

# INCREASED ACCESS TO CULTURALLY SAFE CANCER CARE PATHWAYS BY ALBERTA FIRST NATIONS IN RURAL REMOTE AND ISOLATED COMMUNITIES



The Alberta First Nations  
Information Governance Centre

CANADIAN PARTNERSHIP  
AGAINST CANCER



PARTENARIAT CANADIEN  
CONTRE LE CANCER



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The Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities core project team would like to gratefully acknowledge the support received from multiple stakeholders and financial support from the Canadian Partnership Against Cancer to produce and print this document.

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# ACKNOWLEDGMENTS

*“The journey with cancer continues for many people, and some have now made their way to the spirit world. The opportunity to walk alongside those in a journey with cancer has been an honor and a privilege. We shared tears, hugs, hope, anxiety, and fear during our journey together. We have pollinated many hearts and minds to be thoughtful, compassionate, and committed in supporting & working on the quest of bringing about changes to cancer care. Care that will create better outcomes and experiences for our people within the Cancer care system. Research and building trusting relationships have been pivotal to the success of this work.”*

– Lea Bill 2022

**“Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities”** is a collaborative partnership and project between Alberta First Nations and Alberta Health Services, CancerControl Alberta. Without the willingness and commitment of the many individuals who participated during the 2.5-year initiative, the vision and inspired work of this project would not have been possible.

The results from this project have produced an evidence-informed picture of the cancer care experiences of Alberta First Nations, as well as the perspectives of healthcare practitioners about the needs and challenges faced by First Nation patients and families along the cancer care pathway. Additionally, work led by the Alberta First Nations Information Governance Centre was undertaken which enabled First Nations in Alberta to be the first to navigate a process for more comprehensive access and use of First Nations’ population and self-identifiers. These outcomes are expected to provide a basis for future actions that will be used to improve cancer care services and delivery for rural, remote and isolated First Nation communities and to sustain multi-jurisdictional partnerships that have been established.

The project team and partners would like to express our deeply felt appreciation for the commitment of lead communities:

- \* Maskwacis, Treaty 6
- \* Siksika, Treaty 7
- \* Bigstone, Treaty 8
- \* Elders
- \* Knowledge Holders
- \* cancer survivors
- \* families
- \* caregivers and community healthcare providers

Finally, the project team wishes to acknowledge and thank the Canadian Partnership Against Cancer, First Nations Inuit and Métis Program for their foresight and ongoing support of regional partners, including Alberta Health Services, Alberta First Nations organizations, our First Nations Elder Team, cancer patients and communities.



# EXECUTIVE SUMMARY

“Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities” is a coordinated, holistic and comprehensive project with Alberta First Nations and Alberta Health Services–CancerControl Alberta. The project design, grounded in First Nations understandings of health and wellness used a ‘Determinants of Health’ and community-driven approach to focus on the strengths of First Nations. Multi-jurisdictional stakeholder relationships and partners included First Nations Inuit Health, Universities of Alberta and Calgary, Canadian Indigenous Nurses Association and the Indigenous Physicians Association of Canada.

This document is the final report which describes a two-part project and provides a high-level overview of the findings and outcomes. Part A consisted of a needs assessment of First Nation experiences with a focus to increase access to culturally responsive cancer care services and resources in remote, rural and isolated communities. Part A was also designed to improve multi-jurisdictional support of First Nations cancer patients and families along the cancer pathway.

Part B carried out a feasibility assessment of the information, partners, and processes required to use First Nation patient identifiers. This included documentation of the elements essential for a framework or matrix in the development and use of First Nation identifiers in cancer care. The scope of the project was limited to cancer diagnosis, treatment of care and discharge; however, information that was collected also captured issues and challenges experienced by First Nations cancer patients and families along the entire cancer pathway.

We provide a description of data collection and analysis, the results and findings, as well as evaluation outcomes of Part A and B. This information is then used to talk about lessons that were learned and recommendations for moving forward to improve the cancer care pathway for First Nations in Alberta. The voice and experiences of Indigenous people, as the drivers for this work, are discussed throughout the document and speak to the hardships of many First Nations people as they travel on a journey with cancer.

As such, this project and its outcomes can only be viewed as a stepping stone toward the required changes for a culturally appropriate and safe cancer care pathway for Alberta First Nations in rural, remote and isolated communities.



*INCREASED ACCESS  
TO CULTURALLY SAFE  
CANCER PATHWAYS  
BY ALBERTA FIRST NATIONS  
IN RURAL, AND ISOLATED  
COMMUNITIES*

# INTRODUCTION

In 2012, the Canadian Partnership Against Cancer, First Nation, Inuit, and Métis Program launched the Advancing Improvements in Continuity of Care for First Nations, Inuit and Métis Patients in Rural and Remote Communities initiative. This two-part funding opportunity was open to regional applicants and proposals were accepted from several provinces, including Alberta.

Part one, an Expression of Interest, provided \$100,000 for regional applicants to carry out a current state assessment of the cancer care pathway for First Nation, Inuit and Métis people (FNIM) and establish partnerships that could then support project proposals.

In Alberta, this funding supported the development of a partnership and \$800,000 project proposal by Alberta Health Services, CancerControl Alberta, and Alberta First Nations Treaty 6, 7, and 8. The *“Alberta Baseline Assessment Report”*<sup>1</sup> was created and identified several areas of concern for the cancer care pathway available for First Nation rural, remote and isolated communities in Alberta including:

- \* Availability of culturally appropriate services
- \* Federal health policies that limit or dictate access to some services
- \* Location and distances from cancer care services for remote and isolated communities
- \* A tendency for late stage diagnoses
- \* Failure to return for treatment
- \* A lack of coordinated referral processes, on and off reserve

The report also noted that issues, such as increased levels of poverty and trauma added to the complexity of a First Nations experience with a serious illness. Indicating the existence of gaps, challenges and barriers to an appropriate and safe cancer care pathway for *Alberta First Nations*, the *Baseline Report*<sup>1</sup> provided information that would inform and guide the development of a 2.5-year collaborative partnership and project: “Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities”.

<sup>1</sup> Healy, B., Letendre, A., and Voyageur, C. (2016). Alberta Baseline Assessment Report. Alberta First Nations Information Governance Centre.



# BACKGROUND

## PROJECT PARTNERS

Project partners and co-leads included AHS CancerControl Alberta; Provincial Treaty Organizations (Confederacy of Treaty Six First Nations, Treaty 7 Management Corporation, Treaty 8 First Nations of Alberta); Alberta First Nations Information Governance Centre (AFNIGC); University of Calgary, Department of Sociology; and, AHS Aboriginal/Indigenous Health Program. Collaborative partners included Health Canada, First Nations Inuit Health Branch (Alberta); University of Alberta, Department of Nursing and School of Public Health; Aboriginal Nurses Association of Canada (Canadian Indigenous Nurses Association); Indigenous Physicians Association of Canada; AHS Surveillance and Reporting; and AHS Research and Evaluation.

## PROJECT AIMS

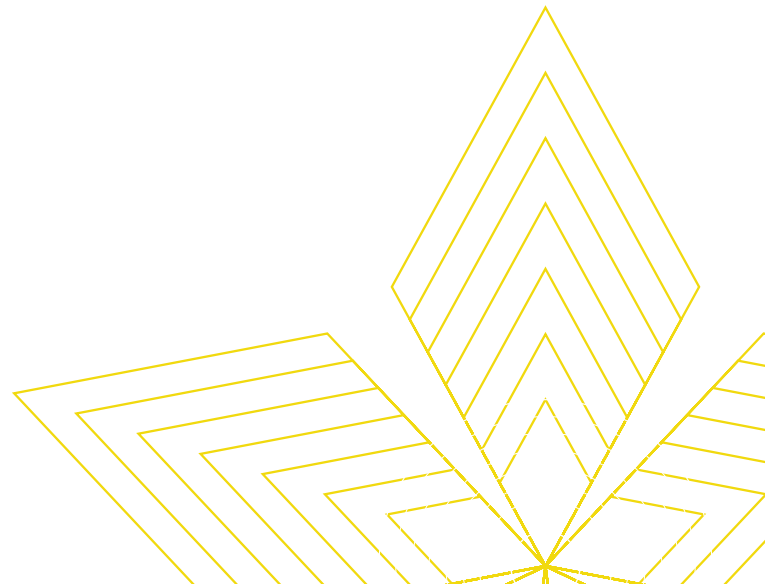
The purpose of the project was to support an improved cancer pathway for First Nations in Alberta. This was inclusive of diagnosis, treatment of care, and discharge or a return to primary-based care. Overall aims of the 2.5-year project were to:

1. Develop and implement a strategy for increased access to cancer care by Alberta First Nations in rural, remote, and isolated communities, and
2. Initiate and implement a strategy for First Nations engagement to support multi-jurisdictional targeted interventions aimed at an improved First Nations cancer care pathway.

## PROJECT OUTCOMES

Anticipated outcomes for the project included:

- Development and dissemination of culturally appropriate and supportive resources for healthcare practitioners on and off reserve, First Nation cancer patients, survivors, caregivers, and communities.
- Enhanced coordination of services across multiple jurisdictions of care, with a focus on points of access for diagnosis, through treatment of care and upon discharge to a variety of primary and community care services;
- Identification and appropriate interpretation of the required elements for an improved cancer pathway in an Alberta First Nation context, considering traditional forms of support;
- Improved cancer care systems' knowledge and awareness of the needs and cultural perspectives of First Nation cancer patients, families, and caregivers;
- Increased awareness and knowledge by First Nation people of cancer and cancer care services;
- Trusting working relationships amongst the Project Team, First Nation partners, and AHS CancerControl Alberta;





# PROJECT STRUCTURE

## PROJECT SCOPE

Scope for the project included:

- Engagement of First Nation leadership, organizations and communities in the development and implementation of First Nation patient identification strategies;
- Identification and improved understanding of the gaps across multi-jurisdictional services of care that impact Alberta First Nation cancer outcomes;
- Increased evidence-based knowledge of the cancer care experiences of Alberta First Nation cancer patients, families, and caregivers;
- Increased health systems' knowledge and awareness of the cancer care challenges and issues for First Nation cancer patients, families, and care providers.

The First Nations cancer pathways project developed a framework that is grounded in First Nations understandings of health and wellness. This work includes a 'Determinants of Health' and strengths-based approach. CancerControl Alberta, with its design, structure, and developing 'person-centred care' philosophy, was considered to be in a key position to carry out and support the project activities and work.

Through the alignment of stakeholder priorities for an improved cancer pathway, a coordinated, holistic, and comprehensive plan was developed to provide evidence and increased understanding of the elements required for long-term impacts on the cancer outcomes of First Nations people. The partnerships, collaborations, and project team established during the baseline assessment phase for this initiative would prove to possess the knowledge and expertise required to carry out the work of the 2.5-year project.

## PROJECT GOVERNANCE AND GUIDANCE

Project governance included a core project team and an extended project team. The core team brought together scientists, managers and coordinators from both Alberta Health Services (AHS) and the Alberta First Nations Information Governance Centre (AFNIGC). Core team members or co-leads would be responsible to carry out the activities and meet the objectives of the project, as well as to oversee project finances. The extended team would include core team members, but also First Nations Treaty organization leads and leads for the 3 communities involved in the needs assessment.

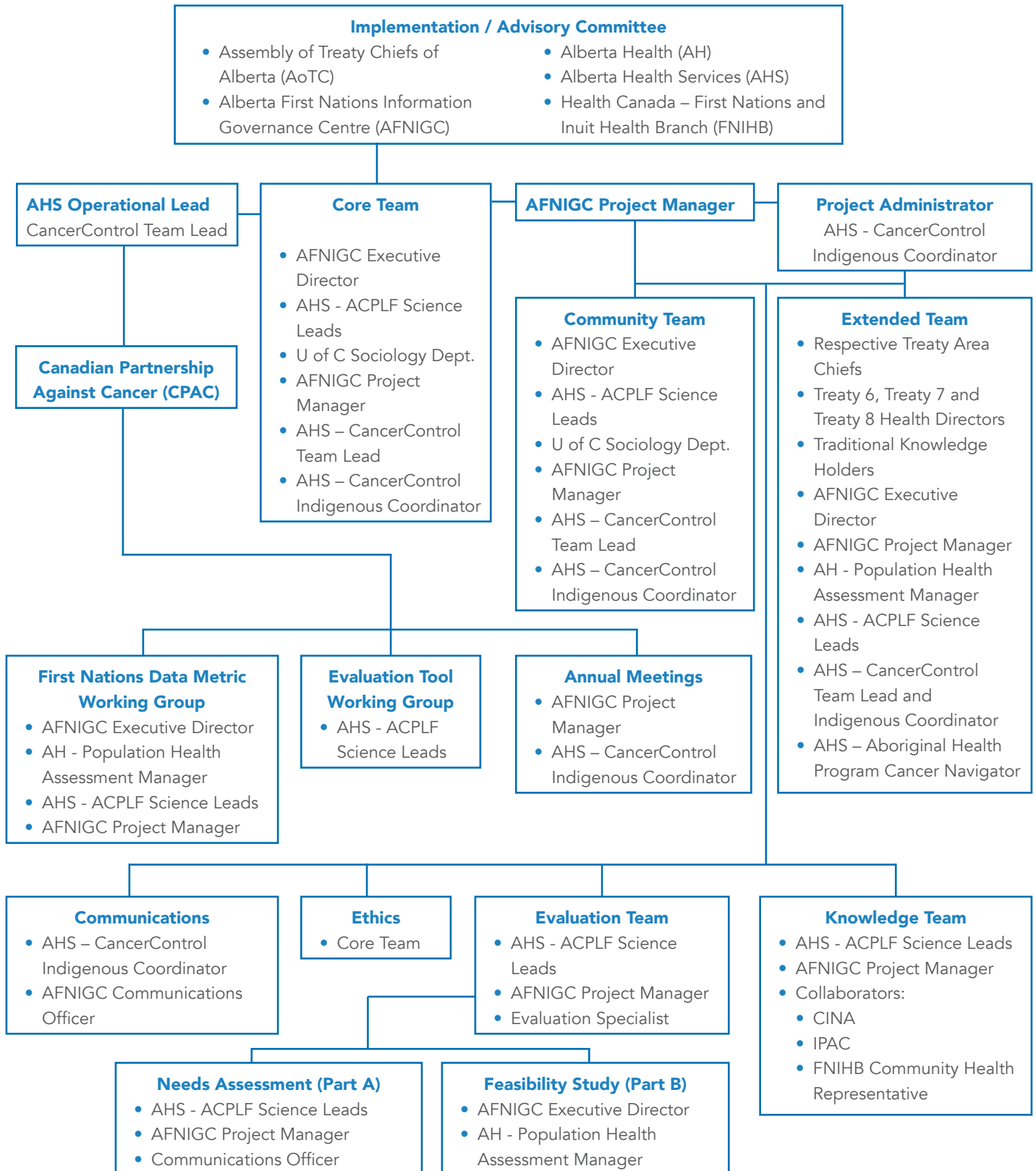
Other extended team members would include the Elder Team and project collaborators such as First Nations Inuit Health, Alberta Health, the Aboriginal Nurses Association, and the Indigenous Physicians Association. Quarterly meetings occurred throughout the project where the process was consensus-driven, consistent with a First Nations 'ethics of practice'. This process was used to share information, plan project activities, discuss strategies, find solutions to emerging issues, and engage in knowledge translation and exchange.

Advisory for the project was provided through several means – quarterly meetings between the core team and the Canadian Partnership Against Cancer (CPAC), presentations and dialogue with First Nations governance structures (Health Co-Management, Assembly of Treaty Chiefs, Treaty region health forums, and community gatherings), consultation at stakeholder events (ANAC/CINA and IPAC national gatherings and board meetings, FNIHB staff orientations, and annual education forums), as well as annual project leadership events.

The annual project leadership events provided important opportunities to establish relationships amongst project partners and key collaborators, raise awareness about First Nations people and ways of knowing, share information with the intention to receive feedback, and understand partner/stakeholder perspectives and share project outcomes.

To appreciate the depth and breadth of the collaborative networking and relationship building that took place during project implementation, Figure 1: First Nations CPAC Project Structure is provided below.

**Figure 1: First Nations CPAC Project Structure**





# METHODOLOGY AND APPROACH

In order for the core team to move forward and begin the planning of activities, it was imperative to gain support for the project from Alberta First Nations leadership. This was received through the Alberta Treaty Assembly of Chiefs, which passed Resolution OIR: 2015/02/05 in February of 2015 (Appendix A). A further engagement with the assembly of Chiefs from Treaty 6, early in the project, identified the need to find ways to include cancer prevention and screening as a priority area for the project and a long-term approach to addressing cancer in First Nations.

Also essential to the success of the overall project, an interchange agreement between AFNIGC and FNIHB was developed for Lea Bill to act as Project Manager. A First Nation's registered nurse, Lea Bill brought with her 30 years of experience in working with First Nations communities across Alberta and the Northwest Territories to the project. Lea also carried with her a wealth of knowledge as a healer, Elder, and Knowledge Holder. Undoubtedly, the leadership provided by Lea Bill contributed to success in engaging First Nations communities and Nation members in culturally appropriate and safe ways in all project activities. This role was expanded to include project oversight, project planning, data management, evaluation and the articulation of First Nations intellectual property and perspectives found within many of the project documents.

## IMPACTS OF CHANGE

Like most time-bound projects, changes occurred that would have impacts on the work and activities. These included:

- » A loss of partners
- » A lack of partner participation
- » A movement and loss of co-leads
- » An expanded role of PM

Of note are the changes in staff at CancerControl, as well as within Treaty region organizations, which would prove to cause delays in project activities and deliverables.

## INDIGENOUS RESEARCH METHODOLOGIES

The need to ground this project within an Indigenous research methodology was described in the proposal:

*Past negative experiences have left an indelible mark on the minds of First Nations people in relation to information gathering and activities of research.<sup>2</sup> In particular, many First Nations communities have been exposed to unethical research, leaving them with little or no benefits for their involvement or challenges with research. Project leads have left communities with knowledge and information with no intention of returning it to the community.*

The 4R's of Research is an approach that incorporates Indigenous Research Methodology (IRM) that provided a simple framework and foundation for the project to develop and carry out identified activities. Talked about by Kirkness and Barndardt<sup>3</sup>, the 4 'R's are considered to be principles that are the basis for successful engagement with First Nation, Inuit, and Métis people, which include: **respect, reciprocity, relevance, and responsibility.**

These concepts functioned to support the production of outcomes reflective of First Nations' worldviews and praxis. Exercised throughout this project, an '**ethics of practice**' or the manner in which engagement was carried out with First Nations partners followed the practices and protocols of First Nations in Alberta. Beginning with a pipe ceremony, the project could then move forward to develop the trusting working relationships essential to success of the work. This included bringing together Elders and Knowledge Holders from each treaty region; selected by First Nations, to provide guidance to the project team in ways that would validate the processes and activities that would follow.

<sup>2</sup> Royal Commission on Aboriginal Peoples, 1996; Smith, 1999

<sup>3</sup> Available online at: <http://www.ankn.uaf.edu/IEW/winhec/FourRs2ndEd.html>, 1999

This creation of the 'Elder Team' included:

- Rema Kootenay
- John Ermineskin (Treaty 6)
- Tereasa Bearchief
- Reg Crowshoe (Treaty 7)
- Doris Courtorielle
- Mike Beaver (Treaty 8)

Together, these Elder/Knowledge Holders would engage in dialogue facilitated by Lea Bill (Elder/Knowledge Holder), leading to the identification of a set of principles suited to guide the practices and activities of the project. An Indigenous logic model was then developed that embraced these principles, which include value and merit, growth, supporting autonomy, reciprocity, success, collaboration and working together and sustainability.

The logic model and the encompassed principles were used as a basis for engagement and activities throughout the project, including the activities of Part A (Alberta First Nations Needs Assessment) and Part B (First Nations Identifiers Framework and Matrix), Indigenous Research Methodology and utilization of an Indigenous logic model helped to uncover evidence of the gaps, challenges, and barriers in systems supports for Alberta First Nation cancer patients and their families. There was also increased awareness and understanding of these experiences created for AHS CancerControl Alberta, decision-makers, and healthcare practitioners. This had all been made possible through the articulation of the Alberta First Nations' cancer patient and family experiences where minimal-to-no documented sources were previously available.

