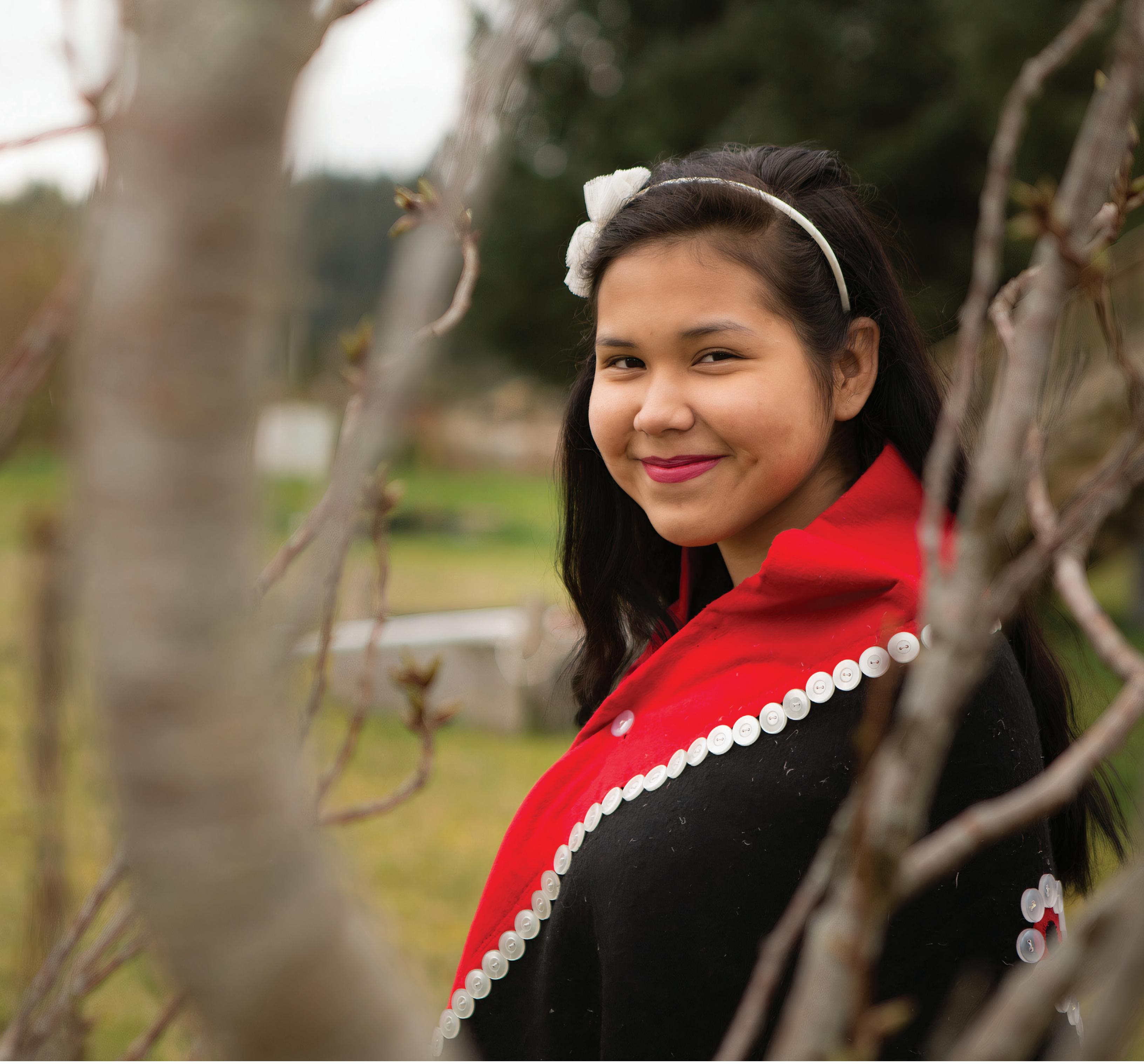


Tripartite First Nations Health Plan

Tripartite Data Quality and Sharing Agreement

ANNUAL REPORT ON PROGRESS

JANUARY 2022 - MARCH 2023

Tripartite First Nations Health Plan

For more information, please visit:

First Nations Health Authority | www.fnha.ca
Province of British Columbia | www.gov.bc.ca/hls
Government of Canada | www.canada.ca/en/indigenous-services-canada.html

Contents

1. Context for This Report

This Annual Report on Progress provides a summary of the work done from January 1, 2022, to March 31, 2023, by the Tripartite partners — the First Nations Health Authority (FNHA), the Government of Canada via Indigenous Services Canada and the Government of BC — to build an equitable and culturally safe relationship around data sharing, stewardship and governance.

The Tripartite Data Quality Sharing Agreement (TDQSA) fulfils action number 28 of the 2006 *Transformative Change Accord: First Nations Health Plan* to "renew the Tripartite Agreement between the Province, Health Canada's First Nations and Inuit Health Branch,[1] and First Nations to ensure federally and provincially held information on First Nations is shared." Schedule B of the TDQSA states that "an annual report on the activities carried out under this Agreement will be developed by the Data Committee, for approval by the Parties, and published within six (6) months of Fiscal Year end" (Schedule B, section 1.8). Section 5.1 (f) of the TDQSA also states that the data committee (now known as the Data and Information Planning Committee (DIPC)) will "Make an annual report to the Parties on progress toward implementing First Nations health information governance capacity within First Nations in accordance with section 5.1(f) of the Agreement" (Schedule B, Section 1.2[d]).

The TDQSA was originally scheduled to expire in April 2020, was then extended to April 2021 and then subsequently extended for an additional three years, expiring in April 2024.

---

1. In August 2017, Indigenous and Northern Affairs Canada was restructured into two new federal departments: (1) Crown-Indigenous Relations and Northern Affairs Canada, and (2) Indigenous Services Canada (ISC). In December 2017, the First Nations and Inuit Health Branch (FNIHB) was formally transferred from Health Canada to ISC. All FNIHB funding and contractual arrangements were transferred to ISC at that time.

2. Context of Our Work

GUIDING PRINCIPLES

The Tripartite partners are furthered by the 7 Directives,[2] the fundamental standards developed by First Nations in over 120 regional and sub-regional meetings that therefore represent broad guiding principles that can guide other Tripartite work, most notably the First Nation Client File (FNCF).

The Data Governance Framework stems from the annual Summary Service Plan[3] in line with the 7 Directives[4] and OCAP®[5] (Ownership, Control, Access, Possession). All principles are well embodied through the First Nations health information governance structure advanced by the Tripartite partners.

