

Alberta First Nations Cancer Prevention And Screening Practices Project Mid Term Synthesis Report

A Synthesis of Cancer Prevention and
Screening Profile Development, Indicators
and Data Linkages, including First Nation
Lead Community Perspectives

First Nations Lead Communities

Maskwacis

Kainai

Peerless Trout



The Alberta First Nations
Information Governance Centre

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The Alberta First Nations
Information Governance Centre



Alberta Cancer
Prevention
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Executive Summary

This report contains a synthesis of the First Nations Cancer Prevention and Screening Practices project work that is specific to work stream 4. Work stream 4 focuses on determining mechanisms to create and report on First Nation cancer prevention and screening profiles, including elements important to cancer prevention and screening planning in First Nation communities.

This work was achieved through a series of engagement sessions with lead communities, experts and co-leads on data and information. This included dialogue on community perspectives in relation to definitions on health, the identification of health indicators, cancer prevention and screening planning and community cancer profiles.

In addition to 3 community sessions (Baseline, Community Feedback, Priority Setting) a meeting took place within each lead community that focused on the development of a community cancer profile. Baseline Sessions were held to collaborate with lead communities on baseline community health data usage for cancer prevention and screening planning. Community Feedback Sessions focused on reviewing the findings from the baseline sessions and planning for the next step of priority setting. Priority Setting Sessions identified themes and indicators the lead communities would focus their prevention and screening planning upon. Finally, Community Wellness Profile Meetings were held to determine the specific data sets, indicators and linkages for the community cancer profile.

The outcomes of this work include significant contributions toward the development of a framework for community planning in cancer prevention and screening. Just as important, is an identification of the processes that have been foundational to create a First Nation-specific pathway for cancer prevention and screening.

A synopsis of the key components essential to the framework are provided along with a diagram of high-level concepts that emerged throughout each of the lead community engagement sessions.

Project Work Stream Overview

This report is a deliverable for the “First Nations Cancer Prevention and Screening Practices Project” data sharing and surveillance work stream 4. First Nations partners to this initiative include the three lead communities of Treaty 6 (Maskwacis First Nation), Treaty 7 (Kainai First Nation), and Treaty 8 (Peerless Trout First Nation).

The purpose and goal of work stream 4 is to determine mechanisms required to create and report on a cancer prevention and screening profile for First Nation communities. The profile is expected to support the development and evaluation of interventions and monitoring differences in cancer risk. Elements to support the development of the profile include determining data linkage feasibility for the creation of First Nation identifiers for external data sources, such as cancer screening registries. This was achieved through bringing together project co-leads and partners, project and community team members and experts with varying expertise on First Nation data and information to participate in a series of Community Sessions and Community Wellness Profile Meetings.

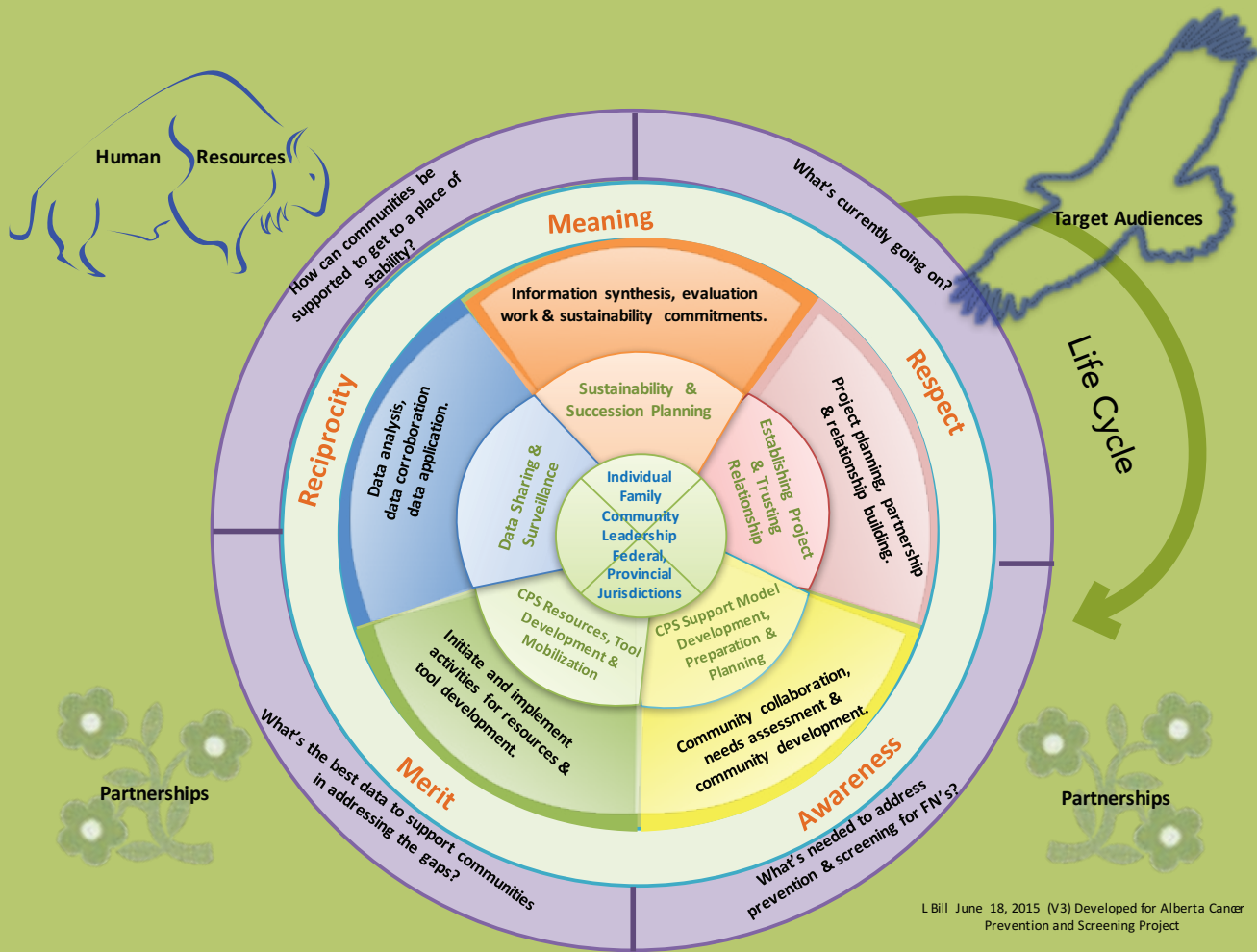
Project co-lead and partner, Alberta First Nations Information Governance Centre (AFNIGC) role involved:

- Ensuring data sharing agreements were in place between the Alberta Health Services, AFNIGC and lead communities.
- Identifying and creating data profiles for each of the lead communities
- Providing OCAP™ guidance with identified and collected data for community profile development
- Facilitating Community Sessions and Community Wellness Profile Meetings with lead communities

The role of the Alberta Cancer Prevention Legacy Fund (ACPLF) team involved:

- Providing a preventative based approach for community health planning and assisting with identifying data sources for the development of the profiles
- Supporting work that entailed developing socio-demographic profiles
- Participating in and supporting Community Profile Wellness Meetings
- Developing required reports, documents and meeting materials

ACPLF Cancer Prevention & Screening Practices Project Logic Model Diagram



These combined efforts were expected to assist in accessing and analyzing prevention and cancer screening data for community profiles and the development of inferences from First Nations Regional Health Survey (FN RHS) data in relation to modifiable risk factors and data.

