Promising Practice

Collaborative Data Governance to Support First Nations-Led Overdose Surveillance and Data Analysis in British Columbia, Canada

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ABSTRACT

First Nations Peoples in the province of British Columbia (BC), Canada, have been disproportionately affected by the overdose crisis. In 2016, a public health emergency was declared by BC's Provincial Health Officer (PHO) in response to the significant rise in opioid-related overdose deaths reported in BC. New surveillance systems were required to identify trends in overdose events and related deaths in the province as a whole, and for First Nations Peoples. Data sharing and analysis processes that adhered to the principles of OCAP® (ownership, control, access, and possession), and to the Truth and Reconciliation Commission of Canada's Calls to Action, needed to be developed. The First Nations Health Authority (FNHA), BC Centre for Disease Control, PHO, and the BC Ministry of Health have worked collaboratively to facilitate identification of First Nations persons in surveillance data for appropriate analysis by FNHA. This paper outlines the data stewardship and governance context, principles, and operational considerations for creating overdose surveillance systems to measure overdose events among First Nations Peoples in BC.

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List of Abbreviations

BC: British Columbia

BCCDC: BC Centre for Disease Control

BCCS: BC Coroners Service

Client File: BC First Nations Client File

Cohort: BC Provincial Overdose Cohort

FNHA: First Nations Health Authority

FNIGC: First Nations Information Governance Centre

OCAP: ownership, control, access, and possession (OCAP® is a registered trademark of the FNIGC; <https://fnigc.ca/ocap-training/>)

PHO: Provincial Health Officer

TRC: Truth and Reconciliation Commission of Canada

Introduction

The effects of the opioid-driven overdose epidemic have been felt strongly in North America. In Canada, the province of British Columbia (BC) has been particularly affected. First Nations Peoples in BC are disproportionately affected by the overdose crisis. While First Nations people comprise 3.4% of the population of BC, they represented 12.8% of all persons who died of overdose in 2018. This is 4.2 times the overdose mortality rate seen in other residents of BC, and is a 21% increase over First Nations overdose deaths reported in 2017 (First Nations Health Authority [FNHA], 2019a). First Nations women are disproportionately affected, with higher rates of overdose events and deaths compared to other BC women. Key differences also exist in

the geographical distribution of overdoses among the First Nations population, differences that have influenced resource and program planning across BC (FNHA, 2019b).

FNHA, the first province-wide health authority of its kind in Canada, was established in October 2013 after the signing of the BC Tripartite Framework Agreement on First Nations Health Governance by FNHA (endorsed by the First Nations Health Council), Province of BC, and Government of Canada in October 2011. FNHA assumed responsibility for the design, management, and delivery of health services formerly delivered by Health Canada for all Status First Nations people in BC. FNHA's mandate is to provide a health governance structure that reduces health inequities faced by First Nations populations, and to improve health outcomes by addressing gaps in health services through the provision of culturally safe services that include First Nations people in policy and program development (FNHA, n.d.-a).

When BC's Provincial Health Officer (PHO) declared a public health emergency in April 2016 in response to a rise in drug overdoses and deaths, a provincial public health surveillance system was established. The goal of the surveillance system was to monitor the incidence of overdose cases (fatal and nonfatal), and identify trends across time, geography, and demographic characteristics. Several data sources were monitored to produce a composite picture of overdose events, including paramedic-attended overdoses, presentations to emergency departments, and deaths identified by the BC Coroners Service (BCCS). Various additional data sources were linked to construct a comprehensive understanding of the population at risk of overdose, identify risk factors, and monitor the effectiveness of interventions. This linkage of surveillance and administrative healthcare data resulted in the development of the BC Provincial Overdose Cohort (the Cohort), an amalgamation of surveillance and administrative healthcare data of people who have a health record indicating a drug-related overdose. The BC Centre for Disease Control (BCCDC) led the development of the Cohort in collaboration with the regional health authorities, FNHA, the Ministry of Health, BC Emergency Health Services, and BCCS. Specific case definitions and linkage methodology are published elsewhere (MacDougall et al., 2019). The Cohort is refreshed annually and complements the real-time surveillance efforts through data linkage, but sacrifices timeliness given the complexity of data integration and analyses.

