



Data and Information Governance

CASE STUDY REPORT



AS PART OF THE EVALUATION OF THE
TRIPARTITE FRAMEWORK AGREEMENT ON
FIRST NATION HEALTH GOVERNANCE

Data and Information Governance Case Study
Prepared by Praxis Management Inc.



First Nations Health Authority
Province of British Columbia
Indigenous Services Canada

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The work represented in this report is carried out on the unceded territories belonging to self-determining First Nations in what is now British Columbia. The Tripartite partners acknowledge and thank those who took the time to share their guidance and wisdom.

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Acronyms

Acronym / Abbreviation	Full Term
BCCA	BC Cancer Agency
CIRNA	Crown-Indigenous Relations and Northern Affairs Canada
CMO	Chief Medical Officer
CSBC	Cardiac Services BC
DIPC	Data and Information Planning Committee
Framework Agreement	<i>British Columbia Tripartite Framework Agreement on First Nations Health Governance</i>
FNCF	First Nations Client File
FNHA	First Nations Health Authority
FNIHB	First Nations and Inuit Health Branch
FOIPPA	<i>Freedom of Information and Protection of Privacy Act</i>
HSM	Health System Matrix
MOH	Ministry of Health
OCAP® principles	Ownership, Control, Access and Possession principles
OPHO	Office of the Provincial Health Officer
TDQSA	Tripartite Data Quality and Sharing Agreement
TFNHP	<i>Tripartite First Nations Health Plan</i>
Transformative Change Accord	Transformative Change Accord: First Nations Health Plan

Terminology

The Canadian *Constitution Act* specifies that the Aboriginal peoples of Canada include the Indian (First Nations), Inuit and Métis peoples of Canada.¹ Increasingly, the term “Indigenous” is used in place of the term “Aboriginal,” with an analogous meaning. In this report, the terms “Indigenous” and “Aboriginal” are used as they are in the source documentation cited.

The term “First Nations” is frequently used within this report. This term includes individuals with and without status under the *Indian Act*.²

This report uses a range of data sources, some of which rely on self-identification of ethnicity to identify Indigenous sub-populations and others that are based on deterministic data linkages using the First Nations Client File. Following the protocol used in Provincial Health Officer and the First Nations Health Authority Chief Medical Officer reporting,³ the term “Status First Nation” will be used in place of “Status Indian” in places in this report that refer to the First Nations Client File, recognizing that the legal connotation of the term “Indian” originates from a colonial framework.

The terms “at-home”, “in-community” and “community-based” are used to refer to geographically based First Nations communities, whether they qualify as “reserves” under the *Indian Act*, or whether the First Nation has signed a modern treaty or holds title to the land. The term “away from home” signifies First Nations individuals that live away from their First Nation community.

¹ Government of Canada. (n.d.). *Constitution Acts 1867 to 1982*. Retrieved from: <https://laws-lois.justice.gc.ca/eng/Const/page-16.html?txthl=inuit#inc>.

² An act to amend and consolidate the laws respecting Indians, S.C. 1876, c. 18.

³ Office of the Provincial Health Officer and First Nations Health Authority. *Indigenous Health and Well-being: Final Update, 2018*. Retrieved from <http://www.fnha.ca/Documents/FNHA-PHO-Indigenous-Health-and-Well-Being-Report.pdf>.

Table of Contents

ACRONYMS	1
TERMINOLOGY	2
EXECUTIVE SUMMARY	4
PURPOSE AND APPROACH	5
SECTION 1: UNDERSTANDING FIRST NATIONS PERSPECTIVES ON DATA GOVERNANCE	6
SECTION 2: HISTORY OF FIRST NATIONS HEALTH DATA GOVERNANCE IN BRITISH COLUMBIA	9
2.1 OCAP® PRINCIPLES	9
2.2 TRANSFORMATIVE CHANGE ACCORD (2005)	10
2.3 TRANSFORMATIVE CHANGE ACCORD: FIRST NATIONS HEALTH PLAN (2005)	11
2.4 TRIPARTITE FIRST NATIONS HEALTH PLAN (2007)	12
2.5 TRIPARTITE DATA QUALITY AND SHARING AGREEMENT (2010)	12
2.6 BC FIRST NATIONS CLIENT FILE (2011)	13
2.7 BC TRIPARTITE FRAMEWORK AGREEMENT ON FIRST NATIONS HEALTH GOVERNANCE (2011)	13
2.8 BC FIRST NATIONS PERSPECTIVES ON A NEW HEALTH GOVERNANCE ARRANGEMENT (2011)	14
SECTION 3: BC FIRST NATIONS HEALTH GOVERNANCE – SUCCESSES, CHALLENGES AND EMERGING OPPORTUNITIES	15
3.1 FIRST NATIONS DATA GOVERNANCE INFRASTRUCTURE AND CAPACITY	15
3.2 IMPORTANT PARTNERSHIPS AND COLLABORATIONS	18
3.3 OPPORTUNITIES AND CHALLENGES	26
SUMMARY	30
APPENDIX A: INTERVIEW QUESTIONS	31
REFERENCES	34

Executive Summary

This case study on First Nations data governance was prepared to support the evaluation of the *British Columbia Tripartite Framework Agreement on First Nations Health Governance* (Framework Agreement). It is intended to both fulfil the Framework Agreement's legal reporting obligations and to encourage and guide the continuing evolution of First Nations data and information governance (here mostly shortened to "First Nations data governance") within the context of First Nations health transformation.

The case study begins by outlining the progression of First Nations data governance to date, exploring the increasing recognition of its importance through key consensus papers, health plans, legal agreements and formal processes that have supported British Columbia First Nations agenda of self-determination and health transformation for over nearly two decades. It also recognizes the foundational importance of Ownership, Control, Assess, Possession (OCAP®) to First Nations data governance.

Within this historical context, the case study highlights some of the important partnerships, events and activities associated with data governance occurring during the first five years following the transfer of health from the First Nations and Inuit Health Branch (FNIHB), which until December 2017 was part of Health Canada and then transferred to the newly created federal department of Indigenous Services Canada. Key events discussed include the establishment of the First Nations Health Authority (FNHA) to represent British Columbia (BC) First Nations and serving as their data steward; the continuing evolution of key partnerships with the BC Ministry of Health (MOH), the Office of the Provincial Health Officer (OPHO) and other organizations across the BC health sector; and the increasing capacity of First Nations to assume full governance of their data, as envisioned in the *Tripartite Data Quality and Sharing Agreement* (TDQSA) (2010).

The case study also notes some of the important emerging opportunities likely to support the continuing progression of First Nations data governance over the next five years, such as the new FNHA data strategy, and it discusses several current challenges to be addressed, including increasing First Nations access to First Nations Client File data and work yet to be done to improve clinical information systems and patient record sharing.

Purpose and Approach

A core component of the 2011 *British Columbia Tripartite Framework Agreement on First Nations Health Governance*⁴ (Framework Agreement) (Section 10 (1)) requires that the Tripartite Partners, through the Tripartite Implementation Committee, evaluate the implementation of the Framework Agreement every five years. The first evaluation was completed in 2019 and the report will be publically released in 2020. It is intended to both fulfil legal obligations under the Framework Agreement and to provide the Tripartite Partners with information to encourage and guide continuous growth, evolution and effective functioning of the partnership and implementation of commitments.

Data governance is a core foundation of First Nations health transformation, therefore the Tripartite Evaluation Working Group commissioned a case study of First Nations data governance as part of the evaluation. The case study begins with acknowledging the critical importance of Ownership, Control, Access, Possession (OCAP®) principles to First Nations data governance and details how this has been fundamental to the BC First Nations health transformation process since its inception. Within that context, the case study highlights some of the critical achievements and underlying success factors to date and identifies some of the current and anticipated challenges and opportunities.