The role of First Nation lead communities involved participation in activities during Community Sessions and Community Wellness Profile Meetings to establish a baseline of understanding regarding data for cancer prevention and screening needs and support. This then led to establishing priority theme areas and indicators for the development and implementation of community-specific cancer prevention and screening plans. Evaluation components were embedded into the Community Sessions and Community Profile Wellness Meetings and processes and are reported in separate documents.

The project logic model shown above provides a contextual overview of the Cancer Prevention and Screening Practices Project and where work stream 4 fits into the overall project.

Community Sessions & Community Wellness Profile Meetings

Project team members at each of the Community Sessions and Community Wellness Profile Meetings varied. Team members included ACPLF Science lead Dr. Angeline Letendre and CancerControl Alberta (CCA) Operations Coordinator Surveillance and Reporting Bethany Kaposhi, AFNIGC Executive Director Bonnie Healy, Research Engagement and Project Oversight Manager Lea Bill, Project Coordinator Janetta Soup and Director of Operations Tina Apsassin. Additionally, Alberta Health (AH) Population Health Assessment Manager Amy Colquhoun and AFNIGC Data Analysts Anita Konczi and Chyloe Healy. First Nations Inuit Health Branch (FNIHB) Data Analysts Vukasin Todorovic and Ibrahim Agyemang also attended the community sessions.

Each community established a core team consisting of the Health Director, the Community Prevention Practitioner and 2 Knowledge Holders/Elders (1 male: 1 female). Other team members who have attended a community session include program managers, community health nurses, community health workers/ health promotion workers, home care staff and leadership. In some cases, the community Chief and a health portfolio holder have been part of the community sessions, as well as other Knowledge Holder Elders from the community.

Community Profile Model

AFNIGC, currently leading work to support First Nation community access to their data, has generated a template for a First Nations Community Profile: “Sacred Fire Community Wellness Profile Guide”. The template or guide provided in Appendix A, consists of 10 themes that may be considered as foundational components for each community to begin building their profile. The themes are:

- Welcome to the Community
- Land and Environment
- Services
- Our People (demographics)
- Our Identify/Culture
- Health Determinants (identified by communities)
- Health Status
- Community and External Services (includes partnerships & service delivery models used by the community)
- Resources and Supports (assets & strengths found in the community)
- Goals and Aspirations (2-3-5 year planning in community health & wellness)

Cancer Prevention and Screening Profile

Engagement designed to establish an understanding of baseline cancer prevention and screening profile data assisted communities in identifying community specific cancer prevention priorities and indicators. The Community Wellness Profile meetings focused on identifying specific data sets, gaps and linkages needed to support a wellness approach informed by First Nations experiences with cancer. The priorities for cancer prevention and screening and related data included many elements of health services delivery, access and competing health issues. The Community Sessions and Community Wellness Profile Meetings, provided community's and their core team members a greater understanding and appreciation for the complexity of their community health status and landscape. AFNIGC and ACPLF team members have gained an appreciation of the efforts needed to address and support change. This includes successful navigation by First Nations of complex health systems, including the barriers and challenges faced when attempting to access health services specific to prevention and screening services. The cancer prevention and screening profile is a subsection of the community wellness profile and is linked through the components of; Welcome to the community/community landscape, Identity and culture, Land and environment, Services outside and within community, Health status, and Resources and supports.

Definition of Health

The opportunity to discuss what health means from a cultural and community perspective was an important process for the communities. Having an opportunity to explore what health meant provided the segway for communities to describe health from their cultural understanding, as well as relevant practices of health management. Language and connection to the land were key elements in defining health and specific traditional practices which are viewed as enhancing health through preventing cancer and supporting overall wellness. Definitions as described by the community teams have been provided in the community specific sections of this report.

Cultural Knowledge Understanding and Traditional Practices

Cultural knowledge, understanding and active engagement in traditional practices are all viewed as critical to maintaining good health, preventing disease and returning to optimum health after experiencing an illness. This includes the necessity to transfer traditional knowledge and information about health and wellness to younger generations to repair disconnect from culture and traditional health knowledge that are seen as contributing factors to unhealthy lifestyle choices.

Cultural training to health care providers was identified as an important strategy and approach to increasing understanding of traditional health practices and for promoting collaborative relationships between primary health care providers, including physicians, specialists and nurse practitioners. Each of the lead communities also recognized and spoke about an awareness and belief in the diversity, strength and capacity of specific traditional health practices and knowledge and their associations with ceremony and nature-based medicines.



The Environment

Environment was viewed from 2 different perspectives. First, the environment reflected relationships to the land and its importance in promoting health and wellbeing through ceremony, medicines and connections to traditional cultural practices. The second perspective was linked to those elements that support a healthy community environment, such as housing and the ability to have influence on environmental cleanup where contamination has and continues to occur. How healthy a community environment is was also seen as linked to the location and availability of health services that are free from racism and discrimination. Experiences with racism among First Nation community members surfaced at each community session and meeting. The need to address these circumstances was viewed as imperative to improved trust of services and service providers, which may then result in improvements in prevention and increases in screening at the community level.

Access to Resources, Supports, Knowledge and Data

This feature was described broadly and linked to health services (primary care and screening), which includes access to traditional cultural supports, land use areas for food and medicines, and access to Indigenous knowledge holder practitioners within and outside of communities. Access to resources and services included: improved human resource and community ratios; sustainable resources for traditional based supports such as Elder Knowledge Holder outreach to families and cancer survivors and other traditional knowledge practices in support of teaching healthy life choices; access to screening services; access to physicians or specialists; and access to knowledge and information about cancer, screening, advocacy and appropriate follow-up services for patients with a diagnosis or whom have received treatment for cancer and are in need of ongoing screening.

Knowledge access was talked about in the contexts of being able to utilize space for traditional practices, the importance of transferring knowledge to younger generations and sharing knowledge at the community level. Access to health education in prevention and screening and the transfer of information through home visits were identified as the best approach to ensure information was being received and understood in the ways in which it was intended. Knowledge Holder Elders spoke of home and hospital visits as an important supportive traditional practice for families and felt outreach through home visits were a key element to improving access to knowledge and information about cancer, cancer prevention and screening and related services.

Access to screening data was also identified as an issue and plans to resolve the barriers were initiated during this project. An appreciation for the power of data was realized once community teams began to understand their value in how they could use the data to support their planning, monitoring and evaluation of cancer prevention and screening and other health programming. With this understanding there emerged an eagerness to incorporate and leverage data for program planning and development.

