

TRIPARTITE
DATA QUALITY AND
SHARING AGREEMENT

2018-2019
**ANNUAL
REPORT**
ON PROGRESS



Tripartite First Nations Health Plan





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 | <https://www.canada.ca/en/indigenous-services-canada.html>

©2020 Copyright for this publication is held jointly by the First Nations Health Authority, the British Columbia Ministry of Health and Indigenous Services Canada. Any proposed amendments or changes to content in the future require the approval of all three parties. This publication may be reproduced without permission provided the source is fully acknowledged.

Contents

1. Glossary.....	4
2. Context for the Report.....	8
3. Context of Our Work.....	9
4. Progress to Date on Fulfilling the Purposes of the Tripartite Data Quality and Sharing Agreement	12
Article 3.1.a	12
Article 3.1.b.....	13
Article 3.1.c/Article 3.1.f.....	15
Article 3.1.d.....	16
Article 3.1.e.....	17
5. Progress to Date on the Major Deliverables of the Tripartite Data Quality and Sharing Agreement	19
Article 5.1.a	19
Article 5.1.b.....	22
Article 5.1.e.....	22
Article 5.1.d.....	22
Article 5.1.f.....	24
Article 5.1.g.....	24
6. Lesson Learned	25
7. Looking Ahead.....	26
8. Appendix 1 – Progress on Data Access Requests, 2018 and 2019.....	27
9. Appendix 2 – Priority Areas of Interest (as specified in the Tripartite Data Quality and Sharing Agreement, Appendix 1)	42

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 data sets 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 First Nations Health Authority 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 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 and procedures required for the overall administration and co-ordination of the TDQSA and its annexes, and makes recommendations on research activities and access to data to the FNCF Data Steward. Data access requests to 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 prior to 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 involved 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, with responsibility for supporting the work of the DIPC.
- **DIPC Secretariat:** In order to develop the necessary training and knowledge exchange between BC Ministry of Health and the First Nations Health Authority (FNHA), the DIPC Secretariat position, a secondment position, was created in 2014 for an FNHA employee within the ministry. This role was created to co-ordinate the FNCF and oversee FNCF data linkages, provide secretariat functions to the DIPC, and to provide input into ministry and FNHA First Nations data governance issues. Originally situated within the Office of Indigenous Health, as of 2016, the position moved to the ministry's Health Sector Information, Analysis and Reporting Division. 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 peoples registered under the *Indian Act*, and their unregistered descendants born after 1986 for whom entitlement-to-register can be determined and is linkable on 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 British Columbia. The FNCF is linked to other data sets to produce FNCF data as authorized by the DIPC and the FNCF Data Steward.

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

- **First Nations Client File (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.

- **First Nations Client File (FNCF) Data Steward:** The agency appointed by the tripartite partners to have custody of the FNCF. The responsibilities of the Data Steward are to create the FNCF, as authorized in the memorandum of understanding, and perform 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 in place 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* (British Columbia) 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.
- **Joint Project Board:** Established in 2012, the Joint Project Board is a senior bilateral forum between the Ministry of Health and the FNHA. Joint Project Board priorities are guided by the joint Letter of Mutual Accountability between the partners, and the Joint Project Board continues to operate as a key mechanism to enhance partnerships and co-ordination between the FNHA, the Ministry of Health, regional health authorities and partner organizations to ensure that the needs of First Nations people are integrated across the provincial health system. Each year, an annual report

will be completed to monitor progress and evaluate outcomes on shared priorities outlined in the Letter of Mutual Accountability.

- **Partners:** The FNHA and the Province of British Columbia (Ministry of Health). Although it is not a formal signatory to any FNCF DARs after October 1, 2013, the Government of Canada (Indigenous Services, First Nations and Inuit Health Branch) 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).
- **Personal Information:** Personal information as defined in the *Freedom of Information and Protection of Privacy Act* [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.

2. Context for the Report

This Annual Report on Progress provides a summary of progress made by the tripartite partners – the FNHA, the Government of Canada (Indigenous Service Canada), and the Government of British Columbia (Ministry of Health) – in building an equitable and culturally safe relationship around data sharing and data stewardship. These terms were described in the TDQSA, signed in 2010. The 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 Branch¹, 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 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]). DIPC experienced delays in advancing the 2018 TDQSA Annual Report due to the COVID-19 pandemic; therefore, this document fulfils the requirement to report on progress and DIPC activities for both the 2018 and 2019 calendar years.

¹ In August 2017, Indigenous and Northern Affairs Canada was re-focused 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 transferred to ISC at that time.

3. Context of Our Work

A number of significant events took place in 2018 and 2019 that impacted the work of the FNHA, Ministry of Health, Indigenous Services Canada and the DIPC as a whole. Note that while not all of the following events involved DIPC, they are relevant to its First Nations health data and information mandate.

- *Health Information Management Act (HIMA) Policy*: The Ministry of Health has started policy work to support updating BC's information and privacy legislation related to the health care sector to contain it under one act. BC is the only province that does not have a single health information and privacy act. The aim is to support primary care networks and the sharing of information between health care providers.
- Publication of *the Indigenous Health and Well-Being Final Update*², as per commitments in the Transformative Change Accord (a joint publication of the Office of the Provincial Health Officer and the FNHA)³.
- Publication of the article "*Indigenous approaches to health and wellness leadership: A BC First Nations perspective.*"⁴
- 'X' gender identity is now recognized on government ID.⁵ British Columbians who do not identify as male or female will have the choice to display an X as a third option in the gender field of a provincially issued driver's licence, identity card, birth certificate and BC Services Card.
- The FNHA began developing a data strategy to better communicate and use data throughout the organization. To date, the FNHA has focused on building its technology capacity (server farm), and it is now shifting its focus to population health surveillance and a strong First Nations Health Information Governance structure consistent with OCAP®⁶ and Seven Directives.⁷

² <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/office-of-the-provincial-health-officer/reports-publications/special-reports/indigenous-health-well-being-2018.pdf>

