

Data Governance Discussion Paper: rolling draft

Objective: To advance BC First Nations collective interests related to data governance and information management, including research, surveys, administrative data, surveillance and data analytics and statistical functions.

BC First Nations Data Governance Initiative
First Nations Health Authority
First Nations Information Governance Centre

Contents

Purpose of the Paper	02
Demonstrated Need	04
Data Governance in Action: First Nations Health Authority Case Studies	06
Population Health and Wellness	08
Mandate for a National Strategy	10
Data in support of Self-determination	12
Canada's Open Government Plan	12
Social Determinants and Data	13
Measuring Relationships, Outcomes and Investments	15
Regional Information Governance Centres	16
A BC First Nations Data Governance Model	18
Data Governance and the First Nations Health Authority	20
Public Institutions and First Nations Data Governance: UBC Principles of Engagement	20
BC First Nations Common Data Governance Principles	22
Questions for Discussion	25
Additional Context	26

Purpose of this Paper

Almost 20 years ago, the Chiefs in national assembly expressed their desire to protect First Nations data – they committed to assert ownership and assume control over the access and possession of First Nations data generated by other governments and/or researchers. In 2010 the Chiefs supported the advancement of these interests through establishing the national First Nations Information Governance Centre (FNIGC). The FNIGC is an independent institution governed by a national board that is co-chaired by the national Assembly of First Nations. The FNIGC has expertise in data governance, survey administration, data protection, data collection and statistical analysis and reporting. The FNIGC oversees the Regional Health Survey and other national surveys and acts as the national First Nations data centre.

OCAP™- Ownership, Control, Access, Possession: asserting data sovereignty

The members of the national FNIGC Corporation are provincial/territorial First Nations organizations from across Canada. Collectively, representatives from these regional organizations govern the national corporation, providing strategic direction in the achievement of the national vision that **every First Nation achieves data sovereignty in alignment with their own, unique worldview**. In BC, the First Nations Health Authority (FNHA) is the regional organization that is the member of the FNIGC and they are also the current steward of data generated through the FNIGC sponsored national surveys such as the Regional Health Survey – the FNHA is the BC regional data centre.

The national FNIGC has received funding from Indigenous Services Canada to implement direction from the AFN Chiefs in Assembly to develop a national First Nations Data Governance Strategy and begin formalizing the loose network of regional organizations currently administering the national surveys into a well-organized network of regionally governed First Nations Information Governance Centres. These regional institutions will assist Nations in asserting ownership and control over population data generated through the national surveys and in building capacity in information management and reporting.

Since 2006, through a series of health plans and agreements, Consensus Papers and the 7 Directives, BC First Nations have established a clear mandate for the work in health data governance and information management. The FNHA was directed to:

- Create a First Nations leadership position specifically responsible for monitoring and reporting on the health of First Nations people in BC and tracking progress against health & wellness indicators.
- Work with the BC Health Authorities to examine and supplement health data collection, health status monitoring, and reporting systems used by the BC Health Authorities which include First Nations-determined indicators of health and wellness.

- Develop clinical information and patient record systems and protocols with the BC Ministry of Health and BC Health Authorities for the sharing of patient records, consistent with the law, to better serve First Nations patients and to enable greater First Nations control over the use, collection and access to health data relevant for the improvement of health services and to better monitor and report on First Nations health in BC.

Seven Directives

<https://www.fnha.ca/about/fnha-overview/directives>

1. Community-driven, Nation-based
2. Increase First Nations Decision-making and control
3. Improve Services
4. Foster Meaningful Collaborations and Partnerships
5. Develop Human and Economic Capacity
6. Be Without Prejudice to First Nations Interests
7. Function at a High Operational Standard

During the creation of the FNHA, participants in the regional engagement process identified data governance as a building block of transformation. In 2016, a round of regional engagement sessions was held to gain input into development of wellness indicators, to discuss the concept of identity management, and to gain input into the establishment of data governance principles to guide research and information management activities. The key themes emerging from this round of regional sessions at that time have guided work that has started to reflect this desired transformation. This paper will serve to advance this ground-breaking work.

In preparing for the transfer of the First Nations Inuit Health Branch services to the FNHA, BC First Nations provided the FNHA with a mandate to address data governance; to ensure that BC First Nations had control over how First

Nations data was collected and protected; and to begin developing wellness indicators. In general, the mandate acknowledges that data will be governed by BC First Nations, regardless of which institution is holding it, and calls on the FNHA to ethically house and utilize this data to support BC First Nations health and wellness.

In 2016, FNHA and the BC First Nations Data Governance Initiative (BCFNDGI) initiated the work to define governance standards through regional engagement; this work is now being brought forward for further engagement in order to develop an overarching set of data governance principles for adoption by BC First Nations collectively. These principles will help to inform the FNIGC, FNHA, federal and provincial governments, educational institutions, research bodies, independent agents, and First Nations organizations of the expected treatment of First Nations data.

This paper is a working document and is limited to the information available at the time of writing. It builds upon previous FNHA/BCFNDGI data governance engagement sessions and the mandate established during transfer and it serves as a communication tool to set the stage for upcoming regional caucus session discussions. These discussions will lead to further dialogue at the Gathering

Wisdom for a Shared Journey forum in January and the eventual adoption of principles and concepts related to advancing BC First Nations’ interests in data governance nationally and regionally.

At a national level, the Government of Canada has been participating in an international movement to open government records to the public. Canada has always considered that the data that is generated through First Nations programs and services is owned by them and therefore subject to the Open Government commitment. The BC First Nations Data Governance Champion included 5 other regions in a project related to measuring Nation-to-Nation relationships and at the same time, tabled a paper through which they lobbied Treasury Board, the government agency that is responsible for the Open Government plan, to recognize that Indigenous people own the data that relates to them.

This paper is a first step in asserting data sovereignty, collectively, making way for each Nation to take ownership and control over their respective intellectual property, including language and cultural knowledge. The Open Government Plan has evolved to now include recognition of Indigenous data ownership. The onus is now on First Nations governments to assert data sovereignty and articulate standards for the treatment of First Nations data. This paper serves to advance BC First Nations interests in data governance, collectively.

