

The Cancer Story

Canadian cancer control in First Nations populations living off-reserve in rural, remote and isolated areas

Prepared by CancerCare Manitoba
Commissioned by The Canadian Partnership Against Cancer

Acknowledgments

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The Cancer Story: Canadian cancer control in First Nations populations living off-reserve in rural, remote and isolated areas. January, 2013

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Introduction

Partners

The Canadian Partnership Against Cancer (The Partnership) is a federally funded organization focused on accelerating action on cancer control for all Canadians. In 2011, The Partnership released its First Nations, Inuit and Métis Action Plan on Cancer Control, a national strategy to improve the cancer journey as experienced by First Nations, Inuit and Métis peoples in Canada. To build foundations for future actions, The Partnership required information on the current cancer journey, including gaps and barriers, and innovative or culturally responsive practices or models affecting these populations. CancerCare Manitoba was contracted to produce *Canadian cancer control in First Nations populations living off-reserve in rural, remote and isolated areas*, an environmental scan to:

1. identify the cancer care pathway for First Nations people living off-reserve in rural, remote or isolated communities; and
2. identify leading models and practices from around the world that may have relevance for First Nations populations in addressing cancer in Canada.

CancerCare Manitoba (CCMB) is a provincially mandated organization that provides cancer services to the people of Manitoba. With its experience working with First Nations peoples and its existing national connections with provincial cancer agencies and cancer programs, CancerCare Manitoba was in an ideal position to execute the above project.

Approach

To ensure the information gathered was as comprehensive as possible, several different approaches were employed. A thorough literature review was conducted to determine what is already known in published materials related to cancer and First Nations people. A University of Manitoba Health Librarian assisted the project team to locate peer-reviewed literature. The Aboriginal Health Librarian from the University of Manitoba also performed a similar search, but focused on non-peer reviewed (grey) literature. Approximately 349 peer-reviewed articles and 164 grey literature sources were relevant to the project. As part of this scan, models and practices were identified as leading or promising activities. Definitions of these terms, along with a full list of all leading and promising practices and models can be found in the appendix.

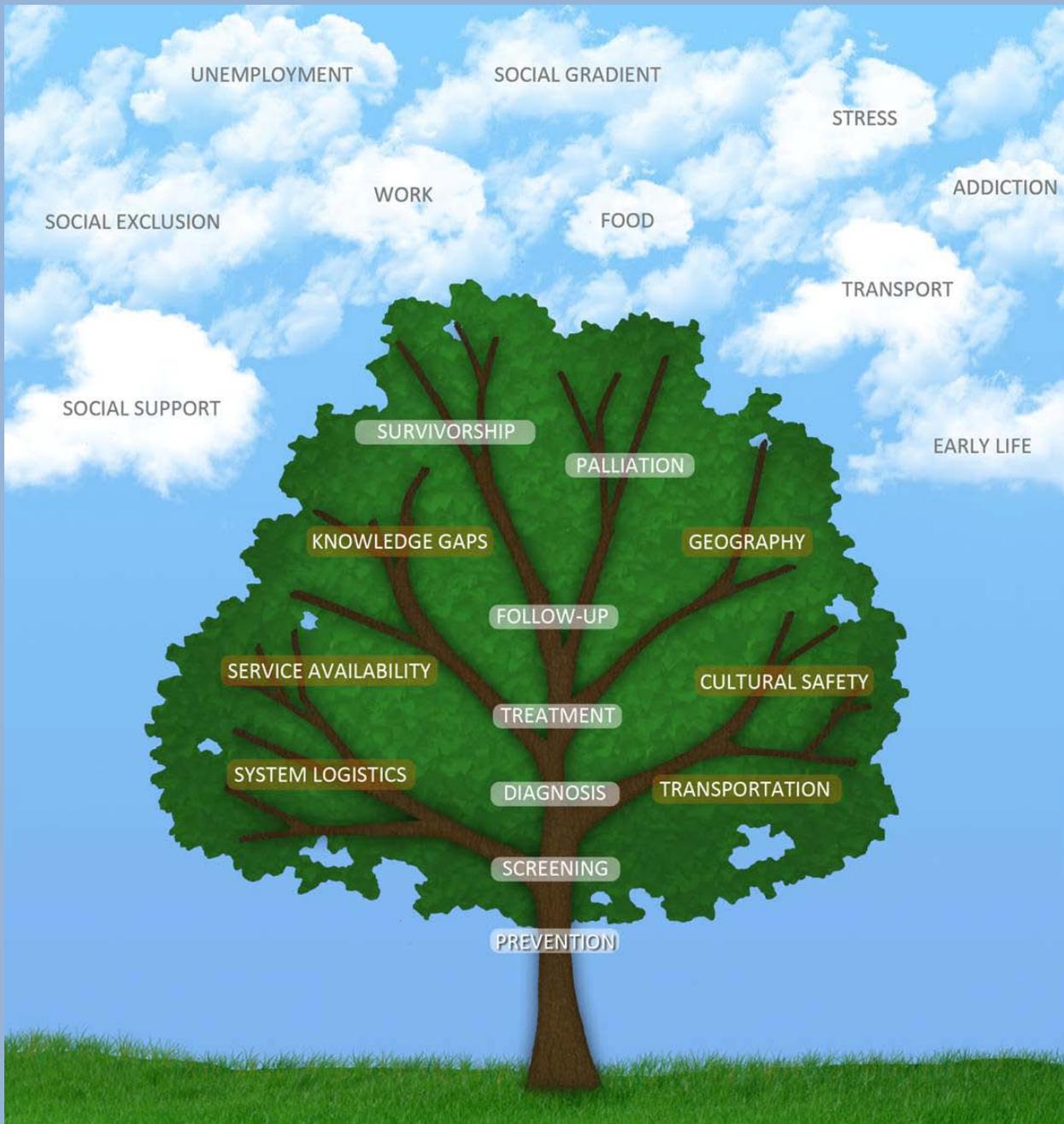
The project team also conducted an online survey focused on having people share information on culturally responsive cancer-related programs, services and resources across Canada. This

was an important part of the information gathering process as not all programs, services or resources are listed or are available online. A total of 305 people were invited to complete the survey. Invitations were sent to individuals representing the Provincial and Federal Health Ministries and First Nations departments, regional health authorities, First Nations organizations and representative bodies, provincial cancer agencies and other health and cancer care related organizations. A total of 67 surveys were completed.

To describe the cancer care pathway and to learn more about the programs, services and resources identified, key informants from across Canada participated in the project. A total of 39 key informants were involved through interviews and focus groups. Key informants were from a range of positions and organizations, including those in management, administration, patient navigation and direct patient care. Representatives from Provincial and Federal governments, First Nations organizations, cancer care agencies and programs, regional health authorities, and other health and cancer care related organizations were included in the project.

It is important to clarify that much of the information shared with us by participants' primarily referenced on-reserve First Nations populations. Information specific to First Nations living off-reserve was difficult for participants to relay as this population may not be as easily identified as compared to First Nations people living on-reserve.. It seemed that 'living on-reserve' was how some participants distinguished First Nations people from other cultural groups. Moreover, depending on the contacts available in a particular region, on-reserve contacts were interviewed in an effort to gain some understanding of the issues relevant in that area, or due to the contacts' expertise with First Nations people and cancer issues. In addition, due to the limited number of interviews, statements may not be representative of entire provinces or territories.

This report is presented in a way to be relevant for provincial cancer agencies, primary care providers, governments and policy makers.



The cancer journey is characterized by: *“a lot of gaps”*

The Cancer Pathway

Key Informants provided a wealth of knowledge on the cancer journey, its gaps and barriers, and leading models and practices regarding cancer control. The vast body of information collected has been distilled down to six major themes consistently referenced by key informants from across Canada. To demonstrate how people travel the cancer journey, what key gaps and barriers exist, and how the leading models and practices address the gaps and barriers identified, the following discussion is framed using a tree analogy.

In many First Nations cultures, the concept of following one's true path is fundamental to everyday life. The path can be gifted, discovered or learned, and has many names. The Good Life, The Red Road or The Good Path is sometimes illustrated using a tree. The tree analogy demonstrates how one travels easily down the central trunk if they adhere to the Grandmother and Grandfather Teachings and do not stray far from the path. If one loses a teaching, or strays from the path, their journey takes them down a branch; the person finds themselves stuck in an undesirable place in life. By reversing the steps taken away from the path, one can return again to The Good Life, and will have learned valuable lessons in the process.

The tree analogy can be adapted to demonstrate many pathways; here it will be used to illustrate the cancer journey and the ways some patients' journeys can deviate from the simplest paths due to the gaps and barriers identified by the key informants, and how the leading models and practices can help ensure patients and families remain on the easiest path.

In the tree diagram, the boxes along the tree trunk demonstrate the 'ideal' cancer journey which starts with prevention, and flows through to survivorship or palliation. The orange boxes among the tree branches represent the key barriers and issues that were shared with us by participants. The wording in the clouds represents the social determinants of health which affect the entire cancer journey.

The National Story

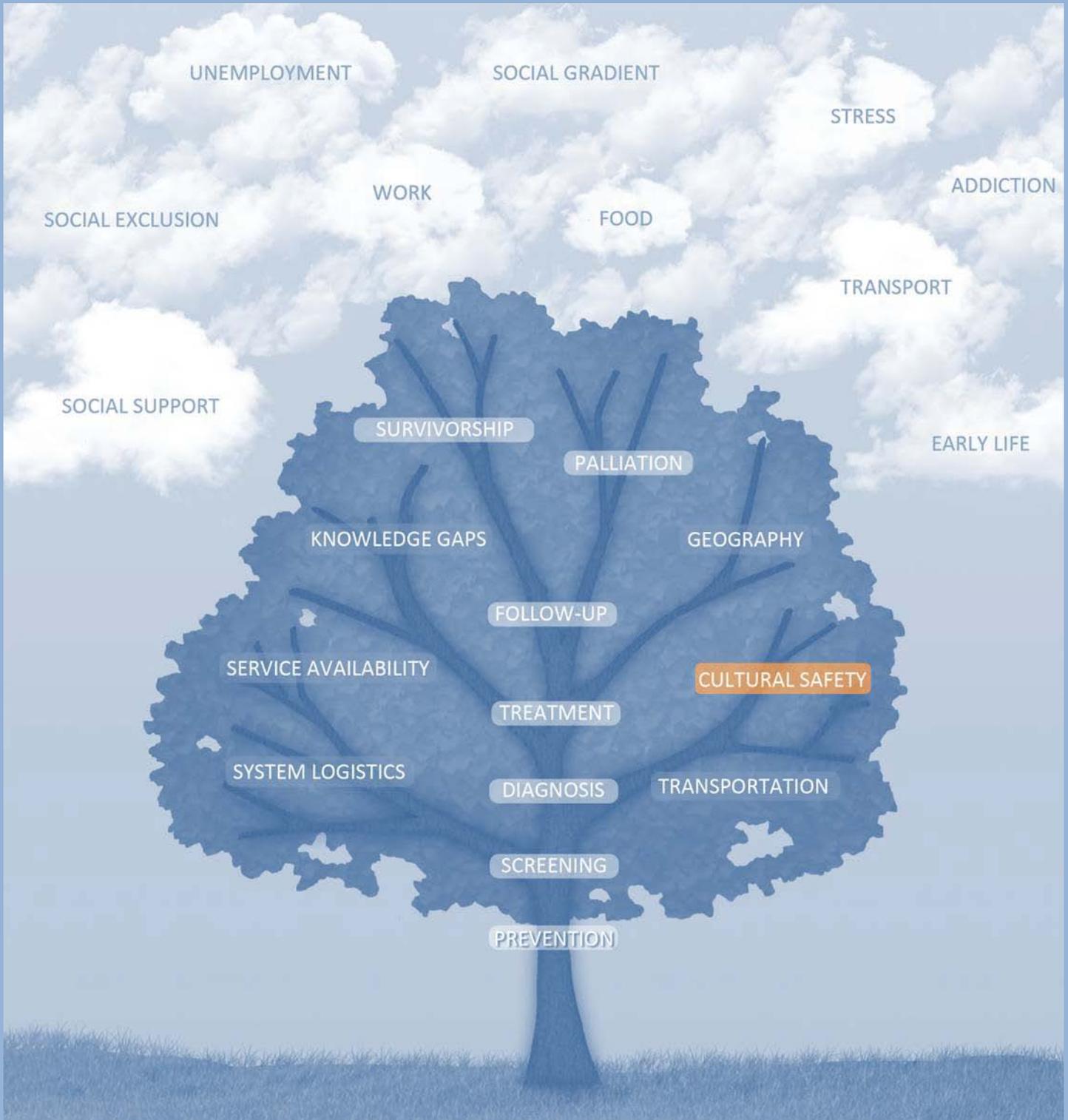
Although there are many differences in terms of opportunities, gaps and barriers in cancer control across Canada for First Nations people living off-reserve, numerous similarities were shared by project participants. The resulting narrative forms a national perspective of the key issues affecting cancer control and access to care for First Nations people as shared by the participants.

Key issues include:

- ▶ culture and culturally responsive care
- ▶ system logistics, availability of services and health care professionals
- ▶ the roles of the social determinants of health, education, transport and geography

These themes are complex and inter-related, however, by understanding and addressing these areas as well as learning from leading models and practices, the result will be that patients and their families can find and follow an easier pathway to cancer care and treatment. It is important to recognize the complexity of the factors that affect whether a person is able to access health care. Therefore, the ordering of influential themes in this report is not meant to demonstrate a priority of issues as each of the areas is relevant in their own way.

*“We need to look at things from a holistic approach:
mind, body and spirit”*



Culture & Culturally Responsive Care

What do we know?

Many participants identified a lack of culturally responsive/safe care as a barrier to accessing health care.

- Participants identified specific issues such as:
 - The differences between Traditional and Western world views and the implications for health care
 - Receiving information that was overly complex
 - Requiring information in multiple languages
 - Real or perceived racism
 - The need for care providers to recognize the prevalence and impacts of abuse among patients and families
 - The role of patients' fear and mistrust in the system

- Traditional and Western views of health and health care are different.
 - One participant described how the Traditional understanding of health and wellness uses a holistic view of health, considering the balance of mind, body and spirit, while the Western medical model tends to focus on the absence of disease. It is important to acknowledge the role of mind, spirit and emotion in the healing process.

“If you just focus on the disease, you miss the whole person.”

- How language is used and which languages are available is important.
 - Using the word “cancer” may be inappropriate for some people.
 - One participant shared how Elders she worked with encouraged them to talk about wellness and “checking for a healthy...” rather than “cancer screening”.
 - Another participant shared a story about perspectives on death and dying using one community as an example where it is not acceptable to say “death” or “palliation”, nor discuss life expectancy or expected death and to do so is offensive and arrogant.
 - It is important to have information available in First Nations languages and to have interpreters available when needed.
 - In some regions, language was a major issue and it affected where health care could be accessed. This could mean requiring travel over greater distances to be able to access care in their language.

- Consider historical context.
 - Participants discussed the importance of considering the history of First Nations and the role of fear and mistrust with the medical system.
 - As one participant mentioned, “if screening doesn’t go well, a person may not seek more care”, alluding to the importance of culturally appropriate care; health care providers must help alleviate fears and create a trusting environment by supporting the patient.
 - Participants all discussed the importance of considering an individual’s personal history, especially when it comes to sensitive areas such as those where cancer screening is done. Therefore, it is integral that screening is completed in a way which is appropriate for the specific population being served.

“Lack of culturally safe service is a barrier to access.”

Why is this important?

It is vital that care is respectful and supportive of all beliefs and cultures.

- Participants shared many stories reflecting the importance of health care providers considering the role of culture when working with patients, especially when designing cancer screening programs.
- For further information about the relevance of culture, language and history in healthcare for Aboriginal and Indigenous populations see the references (1-14).

“Health is viewed in a different way.”

How can cancer care be improved?

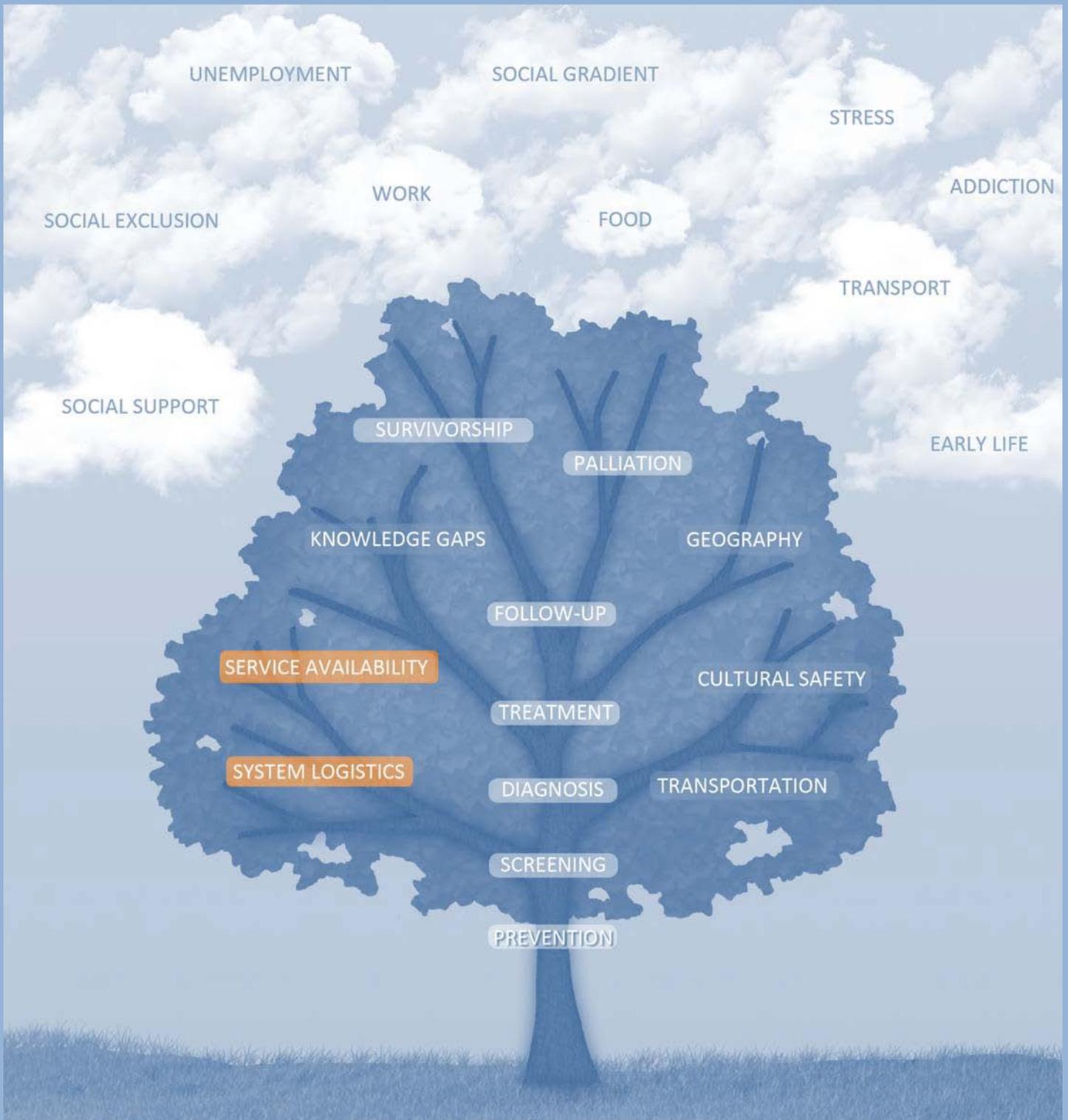
To be effective, cancer service delivery and screening initiatives need to be culturally responsive.

- Examples of emerging and leading practices developed in Canada include:
 - The Eagle Moon Health Office in Regina is currently working on a potentially leading practice focused on bringing Elders and Knowledge Keepers with oncology-related health care workers together to develop a common understanding and a tool to help facilitate knowledge sharing. The goal of the initiative is to improve cancer service delivery for Aboriginal people by changing

the approach taken to service delivery and building respect and support for Traditional care models.

- Alberta Health Services: Screening for Life – Aboriginal cancer screening education toolkits for breast, cervical and colorectal screening. The kits include numerous pamphlets, posters, cancer information wheels, presentations, example stories and hands-on models.

“People get lost in the maze”



System Logistics & Service Availability

SCREENING

What do we know?

Participants noted that the availability of screening varies greatly within regions and across the country.

- For breast screening, many provinces have a bus or van that can travel into rural and remote communities to deliver screening on a bi-annual basis. However, residents in most isolated communities would likely need to leave the community to access breast screening.
- Availability of cervical screening varies depending on local health care providers, including the availability of nurses or nurse practitioners who are trained to perform Pap tests.
- In most cases, colorectal screening tests (fecal occult blood tests or FOBTs) are available from family physicians, or may be mailed out directly to clients depending on the screening program in each province/territory.

"Clients have to travel to services to frequently"

Why is this important?

Availability of screening is a key factor affecting screening participation.

- Location and availability of screening affect participation in screening programs.
- For more information about the factors that affect screening decisions, including the role of culture, knowledge and comfort levels, the role of other life priorities and the challenges of gaining access see the references (1;8;15;16) on page 33.

SUSPICION & TREATMENT

What do we know?

Participants identified that getting people into the system at the "front end" or diagnostic stage was a barrier.

- First Nations people tend to have lower screening rates. When combined with the many other barriers in accessing health care, cancers are often diagnosed at later stages (10).

"Even if you have symptoms, it may not be easy to get medical help."

- Many issues affect screening rates such as availability of service and cultural responsiveness of screening services. It has also been found that coordination and planning at the community level are key to screening program success.
- Many participants identified the lack and/or irregularity of availability of primary care.
 - One participant talked about patients traveling back and forth between their primary care physician/nurse practitioner and specialists repeatedly before a diagnosis was made.
- A number of participants discussed how once a patient is in the system and if they are engaged in the process, then the rest of journey proceeds more smoothly in terms of availability of care. Findings from Nova Scotia are similar (10).
 - One participant noted that for people living off-reserve in rural, remote or isolated communities, it may be more complicated and less organized than for those living on-reserve due to the lack of coordination that can be completed on the patients behalf.
- Travel is nearly always required for diagnosis and treatment, especially if someone is living in a remote or isolated community.
 - As participants discussed, it is very difficult for patients to leave the support network of family and friends to face a cancer diagnosis and treatment alone.
 - Some participants identified that due to distance, lengthy stays in an unfamiliar place and the fear of dying alone in the city, patients may choose to forgo treatment and stay home.
- Lack of options.
 - One participant stated that if a patient feels they are not being listened to, or if they want a second opinion on a health issue, it is not always possible when living in a rural, remote or isolated area. If there is funding available for travel it will likely only cover costs to the *nearest* health care provider, even though it may be a care provider with which a patient has a negative relationship.
 - The lack of patient choice and control within cancer care was also found in the literature (17).

“People need to have the right people to talk to.”

Why is this important?

People need to be able to access primary care and screening services since the stage at which the cancer is diagnosed has a significant impact on survival.

- Patients with late stage cancers have the poorest prognosis.

- Patients need to feel supported and be able to have members of their support network with them when they must face a cancer journey.

FOLLOW-UP, SURVIVORSHIP & PALLIATION

What do we know?

There is a lack of services for survivorship and palliation.

- Many participants discussed the complete lack of services available, especially those that are culturally responsive for First Nations people for survivorship or palliation.
- Although many participants directly referenced the lack of homecare available on-reserve, it seems there is a lack of homecare services available overall, in many regions.
 - Many participants also discussed the role of culture especially in reference to palliation and people's desire to pass at home and how, in many cases, this is not possible, contradicting cultural values.
 - A number of participants explained how, depending on geography a patient may need to travel very far to receive end-of-life care in a hospital and therefore family may not be able to be with them, further increasing emotional distress for the patient.
- Coordination of services is lacking.
 - Many participants discussed the lack of coordination of service when people were going back to community, specifically a lack of discharge planning and communication with homecare in the community.
 - It is important to note there were some exceptions, where planning and communication between the cancer center and the community was effective.
 - According to one report from Ontario, the lack of written care plans is a gap that can lead to fragmented care delivery (17).

“Patients say that leaving cancer care is the scariest part of their journey.”

Why is this important?

A lack of follow-up, survivorship and palliation services in rural, remote and isolated communities could mean increased difficulty for the patient returning home.

- Ineffective communication services and lack of services in the community can result in a complicated and emotionally difficult cancer journey.

“Lack of coordination means gaps in care, and the patient suffers.”

- It is important to note that in some cases the process can be relatively smooth.

ACROSS THE CANCER JOURNEY

What do we know?

Some geographic areas have limited service availability.

- Participants discussed how, overall, in some areas there are very few services available, requiring people to travel even for basic medical attention.
- Many participants talked about the challenges of getting people into the system on the ‘front end’ of the journey.
- It is also important to consider the limited or lack of availability of specialists. For example, the limited availability of gynecologists in some regions.
- A few participants also discussed the disconnect between communities and the cancer care organizations, where communities were unaware of the cancer care organizations and/or their roles in providing care.
- A couple of participants noted that in some cases rural, remote and isolated First Nations communities experience greater service availability and follow-up, and decreased wait times, compared to non-First Nations rural, remote and isolated people due to different funding structures on-reserve. However, it is important to clarify that “better” does not mean “ideal”.

“Use telehealth for follow-up and support.”

- Coordination of care is lacking.
 - Participants discussed how in many cases, especially when exiting the cancer system and returning home, there was a lack of communication, resulting in confusion for patients, families and local health care providers.
 - A number of participants noted the role of the primary care provider in ensuring the “smoothness” of the cancer journey through advocating for their patient.
 - According to one report “Achieving effective pathway management across the whole cancer system is crucial” (1, p. 7)
- Three provinces (Ontario, Manitoba and British Columbia) have prioritized First Nations, Metis and Inuit cancer control in an effort to begin to address the additional barriers faced by First Nations, Metis and Inuit patients and their families across the whole of the cancer journey.
- Due to the important role of health care providers and issues related to geography and transportation related issues, these topics are further explored in individual sections.

See the Health Care Providers section on page 21 and the Transportation and Geography section on page 24.

Why is this important?

The availability of care services and system logistics must be improved to help reduce the burden of cancer for First Nations people.

- Access to primary health care and improving screening rates must be accomplished to help diagnose cancers sooner.

How can cancer care be improved?

With community specific adaptations, the following leading practices and models may help meet some of the needs for cancer care services.

- Addressing transportation issues through the use of telehealth (Leading Model):
 - Native People for Cancer Control Telehealth Network
 - The Network’s goal is to “use telehealth to prove and improve access to culturally sensitive and relevant post diagnosis services for remote and rural American Indians and Alaska Native communities” (18). For further information see the references (6;18).
 - It is important to note that many regions in Canada already use telehealth to some extent; however, in many areas there is room for increased usage.
- Provide Treatment Closer to Home (Leading Model):
 - The Community Oncology Program model of care
 - Although not culturally responsive, this model of care is successful in delivering treatment and providing support closer to home. CancerCare Manitoba works in partnership with the Regional Health Authorities to provide prevention, early detection, diagnosis, treatment, and rehabilitation services at 16 locations in rural Manitoba.
- Home-Care Discharge Planning (Leading Practice):
 - Cape Breton Home-Care Discharge Planning: the program objective is to provide a home care discharge plan to First Nations clients who need one, when they

“Use telehealth for follow-up and support.”

“Programs must be designed on a community by community basis; there is no one size fits all”

leave hospital and return home to their reserve. Although focused on patients living on-reserve it may be able to be adapted for those living off-reserve (19).

- Culturally Responsive Navigators (Leading Practice):
 - Native Sisters – The Native American Women’s Wellness through Awareness Program
 - The focus of the program is to train Native American women as navigators to provide emotional support and advocacy throughout recruitment, screening and follow-up appointments. This program differs from other navigator type positions as it begins with cancer screening allowing for more time to develop relationships and build trust through a cancer journey (20).
 - Aboriginal Patient Navigators
 - For example, the Aboriginal Patient Navigator located in the Juravinski Cancer Centre in Hamilton, ON. The Aboriginal Patient Navigator assists patients and family through a variety of means such as providing support at clinic visits, helping with communication with care providers, arranging language services, and helping patients find and connect with services including Traditional Healers (21). For further information visit: <http://jcc.hhsc.ca/body.cfm?id=84>.

Healthcare Providers

What do we know?

Developing trust with healthcare providers is important.

- Lack of continuity of care was a frequent topic amongst participants.
 - Many participants talked about the lack of continuity of care in rural, remote and isolated communities due to transient health care providers. It is important to highlight the role that this plays in building relationships and trust between health care providers and patients.
 - One participant discussed how the role of trust with a health care provider may affect whether a patient would be willing to share that they are using traditional medicines.
 - Another participant shared how “Local health care providers may not know if a patient is a cancer survivor because of transient staff or the patient may be reluctant to re-tell their cancer story to new staff”.

- Health care providers are looked to as information sources.
 - Some participants talked about the role of local health care providers in educating patients about screening and promoting screening.
 - A couple of participants discussed the important role of primary care workers in supporting and advocating for their patients through a cancer journey and helping make the journey more “smooth”.

- Health care providers need to be aware of the diverse cultural beliefs and values of their patients.
 - Participants discussed the lack of culturally responsive knowledge shown by health care providers in many different settings.
 - One participant discussed the importance of positive encounters with health care providers and how a negative experience may make a person not want to go back and seek further care.
 - Participants also discussed the lack of oncology-related knowledge shown by health care providers, some mentioned specifically the lack of knowledge as it relates to providing follow-up care for cancer patients.

- Health care providers can make assumptions.

“Local health care providers may not know a patient is a cancer survivor”

- One participant discussed the impact assumptions can have and the ramifications for care:
 - “Assumptions by health care providers on whether Aboriginal people would pursue treatment or care can affect whether care is offered.”

Why is this important?

Health care providers play key roles in providing and facilitating health care.

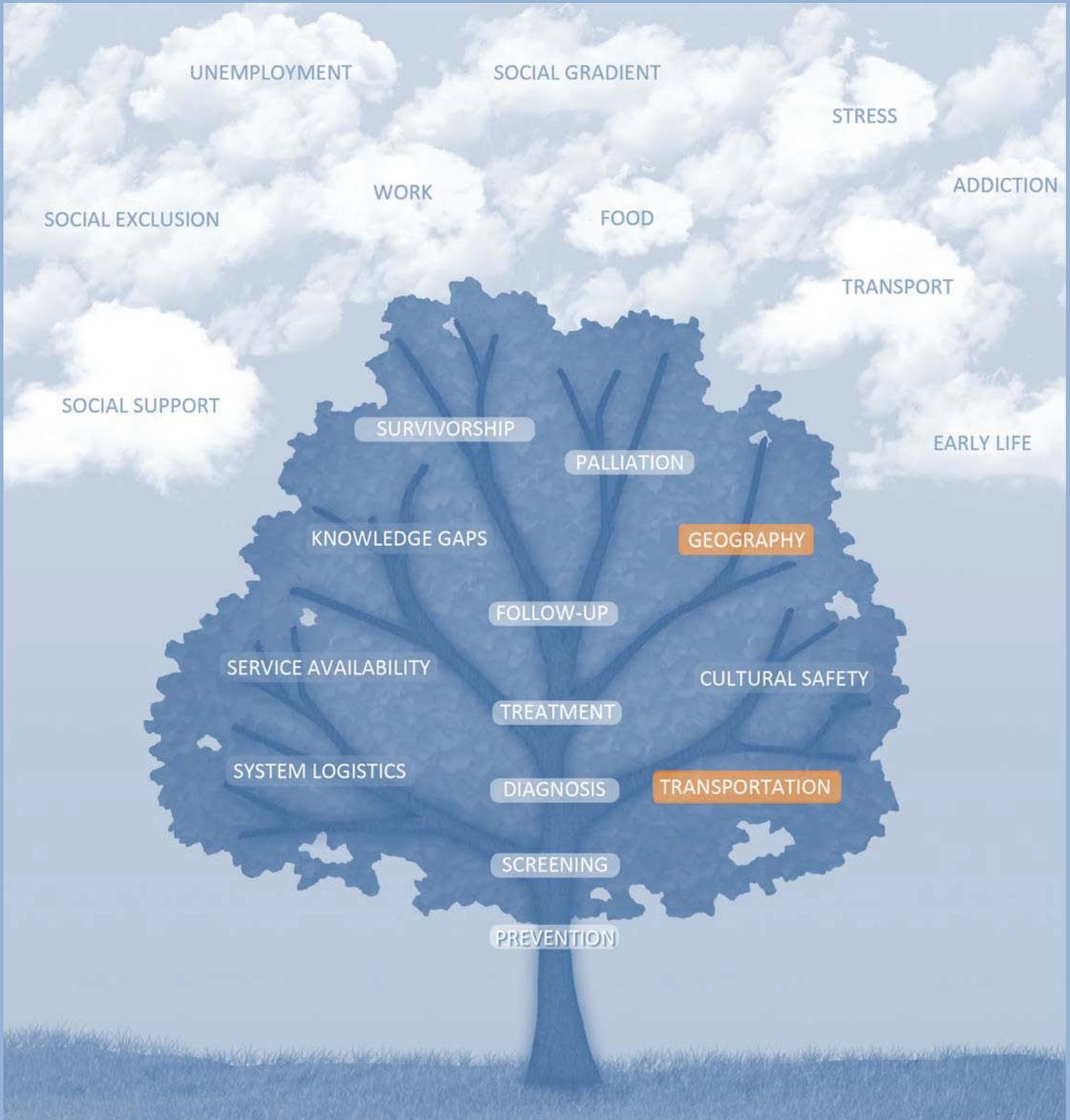
- It is integral that healthcare providers are knowledgeable about cancer and can provide respectful, culturally responsive care.

What can help improve cancer care?

Providing education for health care providers is paramount.

- The Reproductive Health Screening Project: Trained nurses and provided support for Pap tests, clinical breast exam and bi-manual exam. Focus was on providing woman-centred care in 45-minute wellness appointments to help facilitate trust and relationship building between community women and nurses.
- The Palliative Care Front Line Education program in Nova Scotia. This leading education program includes lectures, exercises, group discussion and application of theory to real life scenarios. The program includes a First Nations Module for Non-First Nations Health Professionals with a focus on enhancing the understanding of history, culture, traditions and health issues experienced by Aboriginal groups in Atlantic Canada.

“Distance can make a difference”



Transportation & Geography

What do we know?

Transportation to medical care for people living in rural, remote and isolated communities is a well-recognized barrier and one that was shared repeatedly.

- A key factor of transportation was the associated cost.
 - This is particularly relevant for First Nations people living off-reserve in rural, remote or isolated communities.
 - Participants shared about how, in most cases, a First Nations community would not cover the travel costs for one of their members living off-reserve. However, it was noted that much of this depended on the capacity of the community, and if they were able (financially) to provide support and the community specific policies.
- “Rurality is a barrier”***
- The sheer distance some people must travel to seek care is a barrier.
 - Participants described how inconceivable it is to send someone who is quite ill on a lengthy bus ride to reach a medical service centre.
 - People living in remote or isolated areas may require plane travel or travel on ice roads.
 - It is also important to highlight the role of weather and how weather can affect travel and access to services.
 - For example:
 - Severe weather may cancel flights or make road travel un-safe.
 - Forest fires in Ontario displaced many residents one year and delayed the travel of mobile breast screening to the area.
 - For many, travel to access health care means leaving behind the support network of friends and family, and possibly leaving children in the care of someone else.
 - This can be especially troubling when travel is required to receive a cancer diagnosis and/or treatment.
 - For example, if someone from an isolated community is in the south receiving treatment, it would likely be prohibitively expensive and uncomfortable for someone who is quite ill to travel home to visit family and friends between treatments.

- Someone living further south, much closer to a treatment centre may be able to visit family and/or have visitors and receive that much needed support through their journey.
- Geography plays a role in terms of access to healthy foods and support services.
 - Living in a rural, remote or isolated community changes the availability and selection of food choice, which often come with higher prices than the foods available in more southern areas, further contributing to everyday challenges in health and becoming healthy again as a cancer survivor.
 - As many participants identified, it is important to highlight the lack of support services for survivors in many rural, remote and isolated communities and the sheer distance that they would have to travel to access these services.

Why is this important?

The role of geography and transportation are integral in accessing health care.

- Changes must be made to help reduce the burden of transportation for patients and families.

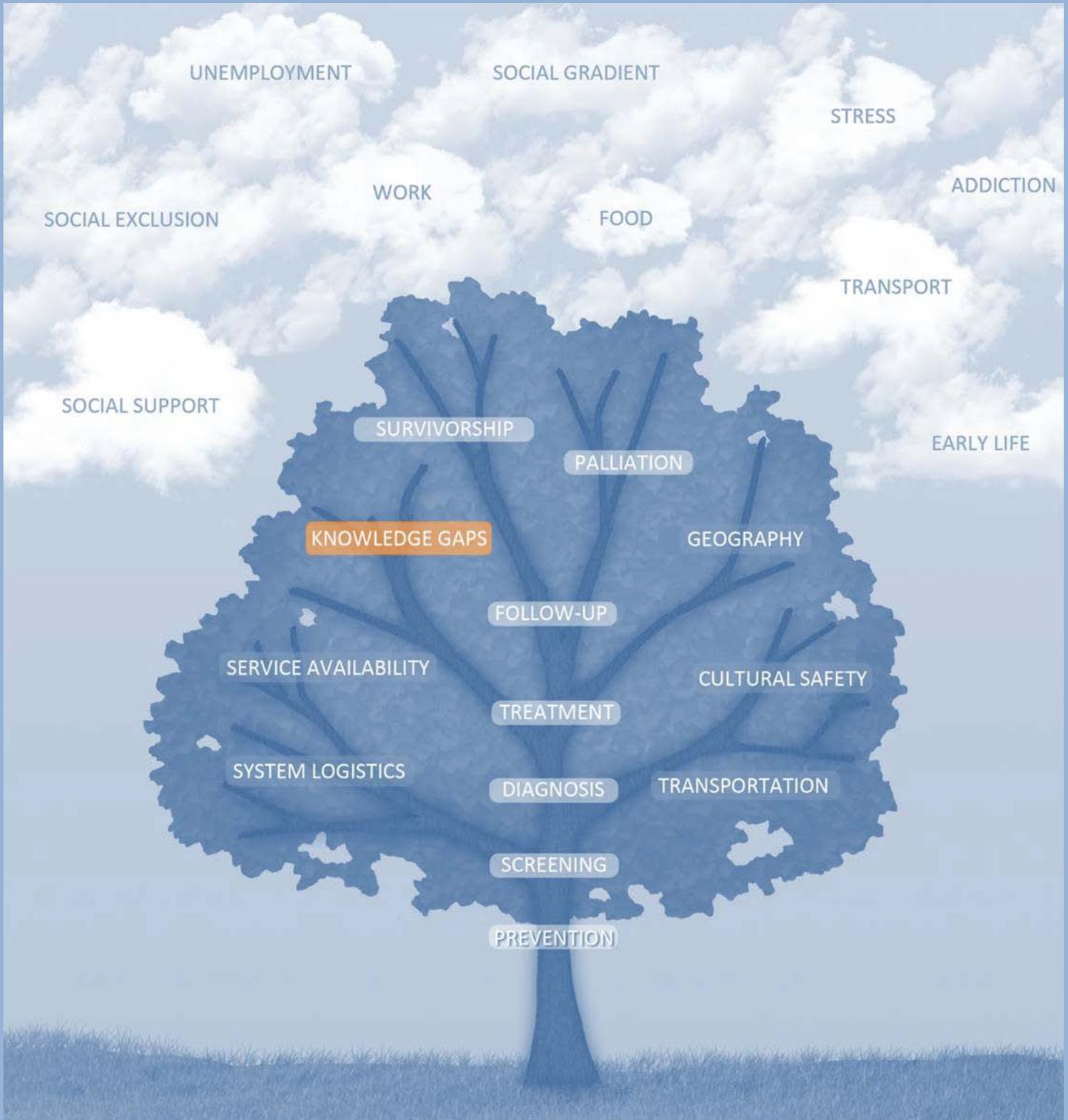
“Distance can make a difference”

How can the challenge of transportation be reduced?

This section provides leading examples of addressing the challenge of transportation:

- Make services available closer to home so travel can be reduced or eliminated via the previously described:
 - Community Oncology Program
 - Use of telehealth
- Make transportation more affordable for patients and families.
 - Northern Patient Transportation Program (leading practice): The focus of the program is to subsidize transportation required for medical care to the nearest location for those living in the designated northern area (22). This program is available to all residents who do not have other forms of coverage. Although not culturally responsive, this practice could be of use in other regions where bus transport is appropriate.
 - The Saskatchewan Transport Company Medical Pass (leading practice): With a letter of authorization from a physician confirming that the travel is for medical purposes, a medical pass can be purchased for \$53.95 which is valid for unlimited travel for 30 days between two pre-determined locations (23). Although this opportunity is not culturally responsive, this practice could be of use in other regions where bus transport is appropriate.

“(There is a) need to create more awareness”



Knowledge & Education

What do we know?

The lack of cancer knowledge creates a gap that affects care.

- More cancer-related education is required.
 - Nearly all participants noted the lack of knowledge about cancer and cancer screening is a barrier.
 - Participants also discussed the lack of culturally responsive educational materials, including the availability of information in First Nations languages and the requirement of this information in creating awareness.
 - Several participants highlighted the need to address cancer myths.
 - The lack of knowledge and awareness about cancer is something that has been shared in literature from Canada, the United States, Australia and New Zealand (4;7;8;10;13;14;24).
- Patients and families need more information about how the system functions.
 - A lack of information about how the system works and the various options and locations for care that are available, causes confusion and delay.
 - Many participants explained how confusing the experience can be for patients and that many were unsure or unaware of what their options were.
 - One participant described the lack of education about a person's own health and uncertainty about how or when to self-advocate as a barrier.
- It is important to reiterate that, as described by participants, all education must be developed and delivered in a culturally responsive way.
- A number of participants highlighted the need to recognize, respect and be inclusive of Traditional knowledge.