Article 4 of the original 2010 TDQSA expects that activities will be undertaken in a manner consistent with and in furtherance of the principles of respect and recognition, commitment to action, nurturing the relationship and transparency. Since then, additional principles have been adopted, including the Truth and Reconciliation Commission of Canada defining reconciliation as "an ongoing process of establishing and maintaining respectful relationships." Article 31 of the *United Nations Declaration on the Rights of Indigenous Peoples* confirms that "Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures."

---

2. First Nations Health Authority. 7 Directives.
3. FNHA-Summary-Service-Plan-2022-2023
4. First Nations Health Authority. 7 Directives.
5. First Nations Information Governance Centre. The First Nations Principles of OCAP.

UPDATES

- First Nations in BC continued to be impacted by the effects of the COVID-19 pandemic, the toxic drug public health emergency that was declared in 2016 and that shows few signs of ending, extreme climate change-related events and systemic racism within the health care system. During the period covered by this report, surveillance data for the toxic drug crisis and COVID-19 were published monthly, whereas all other data was collected and reported annually.

- COVID-19 data for First Nations in BC was made available through a partnership entered into in 2020 between the FNHA and the Provincial Health Services Authority, which includes the Ministry of Health and the BC Centre for Disease Control (BCCDC), and extended until June 2023. Despite some public health mandates being eased or eliminated in 2022, there were more deaths related to COVID-19 in 2022 than in any other year.[6]

- BC declared a public health emergency in relation to the toxic drug overdose crisis in April 2016. In response to Goal 3.4 of the FNHA Annual Report for 2022-2023 to "prioritize the implementation of coordinated, comprehensive and evidence-based approaches to reducing the impact of the toxic drug crisis," a more substantive picture was constructed through monthly analysis of data from the FNCF, BC Emergency Services, the BCCDC and the Coroner's Report. In 2022, although overdoses/ poisonings decreased for the first time by five per cent from the previous year for BC citizens overall, there was a 6.3% increase in deaths within First Nations communities.[7]

- The Urban and Away-From-Home Survey 2021 Results Report was the first time the FNHA engaged specifically with First Nations people living in urban centres and away from home to understand how they access health and wellness information. This shaped a communication and action plan whereby FNHA team members went to events across the province in 2022 to inform individuals about health and wellness services and programs available through the FNHA. This includes the FNCF and Health System Matrix linkage to other datasets to create data products for First Nations living in urban centres and away from home.

- In 2021, the FNHA developed the Anti-Racism, Cultural Safety and Humility Framework and the Anti-Racism, Cultural Safety and Humility Action Plan.[8] A year later, the FNHA and the Health Standards Organization released the British Columbia Cultural Safety and Humility Standard, a tool that will enable organizations to address Indigenous-specific racism and build a culturally safe health care environment.

- In November 2022, the Government of British Columbia marked the two-year anniversary of the release of *In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in B.C. Health Care*.[9] The inaugural annual report released in December 2022 documented the collective efforts to begin implementing the 24 recommendations of the In Plain Sight report.[10]

---

6. CBC British Columbia. "2022 was the deadliest year of the COVID-19 pandemic in B.C. What's next?". December 29, 2022. Accessed at: www.cbc.ca/news/canada/british-columbia/2022-covid-year-in-review-1.6699063
7. FNHA. First Nations and the Toxic Drug Poisoning Crisis in BC, January-December 2023. Accessed at: https://www.fnha.ca/Documents/FNHA-First-Nations-and-the-Toxic-Drug-Poisoning-Crisis-in-BC-Jan-Dec-2023.pdf.
8. FNHA, First Nations Health Council and First Nations Health Directors Association. Anti-Racism, Cultural Safety & Humility Action Plan. April 22, 2021. Accessed at: https://www.fnha.ca/Documents/FNHA-FNHC-FNHDA-Anti-Racism-Cultural-Safety-and-Humility-Action-Plan.pdf
9. In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in B.C. Health Care. November 2020. Accessed at: https://www.fnha.ca/Documents/FNHA-FNHC-FNHDA-Anti-Racism-Cultural-Safety-and-Humility-Action-Plan.pdf.
10. Ministry of Health, Indigenous Health and Reconciliation Division. In Plain Sight Annual Report, May 2021-May 2022. Accessed at: https://www2.gov.bc.ca/assets/gov/government/ministries-organizations/ministries/health/office-of-indigenous-health/in-plain-sight-annual-report-2022.pdf

- The new *Health Professions and Occupations Act* is a commitment to cultural safety and humility and aims to improve governance systems.

- The *Anti-Racism Data Act* was passed in May 2022 to help dismantle systemic racism and discrimination faced by Indigenous and racialized British Columbians. Data collected under the Act will help identify gaps so that they can be addressed in programs and services.

DATA MANAGEMENT WORKING GROUP (DMWG)

The DMWG continues to support the ongoing activities of the DIPC. The DMWG is made up of representatives from the FNHA and the Government of British Columbia. The bi-weekly meetings are chaired and organized by the DIPC Secretariat held within the FNHA. The DMWG's purpose and responsibilities are to:

- Provide technical and detailed support and project management relating to proposed and/or approved Data Access Requests (DARs). Each DAR is managed by an assigned project lead or project director (if a project lead is not available) that provides overall leadership to the project, including leading and/or assigning work.

- Conduct technical reviews of DARs and provide feedback and advice for the data requesters to ensure fulsome DARs are completed. The feedback and advice includes, but is not limited to, data governance, research and First Nations' perspectives. The DMWG ensures that all information required in a DAR is complete and all supporting documents are available for DIPC review.

- Develop processes, forms and tools to facilitate the work of the DIPC, as well as the appropriate management and use of FNCF data.

