



Tripartite First Nations Health Plan



TRIPARTITE DATA QUALITY AND SHARING AGREEMENT

2016/2017 Annual Report on Progress

**Tripartite Data Quality and Sharing Agreement
Annual Report on Progress
2017**

Last Updated: December 21, 2018



Tripartite First Nations Health Plan

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1.0 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 request received by the Data and Information Planning Committee and subsequently the First Nations Client File (FNCF) Data Steward for approval for linkage of other data sets to the FNCF.
- **Data and Information Planning Committee (DIPC):** Originally referred to as the Data Quality and Sharing Committee in the TDQSA, this committee's name changed to the Tripartite Data and Information Planning Committee in April 2011. After October 1, 2013, when the FNHA assumed the programs, services and responsibilities formerly handled by Health Canada's First Nations Inuit Health Branch – Pacific Region, the committee's name changed to the Data and Information Planning Committee (DIPC). The DIPC is 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 First Nations Client File (FNCF) Data Steward. Data access requests to the FNCF are approved by consensus among 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).
- **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 Data and Information Planning Committee.
- **First Nations Client File (FNCF):** The FNCF is a cohort of BC resident First Nations people registered under the *Indian Act*, and their unregistered descendants born after 1986 for whom entitlement-to-register can be determined, linkable on their BC Ministry of Health Personal Health Number. The First Nations Client File is the product of a record linkage between an extract of the Indigenous & Northern Affairs Canada (INAC) Indian Registry and the BC Ministry of Health Client Registry.

The tripartite partners agree the FNCF is the best available method of access to 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 Data and Information Planning Committee 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 INAC authorizing the disclosure of information contained in the Indian Registry to the Ministry of Health on an annual basis. The FNCF was initially created in 2011, and is updated incrementally using a fresh extract from the BC Client Registry and the INAC 'Indian

Registry.’ An updated 2015 FNCF will be available in 2017.

- **First Nations Client File (FNCF) Data:** Data generated in response to approved requests by the Data Steward, through use of the First Nations Client File 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 socio-economic determinants of health, and 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 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 FOIPPA; (e) a person or group of persons; or (f) an entity prescribed in the FOIPPA Regulation. The ISA sets conditions on the collection, use or disclosure of personal information by the parties to the agreement.
- **Partners:** The First Nations Health Authority (FNHA) and the Province of British Columbia (Ministry of Health [MoH]). Though not a formal signatory to any First Nations Client File Data Access Requests after October 1, 2013, the Government of Canada (Department of Indigenous Services, First Nations and Inuit Health Branch [FNIHB]) continues to participate on the Data and Information Planning Committee as an observer.
- **Partner Voting Members:** Two members of the Data and Information Planning Committee, appointed by each partner, to vote on decisions related to the approval of First Nations Client File Data Access Requests. Decisions require the unanimous approval of each partner voting member (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.

2.0 Executive Summary

The development and realization of the tripartite partnership between the Government of Canada, the Government of BC, and BC First Nations has been many years in the making. Seven years have now passed since the signing of the BC Tripartite Framework Agreement on First Nation Health Governance (Framework Agreement). By continuing to strengthen effective health-system-strengthening collaborations, honouring commitments, aligning priorities and strategies, and facilitating collective action, the tripartite partners achieve their vision of improving health and wellbeing for First Nations and Indigenous peoples in BC.

This year's Tripartite Data Quality and Sharing Agreement (TDQSA) Annual Report provides an overview of Data and Information Planning Committee (DIPC) progress for 2017. Since the creation of the First Nation Client File (FNCF) in November 2011, there have been fifty-one FNCF data access requests (DARs) that have been reviewed by DIPC. In 2017, DIPC worked actively on seventeen DARs. See Table 1 for more details.

There were also a number of significant events that took place in 2017 that impacted the work of the First Nations Health Authority (FNHA), Ministry of Health (MoH), and Department of Indigenous Services Canada (DISC). These included:

- A research article ¹comparing cancer development and survival between First Nations and other residents in BC was published in October 2017, enabled by a FNCF linkage. The research article informed *Improving Indigenous Cancer Journeys: A Road Map*, ² a collaborative strategy to improve cancer care and supports for Indigenous peoples, announced in December 2017. The strategy was the result of a multi-year partnership between the BC Cancer Agency, FNHA, Métis Nation BC, and the BC Association of Aboriginal Friendship Centres (BCAAFC). DIPC had particular interest in this work, given that First Nations cancer data was facilitated by a FNCF linkage, and given that the resulting innovative strategy was an excellent example of effective partnership.
- In April 2016, BC's Provincial Health Officer declared a public health emergency under the *Public Health Act* due to the unprecedented increase in overdose events and overdose deaths in the province. A tremendous amount of work was advanced in 2017 to mitigate the disproportionate impact on First Nations people in the overdose crisis. In August 2017, FNHA released a report of preliminary findings, providing a snapshot of First Nations overdose events from January 1, 2015- November 30, 2016 and First Nations overdose deaths between January 1, 2015- July 31, 2016. Data in the report were sourced through a FNCF linkage. FNHA and its partners have committed to work together to speed up data linkage processes and implement actions based on timely data.