“The idea ‘if I don’t acknowledge it, it will go away’ is common.”

Why is this important?

Using culturally responsive initiatives will help increase cancer knowledge and understanding of how the health system works.

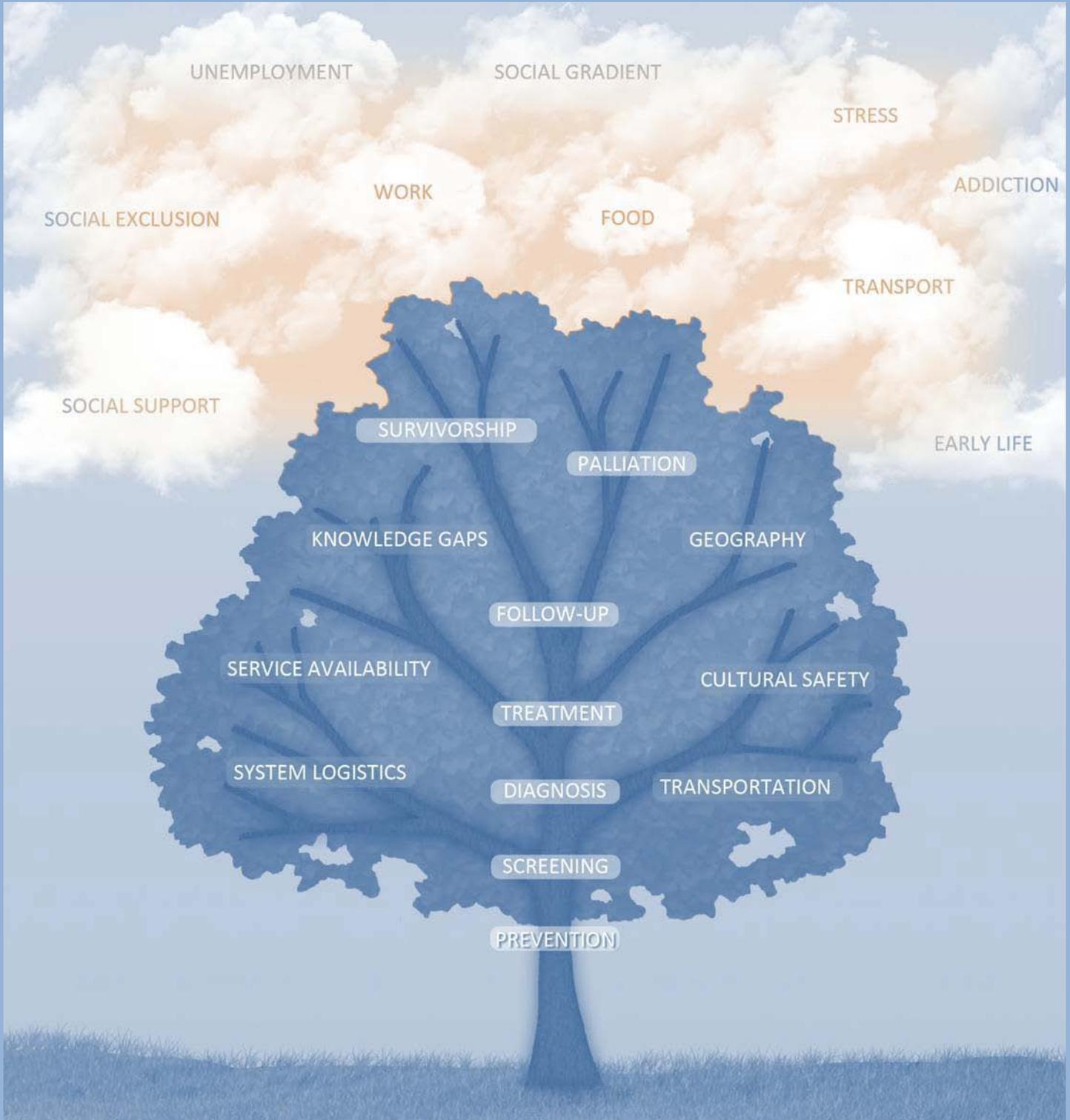
- It is essential to work with communities to develop educational tools and initiatives.

How can knowledge about cancer be increased?

Culturally responsive teaching tools and resources (Leading Practice):

- The previously discussed screening toolkits from Alberta Health Services and Cancer Care Ontario are examples of leading culturally responsive practices to develop appropriate materials to help increase knowledge about cancer and cancer screening.
- Cancer 101- A Cancer Education and Training Program for American Indians and Alaska Natives: “Cancer education resources developed in collaboration with American Indians and Alaska Natives to improve cancer knowledge, action regarding cancer control in tribal settings, and survival rates for members of their communities.”
 - A train-the-trainer program that could be used as an example on which to develop a similar education program relevant to First Nations people in Canada.

“The social determinants of health affect you even before you are born”



Social Determinants of Health

What do we know?

The complexity of the social determinants of health is a prime example of how it is not just one factor, but many, that influence whether someone is able to access health care.

- Many participants directly referenced the role of the social determinants of health (SDH) in accessing health care services, while others discussed factors that are part of the SDH, such as the role of poverty and access to transportation.
- The social determinants include many things, like the roles of: the social gradient, stress, early life, social exclusion, work, unemployment, social support, addiction, food, and transport (WHO, 2003). Many of these factors are relevant at varying levels for First Nations people across Canada.
- The role of the SDH affect a person’s day to day priorities, including accessing health care.
 - One participant described how if a mother is struggling to put food on the table for her children, she is not likely going to consider putting in the time and expense through time off work, child care and travel costs to attend breast screening.
 - It is important to consider how the SDH impact all aspects of health including all facets and stages of the cancer journey. With so many day-to-day priorities, preventative care (screening) or seeking medical attention for symptoms, simply may not make the list.
 - Therefore, as one participant described it: “People are in survival mode, cancer screening and self-care is not a focus”, contributing to the high number of late stage diagnoses among First Nations people.

“Disadvantage has many forms and can be absolute or relative”

– World Health Organization

“How can you receive homecare if you are homeless?”

- SDH can affect the entire cancer journey.
 - For example, despite symptoms, someone may put their family’s health ahead of their own and may not seek medical care until symptoms become severe.
 - To seek health care, a person may have to travel great distances to receive a diagnosis, leaving behind their support network and forcing them to leave their responsibilities in someone else’s hands.
 - For a single mother this may be a particularly difficult part of the journey as she may have a difficult time finding someone who is able, and she feels comfortable with, to leave in charge of the care of her children.
 - The battle of maintaining child care and family obligations continue throughout treatment, especially in situations where someone must receive treatment a great distance away from their community.

- Participants also discussed many practical issues related to socioeconomic status that are very real barriers for some people.
 - For example, “what if they do not have a phone?” It would be very challenging for a patient to connect with their health care providers and vice versa if the patient does not have a phone.
 - Many participants shared about how many people moved around a lot to access employment or education opportunities, from on-reserve, to off-reserve in other communities and to urban areas. If a patient cannot be found efficiently to deliver a result, it causes delays in the cancer journey.

“People are just trying to get through the day”

Why is this important?

There are very real barriers and challenges that affect if and how a person is able to access health and cancer care.

- By reducing barriers, an improvement in care can be realized.

How can cancer care be improved?

Addressing the social determinants of health is very complex and must be addressed through partnership across policy areas.

Many of the previously listed models and practices aim to support and build capacity within communities which may help in addressing some aspects of the social determinants of health.

Conclusion

The National Story provided an overview of the commonalities in participant responses regarding the key issues for cancer patients in their regions. In addition, some leading practices and models that address aspects of the issues faced by First Nations cancer patients were presented. Many leading practices and models of care were identified as part of this project. A few were referenced in-text, while a complete list of the leading and promising practices, models and resources are included in the appendix.

It is important to understand the complexity of the issues that affect a person's ability to access health care. These issues are strongly inter-related, therefore the information is difficult to present in a linear fashion. Therefore, the reader is reminded that the ordering of the key themes is not meant to imply a ranking of the issues as they are all very important to address.

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British Columbia

Canadian cancer control in First Nations populations living off-reserve in rural, remote and isolated areas

British Columbia Profile

British Columbia has the best cancer outcomes in Canada with the lowest age-standardized mortality rates for males and females. However, outcomes from cancer are significantly worse amongst First Nations, Metis and Inuit peoples including higher rates of late stage diagnoses and mortality (BCCA, 2011).

What do we know?

- British Columbia has the lowest incidence rates for both colorectal and lung cancer rates in all of Canada (CCS, 2011).
- For 2011, 22,100 new cases of cancer and 9,300 cancer related deaths are projected in British Columbia (CCS, 2011).

Population Sketch

British Columbia's Aboriginal population is young; median age is 28.1 years (Statistics Canada, 2007), compared with the media age of 40 for the non-Aboriginal population in Canada (Statistics Canada, 2011). 28.2% are under 15 years of age (Statistics Canada, 2007).

Of the Aboriginal identity population, 7.4% identified their mother tongue as being an Aboriginal language, while 2.2% speak an Aboriginal language most often at home. Another 9.3% declared knowledge of Aboriginal language(s) (Statistics Canada, 2007).

By the numbers

Population: 4.07 M

Overall population living in rural areas:

- 14%
- 553,490
(Statistics Canada, 2006)

Geography/Size:

- 9.5% of Canada
- 924,815 square km
(Statistics Canada, 2007)

First Nations

- According to the British Columbia Assembly of First Nations, there are 203 First Nations in British Columbia (BCAFN, 2010).
- First Nations people live in many areas in British Columbia see the box *Population & Location* for details.

How is cancer care provided?

As described on the BC Cancer Agency website: The BC Cancer Agency, an agency of the Provincial Health Services Authority, provides a province-wide, population-based cancer control program for the residents of British Columbia and the Yukon. The Agency accepts patients who have been diagnosed with cancer and are referred by a physician. Its mandate covers the spectrum of cancer care, from prevention and screening, to diagnosis, treatment, and through to rehabilitation. (BCCA, 2012)

Facilities and Programs

The BC Cancer Agency website describes the following facilities and programs:

The BC Cancer Agency operates five regional cancer centres, providing assessment and diagnostic services, chemotherapy, radiation therapy, and supportive care. Each of the BC Cancer Agency's centres delivers cancer treatment based on provincial standards and guidelines established by the Agency (BCCA, 2012).

The Communities Oncology Network is a collaborative partnership with 19 community-based cancer centres, six community based cancer services, and 10 consultative clinics across the province, in conjunction with the BC Cancer Agency's five regional cancer centres. The network also supports appropriate delivery of patient care and support in 27 other community hospitals (BCCA, 2012).

The Surgical Oncology Network includes all providers of surgical oncology services from surgeons in remote areas to sub-specialists. Its vision is the best possible outcomes for all cancer surgery patients in British Columbia (BCCA, 2012).

Population & Location

Aboriginal identity:

- 196,075 total population
 - 51,055 on-reserve
 - 27,945 rural
 - 117,070 urban

First Nations identity:

- 129,580 total population
 - 49,270 on-reserve
 - 14,025 rural
 - 66,280 urban

Multiple Aboriginal identity:

- 1,655 total population
 - 40 on-reserve
 - 370 rural
 - 1,250 urban

Statistics Canada, 2006

The goal of the Family Practice Oncology Network is to assist the BC Cancer Agency in its mandate to improve cancer control in the province, by providing support and connections to family physicians. Every family physician in BC is welcome to take part in this initiative (BCCA, 2012).

The BC Cancer Agency initiated Canada's first population-based program for the early detection of breast cancer. The Screening Mammography Program of BC is offered in more than 100 communities, through permanent sites and mobile screening vans (BCCA, 2012).

Colorectal cancer screening is currently being piloted in three BC communities (BCCA, 2012).

The previous section provides a list of some of the key services provided by BCCA.

Northern Cancer Control Strategy

The *Northern Cancer Control Strategy* is described as:

Through the Northern Cancer Control Strategy (NCCS), the BC Cancer Agency, Northern Health, and the Provincial Health Services Authority are working together to improve cancer care in northern B.C.

The strategy is focused on cancer services delivered in the region covered by Northern Health – which is the northern two-thirds of British Columbia (including Quesnel). Over 300,000 people live within the Northern Health boundaries.

The NCCS has been developed to meet the unique needs of northern communities. The strategy includes a range of cancer services to bring care closer to home:

- Prevention and Health Promotion
- Screening
- Detection and Diagnosis
- Treatment
- Supportive care and Rehabilitation
- Palliative Care

In addition, enhancements will be made across the North in the areas of Telehealth, Aboriginal Health, patient navigation, and research and evaluation (Northern Cancer Control Strategy, 2012).

Transformative Change Accord

As described on the Transformative Change Accord website:

In November 2005, the Province, the federal government and the BC Assembly of First Nations, First Nations Summit, and Union of BC Indian Chiefs signed the Transformative Change Accord (TCA) to:

- close the social and economic gap between First Nations and other British Columbians,
- reconcile Aboriginal rights and title with those of the Crown, and
- establish a new relationship based upon mutual respect and recognition.

(Transformative Change Accord, 2012)

According to the Plan, “On November 27, 2006, the British Columbia First Nations Leadership Council (FNLC) and the Province of British Columbia negotiated the ten-year Transformative Change Accord: First Nations Health Plan (TCA:FNHP), (attached as Appendix “A”), which identifies twenty-nine actions intended to close the gaps in health status between First Nations people and other British Columbians” (Tripartite First Nations Health Plan, 2007).

Based on the First Nations Health Plan there are four governing structures:

- First Nations Health Council
- First Nations Health Directors Association
- First Nations Health Governing Body
- Provincial Committee on First Nations Health (First Nations Health Council, 2011).

For the further detail on the status of the *Transformative Change Accord* review the *New Relationships with Aboriginal People and Communities in British Columbia, Annual Progress Report 2009-2010* available from:

http://www.gov.bc.ca/arr/reports/down/annual_report_2009_10.pdf

Provincial Themes

Participants from British Columbia discussed many opportunities, gaps and barriers. Many of the issues discussed were similar to those discussed in the National Story. The three issues that were most commonly discussed by participants were issues and barriers that affect the whole of the cancer continuum, including the role culture and culture responsiveness, education and system logistics/ service availability. It is important to note that participants did discuss many other barriers and challenges but these issues came to the forefront. This section is focused on the top three themes shared by participants.



Culture & Culturally Responsive Care

What do we know?

Participants from British Columbia often discussed the importance of cultural appropriateness of health care. Stating things like: “Some feel it (the body) is a sacred thing and not to be prodded by strangers”. This is particularly important in reference to cancer screening.

Participants also shared about the importance of considering the historical context and the previous experiences of in individual.

- For example one participant talked about considering the “relationships between First Nations and the medical system”, while another specifically referenced the possibility of “bad past experiences with health professionals”.

“Lack of cultural safety is a barrier at all levels”

“Cultural relevance of services is vital”

Knowledge & Education

What do we know?

The role of education in cancer related issues was shared as an important issue.

“Dispelling myths surrounding cancer”

- It was said that there was a “lack of awareness of importance of screening/diagnosis and lack of awareness of available services”
 - Also, that there is a need for “cultural education for health professionals and cancer education (knowledge of disease and available services) for patients”
- One participant also discussed the importance of addressing myths related to cancer sharing the examples of:
 - “If there is no history of breast cancer in my family then I do not need a mammogram;
 - I found a lump and thought that it would go away on its own; and,
 - Mammograms are very painful and I will have to be exposed in an indecent way”.

System Logistics & Service Availability

What do we know?

The lack of available services and the logistics of accessing services was a barrier that was described by participants.

- Participants discussed how getting into the system can be a challenge but that “once in the system, the services are not too bad”.
- In reference to travel for breast screening, one participant mentioned how combining the screening trip with another event like shopping is positive and that people appreciate the safety of being in a group.
- One participant talked about how in some cases telehealth can be used to provide services, but that travel is still required for many services.
- Another participant described the lack of services, especially on reserve stating that there is “no support, people go away for treatment and come back to nothing – (it)affects living and dying”.

***“Less service availability
and greater wait times
for First Nations”***

- One participant identified that “there are some grassroots breast cancer survivor groups” but that it was unlikely there were any such groups in isolated communities.

Geography has a substantial impact on service availability. One participant said that “Longer wait times (are) strongly related to geographical barriers”, while another stated that “cultural values and geographic barriers leading to lack of services dictate a need for palliation tailored for First Nations (people)”

This brief section presents the three themes most referenced by participants. Many other issues and themes such as the importance of addressing transportation issues and the role of the social determinants of health were also discussed by participants as described in the National Story.

Up and Coming in British Columbia

New and promising projects and program in British Columbia were identified by participants or project staff. Below is a list of a few up and coming projects and programs in BC. This list is not exhaustive and regularly updated lists of project and programs can be found at: www.cancerview.ca

BC Cancer Agency Centre for the North

- The Centre is located in Prince George, BC and will be opening in the summer of 2012. The cancer center will provide radiation therapy, systemic therapy, supportive care and population oncology with the goal “to bring care as close to home as possible” <http://centreforthenorth.plenaryprojects.com/about-the-project/>

Pilot programs at the Community Oncology Clinics

- Informal Saturday meetings hosted by general practitioners specialized in oncology and a dietitian where survivors can talk, be educated, ask questions and receive psychosocial support

Pilot project underway in the North to determine unmet needs of cancer survivors

- Survivorship care plans will be developed and piloted in First Nation and non-First Nation communities in 2012 and evaluated for effectiveness to help support future program development/delivery.

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Alberta

*Canadian cancer control in First Nations
populations living off-reserve in rural, remote and
isolated areas*

Alberta Profile

Cancer is a significant health issue in Alberta. The five leading causes of cancer-related death in Alberta First Nations are:

- lung (19.5%)
- colon (9.2%)
- breast (8.8%)
- stomach (5.8%)
- prostate (5.0%)
(Health Canada, 2011)

In Alberta the top four causes of death include: injuries, disease of the circulatory system, neoplasms and diseases of the respiratory system. These are similar for First Nations and non-First Nations people (Health Canada, 2011).

Population Sketch

Alberta's Aboriginal population is young; the median age is 24.8 (Statistics Canada, 2007) years compared with age 40 for the non-Aboriginal population in Canada (Statistics Canada, 2011). In Canada overall, 48% of the Aboriginal population was under age 24, compared with 31% of the non-Aboriginal population (Statistics Canada, 2011).

Of the Aboriginal identity population, 15.5% identified their mother tongue as being an Aboriginal language, while 8.0% speak an Aboriginal language most often at home. Another 18% declared knowledge of Aboriginal language(s) (Statistics Canada, 2007).

By the numbers

Population: 3.26 M

Overall population living in rural areas:

- ▶ 18%
- ▶ 545,330
(Statistics Canada, 2006)

Geography/Size:

- ▶ 7% of Canada
- ▶ 640,045 square km
(Statistics Canada, 2007)

First Nations

- According to Aboriginal Affairs and Northern Development Canada, there are 45 First Nations in Alberta, and 140 reserves (AANDC, 2010).
- First Nations people live in many areas in Alberta. The box *Population & Location* provides the details.

What else do we know?

- First Nations people are dying at younger ages than the non-First Nations population (Health Canada, 2011)
 - There is a growing life expectancy gap where the life expectancy is now 12.2 years lower than non-First Nations compared to 9.6 years lower in 2000 (Health Canada, 2011).

How is cancer care provided?

Alberta Health Services (AHS) is responsible for the prevention and treatment of cancer; Alberta does not have a provincial cancer agency. AHS offers a variety of programs, services and facilities that work with those affected by cancer, as well as providing programs to help Albertans reduce their risk of developing cancer.

Facilities and Programs

This section highlights a few of the cancer related programming as described on the AHS website:

- Community Cancer Centres are located within local regional hospitals/health centres. They deliver a range of treatments and care options to cancer patients as close to home as possible, including outpatient chemotherapy, education and support. There are 11 community cancer centers (Alberta Health Services, 2012).
- Four Associate Cancer Centres deliver a range of treatments and care options to cancer patients in their home communities including outpatient chemotherapy, education and support for cancer patients. Physicians, nurses and pharmacists receive certification

Population & Location

Aboriginal identity:

- ▶ 188,365 total population
 - ▶ 41,275 on-reserve
 - ▶ 32,560 rural
 - ▶ 114,535 urban

First Nations identity:

- ▶ 97,280 total population
 - ▶ 40,195 on-reserve
 - ▶ 11,180 rural
 - ▶ 45,900 urban

Multiple Aboriginal identity:

- ▶ 1,220 total population
 - ▶ 20 on-reserve
 - ▶ 200 rural
 - ▶ 990 urban

Statistics Canada, 2006

through the Cross Cancer Institute and the Tom Baker Cancer Centre. They see new patients as well as follow-up patients and can refer patients to a Community Cancer Centre should this be closer to their home community (Alberta Health Services, 2012).

- Provincial Cancer Patient Navigation: Cancer patient navigators support patients and their families in a number of ways. This service is available to anyone receiving cancer treatments, including family members. There are three cancer centers which have navigators (Alberta Health Services, 2012).
- Screen Test: Alberta Breast Cancer Screening Program: A breast cancer screening mammography service that is part of the Alberta Breast Cancer Screening Program (ABCSP). Includes mobile screening mammography services in rural Alberta locations (Alberta Health Services, 2012).
- Colon Cancer Screening: This service offers comprehensive care, with a focus on screening and detection of colon cancer (Alberta Health Service, 2012).
- Alberta Cervical Cancer Screening Program: ACCSP is dedicated to increasing the number of women aged 21 to 69 who have regular Pap tests (Alberta Health Services, 2012).

This section highlights a few of the key programs offered through Alberta Health Services. It is important to note that there are many other programs and educational classes offered that are not outlined here. For more information visit:

<http://www.albertahealthservices.ca/services.asp?pid=stype&type=7>

Provincial Themes

Participants from Alberta discussed many opportunities, gaps and barriers within the province. Many of the issues discussed were similar to those discussed in the National Story. The three issues that were most commonly discussed by participants were issues and barriers that affect the whole of the cancer continuum, including the role culture and cultural responsiveness, education and system logistics and service availability. While participants did discuss many other barriers and challenges the following issues seemed to be the most commonly discussed. This section is focused on the top three themes shared by participants.



Culture & Culturally Responsive Care

What do we know?

The importance of considering culture and providing culturally responsive care was shared by participants.

- One participant talked about the role of language describing the importance of having information available in culturally appropriate languages.
- Another participant described how “we are different in how things are dealt with in palliative care and upon death” and how there is a “need for training/education on the cultural approaches of death and dying.”
- Participants reiterated the importance of “cultural understanding from health professionals”.
 - One participant explained how “if people have a bad experience, they do not want to go back”.
- One participant described how it is important to understand that some people “may want to try traditional medicine and consult with family and elders before treatment”.

“How do you even begin to talk? Communication is hard.”

Knowledge & Education

What do we know?

Education was recognized as an important issue in all aspects of health and health care.

- Participants identified the importance of providing cross cultural training for health care providers.
 - One participant stated that it would be good if “all health care providers in the cancer care facilities did mandatory cross cultural orientation/training program”.
 - It was also mentioned that it is important to create awareness about jurisdictional issues in terms of health care.
- Participants highlighted the importance of increasing knowledge about cancer for First Nations people.
 - Participants discussed the need to ensure communication and educational materials are in terms people can understand and that materials should be made appropriate for visual learners.
- One participant identified that she felt there is a knowledge gap about why a client may take a long time to seek care or why a patient chooses to stop treatment.

System Logistics & Service Availability

What do we know?

Participants shared their insights about some of the issues, gaps and barriers about service availability in Alberta.

- It was shared that there was a “need for all health facilities to collaborate and integrate information on what they do and the services they provide” to help improve the system.
- Participants spoke about the lack of services in some areas stating things like “some places don’t have doctors” and how some “may have to travel far for care”.
- Moreover, participants identified how some patients feel like they have no support when facing challenging situations like screening or a cancer diagnosis.

“No one there if you fall”

- Many participants spoke about the importance of palliative care that “people shouldn’t need to die in hospital” and how care providers “need to work with families because it is scary”.
- One participant explained how system logistics can delay treatment. It was described that a person may go to Edmonton with pelvic pain, and receive a very unexpected cancer diagnosis. The person may need to return home to talk with people first before deciding on treatment.

Participants from Alberta discussed a number of issues that are barriers across the cancer continuum. In describing the vastness and importance of cancer related issues one participant said:

“I feel there is just so much that needs to be done and said
in this area.”

This section presented the top three issues as described by participants, however, it is integral to highlight that many other opportunities, gaps, barriers and challenges were shared with us by participants as described in the National Story.

Up and Coming in Alberta

This section highlights some examples of up and coming projects and programs in Alberta. This list includes programs and projects that were identified by participants or project staff, and is not meant to be exhaustive. Regularly updated lists of project and programs can be found at: www.cancerview.ca

- Project in progress: working with First Nations people living on and off reserve, Metis and Inuit in Alberta, to learn about the barriers and challenges about issues related to cancer.
 - Involved 200 people from across the province.
 - Project report is in development.
- Alberta Cervical Screening Program:
 - Implemented a change in screening guidelines.
 - Late in 2011 the program began sending out letters with pap test results and to remind women of overdue tests.
 - For more information visit: <http://www.screeningforlife.ca/cervical/>

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Saskatchewan

*Canadian cancer control in First Nations
populations living off-reserve in rural, remote and
isolated areas*

Saskatchewan Profile

Cancer is a significant health issue in Saskatchewan. Historically, breast cancer in Aboriginal women in Saskatchewan was low, however, it is now on par with women in the general population and similar rises have been reported in colorectal cancer (U Sask 2000).

What else do we know?

- Saskatchewan has the highest prostate cancer mortality rate (CCS, 2011).
- For 2011, 5,300 new cases of cancer and 2,400 cancer related deaths were projected for Saskatchewan (CCS, 2011).

Population Sketch

Saskatchewan's Aboriginal population is young. The median age is 21.7 years (Statistics Canada, 2007), compared to 40 years for the non-Aboriginal population in Canada (Statistics Canada, 2011); 35.7% are under 15 years of age. (Statistics Canada, 2007).

Of the Aboriginal identity population, 25.6% identified their mother tongue as being an Aboriginal language, while 16.1% speak an Aboriginal language most often at home. Another 85.6% declared knowledge of Aboriginal language(s) (Statistics Canada, 2007).

By the numbers

Population: 0.95 M

Overall population living in rural areas:

- 30%
- 289,475

(Statistics Canada, 2006)

Geography/Size:

- 6.5% of Canada
- 588,267 square km

(Statistics Canada, 2007)

First Nations

- According to Aboriginal Affairs and Northern Development Canada there are 70 First Nations in Saskatchewan (AANDC, 2010). However, according to the Federation of Saskatchewan Indian Nations, they represent 74 First Nations (FSIN, 2012).
- First Nations people live in many areas within the province of Saskatchewan. For details, see the *Population & Location* box.

How is cancer care provided?

As described on the Saskatchewan Cancer Agency website: The Saskatchewan Cancer Agency is the corporate body established under and regulated by the Cancer Foundation Act with responsibility for conducting a program for the prevention, diagnosis, treatment and follow-up of cancer in Saskatchewan (SCA, 2012)

Facilities and Programs

- Two comprehensive treatment centres are located at Allan Blair Cancer Centre, Regina and Saskatoon Cancer Centre, Saskatoon. Services include oncology care, treatment and support services (SCA, 2012).
- As described on the website:
 - The Community Oncology Program of Saskatchewan (COPS) is a program of the Saskatchewan Cancer Agency and coordinated by the Saskatoon Cancer Centre and the Allan Blair Cancer Centre in partnership with the health regions. The primary goal of COPS is to provide cancer patients with care, treatment and support in or near their home communities. There are 16 COPS centres located in regional hospitals throughout Saskatchewan.
 - COPS centres have nurses, pharmacists, pharmacy technicians and social workers who are specially trained in providing cancer care. They remain in close contact with the cancer care teams at the Allan Blair Cancer Centre in Regina and the Saskatoon Cancer Centre (SCA, 2012B)
- According to the website the following screening programs are offered:

Population & Location

Aboriginal identity:

- 141,890 total population
 - 49,015 on-reserve
 - 26,355 rural
 - 66,520 urban

First Nations identity:

- 91,400 total population
 - 47,765 on-reserve
 - 8,175 rural
 - 35,465 urban

Multiple Aboriginal identity:

- 625 total population
 - 20 on-reserve
 - 170 rural
 - 435 urban

Statistics Canada, 2006

- Screening Program for Colorectal Cancer
 - The Screening Program for Colorectal Cancer is a screening program for the detection of colorectal cancer. The program is currently being phased in across the province.
- Prevention Program for Cervical Cancer
 - The Prevention Program for Cervical Cancer is a screening program of the Saskatchewan Cancer Agency dedicated to the prevention of cervical cancer.
- Screening Program for Breast Cancer
 - The Saskatchewan Screening Program for Breast Cancer is a province-wide program for the early detection of breast cancer using screening mammography.

(SCA, 2012C)

This section highlighted some of the key programs and services offered by the Saskatchewan Cancer Agency.

Provincial Themes

A number of participants from Saskatchewan participated in this work. Each shared a wealth of information about the opportunities, gaps and barriers faced by First Nations cancer patients in Saskatchewan. Some shared great detail about the cancer journey, while others shared insights about the key issues that have an impact across the cancer journey. This section focuses on what was interpreted to be three key issues across the cancer journey in Saskatchewan; culture and culturally responsiveness, education and knowledge, and system logistics and service availability.



Culture & Culturally Responsive Care

What do we know?

Participants talked about the importance of providing culturally responsive/safe care.

- Providers must recognize cultural differences and respond in a culturally safe manor.
 - Participants stated that it is important to understand that the “focus of health is different” and that you “miss the whole person if you only deal with the disease”.
 - Many participants identified the importance of being culturally responsive in the use of language and how in some cases it is inappropriate to say “cancer”.
- Participants highlighted the need for providers to establish trust and consider the history of the people.
 - Healthcare providers must understand the significance of First Nations peoples’ trust in the system and with healthcare providers.
 - Recognize the role of fear and real or perceived prejudice

“Cancer is fear”

- Participants also mentioned the importance of considering the fear that some people feel about leaving their community for health care.
- Participants stated that there was a “need to better engage with community” and to “build the (educational) tools with the community” in a culturally responsive way.

Knowledge & Education

What do we know?

Participants shared that providing education, and recognizing Traditional knowledge are key steps in improving the cancer story among First Nations people.

- It was identified that there was a lack of “awareness about risk factors” and in some cases a “lack of acknowledgement of the role of tobacco” in cancer.
- Highlighting the need for more education and culturally responsive education, one participant stated:
 - “there are a lot of gaps – gaps in information, especially in a way that is respectful” and that there are “gaps in effective communication”
 - Moreover, multiple participants identified the importance of working with communities in a culturally appropriate way to develop educational tools.
- One participant discussed the role of individual health literacy and identified the need to increase knowledge about chronic disease.
 - Another participant further noted the importance of health education, referencing how some “people feel they know their own health status” and that “if they are feeling better, they are better”.

“Need to learn from them, their perspective is what is best”

“People feel they know their health status”

System Logistics & Service Availability

What do we know?

Participants identified a number of gaps in service availability and some issues related to system logistics.

- Participants shared about how “the challenge is getting people into the system” but that once in the system, engaged in treatment or follow-up then it is better.
- Participants highlighted the need for improved service availability.
 - For example one participant stated that with living in remote areas “there are increased challenges” for transitioning from cancer care back into primary care, explaining that it is important to understand what types of care are or are not available in a community.
 - A number of participants discussed the importance of care providers considering the commonly faced issues like the availability of healthy food, and the social determinants of health.
 - The lack of palliative care available in some areas was a topic referenced by many participants and was identified as a “huge gap”. Moreover, one participant stated that “true palliative care” was a gap across the province.
- When discussing system logistics and coordination of care, one participant discussed how in some instances test results are shared with the family physician, while in other they “often need to track down what happened and what kind of follow-up care is needed”.
 - In talking of wait times, one participant stated that there are “a great variety of wait times depending on many factors – related to both the health system and the patient”.

It is also important to acknowledge the role of the social determinants of health. Many participants from Saskatchewan did highlight the importance of these factors as they affect a persons’ ability to seek health care. This section presented the top three issues based on what participants shared with us. It is important to acknowledge that participants did describe many other barriers and challenges as presented in the National Story.

Up and Coming in Saskatchewan

This section highlights some examples of up and coming projects and programs in Saskatchewan. This list includes programs and projects that were identified by participants or project staff and is not meant to be exhaustive. Regularly updated lists of related projects and programs can be found at: www.cancerview.ca

CLASP – HEY! (Health Empowerment for You!) Project. The focus of this project is to engage youth and promote health behaviors among youth. This project was developed based on request for proposals from the Partnership.

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Manitoba

Canadian cancer control in First Nations populations living off-reserve in rural, remote and isolated areas

Manitoba Profile

Cancer is becoming an increasingly significant issue amongst Manitoba's diverse First Nations, Metis and Inuit populations. In Manitoba, the highest lung cancer incidence rates are found in the northern regions, as well as the highest all-cancer mortality rates (CCMB-CHA, 2010).

What else do we know?

- There were 6,100 new cases of cancer and 2,800 cancer deaths projected for 2011 in Manitoba (CCS, 2011).
- As one of the first provinces to implement colorectal cancer screening, Manitoba has the highest rates of colorectal cancer testing (47%) in Canada (CCS, 2011).

Population Sketch

Manitoba's Aboriginal identity population is about 15% of all Aboriginal people in Canada. It is a young population; median age for the Aboriginal Identity population is 23.9 (Statistics Canada, 2007) as compared to 40 for the non-Aboriginal population in Canada (Statistics Canada, 2011); 33.2% are under the age of 15 (Statistics Canada, 2007).

Of the Aboriginal identity population, 21.6% identified their mother tongue as being an Aboriginal language, while 13.1% speak an Aboriginal language most often at home. Another 25.2% declared knowledge of Aboriginal language(s) (Statistics Canada, 2007).

By the numbers

Population: 1.1 M

Overall population living in rural areas:

- 23.7%
- 268,075
(Statistics Canada, 2006)

Geography/Size:

- 6% of Canada
- 552,396 square km
(Statistics Canada, 2007)

First Nations

- According to the Assembly of Manitoba Chiefs (AMC) there are 64 First Nations in Manitoba.
- First Nations people live in many areas in the province of Manitoba. See the box *Population & Location* for details.

How is cancer care provided?

CancerCare Manitoba (CCMB) is charged by an act of Manitoba legislature with responsibility for cancer prevention, detection, care, research and education for the people of Manitoba. The agency is dedicated to excellence in cancer care, to enhancing quality of life for those living with cancer and blood disorders, and to improving cancer control for all Manitobans. It also provides services to populations from the Kivalliq region of Nunavut, northwestern Ontario, and Saskatchewan.

Facilities and Programs

As described on the website:

- Two tertiary centres are located within/near the major teaching hospitals in Winnipeg – the MacCharles Unit and the St. Boniface Unit. Both provide oncology/hematology care, treatment and support services.
 - Four urban community hospital sites with oncology programs jointly managed by the Winnipeg Regional Health Authority and CCMB (CCMB, 2012).
- The Western Manitoba Cancer Centre, a partnership between CCMB and Brandon Regional Health Authority, provides access to radiation therapy as well as chemotherapy and support services (CCMB, 2012).
- Announced in February 2012, the new Community Oncology Program integrates two nationally respected models of delivering community-based cancer care – the Community Cancer Program Network (CCPN) and the Uniting Primary Care and Oncology Program (UPCON). By combing their efforts, this new program will provide the leadership required to meet ongoing challenges in community care and enable patients living outside of Winnipeg to receive cancer care closer to home. Sixteen Community Cancer Program sites (including one Community Cancer Resource and Support Program

Population & Location

Aboriginal identity:

- 175,395 total population
 - 56,765 on-reserve
 - 30,855 rural
 - 87,780 urban

First Nations identity:

- 100,645 total population
 - 55,825 on-reserve
 - 9,560 rural
 - 35,260 urban

Multiple Aboriginal identity:

- 685 total population
 - 25 on-reserve
 - 135 rural
 - 525 urban

Statistics Canada, 2006

(CCRSP) operate as outpatient units located in community hospitals and are staffed by a multidisciplinary team of family physicians, nurses, pharmacists, and may include other health professionals. The oncologist (usually based in Winnipeg) maintains ongoing contact with the CCP team and retains overall responsibility for the patient's care.

- The former UPCON Network, now under the Community Oncology Program, ensured that people with cancer attending partner clinics experience better coordination of their care between their different care providers. Shared care of the cancer patient is enhanced by supporting more than 350 primary care providers in a variety of ways including access to electronic health records and educational opportunities. As of November 2011, 41 clinics (24 in Winnipeg and 17 in rural/northern regions) are participating (CCMB, 2012B).
- BreastCheck, in partnership with CancerCare Manitoba and Manitoba Health, is a program to check women ages 50 and older for early signs of breast cancer. Mobile mammography services have been available to rural and northern communities since 1998. Breast health resources are available in many languages including Cree and Ojibwe (CCMB, 2012).
- ColonCheck, in partnership with CancerCare Manitoba and Manitoba Health, targets individuals of average risk between the ages of 50-74 for screening with a Fecal Occult Blood test (FOBT). Over time, ColonCheck will be inviting eligible people from all regions of the province. Colorectal resources are also available in other languages including Cree and Ojibwe (CCMB, 2012).
- MBTelehealth is a multiple site, province-wide telehealth network managed by the Winnipeg Regional Health Authority utilizing two way video-conferencing technology. Teleoncology enhances access to services in rural and remote areas and provides specialized, consultative services to patients and families in rural sites equipped with MBTelehealth; MBTelehealth is also used for continuing educational sessions; community providers to participate in administrative functions; and televisitation visits between patients and family members (CCMB, 2012).

This section presented some of the key programs offered by CancerCare Manitoba.

Provincial Themes

Participants in Manitoba identified a number of opportunities, gaps and barriers. Although a number of issues were discussed, three key themes across the cancer journey could be identified; the roles of culture and culture responsiveness, knowledge and education and system logistics/service availability. This section presents a summary of what Manitoba participants shared about the top three themes.



Culture & Culturally Responsive Care

What do we know?

Participants emphasized the need to respect culture and provide culturally responsive care.

- Participants highlighted the role of the provision of culturally responsive care and the role of developing trust with health care providers.
 - The importance of healthcare providers' demonstrating cultural safety was shared by many participants.
 - The idea that the assumptions that some health care providers may make about "whether Aboriginal people would pursue treatment/care affects whether care is offered" was shared by one participant.
 - In consideration of the historical context, the role of trust with health care providers was identified as a key issue.
 - One participant acknowledged the importance of developing trusting relationships with health care providers, while another participant explained how it "takes a long time to build trust in communities, regardless if it's a First Nations community or not".

"Incorporate Traditional Healing components into screening promotion and education"

- Another participant explained how a patient may not tell a health care provider if they are using Traditional Medicines if they do not trust the provider.
- Participants shared about the role of language and providing care and information in appropriate languages and using clear language.
- The vital role of family and community support was also identified. One participant stated how “some people want to stay in community, they don’t want to leave to die alone in the city, and would rather not pursue treatment because they prefer to die at home” .
 - It was also said how people “do not want to come home without a body part” so they may “make the choice not to have treatment”.
 - One participant highlighted how “asking patients to make decisions and experience hardships alone goes against the culture”.

Knowledge & Education

What do we know?

Participants spoke repeatedly about the crucial role of education.

- Participants stressed the importance of providing education about cancer, screening and symptom recognition.
 - Moreover, the significance of providing education in an appropriate way through sessions in the community and the use of local and plain languages was also discussed.
 - It was also stated that it is important to “relate education to current realities”, implying that the relevance to culture and the social determinants of health be incorporated.
- One participant highlighted the need for education about treatment options and the role of the health care provider in emphasizing the importance of treatment as some people say “I have cancer, I’m going to die, why should I go for treatment?”.
- Several participants spoke about people being reluctant to seek health care sooner; “they know they are sick, but they refuse to find out what it is”, and how some people “may not accept illness” or “resist medical attention”.

“Sometimes people think symptoms need to be severe to warrant a doctor’s visit”

- One participant shared the importance of providing education about health and increasing health literacy.

System Logistics & Service Availability

What do we know?

Participants identified several opportunities, gaps and barriers in relation to system logistics and service availability in Manitoba.

- Participants described the role of health care providers in providing accessible and continuous care:
 - In some areas the lack of service providers was identified as a key barrier. Furthermore, the impact of staff turnover on continuity of care was also highlighted as a barrier.
 - A number of participants also highlighted the role that a health care provider can play in advocating for patients.
 - One participant identified how important it is that the local health care provider have oncology related knowledge and be aware of appropriate referral processes.
 - It was also pointed out that local health care providers need to advocate for their patients to ensure that the diagnostic journey goes smoothly.
- Several participants identified the role of improving system logistics.
 - One participant described how, in some instances, communication may be lacking as “diagnostic paperwork or information from CCMB is not received, or goes into a chart and is not read or dealt with, or may be sent to wrong unit/nurse”
 - One participant did identify that “CCMB is good at discharge planning/follow-up, and keeping nursing stations/CHRs in the loop”
 - Participants mentioned the use of telehealth and one participant stated that “telehealth is used, and more would be good, (because it) keeps people on track”.
- A number of participants identified how access to care varies when comparing rural and urban communities:

“Care is driven by the local health care provider”

- Participants explained that care needs to be provided as close to home as possible.
 - In terms of access to care, “for First Nations people living off-reserve, compared to the general population – there is little or no difference” for those living in the same parts of the province.
 - For First Nations people living off-reserve compared to First Nations people living on-reserve – both in rural or remote communities there are many disparities to consider including:
 - Funding for transportation and lodging
 - Bands’ capacity to assist/absorb medical transportation costs
 - One participant highlighted the barriers of “INAC processes, identification needs (ID cards), cultural safety, and voluntary Self-Identification needs” for all First Nations people.
- For access to services:
“differences exist
between urban and rural
or remote
(communities)”***
- A number of participants highlighted the lack of availability of survivorship and palliative care services.
 - For survivorship services, participants identified that there would be a lack of services for those living in rural and remote areas.
 - For palliative care, participants identified a number of gaps:
 - One participant described how a First Nations person living off-reserve in a northern community may not qualify for service from the band, but some bands will provide care regardless.
 - Some towns have more access due to geography or size.
 - Physicians are not specifically trained in pain management.
 - Other supports like medical supplies may not be available.
 - There are some misunderstandings between healthcare providers and the patient/family about the appropriate time to move into palliative care.
 - Home care may not be available due to capacity issues, which are more pronounced in Northern rural and remote communities.
 - Participants highlighted the hardships experienced by someone required to leave their community to pass on and the additional challenges and feelings of isolation that would be caused.

