

First Nations' Data Governance: Measuring the Nation-to-Nation Relationship

Discussion Paper

Prepared for the **British Columbia First Nations' Data Governance Initiative**
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Executive Summary

The federal government has made a commitment to establish Nation-to-Nation relationships with the Indigenous people of Canada. Both the Inuit and the Metis have recently signed Nation-to-Nation relationship agreements. Canada must now recognize and relate to the 50 or so unique Indigenous Nations that the 630 +/- First Nations Communities across Canada associate with, and formally relate to each, on a Nation-to-Nation basis.

Nation (re)building is underway and members of Indian Bands are reclaiming their pre-colonial identity as constituents of linguistically and culturally diverse Nations. Through Community Development processes they are redefining themselves in terms appropriate to their individual culture and customs. Nation (re)building is self-determination; defining the Nation and the citizens that make up the Nation and engaging in rebuilding their family/clan/community/Nation-based institutions. Community Development is citizens defining their vision for themselves and for their environments and then working together, to achieve described outcomes. Many citizens live in reserve based communities, but not all. Nations are reclaiming their citizens living at home and away.

A number of United Nations forums demonstrate that “indigenous representatives have raised concerns about the relevance of existing statistical frameworks for reflecting their world views and have highlighted their lack of participation in data collection processes and governance. As a result, the collection of data on indigenous peoples is viewed as primarily servicing government requirements rather than supporting indigenous peoples’ development agendas”¹. Nations within Canada are focused on defining and measuring wellbeing; moving away from the existing measurements depicting the state of chronic health and social conditions experienced by status Indians normally residing on reserve. Currently, Canada is not responsible for reporting on wellbeing of Indigenous citizens; measuring and reporting on investments and outcomes associated with Community Development is the responsibility of each of the 50 plus Indigenous Nations of Canada. Federal government reporting should focus on progress in achieving healthy Nation-to-Nation relationships and enabling Nation (re)building; the development of effective Community-driven, Nation-based institutions to care for a Nation’s citizens and their lands, as well as the development of community and nation-centered institutions dedicated to citizens and the protection of their lands.

It is fundamental that the federal government understands that First Nations controlled national institutions and organizations are not Nations. The federal government cannot continue to enter into agreements with these organizations/institutions without first re-establishing relationships with the Nations themselves. It is through the relationship building process that the Nations will define who, organizationally, represents them, locally, regionally and nationally. In this vein, and according to the Royal Commission on Aboriginal Peoples, the federal government would need to respectfully participate in 50 some caucus tables to facilitate the establishment of Nation-to-Nation relationships with the First Nations of Canada. Each unique Indigenous Nation will then define in culturally appropriate terms, what they expect from this relationship. The goal of this paper is to

¹ Walter, Maggie. “Data politics and Indigenous representation in Australian statistics.” *Indigenous Data Sovereignty: Toward an Agenda*. Tahu Kukutai and John Taylor, Eds. Canberra, 2016. p 3.

present a very high level perspective on what a Nation-to-Nation relationship might look like and how it could possibly be measured.

Recognition of the approximately 50 independent and unique Indigenous Nations across Canada whose territories extend across provincial and territorial boundaries, is the first step in establishing this new Nation to Nation relationship; a relationship that recognizes the linguistically unique Nations that existed across Canada (North America) prior to contact with European Nations. In the interim, federal focus in areas that will assist in nation (re)building and data sovereignty, having the largest impacts on the nation-to-nation relationship, include:

- Dedicated, multi-year funding for comprehensive community planning (CCP)
- Collaboration and integration within and across federal departments, and determining what the reciprocal data needs are in partnership with First Nations
- Making relevant data and metrics available to help support Indigenous government decision-making
- Supporting First Nations access and assessment of existing datasets to align adequately with their data needs

The result will be moving away from program-oriented approaches (to funding, to data collection, to relationships) toward more coordinated and streamlined support for a community's priorities and Nation (re)building efforts.

While there are a number of resources that have been developed to help First Nations develop community wellness indicators, the topic of Nation-to-Nation relationship indicators seems relatively unexplored. Regional respondents indicated the following factors are important in the development of indicators to measure the Nation-to-Nation relationship:

- measuring ties to culture, the foundation and identity of a nation, including language use and retention, stewardship(land use), sustainable development, shared decision making and revenue sharing, cultural heritage and spiritual practices;
- measuring consultation, accommodation and consent, and whether government partners are living up to their commitments;
- wellbeing indicators tracking outcomes on the social determinants of health; and
- shifting the focus from a model that produces many not so useful numerical statistics to one that produces fewer, but more meaningful indicators, whether numerical or descriptive.

While Nation-to-Nation relationships are under development, replacing the archaic grants and contributions system with a Community driven, and Nation based investment and accountability strategy is an appropriate first step. Realigning program-based planning, investment, management and reporting functions with Community development and Nation rebuilding plans will have a positive impact on federal/First Nation relationships immediately and at the same time, increase accountability for expenditures and outcomes. The Communities of each Nation will define and continuously measure their Nation-to-Nation relationship, through their rebuilding processes.

Purpose of this Paper

The Indigenous Nations of Canada are taking a lead role in defining the expectations of a Nation-to-Nation relationship with Canada. Many are resuming the responsibility for planning, managing and reporting with and to their people. Last year, the Nations in Assembly, passed a resolution (57/2016) in which they recognize Indigenous data sovereignty as a cornerstone of Nation Rebuilding, calling on the federal government to fund:

- Engagement on data governance between First Nations leadership within each respective region.
- The establishment of a First Nations data governance champion within each region, identified by First Nations regions themselves.
- The development of fully functional regional First Nations information governance centres.
- Coordination of First Nations regions, data governance champions and national partners to establish a national First Nations data governance strategy.²

The British Columbia First Nations' Data Governance Initiative (BCFNDGI) Champion drafted this resolution; and BC continues to play a lead coordination role in pulling together this national First Nations data governance strategy. The BCFNDGI, a tripartite initiative, has incrementally demonstrated a logical approach to achieving effective management of resources and enabling efficient reporting.

The 2016-2017 Data Governance Workplan tasks the BCFNDGI to work with other First Nations data Champions from across Canada, First Nations leadership, federal, provincial/territorial governments to begin defining the outcomes and evidence of a Nation-to-Nation relationship. Deliverables for this activity include:

- Conduct research into the measurement of the state of government / indigenous relationships;
- Create a discussion paper and recommendations related to development of indicators to measure Nation-to-Nation relationships;
- Engage Regional Champions in carrying out regional reviews of recommendations and providing input; and
- Prepare draft definition (outcomes) and indicators to measure the progress towards this ideal, for presentation to leadership at the First Nation, federal and provincial / territorial levels.

The objective of this discussion paper is to inform federal - First Nations, Nation to Nation relationship building and to begin to establish a benchmark for measuring the achievement of defined relationship outcomes:

1. Increase understanding of existing commitments related to Nation-to-Nation relationships and how they might be measured.
2. Increase awareness of the need to develop relationship indicators.
3. Better prepare First Nations to advance discussions at governance tables.
4. Provide a path forward to guide engagement and relationship building, on a Nation-by-Nation basis.

² Assembly of First Nations. Resolution 57/2016. Annual General Meeting. Niagara Falls, 2016.

Methodology

The team carried out document research and conducted interviews with representatives from regional First Nations data governance centres to inform the development of the discussion paper and lay out preliminary recommendations related to development of indicators to measure Nation-to-Nation relationships. The focus of the research and environmental scan included:

- The state and history of regional First Nations data governance initiatives across the country;
- Regional considerations on the nature of Nation-to-Nation relationship and the form nations take across the country; and
- Regional First Nations data sovereignty, Nation-(re)building and intergovernmental relationships.

Documents reviewed included bilateral and tripartite agreements between First Nations and federal and/or provincial/territorial governments; descriptions of regional First Nations data governance initiatives, their histories and priorities; resources to support capacity development in community planning, indicator development and evaluation; academic papers and other articles on indigenous data sovereignty, open data and Nation-to-Nation relationships.

Interviews discussed the founding and governance of regional First Nations data governance initiatives; their relationships and accountability to First Nations in each region, and the state of relationships with federal, provincial/territorial governments and other institutional partners or actors (e.g., universities); as well as work that has been done to develop indicators to measure and evaluate the success of relationships between First Nations and/or the federal and provincial/territorial governments and other institutions. Interview questions and participants can be found in Appendix B.

Background on First Nations Data Governance Initiatives

“Our people have always done research or we wouldn’t be here. We just didn’t call it that.”

- Chief Norman Bone, Keeseekoowenin.

First Nations across the country have fought for and developed First Nations-led data governance initiatives in a variety of different ways. First Nations are developing their own regional processes for First Nations governance of First Nations’ data and have been working toward Nation-to-Nation relationships in data governance. Regional First Nations information governance initiatives have been developed at the provincial/territorial level in Manitoba, Alberta, British Columbia, Yukon, Quebec and Labrador and Saskatchewan. The regional summaries in Appendix A are based on document review and interviews with regional data governance leads. In brief:

In Manitoba, in 1996, the Assembly of Manitoba Chiefs (AMC) mandated Tribal Health Directors to form the Health Research Information Governance Committee (HRIGC) to provide oversight of the Regional Health Survey (RHS), and provide advice to researchers working on First Nations issues with First Nations partners. It also helps build First Nations capacity for data sovereignty, serves as regional coordinator of surveys and carries out research partnerships to promote holistic health.

The AFNIGC is an incorporated entity whose membership is the Assembly of Treaty Chiefs (AoTC) implements and advances OCAP® principles by improving the impact of research and information on First Nations health and wellbeing, providing governance and oversight on research initiatives and surveys, hosting First Nations data and building capacity for First Nations data collection, governance and management.

In 2013, the Tripartite Committee on First Nations Health partners created the British Columbia First Nations Data Governance Initiative (BCFNDGI) Strategic Framework to clarify the roles of each party in data governance, including timely access to accurate information for effective planning and program implementation, common data standards across governments, reinforced transformative change (e.g., shift from deficit orientation to wellness) and increased efficiencies and consistency. The aim of the BCFNDGI, which is led by and for First Nations, is to implement the commitments outlined in the new agreements and report on comprehensive wellbeing for individuals, families, communities, nations and regions.

Yukon First Nations have signed self-government agreements with the federal and territorial governments recognizing these First Nations as governments and establishing the framework for their relationship. Yukon First Nations are still in the exploratory phase in developing First Nations data sovereignty in their territory. Currently, the Council of Yukon First Nations (CYFN) plays a key role as data steward for information collected in Yukon through national surveys initiated by the FNIGC, as a promoter of OCAP and advocate for research and publications that advance First Nations health and well-being.

The First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) is mandated by the Assembly of First Nations Quebec-Labrador to support the First Nations in achieving their objectives. Its mandates in this regard include conducting and collaborating in research projects and evaluations, and coordinating population surveys. The FNQLHSSC also supports the development of capacities of First Nations communities and organizations in the areas of information management and governance. It works with advisory committees that include representatives of First Nations communities and organizations. Through their expertise and knowledge of local issues, these committees have the mandate to support the FNQLHSSC in carrying out its activities.

These initiatives illustrate:

- Some of the strongest leadership in reclaiming Indigenous data sovereignty began in the health field with the First Nations Regional Health Survey in the mid-1990s. Thus many of the indicators developed by First Nation entities to date are related to health and wellbeing as defined by First Nations. In some jurisdictions, such as BC and Quebec and Labrador, this work has begun to expand past the health field into the social services field as well.
- The different governance configurations illustrate the diversity in how Nations constitute themselves, but a commonness of approach. “Neither governance arrangements nor social collectivities are static; they are dynamic entities that may be modified and reconfigured according to changing conditions and needs”³. There are Nations in Canada that are based on linguistic lines, and others that have formed in response to government policies and approaches, and others still that have aligned for political and economic reasons.

³ Walter Maggie. p 118.

- Currently there are varying capacities for data collection, community development, and Nation (re)building; some of which are depended on the number of First Nation Bands per province/territory. The largest data governance challenges are associated with the small size of individual communities.
- Across the country First Nations seek to shift from an approach where First Nations data is siloed in different departments to organizing comprehensive data based on Nation priorities and in line with First Nation practices.
- Many regions are seeking tripartite data relationships with provincial and federal governments for the purposes of resources for research, policy analysis, education and training and supporting holistic health in First Nations communities.

