

The Alberta First Nations
Information Governance Centre

Alberta FNIGC Operations and Research Projects 2021-22 Annual Report



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Message From Alberta FNIGC Board and Director of Operations

Greetings Alberta First Nations AGM Delegates and Members

The 2021-2022 fiscal period marked the second year of the COVID – 19 global pandemic which posed a series of unique and ongoing challenges for Alberta First Nations and around the planet.

Even during these unprecedented times, we have continued to work with and for Alberta First Nations on building capacity, participating in research with prior and informed consent, increasing knowledge of data, data use, and data visualization tools, all in partnership with Knowledge Holders from each nation.

The work of Alberta FNIGC is fundamental to nation-building for many reasons; one of which would be “information is power”. Information gets us to where we are, what we want, and what we aspire to.

The Alberta FNIGC has played a significant role in redefining how data and data-sharing agreements handled and applied; holding organizations, funders, and researchers accountable and ensuring adherence to OCAP ® principles.

We are proud to report the Alberta FNIGC continues to be known for its leadership in best practices and is the standard for other regions currently aspire to. As such, Alberta FNIGC has developed a national reputation as a leader in First Nation Information Governance, and as a Regional Information Governance Centre. This report shows how much work has been achieved in 2020 and 2021 and highlights the scope and diversity of partnerships and outcomes.

Lea Bill (Executive Director)
For

Kiaayo Tamisoowo
Chief Stan Grier
Chairman of the Board, Alberta FNIGC



Purpose

To report on operations activities and current research projects and activities

Background

Mandate:

The AFNIGC promotes, protects and advances the First Nations' principles of OCAP™, the inherent right to self-determination and jurisdiction in research and information management.

AFNIGC Vision and Mission Statement

Vision

The Alberta First Nations Information Governance Centre (AFNIGC) is a leader in strengthening First Nations Sovereignty in data and information governance for the well-being of the sovereign Nations, members, and Peoples of Treaty 6, 7, and 8 in recognition and respect of each distinct knowledge system.”

Mission

The Alberta First Nations Information Governance Centre (AFNIGC) is a not-for profit, First Nations-owned organization working to promote, protect, and advance the First Nations' Ownership, Control, Access, and Possession (OCAP®) principles, the inherent right to self-determination, and jurisdiction in research and information management. Our organization supports partnerships with our Nation members in respect of free, prior, and informed consent to promote credible data owned by First Nation Peoples.

Operations Core Strategic Objectives

- Apply a Community-driven and Nation-based approach
- Ensure data collection, and applications are inclusive, meaningful, and relevant to First Nations
- Ensure tools are effective, adaptable, and accessible and appropriate for First Nations
- Ensure partnerships are connecting Nations to strengthen data sovereignty and demonstrate the impact of First Nations information governance

Objective 1: Community-Driven Nation-Based Approaches

Goal: Assist First Nations, in the development of a First Nations health monitoring framework that defines self-determination in distinct Nations culture and languages; adhere to a respectful, ethical process in developing identifiers and draw on culturally and locally relevant understandings of health at the community and regional level; ensure that the First Nations Health Surveillance in Alberta is both meaningful and beneficial at the community level and promote positive change.

Objective 2: Ensure data collection, and applications are inclusive, meaningful, and relevant to First Nations

Goal: Ensure the First Nations have the human, technological, and infrastructure resources to fully participate in, and benefit from, First Nations health surveillance activities.

Objective 3: Ensure tools are effective, adaptable, and accessible and appropriate for First Nations

Goal: Ensure that First Nations Health Surveillance tools and activities are implemented in a coordinated, manageable, and accountable manner to ensure project success.

Objective 4: Ensure partnerships are connecting Nations to strengthen data sovereignty and demonstrate the impact of First Nations information governance

Goal: Evaluation of the First Surveillance System with focus on (1) benefit to First Nations, (2) OCAP® compliance, (3) timeliness of implementation, identification, and elimination of data gaps, and (4) overall cost of the system. Ensure transparency, accountability, efficacy, and sustainability of the First Nations Health Surveillance Framework.

Staffing

The pandemic has impacted the way we deliver our services and accomplish the work of AFNIGC. AFNIGC has a core complement of staff

- Executive Director
- Chief Financial officer
- Senior Data analyst
- Reception/Admin support

Projects are staffed on a fixed term contract basis for the duration of a project.

Current research projects supporting additional staff include:

Cancer prevention and innovation: Cancer Prevention and Screening - supports a project coordinator position

Ihelti, Restoring Healthy Family Systems Project .5 Research assistant

Data analyst .5 position – supported by all research projects

Digital Meeting Administrator/Facilitator & Support Specialist – support from all projects

National Data Strategy – Executive Co-lead

Alberta Innovates Project – Full Time Research Assistant beginning October 3, 2022

COVID Impacts

We adapted our work to primarily meeting through Virtual means however we were able to have some in person meetings with COVID protocols in place when the window opened for us to have in person meetings and engagement sessions.

AFNIGC Prepared an extensive information package on COVID and data to support Health Directors with pandemic planning.

Core Funding

Alberta FNIGC is on a 5-year core funding arrangement with ISC for 250k per year to support health surveillance and reporting for Alberta First Nations.

Indigenous Services Canada Funded Projects

Aboriginal Diabetes Initiative (ADI)

The Regional gathering/training was to update First Nations ADI Best Practices Guidelines and to have opportunity to discuss, plan and increase awareness of best practices. The event was prepared to launch in March 2020 just before year end. In light of the Medical Health Officer announcements on COVID19, AFNIGC and the Prevention Sub-Committee of HCOM decided to postpone and an extension was provided until March of 2021. The pandemic has impacted all communities requiring their staff to focus

on pandemic management. We are still hopeful to deliver this training now virtually since restrictions will continue to be a factor in being able to deliver the training, the program delivered in the new year.

Health Surveillance – Health Status Report (Web Based)

Web Site is complete and AFNIGC and has been made available to First nations through the Alberta FNIGC Web site, this project is now complete however work is underway to expand the work through the National Data Strategy work and through the COVID safe restart work.

Indigenous Early Learning and Child Care (IELLC)

Work is complete and draft reports were provided to the special committee as soon as these were completed, the final environmental scan reports are with our graphic designer and are just about ready for release to communities.