³ <http://fns.bc.ca/our-resources/the-transformative-change-accord-first-nations-health-plan-supporting-the-health-and-wellness-of-first-nations-in-british-columbia#:~:text=The%20Transformative%20Change%20Accord%3A%20First%20Nations%20Health%20Plan,recognition%20and%20respect%20for%20Aboriginal%20rights%20and%20title.>

⁴ Gallagher, J. (2019). Indigenous approaches to health and wellness leadership: A BC first nations perspective. *Healthcare Management Forum*, 32(1), 5-10. doi:10.1177/0840470418788090. <https://journals.sagepub.com/doi/full/10.1177/0840470418788090>

⁵ <https://news.gov.bc.ca/releases/2018HLTH0079-002116>

⁶

<http://www.afnigc.ca/main/index.php?id=ocap&content=OCAP%20FAQs#:~:text=%20First%20Nations%20can%20participate%20in%20OCAP%C2%A9%20implementation,to%20preserve%20ownership%2C%20and%20other%20intellectual...%20More%20>

⁷ <https://www.fnha.ca/about/fnha-overview/directives>

- In the reporting period covered by this annual report, the TDQSA was extended to April 15, 2020. The agreement was subsequently extended for one additional year.
- The FNHA CEO departed in October 2019 and an interim CEO took over the role. The FNHA Vice President of Policy, Planning and Quality also departed in October 2019 and a new data lead transitioned in.
- A new Project Director, Data Liaison, was hired in June 2019 as the previous Project Director, First Nations Client File, resigned in January 2019.
- The DMWG experienced some change in membership. The DMWG continued to review new DARs and DAR amendments and to work on other administrative tasks such as DAR prioritization methodology development and process improvement.
- The First Nations Health Council, Government of Canada and Province of BC signed *the Memorandum of Understanding on Tripartite Partnership to Improve Mental Health and Wellness Services and Achieve Progress on the Determinants of Health and Wellness* in July 2018.
- The FNHA signed annual Letters of Mutual Accountability with the Ministry of Health and Letters of Understanding with the Ministry of Mental Health and Addictions to guide collaborative priorities for the health and wellness of First Nations people in BC.
- Through the Overdose Emergency Response Centre, partnerships between the Ministry of Health, Ministry of Mental Health and Addictions, the FNHA, health authorities and other provincial and community-based agencies have been strengthened during this reporting period.
- In November 2019, the Government of BC passed the *Declaration on the Rights of Indigenous Peoples Act*⁸ (the Declaration Act). The Declaration Act requires the Government of BC, in consultation and co-operation with Indigenous peoples, to ensure that existing and future provincial laws are in alignment with the United Nations Declaration on the Rights of Indigenous Peoples.
- The first five-year Evaluation of the BC Tripartite Framework Agreement on First Nation Health Governance⁹ was developed and presented to BC First Nations leadership at Gathering Wisdom for a Shared Journey X in January 2020 (outside of this reporting period). The evaluation includes other lines of evidence, including the Data and Information Case Study Report.
- Although not part of the reporting period, it is important to note that COVID-19 was declared a global pandemic by the World Health Organization, and a BC public health emergency by the Provincial Health Officer, in March 2020. The tripartite

⁸ <https://declaration.gov.bc.ca/>

⁹ <https://www.fnha.ca/Documents/Evaluation-of-the-BC-Tripartite-Framework-Agreement-on-First-Nations-Health-Governance.pdf>

partners all actively engaged in COVID-19 mitigation, preparedness, response and recovery to support First Nations communities. In May 2020, it was announced that the FNHA Chief Medical Officer Dr. Evan Adams (Tlesla II) would be joining Indigenous Services Canada on a two-year appointment as Deputy Chief Medical Officer of Public Health, to support a nation-wide response to the COVID-19 pandemic. Dr. Shannon McDonald is now acting Chief Medical Officer and Dr. Nel Wieman is acting Deputy Chief Medical Officer. These changes may impact DIPC timelines in 2020.

- The Canadian Institutes of Health Research began consultations on the draft Tri-Agency Research Data Management Policy in 2018.¹⁰ The FNHA participated in the consultation and advised on engaging First Nations organizations with a mandate in this area directly, including the First Nations Information Governance Centre and its governance representatives, and creating a separate policy for Indigenous peoples and First Nations data governance. Research ethics boards have been preparing for implementation of the final policy. The FNHA is a partner in the harmonized ethics review process in BC, led by Research Ethics BC, which is funded through the Academic Health Science Network.

The Truth and Reconciliation Commission of Canada defines reconciliation as “an ongoing process of establishing and maintaining respectful relationships.” Article 31 of 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....” These principles are well embodied through the First Nations Health Information Governance structure advanced by the tripartite partners.

The tripartite partners are guided by Seven Directives,¹¹ the fundamental standards that were developed by First Nations in over 120 regional and sub-regional meetings and thus represent broad guiding principles that can guide other tripartite work, including FNCF data access. The principles of OCAP®¹² are respected by the tripartite partners through their work with the FNCF.

¹⁰ <https://cihr-irsc.gc.ca/e/51017.html>

¹¹ <https://www.fnha.ca/about/fnha-overview/directives>

¹² <https://fnigc.ca/ocap>

As demonstrated by the accomplishments and progress made in 2018 and 2019, the tripartite partners are committed to enhancing knowledge exchange through respectful data sharing and stewardship of the FNCF.

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

Article 3.1.a

Establish a framework 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 registration.**

To support the implementation of the TDQSA, the partners created a framework with three key structures, as well as foundational documents that guide the work of these structures.

The DIPC formally reports to the FNHA-Ministry of Health Joint Project Board. Progress updates are a standing agenda item at these Joint Project Board meetings, allowing the senior executives and program area leads from both organizations to understand the technical aspects of data and information processes.

Progress in 2018 and 2019

The DIPC met four times in 2018 and once in 2019. There are 23 active DARs (see Appendix 1 for more details). There continues to be significant learning through the DAR development and review processes. Each DAR presents a unique context, leading to new questions and implications.

