



# CONSIDERATIONS, IMPLICATIONS, AND BEST PRACTICES FOR PUBLIC HEALTH SURVEILLANCE IN INDIGENOUS COMMUNITIES

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de la santé autochtone

INDIGENOUS KNOWLEDGE(S) AND PUBLIC HEALTH

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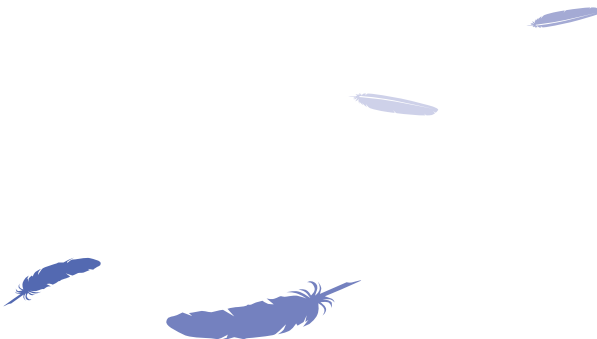
# INTRODUCTION

Public health surveillance is the “ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice” (Centers for Disease Control and Prevention [CDC], 2014, p. 8). The goal of public health surveillance is to provide information that is useful to inform public health action. The CDC (2014) outlines seven primary uses of public health surveillance, including to:

- identify patients and their contacts for treatment and intervention;
- detect epidemics, health problems, [and] changes in health behaviours;
- estimate the magnitude and scope of health problems;
- measure trends and characterize disease;
- monitor changes in infectious and environmental agents;
- assess effectiveness of programs and control measures; and
- develop hypotheses and stimulate research (p. 14).

In Canada, the responsibility for public health surveillance is shared across local, regional, provincial/territorial, and federal health agencies – with each agency operating their own data collection system, with their own definitions and measures. As a result,





there are severe gaps in the scope and coverage of surveillance data. As acutely emphasized by the recent COVID-19 pandemic, Canada's surveillance capacity is also challenged by key gaps in surveillance infrastructure, expertise, and governance, which hinder an effective coordinated response to emergencies (Keynan & Buckeridge, 2023). Nowhere are these gaps and inequities more notable than in relation to Indigenous<sup>1</sup> health data.

Canada's public health surveillance systems currently face new challenges and opportunities for Indigenous communities. These systems have been changing in response to new diseases and health threats,<sup>2</sup> the emergence of new data governance norms and data sources, as well as innovations in data collection methods and analytical techniques. Principles of ethics, equity, and data ownership are increasingly being applied to data specific to First Nations, Inuit, and Métis populations; yet there is still uncertainty over how these principles can be applied to new data sources and data collection technologies. Additionally, it is well known that some populations are vulnerable to health inequalities due to the social determinants of health, including Indigenous Peoples. As such, public health surveillance systems focused exclusively on disease surveillance will not provide very useful information for addressing health issues in Indigenous communities. Instead, consideration for the social determinants of health, including

racism, discrimination, historical trauma, and socio-economic inequities, along with indicators for vulnerable groups, must be integrated into public health surveillance. These issues are driving efforts to build better coordinated, equitable, and effective public health surveillance systems across Canada.

This report provides a review of the literature on public health surveillance in Indigenous communities in Canada to identify what works and does not work in relation to Indigenous health. It aims to inform public health policy makers and decision makers in their efforts to reform public health surveillance in Canada in ways that better respond to the needs and priorities of Indigenous Peoples and communities. The paper begins by outlining the methods used to identify relevant literature. Second, a brief overview is provided on the colonial history of public health surveillance in Indigenous communities and the legacy of mistrust it left behind. Third, key challenges that exist in relation to current public health surveillance practices in Indigenous communities are identified. Fourth, issues and opportunities in relation to the Indigenous data sovereignty and governance movement are examined, including some examples of best and promising data governance practices. The final section outlines a set of recommendations for enhancing public health surveillance in Indigenous communities in Canada.

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<sup>1</sup> The term "Indigenous" is used throughout this paper to refer to First Nations peoples, Inuit, and Métis peoples collectively, regardless of registered status or location of residence. When referring to specific Indigenous groups, the terms "First Nations", "Inuit", or "Métis" will be used.

<sup>2</sup> Such as COVID-19, monkeypox, Lyme disease, and others.

# METHODS

Academic literature was identified through Google Scholar, MedLine (EBSCO), and PubMed Central. Search terms included: “health data” OR “public health surveillance” OR “health system measurement” in combination with either “Indigenous” OR “First Nations” OR “Inuit” OR “Métis” AND “Canada.” Grey literature was sourced from the National Collaborating Centre for Infectious Diseases (NCCID), the National Collaborating Centre for Indigenous Health (NCCIH), and the Public Health Agency of Canada (PHAC) websites. Bibliographies of relevant literature were also searched for further information.

The review was completed in February 2024, with few search constraints applied. Only literature published in English was reviewed due to the author’s language limitations. The literature review also excludes any potential sources of information that were not freely accessible through the University of Northern British Columbia’s database access. This literature review was not undertaken using a systematic review protocol and thus may not be inclusive of all relevant literature.





# HISTORICAL CONTEXT


Efforts to reform Canada's public health surveillance systems should be informed by a good understanding of Indigenous Peoples' history with data collection processes and research,<sup>3</sup> which has historically been problematic. In the past, data collection was imposed by outside authorities and reflected an ongoing oppressive colonial relationship (Bruhn, 2014). State sanctioned surveillance was (and in many cases still is) rooted in a framework of systemic racism – one that is based on a “racist assumption that the colonial state has the authority to override pre-existing Indigenous laws and social systems” to collect data (Marsden et al., 2020, p. 822). This assumption has justified the conduct of extractive and unethical research by non-Indigenous researchers in Indigenous communities, including the desecration of grave sites; the collection and use of human samples without informed consent or authorization (Flicker & Worthington, 2012; Smylie & Firestone, 2015); unethical experimentation on Indigenous people (Mosby & Swidrovich, 2021); intellectual theft of cultural knowledge and assets for the researcher's own personal and professional gain (Marsden et al., 2020; Smylie & Firestone, 2015); and failure to share results of research with communities for their ownership and benefit (Flicker & Worthington, 2012; Smylie & Firestone, 2015).

Research and surveillance data have been used to falsely demonstrate Indigenous Peoples' inability to be self-determining, to marginalize Indigenous Peoples, to question their right to be Indigenous, and in turn, to rationalize ongoing unequal power relations and inequalities between Indigenous and non-Indigenous people (Walter & Suina, 2019). Foucault (1986) outlines a pathway for how data collected on Indigenous Peoples enable colonial governments to exert power

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<sup>3</sup> While there is a distinction between research and public health surveillance activities (public health surveillance involves routine data collection processes using standard, broadly accepted methods, while research can involve non-standard or experimental methods and does not need to be routinely collected), both are data collection activities that share similar methods and have overlapping agendas (Lussier et al., 2012). Indigenous Peoples' distrust of Western data collection processes is rooted in both of these types of activities collectively.





*... colonization and globalization of “Western ideas, values, and lifestyles ... resulted in epistemicide, suppression and co-optation of Indigenous knowledges and data systems,” limiting Indigenous Peoples’ ability to recover, develop, and sustain their own knowledge*

(Russo Carroll et al., 2020, p. 2).

over Indigenous populations. Control over data collection processes allows one actor to create knowledge about a particular group and impose that knowledge as truth when making decisions about that group and developing policy interventions (as cited in Purdy, 2015, p. 4). As Lovett and colleagues (2019) note, the Canadian Census of Population has been an “indispensable tool of colonization; indeed, the census has long been tied to the exercise of power and statecraft” (p. 27).

Historically, power over knowledge creation and dissemination has been used as a tool to maintain inequalities between populations (Purdy, 2015), silence Indigenous

voices (Lambert & Henry, 2020), and justify decisions that support colonial government aims (Marsden et al., 2020). For example, data have been used in the past to justify colonial settlement on presumably empty Indigenous lands; removal of Indigenous children from their families and placement into the child welfare system; imposition of a draconian public health response to the tuberculosis (TB) epidemic that forcibly removed Indigenous TB patients from their home to distant TB sanatoriums (Hendl & Roxanne, 2022); and to fuel a policy era by the federal government to resolve the so-called “Indian problem” (Marsden et al., 2020). Further, colonization

and globalization of “Western ideas, values, and lifestyles ... resulted in epistemicide, suppression and co-optation of Indigenous knowledges and data systems,” limiting Indigenous Peoples’ ability to recover, develop, and sustain their own knowledge (Russo Carroll et al., 2020, p. 2).

Indigenous people have had longstanding suspicions around research and data collection processes. Based on Western methodologies, much of this research produces statistics that are almost exclusively focused on Indigenous “difference, disparity, disadvantage, dysfunction, and deprivation,” which are generally





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referred to as 5D data (Walter & Suina, 2019; p. 235; see also Walter et al., 2021). This type of data tends to aggregate and decontextualize data from Indigenous Peoples' social and cultural contexts, resulting in statistics that over-represent Indigenous Peoples in deficits-based data. Under the guise of 'objectivity', this deficit discourse has had harmful consequences for Indigenous Peoples (Walter & Suina, 2019, p. 233; see also Cormack et al., 2019). Walter and Suina (2019) argue that this type of data presents a "raced reality," derived from the "social, racial, and cultural" positions of its creators, who decide which issues are investigated and which


data are collected. In addition to its futility, this type of data undermines Indigenous Peoples' ability to define and meet their own data needs (Bruhn, 2014).

Indigenous Peoples' experiences with colonialism and subsequent mistrust of mainstream government institutions, public health surveillance, and research may act as barriers to their participation in surveillance and research activities, such as self-identifying as Indigenous during health care interactions in an attempt to avoid further stigmatization and racism (Sabeti et al., 2021). Indigenous people may see "surveillance" as "oppressive and ... perpetuating

colonial relationships" (O'Neil & Blanchard, 2001, p. 5). As a result, the failure to include Indigenous Peoples in data collection processes and quantitative analyses increases the risk that they will be undercounted, and therefore under-, mis-, or not-represented in policies and programs that flow from those data (Walter & Suina, 2019).





A close-up photograph of water ripples over rocks. The water is dark and reflects the surrounding environment, creating a complex pattern of light and dark colors. The rocks are visible in the background, showing various shades of brown and green. A white text box is overlaid on the left side of the image, containing a quote and a citation.

*Inconsistencies in the way indicators are defined and how data is collected across jurisdictions, surveillance instruments, and surveillance cycles can make it challenging to draw comparisons or track changes over time*

(Bader et al., 2023).



# CHALLENGES TO EXISTING MAINSTREAM PUBLIC HEALTH SURVEILLANCE SYSTEMS



Canada's approach to public health surveillance faces numerous challenges, applicable across all populations. Many of the challenges facing public health surveillance in Canada can be attributed to its fragmented healthcare systems, which is comprised of 13 publicly funded provincial/territorial healthcare systems and the federal healthcare "system."<sup>4</sup> Each of these systems has its own criteria and definitions for the collection of health data, creating an uncoordinated and inefficient system that makes it challenging to draw comparisons across populations and respond to public health issues in an effective way (Anderson et al., 2006; Canadian Institute of Population and Public Health [CIPPH], 2021; Coleman et al., 2016).

As a result of these uncoordinated systems, there may be a lack of publicly accessible statistics on specific health indicators or in specific geographic areas; a lack of standardized codes for diagnoses, resulting in misclassification or under-reporting of cases; and a failure to keep databases up to date (Bader et al., 2023; Pollock et al., 2018). Inconsistencies in the way indicators are defined and how data is collected across jurisdictions, surveillance instruments, and surveillance cycles can make it challenging to draw comparisons or track changes over time (Bader et al., 2023). Population-level tracking of incidence and risk factors are not widely or routinely available across all jurisdictions for many health issues, including suicide

(Pollock et al., 2018), overdoses (Sabeti et al., 2021), and acute and chronic disease (Smylie & Firestone, 2015). Data are often not stratified by sex, age, province or territory, or rural or urban residence, which poses further barriers for health planners when considering the intersections between determinants of health (Haworth-Brockman & Keynan, 2019). Further, provinces and territories voluntarily provide public health data to support the federal government's national surveillance efforts; this voluntary reporting leads to a fragmented approach to data collection and sharing (Essue et al., 2018; Haworth-Brockman & Keynan, 2019), and prevents a uniform and systematic approach to surveillance.

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<sup>4</sup> The federal healthcare system includes those health programs and services provided by Health Canada, the Public Health Agency of Canada, and for status First Nations people and Inuit from the First Nations and Inuit Health Branch of Indigenous Services Canada.

Canada has also experienced an erosion of health surveillance capacity at national, provincial/territorial, and regional/local levels, which poses a threat to population health and healthcare system sustainability (Hancock, 2017, National Collaborating Centre for Indigenous Health [NCCIH], 2023). This includes less prioritization of public health within governments and health authorities, reduced independence for Medical Officers of Health, limitations in the scope of public health due to being combined with primary care, and decreased funding for public health. With public health's focus on determinants of health and social equity, reduced surveillance capacity has the potential to disproportionately impact populations already experiencing significant health inequities, including Indigenous populations (Hancock, 2017).

These general challenges combine with unique challenges associated with data collection with Indigenous populations, creating some serious deficiencies in Indigenous health data across all jurisdictions. The challenge of having multiple jurisdictions involved in data collection is compounded in an Indigenous public health surveillance context by a high degree of mobility of

Indigenous people between rural/remote and urban jurisdictions, where Indigenous identity may not be captured in health data, and by Indigenous ethnic mobility<sup>5</sup> (Andersen, 2016).

The federal government's health transfer policy, which facilitates the transfer of administrative responsibility for some federally funded health services to First Nations and Inuit communities, also contributes to fragmented health surveillance capacity across Canada (Lavoie et al., 2010; Spasovska, 2012). The policy compounds difficulties of cross-jurisdictional communication and coordination between the federal government, which has responsibility over health programming on reserve, and provincial/territorial governments, which have responsibility over public health surveillance (MacIntosh, 2008; Spasovska, 2012). In turn, Canada's fragmented health surveillance capacity can make it challenging for Indigenous communities to monitor health outcomes, hampering their efforts to identify and assess the effectiveness of needed public health activities (MacIntosh, 2008; Pollock et al., 2018) and control disease outbreaks (CIPPH, 2021). Though some positive developments<sup>6</sup> were achieved,

the COVID-19 pandemic acutely highlighted the lack of access to adequate and timely data infrastructure in Indigenous communities (Pickering et al., 2023; Rowe et al., 2020).

Surveillance data is generally based on populations who have contact with the healthcare system, excluding those who do not seek help from the healthcare system or report health issues due to stigma, privacy, or other concerns (Pollock et al., 2018). Indigenous communities face some unique barriers to accessing health services that affect population data coverage in public health surveillance processes, including racism, stigma, and discrimination; privacy and confidentiality concerns; and limited access to health services. Colonialism and colonial worldviews perpetuate multi-layered and intersecting forms of anti-Indigenous racism, discrimination, and stigma that affect how Indigenous people are treated in healthcare systems (Logie et al., 2019; Mill et al., 2009, 2011; Pickering et al., 2023). Racism, stigma, and discrimination are known barriers to health seeking behaviours and engagement in care (Stangl et al., 2019). Many Indigenous people also live in rural and remote communities where care

<sup>5</sup> Ethnic mobility refers to Indigenous respondents who newly identify their Indigenous identity in surveys.

<sup>6</sup> For example, national recognition for the need to establish Indigenous COVID-19 data sovereignty and governance guidelines (Austin et al., 2020).





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*Indigenous communities face some unique barriers to accessing health services that affect population data coverage in public health surveillance processes, including racism, stigma, and discrimination; privacy and confidentiality concerns; and limited access to health services.*

providers and patients are well-known to each other and social networks are close, raising privacy and confidentiality concerns that may prevent patients from disclosing an illness (Kumar, 2016; Mayan et al., 2019; Shen et al., 2019). Access to health services may further be limited in some communities due to small population size and/or geographic remoteness. These unique barriers can influence public health surveillance processes that rely on data collected at the point of care.

The lack of health care infrastructure in some Indigenous communities, particularly in northern and remote communities, can also

pose a challenge for population data coverage. Indigenous communities often have access to only a nursing station, requiring patients to be transferred to regional hospitals or southern tertiary care institutions for more serious conditions. As a result, individuals receiving care outside of their community may be counted in provincial/territorial data, where Indigenous identity may not be captured (Pollock et al., 2018). Disaggregated data are needed at the sub-provincial level to inform local health planning and service delivery (Smylie & Firestone, 2015).

Finally, existing national, provincial/territorial, and

health system datasets are also characterized by some key deficiencies that make it challenging for First Nations, Inuit, and Métis communities to access health data that supports local health service planning and delivery. These challenges include population and geographic coverage, data quality issues and biases, and appropriateness of existing data sources and indicator frameworks. These challenges are discussed below. Collectively, they highlight the need for a harmonized data framework to enable timely and comparable population health statistics across jurisdictions (Hamm et al., 2021).

## Population coverage

Smylie and Anderson (2006) remark that for epidemiological data to be useful for Indigenous Peoples, “enumeration of the population of interest must be as complete as possible; and the count of the event of interest in that population, as accurate as possible” (p. 602). However, current methods of data collection systematically exclude a substantial segment of Indigenous populations, particularly non-status First Nations, Métis, and urban Indigenous populations (Anderson et al., 2006; McGill et al., 2023; Smylie & Firestone, 2015). This section describes some of the key challenges to collecting Indigenous population health data.

## Use of Indigenous identifiers

There is a lack and inconsistent use of Indigenous identifiers in existing national and provincial/territorial data sources. In fact, coverage of non-Census-derived Indigenous health data can vary widely, with some data sources having no coverage of Indigenous populations and others having over 90% coverage, depending on the region and the data source (Smylie & Anderson, 2006). Even in the context of the COVID-19 pandemic, equity data reporting,<sup>7</sup> including by Indigenous identity,

remains lacking across provincial/territorial, health region, and local population data (Blair et al., 2021; Pickering et al., 2023). These gaps in identity data are problematic from a human rights standpoint as it means that large segments of Indigenous populations are not informing evidence-based interventions (Smylie & Firestone, 2015).

### Federal data collection

The federal government, primarily through Statistics Canada, is responsible for a number of data programs and surveys that involve all Canadians. Table 1 provides an overview of some of the common health-related surveys administered by the federal government and its various departments and agencies and their inclusion/exclusion criteria for Indigenous identity collection. As can be seen, some of the data sources include indicators for First Nations people living on reserve and Inuit living in Inuit Nunangat, but exclude indicators for non-status First Nations, Métis, and urban Indigenous populations (Smylie & Firestone, 2015). Others, include an Indigenous identity question but the survey specifically excludes First Nations people living on reserve. Additionally, national surveys often omit institutionalized and homeless populations, excluding

Indigenous Peoples as applicable (Anderson et al., 2006; Pollock et al., 2018). These challenges have a ripple effect on other health data sets that draw their Indigenous identity population sample from Statistics Canada surveys, resulting in an under-estimation of Indigenous populations.

Other data quality challenges may also result in an under-estimation of Indigenous populations. For example, prior to 2011, it was sometimes difficult for national health surveys like the CCHS, NLCYS, and MES to generate a representative sample of Indigenous people that allowed for the disaggregation of First Nations, Inuit, and Métis population groups. This was because the CCHS, NLCYS, and MES drew from the long form of the Census, which is only administered to a subset of the Canadian population and thus does not include a representative sample of Indigenous participants (Smylie & Firestone, 2015). The inclusion of Indigenous representation in national population surveys has also been challenged by the non-participation of several First Nation reserves, as a block, in select national population surveys (e.g. 2001 and 2006 Census) and by Indigenous individuals who choose not to participate in the survey for a variety of

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<sup>7</sup> Defined as reporting of data related to health inequities and influencing factors, such as those related to demographic diversity and experiences of exclusion, including income, social status, race, gender, education, and physical environment.



TABLE 1: COLLECTION OF INDIGENOUS IDENTITY INFORMATION IN FEDERAL GOVERNMENT HEALTH SURVEYS

Survey	Identity inclusion/exclusion
General surveys	
Census of Population (the Census) (Statistics Canada)	Indigenous identity included in a subset of the sample, varying across Census years, from 20% in 1996-2006 to 30% in 2011; however, in that year, completion of the survey was made voluntary. Identity is inclusive of status and non-status First Nations, Inuit, and Métis populations; those who have registered status or not under the <i>Indian Act</i> , with additional questions used to identify urban, rural, and remote Indigenous populations (Statistics Canada, 2022a).
Canadian Community Health Survey (CCHS) (Statistics Canada)	Indigenous identity question is included and inclusive of status and non-status First Nations peoples, Inuit, and Métis peoples, but survey specifically excludes First Nations people living on reserve. No way to ascertain urban, rural, or remote residence (Pollock et al., 2018; Statistics Canada, 2021).
National Longitudinal Child and Youth Survey (NLCYS) (Statistics Canada)	Indigenous identity data is collected by residents of the Yukon, Nunavut, and the Northwest Territories, but excludes registered status and people living on First Nation reserves (Statistics Canada, 2008). No way to ascertain urban, rural, or remote residence.
Canadian Maternity Experiences Survey (MES) (Public Health Agency of Canada's Canadian Perinatal Surveillance System in collaboration with Statistics Canada)	Indigenous identity question is included and is inclusive of First Nations, Inuit, or Métis populations but excludes status/non-status populations (Public Health Agency of Canada [PHAC], 2006, 2009). No way to ascertain urban, rural, or remote residence.
	

