

TRIPARTITE DATA QUALITY AND SHARING AGREEMENT

2015-2016 Annual Report on Progress



Tripartite First Nations Health Plan



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 B.C. 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 B.C. Ministry of Health (MoH) Personal Health Number. The FNCF is the product of a record linkage between an extract of the Indigenous & Northern Affairs Canada (INAC) Indian Registry and the MoH 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 B.C. Ministry of Health (MoH) and INAC authorizing the disclosure of information contained in the Indian Registry to the MoH on an annual basis. The FNCF was initially created in 2011, and is updated incrementally using a fresh extract from the B.C. 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 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 B.C. 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 B.C., 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 B.C. 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 FOIPP 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 (Health Canada 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 Context for the report

This annual report documents the progress made by the tripartite partners – the First Nations Health Authority (FNHA, formerly known as the First Nations Health Society), Government of Canada (Health Canada), and the Province 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 April 2010 by earlier iterations of the current partners – B.C. Ministry of Health Services and the Ministry of Healthy Living and Sport (now the MoH), the First Nations Health Society (now the FNHA), and Health Canada. The 2010 agreement fulfills Action number 28 of the 2006 Transformative Change Accord: First Nations Health Plan (TCA: FNHP), 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: “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 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)). This report is presented to fulfill these obligations for calendar years 2015 and 2016.

The original TDQSA term expired in April 2015, with an automatic one-year extension. The TDQSA was extended effective September 3, 2015 to maintain the term of the Agreement to April 16, 2019.

3.0 Context of our work

In 2015 and 2016, personnel changes within the FNHA and the MoH had some impact on the Data and Information Planning Committee (DIPC) as new staff were oriented and trained on the work.

- A Co-Chair left the MoH for a new job at the FNHA; therefore, a new Co-Chair was appointed from the MoH.
- There was turnover in the DIPC Secretariat role.
- The MoH Chief Data Steward retired, and a new Chief Data Steward was hired.
- A new reporting relationship was finalized, with the DIPC now reporting to the FNHA-MoH Joint Project Board.

4.0 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 2015-2016
<p>Article 3.1.a</p> <p><i>Establish a framework for the Parties to: (i) continually improve the quality and availability of First Nations Data;</i></p> <p><i>(ii) facilitate the sharing of FNCF Data in response to research questions approved in accordance with this Agreement; and</i></p> <p><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></p>	<p>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.</p> <p>The DIPC, the Data Management Working Group (DMWG) and the TDQSA Secretariat (now referred to as the DIPC Secretariat) were established to implement the work described in Article 3.1.a:</p> <ol style="list-style-type: none"> 1. The DIPC met six times in 2015 and five times in 2016. The DIPC worked on 22 separate data requests (eight of these being new in 2015, and five new in 2016) (see Table 1 for more details). Progress updates were added as a standing agenda item to FNHA-MoH Joint Project Board meetings (met five times in 2016). <p>There has been significant learning through the review of data access requests (DARs) and development of processes. Each DAR involved its own context, questions and implications.</p> <ol style="list-style-type: none"> 2. The DIPC was supported by the DMWG. The DMWG met biweekly in 2015 and 2016, chaired by the DIPC Secretariat. The DMWG is made up of representatives from FNHA and MoH. Its purpose and responsibilities are to: <ol style="list-style-type: none"> a. Provide technical and detailed support to project management relating to proposed and/or approved DARs. Each DAR is managed by an assigned project lead that provides overall leadership to a project, including leading and/or assigning work relating to individual projects.

Purpose	Progress in 2015-2016
	<p>b. Develop processes and tools to facilitate the work of the DIPC, as well as appropriate management and use of First Nations Client File (FNCF) data.</p> <p>c. Provides a forum for discussion of partner data issues, projects and supports.</p> <p>3. The DIPC Secretariat role is undertaken by an FNHA staff member, seconded to the MoH. The functions of the DIPC Secretariat:</p> <ul style="list-style-type: none"> - Support the work of the DIPC and the DMWG. - Facilitate fair and impartial process and decision-making, and consistent and equitable access to information for potential applicants. - Be a dedicated resource to coordinate the work of the DIPC, including preparing synopsis of research proposals and communicating with applicants to seek clarifications requested by the DIPC. - Conduct an initial review of new FNCF DARs to ensure the request is clear and that all necessary information and documentation are submitted. - Track the status and progress of DARs, and for some projects, provide project management. - Document the use, approval and outcome of FNCF decisions for reporting and auditing purposes. - Assist in the preparation of policies, procedures and tools that will facilitate the work of the committee, and the use of the FNCF. - Assist in the preparation of data sets and any in-house analysis required by DARs. - Be a mechanism for knowledge exchange between the current FNCF Data Steward (MoH) and the FNHA to determine future options for the ongoing use of First Nations data by the FNHA. - Provide progress reports to the FNHA-MoH Joint Project Board.