The methodology included a review of relevant tripartite literature and documents, and semi-structured interviews with 21 key informants including fourteen FNHA staff; five current or former representatives from the Ministry of Health; a member of the First Nations Health Council; and two representatives from Indigenous Services Canada and the Canadian Institute for Health Information.

Although the interviews were guided by a set of questions (Appendix B), respondents were encouraged to address the areas in which they had most experience and information and were encouraged to provide any additional information they thought relevant. Interviews were not recorded, but the interviewer took notes and assumed responsibility for analysis and interpretation. All respondents were generous with their time, information and insights.

A limitation of the case study is the inability to speak to the regional and/or local level data governance and information sharing contexts within BC, or more broadly across other jurisdictions due to the focus on provincial-level key informants from the FNHA and the MOH.

⁴ *British Columbia Tripartite Framework Agreement on First Nation Health Governance, 2011*. Retrieved from <https://www.fnha.ca/Documents/framework-accord-cadre.pdf>

Section 1: Understanding First Nations Perspectives on Data Governance

Data governance refers to the overall management and stewardship of data, usually including consent and data collection, analysis and interpretation, and disclosure and sharing. Privacy legislation establishes the legal parameters, with the protection of individual privacy and security being the fundamental aims. Ownership and accountability for data is usually considered the responsibility of the collecting organization (or researcher).

The foundations for a sound data governance program typically include a governing body or council, a defined set of procedures and a plan to execute those procedures. Individual organizations are responsible for putting in place policies and procedures consistent with relevant legislation.

For First Nations, data and information governance is a critical component of sovereignty, self-determination and respect of Nation-to-Nation relationships. Health data gathering is informed by unique ethical, rights-based, policy and practice imperatives that include Indigenous participation and leadership throughout indicator development, data collection, management, analysis and use.⁵ As such, First Nations data governance extends beyond the protection of privacy and assurance of security.

Historically, the collection of First Nations data and information was frequently associated with enumeration, often within oppressive colonial constructs. Within this context, First Nations information was collected, interpreted, reported and used without First Nations knowledge or explicit permission. These events are now widely accepted to have contributed to a wide array of social, economic and psychological harms.

However, even in more recent times, the health of First Nations people and communities has been reported using a “deficit lens,” which has often portrayed an entire population as inherently inadequate and unequal, while ignoring systemic, socio-economic and other contextual considerations. At the same time, the resolute progress of many First Nations communities to overcome these challenges has often been overlooked. These experiences serve as a continual reminder to First Nations of the importance of careful vigilance over their data and information to avoid it being collected, analyzed and reported without their explicit knowledge, without due regard to First Nations *principles, values and traditions*, and in the absence of understanding the people and their context.

⁵ Janet Smylie and Michelle Firestone. *Back to the Basics: Identifying and Addressing Underlying Challenges in Achieving High Quality and Relevant Health Statistics for Indigenous Populations in Canada*, 2015.

Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4716822/>

National and provincial commitments to First Nations health transformation and self-determination have increased the need for First Nations communities and organizations to have ready access to their data to properly support planning, policy development and management activities. However, while many steps have been taken to improve data access, First Nations often continue to face barriers in accessing and repatriating data on their own populations.

Clearly this history, the continuing experiences of First Nations people in relationship to data and the collective philosophy that underlies First Nations traditions profoundly influences the First Nations conceptualization of data governance. It helps explain why First Nations data governance cannot be defined or achieved merely by protecting privacy and assurance of security. It helps clarify why there is often such tension and disconnect between First Nations perspectives on data governance and those of organizations whose data management and control policies are driven primarily by privacy legislation.

It is this history that fuels First Nations passionate commitment to Own, Control, Access and Possess their data, the four OCAP® principles widely recognized as the foundations for First Nations data governance. First Nations data ownership and possession represents sovereignty as a nation. It avoids the risk of others writing their narrative, enabling First Nations to tell their own story from their perspective and within their context. Data ownership and possession ensures First Nations have unfettered access to their data, which is critical to self-determination and control over the social and economic factors that contribute to health and well-being.

The *United Nations Declaration on the Rights of Indigenous Peoples* (2007) provides a succinct global perspective on data governance for Indigenous people. Within the context of the United Nations Declaration on the Rights of Indigenous Peoples, appropriate data governance encompasses the right of Indigenous peoples to self-determination, to freely determine their political states and to freely pursue their economic, social and cultural development.⁶ In November 2019 the Government of BC enacted the *Declaration on the Rights of Indigenous Peoples Act*⁷ which reaffirms the application of the *United Nations Declaration on the Rights of Indigenous Peoples* to the laws of BC (i.e. the Act mandates that the government to bring provincial laws into alignment with UNDRIP).

In Canada, First Nations data governance is still evolving, although BC First Nations are recognized as national leaders in this area. This can largely be attributed to the vision of a small group of First Nations leaders⁸ who recognized very early the

⁶ *United Nations Declaration on the Rights of Indigenous Peoples, 2007*. Relevant sections that have applications to data governance include Articles 3, 4, 5, 15(i), 18, 19, 23, 31 and 33. Retrieved from <https://www.un.org/development/desa/indigenouspeoples/wp->

⁷ Bill 41 – 2019 *Declaration on the Rights of Indigenous Peoples Act*. Retrieved from <http://www.bclaws.ca/civix/document/id/bills/billscurrent/4th41st:gov41-1>

⁸ Grand Chief Doug Kelly, Gwen Phillips and Dr. Shannon Waters were identified among others.

foundational significance of First Nations data governance to the emerging health transformation agenda. Their awareness and commitment to data governance ensured that data governance was embedded throughout the health plans, agreements, policy statements and processes developed over subsequent years and described in the next section of this report.

Section 2: History of First Nations Health Data Governance in British Columbia

This section outlines the evolution of First Nations data governance as documented in key consensus papers, health plans, legal agreements and formal processes supporting the BC First Nations agenda of self-determination and health transformation over the past two decades. First Nations data governance is a constant theme throughout these documents, reflecting its foundational role to the progress of the health transformation agenda to date.

2.1 OCAP® Principles

Developed in 2002 by the First Nations Information Governance Committee, (now the First Nations Governance Centre⁹), the four OCAP® principles of ownership, control, access and possession¹⁰ are foundational to BC First Nations' Health Plans, agreements and processes, supporting the development and realization of health data governance within the context of BC First Nations health transformation agenda. The First Nations Information Governance Committee developed the principles largely in response to the concerns outlined in the previous section, and with particular reference to the collection and use of First Nations data for research purposes that often were not aligned with First Nations concerns and priorities and resulted in inappropriate handling of data collection, analysis, interpretation, and sharing.

The OCAP® principles are intended to represent the intertwined principles and values of the First Nations worldview of jurisdiction and collective rights. Together they serve as an expression of First Nations jurisdiction over information about First Nations and reflect First Nations commitments to use and share information in a way that brings benefit to the community while minimizing harm. However, it is also widely recognized that OCAP® principles are often perceived by non-First Nation organizations to be daunting, pointing to the need for clear guidance on how to operationalize these principles in their respective environments.

