INSTITUTE FOR CIRCUMPOLAR HEALTH RESEARCH

PATHWAY FOR COMMUNITY DIALOGUE ON

INDIGENOUS HEALTH DATA GOVERNANCE

FINAL REPORT

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The Firelight Group

Institute for Circumpolar Health Research

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ACRONYMS

AFN — Assembly of First Nations

AFNIGC — Alberta First Nations Information Governance Centre

ARI – Aurora Research Institute

ATIPP — Access to Information and Protection of Privacy Act

BCFNDGI — British Columbia First Nations Data Governance Initiative

CCDSS — Canadian Chronic Disease Surveillance System

CIHI – Canadian Institute for Health Information

CINE – Centre for Indigenous People's Nutrition and Environment

CINUK — Canada-Inuit Nunangat-United Kingdom Arctic Research Programme

CIRNAC — Crown-Indigenous Relations and Northern Affairs Canada

COO — Chiefs of Ontario

FNC — First Nations Centre

FNHA — First Nations Health Authority

FNIGC — First Nation Information Governance Centre

FNIHB — First Nations and Inuit Health Branch

FPIC – Free, Prior, and Informed Consent

GNWT — Government of Northwest Territories

HIS — Health Information System

ICES — Institute for Clinical Evaluation Sciences

ICHR — Institute for Circumpolar Health Research

IR — Indian Register

ISC — Indigenous Services Canada

ITK — Inuit Tapiriit Kanatami

KFN — Katl'odeeche First Nation

MFNERC — Manitoba First Nations Education Resource Centre Inc.

NAC – Nunavut Arctic College

NAHO — National Aboriginal Health Organization

NASDF — Nishnawbe Aski Development Fund

NRC — National Research Council of Canada

NWT — Northwest Territories of Canada

NWTMN — Northwest Territory Métis Nation

OCAP® — Ownership, Control, Access, and Possession

OCAS — Ownership, Control, Access, and Stewardship

PHAC — Public Health Agency of Canada

RHS — Regional Health Survey

SDOH — Social Determinants of Health

SLFNHA — Sioux Lookout First Nations Health Authority

TUS – Traditional Use Studies

UAKN — Urban Aboriginal Knowledge Network

UKRI — United Kingdom Research and Innovation

UNDRIP — United Nations Declaration on the Rights of Indigenous Peoples

WHO – World Health Organization

1. PROJECT BACKGROUND

1.1 ICHR BACKGROUND

Developed from the Arctic Health Research Network, in 2005 the Institute for Circumpolar Health Research (ICHR) was developed by Northern community members, doctors, academics, and researchers.[1] The Institute was founded to advance the health and wellness of Northern people and communities in the areas of scientific inquiry and public policy. ICHR is an independent, non-profit organization, registered under the Northwest Territories Societies Act. It is engaged in research, training, facilitation, knowledge synthesis, exchange, and dissemination.[2]

The ICHR has been actively involved in research focused on understanding the role of health systems and health data in contributing to Indigenous health, wellness, and care. The Pathway for Community Dialogue on Indigenous Health Data Governance project commissioned by the ICHR is an effort to better understand the challenges and opportunities surrounding Indigenous health data governance and access in the Northwest Territories (NWT). This project was conducted in three phases, including setting the foundation through an environmental scan of Indigenous health data governance in Canada and facilitating conversations with key partners. This toolkit is based on an assessment of the documents reviewed and the engagement sessions.

1.2 WHY A TOOLKIT?

This toolkit has been developed to support Indigenous leadership and community conversations in the area of health data governance and the collection and use of Indigenous health data. This project came out of the need and desire of communities to develop and use their own health data, with recognition that there are unique considerations in the North, and a wide disparity in capacity around data collection and use across communities.

This toolkit has also been developed to support territorial governments, health authorities, and health researchers in generating shared understandings of the ethical collection, use, and management of Indigenous health data, based on values and principles rooted in Northern Indigenous cultures and traditions, and reflect community realities, goals, and priorities.

More specifically, this toolkit is intended to:

- Improve efforts in data sovereignty through supporting Northern Indigenous communities to build capacity and advance their own work in health and wellness data collection, use, and management;
- Support integration of traditional knowledge into approaches to collecting, using, and managing data;

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[1] ICHR, "Institute for Circumpolar Health Research," About Us l Institute for Circumpolar Health Research, November 7, 1970, https://www.ichr.ca/about/

[2] Ibid.

- Support community informed, culturally relevant, evidence-based prioritization and decision making in community health planning;
- Build community capacity to monitor and respond to changes in health and wellness;
- Strengthen rationale for investments in community health and wellness initiatives; and
- Support transparency and trust in data collection and use, and in reporting to communities.

1.3 HOW TO USE THIS TOOLKIT

This toolkit can be used in several ways, depending on objectives, purpose, and existing capacity.

- For those beginning their data governance journey, the toolkit can be read section by section, with each section providing background information and links to valuable resources. Each section builds on the next, and when viewed as a whole, provides a strong foundation for getting you started!
- Those who are interested in specific aspects of data governance, including community dialogue on data, can skip to specific sections to inform their work; and,
- Those who already have a strong foundation in community health data governance, and are in need of specific tools or resources, can use the resource links listed in each section, or in the compiled resources at the end of the report.

2. THE BASICS

Before diving into health data governance, it is first important to have a basic understanding of what health data is, the different types of health data, and data collection methods. This section provides a background on these topics, as well as a snapshot of some of the different stakeholders involved in Indigenous health data and health data governance.

2.1 WHAT IS HEALTH DATA?

Data refers to distinct pieces of information, usually formatted and stored in a way that is can be used for a specific purpose. In short, data is raw, unorganized facts that need to be processed and analyzed.[3] Health data is data that relates to the health of an individual person or to a population. Information is gathered from a variety of health information systems (HIS) and other tools used by health care professionals, researchers, and governments, among others. Health data can be used in a variety of ways to better understand how well health systems and processes are performing, identifying risk factors, and improve diagnosis and treatments for patients.[4] The collection of health data assists in strengthening the quality of health programs and services, advancing health research, improving communication between doctors and patients, and enhancing overall health outcomes.

2.2 TYPES OF HEALTH DATA

Let's dive a little deeper. We now have an idea of what health data is, but there are different types of health data. The two main categories are quantitative and qualitative data.

- **Quantitative health data:** Quantitative health data is measurable, often used for comparisons, and involves numerical and/or statistical analysis of individuals, populations, behaviours, conditions, or other health-related events. For example, quantitative data may include age, weight, temperature, or the number of people suffering from a specific chronic illness.[5]

- **Qualitative health data:** Qualitative health data is a broad category of data that consists of various types of non-numerical data relevant to health. This type of data is observed, but not measured. Instead, it uses words to describe a particular health-related situation or event. For example, qualitative health data may include a questionnaire aimed at short answer responses, or information

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[3] Bonnie Erickson and Terry Nosanchuk. *Understanding data*. (UK: McGraw-Hill Education, 1992), 1-3. https://books.google.com.my/books?hl=en&lr=&id=vH5EBgAAQBAJ&oi=fnd&pg=PP1&dq=understanding+data&ots=VxFe1Jb7HY&sig=DMcrZF2ZGqJS_WtiWaaQNSIrnxl&redir_esc=y#v=onepage&q=understanding%20data&f=false

[4] Roberta Pastorino et al., "Benefits and challenges of Big Data in healthcare: an overview of the European initiatives." *European journal of public health* 29, no. Supplement_3 (2019): 23-27. https://academic.oup.com/eurpub/article/29/Supplement_3/23/5628051

[5] Jesko Hentschel. *Distinguishing between types of data and methods of collecting them*. (Washington: World Bank Publications, 1998), 7-9.

shared through longer stories, experiences, and perceptions from interviews or focus groups.[6]

Qualitative research methods and data are especially important in Indigenous research in that they can meaningfully and respectfully include Indigenous knowledge and worldviews in health data. For example, qualitative approaches to data collection allow for oral knowledge transfer and storytelling approaches. These can be a useful tool to break traditional Western paradigms that historically dominate research, and to ensure an Indigenous lens is captured in health data.

The data collection methods described below include qualitative and quantitative methods, and sometimes a combination of both.

2.3 DATA COLLECTION METHODS

Quantitative and qualitative health data can be collected in a variety of ways. Different data collection methods can be chosen depending on the purpose of data collection and intended use. Each data collection method has its own benefits and limitations.[7] It is often ideal to use both quantitative and qualitative collection methods in order to obtain a comprehensive data set of both numerical and measurable quantitative data and rich qualitative data based on detailed personal accounts, experiences, and perspectives. Again, it really depends on the purpose of the data collection and what you want to achieve, as well as limitations of time and resources.

Remember, while using any approach, there is an opportunity to centre Indigenous worldviews including understandings of health and wellness. Using qualitative approaches to data collection is a good way to ensure Indigenous knowledge and worldviews are at the forefront, while also respecting Indigenous oral knowledge transfer. Indigenous knowledge and worldviews can also be ensured in quantitative data and data collection by basing the work on the measurement of things that are important to the community (indicators).[8] Developing relevant indicators is discussed in Section 5.3. Common data collection methods are described below.

2.3.1 Health surveys and questionnaires

Health questionnaires are a useful tool for rapid collection of health data. Questionnaires provide a quick and efficient way of obtaining large amounts of information from a large sample of people.[9] Questionnaires also provide flexibility to respondents. Respondents can complete questionnaires at different times and

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[6] Jesko Hentschel, *Distinguishing between types of data and methods of collecting them*. (Washington: World Bank Publications, 1998), 7-9. https://www.researchgate.net/publication/23722068_Distinguishing_between_types_of_data_and_methods_of_collecting_them

[7] Ibid.

[8] Maggie Walter and Michele Suina, "Indigenous data, indigenous methodologies and indigenous data sovereignty." *International Journal of Social Research Methodology* 22, no. 3 (2019): 233-243. https://www.tandfonline.com/doi/full/10.1080/13645579.2018.1531228

[9] S Roopa and Rani M.S, "Questionnaire designing for a survey." *Journal of Indian Orthodontic Society* 46, no. 4_suppl1 (June 2012): 273. https://www.researchgate.net/publication/235801675_Questionnaire_Designing_for_a_Survey

locations, especially if done virtually. Questionnaires can collect both quantitative and qualitative data, depending on the questions asked. For example, quantitative data can be generated from questions where respondents answer by ticking boxes, and qualitative data can be generated through written responses. Health surveys and questionnaires can be administered in-person or online via various tools (e.g., Survey Monkey, Google Forms, KoBo Toolbox, and social media platforms). Indigenous governments and organizations are increasingly using health questionnaires to conduct health needs assessments and assess healthcare programming.

2.3.2 Individual interviews

Interviews are most often qualitative and usually ask open-ended questions to gain information from individual respondents. In this way, interviews can lead to rich and meaningful qualitative data from different perspectives, using the respondents' own words.[10] Qualitative interviews generally take longer compared to surveys or questionnaires, and may reach less people. However, interviews can provide more detailed information from interviewees. In addition, interviews offer a great opportunity for storytelling.

By using closed-ended questions, interviews can also be quantitative. These types of interviews act more like a survey. Quantitative-type interviews would not produce the rich amount of information that is expected from qualitative interviews.

Interviews can be done both in-person and virtually, eliminating issues with venue accessibility. Online platforms that are commonly used for interviews include platforms such as Skype, Microsoft Teams, and Zoom.

2.3.3 Focus groups

Focus groups are a qualitative data collection method centred around generating dialogue with a group of people (generally six to twelve). A facilitator will guide a group based on a predetermined set of questions and topics. Generally, groups are chosen based on shared characteristics. For example, different focus groups could be set up to gain unique perspectives from different age groups like youth or Elders, specific genders, people with common physical or mental characteristics, or groups like nurses, students, or fishermen. In this way, data collection is focused on obtaining information from the perspectives of a specific group rather than the general population.[11] This is a good way to ensure that the unique perspectives from these groups are represented in data.

