



Tripartite First Nations Health Plan

TRIPARTITE DATA QUALITY
AND SHARING AGREEMENT

2020 ANNUAL REPORT





Tripartite First Nations Health Plan

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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 requester/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 (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 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 the responsibility of supporting the work of the DIPC.
- **DIPC Secretariat:** To develop the necessary training and knowledge exchange between BC Ministry of Health (MoH) and the FNHA, the DIPC Secretariat position, a secondment position, was created in 2014 for an FNHA employee within the MoH. 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 MoH and FNHA First Nations data governance issues. Originally situated within the Office of Indigenous Health, as of 2016, the position moved to the MoH'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 MoH Personal Health Number. The FNCF is the product of a record linkage between an extract of Indigenous Services Canada's Indian Register and the MoH 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 datasets 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 MoH and Indigenous Services Canada authorizing the disclosure of information contained in the Indian Register to the MoH 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 MoH, 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 MoH 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 MoH, regional health authorities and partner organizations to ensure that the needs of First Nations people are integrated across the provincial health system. Each year, the partners complete an annual report 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 Canada, 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]).

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. 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 Indigenous Services Canada at that time.

3. Context of Our Work

A number of significant events took place in 2020 that impacted the work of the FNHA, MoH, Indigenous Services Canada and the DIPC as a whole. In particular, the ongoing COVID-19 pandemic significantly affected the work of the tripartite partners. Note that while not all of the following events involved the DIPC, they are relevant to its First Nations health data and information mandate.

- The TDQSA, which was scheduled to expire in April 2020, was extended to April 2021. The TDQSA was subsequently extended for another two years and expires in April 2023.
- The FNHA and MoH began developing a new agreement to replace the existing TDQSA in the summer of 2020. The agreement is currently under development as of the summer of 2021.
- In response to the COVID-19 pandemic and to inform BC First Nations communities, COVID-19 data for First Nations in BC was made available to the FNHA. The quick data access and availability was enabled based on the collaborative work between the FNHA, MoH and the BC Centre for Disease Control (BCCDC). The FNCF was used to identify First Nations in BC who were diagnosed with COVID-19, and to inform the First Nations community leadership in BC about the number of cases, clusters and outbreaks.
- The FNCF was also used to inform COVID-19 vaccination distribution planning. This rapid response was again supported by the MoH, the FNHA and the BCCDC.
- In urgent response to the COVID-19 pandemic and the ongoing toxic drug crisis, the FNHA launched the First Nations Virtual Doctor of the Day² in April 2020 and the First Nations Virtual Substance Use and Psychiatry Services³ in August 2020.
- A report titled *In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in B.C. Health Care*⁴ was released in November 2020. The FNCF was used in the development of the report. The investigation team was provided ministerial-delegated authority to access de-identified row-level data from MoH datasets that are created from linkages to the FNCF.
- In March 2020, the First Nations Information Governance Centre presented the Government of Canada with a First Nations Data Governance Strategy, a federally funded national strategic framework towards achieving First Nations data sovereignty.

² <https://www.fnha.ca/what-we-do/ehealth/virtual-doctor-of-the-day>

³ <https://www.fnha.ca/what-we-do/ehealth/virtual-substance-use-and-psychiatry-service>

⁴ https://engage.gov.bc.ca/app/uploads/sites/613/2021/02/In-Plain-Sight-Data-Report_Dec2020.pdf1_.pdf

- Richard Jock was appointed as permanent FNHA CEO in December 2020.
- The Aboriginal Administrative Data Standard⁵(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 project⁶ based on the Aboriginal Administrative Data Standard. In 2020, the BC Ministry of Citizens' Services initiated a refresh of the 2007 AADS in response to a call from the B.C. Data Council, with executive sponsorship from the Ministry of Indigenous Relations and Reconciliation. The MoH is an active member of the working group.

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 the 7 Directives,⁷ which are the fundamental standards that have been 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®⁸ are respected by the tripartite partners through their work with the FNCF.

⁵ 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

⁶ <https://www.interiorhealth.ca/YourHealth/AboriginalHealth/StrategiesInitiatives/Pages/SelfIDProject.aspx>

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

⁸ <https://fnigc.ca/ocap>

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 legislation.**

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 2020

Despite the competing priorities due to the COVID-19 pandemic, the DIPC met four times in 2020. There were 28 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 and novel idea, thus leading to new questions and implications about the data and its use.