TABLE 1: COLLECTION OF INDIGENOUS IDENTITY INFORMATION IN FEDERAL GOVERNMENT HEALTH SURVEYS (CONTINUED)

Survey	Identity inclusion/exclusion
Indigenous-specific surveys	
Indigenous Peoples Survey (IIPS), formerly Aboriginal Peoples Survey (APS) (Statistics Canada)	Indigenous identity question is included and inclusive of status and non-status First Nations people living off reserve, Métis people, and Inuit (Statistics Canada, 2022b); however, First Nations living on reserve and certain First Nations communities in the Yukon and Northwest Territories are excluded. No way to ascertain urban vs. rural/remote residence.
Aboriginal Children's Survey (ACS) (Statistics Canada)	Indigenous identity question was included and inclusive of status and non-status First Nations children living off reserve, Inuit, and Métis children, but First Nations children living on-reserve are excluded (Statistics Canada, 2007a). Separate surveys were conducted for all Indigenous children living in the territories (Statistics Canada, 2006a) and for James Bay Cree children in Quebec (Statistics Canada, 2006b). No way to ascertain urban, rural, or remote residence.

reasons, including mistrust, low literacy levels, and incomplete enumeration on First Nations reserves,<sup>8</sup> as well as by an unwillingness to share Indigenous identity and/or ancestry information (Smylie & Firestone, 2015). In 2011, identity and ancestry questions were shifted from the mandatory long form Census to a voluntary national household survey. As a result, the Indigenous participation rate was substantially lower, resulting in the suppression of health data

for areas where the Indigenous identity population was less than 250 people, which included almost all census subdivisions, some census divisions, and some census metropolitan areas (Smylie & Firestone, 2015). Recognizing the limitations of a voluntary census of population for small communities and for making comparisons over time, the federal government reinstated the mandatory survey in 2016 (Proudfoot, 2016).

Statistics Canada has conducted several population surveys that aim to address information gaps for Indigenous populations (Table 1). The Aboriginal Peoples Survey (APS), now the Indigenous Peoples Survey (IPS), has been delivered nationally to Indigenous Peoples every 5 to 10 years, while the Aboriginal Children's Survey (ACS) was developed and administered to parents and guardians only once, in 2006-2007. Over time, the development and implementation

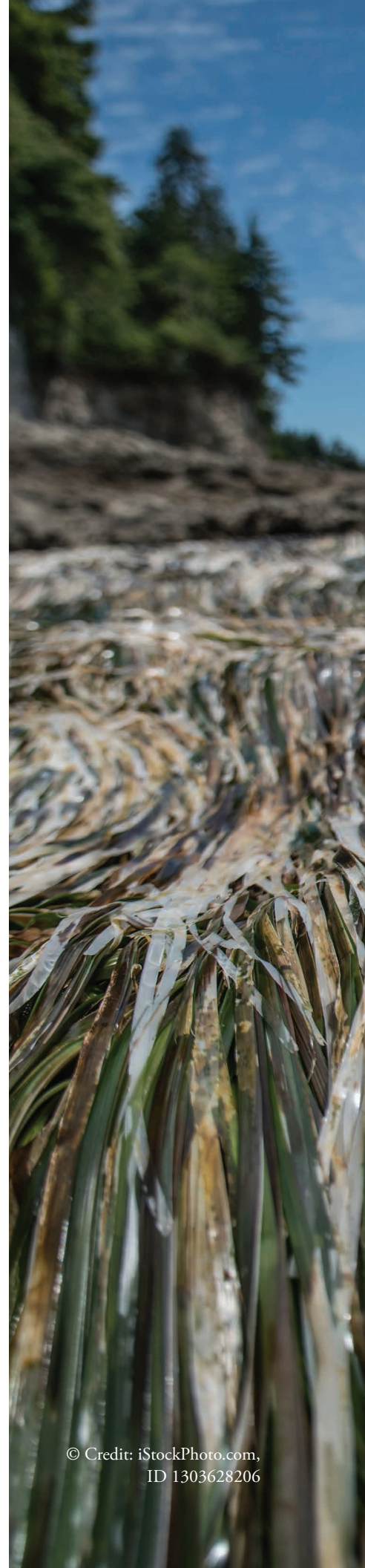
<sup>8</sup> Enumeration refers to the process of establishing eligible voters within a defined boundary. On some reserves, enumeration may be interrupted before the total number of voters has been accurately established.



of these surveys have involved increasing partnership with national Indigenous organizations (Smylie & Firestone, 2015). Despite specifically targeting Indigenous populations, both of these surveys have excluded on-reserve First Nations people and drew on the Census framework, resulting in a significant under-sampling of urban Indigenous people who were homeless, highly mobile, had lower levels of educational attainment, or did not want to participate (Smylie & Firestone, 2015).

The Public Health Agency of Canada (PHAC) maintains data surveillance systems for nationally notifiable diseases. These are infectious diseases that the federal, provincial, and territorial governments have identified collectively as priorities for monitoring and control (PHAC, 2023). Data are submitted by provinces and territories on a voluntary basis to inform the reporting of national disease counts and rates. The collection of Indigenous identity information is thus dependent on whether the province or territory includes an Indigenous identifier in their data collection processes. While Indigenous identifiers may be missing from Canada's Notifiable Disease Surveillance System (CNDSS), there may be the potential to collect specific data for registered First Nations people by linking the data set to provincial and territorial data that provides this information (Anderson et al., 2006).

Health Canada's role in maintaining health statistics is limited; however, Indigenous Services Canada's First Nations and Inuit Health Branch (FNIHB) collects community-based information on immunization programs and communicable diseases, as well as data on health services utilization. Much of this data is project or program specific and relates to program accountability requirements, which may not be very useful for community planning. FNIHB also occasionally publishes statistics on some health and socio-economic indicators (Anderson et al., 2006), including indicators of community well-being (Indigenous Services Canada, 2023). However, data from FNIHB have extensive limitations, such as primarily covering status First Nations people on reserve, with variable coverage for off-reserve First Nations people, Inuit-specific data, and no Métis-specific data (Anderson et al., 2006). FNIHB also has incomplete reporting on some indicators across regions. The former Ministry of Indigenous and Northern Affairs Canada also collected some indicators on status First Nations people and Inuit, though again, there are concerns with the quality of these data (Anderson et al., 2006).



### Other national level data collection entities

Other organizations collect Indigenous health data at the national level but operate outside of federal government ministries, departments, or agencies. Funded by contributions from Health Canada and provincial and territorial governments, the Canadian Institute for Health Information (CIHI) has multiple databases on determinants of health, health status, health system performance, and characteristics of community and health systems, with data arranged by geographic regions (Anderson et al., 2006). In the past, Indigenous identifiers were not necessarily used; however, the CIHI has committed to adopting a distinctions-based approach to data collection on Indigenous populations. Developed with engagement from Indigenous researchers and organizations, in 2022 the CIHI released pan-Canadian minimum standards

for collecting race-based and Indigenous identity data in health systems, as well as guidelines to direct the use of the data (CIHI, 2022). Adoption of these standards by individual health systems, however, is voluntary.

As a First Nations-led, designed, and governed organization, the First Nations Information Governance Centre (FNIGC) was created to address data gaps on the health of First Nations living on reserve across Canada. To date, they have administered three iterations of the First Nations Regional Health Survey (FNRHS). The survey measures health differently than Statistics Canada and other federal government surveys, making cross-comparisons difficult. They have also administered several unique surveys to assess early childhood, education, and employment. Further information about the FNIGC can be found in the next section.

### Provincial/territorial data collection

Other primary data sources are administered at the provincial/territorial level. These include health care utilization datasets, physician billing systems, hospital administrative databases, disease surveillance, and birth and death registration systems. Indigenous-specific health information systems, however, are generally undeveloped at the provincial/territorial level, in part due to a belief that Indigenous health surveillance is a federal responsibility (Smylie & Firestone, 2015). This belief results in inconsistencies in the collection and processing of Indigenous health data across provincial/territorial jurisdictions, with some provincial/territorial systems including Indigenous identifiers while others do not (Pollock et al., 2018). For example, ethnic identifiers are inconsistently collected in birth and death registries across



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provincial/territorial jurisdictions, and their use is very limited in disease surveillance (Coleman et al., 2016).

Even when ethnicity is reported, the lack of standard or universal methods for ethnic identification can result in misclassification (Chino et al., 2019; Hamm et al., 2021), making it difficult to measure changes in health status at the population level (Pollock et al., 2018). Some provincial/territorial jurisdictions use a self-reporting method to identify Indigenous populations, while others verify First Nations status or use other methods of identifying Indigenous populations (Hamm et al., 2021; Pollock et al., 2018; Smylie & Firestone, 2015). For example, Nunavut identifies individuals as Inuit by referring to a digit on Inuit health care cards, while British Columbia links vital statistics with health insurance and other registries with Indigenous status identifiers, including, for example, the ‘Indian’<sup>9</sup> Register or the Non-Insured Health Benefits (NIHB) list. However, the linkage of vital statistics with the ‘Indian’ Register or the NIHB list excludes individuals who are not

registered as ‘Indian’, including non-status First Nations people, Métis people, and some Inuit who are not covered in the NIHB program, as well as individuals whose NIHB programs are administered by an Indigenous organization rather than by the FNIHB<sup>10</sup> (Coleman et al., 2016; Pollock et al., 2018). As a result, these data sources exclude significant segments of Indigenous populations, including urban Indigenous people, who represent more than half of the overall Indigenous population in Canada (National Association of Friendship Centres, 2021).

When an Indigenous identifier is absent in data, geocoding by density of Indigenous population may also be used to identify Indigenous identity. However, this approach only works when the majority of a population within an area is Indigenous. While this method offers some utility for areas comprised primarily of First Nations reserves or in the Arctic, the method is not useful for southern Canada or the increasingly urbanized centres in the North (Pollock et al., 2018). It is also not very useful for distinction-based data, as it cannot distinguish between First


Nations, Inuit, or Métis when any combination of these populations lives within a defined area.

While Indigenous public health surveillance systems remain underdeveloped at the provincial and territorial level, some Indigenous-specific systems have been created in partnership with provincial and territorial governments. These include, for example, the First Nations Health Authority’s Panorama Public Health Surveillance System (FNHA, 2024), the Métis Nation BC’s Métis Public Health Surveillance Program in British Columbia (Indigenous Health, 2024), and the Manitoba First Nations controlled COVID-19 dashboard (Clark et al., 2021), among others. These systems operate on principles of Indigenous data sovereignty and governance (discussed in further detail in the following section).



<sup>9</sup> The term “Indian” is used here as a replacement for the term “First Nations”, as this is the legal term used by the Government of Canada to define who is an “Indian”, as articulated in the *Indian Act*. However, it is important to note that the term is one that many Indigenous people are uncomfortable using to describe themselves (Wilson, 2018) and it is associated with negative and racist connotations.

<sup>10</sup> The First Nations Health Authority in British Columbia is an example of an Indigenous organization that has assumed responsibility over the administration of the NIHB program.



*The lack of a standardized and comprehensive approach to Indigenous identification in federal and provincial/territorial health data results in an underestimation of Indigenous populations. This underestimation masks inequity, impedes health status monitoring, and is a significant barrier in the development of appropriate health policies, programs, and services in Indigenous communities (Pollock et al., 2018).*

### **A call for consistent and routine collection of Indigenous Identity**

The lack of a standardized and comprehensive approach to Indigenous identification in federal and provincial/territorial health data results in an underestimation of Indigenous populations. This underestimation masks inequity, impedes health status monitoring, and is a significant barrier in the development of appropriate health policies, programs, and services in Indigenous communities (Pollock et al., 2018). It is also a barrier in responding to the Truth and Reconciliation Commission of Canada's (2015) Call to Action #19, which "calls upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends." Consistent and routine collection

of race, ethnicity, and Indigenous identity data at the point of service can generate evidence that provides clarity around health and health care statistics for Indigenous Peoples, show where racism and discrimination are occurring within the healthcare system, and be a tool for holding healthcare staff at all levels accountable for their behaviours and attitudes towards Indigenous people (Fowler-Woods, 2023). Efforts are underway to establish mechanisms for ensuring the consistent, systematic, and standardized collection of race, ethnicity, and Indigenous identity data in health care settings, with the federal government identifying this as a priority in its 2023-2026 Data Strategy for the Federal Public Service (Government of Canada, 2024).

To achieve consistent application of Indigenous identifiers across Canada, federal, provincial, and territorial governments must work collaboratively with

First Nations, Inuit, and Métis peoples and organizations to collect appropriate and accurate statistics (Coleman et al., 2016; Fowler-Woods, 2023). Being able to define one's own identity, both individually and collectively, is a central part of self-determination and should be considered the gold standard for Indigenous data collection at federal, provincial, and territorial levels (Coleman et al., 2016; Smylie & Firestone, 2015). Further, efforts to implement a systematic and mandatory policy regarding race, ethnicity, and Indigenous identity data collection as part of healthcare service delivery will require the involvement of First Nations, Inuit, and Métis people in the development of a communication strategy. This strategy can be used to enhance understanding among Indigenous people about the need for systemic change in data collection to dismantle racism within the healthcare system (Fowler-Woods, 2023).





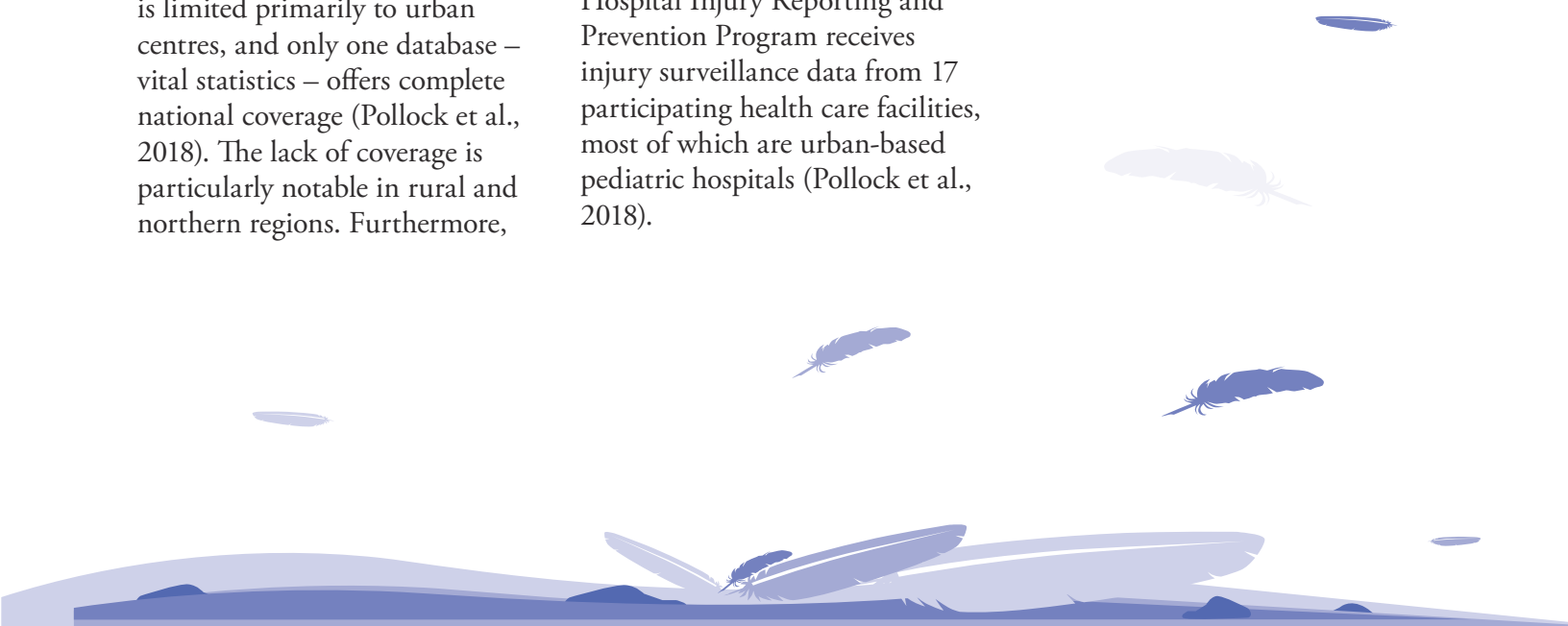
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## Geographic coverage

Geographic coverage is a concern for national public health surveillance systems as they do not capture data from all regions, leaving geographic gaps in some datasets (Pollock et al., 2018). For example, of five databases used in PHAC's suicide surveillance indicator framework, three databases exclude one or more province or territory, one database is limited primarily to urban centres, and only one database – vital statistics – offers complete national coverage (Pollock et al., 2018). The lack of coverage is particularly notable in rural and northern regions. Furthermore,

the National Ambulatory Care Reporting System covers only 64% of emergency departments across Canada, with five regions having no coverage (Quebec, New Brunswick, Newfoundland & Labrador, Nunavut, and the Northwest Territories), much of the north excluded, and only three regions having complete coverage (Alberta, Ontario, and the Yukon) (Pollock et al., 2018). Finally, the Canadian Hospital Injury Reporting and Prevention Program receives injury surveillance data from 17 participating health care facilities, most of which are urban-based pediatric hospitals (Pollock et al., 2018).

Geographic data coverage may also be challenged by the lack of health care infrastructure in some Indigenous communities. When individuals receive care outside of their community, their associated health data may not be available to inform evidence-based health policies and programs in their home communities (Smylie & Firestone, 2015).







*Since accurate baseline data are important for establishing priorities, informing policies, and monitoring trends over time, undercounting can have a significant impact on the funding of initiatives and prioritization of policies, programs, and services*

(Sarfati et al., 2018).

## Data quality concerns and resulting biases and challenges

Gaps in population and geographic coverage often result in a lack of accurate baseline data that is biased towards undercounting (Smylie & Anderson, 2006). Since accurate baseline data are important for establishing priorities, informing policies, and monitoring trends over time, undercounting can have a significant impact on the funding of initiatives and prioritization of policies, programs, and services (Sarfati et al., 2018).

Data quality concerns exist across federal, provincial, and territorial government data sets due to the small relative size of Indigenous populations and their dispersion (Chino et al., 2019; Smylie & Firestone, 2015). For example, at the national level, low response rates and small population sizes in the national Census and federal government surveys can result in the suppression of data for census subdivisions that have less than 25,000 people, which constitute almost one quarter of all census subdivisions in Canada (Smylie & Firestone, 2015). As a result, reporting may only be allowable at the provincial or territorial levels or for First Nations, Inuit, and Métis populations across large jurisdictions (Anderson et al., 2006). This



is particularly problematic in provinces and territories that have low population numbers but numerous small Indigenous communities.

Surveys often use a convenience or non-representative sampling framework, which is not suitable for specific Indigenous subpopulations. This can lead to Indigenous non-response bias, resulting in incorrect estimates of Indigenous health measures (Smylie & Firestone, 2015). Further, the greater the proportion of Indigenous populations missing from data sets, the greater the difference between those missing and those recorded as Indigenous, which increases the potential for biased estimates of disease amongst Indigenous Peoples. This “numerator-denominator bias problem” is amplified when combined with incomplete enumeration of Indigenous Peoples in Census data (Smylie & Firestone, 2015). For example, incorrect or missing data on Indigenous identity collected in death registries and disease counts (numerator) when combined with incomplete enumeration of Indigenous Peoples in the Census (denominator) can result in a substantial under- or over-estimation of Indigenous disease and death cases relative to Census data (Sarfati et al., 2022). While data linkage can improve the quality of the numerator data, in practice linked data is limited

largely to individuals who are registered as First Nations and excludes non-status First Nations people, Métis people, and Inuit.

As noted earlier, Indigenous people may choose not to participate in surveys for a variety of reasons. This is problematic because people who chose to participate in surveys are often socio-economically different from those who choose not to, which can lead to considerable non-response bias. Smylie and Firestone’s (2015) *Our Health Counts* urban Aboriginal health study aimed to address non-response bias by engaging effectively with populations often missed by the Census. Researchers utilized respondent driven sampling to generate a representative sample. This method is similar to snowball sampling but involves recruiting a small number of initial respondents from the target population, then providing them with incentives to recruit additional respondents from their network of friends, creating long referral chains. This method has been found to be effective for reaching hard-to-reach populations in the *Our Health Counts* study (Smylie & Firestone, 2015), as well as in other studies (Schonlau & Liebau, 2012).

Many Indigenous people represent small populations living in northern and rural communities. When a “rare”

health event (e.g. suicide) is experienced, it may be difficult to determine whether a change in the absolute number of cases is attributable to an intervention or to detect statistically significant changes or trends (Pollock et al., 2018; Yiannakoulis et al., 2009). What’s more, when population sizes are small, an error in misclassification can become magnified, leading to significant policy and practice implications (Smylie & Firestone, 2015).