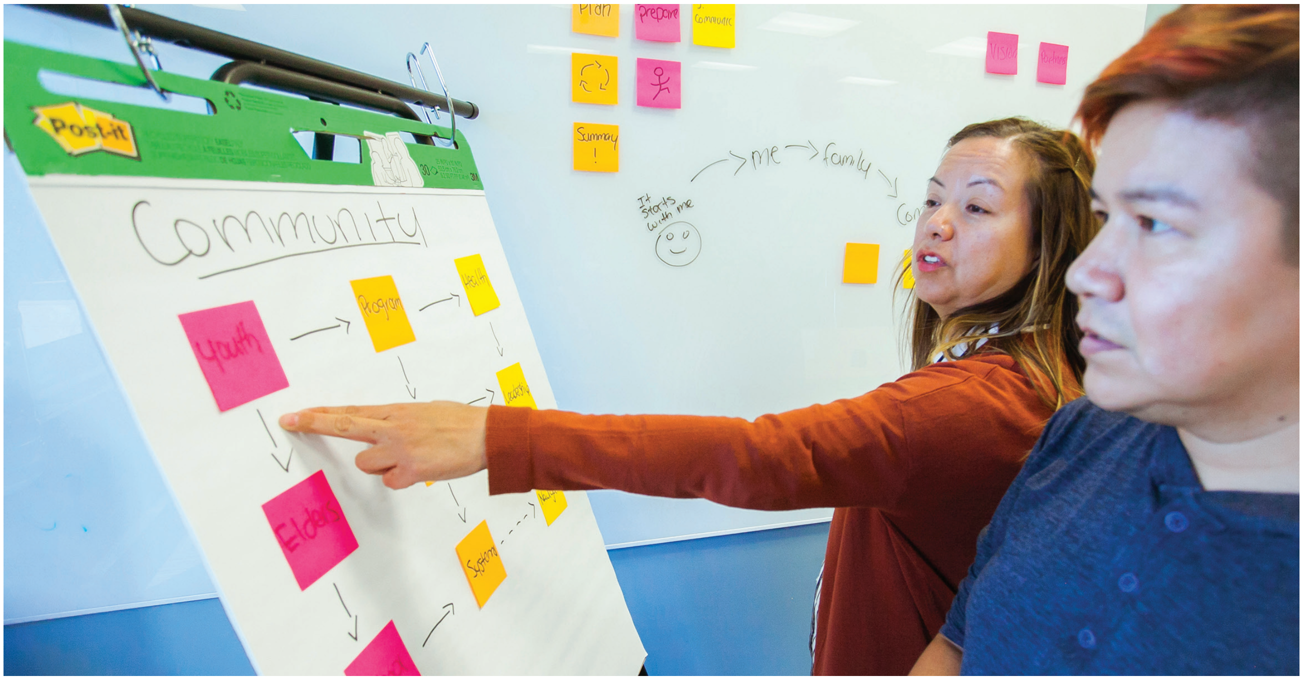
- Document all DIPC and DMWG activities.

- Provide a forum for discussing data issues, projects and supports.

- Make sure that all dissemination of results developed using FNCF data, the FNCF client roster or the FNCF population denominator are available for the DIPC to review. This includes, but is not limited to, peer-reviewed publications, internal and external reports, abstracts, oral presentations, posters and media releases by any of the involved project parties.

- Make sure that the FNCF-linked data is destroyed when a project has been completed, and that a project is closed properly.

3. Progress to Date on Fulfilling the Purposes of the Tripartite Data Quality and Sharing Agreement



ARTICLE 3.1.A

The intent is for the Parties to:

- **Continually improve the quality and availability of First Nations data;**
- **Facilitate the sharing of FNCF data in response to research questions approved in accordance with the Agreement; and**
- **Ensure that FNCF data is appropriately compiled, used and shared by the Parties in accordance with the principles set out in this Agreement and applicable legislation.**

The DIPC Framework will be informed by the Data Governance Framework consultations that started in 2022. Once complete and approved, the DIPC Framework will inform the DIPC Management Policy.

To support the implementation of the TDQSA, the partners created a framework with three key structures and foundational documents that guide the work of these structures. The DIPC Framework will be informed by the Data Governance Framework consultations started in 2022. Once complete and approved, the DIPC Framework will inform the DIPC Management Policy.

The DIPC formally reports to the FNHA-Ministry of Health Joint Project Board. The 2021 Joint Project Board Year In Review states that “Enhancing capacity for data collection and analysis, information sharing and building a robust data governance and steward partnership strategy are key priorities to support decision-making regarding health system strategy and service delivery priorities and to effectively monitor and report on progress.”

PROGRESS IN 2022 WITH COVID-19 DATA

Despite the competing priorities due to the COVID-19 pandemic, the DIPC met five times in 2022. The Committee saw an increasing trend in First Nations health service planning-related data requests from First Nation communities and the FNHA itself.

There continues to be some challenges in the DAR development and review processes, including the need to apply an Indigenous lens to ensure DARs are respectful and meaningful. Each DAR presents a unique context and novel idea, thus leading to new questions and implications about the data and its use. In effect, each DAR case sets a precedent for moving forward to ensure consistent decisions.

An updated copy of the FNCF is transferred annually to the BCCDC and continues to be hosted by the BCCDC to respond to the COVID-19 pandemic, with cases and vaccination data provided daily. There was also a change in the provincial COVID-19 surveillance system in April 2022 to include reported cases, hospitalizations and deaths for the FNHA. As the BCCDC shifted to a weekly reporting schedule, so did the FNHA, which produced reports for its executive and community partners in 2022 and 2023. Data is used to produce annual infographics.[11]

ARTICLE 3.1.B

Create a process for the Parties to develop, promote, and act upon initiatives, and to facilitate and control access to FNCF data for the purposes of such initiatives or other programs or activities.

First Nations health information governance[12] is grounded in foundational documents such as the *2011 Consensus Paper: British Columbia First Nations Perspectives on a New Health Governance Arrangement*.[13]

The Consensus Paper was the result of more than 120 regional and sub-regional caucus meetings with First Nations Chiefs, leaders and senior health professionals informing discussions and negotiations of a new governance arrangement for health programs and services used by First Nations in BC. The Consensus Paper outlines 7 Directives that describe the fundamental standards and instructions for the new health governance relationship. The DIPC uses the 7 Directives to guide its work and decision-making. Directive 2 provides for increased First Nations decision-making and control, and within this, to implement OCAP® in data and reporting.

To prioritize serving First Nations clients first, since 2012, external research requests that include FNHA partners have taken precedence over those that do not due to the limited resources available for linkage to the FNCF.

PROGRESS IN 2022

The DMWG has been reviewing and updating the existing DIPC policies since 2020.

---

11. For Community Leaders
12. FNHA. Data Governance. https://www.fnha.ca/what-we-do/research-knowledge-exchange-and-evaluation/health-information-governance
13. British Columbia First Nations Perspectives on a New Health Governance Arrangement: Consensus Paper. Accessed at: https://www.fnha.ca/Documents/FNHC_Consensus_Paper.pdf

ARTICLE 3.1.C / ARTICLE 3.1.F

ARTICLE 3.1.C

Commit the Parties to work cooperatively toward the development of systems and protocols empowering First Nations to assume stewardship over the use of First Nations data and promote the accessibility of First Nations data and research.

ARTICLE 3.1.F

Commit the Parties to work together to develop the capacity of First Nations in BC to assume eventual custody, control and management of First Nations data.

- The FNHA has been building ongoing partnerships with ancillary service providers for data access and stewardship that will also enable linkages to the FNCF. Examples include the provincial Perinatal Mortality and Morbidity Review Committee (perinatal, neonatal and maternal mortality/morbidity data); the BCCDC[14] and the BC Coroners Service[15] for the toxic drug crisis response; and Trauma Services BC[16] for injury-related research.