The 2018 FNCF began to be developed in 2019. The quality assurance process identified some challenges, and these issues were collaboratively investigated and resolved over 2019 by the FNHA and the Ministry of Health. The identified data quality issues in the first round of the 2018 FNCF included missing data of deceased members of the population cohort after 2017 and a low number of newborns. The tracking of the missing deceased cases has been resolved and the missing data was included in the final 2018 FNCF. The low newborn number continues to be investigated. A possible reason why the number of newborns is low is because of the time lag when registering newborns with BC Vital Statistics. The partners will conduct further analysis to confirm and resolve this issue.

The DMWG supports the ongoing activities of the DIPC. The DMWG met biweekly in 2018 and 2019, chaired by the DIPC Secretariat. The DMWG is made up of representatives from the FNHA and the Ministry of Health. Its purpose and responsibilities are to:

- Provide technical and detailed support and project management relating to proposed and/or approved 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 a DAR and provide feedback and advice for a data requester to complete a DAR. The feedback/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 discussion of data issues, projects and supports.

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 purpose of such initiatives or other programs or activities.

First Nations Health Information Governance¹³ is grounded in foundational documents such as *the 2011 Consensus Paper: British Columbia First Nations Perspectives on a New Health Governance Arrangement*.¹⁴

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 Seven Directives that describe the fundamental standards and instructions for the new health governance relationship. DIPC uses the Seven Directives to guide its work and decision-making. Directive Two provides for increased First Nations decision-making and control and within this to implement OCAP® in data and reporting.

Progress in 2018 and 2019

The following tasks were completed or under development to improve the FNCF DAR process in 2018 and 2019:

- The DAR form evolved based on DIPC feedback and DAR project teams' experience. Starting in 2017, the DMWG worked on revising a fillable PDF version of the DAR form, and the DMWG continued to improve the form over 2018 and 2019. As of the time of this report, an updated version of the form is currently pending DIPC approval.
- A draft of a comprehensive Companion Document to the FNCF DAR process is currently under development. The Companion Document will provide guidance on how to complete DAR forms. This document will be valuable to preserve corporate memory and knowledge in times of turnover and transition, and provide transparency about the role expectations and scope of a DAR Project Manager.
- The DIPC Secretariat maintains a tracking mechanism for FNCF-related projects to ensure transparency and accountability. The tracking mechanism includes an enhancement of the existing FNCF DAR tracking sheet and the development of a DAR progress dashboard.
- A standardized FNCF DAR project process is currently being developed. The standardized FNCF DAR project process includes, but is not limited to, the following steps:
 - DAR intake process
 - Initial review of draft DARs by the DIPC Secretariat
 - Assessing priority of DARs on an ongoing basis by the DIPC and the FNHA-Ministry of Health Joint Project Board

¹³ <https://www.fnha.ca/what-we-do/research-knowledge-exchange-and-evaluation/health-information-governance>

¹⁴ http://fnhc.ca/pdf/FNHC_Consensus_Paper_-_WEB.pdf

- Processes for approvals and sign-off on DARs
- Regular and expedited methods of DAR sign-off
- Processes for amendments to approved DARs
- Processes for secondary data usage of data sets created through DARs
- Incorporating ethics review process into the DIPC intake process
- The DMWG has been developing a DAR prioritization methodology to ensure the submitted DARs are prioritized based on the priorities of First Nations communities and the FNHA, urgency, data linkage complexity and the readiness of recipient to receive and work with data.
- External research requests without FNHA partners have not been accepted since 2012 due to the limited resources available for linkage to the FNCF.

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.

Progress in 2018 and 2019

- The FNHA and the BC Office of the Provincial Health Officer 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 by actively participating on a wide range of committees and working groups, regardless of whether or not First Nations issues or data are involved.

- The FNHA has been building partnerships with ancillary service providers in BC around data access and stewardship that will also enable linkages to the FNCF. Examples include Cardiac Services BC (cardiovascular service utilization data), BC Cancer (access to selected BC Cancer registry data for First Nations), the provincial Perinatal Mortality and Morbidity Review Committee (perinatal, neonatal and maternal mortality/morbidity data) and a Specialized Services Committee joint initiative on diabetes (2015-2018 quality improvement project).
- The Province has been working on building a partnership with the Canadian Institute for Health Information and the FNHA on developing a joint statement for First Nations Health Data Governance.
- As of 2019, the Ministry of Health was the current Data Steward of the FNCF, as per Article 6.3 of the TDQSA. Through the TDQSA, the partners committed to assisting First Nations in developing capacity to assume eventual custody, control and management of First Nations data (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 (Schedule B, Section 1.2.c of the agreement).
- The DIPC Secretariat was involved in the development and quality assurance process for the 2018 FNCF. The secretariat continues to develop capacities of FNCF knowledge, including development, quality assurance and linkage to other data sets that are stewarded by the Ministry of Health. By working and collaborating with key ministry data staff, the DIPC Secretariat has gained knowledge and skills for analyzing administrative health databases.

All parties strive for continuous learning and improvements in policies, safeguards and standards of the FNCF.

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 in British Columbia.

Progress in 2018 and 2019

Fifty-eight FNCF DARs have been reviewed by DIPC since the creation of the FNCF in November 2011. Each of the approved FNCF DARs generates their own data set. These data sets are not available for any other purpose other than that 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 December 2019, there were 23 active projects with the FNCF.

Please see Appendix 1 for a list of projects in progress for the 2018 and 2019 calendar years.

The First Nations Women and Girls' Health Report is being co-developed by the Offices of the Provincial Health Officer and the FNHA Chief Medical Officer, and will use a wellness, social determinants and equity-based perspective to present and examine current data and information on the health and wellness of First Nations women and girls in BC. This report will discuss success stories and areas where there may be room for improvement, and it will make recommendations for the creation of specifically targeted programs to better support the health journeys of women and girls. In this reporting period, the DIPC approved specific amendments and the project team worked to develop and refine multiple information sharing agreements, information sharing plans and partnership letters with various stakeholders. In 2017-18, the data quality issue regarding newborn capture in the FNCF affected the timeline of this project. In 2018, the report was restructured to reflect changing priorities at the FNHA, and in 2019, it was restructured to align with the FNHA Perspective on Wellness Model. The team plans to complete the project before the end of 2020.

