

# Data Resources and Challenges for First Nations Communities

Document Review and Position Paper

Prepared for the Alberta First Nations  
Information Governance Centre

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# Introduction

Within Canada, multiple large data sources can be accessed and analyzed by research teams and communities. Despite the seeming availability, data is not routinely used in planning and advocacy for the benefit of First Nation communities. Data is regularly extracted from Indigenous communities and Indigenous people are “researched to death,” and still we see a consistent deficit of data for use in these communities. Why has meaningful, relevant, and useful data not been put into the hands of those who can use it? Anderson reports that while there are numerous data sources related to Indigenous health with many indicators developed to help understand health trends, “the use of these indicators has not effectively contributed to improved health of First Nations, Metis, or Inuit Peoples” (Anderson, 2006, p. 5).

First Nations communities, leaders, and policy makers now have the opportunity to use data to meet their own needs and bring evidence to their own concerns. This report aims to highlight the challenges with existing data and to offer some current solutions and examples of change that place relevant, meaningful data into the hands of communities and policy makers. This position paper will draw on leading thinking, key documents, and other supporting literature, as well as the author’s background in the subject.

# Why Data?

Data can highlight inequality and bring an evidence-based lens to policy making. Data provides baselines and benchmarks which allow for measurements of change over time and can be used by governments to develop “solid policies and programs effectively, to demonstrate accountability, and to be transparent to their citizens” (Steffler, 2016, p. 149).

Data is inherently political and can help identify priorities, set targets, and hold government accountable. Many First Nations people and communities have experienced data being used for political purposes, but not their own. The content and purposes of data have historically been determined outside of First Nations communities (Otim, 2015), and the misuse of data has led to situations of misappropriation and broken trust. The solution to irrelevant and pathologizing data is, oddly, more data. Good data. Data that is developed by and with and for communities, data that reflect Indigenous worldviews, and data that is both relevant to communities and agreeable to policy makers.

The move towards evidence-driven planning and policy making is a welcome change from the status quo, particularly for First Nations policy, as the use of meaningful data allows for decisions that are based on evidence rather than external value judgments (Otim, 2015). Data, when developed, gathered, and used correctly, provides First Nations with a way to bring evidence to issues that could have otherwise been ignored. When communities become their own data stewards, they can take on a leading role in the direction of their community well-being and in the very definition of that well-being.

# Calls to Action

The call for the use of data in decision-making has made by many organizations, directly or indirectly. Governments, businesses, and civil service organizations are calling for improved accountability and performance through data monitoring. Particularly pertinent to First Nations is the call for data to respond to issues of equity and justice in key documents and commissions such as the Truth and Reconciliation Commission (2015), the United Nations Declaration on the Rights of Indigenous Peoples (2007), the Royal Commission on Aboriginal People (1994), and Indigenous researchers.

## Truth and Reconciliation Commission (2015)

The Truth and Reconciliation Commission was a hallmark effort of the Canadian government to document the experiences of Canada’s residential school students. The Commission includes calls to action to “redress the legacy of residential schools and advance the process of Canadian reconciliation” (Truth and Reconciliation Commission, 2015). Specifically, Article 19 of the document calls for monitoring the progress of closing the gap in outcomes between Aboriginal and non-Aboriginal communities, and to report this progress annually (Truth and Reconciliation Commission, 2015). This work will require the development of a monitoring framework and the ongoing collection of data.

## From the TRC

*Article 19.* We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services. (Truth and Reconciliation Commission, 2015)

### **United Nations Declaration on the Rights of Indigenous People (2007)**

The United Nations Declaration on the Right of Indigenous People was adopted by the UN General Assembly in 2007 but Canada's commitment to the Declaration has been inconsistent. Rather than requiring member states to report on Indigenous outcomes, the Declaration calls on states to allow Indigenous populations access to rights in governance and to an informed decision-making process. Throughout the declaration, states are also required to provide financial and technical assistance to implement the articles. In particular, Article 19 addresses the right for Indigenous people to have access to data and the right for them to obtain "free, prior, and informed consent before adopting and implementing legislative or administrative measure that may affect them." (United Nations, 2007). Also significant is the requirement of technical assistance with data analysis. Article 21 calls for the right of Indigenous people to "the improvement of their economic and social conditions, including areas of education, employment, vocational training and retraining, housing, sanitation, health and social security... States shall take effective measures and, where appropriate, special measures to ensure continuing improvement of their economic and social conditions" (United Nations, 2007).

### **Royal Commission on Aboriginal People (1994)**

The need for data was identified in the 1994 keystone report of the Royal Commission on Aboriginal People. In their response to the report, representatives from the Law and Government Division and the Political and Social Affairs Division of the Canadian federal government (Hurley, 2000) stated four objectives, one of which included explicit reference to enhanced data collection.

#### **From the Report on RCAP**

Developing a New Fiscal Relationship: the government's goals in this area included working toward greater stability, accountability and self-reliance; developing new financial standards with public account and audit systems that conform to accepted accounting principles; assisting First Nations governments to achieve greater independence through development of their own revenue sources; enhanced data collection and information exchange. (Hurley, 2000, emphasis added)

### **Indigenous Researchers and Advocates.**

Indigenous researchers and advocates use data to confront social justice issues in their communities. Data is a powerful tool in the ongoing fight against racism in the healthcare system and to improve Indigenous health generally (Anderson et al., 2006; Smylie and Anderson, 2006). "Meaningful data is critical to understanding and addressing the role of racism in the health disparities experienced by Indigenous people living in Canada" (Allan, 2015). Data lends support and authenticity to issues that could otherwise be swept aside as anecdotal.

