNHRRB). This Board regulates, monitors and controls research with the Nation since 1996. All projects that are conducted with NNHRRB approval must turn their data over to the Nation at the conclusión of their project (Caroll et al, 2019).

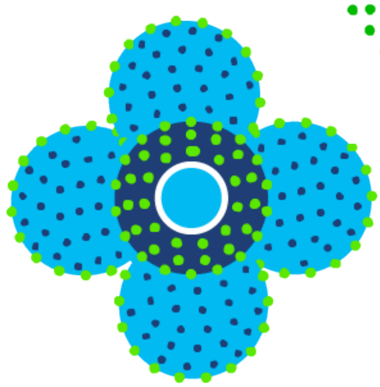
In 1996 the United States Congress authorized four tribal epidemiology centers (TEC) under the Indian Health Care Improvement Act (IHCIA) (TEC, n.d.a). Currently there are 12 tribal epidemiology centers across the United States. The TEC aims to improve American Indians and Alaskan Natives (AIAN) health by "identifying health risks, strengthening public health capacity, and developing solutions for disease prevention and control" (TEC, n.d.b). The TECs are funded by the Centres for Disease Control and Prevention, Indian Health Service, and the National Institutes of Health. The TEC provide technical assistance and evaluation of current service delivery, and support with data collection analysis for Indian Tribes and Tribal organizations (TEC, n.d.a). One of the 12 TECs is the Urban Indian Health Institute (UIHI). Though the UIHI focused on urban AIAN populations during the COVID-19 pandemic they noticed a significant deficit in AIAN data collection (UIHI, n.d.). Like the Métis in Canada, the lack of accurate data collected during the pandemic limited the ability of governmental bodies to make data-driven decisions. The UIHI termed this phenomenon as "data genocide." The UIHI provided six recommendations on the importances of collecting disaggregated data, the standardization of collection and reporting for greater consistency across jurisdictions, and reformation of the public health surveillance system (UHIH, 2021). This case study is an important example of the need for prophylactic data infrastructure upheld by strong data principles and governance for informed decision making regarding health.



FNIM DATA SOVEREIGNTY AND DATA GOVERNANCE

In 1996 the Royal Commission on Aboriginal Peoples (RCAP) published their report which stated the need for First Nations, Inuit and Métis (FNIM) peoples to govern their own data. It recommended that a working group of FNIM peoples be established to 1) collaborate with Indigenous governments and organizations to establish and update statistical databases and 2) promote data governance strategies across nations and communities for collecting and analyzing data. This RCAP recommendation was the catalyst for Indigenous data governance protocols that are now widely known and utilized across Canada. RCAP also normalized the categorization of FNIM peoples into "Aboriginal" and later "Indigenous" groups more broadly which has had detrimental effects to the specific representation of FNIM people in data sets as distinct experiences are rendered insignificant.

Overtime data governance principles have become more structured and specific to community specific research agendas. This is especially true today as Indigenous nations are calling for distinctions based research, specifically distinctions based health research. In response to this push, a number of nation-specific data governance protocols have emerged that are centered in localized knowledge and research priorities/concern. In addition to nation specific protocols, other bodies that are responsible for the governance of health data such as the Canadian Institute for Health Information (CIHI) are beginning to develop strategies with FNIM Peoples and nations to support their health, wellness and data priorities. Such strategies recognize that "data and information about health and wellness are critical tools for self-determination." (CIHI, 2024). The following section describes the work that FNIM nations in Canada have undertaken towards research strategies and distinct data governance protocols.



FIRST NATIONS CONTEXT

Following the release of the RCAP report, the Assembly of First Nations formed a National Steering Committee (NSC) to develop and pilot a First Nations Health Survey which would collect data using both western biomedical and traditional understandings of health and wellbeing (FNIGC, nd). In addition to building capacity to undertake the survey the NSC, which has gone through several iterations, first as the First Nations Governance Information Committee, and now as a registered non-profit, the First Nations Information Governance Centre (FNIGC), developed the First Nations Principles of OCAP. The OCAP Principles, which stand for ownership, control, access and possession, are a tool that support and promote First Nations data sovereignty by asserting that First Nations should have control over data collection processes, including the protection and sharing of data (FNIGC, nd). They have been trademarked to ensure they are only utilized for First Nations data, however they have been adopted nationally and internationally. Ownership states that a community or group owns data in the same way that an individual owns their personal information. Control affirms that First Nations, their communities and/or representative bodies are within their rights to seek control over all aspects of research at any point in time in the research process. Access refers to the fact that First Nations should have the ability to access information about their communities regardless of where it is stored or held. Lastly, possession refers to the physical control and stewardship of First Nations data (FNIGC, nd).

In 2015 the First Nations Information Governance Centre launched The Fundamentals of OCAP, a training dedicated to understanding and implementing the principles in research settings. While the principles are designed for and from a First Nations perspective, they have been widely used by Indigenous and non-indigenous researchers and organizations as a "one size fits all" approach to FNIM data governance, especially since the release of the OCAP training (FNIGC, nd). As the field of Indigenous health research moves towards distinctions-based approaches that respect and draw attention to the diversity amongst FNIM communities, localized and tailored approaches to data governance are necessary to adequately capture First Nations, Inuit and Métis data respectively.

In addition to creating the principles of OCAP, the FNIGC has continued to undertake First Nations health surveys to develop a working repository of First Nations health data. The original survey that was piloted following the RCAP recommendations would also come to involve Inuit leadership to collect Inuit-specific data, and was published as the First Nations Inuit Regional Longitudinal Health Survey. Métis governments were not involved in this survey. Following the initial survey, the FNIGC continued to undertake and publish surveys separate from Inuit, including a First Nations Oral Health Survey (FNIGC, nd). In 2011, after a feasibility study the FNIGC decided to forego the longitudinal survey method in favour of a cross-sectional method to capture specific moments in time. From this point forward the survey was referred to as the First Nations Regional Health Survey. Since this decision the FNIGC has undertaken a First Nations Regional Early Childhood, Education, and Employment Survey, for which a report detailing the findings was published in 2016, and a First Nations Labour and Employment Development Survey of which data collection began in 2018. In addition to larger initiatives FNIGC also created the infrastructure for independent First Nations to create the infrastructure to collect and house their own data which has been a critical aspect of nation building.