⁹ <https://fnigc.ca/>

¹⁰ First Nations Information Governance Centre. *Ownership, Control, Access and Possession (OCAP™): The Path to First Nations Information Governance*, 2014. Retrieved from https://fnigc.ca/sites/default/files/docs/ocap_path_to_fn_information_governance_en_final.pdf

2.2 Transformative Change Accord (2005)

Figure 1: Seven Indicators and Targets¹¹

<p>1. Life expectancy at birth</p> <ul style="list-style-type: none">• <i>Decrease the gap in life expectancy between Status Indians and other British Columbians by 35 per cent by 2015.</i> <p>Mortality rate (deaths due to all causes)</p> <ul style="list-style-type: none">• <i>Reduce the gap in mortality rates between Status Indians and other British Columbians by 35 per cent by 2015.</i>
<p>2. Youth suicide rate</p> <ul style="list-style-type: none">• <i>Reduce the gap in youth suicide rates between First Nations and other British Columbians by 50 per cent by 2015.</i>
<p>3. Infant mortality rate</p> <ul style="list-style-type: none">• <i>Reduce the gap in infant mortality between First Nations and other British Columbians by 50 per cent by 2015.</i>
<p>4. Diabetes prevalence</p> <ul style="list-style-type: none">• <i>Reduce the gap in the prevalence of diabetes between First Nations and other British Columbians by 33 per cent by 2015.</i>
<p>5. Childhood obesity</p> <ul style="list-style-type: none">• <i>Develop a baseline and an ongoing mechanism for collecting data relevant to childhood obesity.</i>
<p>7. Number of practicing, certified First Nations health care professionals</p> <ul style="list-style-type: none">• <i>Develop a baseline and an ongoing mechanism for collecting data relevant to the number of certified health care professionals in BC who are First Nations, and the number of those who are actually practicing.</i>

In March 2005, the Province of BC and First Nations leaders agreed to enter into a “New Relationship” through an Accord, guided by principles of trust, recognition and respect for Aboriginal rights and title. A key focus of the New Relationship was to close the gaps in quality of life between First Nations and other British Columbians.

In November 2005, the Province of BC, the First Nations Leadership Council, and the Government of Canada signed the *Transformative Change Accord: First Nations Health*

¹¹ *Transformative Change Accord: First Nations Health Plan, 2005*. Retrieved from http://www.health.gov.bc.ca/library/publications/year/2006/first_nations_health_implementation_plan.pdf

Plan (Transformative Change Accord), which further strengthened relationships on a government-to-government basis. Within this collaborative context, agreement was reached to develop a 10-year plan to bridge the differences in socioeconomic standards between First Nations in BC and other British Columbians.

These gaps had been identified by the OPHO's first provincial report on the health of Aboriginal people in BC, *The Health and Well-being of Aboriginal People in British Columbia* (2001).¹² The report documented the significant differences in health outcomes between Aboriginal people and other BC residents. The Transformative Change Accord chose seven indicators from this report to monitor and report on the progress for the First Nations health transformation agenda (see Figure 1).

In retrospect, the consolidation of First Nations health data within the Transformative Change Accord and later agreements identifying specific indicators for measurement and monitoring purposes reflected a growing awareness of the importance of data, which became woven throughout the subsequent agreements and plans.

2.3 Transformative Change Accord: First Nations Health Plan (2005)

In 2005, the First Nations Leadership Council and the Government of BC signed the Transformative Change Accord¹³ which identified 29 actions to close the health gaps reported in the BC Provincial Health Officer's 2001 report, and committed the Provincial Health Officer to report on the health and well-being of BC First Nations every five years, with interim reports every two years. The Transformative Change Accord also called for the renewal of a tripartite information-sharing agreement to allow data sharing for research and public health reporting which led to the eventual creation of the BC First Nations Client File (FNCF) (see Section 2.6).

The explicit agreement to use First Nations data to measure, monitor and report on the commitments to improve First Nations health outcomes significantly increased the accountability of both partners. It also drew new attention to the necessity of data accuracy and reliability and the collaborative work required to collect data and report on health outcome indicators.

¹² British Columbia Ministry of Health Planning, Office of the Provincial Health Officer. *The Health and Well-being of Aboriginal People in British Columbia, 2001*. Retrieved from <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/office-of-the-provincial-health-officer/reports-publications/annual-reports/phoannual2001.pdf>

¹³ *Transformative Change Accord: First Nations Health Plan, 2005*. Retrieved from http://www.health.gov.bc.ca/library/publications/year/2006/first_nations_health_implementation_plan.pdf

2.4 Tripartite First Nations Health Plan (2007)

Moving forward on BC First Nations health governance required the commitment of the Government of Canada, which at that time directly provided in-community health services and Non-Insured Health Benefits through FNIHB and managed the Indian Register through Aboriginal Affairs and Northern Development Canada (now CIRNAC).

The *Tripartite First Nations Health Plan*¹⁴ (TFNHP) reflects a tripartite commitment, not only to improve the health and well-being of First Nations in BC, but also to fully involve First Nations in all decision-making about their health. The TFNHP laid the framework for First Nations to take a leadership role in monitoring health outcomes and developing strategies to close gaps in health outcomes.

Recognizing the importance of health data, the Partners also agreed to strengthen First Nations data by developing a plan to support First Nations health data governance. Part of that commitment was to develop First Nations capacity to manage the collection, use and disclosure of First Nations health data and to enhance the ability of First Nations to conduct health research. A memorandum of agreement to share information led to the eventual creation of the FNCF, further detailed below.

At the same time, the TFNHP endorsed establishing a new First Nations health governance structure that would provide for the effective participation of all First Nations in BC in health governance functions. This was the basis for the later establishment of the FNHA.

2.5 Tripartite Data Quality and Sharing Agreement (2010)

The Transformative Change Accord commitments to data governance were the precursor to the *Tripartite Data Quality and Sharing Agreement* (TDQSA)¹⁵. The TDQSA reaffirmed the fundamental contribution of First Nations health data to health transformation and First Nations decision-making, through a clear statement of First Nations health information governance,¹⁶ in alignment with the OCAP® principles of First Nations Ownership, Control, Access and Possession.

Article 3.1 (a) of the TDQSA reaffirmed the TFNHP's prior commitments to improve the quality and availability of First Nations data; facilitate sharing First Nations Client

¹⁴ *Tripartite First Nations Health Plan, 2007*. Retrieved from <http://www.fnha.ca/Documents/TripartiteFNHealthPlan.pdf>

¹⁵ *Tripartite Data Quality and Sharing Agreement* (TDQSA), 2010. http://www.fnhc.ca/pdf/BC_Tripartite_Data_Quality_and_Sharing_Agreement_-_SIGNED_COPY.pdf

¹⁶ First Nations Health Authority Health Information Governance. <https://www.fnha.ca/what-we-do/research-knowledge-exchange-and-evaluation/health-information-governance>

File data; and create new data sets to enable First Nations in BC to monitor the health of First Nations and the success of programs and services provided to First Nations communities.

2.6 BC First Nations Client File (2011)

The TDQSA allowed for the creation of the First Nations Client File¹⁷. The FNCF is a cohort of Status First Nations people registered under the *Indian Act* and resident in BC, and their unregistered descendants born after 1986 for whom entitlement-to-register can be determined and is linkable to their provincial Personal Health Numbers. The FNCF is the product of a deterministic record linkage between an extract of the Indian Register held by Crown-Indigenous Relations and Northern Affairs (CIRNA), the MOH Client Roster and the BC Vital Statistics database.

A Memorandum of Understanding between the MOH and Indigenous and Northern Affairs Canada (now CIRNA) authorizes the annual disclosure of information contained in the Indian Register to the MOH. The FNCF is updated incrementally using a fresh extract from the BC Client Roster and the CIRNA Indian Register, capturing new births, new registrants to the Indian Register, interprovincial migration and death.