Prevention, Screening and Teaching

Prevention through health promotion is desired by communities in spite of many competing priorities. All 3 lead communities discussed the distribution of resources for access to primary care service providers. Seen as “gate keepers” to screening was talked about as a significant challenge for community members and an important concern for community health care providers. Identified as a critical gap in services provided to First Nation community members, there is a shortage of primary care providers who can initiate and address screening needs and then ensure follow-up. In spite of current work and future planning to increase knowledge and understanding of screening, First Nation people are reporting difficulty in entering the health care system for screening and to specialists in a timely manner. Utilization of mobile units are seen as an important strategy and approach and are being utilized by all 3 communities; however, gaps in follow-up and access to screening data to assist their teams in supporting patients at the community level have also been identified. Gender specific programming was identified as a need in order to reach the male population in communities. Including cancer survivors as teachers and applying cultural knowledge transfer approaches were strongly recommended as strategies for prevention, teaching and increasing screening awareness. Outreach approaches with Knowledge Holder Elders included as health care team members to work with a family or cluster of families could enable the transfer of cultural health knowledge to happen in conjunction with primary care service options related to prevention and screening. Collaborative multidisciplinary team approaches with interagency groups already delivering programs was suggested to expand the reach of prevention and screening. All 3 communities have indicated they wish to leave an imprint of a healthy community for future generations rather than the prevailing historical imprint of health inequities and disparity.

Data Use and Management

Data use and management are new activities for First Nation communities. As such, it was recognized that this would entail a steep learning curve for health managers, staff and the data systems managers with regards to First Nations data access, sources and storage. Hence a theme around data use and management became a key element for cancer prevention and screening planning, monitoring and sustainability planning. AFNIGC began providing data management and OCAP™ training sessions to all FN communities through additional funding acquired for the Community Profiles Project. Specific areas of concern that were repeatedly raised during engagement sessions involved access to the right data and application of the right data. These decisions are important to ensure a true picture of the health status of a community and for creating community based cancer prevention and screening plans within a wholistic wellness model. A second outcome of the community profiles work has been with communities to identify and request health trend reports supportive of cancer prevention and screening. Each community has requested data sets from Alberta Health Services (AHS), First Nations Inuit Health Branch (FNIHB) and the First Nations Regional Health Survey (FN-RHS) data.

During the Community Wellness Profile Meetings, data analysts provided advice to communities on what types of data would be most useful to apply to their priorities and the indicators that they each had identified. Where gaps were noted, collaborators identified that there may be challenges in access to the right or best data representative of some of the community indicators. With this in mind, plans are being developed to collect the best data that can support communities with establishing baselines, reflect ongoing monitoring and be appropriate to evaluation purposes, where limited or no data was previously identified nor did previously exist.

Role of Leadership

Role of leadership was an important feature as it was seen as the vehicle by which action is supported at the community level. The long standing relationship between the federal jurisdictions remains an important element as the treaty right to health is entrenched in Treaty 6. Without leadership support, the designated governing body in First Nations communities, each community does not have the power to move on issues. Where collaborative partnerships have been developed, language of treaty rights and more recently OCAP™ language are of critical importance for successful program implementation and sustainability.

First Nations view sovereignty and the right to health as part of their treaty rights. First Nations relationships with the governments of Canada are primarily with the Crown and then with the province. Elder Knowledge Holders, as participating members on each community team, have expressed that First Nations people never relinquished their status as sovereign nations; thus, the need to be conscious of what is being agreed to and the language used within agreements is essential to the protection and preservation of these rights.

Facilitating Actions

“Enablers”, as a feature of this report was changed to “facilitating actions” emphasizing the importance placed on the empowerment of communities to take action through planning. Further, as it pertains to the flow of energy and responsibility, facilitating may be considered a collaborative process in which each partner plays an equal part; whereas, enabling may refer to the superior abilities of one partner over that of the other. Enabling is directed to the receiver and facilitating action has the option of flowing back and forth (reciprocity) or in many directions through collaboration and engagement. Both are critical elements for overcoming the many barriers associated with health services and implementation of community based programs. Facilitating action sets a pathway for achieving barrier free services and programs within and outside the community.

Cancer Prevention and Screening Planning and Profile Framework

Key features of a framework for First Nation cancer prevention and screening planning emerged from the work completed to this point with the lead communities. The framework encapsulates a wholistic perspective based on core precepts which encompass First Nation principles, teachings, protocols and or guidelines and evidence base. The framework includes integrating mechanisms that support community specific cancer profile and cancer prevention and screening planning, development, coordination and implementation. The features described in the following section have been identified as important for successful cancer prevention and screening planning, development, coordination and implementation within the context of community specific data and health indicators. This framework is supported by and dovetails with the "Sacred Fire Community Wellness Model". (Appendix A)

The core precepts identified within the framework were discussed at great length by communities and believed to underpin a successful community based prevention and screening plan development and particularly for early detection, responsive services and successful implementation for positive outcomes.

Recognizing diversity and varying levels of sovereignty the community landscape of First Nations communities informs approaches, partnerships and collaborative efforts for prevention and screening development and implementation of prevention and screening plans.

Facilitating actions are aligned with the core precepts for successful implementation and delivery of comprehensive prevention and screening services, programs and with participation of First Nations.

Indicators identified and translated from a First Nation world view clearly demonstrated an expanded perspective of the role of indicators. Indicators were not merely statistical gauges of success or failure, but also encompassed cultural teachings, relationships with land and medicines, family connectedness and their understanding of a right to responsive health services.

Moving from a deficit perspective to a wellness perspective will take time since current data sources are primarily deficit oriented. Mechanisms for collecting community generated data are not present and will need to be

developed; however, the data sources utilized for the time being provide strong baselines from which to move towards wellness and wellness indicators. Data sources supporting the indicators identified by communities include but are not limited to the following:

- Alberta Health Services
- Alberta Health
- Regional Health Surveys
- Non Insured Health Benefits
- Community Generated Data
- Indigenous Services Canada
- Statistics Canada

