



FNIGC | CGIPN

First Nations Information Governance Centre
Le Centre de gouvernance de l'information des Premières Nations

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*Exploring Pathways to Governance
for a First Nations COVID-19 Dataset*
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First Nations Information Governance Centre

- Rooted in the mid-1990s work to develop the Regional Health Survey and the OCAP® principles
- First Nations non-profit, incorporated in April 2010 with a special mandate from the Assembly of First Nations Chiefs in Assembly (#48–2009)
- Guided by principles, research ethics, and a cultural framework developed by First Nations, for First Nations
- Nations come together through regional processes; regions come together to do national-level work

About FNIGC

Vision

FNIGC envisions that every First Nation will achieve data sovereignty in alignment with its distinct worldview.

Mission

With First Nations, we assert data sovereignty and support the development of information governance and management at the community level through regional and national partnerships. We adhere to free, prior and informed consent, respect nation-to-nation relationships, and recognize the distinct customs of nations.





Core Strategic Objectives

- Our approach is community-driven and Nation-based.
- Our data are inclusive, meaningful, and relevant to First Nations.
- Our tools are effective, adaptable, and accessible.
- Our partnerships connect regions to strengthen data sovereignty.



National Surveys

- Regional Health Survey (RHS) – ongoing
- Early Childhood, Education & Employment Survey (FNREES) – 2016
- Labour & Employment Development Survey (FNLED) – present

Research

- Research that aligns with FNIGC strategic direction and established principles and priorities
- Research on data sovereignty and information governance

Education, Training, & Capacity

- First Nations data sovereignty
- Information governance & management
- OCAP®
- First Nations Data Governance Strategy (FNDGS)

First Nations Principles of OCAP®



- Ownership, Control, Access and Possession
- Collection, protection, use, and sharing of First Nations data
- Benefits community while minimizing harm
- Self-determination, and preservation and development of culture



COVID-19 Related Work

- RHS statistics for shaping a response to COVID-19 in First Nations communities
- Collaborating on a position paper that examines challenges / limitations of First Nations COVID-19 data
 - Regional contexts in relation to First Nations COVID-19 data and data governance
 - Potential role of the First Nations Data Governance Strategy (FNDGS) to alleviate these challenges
- Data Sharing Agreement with ISC to access COVID-19 data

Data Quality Challenges (1)



- Data quality issues regarding counts of First Nations people
 - First Nations identifiers: self-reporting (census or case reports) vs. Indian Registry
 - Exclusion of First Nations based on place of residence or *Indian Act* grouping
 - First Nations population living in urban cities, especially vulnerable populations such as the homeless and/or mobile populations are undercounted

Data Quality Challenges (2)

- Impacts
 - Invisible to health statistics – missed opportunity for evidence-based response to the pandemic
 - Misclassification bias mostly results in underestimated rates and reduced differences
 - Cannot examine intersection with different population groups within First Nations (e.g. people living with disabilities, gender identity) to see if there are disproportionate effects

Data Integration Challenges (1)

- Jurisdictional and complex relationships
- Data flow in the jurisdictions vary and limitations are not transparent or well-documented
- Aggregation of disparate information into two separate datasets
 - ISC dataset excludes First Nations without status or living off-reserve, First Nations in some self-governing communities and potentially those who live on-reserve but seek care outside the community
 - PHAC dataset exclude First Nations who do not self-identify or First Nations that live in provinces / territories that do not report on First Nations identity



Data Integration Challenges (2)

- Impacts of non-integrated information health systems (between federal and provincial health services)
 - challenges with contact tracing and follow-up treatment
 - a fragmented and incomplete picture of the realities of First Nations

Data-Sharing Challenges (1)

- First Nations face barriers for accessing data because the data is often under the control of provincial or federal government and subject to privacy legislation.
- Data sharing agreements and partnerships to access data require significant effort and collaboration, as well as capacity, resulting in significant delays during a pandemic.
- Relationship between provincial / territorial government and First Nations becomes the key for if and how COVID-19 data is shared.

Data-Sharing Challenges (2)

- Need for federal / provincial / territorial / First Nations governance structures that support the flow of data and information and the ability to work across jurisdictions
- Lack of information for small communities / regions – due to measures for protecting individual privacy
 - Involve First Nations in how data is clustered so that it can be meaningful



Role for the FNDGS (1)

- The First Nations Data Governance Strategy (FNDGS) can be instrumental in addressing some of the significant health data governance issues impacting First Nations health surveillance
- The FNDGS proposes a network of 10 Regional Information Governance Centres (RIGCs), which will continue to work together at the national level – as regions currently do in the form of FNIGC.
- These RIGCs can:
 - Act as **catalyst** with the goal to progressively alleviate some of the barriers flowing from an overly complex jurisdictional divide, and legislative and policy vacuums
 - Enable health data governance **partnerships** with each provincial government and Canada
 - Act as data **integrator** with the goal to increase health data access by First Nations' governments, health authorities, and professionals
 - Assume the role of **gatherer, packager, and disseminator**

Role for the FNDGS (2)

- Be a **trusted source of expert advice** and, accordingly, help elevate science-based issues and / or challenges impacting the First Nations' health system
- Address:
 - issues pertaining to the definition and count of status First Nations, as determined by First Nations
 - need for communities and their governments to access the detailed information that they need in full respect of privacy and security of First Nations citizens
 - health (and other) data collection gaps resulting from distrust, racism, lack of understanding, and / or lack of processes or willingness for collecting distinction-based data



Role for the FNDGS (3)

- Be key contributors to the health surveillance system by providing First Nations-led information, analysis, and expert-advice with the goal to help complete representation of data, occurrences and its distribution in the First Nations population off- and on-reserves, including with respect to mobility of First Nations people between their reserve and other communities

Conclusion

- COVID-19 has highlighted several challenges with the current health data systems, resulting in inadequate data available for First Nations to respond to the pandemic.
- The control of data is a necessary element for First Nations self-determination and self-governance. However, this control requires supporting data governance capacity and associated infrastructure.
- Addressing the challenges is a shared responsibility that requires collaboration, coordination, and integration of various actors and knowledges.
- **The FNDGS is a unique cross-road opportunity to create the necessary conditions (capacities) for sustainable dialogues, engagements, collaborations, coordination, and actions for a better health system.**



Thank you

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