## What Kind of Data is Available?

There are five main types of health data available to First Nations communities: census, vital registration, health surveys, health services utilization data, and surveillance systems (Smylie J. A., 2006). Each of these types of data may have multiple sources. The following is a brief overview of each type:

- **Census.** Census data is population level data collected by Statistics Canada.
- **Vital registration.** Vital registration data covers birth, death, marriage, stillbirth, and change of name. This information is collected provincially and can be reported provincially and nationally.
- **Health surveys.** Health surveys collect self-reported health information, often through a mail-out survey. The primary health survey in Canada is the Canadian Community Health Survey administered by Statistics Canada. This survey, however, is not carried out in First Nation communities living on-reserve. The alternative data source for First Nations communities is the Regional Health Survey carried out by the First Nations Information Governance Centre.
- **Health services utilization data.** This data reports on what health services were used by whom. It tells us the number of ambulance trips, cancer treatments, and surgeries in different parts of the country. The bulk of health services utilization data in Canada comes from the Canadian Institute of Health Information (though this data does not identify First Nations subsets) and for First Nations populations from First Nations and Inuit Health Branch – Health Canada and Non-Insured Health Benefits.
- **Surveillance systems.** Surveillance systems are tracking systems that monitor incidence of health conditions, such as provincial cancer registries where all new cases of particular types of cancer are reported by the facility that diagnoses the disease.

There are many sources of data for each of the types listed above. Data that is relevant to health often includes factors that determine health outcomes, like income and kinship support. Information about these determinants of health are collected in census, surveys, and other data sources.

The following sources of data have been identified for use in First Nations planning and development. While this list is not exhaustive, it is a good place to access information to begin data planning. While this list is focused on Alberta, other provinces and territories will have similarly named sources of data.

Type	Name of data set (Source of data)
Census	Canadian census (Statistics Canada)
Vital registration	Vital Statistics Offices (provincial, territorial and national registries offices)
Health surveys	Regional Health Survey (First Nations Information Governance Centre), Canadian Community Health Survey (Statistics Canada), National Household Survey (Statistics Canada)
Health services utilization data	Alberta Health Care Insurance Plan Registry (Alberta Health), Physician fee-for-service (Alberta Health), Ambulatory Care Classification System (Alberta Health), NIHB Pharmacy, Dental, and Vision Utilization data (First Nations and Inuit Health Branch)
Surveillance systems	Communicable Disease Reporting System (Alberta Health), Alberta Cancer Registry (Alberta Health)

For an overview of data sources available to Alberta First Nations communities and a description of the type of data in each, please see Appendix A. For a more extensive review of data sources relevant to First Nations communities, please see The Canadian Partnership Against Cancer report *Where there's a will, there's a way . . . Environmental scan and analysis of existing patient identification systems for First Nations, Inuit and Métis peoples* (2012).

# Data Challenges and Potential Solutions



# The Context of Data Collection and Use

Any attempt to discuss First Nations data extrapolation and use must consider the historical and cultural context of research in these communities.

## Data Context Challenges

### History of data collection and use

In the past, data collection efforts such as the census and broad reaching surveys “were conducted with little input from Indigenous communities and peoples” (Steffler, 2016, p. 151). In fact, Western ‘science’ has been a major tool to justify and sustain processes of colonization, serving as a tool to justify racist policies of subjugation (Kovach, 2010). Additionally, data collection through government agencies has even been used against communities to pathologize and take action against them, such as when it has been used to extract children from their families in the residential school system and the ‘60’s scoop. While an overview of these historical traumas is beyond the purview of this report, it is important to note that government agents knew of families and their children because those parents had shared information with government agents through registry programs, legal involvement, or other course of life activities. Essentially, sharing of personal information and the engagement of these individuals with government systems had led to a situation of deep communal and personal loss, and so mistrust in the system and in sharing information has been solidified.

The lack of involvement of communities in the development and use of data, and the drive for data collection from outside authorities, has led to a situation where Indigenous communities do not trust the data collection process and are often resistant to sharing their information (Royal Commission on Aboriginal Peoples, 1997). “This approach has created a situation in which there is a lack of trust, ‘buy-in,’ and participation on the part of Indigenous communities – inevitably affecting the overall quality of the data” (Steffler, 2016, p. 151).

### Lack of respectful relationships between researchers and communities

While communities may be queried for information, they are often excluded from the interpretation and presentation of resultant findings. When data is collected and used outside of the context of relationship, the data is at best subject to potential misinterpretation by researchers with different paradigms, and at worst can be used to pathologize communities by presenting negative elements without the context of historical trauma and Indigenous worldviews. For example, many communities have been subject to numerous studies on diabetes, HIV, and alcohol consumption that focus on individual decision-making, rather than presenting the health and social challenges these communities face in a broader social context.

Additionally, major challenges exist in protecting communities' right to privacy as researchers push for publication. There are many examples of studies on First Nations people being published by research teams without community approval of the interpretation or presentation of findings. In an example of extreme negligence in the treatment of communities, an Arizona State University research team collected blood samples from the Havasupai Tribe in 1989 and then used those samples without permission for unrelated studies; the research team published those studies without consent from the tribe (American Indian and Alaskan Native Genetics Resource Centre, 2016). It was at a presentation of the findings that a tribe member became aware that the samples were being used without consent and this sparked a lengthy court battle. This gross negligence of community rights related to informed consent and privacy have left many First Nations hesitant to engage in Western research.

### **Research does not reflect community priorities**

Historically, much research has been conducted on topics that pathologize First Nations communities, focusing on chronic health conditions such as diabetes and HIV. While these health issues are important, research has largely failed to examine root causes such as intergenerational trauma, cultural connection, relationships, effects of systemic racism, and spirituality. Epidemiological studies can report on disease burden and set targets for improvement, but "these data can fail to capture equity and other social justice issues in Indigenous health unless guided by objectives that explicitly promote these principles" (Otim, 2015). This research paradigm of reporting pathologies without the broader context and lived experiences leads to misrepresentation of community struggles that does not further the community's well-being.

Community understandings of issues need to be explored and understood before research tools are developed, so that the research provides more complete information. When research is conducted without the voice of the community, key elements or indicators may be excluded. A lack of understanding of variables and relationships among variables can lead to at best, unclear findings, and at worst, misleading findings. The work of defining the issues must be done before data is collected so data elements are not missed. Anderson points out that "it is not possible to use existing data sets to explore community determined priorities or health issues as the data elements collected are predetermined in academic or policy environments and do not reflect an Indigenous worldview" (Anderson, 2006).