In order to reduce health disparities experienced by First Nations people, inequities must be identified to inform decision-making. These inequities include historically limited access to reliable, First Nations-specific data. FNHA's framework for action in response to the overdose crisis (Figure 1) required data upon which to make sound decisions. Unlike regional health authorities, FNHA is not regionally based or confined by geographic boundaries within the province, and it cannot access data on its clients in the absence of a data linkage. The Cohort met these needs through linkage to the BC First Nations Client File (the Client File), a cohort of First Nations residents in BC registered under the Indian Act and their unregistered children who may be entitled to register. This linkage offered robust information on overdose events and deaths among First Nations Peoples.

Figure 1*First Nations Health Authority's Framework for Action*

Note. From A Framework for Action: Responding to the Overdose/Opioid Public Health Emergency for First Nations, First Nations Health Authority, 2017a (<https://www.fnha.ca/Documents/FNHA-Overdose-Action-Plan-Framework.pdf>). Copyright 2017 by the First Nations Health Authority. Reprinted with permission.

While some datasets have recorded self-identification of First Nations status, these tend to have high levels of nonresponse, misclassification, or bias. Mistrust of government institutions can deter First Nations people from participating in surveillance and research activities due to current and historical mistreatment of First Nations, Inuit, and Métis Peoples within the healthcare system (Allan & Smylie, 2015; Smylie & Anderson, 2006). Many people may choose

not to self-identify to avoid further stigmatization and racism during healthcare interactions. Additionally, information about ethnicity is not routinely collected in Canada.

Given the challenges with self-reported identifiers, past experience with data linkage and sharing, and analysis processes that use the Client File, a protocol that adhered to the principles of OCAP¹ and the Truth and Reconciliation Commission of Canada's (TRC's) Calls to Action (TRC, 2015) needed to be developed to support emergency response.²

The FNHA, BCCDC, PHO, and Ministry of Health worked collaboratively to create a new data linkage process to facilitate the identification of Status First Nations persons in surveillance and Cohort data for analysis by FNHA. Two main linkages were established:

1. To support more timely surveillance activities of FNHA, the Client File was linked to the BCCS's report of illicit drug toxicity deaths.
2. The Client File was linked to the Cohort to establish a First Nations-specific cohort which would allow comparisons between First Nations people experiencing overdoses and other residents of BC.

In this paper, we outline the data stewardship and governance model of the First Nations drug-related overdose data, describe the joint analysis and analytic capacity building that occurred, and highlight FNHA's autonomy in data interpretation and knowledge translation. We describe new ways of working collaboratively through developing analytic capacity at FNHA and collectively discussing insights from the data with linkage partners. Providing full ownership of First Nations data to FNHA supports appropriate analysis, interpretation, context setting, language, and dissemination of the data, which in turn upholds First Nations Peoples' right to self-determination.

Supporting First Nations Data Governance: Best Practices and Calls to Action

The First Nations principles of OCAP describe collective rights to control the collection, use, and storage of data about First Nations Peoples (First Nations Information Governance Centre [FNIGC], 2014a). A collaborative partnership between the BC Ministry of Health, PHO, BCCDC, and FNHA aimed to implement these Indigenous data sovereignty principles. This collective and reciprocal partnership supported the creation of an overdose surveillance system for First Nations people through the development of a new data linkage process. This approach also increased the voice of First Nations via the continual collaboration between FNHA and BCCDC, from the inception of the Cohort to the dissemination of findings. Linkages with the Client File provided access to data to assess overall impacts as well as differences in overdose-related health status and outcomes between First Nations people and other residents of BC. This

¹ Standing for ownership, control, access, and possession, OCAP® is a registered trademark of the First Nations Information Governance Centre (<https://fnigc.ca/ocap-training/>).

² Please note that the work outlined in this paper predates the implementation of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) into BC legislation in November 2019, as the BC Declaration on the Rights of Indigenous Peoples Act (DRIPA). The adoption of UNDRIP and DRIPA in BC will likely help to shape future work in this area.

work informed decisions for allocating resources and planning health interventions to support First Nations people affected by the overdose crisis. This partnership highlights the commitment of the provincial government, BCCDC, and FNHA to respond to the TRC's (2015) Calls to Action.

As outlined in the TRC's Calls to Action, OCAP, and the Calls for Justice from the National Inquiry into Missing and Murdered Indigenous Women and Girls (2019), all interventions and programs/services addressing disparities in health outcomes must be centred in Indigenous ways of knowing and doing, with Indigenous people leading the development, planning, and implementation of solutions (FNIGC, 2014a, 2014b; Read et al., 2014; TRC, 2015). This approach is the basis of self-determination, which acknowledges Indigenous Peoples' jurisdiction over data from their communities, and the legal and ethical obligations to provide resources for the development of solutions that address health inequities (FNIGC, 2014b; National Inquiry Into Missing and Murdered Indigenous Women and Girls, 2019). Table 1 highlights how OCAP principles and one of the TRC's Calls to Action (#19) were implemented in the context of the overdose surveillance.