This section reviews the three themes most referenced by participants. Many other issues and themes were also discussed by participants as described in the National Story.

Up and Coming in Manitoba

This section highlights some examples of up and coming projects and programs in Manitoba. This list includes programs and projects that were identified by participants or project staff and is not meant to be all-inclusive.

- CancerCare Manitoba Foundation, Four Communities Project.
 - Four community-led cancer awareness and prevention projects. Each project is designed by the community and may include activities such as the development of educational materials or having a ‘cancer awareness day’.

- CLASP – HEY! (Health Empowerment for You!) Project. The focus of this project is to engage youth and promote healthy behaviors among youth. This project was developed based on request for proposals from the Partnership. There are Manitoba based partners on this project.

- CCMB Cultural Safety Training: The Knowledge Keepers Series
 - A series of lectures presented to create awareness of the many unique First Nations, Metis and Inuit cultures and the many barriers faced by these populations.
 - The first presenter was the Honourable Justice Murray Sinclair who spoke about the impact of residential schools on Aboriginal people and Canadians.

- First Nations, Metis and Inuit Cancer Control and Vulnerable Cancer Patients Programs
 - The First Nations, Metis and Inuit Cancer Control program operates to reduce the burden of cancer affecting First Nations, Metis and Inuit by working with communities, and our partners in care, to implement an enhanced First Nations, Metis and Inuit cancer control program.
 - First Nations, Metis and Inuit Cancer Control will also be endeavoring to address inequities in cancer services among Francophone, New Canadian and other populations experiencing access barriers.

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Ontario

Canadian cancer control in First Nations populations living off-reserve in rural, remote and isolated areas

Ontario Profile

Cancer is a significant health issue in Ontario. The incidence of cancer is growing the fastest amongst the Aboriginal population in the province. Lung cancer accounts for 6% and 7% of all deaths of First Nations in the 45-64 and 65+ age groups respectively - the third overall cause of death. There has been an increase in cancer rates in both sexes in the First Nations population (Shah, 2005).

What else do we know?

- There are higher rates of smoking and obesity than the general population (Shah, 2005).
- The leading causes of death are injury and poisoning, followed by circulatory diseases, cancer, and respiratory diseases (Shah, 2005).

Population Sketch

The Aboriginal population in Ontario has a higher median age than other provinces, such as Saskatchewan, 29.7 versus 21.7 respectfully (Statistics Canada, 2007). Although, still much younger than the median age of 40 for the non-Aboriginal population in Canada (Statistics Canada, 2011).

Of the Aboriginal identity population, 9.8% identified their mother tongue as being an Aboriginal language, while 5.4% speak an Aboriginal language most often at home. Another 12.0% declared knowledge of Aboriginal language(s) (Statistics Canada, 2007).

By the numbers

Population: 12.02 M

Overall population living in rural areas:

- 14.6%
- 1.75 M
(Statistics Canada, 2006)

Geography/Size:

- 10% of Canada
- 907,574 square km
(Statistics Canada, 2007)

First Nations

- According to the Ontario Ministry of Aboriginal Affairs, “The Chiefs in Ontario identify 133 First Nations in Ontario, 127 of which are recognized by the Indian Act. One in four of the 133 First Nation communities are small and remote, accessible only by air or by ice road in the winter. Ontario has more remote First Nations than any other region in Canada.”(ON Ministry of Aboriginal Affairs, 2012)

How is cancer care provided?

“Cancer Care Ontario is the provincial agency responsible for continually improving cancer services, and the government’s cancer advisor” (CCO, 2012).

Facilities and Programs

As described on the website:

As the provincial agency responsible for continually improving cancer services, and the government’s cancer advisor, Cancer Care Ontario:

- Directs and oversees close to \$700 million public health care dollars to hospitals and other cancer care providers to deliver high quality, timely cancer services.
- Implements provincial cancer prevention and screening programs designed to reduce cancer risks and raise screening participation rates.
- Works with cancer care professionals and organizations to develop and implement quality improvements and standards (CCO, 2012)

CCOs Aboriginal Programs:

- work to improve cancer care for Ontario’s First Nations, Métis and Inuit people. These programs are mandated to make sure Aboriginal people in Ontario have access to quality cancer prevention, screening and symptom information that incorporates the Aboriginal holistic approach (CCO, 2011)

Regional Cancer Programs:

- The cancer system is organized into Regional Cancer Programs (RCPs) corresponding with the province's 14 Local Health Integration Networks. RCPs are networks of

Population & Location

Aboriginal identity:

- 242,495 total population
 - 47,515 on-reserve
 - 44,410 rural
 - 150,570 urban

First Nations identity:

- 158,395 total population
 - 47,005 on-reserve
 - 21,580 rural
 - 89,810 urban

Multiple Aboriginal identity:

- 1,910 total population
 - 0 on-reserve
 - 505 rural
 - 1,395 urban

Statistics Canada, 2006

healthcare providers, including regional cancer centres, and stakeholders including patient groups involved in providing cancer prevention, screening, and diagnostic and treatment services in the LHIN (CCO, 2009).

Screening Programs:

- Cancer Care Ontario is involved in the administration of province-wide screening programs for three types of cancer: breast, cervical, and colorectal cancer (CCO, 2010).

The previous section includes some of the key programs facilitated through Cancer Care Ontario.

Provincial Themes

Participants from Ontario shared insightful information about the challenges and barriers faced by First Nations people in the context of cancer care. Participants discussed a number of specific barriers as well as some overall themes such as the role of culturally responsive care, education and system issues. This section focuses on these three issues which affect the entire cancer journey.



Culture & Culturally Responsive Care

What do we know?

Participants discussed the importance of considering the history of First Nations people and providing culturally responsive care.

- It is vital to consider the historical context of a community and its people.
 - One participant described how “community members are rounded up to travel for screening, like how children were rounded up to go to residential school”.
 - Another participant highlighted the need to be aware of issues of past physical and/or sexual abuse, particularly when physical exams are required.
- Healthcare providers must also consider cultural beliefs around health, death and dying.
 - A few participants shared about the cultural beliefs of “It’s my time”, or it’s the “Creator’s way”.
- The lack of culturally safe services was shared as a concern by participants.
 - One participant described about how there have been instances of conflict between Elders and hospital staff due to cultural misunderstandings. Also, as Elders age they may go back to their first

“The lack of culturally safe services is a gap”

language which as it may not be English, can cause additional stress if they must leave their community to receive care.

- Fear and having to leave the community to access care are significant barriers:
 - One participant discussed how some people “don’t want to leave the community for investigations because other people have left the community for health reasons and did not come back” and the community learns that the person has passed away.
- One participant talked about the need for culturally responsive care specifically for palliation:
 - There is a need for “not only a culturally relevant approach, but a culturally appropriate approach that must be tailored on a community by community basis. Cultural diversity within First Nations populations is large – not only do their traditional ways vary, but various individuals and/or communities have differing levels of comfort with western medicines approach to palliation; some are comfortable with, and even prefer the western style approach to palliation”.

Knowledge & Education

What do we know?

A number of participants talked about the significance of cancer education being made available and accessible for communities.

- Participants discussed how they thought promoting and increasing education about cancer screening would help increase screening rates.
 - One participant also talked about how a cancer experience in the family affects willingness to be screened: “if people see a family/community member get diagnosed then will be more willing to go (get screened)”.
 - Participants also spoke about the need to educate children about cancer prevention and that related information should be added into the health curriculum.
- A few participants discussed how people sometimes delay seeking care when a health issue arises.
 - One participant shared about how some people may only start thinking about going for screening “until something comes to bite them”. It was further explained how people may not have realized that service was there before.

- One participant also identified the need for education about the health system so people are better able to navigate services.
- Another participant commented on the importance of building capacity within communities so they are able to care for those who are ill.

System Logistics & Service Availability

What do we know?

Participants in Ontario identified a number of opportunities for improvement in terms of system logistics and service availability.

- There can be challenges in accessing services in some areas and a lack of service in many cases.
 - Participants highlighted that travel to access services is required.
 - One participant identified that they do try to use telehealth when possible, but are trying to determine if delivering difficult information such as diagnoses via telehealth is appropriate or not.
 - Another participant stated “there are no psychosocial supports designed for First Nations people that are dedicated to bereavement or health counseling”.
- One participant highlighted the need for increased surveillance. Surveillance will not only demonstrate need, but will also demonstrate improvements over time.
- A few participants highlighted the frequency of staff turnover and how this affects the continuity of care and access to basic services.
 - Moreover, one participant stated that staffing shortages in some areas are a significant barrier.
- Although the statement related to First Nations living on-reserve, one participant stated how there is a “complete lack of resources within the community; lack of health care professionals, and when nurses are available they lack palliation skill and supplies, and

“Lack of health care providers”

“Care depends on geography”

physicians are generally not stationed near enough to provide the around the clock support access necessary for palliative care “

- One participant also highlighted the challenge of creating solutions when there are multiple funding models that contribute the coordination of health care.

Participants from Ontario highlighted a number of important opportunities, gaps and barriers for cancer care. It is important to reiterate that this section highlights the few issues that came to the forefront. Participants also discussed many other issues and barriers, especially the role of the social determinants of health and setting priorities for accessing care.

Up and Coming in Ontario

New and promising projects and program in Ontario were identified by participants or project staff. Below is a list of a few up and coming projects and programs in Ontario.

- Underscreened/Never Screened project is an ongoing project in many LIHNS focused on engaging with under- and never-screened populations, including First Nations, Metis and Inuit populations.
- Sioux Lookout Meno Ya Win Health Centre is a “fully accredited, 41 acute care bed and 5 chronic care bed hospital; and a 20 bed Extended Care Facility”. This health centre is now able to offer breast screening on a permanent basis, reducing travel for those living in the surrounding areas.

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Québec

Canadian cancer control in First Nations populations living off-reserve in rural, remote and isolated areas

Québec Profile

Cancer is a significant health issue in Québec. It has been found that “in Québec, one-third of all cancer-related deaths – i.e. 33.3% – are solely attributed to lung cancer (27% nationwide). Lung cancer kills twice as many Québec women as breast cancer and close to 4.5 times more Québec men as prostate cancer” (CCS, 2011).

What else do we know?

- More than half of adults, and over a third of young Aboriginal people smoke. The average age when people begin smoking is 12 (FNQLHSSC, 2011).
- Over two-thirds of Aboriginal adults are overweight or obese in Québec (FNQLHSSC, 2011).

Population Sketch

Quebec’s Aboriginal identity population is young. The median age is 31.1 years (Statistics Canada, 2007), compared to 40 for the non-Aboriginal population in Canada (Statistics Canada, 2011) and 25.4% are under 15 years of age (Statistics Canada, 2007).

Of the Aboriginal identity population, 37.1% identified their mother tongue as being an Aboriginal language, while 32.6% speak an Aboriginal language most often at home. Another 39.1% declared knowledge of Aboriginal language(s) (Statistics Canada, 2007).

By the numbers

Population: 7.43 M

Overall population living in rural areas:

- 19.6%
- 1.46 M
(Statistics Canada, 2006)

Geography/Size:

- 15% of Canada
- 1,356,366 square km
(Statistics Canada, 2007)

First Nations

- The Assembly of the First Nations of Québec and Labrador represents ten Nations and 43 communities (AFNQL, 2012).
- First Nations people live in many areas in Québec Quebec. The box *Population & Location* provides details of on-reserve, rural and urban populations.

How is cancer care provided?

There is no provincial cancer agency in Québec. At the central level, the Québec Ministry of Health and Social Services (Ministère de la Santé et des Services sociaux – MSSS) establishes policies and procedures for the health network in its entirety (MSSS, 2008).

Facilities and Programs

In Québec, health care is facilitated through the Québec health and social services system, where there are "approximately 300 institutions providing services in more than 1700 service points, including approximately 200 public institutions, around 50 non-profit institutions under agreement and around 50 private institutions offering residential and long term care" (MSSS, 2008 p. 5).

- There are 18 regional health and social services authorities that organize and deliver services in their respective territories (MSSS, 2008).
- Québec Breast Screening Program: The Québec Breast Cancer Screening Program (PQDCS) offers mammography exams every two years to women aged between 50 to 69 years.
 - Mobile mammography is used (PQDCS, 2012).
- Québec Quebec Colorectal Screening program: The program is not yet fully operational; however, it will be implemented in two phases (PQDCCR, 2012).
- Integrated University Health Network, or Réseau universitaire intégré de santé – RUIS. As described on the website:
 - A portion of Québec territory was assigned to each of the province's four Faculties of Medicine, with the intent to facilitate specialized care, medical education, and medical research throughout the province's many regions.

Population & Location

Aboriginal identity:

- ▶ 108,430 total population
 - ▶ 33,810 on-reserve
 - ▶ 29,620 rural
 - ▶ 45,005 urban

First Nations identity:

- ▶ 65,085 total population
 - ▶ 33,395 on-reserve
 - ▶ 8,125 rural
 - ▶ 23,560 urban

Multiple Aboriginal identity:

- ▶ 960 total population
 - ▶ 25 on-reserve
 - ▶ 225 rural
 - ▶ 710 urban

Statistics Canada, 2006

- Each RUIS has the responsibility to coordinate tertiary health care services through its associated teaching hospitals, and to support the training and development of healthcare professionals in their corresponding regions (RUIS, 2012).
- The Cree Board of Health and Social Services of James Bay (CBHSSJB) was created in 1978. The Board is “responsible for the management of health and social services in the entire Cree territory of James Bay, whether these services be those offered to all other Québécois or those offered to other First Nations by the government of Canada.” (CBHSSJB).

This section highlights some of the key cancer related programs and services offered in Québec.

Provincial Themes

A few key participants from Québec shared valuable information on the cancer journey in their region. Some of the interviews focused on First Nations people living on-reserve, however, it is anticipated that some of the barriers are similar for First Nations living off-reserve in other rural, remote or isolated areas. Although participants discussed many topic areas, there were several that were highlighted, including the key issues of language and transport. This section presents the key issues presented by participants.



Culture, Knowledge & Education

What do we know?

Participants shared about the importance of addressing knowledge gaps and how they should be addressed in a culturally responsive way.

- Participants shared that First Nations people face many language barriers in Québec, in addition to the challenge of accessing Aboriginal languages there is also the issue of accessing services in English.
 - It was said that for those who require service in English they are more likely to seek service in Montreal or other areas where English is more widely spoken. This could mean additional travel time and distance.
- The vital role of culture and beliefs was shared by one participant who spoke of the impact of fear and how some “people may refuse (to talk/learn about cancer), (because they) feel that if they think about it, it may happen”.
- It is important to highlight that there is variation across communities. In discussing breast screening one participant said that “women know, those with high risk do want to be screened”.

“People are afraid to learn about it”

- The role of culture in palliative care was described by one participant where: “people in community may look at end of life differently” and that “people (may) refuse to go for palliative care, they may just stay home”, despite a lack of services.
- One participant stated that it was important to “meet with people and explain” when sharing information and that it is “better if someone with experience (cancer survivor) gets involved”.
- In identifying knowledge gaps, one participant stated that “people may not see the importance of screening”, demonstrating the need to help address the knowledge gaps in some communities.

System Logistics & Service Availability

What do we know?

Participants shared about limited service availability in some areas and provided some examples of programs that are working well.

- There are limited services available in some areas. One participant highlighted the “limited service availability in remote areas” and how “it is not easier for the general population in remote areas”.
 - As for many people living in rural, remote or isolated communities, travel and in some cases, substantial travel may be required to access services.
 - Participants in some regions identified that travel was a very significant barrier for people.
- One participant explained that breast cancer screening on-reserve was working very well. Although delivered on-reserve, the program is working with the community and the Community Health Representatives (CHRs) to help publicize and book appointments for screening which increases success.
 - Appointment times after 5pm and on weekends further increases the availability of service.
- Participants shared that waiting to access some types of services, such as diagnostic services was an issue for all residents.
 - There are some private healthcare services available in the southern part of the province, but they are very expensive.

“Distance can make a difference”

- For the coordination of services from cancer care to care on-reserve, nurse liaisons facilitate the return to community.
 - In some regions oncology specific navigators are available, while in others they are not.
 - Participants stressed that it would be beneficial to have these services in all areas.

Québec participants identified a number of barriers and challenges faced by First Nations people. Variation in responses was found based on regional differences. Additional participation from key informants in Québec would likely have yielded further information on key barriers in the cancer journey for First Nations people living off-reserve.

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New Brunswick

Canadian cancer control in First Nations populations living off-reserve in rural, remote and isolated areas

New Brunswick Profile

Cancer is a significant health issue in New Brunswick. Between 2002 and 2006 approximately 3,912 new cases of invasive cancer were diagnosed annually (NBCN).

What else do we know?

- Lung, colorectal, prostate and breast cancer are the most common cancers in New Brunswick (Department of Health, 2012).
- From 2002-2006, mortality rates improved for: stomach, colon and rectum, lung, prostate and non-Hodgkin's lymphoma in males; colon and rectum breast and cervix uteri in females (NBCN, p. viii).

Population Sketch

New Brunswick's Aboriginal identity population is young compared to the Canadian population but older than the Aboriginal populations in other provinces. In New Brunswick, the median age is 31.5 years compared to 40 in the non-Aboriginal population; 25.2% are under 15 years of age (Statistics Canada, 2007).

Of the Aboriginal identity population, 18.1% identified their mother tongue as being an Aboriginal language, while 8.7% speak an Aboriginal language most often at home. Another 19.8% declared knowledge of Aboriginal language(s) (Statistics Canada, 2007).

By the numbers

Population: 719,650

Overall population living in rural areas:

- 48.3%
- 347,640
(Statistics Canada, 2006)

Geography/Size:

- 0.79% of Canada
- 71,355 square km
(Statistics Canada, 2007)

First Nations

- There are 15 First Nations in New Brunswick recognized by INAC (AANDC, 2008.)
- First Nations people live in many areas in New Brunswick, for details see the *Populations & Locations* box.

How is cancer care provided?

The New Brunswick Cancer Network is described as:

- The New Brunswick Cancer Network (NBCN) is responsible for the development and implementation of an evidence based provincial strategy for all elements of cancer care, including prevention, screening, treatment, follow-up care, palliative care, education, and research (Department of Health, 2010 p. 71).

Facilities and Programs

- Cancer care “is delivered at the regional health authority (RHA) level throughout the province, with tertiary level oncology services via radiation therapy provided in Saint John and Moncton (Dumont)” (Department of Health, 2010 p. 71).
- New Brunswick Breast Cancer Screening Program: The program operates out of 16 screening sites located throughout New Brunswick (NBCN). There is no mobile mammography.

This section provides a snap shot of a couple of key services facilitated through the New Brunswick Cancer Network.

Population & Location

Aboriginal identity:

- 17,655 total population
 - 7,005 on-reserve
 - 6,095 rural
 - 4,550 urban

First Nations identity:

- 12,385 total population
 - 6,910 on-reserve
 - 2,835 rural
 - 2,635 urban

Multiple Aboriginal identity:

- 100 total population
 - 0 on-reserve
 - 30 rural
 - 70 urban

Statistics Canada, 2006

Provincial Themes

This section presents the themes that came to the forefront as issues across the cancer journey for First Nations people, as highlighted by the small number of key informants from New Brunswick.



Culture & Culturally Responsive Care

What do we know?

Participants shared about the importance of providing culturally responsive care.

- One participant stated the “hospital is good at making space available to have gatherings or do chanting”.
 - It was also said that the “Doctors are supportive of people seeking traditional healing”.
- The role of fear about cancer, seeking cancer screening and health care was identified by participants.
- One participant shared that there may be a gap in culturally responsive care, particularly in palliative care.
- The importance of information being available in local languages and in audio form was identified. One participant also stated that the cultural appropriateness of the things like numeric pain scales must be considered.

“There are language barriers.”

Knowledge & Education

What do we know?

There is a need to increase awareness about cancer prevention and cancer screening.

- Participants shared that they thought there is a “lack of awareness about prevention”. Addressing this gap could help reduce the cancer burden in the future.
- One participant shared that there is a “lack of knowledge and awareness of what services are available”.
- Increasing knowledge about cancer and the importance of screening was described as important to help find cancer sooner.
- Moreover, the continued education in many different settings, was said to be key to increasing awareness about cancer.

System Logistics & Service Availability

What do we know?

Participants described how there is limited service availability in some areas, while in others access to services can be smooth and efficient.

- One participant described how in some areas there is limited service availability such as the limited number of gynecologists in the province and how these professionals may be too far away for many clients to access. Having a family physician was described as a factor in whether people have access to services such as screening and in the smoothness of the cancer journey.
- One participant identified the need to have provinces or regional health authorities to have a Memorandum of Understanding (MOU) with First Nation communities for discharge planning. Moreover, as health staff become more familiar with the needs of First Nations people living on-reserve it may influence the care provided to all First Nations patients and families.
- The challenges and delays caused by the travel required to access services was shared by participants.
- One participant identified that survivorship services are available, but “not in an organized way”. It was said there are some survivorship services but that they may not be available in communities.
- According to one participant “telehealth is available, but it is not really used”, illustrating the need for education on existing infrastructure and potential applications.

Participants shared about many of the opportunities, gaps and barriers faced by First Nations patients in New Brunswick. Although this section highlighted some of the key themes that seem to affect the whole of the cancer journey, it is important to note that participants did discuss many other issues such as those identified in the National Story.

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Nova Scotia

Canadian cancer control in First Nations populations living off-reserve in rural, remote and isolated areas

Nova Scotia Profile

Cancer is a significant health issue in Nova Scotia. Atlantic Canada has the highest rates of cancer in Canada (CCNS, 2011).

What do we know?

- High rates of colorectal cancer are found in women in Nova Scotia (CCS, 2011).
- 6,100 new cases and 2,700 cancer deaths were projected for 2011 in Nova Scotia (CCS, 2011).

Population Sketch

Nova Scotia's Aboriginal identity population is young; the median age is 29.5 years (Statistics Canada, 2007), compared to age 40 for the non-Aboriginal population in Canada (Statistics Canada, 2011); 26.1% are under 15 years of age (Statistics Canada, 2007).

Of the Aboriginal identity population, 18.1% identified their mother tongue as being an Aboriginal language, while 11.3% speak an Aboriginal language most often at home. Another 20.6% declared knowledge of Aboriginal language(s) (Statistics Canada, 2007).

By the numbers

Population: 903,090

Overall population living in rural areas:

- 43.9%
- 397,080
(Statistics Canada, 2006)

Geography/Size:

- 0.59% of Canada
- 52,917 square km
(Statistics Canada, 2007)

First Nations

- There are 13 First Nations in Nova Scotia (Mi'kmaq Nova Scotia First Net, 2009).
- First Nations people live in many areas of Nova Scotia. The box *Population & Location* provides these details.

How is cancer care provided?

As described on the Cancer Care Nova Scotia website:

- *Cancer Care Nova Scotia* works to improve cancer care and services for all Nova Scotians.
- Established by the Nova Scotia Department of Health and Wellness in 1998, our mandate is to coordinate, evaluate and strengthen cancer care and services for all Nova Scotians.
- Collaboration is at the very core of how we work to strengthen the cancer system in Nova Scotia. Working together with government, researchers, health providers and administrators, we're making significant inroads in ensuring that Nova Scotia patients and families receive the best, evidence-based care available (CCNS, 2012).

Population & Location

Aboriginal identity:

- 24,175 total population
 - 7,980 on-reserve
 - 8,790 rural
 - 7,400 urban

First Nations identity:

- 15,235 total population
 - 7,900 on-reserve
 - 3,315 rural
 - 4,020 urban

Multiple Aboriginal identity:

- 100 total population
 - 0 on-reserve
 - 35 rural
 - 65 urban

Statistics Canada, 2006

Facilities and Programs

The Cancer Care Nova Scotia website describes the following facilities and programs:

Cancer Patient Navigation: Cancer Patient Navigators are oncology nurses who work for a district health authority. They help child, adolescent and adult cancer patients and their families with a wide range of needs, including: physical informational, psychological, social, emotional, and practical (CCNS, 2012B).

Cancer Patient Family Network: A network developed to provide a formal communication channel for patients, survivors and families. The network flows information to patients, survivors and families but also looks to involve these groups in continuing to improve the cancer system (CCNS, 2012C).

The Nova Scotia Telehealth Network (NSTHN):

- “Nova Scotia is a well-established Canadian leader in using Telehealth as a tool to assist in delivering health care services to its population. After undertaking a successful pilot

project in 1996, the Nova Scotia Department of Health worked with a variety of partners to create Canada's first province-wide Telehealth network.”(NS Gov, 2011).

- “Patients from across Nova Scotia can meet face-to-face with health care professionals located anywhere on the network, without leaving their home communities. This saves patients the time, stress and expense associated with travel. Barriers to health care access including travel costs or inclement weather are removed.” (NS Gov, 2011).

This section included some of the key cancer related programs and services offered in Nova Scotia.

Provincial Themes

There were a number of relevant findings about the barriers faced by First Nations people, as identified by a small key information sample in Nova Scotia. This section presents the key issues as discussed by participants. It is important to note that many other issues were identified as presented as part of the National Story.



Culture & Culturally Responsive Care

What do we know?

The importance of considering culture was shared by participants.

- Participants talked about the need to be aware of, and address, how people feel about an issue, for example “people felt that they were waiting longer than usual” so it is important that the feeling is acknowledged and addressed.
- It was stated that it is vital to be aware of systemic racism and how it affects if, or how, a person accesses care.
- The significance of creating culturally responsive resource materials was identified as “First Nations people need to see themselves in the materials”.
- The availability of communication in appropriate languages was also identified as an issue that can affect the cancer journey in a profound way.

“There may be language issues”

Knowledge & Education

What do we know?

Participants described the vital role of education about cancer and the health system.

- One participant identified that there was “lack of understanding” about cancer related issues.
 - In an effort to increase knowledge about cancer, one participant stated that “community education is necessary”, to increase the “understanding of importance” of screening.
- It was stated by one participant that it is essential to address the “misunderstanding of how the system works”, in an effort to help people navigate the health system.
- One participant shared how some patients may have “received conflicting/confusing information” adding to the challenges already faced during a cancer journey.

System Logistics & Service Availability

What do we know?

Service availability was identified as a significant gap by participants.

- In discussing the barriers to accessing service, participants stressed the challenges of distance and transportation.
- To help increase screening, making services available in a “closer proximity” and ensuring they are “easily available” were identified as ways to decrease barriers to screening.
- The complexity of system logistics and the lack of clarity in the cancer journey was demonstrated by one participant who shared that it seems “people feel lost” when moving from cancer care back into primary care.
- The availability of palliative care was described as “spotty, not consistent, despite cultural desires of dying at home”.

Overall, participants shared about the many barriers and challenges faced by First Nations people in reference to cancer control and care. Participants spoke about many issues, however, the previous three were identified as key to the entire cancer journey.

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Prince Edward Island

*Canadian cancer control in First Nations
populations living off-reserve in rural, remote and
isolated areas*

Prince Edward Island Profile

Cancer is a significant health issue in Prince Edward Island. The leading causes of death for Islanders are heart disease, cancer and stroke (PEI Health and Wellness, 2010).

What do we know?

- There is a strong sense of community in PEI, where more people report a strong sense of belonging to their community than other Canadians (PEI Health and Wellness, 2010).
- Similar rates of overweight and obese children and young adults when compared to Canadians as a whole (PEI Health and Wellness, 2010).
- More than half of PEI residents report their health as very good or excellent (PEI Health and Wellness, 2010).

Population Sketch

Prince Edward Island's Aboriginal Identity population is young; the median age is 24.1 years (Statistics Canada, 2007), compared to 40 for the non-Aboriginal population in Canada (Statistics Canada, 2011); 34.7% are under 15 years of age (Statistics Canada, 2007).

Of the Aboriginal identity population, 6.1% identified their mother tongue as being an Aboriginal language. Another 6.1% declared knowledge of Aboriginal language(s), however no one identified speaking an Aboriginal language most often at home (Statistics Canada, 2007).

By the numbers

Population: 134,205

Overall population living in rural areas:

- 55%
- 73,820
(Statistics Canada, 2006)

Geography/Size:

- 0.063% of Canada
- 5,684.9 square km
(Statistics Canada, 2007)

First Nations

- According to Aboriginal Affairs and Northern Development Canada, there are two First Nations, each with one reserve (AANDC, 2011).
- First Nations people live in many areas in PEI. The box *Population & Location* provides this detail.

How is cancer care provided?

Cancer care is delivered through the Prince Edward Island Cancer Treatment Centre (Prince Edward Island Cancer Treatment Centre, 2012).

Facilities and Programs

As described on the website, the cancer centre “provides holistic care with equal access for all Islanders.” (Prince Edward Island Cancer Treatment Centre, 2012).

- They also provide “Support for programs for screening of selected cancers, surveillance, palliation, treatment and research is provided through basic, applied and clinical research programs in cancer control and patient care” (Prince Edward Island Cancer Treatment Centre, 2012).
- Provincial Breast Screening Program: Is available to all women, and focuses on women aged 40-75 (Health PEI, 2011).
- Prince Edward Island Cancer Treatment Centre also offers a Cancer Patient Navigation Program (Prince Edward Island Cancer Treatment Centre, 2012).

Population & Location

Aboriginal identity:

- ▶ 1,730 total population
 - ▶ 400 on-reserve
 - ▶ 590 rural
 - ▶ 740 urban

First Nations identity:

- ▶ 1,230 total population
 - ▶ 395 on-reserve
 - ▶ 385 rural
 - ▶ 450 urban

Multiple Aboriginal identity:

- ▶ 10 total population
 - ▶ 0 on-reserve
 - ▶ 0 rural
 - ▶ 10 urban

Statistics Canada, 2006

Provincial Themes

Key informant participation provided important information about the cancer journey in Prince Edward Island. It is important to acknowledge that much of the information collected from Prince Edward Island refers to issues faced by the general population with limited information specific to First Nations people.



Knowledge & Education

What do we know?

There is a lack of education about cancer and cancer services.

- One participant stated that there is a “lack of information about cancer and the meaning and benefit of screening” and this affects if or how a person would seek out screening or cancer care.
- Participants described that there was a lack of knowledge about the cancer services available.
- Another participant described how for lung cancer, a person may not seek health care due to feelings they “did it to themselves”.

System Logistics & Service Availability

What do we know?

In most areas the access to services is good, however, there is room for improvement.

- Due to the size of PEI, most people live within 15 minutes of a full service hospital.
 - There is a “provincial mandate that everyone is within 30km of service, although this is not full accomplished to date”.

“Direct mail-outs for colorectal screening has increased participation rates”

- One participant described that transport to screening could be facilitated.
 - Moreover, coordinated screening visits where breast, cervical and colorectal screening are possible.
- Lack of family physician was described as one of the many factors contributing to later stage diagnoses.
- Lack of services was not described as being First Nations specific and that “gaps in survivor care apply to everyone”.
- In discussing palliative care, one participant described how:
 - Some areas are already improving, including palliative care, where a new palliative care centre is being built. It was found that “funding in this area is improving” for those who want to pass at home and that “homecare is a growing area”.
 - It was found that “patients are reluctant to sign up for palliative care out of fear, but when they do, they often express that they wish they had done so sooner because it is a supportive and helpful service”

Participants shared about a number of barriers and challenges affecting First Nations cancer patients in Prince Edward Island. This section represents a snap shot of some of the key issues that affect the whole of the cancer journey.

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Newfoundland & Labrador

Canadian cancer control in First Nations populations living off-reserve in rural, remote and isolated areas

Newfoundland & Labrador Profile

Cancer is a significant health issue in Newfoundland and Labrador. In Canada, Newfoundland and Labrador has among the highest rates of chronic diseases including circulatory disease, cancer and diabetes. (Government of Newfoundland and Labrador).

What else do we know?

- In 2011 Newfoundland and Labrador had the highest colorectal cancer incidence rates (for men and women) compared to the rest of Canada (CCS, 2011).
- For women, the lung cancer mortality rates are lowest in Newfoundland and Labrador when compared to the rest of Canada (CCS, 2011).

Population Sketch

- Newfoundland and Labrador's Aboriginal population is younger than the non-Aboriginal population, but has the oldest median age compared to the Aboriginal population in the other provinces. The median age is 32.3 years (Statistics Canada, 2007) compared to 40 in the non-Aboriginal population in Canada (Statistics Canada, 2011); 23.0% are under 15 years of age (Statistics Canada, 2007).
- Of the Aboriginal identity population, 9.7% identified their mother tongue as being an Aboriginal language, while 7.4% speak an Aboriginal language most often at home. Another 10.6% declared knowledge of Aboriginal language(s) (Statistics Canada, 2007).

By the numbers

Population: 500,610

Overall population living in rural areas:

- 42%
- 210,665
(Statistics Canada, 2006)

Geography/Size:

- 4.1% of Canada
- 370,494 square km
(Statistics Canada, 2007)

First Nations

- There four First Nations in Newfoundland and Labrador (AANDC, 2008).
- First Nations people live in many areas of Newfoundland and Labrador. See the box *Population & Location* for details.

How is cancer care provided?

As described on the website:

- The Cancer Care Program of Eastern Health provides services to cancer patients throughout Newfoundland and Labrador (Eastern Health, 2012).

Facilities and Programs

As described on the website:

- Services provided by the Cancer Care Program of Eastern Health include systemic therapy (chemotherapy), radiation treatment, breast screening, and supportive care (Eastern Health, 2012).
- The Cancer Care Program operates at the Dr. H. Bliss Murphy Cancer Centre in St. John's and also operates regional cancer centres across the province located in Gander, Grand Falls-Windsor and Corner Brook. We also support chemotherapy delivery in a number of hospitals throughout the province (Eastern Health, 2012).
- Oncologists working with the Cancer Care Program hold clinics in the regional centres and also use video conferencing for patient appointments. This helps to reduce the distance patients have to travel for follow up appointments (Eastern Health, 2012).
- Breast Screening: The Breast Screening Program offers breast screening services to women aged 50-69 years at screening centres in St. John's, Gander and Corner

Population & Location

Aboriginal identity:

- 23,450 total population
 - 1,435 on-reserve
 - 13,095 rural
 - 8,920 urban

First Nations identity:

- 7,765 total population
 - 1,405 on-reserve
 - 3,575 rural
 - 2,785 urban

Multiple Aboriginal identity:

- 290 total population
 - 0 on-reserve
 - 135 rural
 - 155 urban

Statistics Canada, 2006

Brook (Eastern Health, 2011). There is no mobile mammography in Newfoundland and Labrador.

- Colorectal Cancer Screening: There are plans to launch a program.
- Cervical Screening: Eastern Health implements the Cervical Screening Initiatives program throughout the communities it serves with cervical cancer screening and prevention integrated into the comprehensive delivery of services (Eastern Health, 2012B).

Provincial Themes

This section presents the key themes that the small number of participants from Newfoundland & Labrador discussed. It is important to note that many other issues were shared, similar to those described in the National Story.



Culture, Knowledge & Education

What do we know?

Participants identified the importance of culturally responsive care and identified that there is a lack of education about cancer and cancer screening.

- Participants identified that it was important to have an “investment in education”, including addressing “education on the benefits of screening”.
 - One participant highlighted that there is a “gap in nurse training in oncology follow-up”.
- The role of culture and historical context was commented on where:
 - One participant highlighted the role of fear as an influence in the decision to participate in screening.
 - While another highlighted the importance of language and how they can impact other barriers.

“Language barriers exacerbate other barriers”

System Logistics & Service Availability

What do we know?

Participants identified a number of opportunities, gaps and barriers in terms of system logistics and service availability.

- The lack of services in some areas was identified as a barrier.
 - In some areas there is “restricted access to physicians” as they would only be available on rotation.

- It was also said that “variance in wait time is associated with level of rurality/remoteness”, describing the role of travel to access service.
- Lack of survivorship care to the point where patients say “leaving cancer care is the ‘scariest moment of their journey’”.
- Participants highlighted the need to “bring more services to clients, rather than having clients travel to services so frequently”.
 - It was suggested that “mobile mammography would help”.
 - The challenge of travel and the associated costs were identified as a key barriers.
 - One participant highlighted the use of tele-oncology as a tool that was regularly used to increase service availability.
 - The use of telephone follow-up was also mentioned, where an oncologist would just talk with a patient over the phone to provide follow-up.
 - Language barriers for the use of tele-oncology and telephone follow-up were also identified.

Participants shared about a number of barriers and challenges faced by First Nations cancer patients in Newfoundland and Labrador. This section represents a description of some of the key issues that affect the whole of the cancer journey.

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Yukon

***Canadian cancer control in First Nations
populations living off-reserve in rural, remote and
isolated areas***

Yukon Profile

Cancer is a concern in Yukon. According to the Canadian Cancer Society, there is large variation in cancer incidence and mortality across Canada; however, the territories have been identified as having high cancer incidence and mortality rates (CCS, 2011).

What do we know?

- Yukon fared better than Canada overall on a number of health indicators, such as high blood pressure, and influenza vaccination (Office of the Auditor General, 2011)
- In other health indicators such as smoking, obesity, and life expectancy, Yukon is behind the average (Office of the Auditor General, 2011).

Population Sketch

Yukon's Aboriginal identity population is young; the median age is 30.1 years (Statistics Canada, 2007), compared to about 40 for the non-Aboriginal population in Canada (Statistics Canada, 2011); 27.2 % are under 15 years of age (Statistics Canada, 2007).

Of the Aboriginal identity population, 11.7% identified their mother tongue as being an Aboriginal language. Another 2.0% declared knowledge of Aboriginal language(s), and 16.4% identified speaking an Aboriginal language most often at home (Statistics Canada, 2007).

By the numbers

Population: 30,190

Overall population living in rural areas:

▸ 30.5%

▸ 9,215

(Statistics Canada, 2006)

Geography/Size:

▸ 5.3% of Canada

▸ 474,711 square km

(Statistics Canada, 2007)

First Nations

- According to the Council of Yukon First Nations, there are 14 First Nations in Yukon (CYFN, 2011).
- First Nations people live in many different areas within Yukon. This information is detailed in the box *Population & Location*.

How is cancer care provided?

Yukon Health and Social Services is responsible for delivering health and social programs for the residents of the territory (Yukon Health and Social Services, 2012), however, the BC Cancer Agency is responsible for cancer control in the Yukon (BCCA, 2012).

Facilities and Programs

- According to Canadian Virtual Hospice:
 - “Whitehorse General Hospital coordinates the care/treatment of people living with cancer in Yukon. Some treatments are available at Whitehorse hospital and others are arranged through the cancer agencies of neighbouring provinces (e.g. Alberta Health Services - Cross Cancer Institute in Edmonton)” (CVH, 2012).
- Whitehorse General Hospital can provide some cancer services (chemotherapy) and is part of the *Communities Oncology Network* of the BC Cancer Agency, however, there is no comprehensive cancer centre in Yukon (BCCA, 2012B).
- Yukon Mammography Program: Mammograms are available as part of the program at the Whitehorse General Hospital (Yukon Hospital Corporation, 2010).
- Cancer Care Navigator: There is a cancer care navigator available at the Whitehorse General Hospital, who is dedicated to guiding patients and families through their cancer journey (Yukon Hospital Corporation, 2010B)

Population & Location

Aboriginal identity:

- 7,580 total population
 - 1,970 on-reserve
 - 2,025 rural
 - 3,585 urban

First Nations identity:

- 6,275 total population
 - 1,860 on-reserve
 - 1,710 rural
 - 2,705 urban

Multiple Aboriginal identity:

- 55 total population
 - 0 on-reserve
 - 0 rural
 - 50 urban

Statistics Canada, 2006

- As described by the website, the mission of the First Nations Health Program at Whitehorse General Hospital is to: “promote the provision of quality, culturally-sensitive holistic health care to Aboriginal people by:
 - Advocating for and guiding Aboriginal people through the acute care health system.
 - Recognizing the impacts of residential school and colonialism on the health of Aboriginal People.
 - Providing social and spiritual support, as well as access to traditional food, medicine and healing practices in an acute care environment.
 - Educating health care providers to increase understanding and awareness of Aboriginal culture to enhance safety and competence” (Yukon Hospital Corporation, 2010C).
 - Programs include: health and social liaison workers; traditional diet program; community liaison/discharge planner; Na’Ku (healing room); and a traditional medicine coordinator (Yukon Hospital Corporation, 2010C).

This section identified a selection of some of the programs and services available in Yukon.

Territorial Themes

Although there were a limited number of participants representing Yukon, much relevant information was collected. This section highlights the key issues shared by participants. Many other issues were shared, including those described in the National Story.



Culture, Knowledge & Education

What do we know?

Participants shared about the importance of education and the consideration of culture.

- Participants identified that there may be a knowledge gap about cancer and specifically about the purpose and significance of screening.
- The role of fear and intimidation was shared as potential barrier for accessing screening.
- Participants also identified the need for further education and support for staff to allow them to provide the best care possible.
- The need for language services was highlighted as there may be language barriers throughout the journey.

“Cancer screening is not on the list of priorities”

System Logistics & Service Availability

What do we know?

In some areas there are challenges in system logistics and service availability.

- Participants shared that there was a “lack of clarity in the journey”. In some cases it seemed there was unnecessary “back and forth between the family physician and other care providers”.
 - The lack of continuity of care in some areas was also highlighted as an issue.
- The complete lack of survivorship care was said to be a huge gap and that “people feel they get left hanging”. It was said that there is just “not a lot of direction or support” for survivors.