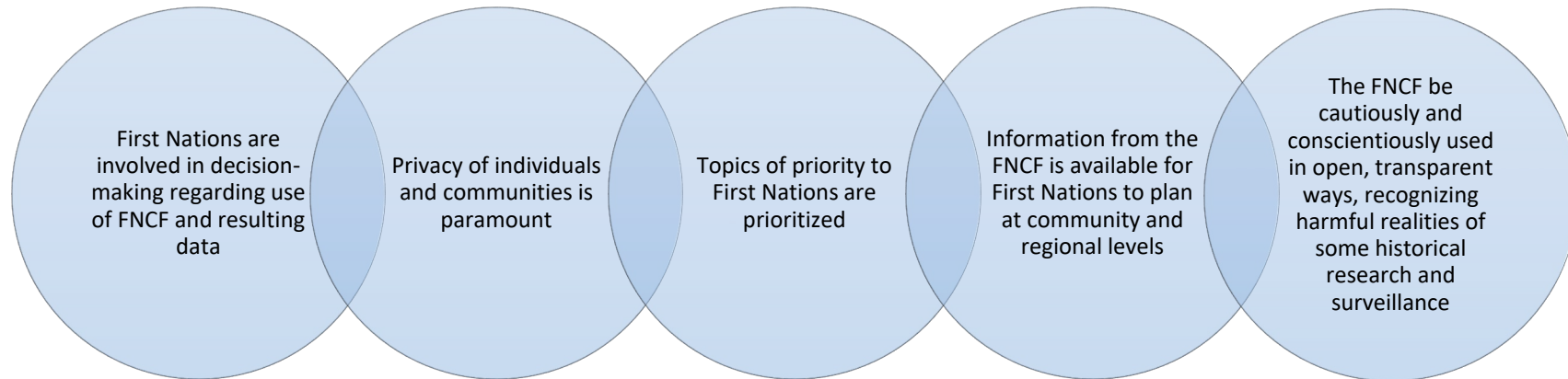
Article 3.1.e

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 vision that:



The DIPC recognizes that mechanisms for First Nations inclusion into FNCF decision-making should and will be developed over time. Mechanisms that have been established to address the principle of First Nations Health Information Governance include:

- The DIPC is co-chaired by the FNHA and Ministry of Health, with one equal vote each.
- The FNHA has representatives on both the DIPC and DMWG.
- FNCF DARs decisions are made by agreement between the two co-chairs (to date, there has not been a time when the co-chairs have not reached agreement). 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), which 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 leading to better services and include First Nations voices during the interpretation and dissemination of project 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.

- To respect the sovereignty that First Nations communities have over their data, along with privacy issues arising from small cell size, 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.
- Emerging publications and results are to be made accessible to First Nations through their public dissemination in a format and method that is both accessible and meaningful to First Nations.
- The FNHA and the Ministry of Health collaboratively developed a process for sign-off on the development methodology, as well as, and a process of quality assurance process of the FNCF.

Progress in 2018 and 2019

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

5. Progress to Date on the Major Deliverables of the Tripartite Data Quality and Sharing Agreement

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 identified in the TDQSA (see Appendix 2 for a complete list) are areas where significant work has occurred in 2018 and 2019.

- **Injuries:** The BC Coroners Service and the FNHA have an existing DAR seeking information on First Nations youth and young adults who have died from injury-related causes. In June 2018, the BC Coroners Service completed a new analysis of their data, using the FNCF to check how accurately the data identified First Nations decedents. Compared to their methodology of identifying First Nations ancestry, the BC Coroners Service discovered that the FNCF was able to detect 60 per cent more First Nations-identified individuals among the deceased, with better accuracy. However, while their data set did not include all First Nations peoples, they found that the findings 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*¹⁵ remained the same. In the future, the BC Coroners Service 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 identification of Indigenous identity.
- The partners are working with Trauma Services BC and the BC Injury Research and Prevention Unit for a project focusing on injury surveillance among BC First Nations people. In 2019, the project team developed a DAR that was approved by the DMWG for presentation to the DIPC, and which was still in progress during this reporting period.
- In June 2018, the FNHA released a report, *First Nations Health Status & Health Service Utilization*¹⁶ that used a FNCF linkage to the Health System Matrix. The Health System Matrix is a data set that includes information on hospital services, physician services, other services and chronic conditions. The report discusses the comparison of BC First Nations and other British Columbia residents' health conditions and health care usage factors per capita use and costs. The report provides evidence-based decision support for community leaders and health policy makers to plan health system and access improvement initiatives, as well as the health and wellness promotion of First Nations in British Columbia. The results validated information about chronic condition prevalence rates for First Nations people and provided new insights. For example, the data indicated that First Nations people:

¹⁵ <https://www.fnha.ca/Documents/FNHA-BCCS-A-Review-of-First-Nations-Youth-and-Young-Adults-Injury-Deaths-2010-2015.pdf>

¹⁶ <https://www.fnha.ca/about/news-and-events/news/report-offers-new-data-on-first-nations-health-status-and-service-usage-in-bc>

- were two times more likely than other BC residents to have had a stroke, and three times more likely to have rheumatoid arthritis;
- who are younger than 50 years had increased rates of mood anxiety, a category that includes Alzheimer’s disease and dementia; and
- who were frail or had high needs, aged 50 to 64, were three times more likely to have diabetes, three times more likely to have osteoarthritis and two times more likely to have hypertension.

Other pertinent findings from the report included information that confirmed that BC First Nations were less likely to access general practitioner/primary care services (outside of hospital), and were more likely to use emergency departments than other BC residents. These findings are useful for health policy-makers when considering health system needs and ensuring equitable access to health care for First Nations people in British Columbia.