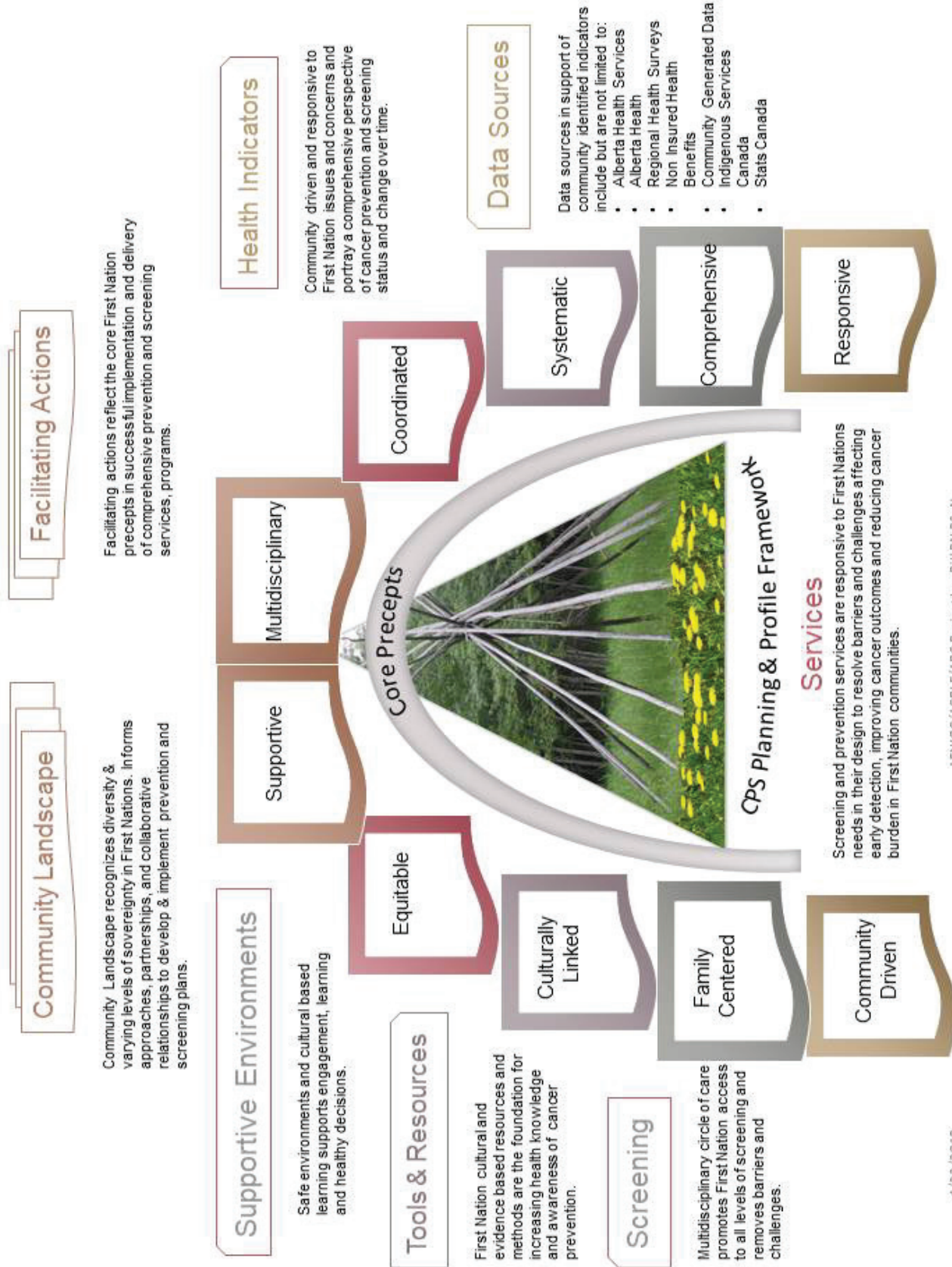
Tools and Resources with the First Nation lens provided by the communities will need to be adapted to support increasing health knowledge and awareness of cancer prevention. Cultural based systems and specifically the use of text versus oral and interactive transference of knowledge and information require dedicated resources in the form of human resources and funding for development of tools.

A multidisciplinary circle of care where screening is introduced at each client encounter with the system requires commitment and resources on the part of services and service providers. These mechanisms and approaches to screening promote access and remove barriers and challenges to screening.

Safe supportive environments act as facilitators for access, engagement, cultural learning and ultimately healthy decisions. Communities believe that the presence of supportive environments and mechanisms extended to families and community health care providers encourage participation and healthy decision making.

The model presented on the following page is an extension of the "Sacred Fire Wellness Model" and is also linked to the tipi where the home fire exists. A space where traditional teaching and families are interlinked and which has been used as the model for traditional knowledge transfer.

The base of the tipi is surrounded by the dandelion plant as it has become the signature plant for this project namely for its medicinal qualities as a prevention medicine of cancer, but also because of its resilient and abundant nature.



AFNIGC/ACPLF/APC Project Lea Bill RN BScN

4/22/2018

Health Indicators Overview

All communities, while unique in their cultural and traditional ways, have stated that data and health indicators need to support their worldviews. This means indicators need to reflect their connections to land and environment, and be inclusive of culture and traditional practices, including language and knowledge transfer systems. Within these contexts, communities have defined health as encompassing improvements by addressing health indicators in a wholistic manner. Health indicators were not seen merely as statistical gauges but include connections with the land, family systems, traditional health practices and the presence of traditional cultural teachings. These descriptions of indicators of health are not currently captured through statistical means. The data identified indirectly will support elements of identified indicators however community specific data relating to these connection indicators and areas of concern will have to be generated by the community.

This section provides a summary of the health indicators and data available for cancer prevention and screening planning in First Nation lead communities. Communities identified health indicators that ranged from a need to address a specific set of issues related to disease and illness (communicable and chronic diseases) to health indicators that are action-oriented and viewed as critical for improved health in the community, such as the ability to implement cancer prevention and screening successfully. The Cancer Prevention and Screening Planning and Profile Framework presented is a useful tool to bring this information together in a comprehensive way to support a First Nation community in their development of a cancer profile. The cancer profile, populated with a community's specific information may then be used as evidence in creating their own Cancer Prevention and Screening Plan.

The following health indicator themes are based on the engagement sessions with First Nation lead communities. Additional themes also emerged through a review of community meeting transcripts and discussions amongst project co-leads. This information was then validated during Community Feedback Sessions in each community.

1. Services

- a. Primary care (availability of physicians, nurses and other health care professionals)
- b. Transportation
- c. Jurisdictional boundaries
- d. Health benefit coverage and extra costs
- e. Companion and translation services
- f. Delivery within communities
- g. Discrimination and racism
- h. Informed consumers of services and rights and choices

2. Screening

- a. Mobile unit availability
- b. Primary care provider access
- c. Knowledge and understanding of screening
- d. Importance of language and knowledge transfer (opportunities for teaching to all ages)

3. Access

- a. To primary care providers
- b. To local health care providers (home visits)
- c. To mental health supports
- d. To cultural supports
- e. To traditional medicines & food
- f. To knowledge and information
- g. To advocacy for services and information

4. Cultural Awareness/Culturally Safe Care

- a. Training of cancer care providers
- b. Racism in the health care system

5. Cultural Supports

- a. Facilities with appropriate space for cultural support services
- b. Inclusion of knowledge holders and practitioners within the health care system

6. Community Supports

- a. Advocacy supports
- b. Mental health supports
- c. Companion and translation support
- d. Incorporating traditional/cultural knowledge methods and activities into programs

7. Health and Wellbeing

- a. Connection with language, culture and land based programming
- b. Encompasses all elements of the community and recognition of diversity within communities. (social determinants of health)

8. Environment

- a. Water quality (access to clean safe water and ongoing monitoring of water quality)
- b. Land contamination from past and present development
- c. Impacts of current and planned development near communities (road and industry development)
- d. Housing and infrastructure safety and access
- e. Safe traditional harvesting and cultural land use areas