It has been suggested that a national data governance strategy that aligns the work these regions have been doing with broader political and reporting reform initiatives across governments can help First Nations across the country to achieve data sovereignty as part of their nation rebuilding and self-governance efforts. A national strategy could facilitate the shift away from the past relationship dominated by governments to one wherein First Nations are surveyed under their own terms, through their lens and for their priorities.

Indigenous-Crown Relationships

The federal government has committed to renewing Nation-to-Nation relationships with First Nations based on recognition, rights, respect, co-operation and partnership, as outlined in the 2016 mandate letter the Prime Minister issued to the Minister of Indigenous and Northern Affairs (INAC).⁴ Minister Bennett continually reinforces the Crown’s desire for Nation-to-Nation relationships. Recognition of the approximately 50 independent and unique Indigenous Nations across Canada whose territories extend across provincial and territorial boundaries, is the first step in establishing this new Nation to Nation relationship; a relationship that recognizes the linguistically unique Nations that existed across Canada (North America) prior to contact with European Nations.

Historical Relationship

A Nation-to-Nation relationship is a strong departure from the relationship of domination and assimilation stretching back at least 150 years, to Confederation and the *British North America Act, 1867*, Canada’s first Constitution. The *BNA* divided Crown powers between the federal and provincial governments, with section 91(24) assigning the federal government exclusive jurisdiction for “Indians” and their lands. The Royal Commission on Aboriginal Peoples (RCAP) observed that, upon confederation: Parliament took on the job with vigour - passing laws to replace traditional Aboriginal governments with band councils with insignificant powers, taking control of valuable resources located on reserves, taking charge of reserve finances, imposing an unfamiliar system of land tenure, and applying non-Aboriginal concepts of marriage and parenting.⁵ Such newly passed laws included the *Indian Act*, introduced in 1876 and implemented by the Department of Indian Affairs and its subsequent iterations.

⁴ Prime Minister Justin Trudeau. [Minister of Indigenous and Northern Affairs Mandate Letter](#). 2016.

⁵ Royal Commission on Aboriginal Peoples (RCAP). *People to People, Nation to Nation. Looking Forward, Looking Back: Policies of Domination and Assimilation*.

Before Confederation, however, in the *Royal Proclamation of 1763*, the Crown recognized the autonomy of Indigenous peoples and the need to make treaties with them as settlers wanted to access the land. As RCAP notes: “The proclamation portrays Indian nations as autonomous political entities, living under the protection of the Crown but retaining their own internal political authority.”⁶ In the Royal Proclamation, the Crown recognized “the first confederal bargain was with First Peoples,” despite the fact that English and French colonists negotiated Confederation only amongst themselves, without reference to or consultation with Indigenous peoples.⁷

It has been well documented that colonization has had a range of impacts on traditional Indigenous governance structures and practices; on Indigenous people and their socio-economic circumstance. Most Indigenous Nations have been fragmented through the imposition of the Indian band and reserve system.⁸ Residential schools and other historic policy had devastating and intergenerational impacts on culture, language, community wellbeing and governance, significantly impacting the nations across the country.

Moving Toward a Nation-to-Nation Relationship

Over the past 35 years or so, through *Section 35* negotiations, providing evidence to RCAP and the engagement processes of the Truth and Reconciliation Commission (TRC), Indigenous leadership has defined many aspects of the Nation-to-Nation relationship: Establishing a new relationship with the Crown includes Indigenous self-government founded in self-determination, legal capacity and access to resources; the recognition of inherent Aboriginal and Treaty rights, as well as the ability to exercise and implement inherent rights and responsibilities; treaty renewal and treaty implementation; fiscal arrangements and resource revenue sharing; and closing the social and economic gaps faced by Indigenous peoples.⁹

The Royal Commission was essentially tasked with defining the Nation-to-Nation relationship through exploring, “What are the foundations of a fair and honourable relationship between the Aboriginal and non-Aboriginal people of Canada.” RCAP found that once strong trading partners with vibrant communities and cultures had been reduced to a dependence relationship with the Crown. Since Confederation, Indigenous peoples lost access to at least two-thirds of their land base, contributing in large measure to the socio-economic gaps between Indigenous peoples and the Canadian population. The health inequities are growing deeper over time not improving amongst Indigenous peoples in Canada.

RCAP called for recognition of three orders of government: federal, provincial/territorial and self-governing Indigenous nations. RCAP defined a nation as “a sizeable body of Aboriginal people that possesses a shared sense of national identity and constitutes the predominant population in a certain territory or collection of territories.” They note that while there are approximately 1,000 reserve and settlement communities across the country, “there are only about 60 to 80 Aboriginal nations.”¹⁰ RCAP proposed four principles as the basis of a renewed relationship:

⁶ Ibid.

⁷ RCAP. *People to People, Nation to Nation. Looking Forward, Looking Back: The Royal Proclamation.*

⁸ BCFNDGI. *Indigenous Information Governance Regional Information Governance Centre Concept Paper*, p 8.

⁹ Nickerson, Marcia. *Characteristics of a Nation-to-Nation Relationship: Discussion Paper.* Institute on Governance and Canadians for a New Partnership. 2017: p 3.

¹⁰ *Highlights from the Report of the Royal Commission on Aboriginal Peoples: People to People, Nation to Nation. The Way Forward.*

1. **Recognition:** Non-Indigenous people need to recognize Indigenous people are the original inhabitants and caretakers of this land. They have distinctive rights and responsibilities flowing from that status. Both sides must acknowledge and relate to one another as partners, respecting each other's laws and institutions and co-operating for mutual benefit.
2. **Respect:** All Canadians should to create a climate of positive mutual regard between and among peoples. This respect provides a bulwark against attempts by one partner to dominate or rule over another. This respect should become part of Canada's national character.
3. **Sharing:** First Nations and Canadian Governments (and their peoples) must give and receive benefits in fair measure. This principle is the basis of many original treaties and is central to the possibility of real equality among the peoples of Canada in the future.
4. **Responsibility:** Partners must be accountable for their promises, must behave honourably, and be accountable for the impact of their actions on the wellbeing of the other.¹¹

Relating to Nations as Nations

It is important that, in a Nation-to-Nation relationship, the Crown is building a respectful relationship with the appropriate counterpart. In many cases, because of the disaggregating effects of colonialism on Indigenous Nations, Indigenous Nations will need to strengthen and rebuild their Nations, restoring governance practices, developing new structures where needed and revitalizing cultures and languages. It is widely acknowledged that the process should be led by Indigenous peoples and supported by the Canadian government, with funding to help support self-directed efforts by Indigenous people to re-amalgamate, whether according to pre-contact territorial and cultural lines or according to new configurations where that makes more sense in contemporary circumstances; this is self-determination. Collaborations that occur across Nations are not for the federal government to determine, and often happen in spite of efforts to disaggregate Nations:

“As has been demonstrated time and time again, governments cannot parachute solutions into communities. Visions need to begin with indigenous communities so that solutions are nation based and community driven.¹²”

Many Indigenous peoples are re-building, re-establishing, re-constituting or re-inventing their self-governance institutions and practices. Interviews with regional Indigenous data governance leads from across the country demonstrated the variety of forms of Indigenous Nations across the country. Some Nations have been able to carry forward their self-identity, citizen, claims over defined territories and governance structures and practices. Others are defined by treaty groups, while others still have been reconstructed as regional entities of individual communities, often around different territorial boundaries, overlapping language clusters, or cultural groupings.

¹¹ Ibid.

¹² Nickerson, Marcia. Institute on Governance / Canadians for a New Partnership: [Characteristics of a Nation-to-Nation Relationship: Nation Building and Nation Re-Building Ottawa Session Summary](#), April 2017. p 8.

In February 2017 the Prime Minister and Inuit leaders signed the Inuit-Crown Partnership Committee. The *Inuit Nunangat Declaration* represents a shared commitment to a renewed Inuit-Crown relationship between Inuit Tapiriit Kanatami and the Government of Canada, that will advance shared priorities between Inuit and the Government of Canada, including the implementation of Inuit land claims agreements, social development, and reconciliation between Inuit and the Government of Canada. As of April 2017 the federal government and Métis Nation of Canada signed the Canada-Métis Nation Accord focussing on the establishment of a permanent forum discussions with the Métis on employment, health and housing for Métis people.

According to RCAP, sovereignty lies with 50(ish) Nations across Canada (as opposed to the 630+ Indian Bands as defined by INAC), each requiring a unique relationship with the Crown. While difficult to define, the Nations are most often defined across linguistic lines. Oftentimes institutions, such as the Alberta First Nations Information Governance Centre or the BC First Nations Health Authority, are extensions of Nations; they exercise authority derived from Nations through processes that are community driven and Nation based (similar to a delegation model). These institutions function under authority given to them by the Nations of a particular region, and as such, they are accountable to these same Nations.

At the national level, while the Assembly of Manitoba Chiefs became a founding member of the First Nations Information Governance Centre (FNIGC) in 2009, the Manitoba Health Research Information Governance Committee emphasized the FNIGC structure is not one in which regional First Nations information governance entities are subordinate to the FNIGC, mirroring Health Canada's FNIHB regions. Each Nation's data governance practices are unique and not a subset to the FNIGC. The FNIGC is an example of a national institution wherein Nations can collaborate, however not to the detriment of Nations having the capacity to empower their own institutions.

Of course it is the desire of most Nations to rebuild their own institutions to strengthen their unique linguistic and cultural identity; this is self-governance. It is acknowledged that no provincial or territorial level institution can assume the responsibilities of Nation rebuilding; the role of external bodies is to enable community development and Nation rebuilding.

Fundamental Relationship Pieces

Recent national dialogues and discussions have begun to define the key features of a Nation-to-Nation Relationship. Cornerstones include:

- Recognizing the 50 +/- First Nations as the unique Indigenous Nations they are.
- Transforming the Indigenous-Crown relationship from a paternalistic relationship of domination and assimilation to a partnership based on recognition of Indigenous Nations' right and ability to self-govern, to look out for and manage the best interests of their citizens, cultures and territories. This includes honouring treaties with a broad understanding of the intent around relationships and commitments.
- Sharing responsibility for protecting and managing the lands and resources in an ethically and sustainable way.
- Rebuilding Indigenous Nations and strengthening Indigenous governance, through processes led by Indigenous citizens and supported by Canadian governments.

- Developing a new fiscal relationship to enable community development and Nation rebuilding and achieve the cultural, social and economic outcomes that are defined by the Nations themselves¹³.

As already stated, Indigenous data sovereignty is a cornerstone of nation rebuilding. Control of and access to data and information by each of the Nations is a key underpinning that will help steer the relationship and drive the efforts of Nation rebuilding.

Relationship Aspirations

According to the regional representatives interviewed, data sovereignty first and foremost includes the **repatriation of First Nations data**, which requires determining both where a Nations information/data are held or collected and consider how data governance or data-sharing agreements can ensure First Nations' control over their data. According to respondents, as a starting point, First Nations also seek to establish **custodial oversight** over their data. In the Nation-to-Nation relationship context, this means that First Nations would be involved in decision-making and priority setting for data collection and use. This would also ensure a governance model integrating First Nations culture and understanding of health and wellbeing. First Nations want data and information relevant to planning and decision-making processes, also reflective of their community and cultural priorities.

Across the country, First Nations have established or are negotiating bilateral or tripartite agreements with federal and/or provincial/territorial governments on health and social system transformation. Such agreements have included commitments to:

- Increasing First Nations involvement in decision-making concerning their data and services.
- Improving the collection, use and sharing of First Nations' data.
- Developing the capacity of First Nations in the area of health information governance, to assume eventual custody, control and management of First Nations' data.¹⁴

Establishing **tripartite agreements** to coordinate provincial/territorial agencies, federal departments, and First Nations service organization participation in community development and nation (re)building could result in:

- Increased collaboration between partners;
- Common data standards;
- Improved understanding of the governments budget process and planning cycle;
- Incorporation of First Nations culture to positively change outcomes;
- Governance models that reflect the needs and realities of First Nations in different regions; and
- Building capacity in the development, delivery and evaluation of programs and services.

¹³ This includes removing the 2% per year cap on increased funding to First Nations; moving from short-term, unstable, proposal-based grant and contribution funding to fair, consistent and adequate Nation-based funding to support long-term planning and program delivery; and supporting the development of First Nations' own revenue sources for economic development.

¹⁴ First Nations Health Council, Canada and B.C. First Nations in BC Tripartite Data Quality and Sharing Agreement, 2010.