Purpose	Progress in 2015-2016
	<p>In addition to the secretariat and committees, the partners ground their work in foundational FNHA documents such as the 2011 Consensus Paper.¹</p> <p>The DIPC has developed a FNCF DAR Companion Document. This Companion Document serves as a guide for decision-making relating to DARs, and is discussed further under Article 3.1.f below.</p>
<p>Article 3.1.b</p> <p><i>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.</i></p>	<p>Tools have been developed for the purposes of adjudicating DARs.</p> <ul style="list-style-type: none"> - The DAR form evolved iteratively, based on DIPC feedback and DAR project team experiences. The DIPC approved the latest version in August 2015. - A fillable PDF DAR form has been developed. - 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 drafted, with the aim of providing all necessary information for filling out a DAR form. This document also contains details about the DIPC governance process, as well as some relevant history and context. DMWG is developing this document, aiming for simultaneous release as the PDF DAR form. For more detail, see section 3.1.c and 3.1.f of this document. - A Project Manager Frequently Asked Questions document was drafted by DMWG, with the aim of clarifying the role and responsibilities of a DAR Project Manager. This document is expected to be especially 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.

¹ The results of more than 120 regional and sub-regional caucus meetings with First Nations Chiefs, leaders and senior health professionals to inform the discussions and negotiations of a new governance arrangement for health programs and services utilized by First Nations in B.C. were rolled into the 2011 *Consensus Paper: British Columbia First Nations Perspectives on a New Health Governance Arrangement*. The Consensus Paper outlines Seven Directives that describe the fundamental standards and instructions for the new health governance relationship. The Data and Information Planning Committee use the Seven Directives to guide their work and decision-making.

Purpose	Progress in 2015-2016
	<ul style="list-style-type: none"> - An FNCF Information Sharing Agreement (ISA) Template was developed, which reduces the time required to build an ISA from weeks to days, while sacrificing none of the legal rigour. Testing of the template occurred 2016. - 'General Conditions of use of the First Nations Client File' were established to evaluate each DAR (see Appendix 2). - A continually updated tracking mechanism documents the status of each DAR to ensure transparency and accountability. <p>Processes have been developed for the purposes of adjudicating and processing DARs. These include:</p> <ul style="list-style-type: none"> - Initial review of draft DARs by the DIPC Secretariat. - Determining priority of DARs on an ongoing basis by the DIPC and the FNHA-MoH Joint Project Board. - Processes for 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. <p>The DIPC has discussed projects that utilize secondary Aboriginal/First Nations identifiers, and the proper process to inform the DIPC of such projects. The DIPC has a vested interest in enhancing First Nations Health Information Governance, and in promoting culturally safe and appropriate work. To this end, it is strongly encouraged that the DIPC be informed of any requests for the use of secondary First Nations identifiers (e.g. MSP Group 21 or self-identification Aboriginal identifier from Vital Statistics) from the MoH, Population Data BC (PopData), and/or Vital Statistics. The DIPC should also be informed of pre-publications using secondary identifiers to provide a cultural and technical lens.</p>