The FNCF was transferred to the BCCDC for a limited time to respond to the COVID-19 pandemic. In 2020, the BCCDC provided a daily update of COVID-19 cases pertaining to First Nations individuals in BC to the FNHA and to First Nations leadership in BC. This data was also used to develop vaccination plans for First Nations communities in BC.

The process of developing the 2020 FNCF began in spring 2020. However, due to the COVID-19 pandemic, other higher priorities took precedence and the development of the 2020 FNCF was put on hold.

The DMWG supports the ongoing activities of the DIPC. The DMWG met biweekly in 2020, chaired by the DIPC Secretariat. The DMWG is made up of representatives from the FNHA and the MoH. 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 DARs and to provide feedback and advice for the data requesters to complete fulsome DARs. 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.
- 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.

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 Governance⁹ is grounded in foundational documents such as the *2011 Consensus Paper: British Columbia First Nations Perspectives on a New Health Governance Arrangement*.¹⁰

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 Two provides for increased First Nations decision-making and control, and within this to implement OCAP® in data and reporting.

Progress in 2020

- The FNHA, MoH and BCCDC worked together for the temporary FNCF transfer to BCCDC to respond to the COVID-19 pandemic. The BCCDC was able to provide the FNHA with daily updated datasets about COVID-19 cases among First Nations in BC. The FNHA analyzes the datasets and provides First Nations community leadership with up-to-date information about their COVID-19 situation. Transferring the FNCF to the BCCDC helped facilitate immunization planning for First Nations communities in BC.

In addition, the following tasks were completed or under development to improve the FNCF DAR process in 2020:

- The DMWG continues to develop and refine 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 the recipient to receive and work with data.

⁹ <https://www.fnha.ca/what-we-do/research-knowledge-exchange-and-evaluation/health-information-governance>

¹⁰ https://www.fnha.ca/Documents/FNHC_Consensus_Paper.pdf

- 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 2020

- 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 the provincial Perinatal and Maternal Mortality and Morbidity Review Committee (perinatal, neonatal and maternal mortality/morbidity data) and the BCCDC, as well as the BC Coroners Service for the toxic drug crisis response and Trauma Services BC for injury-related research.
- As of 2020, the MoH is 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 continues to develop capacities of FNCF knowledge, including development, quality assurance and linkage to other datasets that are stewarded by the MoH. By working and collaborating with key MoH data staff, the DIPC Secretariat has gained knowledge and additional skills for analyzing administrative health databases.

All parties strive for continuous learning and improvements in policies, safeguards and standards regarding 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 2020

Fifty-eight FNCF DARs have been reviewed by the DIPC since the creation of the FNCF in November 2011. Each of the approved FNCF DARs generates their own dataset. These datasets are not available for any other purpose other than what is 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 2020, there were 28 active projects with the FNCF. In 2020, there were more requests for DIPC service planning from BC First Nations communities that were collaboratively working with the FNHA than in prior years.

Please see Appendix 1 for a list of projects in progress for the 2020 calendar year.

- *The First Nations Women and Girls' Health Report*, later named *Sacred and Strong*, is being co-developed by the Office of the Provincial Health Officer and the FNHA Chief Medical Officer. This report 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. During the 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. The team completed the analyses in 2020.
- In 2018, the DIPC approved the perinatal data request project, which requires FNCF linkage to the Perinatal Services BC dataset. The objectives of the project are to establish a baseline and monitor First Nations women and infant health over

time. The project also assists the FNHA and the regional and sub-regional health partners in supporting policy, program and service planning for First Nations women and families in BC. Perinatal Services BC releases annual Perinatal Health Reports focusing on First Nations in BC. Unfortunately, in 2020, the development of this annual report was put on hold due to the COVID-19 pandemic. When it is ready, the report can be used for evidence-based decisions and reporting on perinatal outcomes, policy and programming for First Nations women and infants. The report includes a standardized set of surveillance products at a provincial and regional level. As described below, in 2020, two First Nations communities requested and approved the use of the Perinatal Health Report for their prenatal service planning. These communities will receive their reports when the annual Perinatal Health Report for First Nations in BC is ready.