Rebuilding data sovereignty also requires the **resources and capacity** to conduct comprehensive community planning; undertake censuses and surveys; and manage and analyze data; and carry out decision-making – to govern. In a number of cases, to support Nation rebuilding, First Nations require additional resourcing from Canadian governments to build capacity to manage change and govern their own data.

Renewed accountabilities are also part of a renewed relationship. The accountability question Canada needs to think about is accountability to whom and for what. Historically, accountabilities as defined by the federal government are from communities to the federal government. Among other implications, this has resulted in a failure to collect the appropriate data. This may best be illustrated by Health Canada’s recent overhaul of the Community Based Reporting Template.

A new Indigenous-Crown relationship, based on shared constitutional authority rather than the model of federal fiduciary obligation or managerial role over Indian Bands, will require a new way to report on this relationship and on the outcomes of the relationship.

First and foremost, Nations consider themselves accountable to their citizens. In terms of the nation-to-nation relationship, **reciprocal accountability** is the key goal. This means that each partner is accountable for the actions and effective implementation and operation of their systems, ensuring that the partners are simultaneously independent and interconnected. There are some very practical means by which renewed accountabilities can be established in agreements:

- Roles and responsibilities are clarified, understood and accepted by and for all parties.
- A process for the flow of information.
- Explicit and upon reporting requirements based on each party’s capacities.
- Governance processes to guide the application of regulations, autonomy of each signatory, and conflict resolution.
- Regularly evaluating and reporting on the relationship between First Nations and the federal and provincial/territorial governments¹⁵.

Essentially the Nation-to-Nation relationship is a partnership in which First Nations are treated with due respect and supported to identify their own data needs, develop their own indicators, manage their own survey processes and possess and manage their own data.

Key Relationship Challenges

Regional respondents cited a number of relationship-based or related challenges that impede advancing their data sovereignty goals within their regions, including:

- Universities and other entities collecting First Nations data presume intellectual property rights over that data, as holders of the data. This situation highlights a pervasive problem described by some researchers and practitioners as “data nullius,” analogous to the idea of “terra nullius” or empty lands without owner(s). The idea of “data nullius” is that First Nations data is without ownership, which external entities can feel entitled to possess as intellectual property.

¹⁵ Ibid.

- Advancement on data sovereignty is uneven across the country due to varying relationships between Nations with the respective provincial/territorial governments (e.g., wherein provinces do not want to negotiate with First Nations as partners but continue to take a dominating and assimilationist approach to First Nations). In the absence of tripartite arrangements between each Nation and the federal and provincial governments around data governance, it remains difficult to access First Nations data. The majority of communities do not have protocols in place to enable access to data held by the province.
- Relationships remain imbalanced as the federal and provincial governments hold vastly disproportionate resources compared to First Nations governments, often pressuring First Nations to cooperate with their researchers when they might not have otherwise done.
- Data continues to be published against the wishes, objectives and without the consent of First Nations.
- Being mindful of the impact statistics can have on a population that is systemically disadvantaged (e.g., suicide or obesity rates) and ensuring that data is contextualized in an appropriate manner, as determined by the community.
- A tension exists between First Nations community protocols and health professionals' codes of practice defining and enforcing their professional obligations.
- The current proposal-based short term and insecure funding model leaves First Nations data vulnerable and less secure. The security of First Nations data is dependent on stable core funding.
- "Over-surveying" and making existing data more useful in a wider variety of applications for First Nations needs to be addressed by linking administrative data sets (e.g., the INAC Registry) to existing data (e.g., RHS data) to help draw out stories and issues and provide the context about the realities of First Nations living in their communities.

Relationship Implications of Data Governance

First Nations have a long history of collecting, using and governing the information they need to make decisions related to health and wellbeing, resource management and other issues. Processes to determine which information to collect, how to collect it, for what purpose and under which conditions it will be used were established prior to colonization. However First Nations have been subject to research and data collection by outside entities, for purposes determined by others, eliminating sovereignty over their own data and disabling their decision-making.

RCAP noted, "The gathering of information and its subsequent use are inherently political."¹⁶ The result of which is that much of the data that has been collected on First Nations has been poorly suited for their own purposes. The Auditor General has long questioned the reliability and relevance of much of the data collected by the federal government from band councils.¹⁷

¹⁶ Royal Commission on Aboriginal Peoples. Ottawa, 1996: p 498.

¹⁷ Office of Auditor General. 2002 December Report of the Attorney General of Canada. 2011 June Status Report of the Attorney General of Canada.

As Maggie Walter notes, official statistics on indigenous peoples tends to focus on the “five ‘Ds’ of data on Indigenous people (5D data): disparity, deprivation, disadvantage, dysfunction and difference” and that outside of this framing of Indigenous data, one may find oneself in a “data desert.”¹⁸ Walter describes this as “deficit data / problematic people (DD/PP) correlation,” where enumeration of the highly observable inequality between indigenous and non-indigenous communities becomes tied to a Social Darwinist assumption of racial unfitness.¹⁹ In this frame, the state-Indigenous relationship is seen as “akin to that between a stern but caring parent and a wayward child.”²⁰

Numerical statistics contribute to the problem. Numerical statistics transmute complex social and cultural realities into seemingly neutral data points, which are perceived as impartial, objective social facts. They facilitate unequal power relations, endowing other users of First Nations data with the perceived status of unbiased experts,²¹ defining whom and what indigenous people are, casting them as objects, viewed through the lens of a deficit.²² Walter adds that “The advent of big data, with its tendency to further distance lived social and cultural realities from their database embodiment, has only exacerbated the pejorative power of numbers to further marginalize and dispossess.”²³ The DD/PP correlation shapes the relationship between indigenous peoples and the settler state and society, facilitating the marginalization of indigenous people with respect to settler society.

Historical approaches to data collection have had impacts on the relationship, including an abundance of data that is irrelevant to First Nations priorities and needs, negative perceptions of First Nations perpetuated by a-contextual data, and strained relationships with federal and provincial governments (as well as academic institutions).

OCAP® and the Inherent Right to Data Self-Governance

Of utmost importance to the Nation-to-Nation relationship is the recognition that data and information are resources that have value for Indigenous and non-Indigenous people. First Nations information can be used by the Crown to influence its policy and decision-making with regard to First Nations. Viewed as a resource, the First Nations Information Governance Centre (FNIGC) contends, it is clear that data governance is part of a First Nation’s inherent right and attendant jurisdiction over data:

Inherent right, as it relates to First Nations, implies having the requisite jurisdictional authorities to enact laws and implement governing structures, institutions and processes along with institutional capacities to formulate policies, to design, deliver and evaluate programs, as well as to develop financial, technical and human resource capacities.²⁴

¹⁸ Walter, Maggie. “Data politics and Indigenous representation in Australian statistics.” *Indigenous Data Sovereignty: Toward an Agenda*. Tahu Kukutai and John Taylor, Eds. Canberra, 2016: pp 80-81.

¹⁹ *Ibid.* 82.

²⁰ *Ibid.* 85.

²¹ First Nations Information Governance Centre (FNIGC). “Pathways to First Nations’ data and information sovereignty.” *Indigenous Data Sovereignty: Toward an Agenda*. Tahu Kukutai and John Taylor, Eds. Canberra, 2016:146.

²² Walter, p 85.

²³ *Ibid.* p 86.

²⁴ FNIGC, p 142.

First Nations maintain that only First Nations have the knowledge and authority to manage the collection and use of their information. For close to two decades, the First Nations Principles of OCAP® (ownership, control, access and possession) have played a key role in increasing First Nations' data sovereignty:

- Ownership: First Nations own their information collectively
- Control: First Nations have the right to seek control over all aspects of research and information management processes that impact them. This extends to multiple stages of planning and information management.
- Access: First Nations must have access to information and data about themselves regardless of where it is held. First Nations have the right to manage and make decisions about access to their collective information, generally through standardized protocols.
- Possession: First Nations have the right to physically control data about them. Possession enables the assertion and protection of ownership.²⁵

The OCAP® principles have been described as a “political response to colonialism and the role of knowledge production in reproducing colonial relations.”²⁶ OCAP® emerged against the backdrop of extensive complaints recorded by such organizations as the American Indian Law Center, that First Nations have been subject to too much irrelevant research by and for non-Indigenous people by government, universities and industry.²⁷

In 1995, Health Canada asked First Nations representatives to meet in Ottawa to discuss implementing a national health survey in First Nations reserves. First Nations pushed for the principles that would become OCAP® as the new standard approach to First Nations data governance²⁸. The Regional Health Survey (RHS) became the first national survey to be owned, controlled and stewarded by First Nations, with government access through limited license, anywhere in the world.²⁹ It helped ensure results were more accurate and meaningful to First Nations and built research and information management experience within Nations.

Access to government-held data on their members remains a chronic concern for First Nations leaders. The possession principle of OCAP® reflects a commitment to physically hold the data on a First Nation-controlled server. This principle supports both First Nation community-level capacity and the community's claim to jurisdiction over its data.³⁰ Communities, citizens and organizations are the stewards of cultural data; Nations are the custodians.

²⁵ FNIGC. First Nations Principles of OCAP®. Note: the OCAP® name and logo are registered trademarks of FNIGC, which is charged with protecting the integrity of both on behalf of all First Nations people.

²⁶ Espey, Jennifer “Stewardship and OCAP: A Discussion Paper for the First Nations Statistical Institute” May 2002.

²⁷ FNIGC. p 142.

²⁸ It should be noted that some communities have issues with the approach and ownership of OCAP. Some Nations wanted to put their own symbol on OCAP to make it ensure intellectual property is owned and deemed compliant at the Nation level as opposed to by an external national institution.

²⁹ FNIGC. p 147.

³⁰ Ibid. p 5.

Developing Wellness Based Indicators

“My language, my song, my spiritual beliefs; that is my sovereignty, that's my identity”.

- Former Akwesasne Grand Chief Mike Mitchell.

All regional respondents interviewed emphasized moving away from deficit-oriented indicators, developing positive, wellness-oriented indicators, is key to supporting nation rebuilding and ensuring data produced by those indicators reflects each Indigenous Nation's priorities and perspectives.

Generally, in the health and social service fields, indicators measure trends over time for a population group. They most often measure how individuals within a community are doing in meeting population level goals. It is expected that the picture painted helps to inform policy and decision-making. Indicators can be quantitative or qualitative but for the most part, presence of disease is primarily measured; quality of life is more difficult to measure, as it is subjective. As discussed, existing indicators are not well suited to measuring and evaluating First Nations wellness objectives. Many existing indicators, defined by other parties, are focused on measuring the absence of something negative. This negative framing can facilitate discouragement and self-fulfilling prophecies for the group represented in the statistic and contribute to maintaining the socio-economic gap between First Nations and Canadian populations.³¹ Communities and Nations want to tell their own stories, in their own words.

First Nations across the country have been re-framing the indicators tracked to indigenous-focused frame of wellness.³² In BC, the Tripartite Parties – the First Nations Health Council, Province of British Columbia and Government of Canada – are working together to move beyond health service reform and strictly health-focused indicators to addressing and measuring outcomes for the broader determinants of wellbeing.³³ Both government and non-governmental agencies are preparing to use the social determinants of health as a baseline for looking at holistic community wellness. Beyond these social determinants, Nations and communities also want to track environmental/ecological determinants of health such as the state of community facilities, air, water, nitrogen and phosphorus, food systems, wildlife and ecosystems, and climate change.

A number of interview respondents identified language and culture as particular priorities for First Nations wellness in their regions. Many leaders consider language a foundation of sovereignty, and thus an underpinning of the nation-to-nation relationship.

According to Gwen Phillips of Ktunaxa Nation Council, “the most important component of nation hood is identity: a new relational model recognizes that our people and our culture is our nation building. This means moving away from a program relationship model to one of community development and nation rebuilding that has an outcome of health and wellness for citizens and communities. This requires enabling environments – social, physical and economic – and shared responsibility. Many communities are working on language revitalization and embedding traditions and culture into ceremony and governance”³⁴.

³¹ Geddes, p 2.

³² Ibid. p 3.

³³ First Nations Health Council and Ministry of Aboriginal Relations and Reconciliation. Memorandum of Understanding on the Social Determinants of Health, 2016.