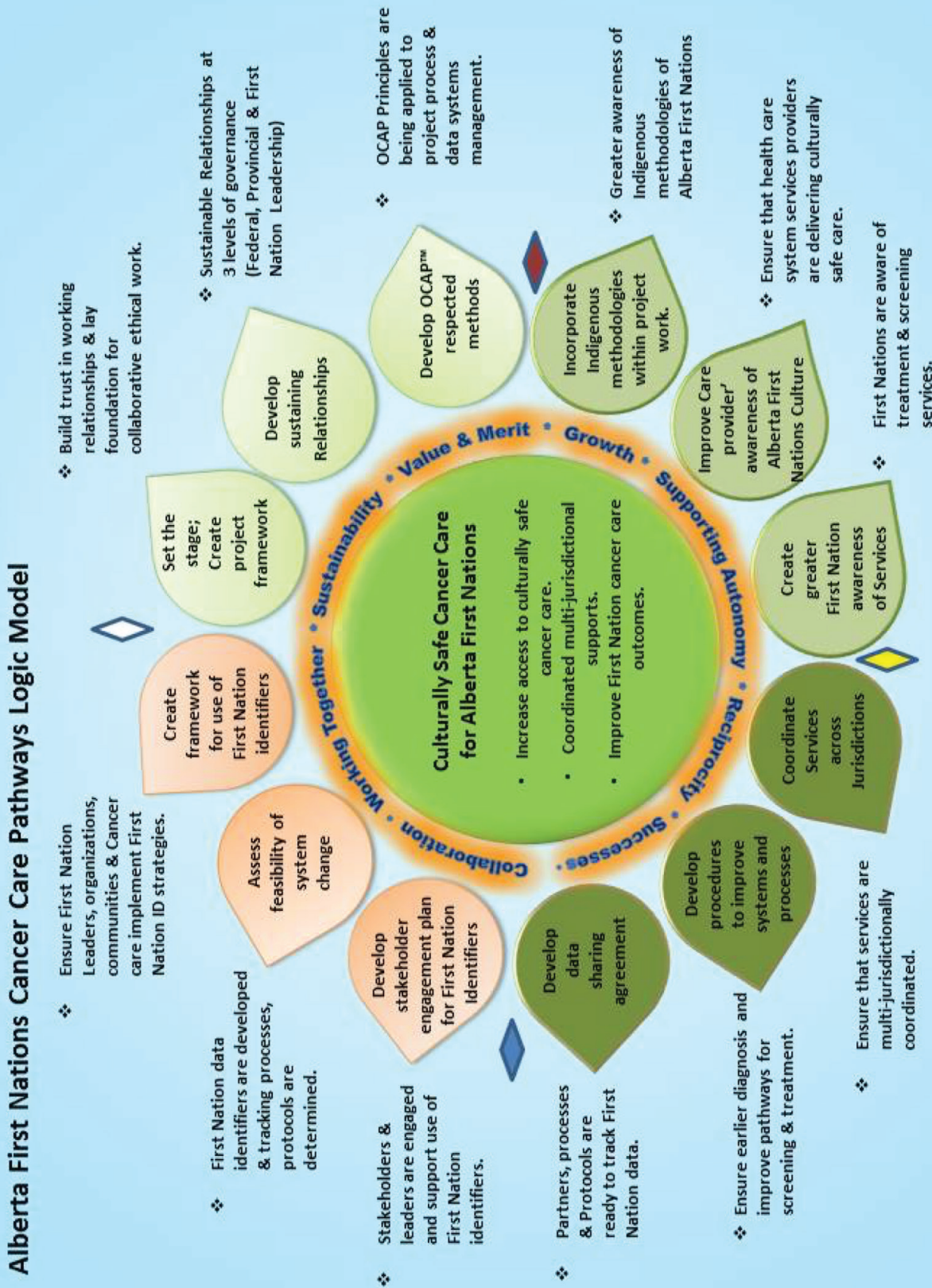
## INDIGENOUS LOGIC MODEL AS THE 'PLANNING APPROACH'

The project Indigenous Logic Model, created by Lea Bill, was utilized as the framework or approach to the work. Much more than a 'snapshot' of the project (generally a function of the 'western' logic model), the model proved to be a tool for teaching, engagement, data collection, and evaluation throughout the project. For instance, a description of each leaf as a set of activities for the project provides a visual image, when viewed in parallel with the seasons of the year, these are analogous to the stages of the project. This description, found in (Appendix B), states:

*The seasons demonstrate a cycle and the process of development for this project. The seasons, beginning in the top upper right if looking at the model straight on are; the budding stage which is the winter season. This is a time of reflection and inner working in preparation for a grander outward display of wisdom and or a planning phase of the work which takes inner strength, wisdom, and knowledge to prepare for the work ahead, the activity leaves are labeled as: set the stage; create project framework, develop sustaining relationships, develop OCAP® respected methods.*

The Alberta First Nations Cancer Care Pathways Logic Model also provides easy referral for each set of activities in relation to outcomes for the project. For example, activities of 'set the stage; create project framework' is connected to an outcome of 'build trust in work relationships and lay foundation for collaborative ethical work'.

Figure 2: The Alberta First Nations Cancer Care Pathways Logic Model





## ETHICAL SPACE

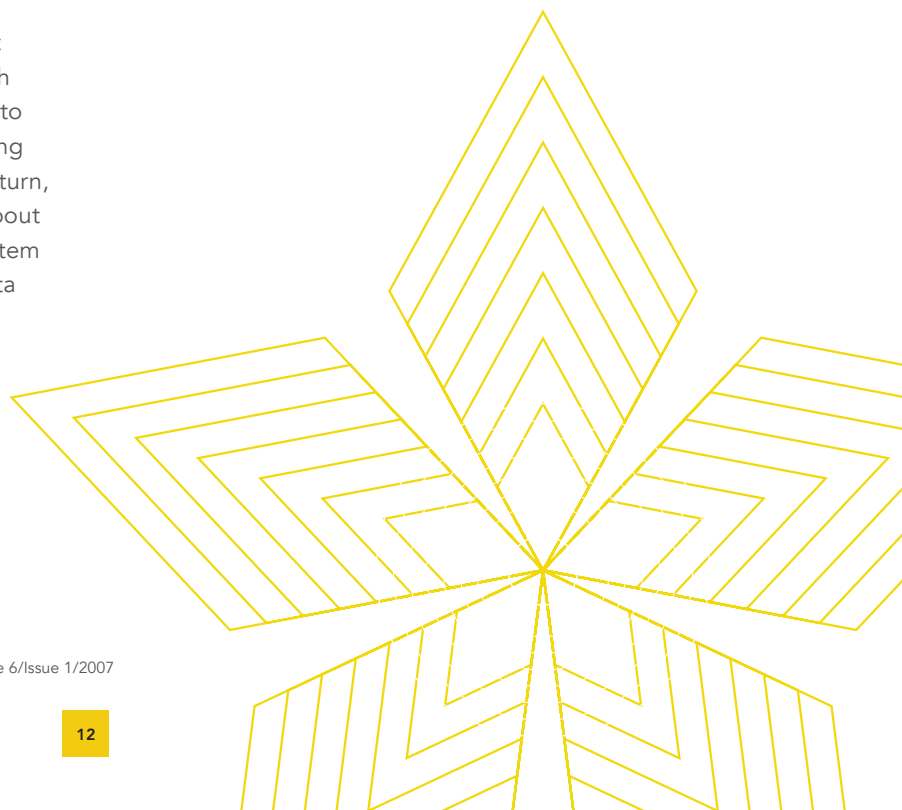
“Ethical Space”, a concept central to engagement among stakeholders, is defined by First Nations researcher and ethicist, Willie Ermine:

*The ‘ethical space’ is formed when two societies, with disparate worldviews, are poised to engage each other. It is the thought about diverse societies and the space in between them that contributes to the development of a framework for dialogue between human communities. The ethical space of engagement proposes a framework as a way of examining the diversity and positioning of Indigenous peoples and Western society in the pursuit of a relevant discussion.<sup>4</sup>*

Assumptions of this framework, and the further work of Alberta First Nation Elder Reg Crowshoe, describe the necessity to create spaces that are principled and a forum for respectful dialogue between cultures or groups with different worldviews. Particularly so when these groups have polarized views on the issues and concerns at hand. From the onset, the core team recognized an important need to create environments that were safe in which partners, collaborators and participants could engage in dialogue and relationship building based on trust. Taking the care and actions required to support such an environment, consideration was given to both First Nations and non-First Nations ‘ethics of practice’, such as the protocol to begin each encounter with prayers to the Creator and the provision of a written agenda along with the taking of meeting minutes. These actions, in turn, would support cross-cultural dialogue and learning about First Nations cancer experiences and the need for system change to improve the cancer care pathway for Alberta First Nations communities.

## OCAP®

OCAP® is a set of principles that reflects First Nation commitments and values regarding the use and sharing of First Nation information in ways that bring benefit to the community while minimizing harm. It is also an expression of First Nation jurisdiction over their own information. The terms “ownership”, “control”, “access”, and “possession” are all elements of information governance that bear important consideration in any project with First Nations people. This includes project methodology, the collection of information and the governance of that information. The methodology described above, taking into account community engagement, principles for analysis and an approach that recognizes First Nation cultures are an important part of OCAP®. Equally important are the elements of information collection, data stewardship and information management. An essential characteristic of a First Nation information system is that the steward of First Nations information be accountable to First Nations leadership through existing governance structures. The AFNIGC provided guidance to ensure project activities reflected and met the requirements of OCAP®.



<sup>4</sup> Ermine Willie, The Ethical Space of Engagement, Indigenous Law Journal/Volume 6/Issue 1/2007

## A MIXED-METHODS PROJECT DESIGN

The project design used a mixed method approach guided by Indigenous Research Methodologies (IRM), viewed as being aligned with Nation-driven and participatory work. IRM provided theory and support for many of the methods that were appropriate to carry out activities of information gathering with First Nations people, including practices such as gifting, and many of the perspectives that are useful to understand, articulate and frame the findings from analyses. This includes the 4R's of Research (respect, reciprocity, relevance, and responsibility) and OCAP® principles.

Also, central to the success of the needs assessment processes and results were elements of community-based participatory research (CBPR) defined as: A "collaborative approach to research that equitably involves all partners in the research process and recognized the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action, and achieving social change to improve health outcomes and eliminate health disparities."<sup>5</sup>

Methods from other appropriate schools of thought were also used in collecting, managing, as well as analyzing the data and information. These included: Grounded Theory for its iterative approach and concurrent data collection and analysis<sup>6</sup>; Phenomenology used to describe a "lived experience" of people<sup>7</sup>; Ethnography to learn about a culture from the people who live in that culture<sup>8</sup>; Historical Methods which allows for the discussion of past and present events in the context of the present condition; and, Meta-Analysis to conduct a rigorous secondary qualitative analysis of primary qualitative findings.<sup>9</sup>

## DATA MANAGEMENT AND COLLECTION

All data collection, storage, and destruction adhered to OCAP® principles. The notes and audio recordings from all data gathering methods were handled according to these principles. Procedures for signed consent forms (Appendix C), and handling of electronic data were protected by ensuring that data sharing agreements and an oath of confidentiality were in place for anyone handling and working with the data. A secure remote desk top was instituted for the data analysis team to ensure that data was not placed off site and to lessen the potential for loss of security. All employees signed an oath of confidentiality form and had secure logons to the system. AFNIGC adheres to the strictest federal and provincial privacy laws. Data (paper notes; audio recordings; electronic files) will be destroyed after five years (by shredding, cross-shredding, and deleting). The results from the CPAC evaluation survey are shared with CPAC and AHS in aggregate form only.

## CONFIDENTIALITY

The consent process required the project team members to go through the consent form with each participant, at which time, participation was contingent on signing the consent form. A copy was then given to the participant and returned to AFNIGC for storage. Participants were also presented with an oath of confidentiality form to further ensure safety for participants sharing their experiences within a focus group session.

<sup>5</sup>WK Kellogg Foundation Community Health Scholars Program

<sup>6</sup> Bryman, A. (2004) Social Research Methods (2nd ed.) Oxford University Press

<sup>7</sup> Greene, M. (1997) The lived world, literature and education. In D. Vandenberg (ed.), Phenomenology and education discourse (pp. 169-190). Johannesburg: Heinemann

<sup>8</sup> Spradley, P. James (1979) The Ethnographic interview Waveland Press, INC.

<sup>9</sup> Timulak, L (2009) Meta-analysis of qualitative studies: A Tool for Reviewing Qualitative Research Findings in Psychotherapy – Journal of Psychotherapy Research Vol 19, 2009, Issue 4-5



# ACTIVITIES AND DELIVERABLES

## BUILDING TRUSTING RELATIONSHIPS

Building trusting relationships was critical to success for this project. Creating a foundation for the project work and activities to proceed included: receiving an Assembly of Treaty Chiefs Resolution; identifying lead communities; meeting with lead communities to garner agreements to participate and obtain letters of support; establishing the Elder Team Advisory; and, planning/hosting extended team meetings to inform stakeholders. Through building these relationships, an avenue would be created to receive partner/collaborator input into all aspects of the project including the engagement process, communications processes, ethics submissions and the procurement of data sharing agreements with AHS and communities. Much of these processes involved co-leads meeting on multiple occasions to plan and articulate how the project would be operationalized. Regular briefing notes were also provided to First Nations leadership, collaborators, and Nations.

## TOOLS AND RESOURCES

Specific tools and resources developed for this project included a work plan, graphics to assist with communications and data gathering, a communication brochure introducing the project, a poster describing the project, an engagement plan, an evaluation plan, and a data analysis plan. Graphics were utilized to explain data collection and linkages for the different components of the project. The Indigenous logic model, as a foundational tool, served to keep the project grounded in an Indigenous process and world view, often not seen in other project approaches. The logic model was also used as a tool that supported the team in describing their project approach, the goals and objectives of the project, principles that supported ongoing respectful trusting relationship building and implementation of project activities.

Specific graphics were also generated to support the communication of concepts for data collection and to enhance the descriptions of project concepts. This is suited to the application and use of oral dialogue; rather than the typical use of written materials and allowed for First Nations participants to have a greater sense of control while discussions about cancer and illness took place. An important element, particularly for data collection about cancer diagnoses, these graphics helped to create a safe environment for individuals in a vulnerable position. An online survey was created to collect data from health care providers we were not able to reach through focus groups sessions. (See Appendix H, I, J, K for details)

## DATA COLLECTION

The task of collecting the data for the needs assessment involved engagement across multiple jurisdictions. The approach used, once again was embedded in building trusting relationships and understanding of the construct of ethical space.

The focus group sessions were structured using a sharing circle format, which established a safe environment for participation. Every session was opened with prayer, a round of introductions, and was then followed by a presentation about the project governance structure, goals, objectives and data collection methods. A talking circle approach, or sharing circle, was taken at each focus group session to ensure everyone had an opportunity to speak without interruption. This approach enabled participants to share their knowledge and experience in a way that was supportive and invariably allowed for healing to take place, particularly for participants who had never had an opportunity to speak of their cancer experiences before. (See Appendix I and J Facilitator Guides) This approach also enabled focus group facilitators to provide teaching and clarification about cancer and cancer care services. Many opportunities for cross cultural teaching and information-sharing during data collection and engagement sessions took place. This is reflected in the knowledge translation and exchange (KTE) data collected.

## DATA COLLECTION PARTICIPANTS

N=NUMBER OF PARTICIPANTS

### COMMUNITY

- Cancer Survivors N=28
- Community Members N=18
- Community Health Care Providers (CHR's, Nurses, Doctors, Managers) N=22

### NURSES

- CINA National Organization N=11
- FNIHB Home Care Nurses N=35

### COMMUNITY HEALTH REPRESENTATIVES

- Treaty 6,7,8 N=41

### HEALTH CARE PROVIDERS

- Cross Cancer Institute and Tom Baker Centre N=13
- Online Fluid survey N=110

### KNOWLEDGE HOLDERS

- Treaty 6,7,8 N=41

### KNOWLEDGE TRANSFER EXCHANGE SURVEYS

- KTE surveys N=113



# RESULTS AND FINDINGS

## PART A

The purpose of Part A was to determine the cancer care needs of Alberta First Nations people through the collection, analysis and reporting of qualitative data and information that informs existing quantitative surveillance data. These data would also articulate an Alberta First Nation cancer patient and family experience along the cancer care pathway.

## OUTCOMES

### First Nations Cancer Experience Gaps, Challenges, and Barriers

First Nation cancer experiences shared during this project revealed 5 thematic areas talked about by cancer survivors: patient supports, Non-Insured Health Benefits (NIHB), pain management, family supports and discharge planning.

Figure 3: First Nations Cancer Experience Gaps, Challenges and Barriers identifies the sub themes that had also emerged. Mental health supports were talked about by the participants in relation to access, availability, the potential difference that this kind of support can make during a cancer diagnosis and the difference mental health supports can make throughout the treatment process. Follow-up upon discharge was often not clearly communicated to the cancer survivor and they reported not knowing what steps were needed to be taken after treatment.

Also, cancer patients spoke about large amounts of literature they were given and how it was overwhelming to look at these once they returned home. Many of the cancer survivors talked about the need for someone to talk to about the experience. This was viewed as essential during the experience and when finishing treatment. Support groups at the community level were also talked about as an important need.

Pain management was identified in relation to being labeled a 'drug seeker'. In these instances, cancer patients were not given the prescribed access to their medications, which resulted in a limited coverage by their drug plan and the lack of a family physician to provide ongoing support in pain management. A referral to a pain management specialist was not offered in most cases.

Family supports were talked about from within a context of added financial burden for the cancer patient and impacts on the resources to support family needs. Significant others were often left out of the process, particularly when it came to increasing understanding about cancer and treatment processes. While some expressed the need for confidentiality they also felt challenged when it came to sharing the information with their significant others and those who were trying to support them at home.

The burden of care often fell on a few family members, due to a lack of knowledge and understanding. This included children who were at times required to stay home from school to support their parent while they were going through the treatment phase of the experience. Concerns were also raised on the effects of radiation on young children as mothers were not able to refrain from being close to their children at times. An example of this was not being able to find caregivers for their children while they received radiation therapy and having to travel to and from the treatment facility with their children. The children and significant others never received any emotional or mental health supports when a family member was diagnosed, which added to the stress that individuals with cancer were already feeling.

Discharge planning was limited for cancer patients most of the time due to communication breakdowns between the different health systems and federal/provincial jurisdictional issues. Some cancer patients were caught in the middle of these policies, which prohibited nurses and service providers from entering the reserve and or from leaving the reserve to provide care. This was reported to be the case even if the patient lived only meters off the reserve.