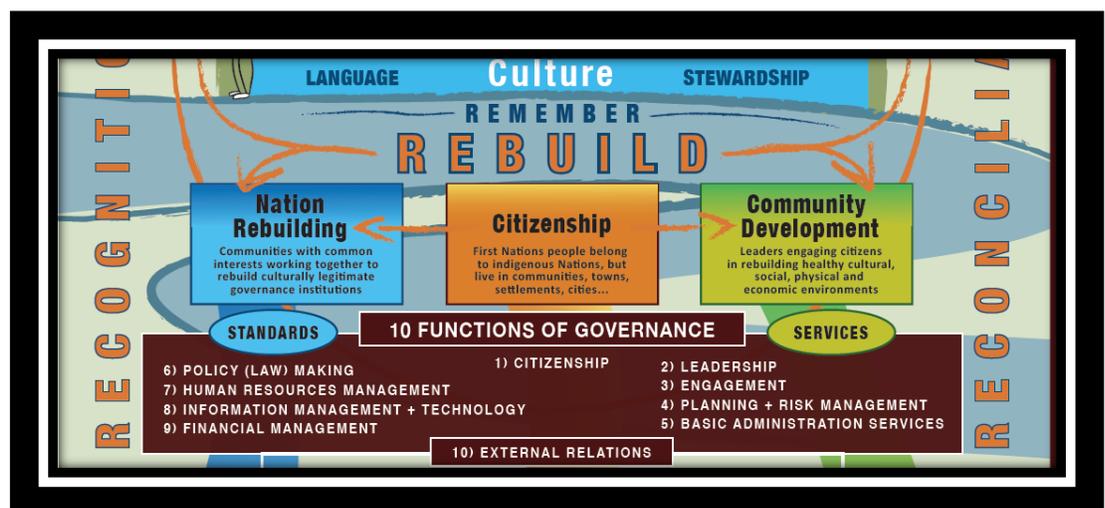
Demonstrated Need

As First Nations assert their self-governance interests and begin Nation rebuilding (developing standards and structures for their own institutions and carrying out the functions of governance) they need infrastructure and info-structure. They need timely access to quality data to plan, manage and account for investments and outcomes associated with their own definitions of well-being; they need data that aligns with their peoples’ vision of a positive future.

Communities are rebuilding the capacity to carry out the functions of governance and they need data to support this work.

Planning and risk management is

a core function of any government. When plans are developed, objectives are set and the data to



measure progress towards those objectives, should also be determined. BC First Nations have set a collective vision of being healthy, vibrant and self-determining. The vision, as defined in measurable terms, can now be operationalized through policy. Data supports all functions of governance, from citizenship through to law making.

As the federal government transfers additional responsibilities to First Nation governments through legislation such as the *Act respecting First Nations, Inuit and Metis children, youth and families*, additional data collection and reporting requirements are also transferred. Data supports planning and service decisions and of course, is essential in reporting on achievements. This particular legislation requires that the provincial government report on the wellbeing of Indigenous children in care and the provincial government has indicated that they want to move to strengths-based indicators that are culturally legitimate. This work aligns directly with the work that FNHA has been undertaking at a provincial level. Development of strategic alliances can provide better support to Nations, reducing costs and redirecting resources to where it is most needed; First Nations governed institutions form part of an expanded First Nations public service.

Information management and the technology is another core function of any government but First Nations governments do not have access to dedicated funding for this purpose through existing federal programs. These funds should be made available through the new fiscal framework that is being proposed. An outcomes-based reporting framework is being proposed by the federal government to provide Nations the freedom to set priorities and report on their progress towards achieving those priorities. The AFN has been leading these fiscal policy reform discussions. An information and discussion session will be held at the Gathering Wisdom for a Shared Journey X forum in January, 2020.

The current funding model does not meet the needs any particular community at any given time; federal funding also comes with a significant burden in administration and reporting. The data collected through federal instruments does not meet the local needs and in many instances this data does not meet the needs of the federal auditor general, either. Reporting reform and fiscal reform initiatives are the current focus of the federal government as they look to devolve services to First Nations governments and institutions. The national First Nations Data Governance Strategy is a key enabler of the eventual program transfer and the related fiscal reform.

Information management and the systems to support it can be costly to acquire and maintain; many First Nations communities are working together with other First Nations, some as Indigenous Nations with historic cultural ties, to generate the economy of scale required to make system acquisition feasible. Acquiring systems is of course only one aspect of the capacity required to manage and govern data; having the human resources in place to actually use the data generated is another costly function that is often best managed collectively.

The need to protect sensitive data such as personal health information, cultural knowledge, administrative and/or survey data that may identify individuals, regardless of where it is being held, is one of the main interests expressed by the Nations and this is why asserting data sovereignty by establishing governance standards, collectively, is a critical step in transformation of services, management and governance systems. In summary, having a common institution mandated by BC First Nations to serve as the steward of BC First Nations data supports the economy of scale needed, and maximizes the power of data to drive enhanced investments for BC First Nations, while also ensuring Nation-based data governance. An important objective of this initiative is to ensure that the Nations have the support that they need as they rebuild; assistance with data governance, information management, surveys and surveillance activities and the related data analytics, to meet their needs.

The *Transformative Change Accord: First Nations Health Plan (2005)* included an assurance to use First Nations data to measure, monitor, and report on the commitments to improve First Nations health outcomes which significantly increased the accountability of the partners. As directed through subsequent political and negotiated transfer agreements, BC First Nations succeeded in transferring a significant block of federal programs to their own institution, the FNHA. Data governance was identified as a high priority by BC First Nations during previous FNHA engagements and in fact it was identified as a pillar of health and wellness transformation.

In 2007 the *Tripartite First Nations Health Plan* committed the partners to strengthening First Nations data by developing a plan to support First Nations health data governance. Part of that commitment, which has been operationalized in the FNHA, was to develop First Nations capacity to manage the collection, use and disclosure of First Nations health data and to enhance the ability of First Nations to conduct health research. Most recently the *Tripartite Data Quality and Sharing Agreement (2010)* was created so as to improve the quality and the availability of First Nations data; facilitate the sharing of First Nations Client File data; and create new data sets to enable First Nations in BC to monitor the health of First Nations and the success of programs and services provided First Nations communities.

This paper will assist in informing the partners to these agreements by setting collective standards related to First Nations data, data governance and information management that are applicable to all agencies serving BC First Nations people, governmental and non-governmental agencies. As per Directive 6, this paper is drafted without prejudice to First Nations interests; First Nations governments are the holders of Indigenous rights and title.

Data Governance in Action: First Nations Health Authority Case Studies

Through mandating a provincial institution to serve as the collective steward of BC First Nations health data, BC First Nations are producing, utilizing, and releasing data in a way that reclaims the health and wellness narrative and is enhancing resources for health and wellness programs and services. The

FNHA recognizes First Nations' data sovereignty and as a regional organization the FNHA will achieve data governance and information management standards set collectively by BC First Nations. Three brief case studies are described below.

Opioid Data Analysis and Release

The analysis and release of First Nation data on opioid overdoses and fatalities is based on a collaborative partnership between FNHA and a number of partners. This First Nations data was provided through data matches approved by FNHA and the Ministry of Health, and FNHA was involved in all aspects of data analysis and interpretation.

Non-stigmatizing products were developed and spokespersons with culturally specific areas of expertise were designated. The communication with First Nations utilized a sequential release of results, with embargoed results firstly to BC First Nations leadership, followed by FNHA's partner organizations who had an opportunity to view the data and contribute to its findings. Once the First Nations communications protocol was completed, a public communication to the media occurred, led by the FNHA Office of the Chief Medical Officer supported by the BC Public Health Officer, BC Coroner, and Minister of Health.

This data has led to increased investment in the opioid response for First Nations people, including \$20 million being targeted for FNHA research and program interventions, over three years.

Better data has led to increased investments targeted at opioid interventions.

Cancer Incidence and Survival Analysis

For this review of First Nations cancer data, a data linkage was approved by FNHA. In this case, the data analysis was completed by BC Cancer, with interpretation of findings completed collaboratively between BC Cancer and FNHA. This collaborative approach allowed for shared teaching and learning opportunities, as well as joint accountability to respond to findings. A community-friendly product as well as a journal publication summarized the findings. In response, an Indigenous Cancer Strategy was developed and announced in December 2017, focused on addressing inequitable utilization of cancer screening and survival for First Nations in BC.