¹ <https://link.springer.com/article/10.1007/s10552-017-0950-7>

² <http://www.fnha.ca/about/news-and-events/news/strategy-for-improving-indigenous-cancer-health-outcomes-launched-in-bc>

- The BC Coroners Service and FNHA have an existing data access request, seeking information on First Nations youth and young adults who have died from injury-related causes. In 2017, a separate report was released, entitled *BC Coroners Service and First Nations Health Authority Death Review Panel: A Review of First Nation Youth and Young Adult Injury Deaths: 2010-2015*. While this report utilized the Aboriginal Administrative Data Standard Identifier to verify First Nations identity (not FNCF linkage), the report demonstrates that understanding and reducing injury-related deaths among First Nations youth and young adults is a priority for the partners.
- A major accomplishment in 2017 was the transition in prescription drug benefits services for First Nations people in BC. On October 1, 2017, First Nations people began receiving services from the province's drug insurance program, PharmaCare (previously covered under Health Canada's Non-Insured Health Benefits [NIHB] program). The PharmaCare formulary for this program is referred to as "Plan W." While DIPC did not play an active role in this work, other teams within FNHA and MoH worked to ensure that the Plan W transition was implemented successfully, and DIPC will follow Plan W progress with great interest.
- DIPC facilitated a FNCF linkage to advance work on the provincial Health System Matrix (HSM). Outcomes of HSM data show usage rates of First Nations people in the emergency room, reflect access to primary care services, health status, and barriers to service delivery. Still in the early days, opportunities to use these data will better position regions to identify the gaps and opportunities to focus efforts and move to measurable, outcomes-based service delivery. FNHA has worked through a conscientious First Nations health information governance process to develop and disseminate HSM data and products. HSM findings will be further available in 2018.

The Truth and Reconciliation Commission's definition of reconciliation, "an ongoing process of establishing and maintaining respectful relationships," is well embodied in data and information work advanced by the tripartite partners. Demonstrated through the accomplishments and progress made in 2017, the tripartite partners are committed to enhancing knowledge exchange through respectful data sharing and stewardship of FNCF.

3.0 Context for the Report

This *Annual Report on Progress* provides a summary of progress made by the tripartite partners - the First Nations Health Authority (FNHA), Government of Canada (Department of Indigenous Services Canada [DISC]), and the Government of British Columbia (Ministry of Health [MoH]) - in building an equitable and culturally safe relationship around data sharing and data stewardship. These terms were described in the Tripartite Data Quality and Sharing Agreement (TDQSA), signed in 2010. The TDQSA fulfills action number 28 of the 2006 *Transformative Change Accord: First Nations Health Plan*, to "renew the Tripartite agreement between the Province, Health Canada's First Nations and Inuit Health Branch, and First Nations to ensure federally and provincially held information on First Nations is shared."

Schedule B of the TDQSA states that: "an annual report on the activities carried out under this Agreement will be developed by the Data Committee, for approval by the Parties, and published within six (6) months of Fiscal Year end." (Schedule B, section 1.8). Section 5.1(f) of the TDQSA also states that the data committee (now known as the Data and Information Planning Committee, DIPC) will: "Make an annual report to the Parties on progress toward implementing First Nations health information governance capacity within First Nations in accordance with section 5.1(f) of the Agreement" (Schedule B, Section 1.2[d]). DIPC presents this report to fulfill these obligations for the calendar year of 2017.

4.0 Context of our work

There were a number of significant events that took place in the calendar year of 2017 that impacted the work of FNHA, MoH, DISC, and DIPC as a whole.

- A provincial election took place in British Columbia in May 2017, and the new Cabinet (including a new BC Minister of Health and Minister of Mental Health and Addictions) were sworn in in July.
- As confirmed by ministerial mandate letters, all provincial ministries have responsibility to adopt and fully implement the United Nations Declaration on the Rights of Indigenous Peoples and Calls to Action of the Truth and Reconciliation Commission.
- The Ministry of Mental Health and Addictions (MMHA) was established under the new provincial government to strengthen the mental health and substance approach in the province. MMHA's first priority is to develop an immediate response to the opioid overdose public health emergency. Close collaboration between MoH, MMHA, FNHA, and other provincial partners was reinforced to respond to the overdose crisis.
- There have been reorganizations and personnel changes in the MoH, which have an impact on TDQSA work. The former Assistant Deputy Minister (ADM) of Population and Public Health (PPH) Division, was appointed as Senior Executive Advisor, Tripartite First Nations Health, MoH and FNHA. The PPH ADM was previously a signatory to the TDQSA. This responsibility has transferred to the ADM of Health Sector Change & Transformation Division.
- The Office of Aboriginal Health in the MoH was renamed the Office of Indigenous Health in September 2017. This shift aligns with the ministerial mandate to implement the Truth and Reconciliation Commission of Canada's Calls to Action and the United Nations Declaration on the Rights of Indigenous Peoples.
- A FNHA Data Secretariat was hired to support the Data Champions Committee (DCC), and this role actively coordinates with the DIPC Secretariat in ensuring robust strategic alignment between DCC and DIPC.
- 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) the Department of Indigenous Services Canada (DISC). In December 2017, First Nations and Inuit Health Branch (FNIHB) was formally transferred from Health Canada to DISC. All FNIHB funding and contractual arrangements transferred to DISC at that time.