## **Data Context Solutions**

### **Improving researcher and organizational capacity**

One of the most important solutions to issues around community trust, respect, and engagement is training and capacity support for research teams who wish to work with these communities. Researchers must understand the history of the partner community, develop relationships to the communities built on mutual respect and learning, and must have a thorough education in the principles of community privacy. As the attention to community rights and privacy in the research process has expanded, so to have the opportunities for researchers and communities to consider their roles in maintaining these rights.

### Implementation of OCAP®

In response to the need for communities to be protected from unaccountable extraction and misuse of data, the First Nations Information Governance Centre developed the principles of OCAP®: ownership, control, access, and possession of data. In its briefest explanation, OCAP® outlines the considerations that would take place if a research team was in full and healthy partnership with community, and provides an opportunity for the research team to make its consideration of the rights of the community explicit. The principles have been detailed not to override relationships, but to ensure that researchers have fully considered the multi-faceted aspects of their relationships to the community and the responsibility that comes with the collection and use of community data.

The adoption and enforcement of the principles of ownership, control, access, and possession (OCAP®) in 1996 was a major step forward for First Nations research and for a set of Indigenous-focused research principles. Through the application of OCAP® principles, communities have input to and ultimate decision making rights over:

- a. the sources of data,
- b. who has access to the data,
- c. who is able to utilize the data, and
- d. how and when the data will be applied both within academia and community (Assembly of Treaty Chiefs, 2013).

### Case Study: Training in OCAP®

The First Nations Information Governance Centre offers online modular training on The Fundamentals of OCAP® (First Nations Information Governance Centre, 2016). While initially intended for community members, this training would serve researchers well and offers an in-depth look at the responsibilities that attend research with First Nations communities. The Alberta First Nations Information Governance Centre is developing training sessions for communities to be custodians and stewards of their own information (Healy, B., personal communication, October 3, 2016).

### Using Indigenous worldviews in research

While research conducted from Western paradigms and without an exploration of context can serve to pathologize communities, research that comes from an Indigenous worldview and methodology can serve to share knowledge, insight, and accurate self-presentation of community experience. The growing body of Indigenous knowledges and worldviews, including the work of Kovach (2010), Tuhiwai Smith (1999), Blackstock (2011), Brant Castalano (2004), and many others offers opportunities for research to be conducted in an emancipatory way, questioning the role of Western paradigms in First Nations communities. Indigenous methodologies present relevant and holistic understandings and interpretations of well-being. Increasingly, Indigenous communities and individuals are working to ensure that their voices and experiences are reflected in research that involves them (Saini, 2012). The holistic nature of Indigenous worldviews offer a more accurate understanding of well-being because “there is good evidence that culture and context matter when it comes to optimal well-being for First Nations peoples” (Blackstock, 2011).

# Data Quality

## Data Quality Challenges

One of the most pressing concerns around First Nations data and data use is the lack of high quality data. Of the data sources listed above (census, vital registration, health surveys, health services utilization, and surveillance systems), few offer data or results that are specific to First Nations because the data does not identify First Nations populations. Data sources that do identify First Nations populations may not have adequate sampling of First Nations populations, leading to data that is not representative (Steffler, 2016, p. 151). This lack of high quality First Nations-specific data limits its utility for communities and policy makers (Anderson, 2006, p. 24).

### Identification of First Nations respondents

Within a data set, various subsets can be drawn out and analyzed separately from other respondents. For example, in a data set with both men and women, an analyst could look at the data separately for each gender. The only way the data can be sorted for this type of analysis if is the data indicates gender for each respondent. Likewise, data can be sorted between the general population and First Nation populations, but only if the data indicates which respondents are First Nations and which are not.

Many data sources do not identify between First Nations and non-First Nations populations so that data cannot be sorted by First Nations status. Determining First Nations identify within a data set has to happen at the data collection level; that information has to be collected at the same time as other data. This is true for data that is collected at the national or the patient level. Patients admitted to health care facilities are not asked to identify their ethnicity as a way to ensure that care is not influenced by race; this is considered to be in keeping with principles of care equity (Cancer Care Ontario, 2004). However, this also means that within the health care system there is “no continuous collection of health information on any Aboriginal group” (Anderson, 2006, p. 13).

While some data collection processes do ask about Indigenous identity, they do not always ask to the level of detail required, lumping non-status First Nations, First Nations, Metis, and Inuit respondents together. The lack of differentiation is significant because “there are differences in health determinants and health status outcomes between First Nations, Inuit, and Metis across geographic regions and for First Nations, across Indian Act defined grouping (ie. Registered compared to non-registered)” (Smylie J. , 2010, p. 2).

### Coverage and Non-response

High quality First Nations data is also difficult to access because in some cases the data has not been collected from First Nations people; that is, First Nations people are not as likely to be represented in data collection in the first place. Lack of representation stems from two issues: coverage and non-participation.

Coverage, or the implementation of data collection in a specific place or population, is a challenge for Canadian governmental data collection initiatives. Some Canadian data collection tools, such as the Canadian Community Household Survey and the Aboriginal Peoples Survey, which collect data on many important elements including Aboriginal status and health status, are not implemented in reserve communities. The Canadian census is the primary on reserve data collection method of the Canadian

government but collects fewer pieces of data and has varying degrees of success in reserve communities. Communities can deny permission for data collection for the census, and it is possible for collection to be interrupted by natural events which results in incomplete data sets, such as forest fires as was the case in northern Ontario communities in 2011.

First Nations communities and individuals may be hesitant to participate in data collection activities due to historical systematic misuse of data and research in these communities to pathologize and justify unnecessary government intervention (see above for further discussion). When communities do not trust the organizations collecting the data or the data collectors themselves, and are not invested in the purpose of the data, it becomes very difficult to garner participation.

## Data Quality Solutions

### Self-identification and identifiers

One approach to overcome issues of identifying First Nations data within larger data sets is to develop a First Nations identifier. In large data sets, an identifier is an element within the data set that shows who is First Nations and who is not. Essentially, it is a question within the data collection process that asks if a respondent is First Nations, and then that information is carried along with all their other information into the data set. An example of an identifier in action is the US cancer registry, which collects information on new cancer cases that includes a question on the ethnicity of the respondent (workshop report). Because this question exists, analysts are able to pull out and analyze data from Indigenous populations within that data set.