There are also biases associated with using mortality data to estimate survival rates, based on the assumption that if a person is not on the mortality registry, that person must have survived (Sarfati et al., 2022). For Indigenous Peoples, for whom the quality of health data is poorer, this assumption can result in a more pronounced over-estimation of survival.



## Appropriateness of existing data sources for Indigenous communities

While current national, provincial, and territorial datasets may be useful for measuring health disparities between Indigenous and non-Indigenous people at larger scales, they are not very useful or appropriate for supporting local and small regional health service planning and delivery (Smylie & Firestone, 2015). Oftentimes, the quality of the existing data is poor and not comparable across jurisdictions, little information is returned to communities, and how the data are reported reflects the needs of funding organizations rather than of communities (Anderson et al., 2006). These datasets may not be easily accessed by Indigenous communities and there may be lengthy delays between event occurrence and data release in administrative data sources that can make it difficult for communities to identify and be responsive to trends (Pollock et al., 2018)

Because existing national, provincial, and territorial datasets are intended to meet goals at a broader level, not local goals, they tend to cover too large a jurisdiction and tend to rely on pan-Indigenous approaches that ignore the diversity of Indigenous Peoples

(Anderson et al., 2006; Lasry et al., 2016; Marsden et al., 2020; Smylie & Anderson, 2006; Smylie & Firestone, 2015). For example, Lasry and colleagues (2016) examined and compared incidence and determinants of traumatic brain injury across several distinct First Nations, Inuit, and non-Indigenous communities in Quebec and found these communities differed significantly in terms of incidence of hospital admission rates and primary causes of injury. They argued that these differences would be obscured in larger jurisdictional datasets. Likewise, Bell and colleagues (2011) measured injury risk factors among on-reserve First Nation communities in British Columbia and found that current provincial measurement approaches were too broad and over-generalized the burden of injury in these communities, with potentially stigmatizing impacts. This made the data not very useful for informing community-based injury prevention interventions. Further, some provinces and territories prevent data sharing on more granular regional locations, ethnicity, and Indigenous status by legislation or policy (McGill et al., 2023). These findings highlight the problematic nature of large jurisdiction surveillance data for community-level decision-making and program development.

More community-based surveillance is needed to enable

researchers to identify why some communities have more severe health outcomes than others and to avoid potentially “stigmatizing effects of current surveillance practices” (Bell et al., 2011, p. 394). Each Indigenous community has its own unique public health priorities and is likely to have different health information needs from those of regional or national organizations. Yet, the lack of available human and technical resources in many Indigenous communities poses logistical challenges for having a fully independent public health information system in each community (O’Neil & Blanchard, 2001). Further, the disparate data sources that are currently dispersed in siloed programs and jurisdictions across Canada need to be consolidated to coordinate data around nations and citizens, introduce efficiencies, and improve community access to the data (Bruhn, 2014).

Data challenges are particularly notable in northern and remote regions. Data are not consistently available and there are gaps in indicator availability, particularly on health system performance indicators, which are based on regions of residence and do not account for patients having to travel outside their communities to access health services (Young et al., 2019). Indigenous-operated health authorities maintain their own health information systems for the purposes of community education and planning, and to





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*... the lack of available human and technical resources in many Indigenous communities poses logistical challenges for having a fully independent public health information system in each community*

(O'Neil & Blanchard, 2001).

ensure accountability with respect to government funded programs (Anderson et al., 2006). They generally collect information on population demographics, non-biomedical determinants of health, immunizations, infectious diseases, health status, and how these indicators interact with determinants of health, and while other contextual indicators may be available, they often vary across regions in terms of availability, consistency, and quality.

Lack of access to technology can pose an additional barrier to accessing existing sources of high-quality data in northern and remote regions, which in turn can constrain efforts to prevent and manage disease

outbreaks (Wilson et al., 2017). Addressing these challenges requires creative and innovative thinking. For example, the lack of access to an immunization information system in Nunavut has been inhibiting case and contact management of vaccine-preventable diseases. Wilson and colleagues (2017) argue that mobile technology could facilitate the implementation of an immunization information system and address related challenges in Nunavut. They propose leveraging the technology utilized to develop Canada's national mobile immunization application, CANImmunize. However, to overcome the unique challenge of limited internet connectivity and cellular coverage in the

north, local health centres and public health authorities would have access to a suite of tools that would allow them to either directly input the vaccination data into the digital platform or store the data offline until it can be synchronized with the centralized database once internet connection has been re-established. They argue that this type of tool would improve the efficiency of vaccine delivery, facilitate timely immunization, improve outbreak response, and target resource allocation to at-risk individuals or underserved communities.

## Indicator frameworks

Population health indicators are used to benchmark and track the health of populations, in the development and monitoring of programs, and to advocate for funding, programs, and policies (Jeffery et al., 2006a). They measure health status; social, economic, and environmental conditions that influence health; and inequities in health outcomes (Jeffery et al., 2006a). The most common domains incorporated in existing population health frameworks include health status, social determinants of health, health behaviours, and health system performance, with the latter three domains having emerged primarily since 2000 (Chan et al., 2024). Most of

these frameworks use summary indicators of health, such as mortality and life expectancy, while a few also include indicators for select health conditions. More recently, psychological and mental health risk factors and/or outcomes have emerged as important indicators of health (Chan et al., 2024). The following sections review western-based indicator frameworks, Indigenous perspectives of health and well-being to inform these frameworks, the appropriateness of using Western-based indicator frameworks in Indigenous contexts, gaps in indicators used to measure Indigenous health, and Indigenous participation in the development of indicator frameworks.

## Western-based indicator frameworks

Many existing Western-based indicator frameworks do not adequately reflect Indigenous perspectives of health and well-being, which can lead to irrelevant data that are not well suited for tracking of health outcomes for Indigenous Peoples (Fowler-Woods, 2023; Roy et al., 2024; Saunders et al., 2023; Tsuji et al., 2023). National, provincial, and territorial models of public health surveillance are often based on a biomedical model, which views health from the perspective of the individual and focuses on physical health only (Smylie & Anderson, 2006; Smylie et al., 2006). As a result, most of the universally recognized indicators used to assess health are deficit-based indicators related to disease prevalence, morbidity, and mortality (Anderson & Smylie, 2009; Smylie & Firestone, 2015). These types of indicators do not capture cultural, spiritual, and interconnected aspects of Indigenous health (Price & Pride, 2023; Stelkia et al., 2023). Within this biomedical context, ‘race’ and ‘ethnic’ categories can be used to presume a link between epidemiological and genetic sciences based on the assumption that only genetic determinants of health influence health (Fowler-Woods, 2023). By ignoring the importance of socio-economic, cultural, and environmental determinants that influence Indigenous health, this can lead to genetic





discrimination, stereotyping, a constrained understanding of health and disease, and a failure to take responsibility for ongoing colonial impacts (Poudrier, 2003; Stelkia et al., 2023). As a result, solutions developed based on this type of science do not address the underlying causes of disease, and thus may not lead to effective solutions for eradicating disease within populations.

This focus of current public health surveillance on biological determinants rather than socio-economic, cultural, and environmental determinants can lead further to problematic deficit-based narratives when reporting health and disease outcomes of populations, including Indigenous communities. These narratives can have harmful outcomes for Indigenous populations, as they can influence how Indigenous people see themselves and are seen by others. Deficit-based narratives can blame Indigenous Peoples for the circumstances of their inequity, problematize Indigenous populations, fuel racist beliefs about Indigenous Peoples, and lead to internalized racism and a sense of failure and deficiency (Thurber et al., 2020). Negative perceptions of Indigenous ‘identity’ can then be used to support – unjustly – paternalistic and regulatory management of Indigenous health, while undermining Indigenous efforts to be self-determining (O’Neil et al., 1998; Poudrier, 2003; Walter et al., 2021).

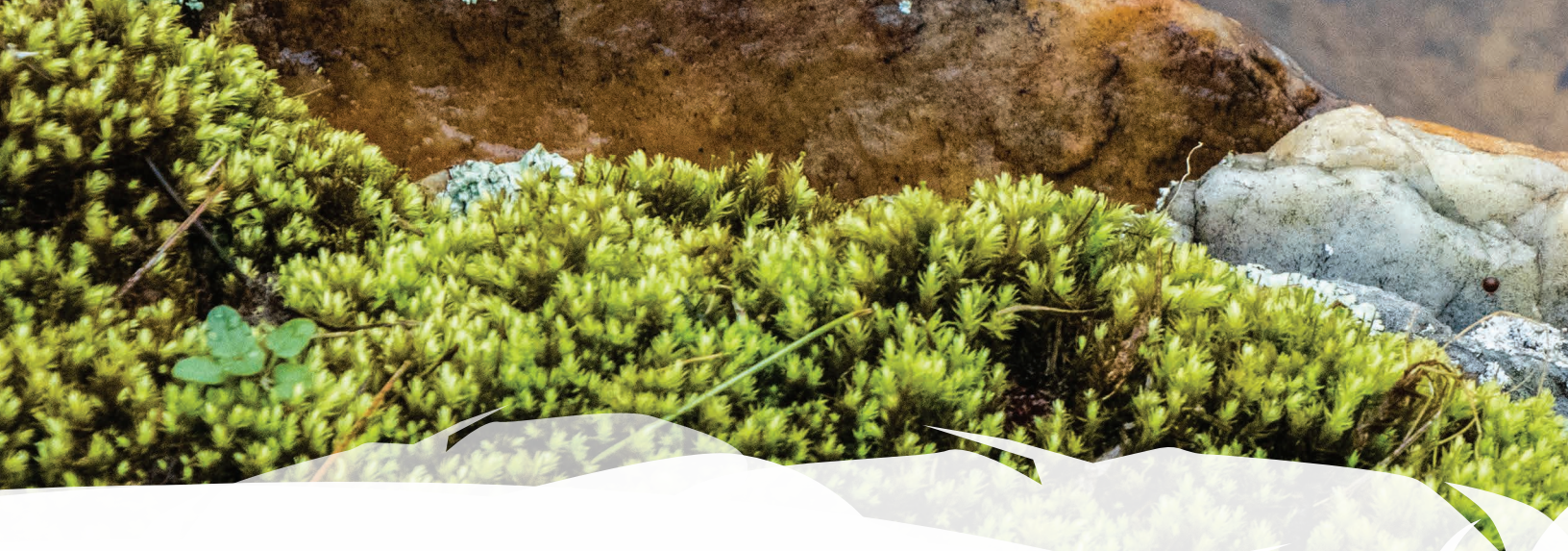
Researchers have highlighted some key limitations to using Western-based indicators in population health reporting for Indigenous populations. Stelkia et al. (2023) summarize these key limitations as a one-size-fits-all approach; a focus on the individual rather than the collective, on deficit-based indicators and unmodifiable risk factors, and on indigeneity as a risk factor; as well as a failure to reflect Indigenous perspectives of health and address the root causes of poor health. Jeffery and colleagues (2006a) also point to the failure of Western-based indicator frameworks to measure community health in terms of positive aspects or strengths. Cooke et al (2008) states that while existing quality of life tools can be adapted to Indigenous contexts, they can provide only a crude representation of well-being as they do not address important subjective or cultural aspects of quality of life, such as access to traditional lands and activities or preservation of Indigenous languages and knowledges.

In assessing the applicability and appropriateness of the Canadian Occupational Performance Measure for use with Indigenous Peoples, Price and Pride (2023) found that while some aspects of the measure had utility across cultures and communities, key aspects of the measure were rooted in Euro-Western epistemologies that fail to

translate across cultures. This included:

- the notion of categorizing and numerically ranking activities and performance;
- a focus on deficits, goals, and results;
- a Eurocentric biomedical approach that focuses on the body and physical health;
- methods of categorizing performance based on Euro-Western assumptions of what matters most;
- a focus on the individual seeking change rather than on the collective and community;
- exclusion of spirituality and human-earth connection components of Indigenous worldviews; and
- a lack of acknowledgement of the larger impact of colonialism on the health of Indigenous people.

There may also be further cultural challenges in using Western-based indicator frameworks and measurement tools, including language barriers, insulting and culturally inappropriate language, and a failure to capture the health issues of most importance to communities (Chan, H.M. et al., 2021).



## Indigenous perspectives of health and well-being

In contrast to Western biomedical conceptions of health, Indigenous models of health, while diverse,<sup>11</sup> are holistic and strive for balance in the physical, mental, emotional, and spiritual realms of life, within the context of relationships with family, the whole community, the surrounding natural environment, and Creator (Anderson et al., 2006; Joseph, 2020; Smylie & Anderson, 2006; Tsuiji et al., 2023). Several studies have attempted to define key attributes of health and well-being for select Indigenous populations. As shown in Table 2, these studies reinforce the importance of balancing spiritual, emotional, physical, and mental/intellectual aspects of health for Indigenous populations and incorporate strengths-based and culture-infused factors,

many of which are overlooked in mainstream population health indicator frameworks.

## Applicability and validity of Western-based indicator frameworks in Indigenous contexts

The fundamental differences between Indigenous and Western conceptions of health call into question the appropriateness and value of using health indicator frameworks and measurement tools that are not specific to Indigenous contexts or have not been validated for use with Indigenous populations (Angell et al., 2016; Auer & Andersson, 2001; Barnabe et al., 2018; Chan, H.M. et al., 2021; Lix et al., 2009; Williamson et al., 2013). Several studies have assessed the applicability and validity of health measurement instruments for specific Indigenous populations.

Some have shown evidence of validity (see for example Gupchup et al., 2001). Others acknowledge that these instruments have limited validity, reliability, or applicability for use with Indigenous populations (Barnabe et al., 2018; Lix et al., 2009; Price & Pride, 2023; Saunders et al., 2023). Still others have either not tested or reported on these criteria (Angell et al., 2016; Roy et al., 2024; Williamson et al., 2013). As a result, Western-based indicator frameworks may not be suitable for use with Indigenous populations. These populations may desire their own public health surveillance models that are holistic and culturally appropriate to improve the relevance and usefulness of health-assessment data sets for community-level planning and evaluation (Smylie & Anderson, 2006).

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<sup>11</sup> For some First Nations people, this view of health is encompassed in the Medicine Wheel (Joseph, 2020), while for Inuit, this holistic understanding is referred to as Inuuqatigiitarniq “being respectful of all people” (Anderson et al., 2006). Métis people have their own conceptualizations of health and well-being that are similarly focused on determinants of health and well-being and grounded in culture (Atkinson et al., 2023).



TABLE 2: ATTRIBUTES OF INDIGENOUS HEALTH AND WELL-BEING

Author	Domains/dimensions of health and well-being
Anderson et al. (2022). Aspects of wellbeing for Indigenous youth in CANZUS countries: A systematic review	<ul style="list-style-type: none"> <li>• Safe and stable living environment</li> <li>• Connection to land</li> <li>• Relationships with others</li> <li>• Sense of belonging</li> <li>• Culture</li> <li>• Spirituality</li> <li>• Knowledge about opportunities</li> </ul>
Angell et al. (2016). The health-related quality of life of Indigenous populations: A global systematic review	<ul style="list-style-type: none"> <li>• Culture</li> <li>• Diet</li> <li>• Land use</li> </ul>
Bartlett (2004). Conceptions and dimensions of health and well-being for Métis women in Manitoba	<ul style="list-style-type: none"> <li>• Practice of spirituality</li> <li>• Feelings of emotions</li> <li>• Nutrition/healthy diet</li> <li>• Physical activity</li> <li>• Caring for the body through rest and avoidance of stress</li> <li>• Keeping one's mind active</li> <li>• Social determinants (i.e. education, employment)</li> <li>• Level of self-understanding and acceptance</li> <li>• Safe environments</li> <li>• Responsibility/caring for others</li> </ul>

TABLE 2: ATTRIBUTES OF INDIGENOUS HEALTH AND WELL-BEING (CONTINUED)

Author	Domains/dimensions of health and well-being
Chan et al. (2024). Frameworks for measuring population health: A scoping review	<ul style="list-style-type: none"><li>• Indigenous population health frameworks have greater emphasis on social determinants of health and physical and social environments, including:<ul style="list-style-type: none"><li>- Politics</li><li>- National and global trends</li><li>- Indicators relevant for the community, such as family, kinship and community health</li></ul></li></ul>
Graham & Stamler (2013). The health-related quality of life of Indigenous populations: A global systematic review	<ul style="list-style-type: none"><li>• Regular exercise</li><li>• Nutrition</li><li>• Importance of traditional diet</li><li>• Vitamin use</li><li>• Living pain free</li><li>• Alcohol and substance use</li><li>• Smoking</li><li>• Having goals and healing from trauma</li><li>• Motivation and positive attitude</li><li>• Healthy relationships</li><li>• Dealing with stress</li><li>• Time for personal care</li><li>• Connections with family</li><li>• Feeling valued</li><li>• Spiritual growth</li><li>• Learning one's traditional language and culture</li><li>• Identity</li><li>• Financial stress</li><li>• Employment</li><li>• Access to health services</li><li>• Having basic needs met</li><li>• Environmental health</li><li>• Racism</li><li>• Politics and restrictions to self-determination</li></ul>



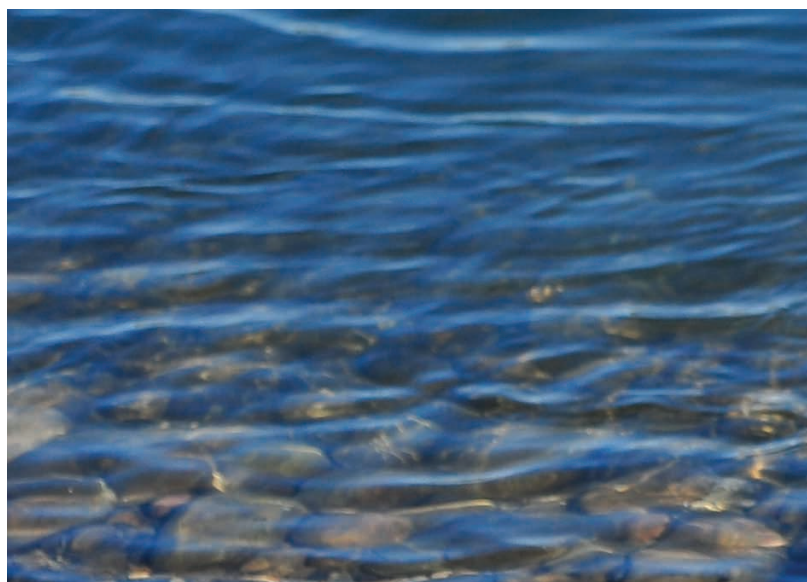


TABLE 2: ATTRIBUTES OF INDIGENOUS HEALTH AND WELL-BEING (CONTINUED)

Author	Domains/dimensions of health and well-being
Kant et al. (2013). Social, cultural, and land use determinants of the health and well-being of Aboriginal peoples of Canada: A path analysis	<ul style="list-style-type: none"> <li>• Prevalence of mental and psychological problems</li> <li>• Quality of health services</li> <li>• Access to cultural sites</li> <li>• Traditional diets</li> <li>• Impact of government regulations on social and cultural life</li> <li>• Sense of belonging to local community</li> <li>• Social ties</li> <li>• Freedom to participate in spiritual activities</li> </ul>
Tsuji et al. (2023). What is wellbeing, and what is important for wellbeing? Indigenous voices from across Canada	<ul style="list-style-type: none"> <li>• Physical, economic, political, social, and cultural domains</li> <li>• Well-being conceptualized from a collectivist perspective</li> <li>• Land and water, sustainability and inherent obligations</li> <li>• Factors identified as important for cultural well-being include:</li> <li>• Being on the land and Indigenous languages and knowledge systems</li> <li>• Sustainable development</li> <li>• Meaningful involvement in decision-making, with free, prior, and informed consent</li> </ul>
Willing et al. (2020). Indigenous voices on measuring and valuing health states	<ul style="list-style-type: none"> <li>• Health of individual within the collective and their environment</li> <li>• Spiritual health</li> <li>• Physical health</li> <li>• Community support</li> <li>• Economic impacts of ill health</li> <li>• Social impacts of ill health</li> <li>• Relationships</li> </ul>

*Indigenous people need culturally appropriate indicators that encompass “Indigenous ways of knowing and being and the impact of colonisations that include(s) disruptions to family, culture and spirituality, and relationships with land which are not currently captured by epidemiological statistics”*

(Mashford-Pringle et al., 2019, p. 139).



## Indicator gaps

Indigenous groups have spoken about the importance of having both comparable and culturally relevant population health data for their communities (Jeffery et al., 2006a). A core set of comparable indicators is required to enable comparisons across regions, while culturally relevant population health indicators are needed to ensure that information gathered is relevant, appropriate, and meaningful to Indigenous communities, enabling them to create self-determined strategies to foster health and well-being based on community-identified priorities (James, 2023; Jeffery et al., 2006a). The literature highlights major gaps in indicators for measuring the health of Indigenous populations in Canada, including both universally recognized public health indicators as well as

Indigenous-specific and culturally relevant indicators (Roy et al., 2024; Smylie & Anderson, 2006). In particular, there are major gaps in indicators that can measure health status, health system performance, and health services utilization.