Figure 1: Evolution of the Tripartite Partnership



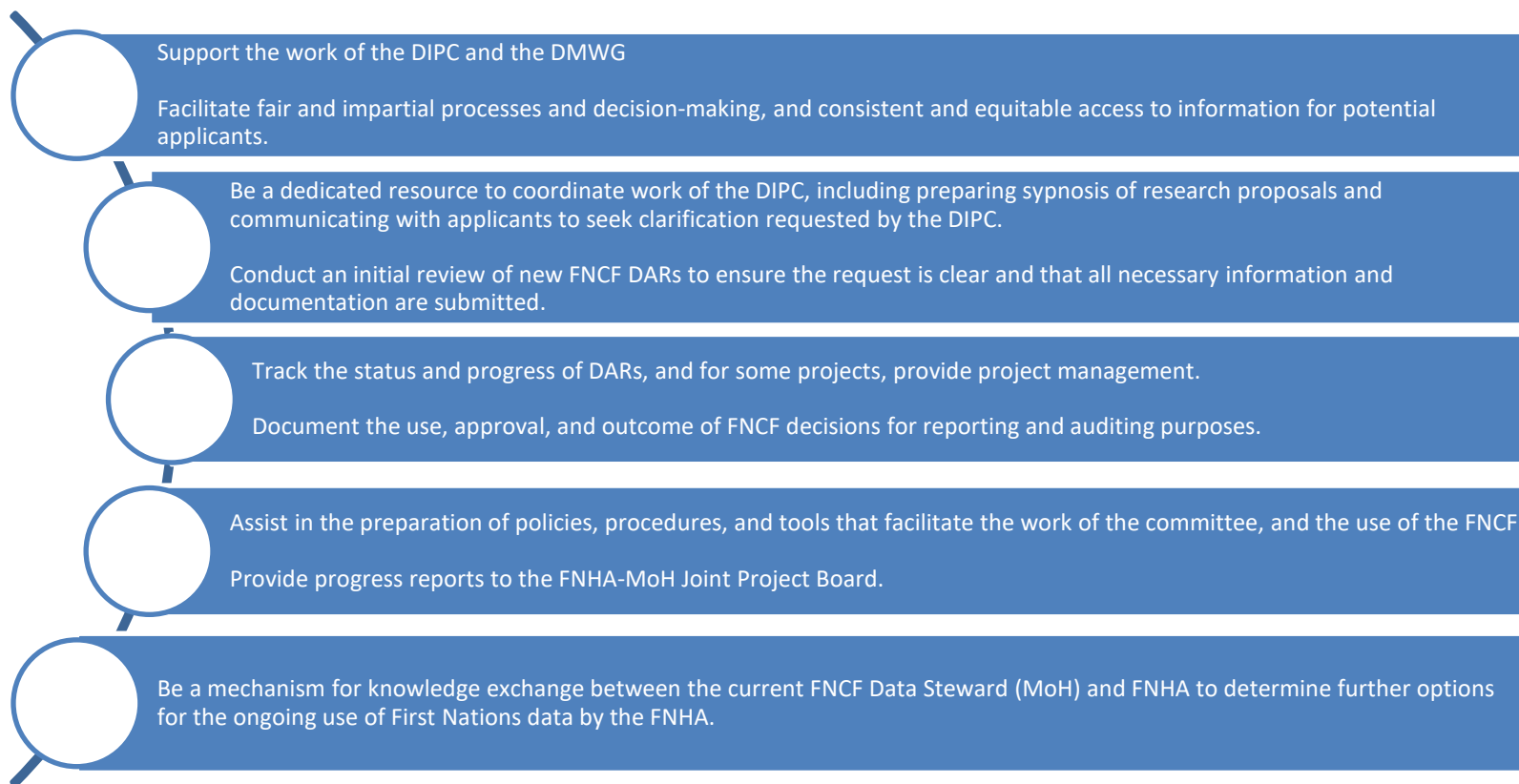
The development and realization of the tripartite partnership between the Government of Canada, the Government of BC, and BC First Nations has been many years in the making. Above is a depiction of milestones and key agreements. This timeline highlights the context of tripartite work, accomplishments, and collaboration with a range of partners.

5.0 Progress to Date on Fulfilling the Purposes of the Tripartite Data Quality and Sharing Agreement (TDQSA)

The purposes of the TDQSA are outlined in the table below, along with the progress to date in each of these areas.

Purpose	Progress in 2017
Article 3.1.a	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.
<i>Establish a framework for the Parties to:</i>	DIPC, the Data Management Working Group (DMWG), and the DIPC Secretariat (previously referred to as the TDQSA Secretariat) were established to implement the work described in Article 3.1.a.
<i>(i) continually improve the quality and availability of First Nations Data;</i>	1. The DIPC met five times in 2017, and worked on seventeen separate data access requests (DARs) (see Table 1 in Appendix 1 for more details). Progress updates were added as a standing agenda item to FNHA-MoH Joint Project Board meetings.
<i>(ii) facilitate the sharing of FNCF Data in response to research questions approved in accordance with this Agreement; and</i>	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.
<i>(iii) to ensure that FNCF is appropriately compiled, used and shared by the Parties in accordance with the principles set out in this Agreement and applicable legislation.</i>	The FNCF Automation Project was proposed in 2015 and implemented in 2016, with the ultimate aim of transferring the FNCF-generation process into the hands of FNHA. The FNCF 2015 was fully automated with mostly successful results. Minor issues meant that quality assurance testing and
specific problem-solving occurred in 2017 for the next iteration of FNCF.	2. DMWG supports the ongoing activities of DIPC. The DMWG met biweekly in 2017, chaired by the DIPC Secretariat. The DMWG is made up of representatives from FNHA and the MoH. Its purpose and responsibilities are to: a. Provide technical and detailed support and project management relating to proposed and/or approved DARs. Each DAR is managed by an assigned project lead that provides overall leadership to the project, including leading and/or assigning work. b. Develop processes and tools to facilitate the work of the DIPC as well as appropriate management and use of FNCF data. c. Provide a forum for discussion of data issues, projects and supports.

3. The DIPC Secretariat role, created in 2012, has been undertaken by an FNHA staff member, seconded to MoH. MoH provides additional Secretariat support. The functions of the DIPC Secretariat are listed below:



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

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 utilized 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 their work and decision-making.

Purpose

Article 3.1.b

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

Tools have been developed to advance the FNCF DAR process.