Health Systems Matrix

The HSM provides an example of a database, created through a data linkage, which has been stored, analyzed, reported, managed and governed exclusively within FNHA. HSM includes provincially-sourced physician, hospital, residential care and home and community care services data. This database has enabled FNHA to explore and assess the performance of the provincial health system in meeting First Nations' needs.

Initially provincial HSM findings were shared with the FNHC, FNHDA, Chiefs, Councils and health directors via a webinar format. From that point on, the focus of this data's analyses has been to support the work of the regions and sub regions within FNHA. HSM data have been used to guide and support

relevant service planning and evaluation activities, and has proven particularly helpful in supporting primary care transformation by providing comparison data on First Nations versus general population service utilization in key areas, such as general practitioner use and attachment and emergency department visits.

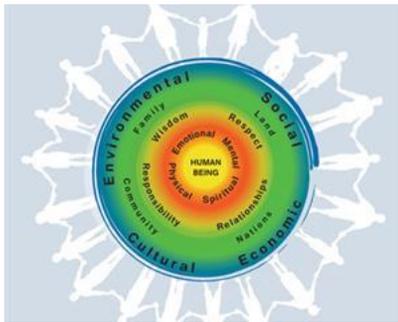
These analyses have identified specific service gaps in the province and provided the basis for improvement targets. As well, the data has justified increased resources from regional health authorities in other areas to support planning for First Nations health needs and ensure that services for the First Nations population are sufficient.

Population Health and Wellness

BC First Nations recognized the importance of working together as Nations in a space operating without prejudice to their rights and title. Recognition of rights is, however, very important and one of the key directives guiding the work of the FNHA is that health governance under the transfer and the associated delivery of programs and services be Community-driven, Nation-based; each Nation will determine their own health outcomes and indicators that align with their unique cultural worldview.

When establishing population-level health indicators, it is critically important that each unique cultural/linguistic group be considered a unique population in relation to measuring wellbeing. Although there is a need for provincial population health indicators related to overall health and wellness outcomes, developing indicators that relate to an individual Nation's health and wellness is in itself an act of self-determination. It is possible to aggregate data upwards, but very difficult to find a

smaller population in a bigger dataset, if the identifiers are not in place.



The First Nations Perspective on Health and Wellness recognizes the need to address physical, mental, emotional and spiritual wellbeing in order to achieve desired, holistic health and wellness outcomes; to address the determinants of health and wellbeing. A holistic approach to service delivery must be supported by a holistic approach to data.

It is important to bring data together from a variety of sources in order to create an overall picture of a Nation's wellbeing. Supporting the communities to achieve Nation-based data governance and information management capacity is an immediate BC priority.

Through strategic data initiatives governed by the Nations, the FNHA has been building a base of population data that aligns with the First Nations perspective on wellbeing. Incrementally, the system will shift from reporting only on disease, illness and injury and begin to report on the health and wellbeing of our people using culturally appropriate indicators. A new set of provincial population health indicators for First Nations people are being developed in partnership with the BC government;

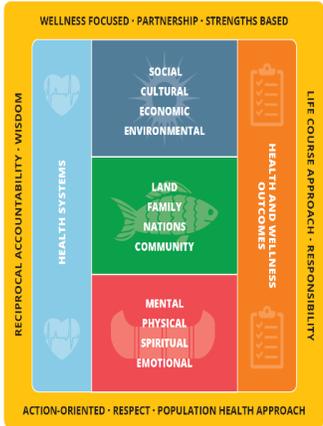
this will ensure that the resources associated with data collection and analysis provincially, also support First Nations to meet their data-related needs.

This provincial-level indicator development work has been guided by information provided through previous caucuses and data governance engagement sessions, through information collected from community and regional health and wellness plans and from other research undertaken across the province. Asserting data governance over health data will provide the base from which the Nations can assert ownership and control over other data that relates to and is required for, reporting on the overall wellbeing of BC First Nations people, families and communities at both provincial and national levels.

The BC First Nations Data Governance Initiative; a collaboration of diverse BC First Nations including Seabird Island, Cowichan Tribes, Gitksan Government Commission, Heiltsuk Tribe, Penticton Band and the Ktunaxa Nation, has been working closely with the FNHA since 2012, to engage with and listen to BC First Nations as they express their interests in health and wellness transformation - data governance is integral to service reform. Over the years, numerous resources have been developed to assist Nations in building capacity to measure their own well-being. These resources are housed at www.bcfndgi.com and they also include data governance policies, an indicator development guide, a guide to First Nations planning and reporting standards, and many other data-related resources.



As the FNHA continues to transform the former Health Canada branch, moving from a sickness system to a wellness system, the data that is collected must align with this transformation. For the most part the federal and provincial governments measure the population in terms of disease, injury and illness. Over time, indicators relating to well-being will replace the provincial sickness indicators currently being used to report on the health status of First Nations people. First Nations have stated that they want to measure their return to a state of wellness; cultural, social, environmental and economic wellness. The first fifteen of these new wellness indicators were released by the FNHA’s Chief Medical Officer and the Provincial Health Officer at Gathering Wisdom for a Shared Journey IX, and the first baseline data report for these indicators is being released at Gathering Wisdom for a Shared Journey X in January 2020.



The FNHA is working towards enabling Community-driven, Nation-based reporting on the collective vision of healthy, self-determining and vibrant BC First Nations children, families and communities. This paper will advance the shared vision that First Nations governments have timely access to quality data to plan, manage and account for the well-being of their citizens, regardless of where they reside; quality is being defined by the Nations. Having quality data will provide BC First Nations with the ability to measure the shared provincial vision and to track progress towards achieving regional health and wellness outcomes expressed by the Nations; having population data that spans across the social determinants will also help with targeting federal and provincial funding to address priorities. This work began during previous caucus engagements and data governance sessions and will continue for as long as necessary. Reporting on institutional effectiveness and reporting on the relationships with regional partners is an important aspect of accountability. Following is a link to the FNHA regional data governance engagement session video: <https://www.youtube.com/watch?v=EaUSbUPiV14>

As a new institution, the FNHA must undertake evaluations of its effectiveness; change takes time and the data required to measure institutional effectiveness as defined by BC First Nations through the Vision, Values, Seven Directives and Regional Health and Wellness Planning, was not included in the Health Canada institutional transfer. Evaluations of the first five years of FNHA operations are wrapping up and reports are being made available to BC First Nations; presentations will take place at fall caucus sessions and detailed reports will be available to the Nations. Standards for the collection, protection, access, use, sharing of BC First Nations' data will be drafted through this upcoming caucus engagement and subsequent work with Leadership and community experts.

Through the caucus engagements and subsequent work, BC First Nations will define their interests in relation to a national First Nations data governance strategy and will develop standards for the treatment of First Nations population data generated by the FNHA or other government institutions, by researchers or through national surveys, following Community-driven and Nation-based data governance and warehousing model.