Indigenous people need culturally appropriate indicators that encompass “Indigenous ways of knowing and being and the impact of colonisations that include(s) disruptions to family, culture and spirituality, and relationships with land which are not currently captured by epidemiological statistics” (Mashford-Pringle et al., 2019, p. 139). Public health surveillance needs to adopt strengths-based approaches that shift the focus from a sole examination of biological indicators of disease and risk factors, which can promote harmful or unproductive

narratives, to a more holistic examination of indicators of individual and community well-being, including community assets, strengths, and protective factors (Bryant et al., 2021; Lee et al., n.d.; Saunders et al., 2023). Thurber et al. (2020) argue that a positive outcomes approach that explores health resources, what works, and what can be built upon is needed to further the health of Indigenous populations. Such indicators are rarely built into existing mainstream health indicator frameworks.

Social, environmental, and behavioural determinants of health indicators can provide context for health outcomes and enable Indigenous communities to adequately address health issues and improve health outcomes among their community members (Mashford-Pringle et al., 2019). They are also useful for federal,





*Since culturally safe care is determined by those who receive that care, First Nations, Inuit, and Métis peoples must be involved in helping to identify where the problems are so that quality improvement efforts can be targeted in these areas* (CIHI, 2021; Johnson & Sutherland, 2022).

provincial, territorial, and local policy makers to implement structural changes needed to decrease health disparities and improve patient care and patient-provider relationships (Graham & Stamler, 2013). While commonly included in health measurement processes, these types of indicators are less often adapted to local cultures and protective factors, such as cultural identity, extended family, sense of community, social supports, community networks, and organizational involvement (Wark et al., 2021). There is also a lack of indicators to capture the historical contexts that underlie poorer health outcomes for Indigenous Peoples, such as intergenerational trauma, separation from traditional homelands, and forced and attempted assimilation, as well as Indigenous indicators that contribute to resilience and well-being, such as cultural

continuity, traditional medicines, and traditional healing practices (Mashford-Pringle et al., 2019). These types of contextual indicators are considered key aspects of health and well-being for Indigenous populations and are needed to assess health risks (Mashford-Pringle et al., 2019). Indigenous populations are also not captured well in health system performance data. In addition to the limited opportunities to self-identify as First Nations, Inuit, or Métis when accessing care through provincial health systems, there is also a lack of data measuring Indigenous health services (Anderson et al., 2006; Chino et al., 2019; Minore et al., 2009) and measurable indicators on health system attributes like leadership, governance, innovation, and efficient allocation of resources (Young et al., 2019). Indicators of health system performance

often focus on addressing gaps and deficiencies rather than on measuring progress towards identified goals (Bruhn, 2014). Further, there is widespread recognition of the importance of providing culturally safe, anti-racist, and trauma-informed care to improve health system performance for Indigenous people, yet measures have been minimally developed to evaluate cultural safety actions and interventions (Johnson & Sutherland, 2022). Since culturally safe care is determined by those who receive that care, First Nations, Inuit, and Métis peoples must be involved in helping to identify where the problems are so that quality improvement efforts can be targeted in these areas (CIHI, 2021; Johnson & Sutherland, 2022).



To be useful for Indigenous communities, health measurement indicator frameworks need to focus on prevention, service utilization, and outcome indicators that are relevant to Indigenous communities (Mashford-Pringle et al., 2019). Indicators are needed in relation to the “availability, accessibility, effectiveness and cultural appropriateness of health services” to identify areas in need of funding and supports and improve health outcomes (Mashford-Pringle et al., 2019, pp. 139-140), as well as hold health professionals accountable for providing culturally safe health services (Mashford-Pringle et al., 2023). Performance frameworks need to be developed and uniquely adapted to northern conditions as a pathway to improving health system performance in these regions, which requires inclusion of Indigenous values into indicators and engagement with Indigenous leadership, communities, and patient representatives (Young et al., 2019). For example, culturally appropriate services may incorporate local cultures, languages, and ceremonies. Measuring the performance of these types of services is often better done using qualitative evaluation processes because they better reflect the impact of interventions on participant health and tend to capture process-related and empowerment domains that are generally overlooked in quantitative processes (Chando et al., 2021).

While the federal government has expressed its commitment to addressing the Truth and Reconciliation Commission (TRC) of Canada’s (2015) Call to Action #19 to establish measurable goals to identify and close gaps in most health outcomes, progress on this front has been limited to date (Yellowhead Institute, 2023). Federal, provincial, and territorial officials have been working towards the development of common standards and policies related to data; however, the development of a broader suite of indicators in relation to Indigenous health has not yet occurred (Health Canada, 2023). This deficiency is particularly notable for population-based health assessments for urban Indigenous populations (Smylie et al., 2018).

### Engaging Indigenous people in indicator development

In moving towards a more holistic and culturally safe health care model, Indigenous people and their communities must be involved as equal participants in indicator identification and data collection processes (James, 2023; Jeffery et al., 2006a; Stelkia et al., 2023). However, utilizing participatory processes to develop health indicator frameworks and instruments for measuring aspects of Indigenous health are not without challenges. The literature highlights some lessons learned in utilizing participatory processes. Ayotte et al. (2024) notes



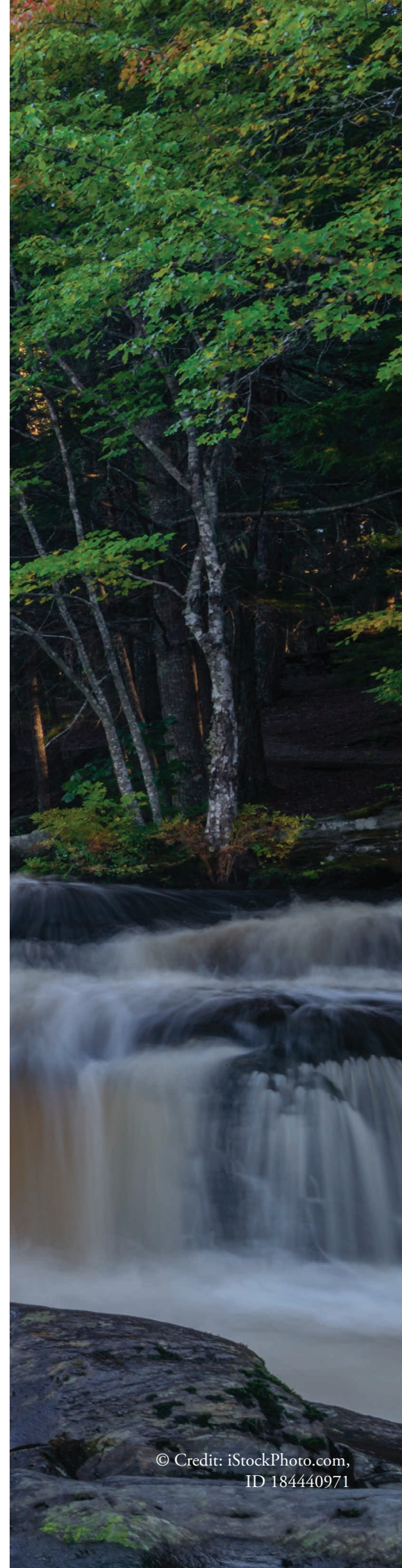
that participatory approaches take a great deal of time and commitment to reconcile differing agendas, build trustworthy and mutually beneficial partnerships, and achieve consensus on a set of indicators that reflect both community conceptions of health and public health surveillance needs for “methodologically robust, temporally comparable, and scientifically rigorous indicators” (Ayotte et al., 2024, p. S16). In the context of adapting the Edinburgh Postnatal Depression Scale (EPDS) to be culturally suitable for use with Indigenous women, A.W. Chan, et al. (2021) highlight the importance of patience and providing adequate time and space to ensure that Indigenous women’s perspectives are incorporated into the wording of questions, the emergent layout of themes, and the scale’s implementation. They recommend using strategies that enhance community engagement and participation, such as the yarning<sup>12</sup> technique.

Some researchers have focused on modifying existing health measurement instruments for suitability with Indigenous populations, with mixed results (see for example, A.W. Chan et al., 2021; Gupchup et al., 2001). Others have built an Indigenous-specific component and integrated

it with existing frameworks. For example, Lauson et al. (2011) describes the development of the Nunavut Health (Our Children) Information System initiative – a comprehensive maternal-child health surveillance system developed through stakeholder engagement. The system involved developing a custom Nunavut-made component and integrating it with two already well-established, non-Indigenous systems. This new system encompasses Nunavut’s need for maternal-child health information across a continuum from 16 weeks gestation until pre-school, and incorporates both comparable and Nunavut-specific indicators, including nutrition, food and domestic security, exposures in pregnancy, birth defects, development, chronic childhood diseases, and paternal information. In addition to considering issues of privacy protection, development of the system also considered the potential use of data for health promotion purposes, ease of use, cost efficiency, technology support, and adaptability to other community and public health systems. The initiative is governed by a subcommittee, with broad representation from all regions across Nunavut, who oversee activities of the system, including vetting potential research questions.

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<sup>12</sup> Yarning is a conversational data collection process that privileges Indigenous knowledge systems and involves encouraging participants to share their stories from the position of their lived experience, using cultural protocols and practices relevant to the people involved (Kennedy et al., 2022). The researcher’s role is not to ask a pre-determined set of questions but to listen for cues related to the research topic.







## Indigenous-specific indicator frameworks

Several examples of Indigenous-specific frameworks exist at both national and provincial/territorial levels. The examples include tools for measuring specific health issues as well as comprehensive health assessments. All of these frameworks were developed through extensive stakeholder engagement and participatory processes and/or partnerships with Indigenous groups. Table 3 lists examples of such frameworks identified in the literature. The table demonstrates how these frameworks generally incorporate both Indigenous and Western knowledge systems, including health status indicators on issues of relevance for Indigenous populations and incorporation of strengths-based elements (i.e., culturally appropriate factors that promote resilience). They are also generally based on a holistic definition of wellness and encompass a broad array of social determinants indicators to help assess health risk. Some frameworks also include a focus on prevention, while the more comprehensive frameworks include indicators related to health system performance and cultural safety (see for example, FNHA & Office of the Provincial Health Officer [OPHO], 2020; Mashford-Pringle et al., 2019).



**TABLE 3: INDIGENOUS-LED AND/OR DESIGNED INDICATOR FRAMEWORKS**

Author	Indicators/domains
<p>Pike et al. (2014). Developing injury indicators for First Nations and Inuit children and youth in Canada: A modified Delphi approach</p>	<p>Four types of indicators – outcome, risk and protective factors, program, and policy – within the following areas:</p> <ul style="list-style-type: none"> <li>• Animal bites</li> <li>• Burns and falls</li> <li>• Community injury prevention, training, and response systems (3 indicators)</li> <li>• Drowning</li> <li>• Focus on indicators that can be acted upon through prevention initiatives</li> <li>• Hypothermia/frostbite</li> <li>• Mortality and hospitalization rates</li> <li>• Motorized vehicle collisions</li> <li>• Potential years of life lost due to injury among children and youth</li> <li>• Self-reported alcohol, solvent, and substance use</li> <li>• Suicide</li> <li>• Violent/inflicted injury</li> </ul>
<p>Auer &amp; Andersson (2001). Canadian Aboriginal communities: A framework for injury surveillance</p>	<ul style="list-style-type: none"> <li>• Core data elements to identify the person injured (demographic elements)</li> <li>• Injury outcomes (include receiving medical treatment, hospitalization, or death)</li> <li>• Location and circumstances associated with injury (including alcohol use and environmental factors such as poor road conditions)</li> <li>• Use of prevention measures (i.e. seatbelts, smoke detectors)</li> </ul>
<p>Fiedeldey-Van Dijk et al. (2017). Honoring Indigenous culture-as-intervention: Development and validity of the Native Wellness Assessment</p>	<ul style="list-style-type: none"> <li>• Connections to family and community</li> <li>• Contributions to community</li> <li>• Culture</li> <li>• Indigenous identity</li> <li>• Language use</li> <li>• Participation in cultural activities and ceremonies</li> <li>• Participation in cultural-based interventions</li> <li>• Physical activity through land-based activities</li> <li>• Relationship to the land</li> <li>• Spirituality</li> </ul>

TABLE 3: INDIGENOUS-LED AND/OR DESIGNED INDICATOR FRAMEWORKS (CONTINUED)

Author	Indicators/domains
James (2023). Measuring what matters: Exploring measures of Metis children’s social and emotional well-being	<p>30 constructs of Métis children’s health within the following domains:</p> <ul style="list-style-type: none"><li>• Childcare and school</li><li>• Community</li><li>• Culture</li><li>• Family and kinship</li><li>• Mind and emotions</li><li>• Parent/caregiver characteristics</li><li>• Physical body</li></ul>
Barbic et al. (2022). Rasch Measurement Theory’s contribution to the psychometric properties of a co-created measure of health and wellness for Indigenous children and youth	<ul style="list-style-type: none"><li>• Spirituality</li><li>• Emotions</li><li>• Physical health</li><li>• Mental health</li><li>• Contextual indicators</li><li>• Importance of culture</li><li>• Time with Elders</li><li>• Connection to land</li><li>• Learning Indigenous languages</li><li>• Traditional medicine</li></ul>





TABLE 3: INDIGENOUS-LED AND/OR DESIGNED INDICATOR FRAMEWORKS (CONTINUED)

Author	Indicators/domains
First Nations Health Authority & Office of the Provincial Health Officer (2021). First Nations population health and wellness agenda	<ul style="list-style-type: none"> <li>• Acceptable housing</li> <li>• Age-standardized mortality rate</li> <li>• Alcohol-attributable deaths</li> <li>• Avoidable hospitalizations</li> <li>• Children with healthy body mass index</li> <li>• Children with healthy teeth</li> <li>• Connection to land</li> <li>• Cultural safety and humility in receiving health services</li> <li>• Cultural wellness</li> <li>• Diabetes incidence</li> <li>• Education</li> <li>• First Nations health care providers</li> <li>• Food security</li> <li>• Infant mortality</li> <li>• Infants born at a healthy birth weight</li> <li>• Life expectancy at birth</li> <li>• Mental and emotional well-being</li> <li>• Physical activity</li> <li>• Self-determination</li> <li>• Serious injuries</li> <li>• Smoking rates of commercial tobacco</li> <li>• Youth/young adult death by suicide</li> </ul>
Mashford-Pringle et al. (2019). Rethinking health service measurement for Indigenous populations	<ul style="list-style-type: none"> <li>• Community self-determination and empowerment</li> <li>• Cultural safety training</li> <li>• Distribution of services relative to population and outcome indicators</li> <li>• Expenditures</li> <li>• Feedback mechanisms</li> <li>• General service needs</li> <li>• Human resources/workforce</li> <li>• Patient ethnicity</li> <li>• Patient preferences for care and holistic needs</li> <li>• Service availability and access</li> <li>• Service evaluation</li> <li>• Social determinants</li> <li>• Surveillance and monitoring systems</li> </ul>

TABLE 3: INDIGENOUS-LED AND/OR DESIGNED INDICATOR FRAMEWORKS (CONTINUED)

Author	Indicators/domains
Ayotte et al. (2024). The Qanuilirpitaa? 2017 Nunavik Health Survey: Design, methods, and lessons learned	<ul style="list-style-type: none"><li>• Dietary and lifestyle habits</li><li>• Food security</li><li>• Inuit culture adherence</li><li>• Physical health</li><li>• Sociocultural determinants of mental health and substance use</li><li>• Socioeconomic status</li></ul>
Chando et al. (2021). Outcomes reported in evaluations of programs designed to improve health in Indigenous people	<ul style="list-style-type: none"><li>• Access</li><li>• Attitude</li><li>• Behavioural</li><li>• Clinical</li><li>• Community</li><li>• Economic</li><li>• Empowerment</li><li>• Environmental</li><li>• Knowledge/awareness</li><li>• Process-related</li><li>• Quality of life</li><li>• Social</li><li>• Trust</li></ul>
Jeffery et al. (2006a). Engaging numbers: Developing health indicators that matter for First Nations and Inuit people; Jeffery et al. (2006b). Community health indicators toolkit	<p>Unique Inuit indicators include:</p> <ul style="list-style-type: none"><li>• Community caring</li><li>• Non-income measures</li><li>• Prosperity</li><li>• Resources in community generated by Inuit economic activities and distributed fairly</li><li>• Sustainable use of the land</li><li>• Viability of land, plants, and animals</li></ul> <p>First Nations community health indicators:</p> <ul style="list-style-type: none"><li>• Addiction issues</li><li>• Economic viability</li><li>• Environment</li><li>• Food security</li><li>• Health issues</li><li>• Healthy lifestyles</li><li>• Identity &amp; Culture</li><li>• Services and infrastructure</li></ul>



TABLE 3: INDIGENOUS-LED AND/OR DESIGNED INDICATOR FRAMEWORKS (CONTINUED)

Author	Indicators/domains
<p>Pauktuutit Inuit Women of Canada et al. (2012). Developing an Inuit-specific framework for culturally relevant health indicators incorporating gender-based analysis</p>	<ul style="list-style-type: none"> <li>• Disease rates, especially diabetes, cancers, and tuberculosis</li> <li>• Nutrition</li> <li>• Overcrowding</li> <li>• Socio-economic determinants, including income, education, and wage employment</li> </ul> <p>Inuit-specific cultural framework:</p> <ul style="list-style-type: none"> <li>• Country food availability, acquisition, and consumption</li> <li>• Elders' intergenerational knowledge transfer</li> <li>• Frequency of contact with Elders</li> <li>• Multigenerational proximity</li> <li>• Proficiency in Inuit language</li> </ul>
<p>Smylie et al. (2018). Our health counts: Population-based measures of urban Inuit health determinants, health status, and health care access; Firestone et al. (2014). Concept mapping: Application of a community-based methodology in three urban Aboriginal populations</p>	<p>Social determinants measures:</p> <ul style="list-style-type: none"> <li>• Age</li> <li>• Annual personal income</li> <li>• Education</li> <li>• Food insecurity</li> <li>• Gender</li> <li>• Mobility in past 5 years</li> <li>• Overcrowding</li> <li>• Residency status</li> <li>• Valid OHIP<sup>13</sup> number</li> <li>• Wage-earning job</li> </ul> <p>Health status measures:</p> <ul style="list-style-type: none"> <li>• Access to health care</li> <li>• Most common chronic diseases diagnosed by health care provider</li> </ul>

<sup>13</sup> Ontario Health Insurance Plan.

TABLE 3: INDIGENOUS-LED AND/OR DESIGNED INDICATOR FRAMEWORKS (CONTINUED)

Author	Indicators/domains
<p>PHAC (2014). Summary of key findings from the A-Track pilot survey (2011-2012); Tarasuk et al. (2014a). Key findings from a national enhanced HIV surveillance system: 2010-2012; Tarasuk et al. (2014b). A pilot behavioural and biological surveillance survey for HIV and other bloodborne infections among Aboriginal people in Regina, Saskatchewan</p>	<ul style="list-style-type: none"> <li>• Access to health services</li> <li>• Demographics</li> <li>• Drug use</li> <li>• HIV and hepatitis C testing/treatment history</li> <li>• HIV-related knowledge</li> <li>• Placement in foster care</li> <li>• Removal from families during childhood</li> <li>• Residential/boarding school</li> <li>• Sexual behaviour</li> <li>• Stability of housing</li> <li>• Testing for HIV, HCV, and syphilis antibodies</li> <li>• Time in a correctional facility</li> </ul>
<p>Moriarity et al. (2021). Health measures of Eeyouch (Cree) who are eligible to participate in the on-the-land Income Security Program in Eeyou Istchee (northern Quebec, Canada)</p>	<ul style="list-style-type: none"> <li>• Inflammatory markers</li> <li>• Mercury exposure</li> <li>• Physical health indicators related to obesity, diabetes, cardiovascular diseases</li> <li>• Self-reported weekly activity on the land</li> <li>• Traditional diet consumption</li> </ul>
<p>Anderson et al. (2006). First Nations, Métis, and Inuit health indicators in Canada; Duhaime &amp; Lévesque (2014). Aboriginal Peoples Survey, Canada (APS)</p>	<ul style="list-style-type: none"> <li>• Chronic health conditions</li> <li>• Disability</li> <li>• Education</li> <li>• Employment</li> <li>• Fertility</li> <li>• Health</li> <li>• Housing</li> <li>• Income</li> <li>• Indigenous identity</li> <li>• Language proficiency</li> <li>• Lifestyle</li> <li>• Marital status</li> <li>• Mobility</li> </ul>




TABLE 3: INDIGENOUS-LED AND/OR DESIGNED INDICATOR FRAMEWORKS (CONTINUED)

Author	Indicators/domains
Lee (n.d.). FNHA Wellness indicators	<ul style="list-style-type: none"><li>• Access to care</li><li>• Access to traditional medicine</li><li>• Balance (physical, emotional, mental, and spiritual health)</li><li>• Community strengths</li><li>• Connection to culture</li><li>• Guiding own wellness journey</li><li>• Knowledge of First Nation language</li><li>• Social determinants of health (neighbourhood &amp; environment, education, etc.)</li><li>• Social support</li><li>• Support from family, friends, &amp; community</li></ul>



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*...in the absence of Indigenous involvement in data collection, interpretation, and dissemination, health statistics often portray Indigenous health in stigmatizing and deficit-based narratives, which is detrimental to health and well-being*

(Pollock et al., 2018).