9. Barriers & Challenges

- a. Attitudes, beliefs and actions of service providers
- b. Disconnected data systems and management (monitoring, follow-up and planning)
- c. Appropriateness of services for geographic and diverse community landscapes (screening and primary care access)
- d. Knowledge, language (medical knowledge & terminology) use during screening, prevention and diagnostic procedures
- e. Lack of health care human resources at the community level (staff turnover)
- f. Funding arrangements and allocations of funding for programs
- g. Unsupportive and discriminatory policies
- h. Lack of quality assurance systems (health care services and administration and environment)
- i. Limited or inaccessibility to support services (transportation, mental health, navigation & liaison, companion, cultural, interpreters, primary care providers)

10. Facilitating Actions

- a. Meaningful, respectful, collaborative planning and partnering between jurisdictions and leadership, health care providers and traditional health knowledge holders (community, federal and provincial, and treaty regions)
- b. Recognition of the value of traditional health knowledge systems, protocols and methods of health management and prevention
- c. Developing collaborative relationships between traditional health knowledge holders and medical health care providers
- d. Empowering communities (use of community informed approaches in which lead communities have identified their priorities and methods for implementing cancer prevention and screening plans) and health care systems (Federal & Provincial) support the processes with the right resources, knowledge and collaborators

11. Injury Prevention

- a. Working through a trauma informed lens
- b. Incorporating land based knowledge and activities which tie in traditional cultural values of respect and protection of family and future generations (potential to address many types of injury affecting health and well-being)
- c. Linking programs for efficiency and resource sharing

12. Community Landscape

- a. Emphasis on family, children, youth, future generations, traditional cultural health knowledge and systems
- b. Necessity to work together within a multi-disciplinary framework in the community and at a systems level (remove the barriers impacting ability to do so)
- c. Recognition of diversity and the impacts on progress toward improving health and wellness and reducing cancer burden within community (geography, partnerships, resources, capacity, leadership priorities, competing issues)

13. Knowledge Exchange Between Systems

- a. Data access, sharing and understanding of data and its application at different levels of health management
- b. Interpretation and understanding of fiduciary (trust relationships) with all jurisdictions (Federal, Provincial, Municipal, community leadership, service provider, health care provider and Indigenous health Elder/Knowledge Holders)

14. Resources and Tools

- a. Resource for male screening recruitment and communication messages
- b. Transmission of key messages are cultural based (visual, oral, and potential use of social media)
- c. Resources and tools for data management at the community level for ongoing monitoring and ease of access to data for planning and quality assurance measures



15. Human Resources/Health Care Providers

- a. Sustainable equitable resources per capita in the form of human resources are basic for successful implementation of health programming
- b. Training and knowledge of the role of co-morbidities with cancer prevention and screening.
- c. Training and understanding of cultural factors, historical trauma, and community capacities for service delivery

16. Community Infrastructure

- a. Size of Health Centres and other infrastructure availability within communities impact service delivery
- b. Location of main service centres in community and the size of the community are important factors for consideration for planning screening events (mobile units may need to set up in different locations to improve access)

17. Healthy Lifestyles

- a. Disconnection from cultural knowledge, language, family and community/land supports is identified as a key factor influencing choices for healthy lifestyle
- b. Patient-doctor relationships and time spent with clients an important element to managing health and making choices for managing chronic and or mental health concerns.

Community Profiles

This section provides a high level overview of each lead community. Reports were generated for the baseline and priority setting sessions, while the information presented here supports previous sections of this report and shows where there are slight differences in community perspectives. Extensive discussion during these sessions about the landscape of the community, health indicators, definition of health, data use, linkages and relevance, along with health services, barriers and challenges and traditional health practices and ways to implement activities for better reach and successful outcomes took place. It's important to note that not all ideas presented may be seen as an indicator however the concepts presented were identified as having relevance and presented for context. High level summaries from each community for cancer prevention and screening planning and the prevention and screening profile are listed for each community along with supporting quotes from Elder Knowledge Holders and community participants.

Important notations from communities are the impacts and benefits experienced by the lead communities. Listed here are feedback comments from each of the communities.

Maskwacis lead team reports that the community has seen positive impacts already and looks forward to the full implementation of their cancer prevention and screening plan.

Kainai community lead team has expressed a great appreciation for the learning and opportunity to work with other communities. Outreach work with the Elder Knowledge Holders and CPP to families and the satellite communities began within the first few meetings of the project and has resulted in catching individuals with early stage cancers.

Peerless Trout community lead team has expressed great appreciation for the opportunity to be part of the project and have indicated that they have learned much from the other communities. These lessons are being applied as they plan and implement their prevention and screening project.

Maskwacis First Nation Cancer Prevention and Screening Profile Development Synthesis

Definition of Health

- “Health has always been attributed to balance of the self as a whole. With this principle is the belief that the health of one was the health of all within a tribe of peoples so in order to keep balance of a tribe the health of an individual was seen as an integral part of the health as whole. Medicines provided by Mother Earth and the relationships to the environment are directly related to sustenance required for survival as an essential requirement to balance the self”.²

Community Landscape

- Comprised of five communities (Samson First Nation, Erminskin First Nation, Louis Bull First Nation, Montana First Nation and Pigeon Lake) with a total population of 16,342, second largest reserve in Alberta
- Land base of 319.8 square kilometers within Treaty 6
- Incorporated entity with a mission of; “The Maskwacis Health Board, with the support of the Maskwacis leadership, competent staff and adequate financial resource, will apply the medicine chest clause to provide the highest quality health care services to the Maskwacis Peoples”.³

Role of Leadership, Government and Sovereignty

- Leadership seen as advocates of good services and health care for community and community members
- Advocacy for the Treaty Right to Health considered a very important role of the community leadership
- Sovereignty contributes to health (land, knowledge, language and cultural ways)
- Sovereignty is creating our own policies and governance practices



Health Indicators

- Indicators are seen as markers that point toward something, or to make it seen for example on a person, or when you see things repeating (predictions, future related)
- Overarching health indicator themes consistently raised were knowledge and understanding of health, use and applications of traditional medicines, cultural values, sovereignty, and health of the environment and transference of cultural health knowledge to future generations

Traditional Knowledge and Medicine

- Physicians and health care providers need to understand traditional methods, medicines and ways of working with traditional practitioners
- Communities would like to work more closely with health care providers
- Protocols and medicines are key pieces of knowledge for community health
- Spiritual connections and traditional knowledge support healthy choices
- Knowledge transfer and teachings to community members, including youth
- Traditional foods as medicine are an important part of health promotion and well being

^{2,3} Maskwacis Health Services Web Site <http://maskwacishealth.ca/aboutus/>

Screening

- Mobile units are an important part of the screening plan based on the community experience so far
- Focus on education and promotion needs of men, youth and cancer survivors
- Address fear of screening and cancer
- Accessibility to referrals, and follow-up with screening, transportation concerns, and access to health care provider screeners (NP, Doctors and mobile units)