Mandate for a National Strategy

In 2016, at the National Assembly of First Nations meeting in Niagara Falls, a resolution was passed calling for the federal government to provide funding for regional Data Governance Champions to carry out engagement on the development of a national First Nations Data Governance Strategy and to begin designing Regional First Nations Information Governance Centres. Funding to begin this work was allocated to the First Nations Information Governance Centre in 2018-19 and regional processes are now underway. Regional organizations are being asked to engage their respective Leadership in establishing a governance model and data centre

In 2016 the AFN General Assembly called for coordination of First Nations regions, data governance champions and national partners to establish a national First Nations data governance strategy (AFN, 2016).

concept for their region. This draft Discussion Paper will be circulated to Leadership during the BC FNHA fall 2019 engagement process and will be brought to Gathering Wisdom for a Shared Journey X for endorsement of a set of data governance principles and a concept for governing and utilizing BC First Nations data for the benefit of BC First Nations.

As noted previously, BC First Nations have been actively engaged in data governance and information management capacity building for decades and have been clear in their demands for better data; they want timely access to quality data. More data does not mean better data and the data that is generated through the many, many funding agreements that First Nations are subjected to do not meet their local needs. Federal and provincial government measure health and wellness based on a population's disease, accident, death rates. They cannot measure the health and wellbeing of First Nations people; the uniqueness of our cultures requires that each Nation define what wellness means to their citizens, as a unique indigenous society.

The federal government has been actively pursuing multiple agendas related to First Nations data and reporting reform; most of these activities take place inside the federal family, without the participation of First Nations governments or the agencies that support them. If First Nations people are involved, it is generally political involvement and not Nation to Nation. Each of these discussions involves a different group of people and there is no common strategy. Discussions have taken place nationally as part of the fiscal reform process and the ten-year grants negotiations for federal funding, as part of the national governance planning pilots, through the modern treaties and self-governing Nations data sharing discussions and there is also an outcomes-based reporting framework (UN sustainable development goals) being proposed...and the list goes on.

The common factor in all of these discussions is First Nation people, communities and Nations; Indigenous people. The federal government must recognize First Nations governments not as Indian Bands but as First Nations governments with the full rights and powers of government and the responsibility to control the intellectual property of the Nation. The reality is that Indian Bands are considered program recipients – not governments. Under the current reporting it is not possible to see the complete picture or tell the whole story of a community's development and the current reporting/accountability requirements cause nightmares and in the worst case, perpetuate the substandard conditions in which First Nations people live.

The desire to 'reduce the reporting burden' has been a goal of the federal government for decades but their efforts have not resulted in less reporting or better reporting. First Nations are now leading this transformation; they are setting objectives through community-led planning, defining indicators that are meaningful to them and they are telling their own stories. Together, BC First Nations will build the

capacity to collect and use data to meet their self-defined needs, sharing with the others on their own terms.

A national First Nations Data Governance Strategy must recognize that each First Nation community is a government unto itself and that each community is also a part of a broader Indigenous Nation collective expressing ownership over identity and asserting inherent rights. A national Strategy must recognize the sovereignty of each Nation. Development and implementation of a national Strategy must be driven by the Leadership in each region.

Data in support of Self-determination:

Data and information management is a foundational component of governance and government; it is a tool that First Nations governments and First Nations organizations can use to support informed and strategic decision-making. Data provides evidence for decision-making and targeting investments; it confirms that government agencies are achieving their objectives and that resources are being used effectively. Data informs planning and risk management functions and it is a common thread through everything a government does. Good data is required to establish and maintain good governance; good governance being defined and measured by the citizens of a particular Nation, of course.

Information management is a function of governance that is common to all BC First Nations governments and organizations and to federal and provincial governments, all of which collect, store and use data to plan, develop, monitor, and improve policies and programs, including programs for First Nations. These federal and provincial systems and the various data and information generated by them, are fragmented and unaligned. Under a program-driven relationship, First Nations governments and organizations are required to report to a variety of organizations and other governments, each of which then hold various critical data related to First Nations. ***A national First Nations Data Governance Strategy will provide recommendations on how to transform reporting and accountability from the inside-out, Community-driven and Nation-based, not from the top-down as is currently the case.***

Canada's Open Government Plan:

Canada's Treasury Board has been publishing a multi-year plan related to their participation in a commitment of governments, internationally, to be more open and transparent to their citizens. The BC government has also committed to this agenda known as the Open Government movement. In one of the first Open Government Plans published by Canada, the only reference to First Nations was limited to making sure that First Nations people were registered to receive national child tax benefits... there was no mention of the Nation to Nation relationship. The federal government then and now continues to believe that they have ownership over the data that is generated by First Nations

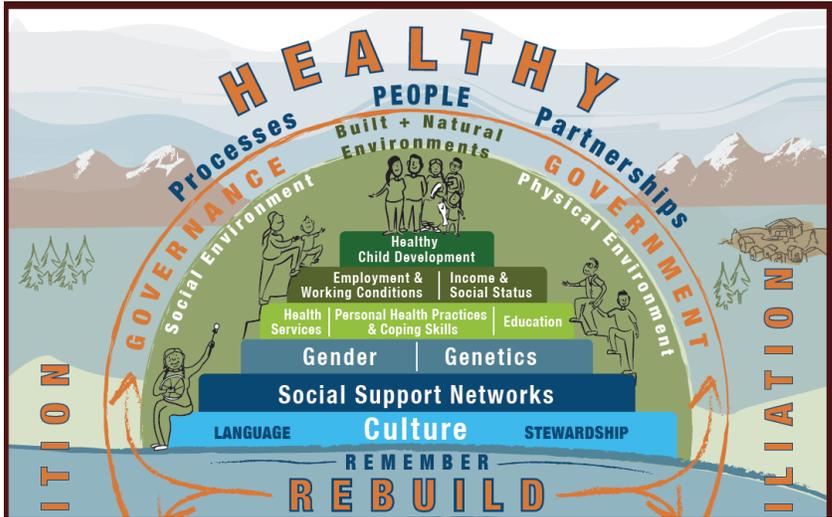
communities in carrying out their business and their intent is to continue sharing data across federal departments and with researchers without the consent of the Nations.

In 2015, the BC First Nations Data Governance Initiative Champion applied significant pressure to the Treasury Board lead on the Open Government Plan and she also engaged with other First Nations groups across Canada to generate additional support for an intervention. Building support from Nations across the country, this group pressured Treasury Board to recognize OCAP™ and they have now committed to work with the First Nations Information Governance Centre to continue with implementation of the Open Government Plan, however, this formal collaboration is yet to begin. FNIGC is preparing to measure such commitments and produce a report-card of how well the federal government is doing in meeting their obligations. This institutional accountability is missing at present and must be part of a national First Nations Data Governance Strategy.