- The Cowichan Tribes Preterm Birth Project was established to understand the higher rate of pre-term births within Cowichan Tribes. The project findings will help to improve service delivery of primary maternal care in the community, inform improved culturally safe and trauma-informed practices, provide polices for the future of the new Cowichan District Hospital facility, and will inform interventions to reduce the rate of preventable preterm births in the community. The collaborative research project team (FNHA and Cowichan Tribes) requested the Perinatal Health Report for the Cowichan Tribes population or their local health areas to gain knowledge around Indigenous and social determinants of health, and help enable the research project team to assess preterm births compared to term births in the community. The DIPC approved the creation and use of the Cowichan Tribes focused Perinatal Health Report in 2020.
- A group of BC self-governing Indigenous governments has partnered to support the use of surveillance, administrative and survey data for capacity development in evidence-based decision making. As a lead, Nisga'a Lisims Government requested the perinatal report to address childhood development. The data is utilized in a collaborative process between the Government of Canada and self-governing Indigenous governments across the country.

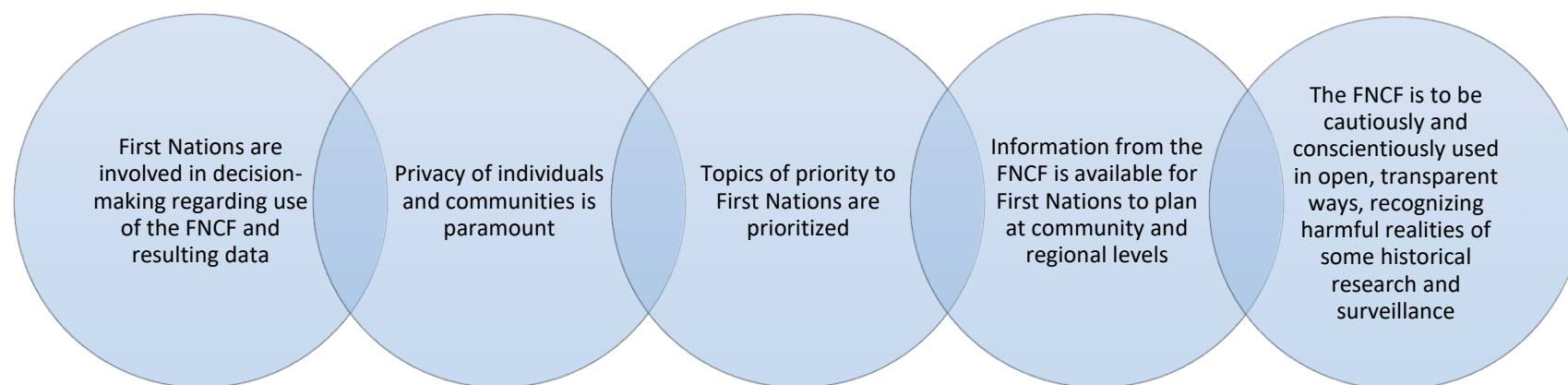
Article 3.1.e

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:



The DIPC recognizes that the mechanisms for First Nations inclusion into 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 MoH, 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 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 to lead to better services for First Nations, 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.
- Some data sets can be based on a small number of people who share a specific set of characteristics, especially if the data is at a community level. The DIPC has not authorized the release of any community-level First Nations data to date to avoid any privacy issues and respecting the sovereignty that First Nations communities have over their data. The DIPC will seek support from communities to develop a solution to share community-level data without privacy concerns.
- An important part of First Nations Health Information Governance is the respectful and inclusive interpretation and use of data. For that reason, the DIPC requests that all publications or reports utilizing the FNCF, the FNCF Client Roster or FNCF population counts be provided to the DIPC for review prior to dissemination. This includes, but would not be 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 their public dissemination in a format and method that is both accessible and meaningful to First Nations.
- The FNHA and the MoH collaboratively developed a process for sign-off on the development methodology, as well as a process of quality assurance for the FNCF.

Progress in 2020

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 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 as identified in the TDQSA (see Appendix 2 for a complete list) are areas where significant work occurred in 2020.