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[10] Kathryn Roulston, and Myungweon Choi, Qualitative interviews." In *The SAGE handbook of qualitative data collection* (London: 2018), 233. https://books.google.com.my/books?hl=en&lr=&id=X0VBDwAAQBAJ&oi=fnd&pg=PA233&dq=Interviews+for+research&ots=AW987y2Aw7&sig=I6gVOc2vBt9n1NHQUZZe-XT1S9o&redir_esc=y#v=onepage&q=Interviews%20for%20research&f=false

[11] Lia Litosseliti, *Using focus groups in research*. (London: A&C Black, 2003), 1-2. https://books.google.com.my/books?hl=en&lr=&id=GwLbQSlRtQAC&oi=fnd&pg=PR5&dq=focus+groups+for+research&ots=tTMKzzmo-k&sig=kq--nzeHWOGmAr2m4POgGo3StkQ&redir_esc=y#v=onepage&q=focus%20groups%20for%20research&f=false

Focus groups are particularly conducive to storytelling and often spark discussion between participants. Generally, the preferred method of undertaking focus groups is in person; however, the COVID-19 pandemic has resulted in a pivot to virtual environments that has generally proven successful.

2.3.4 Observation

Observation is another useful way of obtaining data, especially in the younger population, such as on infants or children where respondent responses and cooperation may be limited. Observation is the simplest method of data collection as very minimal technical knowledge is required, making it a more straightforward and a more accessible data collection method than others.[12] Real-time can offer researchers a good opportunity to identify areas of further research necessary, that may not have been thought of beforehand. However, as observation involves obtaining data precisely as they occur in the most natural setting, it can also be a longer time commitment and effort. Additionally, one challenge of this method is that observation can be quite prone to researcher bias, meaning that the expectations, opinions, or prejudices of the researcher might influence what they perceive and record in an observation. This may be particularly true within an Indigenous context when the researcher is from outside the cultural group.

2.3.5 Secondary Data

Secondary data is data that has already been collected by and readily available from other sources. Obtaining secondary data is less expensive and more quickly obtainable than primary data. It may be the main source of data when primary data cannot be obtained at all. Sources of secondary data may include administrative data, electronic medical records (EMR), literature reviews, data collected through desktop research, and more.[13] Secondary data can provide a wealth of information that supports better understanding of a topic and can also be used to identify gaps in existing data which can be considered to inform and refine primary data collection using the methods above.

For easy viewing, the data collection methods mentioned above are summarized in Table 1.

Table 1: Health data collection methods

Method	**Strengths**	**Weaknesses**

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[12] Christine Urquhart, "Observation research techniques." *Journal of EAHIL* 11, no. 3 (2015): 29-30. https://core.ac.uk/download/pdf/334782654.pdf

[13] Joop J Hox and Boeiie R. Hennie, "Data collection, primary versus secondary." (2005): 593-596. file:///Users/jasheilathalia/Downloads/hox_05_data+collection,primary+versus+secondary.pdf

Surveys	Can obtain large amounts of data through reaching many participants and voices using less resources. Clear specific answers.	Limited detailed information and contextual information. May encounter limited engagement and participation.
Individual interviews	Gain a deeper understanding of individual participants' perspectives. Flexible in topic based on participants interests/ knowledge.	May encounter a limited number of perspectives and voices heard. May not represent the entire community.
Focus groups	Many participants can participate in a short time. Discussion between participants may build ideas and understandings.	Some participants may not feel comfortable sharing in groups.. The larger the group, the bigger the challenges for documenting and organizing information.
Observation	Gain a deeper insight of a population, an issue or an event. This method may help in clarifying and highlighting areas that need more research.	Researcher bias is common with this type of data collection method. It is time consuming and requires a lot of effort.
Secondary data	Saves time and money. It helps to make primary data collection more specific, and we are able to identify where the gaps and deficiencies are. It helps to improve the understanding of the problem.	The accuracy of secondary data is not known. Secondary data may be outdated and no longer relevant.

Now that you have a general understanding of health data and data collection methods, let's take a deep dive into who is involved in the health data world. It is important to note that mutually beneficial partnerships can be formed between organizations, and between community and organizations around research, data governance, and data sharing, to improve community health services and health outcomes, which is further discussed in Section 7.

2.4 WHO IS WHO IN THE HEALTH DATA WORLD?

There are many players with some role or interest in Indigenous health data governance. The table below identifies relevant groups and their relevance to Indigenous health data. Please note that this list is not comprehensive, but is intended to provide a quick look into groups and organizations working within the Indigenous health data landscape with particular relevance to the North.

Table 2: Organizations relevant to Indigenous health data

Organization Type	Details
Indigenous Communities	Data that is collected from community and is relevant to community can drive community planning and decisions. Ideally, data collection, use, and management are community led (or at the very least community informed), and based on community values, aspirations, and needs, which in-turn gives data value and relevance to the community it is collected from. There also may be community resolutions or laws specific to community research and data governance. In these ways, Indigenous data governance and community data governance is a means towards achieving sovereignty and self-determination.
Indigenous Organizations There are numerous regional and national Indigenous organizations with a role in data stewardship, data collection and use, and capacity building.	**First Nations Information Governance Centre (FNIGC)** FNIGC is an independent non-profit organization that supports the development of information governance and management at the community level through regional and national partnerships. FNIGC is the registered owner of OCAP® and also undertakes a number of national surveys including the First Nations Regional Health Survey (RHS), the First Nations Labour and Employment Development Survey (FNLED), and the First Nations Regional Early Childhood, Education, and Employment Survey (FNREEES).

	Qanuippitaa? National Inuit Health Survey (QNIHS) Working Group The QNIHS Working Group is comprised of the four Inuit Land Claims Organizations, in collaboration with Inuit Tapiriit Kanatami (ITK) to design and launch the QNIHS, as a permanent population health survey of Inuit in Canada. The stated goal of the QNIHS is to provide high quality, Inuit determined and owned data to monitor change, identify strengths and gaps, and inform decision-making, leading to improved health and wellness among Inuit in Canada.
	Hotıì ts’eeda Hotıì ts’eeda is a research support unit hosted by the Tłı̨chǫ Government and governed primarily by NWT Indigenous Governments. It is funded by the Canadian Institutes of Health Research. Hotıì ts’eeda connects NWT organizations, and communities with researchers and funding to achieve health research and training goals. It also supports communities and researchers to identify currently available datasets.
Hospitals and Other Care Providers	Hospitals and other care settings hold significant amounts of data. For example, each visit includes inputs into an individual’s medical record. These inputs can include name, date of birth, any test results, prescriptions written, etc. Healthcare systems sometimes have integrated health record systems (eHealth records) where each patient medical record is available to providers across the system. eHealth records have been implemented in all three territories, including: • 1Health in Yukon • HealthNet in NWT • Meditech in Nunavut
Health Authorities	Health authorities often use aggregated patient and system data to measure and report on many indicators. Some examples include wait times, disease rates, and re-admission rates.
Territorial/Provincial Governments	Territories and provinces are responsible for the collection and management of health data within their geographic and legislative jurisdiction. They are responsible for ensuring

	provincial and territorial legislation around privacy protection and data governance is followed within government, while also disseminating data and other information to their populations in a transparent way. Common types of data collected by territories and provinces include: • Vital statistics via health cards; • Health services utilization data via public insurance plans and physician billing regimes; and • Health surveillance data via communicable disease reporting systems, cancer registries, etc. In addition, territorial and provincial governments also collect and report on several indicators around the social determinants of health such as rates of employment, population data, housing, crime rates, and educational attainment, among others. Each of the territorial governments has a bureau of statistics that is responsible for each governments' statistical program. This is an important source of data, including some- albeit limited- Indigenous-specific data. • NWT Bureau of Statistics • Yukon Bureau of Statistics • Nunavut Bureau of Statistics
Federal Government The federal government's involvement in health data generally, and Indigenous health data, is significant.	**The Public Health Agency of Canada (PHAC)** PHAC's mandate is to provide effective national surveillance. Through PHAC, the Canadian Chronic Disease Surveillance System (CCDSS) collects, and reports aggregate administrative data from provinces and territories to track the incidence and prevalence of chronic conditions.
	Indigenous Services Canada (ISC) ISC holds a significant amount of administrative data that can tell us some things about Indigenous health and wellness. For example, each year ISC is required to publish a departmental annual report, as well as individual program annual reports including Non-Insured Health Benefits.
	Statistics Canada

	Statistics Canada produces statistics that help us understand the health of people in Canada including information about the social determinants of health (SDOH). This information is generated through Statistics Canada's Canadian Community Health Survey, Canadian Health Measures Survey, Canadian Cancer Registry and the Vital Statistics Program. Statistics Canada also holds data on Indigenous peoples in Canada, primarily drawn from the Census and the Aboriginal Peoples Survey. This data includes primarily aspects of the SDOH.
Educational Institutions, Researchers, and Research Funding Institutions	**Aurora College and Aurora Research Institute (ARI)** Aurora College and Research Institute work to improve the quality of life for residence of the NWT through supporting culturally sensitive education, training, and research initiatives. ARI conducts research; supports licencing and coordination of research; promotes communication between researchers and communities; advocates for TUS use along with scientific and technological approaches; promotes public awareness of the importance of research (inclusive of TUS; and makes information available to people of the NWT.
	ArcticNet ArcticNet partners with Inuit organizations, Northern communities, universities, and governments. It brings together Arctic researcher, engineers, and mangers to study human health, and natural and social sciences. The network offers training and funding opportunities, including Inuit-led and governed research programs and for norther post-secondary programs.
	Nunavut Arctic College (NAC) NAC provides high quality educational opportunities to residents of Nunavut and advances Arctic research capacity through reviewing NACS research experience, delivering a community research course, and enhancing the Nunavut Research Institute's research licensing database. NAC also has a Collaborative Research Agreement with Memorial University of Newfoundland. NAC is committed to advance arctic research in such areas as:

	- Climate Change Adaptation; - Health and Community; and - Indigenous Approaches to Environmental Management
	Labrador Institute The institute is a division of Memorial University, which leads research, education, policy, and outreach by and for the North. They fund research positions including, but not limited to: - Climate-Sensitive Health Outcomes - Northern Indigenous Mental Health; and - Northern Climate Change & Health
	Yukon University Yukon University partners with First Nations, government, and academic institutions to develop research capacity in the North and research issues important to Northern peoples while integrating western science and Indigenous knowledge.
Mainstream Organizations Working in Health Data There are several organizations that work in health data and research that have some interest in Indigenous health data.	**Canadian Institute for Health Information (CIHI)** CIHI is a federally funded non-profit organization that reports information about the performance of health systems in Canada and the health of Canadians. CIHI has partnered with some Indigenous communities and organizations, such as the First Nations Health Authority (FNHA) in British Columbia and the Sioux Lookout First Nations Health Authority (SLFNHA) in Ontario, on specific projects to support the use of Indigenous health data.
	Canada Health Infoway (Infoway) Infoway is a federally funded non-profit organization tasked with accelerating the adoption of digital health technologies such as electronic medical records.
	Institute for Circumpolar Health Research (ICHR) ICHR is an independent non-profit actively engaged in research, research facilitation, training, synthesis, exchange, and dissemination.

3. BENEFITS AND BARRIERS

So far, we have discussed health data, data collection, and a few of the different organizations operating in the Indigenous health data world. At this stage, you may be wondering: How is health data used? What benefits does it have?

At present, there are both benefits and barriers to health data utilization. Key themes are summarized below.

3.1 BENEFITS OF HEALTH DATA UTILIZATION

Indigenous communities can benefit from the collection and use of health data in a variety of ways. Ultimately these benefits can improve Indigenous health outcomes and work towards Indigenous sovereignty and self-determination. Some of the benefits of using health data that support these ultimate objectives are summarized below.

3.1.1 Detecting and treating illness

With a big pool of health data, early symptoms and warning signs of serious illnesses can be identified much sooner. Treating illnesses at an early stage has also shown to improve long-term health outcomes and is more cost effective than later treatments.[14] For example, with the use of data analytic tools, physicians can combine a patient's specific symptoms with other unique factors such as lifestyle choices, genetic data, and demographics in order to arrive at an accurate diagnosis quickly, while also selecting the best course of therapy to optimize patient outcomes.

3.1.2 Medication and therapy management

Health data can also improve medication therapy management.[15] By using data analytics, physicians and clinical pharmacists can evaluate high volumes of information and patient data to design and implement optimal drug therapies.

3.1.3 Identifying health risk factors

Health data also has the potential to yield valuable insights into health risk factors that lead to disease.[16] This data derived can assist in understanding gaps within health services delivery and be used to update or develop health services to meet the needs of Indigenous populations.

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[14] Roberta Pastorino et al., "Benefits and challenges of Big Data in healthcare: an overview of the European initiatives." *European journal of public health* 29, no. Supplement_3 (2019): 23-27. https://academic.oup.com/eurpub/article/29/Supplement_3/23/5628051

[15] Ibid.

