

Historical context

Data collection efforts and research about Indigenous Peoples have historically been problematic for First Nations peoples, Inuit, and Métis peoples. In the past, outside authorities imposed their own data collection processes on Indigenous communities, based on their own priorities rather than on the needs of the communities. Further, much unethical research, fueled by racist assumptions, was conducted by non-Indigenous researchers and then used to justify ongoing inequalities and inequities between Indigenous and non-Indigenous peoples. Many Indigenous people do not trust mainstream government institutions and public health surveillance processes. This mistrust may pose a barrier to their participation in health surveillance activities. As a result, Indigenous people are not well represented in policies and programs that flow from the data.



Challenges with public health surveillance for Indigenous populations

There are 14 distinct health care systems in Canada – one operated by the federal government for status First Nations and Inuit and one operated in each of the provinces and territories. Each of these systems has their own criteria and definitions for collecting health data, which leads to an uncoordinated and inefficient public health surveillance system. The resulting fragmentation makes it difficult to draw comparisons between jurisdictions. It also makes it difficult to respond to public health issues in a timely and effective way.

The challenges listed above can be particularly harmful for First Nations, Inuit, and Métis populations. A key issue is that Indigenous identity is often not recorded in health data. A variety of factors account for this, including:

- frequent mobility of Indigenous people between rural, remote, and urban areas;
- barriers to care such as racism, stigma, discrimination, or lack of physical access to health services, which can impede public health surveillance that relies on collecting data at the point of care;
- lack of and inconsistent use of Indigenous identifiers (e.g., First Nations, Inuk/Inuit, and Métis) across surveys and surveillance systems;
- low participation of Indigenous populations in surveys;
- incomplete data coverage across urban, rural, remote, and northern geographies; and
- exclusion of distinct Indigenous populations from specific health information systems.³

³ For example, First Nations people residing on reserve are often excluded from surveys to assess the health of populations generally (i.e., National Longitudinal Child and Youth Survey) and Indigenous populations specifically (i.e., Indigenous Peoples Survey), while non-status First Nations, Métis, and urban Indigenous populations are excluded from Indigenous Services Canada data collection efforts and from First Nations- and Inuit-led data collection exercises.



Another challenge is that current datasets do not support local health service planning and delivery. The problems include:

- data covers too large a jurisdiction;
- data collection and interpretation utilize a pan-Indigenous approach;
- data is not comparable across jurisdictions; and
- little information is returned to Indigenous communities to support community planning and decision-making.

Much of data collected by government health surveillance systems is “deficits-based.” That means the focus is on the perceived weaknesses of individuals or groups to the point where they become viewed as “the problem.”

Further, Western-based indicators of health measurement may not lead to useful solutions to health problems for Indigenous populations. This is because they do not effectively capture key – and distinct – indicators of health and well-being for First Nations peoples, Inuit, and Métis peoples. Important indicators for Indigenous Peoples include the cultural, spiritual, emotional, and mental aspects of health, such as connections to family, community, the natural environment, and Creator, as well as the enduring impacts of colonization and ongoing colonialism on First Nations, Inuit, and Métis populations.

The emergence of new data technologies and open, digital, and big data initiatives hold both promise and threat for Indigenous Peoples. While they offer the potential for increased access to timely and relevant data for Indigenous communities, they are also likely to perpetuate existing challenges in public health surveillance for Indigenous Peoples. Further, the new technologies and data initiatives raise ethical concerns about privacy, consent, algorithmic profiling, and the need to protect Indigenous knowledge in digital data infrastructure. Advancements in information technology also carry risks of data weaponization, stigmatization, and racialization. Indigenous researchers and organizations have been advocating for formal mechanisms to assert Indigenous data interests in these types of technologies and initiatives.