- 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. The working group was formed at the request of BC public health leadership and includes public health physician leads from the five regional health authorities in BC, the FNHA, the BCCDC and the Office of the Provincial Health Officer. The monitored items include consequences on mental/ physical health, as well as social, economic and environmental impacts.
- Since the declaration of a public health emergency due to an unprecedented increase in drug toxicity-related deaths in BC in April 2016,¹¹ the DIPC has been an essential partner in sharing data and analytics. Currently, four FNCF toxic drug

¹¹ <https://www2.gov.bc.ca/gov/content/overdose/how-the-province-is-responding>

crisis-related projects are in progress (please see Appendix 1 for details). In July 2020, 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 toxic drug crisis¹² on First Nations in BC, based on data from January to May 2020.¹³ The data revealed that the toxic drug crisis continued to be a severe and persistent threat to First Nations in British Columbia, which had gotten worse with COVID-19, and it highlighted the increasing gap in adverse outcomes between First Nations people and other British Columbia residents. The FNHA developed a Framework for Action: Responding to the Toxic Drug Crisis for First Nations based on four pillars:¹⁴ 1) prevent people who experience drug poisoning from dying; 2) keep people safer when using; 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 toxic drug crisis among First Nations people in BC.

- 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 BC Coroners Service data identified First Nations decedents. Compared to the BC Coroners Service method 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 the BC Coroners Service dataset did not include all First Nations peoples, the BC Coroners Service found that the findings and recommendations in the 2017 report, the *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. The DIPC approved the DAR for this project in 2020.

¹² <https://www.fnha.ca/about/news-and-events/news/first-nations-toxic-drug-deaths-doubled-during-the-pandemic-in-2020>

¹³ <https://www.fnha.ca/Documents/FNHA-First-Nations-in-BC-and-the-Overdose-Crisis-Infographic.pdf>

¹⁴ <https://www.fnha.ca/Documents/FNHA-Overdose-Action-Plan-Framework.pdf>

¹⁵ 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

- The Health System Matrix (HSM) is a dataset that includes information on hospital services, physician services, other services and chronic conditions. The HSM is used to analyze health service utilization and expenditures for First Nations and non-First Nations residents in BC's health authorities. Potential gaps in First Nations access to programs/services will be examined and opportunities for investment or service integration will be identified. In 2020, the new linkage included updates to the HSM and Discharge Abstracts Database (DAD) datasets, as well as the addition of the Pop Grouper (PG) dataset. The DAD data linkage includes conditions of interest not in the HSM. These include ambulatory care sensitive conditions by individual conditions, dental, HIV/AIDS, hospital admissions and readmissions, mental health and self-harm, suicidal ideation and tuberculosis. This data provides insight to those conditions that are not being treated appropriately in primary care and require hospitalization. The PG data linkage provides new insights into the HSM data. It applies a Canadian Institute of Health Information population grouper methodology that builds clinical profiles that help to better understand dominant health conditions. PG data looks at multi-morbidities, variations in health care resources (not yet received by the FNHA) and describes overall population health. Both DAD and PG complement the HSM.
 - In 2020, the number of internal requests fielded for HSM, DAD and PG data was reduced in order for FNHA Health Surveillance to respond to COVID-19. The HSM was used to support pandemic planning. For example, population data from the HSM and Census 2016 was used to identify ages and geographies of populations at risk and the proximity of communities to health care facilities. Data on COVID-19 risk factors, such as multi-morbidity and complex conditions, was taken from the HSM and PG.
 - An external request submitted by the Addressing Racism Investigation team was addressed using a number of FNHA datasets. The HSM and DAD was used to provide First Nations rates and ratios between First Nations and other residents for: emergency department use, hospitalization, various chronic conditions, population segments, mental health and substance use, and attachment to general practitioners and nurse practitioners. Findings are built into the publicly available *In Plain Sight* report.
- The Indigenous Cancer Strategy is a strategic plan to improve First Nations cancer outcomes and experiences in the province. The strategy will help First Nations communities understand their cancer journeys and address their cancer-related concerns. The strategy is considered as one of the key priorities of the FNHA and its partners. In 2020, the DIPC approved the use of the FNCF to enhance awareness and influence the provincial HPV vaccination program to meet First Nations needs. First Nations people are diagnosed with cervical cancer at a higher rate than non-First Nations people. This project seeks to understand the current HPV uptake rates among First Nations and to support ongoing

surveillance and research activities. Both ongoing surveillance and research activities seek to influence and guide quality improvement initiatives planned as part of the Indigenous Cancer Strategy.