[16] Ibid.

3.1.4 *Strengthening health programs and services*

Another benefit of collecting and using health data, is that it helps generate understanding of the quality and effectiveness of health programs and services.[17] Data can be used to monitor and evaluate health services and programs to understand how effective they are at meeting the needs of the community. Many healthcare institutions have monitoring and evaluation (M&E) processes which collect and use data to better understand the health of the populations they work with and to assess the effectiveness of their health services and programs. These health information systems (HIS) collect important high-quality data, capturing information about health service delivery to inform how well health care services respond to the health needs of a specific community. Monitoring and evaluation of health programs and services doesn't necessarily need to involve complicated HIS, data can also be collected and analysed at the community level as well.

3.1.5 *Individual empowerment*

Health data can act as a pathway for First Nations, Inuit, and Métis peoples to engage and take ownership of their own health. When health data (personal medical records, dental records, surgical records, behavioural data, and biometrics data) is stored in a database that is accessible to an individual, this enables participation and engagement with their own health.[18] Access to personal health data ultimately contributes to increased health literacy. The utilization of health data encourages learning and understanding of health issues, health risks and the healthcare options available. This also contributes positively to better interactions with healthcare providers through increased understanding, trust, and agency around personal health and treatment.

3.1.6 *Evidence-based decision-making*

Health data aids the process of evidence-based decision-making and advocacy for Indigenous communities. Decision-making in the health sector and at the community level, without sufficient attention to data-led evidence may lead to a lack of effectiveness, efficiency, and equity in health systems.[19] The collection of quality health data shapes narratives about specific populations/communities and can be used to strengthen their advocacy efforts against inequitable health policies.

3.1.7 *Identifying gaps and advocating for health funding*

Equitable and Indigenous-led data collection, data use, and data sharing has the potential to reveal valuable insights into the healthcare gaps, health contexts and health needs of Indigenous populations in Canada.[20] This information can be a useful tool for

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[17] Rosemary Wyber et al., "Big data in global health: improving health in low-and middle-income countries." *Bulletin of the World Health Organization* 93 (2015): 203-208. https://www.scielosp.org/pdf/bwho/2015.v93n3/203-208/en

[18] Jennifer Walker et al.,"Indigenous health data and the path to healing." *Lancet* 390, no. 10107 (2017): 2022-2023. https://www.researchgate.net/publication/320834839_Indigenous_health_data_and_the_path_to_healing

[19] Rosemary Wyber et al., "Big data in global health: improving health in low-and middle-income countries." *Bulletin of the World Health Organization* 93 (2015): 203-208. https://www.scielosp.org/pdf/bwho/2015.v93n3/203-208/en

[20] Jennifer Walker et al.,"Indigenous health data and the path to healing." *Lancet* 390, no. 10107 (2017): 2022-2023. https://www.researchgate.net/publication/320834839_Indigenous_health_data_and_the_path_to_healing

Indigenous governments and leaders when advocating for funding and resources to be allocated to Indigenous communities.

In summary, effective use of health data can allow for improved diagnostic testing and treatment, risk identification and gaps assessment, improvement of programs and services, and support data sovereignty and self-determination through engagement, ownership, and access. It is also key in providing evidence for informed decision making and advocating for health funding and resource allocation. These benefits can also be utilized to increase Indigenous communities' trust of external partners and share understanding of expectations for and execution of data protections within healthcare.

3.2 CONCERNS AND CHALLENGES

There are many benefits that health data utilization can offer. However, there are also barriers to realizing those benefits as well as legitimate concerns around health data collection and use, as described below.

3.2.1 Data literacy

Like understanding any language, data also needs to be well understood to be useful. It is often the case that outside researchers and institutions collect, analyse, and interpret data, and use it in ways that are familiar and important to them, while the communities who are the subject of that research are not fully involved in the development and implementation of the research processes. This risks creating and worsening disparities and barriers around data literacy within the community.

In order for the community to benefit, data collection processes must be based on community priorities and concerns and build in opportunities to enhance community data literacy. It is important that Indigenous peoples are involved as key decision-makers in how health data is captured, used, and shared. If individuals or communities cannot understand the available data, it is challenging to make informed choices based on this data.

3.2.2 Technological challenges

A significant barrier to effective use of health data is challenges related to sharing data between different computer systems and software. Studies have shown that the use of digital health technologies can reduce workloads and enhance overall health systems.[21] The use of technology within healthcare has the potential to improve the design and delivery of health services and programming therefore improving overall health outcomes. However, in order to ensure health data is collected, stored, and accessed effectively barriers and limitations associated with technology must be improved and be manageable for communities.

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[21] Arthur L. Kellermann and Spencer S. Jones, "What it will take to achieve the as-yet-unfulfilled promises of health information technology." *Health affairs* 32, no. 1 (2013): 63-68.

3.2.3 Historical concerns

First Nations, Inuit and Métis peoples in Canada have been impacted by data inequalities and data exploitation.[22] Historically, data collection activities were largely driven by government agencies, and often used to sustain existing oppressive colonial systems.[23] Not only was data collected and used without consent or input, but it was also used to control and harm Indigenous peoples and communities. For example, data collected by government agencies was used to identify and extract children from their families in the residential school system and in the Sixties Scoop.[24]

Another example arose in British Columbia, where in the 1980s nearly 900 Nuu-Chah-Nulth people provided blood samples for a study on rheumatoid arthritis. Not only did the researcher never report any findings back to the study participants, but in 2000 it was revealed that the researcher used the blood samples in other unrelated studies without informing and seeking permission from the Nuu-Chah-Nulth participants.[25]

These instances of the unethical misuse of Indigenous data has understandably generated concern and feelings of mistrust in the collection and use of data, and highlights the tension that Indigenous communities feel between protecting Indigenous rights pertaining to Indigenous health data and in supporting data initiatives within health contexts.

3.2.4 Legal challenges and concerns

Data sharing may pose legal challenges for Indigenous communities. Considering the sensitive nature of health data and the many ways these types of data can be used, there are concerns about data ownership, data use and data access. Misuse of data and data breaches can harm Indigenous communities and adversely impact their overall health and wellness. In the past, there have been instances where Indigenous peoples have had to take legal action in order to retain ownership and control of their data.[26]

3.2.5 Ownership, control, access, and possession

Related to that, ensuring access to data is also an ongoing issue for First Nations, Inuit and Métis peoples as many Canadian institutions have created barriers that keep Indigenous peoples from accessing their own data. First Nations, Inuit and Métis peoples have the right to freely determine how health information about them is

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[22] Kukutai, Tahu, and John Taylor, "Data sovereignty for indigenous peoples: current practice and future needs." In *Indigenous data sovereignty: Toward an agenda.* ANU Press, 2016.

[23] Standards Council of Canada, “Canadian Data Governance Standardization Roadmap,” 2021, https://www.scc.ca/en/system/files/publications/SCC_Data_Gov_Roadmap_EN.pdf.

[24] Kate McBride, “Data Resources and Challenges for First Nations Communities” (Alberta First Nations Information Governance Centre, 2017), https://www.afnigc.ca/main/includes/media/pdf/digital%20reports/Data_Resources_Report.pdf.

[25] Caroline Alphonso, “Natives and Doctor Locked in Blood Feud,” *The Globe and Mail*, September 22, 2000, https://www.theglobeandmail.com/news/national/natives-and-doctor-locked-in-blood-feud/article1042542/.

[26] Kate McBride, “Data Resources and Challenges for First Nations Communities.” The Alberta First Nations Information Governance Centre., 2017.

collected, used and shared. Data and information about individual and community health and wellness are critical tools for self-determination.

The Canadian government and all other institutions working with First Nations, Inuit, and Métis data must use Indigenous data sovereignty principles that are rooted in an understanding that Indigenous peoples have sovereign rights and the fundamental authority to own and govern their data, regardless of where their data is housed. Furthermore, there is also concern about the ways their health data is shared and the risk for data breaches.[27] Ultimately, Indigenous peoples need to have an assurance that their health data can be securely stored and is compliant with Indigenous data sovereignty and data governance principles like OCAP®, OCAS, and Inuit Qaujimajatuqangit (see 'Appendix A: Glossary' for more information).

3.2.6 Relevance

Often, indicators and measurements that make up health data pertaining to Indigenous peoples are not culturally rooted or relevant. The process of collecting and analyzing Indigenous health data is crucial to ensuring the information collected is relevant and accurate to each specific Indigenous community.[28] Indigenous worldviews emphasize a holistic approach to understanding health and well-being. If an Indigenous worldview is not foundational to the data collection processes and activities, the findings will be incomplete and may even be unacceptable to Indigenous communities. The reality is that colonialism, racism, and inequity in healthcare impact how data about Indigenous peoples are collected and represented. It is essential that all data collection is built on a strong foundation of trust and relationships to minimize the potential for harm and to ensure the respectful collection and use of Indigenous health data.[29] This is supported when Indigenous communities and Nations have established and accepted processes to determine the suitability and necessity of data collection activities.

Further, in order to effectively utilize health data, Indigenous health agencies, communities, and organizations require more human resources, technological infrastructure, funding, and training to incorporate health information management systems that ensure high quality data collection and effective management/use of data. It is important that all parties work together to enable ethical use of health data, and to do it in culturally relevant and appropriate ways. These initiatives must ultimately be rooted in Indigenous principles of data sovereignty and data governance.

4. HEALTH DATA GOVERNANCE

Now that we have shared a basic understanding of health data, its collection and use, and benefits and barriers of health data use, let's move forward to discuss health data governance.

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[27] Tahu Kukutai and John Taylor, "Data sovereignty for indigenous peoples: current practice and future needs." In *Indigenous data sovereignty: Toward an agenda*. ANU Press, 2016.
[28] Kate McBride, "Data Resources and Challenges for First Nations Communities." The Alberta First Nations Information Governance Centre., 2017.
[29] Ibid.

4.1 BACKGROUND OF HEALTH DATA GOVERNANCE

4.1.1 What is health data governance?

Health data governance is a component of information governance which refers to the overall management, collection, and use of health data. It applies to what decisions about data must be made, how they are made, and who makes them. Indigenous health data governance is a core foundational component in realizing Indigenous sovereignty, self-determination, and health transformation.

4.1.2 Historical governance of Indigenous health data

Historically, Indigenous health data has been governed by external colonial governments. These external parties decided what topics would be studied, what type of data was collected, how to collect it, how to report on it, and how it is used. All of this was done without the knowledge or permission of Indigenous Peoples, who were seen as subordinates within this colonial paradigm. This governance structure did not necessarily benefit Indigenous peoples and often caused harm.[30]

Further, Western research was seen as superior and did not adequately recognize Indigenous oral history, science, and/or knowledge transfer. Data was not owned by Indigenous peoples and collection was not relevant to community, as it was not aligned with community aspirations, needs, realities, or priorities, and did not consider Indigenous principles, values, or traditions. While data was ‘taken’ from communities, there was often little benefit to those communities. In addition, there was also often a lack of transparency, reciprocity, and data stewardship. Also, data was often aggregate data, rather than disaggregated. This lumps First Nation, Inuit, and Métis data together as one, not recognizing their distinct cultures, misrepresenting them, and making it impossible for distinct groups to use their own information in a meaningful way. Finally, data was – and still is – often framed in a way that focuses on negative aspects of Indigenous health and contributed to harmful narratives about Indigenous peoples.[31]

While some of these realities still linger, there have been important commitments and actions taken by provincial, territorial, and federal governments to reconcile these negative aspects of historical health data governance of Indigenous peoples. These efforts have largely been a result of the long-time and pain staking efforts of Indigenous peoples to hold governments accountable to recognize their inherent human and Indigenous rights to sovereignty, self-determination, and self-governance.

4.1.3 A path forward for Indigenous health data governance

Indigenous data governance is now recognized by many governments in Canada as a key component of Indigenous self-determination and sovereignty which supports improved Indigenous health outcomes.

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[30] Ibid.

[31] Kathleen Heggie, “Indigenous Wellness Indicators” (Health City Scholar, 2018), https://sustain.ubc.ca/sites/default/files/2018-62%20Indigenous%20Wellness%20Indicators_Heggie.pdf.

Recent commitments by provincial, territorial, and federal governments towards Indigenous sovereignty, and self-determination have supported an increase in efforts to improve Indigenous health data governance. This includes the endorsement of The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), which contains:

- **Article 3:** "Indigenous peoples have the right to self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development."