An aerial photograph showing a dense green forest on the left, a winding river in the center, and a sandy beach on the right. The river flows from the top left towards the bottom right. The forest is composed of many small, coniferous trees. The river is a dark blue-green color. The beach is a light tan color. The overall scene is a natural landscape.

# INDIGENOUS DATA SOVEREIGNTY AND GOVERNANCE

National health data systems do not routinely engage with Indigenous communities in data governance (Pollock et al., 2018). This is problematic for four reasons. First, there is an ethical imperative to be inclusive (Pollock et al., 2018). Excluding Indigenous people and communities in standard data collection practices reinforces an invisibility over time (Hendl & Roxanne, 2022). This can lead to a lack of testing and research in and with Indigenous communities and subpopulations, leaving too much about the specifics of health conditions unknown (Hendl & Roxanne, 2022). Second, in the absence of Indigenous involvement in data collection, interpretation, and dissemination, health statistics often portray Indigenous health in stigmatizing and deficit-based narratives, which is detrimental to health and well-being (Pollock et al., 2018). Third, the exclusion of Indigenous communities and organizations from decision making on data collection, interpretation, and use can lead to misinterpreting results, reporting that is not useful to communities,

and failing to comply with ethical research guidelines (Pollock et al., 2018). Fourth, lack of Indigenous control and ownership of data forces Indigenous communities to rely on data from sources outside of their control, which perpetuates data dependency (Russo Carroll et al., 2021). There is thus a need to build capacity and develop expertise in Indigenous communities on how to use and apply those data.

Indigenous people have the right to “own, control, access and possess data that derive from them... and ... pertain to [them], and to decide how data about them are used (International Work Group for Indigenous Affairs, 2021, para. 2). Infringements on this right result in gaps of information and barriers for community leaders, health policy makers, and practitioners to make informed policy decisions and support the development and evaluation of evidence-based health interventions in Indigenous communities (Smylie & Firestone, 2015).



## Indigenous control of health information systems

“Data, information, knowledge and research” are considered critically important for “accessing resources, influencing government policy, and assessing the effectiveness of policies, services, programs, or public health interventions” (Marsden et al., 2020, p. 923). Many Indigenous nations have recognized ownership of health information as a key component of self-government (O’Neil et al., 1998). Self-determination over health information systems can lead to a generation of data that is relevant to Indigenous communities and aligned with their needs (Walter & Suina, 2019). This, in turn, can improve the implementation of research findings in Indigenous-led strategic planning and decision-making in public health research and programming (Love et al., 2022; Walker et

al., 2017). Further, exercising self-determination is considered critical for empowerment, building capacity, and gaining control over the “wide-ranging forces that affect Indigenous Peoples’ health and well-being at [both] individual and collective levels (Halseth & Murdock, 2020, p. 4).

Self-determination over health information systems affirms Indigenous Peoples’ inherent right to determine:

1. what data are collected pertaining to them and how data are collected,
2. who will have access to this data,
3. how it will be analyzed and interpreted, and
4. how the data are managed, disseminated, and used (Marsden et al., 2020).

As such, self-determination over data allows Indigenous people to challenge Euro-

Western deficit-based narratives by exercising control over how they are portrayed in research (Marsden et al., 2020). They are able to do this by incorporating strengths-based indicators that reflect Indigenous worldviews and by considering their distinct histories and cultural, political, and socio-economic contexts in how data are interpreted. This narrative control is important for disrupting paternalism, dependence, and unequal power relationships between Indigenous and non-Indigenous peoples and data-holding organizations (O’Neil et al., 1998; Poudrier, 2003).

The Indigenous data sovereignty (IDS) movement, which originated in Canada with the development of the *First Nations and Inuit Regional Longitudinal Health Survey* in 1997, has gained traction in recent years (Redden & Kwan-Lafond, 2023). The movement aims to promote Indigenous self-determination



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over data and ensure data reflect distinct Indigenous priorities, values, cultures, worldviews, and diversity. IDS is informed by “unique ethical, rights-based, policy and practice imperatives regarding the need for Indigenous participation and leadership in data processes through the spectrum of indicator development, data collection, management, analysis and use” (Smylie & Firestone, 2015, p. 67). IDS demands that Indigenous data “be used in ways that support and enhance Indigenous Peoples’ collective well-being” (Walter et al., 2021, p. 4).

Indigenous sovereignty over data is an essential aspect of community empowerment and self-determination (Pollock et al., 2018). Given the historical and ongoing effects of colonialism and intergenerational trauma amongst Indigenous people, community empowerment and self-determination can contribute to Indigenous resurgence,

revitalization, community healing and well-being, as well as improved health outcomes (Colbourne & Anderson, 2021; Cornthassel, 2012; Murphy, 2023; O’Neil & Blanchard, 2001). The right to IDS is supported in international laws and covenants, like the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), which “emphasizes the right to participate in decision-making and determine and develop priorities and strategies for exercising [that] the right” (UN General Assembly, 2008 as cited in Pyper et al., 2018, p. 6). This right is also supported in national Indigenous policy recommendations identified by the Royal Commission on Aboriginal Peoples and the Truth and Reconciliation Commission (TRC) of Canada’s Calls to Action. Section 35 of the 1982 *Constitution Act*, with its affirmation of the right to health and health care, including for First Nations

people, Inuit, and Métis people, and entrenchment of a “duty to consult” with Indigenous Peoples prior to enacting legislation and regulations and infringing on potential Indigenous rights, also implies a legal requirement for Indigenous Peoples to be actively involved in all stages of Indigenous health assessment (Smylie & Firestone, 2015).

Public health surveillance in Canada has been slowly transitioning to assert Indigenous rights over population health data and Indigenous data governance (Pollock et al., 2018). This is reflected in the negotiation and implementation of data partnerships and data sharing agreements in centralized and routine data collection and analysis at both federal and provincial/territorial government levels (Smylie & Firestone, 2015). It is also reflected in Indigenous-led governance initiatives such as the development of “Ownership, Control, Access, and Possession”



*Self-determination over health information systems  
can lead to a generation of data that is relevant to  
Indigenous communities and aligned with their needs*

(Walter & Suina, 2019).



(OCAP)<sup>®</sup> principles by the First Nations Information Governance Centre (Pyper et al., 2018), and the emergence of Indigenous designed and controlled data systems (Lovett et al., 2019).

Developing and implementing data governance agreements with select First Nations, Inuit, and Métis communities takes “time, resources, education, and planning” (Love et al., 2022, p. 21). Love and colleagues (2022) share lessons learned from the Pathways TB Project<sup>14</sup> about how to engage Indigenous community partners equally and equitably in negotiating these agreements. Lessons learned included the need to:

1. train and educate all team members and negotiating partners on Indigenous data sovereignty and governance;
2. develop the capacity of peripheral faculty and staff at academic institutions about how to implement UNDRIP, OCAP<sup>®</sup>, and TRC recommendations in research, contracts, and engagement with communities;
3. fund research teams and Indigenous communities in the negotiation of data governance agreements;

4. prioritize the shifting of power dynamics and the building of trust in negotiations;
5. consider key components of Indigenous data sovereignty, such as ensuring the right questions are asked for communities, privacy is respected, data bring social value to communities, communities retain publishing rights of data, data are described as sovereign property of the community, and community consent is obtained for harvesting and publishing data; and
6. ensure that the process is flexible and guided by community needs and priorities.

There is also emerging recognition of the need to include Indigenous population health data linkages in discussions on Indigenous data governance. As part of this debate, a set of five principles, referred to as the SEEDS principles, were developed at an International Population Data Linkage Network conference in 2018 to create a positive data linkage environment that supports Indigenous self-determination (Rowe et al., 2021). The five principles include:

1. prioritizing Indigenous Peoples’ right to self-determination;
2. making space for Indigenous Peoples to exercise sovereignty;
3. adhering to ethical protocols;
4. acknowledging and respecting data stewardship and governance; and
5. working to support reconciliation between Indigenous nations and settler states.

## Indigenous data governance in the digital age

An emerging field of research focuses on Indigenous perspectives on ethics in digital surveillance, genetic science, DNA databanks, and open data resources. This body of research focuses largely on associated risks for Indigenous populations and the need for Indigenous data sovereignty to govern these new data infrastructures, as there are tensions brewing with novel data infrastructures (Walter et al., 2021). While these new data infrastructures can provide some benefits to Indigenous communities, such as relevant and timely data to support pandemic planning, mitigation,

<sup>14</sup> The Pathways TB Project was a community-centered, multijurisdictional collaboration to co-develop public health interventions related to tuberculosis (TB) prevention and care and repatriate TB surveillance data back to the communities.

and surveillance (Russo Carroll et al., 2021), for some Indigenous people, they hold “more threat than promise” (Walter et al., 2021, p. 6).

Potential harms of the new data technologies include their continued prioritization of Western-dominated epistemologies and ontologies and their ongoing focus on nation-state issues, rather than issues that reflect Indigenous people’s lived realities (Walter et al., 2021). As such, they are likely to perpetuate deficit-based narratives of Indigenous Peoples rather than adopt strengths-based narratives that can empower people (Walter et al., 2021). Since digital platforms can utilize data from older datasets, there is also the risk that omitted or missing Indigenous data will be replicated in new datasets, contributing to the under-representation of Indigenous identities in data and over- or under-estimation of relevant indicators (Hendl & Roxanne, 2022; Walter et al., 2021). Furthermore, because data in these new technologies are generally aggregated at large scales, the cultural and geographic diversity of Indigenous Peoples that is needed to enable

community-level planning and service delivery continues to be ignored (Walter et al., 2021). Access to this data may also be restricted by official statistical agencies and institutions or the data may not be amenable to Indigenous requirements (Walter et al., 2021). There are also concerns about the ability of digital technologies and open data resources to provide health and socioeconomic benefits to Indigenous communities, which can exacerbate oppression (Hendl & Roxanne, 2022; Walter et al., 2021).

Ethical concerns have also been raised about privacy, consent, racist surveillance, algorithmic profiling, and the need to protect Indigenous knowledge in digital data infrastructure (Hendl & Roxanne, 2022; Russo Carroll et al., 2021; Walter et al., 2021). Canada has implemented an extensive data protection regime, which includes federal statutes that regulate the collection, use, disclosure, and limitation of personal information by private and public sectors, which is accompanied by some provincial legislation that grants provincial residents with various legal rights with respect to health information

(Williams et al., 2011). Informed consent is used in health research to guide the collection and use of patients’ health data and ensure their privacy and confidentiality (Caulfield et al., 2020). Nevertheless, advances in data science raise new possibilities of identifying patients and breaching their privacy. Many Indigenous people have expressed concern about how privacy will be protected in ‘big data,’<sup>15</sup> open data<sup>16</sup>, and secondary data linkage<sup>17</sup> projects. This concern extends beyond individual privacy to privacy at the community level, since Indigenous communities often have smaller population sizes and are easily identifiable (Bruhn, 2014; Walter et al., 2021).

*Potential harms of the new data technologies include their continued prioritization of Western-dominated epistemologies and ontologies and their ongoing focus on nation-state issues, rather than issues that reflect Indigenous people’s lived realities*

*(Walter et al., 2021).*

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<sup>15</sup> Big data can be defined as “larger, more complex data sets, especially from new data sources” (Oracle Canada, 2023). Oracle Canada (2023) describes big data as comprised of high volumes of low-density, unstructured data (volume); the ability to receive and act on data quickly (velocity), and a large variety of data types that do not fit neatly in a relational database (variety), otherwise referred to as the three Vs of big data. These data sets are so large that they cannot be managed by traditional data processing software.

<sup>16</sup> Open data can be defined as “structured data that is machine-readable, freely shared, used and built on without restrictions” (Government of Canada, 2022). The data are readily available and provided under terms that permit re-use and redistribution.

<sup>17</sup> Secondary data linkage projects entail the linkage of one source of data together with that of another source, such as linking health outcomes data with the ‘Indian’ Register.





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The new technologies carry risks of data weaponization, stigmatization, and racialization. For example, they have been used in other countries to increase policing and criminalization of racialized people (Hendl & Roxanne, 2022). These concerns are amplified in the context of Indigenous Peoples' long history of and ongoing experiences with colonialism and oppression. Russo Carroll et al. (2021) provide an example of how including COVID-19 data from tribal lands in a publicly available online dashboard resulted in the racial profiling of pregnant Native women in an American hospital. As a result, these women were forced to undergo COVID-19 testing and separation from their newborns during the critical period of postpartum bonding while awaiting COVID-19 test results, despite the lack

of evidence that they were at increased risk of COVID-19.

Moreover, since the new technologies primarily store data on either state or private servers, Indigenous people have limited agency on how data pertaining to them is handled or used, with the potential of having this data be misused or abused (Hendl & Roxanne, 2022). For example, Indigenous knowledge may be collected, digitized, and openly shared, without Indigenous Peoples' consent or oversight (Oguamanam, 2019).

Proponents of the IDS movement are advocating for formal mechanisms to assert Indigenous data interests in open, digital, and big data initiatives to address Indigenous concerns. As noted by Walter et al. (2021), a critical tenet of IDS is that "rights

apply regardless of where the data is held or by whom" (p. 4). The International Indigenous Data Sovereignty Interest Group (IIDSIG) was created to respond to concerns about the secondary use of Indigenous data and limited opportunities for benefit-sharing in relation to open data, machine learning, broad data sharing, and big data initiatives (Chino et al., 2019; Russo Carroll et al., 2020). The IIDSIG is comprised of a series of Indigenous data sovereignty networks and individuals who are concerned about the protection of Indigenous rights and interests in such data initiatives. They have been advocating for data-driven research and data use and working to build data capabilities beyond academic institutions to benefit Indigenous communities (Research Data Alliance, n.d.).

The International Group for Indigenous Health Measurement (IGIHM) also works in this space. The IGIHM is guided by the unifying principle of the “right of Indigenous Peoples to count and be counted,” and aims to improve the accuracy and completeness of Indigenous health data to identify and monitor health disparities, measure change between populations within and between countries, and reduce health burdens (Chino et al., 2019, p. 16). The IGIHM recommends three steps for open data infrastructure:

1. engaging Indigenous Peoples as partners and knowledge holders to inform the stewardship of data within open data infrastructure,
2. engaging Indigenous Peoples through platforms that enable capacity building; and
3. jointly developing principles and protocols around governance and stewardship of Indigenous data (Walter et al., 2021).

The IGIHM has published best practice papers on Indigenous mortality, Indigenous data linkage, Indigenous identification, and international efforts to improve statistics. Community engagement and ownership of data is considered one of several best practices in Indigenous health surveillance (Coleman et al., 2016).

The IGIHM offers a set of global principles for reversing historical power imbalances in relation to Indigenous data, ensuring Indigenous worldviews are reflected in Indigenous data, and Indigenous Peoples have opportunities to benefit from the knowledge economy (Russo Carroll et al., 2020). The *Collective Benefit, Authority to Control, Responsibility, and Ethics* (CARE) principles, developed in consultation with Indigenous Peoples, scholars, organizations, and governments, provide a management and stewardship framework for Indigenous digital resources for the benefit of Indigenous Peoples. The CARE principles stipulate that:

1. Indigenous data must facilitate **collective benefit** for Indigenous Peoples;
2. Indigenous Peoples must have **authority to control** and govern data;
3. users of Indigenous data have a **responsibility** to nurture respectful relationships with Indigenous people from whom the data originated, and ensure their rights and well-being are the focus across and throughout data lifecycles; and
4. **ethics** in data practices are maintained (Russo Carroll et al., 2020).

The CARE principles complement the *Findable, Accessible, Interoperable, and Reusable* (FAIR) principles, developed by a wide group of academic and private data stewardship stakeholders at a workshop held in Leiden, Netherlands in 2014 (Wilkinson et al., 2016). The FAIR principles aim to enhance the ability of machines to find, use, and reuse data and are intended to be used in tandem with the CARE principles (Russo Carroll et al., 2020; Walter et al., 2021).





More recently, Huria et al. (2019) released the CONSIDER statement: a collaborative synthesis and prioritization of guidelines for reporting health research pertaining to Indigenous Peoples, drawn from national and international research statements and guidelines. The statement includes eight domains:

1. research governance,
2. research prioritization,
3. research relationships,
4. research methodologies and methods,
5. research participation,
6. research capacity,
7. research analysis and interpretation, and
8. research dissemination.

Indigenous data governance requires investments in building institutional and human resource capacity to manage and utilize health information (O’Neil & Blanchard, 2001). This includes computer training and knowledge about using the internet, learning how to work with other agencies and organizations, as well developing and applying “abilities to govern and manage, solve problems, respond to new situations, make ... evidence-based decisions, to strategically plan, to identify and set priorities, to evaluate, to efficiently manage resources ..., and to take responsibility for success or failure of health interventions” (O’Neil & Blanchard, 2001, p. 5). Federal funding to support investments in data infrastructure and

resources in Indigenous health are oftentimes proportionally less than that given to the general population and come with many strings attached and micro-management (Russo Carroll et al., 2021).

## Best practice examples

In recent years, the impetus for IDS and Indigenous data governance (IDG) has been building, with numerous partnerships between various Indigenous groups and governments to enable Indigenous community leadership and participation in the collection, use, analysis, and sharing of information. This section presents examples of best and promising IDS and IDG practices. While these examples differ in how OCAP® principles are interpreted and embodied, they share some common themes:

1. building trust and maintaining frequent contact among partners;
2. following commitment to begin implementing data linkages with technical capacity;
3. fostering political support;
4. utilizing approaches that support and maintain the spirit and intent of OCAP® principles; and
5. ensuring communities have priority access to data and a voice in data governance (Bruhn, 2014).

While primarily used in data collection, OCAP® principles are now well recognized and acknowledged by federal departments and agencies, like Statistics Canada, and serve as a model for other Indigenous groups who have developed or are developing similar principles (Lovett et al., 2019).

## First Nations Regional Health Survey

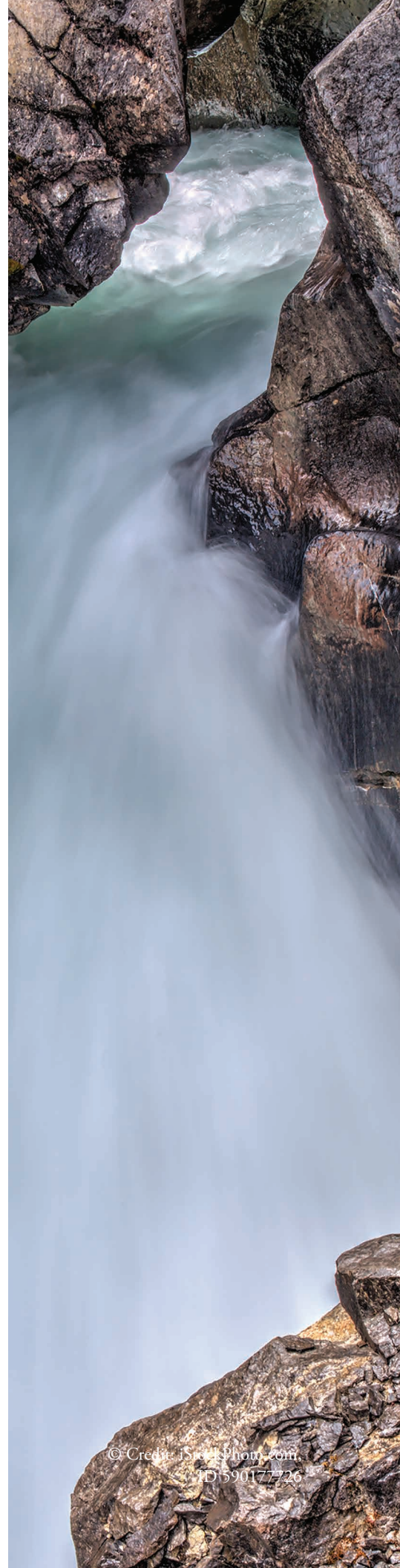
The First Nations Regional Health Survey (FNRHS) is considered an exemplar model of Indigenous governance and management of health data (Smylie & Firestone, 2015). The FNRHS has its origins in the development of the First Nations Inuit Regional Longitudinal Health Survey, which aimed to address data gaps at the national level for First Nations and released its results in 1997 (O’Neil et al., 1998). This initial survey was developed by a national Indigenous Steering Committee, comprised of First Nations and Inuit health and social development experts, for the purposes of creating high quality data that would be relevant to communities (O’Neil et al., 1998). “High quality” was defined as information that was considered trustworthy at the community level, based on questions designed and interpreted by someone familiar with the community, as well as credible (scientifically valid). First Nations people and Inuit controlled all aspects of

the health survey, including administrating funds; designing questions; training Indigenous research administrators, analysts, and interviewers; and interpreting and disseminating information (O'Neil et al., 1998). The survey was later adapted as a regional or provincial tool to respond to the diversity of Indigenous Peoples and a set of standardized questions were developed to enable national-level comparisons.