Participants discussed many barriers faced by First Nations people in Yukon. It is important to clarify that this section presents only some of the key issues that affect the cancer journey. Participants did discuss many other relevant issues such as the role of the social determinants of health including the role of addiction and how it can affect self-care.

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Appendix

***Canadian cancer control in First Nations
populations living off-reserve in rural, remote and
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Leading Models and Practices

Education and Prevention

A. Name/Title of Practice	Cancer 101 – A Cancer Education and Training Program for American Indian/Alaska Natives
B. Type of Practice (Leading, Promising or Best Practice)	Leading
C. General Introduction	“Cancer education resource developed in collaboration with American Indian/Alaska Natives to improve cancer knowledge, action regarding cancer control in tribal settings, and survival rates for members of their communities.”
D. Phase(s) of cancer continuum and types of cancer(s) addressed	Education on cancer/ cancer demographics among American Indian/Alaska Natives and risk reduction/ treatment/ survivorship; all cancers
E. Target populations	<ul style="list-style-type: none"> • Community members, staff of Indian health programs, and Community Health Representatives (CHRs) • Material may also be used for patient/ patient family education
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • Curriculum delivered in 7 30-40 minute modules • 7 modules: (1) overview of cancer among American Indian/Alaska Native, (2) what is cancer?, (3) screening/ early detection, (4) diagnosis/ staging, (5) risks/ risk reduction, (6) basics of treatment, (7) support for patients and caregivers • Adaptable/tailored to learners’ needs • Modules include goals and objectives, pre/post self-assessment, PowerPoint presentation, glossary, references and resource materials
G. Advantages	<ul style="list-style-type: none"> • Train-the-trainer style education takes advantage of existing health care structure and efficiently uses scarce resources by initiating a positive ripple effect; education does not stop at those who attended the workshop (potentially)

	<ul style="list-style-type: none"> • Community oriented approach and adaptability of curriculum to learner needs addresses varying community priorities/ needs • Publication of evaluation report have allowed for efforts to disseminate Cancer 101 as an evidence-based education resource
H. Limitations, disadvantages, or barriers to implementation	<ul style="list-style-type: none"> • Uncontrolled study • Self-selection bias • Narrow evaluation time frame may not have been wide enough to capture all activities/ effects
I. Engagement of Native American communities & enrolment numbers	<ul style="list-style-type: none"> • Community/ American Indian/Alaska Native health organizations engaged in development and implementation • Program offered to all 43 tribes in Pacific Northwest • 79.4% of 101 evaluation study participants were American Indian/Alaska Native; half lived on reserve
J. Overview of processes, discussions and/or negotiations used to implement practice	<ul style="list-style-type: none"> • Details on how workshop students were recruited not included • Modules can be delivered together in a 1 day program, or separately over days/weeks
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • Collaborators include: Cancer Information Service of the Pacific Region (CIS), subcontract with of Spirit of EAGLES (SoE) program (both based at the Fred Hutchinson Cancer Research Center), and the Northwest Tribal Cancer Control Project (NTCCP) at the Northwest Portland Area Indian Health Board (NPAIHB)
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> • 1998: Centers for Disease Control and Prevention (CDC) est. National Comprehensive Cancer Control Program (NCCCP); NCCCP funded NPAIHB to form first tribal cancer coalition; coalition partnered with National Cancer Institute’s CIS and SoE to develop cancer learning tool • 2001: oncology nurse specialist submitted draft of curriculum to NTCCP; reviewed by CIS, SoE, tribal health directors, service unit directors, NTCCP’s Tribal Cancer Control Contacts; survey to identify how curriculum might be improved completed by a CHR, a Tribal Health Director, 7 nurses, 2 physicians, and a building clerk
M. Information being collected in relation to the practice and how this information	<ul style="list-style-type: none"> • Data from pre/post surveys used to assess knowledge, attitudes, perceived benefits and future activities at baseline, immediately post-training, and at 4-6 months

<p>being used.</p> <p>Alternate ways of sharing information used (e.g., stories, videos).</p>	<ul style="list-style-type: none"> Data used in published evaluation study; ongoing feedback used to facilitate participant support by the program
<p>N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible</p>	<ul style="list-style-type: none"> Knowledge scores from pre- to post-exposure changed significantly for all modules except screening/ early detection; likely because evaluation sample suffered from self-selection bias, and many had participated in previous CDC funded National Breast and Cervical Cancer Early Detection Program (they had high pre-test scores) At 4-6 month follow –up 42.1% had conducted an activity in their community and 24.6% were planning an activity Training leaders in cancer control leads to larger community effects; educate and motivate a few to affect many
<p>O. Transferability of practice to communities and/or jurisdictions.</p>	<ul style="list-style-type: none"> Materials are available to all from the website (below); no information on implementation outside of the Northwest, but transferability is likely
<p>P. Contact information.</p>	<p>Cicelly Gabriel Northwest Tribal Cancer Control Project Northwest Portland Area Indian Health Board 527 SW Hall, Suite 300 Portland, Oregon 97201 Phone: 503-228-4185 x319 Fax: 503-228-8182 Email: npaihb@npaihb.org</p> <p>Teresa Guthrie, RN, MN Project Manager, Spirit of EAGLES –American Indian/Alaska Native Leadership Initiative on Cancer Cancer Information Service – Pacific Region Fred Hutchinson Cancer Research Center 1100 Fairview Avenue N., J2-400 Seattle, Washington 98109</p>

Cancer 101 curriculum available at:
http://www.npaihb.org/programs/project/ntccp_cancer_101/

About NCCCP:
<http://www.cdc.gov/cancer/ncccp/about.htm>

(Hill et al., 2010), intro to Cancer 101 http://www.npaihb.org/images/projects_docs/intro.pdf

A. Name/Title of Practice	<p>Native CIRCLE</p> <p>American Indian/Alaska Native Cancer Information Resource Center and Learning Exchange</p>
B. Type of Practice (Leading, Promising or Best Practice)	<p>Couldn't find an evaluation study, but based on the fact that it addresses gaps (cancer knowledge/ risk reduction/ culturally relevant education materials), and reputation of the Mayo Clinic: leading</p>
C. General Introduction	<ul style="list-style-type: none"> • resource center providing cancer-related materials to health care and service providers involved in education, care and treatment of American Indian/Alaska Natives • is the educational arm of the Spirit of Eagles • Mission Statement: <p>“The American Indian/Alaska Native Cancer Information Resource Center and Learning Exchange (Native CIRCLE) exists to stimulate, develop, maintain and disseminate culturally appropriate cancer information materials for American Indian/Alaska Native/Alaska Native educators, health care leaders and students.”</p>
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<p>Awareness and prevention for all cancers</p>
E. Target populations	<p>Community health workers, nurses, physicians etc. that provide services or care to American</p>

	Indian/Alaska Native people
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • Gathers and reviews educational materials from the US and Canada • Distributes (on request) educational material across the US • Part of the Cancer Center at Mayo Clinic • Do not develop original materials, but review available cancer education material for cultural relevance and medical accuracy, making changes where necessary
G. Advantages	<ul style="list-style-type: none"> • Makes use of existing education efforts • Provides a consistent level of quality; Mayo Clinic is a leader in cancer research and treatment • Delivers excellence in both cultural relevance and quality of medical information • Limited quantities of print/CD/DVD material available free of charge on request
H. Limitations, disadvantages, or barriers to implementation	<ul style="list-style-type: none"> • Many Native American communities are rural and suffer from extremely limited health resources (shortages of finances, equipment, and professionals), so urgent care needs overwhelm other health issues • High health provider turnover in Indian Health Service means increased need for staff education- strains resources • Without adequate use of cancer education/ on-going education, learnings from materials/workshops are forgotten
I. Engagement of Native American communities & enrolment numbers	<ul style="list-style-type: none"> • Overseen by Dr. Salmon Kaur, the medical director for Native American Programs at Mayo Clinic's Comprehensive Cancer Center; she is one of two Native American oncologists in the US
J. Overview of processes, discussions and/or negotiations used to implement practice	
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • Established by Mayo Clinic's Comprehensive Cancer in 1999; Native American Program • National Indian Women's Health Resource Center, review materials for appropriateness in different educational settings • Collaborate with Spirit of Eagles program

<p>L. Resources required to develop and implement the practice & history of need and development</p>	
<p>M. Information being collected in relation to the practice and how this information being used.</p> <p>Alternate ways of sharing information used (e.g., stories, videos).</p>	<ul style="list-style-type: none"> • Educational materials are available in a variety of formats (print, audio, video) and at with varying levels of literacy requirement
<p>N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible</p>	
<p>O. Transferability of practice to communities and/or jurisdictions.</p>	<ul style="list-style-type: none"> • Designed to be available/ applicable to diverse communities; as evidenced by materials being collected from/ submitted by regions from all over the US
<p>P. Contact information.</p>	<p>Native CIRCLE Gonda Building - Cancer Education Center 200 First Street S.W. Rochester, MN 55905</p> <p>Telephone: 877-372-1617 Fax: 507-284-1544 E-mail: nativecircle@mayo.edu</p> <p>http://cancercenter.mayo.edu/native_circle.cfm</p> <p>http://www.nativeamericanprograms.org/index-circle.html</p>

A. Name/Title of Practice	
	TAR – Tobacco Addiction Recovery
B. Type of Practice (Leading, Promising or Best Practice)	Promising
C. General Introduction	<ul style="list-style-type: none"> • Program is focused on educating on the difference between traditional and non-traditional tobacco use. • Includes prevention strategies and supports for non-traditional tobacco use.
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Prevention
E. Target populations	<ul style="list-style-type: none"> • First Nations people of all ages
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • Developed many culturally responsive resources which are available online • Program staff travels to communities to deliver a presentation and resources if invited. Presentation include: <ul style="list-style-type: none"> • The Teaching of the White Buffalo Calf • Medicine wheel • The Journey of the White Ribbon – recognition of commercial vs. sacred use • deliver a presentation and leave it with the community in hopes they will continue to use it • can also do a talking circle • Program staff can also train medical staff about smoking cessation and about the culturally responsive tools that are available • there are TAR toolkits available
G. Advantages	<ul style="list-style-type: none"> • Provides support for smoking cessation in a culturally responsive way

H. Limitations or disadvantages - Status of and barriers/successes to implementation	<ul style="list-style-type: none"> • Challenging to make it clear for communities that it is a new message • Go to each community, leave some resources, building up and waiting to be invited
I. Engagement of First Nations, Inuit and/or Métis communities & Enrolment numbers	<ul style="list-style-type: none"> • High smoking rates across Saskatchewan, needed to address smoking rates on reserve (smoking and chewing) • Recognize of the culture and ensured the development of a culturally sensitive and appropriate program and resources • Worked with Elders to develop resources
J. Overview of processes, discussions and/or negotiations used to implement practice	<ul style="list-style-type: none"> • Need to work with communities, will only do a presentation in the community if invited • For the journey of the white ribbon they worked with Elders and pilot tested materials
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • Need to work with communities
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> • Resources are available online • Contact program to invite and they will deliver a presentation – which can be shared and left with community
M. Information being collected in relation to the practice and how this information being used. Alternate ways of sharing information used (e.g., stories, videos).	N/A
N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as	<ul style="list-style-type: none"> • have been to 25 reserves • 50 or so presentations

evaluated by organization responsible	<ul style="list-style-type: none"> • friendship centres • implemented PACT/TAR in curriculum in dentistry, pharmacy and school of public health – 6hr training • Formal evaluation in progress • Note: as smoking cessation is a personal journey ‘quit rates’ are not recorded.
O. Transferability of practice to communities and/or jurisdictions.	<ul style="list-style-type: none"> • Concept is transferable but would need to ensure cultural appropriateness within another context.
P. Contact information.	<p>Janice Burgess 306-586-1700 Janice.burgess@skpharmacists.ca</p>

Screening

A. Name/Title of Practice	Let's Take a Stand Against ... Colorectal Cancer (LTSACC)
B. Type of Practice (Leading, Promising or Best Practice)	Leading
C. General Introduction	<p>Train community educators in order to achieve the following goals:</p> <ul style="list-style-type: none"> • Increase knowledge about colorectal cancer, risk factors, and prevention in Aboriginal communities • Create culturally relevant messages for the population that support and align with ColonCancerCheck (CCC) • Increase the number of Aboriginal people screened for colorectal cancer
D. Phase(s) of cancer continuum and types of cancer(s) addressed	Awareness, screening and prevention of colorectal cancer (CRC)
E. Target populations	<ul style="list-style-type: none"> • Tool kit and train-the trainer workshops aimed at health care and other service providers who work with First Nation, Métis and Inuit people in Ontario on and off reserve/ urban or rural • approximately 1,700 tool kits were directly mailed to health and community service providers and Aboriginal organizations, distributed at conferences, or handed out to workshop participants • training workshops are available to communities on request, where a local partner is identified (typically CHRs, Community Health Nurses or Health Directors)

<p>F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services</p>	<ul style="list-style-type: none"> • tool kit includes: reference manual, facilitators guide, CRC educational playing cards, CRC Signs & Symptoms wheel, posters, & CD with electronic versions of each resource, ready-to-use PowerPoint slide deck, CCC Information Guide and Canada’s Food Guide to Healthy Eating • workshop location/duration/style variable and determined by host community; generally include icebreakers, a PowerPoint presentation, practical hands-on activities, and healthy lunch/snacks • province-wide; Ontario • Developed by Cancer Care Ontario’s (CCO) in association with Canadian Cancer Society (CCS) and The Hôpital regional de Sudbury Regional Hospital (HRSRH) • Workshops facilitated networking/bridging across communities/organizations
<p>G. Advantages</p>	<ul style="list-style-type: none"> • Tool kit resources are sensitive to the cultural realities of First Nations communities; while PowerPoint is more detailed, learning materials feature Aboriginal artwork, and interactive/visual components cognizant of potential literacy barriers • Tool kit is accessible to those rural/remote/isolated • Workshops allow for intercommunity and inter-organization networking • Effective in increasing CRC risk factors, prevention, and screening knowledge in health educators
<p>H. Limitations, disadvantages, or barriers to implementation</p>	<ul style="list-style-type: none"> • Mass mail out of tool kits had mixed success – those received by executive directors/senior level administrators were not passed on; greater utilization when received by those who work with Aboriginal populations • Differences in pre and post-training evaluation prevented meaningful analysis
<p>I. Engagement of First Nations, Inuit and/or Métis communities & Enrolment numbers</p>	<ul style="list-style-type: none"> • Site visits by CCO with 4 First Nations communities, the North Shore Tribal Council, 4 Métis Nation of Ontario Health Branches, and 2 health facilities informed Aboriginal informational needs addressed by LTSACC • Draft material focus groups included representatives from First Nation and Métis communities and Friendship Centers • 26 regional train-the-trainer workshops held, with 378 Aboriginal healthcare providers and educators trained • Evaluation study framework was refined by Aboriginal Cancer and Prevention Team (AC & P) staff, and included interview of workshop participants and also recipient of tool kits

<p>J. Overview of processes, discussions and/or negotiations used to implement practice</p>	<p>(Including Aboriginal and health care organizations)</p> <ul style="list-style-type: none"> • Prior to launch draft material tested in focus groups in 6 representative provincial regions of ONT, and materials/training were piloted in 2 regions • Training promoted by LTSACC tool kit mass mail-out, direct emails, notices on CCO website, and mass media campaign; local partners relied on to promote up-coming workshop within their community • Media campaign – print, radio, and online ads (English and Oji-Cree through <i>Wawatay News</i>); links to LTSACC webpage from partner sites (including National Aboriginal Health Organization)
<p>K. Collaborative relationships, resources or capacity required for development and implementation of the practice</p>	<ul style="list-style-type: none"> • Local partners were integral in organizing and promoting upcoming workshops in their communities • <i>Wawatay News</i>, National Aboriginal Health Organization, Ontario Federation of Indian Friendship Centers and the Aboriginal Nurses Association of Canada hosted links to LTSACC website on their sites
<p>L. Resources required to develop and implement the practice & history of need and development</p>	<ul style="list-style-type: none"> • CCO funded workshop expenses related to travel/mileage, accommodation, meals for participants/co-presenters, as well as facility costs • 2007-2008: \$157,000 spent to support development and pilot implementation, including \$84,000 from First Nations and Inuit Health, Health Canada, \$40,000 from CCO, \$25,000 from the CCS, and \$8000 from the HRSRH Regional Cancer Program • 2008-2011: \$249,500 from Ministry of Health and Long Term Care’s Aboriginal Health Transition Fund (AHTF) used to print LTSACC materials, implementation of print/radio Aboriginal media campaign, staffing of program health educator position, and delivery of workshop training sessions
<p>M. Information being collected in relation to the practice and how this information being used.</p> <p>Alternate ways of sharing information used (e.g., stories, videos).</p>	<ul style="list-style-type: none"> • Survey data from pre and post workshop evaluation for train-the-trainer attendees (on CRC knowledge and program satisfaction) • Key informant interviews of AC & P staff • Survey data from those who received tool kit via mass mail out or on request and did not attend a workshop (including representatives from Aboriginal and health care organizations) • Online survey of both workshop trained and non-trained LTSACC participants

	<ul style="list-style-type: none"> • This data used to inform program evaluation • Alternative sharing includes networking and brainstorming of community education strategies by workshop participants
<p>N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible</p>	<ul style="list-style-type: none"> • There is a demand for cancer education training amongst Aboriginal health care and service providers, and a use for culturally relevant CRC information and materials • “top-down” approach of tool kit distribution (i.e. given to executive directors/senior level administrators did not get passed on); materials effective when placed directly in the hands of those working in the community • Informal workshop format produced high participant satisfaction, increased knowledge, sharing of concrete ideas about how to educate their communities about CRC • online survey respondents: 3 out of 5 reported using LTSACC materials in community education; 60% reached at least 10 community members; 24% reached 75 or more
<p>O. Transferability of practice to communities and/or jurisdictions.</p>	<ul style="list-style-type: none"> • The structure of the program may be replicable (tool kit and workshops), but educational materials must reflect informational/cultural/ language requirements specific to their communities

P. Contact information.

Cancer Care Ontario – Action Cancer Ontario
620 University Avenue
Toronto Ontario,
Canada M5G 2L7
Phone: 416.971.9800
Fax: 416.971.6888

Website:
<http://www.cancercare.on.ca/cms/one.aspx?pagelId=37272>

(Cancer Care Ontario, 2010)

A. Name/Title of Practice	Screening for Life
B. Type of Practice (Leading, Promising or Best Practice)	Leading
C. General Introduction	<ul style="list-style-type: none">• Education resources designed to provide culturally appropriate information on cancer screening to Aboriginal men and women throughout Alberta
D. Phase(s) of cancer continuum and types of cancer(s) addressed	Awareness, screening and prevention of colorectal cancer (CRC), cervical cancer and breast cancer
E. Target populations	<ul style="list-style-type: none">• The resources were developed in partnership with <i>Health Canada - First Nations Inuit Health</i> and other leaders working in Aboriginal Health throughout Alberta.

<p>F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services</p>	<ul style="list-style-type: none"> • Breast Screening toolkit includes: pamphlets, PowerPoint presentation and laminated cards, a breast model, stories, breast health wheels, Canada’s Food Guide, posters, background materials and evaluations pieces. • The colorectal cancer screening toolkit includes: Introduction and background materials, 2 PowerPoint presentations on CD with hard copy speaker notes, resource materials, healthcare worker resources, resource order forms, participant and facilitator evaluation forms, a colon model • The cervical cancer screening toolkit includes: introduction and background materials, 2 PowerPoint presentations on CD with hard copy speaker notes, brochures, posters, a myths & facts sheet, Cervical Clinical Practice Guidelines (CPG), CPG Summary Chart and CPG Wheel for healthcare workers, 2 cancer journey stories, resource order forms, participant and facilitator evaluation forms, a cervical model and pap test supplies
<p>G. Advantages</p>	<ul style="list-style-type: none"> • The toolkits’ resources are sensitive to the cultural realities of First Nations communities; while the PowerPoints are more detailed, the learning materials feature Aboriginal focused interactive/visual components cognizant of potential literacy barriers • Tool kits are accessible to those rural/remote/isolated • Workshops allow for intercommunity and inter-organization networking • Effective in increasing colorectal, cervical and breast cancers risk factors, prevention, and screening knowledge in First Nations men and women
<p>H. Limitations, disadvantages, or barriers to implementation</p>	
<p>I. Engagement of First Nations, Inuit and/or Métis communities & Enrolment numbers</p>	<ul style="list-style-type: none"> • Input into the resources was gathered from Aboriginal men and women through advisory committees, pilot testing, and/or focus groups
<p>J. Overview of processes, discussions and/or negotiations used to implement practice</p>	<ul style="list-style-type: none"> • The breast cancer screening resource toolkit was piloted in several sites to ensure it meets the needs of First Nations and Métis women • The cervical cancer screening resource toolkit was focus tested with the updated brochures to Aboriginal women and Community Health Representatives • The colorectal cancer screening resource toolkit was developed using evaluation results

	from the breast cancer screening resource toolkit and the cervical cancer screening resource toolkit
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • Collaborators include: Alberta Health Services, First Nations and Inuit Health, Alberta Cancer Board, Aspen Health Region, Calgary Health Region, Metis Nation of Alberta and Peigan Health Board.
L. Resources required to develop and implement the practice & history of need and development	
M. Information being collected in relation to the practice and how this information being used. Alternate ways of sharing information used (e.g., stories, videos).	<ul style="list-style-type: none"> • Developed by a committee of Aboriginal health care leaders and Alberta Cancer Board staff • Input from Alberta Health Services and First Nations and Inuit Health collaborators • The kits were piloted in several sites to ensure it met the needs of First Nations and Métis women. In 2010, most of the materials in the kit were updated to reflect the updated Alberta Cervical Cancer Screening Clinical Practice Guidelines released in 2009 • Also updated the kits based on feedback from the Aboriginal breast kit evaluation and colorectal pilot kits
N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible	<ul style="list-style-type: none"> • There is a demand for cancer education training amongst Aboriginal health care and service providers, and a use for culturally relevant cancer screening information and materials
O. Transferability of practice to communities and/or jurisdictions.	<ul style="list-style-type: none"> • The structure of the program may be replicable (tool kit and workshops), but educational materials must reflect informational/cultural/ language requirements specific to their communities and regions

P. Contact information.	Screening for Life Phone: 1-866-727-3926 Website: http://www.screeningforlife.ca/aboriginal/index.html
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A. Name/Title of Practice	The Reproductive Health Screening Project (RHSP)
B. Type of Practice (Leading, Promising or Best Practice)	Leading
C. General Introduction	<ul style="list-style-type: none"> • Purpose: increase women’s access to screening in Northern BC by increasing number of health care providers performing Pap tests, clinical breast exams and breast health education, and by reducing barriers to screening participation
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Recruitment and screening; cervical and breast cancer
E. Target populations	<ul style="list-style-type: none"> • Women in Northern BC communities; higher proportion of women in North are First Nations; under-screened women are over-represented in the North
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • Project trained nurses, at a Northern site, then provided them with support in providing screening services to women in their home communities • Project also trained clinical teaching assistants (CTAs) • BC Women’s Hospital provided training and support for reproductive health screening- Pap test, clinical breast exam and bi-manual exam • Originally 6 intensive days of training; revised in 2002 to be 3 days long to make it more accessible/affordable • Specialized sessions available to nurse practitioners, naturopaths and midwives

	<ul style="list-style-type: none"> • Taught and used women-centred care • 45-minute wellness appointments facilitated the trust/relationship building between community women and nurses; enhanced women’s experience of health services
G. Advantages	<ul style="list-style-type: none"> • Women-centered care addresses barriers to screening; it considers the multitude of factors in women’s lives that affect their health/ their ability to access health services; aims to empower women – all the more important for women to take an active role in their health in North, where health services are more limited • Program targeted cervical health in underserved women, but also served as gateway program; nurses helped women access other health/social services • Cervical cancer screening is cost-effective • Addresses research-supported Aboriginal women’s need for positive relationships with health care providers
H. Limitations or disadvantages - Status of and barriers/successes to implementation	<ul style="list-style-type: none"> • Northern Health has lowest population density of any other health region (307,000 people in an area that covers 2/3s of BC); this makes planning/ delivering any cancer-related services challenging • Barriers to screening include: limited number of doctors, wait times, significant distance/ travel, discomfort, fear, cultural constraints around Pap tests, uninformed about importance/purpose of Pap tests, history of sexual abuse/ violence, lack of confidentiality in small communities, and lack of continuity of care (high physician turnover) • Evaluation is subject to small sample size, bias, and errors associated with self-reporting
I. Engagement of First Nations, Inuit and/or Métis communities & Enrolment numbers	<ul style="list-style-type: none"> • In BC Aboriginals constitute 4.4% of provincial population, but in Northern BC that figure is 15.6% • Trained 44 nurses in 8 Northern communities • Over 130 nurses educated (report unclear on difference between “training” and “education”) • Over 1400 women received Pap tests during 3 year project • Program successful in screening underserved women, such as First Nations (other underserved groups included women from immigrant and religious communities, and younger women)

<p>J. Overview of processes, discussions and/or negotiations used to implement practice</p>	
<p>K. Collaborative relationships, resources or capacity required for development and implementation of the practice</p>	<ul style="list-style-type: none"> • RHSP originally developed by BC Women’s Hospital to address challenges in reaching Aboriginal women with screening • Development through partnership of Northern Health, BC Women’s Hospital and Health Care, and with funding from the Provincial Health Care Transition Fund (PHCTF) from 2003-2006 (\$300, 000) • PHCTF created by federal government in 2000 to support provinces/ territories deliver new approaches to primary health care deliver; BC’s goal was to provide wider range of services at local level • “Partnerships with Carrier Sekani and Babine Nation were key for reaching these First Nations communities, and financial support for training and travel for their nurses (six in total) was provided by their band councils”
<p>L. Resources required to develop and implement the practice & history of need and development</p>	<ul style="list-style-type: none"> • Women in Northern BC have lower participation rates in cervical/ breast cancer screening than rest of BC • First Nations women experience cervical cancer mortality rates 4-6 times higher and screening participation 30% lower than rest of BC; trusting relationship with care provider is a necessary, but missing, element of Aboriginal women’s screening participation
<p>M. Information being collected in relation to the practice and how this information being used.</p> <p>Alternate ways of sharing information used (e.g., stories, videos).</p>	<ul style="list-style-type: none"> • Data collection for evaluation research was mostly qualitative- insights from nurses, CTAs, and patients involved • Evaluation assessed complexity of barriers to cervical screening in Northern BC and determined whether RHSP model addressed them effectively • Qualitative data from surveys/ focus groups/ interviews with nurses and women involved provided information on patient’s experience of the project
<p>N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible</p>	<ul style="list-style-type: none"> • Barriers and not only numerous, but complex and multi-faceted in the North; related to availability of services, women’s discomfort/ fear/ cultural constraints, lack of patient knowledge about cervical health, a history of violence/ sexual abuse; RHSP has reduced these barriers

	<ul style="list-style-type: none"> • Women reported high satisfaction with RHSP services; lengthy wellness appointments helped women feel comfortable and gain knowledge about their bodies/health; as they learned some even began inquiring about mammography services (empowered and taking an active role in their health) • Response to RHSP from nurses, CTAs, doctor, community partners and participating women has been very positive • Program sustainability: nurses need more support for participation in training and also integration of gained screening skills into their already heavy workload; nurses need administrative support (esp. paperwork) so they can focus on service delivery; nurses need more/ongoing education/ training to keep current • Community partnerships/ buy-in is important for program acceptance and sustainability • Cost analysis concluded: expand to 8 more northern communities b/c high patient satisfaction; substantial proportion reached had not been screened in last 5-10 years; many women represent the 29% who are not screened regularly in BC; program can potentially avert cases of invasive cervical cancer, reducing treatment expenditure by \$3.5 million annually; and, costs for health professionals' time is less costly with RHSP • Recommendations include expanding STI component of nurse training
<p>O. Transferability of practice to communities and/or jurisdictions.</p>	<ul style="list-style-type: none"> • Training nurses to perform cervical/ breast screening exams is well documented in the literature as an effective way to address doctor shortages, deliver quality screening, and reach underserved women (particularly First Nations/ Inuit/ Métis/ Native American/ Aboriginal women who can be even more hesitant to access screening from a male provider/ face greater service gaps than women from other groups)
<p>P. Contact information.</p>	<p>Lynda Anderson, Women's Health and Wellness Programs Coordinator, Northern Health</p> <p>Kathy Macdonald, Regional Director of Preventive Public Health, Northern Health</p> <p>Judy Huska, Primary Health Care Transition Fund Coordinator, Northern Health</p> <p>Northern Health, Aboriginal Health Suite 600 - 299 Victoria Street Prince George, BC V2L 5B8</p>

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A. Name/Title of Practice	Feasibility of remote CT colonoscopy at two rural Native American medical centres
B. Type of Practice (Leading, Promising or Best Practice)	Leading

C. General Introduction	<p>Goals:</p> <ul style="list-style-type: none"> • Determine whether adequate examinations can be obtained with remote supervision after a brief onsite training • Share lessons learned with a remote computed tomography (CT) colonoscopy screening program
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Screening; colorectal cancer
E. Target populations	Arizona Native Americans in need of colorectal cancer screening
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • 2 rural Native American medical centres were Fort Defiance Indian Hospital and Tuba City Regional Health Care Centre: 2 rural hospitals with limited availability of optical colonoscopy (OC) and other methods of colorectal cancer screening • Brief onsite instruction included performing a CTC examination on a volunteer to train CT technologists • Both sites performed CTC using standard bowel preparation, fecal tagging, automatic insufflation, and low-dose technique • Studies transferred to University of Arizona Hospital for image quality assessment of stool, residual fluid, distention, and interpretation • Clinical follow-up performed on patents referred for polypectomy or biopsy
G. Advantages	<ul style="list-style-type: none"> • Increases service availability in an underserved area • Facilitates improved urban specialist – rural primary provider coordination • Provides patients with more timely, more culturally relevant (delivered within their community) care, and reduced travel barriers
H. Limitations or disadvantages - Status of and barriers/successes to implementation	<ul style="list-style-type: none"> • Cultural, informational, language, geographical barriers (among others) to participation in colorectal cancer screening still exist, even if it is more available
I. Engagement of First Nations, Inuit and/or Métis communities & Enrolment numbers	<ul style="list-style-type: none"> • 321 patients underwent CTC; 280 of those had been referred for screening examination

J. Overview of processes, discussions and/or negotiations used to implement practice	
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> • Across the US Native Americans suffer a disproportionate burden of colorectal cancer, and Arizona is no exception; increased screening addressing this history of need
M. Information being collected in relation to the practice and how this information being used. Alternate ways of sharing information used (e.g., stories, videos).	<ul style="list-style-type: none"> • Of 321, 295 had acceptable amounts of residual stool, 293 had acceptable levels of fluid, and 294 had acceptable distention • Of 321, 44 had polyps 6mm or larger, with a positive predictive value of 41% for those who received colonoscopy-polypectomy (11)
N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible	<ul style="list-style-type: none"> • “CTC can be successfully introduced to rural and underserved communities, performed locally, and interpreted remotely with satisfactory performance, thereby increasing colorectal cancer screening capacity” • Elements of successful implementation were effective technologist training, referring physician education, careful attention to image transmission, and clearly defined way of communicating with patients and referring health care providers
O. Transferability of practice to communities and/or jurisdictions.	<ul style="list-style-type: none"> • Transferable to other rural health centers with limited access to methods of colorectal cancer screening
P. Contact information.	Arnold C. Friedman Department of Radiology, University of Arizona

1501 N Campbell, Tucson AZ 85724.

(Friedman et al., 2010)

Note: more information on the program is likely available in the above article. I was unable to access the full text.

A. Name/Title of Practice	Messengers for Health
B. Type of Practice (Leading, Promising or Best Practice)	Leading
C. General Introduction	<ul style="list-style-type: none">• Project is based on the Apsáalooke (Crow Indian) reservation, and utilizes a lay health advisor approach to reduce cervical cancer screening barriers, increase knowledge of screening/ prevention , and increase the proportion of Apsáalooke women aged 18 and older receiving Pap• Community-based participatory research model was used; it emphasized community member involvement in all phases of the project
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none">• Recruitment and screening; cervical cancer
E. Target populations	<ul style="list-style-type: none">• Native Americans living on the Apsáalooke (Crow Indian) reservation located in South-eastern Montana; 1991).• About 3300 women age 20 and older reside on the reservation; the number of women ages 18-19 unknown
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none">• 4 year project (2001-2005); project staff worked with women in the region for the first 2 years (development and taking of survey) before the Messengers intervention commenced at the beginning of the 3rd year of the project• In-person survey delivered to 100 randomly sampled women living on/near reservation• Lay-health advisor (LHA) theoretical framework; health advisors (called Messengers in this project) are women from within the community who complete a 2 day training course on cervical health and community outreach• LHA position determined in 3 steps; (1) survey asked women what qualities they value in

	<p>a woman whom they would seek information/support about their health; (2) recommendations solicited from community members in open community meetings – 44 identified; (3) project coordinator individually contacted nominated individuals to see if interested in being Messengers (24 participated in training</p> <ul style="list-style-type: none"> • Messengers provided outreach one-on-one (in Messenger’s home, recipient’s home/work/ etc.) at health fairs, outreach booths, community workshops and school presentations; provided cervical cancer and general health education directly to women (and indirectly to men and youth through these women and various project advertisements) • Messengers received on-going education at monthly meetings and annual retreats)
G. Advantages	<ul style="list-style-type: none"> • Being both trained and lifelong members of the community, Messengers deliver cervical health outreach that is both correct and culturally acceptable
H. Limitations or disadvantages - Status of and barriers/successes to implementation	<ul style="list-style-type: none"> • More than 80% of women surveyed speak Apsáalooke at home; English is a second language and can be a barrier • “Cultural issues, social issues, and economic issues all contribute to a low rate of Pap test screenings”; barriers are numerous and therefore solutions are multifaceted and complex • “in the Apsáalooke culture, many people believe that to say the word ‘cancer’ is asking for the disease to be brought on them” • “modesty, taboos regarding opposite gender medical providers, and traditional healing are cultural beliefs that are maintained in many Native American nation including the Apsáalooke” • Pre and post-data is self-reported; suffers from inflated reporting of screening participation and other self-reporting issues • Negative history between community, researchers and government officials was a barrier • Non-experimental one-group pretest-posttest design means cannot unequivocally say that intervention caused increase in knowledge • Pre-intervention work with the community/ relationship building meant that a randomized control trial was not an option
I. Engagement of Native American communities & enrolment numbers	<ul style="list-style-type: none"> • Project coordinator lives and works on the reserve and is enrolled member of the Apsáalooke tribe; this individual expressed desire to have a cancer project in the

	<p>community – program addressed a health care priority of the community</p> <ul style="list-style-type: none"> • Employed Native undergraduate and graduate students from Montana State University and Little Big Horn College • Staff spend several days each month staying in the community, attending community meetings, serving as a resource, participating in local events and raising general visibility of the project and its team members in order to gain understanding and build trust
J. Overview of processes, discussions and/or negotiations used to implement practice	<ul style="list-style-type: none"> • Montana State University and Apsáalooke community partners began meeting in 1996 to discuss Messenger of health as a potential measure to address cervical health disparity between national averages and those of Northern Plains tribes (which includes the Apsáalooke) • Funding secured in 2001, and project commenced
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • Advisory board created before program-informing survey was developed; board members were male and female health care workers/ physicians/ administrators/ cancer survivors/ women’s health advocates actively involved in target community; board provided input on survey content/ design • 2 project consultants (one Native and one non-Native); they were experts in community-based interventions, cancer, and research with Native Americans; they helped with survey design
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> • Incidence and mortality rates of cervical cancer among Native American women is 2-5 times higher than those of Caucasian women, and mortality rates among Northern Plains tribes women is highest among all Native American women • First phase of the project was the development of a culturally sensitive cervical health survey; it was used to guide the program and ensure benefit to the community
<p>M. Information being collected in relation to the practice and how this information being used.</p> <p>Alternate ways of sharing information used (e.g., stories, videos).</p>	<ul style="list-style-type: none"> • Pre-test (101 women) and post- test (83 of same women) survey gathered baseline information about demographics, beliefs, and understanding about cervical cancer, current health practices, medical experiences and preferences, frequency and history of Pap test, barriers to receiving annual screenings, cervical health risk factors, social support around health issues, and participation in traditional medicine practices • Qualitative measures of success from field notes, meeting minutes, and unsolicited feedback from community members
N. Key learnings or outcomes to date -	QUANTITATIVE EVALUATION:

<p>Evidentiary efficacy or impact, as evaluated by organization responsible</p>	<p>Pretest survey findings:</p> <ul style="list-style-type: none"> • 30% of women did not know of a test to check for cervical cancer • Insufficient knowledge about risk factors like sexual activity at an early age and increased number of sexual partners • Screening participation rates were far below recommended rates (less than 2/3s are being screened on a yearly basis) • Cervical health is not a comfortable topic of conversation with family/ friends/ colleagues • Desired qualities in a Crow woman you would turn to for support/advice? These answers informed recruitment of Messengers <p>Posttest survey findings:</p> <ul style="list-style-type: none"> • Statistically significant increase in pap test and cervical cancer knowledge (increased, but not mastered) • Statistically significant increase in comfort level with discussing cancer issues • Statistically significant increase in number who had heard of a test that checks for cervical cancer, heard about cervical cancer from a source within the community in the past year, and head of Messengers for Health <p>QUALITATIVE EVALUATION</p> <ul style="list-style-type: none"> • More widely accepted than any previous reservation-based research or health project • Acceptance evident in numerous invitations to Tribal Health events/ school fairs etc. extended to Messengers and project staff • Number of community partners has increased over life of the project – growing/ continued acceptance • Increased use of words “Pap test” and “cervix”; breaking down of taboo • Increased participation rates in screening • Increased university and community partner capacity; community members have expressed desire for men’s health program and are now moving to develop one with the university
<p>O. Transferability of practice to communities and/or jurisdictions.</p>	<ul style="list-style-type: none"> • Project investigators credit community-based participatory research approach with the success of the program, and recommend a combination of qualitative and quantitative measures for outcome evaluation; these are principles that can be applied to other

	communities
P. Contact information.	<p>Address correspondence to Suzanne Christopher, Department of Health and Human Development, Montana State University, Bozeman, MT 59717</p> <p>Phone: (406) 994-6321 e-mail: suzanne@montana.edu</p> <p>(for information on training content and evaluation, see Watts, Christopher, Smith, & Knows His Gun McCormick, 2005 – in RefWorks database)</p>
(Smith, Christopher and McCormick, 2004), (Christopher et al., 2008)	

A. Name/Title of Practice	Native Sisters – of The Native American Women’s Wellness through Awareness (NAWWA) program
B. Type of Practice (Leading, Promising or Best Practice)	Leading
C. General Introduction	<ul style="list-style-type: none"> • Culturally relevant patient navigation for Native American women • differs from most navigator programs in that intervention begins at recruitment and screening, as opposed to at diagnosis • Native Sisters are Native American women navigator trained to provide emotional support and advocacy throughout recruitment, screening and follow-up appointments
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Navigation through recruitment, screening and treatment; breast cancer
E. Target populations	<ul style="list-style-type: none"> • Native American women over 40

<p>F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services</p>	<ul style="list-style-type: none"> • Project operated in Denver metropolitan area and Los Angeles/ Orange County area • NAWWA activities: distribution of culturally relevant education materials; free transportation and child care; elder outreach workers; referral-fee vouchers for participants who recruited other women; Native American Breast Cancer Traditional Circle gatherings; appointment reminders; “outcalls” to recruit women over 40; plus navigation by trained “Native Sisters”, who recruit and accompany women to screenings and follow-up tests • Ex. of advocacy: Sisters help patient prepare questions for care provider, and ensure that patient and family understands answers/directives
<p>G. Advantages</p>	<ul style="list-style-type: none"> • Address gap in cancer pathway for Native American women: low screening participation rates • Builds trust/relationships and then delivers information/care in a culturally relevant way; leads to greater adherence • Approximately 90% of NAWWA participants are being rescreened at recommended intervals
<p>H. Limitations, disadvantages, or barriers to implementation</p>	<ul style="list-style-type: none"> • psychosocial barriers: fear/distrust, incorrect belief systems (ex. cancer means certain death; nothing can be done about it; mammograms cause cancer) • psychocultural barriers: culturally/tribally specific (ex. Native Americans don’t get cancer, if they do it’s a punishment from the creator; or cancer is spread by white doctors; discussing cancer invites it) • high turn-over rate of Native Sisters results in high navigator training costs
<p>I. Engagement of Native American communities & enrolment numbers</p>	<ul style="list-style-type: none"> • all Native Sisters are of Native American heritage • navigator duties include preparation of monthly meeting agenda that is discusses with the Chair of the Elders Standing Committee; discuss services being offered through NAWWA
<p>J. Overview of processes, discussions and/or negotiations used to implement practice</p>	<ul style="list-style-type: none"> • 1995–1996: Linda Burhansstipanov, M.S.P.H., Dr.P.H. at AMC Cancer Research Center in Denver, Colo., implemented and evaluated the effectiveness of NAWWA – a variety of low and high-level recruitment strategies were used, and Native Sisters (high-level) was most effective in terms of participation rates and appointment attendance • Promotion activities include info booths at health fairs and Pow Wows (often with mobile screening van on-site)