## VOICES OF FIRST NATIONS CANCER PATIENTS AND CAREGIVERS

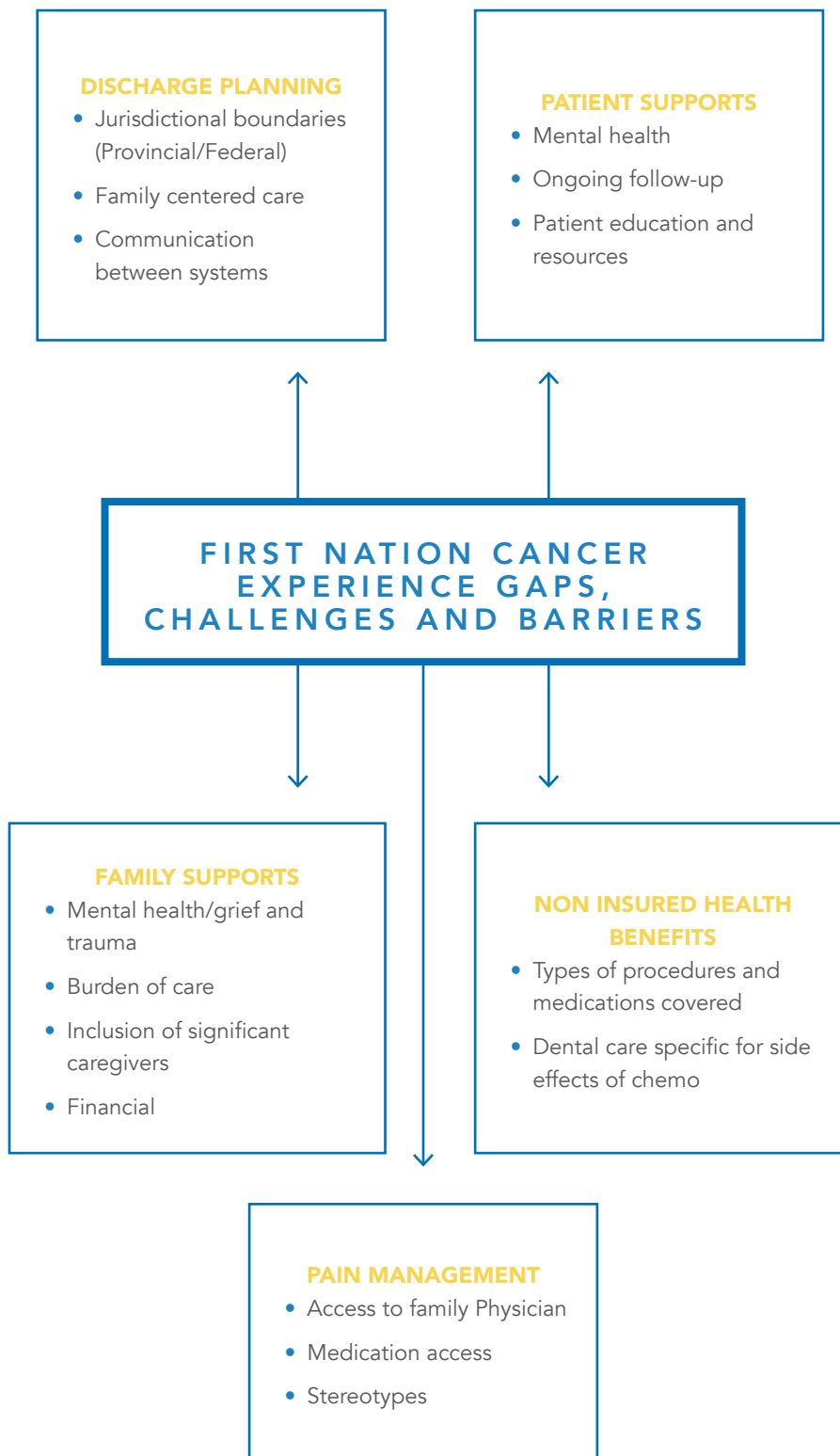
*"When she used to go see the doctor, [my] mom, used to say, arthritis. Every time I go see him that's what he says my mom would say - arthritis, arthritis that's all they say it is."*

*"Towards the end...we had to give him morphine, and I was trained to give him morphine. The nurses wouldn't even come down to give him his medication, so they trained me to give him morphine and every day I had to hide this morphine away because some of my siblings were into drugs. So, I had to hide it."*

*"Even with her prescription, after she was discharged from the hospital, there was no refills on her prescriptions. So, her and I had to set up another doctor in her neighborhood, but they were kind of ignorant. I went with her and they were like, well, what do you need this for? Don't you know that this is a narcotic?"*

*"Even back home, there was no support. Nothing. I just felt really lost and scared. Even the doctors back home, they were doing follow-up with my husband and I just felt there was no empathy to tell us where to go for support. We have eight kids in total, so they were all scared. There should be some kind of support when something like that is being told to a family."*

**Figure 3: First Nations Cancer Experience Gaps, Challenges and Barriers**



## HEALTH SYSTEM GAPS, CHALLENGES, AND BARRIERS

Health system gaps, challenges, and barriers were also identified during interviews with cancer patients and their caregivers. 6 themes emerged: medical transportation, patient cultural resources and supports, diagnosis and screening, communications with healthcare providers and the system, patient resources and supports, and cross cultural understanding.

Cancer survivors often spoke of the many issues related to transportation and raised concerns with having to ride in a medical transportation vehicle with other sick patients. As well, the length of wait times for their return trips and side effects from treatment while riding with others in a group vehicle were concerns mentioned frequently.

An exemplar of these circumstances is provided by a First Nations cancer patient in the following statement,

*"I have seen many on the bus, suffering, they say they want to go to pee, I think it's bad. I tell [the driver] we got to stop. I will piss right there on the road and the driver says you can't piss on the road. The highway, I tell him, I will piss in the god damned truck. This guy now he peed himself, he's got no clothes now. It's the same for the women, they won't say anything. It must be worse for the women..."*

Patient cultural resources and supports were discussed in relation to the lack of available cultural supports for patients in urban settings. This was also raised in the context of not knowing who to contact and what the protocols were.

*"The biggest gaps and barriers I've experienced are the misunderstandings from other health care professionals and underlying racism and other underlying – willful ignorance."*

*"When I got to the cross cancer...I didn't really know there were any cultural things there. Nobody said anything to me about [it]...We were walking and I think there is a little church we went into to there. Right? We used to go to that one and I think there is one across too".*

Diagnosis and screening were spoken about in two ways. First, people spoke about the time it took to get diagnosed and second, people talked about the way the diagnosis was delivered. Reported in one of the quotes above, there

was often a sense of a lack of empathy and care when a diagnosis was delivered. The length of time it took some cancer patients was up to 6 years.

*"It took them about three years, she was on antibiotics off and on, before she actually got diagnosed, because when she first got sick in October they said it was like a canker sore, it'll go away so they gave her antibiotics."*

*"When I first got sick with this, it was in my 19th year but I was not diagnosed until 6 years later. So, I had a hard time for 6 years with the medical profession because I have a rare type of cancer. It's hard to detect."*

Issues in communications with health care providers and the system were referenced in relation to translations of the disease and explaining the diagnosis and/or what to expect during the treatment. Patients were not aware of any communications between their family doctor and the cancer care staff and often remained under the care of the oncologists rather than the physician within the community after the treatment.

*"There are a lot of elders in the community that only speak Cree and maybe the translation, even when they see a doctor or when they want to talk to a nurse, they have difficulty because they might not have someone that can translate for them."*

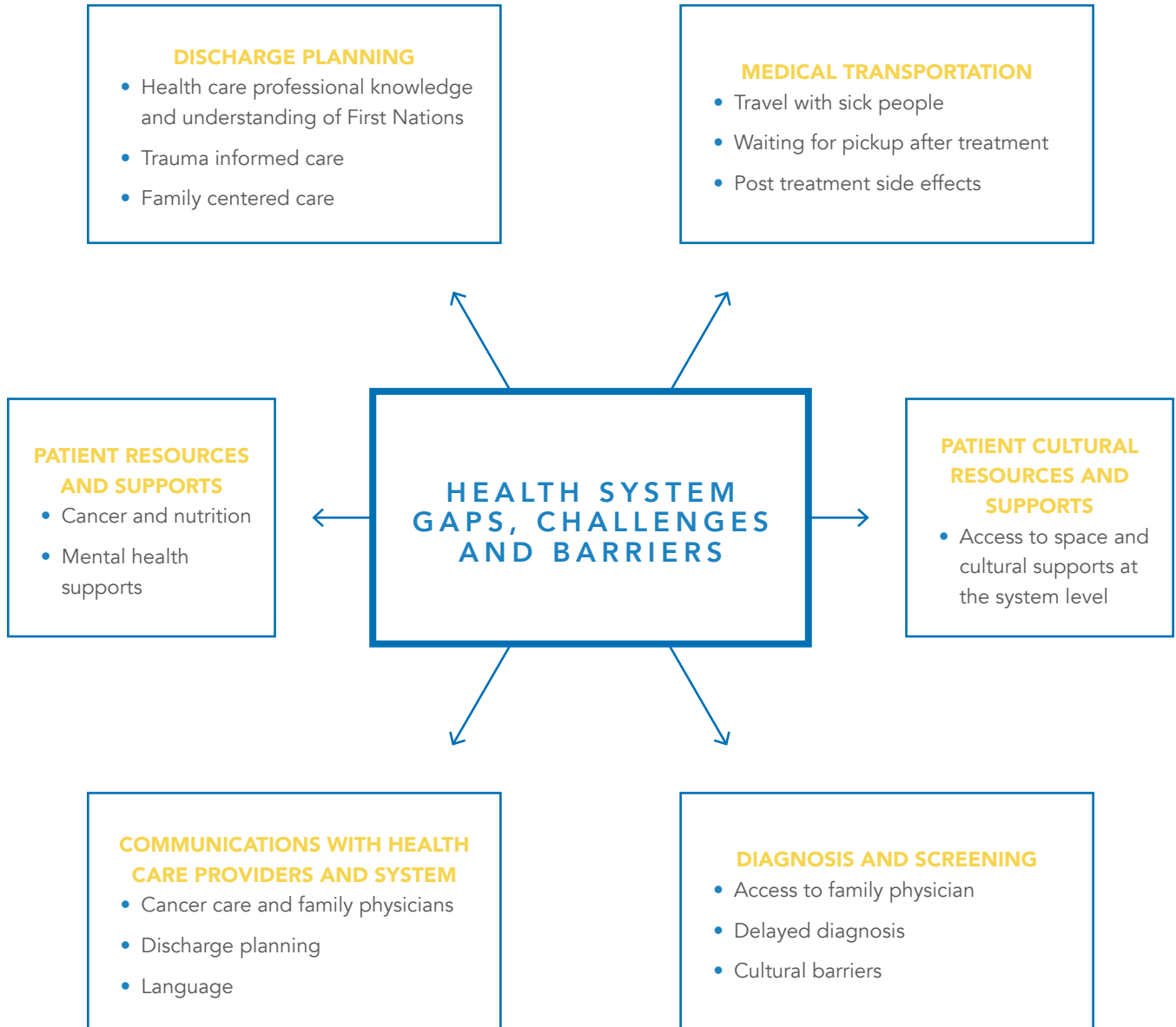
*"So, they didn't do a good job [or provide a] thorough explanation of what they were doing for you. They just said take this and that's it."*

The need to increase cross cultural understanding was identified by healthcare providers within the cancer care system and at the community level. A healthcare provider statement reflects by saying:

*"I think we don't prepare our patients either. For example, we have an agenda as care providers, right? But we often don't communicate that agenda to our patient very clearly. So, we have certain tasks, things that we have to accomplish by the end of the day. So, perhaps maybe the night before, or a couple of days ahead of time, there's actually some very specific tasks that you want the patient to get ready for and we don't even give them that. We expect them to remember all of that in their head and it's really difficult when you're going through a diagnosis and you're worried about your family back at home, and you only have ten dollars left in your wallet."*



**Figure 4: Health System Gaps, Challenges and Barriers**

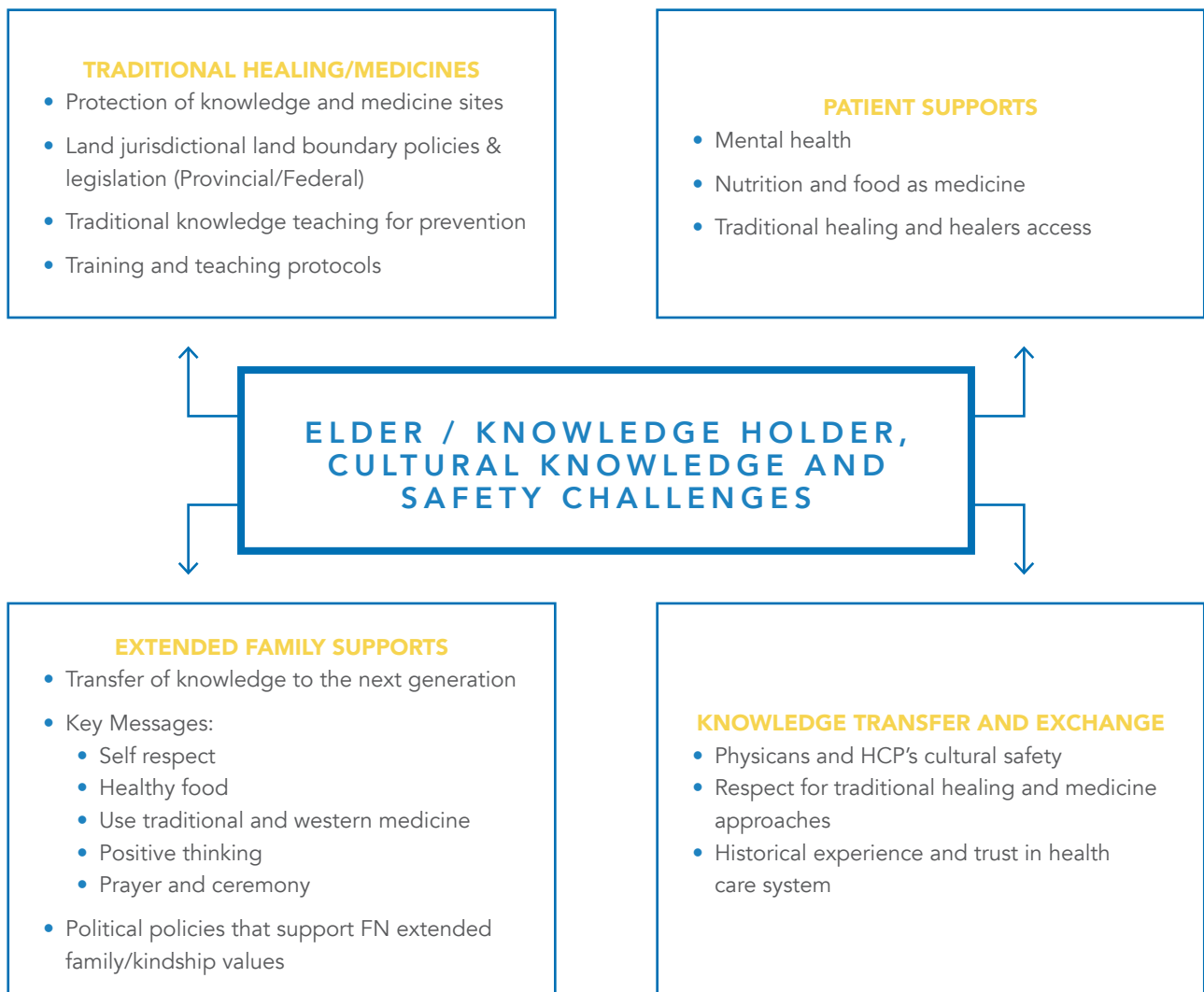


## KNOWLEDGE HOLDER FOCUS GROUPS

Knowledge Holder focus group sessions were held in the three treaty areas. These were meant to specifically engage Elder / Knowledge Holders who understood traditional supports and healing. As a result, the project could capture information about traditional supports related to traditional healing and ceremony, but also other areas of concern in relation to protection of the knowledge and medicine sites. Figure 5: *Elder / Knowledge Holder Cultural Safety and Knowledge Challenges* provides an overview of some of the areas of concern and includes key messages the Knowledge Holders often referred to.

Other main areas of concern of the Knowledge Holders were about patient supports, knowledge transfer and exchange, extended family supports, and the importance of having traditional healing medicines as an option for cancer treatment. There was much discussion around needing to develop better relationships between traditional practitioners and physicians to increase cultural spaces for those choosing to use traditional healing modalities.

**Figure 5: Elder / Knowledge Holder Cultural Safety and Knowledge Challenges**



## PART B

The purpose of Part B was to carry out a feasibility assessment of the information, partners, and processes required to prepare for system change. Part B focused on the use of First Nation patient identifiers. This included documentation of the elements essential for a framework/matrix in the development and use of First Nation identifiers in cancer care. Figure 6: Flow of First Nations Data and Information illustrates the complexities of the engagement required to successfully complete Part B of the project and indicates the often-extended periods of time for necessary governmental processes to occur.

## OUTCOMES

1. A data-sharing agreement with Cancer Control Alberta, and the service provider with authorization by Alberta First Nations Leadership - Treaty, 6, 7, and 8 to support access, control, and use of First Nation data and information. This was completed in 2017 as it took quite long for the groundwork to be put in place.
2. A coordinated feasibility assessment of the information, partners, and processes required to prepare for system change, with regards to the use of First Nation patient identifiers.
3. The creation of a framework for the development and use of First Nation identifiers in cancer care that are designed to increase access to available and newly created cancer care services.

This is the patient identifier for a cancer patient entering the cancer care system and saying, 'I'm First Nations' or to self-identify leading to access to a parallel cancer care pathway for First Nations. This cannot be completed until there is

a First Nations cancer care pathway because First Nation people cannot be asked to self-identify if no alternative exists. Such a request could put them at risk, if there is no pathway in place; therefore, this has been put on hold until the outcomes of Part A are implemented. Once there is a pathway for First Nations to follow, they can self-identify for the purposes of accessing and receiving tools, resources, and care that are culturally specific, appropriate, and safe. A system will also be required to track who is self-identifying and what tools, resources, and care has been provided.

National interest in these processes has occurred because, while Ontario has gone through a process specific to the cancer registry, Alberta First Nations are the first to navigate a process for more comprehensive access and use of identifiers. This process has included leadership and Nation engagement, capacity building within these groups about the use and interpretation of data, and the building of partnerships.

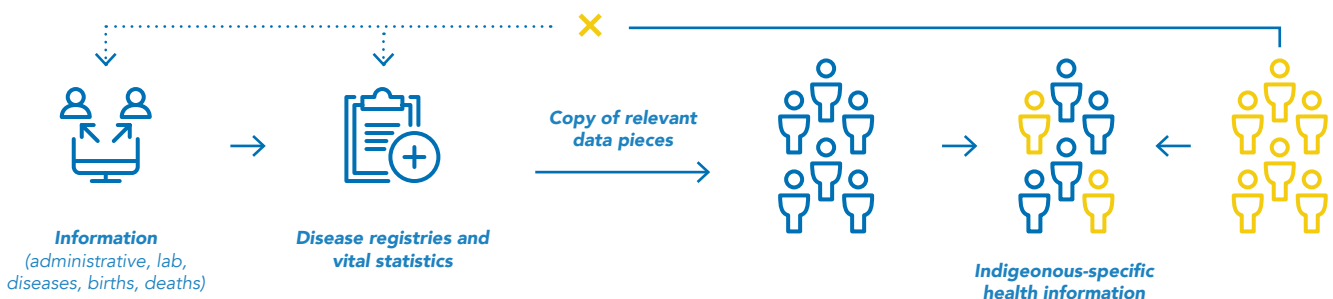
**Figure 6: Flow of First Nations Data and Information**

### WHERE DOES THIS INFORMATION COME FROM?

*Indigenous-specific health information*

#### Data consideration: 'data flow'

Indigenous identifying information from the Indian Registration System (or other identifiers like band lists) is not seen by anyone except a select few data analysts.





# EVALUATION

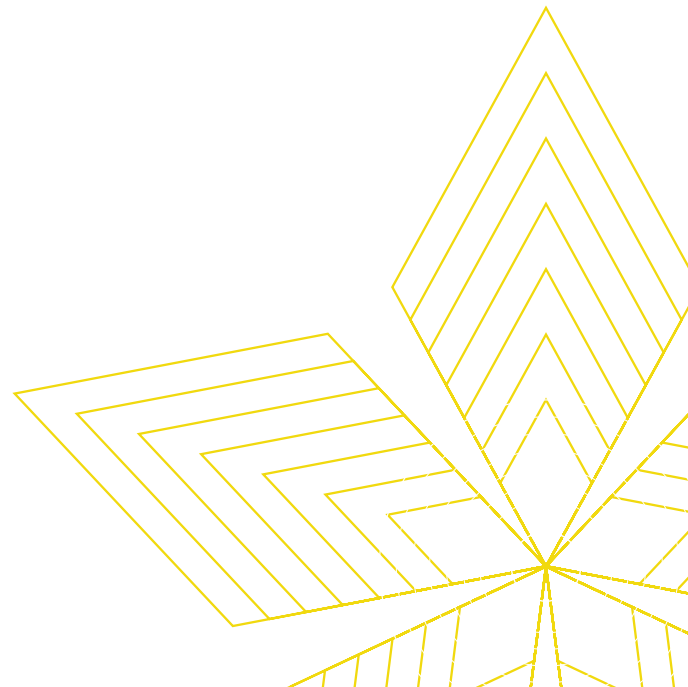
The table below is an outcome evaluation framework that indicates the flow of information in a more linear manner than the Indigenous approach. The evaluation framework was established toward the beginning of the project and lists the outcomes, indicators, and targets the project hoped to achieve. The 'results' section indicates what the project has achieved. Demonstrated from the results, most of the targets were either met or there was movement toward achieving the target.

This project utilized both an Indigenous and a non-Indigenous approach. The outcome evaluation table has been useful in maintaining the direction and focus of the project and in seeing the linkages between what was intended and what was achieved. The project team could see how the actions supported change. This project could utilize both an Indigenous and Western approach to evaluate this project.