FNIGC has been able to leverage significant support from the federal government for their approach to and operationalization of their data collection and governance strategy. In 2018, the federal government allocated $2.5 million over three years to support the FNIGC's design of a national data governance strategy, including efforts to establish regional data governance centres. In 2019, Canada permanently committed to funding the Regional Health Surveys, and FNIGC was promised $78.9 million over seven years. The 2021 federal budget proposes to invest $73.5 million over three years to work towards the development of a First Nations Data Governance Strategy.

INUIT CONTEXT

Since 1996 Inuit have also published several resources for both community members and researchers that support the development of Inuit self-determined research relationships. Although the documents are not designed at specific data governance protocols, they capture Inuit concerns surrounding data governance and provide recommendations towards an Inuit protocol.

The Nunavut Research Institute and the Inuit Tapiriit Kanatami (ITK) released their first resource in 1998 entitled Negotiating Research Relationships: A Guide for Communities. This guide was designed for Inuit in communities across Nunatsiavut (Labrador), Nunavik (northern Québec), Nunavut, and the Inuvialuit Settlement Region of the Northwest Territories (NWT) to understand their rights and responsibilities in negotiating relationships with researchers. It calls for Inuit to be involved in developing research agendas, plans, and tools, as well as the collection, interpretation, analysis and reporting of results to ensure relevance to the community(s) where research is being conducted. While this guide is not designed specifically as a data governance protocol it does reference the ethical storage and maintenance of data. The guide informs community members that they are entitled to a clear understanding and agreement over the control, storage, access and release of data. At the time, the document outlined that research in Inuit communities must be conducted according to the principles of OCAP (Inuit Tapiriit Kanatami, 1998).

In 2006 the Nunavut Research Institute and ITK released a follow up to the 1998 guide entitled Negotiating Research Relationships with Inuit Communities: A Guide for Researchers. This guide builds on the previous by further describing localized concerns about research in the north and calling on researchers to ethically engage and collaborate with Inuit. Listed at the top of the document are concerns that Inuit have about research. Of relevance to data governance, Inuit were concerned about their involvement in the research process, and lack of local data ownership. The guide describes that information is often “placed in a database in a southern institution and communities find themselves unable to gain access, or having to pay for data that they provided " (Inuit Tapiriit Kanatami, 2006, p. 4). The resource also emphasizes the need for informed consent for community members including the importance of communicating to participants about where their data will end up, how it will be used and how they can access it.

Most recently ITK released its National Inuit Strategy on Research (2018) which, similar to the previous guides, calls to have Inuit at the forefront of research agendas, but this time in a concrete strategy with actionable items to address the high number of non-Inuit researchers conducting work in the North. The report outlines five priority areas that ITK has committed to which include 1) Advance Inuit governance in research; 2) Enhance the ethical conduct of research; 3) Align funding with Inuit research priorities; 4) Ensure Inuit access, ownership, and control over data and information; and 5) Build capacity in Inuit Nunangat Research. Unlike the previous guidelines, this report does not call on researchers to implement the First Nations Principles of OCAP, but does reference that Inuit partnership in the governance of Inuit Nunangat research is necessary to broker Inuit access, ownership, and control over Inuit Nunangat data and information.

Distinctly highlighted in this strategy is the need for technology in the north that can build capacity for Inuit stewardship of data. There is a distinct “digital divide” between Inuit Nunangat and southern Canada when it comes to accessing or engaging with research (Inuit Tapiriit Kanatami, 2018, p 27). The authors describe that despite seeking access to data, Inuit do not always have the ability to access it because their institutions cannot afford the technology required to host expensive search engines and platforms where universities and governments house their data (Inuit Tapiriit Kanatami, 2018, p 21). Therefore, ITK highlights the need to improve methods of housing and sharing data in ways that Inuit communities would like to receive it.

Where the ITK’s approach to data stewardship differs significantly from First Nations and Métis approaches is within their inclusion of animals and land in their research strategy. This is primarily due to the fact that 1) Inuit have seen more researchers in the north interested in traditional ecological knowledge since their land claims agreements and, 2) there are specific licensing considerations for research in the arctic.
In 2022 the Government of Canada committed $6.4 million to establish an Inuit Research Network. This funding invests in the four Inuit regions and their respective land claims organizations, Inuvialuit Regional Corporation, Nunavut Tunngavik Incorporated, Makivik Corporation and the Nunatsiavut Government, to guide research that strengthens Inuit health.

MÉTIS CONTEXT

The first Métis specific research engagement guide, the Principles of Métis Ethical Research, was developed by the Métis Centre of the now defunded National Aboriginal Health Organization (NAHO) in 2010 during a Think Tank with Métis researchers, students and organizations. The principles were designed for internal use at the Métis Centre, but were also designed to be utilized by researchers engaging in research with Métis communities. The six principles that were created are: 1) Reciprocal Relationships, 2) “Respect For”, 3) Safe and Inclusive Environments, 4) Diversity, 5) “Research Should”, and 6) Métis Context. The principles are quite surface level, and primarily focus on Métis research contexts including identity and diversity across Métis communities. There is no reference to data governance in this document.

Following the establishment of the NAHO Principles, the Manitoba Métis Federation (MMF) collaborated on an ethical research engagement framework with the University of Manitoba in 2013 for their Framework for Engagement with First Nations, Métis and Inuit Peoples. This document was led by a group of FNIM and allied health professionals and scholars in response to TCPS 2 Chapter 9 which calls for researchers to adopt collaborative approaches with FNIM communities in research as a way to clarify expectations and provide guidance for developing research relationships. Encapsulated in the framework are a set of broad principles that are meant to apply to collaboration across all FNIM research, as well as specific engagement processes for each group. MMF’s engagement process adheres to a set of health specific principles called OCAS which stands for ownership, control, access and stewardship. Ownership refers to the legal possession of data, specifically the Métis Population Data-base which was developed for the Métis Health Status and Health Services Utilization study (Martens, Bartlett et al., 2010). Control is the ability to have power to make decisions. Access focuses on the right or opportunity to use data. Finally stewardship refers to planning and management of resources, specifically the desire to engage in research that will result in positive change for Métis health and health service delivery. Included as an appendix is also a Métis Algorithm which outlines specific pathways and processes for engagement that researchers should follow if they would like to collaborate with MMF on a project. There are different routes for health research involving quantitative and qualitative data. For example, if a researcher is interested in doing quantitative research, including requesting access to Métis Population Data-Base, letters of permission need to be secured from the Manitoba Centre for Health Policy, the corresponding institution’s human ethics research board, and the Health Information Privacy Committee. Along with the letters of permission, a researcher agreement with MMF must also be completed. If qualitative data is being collected then a letter of support and approval from a Human Research Ethics Board needs to be secured (First Nations, Métis and Inuit Health Research Strategic Planning Committee, 2013).

