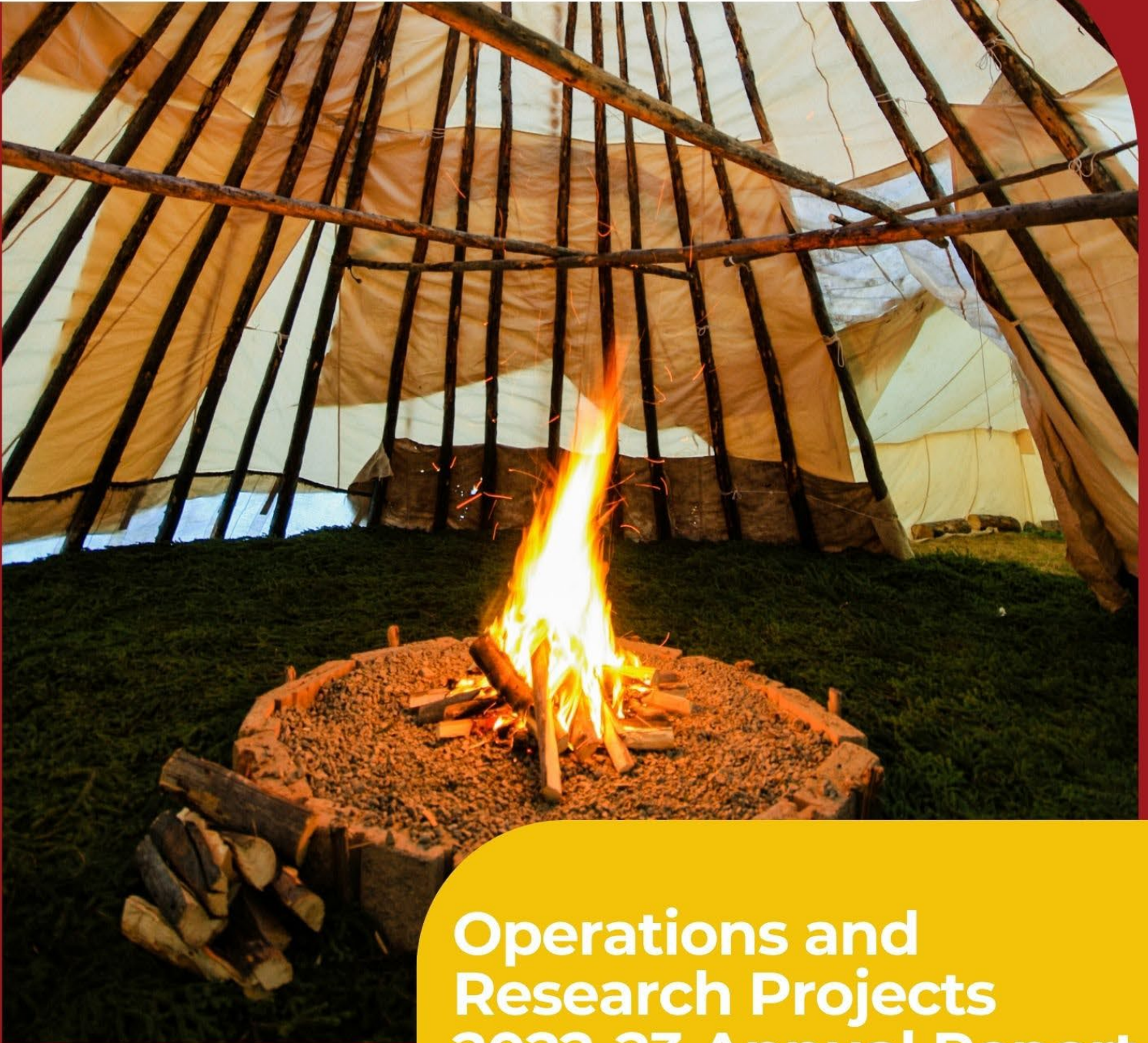




The Alberta First Nations Information Governance Centre



Operations and Research Projects 2022-23 Annual Report

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Message From Alberta FNIGC Board and Director of Operations

Greetings Alberta First Nations AGM Delegates and Members

The 2023-2024 fiscal period marked the return to a new normal after the COVID – 19 global pandemic which posed a series of unique and ongoing challenges for Alberta First Nations and around the planet.

Today, we continue 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 several nations.

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 are handled and applied, holding organizations, funders, and researchers accountable and ensuring adherence to OCAP® principles.

We are proud to report that the Alberta FNIGC continues to be known for its leadership in best practices and is the standard for other regions to model after. 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 2023 and highlights the scope and diversity of partnerships and outcomes.

Board Chair Bernice Martial and

**Lea Bill RN BScN, Executive Director
Traditional Practitioner**

Alberta First Nations Information Governance Center



Purpose

To report on operations activities and current research projects and activities.