- **Article 23:** "Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions."[32]

Principles for data sovereignty and data governance have been developed by Indigenous organizations to further these rights. These include the First Nations principles of OCAP® (ownership, control, access, and possession), the Manitoba Métis principles of OCAS (ownership, control, access, and stewardship), and Inuit Qaujimajatuqangit (translated to "that which Inuit have always known to be true").

These principles reflect the rights, means, and practices for Indigenous peoples to control data about their lands and communities and include both individual and collective rights to access and privacy of data. In short, these principles give jurisdiction to, and support the rights of, each Indigenous group to govern the collection, ownership, and use of its data.

In addition to these commitments and principles, many policies and guidelines have also been developed around Indigenous data and health data with the aim of collecting and using Indigenous data in a way that minimizes harm and the historical challenges mentioned above, while maximizing benefits to communities. Inclusion of these principles and guidelines in implementation of community data governance programs is key to ensuring Indigenous rights in data governance are upheld, and efforts in Indigenous self-determination and data sovereignty are furthered.

A helpful resource which supports this positive path forward in strong Indigenous health data governance is the Data Governance Framework created by the BC First Nations Data Governance Initiative (BCFNDGI). It can be used as an example and template to draft a framework for data governance in your community or organizational setting based on the aims and principles above.

Key to this framework is setting up:

- Data Governance Vision and Principles;
- Governance Structure;

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[32] United Nations. United Nations Declaration on the Rights of Indigenous Peoples (2007).

- Accountability Mechanisms; and
- Data Governance and Privacy and Security Policies.

More information on these topics is also found within the following sections.

4.2 KEY COMPONENTS OF HEALTH DATA GOVERNANCE

In addition to a strong Data Governance Framework, based on Indigenous principles, policies, and guidelines, privacy protection and developing principles and agreements around data sharing are also key to ensuring strong health data governance. Privacy and security of health data must properly manage two competing benefits: an individual's or community's right to protect their information, and the need to collect, use, and share data for reasonable and beneficial purposes. Background and resources to ensure privacy protection and reasonable data sharing are found below.

Each governing body is responsible for developing their own policies and procedures and ensuring that they are consistent with relevant legislation (see Appendix B). These are of particular relevance when entering into partnerships with government and other institutions, which will also require developing additional agreements and contracts which are also discussed at the end of this section.

4.2.1 Privacy protection and privacy agreements

Privacy is the right of an individual, or groups, to control access to their personal health information. It implies an understanding of the purpose and means of data collection, storage, and use, and how individuals or groups can control access to the information collected. Every organization that collects and stores information has an obligation to uphold those rights through privacy protection. Privacy protection is governed through legal frameworks and legislation and Indigenous governments have jurisdiction over the management of information which they hold. Though privacy protection regimes vary, they should be informed by the following key principles:

- Ensuring Free, Prior, and Informed Consent (FPIC) for collection, use, and disclosure of information;
- Accountability to comply with privacy policy, legislation, and principles;
- Identification of the purpose of data collection and use;
- Limiting amount of information collected, including identifiers to that only necessary for the specified purpose;
- Limiting use, disclosure, and retention, of information to that only required for the specified purpose;
- Ensuring information is accurate, complete, and up to date; and
- Safeguarding information through security measures.

Privacy policies need to be in place to ensure these principles are followed and that privacy and security measures are clear, implemented, and maintained in order to prevent unsolicited access to personal and community information. Generally, policies around privacy protection will include, at minimum, clear stipulations on:

- Access to and management of data;

- Prevention of unauthorized access;
- Monitoring of compliance to policies;
- Protection against data loss;
- Data retention and disposal; and
- Awareness measures for clients and partners regarding the collection, use, and disclosure of information.

Examples of privacy policies include:

- The Government of Yukon's Access to Information and Personal Health Information Policy
- The Government of Yukon's Use of Personal Health Information Policy
- FNIGC Privacy Policy
- Indigenous Works Privacy Policy
- British Columbia First Nations' Data Governance Initiative (BCFNDGI) Privacy and Security Policy Manual, which includes a set of templates that can be adapted for use.
- First Nations Centre (FNC) Privacy Toolkit, which includes a Model Privacy Code (see p.15), and a step-by-step Plan of Action (see p.7) to protect community health information. While privacy policies will be informed by the needs and values of each community, they will also need to consider integration with federal and provincial partners and existing privacy legislation. The Privacy Toolkit also provides information about applicable legislation around privacy protection and a table of forms of privacy protection offered by Indigenous, federal, provincial/territorial, and other jurisdictions (see p.5-6).

Particular to the North, government legislation around privacy of health data is informed in the Yukon by the Health Information Privacy and Management Act, and in the NWT, the Health Information Act. There is no territorial legislation specific to health data yet in Nunavut, though rights to access any type of information health by the Government of Nunavut and public bodies is governed under the Access to Information and Protection of Privacy Act (ATIPP).

Further information about legal considerations and relevant legislation to privacy protection can be found in 'Appendix B: Relevant Legislation'.

4.2.2 Data sharing and data sharing agreements

Recognition of the importance of data sharing has been steadily growing and as such, collaboration around data sharing and data linkages have been increasing and improving in recent times. Sharing data ensures more robust information, informed by both Indigenous and non-Indigenous perspectives, is available for users to work towards improving health outcomes.[33]

As already described, there is a history of unethical data collection involving Indigenous people that creates an unequal relationship of power. However, well-designed data

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[33] Jeanette Steffler, "The Indigenous Data Landscape in Canada: An Overview." Aboriginal Policy Studies 5, no. 2 (January 31, 2016). https://doi.org/10.5663/aps.v5i2.26992.

sharing agreements can support a power shift in the relationship between Indigenous communities and partners.[34] They can maximize benefits to community, lead to relevant and meaningful conclusions for the community, and ensure that partners comply with privacy and ethics codes.

Importantly, some organizations who specialize in data repository have experience and expertise in working with Indigenous communities and have become “data stewards” for Indigenous communities they have entered agreements with. Data stewards are intermediaries which hold the relevant data and share it with communities while following community and legal protocols. In this way, developing data sharing agreements with data holders and communities can reduce strain on community resources while upholding data sovereignty.[35]

Data sharing agreements will be unique in each case, as there are many factors to consider. Some of the factors to consider when developing a data sharing agreement include but are not limited to:

- The type of organization or institution the agreement is being made with;
- The legislation on privacy and freedom applicable to the specific partner(s);
- If data sharing is meant to be one-sided or mutual;
- Who will maintain ownership of data if it is ‘blended’ with data from other sources and partners;
- The type of data to be shared;
- The need and purpose of sharing the particular data;
- How the data will flow between partners and others;
- Roles, available resources, and time frame for data sharing and use;
- Limits on use, disclosure, and retention of information; and
- Stipulations on ownership, analysis, and interpretation of data.

Some examples of data governance infrastructure and data-sharing agreements between various partners and Indigenous groups are provided below. These agreements and guidelines can support communities to develop their own data sharing agreements based on their unique values, situations, and needs:

- The Alberta First Nations Information Governance Centre’s (AFNIGC) Framework for a Data Sharing Agreement
- The Government of Yukon’s Information Sharing Agreement Guidance and Information Sharing Agreement Template
- The Northwest Territories Cumulative Impact Monitoring Program Traditional Knowledge Data-Sharing Agreement Sample Template
- The First Nations in B.C. Tripartite Data Quality and Sharing Agreement
- The NAHO Template for a Data-Sharing Protocol in their Considerations and Template for Ethical Research Practices (see p.30)

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[34] Robin P Love et al., "Developing Data Governance Agreements with Indigenous Communities in Canada: Toward Equitable Tuberculosis Programming, Research, and Reconciliation." Health and Human Rights 24, no. 1 (2022): 21.https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9212824/.

[35] Kate McBride, “Data Resources and Challenges for First Nations Communities.” The Alberta First Nations Information Governance Centre., 2017.

- The First Nations in Quebec and Labrador's Research Protocol Data Sharing Agreement Template (see p.76)
- The Central Coast Indigenous Resource Alliance's Information Sharing Agreement Template
- The Multi-Stakeholder Data Sharing Agreement for the Urban Indigenous Health Database Project
- The Manitoba First Nations Education Resource Centre Inc. (MFNERC) Template for Data-Sharing Protocol in Guidelines for Ethical Research in Manitoba First Nations (see p.35)

4.2.3 Other types of agreements and contracts

Besides privacy protection agreements and data sharing agreements, there are many other types of agreements and contracts that can support Indigenous health data governance and compliance with Indigenous data sovereignty and data governance principles. Many of these types of agreements are of particular importance when forming partnerships in data governance with other organizations, governments, or communities. The benefits of partnerships, and factors of successful partnerships, are discussed in Section 7.

One success factor and common practice is to formalize terms and conditions of a partnership through agreements and/or contracts. There are a variety of possible agreements (legally and non-legally binding) that can be developed depending on the type of partnership. These agreements can be developed, evolved, and changed over time as partnerships grow and partners have recognized how to improve their work with each other. The different types of agreements have different purposes.

The Indigenous Data Governance and Management Toolkit identifies the following six types of agreements useful in data governance project partnerships, and their relevance. Examples are also provided which can help to inform the development of these types of agreements relevant to each unique circumstance.

Table 3: Examples of partnerships agreements useful in data governance projects

Non-Disclosure/ Confidentiality Agreements: used to ensure confidentiality of information.	• Government of Yukon Sample Pledge of Confidentiality • Yukon University Sample Confidentiality Agreement for Research • The First Nations in Quebec and Labrador's Research Protocol Template for the Declaration of Confidentiality and the Conduct of Research (see p.86)
Memoranda of Agreement or Memorandum of Understanding: used to outline how partners will collaborate and work together.	• Memorandum of Understanding (MoU) between the Assembly of First Nations (AFN) and Crown-Indigenous Relations and Northern Affairs Canada (CIRNAC)

	• Intergovernmental MoU between the Northwest Territory Métis Nation (NWTMN) and the Government of Northwest Territories (GNWT) • Intergovernmental MoU between the Katl'odeeche First Nation (KFN) and the GNWT
Disclaimers: used as evidence to negate liability for harm caused by using information.	• Office of the Commissioner of the NWT Disclaimer • Nunavut Wildlife Management Board General Disclaimer • Northwest Territories Discovery Portal's Disclaimer, in Terms of Use
Consent: used to confirm free, informed, and prior consent of research participants.	• Nunavut Research Institute's Scientific Research Licence Application for Health Research Consent Form Template (see Section 6). • The World Health Organization's (WHO) Research Ethics Review Committee Templates for Informed Consent Forms The Centre for Indigenous People's Nutrition and Environment (CINE) at McGill University, in partnership with WHO, Indigenous Peoples & Participatory Health Research (see p.32-34). • NAC Template for Participant Consent Form (see p.11). • First Nations in Quebec and Labrador's Research Protocol Consent Forms (see p.86).
Information/Data Sharing Agreements: documents the type of information to be shared between partners and the purpose of sharing the information.	• Examples of data sharing agreements are included in Section 4.2.2 above.
Research Agreements: used to describe the terms and conditions of the research relationship between partners such as universities and other research institutions.	• Memorial University's Indigenous Research Agreement • Research Agreement between an Indigenous Community and CINE in the Indigenous Peoples & Participatory Health Research (see p.26) • Research Agreement Template in First Nations in Quebec and Labrador's Research Protocol (see p.57). • NAHO Template for a Collaborative Research Agreement in their Considerations and Templates for Ethical Research Practices document (see p.21).

	- MFNERC Template for Collaborative Research Agreement in Guidelines for Ethical Research in Manitoba First Nations (see p.23).

4.3 TERRITORIAL CONSIDERATIONS

Besides Federal, Provincial, and Territorial legislation around data governance and privacy protection, it is also important to note that all research conducted in the NWT requires a license or permit. Depending on the type of research it may require multiple licenses. Licensing ensures that the following research policies set out by the GNWT and Aurora College are followed:

- The Scientists Act
- Aurora College Research Policy
- The NWT Science Agenda

Aurora College provides useful information on the types of research licenses required based on thematic area, guidelines on doing research in NWT, and on the application process to obtain required licenses and permits through the POLAR system on their About Licensing Research and NWT Research Policies webpages.