Missing and Murdered Indigenous Women and Girls

Knowledge Transitioning Data Collection: Atchimostakanna – Story Telling Instrument NAP

Background

The MMIWG National Action Plan (NAP) Data Strategy places harmful and oppressive research methodologies to the side, in favor of their four pillars of inclusion, accountability, interconnectedness and impact. With a good heart, the work undertaken by the Data Sub-working group (DSWG), was to transform the data landscape in Canada. The voice and experience of Indigenous women, girls and 2SLGBTQQIA and people inform the way forward, one that is nurturing and meaningful. NAP includes a national commitment to create Indigenous data methodologies based on a community-driven engagement, to reflect the realities of the people and communities involved.

The DSWG identified a Quantitative Indicator Framework organized into four thematic clusters – Culture, Health & Wellness, Human Security and Justice. Each cluster houses core indicators and population specific indicators; all which contribute to the ultimate indicator – safety of our loved ones! This background seeks to inform and identify the cultural entry points of this proposal. The indicators reflect the importance of strengths-based data gathered from a cultural lens in supporting Indigenous methods of collecting information.

Proposal Purpose

Western research methodologies have harmed and silenced the voice nor the true experience of Indigenous women, girls and 2SLGBTQQIA and people across Canada. The marginalized voice within the data space seeks to present a process in gathering rich and lived data. Indigenous Data Sovereignty seeks to mitigate these harms and we offer a data governance system and to bring a data ethical approach and to generation knowledge that honor inclusion and diversity. We seek to investigate and articulate a data tool to support National Action Plan, to improve the safety and well-being of the marginalized voice.

FNIGC Funded Projects

National Outcome Based Framework

Work completed and report submitted to FNIGC

Gender Based Violence Engagement

Work completed and report submitted to FNIGC

FNLED

Much of the data collection was impacted by COVID to the extent that a national report was not feasible thus it was left to each region to decide on whether there is enough data to produce a regional perspective report. Alberta achieved 14% data collection rate on the FNLED.

FNIGC/RHS-4

This knowledge gathering survey has been administered by First Nations Information Governance Centre (FNIGC), in coordination with 10 regional partners including Alberta FNIGC. Alberta FNIGC is an apolitical, non-partisan, incorporated entity that works with each nation through a collaborative approach involving Elders and key stakeholders. We uphold the Elders' teachings and Elders' Declaration - working together and serving ALL nations in our region equitably and fairly. The First Nations Regional Health Survey (FNRHS, or RHS) is the first, and only, national First Nations health survey which collects wide-ranging information about First Nations people living on reserve and in northern communities based on both western and Traditional understandings of health and well-being. The FNRHS or RHS knowledge gathering is usually scheduled to happen every five (5) years, pending favorable environmental conditions

AFNIGC recruited members consisting of health care providers and knowledge holders from the 3 treaty areas to review the survey instrument in July and submitted recommendations. A subsequent meeting was held just before Christmas as a second round of review of the survey instrument. FNIGC advises that there will likely be delays in implementing RHA-4 as a result of COVID. Strategies and plans are underway with each region for different approaches to data collection.

National Data Strategy

The First Nations Data Governance Strategy – FNIGC Pre implementation Work with Regions

Background

In 2016, Leadership from across the country (Assembly of First Nations Chiefs-in-Assembly) adopted [Resolution #57](#), calling on the Government of Canada to fund the development of a national First Nations data governance strategy, including the establishment of fully functional Regional Information Governance Centre's and data champion teams.

Subsequently, [Budget 2018](#) provided:

2.5 million over three years to support the First Nation Information Governance Centre's design a national governance strategy and coordination efforts to establish data governance Centre's.

Due to its strategic importance and First Nations' collective state of readiness, FNIGC and its regional partners chose to deliver the Strategy in two years instead of three.

First Nations engagement across regions included a national summit on data governance jointly hosted by FNIGC and the Alberta First Nations Information Governance Centre (AFNIGC) in February 2019.

On March 31, 2020, FNIGC delivered the comprehensive report, [A First Nations Data Governance Strategy](#).

The Strategy offers an unprecedented path for First Nations to achieve data sovereignty, a cornerstone for nation-rebuilding – which now calls the federal government to support its implementation.

The Strategy tabled two key priorities for action: First, to establish First Nations “Data Champions Teams”¹ at the regional and national levels as a foundational steppingstone to a multi-year phased implementation, and second, to secure bridge funding for the necessary pre-implementation work. ISC has since approved the bridge funding request, unofficially endorsing the Strategy and allowing FNIGC and its partners to undertake the work needed to establish eleven (11) dedicated data governance champion teams across the country – teams that will be equipped with the minimum capacities necessary to unlock key elements of the Strategy with a focus on the most pressing and practical needs at each level for the next three fiscal years.

¹ The term “Data Champion Teams” originates with AFN's Resolution #57/2016

The foresight and direction from the Assembly of Treaty chiefs has positioned Alberta FNIGC as a leader in this process, with an established Regional Information Governance Centre Alberta is prepared to move forward with the next steps of preparing an action plan as required to access funding.

Pre-Implementation Engagement Plan

Early in 2021 FNIGC began working with Regional Board Representatives to engage with regions to support preparing for the implementation of the First Nations Data Governance Strategy (the Strategy).

The Strategy identified two priorities:

- Securing bridge funding for pre-implementation work in 2020-21; and
- Establishing First Nations Data Champions teams at the regional and national levels.

There was consistent, encouraging positive feedback from ISC officials on the strategy which resulted in ISC releasing bridge funding to FNIGC in November 2020, approximately 2/3 of which was provisionally set aside to fund “pre-implementation” work with and within regions.

The bridge funding was requested to support two main streams of pre-implementation work:

- Stream 1: Develop a comprehensive business case with a detailed implementation plan to access funds should they be identified in Budget 2021. This includes scoping out and costing the core functions of fully functional information governance centers; and
- Stream 2: Support regional capacity needs for pre-implementation work with FNIGC, including communication activities within regions.

Alberta engaged all treaty areas through virtual engagement sessions, the dialogue session results supported the submission of a business case for the First Nations Data Governance Strategy.

At the beginning of 2022 Alberta FNIGC brought on an executive Co-Lead to assist with the pre-implementation planning work outlined in the National Data Strategy plan.

Regional Social Survey (RSS)

The First Nations Regional Social Survey (RSS) is a new survey focusing on the well-being of First Nations children and families living on reserve and in northern communities.

The RSS is being carried out by the First Nations Information Governance Centre (FNIGC) and in collaboration with its Regional Partners. Gathering First Nations driven data on social and economic indicators, the RSS hopes to better understand the socioeconomic context and experiences of First Nations children and families.