- The Ministry of Health continues to be the current Data Steward of the FNCF, as per Article 6.3 of the TDQSA. Through the TDQSA, the partners are committed to supporting First Nations to develop the capacity to assume eventual custody, control and management of First Nations data, consistent with Article 3.1.f of the agreement. The TDQSA recognizes that when a First Nations Data Steward is established to take on the role, the Tripartite partners can recommend a change in the FNCF Data Steward as established in Schedule B, Section 1.2.c of the agreement.

- The DIPC Secretariat continues to develop capacities of FNCF knowledge, including development, quality assurance and linkage to other datasets stewarded by the Ministry of Health.

- All parties strive for continuous learning and improvements in policies, safeguards and standards regarding the FNCF, where they will be formally incorporated into the Data Governance Framework.

ARTICLE 3.1.D

Create new datasets to enable First Nations in BC to monitor the health of First Nations and the success of programs and services provided in First Nations communities.

PROGRESS IN 2022

Since the creation of the FNCF in November 2011, the DIPC has reviewed approximately 83 FNCF DARs. Each of the approved FNCF DARs generates its own dataset. These datasets are not available for any other purpose other than what was described in the original application. However, the DIPC has established a policy on secondary data use to capitalize on previous work and avoid duplication of effort while respecting all legislative requirements. At the end of March 2023, there were 13 active projects where health partners were using the FNCF and linking it to their data, and there were an additional six requests from BC First Nations communities to access FNCF data for their own service planning.

---

14. BC Centre for Disease Control
15. BC Coroners Service
16. Trauma Services BC

ARTICLE 3.1.E

Recognize First Nations Health Information Governance and ensure that its principles are respected in all circumstances related to the use, collection and dissemination of First Nations Data and use of the FNCF.

The principle of First Nations health information governance is a central tenet of the DIPC and one that the committee strives to operationalize as it pertains to accountability, privacy and confidentiality, as well as how it relates to the realities of working with administrative health data.

The partners act on their commitment to First Nations in BC for the culturally safe, appropriate and responsible use of the FNCF, and they have developed clear pathways and mechanisms for FNCF data access and decision-making for First Nations.

The partners will continue to work toward the following vision:

First Nations are involved in decision-making regarding use of the FNCF and resulting data

Privacy of individuals and communities is paramount

Topics of priority to First Nations are prioritized

Information from the FNCF is available for First Nations to plan at community and regional levels

The FNCF be cautiously and conscientiously used in open, transparent ways, recognizing harmful realities of some historical research and surveillance

The DIPC recognizes that the mechanisms for First Nations inclusion in FNCF decision-making should and will be developed over time. Mechanisms that have been established to address the principles of First Nations health information governance include:

- The DIPC is co-chaired by the FNHA and the BC Ministry of Health, with each party having one equal vote.
- The FNHA has representatives on both the DIPC and DMWG.
- FNCF DAR decisions are made in agreement between the two co-chairs (to date, there has not been a time when an agreement could not be reached). The co-chairs are supported by committee members who select the co-chair from each respective organization.
- DIPC members compare each DAR against a set of conditions (see Appendix 2) that have been developed using the feedback and insight of community members from key FNHA documents, including the 2011 Consensus Paper. The conditions of use specify that FNCF DARs should be driven by First Nations priorities, involve relevant First Nations partners throughout the project, stimulate action that leads to better services for First Nations, and include First Nations voices during the interpretation and dissemination of results. By ensuring that DARs meet these conditions, the DIPC is advancing the ultimate goal of helping improve the health and wellness outcomes of First Nations.
- Respecting the sovereignty that First Nations communities have over their data, along with privacy issues arising from small sample sizes, the DIPC has not authorized the release of any community-level First Nations data to date. The DIPC will develop these capacities through collaboration with communities over time.

- An important part of First Nations health information governance is the respectful and inclusive interpretation and use of data. For that reason, DIPC requests that all publications or reports that use the FNCF, the FNCF Client Roster or the FNCF Population Count be provided to DIPC for review before they are disseminated. This includes, but is not limited to, peer-reviewed publications, internal and external reports, abstracts, oral presentations, posters and media releases by any of the involved project parties.
- Emerging publications and results are to be made accessible to First Nations through public dissemination in a format and method that is both accessible and meaningful to First Nations.
- The FNHA and the BC Ministry of Health collaboratively developed a process for sign-off on the development methodology, as well as a process of quality assurance for the FNCF.

PROGRESS IN 2022

The FNHA joined Research Ethics BC in 2019 and continues to participate in ethics reviews for projects where FNHA is leading or participating. As a member of the organization, the FNHA has a decision-making role in ethics, ensuring Indigenous self-determination in the research process for studies the FNHA is leading or partnered on.

All regional health authorities and major research universities are partners in Research Ethics BC, which supports a province-wide, harmonized system for research ethics reviews of studies conducted in multiple geographic areas involving the resources, people, patients or data from more than one BC research institution. Although the FNHA does not yet have a research ethics board, the FNHA Research Executive Committee provides an interim ethics review process.

ARTICLE 5.1.A

Support or directly undertake initiatives that will improve the quality and/or interpretation and use of First Nations data, including in respect of the Priority Areas of Interests.

The following priority areas of interest, as identified in the TDQSA (see Appendix 2 for a complete list), are areas where significant work occurred in 2022:

- Examining the societal consequences of the COVID-19 pandemic: This project began in April 2020 to identify, monitor and report on the impact of COVID-19 pandemic-related public health measures on British Columbians. At the request of BC public health leadership, a working group was formed that includes public health physician leads from the five regional health authorities, the FNHA, the BCCDC and the Office of the Provincial Health Officer. Due to other crises, there was no linkage done. Although reports on monitored items include consequences on mental/ physical health, as well as social, economic and environmental impacts, the FNHA included a statement on the Societal Consequences of BC's COVID-19 Response[17] but otherwise did not participate.

- Currently, four FNCF toxic drug crisis-related projects are in progress (please see Appendix 1 for details). An infographic was updated to include the first half of 2022 (January through June) for a mid-year data release, and data was shared at biannual Caucus meetings.