Purpose	Progress in 2015-2016
<p>Article 3.1.c</p> <p><i>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.</i></p> <p>and</p> <p>Article 3.1.f</p> <p><i>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.</i></p>	<p>The MoH is the current Data Steward of the FNCF (Article 6.3) of the agreement.</p> <p>Through the TDQSA, the partners agreed to assist First Nations in developing the capacity to assume eventual custody, control and management of First Nations data (Article 3.1.f). It is recognized that when a First Nations Data Steward is established and able 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.</p> <p>Part of the work for the DIPC is the need to understand and prioritize the policies, safeguards and standards that will need to be in place should the DIPC decide that the FNHA should take over stewardship of the FNCF. This work is ongoing and will be developed over time.</p> <p>One of the main mechanisms for knowledge exchange is through the DIPC Secretariat. By working with key MoH data staff, the DIPC Secretariat can gain knowledge and skills relating to analyzing administrative health databases. Over time, this will build capacity.</p> <p>In order to develop the necessary training and knowledge exchange between the MoH and the 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 through 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 Aboriginal Health, in 2016 the position now sits within the Health Sector Information, Analysis and Reporting Division, MoH. The position also provides regular reporting to the FNHA-MoH Joint Project Board.</p> <p>Data Access Request Companion Document</p> <p>The DIPC has developed a Companion Document. The document provides DAR applicants with guidelines and background information completing DAR Forms. It includes:</p>

Purpose	Progress in 2015-2016
	<ul style="list-style-type: none"> • background information on the TDQSA, First Nations Health Information Governance, the DIPC, and FNCF (Section 1). • an overview of the DAR approval and linkage process (Section 2). • a step-by-step guide to fill out the DAR form (Section 3). • the conditions for use of FNCF and related data (Section 4). <p>All applicants are asked to read through and ensure they understand these principles. Principal data applicants and/or DAR project managers are asked to acknowledge that their project team agrees to abide by these conditions when they sign the DAR form.</p>
<p>Article 3.1.d</p> <p><i>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.</i></p>	<p>Forty-three FNCF DARs have been reviewed by the DIPC since the creation of the FNCF in November 2011. Each of the approved 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.</p> <p>See Table 1 for a listing of projects in progress for calendar years 2015 and 2016.</p>
<p>Article 3.1.e</p> <p><i>Recognize First Nations Health Information Governance and</i></p>	<p>The principle of First Nations Health Information Governance is a central tenet of the DIPC, one that the committee has been striving 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.</p>

Purpose	Progress in 2015-2016
<p><i>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.</i></p>	<p>The partners are aware of their accountability to First Nations in B.C. for the appropriate and responsible use of the FNCF, and have highlighted the need to develop clear pathways and mechanisms for insight into FNCF data access decision-making for First Nations.</p> <p>The partners want to ensure:</p> <ul style="list-style-type: none"> - that First Nations are involved in all decision-making regarding use of the FNCF and FNCF data; - that the privacy of individuals and communities is protected; - that topics of interest to First Nations are prioritized; - that information from the FNCF be available for First Nations to plan at community and regional levels; - and that the FNCF be cautiously and carefully used in an open and transparent way, recognizing the harmful realities of some historical research and government surveillance. <p>The DIPC recognizes that mechanisms for First Nations input into FNCF decision-making should and will be developed over time.</p> <p>Some mechanisms the DIPC has adopted to address the principle of First Nations Health Information Governance include:</p> <ul style="list-style-type: none"> - First Nations Health Authority has representatives on both the DIPC (FNHA Co-Chair) and the DMWG (FNHA Chair). - The secretariat role for the DIPC is filled by a FNHA staff member (currently fulfilling this role on secondment with the MoH). - FNCF DAR decisions are made by consensus among the two co-signatories, with input from and discussion with other committee members. - 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 "2011 Consensus Paper: British Columbia First

Purpose	Progress in 2015-2016
	<p>Nations Perspectives on a New Health Governance Arrangement.” These 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.</p> <ul style="list-style-type: none"> - In addition, respecting the governance of First Nations communities 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. In the future, when communities express interest in community-level data for their own health and wellness planning or evaluation efforts, the DIPC will to work in partnership with these communities in the analysis. The DIPC will develop these capacities through collaboration with communities over time. <p>Emerging publications and results are to be made as accessible to First Nations as possible by disseminating publicly; and researchers will be encouraged to disseminate results in a format and method that is both accessible and meaningful to First Nations in British Columbia.</p>

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

The TDQSA lists seven objectives and deliverables which are provided below along with a brief description of the results and progress in implementation.

Objectives and deliverables	Progress to Date
<p>Article 5.1.a</p> <p><i>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.</i></p>	<p>A number of priority areas of interest were identified in the TDQSA (see Appendix 1 for a complete list).</p> <p>The following progress represents work that has been undertaken to move forward selected priority areas of interest. This it is not an exhaustive list of the progress made toward priority areas of interest.</p> <ol style="list-style-type: none"> 1. Vital Statistics: The development of a vital statistics report is of interest and on the work plan of the DIPC, but of lower priority. 2. On-/off-reserve categorization: There has been evolution in the terminology used to describe the geographical location of First Nations since the creation of the 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 equivalent to on-reserve and 'Away from Home' is not the same as the off-reserve measure. 3. 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.