The information collected from the RSS will help First Nations communities, organizations, and all levels of government develop and support programs and policies aiming to improve the well-being of First Nations families living on reserve and in northern communities. The RSS is a survey by First Nations people for First Nations people.

The RSS represents a continuation of previous work done by FNIGC and its regional partners. Building from the foundational work of the First Nations Regional Health Survey (RHS), the First Nations Regional Early Childhood, Education and Employment Survey (FNREEES), and the First Nation Labor and Employment Development Survey (FNLED), the RSS will provide quality and credible information on the well-being of First Nations children and families on reserve and in northern communities.

Alberta FNIGC role

1. Management of the regional survey process within the region

2. Work in conjunction with FNIGC on RSS planning, development and deployment
3. Develop community engagement/communications strategy for selected First Nations communities
4. Develop and obtain Band Council Resolutions, letter of invitation or community agreement for selected First Nations communities
5. Data collector recruitment, training, management and coordination
6. Data collection coordination and supervision
7. Ensure adherence to methodology (sampling within communities)
8. Monitor data collection quotas (target sample)
9. Ensure protection of confidential information consistent with requirements outlined in FNIGCs Data Protection & Stewardship Protocol
10. Reporting of regional results (Regional report)

COVID Safe Restart

This project is in support of the all the projects associated with information governance and Alberta FNIGC infrastructure to accomplish its mandate and services to Alberta First Nations. It has supported us to continue our engagements through virtual means and supported the organization to build capacity for increased access to data, knowledge for Alberta First Nations. The Alberta First Nations Web site provides COVID information and data updates on a regular basis.

Canadian Partnership Against Cancer Funded Initiatives

Alberta First Nations Cancer Strategy & Practice Change Implementation Initiative (AFNCI)

The "Alberta First Nations Cancer Strategy & Practice Change Implementation Initiative" (AFNCI) is intended to build upon the experiences and outcomes of the Alberta First Nations Cancer Pathways project (A First Nations and Alberta Health Services CancerCare Alberta Partnership & Project from 2013-2016). Viewed as "a steppingstone toward the required changes for a culturally appropriate and safe cancer care pathway for Alberta First Nations", this initial work developed a culturally safe model or approach to address cancer burden and improve cancer outcomes in Alberta First Nations and resulted in a strong foundation and basis for a collective response in moving forward.

The AFNCI is the 2nd collaborative partnership and project between Alberta First Nations (FN) and Alberta Health Services (AHS) that is funded by the Canadian Partnership Against Cancer (CPAC). Supported through the Alberta First Nations Information Governance Centre (AFNIGC) and Alberta Health Services (AHS), the initiative will work toward improvements in 3 primary areas:

1. Development of a First Nations cancer strategy
2. implementation of practice change
3. Sustainability of initiative outcomes

These focus areas are aligned with the First Nations, Inuit and Métis Program - CPAC national strategy and work from the premise that all outcomes are responsive to First Nation community needs and priorities, as well as, AHS organizational standards for "patient-centered" and "high-quality" care. This acknowledges First Nations' philosophies of holistic health and wellbeing, and the role of community knowledge, values, beliefs and culture in decision-making about treatment and care. Further, safe quality care is provided when staff are grounded in principles of "cultural safety", such as appropriate training of care providers, and the right complement of programming, staffing capacity and equipment.

This initiative is focused on improving cancer experiences and outcomes for First Nations patients and families. Through initiative efforts, a more seamless pathway throughout the cancer journey will be created, based on clear directions that are First Nations specific and situated within jurisdictional context. Key priority areas of the AFNCI are:

1. To address priority areas along the cancer pathway that have been identified by Alberta FNs, with particular focus on practice changes that will lead to health system improvements in support of FN patients, families and communities
2. To improve health systems' capacity in addressing the cancer pathway needs of First Nations patients, families and communities, inclusive of prevention and screening, and situated in the development of a First Nations/Indigenous cancer strategy and sustainability plan.

We are continuing to work on project deliverables with virtual meetings and combined meetings whenever possible. AFNIGC Project Team is working in collaboration with Alberta Cancer Care and Canadian Indigenous Nurses Association (CINA) whom also have funded initiatives to help inform the Canadian Cancer Strategy and the Indigenous peoples' specific component of the National Strategy. AFNIGC has a collaborative partnership with CINA to provide Analysis and data Management support to their Project.

AFNIGC produced a report on the Cancer pathways Project and is available on the website for download. This report was submitted to the Canadian Partnership Against Cancer and Cancer Care (Control) in 2017 however was not available for public access.

Environmental Scan: Indigenous-Led Data & Research Governance in Cancer Control

The purpose of the project is to inform Priority 8 of the CPAC 2022- 2027 Business Plan (grounded in the experiences, worldviews and knowledge systems of Indigenous people). Main objectives of the project are to:

- Map current state Indigenous-led data and research governance in cancer control
- Identify promising practices in Indigenous-led cancer control data and research
- Articulate (short, medium, long-term) opportunities for Partnership support of Indigenous-governed research and data systems

The primary outcome of the project is an “integration of key findings for People-specific Indigenous governed research & data systems, including promising practices in cancer control data and research” Project report has been complete and submitted to CPAC for review. Once the project outputs have been completed a complete report will be shared with Stakeholders across the country.

Alberta Health Services Projects

Alberta Innovates project: Knowledge Mobilization to Enhance HPV Vaccine Uptake in Alberta First Nations Youth is a follow-up project to the EHVINA Project.

Due to circumstances beyond the control of the EHVINA Team, including changes within the team, competing priorities within First Nations partner communities, and the onset of the COVID 19 pandemic, only objectives one and two were successfully completed. In alignment with the EHVINA project goals and objective 3) *Map identified barriers and supports using evidence-based, theory-informed and context sensitive knowledge translation intervention strategies and evaluate implementation*, this proposed project intends to build on what was achieved to create a Knowledge Mobilization Strategy that will meet the HPV vaccine and HPV health education and resource needs of First Nations youth, families and communities.