- The Silent Genomes project, a multi-partnership research project that includes the FNHA¹⁶ and is funded by Genome Canada, was kicked off in 2018. The Silent Genomes project seeks to address issues and experiences among Indigenous people regarding poorer access to genomic technologies and related research. The project aims to address these inequities by creating an Indigenous-led and governed genomic database that will provide genomic diagnosis to Indigenous children. The project consists of four activities: 1) integrating Indigenous-led governance, community engagement, community education and student capacity building across all activities; 2) precision genomic diagnosis of children with genetic disease; 3) development of an Indigenous Background Variant Library; and 4) economics of precision diagnosis for Indigenous children. In 2020, the DIPC approved the use of the FNCF for the fourth activity, which seeks to identify the current state of discrepancy in genomic health care and present policymakers with economic evidence for reducing this discrepancy.

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 at birth**

¹⁶ <https://www.bcchr.ca/silent-genomes-project>

- **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.**

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. This new agenda marks a shift away from a biomedical, sickness-based model. The indicators, targets and recommendations were presented at the Gathering Wisdom for a Shared Journey X in January 2020¹⁷ for validation and feedback. The new 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 analysis was in progress in 2020.

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 co-ordinating ethics reviews and the DAR

¹⁷ <http://gathering-wisdom.ca/>

process to streamline the processes for DARs that are submitted by partners for research purposes. Research studies must have an approved ethics application for a DAR to be considered and approved.

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 MoH 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.

6. Lesson Learned

The DIPC identified several lessons learned in 2020:

- Accommodating DARs during the COVID-19 pandemic was challenging as DIPC and DMWG members needed to work on other pandemic-related priority areas and not everyone was available to work with DARs and other requests.
- 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. ISAs require a significant amount of time within each FNCF project work plan.
- The FNCF is a valuable resource to understand health and wellness of First Nations in BC; however, given limited time and resources, the DIPC is unable to review or adjudicate external research DARs at this time.
- A robust policy and framework is required to ensure community priorities and needs are reflected in data requests.
- Personnel changes impacted the committee's work as new staff must be oriented/trained regarding the committee's work.
- DARs have differing levels of complexity that in some cases 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, and to provide high-quality services to requesters despite limited resources.
- Ensuring data requesters understand OCAP® principles¹⁸ is an important aspect of First Nations health information governance and appropriate use of First Nations data.
- Existing DARs and ISAs should be revisited to ensure they still comply with the current processes.

¹⁸ <https://fnigc.ca/ocap-training/>

7. 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 2023.
- The DMWG and DIPC will continue to enhance the knowledge exchange between the MoH and the FNHA, with respect to stewardship of the FNCF.
- The DMWG and DIPC will support regional activities and initiatives by analyzing data at regional levels.
- The DMWG and DIPC will review and update existing policies to enhance the process and work of the DMWG and DIPC to reflect Nation-based and community-identified needs.
 - 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 data-related priorities, including data and information processes. It is anticipated that the COVID-19 response will continue to have a major impact on DMWG, DIPC, TDQSA and tripartite work in 2021.

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

ID	Project Title	Description	Requester	Status update
1	STOP HIV/AIDS cohort linkage (2013-21)	The STOP HIV/AIDS program has evolved from a pilot program to an ongoing province-wide program of the MoH. The aim of this project is to improve the reach of HIV testing, treatment and support across BC 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 communities are able to slow transmission rates and achieve declines in morbidity and mortality due to HIV disease.	Internal Partners	This project was not active in 2020.
2	Heart Information System	To compare the descriptive epidemiology of cardiovascular procedures and related factors between status First Nations living in BC and other BC residents to establish baseline data for developing an FNHA Cardiovascular Strategy.	Internal Partners	This project was not active in 2020.

ID	Project Title	Description	Requester	Status update
3	Chronic Disease Registry ISA	To compare the descriptive epidemiology of various chronic diseases between status First Nations living in BC and other BC residents.	Internal Partners	The original DAR was developed in 2014. The data linkage process and the FNCF access level (the level of private information provided for the data linkage) was reviewed and discussed in 2019 and 2020. The group identified that the FNCF currently shared with the partner includes more private information than necessary. The partners decided to develop a new DAR to update the data linkage process in 2020.
4	Provincial Diabetes Strategy – quality of care indicator	This quality improvement project is aimed at improving the health of people with diabetes by evaluating and redesigning diabetes care 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.	Public Health Partner	No progress in 2020.