The eligibility for being registered under the *Indian Act* has recently changed, as Bill S-3 legislation, which received royal assent in December 2017 and that the federal government is now bringing into force, has amended the *Indian Act* to include registration by First Nations descendants born before April 17, 1985, who lost their status or were removed from band lists due to marriages to non-First Nations men.

The FNCF is currently the best available method of accessing accurate health information about the identifiable majority of status and eligible-for-Status First Nation clients residing in BC.

2.7 BC Tripartite Framework Agreement on First Nations Health Governance (2011)

Building on the previous agreements and plans, the Framework Agreement¹⁸ created the basis needed to establish the TFNHP. It built the foundation for the transfer of federal health programs and resources from the Government of Canada to BC First Nations control and, consistent with the TFNHP, set in motion the establishment of a BC First Nations health governance structure. In 2013, the FNHA assumed responsibility for the functions, programs and services formerly handled

¹⁷ *First Nations Client File, 2011.*

¹⁸ *BC Tripartite Framework Agreement on First Nations Health Governance, 2011.* Retrieved from <https://www.fnha.ca/Documents/framework-accord-cadre.pdf>

by FNIHB. The FNHA continues to be the sole province-wide First Nations health governance institution in Canada.

Figure 2: The Seven Directives¹⁹

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

The Framework Agreement also agreed to greater First Nations control over existing health data and to work towards improving the quality of that data. The role of the FNHA includes, among other things, collecting and maintaining clinical information and patient records and developing protocols with MOH and BC health authorities for sharing patient records and patient information (Section 4.2 (2)(f)).

2.8 BC First Nations Perspectives on a New Health Governance Arrangement (2011)²⁰

Concurrent with the negotiation of the Framework Agreement, BC's First Nations leadership reached out to engage all First Nations in a collective process to discuss the role and structure of the proposed new health governance entity.

This consultation and consensus-building process resulted in a series of consensus papers that in turn supported the establishment of the FNHA. It authorized the FNHA to work on behalf of all BC First Nations and their communities, and committed the new organization to a "Community-driven, Nation-based" approach. The consensus process also established the FNHA, First Nations Health Council and First Nations Health Directors shared Seven Directives as guiding standards for the new health governance structure. Three of the Directives are particularly relevant to First Nations data: Directive #2: Increase First Nations Decision-Making and Control,

¹⁹ First Nations Health Authority Directives. Retrieved from <https://www.fnha.ca/about/fnha-overview/directives>

²⁰ *British Columbia First Nations Perspectives on a New Health Governance Arrangement, 2011*. Retrieved from http://fnhc.ca/pdf/FNHC_Consensus_Paper_-_WEB.pdf

specifically sets out the expectation that OCAP® principles will be used to guide First Nations health data use, including First Nations health reporting, while both Directive #3: Improve Services, and Directive #7: Function at a High Operational Standard explicitly rely on access to First Nations data.

Section 3: BC First Nations Health Governance – Successes, Challenges and Emerging Opportunities

This section provides a high-level review of the progress made in First Nations data governance during the first five years since the transfer of health services from FNIHB, which at the time of the 2013 transfer was situated within Health Canada. It discusses major events and activities, reports on progress towards some of the data governance related expectations set out in the Framework Agreement and identifies both current challenges and emerging opportunities that can be anticipated during the next five years.

3.1 First Nations Data Governance Infrastructure and Capacity

3.1.1 Establishment and Role of First Nations Health Authority

Consistent with commitments included in the TFNHP and realized through the Framework Agreement, the FNHA assumed the transfer of health services from FNIHB in 2013. The creation of a single provincial institution was a transformative step for the First Nations health agenda and specifically for First Nations data governance.

The FNHA now serves as the data steward for several data holdings on behalf of BC First Nations, such as health benefits and surveillance data and data from several BC surveys, including the Regional Health Survey. The FNHA's accountability to BC First Nations is set out in its governance arrangements and includes a commitment to regularly consult with and seek the views of all First Nations and their communities on data governance matters, consistent with the Seven Directives. As a First Nations data steward, the FNHA represents the interests of all BC First Nations when negotiating data-related matters with FNIHB, CIRNA and the MOH.

As a provincial institution, the FNHA has the scope and resources to develop the technological capacity and analytical expertise needed to support comprehensive and evidence-based planning at population, regional and community levels that would otherwise not be feasible. Its increasing use of data that it owns and manages – as well as FNCF-linked data to support policy, planning and service decisions – has contributed to the FNHA's recognition as trusted partner, influencer and decision-maker within the provincial health sector and provided it with the ability to directly

engage with its partners on matters pertaining to data analysis and stewardship, as discussed in more detail below.

The FNHA works on behalf of First Nations to encourage and support the management of First Nations data in accordance with First Nations health information governance and in alignment with OCAP® principles, regardless of where that data is located. It works closely with the MOH, BC health authorities and Medical Officers of Health to communicate and model these core principles and encourage respectful use of First Nations data.

In 2016, the FNHA and the First Nations Health Council collaboratively hosted a series of data governance engagement sessions in each of the five regions in response to an identified need for First Nations communities and organizations to have timely access to quality data to make informed decisions regarding health and wellness. Each session provided an opportunity to discuss First Nations data governance and the importance of identity management procedures, ethical policy and wellness-based indicators. Feedback from the sessions informed developmental work within the FNHA in these areas.

In the past five years, the FNHA has invested in its internal information and technology infrastructure and capacity, including appointing a Chief Information Officer, developing an Enterprise Information Management Strategy, maturing its privacy and ethics capacity, and establishing information and data policies and analytic processes. An executive-level governance body, the Data Champions Committee, guides the development of organization-wide governance policies and processes for data held on behalf of First Nations communities. The Data Champions Committee, comprised of department level data stewards, serves as the FNHA's data access committee, reviewing and approving access, use and reporting of First Nations health and wellness data. A director-level Data Advisory Committee serves as the operational arm of the Data Champions Committee.

The FNHA currently manages several databases on behalf of BC First Nations, including health benefits and surveillance data and data from several BC surveys, including the Regional Health Survey (2002, 2008-10 and 2015-17) (discussed in greater detail below), the First Nations Regional Early Childhood, Education and Employment Survey and the upcoming First Nations Labour and Employment Development. The latter two surveys are recent national initiatives led by the First Nations Information Governance Centre to support the TDQSA's direction to create new data sets to support monitoring First Nations health and the success of programs and services (TDQSA, Article 3.1(d)).

The FNHA's Chief Medical Officer is the FNHA's representative on all public health matters affecting First Nations, and in that role also has explicit responsibility to improve the quality of First Nations health data being collected and to regularly report on the health status of the First Nations population in BC. The Chief Medical

Officer has also assumed the responsibility to monitor all data released by the FNHA, a role referred to in Coast Salish as *migamuwa*, the Watchmon.

Currently, some of the FNHA's key priorities within the data governance context include developing a formal work plan with MOH to continue the evolution of the joint health data relationship and establishing an FNHA data strategy to set out the FNHA's role, key priority activities and data (including surveillance) priorities for the next five years.

3.1.2 Regional Health Survey

The FNHA has assumed responsibility for the design, implementation, analysis and reporting of the Regional Health Survey, providing an example of the FNHA's full expression of the OCAP® principles: Ownership of the data, Control over how it is used, Access by communities to data, and Possession.

The Regional Health Survey is a national survey of the health and wellness of First Nations people living in-community in BC. First developed and implemented by the First Nations Information Governance Centre, the survey collects data on a wide range of issues, including mental health and wellness, primary health care, social determinants of health, traditional wellness, health status and health behaviours.