This research Project proposes to increase the rate of HPV vaccination among Albert First Nations youth living on-reserve through building on the work of the EHVINA project. Objectives of the EHVINA project included:

1. To *establish baseline HPV vaccination rates;*
2. To *identify and validate the known barriers and supports to HPV vaccination; and,*
3. To *map identified barriers and supports onto a theory-informed, context- and culturally- secure knowledge translation (KT) intervention.*

We have begun the work and have a dedicated Research assistant beginning October 3rd 2022

CPI/ACPLF/ First Nations Practices Project: Cancer Prevention & Screening

Project Background

The Alberta First Nations Cancer Prevention and Screening Practices (FNCPS) project is a collaborative partnership initiative between Alberta First Nations communities and Alberta Health Services. This initiative has moved into its 2nd year of Phase II and is supported through the Alberta First Nations Information Governance Centre (AFNIGC) and the Alberta Cancer Prevention Legacy Fund (ACPLF). Current funding supports three First Nation lead communities, one per Treaty region:

- Sunchild First Nation, Treaty 6
- Eden Valley Nakoda Nation, Treaty 7
- Bigstone Cree Nation, Treaty 8

Phase II of this partnership works to provide further evidence of the approach as effective to supporting cancer prevention and screening programming with/by First Nations communities through building on the outcomes and learnings from Phase I.

- Lessons learned thus far through the success of work in Phase I are outlined below:
- Cancer in First Nations communities is impacting all community members
- Resourcing and support for communities must be negotiated throughout the project to ensure success
- Best and promising practices aligned with community practices and protocols establish and maintain ongoing trust
- Community practices and protocols sustain community commitment and buy-in while supporting community action
- Elder/Knowledge Holder support is key to grounding strategies and action in culturally relevant solutions
- Current health education and resources are not suitable and/or effective for First Nations, including language, information, graphics, methods of delivery, service providers

Project Activities

COVID delayed the launching of the 2nd phase because communities were focusing on dealing with the pandemic and due to restrictions related to COVID. Most of the ACPLF staff were deployed to work on COVID contact tracing have slowly returning to their positions. Travel restrictions continued for AHS partners. The partnered communities recruited their staff and received training through virtual methods begin the orientation phases of the project.

The Three (3) First Nation lead communities have been coordinating and managing the activities with both the CPPLs & the CPPs.

New team members of some of these communities such as Bigstone and Eden Valley have been introduced to the projects and their training is still on going on early stages.

CIHR Funded Projects in Partnership with Universities

Emergency Department Quality of Care Project

COVID delayed our ability to conduct any in community engagement sessions however we were able to continue with our project work virtually.

Several reports have been generated from this work and are included in the Appendix's

First Nations Emergency Care in Alberta: Summary of a Descriptive Statistics Study provides an overview of what we learned and why it matters: McLane P, Barnabe C, Holroyd B, Colquhoun A, Bill L, Fitzpatrick KM, Rittenbach K, Healy C, Healy B, Rosychuk R. First Nations Emergency Care in Alberta: Descriptive Results of a Retrospective Cohort Study. BMC Health Serv Res 2021;21(423). <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-021-06415-2>

First Nations Status and Emergency Department Triage Scores in Alberta - Briefing Patrick McLane, Cheryl Barnabe, Leslee Mackey, Lea Bill, Katherine Rittenbach, Brian R. Holroyd, Anne Bird, Bonnie Healy, Kris Janvier, Eunice Louis, Rhonda J. Rosychuk

Impacts of Racism on First Nations Patients Emergency Care: Results of a Thematic Analysis of Healthcare Provider Interviews in Alberta, Canada Patrick McLane, Leslee Mackey, Brian R. Holroyd, Kayla Fitzpatrick, Chyloe Healy, Katherine Rittenbach, Tessa Big Plume, Lea Bill, Anne Bird, Bonnie Healy, Kristopher Janvier, Eunice Louis, Cheryl Barnabe <https://doi.org/10.1186/s12913-022-08129-5>

First Nations Emergency Care Visit Distribution within Alberta Facilities Emergency departments document shows the numbers and percentages of First Nations visits at individual emergency care sites in each zone. This information may be helpful to First Nations organizations in advocacy and planning health services delivery.

Emergency Services Transitions of Care

Engagements were completed and final results are being prepared for manuscript and publication.

Opioid Project (Realist and Meta Ethnographic Review)

Final report distributed to nations and can be found on the AFNIGC web site

I-HeLTI Life Trajectories Restoring Healthy Family Systems Project

AFNIGC together with University of Alberta partners and from across research disciplines and Indigenous communities (Maskwacis, Wood Buffalo/Fort Chipewyan, submitted a grant application to CIHR for a diversity of Indigenous populations through community-based participatory research (CBPR). Key components of the Project are:

- The I-HeLTI project brings together partners from across research disciplines and Indigenous communities to collaboratively support optimal health during preconception, pregnancy, and postpartum for a diversity of Indigenous populations through community-based participatory research (CBPR).
- The strategies utilized will be community-led and community-specific to promote healthy lives for Indigenous families and children.
- Incorporation of the strength and resilience embedded in Indigenous knowledge, wise practices, and cultural teachings will be applied to appropriately design and effectively evaluate strategies that help Indigenous communities move in the direction of rebuilding family and community systems that have been systematically dismantled.
- I-HeLTI is designed to strategically inform the development of a successful national Indigenous-driven I-HeLTI Developmental Origins of Health and Disease (DOHaD) cohort study, with positive impacts on the health of pregnant Indigenous mothers, newborns, their families, and communities.

Healthy Cities Letter of Intent submission (LOI)

AFNIGC was awarded a 25k Planning Grant to develop the submission due in 2022. Grant application focused on urban Indigenous peoples to qualify for IIPH funding. An engagement session was held with knowledge holders to assist with the planning and preparation of subbing for the larger grant.

CONnecting and Coordinating an Enhanced Network for Transitions in Care (CONCENTRIC): A New Model for Spinal Cord Injury Care in Alberta

Purpose

To adopt a community-based approach to design, implement and evaluate a transition in care (TIC) model for persons with spinal cord injury (SCI) that is integrated in a 'provincial hub and spokes system' to improve health outcomes and experiences.

AFNIGC to support the Engagement pieces Service Agreement with Research Team pending

Canadian Medical Association COVID Infection Prevention Grant

20K Recently advised the application was approved. This is a small project to create a Cree language video on COVID.

Video presentation of final product at AGM September 26-28, 2022

New Proposals, Project Submissions and Collaboration Projects

Invasive group A streptococcal infections in First Nations, 2018-2021: a 4-year review Collaboration Project with Gregory J. Tyrrell January 17, 2022

Background

Bacteria and disease: The Gram-positive bacteria, *Streptococcus pyogenes* or group A streptococcus, can cause a range of bacterial infections from self-limiting streptococcal throat infections (strep throat) to much more severe infections such as necrotizing fasciitis (flesh eating disease) and streptococcal toxic shock. In addition to these diseases, infection with these bacteria can also result in sequelae such as glomerulonephritis and rheumatic fever (which can lead to rheumatic heart disease and damage usually targeting the mitral heart valve).