- In addition to the Health System Matrix, chronic disease prevalence and incidences among BC First Nations are being explored through the linkage of the FNCF with the provincial chronic disease registry. In 2019, a chronic disease dashboard was developed in collaboration with the BC Observatory for Population and Public Health for internal use by the FNHA to facilitate chronic disease-related program planning, implementation and evaluation.
- Since the declaration of a public health emergency for opioid-related overdose deaths in BC in April 2016,¹⁷ the DIPC has been an essential partner to better share data and analytics regarding overdose reporting. Currently, four FNCF overdose-related projects are in progress (please see Appendix 1 for details). In May 2019, the FNHA, the Office of the Provincial Health Officer, the BC Coroners Service and the First Nations Health Council jointly released an infographic illustrating the impact of the opioid crisis on First Nations in BC, based on 2018 data.¹⁸ The data revealed that the overdose public health emergency continued to be a severe and persistent threat to First Nations in British Columbia, and it highlighted the increasing gap of the overdose impacts between First Nations people and other British Columbia residents. The FNHA developed a Framework for Action: Responding to the Overdose/Opioid Public Health Emergency for First Nations based on four pillars:¹⁹ 1) Prevent people who overdose from dying; 2) Keep people safer when using;

¹⁷ <https://www2.gov.bc.ca/gov/content/overdose/how-the-province-is-responding>

¹⁸ <https://www.fnha.ca/about/news-and-events/news/first-nations-opioid-overdose-deaths-rise-in-2018>

¹⁹ <https://www.fnha.ca/Documents/FNHA-Overdose-Action-Plan-Framework.pdf>

3) Create an accessible range of treatment options; and 4) Support people on their healing journey. Each pillar has one or more action plans to tackle the overdose crisis among First Nations people in BC.

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, supplemental 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.

Article 5.1.d

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

- **Life expectancy**
- **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.**

In December 2018, the FNHA Office of the Chief Medical Officer and the Office of the Provincial Health Officer released a report, *Indigenous Health and Well-being*.²⁰ The report is the final update based on a 10-year analysis of the seven core health

²⁰ <https://www.fnha.ca/about/news-and-events/news/indigenous-health-improves-but-health-status-gap-with-other-british-columbians-widens>

indicators: life expectancy, mortality, youth suicide, infant mortality, diabetes rates, childhood obesity, and practicing certified First Nations health care professional between 2005 and 2015. The development of the report was enabled by FNCF data linkage. This report was developed with the commitment of First Nations leadership and the Government of British Columbia through the Transformation Change Accord: First Nations Health Plan²¹.

The FNHA and the Office of the Provincial Health Officer will continue to monitor the health and well-being of the First Nations in British Columbia for the next 10 years, through a new Population Health and Wellness Agenda that marks a shift away from a biomedical, sickness-based model. The indicators, targets and recommendations were presented at Gathering Wisdom for a Shared Journey X in January 2020²² (outside of this reporting period) for validation and feedback. The agenda includes 22 indicators to monitor, takes a strengths-based approach to focus on wellness and resilience, and uses two-eyed seeing to bring together First Nations and Western ways of knowing. The Population Health and Wellness Agenda was developed by the Offices of the FNHA Chief Medical Officer and Provincial Health Officer through extensive engagement with BC First Nations. The partners anticipate releasing this report in the near future, when COVID-19 capacity challenges have lessened.

Article 5.1.e

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

During this reporting period, the DMWG has been working to establish a standardized DAR intake process. The FNHA Research and Knowledge exchange team, the FNCF Data Secretariat and the DMWG have been coordinating the ethics review and DAR process to streamline the processes for DARs that are submitted by partners for research purposes. Studies must have an approved ethics application for a DAR to be considered and approved.

²¹ https://www.health.gov.bc.ca/library/publications/year/2006/first_nations_health_implementation_plan.pdf

²² <http://gathering-wisdom.ca/>

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.

Processes are in place for partners to submit FNCF DARs for program planning and monitoring health outcomes. Although outside of the TDQSA and DIPC process, the Ministry of Health and the FNHA are exploring provincial policy to address health data in local health areas and community health service areas with substantial self-identified Indigenous populations.

Article 5.1.g

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

The FNCF allows for the identification of Status First Nations individuals. Health information of non-Status individuals cannot be produced using the FNCF.

The Aboriginal Administrative Data Standard²³(AADS) (Ministry of Aboriginal [now Indigenous] Relations and Reconciliation, 2007) is a BC government standard that allows for the collection of self-identified Indigenous information, but has not yet been widely implemented in the health care sector. The Interior Health Authority has piloted and implemented the Aboriginal Self Identification Project²⁴ based on the Aboriginal Administrative Data Standard. As of the end of 2019, the Government of British Columbia, including representation from Ministry of Health, was in the early stages of exploring a refresh of the standard to better align with the current context and priorities of Indigenous relations and reconciliation.

²³ https://www2.gov.bc.ca/assets/gov/government/services-for-government-and-broader-public-sector/information-technology-services/standards-files/aboriginal_administrative_data_standards.pdf

²⁴ <https://www.interiorhealth.ca/YourHealth/AboriginalHealth/StrategiesInitiatives/Pages/SelfIDProject.aspx>

6. Lesson Learned

The DIPC identified a number of lessons in 2018 and 2019:

- Sharing health information is complex and is based on a framework of legislation and regulations, judicial rulings, commissioner directives and orders, agreements, policy, best practices, ethics, professional codes/standards and sound judgement. Information sharing agreements take a significant amount of time within each FNCF project work plan.
- The FNCF is a valuable resource that would add value to partner organizations, other government departments and external researchers; however, given its limited time and resources, the DIPC is unable to review or adjudicate external research DARs at this time.
- Personnel changes have an impact on the committee's work as new staff must be oriented to the work of committee.
- DARs have differing levels of complexities that can require the creation of new methodologies or revisions to existing methodologies; new issues that arise may require discussion and collaborative development of additional policies.
- Developing and maintaining quality control of the FNCF requires time and resources. Further involvement of the FNHA on the technical side of the FNCF development would support all activities involving the FNCF.
- Establishing a standardized DAR intake process and output/report reviewing process are important initiatives for accommodating an increasing number of FNCF linkage requests to provide high-quality services to the requesters despite limited resources.
- Supporting data requesters' understanding of OCAP® principles²⁵ is an important aspect of First Nations health information governance and appropriate use of First Nations data.