First Nations across the country are standing united to demand change and are also asserting ownership and taking control of their data through various regional processes. This body of work will contribute to the development of the national First Nations Data Governance Strategy. ***A national First Nations Data Governance Strategy must assert that the federal and provincial governments must relate to First Nations governments not as stakeholders, indigenous peoples, interest groups... but on a Nation to Nation and government to government basis. Further, the parameters for opening indigenous data by any level of government or Crown Corporation will be defined by the Nations, collectively, in absence of assertions of control being made by individual Nations.***

Social Determinants and Data:

When developing the FNHA in BC, the Leadership committed to address the broader determinants of health through their planning processes. This is necessary in order to achieve their collective vision and is part of transforming the health and wellness services that were brought under their control through the establishment of the First Nations Health Authority. As the outcomes



related to health and wellness are more clearly defined over time, from a cultural perspective, measurements to provide evidence of achievement of those outcomes will need to be agreed-upon. A clear message was given during previous engagements with BC Leadership: the FNHA is moving from a sickness system that measures disease, to a wellness system that measures well-being.

Culture is recognized as a foundational determinant of wellness. Nations will determine how to define and measure the vitality of their culture and their people; this is an act of self-government. Data from across departments, ministries, agencies and organizations must be brought together under terms defined by each Nation, to support them in their planning to address the interconnected issues that their citizens face.

The 12 social determinants of health (underlined text in following paragraphs) are environmental conditions, personal characteristics and behaviors that have a direct impact on a human's health and wellbeing. First Nations' cultures - languages and resource stewardship responsibilities - are foundational to their citizens' indigenous identity and identity is directly associated with wellness. When our culture is strong, our social environments are healthy and our social support networks can provide the interventions and supports that a person needs when they are going through life; our families and community members are able to help each other.

Our physical environments - homes, schools, community buildings, homelands, waters... also have a direct impact on human health and wellness: our physical, spiritual, emotional and intellectual wellness. Access to the land for food, recreation, medicine and ceremony is fundamental to our wellbeing and our languages are directly tied to our land and resource stewardship responsibilities as families, clans, tribes, communities and Nations.

From a healthy cultural perspective, concepts of gender balance and role division can be remembered. Gender-based teachings and rites of passage can be reinstated to help build coping skills, character and confidence and ceremony can guide humans in development throughout life. Our environments influence our genetics and genetics determine who we are and also play a key role in our health and wellbeing. Some conditions are inherited and knowing what conditions or diseases we may be predisposed for can help guide our choices throughout life.

Health services and our personal health practices and coping skills (what we do to stay healthy and how we handle stress) are often different for different genders: MFLGBTQ. Gender-related issues and health issues impact on our ability to succeed in educational pursuits and it could be one or more of aspects of our physical, spiritual, emotional and intellectual wellness that impacts our ability to participate meaningfully in education. And the concept of education itself should be considered as the human development process that builds and maintains the foundation of our unique cultures, language and stewardship roles.

When we are performing roles that we value, we enjoy our work and when our employment and working conditions are meeting our needs and we don't have to worry about income, we can build on other aspects of our life; we can consider a profession, a career, a leadership role, becoming a cultural

mentor or focus on raising healthy children... and we can influence how our children and our grandchildren grow and develop. A healthy child grows to be a loving parent. Our culture; our stewardship, our language and our traditions are the foundation of our wellness and should inform all we do as distinct societies. We must remember in order to rebuild.

Many of the resources developed under the BCFNDGI are now being referenced by Indigenous Services Canada as they consider how to move to Nation-to-Nation relationships. One of the most current resources is a poster that illustrates the connection between the various determinants of health, community development and nation rebuilding. A video has been produced as well, to help explain these connections; this video was shown at the spring 2019 caucuses and can be found here: <https://www.youtube.com/watch?v=EaUSbUPiV14>

A national First Nations Data Governance Strategy must recognize that Nations must have access to data from many sources and they must also control the access of others to their data, including data that is being held by external bodies and other governments; data is a critical resource of governance.

Measuring Relationships, Outcomes and Investments:

Every year, Ministers draft plans and receive mandate letters dictating what they are to achieve on behalf of the government during a given year. Many of these plans mention indigenous or First Nations people but the First Nations are not involved in measuring whether these objectives were achieved, or not. ***A national First Nations Data Governance Strategy must recognize the need to measure the performance of federal and provincial governments in meeting their commitments to First Nations governments.*** The Prime Minister of Canada has stated over and over that the relationship with indigenous people is a priority for him; who defines the terms of the relationship and who measures whether it is a good relationship, or not? ***A national strategy must help sort out which level of government is responsible for reporting on what, to whom, when and in what form.***

A national First Nations Data Governance Strategy must recognize the need to measure the commitments made by First Nations governments to their citizens, as well. First Nations governments are more and more, leading their communities in planning and defining goals and objectives in relation to meeting their self-defined governance and service delivery priorities. The mission of the FNIGC recognizes that First Nations governments must have capacity to manage; manage processes, manage resources, manage relationships... and to manage data! Planning and risk management is a function of governance and so is information management and technology.

Fundamentally, a national First Nations Data Governance Strategy must recognize the need to transform the way that individual health and wellness is measured at a population level. In BC, each

unique language group is recognized as a unique population and over time, health and wellness indicators will be developed by each Nation to measure the well-being of their own people, asserting data governance on a Community-driven, Nation-basis.

A national First Nations Data Governance Strategy must recognize the need to hold accountable, organizations that are funded to support First Nations governments politically or technically. These organizations must relate to, take their strategic direction from, and be accountable to, the First Nations governments that they serve. Leadership in each province and territory must set their own standards of accountability working to reduce duplication of function, share responsibility and allocate resources effectively. ***A national First Nations Data Governance Strategy must include a request for sustainable, sufficient and predictable funding to support all aspects of data governance and information management and technology to meet the needs, as defined by each region.***

Many First Nations organizations have been put in place over the years to help address issues such as rights and title, employment, fisheries, education, economic development, child welfare, and of course health as in the FNHA. These organizations are given mandates by Chiefs and Leaders and many are independent not-for-profits. There is no common accountability framework for these organizations to report to BC First Nations governments and this inability to track mandates and maintain accountability has led to a diffusion of resources and an overburden on First Nations leadership and administrations.

A national First Nations Data Governance Strategy must include a regional accountability framework to manage mandates and facilitate reporting to Leaders.

Appended to this document is a set of BC First Nations Data Governance Principles related to a National Data Governance Strategy and to the governance and management of First Nations data, in general. These principles will be refined during the engagement process to ensure BC First Nations feel that they capture all of their interests. The principles will be brought to the Gathering Wisdom for a Shared Journey X forum for endorsement and will then be submitted to the national First Nations Information Governance Centre, who will aggregate all ten regional submissions into a national report for submission to Indigenous Services Canada and Treasury Board.

Regional Information Governance Centres

The second component of the direction given by the Chiefs in Assembly called for the establishment of regional First Nations Information Governance Centres (RIGCs) to formalize the network of First Nations institutions that are the members of the national First Nations Information Governance Centre; to put the legs under the table, so to speak. At present the organizations vary in capacity; the FNHA is currently the regional organization that administers the national surveys such as the Regional Health Survey, in BC. Chiefs and Leaders want to ensure that statistics are accurate and meaningful and that data analytics is available to answer the questions that they need answered.

BC First Nations governments can collectively build the capacity take control over their own data regardless of which government agency is holding it; to control their identity and their destiny, as unique Indigenous Nations and culturally distinct people. Nations can ensure that their citizens are cared for, regardless of where they reside or which government is caring for them.