---

17. FNHA. FNHA's Statement on the Societal Consequences of BC's COVID-19 Response. Accessed at: https://www.fnha.ca/Documents/FNHA-COVID-19-Statement.pdf

- The BC Coroners Service (BCCS) and the FNHA have an existing DAR seeking information on First Nations youth and young adults who have died from injury-related causes. In 2018, the BCCS completed a new analysis of their data using the FNCF to check how accurately BCCS data identified First Nations decedents. Compared to the BCCS method of identifying First Nations ancestry, the BCCS discovered that the FNCF was able to detect 60 per cent more First Nations-identified individuals among the deceased. However, while the BCCS data set did not include all First Nations people, the BCCS found that the conclusions and recommendations in the report *The 2017 BC Coroners Service and First Nations Health Authority Death Review Panel: A Review of First Nation Youth and Young Adult Injury Deaths: 2010-2015*[18] remained the same. In the future, the BCCS plans to factor FNCF data access approvals into their reporting timelines. It is hoped that the implementation of the Aboriginal Administrative Data Standard will also improve the ability to identify Indigenous identity. The partners are also working on a project with Trauma Services BC and the BC Injury Research and Prevention Unit that focuses on injury surveillance among BC First Nations people. Although the DIPC approved this project in 2020, due to the COVID-19 pandemic, the project was put on hold. In 2022, the Privacy Impact Assessment and Information Sharing Agreement for communities were signed to link six databases, with the expectation for the first data in the summer of 2023.

- The Health System Matrix is a dataset that includes information on BC residents' health status (including chronic conditions) and use of the health care system, including by accessing hospital, physician and other services. This data is used to analyze health service use and expenditures for First Nations and non-First Nations residents in BC's regional health authorities. The potential gaps in First Nations' access to programs/services are examined, and opportunities for investment or service integration are identified.

In 2022, the new linkage included updates to the Health System Matrix and Discharge Abstract Database datasets, as well as the addition of the Pop Grouper[19] dataset. The latter looks at multi-morbidities and variations in health care resources (some not yet received by the FNHA) and describes overall population health. These include all health conditions (including longitudinal chronic diseases, HIV/AIDS, mental health and self-harm, suicidal ideation and tuberculosis) identified from inpatient, day surgery, emergency department, hospital clinic, continuing care, home care, physician claims and primary care administrative data. This data provides insight into conditions not being treated appropriately in primary care and that require hospitalization.

ARTICLE 5.1.B

Archive the goals, objectives or activities identified and agreed to by the Parties and set out in the Annex to the TDQSA, as amended, supplemented or replaced from time to time.

The TDQSA states that the partners are able to develop and collaborate on projects or initiatives. See Appendix 1 for more information.

---

[18] BC Coroners Service and First Nations Health Authority Death Review Panel. A Review of First Nation Youth and Young Adult Injury Deaths: 2010-2015. November 2017. Accessed at: https://www2.gov.bc.ca/assets/gov/birth-adoption-death-marriage-and-divorce/deaths/coroners-service/death-review-panel/fnha_bccs_death_review_panel_-_a_review_of_first_nations_youth_and_young_adults_injury_deaths_2010-2015.pdf

[19] Canadian Institute of Health Information

ARTICLE 5.1.D

Oversee the development of First Nations Data in respect of the following seven performance indicators in the TFNHP:

- **Life expectancy at birth**
- **Mortality rates (due to all causes)**
- **Status Indian youth suicide rates**
- **Infant mortality rates**
- **Diabetes rates**
- **Childhood obesity (develop baseline and ongoing mechanism for collecting data)**
- **Practicing, certified First Nations health care professionals (develop baseline and ongoing mechanism for collecting data)**
- **Establish other key indicators, including wellness indicators.**

After extensive engagement, the FNHA and the Office of the Public Health Officer have agreed to continue to monitor the health and well-being of First Nations people in BC through a new Population & Wellness Health Agenda[20] that marks a shift away from a biomedical, sickness-based model. Its indicators, targets and recommendations were presented at the Gathering Wisdom for a Shared Journey X in January 2020 for validation and feedback. The 22 indicators include monitoring, taking a strengths-based approach to focus on wellness and resilience, and the two-eyed seeing perspective to bring together First Nations and western ways of knowing., The baseline report was released in June 2021,
followed by two interim reports and a final report over the next 10 years.

In June 2022, project executives approved a plan to involve FNHA analysts to learn alongside analysts at the Office of the Public Health Officer so they can gain experience with administrative health data with the eventual goal of having the FNHA lead FNCF-based analyses. The majority of the analyses pertaining to the first interim report was complete by March 2023.

ARTICLE 5.1.E

Develop a plan to support and develop the capacity and self-determination of First Nations in B.C. to (i) manage the collection, use and disclosure of First Nations data, and (ii) enhance the ability of First Nations in B.C. to conduct health research.

During this reporting period, the DMWG has been working to establish a standardized DAR intake process. The DMWG and the FNHA Research and Knowledge Exchange team, which includes the FNCF Data Secretariat, have been coordinating ethics reviews and the DAR process to streamline applications submitted by partners for research purposes. Research studies must have an approved ethics application for a DAR to be considered and approved.

---

[20] Population Health and Wellness Agenda

ARTICLE 5.1.F

Develop and implement a program(s) for the collection of information to assist in the development of First Nations health policy and program planning, as well as to monitor health outcomes in First Nations communities.

There is an expedited process of three to five days to have a DAR signed for First Nations requesting data for their own purposes.

VANCOUVER COASTAL REGION

- Southern Stl’atl’imx First Nations communities requested remoteness and accessibility data to help understand attachment quality (whether a patient continued to use the same doctor or health provider over time).
- Tla’amin Nation requested Census and Indian Registry Demographic Data to support Powell River’s Primary Care Network Plan.
- Vancouver Coastal Urban and Away from Home requested First Nations’ population estimates.

VANCOUVER ISLAND REGION

- Cowichan Tribes’ Ts’ewulhtun Health Centre is using Health System Matrix data to contrast spending between First Nations and other residents with the aim of identifying gaps in programs and services, and identifying opportunities for investment and integration.
- The FNHA Vancouver Island Regional Office is using a regional Health System Matrix slide deck and other First Nations-specific data for Vancouver Island to apply for primary care funding.

NORTHERN REGION

- Tahltan Nation wanted a baseline for planning and to track the use of community health programs and services to better meet the needs of Tahltan members and their families as they implement a new five-year community health plan.

ARTICLE 5.1.G

Develop and assist other government agencies, government ministries and government departments to develop comparable data sets for non-status First Nations in BC.

The FNCF allows for the identification of Status Indian and status-eligible First Nations individuals. Health information of non-status individuals cannot be identified using the FNCF. This has not changed.

Looking Ahead

The DMWG, DIPC and TDQSA signatories will continue to support the development of a new agreement through extensive community engagement to replace the current extension of the TDQSA, which expires in April 2024.

Appendices

APPENDIX 1: GLOSSARY

Capitalized terms used in this report have the following meanings:

- **Annex:** A document that sets out initiatives or other programs or activities that the partners have agreed to approve or undertake in connection with the Tripartite Data Quality and Sharing Agreement (TDQSA) and includes annexes developed in respect of the priority areas of interest listed in Annex 1 of the TDQSA, as well as any further annexes developed and approved by the partners in accordance with Schedule A of the TDQSA (referred to as data access requests).