An Indigenous approach was utilized to collect, analyze and report First Nations data and information. These included adherence to OCAP® principles and the significance of reporting information in ways, as recognized by our Elder Team, that are of **value and merit**, that represent **growth** in understanding, that support **autonomy** of First Nations communities, that was carried out in ways that provided for

**reciprocity**, that indicate **success** in better understanding the cancer care needs of First Nations, that represent both First Nations and AHS systems in **collaboration and working together**, and that have been done for the purposes of working toward **sustainability**. Reference to this model throughout the evaluation provided a framework for action, but also activities that would be carried out to meet the overall objectives or desired outcomes of the work inclusive of First Nations contexts, processes, and practices.

All of the Project Team, including the core and extended team members, contributed to the outcomes of the project in substantial and important ways. Challenges certainly occurred along the way, such as communicating effectively with diverse groups of people, the impact of the time required to engage First Nations people in culturally appropriate and safe ways, and consistent participation from all partners. However, in the end, evaluation outcomes reflect a level of awareness about the cancer care needs of First Nations people that did not exist prior to completing this project



## Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:

### Cancer Care – Outcome Evaluation Table

Part A Outcomes	Indicators	Targets	Results
<p>1. Trusting working relationships amongst the Project Team, FN communities and Cancer Care systems.</p>	<ul style="list-style-type: none"> <li>Stakeholders demonstrate willingness for ongoing collaboration with stakeholders invested in the First Nation cancer care pathway.</li> </ul>	<p>All lead communities are continually involved in the project</p>	<p>Service Agreements were signed between AHS and CPAC, and AHS and AFNIGC.</p> <p>Letters of support were provided by all lead communities (n=3), as well as signed data sharing agreements for needs assessments to occur.</p> <p>Letters of support from collaborators to engage in the activities of the project were received from both ANAC/CINA and IPAC, as well as University of Calgary and Alberta collaborators.</p> <p>Core Team representatives were present at 100% (n=&gt;20) of meetings, presentations and focus group sessions that took place in lead communities.</p> <p>Attendance at all annual leadership meetings included representatives from AHS CancerControl leadership, First Nations leadership, Treaty region partners, lead community representatives, Elder Team and Project Team members.</p> <p>Stakeholder and collaborators attended community events, such as Health Forums in lead communities and Treaty Region Knowledge Holder Gatherings.</p> <p>Collaborators engaged in consultative processes on the cancer care needs of First Nations people, including ANAC/CINA and IPAC and FNIHB CHRs and Home Care Nurses.</p>

## Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:

### Cancer Care – Outcome Evaluation Table

Part A Outcomes	Indicators	Targets	Results
<p>2. Greater awareness and use of Indigenous approaches and “ways of knowing” including those that involve the interrelationships and connections between people and systems.</p>	<ul style="list-style-type: none"> <li>Culturally appropriate methods are used to bring together First Nation holistic views of health for understanding and use within primary and oncology healthcare services and delivery.</li> <li>Professionals indicate the ways in which they are more culturally competent as well as the specific changes in practice.</li> <li>Patients indicate that their care was offered in a culturally safe manner.</li> <li>Professionals and patients indicate the ways in which barriers to culturally safe cancer care has been improved or resolved.</li> <li>Health care providers demonstrate increased knowledge of First Nations needs and cultural perspectives as they pertain to health and cancer care.</li> </ul>	<p>Approval processes of Treaty areas are followed</p> <p>Protocol is followed, Elder Team involvement, active involvement of Indigenous knowledge holders</p> <p>Articulation of key descriptors of culturally safe care</p>	<p>Meeting minutes recorded that 60% of meetings followed First Nations protocol by beginning in prayer, however, 100% (n=13) of extended team meetings began this way.</p> <p>Elder Team members were present at all extended team meetings (n=13) and many attended community events in each other’s regions (e.g. Elder Team members and extended team members from CINA, IPAC, and CPAC attended knowledge holder events in Treaty 8).</p> <p>Community representation from each of the 3 lead communities were present at 100% (n=13) of extended team meetings and 100% (n=3) annual leadership events.</p> <p>Majority of meetings were held in Edmonton and Calgary and at least 2 presentations were provided within each lead community.</p> <p>Presentations by core team members were provided at 6 First Nations leadership meetings including the Assembly of Treaty Chiefs and Health Co-Management. AHS discussion is underway between Indigenous Health Program and CancerControl Alberta to incorporate a plan supported by the Treaty region knowledge holders and partners to have professionals trained in cultural safety – Education Day participants (n=32) received a presentation from Cultural Safety lead in Indigenous Health Program.</p> <p>Needs assessment described barriers to culturally safe cancer care from community perspectives: Healthcare Provider online survey (n=110) indicated ¼ themes as ‘barriers to treatment with traditional medicine’ and indicated a cause, ‘Traditional healing not officially included in treatment plans’.</p>

**Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:**

Cancer Care – Outcome Evaluation Table

Part A Outcomes	Indicators	Targets	Results
<p>2. Continued</p>			<p>Needs assessment described barriers to providing culturally safe cancer care from health professional perspectives: Healthcare Provider online survey (n=110) indicated ¼ themes as ‘barriers to treatment with traditional medicine’ and indicated a cause, ‘Potential contraindications created by Traditional Healers and Western Doctors mutual unawareness of opposing treatment plans’.</p> <p>2017 Leadership Event participants (n=32) when asked to ‘Choose one action that would have the most impact in ensuring First Nations patients and families receive culturally safe cancer care’ responded: ‘Safety training for senior decision-makers’; ‘Cultural training – including history; Treaty information – developed by First Nations’; ‘Find common principles amongst cultures’.</p> <p>100% (n=12) of oncology healthcare providers attending focus group sessions reported increased knowledge of First Nations needs and cultural perspectives in relation to health and cancer care.</p> <p>Elder Team members (n=6) interviews identify community-level and system-level barriers for cancer patients and families.</p> <p>Treaty region Knowledge Holders (n=41) responding to KTE articulate descriptors of culturally safe care in relation to traditional forms of support reported in results section as ‘Knowledge Holder Cultural Knowledge and Safety Challenges’.</p>





**Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:**

**Cancer Care – Outcome Evaluation Table**

Part A Outcomes	Indicators	Targets	Results
<p>3. Improved health system awareness, understanding and knowledge of the needs and cultural perspectives of First Nation cancer patients, families and their caregivers by cancer care systems and stakeholders.</p> <ul style="list-style-type: none"> <li>Increased understanding of First Nation challenges for access to cancer care.</li> <li>Increased understanding of the points across cancer care and primary care on which to focus improvement for sustainable impacts on First Nation cancer journey (e.g. diagnosis, treatment of care, and homecare).</li> <li>Increased health systems' knowledge and awareness of the challenges and issues for First Nation cancer patients, families, and care providers along the cancer care pathway.</li> </ul>	<ul style="list-style-type: none"> <li>First Nation patients and caregivers report greater satisfaction with the sustainability of and recognition of system wide changes in culturally appropriate protocols, etc.</li> </ul>	<p>Articulation of descriptors and concepts required for sustainable system-wide change i.e., processes and procedures</p>	<p>Primary source of data to indicate improved awareness of health systems is the KTE evaluation (n=113).</p> <p>100% (n=12) of cancer care focus group participants strongly agree/agree that the information discussed is 'relevant to a challenge/gap that my organization or practice is currently facing' in relation to First Nations people and cancer care.</p> <p>100% (n=12) of cancer care focus group participants strongly agree/agree that they 'plan to use the information in decision-making'.</p> <p>Primary source of data to indicate improved awareness of health systems is the KTE evaluation (n=113).</p> <p>100% (n=12) of cancer care focus group participants strongly agree/agree that the information discussed is 'relevant to a challenge/gap that my organization or practice is currently facing' in relation to First Nations people and cancer care.</p> <p>100% (n=12) of cancer care focus group participants strongly agree/agree that they 'plan to use the information in decision-making'.</p> <p>100% (n=28) cancer patient interviews identified descriptors for areas of changes which are indicated within the 'First Nations Cancer Experience Gaps, Challenges, and Barriers' section of the report on results.</p> <p>Examples include cancer patient interviews (n=28) who reflected on time lapse taken to receive a diagnosis (2-6 years) and access to traditional forms of support. Elder Team (n=6) responses demonstrate that communities are working in their own ways to address cancer in First Nations: "I'm part of that group to do with cancer. I was interviewed by CPAC about cancer in the community and how to deal with cancer patients. Traditionally, we [work with people] who have cancer in our community. When cancer patients come home, they need after care."</p>

## Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:

### Cancer Care – Outcome Evaluation Table

Part A Outcomes	Indicators	Targets	Results
<p>4. Increased awareness and knowledge by First Nation people, their families, and caregivers of cancer and cancer care services:</p> <ul style="list-style-type: none"> <li>Increased awareness and understanding of First Nation cancer care needs across jurisdictions is identified.</li> <li>Increased evidence-based knowledge of the cancer care experiences of Alberta First Nation cancer patients, families, and caregivers.</li> <li>Identification and improved understanding of the gaps across multi-jurisdictional services of care that are shown to have specific impacts for Alberta First Nation cancer outcomes.</li> </ul>	<ul style="list-style-type: none"> <li>More First Nations are aware of the leading cancers within the First Nation population (more First Nations are screened for cancer).</li> <li>Health care professionals report that they are more aware of the experiences of First Nations cancer patients, their families, and caregivers.</li> <li>Health professionals report that there is more coordination of care across jurisdictions.</li> <li>Health care professionals report where the gaps exist.</li> </ul>	<p>50% of First Nation needs assessment participants and families are aware of the leading cancers and availability of screening</p> <p>60% of community and oncology care professionals engaged in the research are more aware of the experiences of First Nation cancer patients, their families, and caregivers</p>	<p>KTE forms (n=113) reflect that each opportunity of engagement with healthcare professionals included teaching and awareness raising about First Nations people and cancer-related needs: 81% (91/113) strongly agree/agree with the statement ‘relevant to a challenge/gap that my organization or practice is currently facing’.</p> <p>2017 Leadership Event participants (n=32) included 10 CancerControl Alberta leaders (31%) who received presentations about First Nations needs assessment outcomes including: challenges at the health system level, gaps in services and care, and the need for traditional forms of support in cancer care.</p> <p>CancerControl healthcare providers focus group participants (n=12) showed 25% (3/12) report awareness of availability of ‘transfer of care processes or resources’</p> <p>2 new resources aimed at support of First Nation, Inuit, and Métis cancer patients and families are ready for distribution in 2017.</p> <p>Needs assessment results report 6 themes for Health Systems Gaps, Challenges, and Barriers including ‘Communications with Healthcare Providers and Systems’ and ‘Cross-Cultural Training’.</p> <p>2016/17 RHS Alberta First Nations female respondents (n=591) when asked ‘Have you had any of the following screening procedures in the past 12 months?’: (cervical or pap), 35.7% reported yes; (mammogram), 22.3% reported yes; (colorectal), 12% reported yes.</p> <p>100% (n&gt;30) of participants at Treaty 8 Knowledge Holder community event with CPAC presentation raised issues about screening.</p>

**Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:**

**Cancer Care – Outcome Evaluation Table**

Part A Outcomes	Indicators	Targets	Results
<p>5. Enhanced coordination of services across multiple jurisdictions of care, with a focus on points of access for diagnosis, through treatment of care, and upon discharge to a variety of primary and community care services:</p>	<ul style="list-style-type: none"> <li>• Programs are ongoing in a sustainable fashion and sustainable funding is committed by Governments</li> <li>• Health care providers are reporting greater satisfaction in service delivery and follow-up is being captured and demonstrated.</li> </ul>	<p>Sustainability plan and additional and committed funds, which include the multi-jurisdictional partners, required for system-wide change</p> <p>20% of lead community health professionals are reporting that multi-disciplinary activities are taking place</p>	<p>Needs assessment has identified critical areas of need for improvement indicating changes required at a systems level including: 'Communications with healthcare providers and systems' and 'Patient resources and supports'.</p> <p>Role identification is stated within Service Agreements between AHS/AFNIGC and Data Sharing Agreements with lead communities.</p> <p>Needs assessment provides evidence of critical area needs for future planning and commitment of funds to improve the First Nations cancer care pathway through data collected regarding patient, family, community, community healthcare provider, community leaders, Knowledge Holder, and Elder Team perspectives: "Once all information has been received [from the needs assessment], the greatest impact will be for program planning and delivery of services, development and provision of information, and assistance to people navigating the huge medical system to get cancer care and follow up."</p>

**Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:**

**Cancer Care – Outcome Evaluation Table**

Part A Outcomes	Indicators	Targets	Results
<p>5. Continued</p>	<ul style="list-style-type: none"> <li>Providers report that gaps in care and patient care planning are being managed in a comprehensive and multidisciplinary fashion</li> </ul>		<p>Leadership event participants (n=32) included senior leadership from CancerControl and First Nations with a café style discussion that included scenarios that can lead to role clarity: Summary points around next steps to sustain partnerships with First Nations include 'Leadership meeting should be ongoing to update partners' and 'A mechanism is needed to move forward together to address issues'</p> <p>Elder Team and Knowledge Holder engagement (n=41) with our team indicate a traditional perspective that lead community professionals and Elders are working together in relation to cancer care within their communities: "Providing more information gives First Nations a better chance to get help. The impact is slow, but a lot of people are working with the right ideas and with the right information. To fast track everything, we need to get more elders to come who are very knowledgeable."</p> <p>99% (n=94) of KTE health care provider respondents (n=113) engaged in focus groups stated they strongly agreed/agreed when asked if they 'plan to use the information in decision-making?'</p> <p>National and international level collaborations demonstrate multi-jurisdictional partnerships now exist to support evidence-base for sustainability in 'system-wide changes': "A community network work was implemented and as a result CINA (ANAC) was able to make greater connections to local and provincial service providers within the Alberta region." and Information taken from Nov/2015 CPAC Dashboard and Status Report: Week of Nov 16– Gail Garvey, Suzanne Moore (WHO @ IARC) coming to meet Elders and the AB Project team, talk with her about how to do collaborative work, challenges they've had to face in their respective countries.</p>



## Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:

### Cancer Care – Outcome Evaluation Table

Part A Outcomes	Indicators	Targets	Results
<p>6. Improved First Nation cancer experiences and needs are identified and modifications are made to existing and developed processes, protocols and resources.</p>	<ul style="list-style-type: none"> <li>-Professionals indicate that cancer care supports have improved.</li> <li>-Professionals indicate that there has been an increase in access to First Nation health care service delivery for patients and their families.</li> <li>-List of tangible products are developed and being applied for better patient outcomes and services.</li> </ul>	<p>20% of health professionals report that new supports are in place for First Nation cancer patients, families, and care providers.</p> <p>50% of oncology and community health professionals refer First Nation cancer patients and their families to cultural supports i.e., Aboriginal Program supportive roles including the Cancer Patient Navigator and Cultural Helpers</p>	<p>CHR Training about cancer knowledge is being planned with FNIHB project collaborator/extended team member.</p> <p>Several newly developed/adapted tools are available at AHS in 2017 for First Nation, inuit, and Métis communities to do cancer planning: Readiness Assessment Resource, Guide to Preparing First Nation, inuit, and Métis Communities for Cancer Prevention, Storywork videos, A Supportive Resource for First Nations People with Newly Diagnosed Cancer,</p> <p>Number of cancer care health professionals attending the Education Day events (n=32) indicates that there are First Nations cancer patients and families accessing care.</p> <p>100% of oncology and community health professionals participating in focus groups (n=53) received information about the Indigenous Health Program supportive roles including the Indigenous Cancer Patient Navigator and Cultural Helpers.</p> <p>100% (n=12) those who participated in focus groups are aware of the availability of services and discussion at level of CancerControl: "As a representative of AHS CancerControl Alberta, I have begun working with First Nations communities to develop partnerships to begin offering psychosocial support through telehealth."</p>

## Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:

### Cancer Care – Outcome Evaluation Table

Part A Outcomes	Indicators	Targets	Results
<p>7. Earlier diagnosis, improved treatment of care experiences and improved discharge and follow up by First Nation patients and care givers because of increased access to cancer care.</p>	<ul style="list-style-type: none"> <li>• First Nation patients and caregivers report increased satisfaction with resources, supports, tools available for cancer control and/or for the cancer journey, (keeping in mind that a positive result may be different from one person to another.)</li> <li>• First Nation patients and caregivers report a greater knowledge of and utilization of community supports systems.</li> <li>• First Nation patients and caregivers report increased satisfaction and competence in transitions from active cancer care to returning home care.</li> <li>• First Nation cancer patients and caregivers report a greater sense of self-determination in their own cancer-care.</li> </ul>	<p>50% increase in First Nation cancer patients, families and care provider's awareness of resources and supports</p> <p>All Alberta First Nation cancer survivors have increased awareness of treatment options and available supports</p>	<p>100% focus group participants (n=181) are aware of new tools to support First Nations cancer patients and families to be made available in 2017</p> <p>100% of community leads (n=3) confirm there is a need for culturally relevant and safe cancer care resources for First Nations cancer patients and families regarding early diagnosis, improved treatment of care, and discharge from cancer care: "Community events and meetings took place where project co-leads were in community and it was beneficial to see that people were willing to listen and share their experiences about cancer. One important insight is the 'disconnect' that community members feel there is between the time when they felt ill and the time when diagnosis occurred. From the perspective of community members, this is a very long time."</p> <p>Community leads (n=3) identify potential for project outcomes to have impact on First Nations people awareness of treatment options and available supports: "The project will eventually benefit the community by providing information-brochures, screening information, websites, screening events, support groups to community members. The project will provide information to the staff working with people in the community who are affected by Cancer and /or a chronic illness."</p> <p>100% of cancer survivors (n=28) reported opportunities to share about their cancer illness is important to help raise awareness of other First Nation people.</p> <p>Elder Team members stated impact on rates is difficult because of a lack of available services: "The only [partnerships with First Nations and cancer] I am aware of are the Elder's Advisory that works with the CPAC project. There is good discussion and we need more of it.</p>

**Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:**

**Cancer Care – Outcome Evaluation Table**

Part A Outcomes	Indicators	Targets	Results
<p>7. <i>Continued</i></p>			<p>Elder Team members indicate that being involved in the project helped to bring the kind of engagement to communities that support First Nations people awareness and choices about cancer care: “The CPAC project team has interacted with knowledge keepers at our gathering in Treaty 8. This has opened a lot of [discussion] on issues about cancer in our community that were never discussed openly before. People are scared of the word ‘cancer.’ The team was excellent in explaining screening and [how that can lead to] early treatment. Interviews were also carried out in Bigstone about cancer. I have been to continuing-care and primary-care forums that [CPAC hosts] and those are very important. A lot of information is shared about cancer and screening.”</p>
<p>8. Established collaborative relationships/roles of advisory and stakeholder groups at 3 levels of impact: individual care; service and delivery; policy and decision-makers.</p>	<ul style="list-style-type: none"> <li>• Sustainable multijurisdictional agreements are in place, which are beneficial for the patients, AHS, and First Nation health delivery systems.</li> <li>• Service providers and First Nation communities, AHS, and Cancer programming indicates sustained relationships.</li> <li>• Sustainable inter-jurisdictional agreements are in place with funding.</li> </ul>	<p>A partnership agreement between local, regional, provincial, and/or federal multijurisdictional stakeholders is in place</p> <p>Lead community cancer patients, families, and care providers have increased access to community-level cancer care programming and supports</p>	<p>Extended team members included Indigenous Health Program senior management present at more than 50% (7/13) of meetings (n=13) leading to awareness of project stakeholders and partners of the supportive services available at AHS for First Nations through AHS.</p> <p>32 cancer care providers attended the 2017 Education Day and received information about the First Nations cancer care needs assessment findings, including 5 medical oncology students, 7 oncology nurses, radiation therapists, nutritionists, social workers, and others. This event was co-facilitated by an oncologist as a ‘champion’ for FNMI cancer care needs.</p> <p>Healthcare system relationships within AHS have increased as noted by statements from a project co-lead: “We have begun to link CancerControl staff with Indigenous Health Program staff in some of our rural communities to work together to better support Indigenous patients.”</p> <p>Partnership agreements between CancerControl Alberta and AFNIGC have ended with the Leadership Event Report stating that discussion raised the needs for ‘continued engagement’ and ‘policy changes’.</p>

**Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:**

**Cancer Care – Outcome Evaluation Table**

Part A Outcomes	Indicators	Targets	Results
<p>8. <i>Continued</i></p>	<ul style="list-style-type: none"> <li>-Cross-jurisdictional team approaches are incorporated into cancer care programming, (e.g. family physicians, traditional health practitioners, mental health workers, nursing, spiritual and ceremony practitioners, etc.).</li> <li>-Partners report sense of transformational change in the way they understand each other.</li> </ul>	<p>Funding agreements are in place between multi-jurisdictional stakeholders</p> <p>Space is provided for traditional health supports to be made available to First Nation cancer patients and their families.</p>	<p>New partnerships across jurisdictions of care include 1) EHVINA 1.2-million-dollar research collaboration with First Nations, AHS Cancer SCN and ACPLF, FNIHB and more, 2) ACPLF 1.7 million First Nations Cancer Prevention and Screening Practices Project in collaboration with First Nations, CINA/IPAC, and more.</p> <p>First Nations cancer survivor story at 2017 Leadership Event expressed increased awareness of services and supports, but also indicated that there is a lack information shared in communities until the needs assessment took place.</p> <p>Evaluation Questionnaire First Nations response when asked, 'What new processes have been initiated for the coordination of care across 2 or more jurisdictions?': "Initial awareness of cancer and cancer care gaps/ barriers and changes required throughout all federal and provincial systems...has been completed. Action required to create total awareness and implement all strategies throughout the jurisdictions of First Nations communities, federal and provincial jurisdictions is needed."</p>



## Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:

### Cancer Care – Outcome Evaluation Table

Part B Outcomes	Indicators	Targets	Results
<p>1. Partners, processes, and protocols have been determined that work together to create a framework for the development, use, and tracking of First Nation data and information</p>	<ul style="list-style-type: none"> <li>List of partners.</li> <li>Partnership agreements in place.</li> <li>Number of meetings.</li> </ul>	<p>As is outlined in the Health Information working group.</p>	<p>First Nations Health Information Working Group is aware of CPAC Project and ongoing meetings include AFNIGC/Project co-lead.</p> <p>2013, the Assembly of Treaty Chiefs (AoTC) in Alberta Resolution No. 2013-06-12/R04 to obtain First Nations identifiers from Indian Registry System.</p> <p>Mandated AFNIGC to develop a First Nations Health Information Governance Agreement and submit an application for the data in partnership with Treaty 6, 7, and 8, Alberta Health, FNIHB, INAC, and AFNIGC.</p>
<p>2. Data sharing needs have been determined and stakeholders/ leadership has been engaged to support required agreements and processes, including development and use of First Nation identifiers for cancer care.</p>	<ul style="list-style-type: none"> <li>Relationships between First Nation leadership and organizations have been established.</li> <li>Protocol for the use of First Nation identifiers has been established and approved by First Nation leadership and organizations.</li> </ul>	<p>Resolution(s) are in place.</p>	<p>Application to access the Indian Registry submitted February 2016, and verbally approved by INAC, September of 2016.</p> <p>A First Nations Health Information Data Governance Agreement was developed in 2016 to develop an Information Sharing Agreement between Alberta Health and INAC.</p> <p>Alberta Health is conducting a Privacy Impact Assessment.</p> <p>Once the IRS data is available, it will be linked to a provincial population registry and Alberta Health will clean the data.</p>

**Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities:**

**Cancer Care – Outcome Evaluation Table**

Part B Outcomes	Indicators	Targets	Results
<p>3. First Nation leadership, organizations and communities are engaged in the design, development and implementation of First Nation patient identification strategies.</p>	<ul style="list-style-type: none"> <li>List of members of each of these groups that have been involved in the process.</li> </ul>	<p>All stakeholders listed have been identified.</p>	<p>Working Groups continue to take place with partners at AFNIGC, Alberta Health, FNIHB and First Nations leadership.</p> <p>Alberta Health Services senior leadership recently invited to the table.</p> <p>Indicators received include: client ID, name, date of birth, sex, residency, Band ID, and vital status.</p> <p>Deterministic linkages will be done through Alberta Health to include name, date of birth, and sex as primary variables that might identify an individual as the same one in our systems.</p>

## DISCUSSION

The Canadian Partnership Against Cancer, First Nation, Inuit, and Métis Program evaluation outcomes for the Advancing Improvements in Continuity of Care for First Nations, Inuit and Métis Patients in Rural and Remote Communities initiative are:

- increasing the understanding and knowledge of First Nations, Inuit, and Métis cancer experiences;
- improving access to culturally-relevant supports and services;
- making cancer diagnosis delivery more culturally-sensitive;
- improving transfer of care between the patient's home community and secondary/tertiary cancer care centres; and,
- increasing the number of jurisdictions with specific actions to advance a First Nations and/or Métis and/or Inuit cancer control strategy.

From this section on First Nations cancer pathways project evaluation, the data and information reported in outcome 3 show that 'increased understanding and knowledge of First Nation, Inuit, and Métis cancer experiences was met through sharing at events, during focus groups sessions with healthcare providers, and by presenting information at a variety of forums, including health forums, Knowledge Holder Gatherings, and even international conferences. An important indicator for this work was that definitive interest exists among cancer care providers (n=32) to improve the way services are provided to First Nations cancer patients. This is the number of those who participated in the Education Day events at a tertiary cancer care facility. However, the very low numbers of cancer care staff engaged during the needs assessment (n=12) or less

than 1-2% indicates there is much work still to be done. Other national-level outcomes can be shown to have been partially met or that work is underway in Alberta to make the changes necessary to improve the cancer experiences of First Nations people. At the least, it has been demonstrated through the work of Part A (needs assessment) and through the success of Part B (data surveillance and First Nation identifiers), that improvements in each of the outcomes identified in our evaluation plan have either been met or are underway. For instance, Part B lists that there are increased numbers of jurisdictions with specific actions identified for a cancer control strategy for First Nations in Alberta based on data and evidence.

Our evaluation does recognize that meeting several of the outcomes developed by CPAC including, improving access to culturally-relevant supports and services, making cancer diagnosis delivery more culturally relevant, and improving transfer of care between the patient's home community and secondary/tertiary cancer care centres, require much more work to say they have been met through the work of one initiative with Alberta First Nation communities and AHS. However, it is with confidence that we report both Part A and B of this project have brought forward evidence of fundamental changes needed to begin developing new standards of care and/or strategy for providing culturally appropriate and safe care to First Nations cancer patients and families. In fact, it can be suggested that a lack of strategy for providing this kind of care to First Nation, Inuit, and Métis people in Alberta has impacted the care received when service providers are not provided with the information and policies to guide this kind of care.

## LESSONS LEARNED

During this project, the guidance and knowledge of the Elder Team has and will continue to inform outcomes through providing an understanding of the significance of cultural knowledge and teachings to an improved cancer care pathway for Alberta First Nations. This includes an understanding of how to use the collected stories in culturally relevant and safe ways, the significance of the collected data in communicating the realities of many First Nations people, and a further articulation of the perspectives of Knowledge Holders about Indigenous methods of support.

The challenges for reporting on the outcomes of this project in ways that are impactful became particularly apparent in working to understand and articulate the significance of the unique experiences of First Nations cancer patients. The effects of these experiences upon families, communities and even nations are much more far reaching than many healthcare providers may envision. Clearly though, a commitment and desire for First Nations to receive equitable care and services was recognized by both First Nations and AHS leadership at the 2017 Leadership Event.

The resources needed to undertake a project of this magnitude were adequate, however the tripartite agreement between CPAC, AHS, and First Nations was challenging. This may be due, in part to a lack of knowledge and understanding of First Nations governance structures and the impacts of multiple jurisdictions responsible for the healthcare of First Nations communities and people. For example, provincial policies and procedures often made getting the work done in a timely fashion difficult.

Building trusting relationships, as a critical aspect to the work was at times not reflected in the actions or willingness to share in the work by all partners. However much of these circumstances may be attributed to a lack of knowledge and understanding about First Nations practices leading to a need to ensure key partners have the

skills and knowledge to effectively communicate, engage, and build trusting relationships with Alberta First Nations. This includes a basic knowledge of First Nations people, their governance structures, and the importance of culture to the health and wellness of these communities (Refer to the Alberta Baseline Report).

As well, the significant roles of Elders and Knowledge Holders is key to ensure the success of projects such as this must be supported by AHS and other stakeholders. Support needs to include a willingness to learn about the importance of protocol, relationship building with AHS Indigenous Health Program staff, and appropriate remuneration for the involvement of traditional teachers, Elders, and Knowledge Holders.

In analyzing and reporting on the outcomes of the project, it cannot be overstated how truly difficult it is for the outcomes to be shared in a way that imparts new knowledge and understanding about the uniqueness of these experiences and their impacts to collaborators and partners. Although it is reasonable to assume that future projections for poor health outcomes in First Nations communities require immediate actions to alter these statistics, the link between how current programming and services are rising to meet these challenges and the changes needed at a systemic level is still somehow lost and perhaps reflected in the minimal actions of collaborators to move quickly toward a 'new way' of doing business.

How First Nation communities and people are viewed is important to build a foundation of trust and support lasting relationships. These relationships should be based on the development of strategies and frameworks that are capable of articulating parallel ideologies, frameworks, and knowledge of health and wellness. These are important for describing the experiences of First Nations people in ways that do not harm or further pathologize their experiences. Moreover, several important outcomes were not anticipated

during this project. For instance, First Nation Elder Team members attended the 2016 Inaugural World Indigenous Cancer Conference in Australia, made possible through funding from CPAC, resulting in several of these members now being engaged by other Indigenous people from other countries. Other positive, but unanticipated outcomes included:

1. Capacity building with First Nation communities on the use of data, including the self-governance piece re: nation-to-nation rebuilding;
2. Alberta Health facilitated a beginning dialogue with Vital Stats and INAC to improve IRS data;
3. The Truth and Reconciliation Commission's 'Call to Action' and #19 being implemented through this process;
4. Health Trends developed in partnership between AFNIGC and Alberta Health that are meant to create awareness on important health surveillance data;
5. A First Nations health status report;
6. A government partnership and article twenty-one, which identifies free, prior, and informed consent that embraces OCAP® and implements the United Nations Declaration on the Rights of Indigenous Peoples; and
7. Community profiles project and the use of these data from a Nation perspective. This reflects an interest in working with communities to put together the data from an Alberta Health, FNIHB, AHS perspective.

## MOVING FORWARD

Sustainability planning during this project was led by AHS CancerControl Alberta because of their capacity and key position to engage First Nations governance, communities, collaborator groups, and other interested organizations. As well, system change at any level – individual pursuit of care, service and delivery, policy, and decision-making - requires active involvement by the cancer care system. Previous work through AHS CancerControl included an exploration of the core elements required to develop a First Nations, Inuit, and Métis cancer strategy. Captured within the 2013 report, *Summarizing Aboriginal Cancer Strategy Documents and Information in an Alberta Context: A Community Oncology Aboriginal Cancer Planning Initiative Report*<sup>10</sup>, the underlying and initial focus of these initiatives included two priority areas of development: 1) Increased First Nations, Inuit, and Métis access to cancer care services and delivery; and, 2) Relationship building with First Nations, Inuit, and Métis peoples.

There are elements of the sustainability plan informed from the needs assessment and the surveillance work of Part B of the project. For example, some activities reflect goals that should be ongoing at AHS CancerControl Alberta, such as bringing Knowledge Holders together with oncology care providers to understand how First Nation cancer patients can benefit from both systems of care. As well, there is a role for other health system partners and collaborators, including First Nation communities to take responsibility for reporting on activities that work towards the following outcomes:

- Improved Cancer Care systems and collaborator awareness;
- Increased understanding and knowledge of the needs and cultural perspectives of First Nations cancer patients, families, and their caregivers;
- Increased awareness and knowledge by First Nations of cancer and care services; and
- Enhanced coordination of services across multiple jurisdictions of care, with a focus on points of access for diagnosis, through treatment of care, and upon discharge to a variety of primary and community care services.

<sup>10</sup> Letendre, A. 2013. *Summarizing Aboriginal Cancer Strategy Documents and Information in an Alberta Context: A Community Oncology Aboriginal Cancer Planning Initiative Report*. Alberta Health Services,



Within the sustainability plan were objectives that have not been completed at this time, however it should be noted that the groundwork is in place for each of these activities to occur. They include:

1. The development of a First Nations Cancer Care Pathways Navigation Map;
2. Plans to explore options for a First Nations Traditional/Spiritual Supports Strategy;
3. Discussion to mandate, as part of staff orientation, phased learning through My Learning Link on Aboriginal e-learning courses linked to performance reviews, beginning with navigators and social workers;
4. Distribution of the A Supportive Resource for First Nations, Métis and Inuit People Newly Diagnosed with Cancer funded through the Alberta Cancer Foundation; and
5. Distribution of the storywork and dialogue project videos - Dialogue and Storywork in Support of First Nations, Inuit and Métis Cancer Patients throughout Oncology and Primary Care Transition Experience funded through CPAC.

A key outcome from this work that influences sustainability are the agreements set in place for data exchange and future First Nations health surveillance within Alberta. The health trend reports produced in partnership with AHS are proving to be a valuable resource in communicating and informing leadership of the gaps and current health status of Alberta First Nations. These reports can be accessed on the AFNIGC website.

Several additional partnerships have been developed and set in motion as a result of the CPAC project.

AFNIGC and the Alberta Cancer Legacy Fund (ACPLF) with Dr. Angeline Letendre and the ACPLF leadership have formed a partnership with 3 lead communities over the next 2 years to carry out a demonstration project, which focuses on supporting First Nation communities to develop cancer prevention and screening plans. The project is framed around assessing supportive environments for cancer prevention and screening planning and implementation of those plans. The model applied includes placing a Community Prevention Practitioner role within a First Nations community to support and assist in the development of the cancer prevention and screening planning. This important role acts as part of First Nations Support Team for cancer prevention and screening, which is led by a First Nations Nurse Practitioner bringing expert clinical knowledge to the team, on-the-ground understanding of the needs of communities, and lived experience as a First Nations person growing up in a First Nations environment.

The Alberta First Nations Information Governance Centre (AFNIGC) has partnered with Alberta Health Services-Alberta Cancer Prevention Legacy Fund, CancerControl Alberta, and the Cancer Strategic Clinical Network to carry out the research study: Enhancing HPV Vaccination In First Nations Populations in Alberta (EHVINA). Funded through the Alberta Cancer Prevention Legacy Fund (ACPLF), the main aim of the study is to develop a knowledge translation strategy for enhancing and supporting the increased uptake of the HPV vaccine in First Nation communities. By applying a Nation-based approach to engage and support First Nations participation in the research, the study will incorporate community needs and raise awareness of the cultural needs of First Nations while enhancing the uptake of the HPV vaccine. A principle of this approach is Nation ownership as a requirement for sustained change to take place.

## RECOMMENDATIONS

Recommendations from this project fall within the initial 3 areas of desired impacts from the proposal

1. individual pursuit of care
2. services and delivery landscape
3. policy and decision-makers.

Strategic priority outcomes identified within the proposal for this project can also be indicated in the outcomes of the project:

- A. best practices
- B. resources and supports
- C. data information gathering framework.

The following recommendations, in no particular order, are taken from the Part A Needs Assessment data and fall within areas of desired impact 1 and 2 or strategic priority outcomes A and B:

- Place an Indigenous Cancer Patient Navigator at the Tom Baker;
- Utilize CHR's in cancer prevention and screening;
- Provide Cancer 101 education for healthcare staff at community level;
- Require supports for males to promote health self-care;
- Provide additional supports and education on medications for cancer;
- Require improvement of services for pain management;
- Raise funds to support First Nation cancer patients;
- Provide nutritional education and supports for those with limited resources, such as 'meals on wheels';
- Develop 'Welcome Home' packages about availability of Nation-level supports and services for patients discharged from cancer care;
- Write patient diagnosis on the prescription to help NIHB processing for supplies;
- Provide more home visits from nurses and CHR's;
- Provide hospice on reserve for palliative patients and those cancer patients requiring help during the treatment phase;
- Teach and educate doctors about cultural safety, traditional healing, and knowledge;
- Develop mechanisms to connect with traditional healers and cultural knowledge holders;
- Assist cancer patients to have a family doctor to access for other/follow-up care and concerns;
- Educate cancer care providers about financial matters for people living on reserve;
- Allow community nurses to provide service to residents off reserve at the Nation-level;
- Encourage early check-ups for people;
- Train healthcare providers on how to provide support to families;
- Provide therapeutic environments;
- Develop a day program for patients and Elders to come together;
- Provide First Nations support groups for people to share their stories;
- Begin cross-cultural training in the schools;
- Make available traditional supports at service-level, i.e., designated site Elders;
- Provide Cultural Camps to share knowledge;
- Provide community healthcare providers with training and workshops on First Nation ways of knowing;
- Provide stress management training for patients and families;
- Educate doctors on cultural safety; and
- Change policies that are barriers at the health center and service-provider level.



## RECOMMENDATIONS (CONT'D)

The following systems level priority areas (policy and decision-makers) are taken from recommendations provided by First Nations and AHS leadership:

- Culturally Safe Care – provide safety training for senior decision-makers and cultural training to cancer care staff that is designed by First Nations;
- NIHB needs to be based on legislation, not policy;
- A First Nations Navigator is needed for the south;
- Introduce traditional medicine without expropriation of knowledge with access to the medicines and providing space for smudge/spiritual practice;
- Provide access to data access to monitor care and disease;
- Develop a framework for Nations to develop cancer care programs;
- Provide linkages to existing supports - communicate what is available, resources and service lists for health centres in community, identify health services available in community;
- Clarify healthcare roles;
- Develop a sustainability approach for resources – keep them updated, standardized, develop oral resources;
- Align First Nations and CancerControl priorities;
- Provide financial support to sustain improved programming;
- Maintain the discussion;
- Develop a program to work with traditional healers – work with Knowledge Holders to provide resources for patients and families wanting access to First Nation healing systems;
- Education for First Nations communities, families, and people about where to access resources;
- Evaluate if cancer patient navigation for Indigenous people makes a difference;
- Provide adequate translation services for serious diagnoses;
- Standardize healthcare provider roles in facilities;
- Address access to care;
- Provide prevention and screening resources with culturally relevant messages;
- Raise awareness on jurisdictional issues such as medical transportation program;







# CONCLUSIONS

“Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote, and Isolated Communities” is a coordinated, holistic, and comprehensive project with Alberta First Nations and Alberta Health Services–Cancer Control Alberta. Grounded in First Nations understandings of health and wellness, the approach included guidance from a core team (project co-leads), extended team (project co-leads and partners/collaborators), an Elder Team (Treaty region Elders and Knowledge Holders) and a leadership committee (First Nations, AHS and Stakeholder leaders). Alberta First Nations ‘ethics of practices’ for engagement, relationship building and activities were followed, which included practices of ceremony and protocol to create safe environments for participation. As key strategies for success, these practices provided a basis for the engagement of all project participants and are reflected in the activities described to carry out the goals of Part A (Needs Assessment) and Part B (Feasibility Assessment).

Results of the needs assessment included thematic areas of:

1. First Nations cancer experience gaps, challenges and barriers;
2. Health system gaps, challenges and barriers;
3. Knowledge Holder cultural knowledge and safety challenges.



**Evaluation outcomes were discussed for Part A and B which included a set of 11 objectives.**

**PART A OBJECTIVES INCLUDED:**

- Trusting working relationships amongst the Project Team, FN communities and Cancer Care systems: Greater awareness and use of Indigenous approaches and “ways of knowing” including those that involve the interrelationships and connections between people and systems;
- Improved health system awareness, understanding and knowledge of the needs and cultural perspectives of FN cancer patients, families and their caregivers by cancer care systems and stakeholders;
- Increased awareness and knowledge by FN people, their families and caregivers of cancers and cancer care services;
- Enhanced coordination of services across multiple jurisdictions of care, with a focus on points of access for diagnosis, through treatment of care and upon discharge to a variety of primary and community care services;
- Improved FN cancer experiences and needs are identified and modifications are made to existing and developed processes, protocols and resources;
- Earlier diagnosis, improved treatment of care experiences and improved discharge and follow up by FN patients and care givers as a result of increased access to cancer care;
- Established collaborative relationships/roles of advisory and stakeholder groups at 3 levels of impact:
  - individual care;
  - service and delivery;
  - policy and decision-makers.