³⁴ Nickerson, Marcia. Institute on Governance and Canadians for a New Partnership. [Characteristics of a Nation-to-Nation Relationship: Nation Building and Nation Re-Building Ottawa Session Summary](#). April 2017. p 9

According to Geddes, First Nations noted that despite its importance, measures of culture are currently missing in most data sets. As a result, there is an enormous need for general data in this area, including language use, participation in cultural activities, eating traditional foods, being out on the land, etc.³⁵ She suggests First Nations develop indicators to track performance on each social determinant of health, asking what success would look like for each determinant to guide the development of appropriate indicators.³⁶ Other resources, such as the CCP Handbook, developed by BC First Nations, detail the steps on how to develop indicators in considerable detail.³⁷

Developing Relationship Indicators

Prime Minister Justin Trudeau and the federal Liberal government have committed to a transformed Nation-to-Nation relationship, based on respect, recognition and a commitment to reconciliation. Canadian governments have made promises of a changed relationship with Indigenous peoples many times in the past. Developing and monitoring performance by establishing Nation-to-Nation relationship indicators would help hold the federal government to its commitments. Tracking and measuring this data can demonstrate whether or not the federal government is acting in good faith on this historic commitment.

While there are a number of resources that have been developed to help First Nations develop community wellness indicators,³⁸ the topic of Nation-to-Nation relationship indicators seems relatively unexplored. One example, however, is the ‘Indigenous Navigator’ project being undertaken by a number of UN organizations and non-governmental organizations. The project has developed a framework that includes tools and indicators for Indigenous peoples to systematically monitor the level of recognition and implementation of their rights. The pilot project has also developed indicators that relate to clusters of rights covered by UNDRIP, including languages, self-government, participation, consultation, lands and resources, consent and recognition of identity.³⁹

Regional respondents indicated the following factors are important in the development of indicators to measure the Nation-to-Nation relationship:

- measuring ties to culture, the foundation and identity of a nation, including language use and retention, land use and spiritual practices;
- measuring consultation accommodation and consent, and whether government partners are living up to their commitments;
- wellbeing indicators tracking outcomes on the social determinants of health; and
- shifting the focus from a model that produces a many numerical statistics that are not very useful to one that produces fewer, but very meaningful indicators, whether numerical or descriptive.

³⁵ Geddes, p 10.

³⁶ Ibid. p 9.

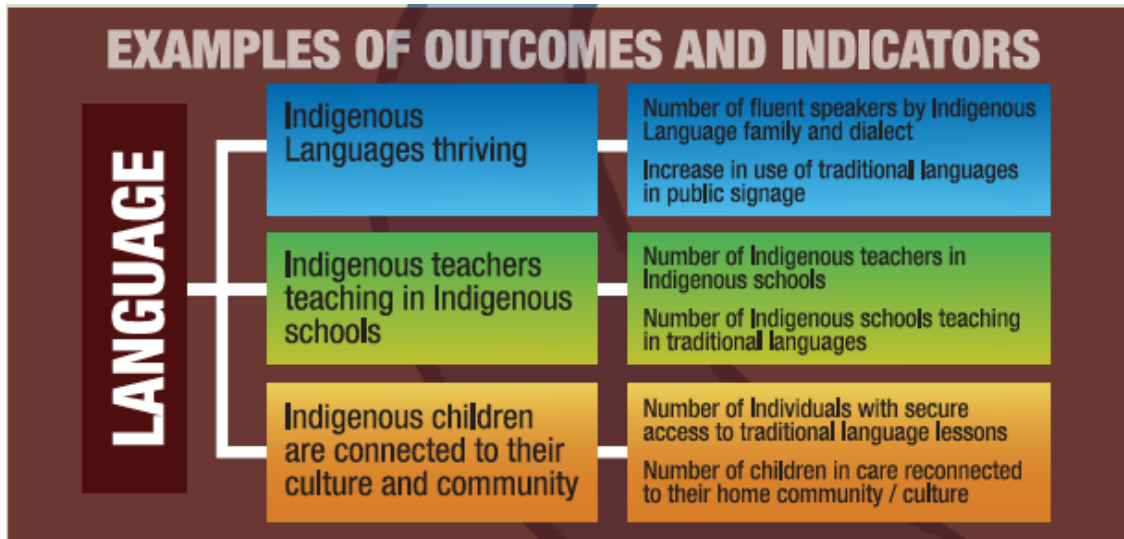
³⁷ Indigenous and Northern Affairs Canada, in partnership with First Nation CCP champions across British Columbia. CCP Handbook - Comprehensive Community Planning for First Nations in British Columbia Second Edition. 2013.

³⁸ As the focus of this project is the Nation-to-Nation relationship, our focus here is on prospective relationship indicators. For more information of social determinants of health indicators being developed by First Nations, see such resources as:

- Geddes, Bronwen. [Measuring Wellness: An Indicator Development Guide for First Nations](#). First Nations of British Columbia, held in trust by Ktunaxa Nation Council. April 2015.
- Horsethief, Christopher. Sample Indicators leading to Ecological Outcomes. 2015.

³⁹ Davis, Megan. Data and the United Nations Declaration on the Rights of Indigenous Peoples. Kukutai, Tahu, and John Taylor, Eds. [Indigenous Data Sovereignty: Toward An Agenda](#). Australian National University Press, 2016: 36.

The British Columbia First Nations' Data Governance Initiative has illustrated a sample of outcomes and indicators stemming from the Nation based goal of language use and retention:



A new relationship will require identifying indicators to help track core objectives in the Nation-to-Nation relationship. Relationship indicators can be either numerical (quantitative) or descriptive (qualitative). For example, based on the objectives listed in the first column in the table below, the following indicators could be used to measure the state of relationships:

Outcomes	Indicators
Canada recognizes each of the 50 (or so) Indigenous Nations individually, not as one homogenous entity	<ul style="list-style-type: none"> Number of Nation to Nation Relationship Agreements in place Indigenous Languages recognized as official languages
Fair fiscal arrangements in place, transferring adequate predictable funding to each of the Nations and their associated Communities directly	<ul style="list-style-type: none"> Number of Nation based spending authorities in place Number of Communities with stable core funding in place
Nation-based institutions delivering culturally appropriate services to their citizens	<ul style="list-style-type: none"> Number of functional Nation based education authorities Number of functional Nation based language authorities Number of functional Nation based child welfare authorities Indigenous social policy framework established to guide the culturally appropriate services
Co-management of natural resources between Canada and Indigenous Nations	<ul style="list-style-type: none"> Number of provincial/territorial stewardship plans approved by Indigenous Nations Number of First Nation citizens involved in land stewardship jobs

Outcomes	Indicators
	<ul style="list-style-type: none"> • Number of Revenue sharing agreements • Number of shared decision making authorities within the watersheds • Number of sustainable economic development initiatives in place
Standards for governance defined by the citizens of each Indigenous Nation	<ul style="list-style-type: none"> • Number of Nation Rebuilding plans in place • Number of Nation based Accountability Frameworks in place
Priorities for community wellbeing are determined by the citizens of each Community	<ul style="list-style-type: none"> • Number of Community Development plans in place • Reports based on Community plans
Nations are reporting on their own wellbeing and the wellbeing of their Communities and citizens	<ul style="list-style-type: none"> • Number of Nations with Information Management systems in place • Number of Nations regularly reporting to their citizens
Canada remains committed to achieving Nation to Nation relationships	<ul style="list-style-type: none"> • Nation defined processes in place (e.g. tripartite meetings) for ensuring the transformation continues in good faith regardless of which political party is governing

While there may very well be common objectives and outcomes many First Nations will want to achieve, every Indigenous Nation is unique in terms of how they will see and evaluate success in reaching those objectives. Several First Nations may share the outcome of ‘increasing cultural practices in the community’, but not all of these communities will define success in the same way. Some may choose to measure the number of children participating in weekly language classes, while others may track the number of artists participating in monthly craft sale or the number of decisions made with elder input.⁴⁰ The difference of approach reinforces the diversity of Nations and the language, land-based, and citizen relationships to be measured.

Data Needs of Nation Rebuilding

Community Development Strategy

First Nations and federal and provincial/territorial governments are working together to support community development, the “process for building and investing in effective, sustainable Indigenous communities, government and services.” While communities are undertaking their own planning processes to support community development, INAC is proposing an Indigenous Community Development National Strategy with four pillars:

1. Community-driven, nation-based planning initiatives, which includes:
 - Dedicated, multi-year funding for comprehensive community planning (CCP) and land use planning (LUP).
 - Funding for shorter-term planning (e.g., strategic planning).

⁴⁰ Ibid. 7.

- Funding governance development and implementation capacity and tools.
2. Indigenous Nation-to-Nation learning [for all parties], including:
 - Funding for conferences and workshops.
 - Funding for tools and resources, such as websites and handbooks.
 - Opportunities for knowledge exchange between Indigenous planners and INAC officials to facilitate implementation of plans.
 - Funding to remain in indigenous communities to support their planning capacity.
 3. Collaboration and integration within and across federal departments.
 4. Strengthening government’s awareness of cultural diversity.⁴¹

In this strategy, Indigenous communities will be empowered to measure their own progress and performance in attaining their community development goals. INAC has committed to making relevant data and metrics available to help support Indigenous government decision-making.⁴² INAC acknowledges that contribution funding targeted programs with inflexible requirements has impacted Indigenous communities and is not consistent with a true Nation-to-Nation partnership. The strategy aims to bring together community development best practices to build a nationally sustainable and flexible model to meet unique and diverse needs of regions.

INAC recognizes community development requires long-term commitment and a move away from program-oriented approaches toward more coordinated and streamlined support for a community’s priorities.⁴³ INAC has pledged to partner with Indigenous people to support and implement community-driven, nation-based planning initiatives.⁴⁴ Effective plans can empower communities to create their own futures and build the tools to respond to change effectively. This gives communities ownership over their future.

Comprehensive Community Planning

CCP is one tool used in Community Development and is described as a community-driven planning process that engages community’s citizens in the development of a long-term vision, goals and action plans for achieving this vision. CCP puts community wellness at the centre of its vision and objective. Community wellness is a holistic concept, representing a balance between physical, mental and spiritual health and difficult to measure and evaluate using conventional measurement tools and data sets.⁴⁵ With wellbeing and sustainability as central principles, CCP considers economic development, social development, environmental management, governance, culture, language, and more.

Nations are undertaking their own surveys and censuses as part of their CCP and evaluation processes to strengthen their autonomy and ability to govern and care for their people and territories. For example, the Tsawwassen First Nation (TFN) conducted a comprehensive survey after signing its treaty to assess:

⁴¹ Indigenous and Northern Affairs Canada. Indigenous Community Development National Strategy Draft, November 17, 2016. p 1.

⁴² Ibid.

⁴³ Ibid. p 2.

⁴⁴ Ibid. p 3.

⁴⁵ Geddes, Bronwen. [Measuring Wellness: An Indicator Development Guide for First Nations](#). First Nations of British Columbia, held in trust by Ktunaxa Nation Council. April 2015: 1.

- The overall wellbeing of its members including health, finances, education and housing.
- How its data compared to neighbouring municipalities.
- The impact the treaty would have on community wellness.

Members were offered an honorarium to encourage full community participation. The full report of results was shared with the membership. Despite the up-front costs, this process has provided the TFN the baseline data it needs to evaluate if its policies and decisions are working, when comparing the baseline to new data in subsequent years.⁴⁶

While many First Nations have done a large community census, fewer have repeated the process with a follow-up census. In some communities, they are seeing that when a second census is done members become more engaged in the CCP process.⁴⁷ The Ktunaxa Nation has conducted 2 census events during their treaty negotiations process to measure engagement and expectations of citizens as well as to determine the Nation's human resource and cultural capacity. Enabling community control of the research processes can help ensure the accuracy and relevance of resulting information and build research and planning capacity within nations and communities.

Information Management Capacity

First Nations will need to assess if existing datasets align adequately with their data needs. In most cases, nations will want to track other indicators of far greater significance and suitability to their people, planning and programming needs than those indicators developed by other entities for their own purposes. To track more suitable indicators nations will need a way to track, analyze and protect their own data.⁴⁸ Server and back-up storage capacity are critical to ensuring the nation has access to this information for generations to come. There are a number of First Nation-owned data management companies that offer various data gathering/storage services (e.g. Mustimuhw, Xyntax).⁴⁹ Within its Indigenous Community Development National Strategy, INAC notes some regions are creating regional planning repositories or databases of First Nation plans shared with the department from all sectors, to help INAC support strategic investments.⁵⁰

⁴⁶ Ibid. p 20.

⁴⁷ Ibid. p 22.

⁴⁸ Ibid. p 18.

⁴⁹ Ibid. p 22.

