LOST IN THE NUMBERS

Learning about First Nations Health Data from the COVID-19 Pandemic

August 2021

Executive Summary

The pandemic has emphasized that First Nations are at greater risk of poor outcomes from the direct and indirect effects of COVID-19 because of systemic inequities, including housing, healthcare, supportive infrastructure, and health outcomes. These inequities have remained unaddressed through the long-standing inactions and negligence of Canada. COVID-19 has made more salient the significant gaps in the Canada's health surveillance systems to the detriment of First Nations' health and rights.

Under the guidance of the AFN National COVID-19 Task Force, the AFN COVID-19 Data Working Group was established to provide support to First Nations in their data and information governance efforts and to address the challenges with First Nations COVID-19 data throughout the pandemic. The Working Group developed this position paper to highlight the need for data and information governance as shown by the COVID-19 experience and to support the position of the First Nations Information Governance Centres "First Nations Data Governance Strategy" (FNDGS). The FNDGS envisions a First Nations-led, national network of regional information governance centres across the country equipped with the knowledge, skills, and infrastructure needed to serve the information needs of First Nations people and communities. Regional engagement sessions were conducted to highlight the diversity of experiences with data during the COVID-19 pandemic.

Canada has committed to working with First Nations, on a Nation-to-Nation basis, to enable the gradual transfer of services to rights holders and advance First Nations self-determination and self-governance. Guidance is provided to the federal and provincial/territorial governments that they can take to support First Nations in having timely access to high quality health data so that they are better equipped to fight against this pandemic, prepare for future health emergencies, prepare for the development of First Nations health legislation and, more broadly, to support First Nations' inherent rights to self-governance, self-determination and data sovereignty. The decisions First Nations rights holders may wish to make regarding their right to data sovereignty and data governance rests with the rights holders. Guidance has been provided to First Nations to support their considerations.

The COVID-19 pandemic is used as a lens through which to examine Canada's public health surveillance system by identifying systemic issues and challenges with respect to its ability to address First Nations health data needs and support First Nations self-determination and uphold inherent and Treaty rights.

The Jurisdictional Quagmire

DATA CHALLENGES	LESSONS FROM COVID-19	IMPACTS ON FIRST NATIONS HEALTH	ROOT CAUSES
• Lack of coordination between provincial/territorial and federal health systems • Limited communication of provincial/territorial systems with First Nations • Emphasized the need for First Nations data sovereignty and respect for First Nations jurisdiction over data	• Decreased ability to contact trace • Inaccurate COVID-19 case counts in community • Limited ability to track service use on and off-reserve	• Spread of COVID-19 in communities • Lack of ability for leadership to assess the risk and mitigate exposures • Limited understanding of service gaps and related health needs	• Historical legislative vagueness rooted in colonial and paternalistic approaches. • Differing views of 'responsibility' for First Nations health and well-being by provinces, territories, and federal governments • Lack of control, ownership, access, and possession of First Nations over their data

A Way Forward

- Development of shared data priorities between different levels of government (tripartite relationships) to bridge jurisdictional challenges.
- As identified through the FNDGS, a proposed national network of 11 First Nations Data Governance Centers (FNDGCs) to function as apolitical bodies responsible for the role of integrating data to increase health data access by First Nations' governments, health authorities and professionals, off- and on-reserve by addressing some of the structural and complex jurisdictional divide and legislative barriers.

Data Quality

DATA CHALLENGES	LESSONS FROM COVID-19	IMPACTS ON FIRST NATIONS HEALTH	ROOT CAUSES
• Absence of disaggregated data and a consistent effort to track First Nations in provincial and territorial surveillance systems • First Nations people required to self-report in Census and provincial/ territorial data sets • Limitations of postal codes to identify residency (on- or off-reserve)	• Inaccurate representations of true count of First Nations • Inaccurate COVID-19 case counts • Inaccurate COVID-19 rates	• Undercounting impacts funding formulae and available resources • Limited detailed information for First Nations leaders • Limited ability to measure the distribution of COVID-19 in First Nations communities • Data sharing agreements improve access to available information but remain hampered by data quality concerns	• Colonial federal definitions of First Nations under the *Indian Register* impact how '*Status Indians'* are tracked. • Failure to recognize self-governing First Nations • Long-standing experiences of racism and distrust with Canada's health and data systems • Provincial/ territorial governments perception of their responsibility and role with regards to First Nations health

A Way Forward

- Recognition by Federal, Provincial and Territorial governments of the importance of collecting Indigenous data and adherence to OCAP® principles as part of their commitment to upholding First Nations rights and promote data sovereignty.
- In partnership with Federal, Provincial and Territorial First Nations partners, the proposed First Nations led FNDGCs could have a leadership role and capacities to enable data policies, standards, and methods; data collection and relationship management with respondents and data holders; data analysis and research; as well as data dissemination, support, and training.