Background

Mandate:

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

Vision:

The Alberta First Nations Information Governance Centre (Alberta FNIGC) 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 (Alberta FNIGC) 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, 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' cultures 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

AFNIGC has a core complement of staff:

- Executive Director – Lea Bill
- Financial Management – Jennifer Black Kettle
- Data management coordinator/Senior Data analyst – Anita Konczi
- Executive Assistant – Gina Rodriguez
- Communications Coordinator – Tammy Plunkett

RHS National Data Strategy

- Data Champion Executive Co-Lead - Shannon Houle
- Administrative Assistant - Doris Roy

Human Resources Support and Management

Real HR – Eleanore Culver

IT Management

Andersen Group of Companies - Kent Viccars

Fixed Term Contractors

Projects are staffed on a fixed-term contract basis for the duration of a project. Current staffing includes Barb Fraser, Angeline Letendre, Elizabeth Kyplain, Lyla Witschi, and Chelsea Blythe.

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.

FNIGC Funded Projects

Regional Health Survey and Regional Social Survey

Purpose

This knowledge-gathering survey has been administered by the First Nations Information Governance Centre (FNIGC). The Regional Health Survey (RHS) and the Regional Social Survey (RSS) are national First Nations health surveys that collect 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. These are research tools to assist First Nations in self-determining and sovereign initiatives.

Background

Even though the Alberta FNIGC was asked to only request RHS4 participation for twenty-eight (28) First Nations in our region, we opted to invite all forty-seven (47) First Nations to the opportunity. This supports and is more in line with the original goal of the inception of the RHS: to be a longitudinal study; and FNIGC's goal to eventually have 100% First Nations participation nationally. Therefore, we have been engaging all forty-seven (47) and offered all the opportunity to participate continuously in both surveys through a Band Council Resolution (BCR). However, once we acquire the BCRs, we still need to ensure all newly elected leaders are fully informed and aware of surveys being conducted in the community. Therefore, we are also requesting that all First Nations add our organization to the list of First Nation departments/businesses, that orientate newly elected councils. This ensures Alberta FNIGC is maintaining and nurturing strong communication relationships with our member treaty First Nations and ensuring our organizational mandate, vision, and mission are being adhered to.

Participating First Nations

There are 23 participating First Nations. Ten from Treaty 6, four from Treaty 7, and nine from Treaty 8. 18 other First Nations. FNIGC National would like to receive at least 3688 Samples from our region. Therefore, with the already acquired twenty-three (23) RHS4 participation First Nations, we could potentially collect 3533. This would be 96% of the requested expectation.

Twenty-one (21) of the twenty-three (23) participating First Nations signed a Band Council Resolution (BCR) for continuous participation in both the RHS & RSS for years to come: Alexis Nakota Sioux Nation, Beaver Lake Cree Nation, Cold Lake First Nations, Enoch Cree Nation #440,

Frog Lake First Nations, Kehewin Cree Nation, Montana First Nation, Saddle Lake Cree Nation, Samson Cree Nation, Whitefish Lake First Nation #128(Goodfish), Stoney (Bears paw), Stoney (Chiniki), Stoney (Goodstoney), Tsuut'ina Nation, Beaver First Nation, Bigstone Cree Nation, Dene Tha' First Nation, Driftpile Cree Nation, Fort McMurray #468 First Nation, Little Red River Cree Nation, Sucker Creek First Nation, Whitefish Lake First Nation (Atikameg) #459, Woodland Cree First Nation – pending BCR.

The two (2) First Nations who signed a BCR only for RHS4 participation were Enoch Cree Nation and Frog Lake First Nations. Both would like us to meet the next leadership on RSS when it is being promoted and possibly discuss future continuous participation in RHS too.

Status

As shared, we are still engaging First Nations, simultaneously, in RHS & RSS continuous participation while in the RHS4 deployment process. These engagements also include some discussions on the First Nations Data Governance Strategy (FNDGS) as they are all interconnected and interdependent.

Arranging meetings with Chief & Council due to busy schedules, full meeting agendas, and/or summer events like cultural events (pow wows, treaty events, etc.), holidays, retreats, and/or no regular meetings in summer months.

We had some flooding and fire evacuations in the northern communities during this reporting period. It slowed engagement substantially.

There were also some political issues with some First Nations who are members of the Blackfoot Confederacy Tribal Council which caused challenges for engagement. We still continue to engage member First Nations and get clarification on how we can better serve.

Deployment of the RHS4 is ongoing as we arrange with participating First Nations. We are still engaging First Nations to arrange meetings with leadership and their health departments to see if we can secure more contiguous participation in Band Council Resolutions (BCR) for the RHS and RSS.

COVID-19 Safe Restart

Background

To enhance capacity and infrastructure to support the fourth and current phase of the First Nations Regional Health Survey (RHS 4), thereby mitigating complexities and burdens imposed by the Pandemic and supporting the safe collection of important COVID-19 health and wellness data, as well as the emergence of innovation in data technologies and corresponding standards.

Status and Next Steps

- We created a video with our Elders. They spoke in Cree about pandemics and their experiences.
- We purchased additional tablets so that the nations could survey many people at once and that we could have some always sterilized and ready to go
- We set up a system where respondents could get their gift cards digitally (through their email) rather than have to handle physical gift cards



CANCER PROJECTS

Canadian Partnership Against Cancer Funded Initiatives

Alberta First Nations Cancer Strategy and Practice Change Implementation Initiative – Phase II (AFNCI – Phase II)

Purpose

The aim of AFNCI – Phase II is to focus on community capacity building by addressing Canadian Partnership Against Cancer priorities 6 (Culturally appropriate care closer to home), 7 (People-specific self-determined priorities) and 8 (First Nations governed research and data systems). Emphasis will be placed on priority 8.