Table 1

Integration of First Nations Data Governance Principles and the TRC's Call to Action #19 in FNHA's Overdose Surveillance System

Guiding Principle	Integration into the provincial overdose surveillance system
<i>OCAP First Nations data governance principle</i>	
<i>Ownership</i> refers to the relationship between a First Nations community and their cultural knowledge / data / information. This principle states that a community or group owns information collectively in the same way that an individual owns their personal information.	<ul style="list-style-type: none"> First Nations communities own data and FNHA has been appointed as the data steward for the First Nations-specific data within the overdose surveillance system. As a data steward, FNHA, in partnership with the PHO, BC Ministry of Health, and BCCDC, maintains a mechanism to protect ownership of First Nations-specific data within the overdose surveillance system. These data governance standards are outlined in an Information Sharing Agreement.
<i>Control</i> asserts that First Nations people, communities, or representative bodies have rights to control how information about them is collected, used, and disclosed / disseminated. This encompasses the entire spectrum of data management, from the data collection agreement and data collection process to disclosure / dissemination of data.	<ul style="list-style-type: none"> The PHO, BC Ministry of Health, BCCDC, and FNHA engage in a collaborative data management process, which starts with the development of a Data Access Request and Information Sharing Agreement to set standards for the protection and integration of First Nations data. Data analysis, knowledge translation, and knowledge exchange of First Nations surveillance data is carried out by FNHA and approved BCCDC analysts.

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Guiding Principle	Integration into the provincial overdose surveillance system
<i>OCAP First Nations data governance principle</i>	
<i>Access</i> refers to the notion that First Nations people must have access to their data and information. This principle also refers to the right of First Nations communities and organizations to manage their collective information and make decisions regarding who can access it.	<ul style="list-style-type: none"> Only designated surveillance team members (data analysts, epidemiologists, data linkage experts, etc.) from FNHA and BCCDC have access to the First Nations surveillance data. FNHA must review and approve of any person accessing these data. FNHA facilitates access to data for First Nations communities within BC while adhering to strict privacy policies that protect individual rights to privacy and anonymity.
<i>Possession</i> is a principle that brings First Nations data within First Nations jurisdiction and therefore within First Nations Peoples' control. Ownership defines the relationship between people and data, whereas possession refers to the physical control of data, hence describes a mechanism to protect ownership and control.	<ul style="list-style-type: none"> BCCDC hosts the overdose surveillance data for First Nations people. FNHA designates surveillance team members from FNHA and BCCDC to have access to the First Nations surveillance data.
<i>TRC's Call to Action #19</i>	
"We call 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. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services" (TRC, 2015, p. 322).	<ul style="list-style-type: none"> Linkage of the Client File with real-time surveillance data and the Cohort has enabled FNHA to assess overdose trends and identify gaps in overdose-related health status, health outcomes, and healthcare utilization between First Nations people and other residents of BC. FNHA has published two reports on the impact of the overdose crisis on First Nations people in BC (FNHA, 2017b, 2019a). These reports were generated from analyses using Cohort and surveillance data. Results from the analyses using the overdose surveillance system has helped FNHA to plan and implement Indigenous harm reduction interventions, expand naloxone training, and increase access of opioid agonist therapy through nursing stations. Analytic capacity, policies, and procedures that have been developed in response to the overdose crisis have increased FNHA's surveillance capacity across other sectors.

Note. Standing for ownership, control, access, and possession, OCAP® is a registered trademark of the First Nations Information Governance Centre (<https://fnigc.ca/ocap-training/>).

BC = British Columbia; BCCDC = BC Centre for Disease Control; Client File = BC First Nations Client File; Cohort = BC Provincial Overdose Cohort; FNHA = First Nations Health Authority; PHO = Provincial Health Officer; TRC = Truth and Reconciliation Commission of Canada.

Data Governance for Overdose Surveillance and Research in BC

Sources of Data

To identify First Nations people within data sources, the Client File was linked with data holdings at the BCCDC and supplemented with administrative health records stewarded by the Ministry of Health. These data sources are described below.