²⁵ <https://fnigc.ca/ocap>

7. Looking Ahead

- The DMWG, DIPC and TDQSA signatories will support the development of a new data and information sharing agreement to replace the current extension of the TDQSA, which expires in April 2021.
- The DMWG and DIPC will continue to enhance knowledge exchange between the Ministry of Health and the FNHA with respect to data stewardship of the FNCF.
- The new provincial reconciliation framework, the *Declaration of the Rights of Indigenous Peoples Act*, will continue to inform the Ministry of Health and the FNHA in terms of their approach. The DMWG and DIPC will continue to support First Nations communities and partners toward self-determination, particularly as it relates to Indigenous self-determination of data and information.
- The DMWG and DIPC will support regional activities and initiatives by analyzing data at regional levels.
- The DMWG is expected to complete the development of a prioritization mechanism for FNCF-related DARs.
- The DMWG is expected to establish a standardized intake and monitoring process of projects with the FNCF.
- Lastly, as mentioned, the COVID-19 pandemic has affected the capacity of all partners to respond to other priorities, including data and information processes. It is anticipated that the COVID-19 response will have a major impact on DMWG, DIPC, TDQSA and tripartite work in 2020.

8. Appendix 1 – Progress on Data Access Requests, 2018 and 2019

ID	Project Title	Description	Requestor	Status update
1	Provincial Health System Matrix Linkage (2014-28)	This project will provide a detailed analysis of regional health authority expenditures and service utilization in the five health authorities disaggregated by First Nations and non-First Nations. Health expenditures will be interpreted and understood in the context of health service utilization, so that potential gaps in First Nations access to programs/services can be examined, and opportunities for investment or service integration between the respective health authority and First Nations can be identified.	Internal Partners	In 2017, the project team did an analysis and packaged the results for the provincial Health System Matrix. The project team presented their work at specific forums throughout 2018, including the Northern First Nations Health Partnership Committee Table in June. At the same DIPC meeting, the DIPC co-chairs approved the use of the template for other health regions/health authorities without full Committee review. In April 2018, a DAR Amendment was submitted to request to break down chronic condition data by age group for specific populations. In 2018 and 2019, the report was shared internally within the FNHA, as well as with regional contacts, communities and external partners.
2	STOP HIV/AIDS cohort linkage (2013-21)	The STOP HIV/AIDS program has evolved from a pilot to an ongoing province-wide program of the Ministry of Health. The aim is to improve the reach of HIV testing, treatment and support across BC	Internal Partners	Findings were approved by the DIPC in 2017. The dissemination plan was broken into iterative phases to ensure maximal utility, access and cultural safety. Phase one was approved by the DIPC in November 2017. The dissemination plan

ID	Project Title	Description	Requestor	Status update
		among those at risk for infection or living with HIV. Monitoring rates of HIV/AIDS, as well as indicators of access to treatment and retention in care among First Nations in BC is critical to determining whether and how we are able to slow transmission rates and achieve declines in morbidity and mortality due to HIV disease.		for the additional phases was developed in 2018.
3	Heart IS	To compare the descriptive epidemiology of cardiovascular procedures and related factors between status First Nations living in BC and other BC residents, in order to establish baseline data for developing a FNHA Cardiovascular Strategy.	Internal Partners	The Provincial Health Services Authority worked to finalize data elements and files to prepare for handing to the Ministry of Health for the FNCF linkage. The FNHA and Cardiac Service BC had discussions about analytic plans in 2018/2019, although these have not yet been finalized.
4	Chronic Disease Registry IS	To compare the descriptive epidemiology of various chronic diseases between status First Nations living in BC and other BC residents.	Internal Partners	A DAR Amendment was approved to expand access to include the FNHA Surveillance team in March 2018. The project stalled due to staffing gaps, but it resumed in May 2018. The Secretariat obtained CDR 2015-16 to transfer to the FNHA in December 2018 and the Secretariat and project team verified that

ID	Project Title	Description	Requestor	Status update
				<p>all files were present, with variables and breakdowns as requested.</p> <p>As of July 25, 2019, the FNHA's Health Surveillance team had reviewed the most recently updated version of Information Sharing Agreement 16-233 (annual linkage of the Chronic Disease Registry with the FNCF). The FNHA's Health Surveillance team has received Chronic Disease Registry data up to 2015 and has developed a Tableau Dashboard (data visualization tool) for internal use within the FNHA. At present, the Health Surveillance team is collaborating with Office of Chief Medical Officer, Health Benefits and Research and Knowledge Exchange teams to develop a comprehensive report on diabetes among BC First Nations, which includes selected indicators from the Chronic Disease Registry data set.</p>
5	Provincial Diabetes Strategy – quality of care indicator (2015-29)	This quality improvement project is aimed at improving health of people with diabetes by evaluating and redesigning diabetes care	Public Health Partner	The report structure was developed collaboratively by the DMWG and the project lead over 2018. A report was presented to the DIPC in December 2018,

ID	Project Title	Description	Requestor	Status update
		management in BC that is sensitive to local, cultural and ethnic needs, including the needs of First Nations people in BC with diabetes. It may also be described as a diabetes integrated primary and community care project.		after which analyses continued and a final report was prepared in 2019.
6	First Nations Client File Demographic Report	The purpose of this project is to provide accurate, accessible geographic-, age- and gender-specific population estimates for First Nations and self-identified Indigenous People in BC as identified in the FNCF, Indian Registry, Medical Services Plan Status Indian Entitlement File (RAPID Group 21), Statistics Canada Census and the National Household Survey, Vital Statistics self-identification flag and residential postal code.	Internal Partners	No progress in 2018 or 2019.
7	Hepatitis C (BCCDC)	A Hepatitis C testers cohort data set has been created as part of an existing project. This project seeks to understand health care utilization, the “cascade of care” and mortality for this cohort. They are now seeking linkage to the FNCF.	Public Health Partner	An Information Sharing Agreement (ISA) for the entire BC population was developed in 2019 and consultations were held with the FNHA before linking the FNCF to the general population data. The FNHA expressed concerns about the additional data variables requested by