The first Métis specific data governance protocol, the Saskatchewan Métis Health Research and Data Governance Principles, were created by Drs. Caroline Tait and Robert Henry in partnership with the Métis Nation Saskatchewan (MN-S). They were designed for use by MN-S and other Métis rights holders in their research and data sharing partnerships, specifically health institutions such as Ministry of Health Saskatchewan (MOH-S), the Saskatchewan Population Health and Evaluation Research Unit, Saskatchewan Health Quality Council and eHealth Saskatchewan. The Principles can also be applied to other sectors such as education, justice, housing, social welfare, agriculture, environment, and natural resources. They are designed to recognize and support the diversity of Métis populations including rural, urban and remote communities and organizations, in an aim to allow for the flexibility for local, regional, provincial and national adaptation to research and data sharing agreements. Similarly, the Métis Nation British Columbia (MNBC) has also developed their own Métis-specific data and data governance process.

In 2021, the Métis National Council called for significant investments in research and surveillance infrastructure to address the lack of Métis health data in the National Collaborating Centre for Indigenous Health's Visioning the Future: First Nations, Inuit and Métis Population and Public Health Report. The MNC outlined that they would like to increase the Nation's health research capacity through targeted spending and community based-research programs. They call for the collection of Métis specific health data through projects that are collected in accordance with OCAS Principles. The information they would like collected includes:

1. Prevalence of diabetes, cancer, cardiovascular disease, chronic obstructive pulmonary disease (COPD), musculoskeletal disorders, arthritis, osteoporosis, mental health, as well as morbidity rates and other health indicators
2. Data set based on variables including age and sex, household income, continuity of care, geography, and other social determinants of health
3. Insight into the comparative health of Métis to non-Métis across jurisdictions
4. Health care utilization

HEALTH & DATA PRIORITIES ACROSS THE MÉTIS NATION

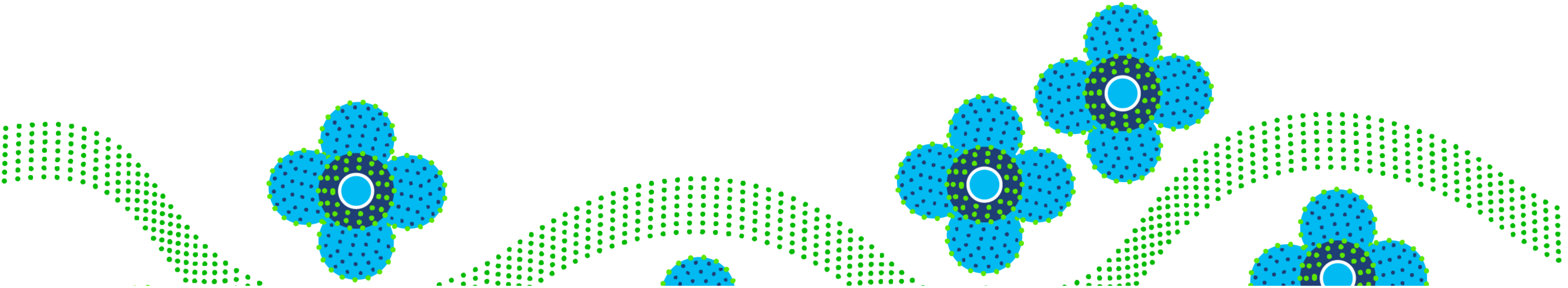
The following table represents **health priorities** outlined by the Métis Nation British Columbia (MNBC), the Métis Nation of Alberta (MNA), Métis Nation Saskatchewan (MN-S) and the Métis Nation of Ontario (MNO). These priorities were retrieved from the 2021 Métis Vision for Health Document and have since been updated through discussions with GMs to include more recent health priorities for each nation.

The table provides an overview of **health data agreements, assessment of current Métis health data governance initiatives**, and **future health data research directions**. The table is to create conversations to move health priority research and data mobilization forward by building connections across the GMs.

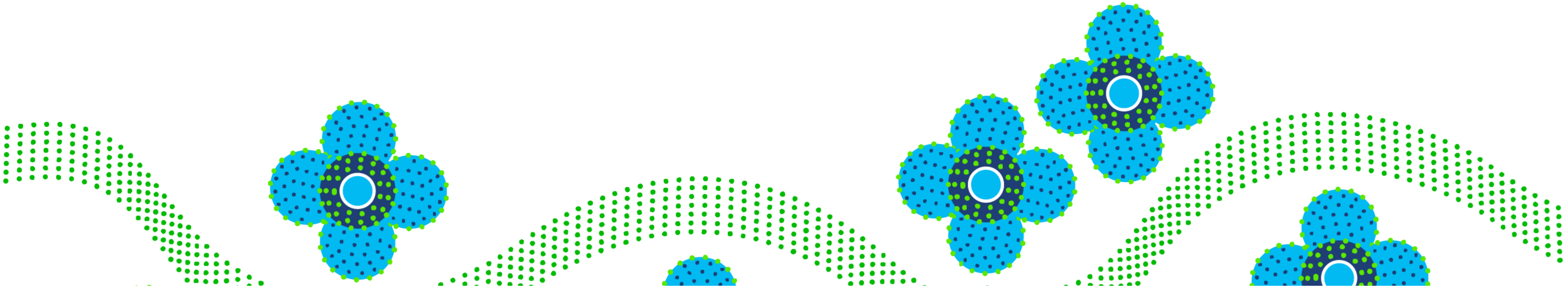
1. Are there opportunities to apply lessons from Governing Members at the national level, or within other Governing Members?
2. Which existing data governance components could be adopted by other Governing Members or at the National level?
3. What are the health and wellbeing priorities or directions for improved care or research that are important to citizens?

It should be recognized that this list may not be exhaustive due to the continued changing needs of communities, but it does provide MNC and GMs a snapshot of what is currently happening across the Métis nation.