**PART B OBJECTIVES INCLUDED:**

- Partners, processes and protocols have been determined that work together to create a framework for the development, use and tracking of FN data and information;
- Data sharing needs have been determined and stakeholders/ leadership has been engaged to support required agreements and processes, including development and use of FN identifiers for cancer care;
- FN leadership, organizations and communities are engaged in the design, development and implementation of FN patient identification strategies.

Although the scope of the project included cancer diagnosis, treatment of care and discharge; much information captured issues and challenges experienced by First Nations cancer patients and families along the entire cancer pathway. Our descriptions of the results and findings from the needs assessment, as well as the outcomes of Part B demonstrate that Alberta First Nations are poised to act as lead partners in the work remaining to improve the cancer care pathways through the development of a culturally informed cancer control strategy for Indigenous people in Alberta. The voices and experiences of Indigenous people, as the drivers for this work, have been presented throughout the document and speak to the hardships of many First Nations people as they travel on a journey with cancer. As such, this project and its outcomes can only be viewed as a stepping stone toward the required changes for a culturally appropriate and safe cancer care pathway for Alberta First Nations in rural, remote and isolated communities.

A close-up photograph of a bird's eye and beak, overlaid with a semi-transparent grid pattern. The grid consists of squares in various shades of brown, tan, and grey. The bird's eye is prominent on the left side, and its beak is visible below it. The overall color palette is warm and earthy.

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APPENDIX

**APPENDIX A:**  
**ASSEMBLY OF TREATY CHIEFS (TREATY NO. 6 –  
TREATY NO. 7 – TREATY NO. 8) RESOLUTION**

**OFFICIAL RESOLUTION FROM THE 2015 WINTER ASSEMBLY OF TREATY CHIEFS  
01R:2015/02/04**



2015 Winter Assembly of Treaty Chiefs  
Treaty No. 6 – Treaty No. 7 – Treaty No. 8

**Resolution:** 01R:2015/02/05

**Subject:** Canadian Partnership Against Cancer Project (CPAC): Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities

**Moved by:** Chief Gordon Auger, Bigstone Cree Nation

**Seconded by:** Chief Charles Weasel Head, Blood Tribe

**Decision:** Carried Unanimously by Consensus

**WHEREAS:**

1. The Assembly of Treaty Chiefs (AOTC) of Treaty No. 6, Treaty No. 7, Treaty No. 8 (Alberta) did meet in a duly convened meeting in the Enoch Cree Nation on February 3, 4 & 5, 2015;
2. The Chiefs derive their authority from the Creator and the citizens of their respective Nations/Tribes, and in the exercise of their inherent authority and Treaty rights are beneficiaries of all aspects of international law, including but not limited to the Charter of the United Nations, the United Nations Declaration on the Rights of Indigenous Peoples, and ILO Convention 169, and from time to time pass Resolutions and provide directives to their representative organizations; and
3. Recognizing historical harm resulting from research in First Nations communities and First Nations assertions of governance over community information, research funding agencies and/or Government Departments/Agencies funding/supporting research projects and data collection initiatives are required to adhere to the First Nations Principles of OCAP™ and are accompanied by a specific research mandate endorsed by the Chiefs with regard to research in the First Nations communities of Treaty No. 6, Treaty No. 7, and Treaty No. 8 (Alberta);
4. Self-determination is a fundamental right of First Nation peoples acknowledged in international law and by *Section 35* of the *Canadian Constitution*, the Crown, in right of Canada has a duty to protect First Nations rights and title as set out in the minimum standards defined by the *United Nations Declaration on the Rights of Indigenous Peoples*.
5. The Assembly of Treaty Chiefs passed a Resolution (30-03-2010-03R) to adopt a research mandate to implement First Nations Leadership's right to self-determination, control, and jurisdiction in reliable

## APPENDIX A: ASSEMBLY OF TREATY CHIEFS (TREATY NO. 6 – TREATY NO. 7 – TREATY NO. 8) RESOLUTION (CONT'D)

### OFFICIAL RESOLUTION FROM THE 2015 WINTER ASSEMBLY OF TREATY CHIEFS 01R:2015/02/04



research and accurate statistics, based on First Nations principles of Ownership, Control, Access and Possession (OCAP™) of First Nations' data, information, and traditional knowledge. The Chiefs continue to assert self-determination and OCAP™ principles, thereby ensuring any research conducted in their communities be OCAP™ compliant; and

6. The Assembly of Treaty Chiefs resolved that any collection, use and disclosure of our data, our information and our traditional knowledge must adhere to the Alberta First Nations Information Governance [AFNIGC] model, clearly stating First Nations are stewards of their own data and therefore would require free, prior and informed consent and that leadership must be involved in every stage of research involving First Nations communities which reflect First Nations' research ethics, values and accountability to Treaty No. 6, Treaty No. 7 and Treaty No. 8 (Alberta);
7. The leadership of the First Nations of Treaty No. 6, Treaty No. 7, and Treaty No. 8 (Alberta) want to ensure that First Nations participate in the governance of all First Nations information, regardless of where it is held, while also sharing information with provincial and federal partners to aid them in fulfilling their roles and duties to improve the health of the citizens of those First Nations; and
8. An Agreement was finalized on August 13, 2014, between the AFNIGC and Alberta Health Services (AHS) that adheres to the principles of OCAP™ to complete the CPAC baseline needs assessment and that the *Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities* proposal was successfully awarded \$799,996 to carry out a 2.5-year project.

#### **THEREFORE BE IT RESOLVED that the Assembly of Treaty Chiefs:**

1. Hereby continue to support the collaborative partnership between the Confederacy of Treaty Six First Nations, Treaty 7 Management Corporation, Treaty 8 First Nations of Alberta, Cancer Control Alberta (AHS), Alberta First Nations Information Governance Centre and Dr. Cora Voyageur, University of Calgary, and the CPAC Committee.
2. Support the Project to advance improvements in continuity of care, to support the development of strategy for increased First Nations access to Cancer Care and to implement strategy for First Nations community and stakeholder engagement to support multi-jurisdictional targeted interventions aimed at an improved First Nation Cancer Care Pathways and Policies to improve survivor rates, Non-Insured Health Benefits, transportation, and end of life care.
3. The results will not diminish, limit and/or omit future health care needs as per Treaty No. 6 Medicine Chest Clause.
4. AFNIGC shall provide ongoing periodic reports to the Treaty No. 6, Treaty No. 7 and Treaty No. 8 [Alberta] Chiefs in writing via the PTOs and this support Resolution not to exceed the 2.5 year time-line of the project without returning to the Chiefs for further dialogue.

Resolution Certified Correct:

  
Bobbi Herrera, Resolution Chair



## APPENDIX B: ALBERTA FIRST NATIONS CANCER CARE PATHWAYS LOGIC MODEL DESCRIPTION

### ALBERTA FIRST NATIONS CANCER PATHWAYS PROJECT LOGIC MODEL DESCRIPTION

This logic model has been created with an Indigenous perspective in keeping with the project activities to incorporate Indigenous methodologies and create a greater awareness of Indigenous ways of depicting concepts and knowledge gathering processes. The center of the diagram depicts the focus of the project along with the goals. Green is chosen as the representative color because it reflects new growth and new beginnings as is within nature and early spring.

The second ring (circle) is haloed by an orange color for protection around the principles of the work. These principles were gleaned from the discussions with the elders at the November 4, 2014 stakeholder meeting in Edmonton and have been identified as; Sustainability, Value and Merit, Growth, Supporting Autonomy, Reciprocity, Success, Collaboration, and Working Together. The principles of Ownership, Control, Access, and Possession (OCAP®) have been embedded into the project agreement and form the foundation for any work with First Nations data, research, and knowledge. OCAP® principles are also incorporated into the logic model to assure application throughout the project work.

The outer ring defines four quadrants of three as represented by the leaves and are color coded to represent the seasons; winter – buds, early spring- just opening of the leaves, summer- full opening of the leaves, and fall - as the leaves begin to change color and eventually offer themselves to the ground.

Leaves have been chosen as the symbol to hold the activities of the project primarily because of their capacity and function. The leaves of the trees harness the energy of the sun and provide sustenance to the earth manufacturing food for everything on the ground. Leaves facilitate the interchange of gases between the atmosphere and the plant body. The mechanism of transpiration by the leaf provides a method of releasing excess water and the transporting of minerals and nutrients to the plant body as a whole. Finally, in some plants the leaves propagate new plants by growing new roots once they return to the ground thus supporting plant sustainability. The seasons demonstrate a cycle and the process of development for this project. The seasons, beginning in the top upper right if looking at the model straight on are; the budding stage which is the winter season. This is a time of reflection and inner working in preparation for a grander outward display of wisdom and or a planning phase of the work which takes inner strength, wisdom, and knowledge to prepare for the work ahead. The activity leaves are labeled as set the stage, create project framework, develop sustaining relationships, and develop OCAP® respected methods.

Each leaf is then aligned with the outcome in the backdrop of the blue sky.

The winter season outcomes are; build trust in working relationships and a foundation for collaborative ethical work, sustainable relationships at three levels of impact (federal, provincial, and First Nations Leadership), and OCAP® principles are being applied to project process and data systems management.

The next season is the spring which is the sowing or seeding aspect of the season. It can be seen as a time of propagating or growing the ideas, vision, and goals of the project. As it is the time in nature where things begin to move, awaken, and germinate. The activity leaves are labeled as; incorporate Indigenous methodologies within project work, improve provider awareness of First Nations culture, and create greater First Nation awareness of services.



## APPENDIX B: ALBERTA FIRST NATIONS CANCER CARE PATHWAYS LOGIC MODEL DESCRIPTION (CONT'D)

The outcomes for the spring season are; greater awareness of Indigenous methodologies of Alberta First Nations, ensure that health care system services providers are delivering culturally safe care, and first Nations are aware of treatment and screening services.

The summer season is a time of full expression, being busy and being in the light of full sun thus lots of growth and development occurs during this time of the season. The activity leaves during this aspect of the season are labeled as; coordinate services across jurisdictions, develop procedures to improve systems and processes, and develop data sharing agreement.

The aligned outcomes for the summer season are; ensure that services are multi-jurisdictionally coordinated, ensure earlier diagnosis, and improve pathways for screening and treatment.

The fall/autumn season is seen as a time of harvest and for nature is the last opportunity to get things done and ready for the forthcoming winter. It's a time of taking stock of the harvest and the provisions for the winter. Fall is a time for finishing things up in preparation for hibernation.

The activity leaves for the fall/autumn season are; develop stakeholder engagement plan for First Nation identifiers, assess feasibility of system change, and create framework for use of First Nation Identifiers.

The outcomes aligned to these activities are; stakeholders and leaders are engaged and support use of First Nation identifiers, First Nation data identifiers are developed and tracking processes, protocols are determined, and ensure First Nation leaders, organizations, communities, and cancer care implement First Nation identifier strategies.

The four directions are also marked out in the model by the four colored diamonds, North - white, East -Red, South - Yellow, and West - Blue. These are intended to clearly mark out the seasons and to also depict the necessity of seeing this work all-inclusive of spiritual, emotional, physical, and mental dimensions of wellbeing for the people traveling the cancer journey.

### References for leaf functions

<http://www.ext.colostate.edu/mg/gardennotes/134.pdf>

<http://www.preservearticles.com/201106188219/what-are-the-five-most-essential-functions-of-leaf.html>

## APPENDIX C: CONSENT FORM



**CPAC Funded Project: *Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities***

**Consent Process for Focus Groups and Table Talks**

**Title:** Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities

**Sponsor:** Canadian Partnership Against Cancer

**Investigator:** Dr. Angeline Letendre, cell: 1-403-471-4355

[This portion of the informed consent form will be read to the participant. Any questions they may have at this point will be answered].

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. I can explain any questions you might have. You will receive a copy of this form.

### **1. What is this form?**

This is the consent form for the table talk and focus sessions taking place in your community. It will give you information about the study so you can make an informed decision about whether or not you choose to take part in this project.

This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate. The consent form lets you know about any known risks that may come up if you participate. Please take some time to read through this document before you agree to participate.

Please also ask us any questions – now or later – or at any time during the research project. If you want to be part of the project, you will have to sign the form at the end of this letter. You will also get a copy of this form for you to keep.

### **2. Who is eligible to participate?**

You must be at least 18 years of age to participate in the research project. If you or a family member has been a cancer patient and you are interested in sharing your story, you are eligible to participate. If you have any physical limitations or special needs (dietary or otherwise) it is important to let us know ahead of time so that we can make sure you are comfortable during the session.

## APPENDIX C: CONSENT FORM (CONT'D)



### 3. What is the purpose of this study?

The purpose of this study is to improve cancer treatments and services for First Nations in Alberta. It will produce reliable and important information that will help develop cancer treatments and services that respect First Nation culture for First Nations people in Alberta.

### 4. What will I be asked to do?

You will be asked to discuss a number of questions in a group setting. It is your choice to participate and you can refuse to participate in any discussion you wish. You can also leave the focus group at any time without penalty and any information you have shared will not be used in the study. The sessions will be audio-taped.

There are two important parts to the sessions. First we ask that you fill out a short pre-survey questionnaire. For example, this questionnaire will ask you questions about your experiences with the cancer services you or a family member received, the availability of culturally safe services and how you were involved in your treatment planning and decision making.

After you finish filling out the questionnaire and it is collected, you will be asked to speak about either your personal cancer journey from the time you learned you had cancer to the current time (Table Talk) or about a friend's or relative's cancer journey (Focus Group).

Here's what the session will look like:

- Opening Prayer
- Welcoming Remarks
- Introduction of Project Team
- Round table introductions
- Review and signing of consent and confidentiality form
- Administering the Pre-survey
- Establishing rules & norms
- Themes for discussions
- Closing remarks
- Closing Prayer

The themes for discussion may include physical environment, immediate and extended family, traditional healers and spiritual supports, local health care administration, community health facilities, family physician/local doctors, oncology (cancer) specialists and nursing staff.

It is important that you know you may skip any question you feel uncomfortable answering. At the end of the session if you feel that you need additional mental/emotional support we will help you to connect with a local service provider.

We will also contact you after the session and that is why we need to collect your contact information on this form. This is because we want share the results of the session with you so that you can make sure they are correct.

## APPENDIX C: CONSENT FORM (CONT'D)



### 5. What are the benefits of participating?

There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve cancer care for First Nation people in Alberta. By taking part in the study you can:

- Help explain to health care professionals, health care leadership, and First Nation leadership what the cancer care needs of First Nations of Alberta are;
- Help develop cancer care services and treatments for First Nations of Alberta that respect First Nation culture; and
- Share stories to help others and begin to change cancer care in areas that are not working well for First Nation people in Alberta.

### 6. Will I receive any payment for taking part in the study?

To thank you for taking the time to participate in this study you will receive a gift and will be entered into a grand prize draw for one of four \$500 gift cards. You will not have to pay for anything.

### 7. Can I stop being in the study?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

If you change your mind and leave the study, your information will be removed and not be used in this project.

### 8. Where will the study take place and how long will it last?

The study will be taking place in communities throughout the three Treaty areas of Alberta (Treaty 6, 7 and 8). Three lead communities have been identified in these areas and are: Bigstone in Treaty 8, Maskwacis in Treaty 6, and Siksika in Treaty 7. We've planned 10 table talk sessions in each community, lasting three (3) hours and followed with lunch.

We ask that you participate in either a table talk session or community focus group. The end date of this project is set for 2017.

### 9. How long will these sessions take?

If you are participating in a table talk session, it will take approximately three (3) hours followed by lunch.

If you are participating in a focus group session, it will take approximately one (1) hour.

### 10. Is what I say going to be confidential?

The research being done in the community may draw attention and if you participate you may be asked questions by other people in the community. We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. It will not be shared with or given to anyone except members of the research team.

## APPENDIX C: CONSENT FORM (CONT'D)



### 11. What are my risks of being in this study?

Talking about your experience may make you feel sad or stressed. The sessions will be culturally appropriate to make you feel more comfortable. We will use the sharing circle model and traditional practices such as prayer and additional helper support. Additionally, we will provide you with contact information to local mental health supports at the Health Centre if you feel you need it.

When you share stories and personal information in a group setting there is the small risk that you will not remain anonymous or that your information will not remain confidential in your community. We will try to make sure this does not happen. Everyone at the session will have to sign a confidentiality form. The rules and norms of the sessions will be discussed before we begin the session and we will ask you and others in the group not to talk to people outside the group about what was said in the group. We will, in other words, ask each of you to keep what was said in the group confidential.

The sessions may take longer than planned. Our team does not want to interrupt those who are sharing. This may cause you physical discomfort or be inconvenient. Please know that we will try hard to not go over the planned time.

### 12. How will my personal information be protected?

All information we collect from focus groups, table talks, and by survey will be kept in accordance with the First Nations Principles of Ownership, Control, Access and Possession (OCAP™). We also received support and endorsement to do this from a resolution from the Alberta Assembly of Treaty Chiefs.

Data will be kept in locked storage at the Alberta First Nations Information Governance Centre's office in Calgary. Within two years of the start of the project, all data collected will be transferred to computer files. Data backed up on discs, together with printouts of coded results, will be retained in locked storage in the Alberta First Nations Information Governance Centre's office. The original pre-survey forms will be shredded.

Notes and transcripts of audio recordings, together with the audio recordings themselves, will be retained in locked storage in the principal investigator's office for up to five years. Names and addresses of respondents will also be retained (in locked storage) on this basis. All data will be destroyed after five years.

All electronic files containing identifiable information will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords.

### 13. What happens to the information I provide?

When the study is over, the researchers may publish their findings. This could happen in published manuscripts, scholarly publications, presentations and lectures.

Only group information will be summarized for any presentation or publication of results, however, individual anonymous quotations from the sessions may be used in the final research paper.



## APPENDIX C: CONSENT FORM (CONT'D)



You will be provided with a final report, as that is what is guaranteed when we use OCAP™ principles.

#### **14. Who do I contact if I have questions or concerns about the project?**

Take as long as you like before you make a decision. We will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact:

The Health Research Ethics Board of Alberta (HREBA) – Community Health Committee (CHC) has granted ethics approval of this project. If you have any complaints or concerns about the ethical conduct of this project, please contact:

HREBA – Community Health Committee  
Suite 1500, 10104 - 103 AVE  
Edmonton AB, T5J 4A7  
Phone: (780) 423-5727 / Toll-free: 1-877-423-5727  
Email: [communityhealth@hreba.ca](mailto:communityhealth@hreba.ca)

You can also contact Bonnie Healy, Operations Manager, Alberta First Nations Information Governance Centre with any questions or comments: [bhealy@afnigc.ca](mailto:bhealy@afnigc.ca) or by telephone at 403.539.5775 or Dr. Cora Voyageur: [voyageur@ucalgary.ca](mailto:voyageur@ucalgary.ca) or by telephone at 403.220.6502.

# APPENDIX C: CONSENT FORM (CONT'D)



CONSENT TO PARTICIPATE IN:

Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities

- I understand what the project is about, and it was explained to me in a language that I use and understand.
- I agree to participate in the project.
- I have been given a copy of this consent form.
- I understand that I can leave the project at any time and that my information will not be kept by or used in the study.
- I understand that any information I provide will be anonymous in the final report.

I am consenting to participate in the:

Table Talk     Focus Group

I agree not to talk about things I heard in the session outside of the session or in the community (I will maintain confidentiality).

I understand that that there is some risk that my information may not remain confidential in the community by participating in the table talk or focus group research.

**If you cannot agree to the above statement please see the researcher(s) as you may not be eligible to participate in this study.**

Participant name: \_\_\_\_\_

Participant signature: \_\_\_\_\_ Date: \_\_\_\_\_

Participant address: \_\_\_\_\_

Participant phone number: \_\_\_\_\_

Participant email: \_\_\_\_\_

Project team member signature: \_\_\_\_\_ Date: \_\_\_\_\_

**APPENDIX D:**  
**MASKWACIS HEALTH SERVICES BOARD MOTION**



**MASKWACIS HEALTH SERVICES**

Box 100 Maskwacis, Alberta T0C 1N0  
Telephone 780-585-3830 Fax 780-585-2203

April 23, 2015, <sup>2015</sup>

Michelle Voyageur  
Provincial Coordinator First Nations, Inuit and Metis, Supportive Care & Patient Experience  
Community Oncology, Cancer\_Control Alberta  
Alberta Health Services  
1500-10123 99 Street  
Edmonton, AB T5J 3H1

Dear Michelle,

The Maskwacis Health Services supports the work of the project we have partnered with on “The Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities”. The project goal is to improve cancer care pathways for First Nations in Alberta;

In 2013, a collaborative partnership was created between the Confederacy of Treaty Six First Nations, Treaty 7 Management Corporation, Treaty 8 First Nations of Alberta, Cancer\_Control Alberta (Alberta Health Services), Alberta First Nations Information Governance Centre, and Dr. Cora Voyageur.