Functions of a regional information governance centre will be determined through further engagement but it is clear at this point that information management and technology is needed to support First Nations governments in carrying out their daily functions as government, that timely access to quality data is needed, and that data must align with BC First Nations concepts of wellbeing.

In Canada there are 60 to 80 Indigenous Nations, according to the government of Canada, with unique languages, culture and histories. There are 34 unique First Nations languages (90+ dialects) – 34 unique Indigenous Nations, with territories in British Columbia. Each Indigenous Nation is unique and some Nations' territories span 7 or more provinces or territories! The Nations of each region (province and territory) across Canada are, through FNIGC activities, collectively formulating their own concept of a regional data centre. Leaders in each province or territory will establish a Regional Information Governance Centre model and will provide input into the national data governance strategy. First Nations governments will have access to data to inform their governance processes. First Nations governments will set standards collectively, for the treatment of data that is currently held by other governments and/or by First Nations organizations.

Governance is a function related to setting strategic direction, empowering institutions and setting standards for these institutions; standards for how they operate as they carry out the business of government such as delivering services to the citizens. In First Nations communities, Band Council is the body that performs governance; they empower the administration as their government, to carry out community business. Setting standards for staff acceptable public behavior, for engagements with external partners, for how many dogs will be allowed in each house...is the work of Council. Setting standards for how the data that relates to all of these functions is treated, is data governance. Setting rules on what data is collected, when and how...when it is shared and with whom...this is governance.

Asserting data sovereignty includes providing First Nations public service agencies and other governments with guidelines on what is expected of them when managing First Nations data. Asserting data sovereignty collectively does not reduce the legitimacy of an individual Nation's assertion of sovereignty; in fact, recognizing each other's sovereignty reinforces it. Built into the principles for First Nations' data governance in BC is the recognition of each Nation's rights as a Nation, to the ownership and control over their intellectual property and identity – their language, songs, stories and anything that relates to them as a unique society. This includes their right to set standards

as First Nation governments, for the treatment of their intellectual property. Governance is portable; data may or may not be, depending on what the governing body says. Data sharing agreements will be negotiated by each Nation as they self-determine the parameters for controlling access and possession.

In BC, FNHA has served as the regional data centre. Since transfer, FNHA has carried out a number of national surveys such as the Regional Health Survey and the Employment, Education and Early Child Development Survey, contributing additional resources to better align the survey process, analysis and reporting with the needs of BC First Nations. BC is now lobbying for a more reasonable allocation of resources from the national FNIGC as there is a historic formula used that is unreasonable.

FNHA expanded data collection and changed the sampling frame to recognize the importance of language and culture as a key determinant of health. The sample frame now includes all BC First Nations, where previously the national FNIGC would exclude small First Nations from the surveys for fear of exposing individuals in the data. Following a Community-driven, Nation-based sampling frame and aggregating small First Nations by linguistic association has resulted in all BC First Nations being included in the base for drawing the survey sample. This is an example of the benefit of having strong regional data centres that are connected directly to First Nations.

A BC First Nations Data Governance Model

During previous engagements it was made clear that BC First Nations do not want to ensure that their citizens are cared for regardless of where they reside. They wanted to ensure that services were accessible and culturally relevant. They wanted governance and services to be Community-driven and Nation-based. Through the proposed data governance model there is no need to build a physical stand-alone data centre to house BC First Nations data currently stored on servers housed in the FNHA offices. This data is protected to the high standards required of a government agency that delivers health services. By adding additional data sets, connecting existing data sets and building additional data analytics capacity at both the central and regional office locations, Nations can access the information that they need for decision making, without having to assume the cost and responsibility for data storage and use.

The data governance and data warehousing model proposed, involves developing standards for bringing data collected from various places over a period of time to a common environment, to make it more accessible for analysis. A regional data centre model, managed by shared expertise, would not require any additional buildings and would enable First Nations governments to make best use of their own data without worrying about the storage and protection issues. In BC the focus of the regional centre will be to support Nations in asserting data governance and in building the information management capacity across their government, to effectively manage local program and service

delivery. The Indigenous Nations of BC will govern Indigenous data; other governments and organizations will manage Indigenous data to the standards set by the Nations.

The vision for BC is to bring additional capacity closer to the Nations through the regional and sub-regional structures, to support Nations in carrying out their data governance and information management functions. Centrally hosting the data will reduce costs and risks; regionally using the data increases First Nations decision making capacity. It is costly to retain data analysts and information management specialists and in many instances, too costly for a single First Nation community or Nation. By working together through a data warehouse model, many First Nations can benefit from sharing data expertise. Nations can set the standards for how the data is treated and control who has access to their data, limiting the cost to any one Nation and maintaining the benefit of ensuring that they have timely access to quality data that is protected to the highest standards.

The data that has been generated through various national surveys is subject to the standards set by First Nations collectively and of course, to standards set by the laws that protect the privacy and dignity of individuals. The FNHA is storing the BC survey data on behalf of BC First Nations; the use of the data is limited to the purposes defined in the survey agreements. Sharing of this data will not occur without the consent of the Nation affected. Data sharing agreements are a necessary instrument in assertion of data governance. Many other agencies collect data related to First Nations people but they do so on their own terms; BC First Nations data governance standards should apply to all First Nations data.

Data sharing agreements should recognize that the Indigenous Nations own their data; that First Nations governments are custodians of data that relates to their citizens or their identity as a society. The standards they set will apply to data regardless of where it is housed or who is acting as steward. Possessing data does not imply ownership; any agency or researcher that has taken possession of First Nations data must do so on the terms set by the Nation.

By applying the same rules to all agencies: federal and/or provincial agencies and First Nations organizations, collectively, First Nations governments can reduce the burden placed on them to be on top of all data-related activities that affect them. As it currently stands, individual researchers, agencies, universities... all establish their own guidelines and processes for carrying out research on First Nations people and external agencies set standards for governing the data generated through these projects! First Nations in BC can collectively assert that they own and will control all BC First Nations data and put the onus on the other governments and external bodies to relate to the Nation directly when considering research on or about them or their people. In the words of Dr. Evan Adams, “nothing about us, without us”!

Data Governance and the First Nations Health Authority

FNHA and BC First Nations are in an ongoing relationship founded on the principle of reciprocal accountability, recognizing that we are all part of the same health ecosystem. In this relationship, FNHA assumes responsibilities and carries out work mandated by BC First Nations in the health plans and agreements and Consensus Papers, including influencing the provincial health system, and delivering and funding health programs and services. BC First Nations are funded by the FNHA to deliver health programs and services, and participate in engagement and other forums to guide the work and priorities of the FNHA. This relationship is connected through shared functions and spaces: planning, quality, programs and services delivery, health administration, evaluation, and governance.

FNHA is accountable to BC First Nations through annual reports and engagement – the quality of which is dependent upon BC First Nations’ upholding their accountability to FNHA for the submission of their reports and participation in governance processes. This relationship between BC First Nations and FNHA as their health authority is ongoing, connected, and reciprocal. The availability and exchange of data is the fuel and foundation to this relationship – it supports quality improvement, ensures accountability, and supports prioritization and decision-making. Through a set of data governance principles, BC First Nations can further enhance the capability and direction for the FNHA as their trusted and expert partner working with them at local, regional, and provincial levels.