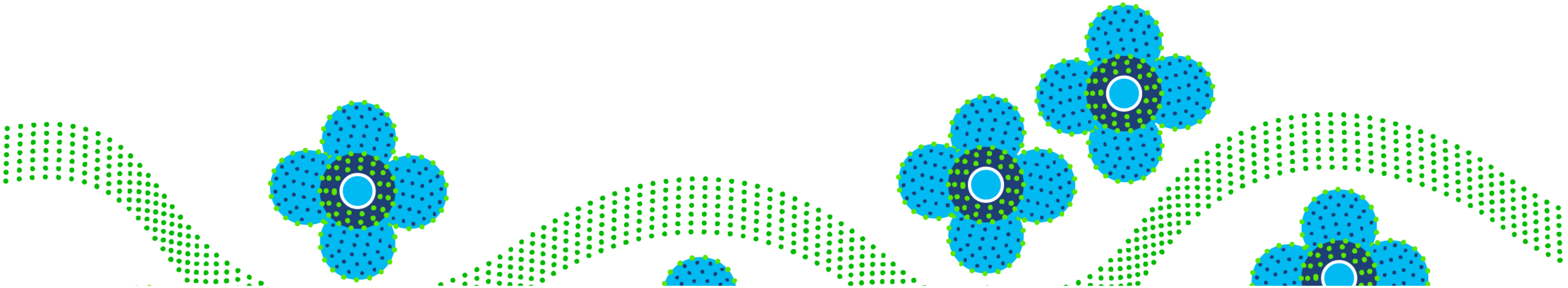
GOVERNING MEMBERS	HEALTH PRIORITIES	HEALTH DATA AGREEMENTS	CURRENT HEALTH DATA STRATEGIES, PRINCIPLES, AND ETHICS	FUTURE HEALTH DATA, RESEARCH, ETHICS, AND MOBILIZATION
MÉTIS NATION BRITISH COLUMBIA (MNBC)	Mental health and harm reduction in women and young girls - gender diverse inclusive Nicotine cessation Screening incidence and prevalence of cancers (data access request) Launching a medical transportation model (pilot program) Adolescent survey Primary care MSDOH	Indigenous Health Tripartite & creation of a fulsome Métis Health Department MNBC Ministry of Health signed Letters of Understanding (LOU) with 5 Health Regional and Provincial Health Authorities Information sharing agreements on toxic drug crisis, COVID 19, and BC Cancer Office of the Provincial Health Officer (OPHO)	Continued stewardship of the Métis Data Governance Committee with a Minister of Digital Governance and Minister of Health as Co-Chairs Data access to citizenship registry for MSDOH - MNBC has the ability to use citizenship registry to connect with the Ministry of Health and pull Métis specific data and is controlled by Métis Data Governance Committee Moving into the research ethics space, i.e., Research Ethics British Columbia. This is the board that research gets funneled through in the province. Currently, the First Nations Health Authority (FNHA) has a team of 8 on the board and now MNBC will have a position on the board for Métis specific projects * MNBC can leverage the Métis National Data Principles as part of the ethics process Office of the Provincial Health Officer British Columbia (OPHO) - Contract renewed to do a baseline and interim report (final report 2030)	The development and future implementation of the Métis data strategy, principles and action plan Translation of health research data for community citizens, policy development, and strategic priorities Creation of regional data sets borne from LOUs



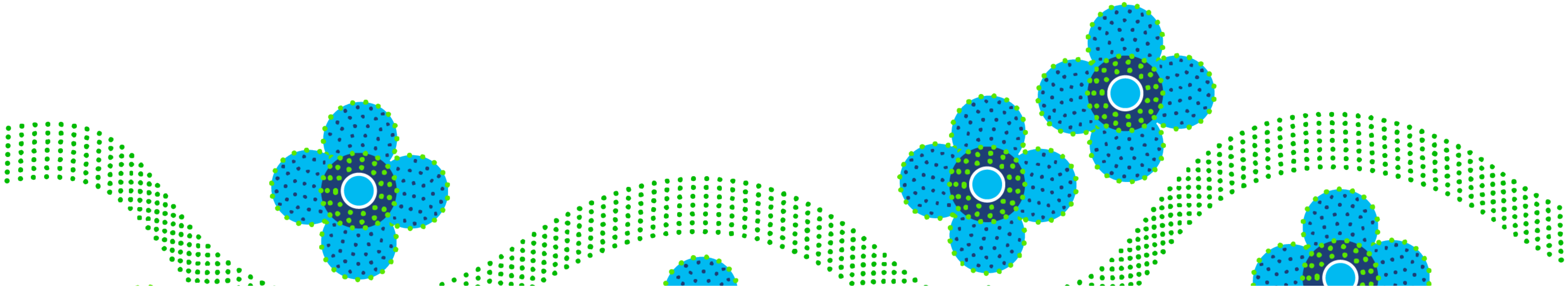
GOVERNING MEMBERS	HEALTH PRIORITIES	HEALTH DATA AGREEMENTS	CURRENT HEALTH DATA STRATEGIES, PRINCIPLES, AND ETHICS	FUTURE HEALTH DATA, RESEARCH, ETHICS, AND MOBILIZATION
MÉTIS NATION OF ALBERTA (MNA)	Cancer care Extended health benefits Access to appropriate care Medical transportation Community-based care Métis specific health care infrastructure Métis specific culturally-safe care Chronic disease Mental health and addictions Maternal and perinatal health Community definitions of health	Alberta Health (see Figure XX on p.8) Canada-Alberta Agreement to Work Together to Improve Health Care for Canadians Information Sharing Agreement Strategy with AHS Public health monitoring (surveys, vital statistics, administrative records, and disease registries)		Improve internal capacity, trust, reportage systems, and ensure individuals and organizations who are collecting Métis data are engaging with MNA A need to move away from self-identification data collection