Background

The “Alberta First Nations Cancer Strategy and Practice Change Implementation Initiative” (FY: 2019-2023) was a high-level collaborative partnership project co-led by Lea Bill (Executive Director, Alberta First Nations Information Governance Centre) and Angeline Letendre (Alberta Health Services Indigenous Science Lead). The Project Team also included Oncology Champions Drs Butts (Cross Cancer Institute) and Gregg Nelson (Tom Baker Cancer Centre), as well as a team of Alberta First Nation Knowledge Holder/Practitioners. Together, First Nations, Alberta First Nations Knowledge Holder/Practitioners and Oncology Care Providers participated in a process inclusive of unprecedented collaborations to inform Cancer Care of First Nation care needs required to support positive cancer care outcomes.

Main goals of this five-year project were 1) To address priority areas along the cancer pathway that have been identified by Alberta FN with particular focus on practice changes that will lead to health system improvements in support of FN patients, families and communities, and 2) To improve health systems’ capacity in addressing the cancer pathway needs of FN patients, families and communities, inclusive of prevention and screening, and situated in the development of a FN cancer strategy and sustainability plan.

Project milestones and key deliverables included:

- Indigenous Collaborative Partnership Framework
- Knowledge Mobilization Plan
- Oncology Care Provider Education and Training
- Indigenous Evaluation Plan

AFNCI – Phase II intends to build upon this work to improve health systems’ capacity in addressing the HPV and HPV Vaccine needs of First Nations patients, families and communities with the availability of online education and training for oncology care providers.

Goals and Objectives:

Goals of the Project:

1. Support community skills and training for First Nations-governed cancer research and data systems by enhancing analytic capacities in data collection, measurement and reporting
2. Provide online culturally responsive and safe resources and tools to support improved First Nation cancer pathways and experience, including education and training for oncology care providers.

Objectives of the Project:

1. To design a First Nations Learning Management System, including training and education modules, to support access by First Nation communities to online resources and tools that

will generate increased First Nations data management skills in cancer and cancer prevention and screening

2. To develop and deliver in-person data management skills and training to First Nations communities to enhance analytic capacities in the collection, measurement and reporting of cancer data
3. To utilize the AFNIGC Learning Management System to pilot online oncology care provider training and education modules developed during AFNCI-1
4. To evaluate the uptake of online training to revise education processes and training modules as needed

Status & Next Steps

- Project Closure & Final Project Report submitted to CPAC for AFNCI – Phase I June 2023
- Project Proposal AFNCI – Phase II submitted to CPAC October 2023
- Project Presentations provided to Cancer Care and Psycho-Oncology Care Leadership and oncology Care Providers & the Canadian Cancer Research Alliance-Canadian Cancer Research Conference, November 12-14, 2023, in Halifax, Nova Scotia

Next Step: CPAC / AFNIGC Service Agreement is under development for Project anticipated start date of April 1, 2024

Key Considerations

- Proposal revisions (funding / deliverables) may be required due to changing funding availability at CPAC.

Knowledge Mobilization to Enhance HPV Vaccine Uptake in Alberta First Nations Youth

Purpose

The aim of this research is to reduce the burden of HPV disease (and cancers) among First Nations women in Alberta by developing and implementing culturally specific and safe interventions. The research is based on collaborative, holistic and culturally safe solutions that are community-driven to ensure that the approach is grounded in the values and realities of First Nations people and First Nations knowledge systems. The work will use modalities that have been determined to be most appropriate by First Nations Elder/Knowledge-Holders and communities themselves.

Background

This research proposes to increase the rate of HPV vaccination uptake by Albert First Nations youth living on-reserve by building on the work and outcomes 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.

The main aim of the “Knowledge Mobilization to Enhance HPV Vaccine Uptake in Alberta First Nations Youth” project is to develop and implement an Alberta First Nation HPV knowledge mobilization strategy inclusive of culturally appropriate and safe resources and tools that promote vaccine uptake among youth on-reserve.

Goals and Objectives:

1. Establish Trusting Community Partnerships Based on Culturally Safe Engagement
 - To build partnerships with First Nations community pilot sites
 - To share EHVINA project outcomes with First Nations community partners
 - To refine the project methodologies based on First Nations knowledge.
2. Create Evidence-Based First Nations Culturally Specific Vaccine Education
 - To determine pilot processes
 - To develop culturally specific vaccine education for First Nations
 - To develop culturally specific HPV health education resources and tools for First Nations
3. Develop & Implement an HPV Knowledge Mobilization Strategy
 - To pilot HPV health education resources and tools in First Nations communities
 - To evaluate and revise strategy components, including HPV resources and tools
 - To develop a culturally specific dissemination plan for HPV resources and tools
4. Conduct a Project Evaluation & Provide Final Reporting
 - To develop Indigenous evaluation components for an HPV knowledge mobilization strategy
 - To align dissemination and evaluation goals and outcomes
 - To provide a final project outcomes report

Status & Next Steps

The project is on target to meet objectives and deliverables through the following activities:

- 2023 Annual Report submitted to Alberta Innovates October 2023
- Online resources and tools are under development at AFNIGC by Indigenous Education Specialist

- Project Team planning underway for early spring engagement with Elders/Youth to receive feedback on resources and tools.