- The DAR form evolved based on DIPC feedback and DAR project teams' experience. The DMWG worked on revising a fillable, PDF-version of the DAR form in 2017, but it was not finalized for incoming project teams to use in this year.
- External (non-partner) research requests have not been accepted since 2012, due to the limited resources available for data analysis and linkage to the FNCF.
- A comprehensive Companion Document to the FNCF DAR process was developed by the DMWG. Still in progress, the Companion Document will ultimately serve as a guide to complete DAR forms, and is discussed further under Article 3.1.f below. This document will be valuable to conserve corporate memory and knowledge in times of turnover and transition, and provide transparency about the role expectations and scope of a DAR Project Manager.

- An FNCF Information Sharing Agreement (ISA) template was developed by a member of DMWG, which has greatly reduced time required to build an ISA from weeks to days, while sacrificing none of the legal rigour. This template was tested in 2016 and is now being used.
- The DIPC Secretariat position maintains a tracking mechanism to document the status of each DAR, ensuring transparency and accountability.

Processes and best practices have been developed for the purposes of adjudicating and processing DARs. These include:

- Initial review of draft DARs by the DIPC Secretariat
- Assessing priority of DARs on an ongoing basis by the DIPC and the FNHA-MoH Joint Project Board
- 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.

Purpose

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.

and Article 3.1.f

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

As of 2017, MoH was the current Data Steward of the FNCF, Article 6.3 of the TDQSA.

Through the TDQSA, the partners agreed to assist First Nations in developing capacity to assume eventual custody, control, and management of First Nations data (Article 3.1.f of the agreement). It is recognized 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).

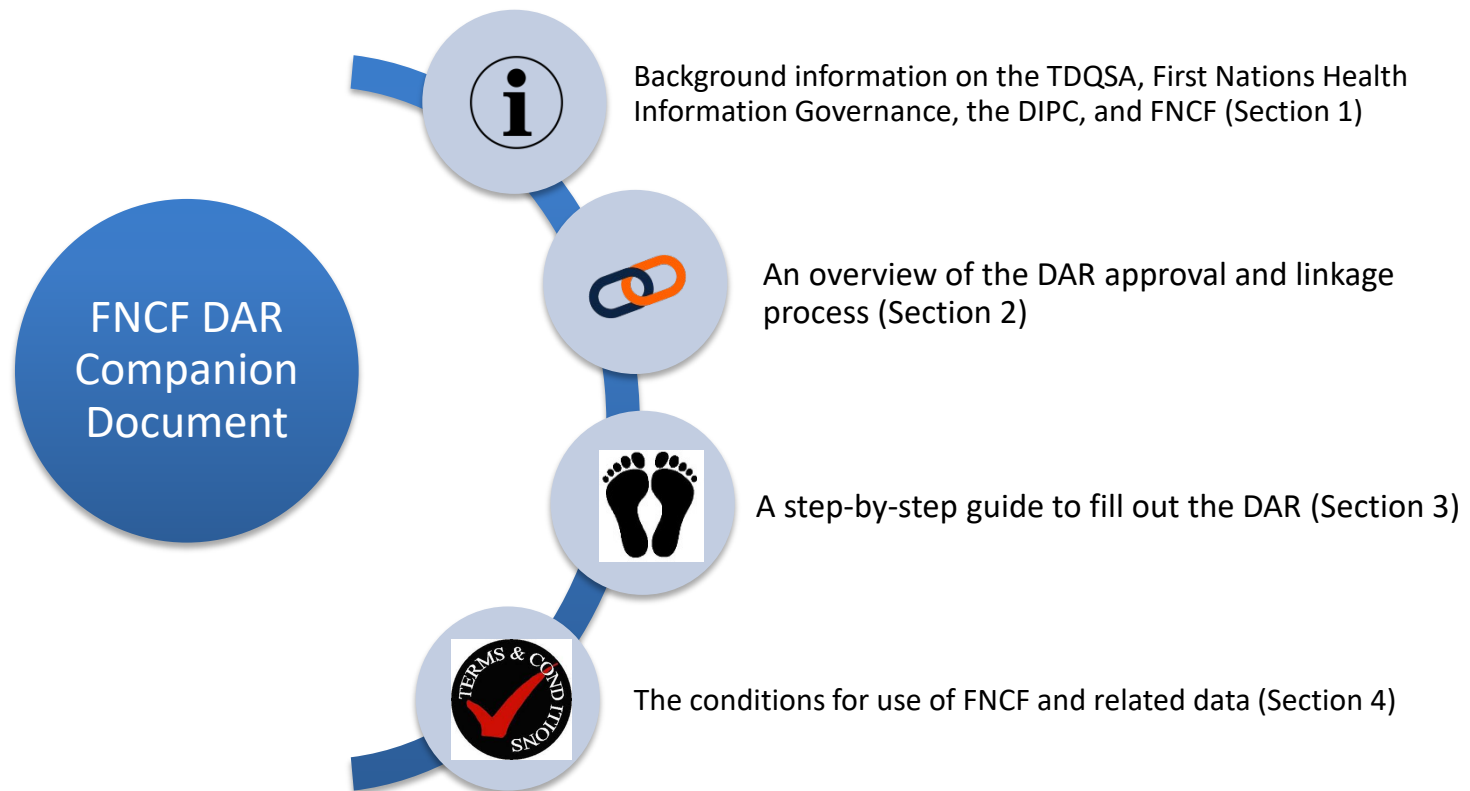
All parties strive for continuing learning and improvements in policies, safeguards, and standards of the FNCF. This work is an ongoing process and will be developed over time.

One of the main mechanisms for knowledge exchange is through the DIPC Secretariat. In order to develop the necessary training and knowledge exchange between MoH and FNHA, a secondment position was created in 2014 for an FNHA employee within the MoH. This role was created to coordinate 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 Health Sector Information, Analysis and Reporting Division, MoH. The position provides status reports to the MoH-FNHA Joint Project Board. By working and collaborating with key MoH data staff, the DIPC Secretariat has gained knowledge and skills relating to analyzing administrative health databases. Over time, this will lead to capacity building for FNHA.