The Alberta First Nations Information Governance Centre (AFNIGC) will host any data that is collected through the project. AFNIGC maintains accountability to First Nations through its membership, which includes all Treaty First Nations of Alberta, as represented by their respective Chiefs.

The objectives of the project are to increase First Nations knowledge and understanding of cancer and cancer care services, educating health care workers about First Nations people in Alberta, improving better coordination of care and services for First Nations people with cancer, increasing access to culturally responsive cancer care services, and developing educational resources and tools to support First Nations cancer pathways. This assists First Nations in assessing their communities' progress in health and well-being, offers scientifically and culturally valid information, enhances First Nations' capacity and control over research, and serves as a model for

**HEALTH IS A TREATY RIGHT SANCTIFIED BY THE TRUE SPIRIT & INTENT OF  
TREATY NO. 6 MEDICINE CHEST CLAUSE**

**APPENDIX D:**  
**MASKWACIS HEALTH SERVICES BOARD MOTION (CONT'D)**

community-based research;

Individuals will choose to participate in the project and will provide their consent for the release of only aggregate results, i.e. no personally identifying information is included in the results;

We understand and accept that the research team has selected data collection methods for which the anonymity and confidentiality of participants cannot be assured within the community, however we understand that anonymity can be assured within the final report.

In conducting the project the project team shall honor both their OCAP™ commitments to the Maskwacis Nations, as well as their obligation to protect the personal privacy of respondents;

AFNIGC will be bound by their contractual and consent commitments, that state that there will be no release or dissemination of any data or information from the project that identifies, or could potentially lead to the identification of a community without authorization from that community's recognized leadership;

Respectfully



Chief Executive Officer  
Maskwacis Health Services

## APPENDIX E: BIGSTONE HEALTH COMMISSION LETTER OF SUPPORT



### Bigstone Health Commission

*Vision: To revive, strengthen and protect members' treaty rights to health and to enhance the quality of life of members and others living on Bigstone Traditional Lands*

Box 1020 Wabasca, AB, T0G 2K0  
Ph (780) 891-2000 Toll free 1-877-767-7060 Fax (780) 891-2623

February 20, 2015

Michelle Voyageur  
Provincial Coordinator First Nations, Inuit and Métis, Supportive Care & Patient Experience  
Community Oncology, CancerControl Alberta  
Alberta Health Services  
1500-10123 99 Street  
Edmonton, AB T5J 3H1

Dear Michelle,

The Bigstone Health Commission supports the work of the project we have partnered with on The Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities. The project goal is to improve cancer care pathways for First Nations in Alberta;

In 2013, a collaborative partnership was created between the Confederacy of Treaty Six First Nations, Treaty 7 Management Corporation, Treaty 8 First Nations of Alberta, CancerControl Alberta (Alberta Health Services), Alberta First Nations Information Governance Centre, and Dr. Cora Voyageur.

The Alberta First Nations Information Governance Centre (AFNIGC) will host any data that is collected through the project. AFNIGC maintains accountability to First Nations through its membership, which includes all Treaty First Nations of Alberta, as represented by their respective Chiefs. FNIGC maintains accountability to First Nations through its membership, which includes all participating Regional Organizations;

The objectives of the project are to increase First Nations knowledge and understanding of cancer and cancer care services, educating health care workers about First Nations people in Alberta, improving better coordination of care and services for First Nations people with cancer, increasing access to culturally responsive cancer care services, and developing educational resources and tools to support First Nations cancer pathways. This assists First Nations in



**APPENDIX E:**  
**BIGSTONE HEALTH COMMISSION LETTER OF SUPPORT (CONT'D)**

assessing their communities' progress in health and well-being, offers scientifically and culturally valid information, enhances First Nations' capacity and control over research, and serves as a model for community-based research;

Individuals will choose to participate in the project and will provide their consent for the release of only aggregate results, i.e. no personally identifying information is included in the results;

In conducting the project the project team shall honor both their OCAP™ commitments to the Bigstone Cree Nation, as well as their obligation to protect the personal privacy of respondents;

AFNIGC will be bound by their contractual and consent commitments, that state that there will be no release or dissemination of any data or information from the project that identifies, or could potentially lead to the identification of a community without authorization from that community's recognized leadership;

Respectfully,



G. Barry Phillips  
Chief Executive Officer

**APPENDIX F:**  
**SIKSIKA HEALTH SERVICES LETTER OF SUPPORT**



**SIKSIKA HEALTH SERVICES**  
**Office of Melvin (Tyler) White**  
**Chief Executive Officer**

Post Office Box 1130  
Siksika, Alberta T0J 3W0  
Telephone Office Direct: (403)734-5601 Cellular: (403) 901-5078  
Fax: (403) 734-3916

May 4, 2015

Michelle Voyageur  
Provincial Coordinator First Nations, Inuit and Metis, Supportive Care & Patient  
Experience Community Oncology, CancerControl Alberta  
Alberta Health  
Services 1500-  
10123 99 Street  
Edmonton, AB  
T5J 3H1

Dear Michelle,

The Siksika Health Services supports the work of the project we have partnered with on "The Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities". The project goal is to improve cancer care pathways for First Nations in Alberta;

In 2013, a collaborative partnership was created between the Confederacy of Treaty Six First Nations, Treaty 7 Management Corporation, Treaty 8 First Nations of Alberta, Cancer Control Alberta (Alberta Health Services), Alberta First Nations Information Governance Centre, and Dr. Cora Voyageur.

The objectives of the project are to increase First Nations knowledge and understanding of cancer and cancer care services, educating health care workers about First Nations people in Alberta, improving better coordination of care and services for First Nations people with cancer, increasing access to culturally responsive cancer care services, and developing educational resources and tools to support First Nations cancer pathways. This assists First Nations in assessing their communities' progress in health and well-being, offers scientifically and culturally valid information, enhances First Nations' capacity and control over research, and serves as a model for community-based research; Individuals will choose to participate in the project and will provide their consent for the release of only aggregate results, i.e. no personally identifying information is included in the results;

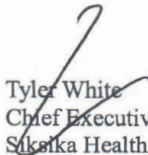
**APPENDIX F:**  
**SIKSIKA HEALTH SERVICES LETTER OF SUPPORT (CONT'D)**

We understand and accept that the research team has selected data collection methods for which the anonymity and confidentiality of participants cannot be assured within the community. However we understand that anonymity can be assured within the final report.

In conducting the project the project team shall honor both their OCAP™ commitments to the Siksika Nation, as well as their obligation to protect the personal privacy of respondents;

AFNIGC will be bound by their contractual and consent commitments, that state that there will be no release or dissemination of any data or information from the project that identifies, or could potentially lead to the identification of a community without authorization from that community's recognized leadership;

Respectfully



Tyler White  
Chief Executive Officer  
Siksika Health Services

Cc: Chief Vincent Yellow Old Woman  
Barry Yellow Fly – Chairman Siksika Health Services Board of Directors  
File

## APPENDIX G: BRIEFING NOTE



### Alberta First Nations Cancer Pathways Project

**Date:** May 24, 2016 **Subject:** Cancer Pathways Project Status Update

**Prepared for:** Assembly of Treaty Chiefs

#### Purpose

To inform Alberta First Nations partners on the current status of the First Nations Cancer Pathways Project.

#### Background

Project partners include Alberta Health Services-Cancer Control Alberta, Confederacy of Treaty Six First Nations, Treaty 7 Management Corporation and Treaty 8 First Nations of Alberta. Additional partners include The Alberta First Nations Information Governance Centre (AFNIGC), First Nations Inuit Health Branch (Alberta), Aboriginal Health Program (Alberta Health Services) and Dr. Cora Voyageur (University of Calgary). Collaborators include Canadian Indigenous Nurses Association and Indigenous Physicians Association of Canada.

The First Nations Cancer Pathways Project aims to improve the First Nations cancer care pathway experience through the following ways:

- Build trusted working relationships amongst the project team, First Nation communities and cancer care.
- Improve cancer care systems' knowledge and stakeholder awareness of the needs and cultural perspectives of First Nation cancer patients, families and their caregivers.
- Increase awareness and knowledge by First Nation people of cancers and cancer care services.
- Enhance coordination of services across multiple jurisdictions of care, with a focus on points of access for diagnosis, through treatment of care and upon discharge to a variety of primary and community care services.
- Identify and interpret elements required for an improved cancer pathway in an Alberta First Nation context, considering traditional forms of support.
- Development and disseminate culturally valid support resources for use by care professionals, First Nation community care professionals, First Nation cancer patients, survivors, caregivers and communities.

## APPENDIX G: BRIEFING NOTE (CONT'D)

### Status

Our Project Manager, Lea Bill had begun and lead the engagement process with the three lead communities (Bigstone, Maskwacis, and Siksika) by providing necessary updates on the project, as well as initial project orientations with Community Liaisons. Data collection began in August 2015, after signing data sharing agreements with each participating nation. To date, a few last interviews are to be collected to complete data collection.

We've also hosted consultative engagement session with the Canadian Indigenous Nurses Association. We hope to host another similar session with the Indigenous Physicians Association of Canada. We're now working on data collection with health care professionals, through focus group session across the three treaty areas and oncology care providers at the Tom Baker Cancer Centre in Calgary. A focus group session will take place with the Cross Cancer Institute in Edmonton as well as the release of an online survey for health care providers beginning in June 2016. The project team was also able to support Elder travel to the World Indigenous Cancer Conference in Australia (April 2016) to share in their experiences as important members of our project team.

### Key Considerations

Leadership support and involvement in this collaborative initiative has to date been successfully carried out. Continued support and involvement for the completion of this initiative is critical for the creation of culturally safe improvements in the planning and provision of care, as well as the long-term strategy and planning required for improved cancer outcomes in these communities.

### Next Steps

A final Project Leadership Event is being planned for the fall of 2016. Our Project Team aims to share project outcomes, including evidence of First Nation cancer experiences collected through the needs assessment and plans for next steps in relation to First Nations cancer data and information. Other important project activities include all of our partners providing analysis of needs assessment findings, sustainability planning session and community events to share information back to lead communities and First Nations partners.

### Important Dates

FN Elder/Indigenous Physicians Gathering Data Collection Completed Preliminary Data Analysis FN Team Sustainability Planning Leadership Engagement Meeting

Writer Name Contact Info:

Lea Bill BScN Project Manger  
587-337-2364 lbill@afnigc.ca

**June 2016 July 2016 September 2016 October 2016 Late Fall 2016**



## APPENDIX H: SURVEY QUESTIONS FOR ONLINE SURVEY

### ONLINE SURVEY QUESTIONS: HEALTH SYSTEM PRACTITIONERS

#### Participant Information

1. Pseudonym \_\_\_\_\_.
2. Gender Drop Down (Male/Female)
3. Age Drop Down (20-30yrs; 31-40yrs; 41-50yrs; 51-60yrs or 61+)
4. Work location? Drop down (Urban, rural, remote or other)
5. Type of work facility? Drop down (First Nations Community, Primary Care Facility, Cancer Care Facility, Physicians Office, Hospital, Community Health Centre, Other)
6. What is your occupation?
  - Primary Care Provider Drop Down (Specialization\_\_\_\_\_.)
  - Oncologist Drop Down (Specialization\_\_\_\_\_.)
  - Oncology Care Provider
  - Nurse Practitioner Drop Down (Specialization\_\_\_\_\_.)
  - Nurse Drop Down (Nurse Administrator; Community Health Nurse; Home Care Nurse; Primary Care Nurse; Palliative Care Nurse; Licensed Practical Nurse, Other)
  - Dietician
  - Nutritionist
  - Social Worker
  - Community Health Representative
  - Mental Health (Specialization\_\_\_\_\_.)
  - Other

#### Survey Questions

1. List the factors you believe influence a First Nation individual's participation in cancer screening?
2. How do First Nations people receive their cancer diagnosis?
  - a. Drop down list (mail, telephone, in person, email, other)
3. Where do First Nations people receive their cancer diagnosis?
4. Have you experienced difficulty delivering a cancer diagnosis to a First Nations patient?
  - a. Yes
  - b. No
- 4a. If you answered yes to question 4 please explain\_\_\_\_\_.
5. Do you believe First Nations patients understand their cancer diagnosis?
  - a. Yes
  - b. No
- 5a. If you answered yes to question 5 please explain\_\_\_\_\_.
6. How long does it take to receive the test results confirming cancer diagnosis?

## APPENDIX H: SURVEY QUESTIONS FOR ONLINE SURVEY (CONT'D)

7. Have you experienced any difficulties delivering the confirmed cancer diagnosis test results to a First Nations person?
  - a. Yes
  - b. No
- 7a. If you answered yes to question 7 please explain\_\_\_\_\_.
8. Where are First Nation patients receiving cancer treatment? Drop Down
  - a. Hospital
  - b. Community Health Facility
  - c. Regional Cancer Centre
  - d. Rural Health Care Facility
  - e. Cancer Centre (Tom Baker Cancer Centre; Cross Cancer Institute)
  - f. Physician's Office
  - g. Other\_\_\_\_\_.
9. Where are First Nation patients receiving cancer care? Drop Down
  - a. Hospital
  - b. Community Health Facility
  - c. Regional Cancer Centre
  - d. Rural Health Care Facility
  - e. Cancer Centre (Tom Baker Cancer Centre; Cross Cancer Institute)
  - f. Physician's Office
  - g. Other\_\_\_\_\_.
10. Are First Nations patients agreeing to recommended treatment options? Drop Down
  - a. Yes
  - b. No
- 10a. If you answered yes to question 10 please explain\_\_\_\_\_.
11. Are you aware of First Nations traditional healing practices?
  - a. Yes
  - b. No
12. Are First Nations traditional healing practices included in cancer care treatment plans?
  - a. Yes
  - b. No
- 12a. Please explain your answer to question 12\_\_\_\_\_.
13. How long does a First Nation cancer patient wait for cancer treatment to begin?
  - a. Less Than One Month
  - b. One-Four Months
  - c. Longer Than Four Months
  - d. Unsure

## APPENDIX H: SURVEY QUESTIONS FOR ONLINE SURVEY (CONT'D)

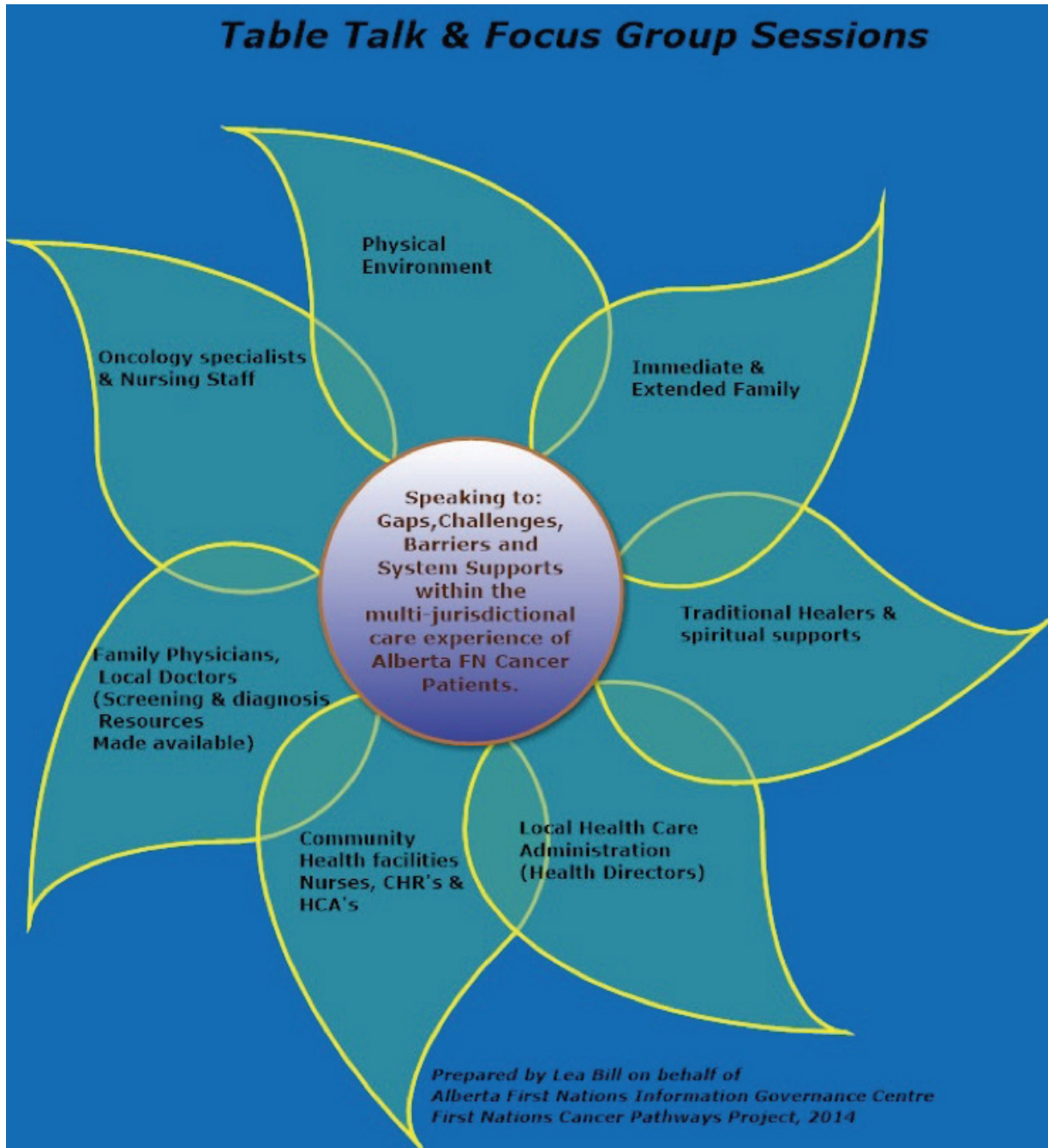
14. At what point of care is follow-up coordinated for the First Nation cancer patient?
  - a. At Time of Diagnosis
  - b. At Start of Treatment
  - c. Mid-Treatment
  - d. Upon Completion of Treatment
  - e. At Time of Discharge
  - f. Other, Please Explain\_\_\_\_\_.
15. What follow-up care is provided for First Nation cancer patients? Please list \_\_\_\_\_.
16. Who coordinates the follow-up care? Please list \_\_\_\_\_.

**You have now answered all of the questions. Are there any other issues that you would like to bring to our attention?**\_\_\_\_\_.