ID	Project Title	Description	Requester	Status update
5	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 2020.
6	Hepatitis C (BCCDC)	A Hepatitis C testers cohort dataset 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	This project is currently on hold.
7	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 rollout of direct-acting antiviral-	Public Health Partner	This project was on hold in 2020.

ID	Project Title	Description	Requester	Status update
		based hepatitis C virus therapy in BC.		
8	Perinatal Data Linkage with First Nations Health Authority	The FNHA is requesting routine linkage to perinatal data for the surveillance and annual 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 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.	Internal Partners	The Amendment to add new analysts was approved in April 2020. The data is now linked and provided to Perinatal Services BC. In August 2020, the FNHA secondee began analyzing the data and the preliminary analyses were completed in September 2020. The guidance to further analyses will be provided by Dr. Shannon McDonald and Dr. Unjali Malhotra from the FNHA. Perinatal Services BC is expected to send an updated PDR dataset to the MoH for linkage with the FNCF by the end of October 2020. As of November 2020, analyses are ongoing, but due to COVID-19 priorities, progress is slow.
9	Provincial Health Officer Indigenous Girls' and Women's Health Report	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	Internal Partners	Data analysis was underway in 2018. However, in 2019, the data quality issue regarding the newborn count in the 2018 FNCF affected the timeline of this

ID	Project Title	Description	Requester	Status update
		<p>girls and women in BC. This report discusses success stories and areas where there may be room for improvement, and it makes recommendations for the creation of specifically targeted programs to support better health.</p>		<p>project. The analysis was completed and the First Nations Women and Girls' Health Report is in the final publishing phase. The magazine draft (summary of the report) will be submitted to the DIPC for review and approval.</p>
10	<p>Opioids Overdose Public Health Emergency Surveillance Project – BC Centre for Disease Control (Main 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 in the FNHA, BCCDC, regional health authorities and the MoH to support decision-making.</p>	Internal Partners	<p>Data linkage for the 2018 Provincial Overdose Cohort was complete in December 2019/January 2020. Cohort build and quality assurance was completed in July 2020. Data is currently being used for analyses; most have been internal thus far.</p> <p>Data linkage and build for the 2019 Provincial Overdose Cohort is ongoing.</p>
11	<p>Opioids Overdose Public Health Emergency Surveillance Project – Fraser Health & Vancouver Coastal Health (Supplement)</p>	<p>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</p>	Public Health Partner	<p>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</p>

ID	Project Title	Description	Requester	Status update
		FNCF. This linkage will support planning, priority setting and evaluation of the opioid overdose prevention strategy in BC.		the year. This linkage has not reoccurred since that time.
12	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 project was on hold until November 2020 when the DAR was reviewed again. In December 2020, BC Cancer data was ready to send to MoH and a discussion was underway about the data delivery.

ID	Project Title	Description	Requester	Status update
13	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, <i>Indigenous Health and Well-being: Final Update</i> , was also released online in December 2018.
14	Opioids Overdose Public Health Emergency Surveillance Project -- Emergency Health Services component	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 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 dataset to the FNCF will be conducted monthly.	Public Health Order	Began receiving Emergency Health Services data in 2020, but there were challenges with usability due to a large number of missing Personal Health Numbers in the data (and therefore preventing the ability to identify First Nations individuals for 40-50% of records in more recent data). To resolve this the MoH developed an additional matching algorithm on top of the Emergency Health Services data to recover more Personal Health Numbers.