While most of the questions were borrowed from standard health survey instruments, some were culture specific. First Nations control over analysis and interpretation of results contributed to a First Nations perspective on health and well-being (O'Neil et al., 1998). First Nations and Inuit participants in that initial survey process also identified the need for program funding for data collection and for the surveys to be kept at arm's length from Indigenous political organizations to avoid perceptions that survey results were driven by political agendas.

The First Nations and Inuit Regional Longitudinal Health Survey set the foundation for a First Nations owned health surveillance system, now administered by the First Nations Information Governance Centre (FNIGC). The FNIGC RHS has been administered several times and the First Nations-driven survey approach has now been expanded to other key areas,

including education, labour, and employment (Lovett et al., 2019). Today, the FNRHS includes both universally accepted Western measures of health as well as traditional First Nations understandings of health and well-being, including a focus on physical, mental, emotional, and spiritual health, and their interconnections, as well as on healthy lifestyle, cultural continuity, and health connection to culture, family, and community (Bruhn, 2014). Data on health outcomes are interpreted and analyzed by First Nations, using a strengths-based narrative that considers health outcomes in connection with other aspects of health. The FNIGC has a license-to-use agreement with Health Canada but maintains ownership, control, access, and possession of the RHS data (Bruhn, 2014). Oversight is provided by ten regional partners, who implement the survey and hold the data collected in their regions. The fieldwork is carried out by trained local community members, and local community leadership must approve the implementation of the survey within their jurisdiction. The quality, integrity, and community accessibility of the data are protected through the development of protocols, codes, and guides (Bruhn, 2014).





## BC's First Nations Health Authority

In British Columbia, the First Nations Health Authority (FNHA) is mandated to collect and maintain clinical information and patient records and to develop protocols with the Ministry of Health and BC Health Authorities for sharing patient information (Bruhn, 2014). In 2010, the First Nations Health Society and the federal and provincial governments signed the FNHA Tripartite Data Quality and Sharing Agreement, which aims to improve the quality of First Nations health data, facilitate data sharing, and ensure proper use of First Nations data by federal and provincial partners. With the transfer of all data

associated with the First Nations Inuit Health Branch (FNIHB) BC region to the FNHA in 2013, and the BC Ministry of Health acting as custodian of this health data, the data quality and sharing agreement allows for the creation of a First Nations Client File that enables data linkages from other sources with the 'Indian' Registry data (Bruhn, 2014). The First Nations Client File is governed by a Data Information and Planning Committee comprised of representatives from the FNHA and BC Ministry of Health – who make decisions about who can access the file on a consensus basis (Nelson, 2014.). The Committee closely coordinates with provincial authorities and communities to honor the spirit of the OCAP® principles (Bruhn, 2014).

This collaborative data governance model works to support First Nations peoples' right to self-determination in public health surveillance, such as in overdose surveillance (Sabeti et al., 2021). A protocol was developed that adhered to OCAP® principles and the TRC's Calls to Action to support an overdose emergency response. This protocol provided the FNHA with full ownership of First Nations data to support culturally appropriate "analysis, interpretation, context setting, language, and dissemination of data" (Sabeti et al., 2021, p. 342). To generate appropriate data, the BC Centre for Disease Control (BCCDC), Provincial Health Officer, and the Ministry of Health work collaboratively with the FNHA to develop a new data linkage process to aide in the identification of status First Nations persons in surveillance. This process involves linking the province's First Nations Client File (Registered First Nations under the *Indian Act* in the province) with data from the BC Coroners Service report of deaths resulting from illicit drug toxicity to generate a First Nations cohort, which enables comparisons between First Nations and other residents of BC.

Control is exercised through engagement between the partners in a collaborative data management process (Sabeti et al., 2021). The process begins with a data access request and information sharing agreement,



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followed up with the FNHA carrying out the work of analyzing, disseminating, and exchanging knowledge related to the data, with the help of approved analysts from the BCCDC. While housed at the BCCDC, a FNHA representative must be present at all meetings involving First Nations data and results of data analysis must be interpreted by the FNHA's surveillance team and shared with FNHA leadership for decisions regarding how, when, and to whom the knowledge is disseminated. Access to the data is facilitated by the FNHA in partnership with the BCCDC, with the FNHA responsible for reviewing and approving any person who wishes to access the data. The FNHA has a mandate within the agreement to return data back to those who own it in a way that “reduce[s] stigma, uses culturally appropriate narratives, and protect[s] peoples’ privacy” (Sabeti et al., 2021, p. 350). Finally, the ‘Possession’ principle is adhered to by ensuring that the FNHA designates surveillance team members from the FNHA and BCCDC who are allowed to access the BCCDC hosted data.

In the case of the overdose surveillance project, the application of OCAP® principles enables a strength-based approach to health reporting that emphasizes resiliency and frames quantitative data in non-stigmatizing ways (Sabeti et al., 2021). It also fosters a culturally



appropriate framework for action to the overdose crisis - one that is focused on preventing fatalities from overdose, keeping people safe when using substances, creating an accessible range of treatment options, and supporting people on their healing journeys. Additionally, this governance model builds First Nations capacity for data analysis (Sabeti et al., 2021), through its First Nations Working Group, led by the FNHA. The Working Group works in parallel with other

groups to undertake data analysis and members of the group are represented in other working groups to “contribute to analytic capacity, provide knowledge and expertise, and learn new methodologies” for conducting data analysis (Sabeti et al., 2021, p. 350).

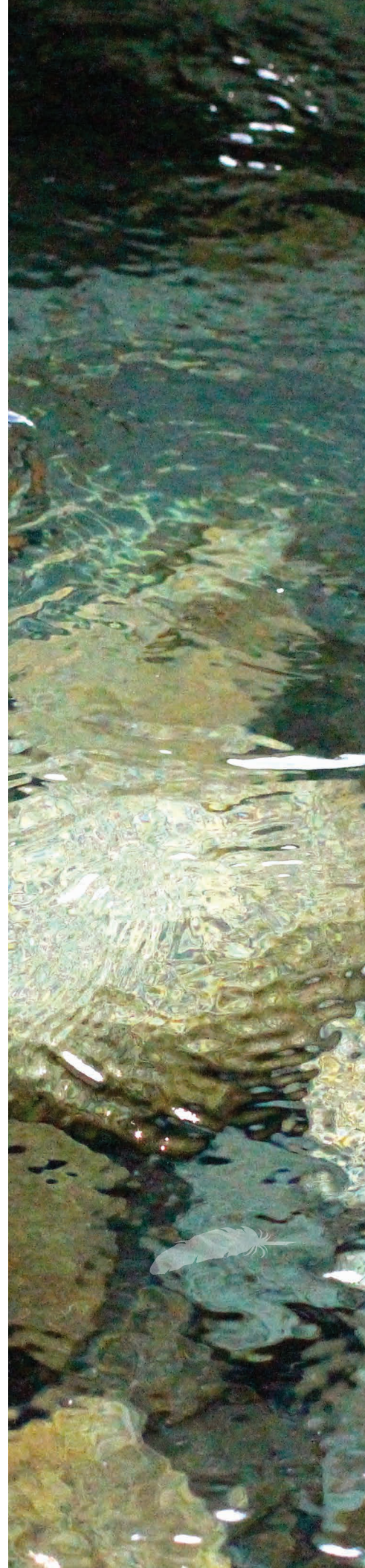




## Institute for Clinical Evaluative Sciences

In Ontario, the Institute for Clinical Evaluative Sciences (ICES), which holds some of Ontario's health-related data, is engaged in an ongoing commitment to Indigenous-driven use and analysis of ICES data (Pyper et al., 2018). The ICES has developed unique data governance and sharing agreements based on the need to be responsive and adaptive to diverse Indigenous partners. ICES has worked in partnership with the Chiefs of Ontario and First Nations communities in the province to ensure First Nations govern federal 'Indian' Register data hosted at the ICES. Individuals who wish to use the data must first secure approval from a First Nations Data Governance Committee, comprised of members appointed by the Ontario Chiefs' Committee on Health (Pyper et al., 2018). Similar governance agreements have also been signed with regional First Nations organizations in relation to data pertaining to members and communities within their respective regions, and with the Métis Nation of Ontario (MNO) to link the MNO Citizenship Registry with studies on chronic diseases. The ICES has also been working in partnership with Tungasuvvingat Inuit to enable research in the province that is grounded in Inuit Qaujimajatuqangit.

To ensure Indigenous-led analyses of Indigenous data, the ICES responds to questions from Indigenous organizations about the health of their people and communities, ranging from single questions to collaborative research projects. ICES also conducts researcher-driven, collaborative, and participatory research with Indigenous partners (Pyper et al., 2018). When working with Indigenous data, the ICES adheres to IDG principles, including OCAP® and Inuit Qajimajatuqangit principles. In its practices, ICES ensures that research builds on principles of Indigenous research ethics, community engagement, mutual capacity building, and Indigenous perspectives and models of well-being. The ICES ensures its analyses address data gaps, context, and linkages, and that its research is useful to inform policies and programs within communities. Researchers using ICES data are required to: "discuss their projects with Indigenous community representatives" and collaborate with them in the planning, implementation, and reporting of studies that communities wish to proceed with; "participate in ongoing initiatives to orient themselves to Indigenous worldviews, research principles, and historical and social contexts;" work with "representative organizations to build [their] capacity" to be involved in the research process; and involve Indigenous communities and







their representatives in the co-interpretation of study results and how they are disseminated (Walker et al., 2017, p. 2022). With the number of partnerships with Indigenous groups growing, the ICES is working towards being a “trusted partner of Indigenous organizations, scholars, and communities by supporting their information needs” (Pyper et al., 2018, p. 8).

### Our Health Counts urban Aboriginal study

In Ontario, the Our Health Counts urban Aboriginal study aims to address gaps in public health data for urban Indigenous populations in the province by developing baseline data on the factors that influence health, rates of chronic disease and disability, and access to health services that are “immediately accessible, useful, and culturally relevant to local, small region, and provincial policy makers” (Tungasuvvingat Inuit & Well Living House Action Research Centre for Indigenous Infant, Child and Family Health and Wellbeing, 2017, p. 12; see also, Smylie & Firestone, 2015; Taylor, 2011). The study is governed by a Governing Council, comprised of membership from provincial Indigenous organizations. The study builds on the strengths of urban Indigenous communities and utilizes community-based research methods, involving interview surveys with Indigenous participants who were living with

homelessness in six urban centres in Ontario (Hamilton, Ottawa, London, Toronto, Thunder Bay, and Kenora), and more recently, in Winnipeg, Manitoba (Well Living House, 2023).

The various Our Health Counts survey projects are led by Indigenous organizations, working in partnership with a research team led by an Indigenous physician (Tungasuvvingat Inuit & Well Living House Action Research Centre for Indigenous Infant, Child and Family Health and Wellbeing, 2017). The surveys were developed with Indigenous organizations and administered by a survey team recruited from local Indigenous communities and conducted in relevant Indigenous languages and English. In this way, the project helped to strengthen capacity and build leadership within urban Indigenous communities. Respondent driven sampling was used to identify eligible participants, while accounting for potential biases in the sampling process. This sampling technique involved giving tickets to study participants and asking them to recruit other participants by sharing the ticket, with a \$10 incentive offered for each person recruited, up to a maximum of five persons. The technique was highly successful in reaching “difficult to reach” populations and addressing a significant knowledge gap on the health of urban Indigenous populations.





## Tui'kn Partnership

In Nova Scotia, the Tui'kn Partnership is funded by the federal Primary Health Care Transition Fund and is led in partnership between the Membertou, Eskasoni, Potlotek, Wagmatcook, and Waycobah Mi'kmaw communities, the Nova Scotia Health Authority, the Nova Scotia Department of Health, FNIHB, and Dalhousie University (Bruhn, 2014). One goal of the partnership was to develop the Unam'ki Client Registry, which provides longitudinal population data for the five Unama'ki (Cape Breton) Mi'kmaw communities. The

registry allows communities to extract population-level data from provincial administrative and clinical registry systems for use in their own planning efforts. The data included in the registry are owned by each of the contributing parties and stored off-site by a trusted third party. OCAP® principles are reflected in the registry's governing policies, procedures, and access structures. Access to the registry is controlled by the Unam'ki Client Registry Data Access Committee, comprised of the five Mi'kmaw health directors from each of the communities and one member from the Nova Scotia Department of Health and Wellness. Data on

indicators for each program are reported and aggregated at the community-level for communities to establish future priorities and inform local health plans. The data cannot be shared for any other purposes without the permission of the respective Mi'kmaw nations (Bruhn, 2014).







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## Qanuippitaa? National Inuit Health Survey

The Qanuippitaa? National Inuit Health Survey builds on previous surveys that operated in Nunavik in 2004 and 2017, and across the Inuvialuit Settlement Region, Nunavut, and Nunatsiavut in 2007-2008 (Qanuippitaa?, 2021a, para. 1). The survey is co-designed by the four Inuit Land Claims Organizations (or their designates) and is intended to be implemented as a permanent population health survey. It is the only Inuit-controlled health survey program that covers Inuit of all ages and from all communities across the four Inuit

regions, including some urban centres. The survey is “informed by Inuit knowledge, values and worldviews, as well as stakeholder engagement and the latest health sciences research” (Qanuippitaa?, 2021b, para. 2). Data are intended to be accessible and used by Inuit and organizations that serve Inuit populations and to support planning action at regional and local levels, with control over who has access to data resting in the hands of Inuit. The governance structure involves collaborative decision-making at sub-regional, regional, national, and international levels. The Qanuippitaa? National Inuit Health Survey Working

Group (comprised of members representing a variety of Inuit stakeholders and governments, as well as the Government of Northwest Territories and Labrador Grenfell Health), works in partnership with Regional Inuit Health Survey Steering Committees. The survey collects data through indicators and processes that have been “approved by Inuit organizations and informed by the insights of Inuit in each region” (Qanuippitaa?, 2021c, para. 2). These indicators are comparable across time and regions.



# RECOMMENDATIONS

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

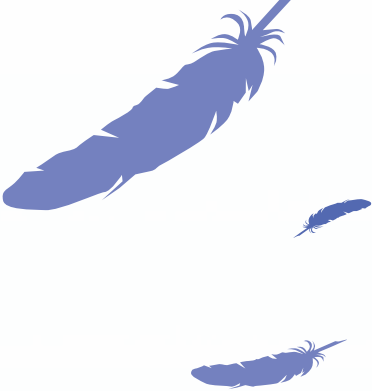
- Add standardized “Indigenous identifiers” to all data sources to ensure appropriate data linkages (Coleman et al., 2016; Pollock et al., 2018; Russo Carroll et al., 2021). Apply these identifiers consistently and accurately across jurisdictions to ensure Indigenous populations are not underestimated in health indicators (Coleman et al., 2016). Identifiers should be based on the “gold standard” of “self-identification” (Coleman et al., 2016; Sarfati et al., 2022; Smylie & Firestone, 2015) to support the rights of Indigenous Peoples to define which community they belong to (Russo Carroll et al., 2021).

- Increase geographic coverage of administrative and health survey data and ensure data collected is representative of urban, rural, remote, and northern populations (Pollock et al., 2018).

- 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 (Sarfati et al., 2022).

- Implement national surveillance systems that provide equitable coverage of Indigenous populations and communities that can inform policy development with systematically collected data (Pollock et al., 2018). The focus should be on developing multiple surveillance systems, each focusing on a specific public health problem (O’Neil & Blanchard, 2001).

- 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 (Pollock et al., 2018). 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 (Coleman et al., 2016). 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 (Coleman et al., 2016). Initiate the development of data access and sharing protocols between Indigenous Peoples and other governments and data holders (Russo Carroll et al., 2021). Ensure principles of Indigenous community ownership and reporting are established and maintained for all data collection practices (Coleman et al., 2016).

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 (O'Neil & Blanchard, 2001; Russo Carroll et al., 2021).

Increase the number of Indigenous epidemiologists and build capacity among Indigenous Peoples to bolster public health expertise and decolonize public health practice (Russo Carroll et al., 2021).

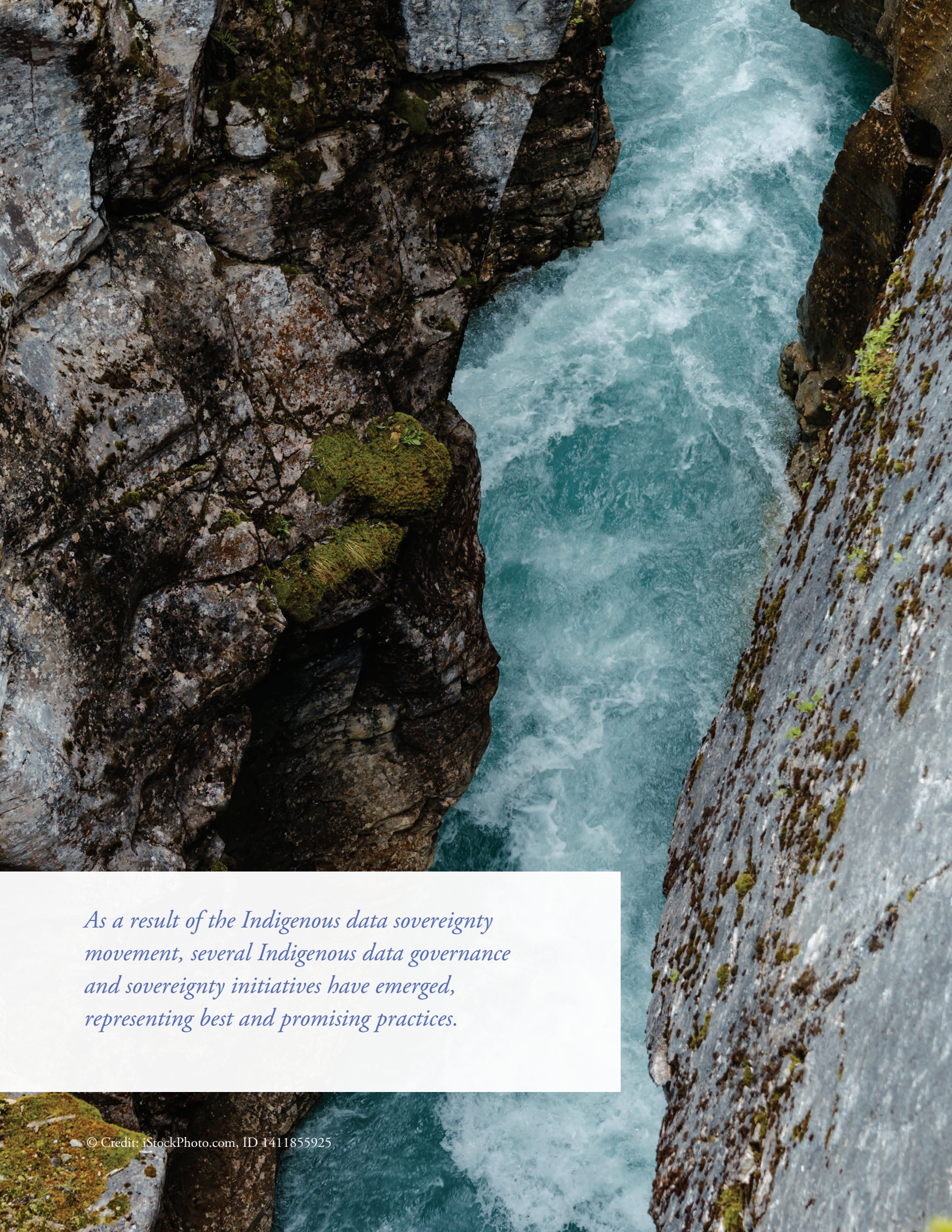
Improve accessibility of Indigenous health data to Indigenous and local governments; frontline, clinical, and public health staff; community organizations; and health system decision-makers to support the identification of priority issues and evaluation of local interventions (Pollock et al., 2018; Russo Carroll et al., 2021).

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 (Pollock et al., 2018). This might include involving Indigenous leaders, activists, scholars, and those with lived experience in mainstream science, data, policy, and decision-making processes (Beames et al., 2021; Hemming et al., 2021; Russo Carroll et al., 2021).

Engage with Indigenous populations to set public health priorities and plan public health surveillance systems (O'Neil & Blanchard, 2001).







*As a result of the Indigenous data sovereignty movement, several Indigenous data governance and sovereignty initiatives have emerged, representing best and promising practices.*



# CONCLUSION



The current state of public health surveillance in Canada has resulted in notable gaps in Indigenous health data. These gaps need to be addressed in the revamping of the surveillance system so that the system can better respond to the emergence of new diseases and new data technologies, as well as increase its application of ethics, equity, and data ownership principles when dealing with data specific to First Nations, Inuit, and Métis populations. The current system continues to reinforce a colonial power relationship between Indigenous and non-Indigenous peoples and is plagued by challenges that result in data that is neither appropriate nor useful for informing decision-making at the local level or developing policies that are effective in addressing health inequities and the root causes of those inequities. These challenges include a lack of coordination in data collection across jurisdictions; inadequate population and geographic coverage; biases in relation to small sample sizes and rare events; data sources that do not respond to the diversity of Indigenous populations; major gaps in indicators that can measure health status, health

system performance, and health services utilization; and indicator frameworks that do not reflect Indigenous perspectives on health and well-being.