- **Data Access Request (DAR):** A data access request for the First Nations Client File (FNCF) or linkage of other datasets to the FNCF. A data requestor/applicant submits a DAR form providing information regarding the applicant, project overview, data access and project methodology, data security, data analysis, dissemination plan and anticipated project risks.

- **Data and Information Planning Committee (DIPC):** Originally referred to as the Data Quality and Sharing Committee in the TDQSA, this committee's name changed to the Tripartite Data and Information Planning Committee in April 2011. After October 1, 2013, when the FNHA assumed the programs, services and responsibilities formerly handled by Health Canada's First Nations Inuit Health Branch – Pacific Region, the committee's name changed to the Data and Information Planning Committee (DIPC). The DIPC is a Tripartite working group with representatives from the FNHA, BC Ministry of Health and Indigenous Services Canada and is responsible for providing overall policy direction under the TDQSA and for the decisions made pursuant to it. To this end, the DIPC has developed standards, policies and procedures required for the overall administration and coordination of the TDQSA and its annexes. The DIPC also makes recommendations to the FNCF data steward on research activities and access to data. Data access requests for the FNCF are approved by mutual agreement of the partner voting members of the DIPC (Schedule B, Section 1.2.b (iii) and Schedule B, Section 1.3.b of the TDQSA) and ultimately signed off by the FNCF data steward for the purposes of compliance with privacy legislation (Section 6.4 of the TDQSA). The DIPC reviews the content of the DARs, as well as all publications or reports that use the FNCF, the FNCF client roster or FNCF population counts before dissemination. This includes, but is not limited to, peer-reviewed publications, internal and external reports, abstracts, oral presentations, posters and media releases from any of the project parties. The respectful and inclusive interpretation and use of data is paramount to First Nations health information governance.

- **Data Management Working Group (DMWG):** A working group, consisting of representatives from each of the partner organizations, that is responsible for supporting the work of the DIPC.

- **DIPC Secretariat:** To develop the necessary training and knowledge exchange between the BC Ministry of Health and the FNHA, a secondment position was created in 2014 for a DIPC Secretariat employee within the BC Ministry of Health. This role was created to coordinate the FNCF and oversee FNCF data linkages, provide secretariat functions to the DIPC, and provide input into Ministry of Health and FNHA First Nations data governance issues. The position was originally housed within the Office of Indigenous Health and was then transferred to the Ministry's Health Sector Information, Analysis and Reporting division in 2016. The position also provides status reports to the BC Ministry of Health-FNHA Joint Project Board.

- **First Nations Client File (FNCF):** The FNCF is a cohort of BC resident First Nations people registered under the *Indian Act* and their unregistered descendants born after 1986 for whom entitlement to register can be determined and is linkable to their BC Ministry of Health Personal Health Number. The FNCF is the product of a record linkage between an extract of Indigenous Services Canada's Indian Register and the BC Ministry of Health Client Registry.

  The Tripartite partners agree that the FNCF is the best available method to access accurate health information about the identifiable majority of status and eligible-for-status First Nations clients residing in BC. The FNCF is linked to other datasets to produce FNCF data as authorized by the DIPC and the FNCF Data Steward.

  The development of the FNCF is made possible through a memorandum of understanding between the BC Ministry of Health and Indigenous Services Canada authorizing the annual disclosure of information contained in the Indian Register to the BC Ministry of Health. The FNCF was initially created in 2011, and is updated incrementally using a fresh extract from the BC Client Registry and Indigenous Services Canada's Indian Register. As of July 2020, the most updated population cohort is the 2018 FNCF.

- **FNCF data:** Data generated in response to approved requests by the FNCF Data Steward, through use of the FNCF to perform linkages to BC provincial databases; may contain personal information.

- **FNCF Data Steward:** The agency appointed by the Tripartite partners to have custody of the FNCF Data Steward are responsible for creating the FNCF, as authorized in the Memorandum of Understanding. The FNCF Data Steward also performs necessary linkages with the FNCF to create FNCF data (Section 6.1.a of the TDQSA). At the time of this publication, the FNCF is under the stewardship of the BC Ministry of Health, Chief Data Steward (Section 6.3 of the TDQSA). There are mechanisms for the partners to recommend a different Data Steward for the FNCF (Schedule B, Section 1.2.c of the TDQSA).

- **First Nations data:** Data regarding the health and demographic characteristics of the First Nations population in the province of BC, including the socioeconomic determinants of health. This data may contain personal information.

- **First Nations health information governance:** A structure, process, and protocol by which First Nations in BC have access to First Nations data and are influentially involved in decision-making regarding the culturally appropriate and respectful collection, use, disclosure and stewardship of that information in recognition of the principle that such information is integral to First Nations policy, funding and health outcomes.

- **Information Sharing Agreement (ISA):** An agreement between a public body and one or more of the following: (a) another public body; (b) a government institution subject to the *Privacy Act* (Canada); (c) an organization subject to the *Personal Information Protection Act* (BC) or the *Personal Information Protection and Electronics Documents Act* (Canada); (d) a public body, government institution as defined in applicable provincial legislation having the same effect as the *Freedom of Information and Protection of Privacy Act* (FOIPPA); (e) a person or group of persons; or (f) an entity prescribed in the FOIPPA Regulation. The ISA sets conditions on the collection, use, or disclosure of personal information by the parties to the agreement.

- **Partners:** The FNHA and the Province of BC. Although it is not a formal signatory to any FNCF DARs after October 1, 2013, the Government of Canada (currently represented by Indigenous Services Canada), continues to participate on the DIPC as an observer.
- **Partner Voting Members:** There are two voting members of the DIPC, one appointed by each partner, to make decisions related to the approval of FNCF DARs. Decisions require the approval of both partner voting members (Schedule B, Section 1.3.b).
- **Perinatal Service BC:** Provides leadership, support, and coordination for the strategic planning of perinatal services. PSBC takes a woman- and family-centred population health approach.

Personal information: Personal information as defined in the *Freedom of Information and Protection of Privacy Act* (FOIPPA) [RSBC 1996], c.165, and all amendments thereto. In this definition, personal information means recorded information about an identifiable individual, other than contact or work product information. The definition of personal information may vary according to different legislation used in a specific DAR project; for example, the *Pharmaceutical Services Act* has a different definition of personal information.

- **Pop Grouper:** The Canadian Institute for Health Information[21] Population Grouping Methodology (POP Grouper) builds clinical and demographic profiles for each person in a population.
- **Privacy Impact Assessment:** A step-by-step review process to make sure personal information collected or used under FOIPPA (see above) is protected.
- **Tripartite Data Quality Sharing Agreement:** Originally signed in 2010 with annual reporting requirements.