GOVERNING MEMBERS	HEALTH PRIORITIES	HEALTH DATA AGREEMENTS	CURRENT HEALTH DATA STRATEGIES, PRINCIPLES, AND ETHICS	FUTURE HEALTH DATA, RESEARCH, ETHICS, AND MOBILIZATION
MÉTIS NATION OF SASKATCHEWAN (MN-S)	Cancer care Mental health and addictions Access to care Affordable health care and medication Elder support Non-insured health benefits Prevention education Youth health Health research and funding Métis health Centres staffed with Métis primary nurses	Data Framework Agreement with the Ministry of Health (linking citizen registry with the provincial registry has been challenging) A Data Sharing Agreement with the Saskatchewan Health Quality Council to access chronic disease data (forthcoming) Collaboration with Saskatchewan Health Authority to access e-healthcare data with citizenship registry Agreement with Cancer Agency (political red tape when data is mentioned) Métis representation on provincial health authorities Region specific services and funding Strong partnerships (with FN, FCs, universities, medical and research institutions, etc) Simplify and reduce bureaucracy to ensure sustainable funding	Saskatchewan Métis Health Research and Data Principles Métis Research Ethics Training Modules	Development of Métis Research Institute (MOU between MN-S and the University of Saskatchewan is underway) These principles should be brought to the Métis Nation Legislative Assembly (MLNA) and a Data Governance 101 workshop series should be established during the MNLA



GOVERNING MEMBERS	HEALTH PRIORITIES	HEALTH DATA AGREEMENTS	DEVELOPED AND IMPLEMENTED HEALTH DATA STRATEGIES AND/OR PRINCIPLES	FUTURE HEALTH DATA, RESEARCH, ETHICS, AND MOBILIZATION
MÉTIS NATION OF ONTARIO (MNO)	Family wellbeing Support for aging citizens Cancer Community support services Cardiovascular disease/ COPD Mental health and addictions services Perinatal care (Nutrition and healthy babies) Tobacco cessation program Gaming and gambling health promotion and awareness program Focus on developing youth health priorities	The data governance and partnership agreement between the Institute for Clinical Evaluative Sciences (ICES) - and the MNO in 2016 - they have access to any administrative health data STBBI - partner with public health Previous listed (2020) Ontario Federation of Indigenous Friendship Centres Our Health Counts The Indigenous Knowledge Network MOU with the Indigenous Cancer Care Unit		Research development agreements focusing on youth



MÉTIS HEALTH DATA PRINCIPLES

NATIONAL MÉTIS HEALTH DATA PRINCIPLES

In their design, the Saskatchewan Métis Health Research and Data Governance Principles © respond to diverse Métis populations (rural, urban, remote), organizations and communities, allowing the flexibility for local, regional, provincial, and national adaptation to research and data sharing agreements. Drawing from existing work on Métis research governance, the principles provide conceptual guidance supporting Métis sovereignty over research development, methodologies, data sharing, data storage and knowledge mobilization. The principles are a tool for Métis governing bodies, communities, organizations, and groups to facilitate research processes more effectively and efficiently, thereby attracting researchers and funding to areas of health and wellness research that are prioritized by Métis people.

The Métis-specific health research and data governance principles emerged out of a partnership between the Métis Nation-Saskatchewan and Drs. Caroline Tait and Robert Henry, and a team of University of Saskatchewan researchers. **The following guide the establishment and implementation of the Saskatchewan Métis Health Research and Data Governance Principles©, and their usage across Métis National Council and Métis Governing Members:**

1. The principles provide Métis stakeholders a set of culturally-grounded research and data governance principles which can guide the establishment of self-determined research partnerships with outside researchers, institutions, and organizations. Apart from health-related research, the principles can be applied for research governance in other sectors, such as environmental, education, justice, social welfare, agriculture, natural resources, and water and land management research and knowledge mobilization.

2. Creation of a data sharing and governance Memorandum of Understanding (MOU) between MNC and GMs. The MOU will outline how data will be collected, analyzed, and reported on. Due to the differing nature of data (e.g., health administrative data, clinical data, patient-oriented research data, biomarker), each domain will require separate data collection, storage and analysis protocols and procedures in the agreement. The MOUs should be based upon the research and data sovereignty of each GM and their citizens.

3. Require researchers who partner with Métis rightsholders in research to know the principles and enact them in their work with community partners, as a guide to building and maintaining research relationships with Métis partners. Outside researchers should position their teams to be guided by Métis partners, including local community people in a collective process of creating safe and inclusive research relationships and environments that are based upon respect, reciprocity, and relevance to the community.

The principles identified are significantly different from the First Nations OCAP® principles. Unlike the OCAP® principles, which emphasize self-determination and inherent rights of First Nations, the six principles of Métis research stress the importance of relationships, respect, and reciprocity between Métis rightsholders, researchers, and decision makers (e.g., government policy makers, clinicians, NGOs). The Métis principles are also less concerned with strict ownership and control of research processes, data, and analysis, and instead highlight the need to build productive, respectful, and safe relationships between Métis rightsholders and their partners. While the Métis principles diverge from the OCAP® principles, simultaneously there is significant and important overlap. Like OCAP®, the principles of Métis research require Métis protocols, knowledge, and values to frame any research design, implementation, analysis, and dissemination. The principles developed by the MC-NAHO are presented below (Métis Centre, NAHO, 2010a).

THE FIRST PRINCIPLE, reciprocal relationships, focuses on building reciprocal relationships through meaningful and authentic engagement of research partners. Relationships can be generated by Métis individuals, communities, or organizations, or by researchers, a research team, or other rightsholders. Three fundamental steps guide this process.

1. **Engaging potential partners by reaching out and sharing ideas for research.** For researchers, this means learning about the history, present day circumstances and culture of local or regional Métis groups prior to approaching them about a research partnership (e.g., What languages do they speak? How many people make up the group? Who is the recognized leadership in the community/region? What Métis-specific health services exist?).

2. **Earning trust and acceptance through collaborative discussions about potential research projects.** This step involves the creation of opportunities for Métis community, group, and organization rightsholders, healthcare leaders and frontline workers, and people with lived experience, to express their ideas about research priorities, methodologies, and knowledge mobilization.

3. **Establishment of broad Métis community/rightsholder involvement that emphasizes reciprocity, respect, and relationality.** The NAHO guidelines state: "Community involvement can come in the form of knowledge of local customs, input into the research design, utilizing community members in the research processes (note: training community members in interview techniques and other research skill sets may be necessary), etc." (Métis Centre - National Aboriginal Health Organization, 2010a, p. 2). Reciprocal relationships in research are characterized by mutual responsibility and benefits for community and research participants, with the explicit expectation that everyone involved has something important to learn from one another. Because Métis communities, locals, and organizational partners commonly struggle with internal capacity to participate fully in research, the design of the projects should reflect the need for financial and human resources to support the involvement of Métis partners.