<p>K. Collaborative relationships, resources or capacity required for development and implementation of the practice</p>	<ul style="list-style-type: none"> • NAWWA program was executed in collaboration with AMC Native American Program of Excellence and the Denver Indian Center (DIC), and the Center for Healthy Aging (CHA)
<p>L. Resources required to develop and implement the practice & history of need and development</p>	<ul style="list-style-type: none"> • Grant funding from Avon Breast Health Fund, The Hearst Foundation, Kenneth Kendall King Foundation, Blue Cross/Blue Shield Foundation, A.V. Hunter Trust, Colorado Cancer League, Robert Wood Johnson Foundation, Susan G. Komen Breast Cancer Foundation, AVON Breast Cancer Leadership Award
<p>M. Information being collected in relation to the practice and how this information being used.</p> <p>Alternate ways of sharing information used (e.g., stories, videos).</p>	<ul style="list-style-type: none"> • Recruitment-participation rates; appointment attendance rates; responsiveness to various recruitment strategies
<p>N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible</p>	<ul style="list-style-type: none"> • High-level strategies produced double the participation rates as low-level • Appointment “no shows” when low level strategies used were 50-80%, and less than 20% for high-level interventions • Most effective high-level strategies: Native Sisters, appointment reminder call, culturally relevant information and outcalls (script for unsolicited calls) • Recruitment vouchers yielded little success • Making positions salaried is key to stability
<p>O. Transferability of practice to communities and/or jurisdictions.</p>	<ul style="list-style-type: none"> • Transferable to various cultural/ethnic groups, but the isolation and dispersion characteristic of rural populations may impede number of women reached by a Native Sister in rural settings • Need for earning trust and building relationships to facilitate knowledge dispersion and screening/treatment participation is a well-documented element of success in health initiatives with Indigenous people of North America and Australia • Navigation is a model of care with documented success; results of Native Sisters adds to this body of evidence

P. Contact information.

Linda Burhansstipanov, M.S.P.H., Dr.P.H.
(303) 838-9359

(Burhansstipanov et al., 1998)

A. Name/Title of Practice	
	Native Women Enjoying the Benefit (WEB)
B. Type of Practice (Leading, Promising or Best Practice)	Leading
C. General Introduction	For little or no charge, nurses at tribal, urban Indian, and Indian Health Service (IHS)-operated clinics are trained to conduct breast and cervical screening exams, test for sexually transmitted infections (STIs), and to promote importance of early detection and follow-up.
D. Phase(s) of cancer continuum and types of cancer(s) addressed	Improve breast and cervical cancer screening participation and follow-up
E. Target populations	Trains nurses who serve Indigenous Americans (American Indian/Alaska Native) on or off reserve
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none">• this a continuation of the Nurses Providing Annual Cancer Screening (NPACS) program• Nurse undertakes 40 hours of intensive on-site training to learn to 1) conduct breast and cervical screening exams and screen for STIs; 2) develop/use patient tracking/reminder systems; 3) educate community/patients about breast and cervical cancer, STIs and screening; 4) provide gender/culturally appropriate care; 5) use continuous quality improvement to operate a “Well Woman Clinic”• Program delivered across the US• Upon knowledge and skill demonstration, nurses receive Native WEB endorsement/approval• Refresher courses are available• Program also trains CHRs to perform outreach and education

G. Advantages	<ul style="list-style-type: none"> • Post-training knowledge and skills are significantly greater and substantial changes in pre to post training behaviors • Increased routine screening for breast and cervical cancer will lower mortality from these diseases; it addresses survival rate disparity in Native American women • Meets cultural preference for female care providers • Nurses are more likely to be long-term residents and/or members of communities they serve than physicians • Addresses need for expanded roles for nurses/physician assistants/technicians where physician shortages exist
H. Limitations, disadvantages, or barriers to implementation	<ul style="list-style-type: none"> • While knowledge and skill improvement was significant, curriculum mastery was not attained • Additional study needed to validate nurse’s perceptions of increased screening numbers
I. Engagement of Native American communities & enrolment numbers	<ul style="list-style-type: none"> • 1995-2000 (more recent data lacking): 131 nurses serving American Indian/Alaska Native/Pacific Islander populations in 33 sites trained in group sizes ranging from 1 to 11 • Overseen by Dr. Salmon Kaur, the medical director for Native American Programs at Mayo Clinic’s Comprehensive Cancer Center; she is one of two Native American oncologists in the US • Training Native American nurses mentioned (number not given)
J. Overview of processes, discussions and/or negotiations used to implement practice	<ul style="list-style-type: none"> • Out of respect for culture and tradition, Native WEB does not advertise itself, but offers services as American Indian/Alaska Native community leaders request them • Ongoing promotion through annual educational networking conferences for nurses/others trained by Native WEB
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • Origin: 3 year (1995-1998) Centers for Disease and Control-funded national program; the (NPACS) program • Housed by Mayo Clinic’s Comprehensive Cancer; Native American programs • Partnered with Spirit of Eagles in 2000
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> • Supported through Population Sciences Portfolio of Mayo Clinic Cancer Center under the Prevention, Detection and Control Program • Seeks outside grant support (ex. In 2001 received \$50,000 award from National Alliance of Breast Cancer Organizations) • Conducts training for CDC-funded programs

	<ul style="list-style-type: none"> • Averages < \$10, 000/clinic ; \$6000 < per nurse basis < \$8000 (including program staff salaries and other expenses) • Clinics with Native WEB trained nurses can serve 140, 000 women 16 years old or older; resulting per patient costs are \$5 - \$10
<p>M. Information being collected in relation to the practice and how this information being used.</p> <p>Alternate ways of sharing information used (e.g., stories, videos).</p>	<ul style="list-style-type: none"> • Post training knowledge and skill demonstration (required for WEB endorsement) • Evaluation of program via telephone interview/survey format; revealed substantial increase in screening promotion efforts • Currently developing e-tracking system to measure women’s screening participation at Native WEB clinics; will produce longitudinal data on potential to decrease mortality rates
<p>N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible</p>	<ul style="list-style-type: none"> • increased levels of clinic commitment to breast and cervical screening post Native WEB training • physician support for nurse training rated high • Clinics with WEB trained nurses: patients demonstrate improved awareness, willingness to be screened, and increased screening uptake
<p>O. Transferability of practice to communities and/or jurisdictions.</p>	<ul style="list-style-type: none"> • Highly transferable; International literature supports the feasibility/ value of training nurses to perform screening
<p>P. Contact information.</p>	<p>Mary Alice Trapp, RN Telephone: 507-284-1075 or Ann Nicometo, Program Coordinator 507-284-4575 Fax: 507-266-2478 E-mail: mtrapp@mayo.edu Native WEB Native American Programs 200 1st ST SW Rochester, MN 55905 http://www.nativeamericanprograms.org/index-web.html</p>

(Petersen, Trapp, Fanal, & Kaur, 2003), (Petersen, et al., 2002), (Sellers, et al., 2002)

A. Name/Title of Practice	Improving cervical screening in a remote aboriginal community- Anangu Pitjantjatjara (AP) Lands
B. Type of Practice (Leading, Promising or Best Practice)	Leading
C. General Introduction	<ul style="list-style-type: none"> Improved cervical screening identified as a priority by women within the target population (program centred around community goals) Program developed to make a measurable difference; increase availability and cultural relevance of cervical cancer screening and raise participation rates
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> Screening; cervical cancer
E. Target populations	<ul style="list-style-type: none"> Aboriginal women eligible for cervical cancer screening and living on Anangu Pitjantjatjara (AP) Tribal Lands
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> Nganampa Health Council (NHC – an Aboriginal - controlled medical service meeting the health needs of Aboriginal people living on the Lands) methodology used in this project: based on community participation model consulted key informants during project development; female Aboriginal health workers and non-Aboriginal staff working for NHC <p>Process of development in 6 stages:</p> <ol style="list-style-type: none"> (1) consultation to identify health issues and ways to address them (2) literature review (3) prioritization of health issues by NHC staff and health workers (4) program development – framework of goals, objectives and strategies (5) program reviewed by participants (Aboriginal health workers and NHC staff) (6) meeting to plan implementation with health workers and midwives <ul style="list-style-type: none"> On the Lands, reminders about cervical screening often given outside clinic in a private conversation with woman concerned Cervical screening incorporated into routine health care; in-file reminder system used

	with good practitioner response
G. Advantages	<ul style="list-style-type: none"> • program strategies chosen by members of target population; culturally relevant • community was involved at every step of program development; goals and strategies reflect community priorities and capacity to address them
H. Limitations or disadvantages - Status of and barriers/successes to implementation	<ul style="list-style-type: none"> • role of Aboriginal health workers on AP Lands was unclear; many trained to perform cervical smears, but few are carried out (unacceptable for some women to receive exam from Health Worker)
I. Engagement of Aboriginal or Torres Strait Islander communities & enrolment numbers	<ul style="list-style-type: none"> • Female Aboriginal health workers chosen as key community informants for their expertise in Aboriginal women’s health and their seniority community
J. Overview of processes, discussions and/or negotiations used to implement practice	
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • 1996, NHC commissioned a women’s health project; aim was to identify health needs of women on the Lands and plan an integrated program addressing those needs
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> • Program authorized by NHC and funded by the Department of Health and Family Services • Anangu Pitjantjatjara (AP) Lands in the north-west of South Australia identified cervical cancer as one of a number of women’s health issues to be prioritised in a Women’s Health Program • “In the Northern Territory 1987-93, Aboriginal women had three times the age adjusted incidence of cervical cancer compared with non-Aboriginal women (32.6 new cases per

	<p>100,000 population compared with 11.7) and 12 times the age adjusted death rate (33.5 deaths per 100,000 population compared with 2.4). In South Australia, though based on smaller numbers, the age standardised annual death rate due to cervical cancer is higher for Aboriginal women (5.3 per 100,000 in Adelaide, 29.7 in country regions) compared with non-Aboriginal women (2.3 per 100,000 in Adelaide, 2 in country regions).”</p>
<p>M. Information being collected in relation to the practice and how this information being used.</p> <p>Alternate ways of sharing information used (e.g., stories, videos).</p>	<ul style="list-style-type: none"> • Information collected used to evaluate program based on scientific validity, practicality, and sustainability on AP lands and cultural acceptability
<p>N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible</p>	<ul style="list-style-type: none"> • importance of health promotion and the vital role of community Health Workers are supported in the literature • trust in a stable understanding staff vital to successful cervical screening • training of non-Aboriginal staff in cultural issues seen as essential • care providers/staff desire moving to a more comprehensive computer system to support recall systems • potential for improving smear quality by using Thinprep technology • “it is appropriate to consider programs and strategies which, if developed using an appropriate model of community empowerment and incorporating practical, effective interventions, are likely to impact positively on the health issues identified”
<p>O. Transferability of practice to communities and/or jurisdictions.</p>	<ul style="list-style-type: none"> • “While the strategies are those selected by women of the AP Lands, and therefore specific to this situation, the process by which this program was developed may have relevance for other Aboriginal communities”
<p>P. Contact information.</p>	<p>Dr. Jennifer Reath, Royal Australian College of General Practitioners Training Program, PO Box 197, North Ryde. NSW 2113</p>

(Reath & Underwood, 1998)

A. Name/Title of Practice	
B. Type of Practice (Leading, Promising or Best Practice)	Northern Territory Breast Screen (NTBS) Promising
C. General Introduction	<ul style="list-style-type: none"> • NTBS is part of the national screening program, Breastscreen Australia • NTBS operates in area lowest population densities in Australia; it is remote from centres of specialized expertise in mammography screening
D. Phase(s) of cancer continuum and types of cancer(s) addressed	Screening; breast cancer
E. Target populations	<ul style="list-style-type: none"> • Residents of the “top end” of Northern Territory (Darwin urban and rural areas, and East Arnhem); relatively small population with a highest proportion of Aboriginals in Australia (most live on tribal lands)
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • Evaluation study undertaken in Darwin from December 1994 to May 1996 during program’s initial 18 months • Free mammographic screening available to all women 40-75 years old • Health promotion strategies directed at target group (50-69 year old women) • 2 yearly mammograms for high risk minority • Screening by mammograms in 2 views; read by 2 qualified readers • Abnormalities followed up at assessment clinics staffed by team including radiographers, radiologist, surgeon, pathologist and counselor • During time of evaluation, mobile screening was not available, and so screening was opportunistic; attempted to screen women when they were in Darwin for other reasons → then in 1996 mobile unit became available in Alice Springs, Katherine, Tennant Creek, and Nhulunbuy (but evaluation data just from Darwin)
G. Advantages	<ul style="list-style-type: none"> • Recognizes conditions in which isolated services operate, while striving to not allow quality of service provision to be compromised
H. Limitations or disadvantages - Status of and barriers/successes to implementation	<ul style="list-style-type: none"> • challenges to program success include small and dispersed population, lack of local radiologists with mammographic experience, and conflict with other pressing health

	<p>issues (particularly in Aboriginal communities)</p> <ul style="list-style-type: none"> • identification of indigenous women relies on self-identification; unlikely that every Aboriginal and Torres Strait Islander self-identified by filling out the necessary form • small sample size of practitioner and client questionnaires may be a source of bias • increasing access is associated with decreasing cost effectiveness in small, remote, widely dispersed populations: policy/ resource allocation barrier • disparity in Aboriginal screening participation is evidence of barriers that have yet to be addressed
I. Engagement of Aboriginal and Torres Strait Islanders communities & enrolment numbers	<ul style="list-style-type: none"> • Screening numbers: 60% of 40-49 target captured, 96% of 50-69 target, and 110% of 70+ group screened • 5% of women screened self-identified as Aboriginal or Torres Strait Islander (proportion of NT population is 10 – 12%) • During 18 month evaluation study 2882 mammograms performed; 98 recalled for assessment ; and, breast cancer found in 10 women
J. Overview of processes, discussions and/or negotiations used to implement practice	<ul style="list-style-type: none"> • NT care providers/ administration negotiated with BreastScreen Australia to ensure that NTBS addressed the unique needs of the NT; achieved compromise on balance between equity of access to services for women in NT and the question or relevance to Aboriginal women living in remote communities • Negotiated to have 10.8% of screening funds diverted to Well Women’s Programs to increase generic health checks for Aboriginal women
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • Territory Health Services Women’s Cancer Prevention Programs assisted with data collection
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> • Funding through cost-shared arrangements between the Commonwealth and NT Governments
M. Information being collected in relation to the practice and how this information	<ul style="list-style-type: none"> • Information collected for evaluation includes number of women screened, proportion of Aboriginal participants, client and provider satisfaction, incidence rates, and result wait

<p>being used.</p> <p>Alternate ways of sharing information used (e.g., stories, videos).</p>	<p>times</p>
<p>N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible</p>	<ul style="list-style-type: none"> • program was successful, which implies mammography screening programs in isolated areas can function effectively • demonstrated that Aboriginal women participated in mammography at half the rate of non-Aboriginal women and therefore recruitment in their population is of interest → especially since NT data shows that incidence rates in Aboriginal women for breast cancer is less than half that of non-Aboriginal, however experience similar death rate from breast cancer (note: data may be outdated/ inaccurate and underestimate Aboriginal cancer) • Waiting time for results and frequency of assessment clinics: monthly clinics meant women in NT waited relatively long time for screening results (not enough volume to justify more frequent clinics) • on average 25% received results within 10 working days (BreastScreen Australia’s performance requirements are that 95% of women should be notified of the results of screening with 10 days of screening) • Recall rates: BS Australian performance requirement: assessment recalls for less than 10% of women in 1st round of screening; observed: 3.4% • Cancer detection rates: no statistically significant difference from performance objectives • Client satisfaction: very high; rated reception staff as helpful/very helpful, information leaflet as clear/very clear, radiographer’s explanation clear/very clear, vast majority of mammograms were ranked as only uncomfortable/mildly painful, but overdue results did cause some anxiety • General practitioner/ DMO satisfaction: half were very satisfied, 31% satisfied, 10% neutral, 5% very dissatisfied • Recommendation: “Aboriginal women should be included in the process of identifying Aboriginal priorities for cancer prevention and screening.”
<p>O. Transferability of practice to</p>	<ul style="list-style-type: none"> • Constraints faced by NTBS are shared by similar programs, so measures taken to reach

communities and/or jurisdictions.	underserved/ Aboriginal women may be transferable <ul style="list-style-type: none"> Clearly though, additional measure need to be taken to increase Aboriginal screening participation rates; program may have lacked cultural relevance
P. Contact information.	Dr. Marg McLean, Regional Public Health, Private Bag 31907, Hutt Hospital, Lower Hutt, New Zealand Fax: +64 4 570 4405 e-mail: Margot.McleanQhvh1.co.nz

(McLean & Condon, 1999)

A. Name/Title of Practice	
Interactive Voice Response (IVR) cervical screening brief advice interface	
B. Type of Practice (Leading, Promising or Best Practice)	Promising
C. General Introduction	<ul style="list-style-type: none"> “IVR is a telephone interviewing technique where the human speaker is replaced by a high-quality recorded interactive script to which the respondent provides answers by pressing the keys of a touchphone.”
D. Phase(s) of cancer continuum and types of cancer(s) addressed	Screening; cervical cancer
E. Target populations	<ul style="list-style-type: none"> Under-screened (lower than recommended participation rates in Pap tests) women of all ages and backgrounds
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> This system implemented as a pilot study in September 2000, in Cessnock, New South Wales (NSW) “IVR system contacted randomly selected households ... and delivered a cervical screening brief intervention. A follow-up CATI (computer assisted telephone interview) was used to assess the intervention.” IVR intervention: (1) according to woman’s pap status an appropriate message was played; (2) under-screened women offered messages addressing barriers (could listen to 0 or more); (3) demography questions asked; and (4) additional information addressing barriers, offer of contact telephone numbers, and the offer of having someone call back (woman could record a question if she wanted) given

	<ul style="list-style-type: none"> • Follow-up CATI survey: delivered 1 month later
G. Advantages	<ul style="list-style-type: none"> • The under-screened were over-represented among interface users • compared to mailed pamphlets: less expensive, more often used, and also accurately recorded the number who listened without expensive follow-up; call charge/participant was \$2,178/661=\$3.30 (500 called, 4492 answered, and 661 listened at least as far as entering Pap status) → equivalent mail-pamphlet project was \$1.96 per household and only 4.1% diaries were used, costing \$1.96/ 4.1%=\$47.80 per completed diary • IVR has potential to be linked to Pap Test Register database to issue reminders in the same manner postal reminders • “IVR could enumerate the contacts made, unlike other methods such as radio broadcasts, where reach is unknown” • Literature suggests that Native American and Aboriginal women have a high need for privacy and sensitivity around cervical health, lack information about the purpose/ importance of Pap tests, face numerous barriers, and that Pap test reminders significantly increase screening rates; IVR interface may address some of these needs
H. Limitations or disadvantages - Status of and barriers/successes to implementation	<ul style="list-style-type: none"> • Drawbacks: phone required, and a consistent phone number
I. Engagement of Aboriginal and/or Torres Strait Islander communities & Enrolment numbers	<ul style="list-style-type: none"> • demographic of this study, although not all Aboriginal, Aboriginals were over-represented in sample (i.e. they used the interface more) • 549 (12%) women listened to the IVR call and 587 (59%) completed the CATI interview
J. Overview of processes, discussions and/or negotiations used to implement	<ul style="list-style-type: none"> • Approval was obtained from University of Newcastle and Hunter Area ethics committees • Information letters mailed one week beforehand explained the project aims and gave

practice	advance notice of the IVR call
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • Funded by grants from Hunter Medical Research Institute and University of Newcastle and from operating funds of the Hunter Center for Health Advancement • Pilot study forms part of doctoral studies of Ross Corkrey, who was supported by an Australian Postgraduate Scholarship
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> • Pap tests are key to reducing cervical cancer; programs promoting Pap tests designed to overcome barriers at all levels are needed • “Previous work by these authors has shown that interactive voice response (IVR) can be used to ask sensitive questions about health behaviours”
M. Information being collected in relation to the practice and how this information being used. Alternate ways of sharing information used (e.g., stories, videos).	<ul style="list-style-type: none"> • IVR call collected Pap status, demographics, if recipient answered, and if they did, at which point listener hung up • CATI survey asked why/why did not participate, acceptability of campaign components (Pap status, demography, informational messages); women who did not listen to IVR call offered another opportunity
N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible	<ul style="list-style-type: none"> • results: easy to use/answer, users thought it was a good idea, under screened and older women used the system more • successfully used by larger number of women, with higher use by recognized risk groups • might be useful to increase cervical screening rates since those at greatest risk used it most • under screened women’s most commonly selected barrier: embarrassment • under screened women more likely to listen to information messages than the correctly screened (statistically significant) • no conclusion as yet if this affected screening rates – future research
O. Transferability of practice to communities and/or jurisdictions.	<ul style="list-style-type: none"> • Use of telehealth tools have been used with documented success in other states, and other countries; this suggests that IVR interface is also transferable
P. Contact information.	Correspondence to:

Dr. Lynne Parkinson, Centre for Research and Education in Ageing, University of Newcastle,
 level 2, David Maddison Clinical Sciences Building, Watt Street, Newcastle, New South Wales
 2300
 Fax: (02) 4923 6323
 e-mail: Lynne.Parkinson@newcastle.edu.au

(Corkrey et al, 2005)

I. Name/Title of Model	
	CancerCare Manitoba BreastCheck, Mobile Breast Screening
II. Type of Model (Leading, Promising or Best Practice)	<ul style="list-style-type: none"> • Leading
III. General Introduction	<ul style="list-style-type: none"> • Mobile breast screening services for rural and northern communities to improve screening access.
IV. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Screening
V. Target populations	<ul style="list-style-type: none"> • All women 50-69 living in rural and northern communities in Manitoba • The mobile also targets specific communities in Winnipeg – within these communities, the women who are underscreened are targeted
VI. Program/ service/ resource history of need and development	<ul style="list-style-type: none"> • Model designed to address a gap in access to breast screening for women living in rural and northern communities. • Prior to the implementation of the mobile unit in 1998 it would have been necessary for women to travel to the south to access breast screening. A permanent site in Thompson, MB was established in March 1998. • The mobile unit travels in a van to communities and is set up in a community location that meets the requirements for the mammography machine and the privacy and wellbeing of the women to be screened.
VII. Engagement of First Nations, Inuit and Métis & Enrolment numbers	<ul style="list-style-type: none"> • The initial program was designed for all Manitoban women and was not First Nations specific

	<ul style="list-style-type: none"> • The program worked with one First Nations, on-reserve community and developed a First Nations specific resource. • This resource is now being sent out in place of the standard breast screening information in the invitation letter to women eligible for screening living in known First Nation communities.
VIII. Description of Model: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • The Manitoba Breast Screening program (MBSP) was established in 1995 to provide free breast screening to Manitoba women 50 to 69 years of age. • In 1998 mobile services were made available to rural and northern communities to improve screening access. In September 2008, Manitoba Health removed the upper age limit for breast screening and now eligible woman 50 years of age and over are welcome to attend. • The goal is to reach 70% of the population of women 50 to 69 years of age. Community and Regional Health Authority assistance are required to find a suitable location, promote screening and find volunteers when needed. • The mobile unit is a special van that is driven to communities. The mobile screening unit consists of: a mobile unit, a portable dark room, x-ray film, DVD player, signs, literature, and teaching tools.
IX. Barriers to implementation	<ul style="list-style-type: none"> • Can be challenging to recruit women to participate in screening in some communities. • Is no clear way to identify First Nations populations from screening lists. • Postal codes can be used in some areas as a proxy to help identify First Nation populations based on the knowledge of where First Nation communities are both on and off reserve.
X. Key learnings, evidentiary efficacy or impact	<ul style="list-style-type: none"> • Detailed data including the number of women eligible for screening, the number of women expected to attend screening and the number of women to do attend screening is documented community by community using postal code FSA's • The screening program also monitors who is non-responsive to screening invitations.
XI. Contact information.	<p>BreastCheck 25 Sherbrook St, Unit 5 Winnipeg, MB R3C 2B1 Monday - Friday, every second Saturday call to confirm.</p>

8:00 AM - 5:30 PM
Closed holidays
E-mail:
breastcheck@cancercare.mb.ca
Appointments:
(204) 788-8000
1-800-903-9290
Administration:
(204) 788-8633

XII. Source

http://cancercare.mb.ca/home/prevention_and_screening/

System Change

I. Name/Title of Model	Aboriginal Women’s Cancer Care Project (AWCCP): an example of the Participatory Research Model in action
II. Type of Model (Leading, Promising or Best Practice)	Leading
III. General Introduction	<ul style="list-style-type: none"> • AWCCP used a participatory action research (PAR) model guided by an Aboriginal advisory group • AWCCP was designed to increase understanding of the intersection of culture, identity, and health systems in Aboriginal and Native American women’s experience of and access to cancer care • Investigating health and cancer beliefs, decisions, and health care experiences of Canadian Aboriginal and Native American women with breast and gynecological cancer • AWCCP: exploratory qualitative study • Goal of PAR: improve participant lives through structural change
IV. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Research; breast and gynecological cancer
V. Target populations	<ul style="list-style-type: none"> • Canadian Aboriginal and Native American; women; on and off-reserve
VI. Program/ service/ resource history of need and development	<ul style="list-style-type: none"> • Publication submitted from Wilfred Laurier University, Department of Psychology, CAN • AWCCP supported by grant from Canadian Institute of Health Research • AWCCP part of a larger study: “Intersecting Vulnerabilities of Women With Breast and/or Gynecological Cancers: Gender, Age, Income and Aboriginal Identity” (coprincipal investigators are T. Mitchell, M. Fitch, and C. Sinding)
VII. Engagement of First Nations, Inuit and Métis & Enrolment numbers	<ul style="list-style-type: none"> • Members of the research population were involved at all stages of research process • Of 2 coprincipal investigators, one is a Native American

	<ul style="list-style-type: none"> • Study’s project coordinator is Aboriginal • Advisory groups is made up of 6 individuals from 5 culturally and geographically different communities; Inuit, Mohawk, and Ojibway • 5 locations included 2 reservation communities, an off-reserve urban population, and Inuit women travelling from their northern communities for urban health services
<p>VIII. Description of Model: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services</p>	<ul style="list-style-type: none"> • “PAR methods are viewed as appropriate and increasingly essential in conducting research with vulnerable, hard to reach, or medically underserved populations; research values are empowering and restorative and because of the explicit commitment that the outcomes should benefit the participants and/or their communities” • Study involved “in-depth, individual, open-ended qualitative interviews with 6 cancer survivors, 2 family members, and 2 health care practitioners in each community” <p>Challenges and strategies used to address them:</p> <p>Challenge: <i>Identity and Subject Location: Two Voices</i></p> <ul style="list-style-type: none"> • “challenges ... for entry and acceptance of non-Native researchers” and “identity, trust, and entry issues experienced by Aboriginal and Native American researchers has rarely been acknowledged” • Non- native author: issues of history, identity, voice, oppression, resistance, and transformation are constant; have been welcomed/scorned, trusted/mistrusted, often in cyclical patterns that resonate strongly with potent histories rather than personal acts or contemporary relations • Aboriginal author: hypervigilance in both academic and Aboriginal research communities; constant balancing act that leaves little room for error and even less space for both worldviews to play out successful <p>Strategy:</p> <ul style="list-style-type: none"> • Partnership of a Non-Native and a Native American coprincipal investigator; Intercultural partnership provides perspective and support when faced with challenges related to race and ethnicity

- “Making the tensions conscious and sharing them first with each other and then with the research community is a strategy to address the inherent challenges of conducting research in Native American and Canadian Aboriginal communities”
- PAR and OCAP principle offer challenges to researchers, but also produce significantly more credible and beneficial research by, for and about communities/ individuals

Challenge: *Developing Community Research Partnerships*

- Many granting agencies, universities, Aboriginal and Native American communities are striving to est. best practices of research, but guidelines/published accounts of experience in conducting research in this context are limited
- Every community approached by AWCCP has specific ethics protocols for conducting research, as did manner in which researcher is to approach community
- Some required consult health advisory board first, others required approach band council first- and if done in the wrong order suspicion of trying to circumvent ethics process – even with eventual approval it took concerted effort to re-establish any trust

Strategy:

- Developed and submitted 6 ethics research protocols: 1 per community or institutional partner (universities, college health sciences center, First Nation, Aboriginal research institute, and a reserve)
- Patience and flexibility: 2 weeks, 2 months, or 2 years to review, and not at all for reserve community

Challenge: *Individual or Community: Who Has the Authority to Give Consent?*

- Experienced direct conflict between principles of OCAP and the laws and values of the community partners with the individual wishes of community members
- Individuals- concerned about their own autonomy and rights being suppressed for the “good” of the community
- Conventionally consents is established with individuals- but in this study, acknowledged sovereignty of communities by not interviewing individuals within communities that did

not provide ethics approval

- Research challenge: several individuals (cancer survivors, a family member, and a healer) questioned decision to abide by decision of their community's ethics council

Strategy:

- Advisory group guided researchers to respect sovereignty and governance of local community by not interviewing cancer survivors off reserve – this did not diminish individual survivors feelings of being excluded/silenced
- Do not believe academic/research community should try to circumvent these issues, which are the domain of the communities themselves – although conundrum of individual versus community consent needs to be acknowledged/respected

Challenge: *Privacy and Confidentiality of Data*

- Protection of participants' rights to privacy and confidentiality – of concern because increasing demand by band councils in CAN and tribal groups in US to have access to and possession of all raw data (as per OCAP)
- Management of confidential highly sensitive cancer experience is serious responsibility of researchers
- Data storage must be agreed upon and written consent obtained from each participant

Strategy:

- Community explicitly requested to store all raw data in community archive – solution: negotiated middle ground
- First- researcher must establish understanding of right to access and ownership, but raise concern that storage of confidential data must be choice of individual participants
- Despite OCAP, some people may not wish to have personal transcripts stored in their community
- Access to data was stage dependent – ownership remained with participants
- The following approach was accepted by participating communities:

1) Raw data → access only to interviewer, transcriber, participant and primary investigator

2) Secondary data → any identifying markers removed through process of member checking (interviewer, with participant, check for correctness and privacy)

3) Marker removed data → accessed by larger research group

4) Third stage: data analyzed and thematically organized into findings → accessible to advisory group, the Aboriginal community (including chief and council), and larger research community
Challenge: *Research Takes Time*

Example:

- Researcher made contact with community Aboriginal cancer support group in 2001 on a reservation; support group met with researcher on and off reserve and expressed desire to share survival and hope with other communities
- They discussed conducting interviews – researcher attended meetings regularly over a period of 18 months, obtained funding and ethics approval from her university, and had explicitly asked during first and subsequent survivor meetings if she needed permission of chief/council and was told no
- 18 months in, funding in hand, ethics approval from university, had not collected any data, was abruptly told at community meeting that she had breached all research protocols and must now seek approval from the community ethics review council before proceeding (found this out when returning to collect signed ethics/consent forms from survivor group)
- Approval was withheld and original group that inspires AWCCP had to be omitted from the study

Strategy:

- Start from beginning to redress any perceived or actual breaches of protocol

	<ul style="list-style-type: none"> • Established Aboriginal advisory group (representatives from 6 communities, including 2 from survivor group’s community, which included one survivor support group member) • Time remains a challenge- lots of work, but still small sample sizes • In 2 ½ years: 10 research participants (not including original survivor group members- who weren’t interviewed), developed advisory committee, obtained 6 ethics approvals, developed partnerships with 2 reservation communities → significant achievements in building the foundation for ethical and successful research partnerships • Research partnerships formed with Canadian Aboriginal and Native American communities rather than with individuals or groups – these partnerships are consistent with ethical demands of OCAP
<p>IX. Barriers to implementation</p>	<ul style="list-style-type: none"> • “Although there are guidelines, such as ongoing involvement of participants throughout all stages of the research, there are no clear guidelines as to how the ongoing research relationship is to be developed or how one negotiates power issues within the field” • The “research chill”: feel “researched to death”; “Epidemiological studies, for example, have depicted Aboriginal and Native American peoples as sick, powerless, and lacking in capacity, information that is used to reinforce unequal power relations, paternalism, and dominance and to undermine their aspirations for sovereignty.” • Disconnect between Aboriginal philosophies and positivist science • Positive move toward increased empowerment/ sovereignty also means time is needed to establish clearer partnership guidelines and practices; until then “approval of research projects can be met with considerable scepticism, often waiting months for community approval with a very low success rate.”
<p>X. Key learnings, evidentiary efficacy or impact</p>	<ul style="list-style-type: none"> • “Clearer practice guidelines will ensure that research in Aboriginal communities will increasingly prioritize community- versus career-building outcomes.” • history shapes all current research relationships; “research within communities is constrained and defined by historical relations of dominance, on-going issues of achieving sovereignty and reclaiming ownership of indigenous knowledge, and prior negative experiences with research” • time is essential (indefinite periods), and this is a source of tension for university based researchers → hence the usual rates of publication under which researchers are evaluated by in a given field of study must be reconsidered when operating under OCAP

	<p>and PAR; less publication does not necessarily equate poorer performance on researcher's part</p> <ul style="list-style-type: none"> • grant funding agencies, ethics review boards and university promotion and tenure committees must acknowledge the former- time is essential for building of sustainable relationships in the OCAP era • ideals of PAR are not enough, and the principles of OCAP, when conducting research partnership with Aboriginal communities; are essential but not yet adequately articulated in practice; necessary but not sufficient • difficulty engaging OCAP principles due to dissonance between OCAP and the demands/constraints of mainstream research institutions • “authentic PAR informed by OCAP shift existing power relations and recalibrates the balance of risks and benefits for researchers and communities”
XI. Contact information.	<p>Lisa Castro, Native American Cancer Research (NACR) 3022 South Nova Road, Pine, CO 80470-7830 Phone: (303) 838-9359 Fax: (303) 838-7629 E-mail: natamlisac@aol.com</p>

I. Name/Title of Model	
	Cape Breton Home-Care Discharge Planning
II. Type of Model (Leading, Promising or Best Practice)	Leading
III. General Introduction	<ul style="list-style-type: none"> • Program objective: provide a home care discharge plan to First Nations clients who need one when they leave hospital and return to their reserve
IV. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Treatment (creating a home care plan upon hospital discharge); all cancers
V. Target populations	<ul style="list-style-type: none"> • First Nations people in Nova Scotia being discharged from hospital who live on reserve and require a discharge plan

VI. Program/ service/ resource history of need and development

- Model designed to address a gap: there was no protocol to ensure care needs of patients returning to reserve upon discharge from hospital were communicated to Band-employed nursing staff by discharge planners – often times care needs were unmet
- Pilot project was an initiative of the Aboriginal Health Transition Fund Project: Improving the Provision of Home Care for First Nations Living on Reserve in Nova Scotia; they funded the evaluation/ evaluation report
- Pilot evaluation part of broader work that culminates in Provincial Home Care Framework for First Nations People living on Reserve

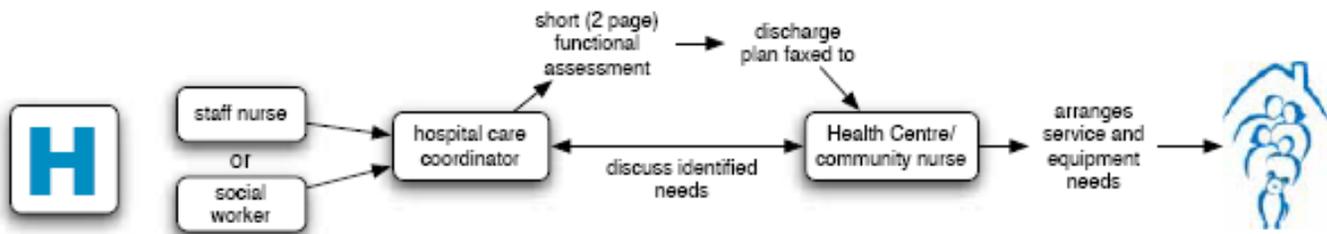
VII. Engagement of First Nations/ Métis communities & enrolment numbers

- Initial set-up / communication work done by Michele Landry of Union of Nova Scotia Indians (UNSI); Landry also assumed role of central coordinator
- 25-35 First Nation clients/ year receive discharge plans (small number is why program worked even though it received no dedicated funds)

VIII. Description of Model: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services

- Hospital-based coordinator complete 2-page functional assessment about mobility/ other key issues around client capacity to function outside of hospital
- Identifies information needed to activate short-term service in home until community based coordinator conducts home assessment to develop home care plan
- Upon discharge, case management/ services provided by a First Nations community

Home Care: Discharge Client Flow



IX. Barriers to implementation/ limitations

- Some clients reluctant to accept hospital care/ support; these clients would often say whatever it took to get out of hospital sooner, including that family/ community supports were available to them that really were not; partially an issue of culture and language;

	<ul style="list-style-type: none"> • Home care services not available on evenings/ weekends on reserve; also experience shut-downs due to a death or other reasons; so, patients ready for discharge are often held back over weekends, contributing to bed shortages • Care providers in rural/ remote communities often have multiple roles, which makes them difficult to reach • Communities do not have access to long-term/ specialized care; falls on home care to fill service gap • At the time of report, there was no cancer care navigator; a combined cancer care navigation and discharge planning support position was proposed • Lack of synchronization between provincial and federal government/ their two streams of health services • Gaps in operating resources (mostly human resource and program support): ongoing communication with stakeholders involved; targeted education for unit managers; updating community information sheets and posters; data roll up and tracking; and, annual meeting
<p>X. Key learnings, evidentiary efficacy or impact</p>	<ul style="list-style-type: none"> • Factors that contributed to program success: did not require significant resources; integrated into existing system smoothly; was a win-win for First Nations communities and Cape Breton District Health Authority (CBDHA); supported by all partners; Memoranda of Understanding (MOUs) embedded roles, responsibilities, and expectations within organizational structures; and, partners demonstrated good will/ in-kind support • Role of First Nations interpreter was highlighted as critical; provided relevant community supports with information about First Nations residents in the hospital and gives home care coordinators notice when clients will be discharged; also communicates directly with patient and family about worries/ available services/ Non-Insured Health Benefits program (NIHB) • Reduced unnecessary long waits in hospital, avoidable readmissions and complication rates • Pilot project (July 2002 – January 2002) was successful and has become normal practice in the Cape Breton Health District (home to 60% of province’s Reserve population), and is potentially being expanded to entire province

XI. Contact information.

For more information about the project
*'Improving the Provision of Home Care for
First Nations People Living on Reserve in Nova Scotia'*
please contact:
Department of Health, Continuing Care Branch
Tel: (902) 424-7807
Fax: (902) 424-0558

(Hampton-and-Hampton for the Nova Scotia Aboriginal Home Care Steering Committee, 2008)

A. Name/Title of Practice	Feasibility of self-sampling and human papillomavirus testing for cervical cancer screening in First Nation women from Northwest Ontario, Canada: a pilot study
B. Type of Practice (Leading, Promising or Best Practice)	Promising
C. General Introduction	<ul style="list-style-type: none">Objective of pilot: use self-sampling HPV tests to raise screening rates among Native American women, who are underserved and experience cervical cancer incidence rate 6 times that of the general Canadian population
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none">Screening; cervical cancer
E. Target populations	<ul style="list-style-type: none">First Nations women in Northwest Ontario; pilot study aimed at on reserve, but were attempting to assess feasibility for underserved populations in general

F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • Fort William First Nation (FWFN), Ontario hosted pilot; next study to include all 10 Northern Superior Communities • Thunder Bay Regional Health Institute with National Microbiology Laboratory (Health Canada), Northern School of Medicine, Thunder Bay Regional Health Sciences Centre, and Dilico Family Health Team • Survey seeks to identify patient preferences (patient centered care)
G. Advantages	<ul style="list-style-type: none"> • Demonstrated preference for self-sampling could mean higher screening participation • Lower costs of test and reduced health care provider (HCP) hours
H. Limitations, disadvantages, or barriers to implementation	<ul style="list-style-type: none"> • HPV testing (high sensitivity) is not a substitute for the Pap test (low sensitivity, high specificity) • Larger study needed to report statically powerful results • Participant self-selection may mean a biased sample • Over-rated self-reporting regarding screening history is a well-documented occurrence
I. Engagement of First Nations, Inuit and/or Métis communities & Enrolment numbers	<ul style="list-style-type: none"> • Study participants were 49 First Nation women in Fort William First Nation • Ethics approval received by local leadership
J. Overview of processes, discussions and/or negotiations used to implement practice	<ul style="list-style-type: none"> • Recruitment through community meeting; information poster; flyers in public places; flyers sent to all households through weekly Band newsletter; flyers given at parenting workshops, through Band office and DFHT staff; incentive draw for 5, CAD\$100 grocery certificates for participants
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • Ethic approval given by Fort William First Nations Regional Grand Chief (community medical portfolio holder) and research ethics board of Thunder Bay Regional Sciences Centre; agreement adhered to First Nations Information Governance Committee through OCAP • Dilico family health team (DFHT) recruited participants; nurse practitioner was primary contact for 49 women • Samples analyzed at National Microbiology Laboratory in Winnipeg
L. Resources required to develop and implement the practice & history of need	<ul style="list-style-type: none"> • Good relationships established with First Nation community prior to commencing the development/implementation of pilot study

and development	<ul style="list-style-type: none"> Funded by The Northern Health Fund
M. Information being collected in relation to the practice and how this information being used. Alternate ways of sharing information used (e.g., stories, videos).	<ul style="list-style-type: none"> Integrity of self-sampled DNA (very high; 96% tested positive for β-globin housekeeping gene) Overall HPV prevalence (28.6%; normal range) Survey data on participant's demographics, screening history, and opinions on self-sampling
N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible	<ul style="list-style-type: none"> 87.2% willing to participate in self-sampling in future 67% prefer self-sampling to HCP sampling 77.1% found process easy; 61.7% found it comfortable Preferred delivery of sexual health education is from HCP
O. Transferability of practice to communities and/or jurisdictions.	<ul style="list-style-type: none"> Use of Dacron swab is a best practice self-sampling device – transferable aspect First Nation participants had higher than average level of education; education is correlated with greater screening participation –transferability limitation Lower costs due to reduced HCP hours/test transferable quality to all underserved populations Participants has easy access to health center – not representative of smaller/more dispersed, remote communities
P. Contact information.	Correspondence to Dr. Ingeborg Zehbe; zehbei@tbh.net

(Zehbe et al., 2011) white literature

I. Name/Title of Model	Eagle Moon Health Office
II. Type of Model (Leading, Promising or Best Practice)	Promising

<p>III. General Introduction</p>	<p>The objective is to bring First Nations and Metis community members, Elders, and Knowledge Keepers together to determine how services for Aboriginal people can be more accessible and delivered in a manner more aligned to a wholistic understanding. Accessibility does not only mean externally able to reach services but also internal – an individual’s ability to take advantage of reachable services. The goal is to raise awareness and support for the traditional way of health and wellness.</p>
<p>IV. Phase(s) of cancer continuum and types of cancer(s) addressed</p>	<p>The focus is on Breast Cancer, and Aboriginal worldview of “cancer” . Original knowledge holders do not brake down into specific areas but rather look at “cancer” in general. The sophisticated understandings and medicinal knowledge can assist western medicine toward improved health outcomes. Many tribal beliefs and protocols are shared to ensure accurate and supportive interventions. For example, in some traditions, talking about “cancer” is believed to weaken ones defenses and bring the disease on to oneself. The prevention and treatment aspects of the cancer continuum are the main focus, in addition to providing support for the patient and their family to help them cope with the cancer journey.</p> <p>The role of the family can have a critical impact on the way a person deals with cancer. In some cases, a central family figure is the one who “coordinates” information to and from the person with cancer and other family members. Often times, “coordination” involves prayer and ceremonies.</p> <p>The western approach looks at addressing the disease whereas a traditional approach looks at health and wellness – first is negative and second is positive. The negative concentrates on dealing with the body’s disease. The positive concentrates on how one moves forward utilizing mind, body and spirit resources. Spirituality is pivotal. The First people have much to teach the western medicine practice regarding family centered care.</p>
<p>V. Target populations</p>	<p>First Nations and Metis people dealing with or have had family members with cancer is the target. Western service providers are also targeted. The intent is to bridge understanding between differing worldviews of health – understanding that will ultimately have a more positive outcome in service delivery.</p>
<p>VI. Program/ service/ resource history of need and development</p>	<p>There are many differences between the Western Medical Model and the Traditional way of health. Major differences in approach are:</p> <ol style="list-style-type: none"> 1) Medical model looks at absence of disease – Traditional way looks at health and wellness (the journey of health) 2) Medical model attempts to address “what is wrong with a person” whereas the traditional way begins with “what is right”

- 3) Medical model is becoming more multidisciplinary whereas the traditional way has always been holistic in approach.
- 4) Medical model developed primarily from science whereas, the traditional way views “balance” of mind, body and spirit – all parts of self need to be addressed and nurtured. It is important to note that there is also a “science” (for want of a better word) that exists in the traditional world. Knowledge of medicinal ways has been passed on from generation to generation but has not been recognized by a relatively newer way of health (western way).