**Thank you**

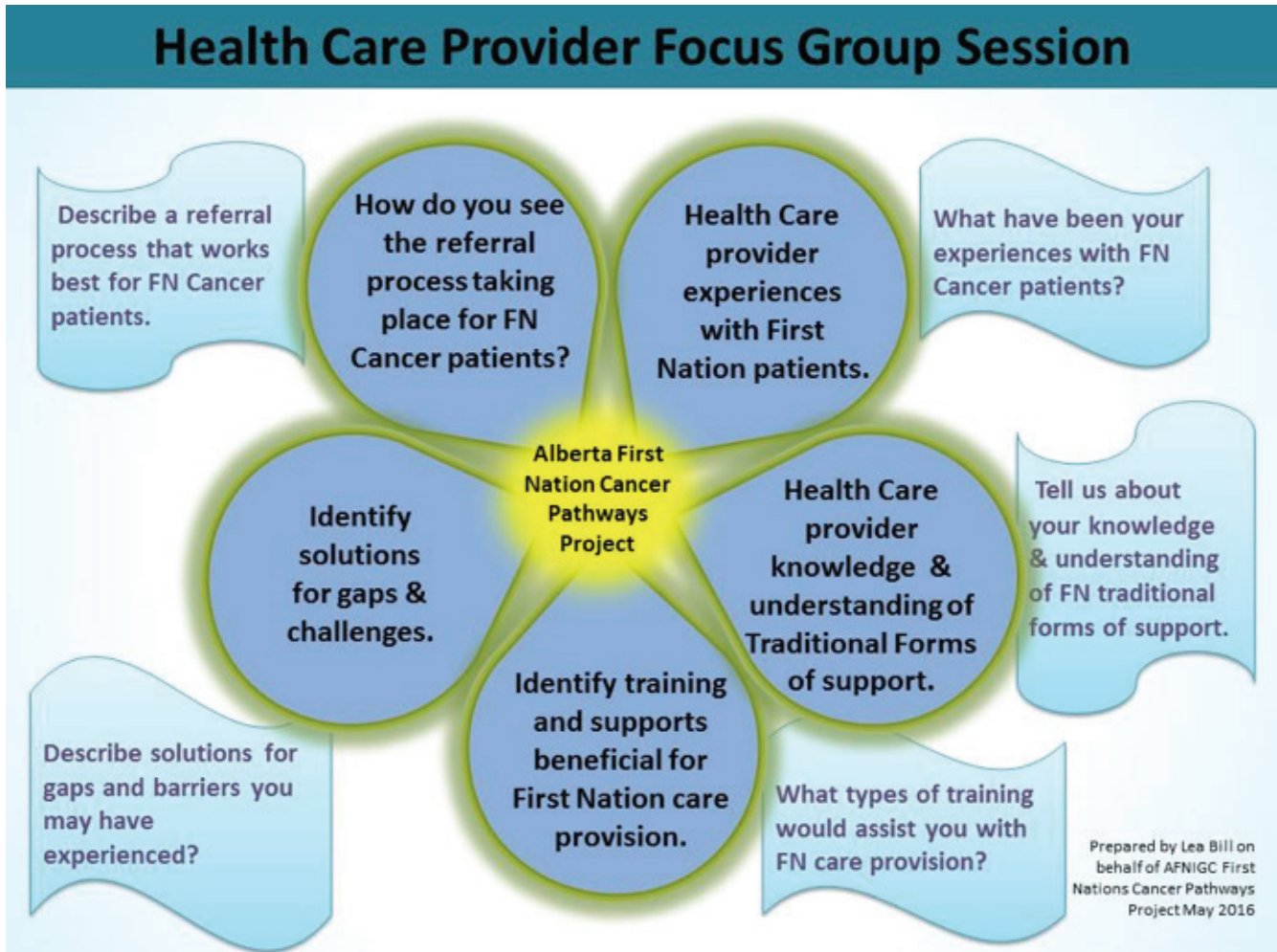
## APPENDIX I: DATA COLLECTION FACILITATION TOOLS

1. Themes Flower Diagram for Table talks and Community focus group sessions



## APPENDIX I: DATA COLLECTION FACILITATION TOOLS (CONT'D)

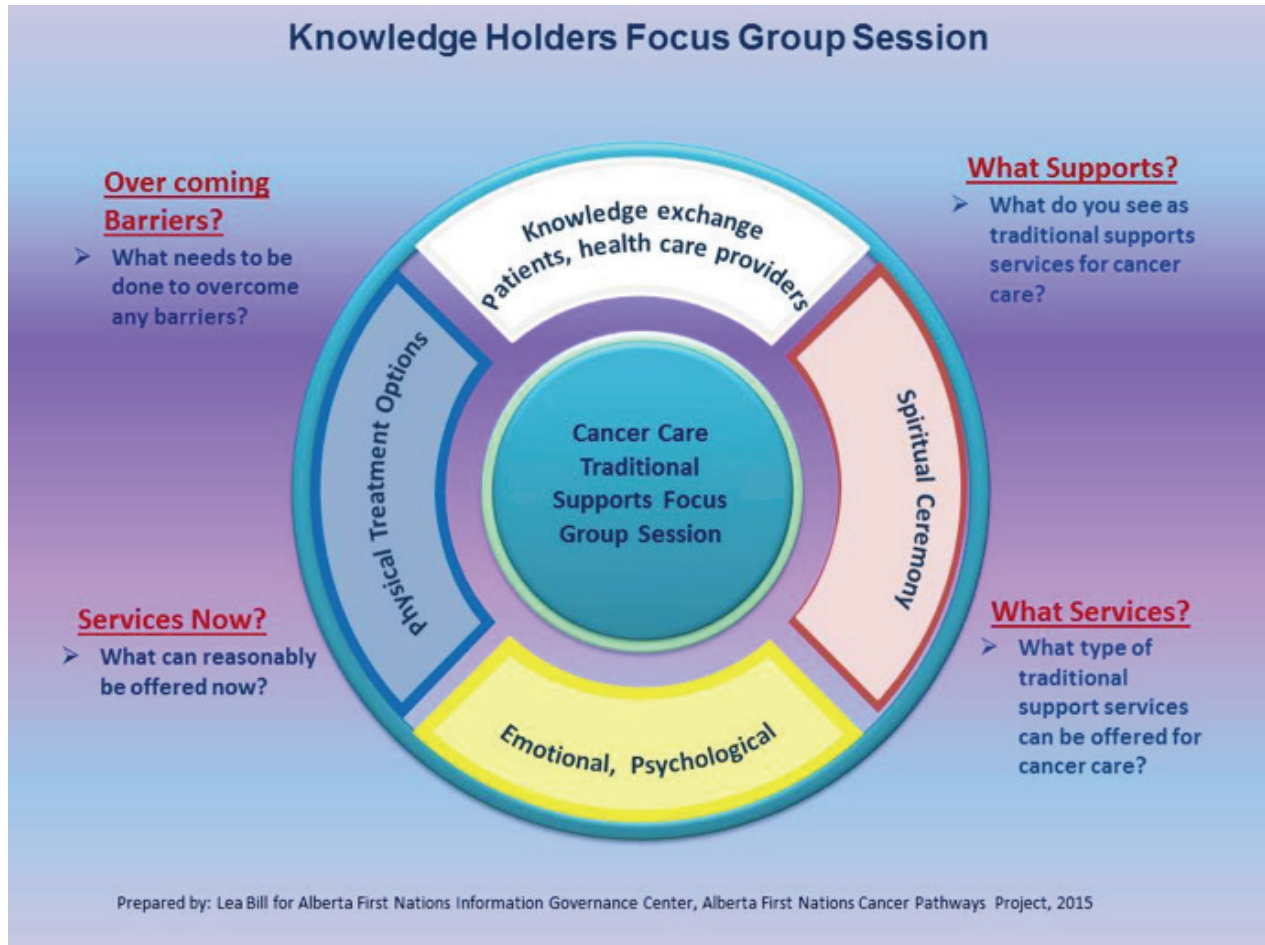
### 2. Health Care Providers Focus Group Session





## APPENDIX I: DATA COLLECTION FACILITATION TOOLS (CONT'D)

### 3. Knowledge Holder Focus Group Session



## APPENDIX J: FACILITATOR'S GUIDE FOR KITCHEN TABLE TALKS

### PATIENT/FAMILY EXPERIENCE

*Purpose: Articulate the patient experience through the cancer journey for members of First Nation communities.*

*Process: Sharing Circle/Kitchen Table Style Discussion.*

*Expected Outcomes: Narratives of patient experience through cancer journey with insights on challenges and supports.*

### WELCOMING REMARKS

Welcome all participants and thank them for taking the time to share their cancer related stories. Remind participants that they can refuse to participate at any time, indicating that any information collected before withdrawing will be retained and may be used in the future. Tell the group that information collected will be held in a locked cabinet at the Alberta Information Governance Centre's office in Calgary, Alberta and that personal information will not be disclosed. Today, people may be sharing stories that may cause them some grief and heartache, and if anyone needs to talk to someone about what they have experienced then there are mental health professionals available. Hand out list of mental health professionals in the community.

This session will last approximately 3 hours, and tea, coffee and snacks will be provided.

Provide the host of the table talks session with tobacco for offering their home. Then, offer one cigarette to each participant to thank them for sharing their story. If participants do not accept the tobacco then let them know that all participants will receive a gift at the end of the session.

### OPENING PRAYER

Please ask an Elder/Individual in the group to offer a prayer to start the session, please provide the person with tobacco that is provided.

### INTRODUCE PROJECT AND PROJECT TEAM

The facilitator will introduce the project details:

- Introduce team members.
- The purpose of this project is to improve cancer pathways for First Nation people in Alberta. This includes, but is not limited to access to services, patient care and quality of care that people experience on their cancer journeys.
- So why did this project start? First Nations in Alberta are not going to the doctor and are being diagnosed late in their disease and dying more often from cancer.
  - The number of new cancer cases in Alberta First Nations (excluding non-melanoma skin cancer), between 1997 and 2010, was reported to be 2,726.
  - The survival rate of First Nations with cancer five years after diagnosis is 53 percent. First Nations in Alberta have significantly lower survival rates than non-First Nations across all time periods.
- This project is in partnership with CancerControl Alberta, Treaty 6, Treaty 7, Treaty 8, and the Alberta First Nations Information Governance Centre and other native and non-native organizations.
- This project has been officially launched with a pipe ceremony.
- We want to learn more about your cancer experience.
- Explain that there will be a person recording the information.

## APPENDIX J: FACILITATOR'S GUIDE FOR KITCHEN TABLE TALKS (CONT'D)

### CONFIDENTIALITY FORM

Hand out the confidentiality form and inform the group that each participant is required to read, sign and return the form to the facilitator to participate in the kitchen table discussions.

Ask participants to keep all information that they have heard in this session private and do not share what they have heard today.

Anyone that does not sign a form cannot be part of the discussions.

### PRE-SURVEY

Ask participants to take 5 minutes to fill out the CPAC Evaluation Survey.

### RULES AND NORMS

Note to facilitator: please allow participants as much time as they need to complete their sharing.

- Time: The session will take about 3 hours to complete.
- Speaking: A talking stick, feather or rock will be used to indicate whose turn it is to speak. When the participant is done talking, he or she will pass the sharing circle tool to the next participant on the left of them.
- Listening: Please listen to each person, and do not ask any questions while they are speaking.
- Participation: We will go around in a circle to hear each person's comments. If you do not wish to participate, please indicate this when it is your turn.
- Expectation: Each person will talk about their cancer journey in any way that they see fit.
- Confidentiality: Please remember that information that is shared remains in this session.

### THEMES FOR DISCUSSION

In front of you there is a diagram of a flower, many First Nations people view the world in a holistic way of mind, body and spirit. This design came through via prayer, ceremony, and with conversations with Elders. Each petal represents a part of the cancer journey.

Explain the themes for discussion as follows:

- Physical Environment: Community facilities, home of the person, cancer care treatment rooms and examination rooms, hospitals, and doctor clinics.
- Immediate and Extended Family: The spouse, children, brothers, sisters, aunts, uncles, grandparents cousins and can also be people who have been adopted into the family formally and through ceremony.
- Traditional Healers and Spiritual Supports: People identified within the community as traditional healers, support people with traditional knowledge and or designated ceremonial rights. This may include people the family has identified as their spiritual advisor or teacher.
- Local Health Care Administration: Health Director, Nurse In-Charge, and health board as applicable.
- Community Health Facilities: Nurses, CHRs, HCAs: Home care program staff which consist of RN's and home health aides, elder program support services, and other professionals such as the physiotherapist, nutritionist, etc.
- Family Physician, Local Doctors: Community health doctors, rural doctors.
- Oncology Specialists and Nursing Staff: Employees working at the Cross Cancer Institute and Tom Baker Cancer Centre, Regional Cancer Centre's and Associate Cancer Centre's.

## APPENDIX J: FACILITATOR'S GUIDE FOR KITCHEN TABLE TALKS (CONT'D)

Ask the participants to please look at the diagram and take a moment to think about what each petal means to him/her. The purpose of the diagram is to help individuals to think and talk about his/her cancer journey.

### ROUNDTABLE INTRODUCTIONS

Ask the participants to quickly introduce themselves. Please start clockwise from where you are sitting.

### PROMPTING QUESTIONS

If it appears that individuals need some prompting to stimulate discussion the following are proposed questions:

Physical Environment:	Please describe your experience at the home. Please describe your experience at the clinic. Please describe your experience at the hospital. Please describe your experience at the hospice. Please describe any issues you had with travel.
Immediate and Extended Family:	Who was your primary support person and how did this person impact your care? Can you tell me how your support person found information? What else could your family have done to help?
Traditional Healers and Spiritual Supports:	Did you use traditional care? How did traditional supports impact your cancer journey? Did your oncologist or health professional support your choice to use traditional supports?
Local Health Care Administration:	Are services available locally? Can you explain your local clinic/hospital/band operated health center experience and how did this impact your care? Please describe your experience accessing NIHB. Did you have issues with travel?
Community Health Facilities: Nurses, CHRs, HCAs:	Can you tell me your experience with your local home care team, community health nurse, CHRs and/or HCAs before, during and after your care? Did their hours of service impact your care? Did you receive adequate supplies throughout your treatments?

## APPENDIX J: FACILITATOR'S GUIDE FOR KITCHEN TABLE TALKS (CONT'D)

Family Physician, Local Doctors:	<p>Did you have a family doctor prior to your diagnosis?          What impact did your family doctor have on your diagnosis?          What impact did your family doctor have throughout your care?          Do you have a family doctor now?          How did your doctor work with specialists?</p>
Oncology Specialists and Nursing Staff:	<p>Did you have access to oncologists and oncology nurses after you were discharged?          Did you receive a discharge plan after treatment was completed?          Was there someone in the community to help you?</p>

### CLOSING REMARKS

Again, thank all participants for taking the time to share their cancer related stories.

Remind participants that if the discussion has caused them feelings of grief and heartache that there are people for them to talk to after this session and then refer them to the health professional list that is provided.

Close the discussion in the following way by stating: To show our gratitude for your participation, we are offering you a small gift. Also, please ask the participant to fill out a ballot (hand out the ballot) to be entered into a grand prize. The draw will take place after all kitchen table engagements are completed and the winner will be contacted by phone and email.

Hand out gifts to participants and collect ballots.

### CLOSING PRAYER

Ask the same person that did the opening prayer to do the closing prayer.



## APPENDIX K: FACILITATOR'S GUIDE FOR HEALTH SYSTEM PRACTITIONER FOCUS GROUPS

### Facilitator Guide for Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and Isolated Communities

#### Focus Group

#### Health System Practitioners

#### (Sharing on gaps and barriers, input on resource development)

*For these sessions, summaries of previous findings will have been developed for discussion with providers.*

**Purpose:** Gather input on feasibility of potential resources and to guide their development, and to share findings from community work with service providers.

*To identify resources that support practitioners in providing culturally appropriate care for the cancer journey of First Nation patients and families.*

**Process:** Focus group with system level providers; one at CCI and one at TBCC.

**Expected Outcomes:** Feedback on feasibility of resource development, increased knowledge on the part of service providers on FN specific gaps and barriers to care.

## WELCOMING REMARKS

Welcome all participants and thank them for taking the time to share their cancer related stories. Remind participants that they can refuse to participate at any time, indicating that any information collected before withdrawing will be retained and may be used in the future. Tell the group that information collected will be held in a locked cabinet at the Alberta Information Governance Centre's office in Calgary, Alberta and that personal information will not be disclosed.

Today, people may be sharing stories that may cause them some grief and heartache, and if anyone needs to talk to someone about what they have experienced then there are mental health professionals available. Hand out list of mental health professionals in the community.

This session will last approximately 1.5 hours and lunch will be provided.

## OPENING PRAYER

Please ask an Elder/Individual in the group to offer a prayer to start the session, please provide the person with tobacco that is provided.

## INTRODUCE PROJECT AND PROJECT TEAM

The facilitator will introduce the project details:

- Introduce team members.
- The purpose of this project is to improve cancer pathways for First Nation people in Alberta. This includes, but is not limited to access to services, patient care and quality of care that people experience on their cancer journeys.

## APPENDIX K: FACILITATOR'S GUIDE FOR HEALTH SYSTEM PRACTITIONER FOCUS GROUPS (CONT'D)

- So why did this project start? First Nations in Alberta are not going to the doctor and are being diagnosed late in their disease and dying more often from cancer.
  - The number of new cancer cases in Alberta First Nations (excluding non-melanoma skin cancer), between 1997 and 2010, was reported to be 2,726.
  - The survival rate of First Nations with cancer five years after diagnosis is 53 percent. First Nations in Alberta have significantly lower survival rates than non-First Nations across all time periods.
- This project is in partnership with CancerControl Alberta, Treaty 6, Treaty 7, Treaty 8, and the Alberta First Nations Information Governance Centre and other native and non-native organizations.
- This project has been officially launched with a formal traditional spiritual ceremony.
- We want to learn more about your cancer experience.
- Explain that there will be a person recording the information.

### CONFIDENTIALITY FORM

Hand out the confidentiality form and inform the group that each participant is required to read, sign and return the form to the facilitator to participate in the focus group discussions.

Ask participants to keep all information that they have heard in this session private and do not share what they have heard today.

Anyone that does not sign a form cannot be part of the discussions.

### PRE-SURVEY

Ask participants to take 5 minutes to fill out the CPAC Evaluation Survey.

### RULES AND NORMS

Note to facilitator: please allow participants as much time as they need to complete their sharing.

- Time: The session will take about 3 hours to complete.
- Speaking: A talking stick, feather or rock will be used to indicate whose turn it is to speak. When the participant is done talking, he or she will pass the sharing circle tool to the next participant on the left of them.
- Listening: Please listen to each person, and do not ask any questions while they are speaking.
- Participation: We will go around in a circle to hear each person's comments. If you do not wish to participate, please indicate this when it is your turn.
- Expectation: Each person will talk about their experience with First Nations and the cancer journey in any way that they see fit.
- Confidentiality: Please remember that information that is shared remains in this session.

### ROUNDTABLE INTRODUCTIONS

Ask the participants to quickly introduce themselves. Please start clockwise from where you are sitting.

We will be devising a set of open ended questions covering gaps, barriers, and system supports that arise out of the thematic analysis from kitchen table talks and focus group processes with First Nation communities that will lead this discussion.

## **APPENDIX K:** **FACILITATOR'S GUIDE FOR HEALTH SYSTEM PRACTITIONER FOCUS GROUPS (CONT'D)**

For example:

- Which of these gaps and barriers have you found to be common in providing care to First Nation patients and families?
- What do you see as your role in addressing these gaps and barriers?
- What system level barriers do you encounter when attempting to address these barriers? (e.g. Hospital policy, lack of understanding, etc)
- What supports would help you be more responsive to your First Nations patient and family client needs?

### **CLOSING REMARKS**

Again, thank all participants for taking the time to participate.

### **CLOSING PRAYER**

Ask the same person that did the opening prayer to do the closing prayer.

## APPENDIX L: CANCER CARE HEALTH CARE PROVIDER EDUCATION SESSION AGENDA



### AGENDA Cancer Care Education Day March 30, 2017 8:30 am-2:45 pm Cross Cancer Institute Edmonton, AB

**Chair** Angeline Letendre

**Purpose:** Increase oncology care provider knowledge and awareness of First Nations cancer patient needs

**Process:** Partnered education activities to support increased knowledge and understanding of oncology care providers

**Outcome:** Raise awareness and understanding of the needs of First Nations cancer patients and their families

Time & Agenda Item	Topic	Lead
8:30 - 8:45 am Opening Ceremony		Elders
8:50 – 9:00 am Welcome Remarks		Dr. Charlie Butts
9:00 – 9:30 am Indigenous Health Program	Historical and Cultural considerations with treating Indigenous clients	Marty Landrie
9:30 - 10:00 am Indigenous Health Program	Cultural Competency & Sensitivity Training	Chelsea Crowshoe
10:00 – 10:20 am Nutrition Break		
10:20 – 11:00 am CancerControl Alberta Presentation	Dialogue & Storywork project videos - Cultural Wisdom and Strength; Traditional Medicine	Warren Michael
11:00 - 12:00 am Elder Panel	Access to Traditional Forms of Support in a Cancer Care Environment	Lea Bill
12:00 - 1:00 pm	Lunch	
12:15 – 12:45 pm Brown bag presentation	Non-Insured Health Benefits Presentation	TBD
1:00 - 1:45 pm CPAC project	Alberta First Nations Needs Assessment Outcomes	Angeline Letendre
1:45 – 2:30 pm CPAC project & ACPLF	Building on the First Nations Cancer Pathways Project - Cancer Prevention and Screening Practices Project	Angeline Letendre & Lea Bill
2:30 - 2:45 pm Adjournment	Closing remarks	Marty Landrie & Warren Michael









ALBERTA FIRST NATIONS CANCER CARE PATHWAYS PROJECT

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