Prevention & Education

- Include cancer survivors
- Incorporate with other disease prevention activities
- Important to include youth in educating and teaching
- Physicians role in educating about treatment and prevention
- Teaching on dealing with emotions and stress rather than use of pills
- Focus on increasing understanding of cancer
- Incorporating spiritual ceremonies, which involves physical activity and transfer of knowledge
- Utilize social media and other ways to get the messages out
- Teachings in homes, utilizing elders, family conferences and workshops



Services and Health Care Providers

- Maskwacis aspires to have a community based hospital which incorporates traditional cultural ways
- Wait times impact trust of services and affects whether people return
- Trust in the system is eroded from many reported negative experiences reflecting the need for change through the improvement of services
- Trust exists in Indigenous service providers/physicians
- Trauma informed lens and care is needed
- Nurse Practitioners are already part of the service delivery and possess good relationships with First Nation communities
- Satellite services are important and seen as a solution

Patient Rights, Choice and Autonomy

- Challenge in patients preferences to not access treatment or go for screening. Family supports for these occasions are important
- Advocacy for those patients that do not understand and need language translation and companion support

Facilitating Actions

- Utilizing traditional methods of connecting with the people, home visits and gatherings
- Promoting the use of traditional knowledge transfer, culture and medicines for prevention based in wellness perspectives
- Utilization of Cree language
- Promoting and encouraging regular doctor check-ups
- Involving youth in the development of resources
- Teaching youth about protocols and cultural knowledge
- Working together
- Prevention activities through traditional knowledge and land use, referring people to traditional practitioners and having access to healing centers

Land, Environment and Environmental Health

- Housing and home concerns need to be considered and addressed
- Environment an important part of cancer risk, where land and home contamination exists
- Land contamination affects traditional food and medicine use and safety
- Policies needed to protect land, medicines and cultural knowledge
- Producing gardens and berry farms for health and wellness
- Water contamination a concern, people on bottled water in some locations of the community
- Environmental health concerns identified (safe waste disposal, sour gas leaks, hydro lines and Wifi, cellphones)



Barriers and Challenges

- Transportation concerns are being addressed since the project started
- Historical experience with residential schools has an effect on self-care and trust in relationships with the health care system
- Long standing experiences with racism and discrimination are ongoing and require healing and collaborative efforts by service providers

Data Use and Management

- Maskwacis Health Services has developed partnerships with other projects where data is exchanged
- Screening data is an important element to planning and monitoring

Maskwacis First Nation Quotes

"Glad to be part of this project, important thing to remember is educating our people. So many people are scared to get tested. [I] have told people about the risks of not getting tested".

*Community Participant,
Maskwacis 2017*

"In our culture, we need to keep in mind those who are not yet born... The Creator sees more than we can see. Each meeting is always different and this helps build up our knowledge and understanding of this topic. We cannot quit, the work is hard".

*John Ermineskin,
Knowledge Holder/Elder
Maskwacis 2017*

"Prevention [for] cancer survivors needs to be reviewed again. We need to keep this in mind and pay particular attention to this as it seems to be recurring over again with community and family members".

*Victor Bruno,
Knowledge Holder/Elder
Maskwacis 2017*

Kainai (Blood Tribe) Cancer Prevention and Screening Profile Development Synthesis

Definition of Health

- “Health is intimately linked with the environment. Health is tied to connections to the land, animals, plants, one another and being close to the earth. Having strong faith in these elements along with the language to communicate and understand from a Blackfoot worldview, which is multifaceted and holistic.”⁴

Community Landscape

- Large reserve made up of 13 smaller community sites with Standoff being the location where services are provided (all main facilities for services are located in Standoff with satellite clinics in smaller communities)
- Geographical space of Kainai (Blood Tribe) encompasses 549.7 square miles (1423.8 square kilometers). Population approximately 12,200
- Cardston Clinic provides professional services, health records services, pharmacy, physio therapy and dental clinic
- Community owned food market opened in December of 2016
- Repatriated traditional systems of community and governance entrenched in Blackfoot Knowledge and ways of knowing

Leadership Role and Support

- Leadership is guided and supported by the traditional systems of the community
- Elder/Knowledge Holders actively work with community leadership

Health Indicators

- Indicators identified as being connected to the environment
- Indicators need to encompass elements of the community based in holistic perspectives
- The loss of community and movement to re-instating community systems within a Blackfoot context are viewed as the most powerful indicators of health which also support other indicators of health
- Family structures and child rearing practices with prayer and ceremony support
- Connections within the community and traditional practices of connecting through visiting, gathering, ceremony, traditional practices, transference of knowledge through ceremonial transfer methods
- Social interaction
- Family structures and identity, including number of grandmothers and grandfathers, and also number of grandmothers and grandfathers faced with sickness, (chronic disease and cancer), number of individuals supporting loved ones with health challenges
- Biophysical health indicators, such as chronic disease, physical inactivity, stress, misuse of substances and effects from tobacco and medications
- Communicable disease (TB, Hep C, STI)
- Growth of Sun Dance camp from 30 (1950) to over a 100 tepees is viewed as a powerful indicator of growing sovereignty and health

⁴ Blood Tribe Department of Health Web Site <http://btdh.ca/about-us/>

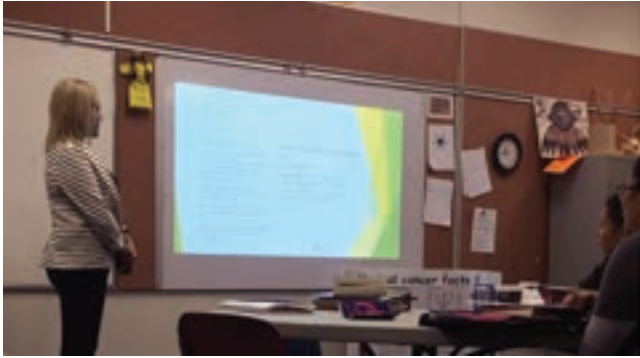
Traditional Approaches and Community Systems Change Within a Blackfoot Context

- Challenges associated with working within a western system and trying to incorporate traditional systems and practices
- Western approaches of fear tactics is contradictory to traditional system approaches of support, kindness, prayer, hope, respect and acknowledgement of strengths and wisdom held within Blackfoot societies
- Original community structural systems of societies and ceremonies linked to each are intact and continue to be the source of strength for health and those practicing are increasing as community members find their way back
- Community came together to support through home visits and acts of kindness that are seen as an important component of successful implementation of prevention and screening work
- Application of methods and tools in addressing stress and trauma (sage, sweet grass, drumming, singing)
- Necessity for reconnection to the medicines and mechanisms for healing to take place, knowledge transfer, learning and understanding the processes and protocols as examples that no one is alone when entering into a society
- Importance of sharing traditional names and stories within the community to reinforce spiritual connections within the community
- Increasing cultural education of the young
- Important role of Elders and Knowledge Holders
- Prayer as a foundational element for all activities