⁵⁰ INAC, p 8.

Developing Common Data Standards Across Governments

Stratejuste describes three basic models of data governance:

1. Single-organization data hierarchy - Data governance occurs largely in a self-contained unit. These often enlist advisory bodies or committees.
2. Data partnership - Involves equal parties with reciprocal data needs, equal interest in sharing, similar technical capacity and legal position, and so on. Parties jointly govern the data asset. Requires trust and confidence that data is secure, confidential and will not be misused. The data must also be relevant and of high quality.
3. Data commons – A research community to facilitate exchange of knowledge within a given community. Even data shared in the commons retains a formal owner, who may choose to sets terms of use in addition to the rules that govern use in the larger community.⁵¹

The current federal funding model, wherein individual First Nations apply for one to two-year funding under federally determined program and reporting, leaves funding precarious and unpredictable and prevents many communities, without the capacity to write proposals and manage projects, from being able to meet their goals. It also provides haphazard access to administrative data systems by communities with capacity. Instead planning, program development and data collection should be driven by a nation's strategic priorities.

Parties can work together across jurisdictions to develop common indicators and data standards across governments to enable high-level standard data aggregation and sharing with other governments at regional and national levels. Partnerships would acknowledge the major concerns and protocols of the indigenous partners—just as they would the legal constraints of the government ones.⁵²

One proposal for a national network of data systems describes a transformed model of reporting and data collection, with First Nations collecting, owning and storing their own data. This data is linked with provincial and federal data systems through a First Nations data centre at the provincial and then federal levels, which would assure integrity of data and create an integrated First Nations data bank.⁵³ Reporting from communities would roll up into regional and then federal data and statistics.

⁵¹ Stratejuste. P 2-3.

⁵² Ibid. p 6.

⁵³ British Columbia First Nations Data Governance Initiative. Indigenous Information Governance Regional Information Governance Centre Concept Paper – BC.

Appendix A: Summary of Regional Initiatives

Manitoba

Background & Regional First Nations Data Governance Structure

“Our people have always done research or we wouldn’t be here. We just didn’t call it that.”

- Chief Norman Bone, Keeseekoowenin.

The Assembly of Manitoba Chiefs (AMC) has long carried out research as an act of self-determination.⁵⁴ In 1996, the AMC Chiefs mandated Tribal Health Directors to form the Health Information Research Governance Committee (HRIGC) to provide oversight on the new Regional Health Survey (RHS), which would become the first survey of Indigenous people by Indigenous people in the world. Data from each region is rolled up into national RHS reports. The HRIGC is made up of Tribal Health Directors, an Elder and Youth. HRIGC works to educate First Nations to ensure they have the capacity to advance their data sovereignty, by:⁵⁵

- Providing oversight and input into RHS and other surveys.
- Providing review and advice to researchers working on First Nations issues with First Nations partners.
- Ensuring benefits to First Nations through OCAP® and partnership agreements.
- Reviewing, support or deny access to databases regarding FN data within HRIGC and within MB Health (required by Health Information Privacy Act regulations and HIP Committee rules).

In 2005, the AMC Chiefs in Assembly mandated the creation of a Manitoba First Nations Research Centre and Statistical Network (hereafter referred to as the Research Centre), which is now housed in Nanaandawewigamig. After years of negotiating with the University of Manitoba for release of RHS data, the Research Centre was established in 2007. Access to regional data requires HRIGC review and approval. The server also holds the data from the REEES. The Research Centre acts as the secretariat of the HRIGC, regional coordinator of surveys and carries out research partnerships to promote holistic health.⁵⁶ In 2007 the Chiefs identified the principles respectful First Nations research must follow:

- Free, Prior and Informed Consent on a collective and individual basis.
- First Nations OCAP® principles.
- First Nations ethical standards (e.g., Cree, Dakota, Dene, Anishinaabe or Ojibwe).

In 2009, the AMC became a founding member of the First Nations Information Governance Committee (FNIGC). The FNIGC structure should not be interpreted as a simple regional structure mirroring Health Canada FNIHB regions. Each region’s First Nations data governance practices are unique and should not be viewed as a subset to the FNIGC. In 2013, the AMC established the First Nations Health and Social Secretariat of Manitoba and gave it the traditional name of Nanaandawewigamig to prepare for the way for tripartite discussions and ensure resources and

⁵⁴ Nanaandawewigamig (the First Nations Health and Social Secretariat of Manitoba). 2016 Annual General Meeting Presentation.

⁵⁵ Ibid.

⁵⁶ Ibid.

personnel for research, policy analysis, education and training, and support holistic health within First Nations communities.⁵⁷

Existing Relationships

Prior to establishing the Research Centre, the University of Manitoba assumed the role as holder of intellectual property rights to data. However, the actual role was more akin to a contractor engaged to help conduct and analyze the research. First Nations data was considered without ownership; something to which external entities were entitled to possess as intellectual property - as “data nullius,” analogous to the idea that the lands of Turtle Island were considered “terra nullius,” or empty lands (not populated by self-governing peoples).⁵⁸ Today, the relationship with the University of Manitoba Office of Research Ethics and Compliance has improved markedly. Access to First Nations data is no longer approved unless there is HRIGC involvement and approval.

The relationship with the provincial government is struggling. The current provincial government’s attitude toward First Nations is attributed for holding Manitoba First Nations back from making similar progress on data sovereignty as other First Nations in Canada. Perhaps the strongest exception to this stalled provincial relationship is the Ministry of Health, which has an internal policy requiring any First Nations-related data requests or research to be reviewed by HRIGC.

The relationship with the Manitoba region of the Health Canada First Nations and Inuit Health Branch (FNHIB) is also strained. In fact, the AMC Chiefs in Assembly recently passed a resolution calling for FNHIB to remove a senior level staffer who was felt to be top-down with communities, failing to appreciate the inherent right of First Nations to self-government and self-determination.

The more positive relationships Manitoba First Nations have developed with the University and Manitoba Health have developed over time and enabled increased First Nations data sovereignty to move forward in the absence of a formal agreement with either institution.

Development of Indicators & Using Data for First Nations Priorities

Moving away from deficit-oriented indicators towards positive, wellness-oriented indicators, is key to supporting nation rebuilding and ensuring data produced reflects First Nations priorities and perspectives. Since 2002, Manitoba First Nations have been working on new indicators for tracking health and wellness outcomes, developing community-based, culturally relevant set of indicators on quality of life, identity and language, governance, housing and more. HRIGC uses sharing circles and interviews to obtain qualitative data, not just relying on quantitative indicators.

After researching the relationship between language and wellbeing, a top priority became strengthening language use and retention. HRIGC has identified challenges improving language use and retention because so many First Nations people have endured abuse associated with using their mother tongue. The evidence has helped First Nations in Manitoba think about ways to work toward their goal of strengthening language use and retention in balance with the challenges many face in dealing with this legacy of abuse.

⁵⁷ Ibid.

⁵⁸ See also discussion of ‘datum nullius’ in Smith, Diane E. “Governing data and data for governance: the everyday practice of Indigenous sovereignty.” *Indigenous Data Sovereignty: Toward An Agenda*. Tahu Kukutai and John Taylor, Eds. Canberra, 2016: 119-122.

HRIGC noted people feel completing the RHS and REEES requires too much time, acknowledging concerns around both duplication and the relevance of questioning. HRIGC highlighted how few researchers in Canada understand the issue and assume everyone is the same in Canada, with no idea what it is like to live on reserve or to experience racism. HRIGC challenges the Western understanding of statistical validity, arguing now is the time to think differently about what it means to have a representative sample and how to best gather information representative of First Nations communities' experiences and priorities, rather than the priorities of other governments.

To address the inundation of surveys, entities like the HRIGC can help analyze better uses for existing data by linking it to other administrative data sets, such as the INAC Indian Registry, to help draw out stories and provide context about the realities of First Nations living in their communities. HRIGC also aims to expand the data sets to off reserve First Nations residents. They are currently in negotiations with Indigenous and Northern Affairs Canada (INAC) and Manitoba Health toward a data-sharing memorandum of understanding.

Currently HRIGC work does not receive funding from the provincial government or the universities, thus the committee is stretched in its ability to review data requests. The majority of the people on the committee are Health Directors, with a few academic representatives and an elder and youth. However, due to lack of resources, everyone on the committee is doing this work off the side of their desks. HRIGC emphasized that funders are reluctant to provide core funding and rely on pilot projects and year-to-year funding instead. It is difficult if not impossible to retain someone with data governance and information management expertise on year-to-year funding. HRIGC emphasized the security of their data depends on secure, stable core funding. Currently, entities like Canadian Institutes of Health Research or the Social Science and Humanities Research Council and the provincial government and universities rely heavily on the HRIGC for compliance with OCAP[®] and our other criteria, however they do not provide any funding to the committee for the work.

Looking forward, while RHS played an important role in advancing data collection, communities are increasingly looking for additional data they can use, and unless they can benefit from research initiatives, they are opting out of participating.

Alberta

Background & Regional First Nations Data Governance Structure

There are two major components to First Nations data governance in Alberta:

1. Co-management between Alberta First Nations and Health Canada and,
2. The Alberta First Nations Information Governance Centre.

In 1996 the Alberta Assembly of Treaty Chiefs (AoTC) signed a Health Co-Management Agreement with Health Canada's FNIHB-Alberta Region, proving terms for shared decision-making through a Health Co-Management Committee (HCOM) on:

- The conduct and resourcing of program and service delivery.
- The overall allocation of regional resources.
- Common health issues that affect First Nations communities.

The parties agree upon the membership and terms of reference of this committee jointly. Six specialized subcommittees (Children and Youth, Mental Health and Addictions, Prevention Programs, Health Protection, Operations and Support and Non-Insured Health Benefits (NIHB)) make recommendations regarding the needs and priorities of First Nations.⁵⁹ The agreement aims to enable the co-management, co-assessment and co-analysis of FNIHB-Alberta Region programs and services, including data on First Nations⁶⁰.

The bilateral treaty process is not part of the co-management agreement. The treaty process involves the Minister of INAC, with whom an agreement known as an Understanding on First Nations-Canada relations has been signed. It acknowledges the original spirit and true intent of treaty as told by the Elders.⁶¹ Health Canada has committed to participate in discussions on health care as a treaty right pursuant to bilateral treaty processes between the Chiefs of the First Nations of Treaty 6,7 and 8 (AoTC) and Canada as represented by INAC.

The Alberta First Nations Information Governance Centre (AFNIGC) is the Alberta regional affiliate of the national FNIGC. It is the outcome of a 20-year process to strengthen First Nations control and capacity in research processes and in the collection, use and storage of data. The AFNIGC is an incorporated entity whose members are The AoTC. Treaty No. 6, Treaty No. 7 and Treaty No. 8 appoint a Chiefs Senate and delegates from First Nations communities serve on the Board of Directors.⁶² The AFNIGC board meets quarterly.

⁵⁹ Alberta Assembly of Treaty Chiefs and Health Canada. Alberta Co-Management Agreement. 1996. For more information, visit: <http://hcom.ca/>

⁶⁰ The AoTC ratified Resolution II-20 to participate in a two-tiered approach to co-manage Medical Services Branch-Alberta Region Envelope:

1. The administrative process to co-manage the budget and programs of the branch.
2. The bilateral treaty processes for treaty 6 and 7 areas (not part of the agreement)

⁶¹ The Chiefs of the First Nations of Treaty 6, 7 and 8 (Alberta) and Her Majesty the Queen in Right of the Government of Canada as Represented by the Minister of Health Canada. First Nations-MSB Alberta Region Envelope Co-Management Agreement.

⁶² Alberta First Nations Information Governance Centre (AFNIGC). Our Mandate – Governance and Accountability.

AFNIGC receives its funding from the Ottawa-based FNIGC and through a contribution agreement with FNIHB-Alberta. Prior to federal funding cuts, the board reported to the Chiefs on a quarterly basis. Now the AFNIGC is working to ensure leadership is up-to-date through email and written correspondence. The AFNIGC promotes, protects and advances First Nations OCAP® principles, First Nations jurisdiction in research and information management and First Nations' inherent right to self-determination by:

- Increasing the impact of research and information that measures the state of First Nations health and wellbeing;
- Providing sound governance and oversight to research initiatives and specialized surveys;
- Permanently hosting data; and
- Building individual and systemic capacity for respectfully engaging in data collection, analysis and utilization through professional development, training and tools, standards of excellence and access to equitable funding.⁶³

Its mandate is to use research and information collected from First Nations communities to benefit the health and wellbeing of First Nations and to partner with entities that seek mutually beneficial relationships with First Nations through processes that respect the jurisdiction of First Nations over research and data.⁶⁴ The AFNIGC coordinates RHS, REEES and the FNLED survey. Much of the work is health focused, but it also helps support First Nations data needs on education, ASET teams and child welfare.