Indigenous groups affected: Group A streptococcal infections have been shown to be very prevalent in indigenous communities around the world. For example, rates of group A streptococcal skin disease and invasive infections as well rheumatic fever are high in the Australian aboriginal population, the New Zealand Maori and Pacific Islander populations (Carapetis et al., 2016, Gurney et al, 2016). In addition to these indigenous groups, we have also recently documented high rates of invasive group A streptococcal infections in the First Nations population of Alberta (Tyrrell et al. 2021) suggesting possible commonalities globally among indigenous communities with respect to group A streptococcal disease. Focusing on Alberta, our previous study showed rates of invasive group A streptococcal disease in the First Nations population was 6X higher than the non-First Nations population. Interestingly, the predominate group A streptococcal types (*emm* types of which there are >250) were different between the First Nations population and the non-First Nations population suggesting differences in either exposure to group A streptococcal infections, or how it is transmitted or differences in the populations affected.

Rheumatic fever: Rates of rheumatic fever are exceptionally high in New Zealand and Australia where this disease primarily affects indigenous peoples (Aborigines, Maori and Pacific

Islanders). Recently, a cluster of rheumatic fever cases occurred spring 2021 in a First Nations community in Alberta suggesting rheumatic fever is also occurring in indigenous populations in Alberta as well. Evidence strongly suggests that rheumatic fever arises after a prior group A streptococcal throat infection. It is believed that antibodies raised against the group A streptococcus during a strep throat infection cross react with self-antigens in the heart leading to an inflammatory response and in some cases damage to heart valves. This typically occurs 1 to 5 weeks after a strep throat infection. In addition, recent work from New Zealand also suggests that group A streptococcal skin infections also give rise to rheumatic fever (Thomas et al., 2021). Rates of rheumatic fever are high in these native populations as are rates of group A streptococcal skin infections suggesting prior skin infections may be responsible for high rates of rheumatic fever. Interestingly, we also noted high rates of group A streptococcal skin infections in Alberta First Nations population as well. While the linkage between group A streptococcal skin infections and rheumatic fever is not entirely clear, the high rates of skin disease and reports of rheumatic fever in First Nations in Alberta suggest this is worth further investigation.

Objectives

1. To provide an accurate incidence rate of invasive group A streptococcal disease in the Alberta First Nations population from 2018 to 2021.
2. To determine an estimate of group A streptococcal skin infections in First Nations children in Alberta
3. To determine the rate of rheumatic fever in First Nations children in Alberta.
4. To characterize the infecting group A streptococcal isolates in First Nations children through the use of whole genome sequencing of the bacterial isolates.

Epidemiological Study of Invasive *Streptococcus pneumoniae* in the First Nations population of Alberta: 2010 - 2021. Collaboration Project with Gregory J. Tyrrell: January 17, 2022

Background

Bacteria and serotype: *Streptococcus pneumoniae* are a Gram-positive bacterium that can cause both respiratory and invasive disease. The main virulence factor of *S. pneumoniae* is a polysaccharide capsule coating the bacteria. There are 100 different polysaccharide types, also called serotypes. Serotypes are not equal in prevalence with some serotypes being much more common than others are. A very effective vaccine against *S. pneumoniae* termed PCV13 was introduced into Alberta in 2010 and is still currently used. This vaccine is composed 13 serotypes that were more common than other serotypes prior to the implementation of the pneumococcal conjugate vaccine program for children. Prior to this, an earlier vaccine, PCV7 (containing 7 serotypes: 4, 6B, 9V, 14, 18C, 19F, 23F), was implemented in Alberta in 2000. PCV13 (PCV7 serotypes plus 1, 5, 7F, 3, 6A, 19A) has replaced PCV7 and is the vaccine currently administered to children under 2 years of age.

Pneumococcal disease in North America Indigenous populations: While there is much published data regarding invasive pneumococcal disease (IPD) in the general population in Canada, there is little published clinical and laboratory data concerning IPD in the indigenous populations in North America. The indigenous data that is available has focused on specific groups of First Nations people primarily in the United States (US). In these past studies, US investigators have shown that prior to the introduction of the PCV7 vaccine, the rates of IPD among the First Nations population in the US were from 6 to 8-fold higher than that seen in the general population (Lacapa et al. 2008, Singleton et al. 2009). The introduction of the PCV7 vaccine in

2000 into the US and its subsequent use in the Native American population greatly reduced the incidence of invasive disease, however, not to levels present in the general population. For example, previous investigators have found the incidence of IPD in children less than 5 years in the White Mountain Apache population was 473/100,000 pre-7-valent conjugate vaccine introduction (Lacapa *et al.* 2008). This dropped to 120/100,000 post 7-valent conjugate vaccine use. While this drop is significant, it is not to levels present in the general population. In the general US population for children less than 5 years, rates were 96.7/100,000 pre PCV7 use dropping to 23.9/100,000 post PCV7 vaccine introduction (Singleton *et al.* 2009). A study in another Native American population, the Navajo, has shown that this drop in invasive pneumococcal disease rates appears to be driven by the elimination of the PCV7 vaccine serotypes and concomitant rise in non PCV7 serotypes (Weatherholtz *et al.* 2010). This would suggest that non-vaccine serotypes are important causes of invasive pneumococcal disease in Native Americans and perhaps native populations elsewhere in North America. Further work in the Navajo found the major risk factors associated with IPD included chronic renal failure, congestive heart failure, alcoholism and increased body mass index (Watt *et al.* 2007).

Objectives:

1. To determine the incidence of IPD in the First Nations population of Alberta broken down by age, geography and vaccination status for 2010/2021 and characterize the clinical presentation of IPD in this population as captured by Alberta's Notifiable Disease Report form.
2. To determine the pneumococcal serotype distribution among the First Nations population in Alberta broken down by age and clinical presentation over this same period (2010-2021) and further characterize invasive pneumococcal isolates that predominate in the Alberta First Nations population using whole genome sequencing.