THE SECOND PRINCIPLE, respect, highlights respect for individual and collective autonomy, identity, personal values, gender, confidentiality, practices, and protocols across research and knowledge mobilization processes. The principle states:

> Researchers should endeavor to determine if there are any existing practices or protocols in a community and should respect community practices and protocols (if they exist). These practices and protocols can be very different from community to community, and even from individual to individual along a wide-ranging contemporary to traditional continuum (Métis Centre - National Aboriginal Health Organization, 2010a, p. 3).

THE THIRD PRINCIPLE, safe and inclusive environments, requires assurance of cultural safety and inclusiveness of diverse Métis voices and perspectives (e.g., Elders, youth, all gender and sexual identities, diverse geographical regions) across the work of the research partnerships, and all geographical and social contexts. Inclusion of Michif or other Indigenous languages, where culturally appropriate, such as Cree, Dene, or Anishinaabeg as well as cultural concepts and ceremonies only if, and when the appropriate local people decide to include ceremony, reinforces cultural safety, and strengthens every stage of the research and knowledge mobilization processes and outcomes. Outside researchers and institutions must position their teams to be guided by the appropriate provincial, regional or local community people in a collective process of creating safe and inclusive research relationships and environments that are based upon respect, reciprocity, and relevance to the community.

THE FOURTH PRINCIPLE, diversity, extends the idea of safe and inclusive environments, as it recognizes the diversity of Métis perspectives and lived experiences that can influence the design of a research relationship and its process. References by outsiders to "the Métis" can mask the vast diversity of identities, lifestyles, cultural beliefs, and practices of Métis people within local, regional, and national contexts. The principle states:

> There can be a great diversity even within a single Métis community. Individuals within [a] community may, for example, have beliefs that are anywhere along a belief system continuum from very contemporary to very traditional and they may live their lives according to this system of belief. Métis are very diffuse geographically, tending not to live in easily recognized, politically bounded, dense areas…Most Métis are also urban dwellers with about seven out of ten living in an urban area (Métis Centre - National Aboriginal Health Organization, 2010a, p. 4).

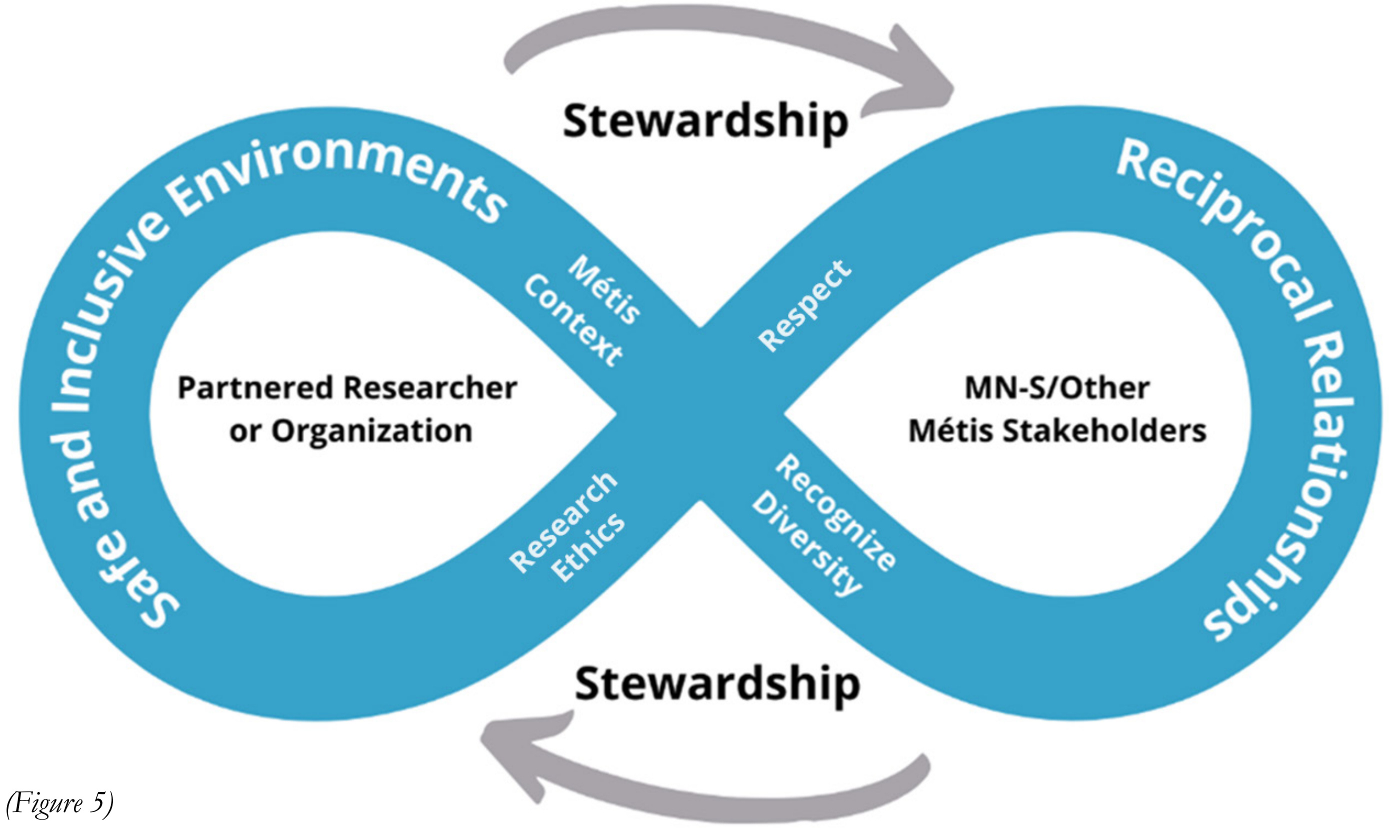
THE FIFTH PRINCIPLE, research ethics, refers directly to the ethical purpose of a research project and the processes that are followed. The principle gives direction to researchers that any research undertaken with Métis people must be relevant to those people, requiring community partners to identify research they deem to be important, have input into the design of the project, and participate in the project's activities at all stages of the research. Research must be beneficial and accountable to the community and acknowledge and protect Métis cultural knowledge and sovereignty.