The identification of these many differences in worldviews outlines the need for the development of more comprehensive and culturally responsive approach to providing healthcare. This is believed to be the answer to the access issues faced by many First Nations and Metis people suffering with illness today.

VII. Engagement of First Nations/ Métis communities & enrolment numbers

Eagle Moon Health Office (EMHO) received its name as a result of a traditional naming ceremony. Before this, it was called the First Nations and Metis Health Office. EMHO, as part of the Regina Qu’Appelle Health Region, works with First Nation and Metis community members primarily toward a two-fold aim: 1) bringing community members together with Regional managers to work out ways health services (i.e. Diabetes, Home Care, Primary Health Care etc.) can be enhanced to better meet the needs of the urban and rural aboriginal population and, 2) to support the availability of traditional ways of health and wellness. Thus, EMHO has an advocate and education role within the region.

There are 17 First Nations communities and several Metis Locals within the region as well as a large urban population. Tribal groups include Cree, Ojibway, Dakota, Lakota and Nakota each with their own particular customs and traditional ways and language. EMHO receives its direction from Elders, Traditional medicine and cultural Knowledge Keepers as well as aboriginal community members.

EMHO staff consists of a Director, an Osciapios (Elder Helper), 2 Traditional Healers, Metis consultant, Mental Health/Addictions consultant, Medical Health consultant, First Nation Elders, Traditional Medicine Keepers and a Metis “Old People”. Consultants lead several working groups comprised of aboriginal knowledge keepers and regional managers.

EMHO has invested a great deal of time and attention to developing relationships to regain trust.. As a

	<p>result, urban and rural First Nation and Metis medicine knowledge keepers, elders and community members have been very open in sharing their knowledge and understanding of ways to achieve health and wellness and do provide EMHO with clear direction. The increasing incidence of cancer among aboriginal people has been one of the community concerns expressed.</p>
<p>VIII. Description of Model: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services</p>	<ul style="list-style-type: none"> • The purpose of the model is to facilitate opportunities for Western and Traditional practitioners to knowledge sharing ultimately improving service to aboriginal people. *(Western practitioners i.e. doctors, BC prevention workers etc. --- Traditional practitioners i.e. Traditional Medicine and Knowledge Keepers etc.) It is important to recognize the value of the “expertise” that exists in both worlds. The model involves education via mutual sharing of the different world views of health and wellness that will positively impact a) approach to service delivery and b) respect and support for the traditional pathway. Wholism is pivotal to traditional understanding as it requires work toward achievement of balance in mind, body and spirit rather than a disease orientated approach which utilizes a multi-disciplinary model. * (western approach begins with disease – traditional approach capitalizes on individual’s strengths related to mind, body and spirit)) • Location: Regina Qu’Appelle Health Region – which includes 17 First Nations communities, several Metis locals and a large urban Aboriginal population • Partners: Saskatchewan Cancer Agency, EMHO Traditional Medicine Keepers and Knowledge Keepers • Supports (w)holistic health – true wholistic health, not holistic health which is often confused with ‘multi-disciplinary teams’ <p>*Elders said to spell it “wholistic” because the term refers to all parts of a person</p>
<p>IX. Barriers to implementation/ limitations</p>	<p>There are several barriers to overcome:</p> <ol style="list-style-type: none"> 1) The majority of those working from the Western Medical Model are not aware of the Traditional way as well as hold inaccurate understanding of the knowledge due to historical dominance of western society and the dismissal of the traditional knowledge. 2) The educational preparation and certification of each are different. Dominance of the western approach considers formal University degrees as the sole source of accreditation. 3) The spiritual component is understood to contribute to wellness by both worlds however it is critical in the traditional way. Spiritual health cannot be discounted and discredited although may be by those that adhere strictly to science. 4) The century-old existence and effectiveness of traditional health and healing ways appears to have

been forgotten by those absorbed in a relatively young western science approach.

5) Addressing the needs of others requires those offering the service to have health themselves. Health begets health. Illness begets illness. This has a major effect on health outcomes of service recipients. Where individuals are in terms of their own wholistic health is difficult to address. For example, someone can obtain a recognized degree indicating that he/she has learned the science and is now able to carry out his/her practice. Lack of emotional and spiritual supportive interventions creates imbalance unconsciously that is likely to spill over to the client resulting in outcomes of mistrust, “non-compliance”, increased anxiety. With the illness there is inevitably emotional and/or spiritual turmoil. Resultant reactions unconsciously spill over to the client – who may be very perceptive of this.

5) Historically, aboriginal knowledge keepers have not been acknowledged, and in fact, had been discredited and barred. .Building trust is not an easy task.

6) Prejudice and tokenism still exists even though society likes to feel they are more tolerant. Breaking down these barriers is a continuous endeavour. Tokenism by the way, is subtle. For example, having an Elder present at a working table has been considered inclusion of aboriginal voice even though the Elder’s voice is either not heard or not considered. Likewise, an aboriginal person may be chosen to participate who does not have the traditional understanding thus ensuring adherence to a medical model approach.

7) Those trained in the health field are considered experts. It has been ingrained in the practice to determine the problems and needs of others. Thus, programs emerge in an effort to “fix” a condition or circumstance. The recipients’ side of the “fix” is not always considered. Achieving openness to go beyond a “fix-it” approach is challenging. *As an added note, the “fix-it” approach doesn’t appear to be working all that well in light of the rising statistics of ill health. Yet, in an effort to address these alarming numbers,, the system seems to add more of what they know. This is difficult to understand given the medical evidence at hand. This suggests “trust” must be developed with western society as well. In this spirit Eagle Moon health Office brings knowledge keepers from both world together to share understandings and enhance mutual respect and trust.

8) We have been told by Aboriginal Knowledge Keepers that it is extremely important to take the time to listen to clients and to develop relationships. Unfortunately, increased incidences of illness, and large numbers of people seeking western services limits the time service providers are able to devote to individual clients. Ironically, time invested with someone can decrease the frequency to see service providers because the person is better able to manage their health effectively.

	9) Data collection has proven to be difficult. Traditional ways do not fit in western categories. An “aboriginal” approach to research is needed thus work with researchers is ongoing to best reflect the benefits of sharing responsibility for the health and wellness of community
X. Key learnings, evidentiary efficacy or impact	Western and Traditional knowledge keepers will identify the type of tool needing to be developed – a tool that will be respectful of aboriginal understanding and helpful for western service providers. This is an on going project and will be evaluated upon completion.
XI. Contact information.	Dorothy Lloyd Dorothy.lloyd@rqhealth.ca Stephanie Cavers Stephanie.cavers@rqhealth.ca
XII. Source	Project Contact Canadian Breast Cancer Foundation http://www.cbcf.org/prairies/YourDollarAtWork/Grants/Pages/2011-Community-Grants-%E2%80%93-Profiled.aspx

A. Name/Title of Practice	Enhancing Cancer Pain Control among American Indians (ECPCAI)
B. Type of Practice (Leading, Promising or Best Practice)	Leading
C. General Introduction	ECPCAI designed to: 1) provide culturally sensitive, American Indian-specific educational materials regarding cancer pain management (CPM) for general distribution to an American Indian lay public for used by care professionals in treating American Indian cancer patients;

	<p>2) provide state of the art cancer pain management info to health care professionals in IHS and tribal clinics for 4 reservation in Minnesota;</p> <p>3) add to body of knowledge concerning effective methods to develop culturally appropriate educational materials for American Indian</p>
D. Phase(s) of cancer continuum and types of cancer(s) addressed	Treatment; all cancers
E. Target populations	<ul style="list-style-type: none"> • Ojibwe of Minnesota cancer patients living on reserve; the 4 participating Anishinabe tribal groups were Fond du Lac, Red Lake, White Earth, and Leech Lake reservations
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • Project and report from the Department of Family Medicine and the Center for Excellence, American Indian Programs at the University of Minnesota Duluth School of Medicine; and from the Division of Education and Research and the Duluth Clinic, St. Mary's/ Duluth Clinic, Duluth, Minnesota • with focus group information developed lay material (pamphlets, plus a poster) for the public → different one for each community, and materials evaluated by second group of elders at each site before distribution • brochure info presented in story format, and addressed concerns highlighted by elders • alternate material developed for clinicians (Clinical Practical Guidelines for Clinicians serving American Indian): provided written guidelines on how to care for Indian people with cancer pain; comprised of information from focus groups identifying cultural themes, behaviors, and barriers with appropriate sections from AHCPR Clinical Guidelines for the Management of Cancer Pain in a written booklet
G. Advantages	<ul style="list-style-type: none"> • Project cultural and informational needs on a community by community basis; greater cultural relevance facilitates stronger knowledge transmission
H. Limitations or disadvantages - Status of and barriers/successes to implementation	<ul style="list-style-type: none"> • clinic personnel concerns regarding pain management: addiction issues and the need for careful monitoring of controlled substances; ensuring patient and not drug seeking friend/relative receives medication; inducing addiction or re-addiction in previously dependent person; managing pain in someone currently addicted to another substance; managing cancer side effects and pain; not knowing what levels of pain can be achieved; and unsure of how to encourage patients to admit or report pain • limitations: study reflects only one particular tribe, and may not be transferable to other

	American Indian people
I. Engagement of First Nations, Inuit and/or Métis communities & Enrolment numbers	<ul style="list-style-type: none"> • Approximately half of project development focus group participants were enrolled tribal members • tribal elder focus groups held to identify barriers to CPM in that particular community in preparation for development of educational materials
J. Overview of processes, discussions and/or negotiations used to implement practice	<ul style="list-style-type: none"> • project development: worked with focus groups comprised of clinic personnel at each of four project sites to obtain information about that clinic environment, clinician’s attitudes and experience with cancer pain management, suggestions for questionnaire, and health education dissemination methods (personnel included physicians, clinic based public health nurses, social workers, community health representative, pharmacists, administrative staff, including Tribal health director) • lay people and clinic personnel feedback was positive- appreciated the training (material developed for clinic personnel was not only the booklet, but delivered in an activity and CME and CUE credit worthy seminar – incentive) and believed it would facilitate pain management delivery
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • supported by National Cancer Institute, Enhancing Cancer Pain Control in American Indian (ECPCAI)
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> • American Indian are known to experience undertreated pain due to their cancers • Contributing factors to insufficient CPM include late reporting of symptoms and pain, and cultural differences in communication; hence motivation for CPM education and delivery that is culturally appropriate
M. Information being collected in relation to the practice and how this information being used.	<ul style="list-style-type: none"> • Project studied tribes’ experience with cancer associated pain and resulting barriers in CPM
Alternate ways of sharing information used (e.g., stories, videos).	

<p>N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible</p>	<ul style="list-style-type: none"> • Ojibwe experience of cancer associated pain: do not report pain until severe (at least >6 on a 1-10 scale); half believed pain invariably accompanies cancer; one quarter did not believe cancer pain can be relieved; do not feel they are taken seriously when they do finally report pain; majority concerned that those taking medication would become addicted; and most believed traditional medicine can help relieve pain • Concerns about potential pain medication addition is not unique to American Indian, but extent of concern is higher among American Indian than other groups • Educational materials developed and tailored for each community successfully transferred knowledge; statistically significant improvement from pre to posttest scores • High agreement (>92%) that educational materials were culturally sensitive • Most important learning: medically sound CPM can also be culturally sensitive
<p>O. Transferability of practice to communities and/or jurisdictions.</p>	<ul style="list-style-type: none"> • Transferability of materials developed is unclear; method in which information was collected and material developed is transferable
<p>P. Contact information.</p>	<p>Barbara Elliot University of Minnesota, Duluth Medical School 155 SMED 1035 University Drive Duluth, MN 55812 Phone: 218 726 6981 Email: belliot@d.umn.edu</p>

(Elliot et al., 1999)

Note: more information on the program is likely available in the above article. I was unable to access the full text.

<p>A. Name/Title of Practice</p>	<p>Native People for Cancer Control Telehealth Network (NPCCTN)</p>
<p>B. Type of Practice (Leading, Promising or Best Practice)</p>	<p>Promising</p>

C. General Introduction	<p>Goal:</p> <ul style="list-style-type: none"> • “use telehealth to provide and improve access to culturally sensitive and relevant postdiagnosis cancer care services for remote and rural American Indian/Alaska Native communities”
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Post diagnosis care, education and survivorship; all cancers
E. Target populations	<ul style="list-style-type: none"> • American Indian/Alaska Native patients, their families, and their health care providers
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • telehealth network hosted cancer (and other health topics) education presentations, case conferences, and cancer survivor support groups • networks in Washington and Alaska • Research and technical staff from the University of Washington
G. Advantages	<ul style="list-style-type: none"> • Teleoncology addresses the need for specialist care among geographically isolated, underserved populations • Reduces coordination gaps between urban/tertiary center specialists and community based primary care providers • Reduces need for (and associated costs of) physician fly-in/ patient fly-out
H. Limitations, disadvantages, or barriers to implementation	<ul style="list-style-type: none"> • Challenges included: technical issues, provider/patient/community acceptance, cultural issues, and engaging partner organizations (ex. Clinics with high staff turnover and limited resources operating in rural/remote areas often had many competing concerns)
I. Engagement of Native American communities & enrolment numbers	<ul style="list-style-type: none"> • Sept. 2006 – Aug. 2009: 9 tribal clinics in Washington and 26 clinics in Alaska participated in telehealth network activities • 27 cancer education presentations; provider attendance of 369 • 44 case conferences; 129 cases discussed • 513 patient encounters

	<ul style="list-style-type: none"> As of Aug. 2009: 2 tribes from Montana, and 5 Northwest Indian College sites (4 in Washington and 1 in Idaho) joined the NPCCTN
J. Overview of processes, discussions and/or negotiations used to implement practice	<ul style="list-style-type: none"> Obtained permission from clinic and tribal entities, with final approval via a Tribal Resolution and/or Memorandum of Understanding signed by the Tribal Council Partners (tribal clinics) engaged in all stages of implementation/evaluation of network (participatory formative evaluation approach) Identified specific IT needs for implementation Provision of technical staff for on-site training of health care providers to ensure competence/comfort with telehealth technology Direct patient care required extra time to explain telehealth/ field questions about confidentiality etc.
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> University of Washington collaborated with tribal councils, health administrators, health care providers and community members (elders, patients, and others) NPCCTN linked with Alaska Federal Health Care Access Network (telehealth network or Alaska Native Tribal Health Consortium- serves > 250 sites); Alaska Rural Telehealth Network; Eastern Aleutian Tribes Corporation; and Southeast Alaska Health Consortium
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> Project supported by the Office for the Advancement of Telehealth's Telehealth Network Grant Program and the National Cancer Institute Installment of hardware and software required in many sites that lacked sufficient internet connection Cultural competency training of NPCCTN university staff facilitated strong relationships between academic and tribal providers and American Indian/Alaska Native people; trust paramount to successful implementation
M. Information being collected in relation to the practice and how this information being used. Alternate ways of sharing information used (e.g., stories, videos).	<ul style="list-style-type: none"> Rates of use of telehealth, and for what purpose; result was even greater capacity for delivering care than was anticipated in terms of number of patients served, number of participating sites, and geographic reach
N. Key learnings or outcomes to date -	<ul style="list-style-type: none"> Gaining provider and community acceptance, working with tribal members,

Evidentiary efficacy or impact, as evaluated by organization responsible	<p>understanding tribal sovereignty and governance, and partnerships with cultural liaisons were all essential elements of program success</p> <ul style="list-style-type: none"> • Community involvement in all stages of telehealth system design/implantation is important • Cultural differences in communication style can lead to failure to recognize cancer symptoms/ treat cancer pain; cultural competency training is valuable • Primary challenge is not hardware limitations, but need to customize software, incorporate telehealth into workflow, train end-users to ultimately provide useful telehealth interventions
O. Transferability of practice to communities and/or jurisdictions.	<ul style="list-style-type: none"> • Telehealth has potential wherever there are highly dispersed, geographically isolated, underserved populations
P. Contact information.	<p>Ardith Z. Doorenbos, Ph.D., R.N., FAAN Biobehavioral Nursing & Health Systems School of Nursing University of Washington Box 357266, Seattle, WA 98195 E-mail: doorenbos@uw.edu</p>

(Doorenbos et al., 2011)

A. Name/Title of Practice	<p>Spirit of Eagles (SoE)</p> <p>Education Advocacy Grants Leadership Elders Survivors/Scholarships; EAGLES</p> <p>American Indian/Alaska Native Leadership Initiative on Cancer</p>
B. Type of Practice (Leading, Promising or Best Practice)	<p>Leading</p>

<p>C. General Introduction</p>	<p>Addresses comprehensive tribal cancer control through partnerships with The Network for Cancer Control Research among American Indian/Alaska Native populations, tribes, multiple cancer centers, Cancer Information Services (CIS), and the American Cancer Society (ACS). This Initiative will assist tribes to:</p> <ol style="list-style-type: none"> 1. Increase community awareness and understanding of cancer 2. Provide training in cancer control research for American Indian/Alaska Native researchers 3. Improve native community channels to the National Cancer Institute (NCI) so that research can be specifically focused on issues that affect native people
<p>D. Phase(s) of cancer continuum and types of cancer(s) addressed</p>	<p>Education, training, clinical trials and surveillance; all cancers</p>
<p>E. Target populations</p>	<p>Native Americans- interested in performing research regarding Native American health/ delivering cancer care/ cancer patients</p>
<p>F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services</p>	<p>Specific aims to support program goals:</p> <ul style="list-style-type: none"> • Building infrastructure to support a nationwide Initiative • Increasing the number of American Indian/Alaska Native researchers, scientists, and medical students involved in cancer control activities in American Indian/Alaska Native communities • Developing, implementing and assessing cancer education among American Indian/Alaska Native community members and their health care providers • Strengthening collaboration of American Indian/Alaska Native communities with NCI, CIS and ACS • Increasing the number of American Indian/Alaska Native patients in clinical trials (prevention, screening, treatment and supportive care) • Providing feedback to the NCI on community-based priorities in the national cancer program <p>During 5-year grant period, because of the strength and breadth of partnerships, SoE:</p> <ul style="list-style-type: none"> • conducted extensive cancer awareness activities

	<ul style="list-style-type: none"> • trained over 150 students and scientists • conducted 9 research pilot projects • mentored 38 cancer control community-based projects across the country
G. Advantages	<ul style="list-style-type: none"> • Native American researchers are more likely to perform research on Native American cancer control in a culturally appropriate, and thus more effective, manner • Building infrastructure facilitates information sharing and horizontal integration, reduces redundancies, and makes efficient use of limited resources • Community level grants mean research/initiatives reflect unique needs of individual communities and brings new talent into leadership roles (empowerment, self-determination and respect of tribal sovereignty)
H. Limitations, disadvantages, or barriers to implementation	<ul style="list-style-type: none"> • Gaps in grade school curriculum/education in areas of low socio-economic status (Native Americans are over-represented in this group) precipitate low post-secondary participation • Challenges related to miscommunication or lack of communication, isolation, high staff turnover, lack of training, or inability to engage the community in the proposed activities
I. Engagement of Native American communities & enrolment numbers	<ul style="list-style-type: none"> • All materials are reviewed by the medical director (Dr. Judith Salmon Kaur) for medical accuracy; Dr. Kaur is one of two Native American oncologists in the US and is the medical director for the Native American Programs of the Mayo Comprehensive Cancer Center • Native American Cancer Initiatives (NACI) is a Native-owned corporation • Funded American Indian/Alaska Native research students • With Association of American Indian/Alaska Native Physicians (AAIP) supported, educated and received input from American Indian physicians • Community level grants awarded
J. Overview of processes, discussions and/or negotiations used to implement practice	<ul style="list-style-type: none"> • with CIS; reviewed cancer info materials for cultural relevance, provided technical assistance to tribes, identified partnership opportunities, and provided outreach workers to coordinate community events • with National Indian Health Board (NIHB): provided current cancer topic workshops at NIHB Annual Consumer Conference, covered SoE activities in organization's newsletter, and distributed community grant RFAs to all NIHB members • partnered with University of Arizona Native Researchers training program and Oregon Health Sciences University to develop focused cancer control research training; SoE

	<p>funded 10 American Indian/Alaska Natives per year for 3 years, plus ongoing training/support</p> <ul style="list-style-type: none"> with NACI provided specific educational outreach programs (notably clinical trials) that were culturally competent
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> Network for Cancer Control Research Among American Indian/Alaska Native and Alaska Native Populations is the scientific advisory board for the SoE grant collaborate with Native CIRCLE and Native WEB partnerships: Fred Hutchinson Cancer Research Center, Native American Cancer Research (NACR), Oregon Health and Sciences University, Native Researchers Cancer Control Training Program, University of Wisconsin Paul P. Carbone Comprehensive Cancer Center, Alaska Native Tribal Health Consortium, Mayo Clinic Comprehensive Cancer Center
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> Est. 2000; one of eighteen NCI-funded Special Populations Networks (initially a 5 year grant, but program still ongoing due to demonstrated success)
<p>M. Information being collected in relation to the practice and how this information being used.</p> <p>Alternate ways of sharing information used (e.g., stories, videos).</p>	<ul style="list-style-type: none"> Document number and progress of awareness activities, pilot projects, scientists training, partnerships founded, and have published over 90 papers (as of 2006); great breadth and depth of data collection
N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible	<ul style="list-style-type: none"> Participatory action research is playing an essential role in changing the way that cancer is perceived and treated among American Indian/Alaska Native populations How best to support struggling programs through regular communication, site visits, referral for needed resources, and additional mentoring
O. Transferability of practice to communities and/or jurisdictions.	<ul style="list-style-type: none"> Transferable; supporting the education of indigenous researchers in order to study their own ethnic/cultural group facilitates the principles of OCAP Transferable; coordination of various cancer care/research organizations to share information and build a national strategy
P. Contact information.	Spirit of EAGLES

American Indian/Alaska Native Leadership Initiative on Cancer
 Operations Director
 Rochester, MN 55905

Telephone: 507-266-3064
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E-mail: Baukol.Paulette@mayo.edu

http://cancercenter.mayo.edu/spirit_of_eagles.cfm

<http://www.nativeamericanprograms.org/index-spirit.html>

Grant support:
 U54-CA153605-01

(Kaur et al., 2006)

A. Name/Title of Practice	The Community Cancer Programs Network (CCPN)
B. Type of Practice (Leading, Promising or Best Practice)	<ul style="list-style-type: none"> • Bringing Cancer Care Closer to Home (Leading)
C. General Introduction	<ul style="list-style-type: none"> • The CCPN is a longstanding and innovative program of CancerCare Manitoba (CCMB) that works in partnership with Manitoba’s Regional Health Authorities (RHAs) to enable patients to receive their cancer care & treatment closer to home. Patients receive their cancer care at sites called “Community Cancer Programs” or CCPs , which are outpatient units located in community hospitals. The care is provided by a multi-disciplinary team of health professionals trained in oncology.

<p>D. Phase(s) of cancer continuum and types of cancer(s) addressed</p>	<ul style="list-style-type: none"> • Since 1978, CCPs have been growing in both number and responsibility, and have become increasingly involved in providing care across the cancer spectrum in areas such as prevention, early detection, diagnosis, treatment, rehabilitation and palliation. Most cancers can be treated safely at a Community Cancer Program location (CCP). • More recently, the CCPN has been supporting the implementation of Rural Cancer Patient Navigation Services, which helps patients and their families navigate the system through all phases of the cancer journey including suspicion, diagnosis, treatment, and followup as well as issues that may be faced in survivorship, palliative care and bereavement.
<p>E. Target populations</p>	<ul style="list-style-type: none"> • Cancer patients, their families and their health care providers outside the city of Winnipeg (rural and northern Manitoba)
<p>F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services</p>	<ul style="list-style-type: none"> • The CCPN is comprised of 16 Community Cancer Programs (CCPs) and 1 Community Cancer Resource Support Program (CCSRP). Each RHA has one or more Community Cancer Programs within their region. • CCPs are a multi-disciplinary team of Family Physicians, nurses, pharmacists, pharmacy technicians who have received specialized education in oncology. • Some CCP sites are also supported by social workers, spiritual care workers, palliative coordinators, dietitians, clerical staff, volunteers and others. • Collaboration between CancerCare Manitoba specialists and the staff of the CCPs and the CCSRPs are supported through the use of the MBTelehealth Network which offers opportunities for consultation and education via videoconferencing. • Improved communication of health information at all CCP locations through the implementation and use of ARIA, CancerCare Manitobas electronic health record.
<p>G. Advantages</p>	<ul style="list-style-type: none"> • For Manitobans living outside of Winnipeg, a cancer diagnosis often means traveling for treatment far away from the comforts of home and the support of family and friends. Patients who are eligible to receive care at a CCP closer to their home would ultimately cut down on travel time and expenses, and the disruption caused by the cancer diagnosis and treatment would be minimized. Not having to drive into the city on highways through all kinds of weather conditions is another advantage to consider, in terms patient safety.
<p>H. Limitations, disadvantages, or barriers to implementation</p>	<ul style="list-style-type: none"> • CCPs are diverse (multi-site, multi-disciplinary, multi-regional and ever-changing). The challenge is achieving continuity / clarity when communicating information, and providing

	<p>education and resources to this diverse group of stakeholders whose priorities vary based on geographical & socioeconomic needs.</p>
<p>I. Engagement of First Nations, Inuit and/or Métis communities & Enrolment numbers</p>	<ul style="list-style-type: none"> • The CCPN office has begun working with First Nations, Metis and Inuit Cancer Control at CCMB on developing plans to provide information, education, and support to First Nation communities throughout Manitoba about cancer prevention & treatment. CCPs are located in all regions with FN communities.
<p>J. Overview of processes, discussions and/or negotiations used to implement practice</p>	<ul style="list-style-type: none"> • 1978: The Community Cancer Programs Network began as a pilot project and five rural CCPs were opened (Brandon, Dauphin, Flin Flon, The Pas, and Thompson). Initially the program focused on delivering chemotherapy treatment to breast cancer patients in rural Manitoba. • 1983-84: the pilot project was evaluated and the “Outreach Program” was funded by MB Health. • 1988: the impact on survival and quality of life was evaluated. • 1993: the Outreach sites were renamed Community Cancer Programs and the main Outreach Office renamed the Community Cancer Programs Network. • 2012: The program has grown to 16 CCP sites and has become increasingly involved in providing care across the cancer spectrum for most cancer diagnoses at sixteen CCPs with at least one CCP in each RHA. In addition, the CCPN welcomed the first Community Cancer Resource & Support Program (CCRSP) in 2010. The focus of the CCRSP is supportive care across the cancer spectrum, from pre-diagnosis through survivorship or palliative care and is staffed by a Nurse Navigator and Oncology Social Worker. Unlike the CCPs, the CCRSP does not provide chemotherapy treatment.
<p>K. Collaborative relationships, resources or capacity required for development and implementation of the practice</p>	<ul style="list-style-type: none"> • The CCPN is based on a shared care model, meaning that while the referring oncologist retains overall responsibility for treatment plans, the care is delivered by CCP staff (comprised of a multidisciplinary team of family physicians, registered nurses, pharmacists, and other health care professionals trained in oncology). • The CCPN collaborates with all staff and departments at CancerCare Manitoba, as well as with RHA managers, to ensure that there is patient continuity of care and that CCP staff receive appropriate training, education and ongoing support.
<p>L. Resources required to develop and</p>	<ul style="list-style-type: none"> • Resources required include staffing for the Community Cancer Programs Network

implement the practice & history of need and development

Administrative Office (located at the MacCharles Site of CancerCare Manitoba in Winnipeg), which consists of a Program Director, Medical Director, Nurse Educator, Community Liaison Pharmacist, Professional Development Coordinator, Supportive Care Coordinator, Information Coordinator, Rural Navigation Lead and an Administrative Assistant.

- These staff work with CancerCare Manitoba and Manitoba's RHAs to enable patients who live outside Winnipeg to receive their cancer care and treatment closer to home in a safe and effective manner.
- The role of the CCPN Office is to support the Community Cancer Program (CCP) staff with education and training; up-to-date information; administrative support; data analysis; program planning & development and quality assurance.
- These initiatives also help rural and northern communities develop local cancer care expertise, as well as improve recruitment and retention of health workers.
- In addition to the above, the CCPN office is responsible for the planning and organization of the Community Cancer Care Conference, an annual event which brings together CCP staff and cancer care experts from CancerCare Manitoba and beyond, ensuring that CCP staff remain current and well-versed in the latest trends in cancer care.
- CancerCare Manitoba shares standards, policies and procedures with CCPs.

M. Information being collected in relation to the practice and how this information being used.

Alternate ways of sharing information used (e.g., stories, videos).

The data collected (below) by the CCPN office has been used for budget and operational planning, staff funding, presentations and education.

- New Patient Referral Data
- Nurse Navigator Data
- Nursing Workload Data
- Physician Clinic Visit Data
- Treatment Data (types and numbers of treatments)
- Patient Community of Residence Data

CCPN Staff participate in health fairs for health professionals and the public (e.g. Norway House, Sagkeeng) by manning displays and doing presentations. A patient story video was

<p>N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible</p>	<p>developed as part of the Community Cancer Care Conference held in Brandon in 2011.</p> <ul style="list-style-type: none"> • Some, but not all, CCPs provide their patients with the CCPN Patient Satisfaction Survey. This survey evaluates patient satisfaction within 5 domains: the CCP environment, information / resources provided, meeting of physical & emotional needs and the organization / delivery of care. The survey is intended to be offered to all new patients referred to a CCP for completion at mid-point or later in their treatment course. There are some limitations to the data reported, namely that the CCPN Office currently does not control the methods for survey distribution to patients (i.e. the number of surveys handed out or to who, the method, or at what point in time). • Each survey received is reviewed and if a “comment” of concern regarding a patient’s care and / or treatment is identified or a patient has made a “specific request for a reply” and contact information is provided, the CCPN Program Director and / or and / or Medical Director is notified. Appropriate action is then taken to address concerns as necessary. • CancerCare Manitoba’s Patient Navigation Department has done a province-wide patient satisfaction survey in recent years using the Picker methodology.
<p>O. Transferability of practice to communities and/or jurisdictions.</p>	<ul style="list-style-type: none"> • Manitoba was the first cancer program to establish a community cancer program. Many other provinces have initiated programs based on the learnings of the CCPN.
<p>P. Contact information.</p>	<ul style="list-style-type: none"> • Community Cancer Programs Network (Office) ON4034-675 McDermot Avenue Manitoba R3E 0V9 Fax: (240) 786-0184 <p style="text-align: right;">CancerCare Winnipeg, Manitoba Phone: (204) 787-5159</p>

Report on National Forum on First Nations, Inuit, and Métis Cancer Control (2008):

Practice/program/resource	Description
The Alberta Breast Cancer Screening Program (Culturally relevant materials)	developed an Aboriginal Breast Cancer Education Toolkit to help Aboriginal health workers provide information about cancer screening to First Nations and Métis women
Cancer Care Ontario’s Aboriginal Cancer Strategy Team (Culturally relevant materials)	<ul style="list-style-type: none"> • materials (pamphlets, playing cards, posters, videos, calendars, radio PSA’s, teaching wheels etc.) developed by and for Aboriginal communities • aimed at increasing awareness of cancer in general and to address specific topics such as tobacco use and overcoming barriers to cancer prevention and screening • CCO also manages a website www.tobaccowise.com; educates about traditional versus commercial uses of tobacco
The Blue Light Campaign of the Nunatsiavut Department of Health and Social Development (First Nations/Inuit/Métis community-based activities)	<ul style="list-style-type: none"> • creating community awareness about smoking by placing a blue light outside every home that is smoke free; Labrador
The Quit to Win! challenge (First Nations/Inuit/Métis community-based activities)	<ul style="list-style-type: none"> • funded by Health Canada, provides incentives for youth to stop smoking; Nunavut
Community Coordinator position is funded by the Canadian Cancer Society – Ontario Division as part of the Screening Saves Lives project (First Nations/Inuit/Métis community-based activities)	<ul style="list-style-type: none"> • Aboriginal nurse, responsible for the Manitoulin Island area, conducts educational programs and trains lay health educators to promote cancer screening and prevention in the communities • CCO’s Aboriginal Cancer Strategy Unit provides small-scale community capacity building grants to First Nation, Métis communities for tobacco cessation pilots; unit works with communities to customize the intervention based on community need • Ontario has a video called “In Our Own Words” based on First Nation, Métis and Inuit

	experiences in the cancer system.
The Aboriginal Health Transition Fund (First Nations/Inuit/Métis community-based activities)	<ul style="list-style-type: none"> • adaptation project Norway House is piloting a community engagement model in Manitoba • Among various projects, community's working group is developing a navigation system to help address the gaps between diagnosis and treatment
Saskatchewan Cancer Agency's Breast Screening Program, in collaboration with First Nations and Inuit Health and First Nations tribal councils (First Nations/Inuit/Métis community-based activities)	<ul style="list-style-type: none"> • Adds one community with low participation rates each year as an area of focus • Working with Community Health Representatives to educate and recruit eligible women, participation rates have increased dramatically • The Agency has also developed a breast screening navigation program in communities for women who need to receive further diagnostic testing.
The First Nations of Quebec and Labrador Health and Social Services (cancer journey)	<ul style="list-style-type: none"> • autonomous organization that provides primary care to communities and coordinates with provincial services, resulting in seamless care for patients
Juravinski Regional Cancer Centre in Hamilton, Ontario and by Cancer Care Nova Scotia (cancer journey)	<ul style="list-style-type: none"> • Aboriginal patient navigation programs have been established • Nova Scotia program also includes a video describing the patient journey
NWT Breast Health Patient Navigation and Cancer Patient Navigation (cancer journey)	<ul style="list-style-type: none"> • Regionally, a pilot project is underway focusing on the implementation of Traditional Practitioners with land medicines in a community health care center • Territorially, Aboriginal Wellness Program is being implemented; will offer access to Traditional Practitioners, medicines, traditional foods, and appropriate ceremonies
Canadian Hospice Palliative Care Association produced handbook (cancer journey)	<ul style="list-style-type: none"> • supports First Nations patients and caregivers, plus an inventory of resources and tools for palliative care for use by First Nations and Inuit communities • association also sponsored a roundtable meeting to identify key issues in palliative care
Saint Elizabeth Health Care's @YourSide Colleague (health human resources)	<ul style="list-style-type: none"> • Piloted successfully with 35 First Nations across Manitoba • program includes a web-based learning component and self-directed courses on cancer, screening and treatments • has since been shared with First Nations communities and health authorities across

	Manitoba, British Columbia and Saskatchewan
Partners for Inter-professional Cancer Education (health human resources)	<ul style="list-style-type: none"> • program includes cultural sensitivity and safety training • Nova Scotia
Cultural safety training (health human resources)	<ul style="list-style-type: none"> • part of its First Nations, Inuit and Métis Cancer Control Strategy, developed by Cancer Care Manitoba • mandatory two-day cultural safety training for all employees
Manitoba's Centre for Aboriginal Health Research program: Access to Quality Cancer Care and Control of Cancer for Manitoba First Nations (research and surveillance)	<ul style="list-style-type: none"> • a partnership between the Centre, First Nations and governments • includes a surveillance system which uses data linkage to capture cancer information on over 90% of First Nations populations living on reserves • project will also identify a framework for a culturally appropriate knowledge translation process that will allow research findings to be applied to the communities, and will increase capacity for health-related decision making by all parties
Pilot project: asks a cultural identifier question for the Ontario Cancer Registry (research and surveillance)	<ul style="list-style-type: none"> • Cancer Care Ontario is working with two Regional Cancer Centres • Funded by the Ministry of Health and Long-Term Care • asks a cultural identifier question for the Ontario Cancer Registry • This small-scale model will be evaluated and, if successful, may be applied to the remaining cancer programs in the region
Aboriginal Cancer Strategy (guidelines, quality and standards)	<ul style="list-style-type: none"> • Being developed in Alberta, and includes an environmental scan and needs assessment
5 year strategy developed for Aboriginal Cancer Control (guidelines, quality and standards)	<ul style="list-style-type: none"> • In Ontario • Strategy will be renewed in 2009-2010
Discussion Paper and Fact Sheets on Inuit cancer control	<ul style="list-style-type: none"> • Developed by Inuit Tapiriit Kanatami (ITK) • Based on the priorities identified in these documents, ITK is developing a cancer control advocacy platform

(Canadian Partnership Against Cancer, 2008)

Resources and Programs from the National Forum on Cancer Care for all Canadians report (2008):

Practice/program/resource	Description
<p>Nunavut Qullit Status of Women Council, Women and Cancer</p> <p>P 867 979 6690 toll free 866-623-0346 nbcproj@qnsu.ca</p>	<ul style="list-style-type: none"> • Advocating for equitable care and developing appropriate resources for Nunavummiuts since 2001; initial focus Breast Cancer and is now including other forms of the disease • Past activities: <ul style="list-style-type: none"> ○ Weekend retreat for women living with cancer ○ Support and advisory group for patients ○ Research/statistical inquiry • Present activities: <ul style="list-style-type: none"> ○ Develop resources/ website/ workshop materials/ health kits on cancer ○ Access funding for evaluation report ○ Participate/ present at workshops/ conferences ○ Increasing human resources through education and training ○ Raise public awareness through media ○ Support women through telehealth • Next 5 years: <ul style="list-style-type: none"> ○ Expand focus to include youth, survivors, the healthy; promote self-advocating for health services/care ○ Lobby for incentives to draw students to medicine ○ Advocate for increased services in the Territory
<p>The Manitoba Breast Screening program: Integrating Aboriginal Group Trips into the Mobile Scheduling System/ Improving access to breast screening for First nation women from small, isolated Manitoba communities</p> <p>Katie Watters, Education Coordinator</p>	<ul style="list-style-type: none"> • uses a variety of strategies to reach aboriginal women; mobile sites have been set up in or near 17 rural and northern Aboriginal communities eliminating the transportation barrier for those communities • inner city sites and contacts with inner city agencies has improved access for urban aboriginal women • program has integrated the concept of group trips into mobile scheduling ensuring that all Manitoba Aboriginal communities are contacted when the mobile is near their community

<p>katie.watters@cancarecare.mb.ca Edythe Lucas, Mobile coordinator edythe.lucas@cancercare.mb.ca</p>	<ul style="list-style-type: none"> • Results have been very positive • Funding covers costs to fly women from 9 very isolated communities without screening access to the closest screening site (mobile or fixed) via charter flights
<p>Community Inclusion resources at the Canadian cancer Society</p> <p>Margherita Zorzetto, LLB, LLM Community Inclusion Coordinator, Strategic Initiatives Canadian Cancer Society, BC & Yukon Division mzorzetto@bc.cancer.ca www.cancer.ca</p>	<ul style="list-style-type: none"> • The Canadian cancer Society, BC-Yukon Division has a strong commitment to involve and include diverse communities, provide services that are accessible to all and to value and enable the diverse contribution that groups and individuals make to the organization. • Role: champions Community Inclusion activities, monitors progress in this area and serves as a forum for sharing information and for open dialogue • Community Inclusion Grants: provide funding for internal ‘seed projects’ that strengthen our ability to be inclusive • Emergency aid assistance available to people that find it hard to meet their cancer treatment related expenses
<p>Aboriginal Cancer Care Unit of Cancer Care Ontario</p>	<p>Mission:</p> <ul style="list-style-type: none"> • responsible for developing and building an Aboriginal Cancer Strategy by basing it on a holistic approach to cancer prevention, screening and research • will accomplish this through tracking policies, environmental scanning, developing training modules, establishing partnerships, networking with regions, implementing community-based pilot projects and creating linkages on Aboriginal cancer issues <p>Current Activities:</p> <ul style="list-style-type: none"> • community learning services, research, newsletter, video project, patient navigation, Aboriginal relationship development series, and Aboriginal tobacco strategy
<p>Aboriginal Initiatives Canadian Cancer Society, Manitoba</p> <p>George Wurtak gwurtak@mb.cancer.ca</p>	<ul style="list-style-type: none"> • Work with the Aboriginal community to develop a holistic approach for cancer prevention and to support people living with cancer • Guided by an Aboriginal Advisory Council, consults with Aboriginal leaders and communities, conducts joint education sessions, helps communities develop their own support systems and advocates for healthcare-system improvements for the cancer journey • activities: sharing circles, support group start-up, brochures in Aboriginal language/ imagery, including general cancer awareness and site specific information, cancer control models based on the medicine wheel teachings, transportation and practical support,