#### Case study: Self-identification and identifiers

Indigenous information can be pulled out of data sets if Indigenous respondents are properly identified. Across Canada there are several initiatives to identify First Nations patients in patient identification systems. These include:

- Aboriginal Administrative Data Standard (BC),
- Mustimuhw Community Electronic Record (BC, MB, SK),
- Aboriginal Identity Indicator in Cancer Patients – Protocol (ON),
- Newfoundland and Labrador Aboriginal Administrative Data Identifier, and
- Electronic Medical Record: Ethnicity Reference Set (CIHI/Infoway, national). (CPAC, 2012)

### Alternative data sources

One way to produce high quality data for First Nations with a process that improved participation in data collection was the implementation of the Regional Health Survey (RHS). The RHS is a survey that closely aligns in content and form to the Canadian Community Health Survey and is owned, managed, and facilitated by the First Nations Information Governance Centre (FNIGC). The Assembly of First Nations Chiefs in Assembly, the Chiefs Committee on Health, and First Nations regions across the country mandated the FNIGC to carry out the work of the RHS and provide ongoing governance (First Nations Information Governance Centre, 2016). This survey is an effort to maintain high quality data on the well-being of communities that is available for community and agency use. The RHS maintains its own code of ethics to protect the data and to facilitate the benefit that the data brings to communities (First Nations Information Governance Centre, 2016).

### Data Linkages

Data sets that do not contain First Nations identifiers could have that information added to the data set through a process called 'linking.' Linking is when two data sets are merged, case by case, based on a shared value in each data set. For example, cases in a data set can be identified as First Nations by linking to the Indian Register if there is a variable in each set that is identically shared. Imagine you have a data set with health information and a Unique Lifetime Identifier (ULI) for each case, and the Indian Register with First Nations status and Unique Lifetime Identifier for each case. By matching cases according to ULI you would then be able to determine the status for each case. This way, respondents who are in the Indian Registry could be identified and their data pulled into a separate data set. This work requires strong technical capacity and access to both the data set in question and to the Indian Registry. At present, "the ethics of this practice without appropriate consent from Indigenous governing bodies has been a challenge. Consequently, use of the information in the Indian Register now requires negotiation on a project by project basis" (Anderson, 2006, p. 12). An important limitation of this technique is that this linkage would not identify non-status First Nations who are not listed in the Indian Registry.

#### Case study: Data linkage in Nova Scotia

Five First Nations communities have worked to create the Unama'ki Client Linkage Registry that links Indian Registry data to provincial data. The process of creating the registry included the development of service, authorization and data-sharing agreements, band council resolutions and approvals from data access and research committees. Access to the Registry is controlled by a data access committee made up of representatives from the five communities and the Nova Scotia government. The data provides information about health status and health service utilization. Drawbacks of the database include missing information about community-based mental health services, and the inability to capture the health of the community in a holistic way as the kinds of information used are limited to what is available in the externally determined data sets. The Nova Scotia Mi'kmaq Health Indicators Framework includes the social determinants of health which are not captured in the Client Linkage Registry (Rudderham & Tui'kn Partnership, 2014).

From JRI (2016) Alberta Cancer Surveillance in First Nations Communities – Literature Review. Unpublished Report.

# Data Jurisdiction

## Data Jurisdiction Challenges

Where high quality data does exist, it can be difficult to access the data in a way that is geographically relevant. This is because the data sets often apply to larger regions than are meaningful for community-based planning. Another problem is that data comes from different sources, and so may have different regional coverage and different ways of measuring variables so data cannot be compared across sources. Finally, the multijurisdictional nature of accessing data can lead to barriers and delays for communities wishing to use the data.

### Data sets are too geographically broad

Population-level data that is available to communities to access without special permissions comes in aggregate form, such as publically accessible census data. Aggregate data is individual data that is grouped together by area, often by local governance areas (LGA). While larger cities such as Calgary are made up of multiple LGAs, there may be many smaller communities in rural areas within one LGA. Larger rural LGAs group together data from multiple smaller towns. These larger data sets that cover wider areas that are limited in their utility for planning at the regional or community level (Anderson, 2006). To be useful for community planning, this data needs to be made available in subsets that cover individual communities. However, data is not available at the community level because it was not collected with the intention to be used at that level of granularity. This is a significant barrier for First Nations and non-First Nations communities.

### Using multiple sources of data

Multiple data sets from multiple sources can be difficult to blend into a full picture of the health of communities because various data holders have different ways of measuring and collecting information. Data holders may use different geographic areas to report data, and may aggregate data in different ways for reporting. This is true for data use at the small community level and at the national level, where differences in provincial measurement standards can prohibit comparability of data across provinces. For example, in Ontario, new cases of HIV are reported with ethnicity identifiers, while in Manitoba ethnicity data is not collected on new HIV cases. This difference in data collection is a barrier for generating an accurate national rate of HIV incidence that is specific to ethnicity. The same is true of generating a national cancer rate because "each provincial/territorial cancer registry has its own practices for registering and following incident cancer cases and documenting cancer related mortality. This means that to compare cancer control data within ethno cultural identifiers across jurisdictions, one has to consider feasibility issues associated with different data sources and collection approaches that exist today" (The Bridge Consulting Group, 2012).

### **Ownership and control of data**

With data from multiple sources, it is vital that communities determine the most appropriate way for their collective data to be managed. Where is the data stored? Who has access to it, and for what purposes? Communities have the right to protect their data and share it as they choose; communities should be involved in the use and presentation of their data, ensuring that the interpretation of data is rooted in community context and recognition of the colonial history experienced by First Nations.

Some of the laws that surround privacy of information for data collected on the general public do not extend onto data collected within First Nations communities. In fact, there is “no law in place that protects personal health information in First Nations communities, outside of federal, and some provincial activity” (National Aboriginal Health Organization, 2005). “The federal Personal Information and Electronic Documents Act (PIPEDA) applies in a limited way to Band Council personnel records and commercial operations, and the Alberta Health Information Act (HIA) applies to health professionals operating in First Nations health clinics. This results in a gap in privacy legislation on reserve, unless the information is personnel records, commercial records or client files” (Yao, 2016). As data becomes more widely collected, attention is required to ensure that privacy is protected on-reserve.