The Patient/Client

- Supporting families to focus on healthy living and wellness as advocates for themselves
- Addressing screening from a family approach rather than individually
- Building relationships with families and community members (individual experience is a family experience so no one is alone)
- Trauma lens needed in view of historical experiences
- Recognizing the impacts of family structure breakdown and the dynamics it sets up (fentanyl, other substance misuse, child apprehensions coupled with illness)
- Necessity to address the gap seen with male health concerns (lack of screening, health check-ups)
- Increasing knowledge and understanding of cancer and effects on the body and removing the fear of cancer
- Applying traditional practices while engaging with patients (home visits, prayer, ceremony, gifting, being connected)



Health Care and Other Service Providers

- Health care and service providers returning to work in the community are overwhelmed with the number of trauma related issues faced by community members compared to outside the community
- Recognition of the importance of trauma informed lens, being empathetic, compassionate and understanding the context of community member experiences
- Health care service provider/patient ratios inadequate to meet community demands and needs
- Recognizing traditional approaches to engaging community members and patients may improve access and desired outcomes of programs
- Experience of racism with off reserve services impacts trust and access to services
- Access to services impacted by transportation issues (size of community, distance of travel, lack of vehicles, no community bus services)
- Policy for transportation is for off reserve services
- Many competing issues to address (TB, Fentanyl crisis)
- Multiple physicians providing care to a patient is challenging for the patient

Environment and Environmental Health

- Oil and gas development (fracking, burning gas) are identified as impacting the health of community members
- Air and soil quality impacts from surrounding and on reserve agriculture practices
- Lands department seen as an important stakeholder to address community concerns in cancer prevention and screening
- Safe drinking water important for health
- Community level regulation for local farmers and those leasing reserve land are identified as having important impacts on environmental factors related to cancer
- Traditional food harvesting areas need to be protected from environmental effects (pesticides, oil and gas contamination)

Screening and Prevention

- Health promotion is a priority even with many competing issues
- Challenges with promoting screening with male population
- Family cluster health promotion outreach with the smaller communities recommended for better success
- Mobile units would have better success if more time and flexibility to move locations were considered in view size of population and community geography
- Advocate for prevention and screening to as many people as possible
- Teachings about food and diet and food preparation
- Combining cancer related health promotion with other programs such as diabetes program
- Leave a positive imprint of a healthy community for future generations



Facilitating Actions

- Needs assessment of the different communities to assist with planning and identify specific methods of support for participation in prevention and screening and health activities/programs
- Bridging of traditional and medical model approach to best support community programs and community members
- Utilization of Elder/Knowledge Holders to help facilitate traditional approaches to program delivery and supports to clients
- Utilizing traditional methods such as drumming, prayer, ceremony to support families and clients
- Working together as programs and service providers
- Developing oral/video based resources not everyone reads pamphlets and positive use of social media
- Love and support are crucial elements of care and support, along with positive thinking
- Promoting idea of own berry farms
- Teaching and training of health care providers about cultural traditional practices and the support it offers to community
- Companion supports for language barriers by older generation during physician visits
- Physical health impacts on mental health, supporting and promoting positive mental health coping methods (ceremony, physical activity, community connecting)

Barriers and Challenges

- Racism a major concern has posed much challenge for patients seeking and receiving services
- Transportation poses challenges due to proximity to services on reserve, policies governing the services, and deficient resources to fulfill the demands
- Short term funding for projects is prohibitive of sustainable actions and planning
- Competing health concerns and issues coupled with health care provider resource shortage
- Health promotion and prevention activities are pushed to a lower level of priority

Data Use and Management

- Data reliability concerns for tracking due to data based on postal codes and difficulty to get data without patient identifiers
- Immunization program has a record tracking system in place
- Data is a tool for change
- Data sharing needed at the community level to enhance working together and towards similar outcomes
- Data access and use has limitations as a result of patient identifier absence
- Data sources and sets are identified as (NIHB, immunization, Alberta Health administration data, pharmacy data)

Kainai (Blood Tribe) First Nation Quotes

"I keep repeating and I strongly express it's with home visits that we do... with each household that we go to, the feedback we get from the family is that this stuff is so informative".

*Dorothy Daychief,
Knowledge/Elder,
Kainai First Nation 2017*

"It's the knowledge the air, the water, the animals... and all of these animals have something to heal the community".

*Joe Spotted Bull,
Knowledge Holder/Elder,
Kainai First Nation 2017*

"We need the testing and the screening but we also need the prayer, the herbs and the natural healing methods".

*Community Participant
Kainai First Nation 2017*

Peerless Trout Cancer Prevention and Screening Profile Development Synthesis

Definition of Health

- “Health is defined as being active, living longer for your children and grandchildren and being disease free. It encompasses good food, learning no matter how old you are, being connected to family, language and traditional land activities.”

Community Landscape

- Peerless Trout First Nation (PTFN) is a young community in relation to population and its existence with recent independence from the larger community of Bigstone
- Funding arrangements differences from other First Nation communities result
- Geographically the community is semi isolated with a new health centre facility and surrounding infrastructure being built
- Community members utilize land based activities of harvesting food and recreational activities
- A major road development is in progress which is seen as a good thing that will also have negative effects
- The community has a large Christian based culture with land based activities unlike other First Nation communities who practice traditional ceremony and traditional healing methods and medicines

Leadership Role and Support

- Leadership is seen as an important support for community health care providers by being actively involved with the planning and development of programs since the inception of the community as an independent First Nation

Health Indicators

- Health indicators include environmental health (water, land), physical health (chronic diseases), physical activities, mental and emotional wellbeing, traditional land based activities, maternal and child health (immunizations, birth defects, prenatal health, family supports and connections), health service utilization, communicable disease rates and a sense of well-being (kindness and happiness)

Health Services and Health Care Providers

- In the process of becoming a reserve receiving services primarily from Alberta Health translates to less services provided by Health Canada to other First Nations
- Racism influences on access to services primary care and screening
- Language barriers between service providers and clients, terminology used is not being understood, especially with physicians
- Transportation has impacts at multiple levels, such as missing appointments, long distances for travel and the time from when clients are dropped off and picked up from appointments (there may be up to 3 different drop off and pick up points for a patient, clinics are often closed when patients are dropped off or picked up)
- Full time Nurse Practitioner is seen as an important solution for access to services and screening
- Raise cultural awareness of health care providers and the challenges for patients living in a semi isolated region
- Tracking systems needed for services and access to services

Physical Activity/Traditional Activities/Traditional Practices

- Community is located in an area where traditional hunting, trapping, canoeing and outdoor/traditional land use is still present and contributes to health and wellbeing
- Promotion of activities with children and youth
- Loss of traditional culture needs to be further understood and is talked about as land based living and Indigenous language use with half the community speaking fluent Cree
- Land based activities and teaching are identified as a healthy way to promote health and making healthy choices