	<p>education with regards to the importance of screening, regular check-ups and healthy living</p> <ul style="list-style-type: none"> evidence of success: > 80% of calls from Aboriginal Communities to Cancer Information Service (toll-free telephone information) emanate from communities where program has been active
<p>Aboriginal Women's Breast Health "Train the Trainer" Program</p>	<ul style="list-style-type: none"> <i>Health Promotion and Education Services, Ontario</i> <i>Objective:</i> impart breast health knowledge to Aboriginal front-line workers who will provide breast health education and awareness to Aboriginal women in their communities <i>Methods:</i> developed a culturally specific Breast Health Train-the-Trainer Manual consisting of 4 modules: <ol style="list-style-type: none"> 1) Traditional Knowledge and Aboriginal Women's Health, 2) Breast Health 3) The MammaCare Method of Breast Self-Examination 4) Healthy Lifestyles <ul style="list-style-type: none"> 19 Aboriginal community and social services workers completed the two-day workshop and 18 OBSP staff attended the cultural awareness training
<p>The "Appearance" of Time: Compassionate Communication in Cancer Care – Poster</p>	<ul style="list-style-type: none"> Lack of time: well recognized as a justification for the inability to deliver cancer care in a way that meets cancer patients' communication needs Communication with respect to time is a challenge even among patients and health care providers who share a common language/culture – effects of time shortage on communication become a far greater access barrier in the context of diversity Findings: expressions/actions “related to time on the part of clinicians become the signifiers to which cancer patients pay careful attention in interpreting compassion, caring and clinical competence”; studied “what differentiates clinicians who compromise communication because of their attempts to control time and those who facilitate compassionate communication even within severely limited time”
<p>Understanding The Current Practice Of Interpreting: Interpreters' Experiences In Cancer Care Settings - Poster</p>	<ul style="list-style-type: none"> Objective: understanding daily practical experience of interpreters in cancer care settings Main themes identified: Clarification of interpreters' roles and duties; interpretation as more than translation of languages; impact of practitioners on interpreter's performance; dealing with family members' presence; and, patients' understanding of care providers'

	<p>message</p> <ul style="list-style-type: none"> • Interpreters face ethical and practical dilemmas and there is a need to review current training programs/standards
Aboriginal Patient Navigator Framework	<ul style="list-style-type: none"> • designed to assist patients/clients and their families to navigate the Ontario cancer system; individual Navigator is hired to work within the Regional Cancer Centre to assist any Aboriginal clients coming through the system • presently coordinated in conjunction with the Aboriginal Cancer Care Unit (ACCU) of CCO
<p>Peer Support: Overview of Support Services offered by the Canadian Cancer Society</p> <p>Wendy McDermid, Director, Program Services Canadian Cancer Society Ph: 790-5808 wmcdermid@sk.cancer.ca</p>	<ul style="list-style-type: none"> • Canadian Cancer Society screens/recruits volunteers who have been diagnosed with cancer in the recent past and volunteers who have been a caregiver to someone diagnosed with cancer; volunteers are trained to provide peer support – to share personal experiences, to offer hope and encouragement, to provide information on practical supports and referrals to services people might require • Learned- closer the match between volunteer and client the better the support • Also provide: practical support (volunteer drivers, financial assistance, wigs/temporary prostheses); information (toll free info service staffed by nurses or social workers M-F 9-18 at 1-888-939-3333); prevention messaging via displays, presentations, website, pamphlets, events; and other services
<p>Aboriginal Patient Navigator Services- Juravinski Cancer Centre</p> <p>M. Lee Styres Loft Aboriginal Patient Navigator 905-387-9711</p>	<ul style="list-style-type: none"> • Aboriginal Needs Assessment (2002), conducted by the Aboriginal Cancer Care Unit, Cancer Care Ontario strongly recommended that Aboriginal Patient Navigator positions be established at Cancer Centres in Ontario • collaborative efforts of the Juravinski Cancer Centre and Six Nations Health Services have resulted in the implementation of the Aboriginal Patient Navigator Project <p>Criteria for a referral to Aboriginal Navigator:</p> <ul style="list-style-type: none"> • Patients and their families who self-identify as having Aboriginal ancestry • Patients who self-identify as being part of an Aboriginal family • Aboriginal cultural needs
<p>"Below Their Notice": Exploring Women's Subjective Experiences Of Health System Exclusion</p> <p>Terry Mitchell, Assistant Professor, Wilfrid</p>	<ul style="list-style-type: none"> • investigate the mechanisms and pathways by which social inequalities in health are generated or maintained in cancer care • examined critical moments in participants' narratives that paralleled one another; findings reveal common themes of exclusion (Not Getting Medical Care, Not Getting Supportive Care) across marginalized populations who are often "below our notice"

Laurier University, Waterloo, ON
Judy Gould, Researcher, Women's College
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Access to Quality Cancer Care & Control
 for Manitoba First Nations

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- there has been minimal investment in producing surveillance and monitoring information across the continuum of cancer care from prevention to palliation for First Nations people
- network theme: develop First Nations Cancer Care and Control Knowledge Translation (KT) Research Process in order to translate, synthesize and mobilize cancer surveillance and monitoring information; and produce comparative surveillance/monitoring information
- Question asked by KT-NET research: “What is the most effective and culturally relevant FIRST NATION cancer care and control knowledge translation research process to reduce the burden of cancer and to improve survivorship and quality of life?”
- network capitalizes on unique administrative and survey databases and a unique partnership structure – will make significant contribution to development of provincial and national cancer care and control models
- team is positioned to: “develop surveillance/ monitoring systems for First Nations; comprehensively investigate factors influencing risk, screening, progression and health service outcomes in cancer; and to create a permanent network and provide the transdisciplinary expertise to produce high calibre researchers capable of working in a cross-cultural environment”

(Palaty, 2008)

Survivorship & Palliation

A. Name/Title of Practice	Native American’s Cancer Survivors’ Support Network
B. Type of Practice (Leading, Promising or	Promising

Best Practice)	
C. General Introduction	<ul style="list-style-type: none"> • Public health program; designed to increase survival from cancer and quality of life post diagnosis • “An educational community-based research study created in 1998 to help improve the quality of cancer care and the quality of life for all American Indian/Alaska Native and First Nations cancer patients and their loved ones.”
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Survivorship (support group) and surveillance (data collected from support group); all cancers
E. Target populations	<ul style="list-style-type: none"> • American Indian/Alaska Natives and Canadian Aboriginal patients and their loved ones; inclusive of on and off-reserve individuals • Initially aimed at breast cancer survivors, but soon expanded to include all cancers
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • Addresses support issues for patients/families dealing with cancer; program aims to learn how cancer is affecting Native communities • Aims to improve quality of life by improving coping, “defined as a process by which individuals adapt to the vast array of demands inherent in the diagnosis of cancer rather than to the diagnosis itself”, through accurate medical information and interaction with those with similar experiences • Connect to network via self-/ provider/ community referral; most referrals come from community members and Native American organization • 3 arms: (1) Service Users [cancer patients], (2) Contributing to Native Knowledge [those who have completed treatment and want to take part in survey], and (3) Loved Ones [providing cancer support to family members and need information/ social support] • Once referred and consent signed, Network provides: Native-specific print and video informational/ <i>support materials</i> and long-distance calling cards mailed to member; the director personally provides <i>one-on-one telephone support</i> or assigns alternate supervisor as contact; <i>assists obtainment of quality cancer care</i> with information on where and how, and counsel given to those who have received inappropriate care; <i>assistance in getting other needed services</i> like food insecurity or comorbidity issues; and, <i>survey</i> so survivors

	can share experience and help others
G. Advantages	<ul style="list-style-type: none"> • Addresses that fact that cancer control is about more than disease treatment; the diagnosis affects every aspect of a patient’s life, and subsequently these stresses impact ability to survive • Opening the dialogue about cancer has particularly large potential among Native American, and Canadian First Nation communities; many of which harbor cultural taboos around discussing cancer; helps to address a cultural barrier to cancer care • Addresses gap in literature about Native-specific cancer experience
H. Limitations or disadvantages - Status of and barriers/successes to implementation	<ul style="list-style-type: none"> • Cultural norms that dictate little or no discussion of cancer are pervasive (ex. to talk about cancer is to invite it, or cancer is a death sentence/ nothing can be done so there’s no point in addressing it) • While patients are referred to network, those who enroll may represent those who take a more active role in their own health; network database may suffer from selection bias
I. Engagement of Native American communities & enrolment numbers	<ul style="list-style-type: none"> • 10 focus groups and 5 working groups with Native American cancer survivors across the US helped inform network development • Native owned non-profit initiated program; designed with committee of 40 Native American cancer survivors • 4 training workshops for Natives conducting cancer programs in Indian country; included survivors, program directors, and providers • 75 informal individual interviews of survivors on the organization and format of the network • Initiated in 1999, had over 300 survivors from the US and Canada enrolled by 2001 (report cited written a 3 year point of a 5 year developmental project)
J. Overview of processes, discussions and/or negotiations used to implement practice	<ul style="list-style-type: none"> • 1994 Native owned non-profit organization called Native American Cancer Research (NACR) received numerous requests from Native American cancer patients for information/ resources/ support for cancer care needs not met by tribal programs; created 40 person “community of survivors” to provide direction regarding the program they wanted/ needed • NACR with “community of survivors”, developed national support network

<p>K. Collaborative relationships, resources or capacity required for development and implementation of the practice</p>	<ul style="list-style-type: none"> • Network run by Native American Cancer Research (NACR); they collaborate with the National Indian Health Board (NIHB), Indian Health Services (IHS) New Mexico, Native CIRCLE of the Mayo Clinic (Minnesota location), and other American Indian/Alaska Native organizations • Through support from the Mayo Clinic’s Sprit of Eagles initiative, expanded from Native American breast cancer patients over 20 to include all cancer sites and support people of all ages and both genders
<p>L. Resources required to develop and implement the practice & history of need and development</p>	<ul style="list-style-type: none"> • Native Americans and First Nation Canadians are experiencing rising cancer rates and poorer survival rates; high “burden of cancer” • Funding from The Department of Defense, Mayo Clinic’s Spirit of EAGLES, The National Susan G. Komen Breast Cancer Foundation, and Native American Cancer Initiatives • Previous supporters include The Breast Cancer Fund, The Avon Breast Health Leadership Award and The Graham Foundation
<p>M. Information being collected in relation to the practice and how this information being used.</p> <p>Alternate ways of sharing information used (e.g., stories, videos).</p>	<ul style="list-style-type: none"> • Qualitative and quantitative research done with Network data is based on Social Networking theory and participatory research methods • Research objectives: (1) identify and recruit Native American cancer patients into survivors’ database with support of Native American cancer leaders from geographically diverse areas; and (2) use database to identify patterns of disease and care experienced by Native American cancer survivors • Data collected includes survey (demographics, social network, emotional/ physical/ spiritual well-being, reaction to cancer treatment, health care, and more), and medical records of histologic grade and diagnostic staging
<p>N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as evaluated by organization responsible</p>	<ul style="list-style-type: none"> • Network data reveals patterns of cancer care; gaps shown are partially responsible for poor survivorship among Native Americans and First Nations people • Element of successful development/ practice/ on-going research: viewing community members as shareholders/partners and not simply as “participants” in a study • Self-administered surveys deemed unacceptable by participants; telephone interviews performed • Findings include information on insurance coverage (less than 1/3), types of surgery received, lack of established protocols in some regions, and intervals between diagnosis and treatment (average 3-6 months)

	<ul style="list-style-type: none"> 90% five-year survival rate for breast cancer patients who had been working with the director (n=85), while NCI SEER data report approximately 48% survival for Native Americans; granted this is a small sample, it appears that Network efforts helped women find better and/or broader care
O. Transferability of practice to communities and/or jurisdictions.	<ul style="list-style-type: none"> Enrollment of people from wide variety of cultures, and geographic areas is testament of its transferability
P. Contact information.	<p>Native American Cancer Research about the Network: http://natamcancer.org/community.html</p> <p>For information about the Survivors' Network, including educational modules: Phone: 303-838-9359 Or, call toll-free at: 1-800-537-8295</p>

(Burhansstipanov et al., 2001)

A. Name/Title of Practice	Native People's Circle of Hope (NPCOH)
B. Type of Practice (Leading, Promising or Best Practice)	Promising
C. General Introduction	<ul style="list-style-type: none"> "[Their] mission is to help Native American Cancer survivors, their family members and care givers understand that they are not alone." Primary goal: advocate for quality cancer care for Native cancer survivors; done through local coalition of Native focused cancer support groups NPCON provides "Medicine Bags", transportation assistance, and culturally appropriate print materials for newly diagnosed Is a corporation and coalition of Native American cancer support groups
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> Survivorship; all cancers

E. Target populations	<ul style="list-style-type: none"> • Native Americans all over the US; on and off-reserve; male and female
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • Have chapters in Alaska, Idaho, Oklahoma, Oregon, Arizona and nationwide affiliates • Native American cancer survivors, caregivers, or family members (caregivers/ family members not excluded if non-native) can enroll by phoning the program or signing up on the NPCOH website • Membership services include: reduced registration fee at the annual Roots of Strength Conference for cancer survivors, family members and caregivers; free email account; newsletter; and, free training • Training offered by NPCOH: how to start your own cancer support group; understanding and completing advance medical directives; understanding and completing information releases; and, how to be your own advocate – training apparently offered periodically and travel scholarships are available, however website calendar reveals no recent or upcoming training • Individuals/groups can form local chapter anywhere in the US, chapter requirements include: Minimum 2 members, pay annual \$100 fee (per chapter, not per person), designate chapter president who serves as representative at NPCOH activities, and agree to follow NPCOH financial and administrative policies • Decisions made by each chapter: Who will be a member, what support is provided to newly diagnosed, method of funding, and other decision made to help cancer survivors/ family members/ care givers • “Medicine bag” contents include a cloth bag to hold the pills, thermometer, calendar, paper and pen, hat, tissue, chewing gum, tape cassette, eye cover and other donated items; also includes are two items made by other cancer survivors/ supporters – a beaded necklace and the a lap quilt “With the two handmade gifts [they] pass on to the new diagnosed patient the strength, love and caring of the person making the gift. [They] ask that the maker not work on their gift if they are not feeling in good health.”
G. Advantages	<ul style="list-style-type: none"> • Provides resources so that Native Americans can develop a local support network that

	suits their communities preferences/ needs, with the support of/in coordination with a larger network
H. Limitations or disadvantages - Status of and barriers/successes to implementation	<ul style="list-style-type: none"> • Website information is incomplete, and furthermore much of their target population lacks access to computers and/or internet; little published information on NPCOH; other methods of advertisement unclear • Unless website has just not been updated; it appears that training/ activities have ceased
I. Engagement of First Nations, Inuit and/or Métis communities & Enrolment numbers	<ul style="list-style-type: none"> • Founder and director of NPCOH is Cece Whitewolf: cancer survivor who shut down her law practice to pursue development of cancer support network for Native Americans, by Native Americans
J. Overview of processes, discussions and/or negotiations used to implement practice	
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • Partners with tribal, native and non-native organizations to raise awareness about needs of native cancer survivors among health policy stakeholders
L. Resources required to develop and implement the practice & history of need and development	
M. Information being collected in relation to the practice and how this information being used. Alternate ways of sharing information used (e.g., stories, videos).	
N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as	<ul style="list-style-type: none"> • Local chapters are key because to feel supported survivors need to “see” the helper; face to face has greater impact than telephone contact; emailing and computer contact not

evaluated by organization responsible	effective
O. Transferability of practice to communities and/or jurisdictions.	
P. Contact information.	<p>Celeste (Cece) Whitewolf Director of Native People's Circle of Hope (A coalition of Native cancer survivors and support groups.)</p> <p>9770 SW Ventura Ct. Tigard, OR 97223</p> <p>admin@nativepeoplescoh.org</p> <p>(503) 970-8004 (503) 245-2253 fax</p> <p>www.nativepeoplescoh.org</p>

A. Name/Title of Practice	Telehealth for Cancer Support Groups in Rural American Indian/Alaska Native Communities
B. Type of Practice (Leading, Promising or Best Practice)	
C. General Introduction	
D. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> Survivorship through support groups; all cancers

E. Target populations	<ul style="list-style-type: none"> • Rural dwelling American Indian/Alaska Natives in Washington and Alaska Natives in Alaska; on reserve
F. Description of Practice: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	<ul style="list-style-type: none"> • Support groups broke sir winter holidays and summer activities • Meetings led by an urban based facilitator; either from Alaska Native Tribal Health Consortium in Anchorage, the University of Washington in Seattle, or the Fred Hutchinson Cancer Research Center in Seattle; each site had a local meeting coordinator (nurses/ social workers/ tribal members who were cancer survivors) • Videoconference usually set up in rural tribal clinic conference room (technical support for setting up/ using videoconferencing software available from the university site) • Meeting usually 2 hours long and held monthly • Participants: survivors, and their family and caregivers • Meeting content varied, included group counseling, education programs (used Cancer 101 modules – described above), other presentations by content experts, and information on desired topics solicited from participants at the first meeting (ex., pain management, psychological support, clinical/ legal EOL issues) • Video conference software made use of voice-activated technology; so at all sites whomever was speaking appeared onscreen •
G. Advantages	<ul style="list-style-type: none"> • Distance from participating remote sites to nearest available in-person support group was 39-1190 miles, and air-travel would have been the only way to reach nearest in-person support group for most individuals • Connecting with other cancer survivors is very important to patients – this may be even more important in small, isolated rural communities where survivors are typically fewer in number
H. Limitations or disadvantages - Status of and barriers/successes to implementation	<ul style="list-style-type: none"> • Lack of hardware/ internet connection/ computer proficiency in some areas were a challenge • No of male support group participants; speculated cause was differing cultural norms for self-expression for men and women and/or discomfort with mixed gender groups (although, support groups are predominantly female for most racial groups and those of varied socio-economics status)

	<ul style="list-style-type: none"> • Survey sample was small, and included American Indian/Alaska Native people from only 2 states • Self-reported data used; inaccurate • Self-selection bias
I. Engagement of First Nations, Inuit and/or Métis communities & Enrolment numbers	<ul style="list-style-type: none"> • 12 support group meeting between Feb. 2008 and Sep. 2008 • In total 25 rural tribal sites in Washington and Alaska participated • Ave. 6 sites/ meeting • Range of attendees/ meeting was 6-57; average 36 • Range of attendees/ site/ meeting was 2-11
J. Overview of processes, discussions and/or negotiations used to implement practice	
K. Collaborative relationships, resources or capacity required for development and implementation of the practice	<ul style="list-style-type: none"> • Support groups are a component of the Native People for Cancer Control Telehealth Network (NPCCTN) described above
L. Resources required to develop and implement the practice & history of need and development	<ul style="list-style-type: none"> • Videoconference hardware and software required, in addition to adequate internet connection; some technical assistance/ training was also needed • Geographical barriers, and low population density meant that in most sites, before the videoconferencing, support groups were completely unavailable to villagers diagnosed with cancer
M. Information being collected in relation to the practice and how this information being used. Alternate ways of sharing information used (e.g., stories, videos).	<ul style="list-style-type: none"> • After 5th meeting, surveyed 50 survivors via phone/ email/ mail (allowing for varying literacy levels); collected data on demographics, Telehealth Satisfaction Survey (Health Canada, 2007), and open ended questions; 32/50 responded; all were female
N. Key learnings or outcomes to date - Evidentiary efficacy or impact, as	<ul style="list-style-type: none"> • Survey found that vast majority of survivors were diagnosed at late-stage, most had breast followed by lung cancer, nutrition was a top informational need, side effects/

<p>evaluated by organization responsible</p>	<p>general cancer information/ cultural issues related to cancer also informational needs, and high levels of satisfaction with the facilitation of the support group</p> <ul style="list-style-type: none"> • Over a course of several months, participants from western Washington and throughout Alaska were able to develop a level of comfort and trust – important elements of a useful support group • Participants benefited from learning that they were not alone • Participants were satisfied with audiovisual quality of videoconference; on-site local coordinator who was proficient in use of the hardware/software enhanced satisfaction • Videoconferencing found to be a viable method for delivering support group meeting to rural/isolated American Indian/Alaska Native communities
<p>O. Transferability of practice to communities and/or jurisdictions.</p>	<ul style="list-style-type: none"> • Although the program addressed gaps/ barriers that are shared by First Nations/ Metis/ Native Americans throughout the continent, the sample consists of people from only 2 states, and may not be entirely generalizable to the broader indigenous peoples community • Telehealth is always worth considering when dealing with isolated communities/ geographical barriers
<p>P. Contact information.</p>	<p>Author Contact: Ardith Z. Doorenbos, PhD, RN, FAAN, can be reached at doorenbos@u.washington.edu, with copy to editor at CJONEditor@ons.org.</p>

<p>I. Name/Title of Model</p>	<p>Helping Hands</p>
<p>II. Type of Model (Leading, Promising or Best Practice)</p>	<p>Leading</p>
<p>III. General Introduction</p>	<ul style="list-style-type: none"> • “Developed end-of-life care services for 32 Alaskan Native villages throughout a 47,000-square-mile area of Bristol Bay (BBA), building on existing networks.” • Offers EOL care that combines cultural practices with contemporary palliative care measure in order to allow Alaska Natives to be cared for at home through end of life

	<ul style="list-style-type: none"> • Village-focused program delivers multidisciplinary care through the combined efforts of volunteers and primary care givers, with a regionally based physician and home health nurse
IV. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Palliation; all life-limiting cancers
V. Target populations	<ul style="list-style-type: none"> • Alaska Natives living in the Bristol Bay region (34 villages in southwest Alaska); on reserve
VI. Program/ service/ resource history of need and development	<ul style="list-style-type: none"> • Due to lack of services most Alaska Natives were dying alone in hospitals or nursing homes hundreds of miles from home; nearest tertiary care hospital is in Anchorage (329 air miles away) • In a 1994 survey 84% of BBA community health aids/ physicians (CHA/Ps) expressed desire for palliative care training • Advisory group of agency reps, nurses, Alaska Native villagers, physicians, and others, helped design the program • Lack of success with past use of mainstream program materials led to creation of culturally sensitive materials • Program principle investigator and volunteer coordinator met with tertiary (Anchorage) hospital medical, nursing and social service staff to explain Helping Hands and ensure program awareness
VII. Engagement of Native Americans & enrolment numbers	<ul style="list-style-type: none"> • Developed and gave out “beautifully crafted, culturally relevant” journals used by patient and family to record histories/stories/wisdom; reflected traditionally high value placed on elders for their wisdom • Villagers included in program development advisory group • Focus groups with elders from 3 different BBA cultures held for input on program design and materials (support requested from tribal councils before meetings were held); focus groups facilitated by medical anthropologist who had worked with area senior service programs • Community volunteers and their paid coordinator were Alaska Natives • Nurse coordinator interviewed villagers for program evaluation
VIII. Description of Model: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience	

and horizontal integration of services

- Grantee site: Bristol Bay Health Corporation, Dillingham, AK
- Average length of patient stay >365 days; longer than expected life once patients returned to home village
- Helping Hands model based on Alaska’s successful emergency medical service model; involves trained volunteers/caregivers in villages under medical direction/technical assistance from central location (Dillingham- small IHS hospital in BBA, or Anchorage- tertiary hospital)

Elements of Helping Hands service delivery:

- Identify primary caregiver for each patient, and training village-based workers in EOL care
- Home health nurse visited patient in home regularly and provided telephone support
- Individualized care plans incorporated basic village resources (physical, occupational, and respiratory therapy not available)
- Treatment focus was pain and symptom management in combination with training for family , care providers and volunteers
- Patients most often referred to Helping Hands by physicians, but can also be referred by other health care providers, families, friends, or social service agencies
- Once referred needs are assessed (durable medical equipment, pain management, physical assessment, caregiver ability/stability, need for/acceptance of services and volunteer assistance); patient goals are determined; individual care plan developed that supports village lifestyle; trust is established
- Nurse works with physician who orders medications; nurse visits weekly and provide phone/radio support between visits; volunteers/community health aids provide support and information when nurse is not in village; during evenings/weekends caregivers can call tertiary center and speak to nurse/physician
- Physicians see patients in the village during scheduled visits (4-5 times/year)
- When trust is established, nurse discusses DNRs and living wills with family
- After death, nurse follow-up visits for grief support; nurse often attends funeral (if asked); no funeral home so nurse often asked to assist with the body
- Notable component of volunteer work: Peer Helpers is a state funded substance abuse and suicide prevention program that recruits and trains youth volunteers in support care; they help elders with chores and respite care, and recording stories/wisdom in Helping Hands journal (important mode of cultural preservation since many elders do not write)
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IX. Barriers to implementation/ limitations

- Because of weather, terrain, and distance, most villages are airplane access only
- Communities are small, and community health aids are usually related to many residents; confidentiality is a difficult issue
- Getting durable medical equipment into villages was prohibitively difficult

	<ul style="list-style-type: none"> • Unable to meet federal regulations for hospices; require nurses to be able to reach patients in under an hour, which is impossible in most of the region; therefore ineligible for Medicaid reimbursement • Staff turnover caused delays; challenges associated with developing nation conditions, constant travel on small planes, and coordinating care with very limited resources was difficult for staff • Focus groups were cancelled/ rescheduled due to weather • Subsistence living and associated seasonal out of village hunting and fishing meant few/none were available to stay and care for elders during these times
<p>X. Key learnings, evidentiary efficacy or impact</p>	<ul style="list-style-type: none"> • Focus groups with elders produced information key to program/material design • Once program was active, Elders moved back home from Anchorage (where they had emigrated for care), and physicians at tertiary center allowed patients to go home since EOL care was now available in the community • Before program in 1997, 33% of those with life-limiting-illness (mostly cancer) had home deaths; by 2001 (program initiated 1999) figure rose to 77% (62% were Helping Hands patients) • Incorporating EOL care into existing health care delivery increases scope and enhances generalizability • Soliciting community input during development essential to community buy-in, plus on-going input on what is/isn't working • Families reported high satisfaction; valued having one place to call for all care questions/concerns/needs • Program has been maintained past grant funding period in Bristol Bay; furthermore, Alaska Native Tribal Health Consortium (ANTHC), based in Anchorage, have received \$1.6m (USD) from National Cancer Institute (NCI) to replicate the program and provide palliative care training program for health care providers of Alaska Native throughout the state • “ most important finding ... is that contemporary palliative care combined with traditional customs can create a cost-effective, culturally sensitive, palliative care program”
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(Byock et al., 2006), (DeCourteny et al., 2003)

I. Name/Title of Model	
II. Type of Model (Leading, Promising or Best Practice)	When Cure is No Longer Possible Leading
III. General Introduction	<ul style="list-style-type: none"> • University of New Mexico (UNM), Health Sciences Center with the Zuni Home Health Care Agency (ZHHCA) and the Zuni Comprehensive Community Health Center were awarded grant funding from the RWJF Promoting Excellence in End-of-Life Care program • Demonstration project “Created a palliative care network in 7 rural communities within 3 distinct subcultures in collaboration with hospices, and assisted the Zuni Home Health Care Agency (ZHHCA) in establishing a Native American palliative care program.” • UNM did not provide direct care, but aimed to develop state-wide Palliative Care Education and Training (PERT) office; Indian Health Service aim was to create a certified hospice in Zuni Pueblo (1 of the 7 PERT network communities) → the following model description will focus on the Zuni palliative care model
IV. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Palliation; all life-limiting cancers
V. Target populations	<ul style="list-style-type: none"> • Native American patients with life-limiting illness (leading diagnoses were cancer, end-stage dementia, and end-stage renal disease) in the Pueblo of Zuni, New Mexico
VI. Program/ service/ resource history of need and development	<ul style="list-style-type: none"> • Formal palliative care service is largely unavailable to rural/reserve dwelling American Indian/Alaska Natives • Dramatic increase in life expectancy of American Indian/Alaska Native people due to advances in infectious disease control has meant climbing chronic illnesses and associated demand for palliation

<p>VII. Engagement of Native Americans & Enrolment numbers</p>	<ul style="list-style-type: none"> • Entire region is a health care shortage area; there was no formal organization of care for the dying and none of the medical, nursing, or aid staff had formal palliative care training • This effort was a response to a request for proposals born within the community; it reflected the values and needs of the Zuni community (as opposed to being introduced from outside) • Acceptability of proposed palliative services, and strategies for language use in implementation were discussed at the home tribal health agency • Formal survey developed with Cultural Advisory Committee; collected community member input on service needs, the caregiving process, and communication issues (between/within families and professionals) • Zuni Pueblo, with population on 10,000 on 400, 000 acres in one of the oldest and largest continuously occupied Indian villages in the US; their demographics are representative of many other American Indian/Alaska Native groups, many speak their own language, and traditional ceremony/medicine practice is common • Albuquerque Indian Health service was a full partner in this project
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VIII. Description of Model: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services

Elements of hospice design:

- Consistently demonstrate respect for cultural beliefs regarding death/dying
- Self-sustaining; meet federal and state Medicare/Medicaid hospice provider guidelines to obtain reimbursement
- Palliation is part of continuum of quality EOL care, integrating local IHS hospital and staff
- Potentially serves as model for culturally appropriate, proficient, financially viable, quality EOL care in other rural American Indian/Alaska Native/ Alaska Native communities

Role of the Zuni Home Health Care Agency:

- Identify community’s palliative care needs
- Create culturally appropriate tools
- Develop administrative capacity and staffing capacity necessary to be Medicare/ Medicaid certified
- Acquire charitable funding for those ineligible for Medicare, Medicaid or private insurance
- Train staff in palliative care
- Secure contracts with IHS hospital for pharmacy, physical therapy, and part-time hospice medical director services

Role of Zuni Comprehensive Community Health Center:

- Provide palliative care training for hospital-based medical and nursing staff who give EOL care
- Develop contract for provision of inpatient hospice care to meeting requirements of Medicare/ Medicaid hospice benefit
- Develop inpatient hospice care policies and procedures
- Acquire palliative care formulary resources
- Support ZHHCA through informal technical consultation, and, where possible, provision of professional staff on contract basis

Role of New Mexico Health Science Center (UNM):

- Provide clinical and administrative training to ZHHCA and IHS hospital staff
- Provide technical assistance for development of culturally appropriate hospice tools (ex., clinical evaluation tools, consent forms)
- Provide technical assistance for community consultation process (survey)
- Provide funding to help coordination between ZHHCA and rural New Mexico hospice network

<p>IX. Barriers to implementation/ limitations</p>	<ul style="list-style-type: none"> • Zuni have cultural guidelines that dictate how death is talked about and how the dying are dealt with; while need for improved end-of life services is clear, how to deliver it in a culturally acceptable framework (which is essential) was unclear • Cultural underpinnings and literacy levels made development of meaningful survey tool difficult • Rurality meant limited availability of health human resources (obtaining and retaining professionals is extremely difficult), prohibitive travel requirements for professional training, and limited communication infrastructure; despite 2 years of advertising, Zuni unable to attract a hospice nurse necessary for certification and subsequent funding • Small agencies (like ZHHCA) have very limited administrative resources • When collaborating, must deal with as many sets of governing regulations and policies as organizations • Most significant challenge reported is lack of adequate reimbursement (funding) to meet patient needs
<p>X. Key learnings, evidentiary efficacy or impact</p>	<ul style="list-style-type: none"> • Lessons learned: <ul style="list-style-type: none"> ○ post death “Family Interviews Questions” for evaluation are useful and exportable; knowledge about breaking bad news, roles of family caregivers and culture is transferable ○ Continuing education for health provides necessary to maintain quality care

- Local tribal leadership must lead development
- Effective reservation-based EOL care program will cross multiple boundaries and involve multiple agencies
- Flexibility/ cooperation on part of local health system needed to deal with staff shortages
- Communities need support of region hospice networks and university/tertiary centers
- Developed a visual analogue pain scale applicable to all clinical settings, and adapted it to local languages
- Project details have already been solicited by many organizations/conferences including the IHS Leadership Council which lead to funding of national team training in palliative care and at that national event hospice project was presented as model for potential replication at other IHS sites; the model address challenges common to rural communities of non-majority culture
- Project was maintained past grant period and even expanded to include palliative care section in geriatric department, palliative care fellowship program, and telemedicine program for family medicine residents
- Advice from project staff: “Patience and then some.”

XI. Contact information.

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Project synopsis: <http://www.mywhatever.com/cifwriter/content/41/pe1255.html>

(Finke et al., 2004), (Byock et al., 2006)

I. Name/Title of Model

Rural Palliative Care Model (RPCM) in Western Australia (WA)

II. Type of Model (Leading, Promising or Best Practice)

Leading (no evaluation available yet, but model clearly address gaps in palliative care)

III. General Introduction	<ul style="list-style-type: none"> • RPCM is a quality improvement framework; supplements the Palliative Care Model of Care • Goal: “develop sustainable regional palliative care services that will meet the criteria for, at minimum, Palliative Care Australia specialist palliative care Level 1 service capability and resources to provide palliative care according to the needs of patients and families in their local community.”
IV. Phase(s) of cancer continuum and types of cancer(s) addressed	<ul style="list-style-type: none"> • Palliation; all cancers
V. Target populations	<ul style="list-style-type: none"> • Rural palliative care patients in Australian state of Western Australia – with special attention to Aboriginals/ Torres Strait Islanders (Indigenous Australians)
VI. Program/ service/ resource history of need and development	<ul style="list-style-type: none"> • Palliative care (PC) in WA developed in an ad hoc way, leading to inconsistencies in palliative care coordinator roles and fluctuating levels of integration/coordination across rural health region • Literature reflects patient desire for homecare, especially at end of life • Indigenous Australians have higher mortality rates, yet 70% of services in WA did not provide palliative care to Indigenous patients over year leading up to model study • Insufficient planning of governance structure regarding PC • Rural service require PC implementation education and improved clinical pathways • Palliative Care Network analyzed the Rural Audit to develop RPCM
VII. Engagement of Aboriginals/ Torres Strait Islanders & Enrolment numbers	<ul style="list-style-type: none"> • Indigenous organizations consulted on community palliative needs, health care providers who work with Indigenous Australians interviewed, but specifics not given in model description
VIII. Description of Model: location/ partners/ stakeholders/ jurisdiction/ support of holistic health/ contribution to community resilience and horizontal integration of services	
<p>Foundational principles of RPCM (same as Palliative Care Model of Care):</p> <ul style="list-style-type: none"> • Service provision for patients with life-limiting illness, regardless of diagnosis • During illness, meet palliative care need of patients and their families • Deliver care in hospital, palliative care unit, residential care or home 	

- Identify partnerships between palliative care specialists and primary care providers

Principles of special importance to rural/remote areas:

- Palliation is multidisciplinary and an integral part of health care system
- Patients with life-limiting illness can access quality care that meets their needs and is provided by staff that is both adequately trained and support by palliative care specialist
- Spending as much time as possible at home and in community is a right of patients with life limiting illness – so, where possible follow-up care will be provided in local community settings, or with telehealth, to avoid any unnecessary travel and its associated burden to patients and their families
- Patients will experience care that is coordinated across settings and providers
- Palliative care is culturally appropriate

RPCM recommends a framework, to be applied by each of WA Country Health Service (WACHS) regions – key elements:

- Regional governance → each region will have a Steering Committee comprised of stakeholder such as residential care, Aboriginal Medical Services, private health services, public hospitals, community services, general practice, visiting palliative care medical specialist, Regional Coordinator, Home and Community Care, mental health services, and allied health
 - A regional coordination role for each WACHS region → model of coordination according to region, but coordinator will be responsible for standard of clinical care and alignment of processes, protocols and systems across the region
 - Local care coordination → each patient will have an identifiable single point of coordination to ensure they have a comprehensive care plan, and are all tracked on one information system within a region
 - A PRN approach to care for unique cases → could involve accessing training to address a unique/novel need associated with a particular case
 - Access to medical care → each patient will have a general practitioner or medical officer locally, and each region will have sustainable plan of access to best practice palliative care
 - Regional multidisciplinary palliative care special interest groups → multidisciplinary group of key service providers and stakeholders that will ensure communication/coordination, clinical reviews, workforce issues, professional development, consistency in
-

policies/protocols, community awareness, volunteer support, special needs are met, effective equipment use, and service evaluation

- Statewide rural palliative care special interest group → will provide feedback to WACHS on governance, clinical, and rural issues; will ensure that palliative care adheres to consistent standards and remains a topic of focus
- Formal links with urban palliation specialists → palliation specialists will strengthen primary care giver skills through education and mentorship; Telehealth will allow access to ongoing consultation
- Indigenous palliative care partnerships → partnerships at regional level with Aboriginal Health Service and communities to facilitate holistic and culturally appropriate and palliative care for Indigenous people

IX. Barriers to implementation/ limitations	<ul style="list-style-type: none"> • Plan for model implementation must be planned; suggested coordination between WACHS, Palliative Care Network and local service providers • Need a state-wide PC education curriculum to provide health professionals with PC training • Strategies to provide culturally appropriate Indigenous palliative care must be developed with Aboriginal Health Services and other Indigenous health stakeholders • Higher burden of disease among WA rural residents; related to higher proportion of Indigenous Australians who experience higher rates of mortality (and deaths involve higher rates of co-morbidity)
X. Key learnings or evidentiary efficacy or impact	<p>Too soon for model to have been fully implemented and/or evaluated (and certainly long term health benefits cannot have accrued yet). Model was designed based on evidentiary literature and needs assessment to address gaps in current model (or lack of state-wide model).</p>
XI. Contact information.	<p>WA Palliative Care & Cancer Network Level 1, 1 Centro Ave Subiaco Western Australia 6008</p>

(Department of Health, State of Western Australia, 2008)

Operational definitions

Term	Operational definition
Aboriginal Peoples	Indigenous peoples including First Nation's peoples on and off reserve, Métis and Inuit (CPAC, 2008)
Access	"availability of services" or the "provision of services in a way that is both responsive to the needs of users and open to the participation in planning of services by underserved groups" (CPAC, 2008)
Best practice	<ul style="list-style-type: none"> • a specific action or set of actions with proven evidence of success • has potential for replication or adaptation • evidence of success demonstrated through qualitative and quantitative information (SEHC)
Cancer System	<ul style="list-style-type: none"> • A system designed to deliver care. It is made up of various oncology specialists, other care providers (paramedical and non-medical), and agencies concerned with care of the patient throughout the cancer spectrum, from pre-diagnosis through to diagnosis and treatment, to post-cancer care, survivorship, palliative care and bereavement • an "objective identity" in that it offers the same services to all Canadians; however, each Canadian <i>may</i> approach the cancer system from a different, individual perspective which could influence their care (CPAC, 2008)
Community	<ul style="list-style-type: none"> • a group of people • notoriously elastic term, meaning many different things to different people in different contexts; can be identified as such by its members, or be ascribed by outsiders; can be based on geography, identity, activity, specific goals, status, or social, economic, or political ideology or affiliation (CPAC, 2008)
Cultural competency	A set of behaviours, attitudes and policies that come together as a system, agency or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations ⁴⁵ . The phrase 'cultural competency' refers to the abilities of caregivers and organizations to respond respectfully and effectively to the unique needs of all patients and families. The term is often used interchangeably (but there are inherently different concepts and these should be recognized) with that of cultural safety, cultural awareness, cultural sensitivity, and others. (CPAC, 2008)
Culturally Competent	incorporates culturally sensitive, relevant, appropriate, acceptable concepts (Burhansstipanov,1999)

Culturally Relevant	specifically targeted to a definite culture (Burhansstipanov,1999)
Culturally Sensitive	respectful of the specific culture’s beliefs, practices and so on (Burhansstipanov,1999)
Culture	“a dynamic system of rules, explicit and implicit, established by groups in order to ensure their survival, involving attitudes, beliefs, norms and behaviors shared by a group but harbored differently by each specific unit with the group, communicated across generations.” (Matsumoto, 2000)
Ethnicity	broad groupings of Americans on the basis of both race and culture of origin” (Phinney, 1996)
Isolated	no year-round road access; air access by scheduled or non-scheduled flights; telephone and/or radio services (SEHC) *
Leading model	<ul style="list-style-type: none"> • define the focus, philosophical basis, and resulting structure/infrastructures and processes needed to provide care such as the medical model of care (disease based) or First Nations model of care (tradition based) • should be balanced across the cancer care continuum, and include the coordination of cancer care pathways between reserve-based primary care and cancer treatment centres (SEHC)
Leading practice	<ul style="list-style-type: none"> • have shown to be at the forefront of change and address important barriers or gaps • Leadership may include formal evaluation and peer-reviewed publication; a lack of formal evaluation will not exclude a practice from being considered leading (SEHC)
Métis	<ul style="list-style-type: none"> • In Ontario and west, the following definition applies: “<i>Métis means a person who self-identifies as Métis, is distinct from other Aboriginal peoples, is of historic Métis Nation ancestry, and is accepted by the Métis Nation.</i>” • In Quebec and east, each region has its own definition. The Métis population in the province of Quebec is comprised of all the ones that identify as Metis, according to the community based citizenship code for the Métis Nation in the province of Quebec. <p>(Source: http://nationmetisquebec.ca/html/eng/quebec-metis-nation/quebec-metis-nation.htm)</p> <p>(SEHC)</p>
Ownership, Control, Access, and Possession (OCAP)	<ul style="list-style-type: none"> • set of principles developed to ensure ethical and beneficial research that conforms to the cultures and needs of Aboriginal communities and serves to value and preserve

	<p>indigenous knowledge bases (Mitchell & Baker, 2005)</p> <ul style="list-style-type: none"> • a set of principles in evolution, and not an Aboriginal methodology (Schnarch, 2004)
Patient Navigation	a process that provides support and information to cancer patients, their families, survivors and health professionals through the cancer continuum (CPAC, 2008)
Participatory Action Research	systematic inquiry, with the collaboration of those affected by the issues being studied, for purposes of education and taking action or effecting social change (Green et al., 1995)
Promising practice	a specific action or set of actions that demonstrated potential of becoming a best practice, but requires further documented evidence of success (SEHC)
Remote	road access 20- 90 km to physician services (SEHC) *
Rural	road access greater than 90 km to physician services (SEHC) *
Transformational model/practice	
Underserved or Vulnerable populations	those who are at risk of poor health outcomes as a consequence of systemic barriers for equity in access to care services (CPAC, 2008)

*In most of the literature specific distances were not reported, so the terms rural/remote/isolated were used in the way each author used them within their article

Culturally Responsive Resources and Services

In order to effect positive change in cancer control among any population, the message and the media used to present it must resonate with the end-user. In light of this, many organizations are producing resources or providing services that invite the attention of First Nations and Metis peoples. The two following quotes illustrate the importance of cultural responsiveness in cancer control.