First Nations Client File Data Access Request Companion Document

As previously mentioned, the FNCF DAR Companion Document is currently under development and is not yet published. When finalized, this document will provide DAR applicants with guidelines and background information to inform the completion of a DAR form. It includes:



Purpose

Article 3.1.d

Create new data sets to enable First Nations in BC to monitor the health of First Nations and the success of programs and services provided in First Nations communities in British Columbia.

Fifty-one 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 in order to capitalize on previous work and avoid duplication of effort, while respecting all legislative requirements.

See Appendix 1 for a listing of projects in progress for the calendar year of 2017.

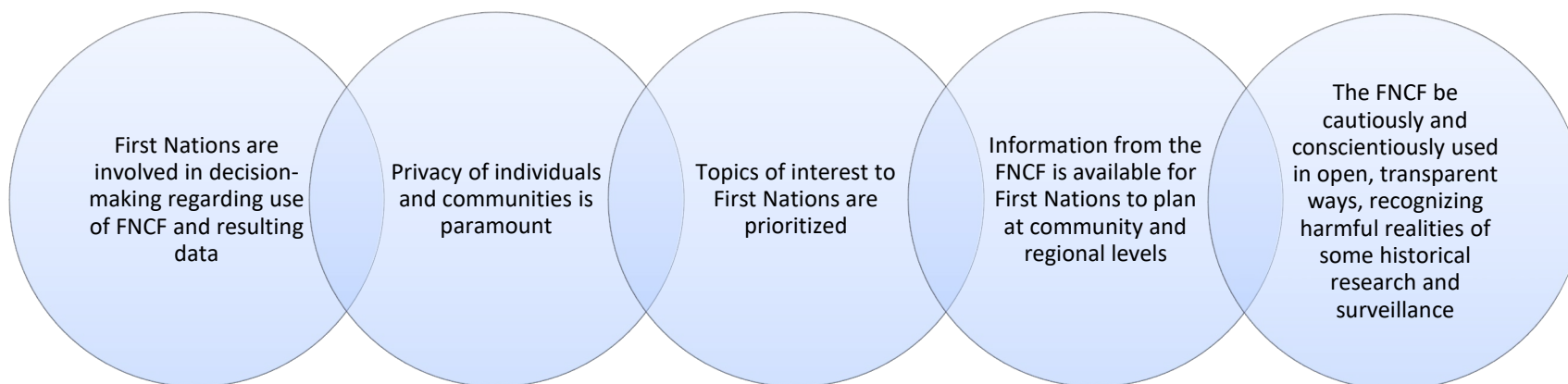
Article 3.1.e

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 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 FNCF, and have developed clear pathways and mechanisms for FNCF data access decision-making for First Nations.

The partners work to ensure that:



DIPC recognizes that mechanisms for First Nations input into FNCF decision-making should and will be developed over time.

Mechanisms to address the principle of First Nations health information governance include:

1. DIPC is Co-Chaired by FNHA and MoH, with one equal vote each (by consensus).
2. FNHA has representatives on both the DIPC and DMWG

3. FNCF DARs decisions are made by consensus among the two Co-Chairs (to date, there has not been a time when Co-Chairs have not reached consensus). The Co-Chairs are supported by committee members, selected by the Co-Chair from each respective organization.
4. 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, should involve relevant First Nations stakeholders throughout the project, should stimulate action leading to better services, and should be inclusive of First Nations voices during the interpretation and dissemination of project results.
5. In respecting the autonomy 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.
6. Emerging publications and results are to be made as accessible to First Nations by disseminating publically, and in a format and method that is both accessible and meaningful to First Nations.

6.0 Progress to Date on the Major Deliverables of the Tripartite Data Quality and Sharing Agreement (TDQSA)

The TDQSA lists seven objectives and deliverables, articulated as specific articles below, along with a brief description of the results and progress in implementation.

Objectives and Deliverables

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 off-reserve measure. In 2017, DIPC recommended that ‘home/away-from-home’ be approved as the preferred variable in FNCF

Progress to Date

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 2017. This is not an exhaustive list of the progress made toward priority areas of interest.

1. On-/off-reserve categorization: There has been a transformation in the terminology used to describe the geographical location of First Nations since the creation of FNCF in 2011 from ‘on-’ and ‘off-reserve’ to ‘home’ and ‘away-from-home.’ The 2014 FNCF and Calendar Roster include fields to capture this more current terminology. ‘Home’ is defined as living in the same local health area as the band to which an individual is registered, and ‘away-from-home’ is defined as living outside the local health area in which the band to which they are registered is located. Please note that ‘home’ is not exactly equivalent to on-reserve, and ‘away-from-home’ is not the same as