With support from the FNIGC legal counsel the AFNIGC developed privacy policy templates for communities to use in the development of their own privacy policies. Research efforts are focused strictly on First Nations living on reserve and promoting data sovereignty.⁶⁵ The AFNIGC works to ensure its participation in research is not creating “have and have not” communities in terms of capacity and infrastructure. Larger communities have an easier time getting resources, in many cases, while the smallest communities struggle to set up the systems and find and retain the talent needed. RHS funding does not support the AFNIGC doing face-to-face work in communities.

Relationships

In its 18th year of implementation, the HCOM Secretariat evaluates and reports annually on the success of the relationship and in implementing the agreement. There are five health co-management priorities:

1. Increase collaboration between partners.
2. Positively change health outcomes.
3. Improve collection, access and use of health data.
4. Achieve strategic outcomes:
 - Improved immunization rates.
 - Reduced rates of teenage pregnancies.
 - Increased initiation to alcohol.
 - Accredited Health Director training.
 - Prevention of child abuse.
 - Reduced incidence of gang-related activities and incidence of family violence.
5. Re-commitment to Co-Management principles.

⁶³ Ibid.

⁶⁴ Ibid.

⁶⁵ AFNIGC. [Frequently Asked Questions](#).

The latest evaluation report on the agreement and operation of the co-management structure was issued in 2015. It notes that the HCOM structure has grown into a well-recognized and credible organization with a well-defined committee structure and Health Secretariat. A 2011 evaluation found the model is viable, but responses were mixed.⁶⁶

What's Working	What's Not Working
A unique model, giving Alberta First Nations an advantage relative to First Nations in other provinces	Limited collaboration within HCOM ("we/they" attitude, not "us," prevails)
Streamlined sub-committee structure	Competitive funding disputes occur between Treaty areas
Sub-committees are increasingly aware of FNIHB operational plans and budgets	Funding formula remains problematic
Website is well done, but not up-to-date with minutes from committees	Mandate to co-manage, co-assess and co-analyze is not being met – FNIHB had not been properly consulting until recently
FNIHB Regional Executive Officer doing well in supporting overall operation of HCOM and involving Chiefs in decision- making	Critical health needs not being met in a timely manner, including jurisdictional issues, due to lack of communication, funding flow decisions, etc.
	High turnover of subcommittee members; new co-chairs not receiving orientation on HCOM operation
	Health Secretariat not functioning well – inaccuracies in minutes, late notice of meetings and agendas

This evaluation led to several recommendations:

- Terms of reference needs to be reviewed and ratified by AoTC and reviewed annually by all parties.
- Improve HCOM communication flow and accountability.
- First Nations must be involved in decision-making, setting priorities in addressing First Nation health needs.
- Committee members need to understand the federal government's annual budgetary processes and the timeframe its planning cycle.
- Incorporate First Nations culture throughout the organization and sub-components.⁶⁷

The HCOM relationship is now undergoing another evaluation cycle. Concerns have been expressed over whether FNIHB is picking favourite communities. There is also concern the evaluation is not looking at whether the agreement is saving lives and improving health outcomes. The AFNIGC expressed frustration over the meaningfulness of the evaluation process.

The provincial government is not a signatory to the HCOM Agreement. A number of years ago, the province asked FNIHB-Alberta for access to the Indian Registry, bypassing First Nations themselves. First Nations used to pay health care premiums in Alberta, so the province was accustomed to receiving this information as a matter of course. At the time of this request, Alberta First Nations did not have a data governance structure, so were unable to prevent the information from being

⁶⁶ Ibid. p 5-6.

⁶⁷ Ibid. p 6.

disseminated and used widely throughout the provincial government. In 2013, the AFNIGC issued a public letter calling on the provincial government to cease and desist accessing First Nations data without consent. The AFNIGC has offered to help the provincial government with appropriate First Nations engagement in the future.

Development of Indicators & Using Data for First Nations Priorities

When linking RHS data with administrative data, particularly the Indian Status Registry, the AFNIGC found that not one student from a large community was on the provincial school registry. This led them to begin cleaning the membership list to get more quality data about the community.

The AFNIGC described its ongoing work with Alberta First Nations as reframing health indicators from a deficit-orientation of the Western epidemiological perspective and approach, to “indigenized” health indicators, or indicators from a First Nations understanding of the world. AFNIGC works with elders and community members to develop indicators measuring ties to land use, community health and wellbeing, language retention, and cultural and spiritual practices engaged in by community members. At this stage, the AFNIGC is not developing indicators but having communities start to define things from their worldview, and First Nations are becoming more engaged and excited about research from their perspective.

The AFNIGC is working with communities to populate their community profiles; however, the AFNIGC is not retaining this information out of concern that other partners cannot protect community-level data (e.g., provincial and federal governments). The AFNIGC is also talking with communities about the benefits of clustering their data based on Tribal Councils or similar aggregates to those used by the province, and working to enable community-level data storage to ensure OCAP® standards are being met.

AFNIGC has also observed a breakdown in the transfer of cultural knowledge, including language, from one generation to another. With elders facing higher rates of substance abuse and other socio-economic problems, many do not live beyond 65. In other communities, such as in Lakota communities, language retention is high and few members leave the community.

British Columbia

Background & Regional First Nations Data Governance Structure

A precedent-setting agreement amongst BC First Nations leadership, and the provincial and federal governments (the parties) led to the establishment of the First Nations Health Authority (FNHA), the first indigenous health authority to cover an entire province. After years of negotiation and various tri-partite agreements, transfer of FNIHB-BC programs to the new FNHA occurred in 2013; without prejudice to First Nations interests. Four entities were created by the health transfer agreement: the First Nations Health Council (leadership), First Nations Health Authority (management), First Nations Health Directors Association (services) and the Tripartite Committee on First Nations Health (relationships).

Guided by the First Nations Health Council (FNHC), the regionally appointed/elected leadership body, the FNHA Board assumed responsibility for policy development and management of health programs delivered by the Health Canada First Nations and Inuit Health Branch of the BC Region. The First Nations Health Authority staff work closely with the First Nations Health Directors from across BC, following 7 governance directives, the first being that all relationships and services be Community driven and Nation based. This landmark legal agreement ensures BC First Nations have a major role in the planning and management of health services for First Nations through assuming responsibility for the programs and services and also providing influence over the provincial health system that serves all residents of BC.

The Tripartite Committee on First Nations Health (Tripartite Committee) is the primary forum for engagement with the federal and provincial governments, related to implementation of the transfer agreement. The 2010 British Columbia Tripartite Data Quality and Sharing Agreement promoted a commitment to ensure the sharing of federally and provincially held information on First Nations was done in accordance with standards set by BC First Nations governments; however this agreement was negotiated prematurely. Data governance and information management are now being reconsidered as the FNHA begins the transition to measuring health and wellness as conceptualized by the various Nations across BC, through their planning processes. The Nations have worked with FNHA to develop a new set of indicators that will shape provincial level reporting. BC First Nations entrusted the 4 entities with a vision of healthy, self-determining and vibrant, BC First Nations children, families and communities.

The First Nations Health Council is responsible for establishing effective partnerships to begin addressing the broader social determinants of health and they have, over the past year, established relationships with both federal and provincial governments, to affect change across multiple Ministries and Departments⁶⁸. Through a regional caucus structure, the conversations with the other governments have been brought closer to home. First Nations leaders meet with the provincial and federal governments regularly, through the Health Council structures.

Early on in the development of the FNHC and the FNHA, BC First Nations leadership identified data and data governance, as a cornerstone of the institutions and of First Nations governance, in general. The First Nations Health Council signed a Data Governance Strategic Framework on behalf of BC First Nations, through which a collaboration of First Nations governments has been demonstrating the shifts necessary in relationships, investments and accountabilities, to achieve

⁶⁸ Partnership Agreements can be found on the [Council website](#).

good governance. The British Columbia First Nations Data Governance Initiative (BCFNDGI) Strategic Framework lays out the role of each of the parties in the data governance relationship. The framework set out to achieve the following vision and key objectives: Governments (First Nations, federal and provincial) have timely access to quality data, to plan, manage and account for investments and outcomes associated with First Nations wellbeing.

Informed Planning and Accurate Reporting

- First Nations will have access to accurate information to effectively plan and implement change at the community level.
- Governments will be able to generate complete, specific and accurate reports associated with outcome statements that will measure investments in communities.
- Access to breadth of data provides better indications on trends, problems, solutions etc.
- Reporting is rationalized, simplified, and consistent.
- Reports will be available at the local, regional, provincial and national levels.

Common Data Standards across Governments

- Administrative data collected via a sustainable workflow model that is integrated into the daily operations of First Nations governments building in accountability at many levels.
- Building citizen trust in government through accuracy, timeliness and breadth of reporting.
- BC First Nations' Data Governance Initiative will be a flagship in effective and quality data models.

Reinforced Transformative Change

- Wellbeing can be measured holistically and development can be broad based and culturally relevant.
- Increased system wide capacity enhancement in data governance, data management, and Information Sharing as a foundational component of all First Nations governments and governance.
- Policy will reflect the data and research, and in turn the investments, and thus more accurately address the needs and hopes of First Nations at the individual, community and nation levels.

Increased Efficiencies

- Approach to data management will increase the capacity of First Nations and be sustainable in the long-term.
- Investments managed through automated systems will increase compliance
- Information sharing will eliminate the significant redundancies in both data collection and reporting.
- Standardized use of locally developed systems reduces individual capital and maintenance costs.
- First Nations working together facilitates collaboration, maximizes efficiencies and builds local capacity.⁶⁹

The BCFNDGI, led by and for BC First Nations, implements some of the political commitments outlined in Tripartite Data Quality and Sharing Agreement and other tripartite and bilateral

⁶⁹ Strategic Framework.

agreements founding the new relationship and FNHA. It aims to take a citizen-centred approach to data management, with data being drawn from multiple sources to report on the comprehensive wellbeing for an individual, a family, community, nation or region. Currently, most data is organized by program, which is not acceptable to First Nations. A key first step in managing data in this way is to ensure that each individual is correctly identified, regardless of where services are received.⁷⁰ Nations are asserting self-determination and this includes implementation of citizenship processes.

To assist First Nations in developing the technological and human resource capacity to collect, manage, report on, own and share, as appropriate, their communities' data, the BCFNDGI is currently supporting Demonstration Sites, in six Nations with 13 First Nation communities. A number of the Demonstration Sites use locally developed First Nations program administration and data collection systems to manage data collection and reporting and a project this year focuses on demonstrating what is required at the Community level, to manage change from paper to computer based systems. Over the years, each project has been building upon the previous year's work, developing policies, guidelines, tools and approaches to support data governance within all First Nations in BC.⁷¹

The goal is to have Nations provide custodial oversight in data governance and to establish tripartite agreements to coordinate provincial agencies and First Nations service organization participation in Community Development and Nation Rebuilding under a regional Collaboration Framework, supporting governance transition activities, such as the development of the Data Governance Strategy and BC Data Centre. Data hubs in each of the five sub-regions would facilitate Nation-based data back up and aggregation, cleansing and reporting. The Nations would collaboratively govern these data centres at the sub-regional level and also at the provincial and national levels. Sub-regional data would be backed up at the provincial First Nation Data Centre and as appropriate, cleansed and aggregated for reporting.⁷²

BCFNDGI is helping to facilitate a shift from federal and provincial government program management to First Nation governments managing investments, with nation-based spending authorities replacing departmental authorities and investments targeted to Community Development and Nation Rebuilding under one comprehensive funding agreement. This will enable Nations to report on the wellbeing of their own communities and citizens. Reporting would be based on an agreed upon (tripartite) set of high level wellbeing outcomes, with Nations developing local indicators and data elements to match their current developmental status, rather than trying to report by program. This shift will also enable Nations to provide comprehensive, outcome-based reports to their citizens and the general public and to enable Indigenous Affairs to account for investments and outcomes associated with those investments, under the envisioned Nation-to-Nation relationship.

⁷⁰ Strategic Framework, 14.

⁷¹ BCFNDGI Communities.