Next Step: Develop a Final Knowledge Mobilization Strategy including a communication plan for the dissemination of resources and tools.

Key Considerations

- First Nations Pilot Community Partners confirmed: Alexis First Nation, Bigstone Cree Nation, Cold Lake First Nation and Enoch Cree Nation
- Processes for First Nation community online access and use of resources will be aligned with AFNIGC Learning Management Systems

AFNIGC Learning Management System (LMS) Development

The education project to transfer the *Guide to Preparing Indigenous Communities for Cancer Prevention* onto a Moodle LMS commenced in October 2023. In preparation for this project, IT specialist Kent Viccars provided an introduction to the project details. The use of Moodle as an LMS was familiar to our consultant Elizabeth as an employee at Health Canada and as a student taking online courses such as inoculant certification. She was able to gain accessibility to the LMS and started to familiarize herself with the different parts of the course development features.

The course for the binder, *Guide to Preparing Indigenous Communities for Cancer Prevention*, and some of the *Indigenous Community Readiness Model for Cancer Prevention and Screening* are now on the <https://lms.afnigc.ca> website. We are also in the process of formatting the text and additional images in collaboration with the communications coordinator.

Connecting Health Professionals and First Nations with Culturally Safe Access to Cancer Prevention & Screening

Purpose

Connecting Health Professionals and First Nations with Culturally Safe Access to Cancer Prevention & Screening" is a pilot project aimed at promoting the prevention and early detection of cancer and related chronic diseases through online interventions using the Alberta Health Services 'Connect Care' platform and the Alberta FNIGC Learning Management System.

Background

Many examples of Indigenous Peoples' experiences with the healthcare system demonstrate unacceptable health disparities that Indigenous deter access to much needed care in order to avoid racist encounters from health care providers. Cultural safety is an important approach that considers how social and historical contexts, as well as structural and interpersonal power imbalances, shape health and healthcare experiences. As an organization-wide value, Indigenous Cultural Safety, is promising for cancer prevention, early detection, and screening to improve the health outcomes of First Nations. This project is designed to increase access to culturally safe resources by healthcare professionals and First Nations, and to provide tools and strategies to combat the impacts of anti-Indigenous racism in accessing healthcare.

Goals and Objectives:

Goals of the Project:

1. Increased availability of First Nations-specific resources for cancer prevention, early detection and screening
2. Increased access to Connect Care (and access to Alberta FNIGC Learning Management System)
3. Develop and implement an Indigenous Knowledge Mobilization Framework

Objectives of the Project:

1. Improve the overall health of First Nation Albertans by supporting evidence-based interventions through increased access to culturally safe resources for prevention, early detection, and screening
2. Build increased capacity for cancer research and innovation excellence with AHS through the articulation and implementation of an Indigenous knowledge translation/ mobilization framework to support healthcare professionals and First Nations communities regarding prevention, early detection and screening in Alberta First Nations
3. Promote the sustainability of improved cancer outcomes in First Nations by utilizing existing healthcare system infrastructure and capacities - 'Connect Care Platform' - of the healthcare system to provide increased access to culturally safe resources for both healthcare professionals, including oncology and primary care, and First Nations

Status & Next Steps

- Project Annual Activity Report submitted to Alberta Health June 2023
- Project Launch at Sundance took place in August 2023
- Project Advisory has included 1) Elder/Knowledge Holder/Youth Engagement & Final Dialogue Sessions with Oncology Champions and Elder/Knowledge Holders regarding Oncology Care provider health and education needs.

Next Step: Engagements with Alberta/National health organizations including Oncologists, Physicians, Nurses/NPs, Social Workers, etc. to identify healthcare provider resource needs are being planned for early spring of 2024.

Next Step: Dialogue and engagement with AHS to align Connect Care processes and AFNIGC Learning Management Systems processes to support Training for healthcare providers and First Nations communities to access and use resources for cancer prevention, early detection, and screening.

Next Step: a 'Recruitment Process' including pilot processes for oncology care provider training and education are being planned with Cancer Care leadership.

Key Considerations

Development of an Indigenous Knowledge Mobilization Strategy that includes objectives, methodology, and performance indicators to track resource & knowledge needs and uptake regarding cancer prevention, early detection, and screening in First Nations populations.

Evaluation in the Implementation of CPSI First Nations Community Support Team Model

Purpose

The purpose of FNPP - Phase II is to demonstrate the effectiveness (reliability and validity) of the First Nations Community Support Team Model and approach in supporting First Nations communities to develop, implement, and evaluate cancer prevention programming based on healthy lifestyle choices that will contribute to improved cancer outcomes.