- DARs. In 2017, DIPC approved ‘home/away-from-home’ as the preferred variable for incoming FNCF DARs, and will review its recommendation within one year (by the end of 2018), to ensure that recommendation remains workable.
- 2. Diabetes and Chronic diseases:** Chronic disease prevalence and incidence are being explored as part of a project examining the prevalence and incidence of First Nations chronic diseases through a linkage to the provincial chronic disease registries. Work on a Provincial Diabetes Strategy project was also advanced in 2017.
 - 3. Communicable Disease:** The partners are working with the BC Centre for Disease Control to develop a communicable disease report. Results were approved in 2017, and the project team continued to develop and refine an appropriate dissemination plan. The FNCF is also being used to assess the burden of HIV/AIDS among First Nations in BC, as well as access to treatment and retention in care, from a linkage with the STOP HIV/AIDS Cohort at the BC Centre for Excellence in HIV/AIDS. The STOP HIV/AIDS report and dissemination plan were approved by DIPC in 2017.
 - 4. Cancer:** A research article comparing cancer development and survival between First Nations and other residents in BC was published in October 2017, enabled by a FNCF linkage. The research article informed *Improving Indigenous Cancer Journeys: A Road Map*, a collaborative strategy to improve cancer care and supports for Indigenous peoples, announced in December 2017. The strategy was the result of a multi-year partnership between the BC Cancer Agency, FNHA, Métis Nation BC, and the BC Association of Aboriginal Friendship Centres (BCAAFC). DIPC had particular interest in this work, given that First Nations cancer data was facilitated by a FNCF linkage, and given that the resulting innovative strategy was an excellent example of effective partnership.
 - 5. Injuries:** The BC Coroners Service and FNHA have an existing FNCF DAR seeking information on First Nations youth and young adults who have died from injury-related causes. In 2017, a separate report was released, entitled *BC Coroners Service and First Nations Health Authority Death Review Panel: A Review of First Nation Youth and Young Adult Injury Deaths: 2010-2015*. While this report utilized the Aboriginal Administrative Data Standard Identifier to verify First Nations identity (not FNCF linkage), the report demonstrates that understanding and reducing injury-related deaths among First Nations youth and young adults is a priority for the partners.
 - 6. Baseline data:** Many of the initiatives underway contribute to baseline health data for First Nations. The Provincial Health Officer (PHO) and FNHA Chief Medical Officer (CMO)’s Indigenous health reports and interim updates support baseline data. The reports and interim updates have historically measured seven health indicators laid out in the *Transformative Change Accord: First Nations Health Plan*; however, the PHO and CMO have developed fifteen additional wellness indicators that will be measured in subsequent reports. Significant work on the PHO/CMO interim report and Indigenous Women’s report occurred in 2017, with anticipated completion dates in 2018/19.
 - 7. Health Care Utilization:** DIPC facilitated a FNCF linkage to advance work on the Health System Matrix (HSM), both for a pilot project in the Interior region and subsequently for the provincial system. Outcomes of HSM data show usage rates of First Nations people in the emergency room, reflect access to primary care services, health status, and barriers to service delivery. Still in the early days, opportunities to use these data will better position regions to identify the gaps and opportunities to focus efforts and move to measurable, outcomes-based service delivery. FNHA has worked through a conscientious First Nations health information governance process to develop and disseminate HSM data and products. HSM findings will be further available in 2018.

Article 5.1.b

Achieve the goals, objectives or activities identified and agreed to by the Parties and set out in the Annexes 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, which would be developed as annexes.

See “Progress to Date” description for Article 3.1.b .

Article 5.1.c

Adopt and implement the process for: i) reviewing proposed initiatives as set in Schedule B of the TDQSA; and ii) reviewing the Data Access Requests, in collaboration with the Data Steward.

Article 5.1.d

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

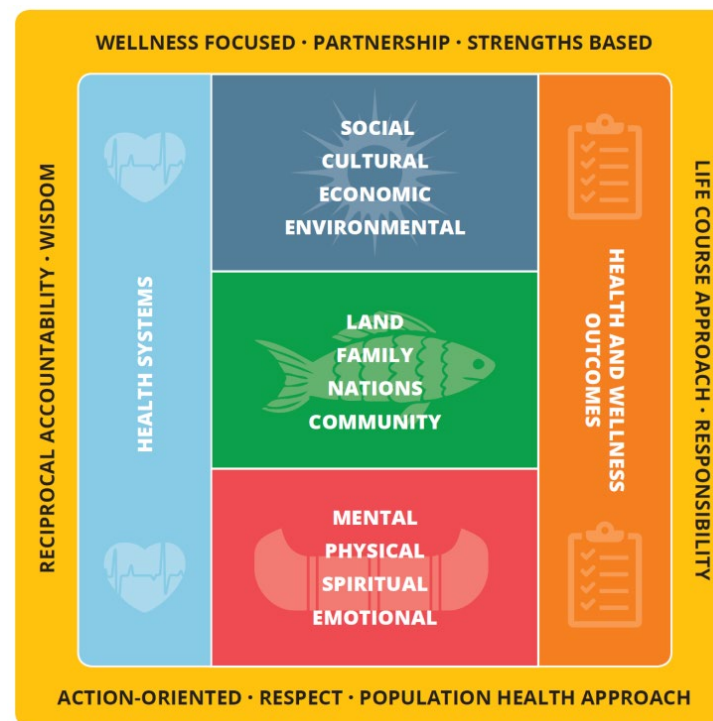
The following 15 renewed wellness indicators are:

1. Education
2. Food Security
3. Adequacy of Housing
4. Cultural Wellness
5. Experience of Cultural Safety & Humility in Receiving Health Services
6. Avoidable Hospitalizations

The Provincial Health Officer (PHO) and FNHA Chief Medical Officer (CMO)’s Indigenous health reports and interim updates support baseline data. The reports and interim updates have historically measured seven health indicators laid out in the *Transformative Change Accord: First Nations Health Plan*. The Offices of the PHO and CMO are scheduled to release a final interim update reporting on the seven original indicators in 2018.

Another provision in article 5.1.d. of the TDQSA is to establish other key (especially wellness-focused) indicators. In 2017, significant work occurred toward achieving this goal. The renewed set of fifteen additional indicators and associated reports will bring together knowledge to support and inform policy, initiatives, and approaches at various levels.