Objectives and deliverables	Progress to Date
	<p>4. Communicable Disease: The partners are working with the B.C. Centre for Disease Control (BCCDC) to develop a communicable disease report. This report is currently in the queue awaiting data linkage. The FNCF is also being used to assess the burden of HIV/AIDS among First Nations in B.C., as well as access to treatment and retention in care, from a linkage with the STOP HIV/AIDS Cohort at the B.C. Centre for Excellence in HIV/AIDS.</p> <p>5. Cancer: The tripartite partners have worked with the B.C. Cancer Agency to develop a First Nation cancer report. Data has been linked, analysis completed, and a manuscript has been developed and submitted for publication to a peer-reviewed journal.</p> <p>6. Injuries: The B.C. Coroners Service, in partnership with the FNHA, submitted a DAR, seeking data linkage on First Nations youth and young adults who have died from injury-related causes. In 2016, this DAR was elevated to high priority, and the DIPC Secretariat has actively supported this DAR process.</p> <p>7. Baseline data: Many of the initiatives underway contribute to baseline health data for First Nations. The Provincial Health Officer's reports and interim updates support baseline data.</p> <p>8. Health Care Utilization: An analysis of health expenditure data is underway through a DAR being led by the FNHA and Interior Health. The intent is to replicate this analysis in other health authorities</p> <p>9. Community Health Plans: The collection of information required for community health plans is a longer-term DIPC priority. This work will require more discussion and collaboration with the First Nations Health Directors' Association and regional tables.</p>

Objectives and deliverables	Progress to Date
<p>Article 5.1.b</p> <p><i>Achieve the goals, objectives or activities identified and agreed to by the Parties and set out in the Annexes to the TDQSA, as amended, supplemented or replaced from time to time.</i></p>	<p>The TDQSA states that the partners are able to develop and collaborate on projects or initiatives, which would be developed as annexes.</p>
<p>Article 5.1.c</p> <p><i>Adopt and implement the process for: i) reviewing proposed Initiatives, as set in Schedule B of the TDQSA; and ii) reviewing Data Access Requests, in collaboration with the Data Steward.</i></p>	<p>See “Progress to Date” description for Article 3.1.b</p>
<p>Article 5.1.d</p> <p><i>Oversee the development of First Nations Data in respect of the following seven performance indicators in the TFNHP:</i></p> <ul style="list-style-type: none"> - <i>Increased life expectancy</i> - <i>Mortality rates (due to all causes)</i> - <i>Status Indian youth suicide rates</i> - <i>Infant mortality rates</i> - <i>Diabetes rates</i> - <i>Childhood obesity (develop baseline and ongoing mechanism for collecting data)</i> 	<p>In November 2015, the Office of the Provincial Health Officer released an interim update examining progress on the seven performance indicators from the Tripartite First Nations Health Plan. The 2014 FNCF was utilized to measure progress on five of these indicators.</p> <p>Status Indian youth suicide rates:</p> <p>In 2015, a DAR to examine suicide rates was proposed, approved, and analyzed. The report was released to DIPC in 2016.</p> <p>In 2016, a DAR was developed on the relationship between youth suicide rates and cultural continuity indicators in tribal councils. This DAR was conceived as an update to the following study: Chandler, M.J. & Lalonde, C.E. (2008). Cultural continuity as a moderator of suicide risk among Canada’s First nations. In Kirmayer, L. & Valaskakis, G. (Eds.). <i>Healing traditions: The</i></p>