Collaboration Project Influence of COVID-19 on chronic disease care among First Nations people in Alberta

Dr Dean Eurich, School of Public Health U of A, Dr. Lynden Crowshoe, Faculty of Family Medicine U of C, Bonnie Healy BFC Treaty 7, Senthilselvan Ambikaipakan School of Public Health U of A; Samanani Salim, Okaki Health Intelligence

Lay Abstract

COVID-19 affects patients with pre-existing chronic diseases, like diabetes, more than others. Because we have been focused on caring for and managing COVID-19, other critical care that patients need for chronic diseases may not be happening (e.g., regular check-ups and referrals to specialists). Although COVID-19 is expected to affect all Canadians with chronic diseases, we think the impact on First Nations (FN) people will be much higher due to a lack of health, social, and other supports. Yet, to date, the potential impact is unknown. In partnership with FN health leaders, knowledge users and using appropriate methods for FN people, we will examine how the pandemic is affecting chronic disease care among FN people in Alberta. We will use healthcare usage data, person-reported measures, and storytelling interviews with FN people. We will examine changes in disease diagnosis and healthcare utilization before and after COVID-19. Driven by FN health leaders and knowledge holders, we will also collect person-reported measures from FN people in Alberta with chronic diseases to understand FN views and how COVID-19 has affected their care during the pandemic. Finally, individual stories will further help us understand how COVID-19 has affected chronic disease care among FN peoples. Our novel study with FN people is urgent. This work will allow front-line health directors and leaders

within FN communities to understand how COVID-19 is influencing their communities and people and will assist in service planning post-pandemic. Our existing partnerships with the FN communities will enable the co-creation of materials, use of the data to inform the current and future public health response, and deepen the understanding of how care was affected during the pandemic. We will build awareness and share results together.

Objectives

Using a Two-Eyed Seeing approach, this mixed-methods study aims to examine how the COVID-19 pandemic influences chronic disease management (CDM) among First Nation (FN) people in Alberta using administrative databases, person-reported measures, and narrative-based qualitative interviews. Background: COVID-19 negatively affects patients with chronic diseases. The shift of health resources to focus on COVID-19 may affect CDM. Moreover, this may disproportionately affect FN people. Collectively, health, social, systemic inequities, isolation and restricted travel due to limited resources or COVID-19 have created a ‘perfect storm’ for potentially immense impacts on FN communities. Although COVID-19 affects CDM for all Canadians, we hypothesize the impact on FN people will be substantial. However, to date, the impact is unknown. Methods: Our mixed-methods design includes: a) Administrative Health Data: Using Alberta Health data to identify people with First Nation status (~200,000 people), we will use segmented interrupted time series (ITS), regression model, to examine changes in healthcare before and after COVID-19 (March 2018- April 2022) compared to matched non-FN controls. Using ARIMA models, we will then forecast weekly future healthcare utilization (2022-24) in patients with chronic diseases. b) Person-reported measures: This online survey will be co-developed with FN leaders (e.g., community health directors) for FN people in Alberta (on- or off-reserve) with 1 or more self-identified chronic diseases. Using the Dillman method to maximize response, we will collect sociodemographic information and CDM experiences during COVID-19. c) Qualitative Data: With FN leaders, we will invite FN people to participate in individual interviews. We will use narrative-based storytelling with thematic analysis to gain insight into how COVID-19 has influenced CDM among FN peoples. Significance: Our novel study among FN people is urgent. Our mixed-methods design to gain FN perspectives around CDM during COVID-19 will provide a comprehensive understanding of this important issue. Most importantly, this work will allow front-line FN health directors to understand how COVID-19 is influencing their communities and assist in CDM planning post-pandemic. This study may inform future population-based health services research, modelling the study of both healthcare and personal experiences.

Healthy Cities Team Grant Submission

In review process with CIHR anticipate results in November of 2022

Abstract

Supporting Healthy Lifestyle Choices to Promote Mental Health & Wellbeing in Indigenous Youth “Aging-Out-of-Care” to Urban Settings An intent of this research is to examine and explicate implementation science and implementation testing from within Indigenous contexts. The study plans to identify Indigenous principles inherent and foundational to implementation science, such as integrated KTE or knowledge mobilization, but it will also further develop the scholarly dialogue around ‘implementation testing’ within vulnerable populations who experience multiple and complex inequities to health. In Canada, 52.2% of children in foster care are Indigenous, but account for only 7.7% of the child population according to Census 2016. This means 14,970 out of 28,665 foster children ‘in-care’ homes under the age of 15 are Indigenous. The aim of this research is to support Indigenous youth, ages 12-17, as they ‘age-out-of-care’ in making healthy lifestyle choices that can impact their mental health and overall wellbeing while preventing chronic illness later in life. three areas of focus include: Implementation research based on implementation science and Indigenous holistic concepts of health to produce evidence of scalable and sustainable interventions that support the healthy lifestyle choices of Indigenous youth as they ‘age-out-of-care’ to an urban setting; Strengthen and build the capacity of health practitioners and trainees in implementation science and enhancement of services and resources to

support the mental health and wellbeing of Indigenous youth; and, Mobilize evidence-based outcomes to support Canadian cities in planning and implementing a model and framework unique to urban contexts and needs of the Indigenous youth, who will ‘age-out-of-care’ to an urban setting.

Significance of the Research

The significance of this research is underscored by the continuous growth of urban Indigenous communities, with more than half of all First Nations, Inuit and Métis (FNIM) peoples residing in an urban setting¹. The numbers of youth in care are also predominantly Indigenous across most jurisdictions in Canada^{2,3}. In British Columbia (BC) of the 5,259 youth in care 3,548 were Indigenous. Of 1000 youth in BC 2 would be non-Indigenous and in care while 37 would be Indigenous and in care³. In Alberta (AB), Indigenous children represent approximately 10% of the child population (ages 0-17) while accounting for 69% of children and youth receiving services in care and 62% receiving of the children receiving Child Intervention services in March 2020. According to Greenwood et al⁴, Indigenous peoples experiencing health disparities around the world have consistently identified colonialism as “perhaps the most important determinant of their (ill) health” (p. xxii). In Canada, colonial policies enforcing the anthropogenic nuclear family system, assimilation, genocide, and Indigenous child removal have had devastating impacts on Indigenous kinship and governance systems⁵. The recognition of this colonial violence has resulted in federal government settlement agreements for Indigenous child removal systems that span the entire history of Canada from Indian Residential Schools (1872-1997), the Sixties Scoop (1951-1991), and current child welfare, often referred to as the millennial scoop (1991-2022)⁶. Still, Indigenous communities face long term impacts of colonialism reflected in low rates of educational attainment, high rates of suicide among children and youth, youth addictions and behaviors to cope with trauma and an overall loss of healthy Indigenous identity.² However, resurgence in work rooted in land-based learning and sharing of traditional knowledge provide cultural continuity and act as a protective factor in preventing suicide and supporting wellbeing among IY⁷. Emphasizing resurgence and cultural continuity, this research will build on a collective understanding that prior to colonization Indigenous nations had complete and complex systems of governance whereby the physical and spiritual world were interconnected⁸.