Figure 2: PHO/CMO Indigenous Wellness Indicators



7. Community Strength and Resilience
8. Ecological Health
9. Level of Physical Activity
10. Number of Children with Healthy Teeth
11. Smoking Rates of Commercial Tobacco
12. Infants Born at a Healthy Birth Weight
13. Alcohol-Related Deaths
14. Serious Injuries Requiring Hospitalizations
15. Self-Reported Mental and Emotional Well-Being

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.

In 2017, an issue emerged in terms of FNCF data quality. MoH staff attempting to analyze data on First Nations newborns for PHO/CMO Indigenous Women's Report noted a decrease in newborns, when in fact an increase was anticipated. The team suspected that there was a capturing issue with FNCF, so the team investigated and discovered the main issue: missing father's personal health number (PHN) affecting eligibility criteria. The source issue appeared to originate in Vital Statistics, and thus would not only affect this specific DAR, but other projects.

Utilizing a process that Vital Statistics has used, name matching, the project team was able to fix eligibility criteria for newborns to be included in the cohort for their specific project. Vital Statistics was also informed. While the FNCF automation process is recognized as an important efficiency, DIPC will continue to ensure rigorous data quality efforts are in place, to catch and fix important issues such as the newborn issue in 2017.

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 to allow partners to submit FNCF DARs for the purposes of program planning and monitoring health outcomes.

Article 5.1.g

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

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 Standard (Ministry of Aboriginal Relations and Reconciliation, 2007) is a BC government standard that allows for the collection of self-identified Status and non-Status information, but has not yet been widely implemented in the health care sector.

7.0 Lessons Learned in 2017

7.0 Lessons Learned in 2017

DIPC identified a number of lessons in the first seven years of implementing the Tripartite Data Quality and Sharing Agreement, including:

The sharing of 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 up a significant amount of time within each FNCF DAR project work plan.

The FNCF is a valuable resource that would benefit health partner organizations, other government departments as well as external researchers; however, with limited time and resources, 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 is oriented to the work of the committee

DARs have differing levels of complexities which can create new methodologies may be created and/or revised and new issues arise that require discussion and collaborative development of additional policies



8.0 Looking Ahead

8.0 Looking Ahead

As the Tripartite Data Quality and Sharing Agreement (TDQSA) continues to be implemented, the following can be expected in the future:

- Work will be undertaken to establish new or updated Information Sharing Agreements in anticipation of the expiration of the TDQSA in April 2019
- Continued and enhanced knowledge exchange between MoH and FNHA with respect to data stewardship of the FNCF
- Emerging data on topics set out as priority areas by DIPC
- Emerging data will increase the ability of First Nations Community and partners to monitor health and measure the success of programs and services provided in B.C. First Nations communities. Increased data also support regional activities and initiatives through analysis of data at regional levels
- The Office of Indigenous Health (OIH) will be repositioned into a different division in January 2018. This will allow OIH to play a more strategic role in the Ministry
- There will be personnel and organizational changes in the calendar year 2018 with the anticipation of a re-positioning of the MoH Co-Chair role.



9.0 Additional Reading

First Nations Health Authority. (2011). *British Columbia First Nations Perspectives on a New Health Governance Arrangement: Consensus Paper*. Retrieved from www.fnhc.ca/pdf/FNHC_Consensus_Paper_-_WEB.pdf.

Ministry of Aboriginal Relations and Reconciliation. (2007). *Government Standard for Aboriginal Administrative Data*. Retrieved from www.cio.gov.bc.ca/local/cio/standards/documents/standards/aboriginal_administrative_data_standards.pdf.

Provincial Health Office. (2015). *The Health and Well-being of the Aboriginal Population: Interim Update*. Retrieved from <http://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/office-of-the-provincial-health-officer/reports/publications/special-reports/first-nations-health-and-well-being-interim-update-nov-2015.pdf>

Tripartite Committee on First Nations Health. (2017). *Together in Wellness: Tripartite Committee on First Nations Health Annual Report (October 2016-October 2017)*. Retrieved from <https://www2.gov.bc.ca/assets/gov/government/ministries/organizations/ministries/health/office-of-indigenous-health/together-in-wellness-2016-17.pdf>

Appendix 1 – Table 1: Progress on Data Access Requests, 2017

Project Title	Description	Requestor	Status update
1. Cancer (2012-18)	To compare the descriptive epidemiology, incidence, mortality, survival and trends over time of populations with various types of cancer between Registered “Status Indians” Living in British Columbia and the general BC population. If differences exist, to offer recommendations in closing the inequalities, and to influence future program planning in this area.	Public Health Partner and Internal Partner	Linkage has occurred and data is being analyzed. The project team analyzed findings and developed a manuscript. The manuscript was reviewed and approved by the DIPC. The peer-reviewed journal article was published in September 2017, and informed the Indigenous Cancer Strategy released in December 2017. ³
2. Interior Health Expenditure Project (2013-22)	This project will provide a detailed analysis of regional health authority and First Nations expenditures and service use in Interior Health’s seven Interior Nations. Health expenditures will be interpreted and understood in the context of health service use, so that potential gaps in First Nations access to programs/services can be examined, and opportunities for investment or service integration between Interior Health and First Nations can be identified. The First Nations Client File will be linked to the Health System Matrix databases from 2009 to 2013, and will provide essential information regarding health service use of Interior Nations. Comparisons between Interior Nations and the general population will inform the expenditure gaps analysis, assist in transformation, and can be used to better target future health expenditure investment and service integration in Interior Health.	Internal Partners	Presented amendment at January 26, 2017 DIPC meeting and went through approval process. DMWG fast-tracked the approval of specific DIPC-approved dashboard products has been successful in testing iterations. Expansion of access amendment was signed off. Project is now considered closed, in light of impending availability of Provincial HSM results.
3. Provincial Health System Matrix Linkage (2014-28)	This project will provide a detailed analysis of regional health authority (HA) 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	Internal Partners	In 2017, project team did analysis and packaged results for the provincial Health System Matrix. Project team began presenting at specific forums and will continue First