Although the First Nations Information Governance Centre continues to govern the Regional Health Survey at the national level, the FNHA has assumed implementation responsibility in BC. In response to community leadership requests and the directives and mandate from First Nations in BC, the FNHA expanded the sampling strategy for the third Regional Health Survey phase in 2015-2017. This allowed more people and communities to participate, which ensured sufficient sampling to allow reporting out at the regional level in 2019.

Regional tabular reports are ensuring that FNHA regional offices have improved access to the Regional Health Survey data. FNHA research staff works to brief FNHA regional offices on the Phase 3 regional-level results, to be cascaded down to communities. The FNHA has also committed to conducting a fourth phase of the Regional Health Survey, with data collection planned for 2020.

The FNHA's comprehensive work on the Regional Health Survey, as well as other databases, such as the First Nations Regional Early Childhood, Education and Employment Survey and the upcoming First Nations Labour and Employment Development survey noted above, demonstrates its growing data governance capacity. The 2019 federal budget included nearly \$80 million over seven years to support improved First Nations access to better information to make informed decisions and deliver high-quality services. These funds include permanent funding for the Regional Health Survey as well as the establishment of First Nations regional data centres. The opportunity for the FNHA to assume responsibility for the BC First

Nations data centre is an important consideration for the developing data strategy (see Section 3.3.1).

3.2 Important Partnerships and Collaborations

3.2.1 FNHA and Office of the Provincial Health Officer Partnership

Numerous respondents interviewed for this case study observed the importance of *trust* within First Nations data governance. The positive and trusting working relationship between the FNHA Office of the Chief Medical Officer (CMO) and the Office of the Provincial Health Officer (OPHO) is widely recognized as having been instrumental in the progress achieved in First Nations data governance.

The principles identified by the OPHO-CMO team that guide all joint endeavours include reciprocal accountability, wisdom, partnership, responsibility, respect and action-orientation. Principles identified to guide the work products include a wellness-focused, strengths-based, life-course and population health approach. By solidifying these principles, the two teams have built a partnership founded on respect and accountability and they choose to focus on the strengths, wellness and resilience of First Nations people, while representing life experiences of all ages of the population.

As noted above, the OPHO demonstrated an early commitment to better understanding, reporting and improving Indigenous population health and has consistently supported the First Nations health transformation agenda since 2001.²¹ The first comprehensive report on the health of BC First Nations substantiated the significant gaps in health outcomes between Indigenous people and other BC residents. The data provided in this report served as the basis for the Transformative Change Accord's commitment to establish a ten year plan to bridge the differences in socio-economic standards between First Nations in BC and other British Columbians.

The TFNHP committed to establishing an Aboriginal Physician Health Advisor within the OPHO, a position that later was elevated to Deputy Provincial Health Officer, and to regular monitoring and reporting on Indigenous health. The early value of incorporating a senior Indigenous perspective in the OPHO ensured that the First Nations data used for these and other OPHO reports was consistently analyzed, interpreted and reported within a First Nations context and perspective, consistent with OCAP® principles.

²¹ British Columbia Ministry of Health Planning, Office of the Provincial Health Officer. *The Health and Well-being of Aboriginal People in British Columbia, 2001*. Retrieved from <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/office-of-the-provincial-health-officer/reports-publications/annual-reports/phoannual2001.pdf>

In 2009, the OPHO released a second and more comprehensive report, *Pathways to Health and Healing – 2nd Report on the Health and Well-being of Aboriginal People in British Columbia*²². In addition to reporting on the progress on the seven indicators identified in the 2007 TFNHP, it also provided additional socio-economic, educational, health and other related data. By expanding reporting beyond usual health measures, the OPHO formally recognized and validated the importance of environmental factors to First Nations health status.

Currently the FNHA CMO and OPHO are collaboratively developing a comprehensive report on the health and wellness of Indigenous women and girls living in BC. This report will draw on a mix of data and stories to highlight the many ways in which females and female-identifying Indigenous peoples are thriving and self-determining as well as those areas where systemic barriers continue to impede their wellness as they age through the life stages.

Since 2009, the OPHO and the FNHA CMO have worked together to release formal “Updates” (in 2012, 2015 and 2018) on the progress on the seven indicators. These reports have also provided in-depth analysis of several health issues that are important to First Nations health improvement. The 2018 update provides the final progress report on the initial seven indicators first set out in the Transformative Change Accord and First Nations Health Plan and later committed to in the Framework Agreement, and presents 15 new indicators jointly agreed to by the OPHO and the FNHA and that will be monitored over the next 10 years.

The first iteration of the new First Nations Population Health and Wellness Agenda will be released early in 2020, including baseline measures and targets. The 15 indicators will be monitored as part of the ongoing five-year evaluation requirement of the Framework Agreement.

Importantly, the new report will also incorporate other uniquely First Nations indicators. A key aspect of the OCAP® principle of Control is the opportunity to select the indicators by which First Nations health is measured and monitored. This is not to dismiss the relevance of the original Transformative Change Accord indicators to the health transformation agenda, but rather to acknowledge the importance of the broader and more complex First Nations perspective on health and wellness and wellness-based approach. Whereas most health databases focus primarily on health deficits, such as disease, injury and disability, the new indicators will prioritize a First

²² British Columbia. Provincial Health Officer. *Pathways to Health and Healing – 2nd Report on the Health and Well-being of Aboriginal People in British Columbia*, 2009. Retrieved from <https://www2.gov.bc.ca/assets/gov/government/ministries-organizations/ministries/health/office-of-indigenous-health/abohlth11-var7.pdf>

Nations lens and explore health and wellness from a wholistic perspective, in fulfillment of Section 6.1(1)(d)²³ of the Framework Agreement.

The First Nations Perspective on Health and Wellness incorporates First Nations determinants of health, honours the complexities of Indigenous teachings and current socio-cultural and institutional contexts, and guides the FNHA and the health system's understanding of health and wellness. It acknowledges that wellness is intergenerational – that the wellness of a population is shaped by that of their ancestors, and in turn shapes the wellness of their descendants and future generations.

The Population Health and Wellness Agenda will contribute to the shift from a sickness-based system to a wellness-based system by identifying indicators that measure what keeps people well, using strengths-based and culturally safe language and methodologies, recognizing and upholding the value of relationships and the importance of family and community, and acknowledging the roots of wellness, including socio-cultural, economic and institutional determinants of health, as well as supportive systems (e.g., self-determination, strong culture, healthy lands). Some of this work will involve developing data indicators not yet in existence. For example, one of the indicators identified within the Population Health and Wellness Agenda relates to ecological wellness and connection to land.

The FNHA CMO and the OPHO recognize that markers of ecological health would vary geographically across traditional territories. To support establishing uniquely First Nations indicators, the FNHA CMO is currently leading a project funded by the Canadian Institute for Health Research to develop indicators more closely aligned with these Indigenous perspectives and better reflecting what First Nations people judge to be of value within that broader concept of wellness, including sovereignty and land and territory. The BC First Nations Data Governance Initiative²⁴ has also addressed the importance of developing and recognizing community-based, Nation-driven indicators to augment current reporting.

By developing a positive and trusting working relationship, the FNHA CMO and the OPHO have ensured that First Nations data is consistently analyzed, interpreted and reported appropriately, that a strength-based approach is always taken, and that the First Nations narrative is recognized. This partnership continues to be an excellent example of how First Nations data governance can be well implemented.