Similarly, no scientific research (including health research) in or based in Nunavut is possible without obtaining a license or permit, under the territorial legislation of the Scientists Act. NAC and the Nunavut Research Institute provides guidance on how to obtain a research license, and specifically for health research in their publication Obtaining a Research License under Nunavut's Scientists Act: A Guide for Applicants (see p.12). The application for health research can be completed on Nunavut Research Institute's webpage.

5. DEVELOPING A COMMUNITY VISION

Now that we have gone through the data governance background and some of its key principles and components, where do we start in developing a community vision for health data collection and use?

Developing a community vision of health and wellness is key to providing direction on achieving the future you want for you community. A vision statement is used to guide strategic planning, decision making, and leadership. It is the starting point to work towards developing measures, objectives, goals, and actions that work towards realizing that future.[36]

Below are some examples of vision statements of Northern Indigenous communities:

- NunatuKavut Vision Statement[37]

"Our Vision is to govern ourselves, providing and caring for one another, our families, and our communities while nurturing our relationship with our land, ice, and waters.

Immminik aulatsiluta, sakKititsiKattavugut amma ikKasotiKatigeKattavugut, ilagijattinut, amma nunagijattinut piguvalliaKullugit ilagennigijavut nunattinut, sikumut amma imannut."

- Deh Gáh Got'ie Dene First Nation Vision Statement[38]

"We the Tthets'ek'ehdeli Got'ie, are proud of our Dene traditions, language, and beliefs. We value and respect the land, water, and animals that have sustained us for many generations. We shall continue to use and respect our natural resources. Building on the knowledge and skills of our people, we shall work together to create a healthy, sustainable future for ourselves and our children. We shall strive to find a balance between the traditional and modern ways of life."

5.1 DEVELOPING A VISIONING PROCESS

A community vision can be developed through any community planning processes, that meaningfully engages numerous community members to ensure community-wide relevance. It can be developed as part of a larger comprehensive community plan, but can also be developed on its own, and can guide the formation of a community plan in the future if you do not already have one.[39]

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[36] Nishnawbe Aski Development Fund, "COMPREHENSIVE COMMUNITY PLANNING TOOLKIT" (NADF, 2018), http://www.nadf.org/upload/documents/ccp-toolkit-2018-v2.pdf.

[37] Nunatukavut, "Our Vision at NCC." Accessed August 18, 2022.

[38] Dehcho First Nations, "Tthets'éhk'edélî First Nation." Accessed August 18, 2022.

[39] "FIRST STEPS: VISIONING AND MAPPING A PATH FORWARD," DGMT Data Governance Management Toolkit, accessed August 26, 2022, https://indigenousdatatoolkit.ca/getting-started/first-steps-visioning-and-mapping-a-path-forward/.

By engaging the breadth of diversity within a community, the visioning process can bring people together to express their hopes for the future, and inspire them into action towards a positive common goal.

Exploring five key questions can help guide community members to think deeply about what matters to them and how they envision an ideal future.

- What kind of community and people do we want to be in the future (5, 10, 20, 200 years)?
- Compared to now, what do we hope will change, or be different in our community?
- What are we proud of within our community?
- What do we hope will stay the same?
- How would we like our community to be viewed by others?

It is important to really dig down into these questions and get very specific. There are many things to think about, from social relationships, to values, to how each aspect of a positive future relates to each other, as well of what may need to be discarded, renewed, preserved, and protected. It is also important to consider the breadth of social and ecological determinants of health and wellness when considering a vision that is comprehensive and encompasses all desired aspects of a desired future.

If your community does not yet have a community vision, or vision of health and wellness, the Nishnawbe Aski Development Fund (NASDF) has produced a Comprehensive Community Planning Toolkit which includes step-by-step guidance on developing a community vision (see p.77). This can be used to support the development of a community vision of health and wellness either alone, or as part of a comprehensive community development plan.

Once a vision of community health and wellness is defined, its components can be broken down into goals. Objectives can then be developed to meet these goals, and outcomes can be defined to meet objectives. Finally, indicators will need to be developed to measure progress towards these outcomes using data (see Section 5.3).

5.2 DEVELOPING A COMMUNITY VISION AND VALUES FOR HEALTH DATA

Beyond a community vision, it important to also have a clear vision specific to health data governance within the community. Like a community vision, a health data governance vision needs to be based on community values and have specific objectives that can be actioned to work towards that vision. This vision set the stage for all data governance work in your community.

Below are examples of visions statements towards Indigenous data governance and research:

- Inuit Tapiriit Kantami (ITK) Vision Statement for Inuit Nunangat Research[40]

  "Inuit envision research producing new knowledge that empowers our people in meeting the needs and priorities of our families and communities. We see achieving self-determination in research as the means for ensuring that research governance bodies, policies, and practices are consistent with this vision."

- British Columbia First Nations Data Governance Initiative Vision Statement[41]

  "Nations govern and protect all Nation data and information wherever it resides, supporting the needs of the Nation, communities, Nation Organizations, and Members as well as the needs of the partners we collaborate with."

Specific objectives will need to be defined in order to meet these visions. As an example, ITK's National Strategy on Inuit Research lists four key priorities areas in relation to their vision[42]:

- Advance Inuit governance in research;
- Enhance the ethical conduct of research;
- Align funding with Inuit research priorities; and
- Ensure Inuit access, ownership, and control over data and information.

An example of objectives from ITK's National Strategy on Inuit Research first priority area is found listed in Table 3.

Table 4: ITK National Strategy on Inuit Research Priority 1 Objectives

ITK NATIONAL STRATEGY ON INUIT RESEARCH - OBJECTIVE EXAMPLES

Priority 1: Advance Inuit governance in research

Objectives:

- Achieve greater Inuit representation and decision-making in research governance, including the Tri-Council Agencies
- Reform research-related legislative, regulatory, and policy mechanisms impacting Inuit Nunangat
- Advance Inuit research priorities through Inuit Nunangat research governance bodies
- Ensure Inuit self-determination in establishing research governance bodies, including selection processes
- Establish accountable, coordinated, and transparent approaches to Inuit Nunangat research.

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[40] Inuit Tapiriit Kanatami, "National Inuit Strategy on Research." Ottawa, ON: Inuit Tapiriit Kanatami, 2018.
[41] BC First Nations Data Governance Initiative, "Data Governance Tools." Accessed August 18, 2022.
[42] Inuit Tapiriit Kanatami, "National Inuit Strategy on Research." Ottawa, ON: Inuit Tapiriit Kanatami, 2018.

As mentioned, it is important that Indigenous health data governance visions and principles consider and reflect community values. Each community will have its own set of values.

An example of Inuit societal values from the Government of Nunavut[43] is below:

- Inuuqatigiitsiarniq: Respecting others, relationships and caring for people.
- Tunnganarniq: Fostering good spirits by being open, welcoming and inclusive.
- Pijitsirniq: Serving and providing for family and/or community.
- Aajiiqatigiinniq: Decision making through discussion and consensus.
- Pilimmaksarniq/Pijariuqsarniq: Development of skills through observation, mentoring, practice, and effort.
- Piliriqatigiinniq/Ikajuqtigiinniq: Working together for a common cause.
- Qanuqtuurniq: Being innovative and resourceful.
- Avatittinnik Kamatsiarniq: Respect and care for the land, animals, and the environment.

Further, Indigenous Data Governance and Management Toolkit's Creating a Vision, Principles, and Objectives for Data Governance & Management document provides a useful guide to developing a vision, principles, and objectives for self-governing Indigenous governments in regards to governance and management of socio-economic data. This resource can be used and adapted to a community data governance context.

In short, their guidance includes the following steps in the development of vision, principles, and objectives:

- Determine who should be involved in the visioning process. This can include data governance partners, community members, leadership, and staff, and anyone affected by health data governance;
- Review and build from existing community health and wellness plans and visions. This will ensure the health data governance plan aligns with the overall community vision of health and supports working towards those goals;
- Consult with those identified in the visioning process. Information from these groups will support decision makers to develop vision, principles, and objectives, which reflect valuable feedback from those involved and affected.
- Develop the vision, principles, and objectives, with decision makers based off of information from the above steps;
- Communicate what you have developed to all those involved and affected; and
- Finally, implement the health data governance vision, principles and objectives, through standardized practices.

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[43] Government of Nunavut, "Inuit Societal Values | Government of Nunavut." Accessed August 18, 2022. https://www.gov.nu.ca/information/inuit-societal-values.

5.3 DEVELOPING WELLNESS INDICATORS BASED ON COMMUNITY VISION AND VALUES

This section will help you to understand the basics of indicators including what they are, what they are used for, types of indicators, which indicators reflect your community vision and values, and how to develop a set of comprehensive and practical indictors to capture a holistic picture of community health and wellness.

5.3.1 What is an indicator and how do we use them?

At its most basic, an indicator is a data-based measurement that tells us about a situation or state of something. Indicators can be used to measure outcomes, track performance and progress towards goals, and support decision making, through evidence-based understanding. Usually, indicators are measured using a number or percentage. They can also be measured using descriptive information, for example, stories. Some examples of common indicators used to measure community wellness include health status, unemployment rates, crime rates, etc.

5.3.2 What should we measure?

Historically, what we measure becomes the priority. For example, if increasing efficiency of our healthcare systems is a goal and it is measured based on the length of wait lists, efforts will go into reducing wait times; If the goal is poverty reduction, and the measurement is based on income, efforts will go into increasing employment and wages. It is therefore important to first understand community vision, values, and goals before defining the outcomes that we are trying to measure. Once we know what outcomes we want to achieve, we can develop or select appropriate indicators to measure and track those outcomes. Types of indicators to draw from are described below.

5.3.3 What types of indicators are relevant to health and wellness?

A. Health Outcome Indicators

Traditional health outcome indicators are generally designed to measure population health or health system performance. These important indicators are more ‘classic’ indicators, that are narrowly focused on health from a settler perspective. Regarding health status, they often focus on physical aspects of health that can be quantified. For example, life expectancy, infant mortality, or rates of chronic disease. Examples of health systems performance indicators might be, percent of people immunized against a disease, regular access to a doctor, or effectiveness of a health service. Traditional health indicators also measure things like determinants of health, like smoking, amount of physical activity, or exposure to pollutants.

B. Indigenous Wellness Indicators

While there is very good rationale for measuring health outcomes like life expectancy, infant mortality, rates of chronic diseases, etc., it is worth questioning whether these types of metrics alone are telling the complete story of health and wellness from

Indigenous perspectives. In addition, traditional health indicators often focus on measuring negative aspects of a population, such as rates of substance abuse or unemployment. While this information is important to know, what is missed when these are the only narratives about communities are the valuable stories of community strength and resiliency. A deficits focused approach risks reinforcing harmful and narrow narratives about Indigenous peoples. In contrast, Indigenous indicators are more often strengths based and allow communities to tell their own story about their own people, on their own terms - an important aspect of self-determination.[44]

Indigenous indicators are developed by Indigenous peoples and groups to measure community wellness based in Indigenous worldviews and values. Where some cultures may think of “health” as just the absence of disease, an Indigenous community may view health and wellness of the human population as just one part of the overall health and wellness of the community.

For example, the Inuit Circumpolar Council webpage offers insight into an Inuit perspective of health and wellness which recognizes that mental and physical health are intertwined, and intricately connected to community health and the health of the land. Recognizing the strong connections between the health of Indigenous Peoples and the health of the land, it may also be wise to also consider indicators which measure ecological determinants of health, such as the state of the air, water, wildlife, ecosystems and climate change.

Similarly, the FNHA provides a visual depiction and detailed description of their holistic and comprehensive Perspective on Health and Wellness based on First Nations culture and worldview. This model can be adapted and customized freely to meet the vision and values of each unique culture and community.

C. SDOH indicators

Social determinants of health (SDOH) are non-medical factors that influence health outcomes. They encompass the social environment and conditions we live in from birth to death, and are shaped by the systems which surround us, such as social norms, policies, and politics, which influence (and are influenced by) the distribution of money, power, and resources.[45]

SDOH can include things like income, education, employment, food security, and housing among many other factors. Indigenous peoples’ health and wellness is also affected by a range of historical and culturally-specific factors, including colonization, loss of language, and racism. ITK has identified eleven factors as key social determinants of Inuit health, which can be found in their report on Social Determinants of Inuit Health in Canada (see p.8) as an example.

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[44] Kathleen Heggie, “Indigenous Wellness Indicators” (Health City Scholar, 2018), https://sustain.ubc.ca/sites/default/files/2018-62%20Indigenous%20Wellness%20Indicators_Heggie.pdf.