---

[21] Canadian Institute for Health Information

APPENDIX 2: ACTIVE PROJECTS

There were 19 DARs over the reporting period: six data requests filled upon request of First Nations (see 5.1.f) and 13 in conjunction with the BC Ministry of Health and/or the Provincial Health Services Authority. Most DARs are ongoing projects that will take place over several years, although there are occasional one-time-only requests or requests for new types of data to be added to existing projects to reflect emerging health matters. Updates on data analysis and its knowledge exchange are provided at FNHA caucuses. When DARs are requested by First Nations and their recognized organizations, their data goes directly to them.

*Sub-project section included only if there is one described.

1 CHRONIC DISEASE REGISTRY

Description	Status Update
To compare the descriptive epidemiology of various chronic diseases between status First Nations living in BC and other BC residents.	A five-year information sharing agreement was signed in June 2022 between the FNHA, the Office of the Provincial Health Officer and the Ministry of Health, after which the analysis commenced.

2 PERINATAL DATA LINKAGE WITH FIRST NATIONS HEALTH AUTHORITY

Description	Status Update
The FNHA requested routine linkage to Perinatal Services BC's data for the surveillance and annual reporting on the health of First Nations mothers and infants in BC. Perinatal data provides a picture of the well-being of First Nations pregnant women and infants. Prenatal care is a major indicator of the health outcomes of infants. The data will support the planning of culturally relevant perinatal care and will be used to measure access to perinatal care by First Nations women and infants.	The surveillance report for the Cowichan Tribes had a specific focus on pre-term birth-related indicators in 2020. The data was refreshed and analyzed in March 2023.

3 PROVINCIAL HEALTH OFFICER INDIGENOUS GIRLS' AND WOMEN'S HEALTH REPORT

Description	Status Update
To use a wellness, social determinants of health and equity-based perspective to present and examine current data and information on the health and well-being of Indigenous girls and women in BC. This report discusses success stories and areas where there may be room for improvement and makes recommendations for the creation of specifically targeted programs to support better health.	Analysis complete. The findings of this initiative were published in a report titled *Sacred and Strong: Upholding our Matriarchal Roles — The Health and Wellness of BC First Nations Women and Girls*, released publicly in two companion documents: one in 2021 and a technical supplement in 2022. This project is now concluded.

4 POPULATION HEALTH AND WELLNESS AGENDA, FNHA CHIEF MEDICAL OFFICE AND OFFICE OF THE PROVINCIAL HEALTH OFFICER

Description	Status Update
The purpose of this project is to serve as the next phase of reporting for the indicators established in the *Transformative Change Accord: First Nations Health Plan* that was released in 2006. It includes the seven original health indicators as well as 15 additional indicators that reflect a strengths-based approach and incorporate dimensions of the FNHA perspective on wellness. Data is being resourced from multiple sources to support these 22 indicators, 10 of which are derived from FNCF linkages	Work for the first interim report continued between January 2022 and March 31, 2023. In June 2022, project executives approved a plan to involve FNHA analysts to learn alongside Office of the Provincial Health Officer analysts so that the FNHA team could gain experience with administrative health data, with the eventual goal being that the FNHA will lead FNCF-based analyses. The majority of the analyses were completed by March 2023 and drafting of the report commenced.

5 OPIOIDS OVERDOSE PUBLIC HEALTH EMERGENCY SURVEILLANCE PROJECT — BC CENTRE FOR DISEASE CONTROL (MAIN COMPONENT: PROVINCIAL OVERDOSE COHORT)

Description	Status Update
To develop a linked public health surveillance database within the BCCDC to support planning, priority setting and evaluation of the opioid overdose prevention emergency strategy in BC. The anonymized linked database will be used by analysts in the FNHA, BCCDC, regional health authorities and the BC Ministry of Health to support decision-making.	Data up to December 31, 2020, was added to the Provincial Overdose Cohort as of March 2023.

6 OPIOIDS OVERDOSE PUBLIC HEALTH EMERGENCY SURVEILLANCE PROJECT — EMERGENCY HEALTH SERVICES COMPONENT

Description	Status Update
Timely access to BC Emergency Health Services – BC Ambulance Services data during the opioid crisis aligns with the vision as outlined in the Tripartite First Nations Health Plan (2007). The BC Provincial Overdose Cohort provided the first statistics on how the overdose crisis is affecting First Nations populations; however, it is a large and complex linkage that requires several weeks to produce, and it is only refreshed annually. In the interests of pursuing timelier surveillance information for First Nations populations, a more “real-time” linkage of the BC Emergency Health Services data set to the FNCF will be conducted monthly.	Monthly updates were provided to senior leadership as well as various overdose response teams. The 2022 data from this linkage was used to inform the public release of data via a half-year infographic, which was then updated to include data for the full 2022 year and released in 2023. Data was also shared at Caucus 2022 and for Health System Matrix reports. Lastly, the data was used to prepare youth-specific regional presentations on the impact of toxic drug crisis on First Nation youth in BC. www.fnha.ca/what-we-do/mental-wellness-and-substance-use/harm-reduction-and-the-toxic-drug-crisis/toxic-drug-crisis-data

7 SUBSTANCE USE CASCADE OF CARE FOR BC

Description	Status Update
First Nations in BC are disproportionately affected by substance use disorders, and a disproportionate number of First Nations people have experienced a fatal or non-fatal overdose in BC since 2015. This project serves two purposes: 1) create and monitor an opioid use disorder cascade of care and 2) analyze outcomes for people living with HIV and substance use issues.	After the project team moved from the BC Centre for Excellence of AIDS/HIV to the Centre for Health Evaluation and Outcome Sciences, the datasets were also transferred after approval of a DAR amendment. Key results were shared at Caucus 2022 and 2023. Results from this linkage were used to create data presentations for sub-regional and regional Fall Caucus 2023 meetings and Health Systems Reports. Data up to December 2021 is being used to prepare youth-specific regional presentations on the impact of the toxic drug crisis on First Nation youth in BC.

8 FIRST NATIONS CANCER RESEARCH AND SURVEILLANCE PROJECT (CANCER 2)

Description	Status Update
The Indigenous Cancer Strategy is a five-year strategic plan to improve First Nations cancer outcomes and experiences in the province, and its implementation is a key priority of both BC Cancer and the FNHA. As knowledge development is one of the Indigenous Cancer Strategy's seven strategic priorities, the FNHA and the University of British Columbia have invested $3 million over the next 10 years to establish an FNHA Chair in Cancer and Wellness at UBC. The data developed as a result of this DAR will support the work of this Chair and allow the FNHA and BC Cancer to fulfil their Indigenous Cancer Strategy promise to communities to better document and understand First Nations cancer journeys, and to respond to community cancer concerns with relevant data.	Ethics were amended in November 2021. In the meantime, because of the contract with the data analyst at BC Cancer, the data was released to BC Cancer under special condition in October 2021. The analyses were in progress in 2021.

