

ACHIEVING STRENGTH THROUGH NUMBERS: FIRST NATIONS, INUIT, AND MÉTIS HEALTH INFORMATION

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A Population Health Approach to Health Information

Population health has been defined as “the health outcomes of a group of individuals, including the distribution of such outcomes within the group.”¹ In a population health approach, health status outcomes (ie. life expectancy, quality of life, and the presence or absence of disease) are linked to health determinants (ie. income, employment, education, housing, and food security). Population health models can be useful in the field of Aboriginal² health as they are concerned with addressing health inequities among population groups through policies and interventions. Population health frameworks also allow for more holistic definitions of health and wellness that can include not only physical, but also mental, emotional, spiritual, community, and environmental factors.

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. There are five principal sources of health information:



- census
- vital registration (ie. birth, death, and marriage certificates)
- health surveillance systems (ie. disease and cancer registries and reporting)
- administrative data from primary care and hospitals
- health surveys

When population based rates are calculated from these data sources, the

counts of the population of interest should be as complete as possible; and the count of the event under study (ie. death, illness, health service encounter, preventative health activity) in that population as accurate as possible. Rates based on incomplete population counts are described as having problems of coverage; rates based on faulty data or calculation methods are described as having problems of quality.³



The Need for Useful and Reliable Data that is Inclusive of All First Nations, Inuit, and Métis People

In the preceding section, we learned that a population health approach to health information requires as complete a count of the population of interest and event under study as possible. It follows that if the population of interest is Aboriginal people living in Canada, datasets need to be inclusive of all persons who self-identify as First Nations, Inuit and Métis. If a group is excluded from the count because of place of residence and/or registration status as per Indian Act legislation, then the count is incomplete in its coverage of the Aboriginal population and this needs to be noted. The inequities of health determinants and health status facing First Nations, Inuit, and Métis people, while variable, are not limited to a particular geographic region or Indian Act defined subpopulation.

According to the 2006 census, just under 1.2 million persons in Canada report Aboriginal identity.⁴ 62% identified as 'North American Indian' (includes First

Nations persons both registered and not registered under the Indian Act), 34% identified as Métis, 4% identified as Inuit.

While all groups of Aboriginal peoples in Canada experience inequities in health outcomes compared to non-Aboriginal Canadians, there are differences in health determinants and health status outcomes between First Nations, Inuit, and Métis across geographic regions and for First Nations, across Indian Act defined grouping (ie. registered compared to non-registered). This is linked to different histories, cultures, social and political systems and health service infrastructure depending on the Aboriginal subpopulation. These differences mean that solutions for resolving disparities in health usually should be tailored to meet the needs and structures of a particular First Nations, Inuit or Métis group at the local or small region level. For these reasons, it is very important that health information can be separated out or "disaggregated" in data subsets that are specific to First Nations, Inuit, or Métis subgroups. It is also essential that these "disaggregated" First Nations, Inuit, and Métis datasets are available at different

levels of geographic aggregation, so that health stakeholders can access national, provincial/territorial, regional, and community level health data.

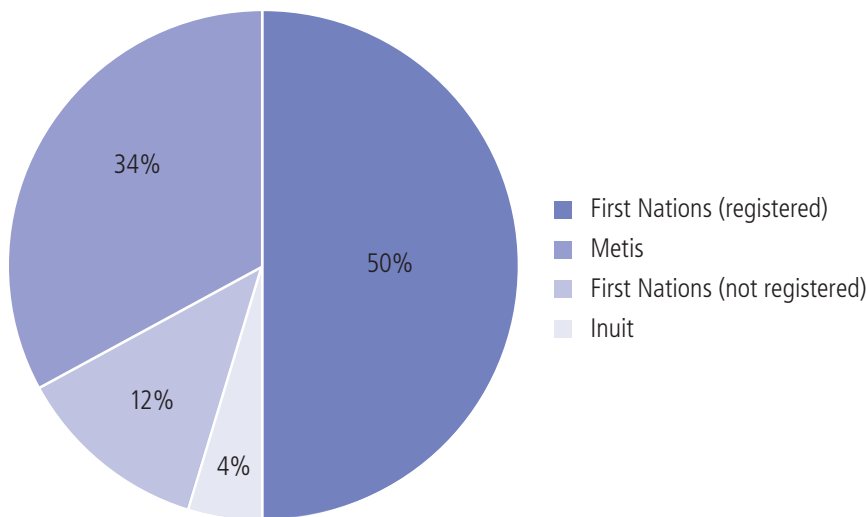
In the next section, we will discuss key health information issues, including coverage. Particularly problematic from a human rights perspective is the systematic exclusion of certain subpopulations of Aboriginal people from data collection according to ethnicity, place of residence, and/or Indian Act grouping. For example, First Nations persons who are not registered, Métis, and Inuit living in urban areas have not been included in most Aboriginal health data initiatives.