[45] World Health Organization, “Social Determinants of Health,” (World Health Organization, 2022), https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1.

SDOH can influence health outcomes and health equity in both positive and negative ways. In fact, there is increasing recognition that social determinants are prominent factors which can me more important than healthcare or lifestyle choices in influencing health.[46]

In some cases, health systems are beginning to include metrics to track and measure elements of the SDOH. Understanding how these elements are impacting health outcomes can be a powerful tool for communities and governments to advocate for programs addressing the SDOH. This also reflects a more holistic understanding of health and its relationship to social factors.

There are already many tried and tested health, wellness, and SODH indicators and survey questions available from existing resources. You can review the resources below which will help to develop and select the indicators most appropriate for your community, based on the identified community vision and values. It is also possible to adapt these indicators if they don't quite match the outcomes that you are trying to measure.

- AFNIGC provides a guide to co-designing indicators to monitor and measure First Nations health in their publication Indigenous Health Indicators, which also includes a comprehensive set of health and wellbeing indicators.
- BCFNDGI also provides a guide to help develop and track indicators, as well as many sample indicators in Measuring Wellness: An Indicator Development Guide for First Nations.
- Indigenous Data Governance and Management Toolkit provides a guide to Designing Indicators using logic models.
- Statistics Canada has over 80 health indicators which are used to measure the health of the Canadian population and the effectiveness of the health care system, which can be found by following the links in their Health Indicators Data Tables and Definitions.
- ITK provides a report on Health Indicators of Inuit Nunangat within the Canadian Context, which reports on health indicators used by census, and analysis of health status of Inuit Nunangat over two distinct time periods.
- The City of Vancouver's provides information and examples on Indigenous Wellness Indicators, including urban Indigenous wellness indicators in the Healthy City Strategy.

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[46] Ibid.

6. ASSET MAPPING

A good way to understand where a community is presently at in their data governance journey is identifying and mapping the relevant assets and resources that already lay within community. This approach can be empowering for individuals and the community as it encourages people to focus on, recognize, use, mobilize, and build off the strengths and assets that already exist within community, rather than focussing on what does not yet exist. In these ways, it can support community engagement, increase internal capacity, and capacity for informed decision making. Importantly, it will ensure that health data governance is built starting at the community level, rather than externally, which supports efforts in sustainability of community health data governance while fostering long-term efforts in data sovereignty and self-determination.

When talking about assets we are referring to any resources within community that can be used within a health data governance framework. Assets may belong to an entire community, or they may be particular to individuals, groups, or organizations within a community. Assets may include existing resources that can support community data governance such as:

- Individuals, organizations, institutions, and networks;
- Skills, experience, and abilities;
- Heritage, knowledge, and beliefs;
- Infrastructure and equipment; and
- Existing data or data governance frameworks, policies, and procedures, and data.

For example, it is useful to know whether community members or organizations have worked with, have any experience in, or are interested and motivated to work in research development, data collection, data analysis, data management, or administration or communication, and with researchers and other partners.

Knowledge holders in this realm could also inform on the history, concerns, or benefits and best practices related to their past experience regarding data use, research, or partnerships for example. It would also be important to identify if there are any existing, policies, procedures, or frameworks related to or that could be relevant and or adapted towards community health data governance.

The table below provides a summary of several approaches to formal asset mapping that may be helpful in identifying the existing resources within your community.

Table 5: Summary of key asset mapping approaches

	Method(s)	Output type	Strengths	Limitations
ABCD Asset-Based Community Development	Community meetings; group interviews; focus groups; workshops; surveys; individual interviews	Process and spatial (e.g., asset wheel, skills inventory)	Emphasis on community empowerment and collaboration	Lack of clearly defined process, particularly in mobilising results or the role of external organisations; Does not account for power imbalances within community
UAI Unitary Appreciative Inquiry	Dialogue and reflection	Process	Emphasis on holistic perspectives, emancipation/ self-transformation	Methods, analytical approach poorly defined Lack of tangible output Limited applicability to large group contexts
PIRHANA Participatory Inquiry into Religious Health, Assets, Networks, and Agency	Defined four-step process based on separate workshops with community members and with area/ regional/ national leadership	Process and spatial (e.g., spatial database of RHAs, or Religious Health Assets)	Makes direct links between religion/faith and health and wellness Designed for use in diverse cultural contexts	Lack of clarity on what constitutes an RHA Need to take care in adapting and translating concept of RHA to local contexts Assumes all community members want

				to collaborate and participate equally
CHAMP Community Health Assets Mapping for Partnerships	Mix of qualitative and quantitative techniques in targeted community forums or workshops (adapted from PIRHANA)	Process and spatial (e.g., thematic analysis of community members' views of local health services; map of health services provided in local community)	Purpose is to create connections between community health assets and health facilities Designed for use in diverse cultural settings	Assumes all community members want to collaborate and participate equally
SLA Sustainable Livelihoods Approach	Mix of quantitative and qualitative methods, including key informant interviews, PRA techniques, and household surveys	Process and policy output (e.g., reports for design of 'development interventions')	Based on recognition that all people have abilities and assets that can be enhanced to improve their lives	Little clarity on methods, analyses, or output; more useful as impact assessment tool
GIS Geographic information systems	Mix of quantitative and qualitative to visualise, analyse, and represent relationships between assets in spatial context	Spatial	Wide ranging application, powerful when combined with other approaches	Availability of technological equipment, software, user capacity
Photovoice	Photography, interviews	Process and spatial (e.g., images integrated with maps)	Facilitates power balances and builds trust	Representation of intangible assets

			Responds to cultural preferences	Cost and availability of equipment Risk of low participant retention

Once community assets and resources are identified and mapped, they can be assessed, built on, and mobilized to develop or strengthen the implementation of community health data governance. Gaps can also be identified which can inform where capacity can be built in community, and where partnerships would be beneficial.

7. BUILDING PARTNERSHIPS IN HEALTH DATA

7.1 PARTNERSHIP BEST PRACTICES

Once you understand what resources are in the community, and what gaps are present, you can decide if and how partnerships would be beneficial. Respectful and meaningful partnerships can help to fill gaps, build community capacity, improve and increase community relevant data and access to data, and ultimately, improve health outcomes.

7.2 RESPECTFUL, MEANINGFUL, AND MUTUALLY BENEFICIAL PARTNERSHIPS

Developing positive, ethical relationships and partnerships create opportunities of Indigenous communities and organizations in the area of health data. Although research partnerships can be complex, there are many benefits for all partners, and towards research outcomes that can be adopted at the community level. Respectful partnerships that are founded on, ensure, and recognize inherent rights of Indigenous peoples to self-determination and self-governance are able to change the trajectory of colonialism as well as provide Indigenous comminutes the benefit of becoming owners and managers of their own data that can be used to create a path forward for improved well-being.

Developing partnerships can also generate capacity to build and leverage Indigenous and community research capacity and to ensure relevance, mutual understanding, transparency, and access around health data collection, use, and management. In this way, researchers, government, and Indigenous community partners are equally and equitably informed to co-develop health interventions to support positive change which is most relevant to Indigenous communities, culture, and world view.

Many Indigenous communities and organizations are recognizing and benefitting from respectful data governance and research partnerships with researchers, government, and institutions. Increasingly, communities and organizations are taking the initiative to ethically collaborate with and mobilize Indigenous data governance with partners while ensuring respect of Indigenous rights and knowledge as outlined in UNDRIP, principles such as OCAP®, the report of The Truth and Reconciliation Commission, and Indigenous led guidelines and policies.

7.2.1 Examples of Respectful, Meaningful, And Mutually Beneficial Partnerships

- Research relationships in Inuit Nunangat have been evolving in recent years and have been increasingly beneficial to Inuit. ITK recognizes that both Inuit and researchers have benefited from the progressive development of meaningful partnerships between Inuit and researchers, governments, and academic institutions. Inuit have applied this research and pursued relevant research priorities. ITK continues to seek consistent research relationships across Inuit Nunangat to strengthen the impact and effectives of research in the region.[47]

- The Canada-Inuit Nunangat-United Kingdom Arctic Research Programme (CINUK) 2021-25, is one recent partnership between Inuit Tapiriit Kanatami, United Kingdom Research and Innovation (UKRI), POLAR Knowledge Canada, the National Research Council of Canada (NRC), Parks Canada Agency, and Fonds de recherche du Québec, that exemplifies the benefits of partnership that works towards improving the efficacy, impact, and usefulness of research taking place on Inuit lands in a way that recognizes and embraces the value and importance of undertaking research in a mutually respectful and empowering way with Inuit researchers and communities.[48]

- The Institute for Clinical Evaluative Sciences (ICES) also has many ongoing successful and mutually beneficial partnerships with a diverse range of Indigenous organizations and communities. The institution promotes Indigenous data principles and Indigenous rights to access and use Indigenous data to support Indigenous health and self-determination and is committed to Indigenous-driven data usage to promote wellbeing, healing, and effective policy for Indigenous peoples. As holders of Indigenous data, ICES works to be a trusted partner of Indigenous communities and organizations by supporting information needs and promote Indigenous-driven use of databases held at the institution. The institution also works with Indigenous partners to develop unique data governance agreements and processes which ensure that researchers work with Indigenous organizations when conducting research with Indigenous communities. ICES have also established a team to support response to community-initiated research priorities and answering community-initiated research questions.[49]

- The Urban Aboriginal Knowledge Network (UAKN) identifies their multiple partnerships as the root of their success. They have several layers of partnerships throughout Canada, including with communities, governments, academic institutions, and Friendship Centres. This has allowed UAKN to be increase effectiveness in improving the life of urban Indigenous Peoples through improving information gathering, knowledge exchange, and reconciliation.[50]

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[47] Inuit Tapiriit Kanatami, “National Inuit Strategy on Research” (Inuit Tapiriit Kanatami, 2018), https://www.itk.ca/wp-content/uploads/2018/04/ITK_NISR-Report_English_low_res.pdf.

[48] Canada, Polar Knowledge, “Successful Canadian, Inuit and UK Research Teams Announced For Major New Arctic Research Programme.” News releases, May 11, 2022. https://www.canada.ca/en/polar-knowledge/news/2022/05/successful-canadian-inuit-and-uk-research-teams-announced-for-major-new-arctic-research-programme.html

[49] Evelyn Pyper et al., “Walking the Path Together: Indigenous Health Data at ICES.” Healthcare Quarterly 20, no. 4 (January 20, 2018). https://www.longwoods.com/content/25431/walking-the-path-together-indigenous-health-data-at-ices.

[50] Urban Aboriginal Knowledge Network, “Partnerships.” UAKN. Accessed August 18, 2022. https://uakn.org/about-us/partnerships/.

7.3 KEY FACTORS OF SUCCESSFUL PARTNERSHIPS

Developing partnerships in community research and data governance will be unique in each circumstance. These are just a few examples of successful partnership initiatives, benefits, and approaches. Meaningful partnerships like these are based on respect for the aspirations of Indigenous communities, respect for data sovereignty, respect for culturally appropriate processes and protocols in research activities and data collection, capacity building, and framing traditional knowledge, culture, and worldviews as the foundation of the partnership and work.

Key factors in developing successful partnerships gleaned from the examples above and in the next section include, but are not limited to the following practices:

- Partnerships are guided by Indigenous community values, research principles, and governance protocols;
- Time is spent building trust in order for partners to undergo equitable discussions;
- Partnerships are made formal through agreements such as Memorandum of Understandings (MOUs), research agreements, data sharing agreements, and other types of agreements and contracts;
- Partnerships require full engagement and co-development at every stage of a project;
- Non-Indigenous partners are educated and trained in Indigenous sovereignty and data governance, including training regarding OCAP® and other principles, UNDRIP, and the TRC;
- There are clear roles, responsibilities, and communication lines between partners;
- All permissions are secured from Indigenous governance entities;
- Capacity building of Indigenous partners is included through recruitment/inclusion of Indigenous leaders, staff, and graduate students;
- Indigenous priorities, values, worldviews, and knowledge is centred and valued;
- Community engagement and feedback is prioritized to ensure richer relevant, higher-impact partnerships and projects; and
- Support and capacity are provided to Indigenous research teams and communities in the negotiation of data governance agreements.

The types of contracts and agreements will be dependent on the type and objectives of the partnership. Please feel free to rely on the examples and templates in Section 4 to guide you.