## **Data Jurisdiction Solutions**

### **Extrapolation of data based on geographic identifiers**

Some health authorities have had success extrapolating information about First Nations patients based on non-Indigenous identifiers. Postal codes that are specific to reserve communities, for example, can be used as a proxy to identify individuals who are very likely Indigenous. This is how Alberta Health captured rates of cancer until 2009, when the discontinuation of health care premiums meant that patient postal codes were no longer collected. If data sets have information that is unique to a community, such as postal code, it is possible to pull out information about people with that postal code and analyze the data with the stated assumption that those individuals are Indigenous.

### **First Nations community code of privacy**

First Nations communities have jurisdiction to create by-laws around data and privacy. As noted above, there is a gap in privacy legislation for on-reserve data that is not contained in “personnel records, commercial records or client files. The best way to resolve that gap is for First Nations to enact their own privacy laws” (Yao, 2016). This gap in legislation can be addressed in the long term by amendments to federal and provincial legislation, and more directly through “the exercise of First Nations’ jurisdiction” (Yao, 2016).

#### **Case study: First Nations community code of privacy**

The National Aboriginal Health Organization produced the Privacy Tool Kit to share information about data privacy with communities. The toolkit includes a model privacy code, which is a version of the National Standard of Canada: Model Code for the Protection of Personal Information (the CSA Model Code). Based on ten principles for the protection of personal information, the model code in the toolkit is written for a generic First Nation and calls for independent oversight of its principles. This code can be adopted by any First Nation to apply to the collection, use, and disclosure of personal information (National Aboriginal Health Organization, 2005). The model code can be found within the toolkit here: [http://www.naho.ca/documents/fnc/english/FNC\\_PrivacyToolkit.pdf](http://www.naho.ca/documents/fnc/english/FNC_PrivacyToolkit.pdf).



# Data Content

## Data Content Challenges

### Indicators and measurements are not culturally approved or relevant

As noted above, there are data sets that can be linked with population identifiers to produce First Nations-specific data. The utility of these data sets, however, is bound by the questions that were used to collect the data. A data set only includes information that the developers of the data collection tool deemed important. For example, a cancer registry can report on where a patient's cancer took place, but cannot tell us about the patient's relationships, nutritional habits, or any other factors that they were not asked about during that data collection. This limits what the data can be used for.

It is the right of First Nations to "construct knowledge in accordance with self-determined definitions of what is real and what is valuable" (Brant Castellano, 2004). Indigenous worldviews take a holistic approach to understanding well-being. If an Indigenous worldview is not incorporated into research activities from the outset, the findings will be incomplete and may even be unacceptable to First Nation communities. "Research must be integrated with cultural and traditional knowledge, such as Indigenous languages and history (Steffler, 2016, p. 150)" so that the findings are meaningful and relevant.

## Data Content Solutions

### Community engagement in research agenda setting

Community engagement in research projects has long been called for from research entities. However, the call for engagement can only be made once the community is invited to participate, which is typically once the project has already begun and the research agenda has been set. Integrating community voices and worldviews into research must begin at the outset of a project and should inform the theoretical background of the work, the research questions, the development of data collection tools, and the interpretation of data. Collaborative work in this manner not only leads to better research, but to increased community sovereignty as the community is involved in how it is understood and represented. "To a large extent, meaningful collaboration is about respecting the aspirations of Indigenous communities, their members, and the process and protocols of data collection and research activities in those communities and of those individuals" (Steffler, 2016, p. 160).

Researchers interested in working with Indigenous communities must engage with these communities before the research agenda is even developed, thereby allowing the project to be shaped by community priorities and interpretations. Relationships like this require time, the development of trust, and a research team that places value on collaborative work.

### Community-driven data development

Community-driven data development and the creation of community-specific indicators is a powerful step towards emancipating community health. Communities can work towards developing their own indicators of well-being and collecting data to monitor these indicators. The process of assembling a community team, conducting community consultation, developing indicators, accessing, and collecting data to monitor those indicators, and then tracking them over time is a resource-intensive process, but a process that is taking place in Indigenous communities already.

### Case study: Community-driven data development in Oregon

The Indian Community Health Profile Project of the Northwest Portland Area Indian Health Board (2003) provides tools and educational resources to guide communities in developing a community profile based on community-identified indicators. The toolkit includes a standard community profile template and outlines the process for adapting it to individual communities, along with information on how to gather each piece of data. The toolkit is designed for and used in Indigenous communities. The toolkit can be found at: [http://www.npaihb.org/images/resources\\_docs/Toolkit\\_Final.pdf](http://www.npaihb.org/images/resources_docs/Toolkit_Final.pdf)

# Community Resources and Capacity for Data Access

## Community Resource and Capacity Challenges

### Community capacity for data access and use

Data exists that communities can use for their own purposes, and there are opportunities for communities to engage with researchers or develop their own data agenda. However, a major limitation facing First Nations communities is the lack of time and resources to do this work.

Data is only as useful as the ability of communities to assess and respond to it. For communities to engage with data, there has to be local capacity to access, collect, and analyze it. In general, there is a lack of training and education for communities to do this work. "Inadequate human resources, including the capacity of front line service providers who act as data collectors, limit the ability to collect, analyze, and therefore respond to Indigenous-specific health indicators." (Anderson, 2006, p. 26) With many pressing needs, communities struggle to prioritize number crunching over frontline care, especially when "some tribal councils and program managers may not have a comprehensive view of available data that could help them make decisions" (Schultz, 2014) they also may not understand the ways data can be used for planning.

Data coming from multiple sources is difficult to work with not only for the challenges of varying measurement listed above, but for the practical reasons that accessing data from multiple sources can be time consuming and take up valuable human resources. First Nations communities face specific barriers to accessing data because it comes from multiple jurisdictions and data holders, such as FNIHB, NIHB, and provincial authorities. This multijurisdictional nature of data, particularly of health data, can stall the development of a comprehensive picture of well-being. Along with challenges of the community to access these various sources of data, the work is hindered by a lack of communication among data holders so that measurements and standards are not consistent between sources (Anderson, 2006). Sharing information across data system raises issues of privacy and confidentiality.