Key Issues in the Collection, Analysis, Management, and Application of First Nations, Inuit, and Métis Health Information

Coverage and quality of data:

There are large gaps in the coverage of Aboriginal health data in Canada. A key challenge with respect to coverage is the absence or inconsistency of First Nations, Inuit, and Métis ethnic identifiers in vital registration systems, primary care and hospital administrative datasets, as well as acute and chronic disease surveillance systems. As a result, First Nations, Inuit, and Métis people are largely invisible in the majority of provincial and territorial health datasets. Cross linkages of these provincial/territorial health datasets to First Nations, and more recently Métis registry lists, provide a partial solution, however such linkages are limited by the quality of the registration lists and exclude First Nations and Métis persons who are not registered. In some regions, postal code can also be used as a proxy for Aboriginal ethnicity, however this method is limited to First Nations reserves with a specific postal code or regions where the large majority of the population is Aboriginal (ie. Nunavut).

Aboriginal Population Distribution in Canada (Census 2006)



Additional data quality challenges have been linked to the use of substandard data sources and/or the application of substandard methods in Aboriginal health data work,⁵ where at times there appears to be a double standard with respect to Aboriginal data quality compared to mainstream data. National health surveys are commonly underpowered in their ability to provide First Nations, Inuit, and Métis specific information at the regional level and exclude on-reserve populations.

Indigenous data governance and management: Over the past decade, First Nations, Métis, and Inuit governing authorities in Canada have increasingly advocated for the recognition that the right to self-government includes the right to self-governance of population health information. Fundamental to any First Nations, Inuit, and Métis health information system is the involvement of the appropriate First Nations, Inuit, and/or Métis governing body or organization in the governance and management of health datasets. This is usually the governing body

or organization that has jurisdictional authority for the Aboriginal group and geographic area that match the group for and geographic level to which the data is disaggregated. The First Nations Regional Longitudinal Health Survey (FNRLHS) is an example of a First Nations governed and controlled health data initiative.⁶

Culturally relevant health measurement: Indigenous models of health are diverse and can differ from non-Indigenous models. In response to the need for health indicators that reflect Indigenous ideas and systems of health, several Aboriginal groups in Canada have started to develop culturally specific health measurement models.⁷ There is a need for locally relevant and customized First Nations, Inuit, and Métis health indicators in addition to the more universally recognized public health measures.

Complexity of jurisdiction: Health systems are set up very differently depending on Aboriginal ethnicity (First Nations with or without registered status,

Inuit, and Métis) as well as geography (remote, rural, on-reserve, urban). Service jurisdiction is complex, and depending on ethnic identity and geography will be federal, provincial/territorial, health region, Aboriginal governing authority or a combination. This complexity extends to health information systems. Multiple jurisdictions can be involved in collecting, analyzing, disseminating, and responding to health information and the levels of interface vary.

Infrastructure and Human Resource Capacity: A review of Indigenous health information systems in Canada reveals a lack of infrastructure at all levels to support the collection of relevant Indigenous specific health indicators as one of the major themes.⁸ Gaps in public health human resources have already been identified as a major problem in Canada. In Aboriginal public health, these gaps are especially severe. For example, currently we are only able to identify between ten and twenty persons of Indigenous ancestry with graduate level training in public health.⁹

Dissemination and Application: Dissemination of health assessment information back to key Indigenous health decision makers, particularly at the local and small region level has been identified as a major gap in existing health information systems.¹⁰ Another key challenge that needs to be addressed is ensuring that decision makers have the capacity and resources to respond to health assessment information when it is available. For example, information regarding core public health determinants and indicators such as the lack of availability of potable drinking water and epidemic/endemic rates of youth suicide are available for rural First Nations communities in many parts of the country. However, local and small region decision makers are not adequately resourced or empowered to be able to mount an appropriate public health response.

Data Use Suggestions

The following suggestions can help guide Aboriginal health information workers:

- Be clear about which Aboriginal groups are included and excluded from your datasets
- If you are a public health/population health worker be sure that you are striving to include ALL of the Aboriginal people in your area of jurisdiction
- Seek to amend the systematic exclusion of a particular Aboriginal subpopulation and/or substandard data quality/methods
- If you are a health data worker at the federal, provincial/territorial, regional, or community level, identify who are the relevant First Nations, Inuit, and Métis stakeholder groups at your level of jurisdiction and seek them out as health data partners; get to know their data needs and priorities
- Try to do things that contribute to Aboriginal health data human resource capacity and infrastructure; for example, mentor an Aboriginal health data worker or student and/or do that extra data run for an Aboriginal organization or governing body
- Try and work through cross-jurisdictional barriers that are preventing excellence in Aboriginal health data systems
- Support the articulation and development of Indigenous specific health measures and frameworks

Resources for First Nations, Inuit, and Métis Health Information Workers

Aboriginal health surveys:

- First Nations Regional Longitudinal Health Survey:
www.rhs-ers.ca/english/
- Inuit Health Survey:
<http://inuithealthsurvey.ca/>
- Aboriginal Peoples Survey:
www.statcan.gc.ca/aboriginal/aps/5801794-eng.htm
- Aboriginal Children's Survey:
www.statcan.gc.ca/aboriginal/acs/5801793-eng.htm
- Census Aboriginal population profiles (webtool): <http://www12.statcan.ca/english/census06/data/profiles/aboriginal/>

Provincial/territorial registry linkage initiatives:

- BC First Nations Leadership Council, British Columbia Ministry of Health and Health Canada:
www.umanitoba.ca/centres/cahr/researchreports/building_health_research_relship.pdf
(see performance tracking section)

Aboriginal and University health information partnerships:

- Assembly of Manitoba Chiefs and University of Manitoba:
www.umanitoba.ca/centres/cahr/researchreports/building_health_research_relship.pdf

Partnerships between disease surveillance bodies and Aboriginal groups:

- Cancer Care Ontario:
www.cancercare.on.ca/english/home/about/programs/aborstrategy/

Initiative to enhance Aboriginal infant mortality rate information:

- The Canadian Perinatal Surveillance System, Health Information Analysis Division – First Nations and Inuit Health Branch, Inuit Tapiriit Kanatami, and Métis National Council Joint Working Group on First Nations, Inuit, and Métis Infant Mortality Data:
Contact cpss@hc-sc.gc.ca
- **First Nations Epicentre of Alberta:**
<http://www.fnepicentre.org/> - HAS CEASED OPERATIONS

Endnotes

¹ Kindig, D. & Stoddart, G. (2003). What is population health? *American Journal of Public Health*, 93(3):380-3.

² 'Aboriginal' throughout this fact sheet refers collectively to the Indigenous inhabitants of Canada, including First Nations, Inuit and Métis peoples (as stated in section 35(2) of the Constitution Act, 1982).

³ Smylie, J. & Anderson, M. (2006). Understanding the health of Indigenous peoples in Canada – key methodologic and conceptual challenges. *Canadian Medical Association Journal*, 175(6):602-605.

⁴ Statistics Canada (2008). *Aboriginal Peoples in Canada in 2006: Inuit, Métis, and First Nations*, 2006 Census. Ottawa, ON: Ministry of Industry. Statistics Canada catalogue number 7-558-XIE

⁵ Smylie & Anderson (2006).

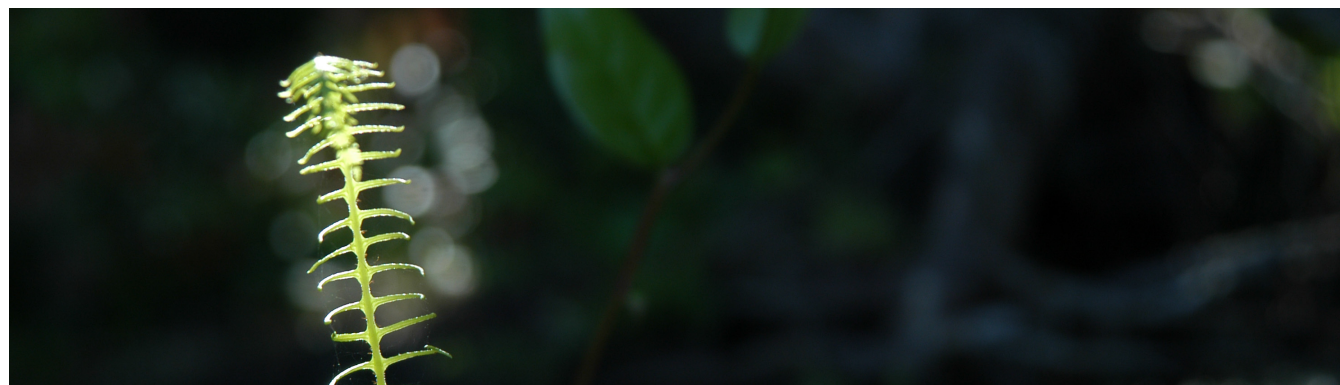
⁶ The First Nations Regional Longitudinal Health Survey can be accessed at <http://rhs-ers.ca/english>

⁷ Smylie & Anderson (2006).

⁸ Anderson, M., Smylie, J., Anderson, I., Sinclair, R., & Crengle, S. (2006). *First Nations, Métis, and Inuit Health Indicators in Canada: A background paper for the project 'Action oriented indicators of health and health systems development for Indigenous peoples in Canada, Australia, and New Zealand'*. Melbourne: Onemda VicHealth Koori Health Unit, University of Melbourne, Discussion Paper 18. http://www.onemda.unimelb.edu.au/docs/dp18_1.pdf

⁹ Smylie & Anderson (2006).

¹⁰ Ibid.



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