ID	Project Title	Description	Requestor	Status update
				the BC Centre for Disease Control (BCCDC) team. The FNHA and BCCDC teams met to discuss the inclusion of these additional data sources, and the BCCDC team agreed to develop and share a project proposal that highlights the objective of the original ISA and reasons for including additional data sources in the project. The request is currently on hold.
8	Hepatitis C (BC Centre for Excellence in HIV/AIDS)	The overall objective of this project is to describe and evaluate the use and overall impact (e.g., effectiveness, safety) of the ongoing roll-out of direct-acting antiviral-based hepatitis C virus therapy in BC.	Public Health Partner	This project is on hold and will be considered in the future, in sequence to other similar DARs submitted to the committee. There was no progress in 2018 and 2019.
9	Perinatal Data Linkage with First Nations Health Authority	The FNHA is requesting routine linkage to perinatal data for the surveillance and annually reporting on the perinatal health of First Nations mothers and infants in British Columbia. Perinatal data will provide a picture of the well-being of First Nations pregnant women and infants. Prenatal care is a major indicator of	Internal Partners	The DAR was originally approved in November 2016 and an ISA was signed in August 2018. In 2018-2019, project team members from the FNHA and Perinatal Services BC worked collaboratively to discuss, develop and refine perinatal indicators to be included in the FNHA's preliminary Perinatal Surveillance Report. The Perinatal Services BC team sent

ID	Project Title	Description	Requestor	Status update
		<p>the health outcomes of infants. The data will support the planning of culturally relevant perinatal care and will be used as a tool to measure the perinatal care access that First Nations women and infants experience.</p>		<p>updated Perinatal Data Registry data to the Ministry of Health (2011/12 to 2017/18), and the ministry sent the FNCF-linked Perinatal Data Registry data set back to the Perinatal Services BC team in the fall of 2019.</p> <p>The project team submitted DAR Amendments to the DMWG in the fall of 2019 to extend the timeline of the data set from 2014-2018 to 2000-2018, as well as to add additional calculated values (derived variables).</p>
10	<p>PHO Indigenous Women’s Health Report</p>	<p>To use a wellness, social determinants and equity-based perspective to present and examine current data and information on the health and well-being of Indigenous women in BC. This report will discuss success stories and areas where there may be room for improvement, and it will make recommendations for the creation of specifically targeted programs to support better health.</p>	Internal Partners	<p>The analysis of data was underway in 2018. However, in 2019, the data quality issue regarding the newborn count in the 2018 FNCF affected the timeline of this project.</p>
11	<p>Opioids Overdose Public Health</p>	<p>To develop a linked public health surveillance database within the</p>	Internal Partners	<p>Data linkage for Provincial Overdose Cohort (POC)-2017 completed in</p>

ID	Project Title	Description	Requestor	Status update
	<p>Emergency Surveillance Project – BC Centre for Disease Control (Main Component)</p>	<p>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 Ministry of Health to support decision-making.</p>		<p>December 2018. Analysis of POC-2017 informed the FNHA press release “First Nations Overdose Deaths Rise in 2018”.</p> <p>Results from POC-2017 were also presented at the FNHA’s Regional Wellness Forums in the spring of 2019.</p> <p>Data linkage of POC-2018 was completed in December 2019, followed by a quality assurance check between January and June, 2020. Analysis of POC-2018 started in July 2020.</p> <p>DAR Amendments 4 to 8 were submitted to the DIPC in 2018 and 2019. The requests include the addition of BC Corrections data, Ministry of Health Mental Health Data Warehouse data, Ministry of Social Development and Poverty Reduction data, the addition of the BC Centre on Substance Use team in the Prescribing Pattern Working group, updating the First Nations Reference Cohort, the FNHA’s access to the postal codes of First Nations individuals, and the addition of new analysts.</p>

ID	Project Title	Description	Requestor	Status update
12	Opioids Overdose Public Health Emergency Surveillance Project – Fraser Health & Vancouver Coastal Health (Supplement)	To supplement the linked public health surveillance database within the BCCDC by performing two additional separate linkages, linking National Ambulatory Care Reporting System data at Fraser Health and Vancouver Coastal Health with the FNCF. This linkage will support planning, priority-setting and evaluation of the opioid overdose prevention strategy in BC.	Public Health Partner	Data linkage occurred, informing the August 2017 FNHA release Overdose Data and First Nations in BC: Preliminary Findings . Given the elevated priority of this DAR, the DIPC remained closely connected with the project team throughout the year.
13	Aboriginal Youth and Young Adult Death Panel	The BC Coroners Service, in partnership with the FNHA, convened a Death Review Panel in December 2016 focused on First Nations youth and young adults who died of injury-related causes between 2010-2015. The Death Review Panel is a mechanism for reviewing death to provide the Chief Coroner with advice on medical, legal, social welfare and other matters concerning public health and safety and the prevention of deaths.	Internal Partners	The project lead presented the results of the re-analysis of the 2017 BC Coroner's Service Child Death Review of First Nations Youth and Young Adult Injury Deaths (2010-2015) at the February 19, 2019, DIPC meeting. The BC Coroner's Service discovered that the FNCF was able to identify 60 per cent more deaths among First Nations peoples. However, while their data set did not include all First Nations peoples, they found that the findings and recommendations in the report remained the same. In the future, the BC Coroner plans to factor in FNCF data access approvals into their reporting timelines. It is hoped that the

ID	Project Title	Description	Requestor	Status update
				implementation of the Aboriginal Administrative Data Standard will also improve identification of Indigenous identity. This project is considered to be closed.
14	First Nations Cancer Research & Surveillance Project (Cancer 2)	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 (UBC) 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.		The DAR was approved by the DIPC in 2019. However, there was no progress in 2019.