Public Institutions and First Nations Data Governance: UBC Principles of Engagement

The University of BC is working towards establishing formal Principles of Engagement in relation to Indigenous peoples through their Indigenous Research Support Initiative. As a public institution the University is considering how to respond to the political directive to align with the UNDRIP, a requirement of all Canadian government and public institutions. While the University absolutely understands the need to respect the local First Nation government upon whose territory they sit, they have been struggling to find the path to recognition of inherent rights holders more broadly. Without recognition, reconciliation cannot happen.

Additionally, the University has established a Residential Schools Dialogue Centre to provide access to public residential school records in a supported environment. They have been seeking guidance on how best to facilitate public access to these records and recently held a round of dialogue sessions in various locations around the province to advance this conversation along with the dialogue on principles of engagement with First Nations people.

The University also holds First Nations data that is generated through various research projects and they are seeking advice on how best to govern this data. UBC is generating principles through this engagement to give them a sense of what BC First Nations expect from public institutions, relationship-wise and in regards to treatment of their intellectual property and/or research data.

UBC has drafted a paper to be shared with BC First Nations; they will be soliciting feedback as they evolve their policies and practices to achieve the objectives of the UN Declaration on the Rights of Indigenous Peoples and the standards set by BC First Nations. This paper is being made available as part of this data governance engagement and is appended to this document; it is one example of a public institution's commitment to recognizing the rights of BC First Nations.

DRAFT Guiding Principles for recognition of data sovereignty and governance of Indigenous data assets held at the University of British Columbia:

- a) UBC recognizes Indigenous self-governance and self-determination.
- b) Engagement and data governance will be informed by Indigenous communities following a Community-driven and Nation-based pathway.
- c) Recognition of Indigenous peoples' ownership and right to control their data, as asserted by Indigenous governments.
- d) Recognition that access and possession of Indigenous data must be respectfully permitted by the relevant authority; this applies to the collection, protection, use and management of data, records and information.
- e) UBC helps to advance the interests, rights and jurisdiction of Indigenous Nations with respect to reclamation of information in UBC's possession including research data, records and other types of information.
- f) Indigenous data governance standards apply to data that relates to each Nation and their identity as distinct people, communities and Nations, regardless of where the data is held across the UBC.
- g) Individual rights and privacy are protected, while collective rights, privacy and security are evolving.
- h) Adoption of common approaches to advancing data-related interests and issues will be considered.
- i) Collaboration on projects will increase the capacity of Indigenous partners to manage and govern their own data and information.
- j) All activities of the UBC IRSI will be transparent and consistent with co-developed management processes.

BC FIRST NATIONS COMMON DATA GOVERNANCE PRINCIPLES

ASSERTING OWNERSHIP AND TAKING CONTROL

The First Nations Information Governance Centre envisions that every First Nation will achieve data sovereignty in alignment with its distinct world view. (Ratified by FNIGC's Board of Directors on June 6, 2018)

The following principles reflect the starting point in BC First Nations' collective assertion of Indigenous Data Sovereignty:

- OCAP™ principles will apply to all Indigenous data; the principles will be further defined by each Nation as they assume data governance.
- Data governance is an act of sovereignty; each Indigenous Nation has a right to govern the data that relates to their identity as a distinct society; their historic and contemporary identity.
- BC is home to a great diversity of Indigenous languages with 34 unique Indigenous languages currently being spoken; these languages consist of approximately 90 dialects. Language is central to identity; Indigenous Nations assert ownership over their intellectual property. Each Nation's respective language and the songs, stories, dances, images and any and all concepts relating to their particular cultural identity, is the property of that Nation.
- Each Indigenous language group is recognized as having the authority to protect and control the use and treatment of their respective intellectual property, according to their own laws and policies.
- Data governance, research and information management are functions of governance; institutions will govern data according to standards set by the Nation, or Nations collectively; these standards will meet or exceed generally acceptable standards for the protection of culturally sensitive data, protection of privacy and preservation of human dignity.
- The First Nations Health Authority will apply the Seven Directives to data governance activities, ensuring that data governance, surveillance and information management agreements, policies and procedures align with the Vision, Values, Principles and other governance standards set by BC First Nations.
- Indigenous Data Governance principles will apply to Indigenous data in the possession of federal and provincial governments and public institutions such as universities and colleges and their faculty, and will extend to research activities undertaken by these institutions or affiliated individuals.
- Indigenous Data Governance principles will apply to First Nations organizations and individuals as well as non-governmental organizations providing services to Indigenous people.
- Data with a focus on First Nations people, generated through surveys and surveillance activities, will be governed by BC First Nations collectively.
- Data sharing agreements will acknowledge data ownership.

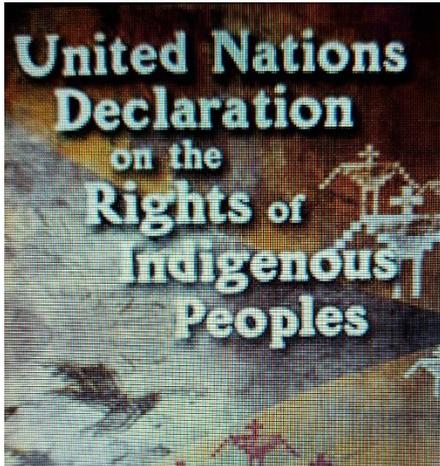
- National surveys will be designed in such a way as to first and foremost, answer the questions that are relevant to the regions at the time of design, with a limited number of national questions common to all regions being included once regional priorities are met.
- First Nations community, cultural and content experts will be included in the design of national surveys.
- National surveys will be phased out over time and replaced with Community-driven, Nation-based surveys and census instruments, enabling longitudinal data analysis.
- A national First Nations Data Governance Strategy must recognize that each First Nation community is a government unto itself and that each community is also a part of a broader Indigenous Nation collective expressing ownership over identity and asserting inherent rights. A national Strategy must recognize the sovereignty of each Nation. Development and implementation of a national Strategy must be driven by the Leadership in each region.
- A national First Nations Data Governance Strategy will provide recommendations on how to transform reporting and accountability from the inside-out, Community-driven and Nation-based, not from the top-down as is currently the case.
- A national First Nations Data Governance Strategy must assert that the federal and provincial governments must relate to First Nations governments not as stakeholders, indigenous peoples, interest groups... but on a Nation to Nation and government to government basis. Further, the parameters for opening indigenous data by any level of government or Crown Corporation will be defined by the Nations, collectively, in absence of assertions of control being made by individual Nations.
- A national First Nations Data Governance Strategy must recognize that Nations must have access to data from many sources and they must also control the access of others to their data, including data that is being held by external bodies and other governments; data is a critical resource of governance.
- A national First Nations Data Governance Strategy must recognize the need to measure the performance of federal and provincial governments in meeting their commitments to First Nations governments.
- A national strategy must help sort out which level of government is responsible for reporting on what, to whom, when and in what form.
- A national First Nations Data Governance Strategy must recognize the need to measure the commitments made by First Nations governments to their citizens, as well.
- Fundamentally, a national First Nations Data Governance Strategy must recognize the need to transform the way that individual health and wellness is measured at a population level.
- A national First Nations Data Governance Strategy must recognize the need to hold accountable, organizations that are funded to support First Nations governments politically or technically.