THE SIXTH PRINCIPLE, Métis context, requires researchers to be familiar with the history of Métis people, specifically the local history of the community/organization they are conducting research with. As with other Indigenous peoples, Métis people have diverse generational histories. The principle states:

> Knowing history is necessary for understanding Métis values and Métis knowledge. Understanding Métis values and knowledge is important for ensuring that a Métis context is taken into account during research processes and design. Knowing history and the Métis context can also help researchers navigate the political and geographic complexities that may arise (Métis Centre - National Aboriginal Health Organization, 2010a, p.4).

Researchers and institutions working with Métis people must be aware that historical oppression and marginalization of Métis people has a direct impact on who Métis people are today. To ensure cultural safety, at a minimum, researchers and institutions need a firm understanding of the local and regional history of the Métis they would like to work with. Seeking support from local Métis Elders and knowledge keepers is key to grounding research within the history and experience of the people. Institutions and researchers are encouraged to develop this understanding before attempting to form research partnerships.

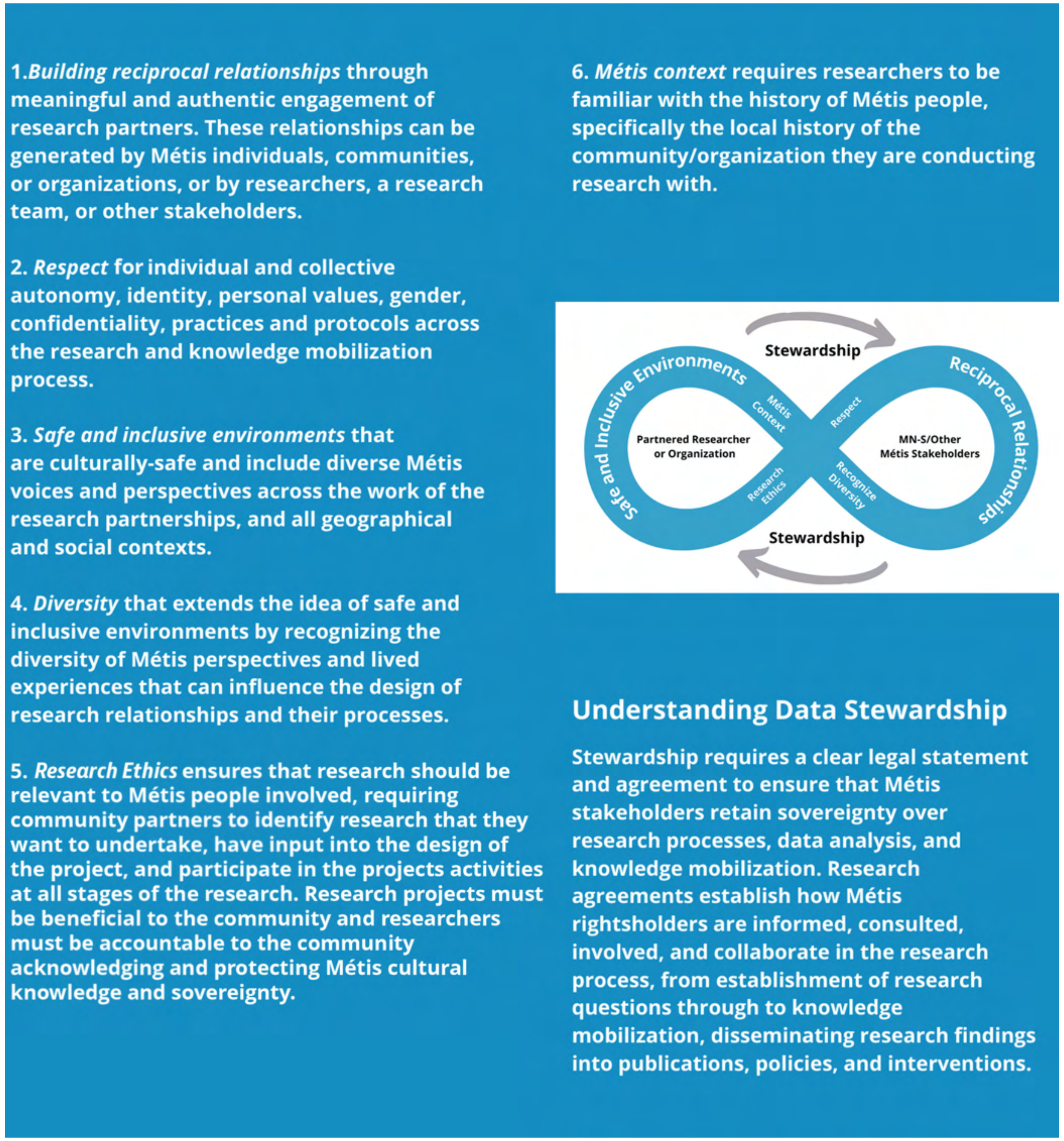
The research and data governance model for Saskatchewan is designed to represent the foundational principles of research governance and knowledge mobilization, including the research and data sovereignty of Métis peoples (see Figure 4). In the model, the principles continuously guide the relationship between Métis rightsholders and their partners, ensuring the sacredness and longevity of the relationship, and the protection of the agreements established by the respective community and institutional research partners.



(Figure 5)
Métis Data Principles - Tait and Henry, 2023

These data governance principles modify the MC-NAHO principles as the foundational basis upon which data stewardship is agreed upon and managed by Métis rightsholders and researchers (Métis and non-Métis), or institutional partners (e.g., postsecondary institutions, governments). As noted, Métis communities, groups, and organizations often lack the required infrastructure and resources to manage and house research data; therefore, stewardship of data by researchers and outside institutions is commonly required. In our data governance principles, stewardship is also based upon historical governance principles employed by the Métis, "the laws of the buffalo hunt," whereby traditional practices were employed and guidance given to all individuals involved in the hunt so that they clearly understood their roles and followed the hunt's cultural protocols (Louis Riel Institute, n.d.; Manitoba Métis Federation, 2002; University of Manitoba, n.d.). Because of the dangers involved in the hunt and the need for precision, all members adhered to the laws of the hunt, which were essential for success. The traditional laws and the success of the buffalo hunt provided Métis people with a cultural strategy to facilitate and ensure their survival and betterment. As Figure 4 above indicates, stewardship—how the group understands their relationships with one another, how they understand and treat the outcome of their collective efforts, and how they sustain and manage their relationships and the products of their work—is based upon the principles that define the relationship.