ID	Project Title	Description	Requestor	Status update
15	Focus on First Nations in the Integrated Board Reporting (IBR)	The quarterly Integrated Board Report (IBR) provides a provincial view of performance on a common set of performance metrics reported to health authority boards. As per the agreement between senior executives at the Ministry of Health and the FNHA, the provincial health system's responsiveness to First Nations people will be determined, as measured by the performance indicators included in the IBR. These results will help inform future health service outreach and delivery practices.	Internal Partners	Although the DAR was present in December 2019, there was no progress made in 2019. Given the mechanism for deriving the IBR metrics, the Ministry of Health IBR team would need direct and identifiable access to the whole FNCF. However, given that direct/whole FNCF access is deliberately limited to the Ministry of Health Data Provisioning Team and the Office of Provincial Health Officer Epidemiology team, the project team is concerned about expanding that group without establishing a firm relationship with a potential new party (in this case, the Ministry of Health IBR team). The project is on hold until this can be established.
16	Indigenous Health and Well-being	To report on the five indicators identified in the Transformative Change Accord: First Nations Health Plan that are feasible to report on using administrative data.		In 2018, the result of the analysis was shared at Gathering Wisdom in May and the Tripartite Committee for First Nations Health in September. The report, Indigenous Health and Well-being: Final Update, was also released online in December 2018.
17	Opioids Overdose Public Health	Timely access to BC Emergency Health Services – BC Ambulance	Public Health Order	The DAR was approved by the DIPC in September 2018. An ISA was developed in

ID	Project Title	Description	Requestor	Status update
	Emergency Surveillance Project -- Emergency Health Services component	Services data during the Opioid Crisis aligns with the Vision as outlined in the Tripartite First Nations Health Plan (2007). The BC Provincial Opioid Cohort has 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.		2019 and signed in the fall of 2019. The data linkage process was in progress in the winter of 2019.
18	Population Health & Wellness Agenda, CMO/PHO	This is a joint project between the Office of the Provincial Health Officer and the Office of the Chief Medical Officer at the FNHA. 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	Public Health Partner	The DAR was approved in September 2018 by the DIPC. The project was on hold while the 2018 FNCF was being developed and quality assurance was performed.

ID	Project Title	Description	Requestor	Status update
		<p>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. The scope of this linkage is only the 10 that are FNCF-linked.</p>		
19	<p>Substance Use Cascade of Care for BC</p>	<p>First Nations in BC are disproportionately affected by substance use disorder, and a disproportionate number of First Nations people have experienced a fatal or non-fatal overdose in BC since 2015.</p> <p>This project serves two purposes:</p> <ol style="list-style-type: none"> 1. Creating and monitoring an opioid use disorder cascade of care. 2. Analysis of outcomes for people living with HIV and substance use issues. 	Internal Partners	<p>The DAR was approved in September 2019, and a DAR Amendment was submitted in December 2019. The amendment requests included accessing provincial corrections, perinatal services and national ambulatory care reporting system data. The DIPC requested more involvement of the FNHA in its work. The DAR amendment was conditionally approved in December 2019 with a condition that the project team would include the DIPC’s feedback to the DAR Amendment.</p>
20	<p>Provincial Health System Matrix Linkage (round 2)</p>	<p>This was a draft work item in the draft 2015/2016 Joint Project Board (JPB) work plan. The goal is to understand the First Nations population relative</p>		<p>Multiple DAR Amendments based on the original Health System Matrix Linkage project (round 1) were submitted in 2019. The ISA Amendment requests include: 1)</p>

ID	Project Title	Description	Requestor	Status update
		<p>to key systems and/or JPB strategic directions (for example, the First Nations population within the health system’s key target populations in the setting priorities document; establishing a baseline to measure the impact of JPB projects on primary health care for BC First Nations).</p>		<p>Allow access by named FNHA staff to prepared Tableau dashboards; 2)The Discharge Abstract Data (DAD) analysis is requested to include tuberculosis data; 3) Expand the scope of the project to include solicitation/intentional self-harm data; 4) Cover a number of methodological changes, 5) Add the Canadian Institute for Health Information Population Grouper in addition to the Health System Matrix 6) Add two more data items: the CHSA regional breakdown and the Home/Away variable, 7) Add mental health information, and 8) Residents adding new analysts. All the amendments were approved in 2019. The data linkage was in progress in 2019.</p>
21	<p>Opioids Overdose Public Health Emergency Surveillance Project -- Monthly Coroners component</p>	<p>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 at the FNHA, BCCDC, regional health authorities and the Ministry of Health to support decision-making.</p>	<p>Internal request based on Public Health Order</p>	<p>The original ISA to link the BC Coroners Service (BCCS) data set with the FNCF was signed on November 2017, which allowed the FNHA to access the BCCS’s aggregate-level overdose deaths data set. The FNHA obtained access to the monthly aggregate level data set in 2018.</p> <p>In March 2019 an amendment was approved and signed that allows the</p>

ID	Project Title	Description	Requestor	Status update
				<p>FNHA to access de-identified record-level overdose deaths data from the BCCS.</p> <p>Result from descriptive analysis of this FNCF-linked data set are incorporated into Opioid Quarterly Reports and presentations in Senior Opioid Response Team meetings. The FNHA issued press releases from this data set in May 2019 and July 2020.</p>
22	First Nations Injury Surveillance	<p>The burden of morbidity, mortality and disability from injury in British Columbia 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 British Columbia.</p>	Joint Partner Project	The DAR was developed in 2019 and was pending DIPC approval in 2019.

ID	Project Title	Description	Requestor	Status update
23	Perinatal Data - Cowichan Tribes	The amendment requests the development of a one-time Cowichan Tribes Perinatal Surveillance Report that will contain the same set of indicators prepared for the FNHA's provincial and regional reports. The report will support the Cowichan Tribes Pre-term Birth project.	Joint Partner	This DAR Amendment was a secondary data use request for Perinatal Service BC data. The DIPC approval was pending in 2019.

9. Appendix 2 – Priority Areas of Interest (as specified in the Tripartite Data Quality and Sharing Agreement, Appendix 1)

Priority Areas of Interest

In addition to First Nations-driven research that looks at First Nations health from a wellness perspective, the tripartite partners have identified a number of additional common priority issues, and they acknowledge the benefit of collaboration in addressing those issues. The partners will draw on existing and new data sets, held or administered by British Columbia 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, in order 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 the First Nations people who are located in British Columbia.
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 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 practicing First Nations in BC 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.