Trust and Transparency

DATA CHALLENGES	LESSONS FROM COVID-19	IMPACTS ON FIRST NATIONS HEALTH	ROOT CAUSES
• Distrust in data systems and associated privacy concerns means that First Nations leadership can choose to not participate in data collection. • Fear of stigmatization and racism limits self-reports of First Nations status • Limited access to aggregate community level data for First Nations	• Inaccurate COVID-19 and First Nations population data • Where present, First Nations led data initiatives has been successfully used by leadership to advocate for First Nations needs and priorities.	• First Nations leadership has access to limited information to support their emergency planning and health response needs • Current systems continue a legacy of distrust for First Nations health care, impacting individuals desire to seek care.	• First Nations challenges to access information are hampered by the *Privacy Act* definitions of 'government' that exclude First Nations • Federal, territorial, and provincial privacy legislation cannot be respectful of OCAP® because the collective identity of Nations is not protected, only individual privacy is protected. • Distrust of the Canadian health care system as result of historical and on-going experiences with racism

A Way Forward

- Only through the assertion of First Nations data sovereignty and governance, will trust in First Nations data and the systems by which it is collected be improved.
- The proposed 11 FNDGCs have the potential to play an important role to help change perceptions, attitudes and behaviors preventing effective participation to the health surveillance system and, more broadly, to important data collection needs.

Capacity

DATA CHALLENGES	LESSONS FROM COVID-19	IMPACTS ON FIRST NATIONS HEALTH	ROOT CAUSES
• The influx of data resulting from the COVID-19 pandemic overwhelmed already strained health care capacity in communities and regions.	• Nurses and health centre staff were stretched to meet the needs associated with COVID-19 and other health needs and were often also the ones responsible for data entry and tracking • Data sharing agreements take time and capacity that was not afforded during the pandemic to improve access to data.	• Focusing on COVID-19 reduced First Nations' abilities to track and manage other health concerns and community emergencies. • The current capacity limitations of First Nations to not only work with but understand their data, limits their ability to protect against the improper usage or interpretation of data.	• Persistent under-funding and the management of multiple crises means that First Nations face consistent financial, human resource and infrastructure capacity challenges.

A Way Forward

- First Nations require significant sustainable and predictable investments to build their data governance and information management, technology, and infrastructure capacity, including investments in human resources.

Relationships

DATA CHALLENGES	LESSONS FROM COVID-19	IMPACTS ON FIRST NATIONS HEALTH	ROOT CAUSES
• The relationship between Provincial/Territorial governments and First Nations becomes the key driver for if and how information is shared and the ability of First Nations to influence decisions.	• The willingness and existing relationships with provinces and territories directly impacted First Nations access to COVID-19 data and consequently, their ability to advocate for data informed policy and supports.	• The regional variability of relationships with First Nations and their respective provincial/territorial governments directly impacts the quality support and care provided to First Nations.	• Without a legislative backing, the jurisdictional challenges place the responsibility to build relationships with First Nations with the provincial and territorial government who often see this responsibility as belonging to the federal government. • Relationships can be unstable as they may depend on one or a few key individuals • Political relationships can shift with a change in government at federal, provincial, and territorial levels

A Way Forward

- First Nations have the right and responsibility to determine their own programming on health and wellness. This right must be recognized through the actions of provinces, territories, and Canada in building respectful relationships with First Nations.
- The proposed 11 FNDGCs can be instrumental by aggregating data governance capacities at the regional levels, facilitating, and making possible the establishment of data access protocols and processes, but for these regional centers to be effective, provinces and territories must be willing partners at the table, alongside Canada and First Nations.

The absence of conclusive COVID-19 First Nations data has made it challenging for First Nations to respond to the needs of the pandemic. Improving timely access to high quality health provides opportunities for First Nations to improve their ability to successfully provide public health communication to their Nations by more accurately assessing and communicating the amount of risk they are exposed to within a public health emergency. It increases the ability of leadership to effectively plan, respond and evaluate their actions and protect the well-being of their communities. Increased emphasis and willingness of governments to enter into data sharing agreements enhances the ability of First Nations to identify the impacts of the virus on their communities and tell the stories of the fareaching impacts of the pandemic. First Nations driven research can be used to further strengthen this data and show the power of balancing strengths as well as deficits in the data story.

The *Department of Indigenous Services Act* (2019) and the *Department of Crown-Indigenous Relations and Northern Affairs Canada Act* (2019) mandate the Government of Canada and the Ministers of ISC and CIRNAC to support the gradual transfer of ISC responsibilities to Indigenous Nations, their governments, and their organizations or institutions and to build the capacity to meet these needs. Building data governance capacity is a required element in this journey and the Government of Canada must provide the resources to build this capacity.