Development of Métis-specific research and knowledge mobilization curricula for Métis community and organization partners, and for researchers wanting to partner with Métis rightsholders has been created by Dr. Tait and the SK-NEIHR. This curriculum is based upon the principles outlined in the report and will be made available online. Once established, researchers should be required to complete the training prior to receiving approval from MNC or a GM to handle Métis specific data. Métis communities and organizations should be encouraged to require any researcher requesting a partnership with them to complete the training in advance of a partnership being formalized. Completion of the training will help communities identify researchers who are familiar with the principles and the guidelines for undertaking research with Métis rightsholders. The training will strengthen capacity-building within Métis communities and organizations, with its focus on education about different types of health research methodologies and data; research funding, administration, and reporting; research ethics; and Métis sovereignty and self-determination in research.



1.*Building reciprocal relationships* through meaningful and authentic engagement of research partners. These relationships can be generated by Métis individuals, communities, or organizations, or by researchers, a research team, or other stakeholders.

2. *Respect* for individual and collective autonomy, identity, personal values, gender, confidentiality, practices and protocols across the research and knowledge mobilization process.

3. *Safe and inclusive environments* that are culturally-safe and include diverse Métis voices and perspectives across the work of the research partnerships, and all geographical and social contexts.

4. *Diversity* that extends the idea of safe and inclusive environments by recognizing the diversity of Métis perspectives and lived experiences that can influence the design of research relationships and their processes.

5. *Research Ethics* ensures that research should be relevant to Métis people involved, requiring community partners to identify research that they want to undertake, have input into the design of the project, and participate in the projects activities at all stages of the research. Research projects must be beneficial to the community and researchers must be accountable to the community acknowledging and protecting Métis cultural knowledge and sovereignty.

6. *Métis context* requires researchers to be familiar with the history of Métis people, specifically the local history of the community/organization they are conducting research with.

Understanding Data Stewardship

Stewardship requires a clear legal statement and agreement to ensure that Métis stakeholders retain sovereignty over research processes, data analysis, and knowledge mobilization. Research agreements establish how Métis rightsholders are informed, consulted, involved, and collaborate in the research process, from establishment of research questions through to knowledge mobilization, disseminating research findings into publications, policies, and interventions.

(Figure 6)
Métis Data Principles - Tait and Henry, 2023

RECOMMENDATIONS

1. DISSEMINATION OF THIS REPORT.

a. Governing Members expressed that they are best suited to support community engagement sessions with their citizens. For effective citizen engagement and dissemination of this report, MNC should provide funds and resources to each Governing Member to support a wide net of engagement.

2. THE DEVELOPMENT AND IMPLEMENTATION OF AN ONGOING, COMPREHENSIVE CANADA-WIDE MÉTIS HEALTH SURVEY.

a. Having new datasets would allow for a better understanding of certain health and well-being outcomes and help guide what priorities to focus on when it comes to improving Métis health and well-being including strength-based components.

b. To move beyond self-identification, MNC must work with Governing Members to create a national Métis citizenship mechanism to understand Métis health and well-being in a national context.

c. The MNC in partnership with the Métis provincial governing bodies should develop a five-year work plan with the Canadian Institutes of Health Research (CIHR to help guide the implementation of a National Metis Health Strategy of Research. A key component of the work plan will be the creation of

d. Métis Research Centre with funding from the Tri-Agency Funding Programs (the Social Sciences and Humanities Research Council of Canada, the Canadian Institutes of Health Research and the Natural Sciences and Engineering Research Council).

3. CREATE AN ARMS-LENGTH CENTRE TO MANAGE MÉTIS DATA.

a. It is recommended that MNC work with GMs to create and implement an arms-length entity (Centre) to control national and regional data collection. Infrastructure should be created with support from the Tri-Agency Funding Programs similar to the First Nations Information Governance Centre and the National Inuit Research Network.

b. The Métis Research Centre will need to provide support to GMs to run reports and data analysis as there is a lack of resources at the provincial levels.

c. An integrated data collection system should be created for MNC and GMs to allow for effortless data sharing and management.

d. With Bill C-53 and the continued movement for Métis self-government, an arms-length data body will help to improve data governance and sovereignty to align with international, national, and provincial laws and legislation to data rights (e.g. Freedom of Information and Protection of Privacy Act (FOIP), Health Information Acts, Personal Information Protection and Electronic Documents Act (PIPEDA), etc.). An arms-length Centre is a safety mechanism for citizens wherein their data cannot be shared, stolen, or sold. It will provide a sense of ease that citizen-level data will not be used against them by governing bodies.

4. TRAINING OF MÉTIS DATA PRINCIPLES THROUGH THE SK-NEIHR FOR GM HEALTH TEAMS, MÉTIS COMMUNITIES, UNIVERSITY ETHICS BOARDS, AND ALL RESEARCHERS WHO WISH TO WORK WITH MÉTIS HEALTH DATA.

a. The SK-NEIHR has developed training modules for the Métis Data Principles and this training should be continued through this network until the needed infrastructure and agreements are in place to hold it within the Métis Research Centre.

5. UPDATE THE TRI-COUNCIL POLICY STATEMENT FOR ETHICAL CONDUCT FOR RESEARCH INVOLVING HUMANS CHAPTER 9 TO INCORPORATE MÉTIS DATA PRINCIPLES.

a. The TCPS 2 Chapter 9 policy is broad and researchers generally need to adapt the policies to fit the cultural protocol of the Indigenous Peoples, communities, and or nations they are working with which has typically been geared towards OCAP®

NEXT STEPS

1. A key priority is to ensure the implementation of this report, promote community validation and ownership of recommendations, and maintain momentum and leadership around key recommendations outlined above. We propose that the Métis National Council fund and coordinate additional meetings that bring together the Métis governing bodies, other interested communities, Indigenous organizations, academics, governments, and leaders to discuss the report and prioritize recommendations.

2. The National Métis Health Data Strategy should be implemented into the larger National Métis Data Strategy to frame the process of how research and data is to be collected with and for Métis Peoples, communities, and governments.

3. Present the National Métis Health Data Principles to the Canadian Institutes of Health Research Science Council (SC).

a. SC develops, implements and reports on CIHR's research and knowledge translation strategy, in accordance with the CIHR Act and the overarching strategic directions set out by Governing Council. This includes approving funding for all research and knowledge translation initiatives.

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