⁷² BCFNDGI. Indigenous Information Governance Regional Information Governance Centre Concept Paper – BC, p 12.

Relationships

The First Nations Health Council acknowledges that it is necessary to transform relationships, before service transformation can occur. With this in mind, they have established relationship agreements with the federal and provincial governments, to work on a Community driven, Nation basis, to affect change across the broader social determinants. A ten year commitment has been made by the province of BC and the Minister of Indigenous Affairs recently signed an MOU with the Health Council, to focus collaboration with Nations on achieving the vision of healthy, self-determining and vibrant BC First Nations children, families and communities. These agreements are both in the early stages of implementation, but have already had positive effects on relationships between the provincial government and First Nations Chiefs and leaders.

While relationships have improved considerably between the tripartite partners over the past decade, challenges remain. Because of the comparatively vast resources federal and provincial governments have and the undefined Nation to Nation relationship, First Nations must still cooperate with external funders, researchers and other organizations that in effect, pull them in many different directions, mainly away from the critical work of Community Development and Nation Rebuilding. The Inherent right of each Nation to govern stems from each Nation's identity as a unique Nation, with a unique language, customs and history, and regaining sovereignty over data translates to ownership of that data and therefore, ownership of identity and destiny. Each Nation needs to define their own research agenda and methodology, while also exploring options for syncing common data standards at the regional and national levels.

Key factors for relationship success cited included being clear and agreeing on what each other's roles are; and being accountable for one's commitments. This means going beyond the approach of government saying "I understand, but can do nothing" to being responsive. Some relationship indicators on consultation and accommodation and whether or not government partners are living up to their commitments made in agreements have been developed in this region.

The Tripartite Committee is composed of senior representatives from First Nations and federal and provincial governments. This committee:

- Coordinates and aligns planning, programming, and service delivery between the FNHA, BC Health Authorities and the BC Ministry of Health, including review of multi-year plans.
- Facilitates discussions and coordinates planning and programming among the partners.
- Provides a forum for discussion on the progress and implementation of the agreements that established this new First Nations health governance system.

The committee meets at least twice per year to measure progress of Health Plans and discuss any needed changes to roles, powers, or funding.⁷³ The Committee oversees the development and implementation of the Tripartite Evaluation Plan for the BC First Nations Health Governance structures, including of course, the Indicators to be used in measuring relationships and the results of these relationships.

⁷³ Institute on Governance.

Development of Indicators & Using Data for First Nations Priorities

Sovereignty is about more than treaties. It is all about the expression of who you are, as a Nation, and the subsequent recognition of that. Sovereignty exists in action. Data sovereignty is about the ability to tell one's own story about one's self (Community/Nation). To move deeper in nation rebuilding, First Nations need to go past just owning their data to truly reclaiming their identity and destiny. The BCFNDGI emphasized that each Indigenous Nation has, from time immemorial, been a data collector, surveillance officers and governors. For example, in one Nation, there was a designated Duck Chief, a Deer Chief, a War Chief, and so on. Each of those leads, through governance processes, undertook surveillance and made policy over their respective areas of expertise. These Nation-based data leads and monitors performed surveillance in the interests of their Nations and their ongoing ability to provide for their people, live well in and defend their territories and steward their cultures. Nations across Canada are reestablishing processes of governance and developing institutions to carry out these processes.

Chiefs across BC are through various tables, collaborating with other governments to define the responsibilities and accountabilities for reporting to their citizens' on Community and Nation wellbeing at the population level. It is envisioned that the current program based reporting will shift to a Community-driven, Nation-based model, with investments realigned with Community Development and Nation Rebuilding plans including funding to carry out governance functions and continuous development. Each region will develop a data governance transition strategy, which will be coordinated nationally, to transition from program reporting to Nation-based reporting. The BCFNDGI produced a set of posters related to [Community Development and Nation Rebuilding](#), as a high level guide to carrying out this work.

It is envisioned that the Chiefs in each province and territory will establish and govern over their own form of a Regional First Nations Information Governance Centre (RFNIGC) and that these Centres would form a national network through which to support Nation-to-Nation capacity building. First Nations leadership will collaborate with other governments to establish reporting standards in their region, but under a national framework, with the objective of Indigenous control of Indigenous data.

The BCFNDGI also emphasized the role of each Nation's data steward(s) is not simply to protect data; First Nations data does need to be protected against misuse and misappropriation, but simply focusing on protection as the end in itself can risk perpetuating a static notion of Nation, as opposed to a Nation as a living and evolving entity. Each Nation's data steward(s)'s role goes further, to help facilitate that Nation's rebuilding. Data governance for Nation Rebuilding entails moving past protection to enabling each Nation to track their progress towards achievement of their own vision and to tell their own story of their journey back to self-government.

Yukon

Background & Regional First Nations Data Governance Structure

Eleven of the 14 First Nations in the Yukon have signed self-government agreements with the Government of Canada and the Government of Yukon recognizing these First Nations as governments and establishing the framework for their relationships. The plans and agreements for each self-governing Yukon First Nation (SGYFN) are interrelated and work together to structure self-government and program/service delivery in the Yukon. Final agreements are based on the Umbrella Final Agreement (UFA) with specific provisions for each First Nation. The UFA creates public government institutions, defines the quantum of settlement land, and includes a commitment to negotiate self-government agreements. The final agreements provide for the negotiation of self-government agreements, which allow SGYFNs to make decisions in relation to their lands, resources, governments and programs and provide for financial compensation, identify settlement land for each SGYFN, and outline land and resource ownership, tenure, and management issues. Final Agreement Implementation Plans identify the activities, timeframes and resources that have been agreed upon to give effect to the final agreement. Self-government empowers a SGYFN to govern itself in a manner that is responsive to the needs and interests of its people.⁷⁴

Yukon First Nations are still in the exploratory phase of First Nations data sovereignty in their territory. They collaborate with the Council of Yukon First Nations on data gathering initiatives such as the First Nations Regional Health Survey. CYFN, in turn works together with the First Nations Information Governance Centre (FNIGC) in Ottawa on national First Nations specific surveys. The biggest challenge identified in the Yukon is the small size of communities making community level analysis difficult. The Yukon also has a different First Nations political situation than the rest of the country. For example, there are no reserves in the Yukon. The Yukon First Nations Health and Social committee (chaired by CYFN) facilitates survey research in each community by championing capacity building in data collection that is OCAP® compliant. In data gathering initiatives to date CYFN has included all Yukon First Nations in order to allow for a more representative Yukon-level analysis. CYFN is also the data steward for the data collected by CYFN in the Yukon First Nation Communities.

An advisory committee of health and social directors is appointed by the Chiefs and Councils of First Nations communities to work on surveys and analysis. Many in communities are not educated or experienced in data governance. Another key challenge is the turnover of trained staff in remote communities.

Relationships

Yukon data gathered through survey collaborations with the FNIGC is kept and controlled by CYFN and shared with FNIGC for national level analysis only. The Council is committed to OCAP® and follows the principle that a Nation and its people should not be surveyed unless there is a benefit to the community. There is no university in the Yukon, but many university affiliated researches come to the Yukon to collect data and it is hard for the Council of Yukon First Nations to know the complete list of who may be in the Yukon seeking or obtaining First Nations data. Their goal is to grow in capacity and ensure it is known widely that those seeking First Nations data in Yukon should consult with the Council of Yukon First Nations and respect OCAP®. In some cases, individual communities may have their own agreements in place with external researchers.

⁷⁴ Department of Indian and Northern Affairs Canada, Building the Future: Yukon First Nation Self-Government, 2008.

The relationship with the territorial government is fairly good; when the territorial government wants to do research, they are mindful to connect with the Council of Yukon First Nations and the health and social development commission, chaired by CYFN. The territorial government was given permission to present Yukon First Nations RHS statistics in the Yukon 2016 Health Status Report. Its focus was substance abuse, and the Territory was mindful to place the findings in context. This process was described as a good model for presenting First Nations data in its cultural and historical context. The basis of this success was attributed to collaboration and respect.

Development of Indicators & Using Data for First Nations Priorities

The Yukon region is using information collected through the community surveys developed by FNIGC as indicators. Through its role on the board, the Yukon tries to influence the development of the FNIGC indicators and processes. A key priority is changing the methodology from its traditional quantitative model with its focus on death and illness. Yukon reports on RHS findings provide context, culturally based artwork and quotes from elders.

The Yukon region made a concerted effort to determine how many people attended Truth and Reconciliation Commission (TRC) events, which they attended and in which ways they events were useful. They are also collecting information on what extent people are still involved in traditional activities such as sewing, beading, canning, trapping, snowshoe-making and the extent to which citizens practice spirituality. These are all attempts to collect information that help measure how people are moving forward, how they are looking after themselves instead of staying stuck in a paradigm that measures negatives and gaps and not the full picture.

Yukon First Nations have not had the opportunity to undertake Comprehensive Community Planning. Reserve communities get INAC support for this process, while self-governing Yukon First Nations do not get this support.

Quebec

Regional structure and context of information governance for the First Nations

In 1975, the Cree and Inuit signed the *James Bay and Northern Quebec Agreement (JBNQA)* with the Government of Quebec and other signatories. This agreement allowed them to achieve self-determination, in part, in the area of health. It gave the Cree and Inuit the power to create their own regional entities for managing their education as well as health and social services.⁷⁵ In 1978, the Naskapi signed a similar agreement with the Government of Quebec, namely the *Northeastern Quebec Agreement (NEQA)*. Seven years later, in 1985, Quebec's National Assembly adopted a resolution recognizing the rights of Aboriginal peoples, including the right to self-determination, for the Inuit communities and ten First Nations: Abenaki, Algonquin, Atikamekw, Cree, Inuit, Maliseet, Mi'gmaq, Mohawk, Naskapi and Wendat. In 1989, the federal government adopted a policy for establishing a framework to transfer health services from Health Canada to the First Nations so that they could attain self-determination in health, under the conditions negotiated between Health Canada and the communities. Funding for the communities that wished to implement their own health programs was provided by FNIHB.⁷⁶

Through these agreements and several others, the majority of First Nations in Quebec and some of the tribal councils took over responsibility for the planning and delivery of their health and social services. The communities that did not sign agreements and thus did not receive the transfer of their services remain under the authority of the Government of Canada.⁷⁷

The First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) is a non-for-profit organization mandated by the Assembly of First Nations Quebec-Labrador to work with the Quebec First Nations. The FNQLHSSC is made up of seven sectors: administration, early childhood, health, information resources, research, social development and social services. The research sector conducts research projects and evaluations, coordinates population surveys, and carries out activities with regard to the surveillance of First Nations health and health determinants.

Further to complying with and promoting the principles of OCAP®, the FNQLHSSC works with different advisory committees and representatives of the First Nations communities and organizations. One objective of the research sector for future realization is to produce, along with external collaborators, an inventory of all the research projects in Quebec, including those conducted by universities. It has developed various statistical tools and analysis products based on national surveys, for the use of the First Nations communities and organizations. The FNQLHSSC works in close collaboration with the communities, particularly with the health and social services directors. It favours the recruitment of local interviewers and has the goal of building the communities' capacities so that they can improve the good governance of their information, by conducting their own interviews and developing their own tools. This network allows the FNQLHSSC to plan and carry out province-wide surveys in collaboration with the communities.

⁷⁵ Les Publications du Québec, *James Bay and Northern Quebec Agreement and Complementary Agreements*, 1998.

⁷⁶ First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC). Quebec First Nations Health and Social Services Governance Process. *Portrait of the Rights, Laws, Policies and Agreements Concerning Health and Social Services for the Aboriginal Peoples of Canada*, p. 15.

⁷⁷ First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC). [A renewed approach to governance fostering self-determination](#), 2nd edition, April 2016, p. 22.

Health and social services governance process

Health and social services governance is a source of concern for the First Nations in Quebec, Canada and elsewhere in the world. To overcome the gap in health and well-being between the First Nations and the non-Aboriginal population in Quebec, the First Nations have devoted efforts for bringing about a profound transformation in the structure of health and social services governance. The health and social services governance process in the Quebec First Nations is intended to contribute towards improving the provision of and access to local and regional services, through the implementation of a governance model adapted to the realities and needs of the Quebec First Nations. Following are the two objectives of this process:

1. Reinforce the decision-making capacity of communities and regional organizations in health and social service governance related to existing programs, services and initiatives in health and social services.
2. Reinforce the partnerships with government institutions, based on a model adapted to the realities and needs of the First Nations.⁷⁸

The Quebec First Nations are envisaging the possibility of transferring authority for health in a way somewhat similar to how the British Columbia First Nations Health Authority did so, but with social services included.⁷⁹

During the past three years, an inventory of models and best practices in health and social services government was created. Regional meetings were held so that the decision-makers in the communities could give their opinions about the current governance structure, define the desired changes and validate the governance models suggested as options.⁸⁰ A new model for health and social services governance will be presented to the Chiefs of the Assembly of First Nations Quebec-Labrador for approval.