8. PROMISING MODELS

This section provides deeper insight into how these partnerships work in action through the description of several more detailed examples.

8.1 CHIEFS OF ONTARIO AND THE INSTITUTE FOR CLINICAL EVALUATIVE SCIENCES

The Chiefs of Ontario (COO) was established to support First Nations in Ontario as they assert their sovereignty, jurisdiction, and their chosen expression of nationhood. The mandate of the Chiefs of Ontario office is to facilitate the discussion, planning, implementation, and evaluation at local, regional, and national levels on issues affecting the First Nations people of Ontario.[51]

ICES is an independent, non-profit research institute that applies the study of health informatics for health research and health outcomes research in Ontario, Canada. The institute frequently works with Indigenous health data and Indigenous communities.[52] Indigenous-led use of the databases held at the ICES has resulted in ongoing partnerships between ICES and various Indigenous organizations, stakeholders, and communities. Considering the sensitivity and nature of Indigenous health data the ICES has developed a few guiding principles to ensure that Indigenous research and data is managed effectively and in culturally appropriate ways.

The COO and the ICES have established a data sharing agreement as of 2012.[53] The COO initiated the transfer of the federal Indian Register (IR) to ICES from Indigenous and Northern Affairs Canada and the linkage of the IR data to ICES' data holdings. This data agreement ensures that First Nations govern IR data at ICES.

The COO-ICES partnership emphasizes establishing ongoing partnerships with diverse Indigenous organizations and communities, consulting Indigenous partners to develop unique data governance and data sharing agreements, and are responsive and adaptive to various Indigenous partners and their perspectives.

In addition, the COO and ICES Works closely with other First Nations communities and organizations to ensure that First Nations' data sovereignty is upheld and has developed and implemented support processes for Indigenous partners and organizations access IR data. Lastly, the ICES Ensures that First Nations IR data is governed in accordance with OCAP® principles.

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[51] "About." Chiefs of Ontario, August 19, 2022. https://chiefs-of-ontario.org/about/
[52] ICES, "About," About ICES, accessed August 24, 2022, https://www.ices.on.ca/About-ICES
[53] Chiefs of Ontario, "Research," Chiefs of Ontario, accessed August 24, 2022, https://www.ices.on.ca/Research/Collaborations-Partnerships/Chiefs-of-Ontario

8.2 ESKASONI FIRST NATION

The Eskasoni First Nation is one of the fastest-growing First Nations communities in Canada.[54] At present, the Eskasoni First Nation is in the midst of a population boom and consequently there has been a need for more health and wellness programming within the Eskasoni community. Many of the programs introduced like the Aboriginal Head Start Program are funded by Health Canada’s First Nations and Inuit Health Branch (FNIHB). FNIHB primarily relies on the First Nations Regional Health Survey (RHS) for policy, planning, programming, and renewal purposes.

The health and wellness initiatives and programs within the Eskasoni First Nation community have benefited from the data collected by RHS. RHS data has been vital to the funding of many programs and initiatives for the community, from elder care and vaccine programs to housing and oral health initiatives.

8.3 TŁĮCHǪ GOVERNMENT AND DEDATS’EETSAA,

The Tłı̨chǫ Research and Training Institute Dedats’eetsaa was established by the Tłı̨chǫ Government in 2013. The institute’s mandate is to advance the study of Tłı̨chǫ lands, language, culture and way of life through research, training, education and monitoring.[55]

All the research and activities supported by Dedats’eetsaa are done within a Tłı̨chǫ cultural framework, ensuring that research projects have full community control and are built on meaningful partnerships with Tłı̨chǫ leadership and communities. The approach of Dedats’eetsaa includes:

- Supporting and facilitating research projects and activities to meaningfully involve elders and youth;
- Supporting and facilitating research projects and activities to build capacity and train Tłıchǫ researchers, students, and community liaisons;
- Developing and using Indigenous research design and community methodologies;
- Maintaining a website, which includes information about Tłı̨chǫ research, culture and history, and information about ongoing and past research projects in the region;
- Developing a Tłıchǫ digital database of oral history, maps, photographs, video and other documentary resources, and working with researchers who wish to use these resources;
- Reviewing research proposals submitted for licensing and providing support and assistance to licensed research projects;
- Coordinating ongoing research in social, health and wellness, cultural and environmental concerns in the Tłı̨chǫ region;
- Supporting and collaborating with research partners to conduct independent research on areas of interest to the Tłıc̨hǫ; and

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[54] Eskasoni, “About Us,” Eskasoni Mi'Kmaw Nation, accessed August 24, 2022, http://www.eskasoni.ca/About/

[55] John B Zoe, “Tlicho Research and Training Institute,” About Dedats'eetsaa, accessed August 24, 2022, https://research.tlicho.ca/about/about-dedatseetsaa

- Hosting the Tłı̨chǫ Digital Archives, a collection of digital, audio, video and document files on Tłı̨chǫ lands, culture and history.

Photo: Dedats'eetsaa Elder Advisors, [*https://research.tlicho.ca/about/elder-advisors*](https://research.tlicho.ca/about/elder-advisors)

9. CONCLUSION

The last few decades have ushered in a new and exciting era where Indigenous communities are pushing back against colonial narratives and in their place telling their own stories of challenges, survival, resilience, innovation, and brilliance rooted in Indigenous ways of understanding, being, and doing. The collection, use, and protection of health data by Indigenous communities themselves represents a foundational pillar in these changing narratives and in the advancement of Indigenous self-governance and rights to self-determination.

It is our hope that, no matter your level of knowledge or experience, you have found useful concepts, tools, and examples throughout the document and in the appendices that follow to support you on your data journey!

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USEFUL RESOURCES

Title	Organization	Description	Link
Considerations and Templates for Ethical Research Practices document	National Aboriginal Health Organization (NAHO)	Provides guidelines and templates for ethical research practices with First Nation, including on participatory research, codes of ethics, collaborative research agreements, and data sharing agreements and protocols.	https://ethicshub.ca/wp-content/uploads/2020/05/44-Template-for-a-Collaborative-Research-Agreement.pdf
Data Governance and Management Toolkit	SGIG Data Steering Committee	A comprehensive data governance and management toolkit for self-governing Indigenous governments. Provides resources, templates, and guidelines for data governance. Focussed on socio-economic data, but can be applied to governance of many types of data.	https://indigenousdatatoolkit.ca/
Data Governance Framework	British Columbia First Nations' Data Governance Initiative	Provides an example of how a Data Governance Framework can be drafted. It outlines the governance structures; accountability mechanisms; and governance, privacy, and security policies that work to prevent issues and protect individuals and their data.	https://static1.squarespace.com/static/558c624de4b0574c94d62a61/t/558c75a5e4b0391692159c81/1435268517023/BCFNDGI-Data-Governance-Framework.pdf

Framework for Data Sharing Agreement	The Alberta First Nations Information Governance Centre (AFNIGC)	A template or guideline that outlines the factors to consider and include when developing data sharing agreements between Indigenous Peoples and partners.	https://www.afnigc.ca/main/includes/media/pdf/community%20resources/Data_Sharing_Agreement.pdf
Guidelines for Ethical Research in Manitoba First Nations	Manitoba First Nations Education Resource Centre Inc.	A guideline and framework to provide direction for conducting research on Manitoba First Nations. The guideline provides templates for code of research ethics, collaborative research agreements, and data-sharing protocols, that can be adapted to different contexts	https://ethicshub.ca/wp-content/uploads/2020/05/37-Template-for-a-Collaborative-Research-Agreement.pdf
Health Indicators Data Tables and Definitions	Statistics Canada	Lists health indicators used by Statistics Canada, and includes definitions of each indicator and most recently available data	https://www150.statcan.gc.ca/n1/pub/82-221-x/2017003/dd-tdd-eng.htm
Indigenous Health Indicators	The Alberta First Nations Information and Governance Centre (AFNIGC)	Provides comprehensive information and guidelines on Indigenous health indicators, designing and selecting Indigenous indicators to monitor and measure health, and a comprehensive set of example health and wellbeing indicators.	https://www.afnigc.ca/main/includes/media/pdf/digital%20reports/Indigenous%20Health%20Indicators.pdf
Indigenous Peoples & Participatory Health Research	World Health Organization and the Centre for Indigenous People's Nutrition and	Provides guidance on how collaborative and ethical health research projects can be set up between Indigenous Peoples and research institutions. It focusses on development of research agreements and provides examples of research agreements and	https://www.mcgill.ca/cine/files/cine/partreresearch_english.pdf

	Environment (CINE) at McGill University	consent forms between research institutions and Indigenous Peoples, communities, and organizations.	
Indigenous Wellness Indicators	The City of Vancouver	Provides information and examples of Indigenous wellness indictors, as well as principles and guidelines to support the process of indicator development.	https://sustain.ubc.ca/sites/default/files/2018-62%20Indigenous%20Wellness%20Indicators_Heggie.pdf
Information Sharing Agreement Guidance	Government of Yukon	A guideline that outlines the factors to consider and include when developing data sharing agreements between the Government of Yukon and partners. Includes steps and a template to draft an information sharing agreement.	https://open.yukon.ca/data/datasets/guidance-forms-templates/resource/8d8a3888-72bc-4720-9a26-05001f445347
Negotiating Research Relationships with Inuit Communities. A Guide for Researchers	Inuit Tapiriit Kantami, Nunavut Research Institute	Provides practical advice to assist researchers who plan to work with Inuit communities in Nunatsiavut, Nunavik, Nunavut, and the NWT.	https://www.nri.nu.ca/sites/default/files/public/files/06-068%20ITK%20NRR%20booklet.pdf

Nindokiikayencikewin: to seek learning or Knowledges. Indigenous Knowledges and Data Governance Protocol	Indigenous Innovation Initiative	Provides understanding of Indigenous Knowledges and data, and guidelines on approaches to collecting and using Indigenous Knowledges and data. It can be used as a model for approaches to Indigenous Knowledges and data governance.	https://indigenousinnovate.org/downloads/indigenous-knowledges-and-data-governance-protocol_may-2021.pdf
NWT Research Policies	Aurora College Research Institute	Provides links to information on NWT research policies including The Scientist Act, The NWT Science Agenda, and Aurora College Research Policy	https://nwtresearch.com/research/nwt-research-policies
Perspective on Health and Wellness	First Nations Health Authority (FNHA)	This webpage provides a visual depiction and detailed description of FNHAs perspective on health and wellness, which is holistic comprehensive, and based on First Nations culture and worldview. This model can be adapted and customized freely to meet the vision and values of each unique culture and community.	https://www.fnha.ca/wellness/wellness-for-first-nations/first-nations-perspective-on-health-and-wellness
Privacy and Security Policy Manual	British Columbia First Nations' Data Governance Initiative	Contains Privacy and Security policies, procedures, and tools related to the management and protection of Nation data and privacy compliance	https://www.bcfndgi.com/s/BCFNDGI_-_FNDG_PRIVACY_AND_SECURITY_POLICY_MANUAL_TEMPLATE_V1.DOCX
Privacy Tool Kit	First Nations Centre	Provides an introduction to privacy in the First Nations context, gaps, principles of OCAP®, privacy protection legislation, privacy resources, and a model privacy code	https://icwrn.uvic.ca/wp-content/uploads/2013/10/FNC_PrivacyToolkit.pdf

Protocols and Principles for Conducting Research with Yukon First Nations	Yukon Research Centre, Yukon College	Provides recommendations and guidelines on conducting research with Yukon First Nations people and communities. Includes ethical considerations, implications for research, protocols, and principles, and research application guidelines.	https://achh.ca/wp-content/uploads/2018/07/Protocol_YukonFN.pdf
Research in the North West Territories. Community Guide to becoming involved in research	NWT Association of Communities, and Pembina Institute	Provides a brief guide on conducting research in the Northwest Territories	https://smp.toolkitnwtac.com/wp-content/uploads/sites/32/2018/02/Community-Research-Toolkit_final.pdf
The First Nations Principles of OCAP® FAQs and training resources	First Nations Information Governance Centre (FNIGC)	The FNIGC webpage provides detailed information on the principles of OCAP® through a variety of FAQs as well as a link to training resources, including The Fundamentals of OCAP® online course.	https://fnigc.ca/ocap-training/
United Nations Declaration on the Rights of Indigenous Peoples	United Nations (UN)	UNDRIP is a non-binding international document that respects and recognizes the human rights of Indigenous peoples. The declaration reflects the minimum standards of Indigenous rights around the world and is intended to serve as a guide and benchmark in the review of a country's Indigenous rights performance. The Government of Canada officially endorsed UNDRIP in 2016, and the Parliament of Canada passed the UNDRIP Act in 2021.	https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf

APPENDIX A: GLOSSARY

Aggregate data	Data presented in a summarized fashion, rather than individual data points for individuals. Aggregate data is often used to tell a more complete story of a community.
Administrative data	Data collected and used as a part of delivering government (Indigenous, provincial/territorial, federal) programs. One common example is the use of financial data from Indigenous Services Canada's (ISC's) Non-Insured Health Benefits Program (NIHB). We can better understand some aspects of Indigenous health by looking at expenditures within the NIHB program.
Best practices	Best practices are examples of ways of doing things that have been determined to be successful.
Community Assets	When talking about assets in this context we are referring to any resources within community that can be used within a health data governance framework. Assets may belong to an entire community, or they may be particular to individuals, groups, or organisations within a community. Assets may include existing resources that can support community data governance such as individuals, organizations, institutions, and networks; skills, experience, and abilities; heritage, knowledge, and beliefs; or existing infrastructure.
Data	Data is structured information that is collected and can include stories, facts, measurements, and observations. It can include either qualitative or quantitative data. **Qualitative data** is often generated through first-hand observation, interviews, questionnaires, focus groups, and storytelling, etc. The results are generally not numerical (counting things). **Quantitative data** usually involves a measurable quantity. Generally, this means measuring something through counting such as numbers of people who are employed, or life expectancy in years.
Database	A database is a structured collection of data that has been organized to make it possible to manage and use. A database can be as simple as a spreadsheet in Excel.
Data governance	In general, data governance refers to what decisions must be made, how they are made, and who makes them, related to the effective management and use of data.