Diet, Nutrition/Traditional Foods

- Need to explore knowledge of edible plants and medicines are not yet known except for berries
- Traditional food harvested from the land while hunting and trapping is consumed by community members

Knowledge Transfer and Education

- Young people (mothers and fathers as the larger percentage of the community population) are identified as an important target population for knowledge transfer and education
- Target large families and to focus on understanding prevention



Screening

- Nurse Practitioner is identified as key health care provider for screening within the community (PAP, FIT)
- Mobile health unit for mammogram screening as an important resource that emphasizes the need for more localized screening

Cancer Prevention and Injury Prevention Considerations

- Injury and cancer prevention have equal importance due to geographical location of community and the traditional land based activities of the community
- ATV's are utilized as a mode of transportation with potential for accidents due to close proximity to a large body of water and long distances to emergency services
- Size and location of the community
- Target populations (mostly young population)
- Human resource capacity of health services within the community



Environment and Environmental Health

- Municipality is part of the community service delivery and plays a role in water monitoring and waste management
- Differences in these processes when compared to other First Nations communities causes limitations in monitoring and follow-up of issues
- Environmental factors identified for housing include overcrowding, mold and water quality
- Weather also impacts access to out-of-community services

Facilitating Actions

- Develop resources that encompass traditional land based activities and approaches
- Land quality assessment to support increased gardening and traditional harvesting
- Resources for safe food storage and preparation
- Partnership building with different groups to increase resources for community activities (good soil needed for gardens)
- Working with youth, families and Elder/Knowledge Holders

Data Access and Data Management

- Health systems data is difficult to access and reports are not provided to the community
- Data requests and increased understanding of data sets can be used for health planning (community advantage of a single postal code for data requests)
- Designated data custodian (Community Health Nurse)
- Data Limitations (No data from FNIHB at this time until reserve status arrangements are completed and resources are put in place)
- Training on privacy and data management is identified as a priority
- FN RHS survey is being carried out in the community
- Nurse Practitioner has access to NetCare & Wolf data systems
- Immunization data is accessed through AHS
- Creation of a community data base identified as a priority
- Data sharing with mobile screening units need to be put in place

Peerless Trout First Nation Quotes

"Traditional hunting and trapping is done throughout the summer months and we eat traditional foods. Since we know what the healthy foods are, we can start eating them. Somehow we need to teach our children and young mothers the importance of healthy eating habits".

*Flora Cardinal,
Knowledge Holder/Elder,
Peerless Trout First Nation
2017*

"Thanks you for coming. Each time we have these sessions, I learn more and more of what our community needs".

*Joe Okemow,
Knowledge Holder/Elder,
Peerless Trout First Nation
2017*

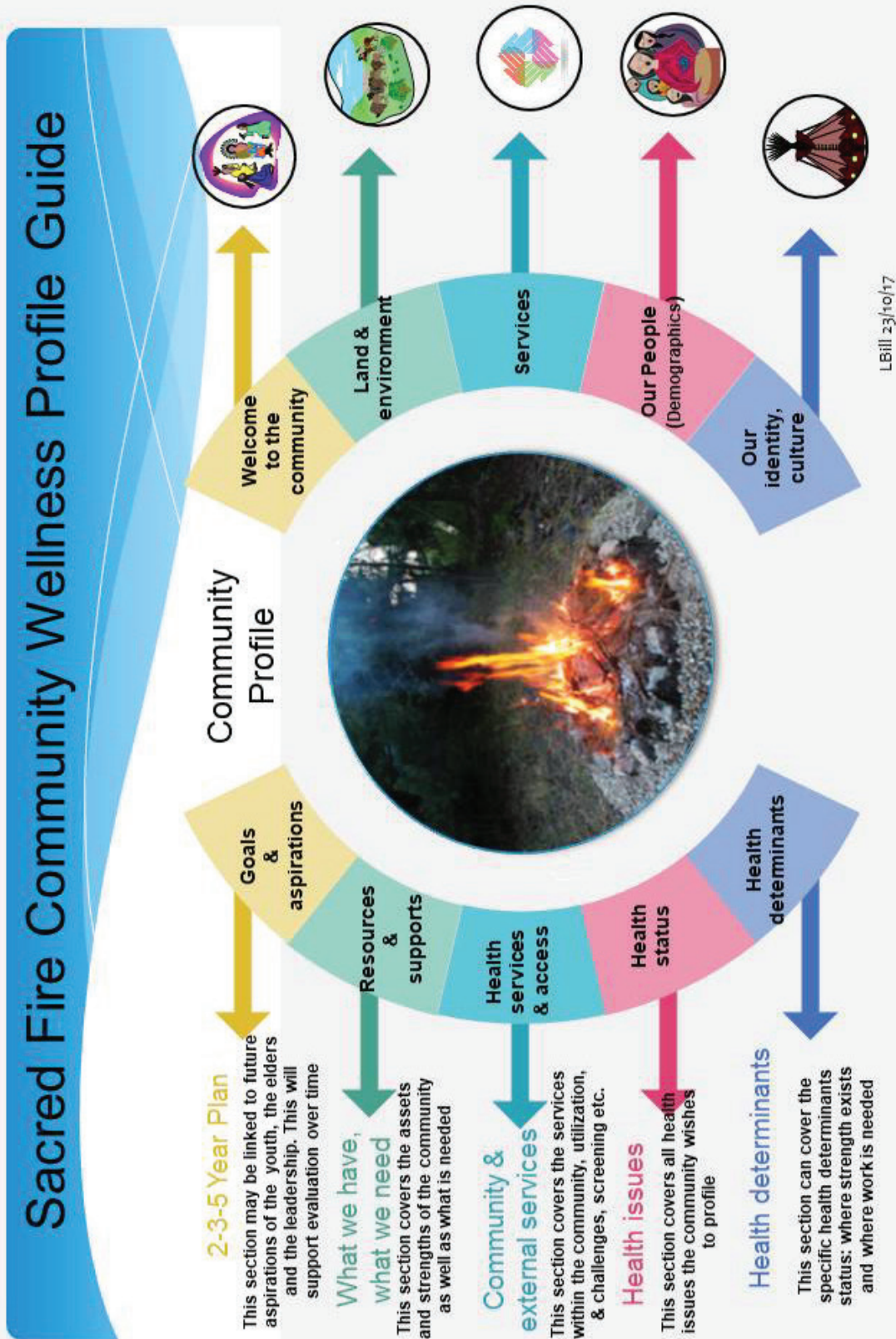
"I want to see children become more active and educating them on diet and going to bed early. I see this is an indicator".

*William Houle,
Council Member
Peerless Trout First Nation
2017*

"This is good practice-sharing values and hearing other people. Health is important for everyone of us. We are stewards of the land and are connected".

*Gilbert Okemow,
Council Member
Peerless Trout First Nation
2017*

Appendix A: Sacred Fire Community Wellness Profile Guide





The Alberta First Nations
Information Governance Centre

Alberta First Nations Cancer Prevention And Screening Practices
Project Mid Term Synthesis Report