Communities also lack required support to tackle the variety of challenges specific to First Nations data such lack of identifiers, content that is not relevant, and navigating multiple jurisdictions -- challenges that non-First Nations communities do not face. At present "there is a lack of infrastructure at all levels to support the collection of relevant Indigenous-specific health indicators" (Anderson, 2006, p. 25).

### Data access from government agencies

First Nations face another challenge in the legislation around data access from government agencies. In some cases, the community may simply not be allowed to access this information because of the precedents created to maintain the data's confidentiality and security. A good example of this is found in Alberta's Health Information Protection Act, which was developed to protect data from unregulated access and use. Within the Act, there is a limited definition of who a data "custodian" is. This definition limits who can access health information. A psychologist or social worker cannot access data unless they are employed with a provincially funded clinic or agency, while a physician or nurse can. This presents an issue when communities or organizations without a resident doctor or nurse would like to access information. Program planners, directors, and facilitators cannot access information without going through a qualified "custodian" (Yao, K., personal communication, March 8, 2016).

## Community Resource and Capacity Solutions

### Support for access through data sharing agreements with data stewards

Accessing data from multiple jurisdictions can be a major barrier for use of data by First Nations communities. Each data holder has special agreements that must be developed with the community requesting data before the data can be shared. In some cases, larger organizations that have expertise working with First Nations communities and working with data have become “data stewards.” By developing data sharing agreements with both data holders and communities, the data stewards act as intermediaries who can hold the data and share it with communities while observing necessary protocols. This reduces the drain on time and resources for communities.

### Case study: Data access in Alberta and British Columbia

Alberta First Nations are in the process of developing a data-sharing agreement with their federal and provincial partners. The Alberta Assembly of Treaty Chiefs passed a resolution in 2013 that confirms their wish to participate in the development and sharing of First Nations data with federal and provincial partners consistent with the OCAP® principles. The Chiefs mandated the Alberta First Nations Information Governance Centre (AFNIGC) to develop a data governance agreement with Canada and Alberta that includes direction on the governance, creation, use, access and disclosure of First Nations public health data in accordance with their governance model (Assembly of Treaty Chiefs, 2013). This data would then become accessible to communities through the AFNIGC.

In British Columbia, there is a tripartite agreement between the First Nations Health Council and the federal and provincial governments. The five-year agreement, First Nations in BC Tripartite Data Quality and Sharing Agreement, was signed in 2010. The agreement supports First Nations control of data use for research and the establishment of a framework to develop and share First Nations health surveillance data. The framework does not include cancer rates as one of the initial key indicators although it may be added. Initial indicators included are life expectancy, mortality rates (all causes), Status Indian youth suicide rates, infant mortality, diabetes rates, and childhood obesity. The agreement also included a commitment to assist the government in developing similar datasets for non-Status First Nations people in BC.

From JRI (2016) Alberta Cancer Surveillance in First Nations Communities – Literature Review. Unpublished Report.

# Conclusion

For Indigenous communities to be able to make evidence-based decisions about their health services, they require data that is meaningful, comprehensive, and accessible. Key papers such as the TRC (2015) and the UNDRIP (2007) speak to the importance of this issues. Barriers include issues around the data itself: how it is collected, the relevance of the measures to Indigenous communities, and the granularity of geographic area in which its reported. Other issues surround the context of the data: lack of trust toward researchers in Indigenous communities, privacy considerations, reporting data in context for First Nation people, and lack of support given to communities to collect and apply it themselves. While this paper has presented many potential solutions, the most significant step towards a healthy data landscape is the development of respectful and trusting relationships with communities. If data work is done in healthy relationships and in deference to self-determination, solutions will naturally present themselves and data will begin to address community needs, support community capacity, and further community well-being.

Many of these solutions are underway in Canada and around the world. Sustaining and spreading this work is the next step. Agencies that collect data must work to include and support the full engagement of Indigenous communities and perspectives in information governance in their mandates. So while some sources of data exist with varying levels of utility, we need more data and we need a different kind of data – data in which First Nations can see themselves echoed, data that offers context and lived experience to numbers. We need research activities to be informed by the priorities of communities who participate in them. And we need data collection to reflect both Western and Indigenous worldviews. As efforts towards these goals continue, First Nations communities will be able to further their own goals and agendas, and fully engage in the direction and definition of their well-being.

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# Appendix A



The Alberta First Nations  
Information Governance Centre

On / Off Reserve	Data Source	Data Elements	Purpose / Comments
On-Reserve only	<b>Regional Health Survey</b>  <b>Phase 2</b> <b>(2008/2010)</b>	3 Surveys - Child/Youth/Adults (can be split into groups; 18-54.99 and 55+)	<b>1000+ variables</b>  <b>Topics/Themes common to all three surveys:</b> <ul style="list-style-type: none"> <li>• Demographics</li> <li>• Dental Care/Health</li> <li>• Education</li> <li>• Health Care Access/Utilization</li> <li>• Health Conditions</li> <li>• Height &amp; Weight</li> <li>• Household characteristics</li> <li>• Injury</li> <li>• Languages</li> <li>• Physical Activity &amp; Sedentary Behaviours</li> <li>• Residential School</li> </ul>
			<b>Topics/Themes common to adult/youth surveys:</b> <ul style="list-style-type: none"> <li>• Community Wellness</li> <li>• Culture, Spirituality, Religion</li> <li>• Depression, Wellness, Personal Supports &amp; Mental Health</li> <li>• Diabetes</li> <li>• Pregnancy, Fertility</li> <li>• Preventative Health Practices</li> <li>• Sexual Health</li> <li>• Smoking, Alcohol, Drug Use</li> <li>• Traditional Medicine</li> </ul>
			<b>Topics/Themes common to child/youth surveys:</b> <ul style="list-style-type: none"> <li>• After School Activities</li> <li>• Nutrition</li> <li>• Traditional Foods</li> </ul>