Data linkages	Data linking is when two or more data sets are merged. For example, a First Nation may work with the health authority to link their membership data to the data available through the health authority. This would allow the community to have a specific and localized picture of their health and wellness.
Data literacy	Data literacy is the ability to understand, create, and communicate data in context, and derive meaningful information from data. In the context of big data, it often means that data literacy requires some capacity in statistics and mathematics.
Data management	Data management refers to the field of management responsible for decision-making and execution of plans related to the planning, monitoring, managing, and oversight over data and data collection.
Data sharing agreement	A formal agreement to share data according to certain terms and conditions. They often include descriptions of the roles and responsibilities of the signing parties.
Data steward	Individuals, departments, or organizations who are responsible for the storage, security and appropriate use of data. These are the people and groups responsible for ensuring data is collected, stored, and used in a manner consistent with the principles and values determined by the community.
Electronic Medical Record	At its most basic, an electronic medical record (EMR) is a digital version of a patient's paper medical record. EMRs often include a patient's medical history, diagnoses, prescriptions, allergies, tests, immunizations, and treatment plans.
Ethics Board	An ethics board or committee is a group that is responsible for ensuring that any proposed research or projects involving data are carried out in an ethical manner. Some Indigenous communities and organizations have developed formal or informal ethics boards to review proposed projects involving community data. One example is the Health Information Research Governance Committee (HIRGC) within the First Nations Health and Social Secretariat of Manitoba (FNHSSM).

Free, prior, and informed consent	Free, prior, and informed consent (FPIC) is a specific right of Indigenous peoples to give or withhold consent on a project that may impact them and/or their territories. FPIC is recognized and affirmed in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). • Free implies that consent is given free from coercion, manipulation, or intimidation; • Prior implies that consent is sought well in advance of the proposed start of the activities; • Informed implies that information about the proposed project is shared prior and throughout the project; • Consent is understood as a collective decision made by rights-holders reached through a process determined by the community themselves.
Health Information Systems (HIS)	A health information system (HIS) is broadly defined as a system that is designed to manage healthcare data, including integration of data collection, processing, reporting. This includes systems that collect, store, manage and transmit a patient's electronic medical record (EMR), a hospital's operational management or a system supporting healthcare policy decision.
Identifier	A piece of data, or a combination of pieces of data, that can be used to identify an individual. Examples include names, dates of birth, health card number, etc.
Indicators	At its most basic, an indicator is an observable concept or characteristic that can be measured. For example, some common indicators used to measure community wellness include unemployment rates, crime rates etc.
Indigenous Indicators	Indigenous indicators are developed by Indigenous peoples and groups to measure community wellness based in Indigenous worldviews and values. While more mainstream research tends to focus on things like employment as a measure of community wellness, Indigenous communities may instead measure things like language use and access to culture and the land as an indicator of community wellness.
Indigenous Data Sovereignty	The right of Indigenous peoples to access, collect, control, and utilize data that emerges from and about their communities, Nations, lands, and cultures.
Inuit Qaujimajatuqangit	Inuit Qaujimajatuqangit, often abbreviated to IQ, is an Inuktitut phrase that comes from the verb rooth “quajima” meaning “to know”. Inuit Qaujimajatuqangit could be literally translated as “that which has long been known by Inuit.” It is also often translated as “Inuit traditional knowledge” or “Inuit traditional

	institutions”. It is used to mean the integration of traditional culture of the Inuit more into their modern governance structure.
OCAP®	OCAP® are a set of principles established by the First Nations Information Governance Centre (FNIGC) that support First Nations self-determination over the collection, protection, use, and sharing of First Nations data. OCAP® stands for ownership, control, access, and possession. According to FNIGC: • Ownership refers to the relationship of First Nations to their cultural knowledge, data, and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information; • Control affirms that First Nations, their communities, and representative bodies are within their rights in seeking control over all aspects of research and information management processes that impact them; • Access refers to the fact that First Nations must have access to information and data about themselves and their communities regardless of where it is held. • Possession refers to physical control of the data. Possession is the mechanism by which ownership can be asserted and protected.
OCAS	OCAS is a set of principles similar to OCAP®, which are subscribed to by the Manitoba Métis. OCAS stands for ownership, control, access, and stewardship. Stewardship refers to the responsibility to Métis to ensure that research is done as rigorously and ethically as possible, in the best interests Métis, and will result in positive changes in Métis health and service delivery.
Social determinants of health	Social determinants of health (SDOH) refer to the non-medical factors that influence the health and well-being outcomes of individuals and communities. Common examples of SDOH include housing, education, employment, social services, and legal status. Indigenous peoples’ health is also affected by a range of historical and culturally-specific factors, including colonization, loss of language, and racism.
UNDRIP	UNDRIP is the United Nations Declaration on the Rights of Indigenous Peoples. It is a non-binding international document that reflects the minimum standards of Indigenous rights around the world and is intended to serve as a guide and benchmark in the review or a country’s Indigenous rights performance. The Government of Canada officially endorsed UNDRIP in 2016, and the Parliament of Canada passed the UNDRIP Act in 2021.

APPENDIX B: RELEVANT LEGISLATION

Title	Jurisdiction	Link	Description
Privacy Act	National	https://laws-lois.justice.gc.ca/eng/ACTS/P-21/index.html	The Privacy Act (PA) is the federal information-privacy legislation of Canada that came into effect on July 1, 1983. The purpose of the Act is to protect the privacy of individuals with respect to their personal information. The act gives individuals significant rights and control over the collection, use, and disclosure of personal information held by federal institutions, and prevents others from accessing that information. The Privacy Act only applies to federal government institutions listed in the Privacy Act Schedule of Institutions. The Act governs the federal government's collection, use and disclosure of information in the course of providing services such as: • Employment insurance; • Border security; • Tax collection and refunds; • Old age pensions; and • Policing and public safety.

Access to Information Act	National	https://laws-lois.justice.gc.ca/eng/acts/A-1/index.html	The Access to Information Act (ATIA) came in to affect in 1983 and applies to all federal government bodies. It gives individuals and corporations the right to request access to records that are under the control of federal government institutions. Under ATIA, the federal government is obligated to provide the information to requesters as long as that information is not exempt, excluded, of personal nature. In this way, the act also protects privacy as well as information that could damage public or private interests.
Personal Information Protection and Electronic Documents Act (PIPEDA)	National	https://www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/the-personal-information-protection-and-electronic-documents-act-pipeda/pipeda_brief/	The Personal Information Protection and Electronic Documents Act (PIPEDA) is a federal privacy legislation for private-sector organizations in Canada. PIPEDA was introduced in 2013 to promote trust and data privacy in the private sector and to govern the collection, use and disclosure of personal information in a manner that upholds the privacy rights of individuals. Under PIPEDA, individuals have the right to access the information the government has about them as well as request for corrections/ amendments to be made. The scope covered by PIPEDA includes: • Making inquiries about the collection or usage of personal Information by an organization; • Seeking advice on who within the organization is responsible For the protection of personal information; • Ensuring organizations use, collect, or disclose personal data in an appropriate manner;

			- Ensuring organizations follow consent regarding personal data and to adhere to proper protection procedures and techniques; and - Reporting the management of personal data within an organization if privacy rights are violated.
Statistics Act	National	https://laws-lois.justice.gc.ca/eng/acts/s-19/fulltext.html	The Statistics Act was passed by the Parliament of Canada in 1918 and was the foundation for the creation of Statistics Canada. The act requires and gives Statistics Canada the authority to collect, compile, analyze, and publish information on the conditions of its country and citizens, while also ensuring that statistics are scientific, impartial, and reliable. The analysis of collected information often supports public and private sector decision making and the development and evaluation of public programs. Under the act, citizens are obligated to provide information to Statistics Canada. However, recognizing the legal powers provided to Statistics Canada to collect information, the Statistics Act also requires Statistics Canada to protect the confidentiality of respondents, and makes a formal commitment to respondents that any information released will exclude identifiers, unless otherwise pre-authorized by the individual.
Health Information Act	NWT	https://www.justice.gov.nt.ca/en/files/legislation/health-information/healt	The Health Information Act is a territorial act introduced by the Northwest Territories in 2015. The Act sets out the rules for the collection, use and disclosure of personal health information.

		h-information.a.pdf	The Act is designed to protect health information and facilitate effective and secure health service provision. The Act is applicable in three contexts: • The use and access of personal health information; • Health data in the custody of a health information custodian; and • Health information in custody that was originally collected to deliver a health service. The Act applies to information held by a variety of organizations and individuals within the health care sector referred to as health information custodians. These health custodians include the: • Department of Health and Social Services (DHSS); • Health and Social Services Authorities (HSSAs); • Physicians who are not employed by the DHSS or HSSAs ("private physicians"); and • Pharmacists who are not employed by the DHSS or HSSAs ("private pharmacists")
Health Information Privacy and Management Act	Yukon	https://yukon.ca/healthprivacy#information-on-health-information-privacy-and-management-act-hipma	The Health Information Privacy and Management Act (HIPMA) was introduced in 2013 by the Government of Yukon. The purpose of HIPMA is to: • Establish secure and effective mechanisms to protect and manage personal health information; • Establish rules for the collection, use, disclosure, and security of health information; and

			- Provides individuals with the right to access their personal health information or request amendments of health information. In addition, the Act aims to improve quality and accessibility of healthcare in recognition that health care in Canada is publicly funded and provides a framework for the development of an electronic health information network. Lastly, HIPMA provides independent supervision by the Yukon's Information and Privacy Commissioner (IPC), to ensure compliance with all its provisions.
Access to Information and Protection of Privacy Act(s)	NWT, Nunavut, and Yukon	*NWT:* https://www.justice.gov.nt.ca/en/access-to-information-held-by-public-bodies/#:~:text=An%20Access%20to%20Information%20and,corrections%20to%20personal%20information *Nunavut:* https://www.nunavutlegislation.ca/en/consolidated-law/access-information-and-protection-privacy-act-	Each of the Northern Territories has its own Access to Information and Protection of Privacy Act (ATIPP). The ATIPP of each territory applies to information held by the territorial government. In general, the ATIPP(s) gives individuals the right to: - Request access to information held by the territorial government or other public bodies; - Provides individuals with the right to access and correct their personal information that is held by the territorial government or other public bodies; - Sets out specific guidelines about when the territorial government or a public body may collect, use and disclose personal information; and - Provides an independent review of decisions made under the ATIPP. The ATIPPs play a crucial role in maintaining government accountability, protecting personal information and establishing the territorial governments commitment to protecting privacy and providing access to information.

		official-consolidation *Yukon:* https://laws.yukon.ca/cms/images/LEGISLATION/PRINCIPAL/2018/2018-0009/2018-0009_1.pdf	