- A national First Nations Data Governance Strategy must include a request for sustainable, sufficient and predictable funding to support all aspects of data governance and information management and technology to meet the needs, as defined by each region.
- A national First Nations Data Governance Strategy must include a regional accountability framework to manage mandates and facilitate reporting to Leaders.

Questions for Discussion:

1. Are there additional data governance principles that you feel need to be included in drafting a national strategy?
2. What special considerations need to be taken into account in advancing a national data governance strategy?
3. What is your biggest hope in relation to data governance and information management?
4. What is your main concern in relation to data governance and information management?
5. What three functions would you see as necessary for a regional data centre to perform?
6. What specific data is of interest to your community or Nation at this time?

Additional Context



Indigenous Nations in the context of British Columbia are diverse. Communities are comprised of First Nations people with a common Indigenous language, or languages and inter-connected stewardship areas. Indigenous Nations in BC are made up of First Nations people that share common cultural expressions, have recognized historical systems of governing across families, clans and communities and who share a common language and a common history. People make up families; families make up communities and communities make up the Nation. Historically, there were many more First Nation communities in existence and many more dialects spoken across the province; impacts of

colonialism have left BC First Nations citizens, communities and Nations in their current state. Taking control and ownership over identity is self-determination.

Indigenous Nations across Canada are in the process of rebuilding their institutions and reclaiming their identity as self-governing societies with distinct languages and cultures. First Nation societies are thousands of years old. Indigenous *people* is the generally accepted, politically correct term used to collectively refer to the people that are citizens of the many individual societies that are indigenous to the lands of what is now known as Canada; indigenous people include the Inuit and many unique First Nations societies. Indigenous people have rights, including inherent rights such as those rights referenced in the United Nations Declaration on the Rights of Indigenous Peoples.

Indigenous intellectual property ownership – asserting collective ownership of expressions such as language, songs, stories... and cultural knowledge in general – is an objective of most Indigenous Nations. In the Nation-to-Nation relationship, recognition of each Indigenous Nations' right to the ownership and control of their intellectual property is fundamental. Language and culture is what makes each Nation unique. Assertion of data sovereignty is a logical step in regaining recognition as an Indigenous Nation whose rights are exercised by the Nation's citizens through their government. Indigenous citizens *belong* to Nations but they live in communities, cities, towns, rural and remote regions... on and off of federal reserves. Indigenous governments have expressed their desire to ensure that an acceptable standard of culturally legitimate services are available to their citizens regardless of where they reside.

Culture, language, identity and stewardship are foundational determinants of health and a fundamental element of nationhood. In British Columbia there exists a greater diversity of First Nations societies than anywhere else in Canada, with approximately 34 First Nation languages and

approximately 90 dialects surviving colonialism. For purposes of this paper, the term First Nation means a First Nation community recognized under the Indian Act or an Indian Band and the term *Indigenous Nation* will mean a group of First Nations communities that have a common language and a shared history of recognizing their own nationhood and collaborative governance.

As is noted on the BC First Peoples' Cultural Foundation's website:

British Columbia's 34 indigenous languages were almost completely obliterated during the infamous reign of the residential schools. In 2013, they remain close to extinction. In a province where English predominates, does restoring them to active use make any sense? Overwhelming evidence suggests that the answer is yes—not only for the First Nations people from whom they were stolen, but for everyone.



FIRST PEOPLES' CULTURAL FOUNDATION

First Peoples' Cultural Foundation is the provincial corporation that is working to revitalize BC's First Nations languages, arts and

culture. The Foundation maintains a database of First Nations linguist information including a table that describes BC First Nation languages, dialects and the FN communities where the languages are spoken. This information is available on the <http://fpcf.ca/> website at <https://maps.fpcc.ca/languages> and is appended to this document for reference.

Recently the federal government enacted the *Indigenous Languages Act*. Section 6 of this legislation, *Rights Related to Indigenous Languages*, recognizes that the rights of Indigenous peoples recognized and affirmed by section 35 of the Constitution Act, 1982 include rights related to Indigenous languages.

The recognition that Indigenous peoples' rights include rights to Indigenous languages is important, but recognition of the languages themselves was not part of the Act. There is an absolute and critical connection between the assertion of Inherent Rights by BC First Nations and their taking ownership and assuming the responsibility for protecting their intellectual property – especially language and cultural properties not currently protected under Canada's intellectual property laws. Indigenous Nations own their languages and their culture; they own their identity. Identity is a key factor in wellbeing and cultural continuity is a consideration related to children's wellbeing, specifically. A healthy child grows to be a healthy adult who becomes a healthy parent, who raises healthy children...

In January 2018, the Government of Canada committed to 6 points of action to address the over-representation of Indigenous children and youth in care in Canada.

1. Continuing the work to fully implement all orders of the Canadian Human Rights Tribunal, and reforming child and family services including moving to a flexible funding model
2. Shifting the programming focus to prevention and early intervention

3. Supporting communities to exercise jurisdiction and explore the potential for co-developed federal child and family services legislation
4. Accelerating the work of trilateral and technical tables that are in place across the country
5. Supporting Inuit and Métis Nation leadership to advance culturally-appropriate reform
6. Developing a data and reporting strategy with provinces, territories and Indigenous partners

In this context, it is believed that each Indigenous Nation should be recognized as the Indigenous partner in relation to First Nations of British Columbia in the implementation of the data and reporting strategy required under the. Children's roots cross over community boundaries and it is collectively the responsibility of BC First Nations governments to ensure that First Nations children are cared for according to the standards, laws and customs of their respective Indigenous Nation, when in the care of the Nation, another First Nations government, or the province.

In response to Action 3 above, on June 21st 2019, the federal government passed an *Act respecting First Nations, Inuit and Metis children, youth and families*. In this legislation it is recognized that every Indigenous child has a right to know who they are and to be attached to their community and their culture. The principle of cultural continuity is described in Section 2 of the Act:

Principle — cultural continuity

(2) This Act is to be interpreted and administered in accordance with the principle of cultural continuity as reflected in the following concepts:

(a) cultural continuity is essential to the well-being of a child, a family and an Indigenous group, community or people;

(b) the transmission of the languages, cultures, practices, customs, traditions, ceremonies and knowledge of Indigenous peoples is integral to cultural continuity;

(c) a child's best interests are often promoted when the child resides with members of his or her family and the culture of the Indigenous group, community or people to which he or she belongs is respected;

(d) child and family services provided in relation to an Indigenous child are to be provided in a manner that does not contribute to the assimilation of the Indigenous group, community or people to which the child belongs or to the destruction of the culture of that Indigenous group, community or people; and

(e) the characteristics and challenges of the region in which a child, a family or an Indigenous group, community or people is located are to be considered.

These two federal laws recognize the rights of First Nations people but they are both weak in recognizing the need to support First Nations governments to acquire the governance and operational capacity to take responsibility for their people. Through this proposed approach to collective assertion of data sovereignty and the development of a Community-driven and Nation-based data governance and information management model, standards can apply to all agencies serving First Nations people.