Nevertheless, some progress has been made towards the development of indicator frameworks that reflect Indigenous perspectives on health and well-being, with culturally relevant and appropriate indicators to support local planning and decision-making in specific Indigenous contexts, developed through participatory processes, partnerships, and engagement with Indigenous groups. These frameworks help fill some of the indicator gaps identified in this literature review and complement universally recognized public health indicators, leading to more relevant data for Indigenous Peoples.

Progress has also been made to improve the quantity and quality of Indigenous health data and ensure data dissemination does not reflect harmful narratives toward Indigenous Peoples. As a result of the Indigenous data sovereignty movement, several Indigenous data governance

and sovereignty initiatives have emerged, representing best and promising practices. These initiatives involve the creation of respectful and sustainable partnerships with Indigenous Peoples and organizations with the goal of enhancing self-determination in the collection, analysis, and dissemination of Indigenous data that can lead to improved health outcomes and health services. However, these efforts also need to extend to the development of new data technologies which, at present, offer the potential for more harms than benefits to Indigenous populations. There is also a need to ensure that Indigenous communities build capacity and infrastructure to support Indigenous-led data collection and analysis efforts. By partnering with Indigenous Peoples and organizations in the design of a more integrated and coordinated public health surveillance system and promoting Indigenous self-determination in data collection, analysis, and dissemination, data can be made more inclusive and reflective of the needs of Indigenous communities, supporting decision-making that can lead to improved health outcomes.



# REFERENCES

- Andersen, C. (2016). The colonialism of Canada's Métis health population dynamics: Caught between bad data and no data at al. *Journal of Population Research*, 33, 67-82.
- Anderson, K., Elder-Robinson, E., Gall, A., Ngampromwongse, K., Connolly, M., Letendre, A., Willing, E., Akuhata-Huntington, Z., Howard, K., Dickson, M., & Garvey, G. (2022). Aspects of wellbeing for Indigenous youth in CANZUS countries: A systematic review. *International Journal of Environmental Research and Public Health*, 19(20), 13688.
- Anderson, M.J., & Smylie, J.K. (2009). Health systems performance measurement systems in Canada: How well do they perform in First Nations, Inuit, and Métis contexts? *Pimatisiwin*, 7(1), 99-115.
- Anderson, M., Smylie, J., Anderson, I., Sinclair, R., & Crengle, S. (2006). *First Nations, Métis, and Inuit health indicators in Canada*. Background paper for the project, "Action oriented indicators of health and health systems development for Indigenous Peoples in Australia, Canada, and New Zealand. <https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=bc2ec3fa221a1f1fa839d62b6d122f49f87b8346>
- Angell, B., Muhunthan, J., Eades, A.-M., Cunningham, J., Garvey, G., Cass, A., Howard, K., Ratcliffe, J., Eades, S., & Jan, S. (2016). The health-related quality of life of Indigenous populations: A global systematic review. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 25(9), 2161-78.
- Atkinson, D., Landy, R., St. Denys, R., Ogilvie, K., Lund, C., & Worthington, C. on behalf of the DRUM and SASH team. (2023). The Red River Cart Model: A Métis conceptualization of health and well-being in the context of HIV and other STBBI. *Canadian Journal of Public Health*, 114, 856-866.
- Auer, A. M., & Andersson, R. (2001). Canadian Aboriginal communities: A framework for injury surveillance. *Health Promotion International*, 16(2), 169-177.
- Austin, C. C., Bernier, A., Bezuidenhout, L., Bicarregui, J., Biro, T., Cambon-Thomsen, A., Russo Carroll, S., Cournia, Z., Wojciech Dabrowski, P., Duflot, T., Garcia, L., Gesing, S., Gonzalez-Beltran, A., Gururaj, A., Harrower, N., Lin, D., Medeiros, C., Méndez, E., Meyers, N., Mietchen, D. et al. (2021). Fostering global data sharing: Highlighting the recommendations of the Research Data Alliance COVID-19 working group. *Welcome Open Research*, 5, 267.
- Ayotte, P., Gagnon, S., Riva, M., Muckle, G., Hamel, D., Bélanger, R.E., Fletcher, C., Furgal, C., Dawson, A., Calarneau, C., Lemire, M., Gauthier, M.-J., Labranche, E., Grey, L., Rochette, M., & Bourchard, F. (2024). The Qanuilirpitaa? 2017 Nunavik Health Survey: Design, methods, and lessons learned. *Canadian Journal of Public Health*, 115(Suppl 1), 7-19.
- Bader, D., Frank, K., & Kohen, D. (2023). Taking stock of Canadian population-based data sources to study child maltreatment. *Child Indicators Research*, 16, 2511-2544.
- Barbic, S. P., Young, N. L., Usuba, K., & Stankiewicz, E. (2022). Rasch Measurement Theory's contribution to the psychometric properties of a co-created measure of health and wellness for Indigenous children and youth. *Journal of Clinical Epidemiology*, 151(151), 18-28.
- Barnabe, C., Crane, L., White, T., Hemmelgarn, B., Kaplan, G. G., Martin, L., & Maksymowych, W. P. (2018). Patient-reported outcomes, resource use, and social participation of patients with Rheumatoid Arthritis treated with biologics in Alberta: Experience of Indigenous and non-Indigenous patients. *Journal of Rheumatology*, 45(6), 760-765.
- Bartlett, J.G. (2004). Conceptions and dimensions of health and well-being for Métis women in Manitoba. *International Journal of Circumpolar Health*, 63(Suppl 2), 107-113.
- Beames, J. R., Kikas, K., O'Grady-Lee, M., Gale, N., Werner-Seidler, A., Boydell, K. M., & Hudson, J. L. (2021). A new normal: Integrating lived experience into scientific data syntheses. *Frontiers in Psychiatry*, 12, 763005.
- Bell, N., Schuurman, N., Hameed, S. M., & Caron, N. (2011). Are we homogenizing risk factors for public health surveillance? Variability in severe injuries on First Nations reserves in British Columbia, 2001-5. *Injury Prevention*, 17(6), 394-400.
- Blair, A., Warsame, K., Naik, N., Byrne, W., Parnia, A., & Siddiqi, A. (2021). Identifying gaps in COVID-19 health equity data reporting in Canada using a scorecard approach. *Canadian Journal of Public Health*, 112, 352-362.
- Bryant, J., Bolt, R., Botfield, J. R., Martin, K., Doyle, M., Murphy, D., Graham, S., Newman, C. E., Bell, S., Treloar, C., Browne, A. J., & Aggleton, P. (2021). Beyond deficit: 'Strengths-based approaches' in Indigenous health research. *Sociology of Health & Illness*, 43(6), 1405-1421.

- Bruhn, J. (2014). Identifying useful approaches to the governance of Indigenous data. *International Indigenous Policy Journal*, 5(2), 5.
- Canadian Institute for Health Information (CIHI). (2021). *Measuring cultural safety in health systems*. <https://www.cihi.ca/sites/default/files/document/measuring-cultural-safety-in-health-systems-report-en.pdf>
- Canadian Institute for Health Information (CIHI). (2022). *Race-based and Indigenous identity data*. <https://www.cihi.ca/en/race-based-and-indigenous-identity-data>
- Canadian Institute of Population and Public Health (CIPPH). (2021). *Building public health systems for the future*. Canadian Institutes for Health Research. <https://cihr-irsc.gc.ca/el/documents/building-public-health-systems-for-the-future-en.pdf>
- Caulfield, T., Murdoch, B., & Ogbogu, U. (2020). Research, digital health information and promises of privacy: Revisiting the issue of consent. *Canadian Journal of Bioethics*, 3(1), 164-171.
- Centers for Disease Control and Prevention (CDC). (2014). Introduction to public health. In *Public health 101 series*. Department of Health and Human Services. <https://www.cdc.gov/training/publichealth101/surveillance.html>
- Chan, H.M., Fediuk, K., Batal, M., Sadik, T., Tikhonov, C., Ing, A., & Barwin, L. (2021). The First Nations Food, Nutrition and Environment Study (2008-2018) – rationale, design, methods and lessons learned. *Canadian Journal of Public Health*, 112(Supple 1), 8-19.
- Chan, S.L., Ho, C.Z.H., Khaing, N.E.E., Ho, E., Pong, C., Guan, J.S., Chua, C., Li, Z., Lim, T., Lam, S.S.W., Low, L.L., & How, C.H. (2024). Frameworks for measuring population health: A scoping review. *PLoS One*, 19(2), e0278434.
- Chan, A.W., Reid, C., Skeffington, P., & Marriott, R. (2021). A systematic review of EPDS cultural suitability with Indigenous mothers: A global perspective. *Archives of Women's Mental Health*, 24, 353-365.
- Chando, S., Howell, M., Young, C., Craig, J.C., Eades, S.J., Dickson, M., & Howard, H. (2021). Outcomes reported in evaluations of programs designed to improve health in Indigenous people. *Health Services Research*, 56(6), 1114-1125.
- Chino, M., Ring, I., Jackson Pulver, L., Waldon, J., & King, M. (2019). Improving health data for Indigenous populations: The International Group for Indigenous Health Measurement. *Statistical Journal of the IAOS*, 35, 15-21.
- Clark, T. C., Best, O., Bourque Bearskin, M. L., Wilson, D., Power, T., Phillips-Beck, W., Graham, H., Nelson, K., Wilkie, M., Lowe, J., Wiapo, C., & Brockie, T. (2021). COVID-19 among Indigenous communities: Case studies on Indigenous nursing responses in Australia, Canada, New Zealand, and the United States. *Nursing Praxis in Aotearoa New Zealand*, 37(3), 71-83.
- Colbourne, R., & Anderson, R. B. (2021). *Indigenous wellbeing and enterprise: Self-determination and sustainable economic development*. Routledge.
- Coleman, C., Elias, B., Lee, V., Smylie, J., Waldon, J., Hodge, F. S., & Ring, I. (2016). International Group for Indigenous Health Measurement: Recommendations for best practice for estimation of Indigenous mortality. *Statistical Journal of the IAOS*, 32(4), 729-738.
- Cooke, M., Guimond, E., & McWhirter, J. (2008). The changing well-being of older adult registered Indians: An analysis using the Registered Indian Human Development Index. *Canadian Journal of Aging*, 27(4), 385-97.
- Cormack, D., Reid, P., & Kukutai, T. (2019). Indigenous data and health: Critical approaches to 'race'/ethnicity and Indigenous data governance. *Public Health*, 172, 116-118.
- Corntassel, J. (2012). Re-envisioning resurgence: Indigenous pathways to decolonization and sustainable self-determination. *Decolonization: Indigeneity, Education & Society*, 1(1), 86-101.
- Duhaime, G., & Lévesque, S. (2014). Aboriginal Peoples Survey, Canada (APS). In A. C. Michalos (ed.), *Encyclopedia of quality of life and well-being research* (pp. 5-8). Springer, Dordrecht.
- Essue, B. M., Milinkovic, D., & Birch, S. (2018). Better data to drive more effective care for people with latent tuberculosis infection in Canada. *Canadian Medical Association Journal*, 190(23), E700-E701.



- Fiedeldey-Van Dijk, C., Rowan, M., Dell, C., Mushquash, C., Hopkins, C., Fornssler, B., Hall, L., Mykota, D., Farag, M., & Shea, B. (2017). Honoring Indigenous culture-as-intervention: Development and validity of the Native Wellness Assessment. *Journal of Ethnicity in Substance Abuse*, 16(2), 181–218.
- Firestone, M., Smylie, J., Maracle, S., Siedule, C., De dwa da dehs nye>s Aboriginal Health Access Centre, Métis Nation of Ontario, and O'Campo, P. (2014). Concept mapping: Application of a community-based methodology in three urban Aboriginal populations. *American Indian Culture and Research Journal*, 38(4). DOI: 10.17953/AICR.38.4.571154UP25876H72.
- First Nations Health Authority (FNHA). (2024). *Panorama program*. <https://www.fnha.ca/what-we-do/communicable-disease-control/panorama#:~:text=Through%20the%20Panorama%20Public,for%20on%20Reserve%20First%20Nations>.
- First Nations Health Authority (FNHA), & Office of the Provincial Health Officer (OPHO). (n.d.). *First Nations population health & wellness agenda: Summary of findings*. <https://www.fnha.ca/Documents/FNHA-PHO-First-Nations-Population-Health-and-Wellness-Agenda-Summary-of-Findings.pdf#%3a-%3atext=The%20First%20Nations%20Population%20Health%20and%20Wellness%20Agenda%2cFirst%20Nations%20health%20and%20wellness%20in%20BC%20that>
- First Nations Health Authority & Office of the Provincial Health Officer. (2021). *First Nations population health and wellness agenda*. <https://www.fnha.ca/Documents/FNHA-PHO-First-Nations-Population-Health-and-Wellness-Agenda.pdf>
- Flicker, S., & Worthington, C. A. (2012). Public health research involving Aboriginal peoples: Research ethics board stakeholders' reflections on ethics principles and research processes. *Canadian Journal of Public Health*, 103, 19-22.
- Foucault, M. (1986). Disciplinary power and subjection. In S. Lukes (ed.), *Power: A radical review* (pp. 229-242). New York University Press.
- Fowler-Woods, A. (2023). Identity as visibility: Perspectives and experiences of Indigenous Peoples in Manitoba with racial, ethnic, and Indigenous identifier data collection within healthcare [Unpublished doctoral dissertation]. University of Manitoba, Winnipeg, Manitoba.
- Government of Canada. (2022). *Open data 101*. <https://open.canada.ca/en/open-data-principles>
- Government of Canada. (2024). *2023-2026 Data strategy for the federal public service*. <https://www.canada.ca/en/treasury-board-secretariat/corporate/reports/2023-2026-data-strategy.html>
- Graham, H., & Stamler, L.L. (2013). Contemporary perceptions of health from an Indigenous (Plains Cree) perspective. *International Journal of Indigenous Health*, 6(1), 6-17.
- Gupchup, G.V., Hubbard, J.H., Teel, M.A., Singhal, P.K., Tonrey, L., Riley, K., Rupp, M.T., & Coultas, D.B. (2001). Developing a community-specific health-related quality of life (HRQOL) questionnaire for asthma: The Asthma-Specific Quality of Life Questionnaire for Native American Adults (AQLQ-NAA). *Journal of Asthma*, 38(2), 169-178.
- Halseth, R., & Murdock, L. (2020). *Supporting Indigenous self-determination in health: Lessons learned from a review of best practices in health governance in Canada and internationally*. National Collaborating Centre for Indigenous Health.
- Hamm, N. C., Robitaille, C., Ellison, J., O'Donnell, S., McRae, L., Hutchings, K., Rochette, L., Phillips, K. A. M., Azimaee, M., Stang, M., Puchtinger, R., McCallum, M., Yang, A., Squires, J., Liu, Y., Svenson, L. W., Shibley, F., Amatya, A., Zhang, B., Ayles, J., & Lix, L. M. (2021). Population coverage of the Canadian Chronic Disease Surveillance System: A survey of the contents of health insurance registries across Canada. *Health Promotion and Chronic Disease Prevention in Canada*, 41(7-8), 230-241.
- Hancock, T. (2017). Erosion of public health capacity should be a matter of concern for all Canadians [editorial]. *Canadian Journal of Public Health*, 108(5-6), e458-460.
- Haworth-Brockman, M. J., & Keynan, Y. (2019). Strengthening tuberculosis surveillance in Canada. *Canadian Medical Association Journal*, 191(26), E743-E744.
- Health Canada. (2023, February 7). Working together to improve health care for Canadians - background. Government of Canada. <https://www.canada.ca/en/health-canada/news/2023/02/working-together-to-improve-health-care-for-Canadians.html#a1>
- Hemming, L., Pratt, D., Bhatti, P., Shaw, J., & Haddock, G. (2021). Involving an individual with lived-experience in a co-analysis of qualitative data. *Health Expectations*, 24(3), 766-775.

- Hendl, T., & Roxanne, T. (2022). Digital surveillance in a pandemic response: What bioethics ought to learn from Indigenous perspectives. *Bioethics*, 36(3), 305-312.
- Huria, T., Palmer, S. C., Pitama, S., Beckert, L., Lacey, C., Ewen, S., & Tuhiwai Smith, L. (2019). Consolidated criteria for strengthening reporting of health research involving Indigenous Peoples: The CONSIDER statement. *BMC Medical Research Methodology*, 19, 173.
- Indigenous Health. (2024). *Métis Public Health Surveillance Program (MPHSP)*. Northern Health. <https://www.indigenoushealthnh.ca/news/metis-public-health-surveillance-program-mphsp>
- Indigenous Services Canada. (2023). *Statistics*. Government of Canada. <https://www.sac-isc.gc.ca/eng/1313164698167/1604595012263>
- International Work Group for Indigenous Affairs. (2021, March 18). The Indigenous World 2021: Indigenous data sovereignty. *International processes and initiatives*. <https://www.iwgia.org/en/ip-i-iw/4268-iw-2021-indigenous-data-sovereignty.html>
- James, A.L. (2023). *Measuring what matters: Exploring measures of Metis children's social and emotional well-being* [Unpublished Master's thesis]. University of Alberta, Edmonton, Alberta.
- Jeffery, B., Abony, S., Hamilton, C., Bird, S., Denechezhe, M., Lidguerre, T., Michayluk, F., Thomas, L., Throassie, E., & Whitecap, Z. (2006b). *Community health indicators toolkit*. Saskatchewan Population Health and Evaluation Research Unit.
- Jeffery, B., Abonyi, S., Labonte, R., & Duncan, K. (2006a). Engaging numbers: Developing health indicators that matter for First Nations and Inuit people. *International Journal of Indigenous Health*, 3(1), 44-52.
- Johnson, H., & Sutherland, J. (2022). *A conceptual framework for Indigenous cultural safety measurement*. National Collaborating Centre for Indigenous Health.
- Joseph, B. (2020). *What is an Indigenous Medicine Wheel?* Indigenous Corporate Training Inc. <https://www.ictinc.ca/blog/what-is-an-indigenous-medicine-wheel>
- Kant, S., Vertinsky, I., Zheng, B., & Smith, P.M. (2013). Social, cultural, and land use determinants of the health and well-being of Aboriginal peoples of Canada: A path analysis. *Journal of Public Health Policy*, 34(3), 461-476
- Kennedy, M., Maddox, R., Booth, K., Maidment, S., Chamberlain, C., & Bessarab, D. (2022). Decolonising qualitative research with respectful, reciprocal, and responsible research practice: A narrative review of the application of Yarning method in qualitative Aboriginal and Torres Strait Islander health research. *International Journal for Equity in Health*, 21, 134.
- Keynan, Y., & Buckeridge, D. (2023, September 26). *Bridging the gaps: A vision for public health surveillance in Canada*. National Collaborating Centre for Infectious Diseases & Public Health Agency of Canada.
- Kumar, A. (2016). HIV/AIDS risk and prevention issues among Inuit living in Nunavut Territory of Canada. *In Vivo*, 30(6), 905-916.
- Lambert, S., & Henry, R. (2020). Surveilling Indigenous communities in a time of pandemic. *Surveillance & Society*, 18(3), 422-425.
- Lasry, O., Dudley, R. W., Fuhrer, R., Torrie, J., Carlin, R., & Marcoux, J. (2016). Traumatic brain injury in a rural Indigenous population in Canada: A community-based approach to surveillance. *CMAJ Open*, 4(2), E249-E259.
- Lauson, S., McIntosh, S., Obed, N., Healey, G., Asuri, S., Osborne, G., & Arbour, L. (2011). The development of a comprehensive maternal-child health information system for Nunavut-Nutaqqavut (our children). *International Journal of Circumpolar Health*, 70(4), 363-72.
- Lavoie, J., Boulton, A., & Dwyer, J. (2010). Analysing contractual environments: Lessons from Indigenous health in Canada, Australia and New Zealand. *Public Administration*, 88(3), 665-679.
- Lee, R. (n.d.). *FNHA Wellness indicators* [Presentation]. <https://www.fnha.ca/Documents/FNHA-Wellness-Indicators-Rebecca-Lee.pdf>
- Lix, L.M., Metge, C., & Leslie, W.D. (2009). Measurement equivalence of osteoporosis-specific and general quality-of-life-instruments in Aboriginal and non-Aboriginal women. *Quality of Life Research*, 18(5), 619-27.