First Nations Client File

The Client File was first created by the Ministry of Health in 2011 and is updated annually. It is produced by creating a probabilistic record linkage of three data sources: (a) Indigenous and Northern Affairs Canada's Indian Registry, (b) BC Ministry of Health Client Roster/Registry, and (c) Vital Statistics (FNHA, 2018).

The Client File is hosted by the Ministry of Health's Chief Data Steward but is controlled by the Data and Information Planning Committee, a tripartite group composed of representatives from the Ministry of Health, FNHA, and Health Canada, created under the Tripartite Data Quality and Sharing Agreement. Under this agreement, the development, management, and control of the Client File must be executed with the collaboration and authorization of FNHA. The data to create the Client File are collected under privacy legislation that does not require consent of individuals, amplifying the responsibility of FNHA to protect the use of the Client File and ensure that it is used only with direct benefit for First Nations people living in BC.

BCCDC Overdose Surveillance Data

The BCCDC overdose surveillance data include data from the BC Drug and Poison Information Centre, BC Emergency Health Services, BCCS, and emergency department data from Northern, Interior, and Island Health regional health authorities.

Ministry of Health Data Holdings

The Ministry of Health data holdings include administrative health data from the BC Medical Services Plan (physician billings), Discharge Abstract Database (hospitalizations), National Ambulatory Care Reporting System (emergency department visits), and PharmaNet (prescription dispensations).

Lived Experience as a Source of Data

Health surveillance often uses a deficit-based approach to convey the prevalence and incidence of disease. FNHA aims to change the narrative and takes a strength-based approach to health reporting. This is particularly challenging in the context of the overdose crisis and working within the limitations of administrative health data. To complement traditional surveillance data, FNHA values data collected from people with lived experience. These stories highlight not only the challenges that First Nations people face but the incredible resilience they possess, which helps to frame quantitative data in a nonstigmatizing manner.

Mechanisms for Data Linkage

In response to the need for data to address the crisis, BC's PHO issued a public health order on April 14, 2016, under Section 53 of the Public Health Act, which allows for emergency provisions in collecting and accessing data that would normally be protected under the BC Freedom of Information and Protection of Privacy Act. Under this order, data from BC emergency departments, BCCS, and BC Emergency Health Services could be accessed by select data stewards, which enabled the development of a Data Access Request and an Information Sharing Agreement between the BCCDC, Ministry of Health, and FNHA for the purpose of linking the BCCDC's overdose surveillance data with the Ministry of Health's datasets and the Client File to create the Cohort (Figure 2). A similar approach supported a data linkage between the Client File and BCCS data to improve surveillance efforts.

Developing a Data Access Request and an Information Sharing Agreement is a resource-intensive, iterative process, requiring multiparty negotiations and obtaining the necessary approvals. An Information Sharing Agreement is a legally binding framework agreed upon by all parties outlining a specific process for data access, analysis, and the intended use of findings that incorporates FNHA's data governance protocols. The issuance of the public health order ensured the rapid assembly of data and development of the agreements required for the creation of the Cohort. The process took 8 months, from the time the Data Access Request was submitted to the time the preliminary data were linked and obtained (Figure 3).

Figure 2*Data Linkage Diagram*

BCEHS=BC Emergency Health Services; ED=Emergency Department; DPIC=Drug and Poison Information Centre; NACRS=National Ambulatory Care reporting System; DAD=Discharge Abstract Database; MSP=Medical Services Plan; MOH=Ministry of Health.

Note. From “Development and Characteristics of the Provincial Overdose Cohort in British Columbia, Canada,” by L. MacDougall, K. Smolina, M. Otterstatter, B. Zhao, M. Chong, D. Godfrey, A. Mussavi-Rizi, J. Sutherland, M. Kuo, and P. Kendall, 2019, *PloS ONE*, 14(1), Article e0210129 (<https://doi.org/10.1371/journal.pone.0210129>). Copyright 2019 by MacDougall et al.

Figure 3*Timeline for the Development of the BC Provincial Overdose Cohort*

Note. BC = British Columbia; DAR = Data Access Request; FNCF = First Nations Client File; FNHA = First Nations Health Authority; ISA = Information Sharing Agreement; MOH = Ministry of Health; PHO = Provincial Health Officer.