³ <https://link.springer.com/article/10.1007/s10552-017-0950-7>

Project Title	Description	Requestor	Status update
	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 HA and First Nations can be identified.		Nations health information governance process to disseminate in 2018.
4. Provincial Health Officer Interim Report 2014 (2014-24)	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: life expectancy at birth; all-cause, age-standardized mortality rate; youth suicide rate; infant mortality rate and age-standardized diabetes prevalence rate.	Internal Partners	Request presented at June 1, 2017 DIPC meeting. DAR approved. The project team and DIPC Secretariat stayed in close contact on this time-bound report in order to fulfill the commitment under the <i>Transformative Change Accord: First Nations Health Plan</i> .
5. 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 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 we are able to slow transmission rates and achieve declines in morbidity and mortality due to HIV disease. The data access request proposes to continue linkage on an annual basis starting Feb. 5, 2014 for the next three years with an option to renew.	Internal Partners	Findings were approved by DIPC in 2017. Dissemination plan was broken into iterative phases (to ensure maximal utility, access, and cultural safety). Phase one was approved by DIPC in November 2017
6. Heart IS	To compare the descriptive epidemiology of cardiovascular procedures and related factors between status First Nations living in BC and the rest of the BC residents, in order to establish baseline data for developing a FNHA Cardiovascular Strategy.	Internal Partners	PHSA worked to finalize data elements and files to prepare for handling to MoH for FNCF linkage. A minor issue occurred within the information sharing plan, which DIPC Secretariat worked to solve.
7. Chronic Disease Registry IS	To compare the descriptive epidemiology of various chronic diseases between status First Nations living in BC and the rest of the BC residents.	Internal Partners	ISA and amendments were approved in various DIPC meetings in 2017. Project team and DIPC Secretariat worked to figure out DAR requirements and re-transfer data as needed.

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Project Title	Description	Requestor	Status update
8. Provincial Diabetes Strategy – quality of care indicator (2015-29)	This quality improvement project is aimed at improving health of the diabetes population by evaluating & redesigning diabetes care management in BC that is sensitive to local, cultural & ethnic needs; including First Nations people in BC with diabetes. It may also be described as a diabetes integrated primary & community care project.	Public Health Partner	Work on a Provincial Diabetes Strategy project was advanced in 2017. Project team presented specific requests and amendments to DIPC, and the committee considered, reviewed, and approved as appropriate.
9. 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 First Nations Client File (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 on 2017
10. Hep 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. An initial meeting with Evan Adams was positive.	Public Health Partner	DAR was approved, and proper documentation including information sharing agreement was developed.
11. Hep C (BCCfE)	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 DAA-based HCV 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.
12. Perinatal Data Linkage with First Nations Health Authority	The FNHA is requesting routine linkage to perinatal data for the purpose of 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 on the health outcomes of infants. The data will support the planning of culturally relevant perinatal care. The data will be	Internal Partners	Originally approved in November 2016, personnel changes and resourcing issues meant that this project was put on hold for part of 2017. It is anticipated that work will be advanced in 2018.

Project Title	Description	Requestor	Status update
	used as a tool to measure the perinatal care access that First Nations women and infants experience.		
13. PHO Indigenous 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 wellbeing of Indigenous women in BC. This report will discuss success stories and areas where there may be room for improvement, as well as recommendations for the creation of specifically targeted programs to support better health.	Internal Partners	Specific amendments were approved by DIPC in 2017, and the project team worked to develop and refine multiple ISA/ISPs and partnership letters with various stakeholders. The data quality issue regarding newborn capture in the FNCF affected the timeline of this project.
14. Suicide and Cultural Continuity on BC First Nations Communities	Update the 2008 Chandler and Lalonde study which identified a relationship between youth suicide rates and cultural continuity indicators in tribal councils. The data requested under this DAR will update youth suicide rates by Tribal Council to identify the extent to which the general reduction in provincial rates occurred across Tribal Councils or was concentrated in a few. The study will also examine the extent to which reductions were related to Tribal Council cultural continuity scores from the 2008 study. An attempt will be made to update the cultural continuity scores if data is available to identify the extent to which current youth suicide rates are associated with current cultural continuity scores within Tribal Councils.	Internal Partners	Project currently on hold, due to complexity of updating the cultural continuity metrics. The MoH project team are remaining in touch with Lalonde to assess feasibility of an update.
15. Opioids Overdose Public Health Emergency Surveillance Project – BC Centre for Disease Control (Main Component)	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 FNHA, BCCDC, the Regional Health Authorities and the MoH to support decision-making.	Internal Partners	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, DIPC kept closely connected with the project team throughout the year.
16. Opioids Overdose Public Health Emergency Surveillance Project –	To supplement the linked public health surveillance database within the BCCDC by performing two additional, separate linkages, linking NACRS data at FH	Public Health Partner	Data linkage occurred, informing the August 2017 FNHA release Overdose Data and First Nations in BC: Preliminary Findings . Given

Project Title	Description	Requestor	Status update
Fraser Health & Vancouver Coastal Health (Supplement)	and VCH with FNCF. This linkage will support planning, priority-setting and evaluation of the opioid overdose prevention strategy in BC.		the elevated priority of this DAR, DIPC kept closely connected with the project team throughout the year.
17. Aboriginal Youth and Young Adult Death Panel	The BC Coroners Service in partnership with FNHA is convening a Death Review Panel in December 2016 about FN 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	A courtesy letter was provided to Indigenous and Northern Affairs Canada regarding this project.

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 acknowledged 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, TB 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.