²³ "Work with the BC Health Authorities to examine and supplement health data collection, health status monitoring and reporting systems used by the BC Health Authorities, which include First Nations-determined indicators of health and wellness"

²⁴ British Columbia First Nations' Data Governance Initiative (BCFNDGI). <https://www.bcfndgi.com/>

3.2.2 Partnership between the First Nations Health Authority, Office of the Provincial Health Officer and the BC Centre for Disease Control

The FNHA and the OPHO are currently working with the BC Centre for Disease Control on a data governance framework specific to the provincial reporting of overdose-related data. The FNHA has been involved in this project since its inception in all aspects of the work, through active participation in a wide range of committees and working groups, regardless of whether or not First Nation issues or data are involved.

One informant commented that this inclusive and participatory approach has engendered a strong sense of trust amongst the partner organizations. This partnership has contributed to capacity building across all partners. For example, the FNHA has had the opportunity to develop provincial surveillance techniques, while the other partners have developed improved data governance practices within the First Nations context.

It also was noted that throughout the response to the public health emergency, the FNHA has provided leadership and guidance regarding the respectful messaging, handling and reporting of highly sensitive and potentially stigmatizing data. Specifically, the FNHA encouraged a person-centric rather than data-centric approach, which is consistent with its own accountability to BC First Nations. It was also observed that the release of overdose-related data was well managed, including joint announcements that ensured a strength-based context within which the numbers could be understood.

The overdose data project raised important issues around sharing data with communities for the FNHA, helping to identify some of the tensions that exist between the FNHA's obligation to consult with communities and provide them with their data, and the risks to individual and community privacy when working with data that is highly sensitive and often involves such small numbers that the potential for identification is increased.

In May 2019, the FNHA visited every region to share its internal overdose data, and was met with strong community support, and received good information and advice. Developing tools and ways to share such sensitive data and developing the strategies to best address them is part of ongoing data governance capacity building for the FNHA, as well as for other partners.

3.2.3 The FNHA and Ministry of Health Partnerships

i. Tripartite Data Quality and Sharing Agreement /Data and Information Planning Committee Bilateral Process

The Data and Information Planning Committee (DIPC) is established under the TDQSA and is responsible for adjudicating requests for access to the FNCF and

related linkages with major health databases. Its working committee, the Data Management Working Group, also reviews and approves pre-publication reports developed from approved linkages.

As of 2019 the DIPC Co-Chairs were the FNHA Deputy CMO and the OPHO's Provincial Indigenous Health Physician Advisor, with First Nations and Inuit Health Branch of Indigenous Services Canada participating as an observer. Its membership and that of the working group are split evenly between the FNHA and MOH.

The DIPC co-chairs share equal decision-making authority, reaching all decisions by consensus. As such, DIPC is an important vehicle by which the FNHA executes the OCAP® principle of Control despite not having physical possession of the FNCF.

A review of the TDQSA commissioned in 2018 before the renewal of the TDQSA in 2019 observed the extent to which joint participation on DIPC contributed early to a positive working relationship between the FNHA and MOH. The joint participation encouraged communication, provided both partners with opportunities to learn about the new FNCF and its potential linkages with BC's health databases, and facilitated knowledge sharing about First Nations data governance, including the application of OCAP® principles.

ii. Provincial Health System Matrix

The FNHA's Access to FNCF data via a linkage with the MOH's Health System Matrix (HSM) data provides a positive example of a well-functioning partnership with the ministry. The HSM includes physician, hospital, residential care and home and community care services data. The linkage with the FNCF enables the FNHA to explore and assess the performance of the provincial health system in meeting First Nations' needs.

The HSM data was reported to be particularly useful in supporting primary care transformation by providing comparison data on First Nations versus other residents' service utilization in key areas, such as general practitioner use and attachment and emergency department visits. These analyses have identified where in the province there are specific service gaps and/or over utilization and provided the basis for improvement targets.

The Divisions of Family Practice and the Collaborative Services Committees are currently implementing a new primary care service model of Primary Care Networks across BC. The HSM First Nations utilization analyses have been shared with them as well as with FNHA regional offices to guide and support relevant service planning and evaluation activities.

HSM data is also being used by the FNHA to identify areas in the province in most need of primary care centres for the First Nations population. It has already proven useful in justifying increased consideration of First Nations health needs and ensuring that services for the First Nations population are sufficient.

For example, in the initial data linkage in 2016, which involved only the Interior Region, linked FNCF/HSM data on mental health and substance use was reported to have been instrumental in substantially increasing the Interior Health's new treatment bed allocation for the First Nations population. Other chronic condition data was also used to support a collaborative FNHA-Interior Health undertaking to improve nursing services frail and high-needs Elders. Furthermore, analysis of linked FNCF/HSM data informed Indigenous cancer strategies. These examples illustrate the utility of the FNCF/HSM data and the types of decisions it can support, which in turns emphasizes the importance of the FNHA having full access to this data.

Consistent with the OCAP® principle of Access, major findings and reports emerging from the FNCF/HSM data were initially reviewed by the First Nations Health Council, First Nations Health Directors Association, and Chiefs/Councils of communities before a wider dissemination to FNHA partners (MOH and the BC health authorities). All requests for HSM data are reviewed by the FNHA's Data Advisory Committee and approved by the Data Champions Committee.

3.2.4 Additional Partnerships

i. FNHA and Cardiac Services BC

Cardiac Services BC (CSBC) is working with the FNHA to develop a series of reports aimed at improving the cardiovascular health of the First Nations population in BC.²⁵ The work includes determining a baseline description of the epidemiology and patterns of cardiovascular service utilization of First Nations people in BC. Through an iterative mutually agreed upon process, the partners will produce a report that will be renewed annually. The cardiovascular health reports will be tailored to the needs of the FNHA and adapted in response to the organization's information needs.

A strong governance process has been established to ensure both a common understanding and continuity for the project. A key component is the transfer of knowledge from the CSBC to the FNHA, enabling the FNHA to assume ownership of the analyses (including data linkage and control), with the CSBC taking on an advisory role as required. The intent of the partnership is that the FNHA will have meaningful and influential involvement regarding the culturally appropriate and respectful analysis, disclosure and stewardship of all First Nations data used in the analyses.

²⁵ FNHA-CSBC *Strategic Framework for Analysis of Cardiac Care*, July 2018.

In accordance with First Nations traditions and values, and consistent with the principles of OCAP® the FNHA will also have access to the combined data set, linking the CSBC clinical dataset (including information on procedure safety and effectiveness, clinical processes and patient outcomes) to the FNCF, inclusive of both First Nations people and other BC residents, upon completion of the usual information sharing protocols governing data sharing in BC.

ii. FNHA and BC Cancer

A partnership between the FNHA, the Métis Nation BC, the BC Association of Aboriginal Friendship Centres and the BC Cancer Agency (BCCA) resulted in *Improving Indigenous Cancer Journeys in BC: A ROAD MAP (2017)*²⁶, a strategy to directly improve the cancer experience for all Indigenous people.

A first step was to develop a better understanding of the epidemiology of cancer across First Nations. The BCCA analyzed BC Cancer registry data for 15 cancers in women and 12 cancers in men, linking 1993-2010 BCCA data with the 2014 FNCF, as approved by the DIPC. BCCA and FNHA representatives collaboratively interpreted the findings, providing an opportunity for shared teaching and learning opportunities, as well as joint accountability to respond to findings. The DIPC and FNHA senior leadership reviewed the final manuscript for external publication.

iii. FNHA and the Provincial Perinatal and Maternal Mortality and Morbidity Review Committee

The FNHA is a member of the Provincial Perinatal and Maternal Mortality and Morbidity Review Committee, which is designated in BC (Regulation 363/95, paragraph (c) of 51(1) of the *Evidence Act*) for the purpose of quality review of perinatal, neonatal and maternal morbidity and mortality.