FNHA's Framework for Action: Responding to the Overdose/Opioid Public Health Emergency for First Nations

The FNHA, First Nations Health Council, and First Nations Health Directors Association are governed by seven directives (FNHA, n.d.-b):

1. Community-driven, Nation-based.
2. Increased First Nations decision-making and control.
3. Improve services.
4. Foster meaningful collaboration and partnership.
5. Develop human and economic capacity.
6. Be without prejudice to First Nations interests.
7. Function at a high operational standard.

Grounded in these directives, FNHA's initial Framework for Action relied on four pillars (Table 2). Although data from the Cohort have informed programming across all four pillars, the largest impact has been in gaining a more detailed understanding of how and where First Nations people are affected by the overdose crisis. In accordance with FNHA's Directive 1, initial overdose response programming has been heavily community focused. Data from the Cohort show that most First Nations experience overdoses outside of their communities, often in urban centres. This has led to the development of an expanded urban strategy to ensure culturally appropriate treatment options are accessible regardless of where First Nations people live in BC.

Table 2

Four Pillars for the First Nations Health Authority (FNHA) Framework for Action, and FNHA-Supported Programming (FNHA, 2019b)

Pillar	FNHA-supported programming
Prevent people who overdose from dying	<ul style="list-style-type: none"> • Take Home Naloxone is available at no cost to First Nations people at BC pharmacies and over 100 registered First Nations Health Centres • Nasal naloxone is available at no cost to First Nations people at BC pharmacies
Keep people safer when using	<ul style="list-style-type: none"> • Peer engagement, coordination, and navigation
Create accessible range of treatment options	<ul style="list-style-type: none"> • Integrated First Nations addiction care coordinator • Intensive case management • Opioid agonist clinic fee payment
Support people on their healing journey	<ul style="list-style-type: none"> • Unlocking the Gates (peer-health mentoring program) • Indigenous harm reduction grants

Building First Nations Capacity for Data Analysis

The principles of OCAP are reflected in the Cohort's analysis process. Health authorities, people with living and lived experience, and other community and government stakeholders are encouraged to submit questions for analysis annually. Stakeholders rank questions in order of highest priority. Then rankings are consolidated into themes to identify the questions of highest interest to the majority of organizations. Working groups are created for each analysis theme and organizations are invited to contribute analytic capacity. A First Nations Working Group, led by FNHA, was created to work in parallel with the other working groups and conduct analyses as directed by FNHA. The other working groups include FNHA representatives to contribute analytic capacity, provide knowledge and expertise, and learn new methodologies needed to conduct each analysis, as all analyses would eventually be replicated by the First Nations Working Group.

The First Nations overdose surveillance data are housed at the BCCDC but are owned and stewarded by FNHA. BCCDC ensures that a FNHA representative is present at all meetings involving First Nations data. Results from the First Nations Working Group are interpreted by FNHA's surveillance team. Once interpreted, results are shared with FNHA leadership for decisions regarding the presentation and publication of First Nations-specific data.

The response to the overdose crisis and the collaborative creation of the Cohort and surveillance system represented an important capacity-building exercise for FNHA. The crisis was a catalyst for quickly increasing resources and infrastructure. As a result, FNHA built a robust health surveillance team and an organization-wide overdose surveillance system. The emergency precipitated the creation of overarching data governance procedures and surveillance infrastructure for urgent public health situations, better preparing FNHA for future public health crises.

By increasing capacity to work in partnership with other organizations, FNHA has executed Directive 4: Foster meaningful collaboration and partnership. FNHA has also used this collaborative process to lead partners by example and demonstrate key values that underlie FNHA's organizational beliefs: the need to respect data and the people they belong to; and the importance of using nonstigmatizing language when analyzing and interpreting data.

Knowledge Translation

Recent data on overdose deaths can be seen in Figure 4, released by FNHA in May 2019. FNHA is mandated to give data back to those who own it. This includes sharing First Nations data in ways that reduce stigma, use culturally appropriate narratives, and protect people's privacy. Privacy can be challenging as data are often granular and may carry a risk of identification for communities, groups, or individuals. To safeguard privacy, FNHA may suppress particular data or share data in novel and nonstigmatizing ways. First Nations people own their data even if the data are not flagged specifically as First Nations. Data from an external source could represent or be inferred to represent First Nations people or communities, if those data are focused on a particular geography or a particular identifier was used. Thus, collaboration

with partners is key to ensuring OCAP principles are adhered to in a model of shared responsibility. For example, BCCDC, in collaboration with BCCS and FNHA, created a policy for public release of general population overdose events at the level of the community health service area. The policy states that data are suppressed or presented with caution if the community is composed of 25% or more First Nations residents or has a traditional First Nations name. In another example, BCCDC and FNHA's analytic teams collaborated on analyses of incarceration data. Due to the overrepresentation of First Nations people in prison populations, these data could potentially lead to further stigmatization, but a simple rule based on geography and population composition was not possible. Ongoing collaboration and review of the analyses were necessary to ensure that First Nations data were protected.