RECOMMENDATIONS

This literature review identified several recommendations for enhanced public health surveillance in Indigenous communities. In no particular order, these include the need to:

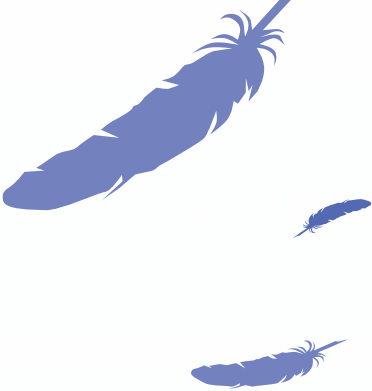
- Add standardized “Indigenous identifiers” to all data sources to ensure appropriate data linkages. Apply these identifiers consistently and accurately across jurisdictions to ensure Indigenous populations are not under-estimated in health indicators. Identifiers should be based on the “gold standard” of “self-identification” to support the rights of Indigenous Peoples to define which community they belong to.

- Increase geographic coverage of administrative and health survey data and ensure data collected is representative of urban, rural, remote, and northern populations.

- Take steps to mitigate and/or measure any major biases in data collection and analysis by undertaking bias analysis, including differences in approaches to identifying Indigenous populations, likelihood of under-ascertaining Indigenous Peoples in the data, comparability of numerator and denominator measures of Indigenous status, quality of data being linked, the appropriateness of comparisons between specific populations, and the appropriateness of the analytic approaches being used when applied to Indigenous populations.

- Implement national surveillance systems that provide equitable coverage of Indigenous populations and communities that can inform policy development with systematically collected data. The focus should be on developing multiple surveillance systems, each focusing on a specific public health problem.

- Improve the quality, comprehensiveness, and timeliness of health data through the harmonization of data collection processes across jurisdictions, achievement of consensus on definitions and measures, integration of additional data sources, and exploration of opportunities for using technological innovations to create real-time monitoring applications. Surveillance should be inclusive and support intersectional analyses.



- Establish best practice in linkage to enhance vital statistics collections and adjust for under-identification of Indigenous Peoples. Ensure data linkage and reporting occurs at the federal and provincial/territorial levels, using standardized data for cross-jurisdictional comparisons.

- Work with Indigenous communities in all stages of data collection, analysis, and dissemination of results. Initiate the development of data access and sharing protocols between Indigenous Peoples and other governments and data holders. Ensure principles of Indigenous community ownership and reporting are established and maintained for all data collection practices.

- Invest in building Indigenous community-controlled health information structures and assist communities in developing their own capacity to perform analytical and dissemination functions of a public health surveillance system.

- Increase the number of Indigenous epidemiologists and build capacity among Indigenous Peoples to bolster public health expertise and decolonize public health practice.

- Improve accessibility of Indigenous health data to Indigenous and local governments; frontline, clinical, and public health staff; community organizations; and health system decision-makers to support the identification of priority issues and evaluation of local interventions.

- Develop a collaborative and inclusive governance model that recognizes the stake that socially excluded populations like Indigenous communities have in relation to health issues identified as a priority for them. This might include involving Indigenous leaders, activists, scholars, and those with lived experience in mainstream science, data, policy, and decision-making processes.

- Engage with Indigenous populations to set public health priorities and plan public health surveillance systems.

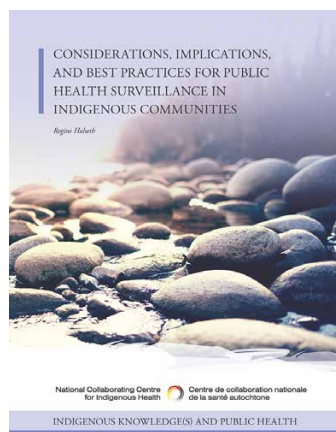
Conclusion

The state of public health surveillance in Canada has resulted in notable gaps in Indigenous health data. These systems need to be improved so they can better serve the needs and priorities of First Nations, Inuit, and Métis communities. Increasing Indigenous self-determination in the collection, analysis, and dissemination of health data is well recognized as critical for improving the quantity and quality of Indigenous health data and ensuring data dissemination does not reflect and reinforce harmful narratives of Indigenous Peoples. Efforts must be directed toward building capacity and infrastructure in Indigenous communities to support Indigenous-led data collection and analysis efforts. There is also a need to partner with Indigenous Peoples and organizations in designing a more integrated and coordinated public health surveillance system that is able to generate health data which is more inclusive and reflective of the needs and health priorities of Indigenous communities.





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