The FNPP Phase II is aligned with ACPLF/CPSI strategic directives:

- 1) To create a coherent and visionary strategy;
- 2) To build logical connections between research and prevention/screening;
- 3) To integrate activities across risk factors and increase collaboration;
- 4) To focus on outcomes; and
- 5) To promote effective knowledge translation and exchange. Reflected in the main objectives of Phase II, the activities designed to fulfill the process, implementation, and evaluation of sub-objectives are intended to advance cancer prevention and screening with/by First Nations in each of these strategic directives and are supported by a scientific protocol.

Organization of training materials and areas of focus have been developed based on the:

- Knowledge & Skills Assessment Analysis Report
- Orientation and Training Outlines
- FNCPSPP Phase II: Community Cancer Prevention Preparedness Guide (CCPPG) & Readiness Model

Background

In 2015, the FNCPSPP project (phase I) was implemented in 3 First Nations lead communities across the Treaty Regions of Alberta (Maskwacis, Treaty 6; Blood Tribe, Treaty 7; Peerless Trout, Treaty 8) to identify, test and evaluate core components needed to create a comprehensive cancer prevention and screening strategy with Alberta First Nations.

The test project included stakeholder engagement and development of evidence-based tools, resources, and programming. This partnership initiative has demonstrated an important example of how Alberta Health (AH) and Alberta Health Services (AHS) are working with First Nation partners to co-design and implement transformative changes in cancer prevention based on First Nation community priorities social and cultural needs.

Goals and Objectives:

Phase II goals: Demonstrate the effectiveness of a First Nations Community Support Team Model and approach as culturally relevant and appropriate for supporting First Nations to engage in cancer prevention and screening planning and activities (implementation testing of the approach with federal, provincial, and community health system, organizational and program partners)

1. Validate the key components of a First Nations Community Support Team Model and approach, including resources and tools reflective of Indigenous practices and protocols, as suitable to support cancer prevention and screening planning by/with Alberta Indigenous communities
2. Co-develop with federal, provincial, and First Nations stakeholders and partners a transition plan for the implementation of a First Nations Cancer Prevention and Screening Sustainability Plan as part of a province-wide Alberta Indigenous Cancer Strategy

Meeting the above process, implementation, and evaluation science objectives will be achieved through five main areas of activity or workstreams. They are 1) Cancer Prevention and Screening Plans; 2) Community Cancer Profiles; 3) Evidence and Information Gathering; 4) Elder/Knowledge Holder Engagement; and, 5) Sustainability and Transition Planning.

Status

- Evaluation conducted and final report rewrite draft compiled.
- The three communities successfully demonstrated that community-led co-development and collaborative partnerships do support real change and an overall increase in knowledge and awareness gained on cancer prevention and screening.



Canadian Institutes of Health Research Funded Projects in Partnership with Universities

Alberta FNIGC Screening Dashboard Project (FNSD) In Partnership with Cancer Prevention and Screening (AHS)

Purpose

The aim of the First Nations Screening Dashboard project (FNSD) is to create a tool that will enable First Nations communities to access Provincial Screening Program (Breast, Cervical, Colo-rectal) data and information in 'real-time'. The FNSD will utilize Alberta FNIGC's existing infrastructure to ensure data and information align with First Nations Principles of OCAP®. AFNIGC will co-lead a pilot of the FNSD with AHS Screening Programs to provide training to First Nations communities in accessing and using their own data.

Background

A 2020 collaborative research project, "Assessing cancer screening and outcomes among First Nations people in Alberta", between AFNIGC and AHS Screening Programs sought to quantify

breast, cervical, and colorectal cancer screening uptake and screening outcomes for First Nation and non-FN populations. The main goal was to identify differences in screening participation and program effectiveness. This study achieved 2 main outcomes. First, a baseline for screening participation and retention was created for First Nations regarding the 3 provincial screening programs – breast, cervical, and colorectal. Second, the study found that there are statistically significant differences in screening participation and retention across Alberta for First Nations in comparison to non-Indigenous people in Alberta. For example, higher percentages of high-risk Pap test results in FN women; higher percentages of stage III and IV diagnoses in FN women; and lower participation and retention rates in FN women compared to non-FN women.

Evidence* supports the potential benefits of increased First Nations community access to ‘real-time’ provincial screening program data and information. Using AFNIGC infrastructure, the initiative is developing processes for First Nation community online access and use of screening data aligned with AFNIGC Learning Management Systems.

Goals and Objectives:

The main desired outcome for this project is to develop a set of parameters to design, test, and operationalize a First Nation Screening Dashboard tool. Components of the proposed project include:

1. AFNIGC, AHS Screening Programs, and Cancer Prevention and Screening Innovations have outlined project roles and responsibilities;
2. The project includes a proposed timeline of activities; and
3. Approximate costs are provided to AFNIGC to take a leadership role in facilitating OCAP® alignment for the project to create a FNSD.