The Provincial Perinatal and Maternal Mortality and Morbidity Review Committee is responsible for identifying provincial issues and making recommendations regarding strategies to address those concerns, including providing regular reports to BC health authorities summarizing and analyzing perinatal, neonatal and maternal mortality and morbidity data. The FNHA's full participation on this committee provides an opportunity for the FNHA to support the respectful handling and reporting of highly sensitive perinatal data, consistent with the FNHA's accountability to First Nations in BC. The FNHA is also represented on the Interior

²⁶ FNHA, the Métis Nation BC, the BC Association of Aboriginal Friendship Centres, and the BC Cancer Agency (BCCA). *Improving Indigenous Cancer Journeys in BC: A ROAD MAP, 2017*. Retrieved from <https://www.fnha.ca/WellnessSite/WellnessDocuments/improving-indigenous-cancer-journeys-in-bc.pdf>.

Health Region's Infant Mortality Review Committee, providing a similar opportunity at the regional level.

iv. FNHA and the BC Provincial Diabetes Evaluation

The BC Provincial Diabetes Evaluation project, sponsored by the Specialist Services Committee, is a joint initiative between MOH and Doctors of BC. The FNHA has been a partner since January 2015.

The aim of a Specialist Services Committee three-year quality improvement project (2015-2018) was to improve the health of British Columbians with diabetes by evaluating and redesigning diabetes care that is sensitive to local, cultural and ethnic needs. In 2015, a comprehensive quantitative and qualitative diabetes environmental scan/needs assessment was conducted, which included all BC regional health authorities and linked data to the FNCF, providing the first opportunity to observe First Nations access to appropriate diabetes care across the province.²⁷

v. FNHA, Canadian Institute for Health Information and Ministry of Health Partnership

The FNHA has been working with the Canadian Institute for Health Information and the MOH to develop a draft Joint Statement on First Nations Health Data Governance. The Statement is intended to systematically embed First Nations data governance with partners through education and communication about First Nations governance and the significance of the OCAP® principles, and to promote and support partners' use of First Nations health data and information in culturally safe and respectful ways.

The draft joint statement affirms and supports First Nations jurisdiction over health data and information and is congruent with the shared reconciliation agenda between First Nations and other Canadians, both nationally and provincially.

Several respondents observed that the FNHA's *Policy Statement on Cultural Safety and Humility*, supported with online training modules and formal commitments from health authority executives and other health leaders such as the BC Quality and Patient Safety Council, has been effective in introducing key principles across the health sector and influencing attitudes and actions. It was suggested that adapting this approach to support increased understanding and integration of First Nations data governance might be equally effective.

²⁷ FNHA. (2015). *Preliminary NEF 2015 Diabetes Nurses Findings Report*, 2015.

3.3 Opportunities and Challenges

3.3.1 Developing a First Nations Data Strategy

During the first few years of the FNHA, eager champions across the organization focused on different aspects of data management and governance. As the FNHA matures, there is an opportunity to align an organization-wide data governance agenda and approach, ensure clarity around corporate data priorities and explore allocation for best use of internal resources.

The forthcoming development of a corporate FNHA data strategy will provide the FNHA executive with an opportunity for in-depth consideration of matters relating to data governance, use and analysis, and to develop priorities, policies and frameworks that support operational priorities and also align with BC First Nations data governance interests, including (as explored in Section 3.3.4 below) exploration of the possession of the FNCF.

Numerous external opportunities, including the federal government's funding for the planning and feasibility of regional data centres and the First Nations Regional Health Survey could create new opportunities for the FNHA that can be fully explored both internally and with BC First Nations during the development of the FNHA data strategy.

3.3.2 Improving First Nations Access to Data

The FNHA's increasing responsibilities for planning, policy and operations have substantially increased the organization's need for ready access to First Nations data, consistent with the TDQSA and the Framework Agreement's Vision of greater First Nations control and access over health data "for the improvement of health services and better monitoring and reporting on First Nations health in BC" (Framework Agreement Section 6.1(f)).

However, FNHA leadership expressed concern with the lack of timely access to FNCF linked data, which routinely undermines the FNHA's capacity to carry out its mandate as set out in the Framework Agreement, meet the expectations of BC First Nations and their communities, and productively work with partners to develop a more integrated health system for First Nations. The CMO reported delays in fulfilling responsibilities to report on the health of BC First Nations because of the inability to access data.

The FNHA's access to FNCF data continues to be on a project-by-project basis. There are routine delays in Access, linkage approvals, and data provision (the latter being the responsibility of the MOH) due to capacity issues and other competing priorities.

The TDQSA Review (2019) (described further in section 3.2.3.i) explored improvements to the adjudication process and also that consideration should be given to the FNHA assuming sole stewardship for the FNCF, consistent with the

TDQSA and with OCAP® principles. Furthermore, it suggested that the FNHA develop a new adjudication process to expedite FNHA requests for internal analytical purposes. These recommendations are under consideration by FNHA and the MOH.

Within the context of that discussion, the MOH's new data management and governance framework (the Health Data Platform) is relevant. The new platform is intended to create a safe and more efficient method for accessing linkable health system data held in numerous databases. The new strategy will take a streamlined criteria-based approach that categorizes data requests based on the level of likely risk associated with the requestor, the intended project, the data requested, the setting in which the data will be used and the intended output.

This approach reflects the Five Safes²⁸ framework (Safe People, Safe Project, Safe Data (de-identified), Safe Settings (approved environments) and Safe Output), and will include processes to respect OCAP® principles and safeguard access to First Nations data.

By introducing consistent and transparent access criteria at the front end of the data access request process for each of the five dimensions, it is anticipated that low-risk requests will be expedited and that this will in turn reduce the waittime for data destined for basic analytical functions and to be provided for ethics-approved research conducted by known and trusted researchers. The MOH anticipates the new approach will free up resources that can then be redirected to handling higher-risk requests and providing increased scrutiny on pre-publication reports (i.e. safe outputs). The new approach may be adapted by the DIPC to improve their current processes.

3.3.3 Legislative Challenges

Legislative issues are impeding information sharing at both provincial and service delivery levels due to a lack of clear authorities in both the *Personal Information Protection Act*²⁹ and the *Freedom of Information and Protection of Privacy Act* (FOIPPA)³⁰. This results in issues for the FNHA to “collect and use” personal information from public bodies, and public bodies to “disclose” personal information to the FNHA. Current interpretation of the FOIPPA, the provincial public sector legislation is such that, as FOIPPA does not apply to the FNHA, row-level data restrictions for analysis apply to the FNHA. This impacts the ability of the FNHA to

²⁸ The Five Safes is a framework for helping make decisions about making effective use of confidential or sensitive data. Developed in the UK, the Five Safes framework proposes that data management decisions be considered as solving problems in five 'dimensions': projects, people, settings, data and outputs.

²⁹ *Personal Information Protection Act*. Available at http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_03063_01

³⁰ *Freedom of Information and Protection of Privacy Act*. Available at http://www.bclaws.ca/Recon/document/ID/freeside/96165_00

conduct more complex data analysis on critical datasets such as the HSM (see Section 3.2.3).