Listen, Hear, Our Voice Project

This project is led by Elder Reg and Rose Crowshoe. Grant Funding received from Canada Library and Archives department.

The Objectives of the project are:

- A. ***Digitize culture and language material for preservation***
 1.
 - Prepare recordings for digitization
 - Describe and arrange recordings
 - Contract a third party to digitize recordings
 - 2.
- B. ***Build capacity***
 3.
 - Create training materials to build digitization skills
 - Train staff/community on digitization
 - Purchase audiovisual digitization equipment
 - Purchase software to digitize audiovisual recordings

The project was supposed to be completed in September 2021, however, there has been some delays, due to COVID pandemic. Project has been extended for another year.

Additional Activities & Outcomes Related to the Core Strategic Objectives

Committee work

Alberta COVID Serology Testing Working Group

National Advisory Committee Canadian Cancer Strategy

FNIGC Board of Directors Alberta Representative

CINA Board of Directors (President)

The Health Quality Council of Alberta (HQCA) on **Informing Mental Healthcare for Children and Youth in Alberta**

United Way

Anti-Racism

REACH PROJECT: Point of Care (POC) Testing for HIV Collaboration work

Working with research & implementation team to ensure OCAP[®] and Data sharing agreements are met with participating First Nations.

Health Care Excellence Canada (HEC) Advisory Group – Anti-racism design collaborative

Appendices

First Nations Emergency Care in Alberta: Summary of a Descriptive Statistics Study

McLane P, Barnabe C, Holroyd B, Colquhoun A, Bill L, Fitzpatrick KM, Rittenbach K, Healy C, Healy B, Rosychuk R. First Nations Emergency Care in Alberta: Descriptive Results of a Retrospective Cohort Study. BMC Health Serv Res 2021;21(423). <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-021-06415-2>

Emergency Departments (EDs) are an important health services resource for First Nations people. This study examined all Alberta ED visits from April 1, 2012 to March 31, 2017 by linking administrative data and First Nations identifiers. The dataset included 11,686,288 ED visits (including urgent and ambulatory visits), by 3,024,491 unique persons. Five First Nation Elder knowledge holders and five First Nations Health Directors helped interpret the results. (1) The study received UofA Research Ethics Board approval (Pro 00082440).

What We Learned

First Nations people use the ED at nearly 3 times the rate that non-First Nations people do.

In 2017, First Nations people made up 4% of the provincial population and 9.4% of provincial emergency visits. (1 p.3)

More First Nations visits end in leaving before completing treatment, compared to non-First Nations visits. (6.7% v. 3.6%). (1 p.7)

First Nations visits are more commonly assigned a lower acuity (less urgent) triage score (59% of visits have triage levels of less urgent or non-urgent, compared to 50.4% non-First Nations visits). (1 p.5)

Why it Matters

Higher ED visit rates may be due to lack of access to primary care, as research suggests a link between access to high quality primary care and emergency care use. (2-6) Studies also suggest that First Nations access to primary care is limited. (7-11) Further research is needed.

First Nations partners felt that leaving without completing treatment may be due to experiences of discrimination (see also 12,13), needing to leave when transport is available, and leaving care to fulfill family responsibilities.

Less urgent triage scores could be related to use of the ED for primary care concerns. However, Zook and colleagues (14) reported under-triage of American Indian patients based on race, and further research on First Nations triage is needed.

What We Learned

First Nations visits are more frequently in the evening hours than non-First Nations visits (43.6% vs. 38.1%) and arrive more frequently by ambulance. (15.3% vs. 10%) (1 p.5)

First Nations women use the ED proportionally more than non-First Nations women and First Nations men. (1 p.4)

Conclusions: First Nations peoples' use of the emergency department may be related to lack of access to appropriate primary care. Further research is needed on the impact of First Nations identity on emergency care processes and outcomes, especially for First Nations women.

*The analyses, conclusions, opinions and statements expressed herein do not necessarily reflect the views of the Alberta First Nations Information Governance Centre (AFNIGC) and are solely those of the author(s).

Why it Matters

First Nations team members felt that presentations to emergency care in evenings and arrival by ambulance may be due to lack of access to transportation. A 2005 study found that use of emergency care may be associated with lack of access to non-urgent medical transportation. (15)

A 2021 Inquiry found that Indigenous women use the ED more than Indigenous men in British Columbia and Indigenous women face a health care gap in obstetrical care. (6) Study partners felt that First Nations men may present to the ED less due to greater reluctance to seek care.



First Nations Status and Emergency Department Triage Scores in Alberta - Briefing

Patrick McLane, Cheryl Barnabe, Leslee Mackey, Lea Bill, Katherine Rittenbach, Brian R. Holroyd, Anne Bird, Bonnie Healy, Kris Janvier, Eunice Louis, Rhonda J. Rosychuk

Emergency departments are an important health services resource for First Nations patients. The project "Understanding and Defining Quality of Care in the Emergency Department with First Nations Members in Alberta" was formed through partnership between First Nations partners, the Alberta First Nations Information Governance Centre, the Universities of Alberta and Calgary, and Alberta Health Services. This study was funded by the Canadian Institutes for Health Research and approved by the University of Alberta Health Research Ethics Board (Pro00082440). This document summarizes findings from a study published in the *Canadian Medical Association Journal* in January 2022.