Figure 4*The Impact of the Opioid Crisis on First Nations in British Columbia*

Note. From *First Nations Opioid Overdose Deaths Rise in 2018* [News release], First Nations Health Authority, 2019a (<https://www.fnha.ca/about/news-and-events/news/first-nations-opioid-overdose-deaths-rise-in-2018>). Copyright 2019 by the First Nations Health Authority. Reprinted with permission.

Existing societal narratives about First Nations people and health reporting tend to focus on overrepresentation of First Nations people with respect to burden of disease. Data are released and occupy the public's attention for a news cycle, only to be quickly forgotten. Stigma and discrimination impact access to healthcare and community services for people who use drugs, resulting in major health and social impacts (Ahern et al., 2007). For that reason, FNHA and BCCDC use people-first language (e.g., "people who use drugs") in order to centre the person in the conversation and recognize that a behaviour is only one aspect of a person's life.

In creating a strategy to give data back to First Nations people, the focus was to avoid pathologizing and restigmatizing people at risk of overdose related to substance use. Highlighting structural factors, such as colonialism and systemic racism, that lead to substance use is vital to appropriately frame the crisis as a societal rather than individual issue. Public health framing is significantly more likely to cause people to support public policy changes than traditional framing which focuses on individual responsibility rather than the impact of social structures and policy (Coleman et al., 2011).

First Nations in BC own their health data, and community leaders must have reasonable access prior to public release. First Nations engagement was central to the knowledge translation and dissemination processes for the overdose data, including a layered release of embargoed presentations with the First Nations Health Council and First Nations Health Directors Association. Leaders refined the messaging and ensured the release of data did not have unintended negative consequences for First Nations people.

Following engagement with First Nations leadership, presentations were conducted at regional caucuses and wellness forums. This allowed for First Nations leadership, communities, and frontline workers to familiarize themselves with these data and provide feedback prior to public release. Data were jointly released by FNHA's Chief Medical Officer, BC's PHO, and BC's Chief Coroner, both in 2017 and in 2019.

Conclusions

Supporting First Nations self-determination in the use of health data requires early engagement with FNHA and/or other First Nations organizations in BC. Since the inception of the Cohort and overdose surveillance system, First Nations have been represented through ongoing engagement with FNHA. In keeping with the principles of First Nations data governance and OCAP, any public communication or release of First Nations overdose data has been led by FNHA. Though the Cohort provided the first available indicators on key First Nations-specific overdose data, the process for its creation was complex and resource intensive. Lack of timely surveillance data has severely impacted the ability to efficiently plan responses to the fluctuating state of the crisis. In the future, access to real-time data must be prioritized over the creation of a historical dataset for retrospective evaluation.

Despite best efforts to adhere to the OCAP principles, it was not possible for FNHA to house and manage the overdose data at the time. Though only FNHA analysts and FNHA-approved analysts from the BCCDC could access First Nations data, data were only accessible at

the BCCDC or remotely via a secure mechanism. Legislative restrictions and systemic data management procedures have affected access to data linked to the First Nations Client File. Although there is agreement to follow OCAP principles, existing privacy legislation does not yet directly confer the authority for FNHA to collect the person-level data required to conduct the analyses possible within the Cohort. The result is an overreliance on partners with finite resources to complete data linkages and house the resulting linked data. Moving forward, a key priority is to ensure the development of platforms that allow physical possession and direct access to the Client File and associated linked data by FNHA and other First Nations organizations.

The overdose crisis has substantially impacted the residents of BC and, in particular, First Nations people. Very few British Columbians are unaffected, including the authors of this paper who have lost family members and friends, and have witnessed firsthand the ongoing harm both to people using substances, and to their loved ones. We approached this project and the resulting data with respect for the individuals, families, and communities they represent. Throughout this crisis, in the face of so much loss, we have seen the incredible resilience of First Nations people in BC. This public health emergency has catalyzed the development of First Nations-led surveillance systems. Collaboration and relationship-building were instrumental in supporting the creation of the Cohort and overdose surveillance system, and in building data governance, analysis, and knowledge translation capacity within FNHA.

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