Over the coming three or so years, the province is exploring new BC health information management legislation which will combine the *Personal Information Protection Act*, which applies to the FNHA, and FOIPPA legislation under a common framework for the health sector. This legislation could set out authorities for the collection, use and disclosure of personal health information within the health sector, including authority for the FNHA to fulfill its stewardship mandate. However, in the short term, the identified solution has been to second an FNHA staff member to the MOH to work on-site or through a secure remote access environment. This issue is under discussion by the MOH and the FNHA given its importance to the requirement for improved data access.

Issues with respect to sharing of clinical information at the point of care are explored below in Section 3.4.

3.3.4 FNHA Ownership and Possession of the BC First Nations Client File

Several respondents expressed strong preference that the FNCF be under the sole authority of the FNHA. From a practical perspective, data possession is recognized as the best mechanism by which First Nations can mitigate risk and assert the principles of Ownership and data Control.

Although FNHA leadership members largely agree in principle that the FNHA should manage the FNCF on behalf of BC First Nations, it is acknowledged that the direct costs and opportunity costs to possess the file are substantial. To date, the FNHA has not been directly involved in managing the FNCF or the processes linking FNCF data with provincial databases. The assumption of total responsibility would commit the FNHA to significant financial investment in new technology, equipment and staff and their training.

On the other hand, the lack of access to timely data is also a high cost, albeit one that is more difficult to quantify. To some extent, access challenges have been ameliorated with the appointment of an FNCF project director (an FNHA employee seconded to the MOH), who supports a technical and hands-on role in the data linkage process. However, this alone is unlikely to change access approval processes. However, it was noted that advancements in technology will likely soon enable the FNHA to have total “virtual control” of the FNCF and this would eliminate the need for physical possession of the dataset on FNHA servers. A more immediate alternative is a remote secure access environment within the FNHA that would allow it to conduct data linkages from a distance.

The development of the FNHA data strategy will provide an opportunity to consider these FNCF-related issues more fully within the context of all data priorities.

3.4 Improving Clinical and Patient Information Systems

In regard to clinical information and patient information, the Framework Agreement, Sections 4.1 (f), (f), and 6.2 (b) (c), refer to expectations regarding the development of clinical information and patient record systems and protocols between the FNHA and MOH and the BC health authorities for sharing patient records. Although there is yet to be significant progress on this issue at the provincial level, there is evidence at the health authority level of an increased understanding of the importance of finding solutions.

The inability of regional health authorities and the FNHA and its regional offices to share clinical information was identified as a barrier to coordinating and integrating clinical services and perceived to interfere with quality management. It was noted that First Nations families and communities are often unable to access patient data as they are transferred from acute care settings back to their home community, interfering with discharge planning and undermining community and family support.

Some local interim solutions were reported in the context of FNHA and Regional Partnership Accords. For example, Fraser Health agreed to integrate a health service organization providing services to First Nations into the Health Authority's patient information electronic medical records system. The FNHA and Interior Health have collaborated on connecting communities to Interior Health's Meditech system and, in an effort to improve communication and discharge planning, have piloted remote access to Interior Health's clinical information system for community health nurses with the Splat'sin First Nation.

The MOH's recently released Digital Health Strategy (September 2019) provides the opportunity for the MOH and the FNHA to jointly address clinical and patient information sharing, which presumably will become easier with the introduction of the new common legislative framework for health sector information. There also will be important linkages with the developing FNHA data strategy.

Summary

First Nations data governance has progressed substantially as a foundational component of the BC First Nations health transformation agenda. Several respondents commented that BC First Nations are recognized as national leaders in data governance. This can be largely attributed to the weight that the BC First Nations health transformation agenda has consistently placed on data governance and the presence of the FNHA, which serves as the data steward for BC First Nations.

While there is still much work to do, the rights of First Nations people and communities to the governance of their data – Ownership, Control, Access and Possession – has become broadly recognized and understood by the MOH and BC health authorities and in many other organizations across the BC health sector. The FNHA, MOH and Canadian Institute for Health Information are working towards a draft Joint Statement on First Nations Health Data Governance to provide more education and communication about First Nations governance and the importance of the OCAP® principles.

The FNHA has developed important data partnerships with the OPHO and these provide strong examples of how First Nations data governance can be well implemented. This case study details only a few of the many partnerships that now provide First Nations with the opportunity to fully participate in all health matters that affect them and in doing so, have greater control over their data.

Although significant progress has been made regarding First Nations access to data and the FNHA continues to expand the databases for which it has responsibility, there are concerns with delays in accessing FNCF data. This is a major challenge for the FNHA to address by developing its corporate data strategy and as part of its evolving collaborative relationship with the MOH. The promise of an FNHA and MOH joint work plan to evolve the health data relationship will also be pivotal in addressing these concerns.

Appendix A: Interview Questions

1. History and Early Development
<p>Tell me a little about how First Nations data governance and information sharing has evolved since the signing of the Framework Agreement in 2011....</p> <ol style="list-style-type: none">1. Who had the initial vision? What was it?2. How widely was the vision understood and shared?3. To what extent was the importance of First Nations data governance to reconciliation and health transformation recognized at that time?4. What were some of the early steps and their challenges? How were they overcome?5. Can you identify some of the specific early 'lessons learned' that continue to be important to First nations reconciliation and health transformation?6. Do you have any information as to the reasoning behind the choice of the 7 Transformative Change Accord indicators, i.e. why those particular indicators were chosen?
2. Current Status (successes, challenges, and opportunities)
<p>Tell me about the progress made in First Nations data governance to date and its current status...</p> <p><i>Successes to date:</i></p> <ol style="list-style-type: none">1. Currently, to what extent are BC First Nations involved in decision-making related to First Nations health data sharing and governance? Provide some examples ...2. Are there obvious places where this is not occurring?3. Describe some of the concrete steps or actions made towards First Nations data governance in the past few years and currently, especially (but not exclusively) related to the specific data sharing and governance commitments outlined in the <i>Tripartite Agreement</i> and the <i>Tripartite Data Quality and Sharing Agreement</i>.4. Please talk a little about how current data sharing and data governance arrangements influence/determine the responsiveness of FNHA and provincial health care services to First Nations health needs, pertaining to any of the following:<ul style="list-style-type: none">- Health policy development,- Service and program planning and development – provincial, regional,

local community,

- Delivery of health services – provincial, regional, local community,
- Service quality improvement
- Program evaluation
- Health status and service utilization reporting
- Health research
- Others?

5. Currently, are First Nations patient records/clinical information appropriately shared between health system partners? Progress, issues or concern?

Potential Challenges:

1. What are some of the current facilitators and challenges to realizing/improving First Nations data governance and information sharing in BC?
2. Specifically, to what extent do you think the current health data collection, health status monitoring and service reporting systems are capturing the story of First Nations health in BC? Where are there opportunities for improvement – any suggestions of specific actions to be taken?
3. To what extent are health status monitoring and reporting systems integrating First Nations determined indicators of health and wellness?
4. What benefits/opportunities /challenges do you see to achieving greater adoption /use of First Nations traditional indicators?
5. What are the opportunities and challenges to improve clinical data sharing?
6. How willing are partners to finding solutions to ongoing data challenges? Specific examples?

Potential Opportunities:

1. What lessons can be shared at this time around First Nations data sharing and governance in BC?
2. What are the opportunities to improve appropriate access/utilization of First Nations health data by researchers to support First Nations health research questions?
3. What are some obvious next steps to actualize these opportunities?

3. Future directions, opportunities and goals (strategic thinking)

Tell me a little about how you see the future of First Nations data governance...

1. Please describe what you see as a future vision for First Nations data governance and information sharing in BC?
2. What are some of the specific steps yet to be accomplished?
3. What are the major challenges?
4. What are the key enablers?
5. What are some key progress targets for the next few years?

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