- Logie, C. H., Lys, C. L., Dias, L., Schott, N., Zouboules, M. R., MacNeill, N., & Mackay, K. (2019). "Automatic assumption of your gender, sexuality and sexual practices is also discrimination": Exploring sexual health care experiences and recommendations among sexually and gender diverse persons in Arctic Canada. *Health & Social Care in the Community*, 27(5), 1204-1213.
- Love, R.P., Hardy, B.-J., Heffernan, C., Heyd, A., Cardinal-Grant, M., Sparling, L., Healy, B., Smylie, J., & Long, R. (2022). Developing data governance agreements with Indigenous communities in Canada: Toward equitable tuberculosis programming, research, and reconciliation. *Health & Human Rights*, 24(1), 21-33.
- Lovett, R., Lee, V., Kukutai, T., Cormack, D., Rainie, S. C., & Walker, J. (2019). Good data practices for Indigenous data sovereignty and governance. In A. Daly, S. K. Devitt, & M. Mann (eds.), *Good data* (pp. 26-36). Institute of Network Cultures.
- Lussier, M.-T., Richard, C., Bennett, T.-L., Williamson, T., & Nagpurkar, A. (2012). Surveillance or research: What's in a name? *Canadian Family Physician*, 58(1), 117.
- MacIntosh, C. (2008). Envisioning the future of Aboriginal health under the health transfer process. *Health Law Journal, Special Ed.*, 67-100.
- Marsden, N., Star, L., & Smylie, J. (2020). Nothing about us without us in writing: Aligning the editorial policies of the Canadian Journal of Public Health with the inherent rights of Indigenous Peoples. *Canadian Journal of Public Health*, 111, 822-825.
- Mashford-Pringle, A., Ring, I., Al-Yaman, F., Waldon, J., & Chino, M. (2019). Rethinking health service measurement for Indigenous populations. *Statistical Journal of the IAOS*, 35(1), 139-146.
- Mashford-Pringle, A., Tan, S., Stutz, S., & Tjong, G. (2023). Designing accountability measures for health professionals: Results from a community-based micro-credential: Case study on Indigenous cultural safety. *BMC Public Health*, 23, 879.
- Mayan, M. J., Gokiart, R. J., Robinson, T., & Tremblay, M. (2019). Community setting as a determinant of health for Indigenous Peoples living in the Prairie Provinces of Canada: High rates and advanced presentations of tuberculosis. *The International Indigenous Policy Journal*, 10(2), 5.
- McGill, E., Coulby, C., Dam, D., Bellos, A., McCormick, R., & Patterson, K. (2023). Canadian COVID-19 outbreak surveillance system: Implementation of national surveillance during a global pandemic. *Canadian Journal of Public Health*, 114, 358-367.
- Mill, J., Edwards, N., Jackson, R., Austin, W., MacLean, L., & Reintjes, F. (2009). Accessing health services while living with HIV: Intersections of stigma. *Canadian Journal of Nursing Research*, 31(3), 168-185.
- Mill, J., Edwards, N., Jackson, R. C., MacLean, L., & Chaw-Kant, J. (2011). Stigmatization as a social control mechanism for persons living with HIV and AIDS. *Qualitative Health Research*, 20(11), 1469-1483.
- Minore, B., Katt, M., & Hill, M.E. (2009). Planning without facts: Ontario's Aboriginal health information challenge. *Journal of Agromedicine*, 14(2), 90-96.
- Moriarty, R.J., Zuk, A.M., Liberda, E.N., & Tsuji, L.J.S. (2021). Health measures of Eeyouch (Cree) who are eligible to participate in the on-the-land Income Security Program in Eeyou Istchee (northern Quebec, Canada). *BMC Public Health*, 21, 628.
- Mosby, I., & Swidrovich, J. (2021). Medical experimentation and the roots of COVID-19 vaccine hesitancy among Indigenous Peoples in Canada. *Canadian Medical Association Journal*, 193(11), E381-E383.
- Murphy, M. (2023). Freedom, self-determination, and Indigenous well-being. In D. Karmis & J. Maclure (eds.), *Civic freedom in an age of diversity: The public philosophy of James Tully* (pp. 256-278). McGill-Queen's Press.
- National Association of Friendship Centres. (2021). *Urbanization and Indigenous Peoples in Canada: Responses for the questionnaire from the Special Rapporteur on the Rights of Indigenous Peoples*. <https://nafc.ca/downloads/unquestionnaire-from-the-special-rapporteur-on-the-rights-of-indigenous-peoples-2021.pdf>
- National Collaborating Centre for Indigenous Health. (NCCIH). (2023). *Public health surveillance 2030 and 2024 core competencies for public health in Canada: Meeting notes from regional consultation – Prince George, BC, October 31, 2023*. Unpublished document.
- Nelson, J. (2014, March 3). *First Nations Health Authority* [presentation]. First Nations Health Authority. [https://med-fom-learningcircle.sites.olt.ubc.ca/files/2014/01/Joanne-Nelson-PPT\\_March-3-2014.pdf](https://med-fom-learningcircle.sites.olt.ubc.ca/files/2014/01/Joanne-Nelson-PPT_March-3-2014.pdf)
- Oguamanam, C. (2019). ABS: Big data, data sovereignty and digitization. In C. Oguamanam (ed.), *Genetic resources, justice and reconciliation: Canada and global access and benefit sharing* (pp. 196-211). Cambridge University Press.
- O'Neil, J. D., & Blanchard, J. (2001). *Consideration for the development of public health surveillance in First Nations communities*. Prepared by the Centre for Aboriginal Health Research, University of Manitoba for the Assembly of First Nations, Health Secretariat, First Nations Information Governance Committee. <https://epub.sub.uni-hamburg.de/epub/volltexte/2010/5150/pdf/Surveillancepaperfinal.pdf>

- O'Neil, J., Reading, J., & Leader, A. (1998). Changing the relations of surveillance: The development of a discourse of resistance in Aboriginal epidemiology. *Human Organization*, 57(2), 230-237.
- Oracle Canada. (2023). Big data defined. *What is big data?* <https://www.oracle.com/ca-en/big-data/what-is-big-data/>
- Pauktuutit Inuit Women of Canada, & Rasmussen, D., & Guillou, J. (2012). Developing an Inuit-specific framework for culturally relevant health indicators incorporating gender-based analysis. *Journal of Aboriginal Health*, March, 24-37.
- Pickering, K., Galappaththi, E. K., Ford, J. D., Singh, C., Zavaleta-Cortijo, C., Hyams, K., Miranda, J. J., Arotoma-Rojas, I., Togarepi, C., Kaur H., Arvind, J., Scanlon, H., Namanya, D. B., Anza-Ramirez, C., & COVID-Observatories Team. (2023). Indigenous Peoples and the COVID-19 pandemic: A systematic scoping review. *Environmental Research Letters*, 18(3), 033001.
- Pike, I., McDonald, R.J., Piedt, S., & Macpherson, A.K. (2014). Developing injury indicators for First Nations and Inuit children and youth in Canada: A modified Delphi approach. *Chronic Diseases and Injuries in Canada*, 34(4), 203-9.
- Pollock, N. J., Healey, G. K., Jong, M., Valcour, J. E., & Mulay, S. (2018). Tracking progress in suicide prevention in Indigenous communities: A challenge for public health surveillance in Canada. *BMC Public Health*, 18, 1320.
- Poudrier, J. (2003). "Racial" categories and health risks: Epidemiological surveillance among Canadian First Nations. In D. Lyon (ed.), *Surveillance as social sorting: Privacy, risk and digital discrimination* (pp. 111-134). Routledge.
- Price, T. & Pride, T. (2023). The Canadian Occupational Performance Measure (COPM): Critiquing its applicability with Indigenous Peoples. *The Open Journal of Occupational Therapy*, 11(12), 1-12.
- Proudfoot, S. (2016). The census is back with a swagger. *MacLean's Magazine* [online], May 4. <https://macleans.ca/news/canada/the-census-is-back-with-a-swagger/>
- Public Health Agency of Canada (PHAC). (2006). *Maternity Experiences Survey, 2006 – Questionnaire*. Government of Canada. [https://www.canada.ca/content/dam/phac-aspc/migration/phac-aspc/rhs-ssg/pdf/question07\\_e.pdf](https://www.canada.ca/content/dam/phac-aspc/migration/phac-aspc/rhs-ssg/pdf/question07_e.pdf)
- Public Health Agency of Canada (PHAC). (2009). *What mothers say: The Canadian Maternity Experiences Survey*. Government of Canada. <https://www.canada.ca/content/dam/phac-aspc/migration/phac-aspc/rhs-ssg/pdf/survey-eng.pdf>
- Public Health Agency of Canada (PHAC). (2014). *Summary of key findings from the A-Track pilot survey (2011-2012)*. Government of Canada. [https://publications.gc.ca/collections/collection\\_2014/aspc-phac/HP40-118-2014-eng.pdf](https://publications.gc.ca/collections/collection_2014/aspc-phac/HP40-118-2014-eng.pdf)
- Public Health Agency of Canada (PHAC). (2023). *Notifiable diseases online*. Government of Canada. <https://diseases.canada.ca/notifiable/>
- Purdy, S. (2015). Surveillance, knowledge and inequality: Understanding power through Foucault and beyond. *The Hilltop Review*, 8(1), 3.
- Pyper, E., Henry, D., Yates, E. A., Mecredy, G., Ratnasingham, S., Slegers, B., & Walker, J. D. (2018). Walking the path together: Indigenous health data at ICES. *Healthcare Quarterly*, 20(4), 6-10.
- Qanuippitaa? National Inuit Health Survey. (2021a). *History*. <https://nationalinuithealthsurvey.ca/about/#:~:text=History-,The%20Qanuippitaa%3F,and%20Nunatsiavut%20in%202007%2D2008>
- Qanuippitaa? National Inuit Health Survey. (2021b). *About*. <https://nationalinuithealthsurvey.ca/about/>
- Qanuippitaa? National Inuit Health Survey. (2021c). *Approach*. <https://nationalinuithealthsurvey.ca/approach/>
- Research Data Alliance. (n.d.). *International Indigenous data sovereignty IG*. <https://www.rd-alliance.org/groups/international-indigenous-data-sovereignty-ig#:~:text=The%20goals%20of%20the%20International,driven%20research%2C%20and%20data%20use>
- Redden, M., & Kwan-Lafond, D. (2023). Indigenous data sovereignty: Moving toward self-determination and a future of good data. In K. Thompson, E. Hill, E. Carlisle-Johnston, D. Dennie, & É. Fortin (eds.), *Research data management in the Canadian context: A guide for practitioners and learners* (Chapter 3). Open Library. <https://ecampusontario.pressbooks.pub/canadardm/chapter/indigenous-data-sovereignty>
- Rowe, R., Russo Carroll, S., Healy, C., Walker, J.D., & Rodriguez-Lonebear, D. (2021). The SEEDS of Indigenous population health data linkage. *International Journal of Population Data Science*, 6(1). 22-32.
- Rowe, R. K., Rowat, J., & Walker, J. D. (2020). First Nations' survivance and sovereignty in Canada during a time of COVID-19. *American Indian Culture and Research Journal*, 44(2), 89-99.
- Roy, L.M., Neill, A., Swampy, K., Auger, J., Campbell, S.M., Chatwood, S., Al Sayah, F., & Johnson, J.A. (2024). Preference-based measures of health-related quality of life in Indigenous people: A systematic review. *Quality of Life Research*, 33(2), 317-333.



- Russo Carroll, S., Akee, R., Chung, P., Cormack, D., Kukutai, T., Lovett, R., Suina, M., & Rowe, R. K. (2021). Indigenous Peoples' data during COVID-19: From external to internal. *Medical Sociology*, 6, 1-8.
- Russo Carroll, S., Garba, I., Figueroa-Rodríguez, O. L., Holbrook, J., Lovett, R., Materechera, S., Parsons, M., Raseroka, K., Rodriguez-Lonebear, D., Rowe, R., Sara, R., Walker, J. D., Anderson, J., & Hudson, M. (2020). The CARE principles for Indigenous data governance. *Data Science Journal*, 19(43), 1-12.
- Sabeti, S., Xavier, C., Slaunwhite, A., Meilleur, L., MacDougall, L., Vaghela, S., McKenzie, D., Kuo, M., Kendall, P., Aiken, C., Gilbert, M., McDonald, S., & Henry, B. (2021). Collaborative data governance to support First Nations-led overdose surveillance and data analysis in British Columbia, Canada. *International Journal of Indigenous Health*, 16(2), 338-356.
- Sarfati, D., Garvey, G., Robson, B., Moore, S., Cunningham, R., Withrow, D., Griffiths, K., Caron, N. R., & Bray, F. (2018). Measuring cancer in Indigenous populations. *Annals of Epidemiology*, 28(5), 335-342.
- Saunders, V., McCalman, J., Tsey, S., Askew, D., Campbell, S., Jongen, C., Angelo, C., Spurling, F., & Cadet-James, Y. (2023). Counting what counts: A systematic scoping review of instruments used in primary healthcare services to measure the wellbeing of Indigenous children and youth. *BMC Primary Care*, 24, 51.
- Schonlau, M., & Liebau, E. (2012). Respondent-Driven Sampling. *The Stata Journal*, 12(1), 72-93. <https://doi.org/10.1177/1536867x1201200106>
- Shen, N., Sequeira, L., Pannor Silver, M., Carter-Langford, A., Strauss, J., & Wiljer, D. (2019). Patient privacy perspectives on health information exchange in a mental health context: Qualitative study. *JMIR Mental Health*, 6(11), e13306.
- Smylie, J., & Anderson, M. (2006). Understanding the health of Indigenous peoples in Canada: Key methodological and conceptual challenges. *Canadian Medical Association Journal*, 175(6), 602.
- Smylie, J., Anderson, I., Ratima, M., Crengle, S., & Anderson, M. (2006). Indigenous health performance measurement systems in Canada, Australia, and New Zealand. *The Lancet*, 367, 2029-2031.
- Smylie, J., & Firestone, M. (2015). Back to the basics: Identifying and addressing underlying challenges in achieving high quality and relevant health statistics for Indigenous populations in Canada. *Statistical Journal of the IAOS*, 31(1), 67-87.
- Smylie, J., Firestone, M., Spiller, M.W., & Tungasuvvingat Inuit. (2018). Our health counts: Population-based measures of urban Inuit health determinants, health status, and health care access. *Canadian Journal of Public Health*, 109(5-6), 662-670.
- Spasovska, I. (2012). *On-reserve First Nations and health transfer policy*. York University.
- Stangl, A. L., Earnshaw, V. A., Logie, C. H., van Brakel, W., Simbayi, L. C., Barré, I., & Dovidio, J. F. (2019). The health stigma and discrimination framework: A global crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*, 17, 31.
- Statistics Canada. (2006a). *Aboriginal Children's Survey – 2006 and James Bay Cree supplement (children – aged 0 to 5)*. Government of Canada. [https://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=getInstrumentList&Item\\_Id=34289&UL=1V&](https://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=getInstrumentList&Item_Id=34289&UL=1V&)
- Statistics Canada. (2006b). *Aboriginal Children's Survey/ Survey of Northern children 2006 (Children – aged 0 to 5)*. Government of Canada. [https://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=getInstrumentList&Item\\_Id=34361&UL=1V&](https://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=getInstrumentList&Item_Id=34361&UL=1V&)
- Statistics Canada. (2007). Detailed information for 2006. *Aboriginal Children's Survey (ACS)*. Government of Canada. <https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5108>
- Statistics Canada. (2008). *Microdata user guide: National longitudinal survey of children and youth – Cycle 8, September 2008 to July 2009*. Government of Canada. <https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=4450>
- Statistics Canada. (2021). Detailed information for 2021. *Canadian Community Health Survey – Annual component (CCHS)*. Government of Canada. <https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&Id=1314175>
- Statistics Canada. (2022a). Definitions and concepts. *Indigenous Peoples reference guide, Census of population, 2021*. Government of Canada. <https://www12.statcan.gc.ca/census-recensement/2021/ref/98-500/009/98-500-x2021009-eng.cfm>
- Statistics Canada. (2022b). *Indigenous Peoples Survey -2022*. Government of Canada. [https://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=assembleInstr&lang=en&Item\\_Id=1389872#qb1398263](https://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=assembleInstr&lang=en&Item_Id=1389872#qb1398263)
- Stelkia, K., Manshadi, A., Adams, E., Wieman, C., & Reading, J. (2023). Weaving promising practices to transform Indigenous population health and wellness reporting by Indigenous indicators in First Nations health. *International Journal of Indigenous Health*, 18(1), 1-11.

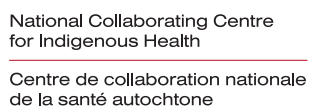
- Tarasuk, J., Ogunnaik-Cooke, S., Archibald, C., MacLean, R., Bennett, R., Kim, J., Malloch, L., & I-Track Principal Investigators. (2014a). Key findings from a national enhanced HIV surveillance system: 2010-2012. *Canada Communicable Disease Reports*, 40(18), 397-407.
- Tarasuk, J., Ogunnaik-Cooke, S., Archibald, C., Poitras, M., Hennick, M., Lloyd, K., Faye, R., Abbas, Z., Bourassa, C., Masching, R., Bennett, R., MacLean, R., Malloch, L., & Kim, J. (2014b). A pilot behavioural and biological surveillance survey for HIV and other bloodborne infections among Aboriginal people in Regina, Saskatchewan. *Canada Communicable Disease Report*, 40(18), 388-397.
- Taylor, K. (2011, December 8). Striking levels of poverty, illness found in Aboriginal People living in urban areas: Study. *Our stories* [Our Health Counts, media release]. St. Michael's Hospital. <http://www.welllivinghouse.com/wp-content/uploads/2014/04/OHC-News-Release.pdf>
- Thurber, K. A., Thandrayen J., Banks, E., Doery, K., Sedgewick, M., & Lovett, R. (2020). Strengths-based approaches for quantitative data analysis: A case study using the Australian Longitudinal Study of Indigenous children. *SSM Population Health*, 12, 100637.
- Truth and Reconciliation Commission (TRC) of Canada. (2015). *Truth and Reconciliation Commission of Canada: Calls to action*. [https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls\\_to\\_action\\_english2.pdf](https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls_to_action_english2.pdf)
- Tsuiji, S.R.J., Zuk, A.M., Solomon, A., Edwards-Wheesk, R., Ahmed, F., & Tsuiji, L.J.S. (2023). What is wellbeing, and what is important for wellbeing? Indigenous voices from across Canada. *International Journal of Environmental Research and Public Health*, 20(17), 6656.
- Tungasuvvingat Inuit, & Well Living House Action Research Centre for Indigenous Infant, Child and Family Health and Wellbeing. (2017). *Community report, Inuit adults, City of Ottawa*. Our health counts: Urban Indigenous health database project. <http://www.welllivinghouse.com/what-we-do/projects/our-health-counts/our-health-counts-ottawa/>
- Walker, J., Lovett, R., Kukutai, T., Jones, C., & Henry, D. (2017). Indigenous health data and the path to healing. *The Lancet*, 390(10107), 2022-2023.
- Walter, M., Lovett, R., Maher, B., Williamson, B., Prehn, J., Bodkin-Andrews, G., & Lee, V. (2021). Indigenous data sovereignty in the era of big data and open data. *Australian Journal of Social Issues*, 56(2), 143-156.
- Walter, M., & Suina, M. (2019). Indigenous data, indigenous methodologies and indigenous data sovereignty. *International Journal of Social Research Methodology*, 22(3), 233-243.
- Wark, K., Cheung, K., Wolter, E., & Avey, J.P. (2021). Engaging stakeholders in integrating social determinants of health into electronic health records: A scoping review. *International Journal of Circumpolar Health*, 80(1), 1943983.
- Well Living House. (2023). *Our health counts*. <http://www.welllivinghouse.com/what-we-do/projects/our-health-counts/>
- Wilkinson, M. D., Dumontier, M., Aalbersberg, U. J., Appleton, G., Axton, M., Baak, A., Blomberg, N., Boiten, J.-W., da Silva Santos, L. B., Bourne, P. E., Bouwman, J., Brookes, A. J., Clark, T., Crosas, M., Dillo, I., Dumon, O., Edmunds, S., Evelo, C. T., Finkers, R., Gonzalez-Beltran, A., et al. (2016). The FAIR guiding principles for scientific data management and stewardship. *Scientific Data*, 3, 160018.
- Williams, J., Vis-Dunbar, M., & Weber, J. (2011). First Nations privacy and modern health care delivery. *Indigenous Law Journal*, 10(1), 100-132.
- Williamson, A., Andersen, M., Redman, S., Dadds, M., D'Este, C., Daniels, J., Eades, S., & Raphael, B. (2013). Measuring mental health in Indigenous young people: A review of the literature from 1998-2008. *Clinical Child Psychology and Psychiatry*, 19(2), 165-329.
- Willing, E., Paine, S.-J., Wyeth, E., Te Ao, B., Vaithianathan, R., & Reid, P. (2020). Indigenous voices on measuring and valuing health states. *AlterNative*, 16(1), 3-9.
- Wilson, K. (2018). *Pulling together: A guide for Indigenization of post-secondary institutions*. BCcampus. <https://opentextbc.ca/indigenizationfoundations/>
- Wilson, L.A., Pakes, B., Murphy, M.S.Q., Atkinson, K.M., Bell, C., & Wilson, K. (2017). Connecting remote populations to public health: The case for a digital immunization information system in Nunavut. *International Journal of Circumpolar Health*, 76(1), 1358566.
- Yellowhead Institute. (2023). *Calls to action accountability: A 2023 status update on reconciliation*. <https://yellowheadinstitute.org/wp-content/uploads/2023/12/YI-TRC-C2A-2023-Special-Report-compressed.pdf>
- Yiannakoulis, N., Svenson, L.W., & Schopflocher, D. P. (2009). An integrated framework for the geographic surveillance of chronic disease. *International Journal of Health & Geography*, 8, 69.
- Young, T.K., Chatwood, S., Ng, C., Young, R.W., & Marchildon, G.P. (2019). The north is not all the same: Comparing health system performance in 18 northern regions of Canada. *International Journal of Circumpolar Health*, 78(1), 1697474.



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