ID	Project Title	Description	Requester	Status update
15	Population Health & Wellness Agenda, FNHA Chief Medical Officer and Office of the Provincial Health Officer	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 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 limited to the 10 that are FNCF-linked.	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. The analysis was in progress in 2020.
16	Substance Use Cascade of Care for BC	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	Internal Partners	On March 30, 2020, a DAR Amendment was submitted to the DMWG to request to add different groups of people and more datasets. The DMWG thought that the DAR Amendment was not

ID	Project Title	Description	Requester	Status update
		<p>since 2015. This project serves two purposes: 1) Creating and monitoring an opioid use disorder cascade of care and 2) Analyzing outcomes for people living with HIV and substance use issues.</p>		<p>ready for DIPC review. The BC Centre for Excellence in HIV/AIDS (BC-CfE) and DMWG met to discuss the DAR Amendments in April 2020. The BC-CfE completed the update of the DAR Amendments in July 2020. The DAR Amendments were presented to DIPC and approved in August 2020. The ISA amendments were in development in September and October 2020, and when the project team submitted DAR Amendment 3, ISA amendment 3 had already been developed. However, an ISA cannot be amended before a DAR amendment is approved. As a result, this created some confusion. The project director requested that the MoH not sign the ISA amendment until DIPC approved the DAR Amendment. The DAR Amendment 3 was reviewed by DMWG in November 2020, and sent with some comments to the requester on November 14. The DIPC co-chairs</p>

ID	Project Title	Description	Requester	Status update
				reviewed the DAR briefly in December 2020 and requested to include the data linkage process map in the DAR Amendment.
17	Provincial Health System Matrix Linkage (round 2)	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 to key systems and/or Joint Project Board 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 Joint Project Board projects on primary health care for BC First Nations).		The FNHA received the HSM dataset in September 2020 and worked on the quality assurance of the dataset in the fall of 2020. At the same time, the FNHA Surveillance Team connected with possible HSM users at the FNHA to discuss how HSM could support their work. In November 2020, FNHA HSM Project Advisory Committee was established. This includes the Health Surveillance and other departments in the FNHA. A project charter and terms of reference for the advisory committee were developed.
18	Opioids Overdose Public Health Emergency Surveillance Project -- Monthly BC	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	Internal request based on Public Health Order	The original ISA to link the BC Coroners Service (BCCS) dataset with the FNCF was signed on November 2017, which allowed the FNHA to access the BCCS’s aggregate-level overdose deaths

ID	Project Title	Description	Requester	Status update
	Coroners Service component	linked database will be used by analysts at the FNHA, BCCDC, regional health authorities and the MoH to support decision-making.		<p>dataset. 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 FNHA to access de-identified record-level overdose deaths data from the BCCS.</p> <p>BCCS surveillance data (ISA 17_125) started becoming available monthly to the FNHA in 2020. Monthly updates are provided to senior leadership as well as various overdose response teams. 2020 (Jan-May) data from this linkage is used to inform public release of data in 2020 and the upcoming 2021 release. Data was also shared at Caucus 2020 and 2021.</p>
19	First Nations Injury Surveillance	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	Joint Partner Project	The DAR was approved in August 2020. The additional documents (ISA and Privacy Impact Assessment (PIA)) were under development in December 2020.

ID	Project Title	Description	Requester	Status update
		<p>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>		
20	<p>Perinatal Data – Cowichan Tribes</p>	<p>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 Preterm Birth project.</p>	<p>Joint Partner</p>	<p>The DAR Amendment was approved in April 2020 and an ISA is not necessary. The FNHA’s Health Surveillance team has completed preliminary analysis of provincial-level data in November 2020. The surveillance team will need to complete local health area level analysis to prepare a report for the Cowichan Tribes project (expected to be complete in the summer of 2021).</p>
21	<p>Silent Genomes Activity 4.2</p>	<p>Relative to other Canadians, Indigenous populations in Canada experience poorer access to genomic technologies and the research that drives them. Accurate</p>	<p>External Partner</p>	<p>In November 2019 the FNHA provided a letter of recommendation to the Silent Genomes team. In January 2020, FNHA DMWG members completed</p>