Objectives and deliverables	Progress to Date
<ul style="list-style-type: none"> - <i>Practicing, certified First Nations health care professionals (develop baseline and ongoing mechanism for collecting data)</i> - <i>and establish other key indicators, including wellness indicators.</i> 	<p><i>mental health of Aboriginal peoples in Canada (pp 221-248). University of British Columbia Press.</i></p> <p>Diabetes rates: Relevant data requests in active 2015-2016 include the Chronic Disease Registry IS, and BC Provincial Diabetes Evaluation & Strategy DARs.</p>
<p>Article 5.1.e</p> <p><i>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.</i></p>	<p>The FNCF Automation Project was proposed in 2015 and implemented in 2016, with the aim of transferring FNCF-generation process into the hands of FNHA. Expected completion of this project is early 2017.</p> <p>See "Progress to Date" description for Article 3.1.c.</p>
<p>Article 5.1.f</p> <p><i>Develop and implement a program(s) for the collection of information to assist in the development of First Nations healthy policy and</i></p>	<p>Processes are in place to allow partners to submit FNCF DARs for the purposes of program planning and monitoring health outcomes.</p>

Objectives and deliverables	Progress to Date
<i>program planning, as well as to monitor health outcomes in First Nations communities.</i>	
<p>Article 5.1.g</p> <p><i>Develop and assist other government agencies, government ministries and government departments to develop comparable data sets for non-status First Nations in BC.</i></p>	<p>The FNCF only allows for the identification of Status individuals, and therefore no non-status health information can be produced using the FNCF.</p> <p>The Aboriginal Administrative Data Standard (Ministry of Aboriginal Relations and Reconciliation, 2007) is a B.C. government standard that allows for the collection of self-identity status and non-status information, but has not yet been widely implemented in the health care sector.</p> <p>While the DIPC administers the FNCF and promotes the FNCF as verifiable data source of First Nations health information, the committee also has an interest in keeping abreast of additional Aboriginal/First Nations identifiers. The DIPC continues to support FNCF DAR projects, with the aim of ensuring that project results are widely but responsibly disseminated to those who can use them.</p>

6.0 Lessons Learned

The DIPC identified a number of lessons learned in the first six years of implementing the TDQSA, 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 judgment.
- Developing information sharing arrangements previously took a significant amount of time within each DAR project work plan; then, in 2015, the DMWG was able to develop an ISA template to facilitate and expedite the process. The ISA template was tested in 2016.
- With each new DAR, new questions often arise that require discussion and development of additional policies, tools or processes. The DMWG and the DIPC have updated their Companion Document to clarify some of these common questions.
- 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, the DIPC has decided that it 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 are oriented to the work of the committee.
- Standardizing the DAR process, whenever possible, increases transparency, consistency, and opportunity for methodological rigor.

7.0 Looking Ahead

As the TDQSA continues to be implemented, the following can be expected in the future:

- Work needs to be undertaken to establish new or updated ISAs in anticipation of the expiration of the TDQSA in April 2019.
- Emerging data will increase the ability of First Nations communities 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.

- Emerging data on topics set out as priority areas of interest in the TDQSA.
- Continued and enhanced knowledge exchange between the MoH and FNHA with respect to data stewardship of the FNCF.

8.0 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 Officer. (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. (2015). *Together in Wellness: Tripartite Committee on First Nations Health Annual Report (October 2014-October 2015)*. Retrieved from http://www2.gov.bc.ca/assets/gov/government/ministries-organizations/ministries/health/aboriginal-health-directorate/final_2015_togetherinwellness_web.pdf

Appendix 1 – Table 1: Progress on Data Access Requests, 2015-2016

Project Title	Description	Requestor	Status update
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 B.C. 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 DIPIC, and in 2016, it was submitted for publication to a peer-reviewed journal.
Communicable Disease (2011-7)	The data linkage will provide the basis for an assessment of the epidemiology and burden of communicable disease in First Nations in B.C. for the years 2002-2013. Such an assessment is essential for the development of effective public health programs and policies, and for the evaluation of programs and interventions aimed at reducing communicable disease burden among B.C. First Nations.	Internal Partners	Linkage has occurred, and data analysis is in progress.
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	Internal Partners	Linkage has occurred, and project team have analyzed findings and developed a preliminary document. This data request has laid foundation for a related data request, Provincial Health System Matrix (2014-28).