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On / Off Reserve	Data Source	Data Elements	Purpose / Comments
On-Reserve only	<b>Regional Health Survey Phase 2 (2008/2010)</b>	3 Surveys - Child/Youth/ Adults (can be split into groups; 18-54.99 and 55+)	<p><b>Topics/Themes unique to adult survey:</b></p> <ul style="list-style-type: none"> <li>• Basic Services</li> <li>• Care Giving</li> <li>• Disability &amp; Home Care</li> <li>• Employment</li> <li>• Food Security &amp; Nutrition</li> <li>• Gambling</li> <li>• Housing Conditions</li> <li>• Income &amp; Sources</li> <li>• Migration</li> <li>• Personal Safety</li> <li>• Suicidal Ideation &amp; Attempts</li> <li>• Water Quality</li> </ul> <p><b>Topics/Themes unique to youth survey:</b></p> <ul style="list-style-type: none"> <li>• Food &amp; Nutrition</li> <li>• Traditional Culture</li> </ul> <p><b>Topics/Themes unique to child survey:</b></p> <ul style="list-style-type: none"> <li>• Breastfeeding</li> <li>• Child Care Arrangements</li> <li>• Emotional &amp; Social Wellbeing</li> <li>• Immunization &amp; Medication Use</li> <li>• Parental Characteristics</li> </ul>
On-Reserve only	<b>First Nations Regional Early Childhood, Education, and Employment Survey</b>	3 Surveys - Child/Youth/ Adults (separated into 6 age categories)	<p><b>1400+ variables</b></p> <p><b>Topics/Themes common to all three surveys:</b></p> <ul style="list-style-type: none"> <li>• Extracurricular Activities</li> <li>• General Health</li> <li>• Language</li> <li>• School Performance</li> <li>• Traditional Teachings</li> </ul>

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On / Off Reserve	Data Source	Data Elements	Purpose / Comments
On-Reserve only	<b>First Nations Regional Early Childhood, Education, and Employment Survey</b>	3 Surveys - Child/Youth/Adults (separated into 6 age categories)	<p><b>Topics/Themes common to adult/youth surveys:</b></p> <ul style="list-style-type: none"> <li>• Access to Technology</li> <li>• Career/Future Aspirations</li> <li>• Employment/Unemployment</li> <li>• Future Orientation</li> <li>• Job Skills</li> <li>• Mastery</li> <li>• Post-Secondary Education</li> <li>• School Attendance</li> <li>• School Climate</li> <li>• Support</li> <li>• Tutoring</li> </ul>
			<p><b>Topics/Themes unique to adult survey:</b></p> <ul style="list-style-type: none"> <li>• Income</li> <li>• Job Location/Commute</li> <li>• Job Satisfaction/ Climate</li> <li>• Language in School</li> <li>• Occupation/Industry</li> <li>• Residential School</li> </ul>
			<p><b>Topics/Themes unique to youth survey:</b></p> <ul style="list-style-type: none"> <li>• Behavioural Indicators</li> <li>• Fear of Success</li> <li>• Learning in School</li> <li>• Parental Education Aspirations</li> <li>• Parental Participation in School</li> <li>• Post-Secondary Readiness</li> </ul>



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On / Off Reserve	Data Source	Data Elements	Purpose / Comments
On-Reserve only	<b>First Nations Regional Early Childhood, Education, and Employment Survey</b>	3 Surveys - Child/Youth/ Adults (separated into 6 age categories)	<b>Topics/Themes unique to child survey:</b> <ul style="list-style-type: none"> <li>• Childcare</li> <li>• Communication with School</li> <li>• Developmental Milestones</li> <li>• Early Developmental Milestones</li> <li>• Head Start</li> <li>• Learning in school</li> <li>• Nutrition</li> <li>• Parental Participation in Learning</li> <li>• Parental Sources of Support</li> <li>• Parent to Child Learning</li> <li>• Strengths and Difficulties</li> </ul>
On-Reserve only	<b>Regional Health Survey Phase 3 (2015/16)</b>	3 Surveys - Child/Youth/ Adults (can be split into groups; 18-54.99 and 55+)	<b>1000+ variables</b> <b>Topics/Themes common to all three surveys:</b> <ul style="list-style-type: none"> <li>• Demographics</li> <li>• Dental Care/Health</li> <li>• Education</li> <li>• Health Care Access/Utilization</li> <li>• Health Conditions</li> <li>• Height &amp; Weight</li> <li>• Household characteristics</li> <li>• Injury</li> <li>• Languages</li> <li>• Physical Activity &amp; Sedentary Behaviours</li> <li>• Residential School</li> </ul>

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On / Off Reserve	Data Source	Data Elements	Purpose / Comments
On-Reserve only	<b>Regional Health Survey</b>  <b>Phase 3 (2015/16)</b>	3 Surveys - Child/Youth/Adults (can be split into groups; 18-54.99 and 55+)	<b>Topics/Themes common to adult/youth surveys:</b> <ul style="list-style-type: none"> <li>• Community Wellness</li> <li>• Culture, Spirituality, Religion</li> <li>• Depression, Wellness, Personal Supports &amp; Mental Health</li> <li>• Diabetes</li> <li>• Pregnancy, Fertility</li> <li>• Preventative Health Practices</li> <li>• Sexual Health</li> <li>• Smoking, Alcohol, Drug Use</li> <li>• Traditional Medicine</li> </ul>
			<b>Topics/Themes common to child/youth surveys:</b> <ul style="list-style-type: none"> <li>• After School Activities</li> <li>• Nutrition</li> <li>• Traditional Foods</li> </ul>
			<b>Topics/Themes unique to adult survey:</b> <ul style="list-style-type: none"> <li>• Basic Services</li> <li>• Care Giving</li> <li>• Disability &amp; Home Care</li> <li>• Employment</li> <li>• Food Security &amp; Nutrition</li> <li>• Gambling</li> <li>• Housing Conditions</li> <li>• Income &amp; Sources</li> <li>• Migration</li> <li>• Personal Safety</li> <li>• Suicidal Ideation &amp; Attempts</li> <li>• Water Quality</li> </ul>