“It is also widely recognized that any strategies for cancer prevention and control need to incorporate an understanding of Aboriginal concepts of cancer and its prevention, and sensitivity to cultural barriers.” (Young, Kliewer, Blanchard, & Mayer, 2000; Barroetavena & Myles, 2005)

“Five key levers that must be addressed to move the agenda forward:

- Changes in attitudes and culture
- Providing information appropriate to individuals’ needs
- Holistic assessment and care plan delivery and evaluation
- Support for those living with and beyond cancer
- Appropriate measurement to ensure effective service delivery” (CCO, 2009)

Below is a listing of Canadian culturally responsive resources and services identified through the search and review peer-reviewed and grey literature.

- **Aboriginal Tobacco Program** of Prevention and Cancer Control, Cancer Care Ontario: resource page of website offers fact sheets, posters and radio recordings on smoking education and prevention
Website: <http://www.tobaccowise.com/resources/>
- **At Your Side Colleague Cancer Care Course**
Provided by Saint Elizabeth Health Care
Website: <http://www.atyourside.ca/>
- **Breast Cancer Tool Kit for Aboriginal Health Care Providers**
Breast Tumour Group Secretariat BC Cancer Agency
- **Cancer Care makes podcasts of workshops available online** (while they do not specify any specifically designed for First Nations, Métis, or Inuit, the podcast format could be useful to rural cancer patients with informational needs):
http://www.cancercare.org/connect_workshops#past_workshops
- **Cancer Info-Kit for First Nations of Quebec: For Caregivers Working With First Nations Populations** (2011)
This document was produced by the:

First Nations of Quebec and Labrador Health and Social Services Commission
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250, place Chef Michel Laveau, Suite 102
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Website: www.cssspnql.com

- **Cancer View Canada First Nations, Métis and Inuit** website:
http://www.cancerview.ca/portal/server.pt/community/first_nations%2C_inuit_m%2C3%A9tis/484
- **Cancer Word Book with Severn Ojibwe (Oji-Cree) Equivalents:** tool developed by the Regional Cancer Care's Aboriginal Cancer Committee and distributed by Thunder Bay Regional Health Sciences Centre. Available at:
http://www.cancerview.ca/idc/groups/public/documents/webcontent/fnim_kc_learn_wordbk.pdf
- **Chee Mamuk Aboriginal Program** – BC Center for Disease and Control: this is a program focused on sexual health, but it is included here for the close relationship between STI testing and cervical health/cervical cancer screening
 - **Mission:** “Chee Mamuk is a provincial Aboriginal program that provides innovative and culturally appropriate sexually transmitted infection (STI), Hepatitis and HIV training, educational resources, and wise practice models. Chee Mamuk’s services are grounded in community, tradition and science in order to promote healthy sexuality and build capacity in Aboriginal communities to prevent the spread of HIV, Hepatitis, and STIs.”
 - **Website:**
<http://www.bccdc.ca/SexualHealth/Programs/CheeMamukAboriginalProgram/default.htm>
 - **Education materials, DVDS, and youth materials available for order at:**
<http://www.bccdc.ca/SexualHealth/Programs/CheeMamukAboriginalProgram/CheeMamukEdMaterials.htm>
- **Clear the air: Protect yourself and your family from second-hand smoke**
 - Canadian Cancer Society
 - Available in Ojibwe and Oji-Cree
 - PDFs available at: http://www.cancer.ca/Canada-wide/Publications/Cancer%20information%20in%20other%20languages.aspx?sc_lang=en
- **Early Detection and Screening: Facts for Men**
 - Canadian Cancer Society
 - Available in Cree, Ojibwe and Oji-Cree

- PDF available at: http://www.cancer.ca/Canada-wide/Publications/Cancer%20information%20in%20other%20languages.aspx?sc_lang=en
- **Echoes of the sisters** [videorecording]: Breast cancer: First Nations women. (2003). [Video/DVD] Vancouver B.C: Motion Visual.
- **First Nations Breast Cancer Society**: a non-profit organization registered in the province of British Columbia since July 04, 1995; mandate is to offer breast cancer education and support to First Nations women; website offers information on breast cancer, healing circles, videos, events, volunteering, testimonials, and more
Website: <http://www.fnbreastcancer.bc.ca/frames.htm>
- **Holding our own** [videorecording]: Strategies during pregnancy & motherhood to stop smoking. (1998). [Video/DVD] Toronto: Magic Lantern Communications.
- **In Their Own Words: The Cancer Journey**
Video: designed to “demystify cancer and provide culturally appropriate cancer information through the voices of First Nations, Métis, and Inuit cancer survivors.”
Video available for viewing at:
http://www.cancer.ca/ontario/support%20services/videos.aspx?sc_lang=en
- **Inside and out** [videorecording]: A tobacco video education project. (2003). [Video/DVD] Edmonton: Nechi Training, Research and Promotions Institute.
- **Let’s take a stand ... Against colorectal cancer! Toolkit**: materials developed by Cancer Care Ontario – Action Cancer Ontario, the toolkit contains culturally relevant evidence based resources and materials to help health providers/educators to inform Aboriginal communities about the need for colorectal cancer prevention and screening using the province’s branded Fecal Occult Blood Test (FOBT); includes colorectal cancer symptom wheel, educational playing cards, 3 different posters, a reference manual, facilitator’s guide, and a CD with electronic copies of materials plus a PowerPoint slide deck
Toolkit contents and ordering information available at:
<https://www.cancercare.on.ca/cms/One.aspx?portalId=1377&pageId=43795>
- **National Indian & Inuit Community Health Representatives Organization (NIICHO)**
national non-profit charitable organization representing First Nation and Inuit Community Health Representatives in Canada: Website’s resource page offers PowerPoint slide decks, speaking notes, educational kits and facts sheet on a variety of health issues, including smoking cessation, nutrition and exercise
Website: <http://www.niichro.com/2004/?page=resources&lang=en>
- **One breath at a time** [videorecording]: Aboriginal people, tobacco and change. (2003). [Video/DVD] Vancouver, B.C: Gryphon Productions.

- **One breath at a time** [videorecording]: Aboriginal people, tobacco and change. (2006). [Video/DVD] West Vancouver, BC; Toronto, Ont: Gryphon Productions; distributed by Kineticvideo.com.
- **Papalooza**: Street Nurse Program that operates in Vancouver hosts Papalooza in the downtown east side annually or biannually (since 2002); nurses screen between 50 -100 women per day at the 3 day event; participants have been up to 42% Aboriginal (Black, 2009)
CDC's Street Nurse website:
<http://www.bccdc.ca/SexualHealth/Programs/StreetOutreachNurseProgram/default.htm>
- **Report on National Forum on First Nations, Inuit and Métis:**
June, 2009, prepared by Canadian Partnership Against Cancer – includes short summaries of initiatives from across Canada in the areas of culturally relevant materials; First Nations/Inuit/Métis community-based activities; cancer journey; health human resources; research and surveillance; and, guidelines, quality and standards.
Available at:
http://www.cancerview.ca/idc/groups/public/documents/webcontent/cpac_fnim_forumreport.pdf
- **Saving a life** [videorecording]. (2007). [Video/DVD] Winnipeg, Man.: Meeches Video Productions.
- **Spirit doctors** [videorecording]. (2006). [Video/DVD] Montréal, Québec: National Film Board of Canada.
- **Toxic homes** [videorecording]. (2006).[Video/DVD] Winnipeg, Man.: Meeches Video Productions
- **Cancer 101**: a project of the Northwest Portland Area Indian Health Board's NW Tribal Cancer Control Project with Sprit of EAGLES; developed a culturally relevant cancer education curriculum and accompanying materials for caregivers working with American Indian/Alaska Natives or Alaska Natives; available free from their website
Website: http://www.npaihb.org/programs/project/ntccp_cancer_101/
- **Native American Cancer Research:** community based, American Indian/Alaska Native, non-profit resource; public website houses information for survivors, caregivers, and educators; there are fact sheets, event schedules (e.g. Survivor Circle meeting schedule – based in Denver), videos, storytelling, questions for your doctor, information on clinical trials, and more
Website: <http://www.natamcancer.org/index.html>
- **Native Sisters-** patient navigation delivered by trained American Indian/Alaska Natives – private nature of breast screening, plus Native women's modesty means male recruiters/ health professionals present a barrier (Burhansstipanov et al., 2005)

Information on Robert Wood Johnson Foundation website:

<http://www.rwjf.org/reports/grr/026400s.htm>

And on Native American Cancer Research website:

<http://www.natamcancer.org/nacrsearch.html?cx=013100573005498318245%3A6muzofc6dg&q=native+sisters&cof=FORID%3A11#914>

- **Native C.I.R.C.L.E.:** source of culturally appropriate cancer education materials
More information online at: http://cancercenter.mayo.edu/native_circle.cfm
Plus, <http://www.nativeamericanprograms.org/index-circle.html>
And, <http://cancercenter.mayo.edu/upload/completelist.pdf>

- **Native American Programs website:**
 - includes information on the programs Native CIRCLE and Spirit of EAGLES
 - downloads and links include: educational materials (including fact sheets in Navajo language); order forms for additional materials; newsletters; cancer organizations/institutes/resources; Spirit of EAGLES partner organizations; and, grant application resourcesWebsite: <http://www.nativeamericanprograms.org/index.html>

- **National Comprehensive Cancer Control Program (NCCCP)** of the Centers for Disease Control and Prevention, includes on its website a list of “success stories” in risk reduction, early detection, better treatment, and enhanced survivorship; some of these involve programs available to Native Americans
Website: <http://www.cdc.gov/cancer/ncccp/state.htm>

- *Tribal tobacco policies [videorecording]: Protecting our communities.* . (1997). [Video/DVD] Scotts Valley, Calif: Tobacco Education Clearinghouse of California.

- **Native American Cancer Survivor Network:** national network – a “community-based research study to help improve the quality of life for all American Indian/Alaska Native, Alaska Native, and First Nation cancer patients and their loved ones”; a project of Native American Cancer Research with the National Indian Health Board and the Indian Health Services in New Mexico, the Native CIRCLE of Mayo Clinic and other American Indian/Alaska Native organizations
More information at: <http://natamcancer.org/community.html>
Network brochure: <http://natamcancer.org/NewSurvBrochure.pdf>
For information call: 303-838-9359 or 1-800-537-8295

- **Association of American Indian/Alaska Native Physicians:** a resource for American Indian/Alaska Native medical students and doctors
 - “A major goal of AAIP is to motivate American Indian/Alaska Native students to remain in the academic pipeline and to pursue a career in the health professions and/or biomedical research, thereby increasing the number of American Indian/Alaska Native medical professionals in the workforce.

AAIP strives to improve the overall health of American Indian/Alaska Native

Communities through a variety of programs. AAIP has fostered several programs that directly address widely acknowledged disparities in American Indian and Alaskan Native health. “

- Website features include: membership sign-up, AAIP program listing, publications, events calendar, member search, resource links, job search, and latest news

Website: <http://www.aaip.org/>

- **National Indian Women’s Health Resource Center:** “national non-profit organization whose mission is to assist American Indian and Alaska Native women achieve optimal health and well-being throughout their lifetime.”

Website (cancer resource page): <http://www.niwhrc.org/Cancer.aspx>

- **Oncology Nursing Society: Multicultural Guidelines**

Available at: www.ons.org/Documents/Library/ONSPublications/multicultural.pdf

Discussed in:

Phillips, J., & Weekes, D. (2002). Incorporating multiculturalism into oncology nursing research: The last decade. *Oncology Nursing Forum*, 29(5), 807-816

Examples features of culturally relevant resources:

- Mini workshops, outreach meetings, and potlucks combined culturally relevant socializing with recruitment and education
- Materials and messages that could be incorporated within a story were better received than simply providing a list of facts or statements
- Cultural relevance of educational materials means: message, artwork, drawings, and photos reflect local community (responsive to images/ voices/ phrasing that looked/sounded like people in their community)
- To be effective, must emphasize benefits to the family and community as opposed to personal benefit; to take care of yourself as primary motivator is considered selfish/ inappropriate (family focus spoke especially strongly to women)
- Emphasizing women as foundation/ backbone of family, future of the youth, and recognition of elders all important outreach messages – personal/ emotional appeals are effective with women
- Messages should be simple, direct and understandable, also sensitive ex. “breast health” not “breast cancer”
- Putting cancer in to context of overall health and well-being well received; reflects values associated with holistic approach to health
- Numerous times in the literature, storytelling is cited as a more effective method of relaying cancer information, instead of a list of facts – traditional way of communicating for many tribes/ regions
(Burhansstipanov et al., 2005)
- Concept of pain in western medicine diverges from that of Native culture – Native Americans understand pain in a more holistic sense (use of a circular pain model, as opposed to a linear one typically used in western medicine) →wide use of varying, but similar, medicine wheel (Burhansstipanov & Hollow, 2001)

- The New South Wales Multicultural Health Communication Service: funded by NSW Ministry of Health to provide information and services to help health professionals communicate with non-English speaking communities throughout NSW
<http://www.mhcs.health.nsw.gov.au/>
- **Indigenous cancer web resource:** “A 'one-stop info-shop' for people working, studying or interested in addressing cancer among Aboriginal and Torres Strait Islander peoples. We aim to provide quality information and resources about how to prevent and/or minimize the harm associated with cancer among Indigenous peoples.”
An incredible resource, the website provide documentation on reviews, programs and projects, organizations, plain language, resources, workforce, policies and strategies, publications and more; all relating to cancer control among Aboriginal and Torres Strait Islander peoples.

Examples of health promotion resources on the site:

A cancer journey for remote Indigenous patients in the Northern Territory	2009	CanNET NT	Booklet
A cancer journey: a cancer story for remote Indigenous patients in the Northern Territory [DVD]	2009	CanNET	Audiovisual
Aboriginal cancer journeys: our stories of kinship, hope and survival	2010	Aboriginal Health & Medical Research Council Cancer Council New South Wales	Booklet
Beat breast cancer, have a free x-ray: regular breast x-rays save lives	2009	BreastScreen WA	Brochure
Breast cancer and you: Aboriginal and Torres Strait Islander women	2010	National Breast and Ovarian Cancer Centre	Audiovisual
Breast cancer in Indigenous women: a National Breast Cancer Centre workshop [power point presentation]	2007	National Breast and Ovarian Cancer Centre	Report
Breast cancer: challenges after treatment	2009	Rural Health Education Foundation	Audiovisual
Cancer information for Aboriginal and Torres Strait Islander people	2010	Aboriginal Health & Medical Research Council Cancer	Resource package

Council NSW			
Chronic disease programs: cancer series 1 (9 part series) [radio]	2011	Aboriginal Resource and Development Services	Audiovisual
Chronic disease programs: cancer series 2 (3 part series) [radio]	2011	Aboriginal Resource and Development Services	Audiovisual
Chronic disease programs: why are people dying? series 04 [radio]	2011	Aboriginal Resource and Development Services	Audiovisual
Fact sheet 8: Cancer in rural Australia	2009	National Rural Health Alliance	Factsheet
Healthy Koori women, growing strong: take care of yourself, have a pap test every two years	2009	Cancer Council, Victoria	Poster
Hey bruz, are you having trouble with your waterworks?	2009	Cancer Council, Victoria	Poster
Hey, you're lookin' good on the outside, but what about the inside?	2009	Queensland Bowel Cancer Screening Program	Resource package
How much sugar is in your drink?	2010	Kimberley Aboriginal Medical Services Council	Poster
Is it your year for a Pap smear?	2008	Northern Territory Department of Health and Families	Resource package
Join the fight against cervical cancer [DVD]	2010	Northern Territory Centre for Disease Control	Audiovisual
Let's talk about living with cancer	2008	Cancer Council Qld	Resource package
Listen you women, your breasts are precious [DVD]	2011	Bosom Buddies NT	Audiovisual
Live strong & healthy, have a pap test every two years	2009	NSW Cervical Screening Program	Resource package

Looking after your breasts: what every Aboriginal and Torres Strait Islander woman should know [flyer]	2009	National Breast and Ovarian Cancer Centre	Leaflet
Looking after your breasts: what every Aboriginal and Torres Strait Islander woman should know [videos]	2009	National Breast and Ovarian Cancer Centre	Online multimedia
Lymphoedema [brochure]	2008	National Breast and Ovarian Cancer Centre	Brochure
Men's business: prostate problems	2009	Cancer Council, Victoria	Brochure
Pap tests: help protect yourself from cervical cancer (Koori)	2010	Cancer Council Victoria	Brochure
Pap tests: what if my pap test is abnormal? (Koori women)	2009	Cancer Council, Victoria	Brochure
Protect our mob from cervical cancer: a pap test every two years could save your life	2009	Cancer Council, Victoria	Poster
Susu (breast) screening brochure	2005	Breastscreen Queensland	Brochure
Take the lead be breast aware	2009	Cancer Council, Victoria	Poster
Take the lead be breast aware: a guide for Aboriginal women	2009	Cancer Council, Victoria	Brochure
Tobacco educational programs	no date	Aboriginal Resource Development Services	Resource package
Wanem morphine	2009	Cancer Council Queensland	Booklet
War within	2010	Queensland Health	Comic
Why Aboriginal women should have regular pap smears	2008	WA Cervical Cancer Prevention Program	Leaflet

Website: <http://www.healthinonet.ecu.edu.au/chronic-conditions/cancer>

Following list is from the Australian Indigenous Health/InfoNet website (under cancer- programs and projects):

Title	Reach	Focus	Evaluated
Aboriginal Health Worker telephone support cancer network	NT	Indigenous	-
Breast Cancer Foundation of WA Indigenous program	WA	Indigenous	-
BreastScreen Australia program	National	Mainstream with Indigenous content	-
Chronic care for Aboriginal people program	NSW	Indigenous	-
Chronic conditions program	Not specified	Indigenous	-
Equity of bowel cancer screening: An epidemiological and qualitative study	SA	Indigenous	-
Indigenous health research program	QLD	Indigenous	-
LungNet	QLD	Mainstream with Indigenous content	-

Title	Reach	Focus	Evaluated
National bowel cancer screening program	National	Mainstream	
National cervical screening program	National	Mainstream	
Supporting women in rural areas diagnosed with breast cancer program	National	Mainstream with Indigenous content	

Australian HealthInfoNet, retrieved from: <http://www.healthinfonet.ecu.edu.au/chronic-conditions/cancer/programs-and-projects>

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Survey Questions

First Nations and Metis Cancer Control Survey

CancerCare Manitoba and Saint Elizabeth Health Care

Page #1

First Nations and Metis Cancer Control Survey The Canadian Partnership Against Cancer recently facilitated the development of the First Nations, Inuit and Métis Action Plan on Cancer Control, engaging First Nations, Inuit and Métis peoples, patients, and organizations involved in cancer control and chronic disease prevention. The Action Plan is posted on the Partnership's Web site (partnershipagainstcancer.ca) and accessible via <http://www.partnershipagainstcancer.ca/node/resources/>. This work is national in scope and is designed to understand the realities of First Nations, and Métis peoples with respect to cancer control, and to identify where progress has been made that can be further leveraged. Your perspectives and expertise are vital to ensuring that the information being compiled is complete and accurate. We would be very pleased if you would participate as a key informant in this work. Please note that all survey responses will be kept confidential; individual responses will not be shared. In partnership, CancerCare Manitoba and Saint Elizabeth are collecting information with the goal of identifying: 1) cancer care programs and services for First Nations and/or Métis populations living on- or off-reserve in rural, remote or isolated areas across Canada. 2) culturally responsive cancer control programs, services and resources for First Nations and Métis populations, especially those originating from First Nations reserves across Canada.

Page #2

Definitions

Cancer continuum: the journey or path an individual with cancer experiences, including cancer screening, suspicion, diagnosis, treatment, follow-up, survivorship and palliative care. Suspicion: the interval between screening, or presentation of symptoms, and diagnosis.

Cancer care: aspects of the cancer continuum for which the individual is dependent on the health system, which are cancer screening, early detection, diagnosis, treatment, follow-up, survivorship and palliative care.

Cancer control: includes elements of cancer care (as defined above) as well as prevention.

Early detection: how the health system enables cancer to be diagnosed in its early stages.

Prevention: refers to evidence-based programs or interventions designed to reduce the risk of developing cancer.

Culturally responsive: a program, service or resource which addresses the specific needs of a cultural group. For First Nations and Métis peoples this may include holistic perspectives on health and medicine, literacy and language needs, cultural beliefs about cancer, and socioeconomic and psychosocial barriers.

Program: a system of services, opportunities or projects, provided on an ongoing basis with devoted funds, usually designed to meet a specific need, i.e.: cancer screening programs.

Service: how cancer control is delivered. An example of a culturally responsive service is the delivery of cancer screening services by health professionals of the same gender.

Resource: information based entities such as educational materials (printed, video, oral or web-based content), support networks (e.g. talking circles) or linkages to other organizations.

Rural: a community with road access to medical services (primary care, diagnostic and treatment services) within 20-90 km.

Remote: a community with road access to medical services (primary care, diagnostic and treatment services) greater than 90 km.

Isolated: a community without year-round road access. The community can be reached by scheduled or non-scheduled flights or winter roads and has telephone and/or radio services.

Urban: a community with 10,000 or more people.

Page #3

What is the name of your organization? (Q1)

In which province or territory is your organization based?

- Alberta

- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon

Branching Information

- Skip to Page 24 if Q2 = No

Page #4

Are you able to describe any programs/services/resources within your region or province/territory targeted toward First Nations and/or Métis populations living on- or off-reserve in rural, remote or isolated areas that are: (a) developed or delivered by your organization, or (b) to which you refer people. (Q2)

Program: a system of services, opportunities or projects, provided on an ongoing basis with devoted funds, usually designed to meet a specific need, i.e.: cancer screening programs.

Service: how cancer control is delivered. An example of a culturally responsive service is the delivery of cancer screening services by health professionals of the same gender.

Resource: information based entities such as educational materials (printed, video, oral or web-based content), support networks (e.g. talking circles) or linkages to other organizations.

Yes

No

Page #5

What is the name of the program/service/resource? (Q21)

Page #6

Please provide the name contact information for the organization responsible for {{ Q21 }}, if organization responsible is not your own.

Page #7

Please provide the following information for {{ Q21 }} What phase of the cancer continuum does it address? (Q3)

Prevention

Screening

Early Detection

Suspicion

Diagnosis

Treatment

Follow-up

Palliation

Survivorship

What type of cancer does it address?

Who is the target population?

Patients
Families
First Nations
Metis
Health Care Providers
Rural
Remote
Isolated
On-reserve
Off-reserve
Urban
Non-specific
Other

What are the main activities of the program/service/resource?

Has the program/service/resource been evaluated?

- Yes
- No
- No Sure

Branching Information

- Skip to Page 24 if Q22 = No

Page #8

Are you aware of another program/service/resource? (Q22)

Yes
No

Page #9

What is the name of the program/service/resource? (Q222)

Page #10

Please provide the name and contact information for the organization responsible for {{ Q222 }}, if organization responsible is not your own.

Page #11

Please provide the following information for {{ Q222 }} What phase of the cancer continuum does it address?

Prevention
Screening
Early Detection
Suspicion
Diagnosis
Treatment
Follow-up
Palliation
Survivorship

What type of cancer does it address?

Who is the target population?

Patients
Families
First Nations
Metis
Health Care Providers
Rural
Remote
Isolated
On-reserve
Off-reserve
Urban
Non-specific
Other

What are the main activities of the program/service/resource?

Has the program/service/resource been evaluated?

- Yes
- No
- No Sure

Branching Information

- Skip to Page 24 if Q23 = No

Page #12

Are you aware of another program/service/resource? (Q23)

Yes

No

Page #13

What is the name of the program/service/resource? (Q232)

Page #14

Please provide the name and contact information for the organization responsible for {{ Q232 }}, if organization responsible is not your own.

Page #15

Please provide the following information for {{ Q232 }} What phase of the cancer continuum does it address?

Prevention
Screening
Early Detection
Suspicion
Diagnosis
Treatment
Follow-up
Palliation
Survivorship

What type of cancer does it address?

Who is the target population?

Patients
Families
First Nations
Metis
Health Care Providers
Rural
Remote
Isolated
On-reserve
Off-reserve
Urban
Non-specific
Other

What are the main activities of the program/service/resource?

Has the program/service/resource been evaluated?

- Yes
- No
- No Sure

Branching Information

- Skip to Page 24 if Q24 = No

Page #16

Are you aware of another program/service/resource? (Q24)

- Yes
- No

Page #17

What is the name of the program/service/resource? (Q242)

Page #18

Please provide the name and contact information for the organization responsible for {{ Q242 }}, if organization responsible is not your own.

Page #19

Please provide the following information for {{ Q242 }} What phase of the cancer continuum does it address?

- Prevention
- Screening
- Early Detection
- Suspicion
- Diagnosis
- Treatment
- Follow-up
- Palliation
- Survivorship

What type of cancer does it address?

Who is the target population?

- Patients
- Families
- First Nations
- Metis
- Health Care Providers
- Rural
- Remote
- Isolated
- On-reserve
- Off-reserve
- Urban

Non-specific
Other

What are the main activities of the program/service/resource?

Has the program/service/resource been evaluated?

- Yes
- No
- No Sure

Branching Information

- Skip to Page 24 if Q25 = No

Page #20

Are you aware of another program/service/resource? (Q25)

Yes
No

Page #21

What is the name of the program/service/resource? (Q252)

Page #22

Please provide the name and contact information for the organization responsible for {{ Q252 }}, if organization responsible is not your own.

Page #23

Please provide the following information for {{ Q252 }} What phase of the cancer continuum does it address?

Prevention
Screening
Early Detection
Suspicion
Diagnosis
Treatment
Follow-up
Palliation
Survivorship

What type of cancer does it address?

Who is the target population?

Patients
Families
First Nations
Metis
Health Care Providers
Rural
Remote
Isolated
On-reserve
Off-reserve
Urban
Non-specific
Other

What are the main activities of the program/service/resource?

Has the program/service/resource been evaluated?

- Yes
- No
- No Sure

Branching Information

- Skip to Page 26 if Q8 = No

Page #24

Are there any other organizations or groups that have developed or currently deliver cancer control related programs/services/resources that you think we should be aware of? (Q8)

Yes
No

Page #25

Please provide name of organizations and contact information, if available. (Q9)

Branching Information

- Skip to Page 29 if Q10 = No

Page #26

Are you able to describe how a patient travels through the cancer system from screening or suspicion to survivorship or palliation? (Q10)

Yes
No

Page #27

Which part of the journey through the cancer system can you describe? (Q11)

Please check all that apply.

On-reserve

Off-reserve

Transition points between on and off reserve

Page #28

Would you be willing to be contacted by telephone to share your perspective on the cancer continuum? (Q12)

Cancer continuum: the journey or path an individual with cancer experiences, including cancer screening, suspicion, diagnosis, treatment, follow-up, survivorship and palliative care.

Yes

No

Page #29

Do you have any other comments? (Q13)

Branching Information

- Complete survey if Q14 = No

Page #30

May we contact you or a colleague by phone with follow-up questions? (Q14)

Yes

No

Page #31

Please provide your name and contact information and/or the contact information for a colleague. (Q15)
If your colleagues or contacts can contribute their knowledge of existing cancer care program/services/resources to this project please forward this survey to them:

Interview Guide

First Nations Cancer Control Key Informant Interview Guide

Hi ____, firstly I would like to thank you for talking with me today. My name is ____ and I am with the CancerCare Manitoba First Nations, Metis and Inuit Cancer Control. We are working in partnership with Saint Elizabeth Health, Provincial Cancer Agencies and First Nations organizations across Canada to better understand the cancer pathway for First Nations people living in rural, remote and isolated communities.

We hope to identify the opportunities, gaps and barriers in cancer control as well as identify leading models and culturally appropriate resources geared towards First Nations peoples.

We are gathering input across Canada through on-line surveys and key informant interviews. Summary reports for each province and territory will be developed. A final draft report based on information gathered from these interviews can be made available for your review prior to finalization. The final report and other tools will be available from the Canadian Partnership Against Cancer in 2012.

This work is funded by the Canadian Partnership Against Cancer in support of the First Nation, Inuit and Métis Action Plan on Cancer Control

This interview today has 3 parts, and is expected to take 10-45 minutes depending on how much information you can share:

- [Part 1](#) is your contact information
- [Part 2](#) asks questions about the cancer journey or [continuum](#)
- [Part 3](#) asks questions about cancer programs, services and resources

We can assure you that no names will be used in the reports.

Do we have your permission to proceed with the telephone interview?

- *if no:*
 - On behalf of CancerCare Manitoba, Saint Elizabeth and the Canadian Partnership Against Cancer I would like to thank you for your time. *[end]*
- *if yes:*
 - Before we begin, do you have any questions?
 - Please feel free to ask questions at any point during the interview.

Part 1: Key Informant Contact Information [back to top](#) [definitions](#) [Part 2](#) [Part 3](#) [Closing](#)

First I will ask you [for/to confirm] your contact information, which will be kept confidential. [\[confirm\]](#)

Name

Title

Organization/Employer

Telephone Number

Email

Mailing Address

Part 2: Cancer Journey [back to top](#) [definitions](#) [Part 1](#) [Part 3](#) [Closing](#)

This section will ask you questions to find out how a patient would go through the cancer journey. We would especially like to know if there are differences in the cancer journey between populations.

Do you feel able to answer questions on how people go through the cancer journey in your region?

Yes

No [\[proceed to Part 3 on page 9\]](#) [Part 3](#)

What community, region, province or territory does your organization serve?

What populations does your organization provide service to?

[check all that apply]

Rural

- road access 20- 90 km to physician services (we added the lower limit of 20 km which is not part of the FNIHB definition)

Remote

- road access greater than 90 km to physician services

Isolated

- no year-round road access; air access by scheduled or non-scheduled flights; telephone and/or radio services

On-reserve

Off-reserve

Urban

Non-specific

Other _____

What cancer care infrastructure is available in your community or region?

Cancer care: aspects of the cancer continuum for which the individual is dependent on the health system, which are cancer screening, early detection, diagnosis, treatment, follow-up, survivorship and palliative care. Early detection refers to how the health system enables cancer to be diagnosed in its early stages.

[check all that apply]

- community-based healthcare providers
 - with training in oncology
- medical service centre
 - nursing station
 - hospital
 - clinic
- pharmacy services
- tele-medicine/-oncology
- cancer screening
 - mammogram
 - PSA (Prostate Serum Antigen)
 - FOBT (Fecal Occult Blood Test)
 - Pap
- diagnostic facilities
 - hematology/blood lab
 - x-ray
 - MRI (Magnetic Resonance Imaging)
 - PET scan (Positron Emission Tomography)
 - CT/CAT scan (Computed [Axial] Tomography)
 - bone scan
 - surgical suites
 - pathology
- palliative care/hospice facilities
- other _____

SCREENING: testing when there are no symptoms for early cancer detection

Where does the cancer screening occur?

[check all that apply]

Breast [mammogram]

- in the community
- < 20 km
- 20-90 km
- > 90 km
- via plane

Who provides breast screening?

- local health professionals
- provincial / territorial cancer agency staff
- hospital
- Other

Cervical [pap]

- in the community
- < 20 km
- 20-90 km
- > 90 km
- via plane

Who provides cervical screening?

- local health professionals
- provincial / territorial cancer agency staff
- hospital
- Other

[Colorectal (stool test, home testing kits that require 1 to 3 samples).

1 stool sample is required for FIT test

3 stool samples are required for FOBT

Need to be clear that the screening

involves only the stool testing and not

the follow-up colonoscopy (if required).]

Colorectal [FOBT or FIT]

- in the community
- < 20 km
- 20-90 km
- > 90 km
- via plane

Who provides colorectal screening?

- local health professionals
- provincial / territorial cancer agency staff
- hospital
- Other

If a person requires a follow-up

colonoscopy, how far do they have to travel for this procedure?

[check all that apply]

Follow-up Colonoscopy

- in the community
- < 20 km
- 20-90 km
- > 90 km
- via plane

Who provides the follow-up colonoscopy?

- local health professionals
- provincial / territorial cancer agency staff
- hospital
- Other

Are transportation costs covered for clients to attend cancer screening, if it is not available in the community?

- Yes
- No

When screening is available, what factors do you think influence the decision to participate?

What would help increase screening participation rates in communities?

Are there differences in screening program availability, follow-up or participation between First Nations and the general population?

SUSPICION: waiting period between first concern and diagnosis
Where does the care occur during the suspicion phase?

Who provides the care during the suspicion phase?

Can you tell us about cancer care wait times between suspicion and diagnosis?

issues/gaps/barriers

Are there differences in service availability, follow-up or wait times between First Nations people and the general population during the suspicion phase?

issues/gaps/barriers

DIAGNOSIS: confirmation that cancer is present or not
Where do clients get diagnostic testing?

Who provides diagnostic testing?

How long does it take to access diagnostic services?

How long does it usually take to receive the results or diagnosis once the testing for cancer is done?

Evidence shows that First Nations people and those living in rural, remote and isolated areas are more likely to receive a late stage cancer diagnosis. What factors do you feel might contribute to this?

issues/gaps/barriers

TREATMENT

Where does the cancer treatment take place?

[check all that apply]

- in the community
- < 20 km
- 20-90 km
- > 90 km
- via plane

Who provides the cancer treatment?

[check all that apply]

- local health professionals
- provincial / territorial cancer agency staff
- hospital
- Other

Can you tell us about cancer care wait times between diagnosis and treatment?

issues/gaps/barriers

On average how long does a person have to wait for their cancer treatment to start (following diagnosis)?

[check all that apply]

- < 1 month
- 1-4 months
- > 4 months
- unsure

Are there differences in service availability, follow-up or wait times between First Nations and the general population during the treatment phase?

issues/gaps/barriers

FOLLOW-UP: regular medical attention

When a patient is finished their cancer treatment, how is their follow-up care coordinated?

Where does follow up care occur?

[check all that apply]

- in the community
- < 20 km
- 20-90 km
- > 90 km
- via plane

Who is involved in providing the follow up care?

[check all that apply]

- local health professionals
- provincial / territorial cancer agency staff
- hospital
- Other

Can you tell us about the transition from cancer care back to primary care?

issues/gaps/barriers

Are there differences in service availability, follow-up or wait times between First Nations people and the general population during the follow-up phase?

issues/gaps/barriers

SURVIVORSHIP: health and life of a cancer survivor

When someone in the community has a history of cancer, do they have access to any programming either in the community or outside the community that deals with health and life of a cancer survivor?

Where can a cancer survivor access supports, resources or programming?

Who provides the care for cancer survivors?

Are there differences in service availability, follow-up or wait times between First Nations people and the general population during the survivorship phase?

issues/gaps/barriers

PALLIATIVE CARE: end of life care and comfort

Where does the palliative or end of life care usually take place?

If a client is dying of cancer and wants to pass at home, can homecare be coordinated?

- Yes
- No
- Not Aware

[check all that apply]

Who provides this homecare?

[check all that apply]

- Home and Community Care
- Palliative care / hospice facilities
- Other

Can you tell us about the transition from treatment to palliative care?

issues/gaps/barriers

Are there differences in service availability, follow-up or wait times between First Nations people and the general population during the palliative care phase?

issues/gaps/barriers

Part 3: Programs, Services and Resources [back to top](#) [definitions](#) [Part 1](#) [Part 2](#) [Closing](#)

Are there any services available in your community or region that meet physical, mental, emotional or spiritual cancer care needs?

[check all that apply]

- exercise groups (walking program)
- peer support groups
- survivorship programs
- sharing circles
- Social Workers/Mental Health Workers
- Traditional Healers/Helpers
- other _____

Are there patient navigation services available in your community or region?

[check all that apply]

- patient orientation
- navigator
- case coordinator
- patient advocate/representative
- other _____

[if yes]

Is the patient navigator located in the community or in the centre where the client is receiving treatment?

- community
- treatment centre

Are there Aboriginal Patient Navigator services available in your community or region?

- Yes
- No
- Not Aware

[if yes]

What is the impact of this service?

Are there regular community outreach programs available in your community or region?

[check all that apply]

- Such as:
- visiting specialists (on a regular basis)
 - tele-medicine/-oncology
 - tele-health educational sessions on cancer care
 - mobile mammography screening (every 2 years)
 - other _____

Are communities contacting provincial cancer agencies to get information?

Is there an established practice for the community to contact the provincial cancer agency?

[Do health care professionals have ready access to check on a client?

Can hcp's check for service availability? i.e.: the next mobile breast screening date in the community]

We are looking for examples of a cancer specific program, service or resource that is working well in your region. Can you give us an example?

Yes

No [\[proceed to Closing on page 12\]](#) [Closing](#)

Program/Service/Resource (PSR) # 1 2 3 4 [\[circle one\]](#)

What is the name of the program/service/resource?

Who/which organization is responsible for developing and running the program/service/resource?

Please provide contact information for the program/service/resource.

What phase of the cancer continuum does it address? [\[Check all that apply\]](#)

- Prevention
- Screening
- Early detection
- Suspicion
- Diagnosis
- Treatment
- Follow-up
- Palliation
- Survivorship
- Other _____

What types of cancer does it address? [\[Check all that apply\]](#)

- All
- Breast
- Colorectal
- Prostate
- Cervical
- Lung
- Other _____

Who is the PSR for?
[Check all that apply]

- Patients
- Families
- Child of Patient
- Survivors
- Males
- Females
- Children
- Youth
- Adults
- Elders
- First Nations
- Métis
- Health Care Providers
- Rural
- Remote
- Isolated
- On-reserve
- Off-reserve
- Urban
- Non-specific
- Other _____

What are the main activities of the program/service or what is the intent of the resource?

Please describe the history of need and development program/service/resource.

Please identify the barriers and/or challenges to implementation and/or success.

Has the program/service/resource been evaluated? How?

Was the program/service/resource effective? In what ways?

Context related – community strengths/assets, leadership, public awareness/interests, access to services, size and location, etc.

Please identify the reasons for success of the program/service/resource.

Operations related – logistics, order of activities, types of tools used, selection of target group, existence of steering/implementation committee, etc.

Good Fortune/chance – coincidence with available expertise/support, ability to dove-tail with other programs activities, etc.

Other

How many people use or participate in the program/service/resource?

For interviewer comment only:

Is this a culturally-responsive P/S/R? Yes No
Is this is leading model or practice? Yes No

[insert rows for additional PSR's as necessary]

[if answered no to sharing PSR's, resume interview here]

Closing [back to top](#) [definitions](#) [Part 1](#) [Part 2](#) [Part 3](#)

Are there any other organizations or groups that have developed or currently deliver cancer control related programs/services/resources that you think we should be aware of? Please provide contact information if available.

Are there any other comments you would like to share with me today?

That concludes all of the interview questions. Do you have any questions?

We would like to offer you our sincere appreciation for taking the time to share your knowledge with us today. We believe your input is vital to informing the next steps for action in First Nations cancer control. A draft report will be emailed to you for your review in the near future.

Definitions

[back to top](#) [back to Part 1](#) [back to Part 2](#) [back to Part 3](#) [back to Closing](#)

Cancer continuum: the journey or path an individual with cancer experiences, including cancer screening, suspicion, diagnosis, treatment, follow-up, survivorship and palliative care. Suspicion refers to the interval between screening, or presentation of symptoms, and diagnosis.

Cancer care: aspects of the cancer continuum for which the individual is dependent on the health system, which are cancer screening, early detection, diagnosis, treatment, follow-up, survivorship and palliative care. Early detection refers to how the health system enables cancer to be diagnosed in its early stages.

Cancer control: includes elements of cancer care (as defined above) as well as prevention. Prevention refers to evidence-based programs or interventions designed to reduce the risk of developing cancer.

Culturally responsive: a program, service or resource which addresses the specific needs of a cultural group. For First Nations and Métis peoples this may include holistic perspectives on health and medicine, literacy and language needs, cultural beliefs about cancer, and socioeconomic and psychosocial barriers.

Resource: refers to information-based entities such as educational materials (printed, video, oral or web-based content), support networks (e.g., talking circles) or linkages to other organizations.

Service: refers to how cancer control is delivered. An example of a culturally responsive service is the delivery of cancer screening services by health professionals of the same gender.

Program: a system of services, opportunities or projects, provided on an on-going basis with devoted funds, usually designed to meet a specific need. i.e.: cancer screening programs.

Rural: a community with road access to medical services (primary care, diagnostic and treatment services) within 20-90 km

Remote: a community with road access to medical services (primary care, diagnostic and treatment services) greater than 90 km distant

Isolated: a community without year-round road access. The community can be reached by scheduled or non-scheduled flights or winter roads and has telephone and/or radio services.

Urban: a community with a population of 10,000 or more people.

Appendix

***Canadian cancer control in First Nations
populations living off-reserve in rural, remote and
isolated areas***