Objectives of the Project:

1. Develop Indigenous data governance parameters and processes for AHS and Alberta First Nations
2. Develop processes to identify nation-specific community data
3. Develop and manage community partner pilot activities
4. Co-develop FNSD evaluation and long-term tracking
5. Launch Online FNSD in 2024

Status & Next Steps

- First Nations community engagements completed to provide the opportunity to pilot processes and access to screening data when available
- AFNIGC outlining OCAP® processes to support the FNSD First Nations Data Governance parameters and developing processes for AHS and First Nation communities including training, communications and health marketing, data collection, analysis & storage

Next Step: The Health Research Ethics Board of Alberta (HREBA) application has been reviewed

Next Step: Draft Project Charter set to be reviewed by project partners: AFNIGC, Screening Programs, and CPSI

Next Step: Confirm processes of FNSD in alignment with AFNIGC Learning Management Systems

Key Considerations

- The co-development of an Evaluation Plan with AHS is required to implement an Indigenous Indicator Framework that supports analysis and a summary of outcomes including “Recommendations for Operations”
- The project requires an extension from April 2024 to December 2024

Evidence*

*See online publication: [Assessing Breast cancer screening and outcomes among First Nations women in Alberta. January 22, 2024](#). Letendre, A., Shewchuk, B., Healy, B., Chiang, B., Bill, L., Newsome, J., Chinmoy, R., Yang, H., & Kopciuk, K. Cancer Control: Sage Publications. DOI: 10.1177/1073274824123076

ANTI-INDIGENOUS RACISM IN EMERGENCY CARE

First Nations Emergency Department Quality of Care Research Project

Project Co-Leads Patrick McLane, Alberta Health Services, Emergency Strategic Clinical Network and University of Alberta, Department of Emergency Medicine. Lea Bill, Alberta First Nations Information Governance Centre (Alberta FNIGC)

Purpose

The purpose of this briefing note is to outline the involvement of the Organization of Treaty 8 First Nations of Alberta in the project in the “Understanding and Defining Quality of Care in the Emergency Department with First Nations Members in Alberta” project.

Background

This research project is a collaboration between First Nations partners, academic researchers, and health authority staff to explore the quality of care for First Nations members within emergency departments (EDs) in Alberta. Current project partners include the University of Calgary, Yellowhead Tribal Council, Maskwacis Health Services, Blackfoot Confederacy, Stoney Nakoda Tsuu T’ina Tribal Council, Paul First Nation Health Services, Kee Tas Kee Now Tribal Council, and the Organization of Treaty 8 First Nations of Alberta.

Widespread disparities in health outcomes for First Nations members, stemming from societal inequities and healthcare disparities, underscore the importance of addressing these issues. The Truth and Reconciliation Commission emphasizes collaborative efforts for reconciliation, particularly in Emergency Departments, where First Nations members seek care at double the rate of non-First Nations individuals, highlighting the need for research to examine differences in care quality and to explore First Nations experiences in seeking care and healing.

Outcomes To Date

- Generated a draft First Nations definition of quality of emergency care by consulting with the Elder Advisory group and other partners. Presented this definition at the Canadian Association of Emergency Physicians annual conference.
- Produced a manuscript showing First Nations patients leave ED without receiving complete care more often than non-First Nations patients and exploring reasons why. This text is at the revise and resubmit stage with the Canadian Medical Association Journal.
- Supported Elenna Laplante, a Métis medical student to complete “Examining intersections of First Nations status and female sex in ED presentations in Alberta: A Population Based Study.”
- Published “Impacts of Racism on First Nations Patients’ Emergency Care: Results of a Thematic Analysis of Healthcare Provider Interviews in Alberta, Canada” (2022) based on 16 interviews with emergency care physicians and nurses.
- Published “First Nations Identity and Emergency Department Triage Scores in the Canadian Province of Alberta: A Retrospective Cohort Study Using Linked Administrative Data” (2022). This article was featured on the journal cover and was read 5605 times online and downloaded in PDF 623 times within five days of publication.
- Published “First Nations Emergency Care in Alberta: Descriptive Results of a Retrospective Cohort Study” (2021) using quantitative data from AHS on Emergency Department visits by First Nations members and non-First Nations persons from 2012-2017.
- Published First Nations Members’ Emergency Department Experiences in Alberta: A Qualitative Study (2021).
- Presented findings at 16 academic conferences, and with over 35 community groups, students, and professional organizations.
- Featured in 8 interviews on local and national radio and 8 television interviews. 10 unique popular media articles describing findings and interviewing study team members.
- Generated summary short format knowledge translation products for First Nations leaders in Alberta, emergency department managers and clinical nurse educators, the Alberta Health Services Wisdom Council, and Indigenous Health at Alberta Health Services.
- Project partners have used project results to obtain further grant funding and for advocacy efforts.
- At Alberta Health Services, the Indigenous Wellness Core has used results to write successful business cases for 15 new full-time equivalent cultural liaisons, as well as funding for Elders.

Treaty 8 First Nations of Alberta Community Engagement

Data capturing First Nations experiences in emergency departments was gathered through sharing circles in Treaty 8 territory in March 2022. The research team actively engaged by presenting findings at events like the Alberta First Nations Anti-Racism Gathering and the Assembly of Treaty Chiefs and sought guidance through Elders Advisory Engagement Sessions from June 2019 to September 2022.

Next Steps

Results from this project supported successful applications for new grants for three projects:

- Equity in Emergency Department Utilization in Alberta for Priority Populations during the COVID-19 Pandemic: Exploring Impacts of Changes to Healthcare and Healthcare Utilization through Administrative Data Analysis and Nominal Group Techniques;
- Developing and Testing Educational Materials and Simulation Training Scenarios to support Indigenous-directed Anti-Racism Efforts in the Emergency Department project; and
- The Advancing Anti-Racist and Equity-Oriented Care in the Emergency Department with First Nations Partners project with selected EDs.