Project Title	Description	Requestor	Status update
	<p>examined, and opportunities for investment or service integration between Interior Health and First Nations can be identified. The FNCF 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.</p>		
<p>Provincial Health System Matrix Linkage (2014-28)</p>	<p>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 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.</p>	<p>Internal Partners</p>	<p>Project built and prepared based on lessons learned from the Interior Health Expenditure DAR (2013-22). Initial data request drafts began in summer 2015, with subsequent iterations. DAR was approved by DIPIC, and is ready for linkage. This data request was a priority in 2016.</p>
<p>Opioid Mortality (2014-27)</p>	<p>This project will assess patterns of service use and other measurable risk factors</p>	<p>Internal Partners</p>	<p>Linkage has occurred and project team completed preliminary analysis; however, the numbers were too small</p>

Project Title	Description	Requestor	Status update
	associated with accidental pharmaceutical opioid-related deaths.		and further analysis was not feasible. Data request is complete. This data request laid the foundation for a related data request, Opioids Overdose Public Health Emergency Surveillance Project (Provincial Health Officer State of Emergency request).
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	Linkage has occurred, and project team analyzed findings and developed a report, " First Nations Health and Well-being: Interim Update " (November 12, 2015). Data request is complete.
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 MoH. The aim is to improve reach of HIV testing, treatment and support across B.C. 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 B.C. 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 DAR proposes to continue linkage on an annual basis starting Feb. 5,	Internal Partners	Linkage has occurred, and project team has analyzed findings. Results were reviewed by the DIPC, who requested further analysis certain aspects of the data.

Project Title	Description	Requestor	Status update
	2014 for the next three years with an option to renew.		
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	DAR submitted and approved in 2015. Information Sharing Plan is under review.
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	Linkage was conducted on 2014 data, and provided to applicant for analysis. Data request amendment proposing expanded access was approved, to account for new analysis staff.
BC Provincial Diabetes Evaluation & Strategy (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 Aboriginal diabetes people in BC. It may also be described as a diabetes integrated primary & community care project.	Public Health Partner	Data request was approved, and ISA is under development.
First Nation Suicide Community Indicators Project (2015-30)	The First Nation Suicide Community Indicators Project project aims at data extraction and analysis of the current rates of hospitalizations and physician visits for self-injuries, injuries, poisoning, overdose, mental health diagnosis by First Nations.	Internal Partners	Linkage has occurred, and project team have analyzed findings and developed publication, which was distributed to DIPC. Data request is complete.

Project Title	Description	Requestor	Status update
	<p>This project is to inform further discussion of the rates and contributing factors in First Nations suicides at the Tripartite Committee on First Nations Health discussion table in November 2015.</p>		
<p>Population Estimates and Demographic Characteristics of First Nations and Self-identified Aboriginal People in BC, A Comparison Between Various Data Sources.</p>	<p>The purpose of this project is to provide accurate, accessible geographic-, age- and gender-specific population estimates for First Nations and self-identified Aboriginal People in B.C. 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.</p>	<p>Internal Partners</p>	<p>Data request approved, and ISA is under review.</p>
<p>GP For Me Evaluation</p>	<p>A GP For Me is a province-wide initiative funded jointly by the Province of B.C. and Doctors of BC to:</p> <ol style="list-style-type: none"> 1. enable patients who want a family physician to find one, 2. increase the capacity of the primary health care system, and 3. strengthen the continuous doctor-patient relationship, including better support for vulnerable patients. 	<p>Internal Partners and External Public Health Body</p>	<p>Data request was reviewed, and found to this linkage would overlap with Provincial Health System Matrix data request (2014-28). To avoid duplication, this data request was closed.</p>

Project Title	Description	Requestor	Status update
BC Hepatitis Testers Cohort: Assessment of the Burden of Hepatitis C to Support Appropriate Prevention, Care and Treatment Using a Comprehensive Dataset of HCV and HIV Testers in BC	Overview redacted from general publication.	Public Health Partner	Data request has been drafted. Cultural safety and appropriateness of indicators under review.
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 used as a tool to measure the perinatal care access that First Nations women and infants experience.	Internal Partners	Data request has been drafted and conditionally approved by the DIPC.
PHO Aboriginal 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 Aboriginal 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	Internal Partners	Related data request had previously been approved, but current data request required further development. Current data request is being drafted.