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On / Off Reserve	Data Source	Data Elements	Purpose / Comments
On-Reserve only	<b>Regional Health Survey</b> <b>Phase 3 (2015/16)</b>	3 Surveys - Child/Youth/Adults (can be split into groups; 18-54.99 and 55+)	<p><b>Topics/Themes unique to youth survey:</b></p> <ul style="list-style-type: none"> <li>• Food &amp; Nutrition</li> <li>• Traditional Culture</li> </ul> <p><b>Topics/Themes unique to child survey:</b></p> <ul style="list-style-type: none"> <li>• Breastfeeding</li> <li>• Bullying (new)</li> <li>• Child Care Arrangements</li> <li>• Emotional &amp; Social Wellbeing</li> <li>• Immunization &amp; Medication Use</li> <li>• Maternal Behaviours (new)</li> <li>• Parental characteristics</li> </ul> <p><b>additional questions in Regional component:</b></p> <ul style="list-style-type: none"> <li>• NIHB</li> <li>• End of Life</li> </ul>
On-Reserve only	<b>FNREEES/RHS</b> <b>Community Survey</b>	12 sub-surveys	<p><b>Topics/Themes</b></p> <ul style="list-style-type: none"> <li>• Early Childhood Development</li> <li>• Education</li> <li>• Employment &amp; Economic Development</li> <li>• External Environment</li> <li>• First Nation Governance</li> <li>• First Nation Identity</li> <li>• Food and Nutrition</li> <li>• Health Services</li> <li>• Housing Policy</li> <li>• Justice and Safety</li> <li>• Shelter and Infrastructure</li> <li>• Social Services</li> </ul>

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On / Off Reserve	Data Source	Data Elements	Purpose / Comments
Both (but difficult to tease out the FN population due to lack of identifiers after 2009)	<b>Administrative Data</b>	<ul style="list-style-type: none"> <li>• Alberta Health Care Insurance Plan Registry</li> <li>• Physician fee-for-service</li> <li>• Hospital in-patient</li> <li>• Ambulatory care classification system</li> <li>• (includes Emergency Department data)</li> </ul>	
Both (but difficult to tease out the FN population due to lack of identifiers after 2009)	<b>Disease Registry Data</b>	<ul style="list-style-type: none"> <li>• Communicable Disease Reporting System</li> <li>• Alberta Cancer Registry</li> </ul>	
Both (but difficult to tease out the FN population due to lack of identifiers after 2009)	<b>Vital Statistics</b>	<ul style="list-style-type: none"> <li>• Births</li> <li>• Deaths</li> <li>• Divorces</li> <li>• Marriages</li> <li>• Name Changes</li> </ul>	Birth and death data are the most useful in the realm of health

# Appendix A



Health  
Canada

Santé  
Canada

On / Off Reserve	Data Source	Data Elements	Purpose / Comments
On/off reserve validity very low in these datasets.	<b>NIHB Pharmacy</b>	Utilization 2010 to 2015 AHFS HICPS Classification- Drug, MSE	Differentiates between Drug and Medical Supplies and Equipment
All data based on band of registration.	<b>NIHB Dental</b>	Utilization 2010 to 2015 - ATC Main Group	Describes main groups of drug utilization
Data pulls information for FN clients living anywhere in AB.	<b>NIHB Vision</b>	Total Utilization - Item Product Type Description	Describes NIHB vision utilization by service type
	<b>NIHB MTS</b>	Utilization 2010 to 2015 - Travel Reason	Describes reason for medical travel. Note data specificity has been lower in recent years. Trips have been described as "Specialist" or "Non-Specialist" in many cases, rather than "Cardiologist" etc.
	<b>NIHB Mental Health</b>	Utilization 2010 to 2015	Describes number of people receiving NIHB crisis counselling

# Appendix A



Statistics  
Canada

Statistique  
Canada

On / Off Reserve	Data Source	Data Elements	Purpose / Comments
Off	Canadian Community Health Survey	<ul style="list-style-type: none"> <li>• Diseases and health conditions</li> <li>• Health</li> <li>• Lifestyle and social conditions</li> <li>• Prevention and detection of disease</li> </ul>	<p>A cross-sectional survey that collects information related to health status, health care utilization and health determinants for the Canadian population. It relies upon a large sample of respondents and is designed to provide reliable estimates at the health region level. The CCHS has the following objectives:</p> <ul style="list-style-type: none"> <li>› Support health surveillance programs by providing health data at the national, provincial and intra-provincial levels;</li> <li>› Provide a single data source for health research on small populations and rare characteristics;</li> <li>› Timely release of information easily accessible to a diverse community of users;</li> <li>› Create a flexible survey instrument that includes a rapid response option to address emerging issues related to the health of the population.</li> </ul> <p>Survey covers the population 12 years of age and over living in the ten provinces and the three territories.</p> <p>Excluded from the survey's coverage are: persons living on reserves and other Aboriginal settlements in the provinces; full-time members of the Canadian Forces; the institutionalized population and persons living in the Quebec health regions of Région du Nunavik and Région des Terres-Cries-de-la-Baie-James. Altogether, these exclusions represent less than 3% of the Canadian population aged 12 and over.</p>

(data available in other topic areas as well)

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On / Off Reserve	Data Source	Data Elements	Purpose / Comments
On reserve	<b>2011 National Household Survey (NHS) community profiles (based on census data from Statistics Canada)</b>	<ul style="list-style-type: none"> <li>• Age</li> <li>• Gender</li> <li>• Marital Status</li> <li>• Families – households</li> <li>• Languages</li> <li>• Religion</li> <li>• Aboriginal Identity</li> <li>• Mobility</li> <li>• Education</li> <li>• Labour Force</li> <li>• Income</li> <li>• Dwellings</li> </ul>	<p>The census data had a good response based on the true community population. This information is useful for planning purposes.</p> <p>The survey includes socioeconomic factors, labour, education, place of work, commuting to work, mobility and migration, language of work, income, earnings, housing and shelter</p>

The above is just an example of what might be available. Your nation may have numerous data sets across various departments.



The Alberta First Nations  
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Data Resources and Challenges for First Nations Communities  
Document Review and Position Paper