We would be glad if the Treaty 8 Organization wished to discuss participating in these new projects.

Developing and Testing Educational Materials and Simulation Training Scenarios to Support Indigenous Directed Anti-Racism Efforts in Emergency Departments

Background

Emergency departments (ED) are an important health service accessed disproportionately by Indigenous populations compared to non-Indigenous populations. Research demonstrates negative experiences (e.g., racism, stereotyping) for Indigenous patients in EDs. This project supports ED clinicians, as they have expressed a need for anti-racism tools and resources tailored to emergency care. The objective is to develop and test simulation modules to train clinicians and nurses to counter racism and provide equity-oriented care for Indigenous people in Alberta emergency departments (EDs).

Simulation Learning Objectives

- Learn about, recognize, and reflect on systemic disparities in health care policy, funding, and delivery for Indigenous peoples which impact emergency department use.
- Discuss how routine emergency department practices of care rationing and patient categorization interact with racism, cognitive biases and stereotypes to lead to disparities in care for Indigenous patients.

- Understand and reflect on how the practice context (e.g., resources, policy, education) shapes provider perceptions about the purposes of emergency care and subsequent treatment of patients.
- Improve knowledge of equity-oriented skills and strategies; describe how they could apply these skills and tools.

Key Findings and Impacts

- Current published ED anti-racism education approaches are largely disconnected from broader anti-racism literature.
- Simulation lessons we developed go beyond the concept of cultural competency to focus on concepts of equity-oriented and culturally safe care, which attend to how racism functions through inequities in power and resources by ‘race’.
- Built foundations for anti-racism education in emergency care through co-design among First Nations, Métis, and non-Indigenous clinicians, researchers, educators, and health systems leaders.
- Co-designed an approach to simulation training focusing on systems factors.
- Co-created understanding that system factors dispose providers to rely on anti-Indigenous stereotypes.

Next Steps

- Evaluation will focus on provider descriptions of actions they can take following the simulation training, rather than changes to their attitudes.
- Simulation training will provide ED clinicians with strategies for countering racist stereotypes and biases that lead to reliance on these stereotypes, thereby theoretically decreasing treatment errors and inequitable care for Indigenous patients.
- With partners we have obtained a \$1.75M CIHR project grant for a four-year anti-racism intervention project to sustain our partnerships.
- This ensures education approaches developed through this project will inform future education efforts in EDs.
- Education materials will be published online for use by Indigenous organizations and EDs in Alberta and beyond, with appropriate adaptations.

Promote Mental Health & Wellbeing of Indigenous Youth Aging Out-of-Care to Urban Settings

Purpose

The aim of this research is to support Indigenous youth, ages 12-24, as they ‘age out of care’, in making healthy lifestyle choices that can impact their mental health and overall well-being and prevent chronic disease later in life. Multiple frameworks and programs have been developed to support Indigenous children in care as they transition or ‘age out of care’ back to the community;

however, no models exist that focus on supports for healthy lifestyle choices of Indigenous youth as they transition into unfamiliar and often unsafe settings. By maximizing the health-promoting potential of cities and urbanized areas in Canada and internationally, this research will support First Nations youth, and their families, experiencing transitions from ‘living-in-care’ to community and urban settings.

Background

The Healthy Cities project was awarded to the Alberta First Nations Information Governance Centre by the Canadian Institutes for Health Research – Institute of Indigenous Peoples’ Health in October of 2022. Representing the single Indigenous proposal funded through the “Healthy Cities Research Initiative”, the project is an international collaborative partnership with Dr. Gail Garvey at the University of Queensland in Australia.

In December 2022, 74% of children and youth receiving services In-Care were Indigenous.¹ As of 2021, the maximum age eligibility for youth aging out of care is 24. Youth between 18 to 24 can apply for the Transition to Adulthood Program (TAP) ‘intended to help prepare youth/young adults in government care...to live independently, pursue education, and build their careers’.² Often the experience of transitioning to an independent living situation for many Indigenous youth has placed them in a precarious position where little or no cultural supports are available. This has contributed to the vulnerability of these youth from harmful impacts when they are expected to survive in unfamiliar and often unsafe environments that include: Loss of connection to community; Loss of identity and how that is defined as an Indigenous youth living in an urban setting. Further, these youth are at risk for higher levels of poverty, homelessness, sexual exploitation, addictions, HIV/AIDS, and suicide, as well as chronic illness later in life due to lifestyles and a lack of healthy choices.

Goals and Objectives:

Goals of the Project:

1. Undertake implementation research,
2. Focus on Indigenous holistic concepts of health,
3. Strengthen and build the capacity of health practitioners, and
4. Mobilize evidence-based outcomes.