What we Learned	Why it Matters
First Nations members were less likely to be assessed as having high urgency health needs when presenting to emergency departments, compared to non-First Nations patients.	Assessment determines how fast a patient is seen by a physician, and is important for health outcomes.
Even after adjusting for patient age, hospital presented to, and other factors, First Nations members were still less likely to be assessed as having high urgency health needs.	This finding shows that First Nations status is related to assessment outcomes, separately from other factors.
For five disease categories (infection; trauma and injury; mental health; substance use; breast, obstetrics and gynecology) and three of five diagnoses examined (long bone fractures, acute respiratory infection, and anxiety disorder) First Nations patients are assessed as having less urgent health care needs.	This finding shows that First Nations people are assessed as having less urgent health needs even when they receive the same eventual diagnoses as non-First Nations patients. This suggests that differences are not simply due to First Nations members using emergency departments for different reasons than non-First Nations people.
Our findings match other studies that show minority group members are less likely to be assessed as having high urgency health needs in emergency departments. Systemic racism may be one cause. Differences in culture and communication between nurses and patients may be a second cause. Lack of access to non-emergency care may be a third cause.	Findings suggest a need for work to ensure culturally safe care in emergency departments and greater access to appropriate and high quality health services for First Nations members in Alberta.

For more information please contact:

Lea Bill, Executive Director, Alberta First Nations Information Governance Centre, lea.bill@afnigc.ca

Patrick McLane, Adjunct Assistant Professor, Emergency Medicine, University of Alberta, mclane@ualberta.ca
Assistant Scientific Director, Emergency Strategic Clinical Network



Impacts of Racism on First Nations Patients Emergency Care: Results of a Thematic Analysis of Healthcare Provider Interviews in Alberta, Canada

Patrick McLane, Leslee Mackey, Brian R. Holroyd, Kayla Fitzpatrick, Chyloe Healy, Katherine Rittenbach, Tessa Big Plume, Lea Bill, Anne Bird, Bonnie Healy, Kristopher Janvier, Eunice Louis, Cheryl Barnabe
<https://doi.org/10.1186/s12913-022-08129-5>

What is this research about?

This study aimed to document emergency care providers' perspectives on care of First Nations patients within Emergency Departments (ED).

Our team conducted interviews with 16 ED nurses and physicians, who spoke to us for about 90 minutes each. This is a rich data set for qualitative analysis, and allows new understandings of how care is delivered for First Nations patients. First Nations research team members provided Indigenous perspectives to the analysis and validated study findings. Results were also validated with Elders in February, 2021.

This document summarizes the research findings, the next two pages offer recommendations for providers, emergency departments and health systems.

What did we find?

- All providers noted that racism and stereotyping occur in EDs. ED providers reported that First Nations patients are exposed to disrespect through tone and body language, experience overt racism, and may be neglected or not taken seriously.
- Providers described cases of patients who received less thorough investigations, were not listened to, were incorrectly assumed to be substance using, had diagnoses missed, and were made to wait long periods.
- Some providers were able to describe determinants of First Nations health by naming colonialism, or giving dates residential schools were open, but did not necessarily see these facts as relevant to their practice.
- Providers sometimes saw the impacts of colonialism (like distrust of healthcare) as an alibi for poor care of First Nations patients within EDs.
- Providers also described strategies they took as individuals to address First Nations patients' barriers to care.

Why does this matter?

- Results show that knowledge of residential schools, intergenerational trauma, and colonialism can coexist with stereotyping and that simplistic, negative, portrayals of First Nations can become defenses for poor healthcare.
- Leaders and educators can use these results to develop anti-racist and anti-colonial education specific to EDs.
- Education for providers should be generated and delivered in partnership with First Nations leaders and knowledge holders.
- Education should demonstrate how First Nations patients are continuing to be disproportionately harmed through poor or lacking care in EDs and equip providers with concrete ways to provide better care in EDs.

Is provider education enough?

- No. While providers described efforts they make as individuals to address the discrimination and barriers to care that First Nations patients face, such individual efforts to address systems issues can easily burn out providers and result in patients receiving very inconsistent care from one provider to another.
- Departments and systems should develop standardized practices to ensure equitable care for all patients.
- Providers must be supported with tools and resources, including time, to provide high quality care to all patients.
- Beyond the ED, systems responses to barriers to First Nations healthcare are required, including funding for on-reserve primary care and First Nations-leadership within health services.
- First Nations governments should have a leading role in improving emergency care systems.

First Nations Emergency Care Visit Distribution within Alberta Facilities

Emergency departments are an important health services resource for First Nations patients. The project “Understanding and Defining Quality of Care in the Emergency Department with First Nations Members in Alberta” was formed through partnership between the Alberta First Nations Information Governance Centre, the Universities of Alberta and Calgary, Alberta Health Services, and First Nations partners. This study was funded by the Canadian Institutes for Health Research and approved by the U of A Ethics Board (Pro00082440). We examined all emergency care visits in Alberta from April 1, 2012 to March 31, 2017. The following tables show the numbers and percentages of First Nations visits at individual emergency care sites in each zone. This information may be helpful to First Nations organizations in advocacy and planning health services delivery.

EDMONTON ZONE

Facility Name	# First Nations ED Visits 2012-2017	% of ED visits in facility by First Nations Patients
Royal Alexandra Hospital	52690	14%
University Of Alberta Hospital	26866	8%
Misericordia Community Hospital	22231	9%
Northeast Community Health Centre	18839	7%
Stollery Children's Hospital	17543	8%
Westview Health Centre-Stony Plain	13105	9%
Grey Nuns Community Hospital	12664	4%
Sturgeon Community Hospital	11155	4%
Devon General Hospital	6335	8%
East Edmonton Health Centre	3679	9%
Leduc Community Hospital	3314	3%
Fort Saskatchewan Community Hospital	2644	3%
Strathcona Community Hospital	2498	2%

CALGARY ZONE

Facility Name	# First Nations ED Visits 2012-2017	% of ED visits in facility by First Nations Patients
Strathmore District Health Services	19162	14%
Peter Lougheed Centre	18397	5%
Sheldon M. Chumir Health Centre	15926	6%
Rockyview General Hospital	15828	4%
Foothills Medical Centre	15286	4%
Canmore General Hospital	12970	17%
Alberta Children's Hospital	11836	3%
Cochrane Community Health Centre	7158	6%
South Health Campus	6537	2%
Oilfields General Hospital	5475	9%
South Calgary Health Centre	4608	2%
Okotoks Health and Wellness Centre	1958	1%
Airdrie Community Health Centre	1848	1%
High River General Hospital	1765	2%
Didsbury District Health Services	1137	2%

Facilities with less than 1000 visits by First Nations members are excluded to protect patient confidentiality.

The Alberta First Nations Information Governance Centre



Head Office

PO Box 410
TsuuT'ina, AB
T3T-0E1

Calgary Sub-Office:

Suite 101, 535 8 Avenue S.E.
Calgary, AB T2G 5S9
(403) 539-5775

Edmonton-Sub-Office

18112 102 Ave NW,