ID	Project Title	Description	Requester	Status update
		<p>genomics-informed diagnosis often rests on the presence of substantive background reference databases from which pathogenic variants can be identified or discovered, yet these genomic resources are increasingly silent with respect to Indigenous populations. Without addressing this divide, the ongoing movement within health care systems toward genomics-driven precision medicine threatens to exacerbate current health disparities.</p> <p>The “diagnostic odyssey” (i.e., the time and resources collectively required to yield a diagnosis) experienced by Indigenous children with a suspected rare genetic condition is one possible manifestation of this disparity.</p> <p>In partnership with the FNHA, Silent Genomes Activity 4.2 aims to fill this gap. The goals of Activity 4.2 are to document the magnitude of the</p>		<p>a review of the data linkage method proposed by the Silent Genomes team, who then updated the ethics approval process on January 30, 2020. UBC completed the review and FNHA reviewed the ethics application. In February, members of the Silent Genome team joined the DMWG meeting and explained the project, and the project director investigated using PopData BC for data linkage. In July 2020 ethics was approved. The DAR is going to be adjusted and submitted for the DMWG's review. The DAR was presented to DIPC and approved in October 2020. The research group was preparing a separate DAR for MoH to access additional data.</p>

ID	Project Title	Description	Requester	Status update
		current genomic health care disparity, generate policy-informing economic evidence for its closing, and deliver this evidence to policy-makers.		
22	HPV	HPV is the primary cause of the majority of cervical cancers. Findings will influence FNHA efforts to enhance awareness and influence the provincial HPV vaccination program to meet First Nations' needs. This DAR is required to support ongoing surveillance and research activities to influence and guide quality improvement initiatives planned as part of the Indigenous Cancer Strategy.	Internal partners	The DAR was presented to DIPC and approved in October 2020. The additional documents (ISA and PIA) were under development for the rest of 2020.
23	COVID-19 FNCF Transfer	Due to the COVID-19 pandemic, the FNCF is going to be transferred to BCCDC. The BCCDC provides daily update of First Nations cases. FNHA Surveillance team will have access to an anonymized dataset and the FNHA project director will have	Internal/External Partners	COVID-19 data is provided by BCCDC to FNHA daily, which the FNHA uses to produce daily reports.

ID	Project Title	Description	Requester	Status update
		access to a non-anonymized dataset.		
24	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. A working group was formed at the request of BC public health leadership; this working group includes public health physician leads from the five regional health authorities in BC, as well as representatives from the FNHA, BCCDC and the Office of Public Health Officer. The targeted items include mental/physical health consequences, as well as social, economic and environmental impacts.	Internal Partners	The DAR was developed and reviewed by the DIPC on August 18, 2020. The DAR was submitted to DIPC. The Public Health Officer requested level 4 access to the FNCF, which was questioned by the DIPC. As a result, the DAR was not approved. In September 2020, the Public Health Officer met DIPC to discuss their request for level 4 access, which they needed to do the analyses quickly because the codes were developed with level 4. The DIPC approved the use of level 4 only for this project (until March 31, 2021). After completing the project, PHO will adjust their codes so that they will be able to complete all of their analyses and reporting based on FNCF level 2 access (September 2020).
25	Perinatal DATA Community Use	A group of BC self-governing Indigenous governments (SGIGs) have partnered to support the use	Community/Internal	The DAR was approved on August 18, 2020. The FNHA's Health Surveillance team completed

ID	Project Title	Description	Requester	Status update
		<p>of surveillance, administrative and survey data for capacity development in evidence-based decision making. This data request is in support of that objective, and the data received will feed into a collaborative process between the Government of Canada and SGIGs across the country. The initial data initiative is focused on early childhood development.</p>		<p>preliminary analysis of provincial-level data in November 2020 and need to complete sub-regional (local health area level) analysis to prepare a report for BC SGIGs (expected to complete in the summer of 2021). These population estimates are used to inform planning for COVID-19 vaccine distribution and administration in First Nations communities. With COVID-19 vaccine rollout, these population estimates are used to estimate uptake of vaccines among First Nations population in BC.</p>
28	<p>Women's Health Report – Opioid data use</p>	<p>To use a wellness, social determinants and equity-based perspective to present and examine current data and information on the health and wellness of Indigenous women in BC. This report will also make recommendations to support better health outcomes. This request is to use opioid data from the Office of the Provincial Health</p>	<p>Internal/External Partners</p>	<p>A DAR amendment for data secondary use was first submitted in December 2020, but the project director asked the project team to submit the DAR to be more transparent. The DAR has been under development as of December 2020.</p>

ID	Project Title	Description	Requester	Status update
		Officer emergency requests to develop additional variables.		

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 several additional common priority issues. The tripartite partners acknowledge the benefit of collaboration in addressing these issues. The partners will draw on existing and new datasets, 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 practising 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.