9 PROVINCIAL HEALTH SYSTEM MATRIX LINKAGE (ROUND 2 AND 3)

Description	Status Update
The goal is to understand the First Nations population relative to key systems.	The FNHA Health Surveillance team completed the creation of provincial and regional slide decks with the round 2 Health System Matrix (HSM) v.10 2017/18 data. The decks were shared within FNHA and uploaded to the FNHA SharePoint site for specific staff access in 2022. The round 3 data refresh (HSM v.13) became available in early 2022.

Sub-project

Service planning for FNHA internally and these regions:

- Fraser Salish DAR for primary care planning
- Interior DAR for Primary Care Network planning
- North Vancouver Island DAR for planning First Nations-led Primary Health Care Centres

10 FIRST NATIONS INJURY SURVEILLANCE

Description	Status Update
The burden of morbidity, mortality and disability from injury in BC is significant. Like many other health issues, injury disproportionately affects the health and well-being of First Nations individuals, families and communities. The surveillance products will compare the descriptive epidemiology (trends and patterns) of different types of injuries, health service utilization and outcomes between First Nations people and other residents of BC.	A privacy impact assessment and information sharing agreement were signed in 2022. Trauma Services BC prepared the injury cohort dataset (BC Trauma Registry, Discharge Abstract Database, BC Emergency Health Services, National Ambulatory Care Reporting System, emergency department visits and BC Vital Statistics Agency) and shared essential data variables with the BC Ministry of Health for linkage with the FNCF in January 2023. Data is expected to be received in the summer of 2023.

11 SILENT GENOMES ACTIVITY 4.2

Description	Status Update
A comparison of Indigenous and non-Indigenous child patient records to- how many were referred for screening for suspected genetic health conditions, and the length of time for a diagnosis.	In 2020, DIPC approved the DAR. A research agreement was under development in December 2021. This project was put on hold due to the delay in starting this activity because of COVID-19 and getting a research agreement in place.

12 COVID-19 FNCF TRANSFER

Description	Status Update
Due to the COVID-19 pandemic, the FNCF was transferred to the BCCDC. The BCCDC provides daily updates of First Nations COVID-19 cases, vaccination uptake, hospitalizations and deaths. The FNHA Surveillance team has access to anonymized data and the FNHA Chief Medical Officer has access to non-anonymized data. The exact variables and data sources have changed over the course of the pandemic.	COVID-19 cases and vaccination data were provided by the BCCDC to the FNHA daily. FNHA produced reports for its executive and community partners in 2022 and 2023. As the BCCDC shifted to a weekly reporting schedule, so did the FNHA. There was a change in the provincial COVID-19 surveillance system in April 2022 (cases, hospitalizations and deaths reported from the Provincial Laboratory Information Solution (PLIS), the Provincial COVID-19 Monitoring Solution (PCMS) and BC Vital Statistics Agency instead of the regional health authority line list. From April 1, 2022, onwards, the FNCF was linked with PLIS, PCMS and the BC Vital Statistics dataset to support ongoing COVID-19 surveillance among First Nations people in BC.

13 EXAMINING THE SOCIETAL CONSEQUENCES OF THE COVID-19 PANDEMIC

Description	Status Update
This project began in April 2020 to identify, monitor and report on the impact of COVID-19 pandemic-related public health measures on British Columbians. A working group that included the FNHA identified items to include, such as mental/physical health consequences, as well as social, economic and environmental impacts.	Due to the massive pandemic crisis, followed by the discovery of unmarked graves at Tk̓emlúps in mid-2021, the FNHA's priority was to meet the needs of First Nations first. This project is now concluded.

14 IMPACT OF COVID-19 PANDEMIC ON LIFE EXPECTANCY

Description	Status Update
The purpose of this project is to assess the impacts of the COVID-19 pandemic and the illicit drug toxicity crisis on the life expectancy of First Nations people. It will enable the FNHA to understand the trends and patterns of different causes of death among First Nations people from 2000 to 2021. Life expectancy analyses will help identify the impact of COVID-19, illicit drug toxicity and other underlying causes of death during the pandemic.	The DAR was approved, the analysis was completed in 2022 and the findings were shared with the FNHA between November 2022 and January 2023. This project is complete.

APPENDIX 3: PRIORITY AREAS OF INTEREST

Priority Areas of Interest Defined by the Tripartite Data Quality & Sharing Agreement, Appendix 1

In addition to First Nations-driven research that looks at First Nations health from a wellness perspective, the Tripartite partners have identified several additional common priority issues. The Tripartite partners acknowledge the benefit of collaboration in addressing these issues, and will draw on existing and new datasets held or administered by BC or Canada to support:

1. Continuation of the annual vital statistics report on birth and mortality-related statistics for First Nations.

2. Identification of First Nations populations living on- and off-reserve/home and away-from-home, regardless of registration status, to better categorize health data as on- or off-reserve/home or away-from-home.

3. Assessment of the epidemiology of diabetes mellitus and other chronic diseases, including prevalence and complications in First Nations people in BC.

4. Assessment of the epidemiology in First Nations of communicable diseases that are reportable under the Provincial Health Act, including, but not limited to, HIV, tuberculosis and vaccine-preventable diseases.

5. Assessment of the epidemiology of cancers in First Nations in BC communities, including, but not limited to, lung, breast, cervix, colon and prostate cancers.

6. Assessment of the epidemiology in First Nations of injury-related morbidity and mortality (including types of injury patterns by age group and region), including, but not limited to, motor vehicle accidents, accidental poisoning, falls and suicide.

7. Establishment of baseline data with regard to First Nations health status so as to enable the measurement of progress by the parties in addressing First Nations health, reviewing the health indicators monitored by the Provincial Health Officer and determining what additional indicators may be needed to assess the population health status of First Nations.

8. Assessment of health care service and program utilization patterns and trends for First Nations in all of Canada, including federal, provincial and regional patterns and trends.

9. Establishment of baseline data and ongoing mechanisms for collecting relevant data with respect to new indicators, including, but not limited to, childhood obesity and the number of practising First Nations in B.C. certified health care professionals.

10. Collection of information about congenital anomalies and genetic conditions in First Nations.

11. Collection of information required for the First Nations in BC Regional Longitudinal Health Survey.

12. Collection of information required for First Nations in BC community health plans.

13. Other projects as identified and agreed upon by the parties.