Describing the Health Status of First Nations in Quebec: Advances and Challenges in Relation to the Evidence

JASP
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COMMISSION DE LA SANTÉ
ET DES SERVICES SOCIAUX
DES **PREMIÈRES NATIONS**
DU QUÉBEC ET DU LABRADOR

CSSSPNQL • FNQLHSSC

First Nations data sovereignty

"Data sovereignty is one of the most pressing issues facing First Nations from coast to coast to coast. [...] Access to timely, relevant, and quality data is essential to effectively advocate for the changes needed to address the health disparities that the Nations have experienced as a result of colonization and systemic racism."

Leona Star, Chair, Board of Directors, *First Nations Information Governance Centre*
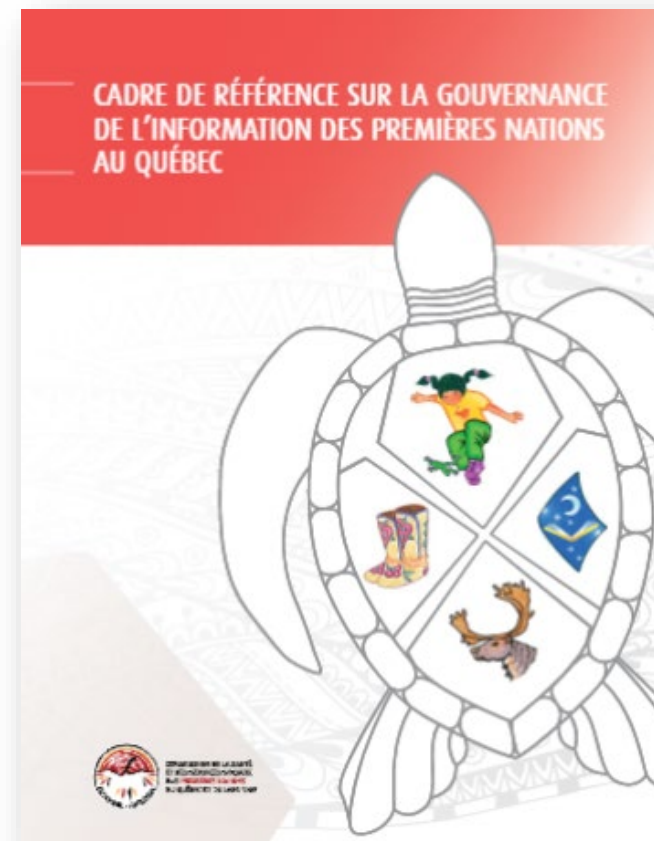
First Nations data sovereignty

- The right of every nation to self-determination and self-government

- The right to govern its information assets (the collection, ownership, and use of its data)

- Recognized by the Constitution of Canada and the United Nations Declaration on the Rights of Indigenous Peoples

- Is part of a decolonization process

A vision of information governance by and for First Nations in Quebec

In harmony with their right to self-determination and their information sovereignty, First Nations in Quebec organize, structure, control, and manage their information heritage according to their values, worldview, and practices so that they can make informed decisions and direct their actions to effectively serve their populations.

CADRE DE RÉFÉRENCE SUR LA GOUVERNANCE
DE L'INFORMATION DES PREMIÈRES NATIONS
AU QUÉBEC

Evidence-based health care decision-making

"Health information is an essential element of any population health initiative. Ideally, this information produces a comprehensive picture of the determinants of health, health system performance, and health status. Such information is required to properly assess health needs and priorities and for the evaluation of health services and programs."

National Collaborating Centre for Indigenous Health (2009).

Achieving Strength Through Numbers: First Nations, Inuit, and Métis Health Information.

A virtual absence of data for First Nations in Quebec

- Non-treaty communities: no information from MSSS sociosanitary files
- Several undocumented core indicators:
  - Life expectancy?
  - Mortality rate?
  - Birth rate?

Challenges for data access

- Legislative and structural challenges
  - Public Health Act
  - Surveillance Act
  - The FNQLHSSC, health centres, health stations, and clinics in non-treaty communities are not part of the Quebec health and social services network

Methodological challenges for data access

- Lack of ethnocultural identifiers in Quebec databases
- Possibility of identification on a geographical basis only: this excludes people living outside the community
- Small populations: confidentiality and statistical power
- Data scattered across all regions of Quebec
- Populations from non-treaty communities excluded from the Quebec population surveys
- Available information: aggregation with non-native populations

Steps taken for over 10 years

- Development of methodologies
- Ad hoc initiatives: pilot projects and research projects
- No sustainable solution due to legislative and structural frameworks
- No formal collaboration or agreement to provide recurring and permanent access to data

Tools developed by First Nations

- Population-based surveys by and for First Nations
  - Repatriation of community data
- Plan for monitoring health status and its determinants
  - PRISME portal
- Data counter
- Culturally relevant health measures

Inquiry Commission on Relations Between Indigenous Peoples and Certain Public Services in Québec

"What is certain, however, is that the limited or non-existent access that Indigenous authorities have to data about their population makes it extremely difficult for them to plan and respond to services that are essential to the well-being of their population."

CALL TO ACTION #5

Make the necessary administrative and legislative changes to enable Indigenous authorities to have easy access to data on their populations at any time, particularly in the area of health and social services.

Thank you!

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