Project Title	Description	Requestor	Status update
	specifically targeted programs to support better health.		
UBC Out of Hospital Cardiac Arrest	Project team wishes to link pre-existing out-of-hospital cardiac arrest data (including precise GPS, quality of CPR metrics, and DOA stats) to establish whether incidence, mortality is different for First Nations than non-First Nations populations.	External Applicant	Data request is identified.
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	Data request was approved. Linkage has occurred, project team have analyzed findings and presented them to the MoH Provincial Health Officer and FNHA Chief Medical Officer. Subsequently, PHO and CMO provided information to Tripartite Committee on First Nations Health in October 2016. Findings were also presented during Gathering Wisdom forum in November-December 2016. Full analysis will require updating of Cultural Continuity indicators, so the project remains open until these updates are received.
Opioids Overdose Public Health Emergency Surveillance Project – BC	To develop a linked public health surveillance database within the BCCDC to support planning, priority-setting and evaluation of	Internal Partners	ISA is finalized. This data request received top priority for the DIPPC, given

Project Title	Description	Requestor	Status update
Centre for Disease Control (Main Component)	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.		the public health emergency on illicit drug overdose deaths, declared in 2016.
Opioids Overdose Public Health Emergency Surveillance Project – Fraser Health & Vancouver Coastal Health (Supplement)	To supplement the linked public health surveillance database within the BCCDC by performing two additional, separate linkages, linking NACRS data at FH and VCH with FNCF. This linkage will support planning, priority-setting and evaluation of the opioid overdose prevention strategy in BC.	Public Health Partner	Information Sharing Plan is drafted and in review.
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	ISA under review. This data request was a priority in 2016.

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

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 B.C. 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 B.C. certified health care professionals.
10. Collection of information about congenital anomalies and genetic conditions in First Nations.

11. Collection of information required for the First Nations in B.C. Regional Longitudinal Health Survey.
12. Collection of information required for First Nations in B.C. community health plans.
13. Other projects as identified and agreed upon by the parties.

Appendix 3 – General Conditions of Use of the First Nations Client File (FNCF)

Each DAR for use of the FNCF, FNCF data, and FNCF denominators should consider how it can integrate principles of the Seven Directives. Requests will be considered by the Data and Information Planning Committee (DIPC), in light of how the Seven Directives are integrated into the proposed project.

See below for examples of how FNCF DARs can integrate elements of relevant Directives:

Principle	Ways in which FNCF DARs can embody this principle
<p>Directive #1: Community-Driven, Nation-Based</p> <p>Program, service and policy development must be informed and driven by the grassroots level.</p>	<p>DARs should be driven whenever possible by local community interests.</p> <p>The results of the project should be of use in the planning and delivery of health care services.</p> <p>The results should be made public and available to First Nations whenever possible.</p> <p>Knowledge dissemination strategies should be integrated into the project to direct the work toward those who would reasonably be expected to enact change with the information.</p>
<p>Directive #2: Increase First Nations Decision-Making and Control</p> <p>Increase First Nations influence on health program and service philosophy, design and delivery at the local, regional, provincial, national and/or international levels.</p>	<p>The results of the project should be of use to the planning and delivery of health care services at local, regional, provincial, national and/or international levels.</p> <p>The principles of First Nations Health Information Governance guide the data management of the project.</p>

<p>Implement Ownership, Control, Access and Possession™ principle regarding First Nations health data, including leading First Nations health reporting.</p>	
<p>Directive #3: Improve Services Support health and wellness planning and the development of health program and service delivery models at local and regional levels</p>	<p>Projects relate to a topic that may reasonably lead to better health outcomes or health care service delivery for First Nations in British Columbia.</p>
<p>Directive #4: Foster Meaningful Collaboration and Partnership Foster collaboration in research and reporting at all levels. Enable relationship-building between First Nations and the regional health authorities and the First Nations Health Authority, with the goal of aligning health care with First Nations priorities and community health plans where applicable.</p>	<p>Project should involve community members or relevant partner representatives, including staff from First Nation communities, the First Nations Health Authority, MoH, First Nations and Inuit Health Branch, health authorities and First Nations Health Directors Association. Ideally involvement should take place throughout the project, including the analysis, interpretation, dissemination of information, and evaluation, as determined by First Nations partners involved.</p>
<p>Directive #7: Function at a High Operational Standard Be accountable, including through clear, regular and transparent reporting. Make best and prudent use of available resources.</p>	<p>Use of the FNCF, FNCF data and FNCF denominators will enable more effective use of existing data sources to inform best practices and policy. Users of the FNCF, FNCF data and FNCF denominators will be accountable through clear, regular and transparent reporting that demonstrates appropriate use and interpretation of the FNCF, FNCF data and FNCF denominators.</p>