Relations

For the FNQLHSSC, the establishment of a nation-to-nation relationship means that the First Nations can play a preponderant role in the decision-making process on all matters affecting them. The FNQLHSSC is working in particular with Health Canada to reduce the number of indicators that are collected and to simplify the template for the reports to be submitted by the communities. The objective is to emphasize on the quality of the indicators and the information that is obtained rather than on quantity.

The federal government has for generations been managing the design and development of health and social services programs for the First Nations, but the Quebec First Nations are challenging the relevance of these programs for their citizens. They are exerting efforts to take over the responsibility for the design, development and implementation of programs that are developed for and by the First Nations. The governance process of these nations is changing accordingly, as have inter-governmental relations.

⁷⁸ FNQLHSSC, p. 2.

⁷⁹ As mentioned previously in the section on British Columbia, discussions are currently being held by the tripartite partners to extend the FNHA governance framework to include the full scope of the social determinants of health.

⁸⁰ *Ibid*, p. 6.

In the meantime, due to the absence of a tripartite agreement on information governance, it is difficult to access information concerning the First Nations. The majority of the communities do not have a protocol for governing access to information held by the province.

Development of indicators and use of information to respond to the First Nations' priorities

The FNQLHSSC considers the indicator dealing with language retention and revitalization to be one of the key indicators for which information is currently obtained on nation-to-nation relations. Culture, which includes language, is seen as being central to self-determination. It is the foundation and identity of a nation. During the consultation of the Quebec First Nations about the new health and social services governance model, the following priorities were brought up:

- The governance model must integrate the First Nations' culture and their vision for health.
- Health and social services must be adapted to the culture of the persons affected by them and must be appropriate.
- Commitments made to transfer, in whole or in part, authority referred to under regulations and agreements must be made official.
- The regulation process must be based on the needs of First Nations in order to guarantee that the communities have a form of local authority.
- The roles, accountability and responsibilities of all signatories must be clear, understood and accepted by the different parties.
- The requirements pertaining to reports must be explicit, understood and accepted according to the capacities of each party.
- The communities and their partners must participate in the decision-making process.
- The commitment of partners must be supported by relevant and specific objectives.
- The flow of information must be structured.
- The development of programs and the delivery of services must be supported by efforts in capacity building.
- Governance must serve to guide the application of regulations, the autonomy of all signatories and the resolution of conflicts.⁸¹

The FNQLHSSC maintains that one of the most important challenges is the limited resources available to the First Nations communities and organizations. They do not have the means to access information concerning them or to create their own information centres. They must therefore request assistance from their partners to develop solid and sustainable capacities in the area of information governance.

The FNQLHSSC is seeking to gain access to the socio-health databases of the province in order to enrich the surveillance portal and improve the communities' access to information. The FNQLHSSC has developed a framework consisting of 300 indicators, 70 of which are dedicated to health and wellness.

⁸¹ *Ibid*,

Saskatchewan

Background & Regional First Nations Data Governance Structure

The Federation of Sovereign Indigenous Nations (FSIN) is made up by 74 First Nations in Saskatchewan, some as part of tribal councils and others independent. The main function of the FSIN is to lobby the federal government for on treaty rights. The FSIN also coordinates and supports First Nation participation in the RHS.

Regional respondents cited Saskatchewan as the only region in the country to have developed Indicator Dashboards, to enable First Nations to monitor its priority indicators to assess their progress in reaching development goals. The Saskatchewan Community Development Strategy (SCDS) is a partnership to support the health and well-being of First Nations people in Saskatchewan. The strategy recognizes the unique goals and strengths of every First Nation and aims to empower First Nations to achieve these priorities. The strategy involves three recurrent components of a community's cycle of planning, implementing and measuring:

1. Comprehensive Community Planning (CCP);
2. Partnerships and Implementation; and
3. Indicator Dashboards.⁸²

Each area of CCP selected by a First Nation is tracked on its dashboard, including governance, to help inform community evaluation, discussion and decision-making.

Relationships

The traditional federal grants and contributions program funding model has left many indigenous communities behind. Many of the relationships required for Indigenous data sovereignty and Nation-to-Nation goals to be reached are just only beginning to be developed. For example, to date, relationships have not been established with the provincial health authorities.

The SCDS is a holistic, strength-based and community-led process to build and invest in effective, sustainable Indigenous governance to support the development of a true Nation-to-Nation partnership. First Nations, Indigenous organizations, INAC staff and other government partners developed the strategy.⁸³ The strategy includes an ongoing engagement process with Indigenous community planners to ensure the community development approach is evergreen and informed by the Indigenous communities it is intended to serve.

Band Councils can confirm their intent to participate in the strategy by signing a Band Council Resolution.⁸⁴ Community Navigators we spoke with confirmed First Nations are stewarding their data closely, requiring written confirmation from Council to access key data.

Community Development is not a program. It is a principled, values-based approach to support the health and wellbeing of Indigenous peoples by empowering communities to manage their own services and build on their own strengths, including culture.⁸⁵ INAC Community Development

⁸² DRAFT-Saskatchewan Community Development Strategy. March 2017: 1.

⁸³ Ibid. p 3.

⁸⁴ Ibid. p 7.

⁸⁵ Ibid. p 4.

Officers act as liaison between Community Navigators, INAC and other government departments and can connect Navigators with appropriate partners during planning and implementation. INAC maintains a database available to First Nations of programs, services and resources. It is updated by CDOs. The database is available to Navigators to use. INAC also maintains the Saskatchewan Region Planning Repository, with all planning documents for each First Nation in the region, to improve knowledge of each First Nation's planning and priorities within INAC.

Regional First Nation-to-First Nation workshops are held every quarter in Saskatchewan, to advance shared learning experiences and build a network of support among Community Navigators. Last year, a committee involving Community Navigator staff from a number of First Nations and INAC staff identified approximately 100 indicators in 8 or 9 key issue areas to enable data comparison across participating Saskatchewan First Nations. Community Navigator staff note it is very challenging to get the data they need and noted that INAC may be able to help facilitate that through a letter describing their roles and responsibilities.

One recommendation was for dashboards to help measure government progress on implementing recommendations of the Truth and Reconciliation Commission (TRC), which is a key way to monitor progress in the Nation-to-Nation relationship.

Development of Indicators & Using Data for First Nations Priorities

In developing a CCP, Indigenous communities themselves determine objectives, strategies and timelines. A CCP highlights the unique goals and vision of the community. Each nation selects its own Community Navigator to lead the CCP process through extensive engagement with members, leadership, administration, elders and youth, on and off reserve. Navigators may also establish a community advisory or planning team to represent different areas of expertise in the community. The Navigator serves as a liaison between the nation, mentors and partners. The Navigator is familiar with First Nation and federal government planning processes. Navigators identify top priorities from the CCP and potential partners that can support the implementation of these priorities.⁸⁶

First Nations develop their own Indicator Dashboard to track data such as graduation and employment rates and can also include goals and milestones with progress updates. Data is gathered by the Community Navigator from federal departments, provincial ministries and other stewards of First Nations data. Each First Nation will control access to their dashboard and decide which data to share publicly and which data should not be made public. The information the dashboard will provide to decision makers will enable them to make informed decisions and show progress to their members. Dashboards are made to easily integrate with basic web platforms, to enable each First Nation to manage their dashboard with limited training needed. First Nations are able to use the regional dashboard at www.skfn.ca for comparative analysis.⁸⁷

The Saskatchewan Community Development Strategy includes funding to facilitate partnerships and mentoring between experienced First Nation planners and new Community Navigators and recognizes the need for a more formal mentorship initiative.

Once it has been developed, the SCDS will measure:

⁸⁶ Ibid., 5-6.

⁸⁷ Ibid., 6-7.

- The number of CCPs developed;
- The number of integrated support teams formed; and
- The number of First Nation priorities identified in CCPs that are implemented.⁸⁸

The Community Navigators we spoke with suggested follow up after the dashboard project has been operating would help inform whether it is truly working toward the commitment to a Nation-to-Nation relationship.

First Nations Information Governance Centre (National)

The First Nations Information Governance Centre (FNIGC), located in Ottawa, serves as the permanent home of the First Nations Regional Longitudinal Health Survey (RHS) and provides training, research and dissemination services to First Nations at community, regional and national levels. It supports the development of regional centres, such as the Alberta First Nations Information Governance Centre (AFNIGC), serving First Nations strategic information and research needs, as determined by the participating regions. FNIGC also helps build capacity in information management, research and data governance.⁸⁹

The FNIGC is the home of the First Nations Data Centre (FNDC), which provides access to unpublished and record-level data from the FNIGC's respected survey work, including the RHS and First Nations Regional Early Childhood, Education and Employment Survey (FNREEES). This data is available to researchers for academic, policy and evaluation purposes on a pay-for-use basis and not for commercial purposes.⁹⁰

Each participating region decides whether to incorporate its regional office into the FNIGC structure. This process is regionally driven. With approval from the FNIGC Board of Directors, any First Nations regional organization may become a member of the FNIGC. The RHS has helped build regional information management infrastructure, with regions serving as the backbone of the survey process. Each region directs the development of its capacity for research, data collection and information dissemination.

⁸⁸ Ibid. p 10.

⁸⁹ First Nations Information Governance Centre (FNIGC). [About FNIGC](#).

⁹⁰ Those seeking to use FNDC data will be subject to a comprehensive screening process that respects the First Nations principles of OCAP®. FNIGC. [The First Nations Data Centre](#).

Appendix B: Interview Questions and Participation

Interviews were conducted over the phone between February and April 2017. Participants included:

- Kathi Kinew, Manager, Social Development and Research Initiatives, Nanaandawewigamig (First Nations Health and Social Secretariat of Manitoba)
- Leona Star, Research Associate & Regional Coordinator, Regional Health Survey & Regional Early Education Employment Survey, Nanaandawewigamig
- Lori Duncan, Health and Social Director, Council of Yukon First Nations
- Helen Stappers, RHS Coordinator & REEES/RHS Data Analyst, Council of Yukon First Nations
- Bonnie Healy, Operations Manager, Alberta First Nations Information Governance Centre
- Nancy Gros-Louis, Research Sector Manager, First Nations of Quebec and Labrador Health and Social Services Commission
- Marjolaine Sioui, Executive Director, First Nations of Quebec and Labrador Health and Social Services Commission
- Gwen Phillips, Provincial Champion, British Columbia First Nations Data Governance Initiative
- Sandra Harris, Program Developer, Gitksan Government Commission
- Joey Tootosis, Flying Dust First Nation, Saskatchewan
- Jasna Eyahpaise, Beardy's First Nation, Saskatchewan

Participants were asked the following questions:

1. Can you describe your region's structure and processes for data collection and governance when carrying out national surveys?
2. What data indicators are being tracked and developed in your region?
3. What relationships are involved in your organization's data governance? (e.g., with federal, provincial / territorial or First Nations governments) Which entities are involved in collecting, managing and accessing that data? What protocols or agreements govern these data management relationships? How are roles and responsibilities allocated / defined?
4. Are these relationships working well? What are the challenges?
5. How would you define and measure a successful relationship? Can you provide examples of such good relationships? Could you describe what makes/shows good relationship in a few words?
6. Is support for planning and data management in the communities /nations adequate?
7. How do you define a Nation? Is one First Nations community a Nation or is a Nation a larger group connected by culture, language or other common bonds? What form does your Nation take? Can you describe its political and administrative structures?
8. What is the role of transforming data governance in reconstructing Nations?
9. Is your Nation tracking any governance indicators? (e.g., Councillor attendance at meetings; meetings between band councils and hereditary chiefs; trust in institutions and representatives over time). What are your Nation's objectives in tracking these indicators?
10. How do we define and account for a Nation-to-Nation relationship? What indicators would be helpful for tracking nation rebuilding and a Nation-to-Nation relationship?
11. What are your goals for data sovereignty? Are you achieving those objectives? Are there any gaps or key next steps that need to be addressed to meet your data sovereignty objectives?

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