Objectives of the Project:

1. Develop culturally based wellbeing indicators for Indigenous Youth, ages 12-24
2. Adapt interventions essential in Indigenous-led Implementation Science.
3. Evaluate the intervention (Healthy Communities Governance & Land-Based Implementation Model) for scale and spread to other populations in an urban context; and,
4. Develop and disseminate knowledge resources for Indigenous/non-Indigenous care practitioners and organizations aimed at supporting the mental health and wellbeing of Indigenous Youth in urban settings, including those ‘aging-out-of-care’.

Status & Next Steps

The project is on target to meet objectives and deliverables through the following activities:

- Project launch, including ceremony took place in August 2023
- Project Team attended and presented at ‘Smart Training Conference’ November 1-2, 2023 & “Healthy Living in Canada” webinar with Honorable Mark Holland, Minister of Health

Next Step: Project Mapping & Summary under development to prepare for in-person meeting

Next Step: Selection criteria for Indigenous student support and mentorship by Project co-leads is underway including 1 Postdoc & 2 Masters’ students

Next Step: Develop Knowledge Mobilization activities with Elders, including ‘cultural land-based skills’ for First Nations youth

Next Step: Complete Partner Site selection and develop capacity sharing agreements

Key Considerations

- First international collaborating partner in-person meeting is set for March 22, 2024, in Melbourne Australia following the World Indigenous Cancer Conference, March 18-20
- The project to support Project Team members, including 2 Elders/2 Youth to attend the conference and in-person Healthy Cities meeting with international Project Team

Health Canada MMIWG Secretariat Crown-Indigenous Relations and Northern Affairs Canada

Missing and Murdered Indigenous Women and Girls Project Phase 2 – National Data Strategy

Purpose

The aim of this research is to address the critical lack of data identified in the National Action Plan (NAP) Data Strategy, particularly around missing and murdered Indigenous women and girls for underserved groups. The NAP recommended focusing on the development of cultural data tools and/or methodologies and the processes of collecting Indigenous data, rather than the collection of data itself. Phase 2 project entitled ***Examining Atchimostakanna – (Story Telling Instrument) Cultural Interactive Data Dashboard: Data Digital Storytelling and Visualization for Elders, Indigenous Women, Men, 2SLGBTQIA+ and Youth and End Users*** proposes to lay the

groundwork for a dashboard logic model and development of a framework to guide the production of useable data for FN communities to apply in decision-making. This 2-year project will examine and develop a cultural interactive dashboard framework that includes useable, understandable, relatable, applicable, and clear information for the communities and end-users.

Background

The Indigenous-Led Data Research Projects Program was provided in 2021-2022 until 2026-2027 to support data projects designed to develop distinctions-based or identity-specific indicators or methodologies to increase knowledge about missing and murdered Indigenous women and girls.

Several streams or pieces of work have already been done to date. Alberta FNIGC tested the Atchimostakanna – (Story Telling Instrument) and completed the environmental scan, noted where the needs are, and identified the following gaps:

- a. FN Women do not have a platform for the data and numbers of the MMIWG data exist in many data sets,
- b. Need to hear any stories of successes, even resources that support them in the efforts to reduce violence,
- c. Need to connect existing data around (Regional Health Survey) statistics on the health and wellbeing of women and community.

The second phase is to respond to the data needs of communities including front-line workers like law enforcement and others.

Goals and Objectives:

Phase 2 goals and objectives of the project:

1. Undertake dashboard data tools development and research
 - a. To design an Logic model and Framework model
 - b. To develop and use key messages to address key issues for communities through interviews and research
2. Identify and connect with existing socio-health research
 - a. To utilize and align with existing data around statistics on the health and wellbeing of communities of violence
 - b. To create a model where data is not segregated
3. Support growing cultural data demands of end-users in decision-making
 - a. To understand the ways of male roles as protectors of the community to be reinstated and reframed using oral tradition audio approaches

- b. To outline and design an extraction base hub
- c. To invite and initiate communication with law enforcement and frontline workers of their data needs

Status

- Exploratory phase: Developed Logic Model and Framework Model
- Research and identify and interview key knowledge users (law enforcement, men and Knowledge Holders/Practitioners, end-users) on the merits of the dashboard in knowledge transfer through key messaging.
- Alberta region invited to participate in Technical Gathering in Ottawa, Ontario on November 15-16th to discuss First Nations women, girls, and 2SLGBTQQIA+ safety and human security.



New Proposals, Project Submissions and Collaboration Projects

Feasibility of Biobanking and Genomic Research:

- We are part of a working group learning about biobanking and genomic research.

- We have heard from many experts and have had 6 learning sessions so far.
- The latest session was on Feb. 6th, 2024, and included Dr. Nadine Caron, Dr. Evan Adams, and Amy Bombay, among others.
- This is just a fact-finding exercise. No decisions are to be made at this point. When the time comes all the information will be presented for the nations to decide upon.

Screening and testing:

- On the horizon is the self-screening initiative for HPV. Read more here.
<https://www.partnershipagainstcancer.ca/topics/hpv-primary-screening-environmental-scan/self-sampling/>
- Cancer screening for the LGBTQ2S community
SCP006A_LGBTQ2S_CS_General_OnePager.pdf (screeningforlife.ca)
- Syphilis and HIV Rapid/Point of Care Testing Implementation Syphilis & HIV Rapid/POCT Testing in Acute Care and Community Sites (SHACC)