

Breaking the Silence



Report on the Inuvialuit Settlement Region Cancer Sharing Circle

January 20 - 21, 2015

Inuvik, Northwest Territories

Strength Spirit Resilient
Inspire Resilient Love Peace
Sharing Courage Inspire Spirit
Love Hope Strength Sharing Bravery
Resilient Inspire Love Hope Strength
Peace Bravery Inspire



Kīspin ki nitawihitīn ā nīhīyawihk ōma ācimōwin, tipwēsīnēn.

Cree

ʔerihtł'ís dēne súliné yati t'a huts'elkēr xa beyéyati theḡ ʔat'e, nuwe ts'ēn yóhtí.

Chipewyan

If you would like this information in another official language, call us.

English

Si vous voulez ces renseignements en français, contactez-nous.

Français

Jii gwandak izhii ginjik vat'atr'ijahch'uu zhìt yinoththan jì', diits'àt ginohknii.

Gwich'in

Hapkua titiqqat pijumagupkit Inuinnagtun, uvaptinnut hivajarlutit.

Inuinnaqtun

ርካታ በበጭነት ለሚሰጥ ልዩነት/ረገድ፣ ድረስም ይህ ሂደት

Inuktitut

UVANITTUAQ ILITCHURISUKUPKU INUVIALUKTUN, QUQUAQLUTA.

Inuvialuktun

K'éhshó got'ine xədó k'é hederi ɣədɪhtl'é yeriniwə nídé dúle.

North Slavey

Edi gondı dehgéh got'ie zhatié k'ée edatl'éh enahddhe nide.

South Slavery

Tłichọ yati k'èè dè wegodiì wek'èhoizọ neewọ dè, gots'ọ goahde.

Tłicho

1-867-767-9052, ext. 49045

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Dedications

This report is dedicated to the Inuvialuit of the Beaufort-Delta Region and to all those in the region whose lives have been affected by cancer. Although talking about cancer was new for many of the sharing circle participants, they openly shared their stories from various stages of their respective cancer journeys. Great respect was shown by all. With our new knowledge and connections we will continue to move forward, gathering strength from one another.

This is awesome. We can do something really big with this. It's so good to see people from so many sides: caregivers, patients, doctors.... This is awesome!

– Participant

Acknowledgements

The Inuvialuit Regional Corporation (IRC) would like to thank a number of important contributors to our cancer sharing circle:

- Many thanks go to Charlie Furlong for serving as lead facilitator of the session and for openly sharing his own personal journey with cancer.
- Thank you to Lillian Elias for being available to provide interpretation services.
- Thank you to the Alberta/Northwest Territories (NWT) Division of the Canadian Cancer Society for donating patient kits to all cancer sharing circle participants.
- But the biggest thanks of all go to all the participants who came from throughout the Inuvialuit Settlement Region. Thank you for your stories, strength, and enthusiasm. Job well done!



Executive Summary

The Report on the Inuvialuit Settlement Region Cancer Sharing Circle details the findings from the Cancer Sharing Circle which took place January 20th and 21st in Inuvik, NWT. Over the course of two days, 28 participants from six different communities in the Inuvialuit Settlement Region gathered to share personal stories and experiences with cancer. The goal of the Sharing Circle was to better understand the impacts of cancer in Beaufort-Delta communities, provide more information to community members on cancer and how it can be prevented and treated, and improve the overall approach to dealing with the disease in these communities.

This Report begins with some initial ways to improve the care and support for cancer patients and families that were identified by participants in the Sharing Circle. Three areas for improvement include support for the cancer patient, support for family and caregivers and sensitivity of health care professionals.

The Report then summarizes a presentation made by Dr. Andre Corriveau, Chief Public Health Officer of the Northwest Territories, which provided information on cancer in the NWT. The presentation includes a short medical explanation of cancer and its risk factors, and then looks at the statistics for cancer rates in the NWT and in Inuvialuit populations in the Beaufort-Delta. This was followed by a question and answer period with Dr. Corriveau, providing participants an opportunity to learn more about cancer risks, screening and treatment, and the work the Department of Health and Social Services is doing to reduce cancer rates and help people dealing with cancer in the NWT.

Participants then discussed some of the challenges and possible solutions in terms of the support available for patients and families in the cancer journey. The report details the findings of a brainstorming session in which participants explored what actions contribute to the emotional, mental, physical, and spiritual health of a community, creating an overall vision for cancer and community health. This session identified a number of ideas on how to achieve this vision for Inuvialuit Settlement Region Communities, including ways to disseminate information, encourage more cancer screening, and provide emotional support and improve the quality of life of people living with cancer.

Included in this report four Appendices: Appendix A: Agenda, Appendix B: Glossary, Appendix C: Cancer Resources and Appendix D: NWT Cancer Posters.

Introduction

The Inuvialuit Settlement Region (ISR) Cancer Sharing Circle was held at Ingamo Hall in Inuvik on January 20 and 21, 2015. Twenty-eight participants from the communities of Aklavik, Inuvik, Sachs Harbour, Paulatuk, Tuktoyaktuk, and Ulukhaktok—including elders, youth, cancer survivors, family caregivers, health professionals, and community leaders—shared their experiences with cancer and discussed successes in their communities as well as what needs to be done to address gaps and challenges throughout the cancer journey in the NWT.

The cancer sharing circle had three objectives:

1. To give community members the opportunity to voice their concerns and share their stories about cancer;
2. To enhance community knowledge and awareness of cancer and how it impacts community members;
3. To motivate community members to initiate their own activities to address barriers and gaps they face in cancer care and support.

Over two days, the facilitators led the participants through plenary discussions, presentations, small group brainstorming and analysis, and fun energizers in order to achieve these objectives. The event agenda is found in Appendix A.



Opening the Discussion

Our elder Lillian Elias opened the cancer sharing circle with a prayer.

Following the prayer IRC Executive Director of Community Development Evelyn Storr welcomed the sharing circle participants on behalf of IRC Chair Nellie Cournoyea.

Sitting in a circle, the participants then introduced themselves one by one. Each ISR community was represented by at least one youth, one elder, and one additional community leader. There were also three participants from the Beaufort-Delta Health and Social Services Authority (BDHSSA), one from the Gwich'in Tribal Council (GTC), and four from the DHSS.

Many sharing circle participants admitted that they had never before spoken about cancer, in public or even among family and friends. Some initially had difficulty opening up, but all agreed that they felt the circle was a safe and supportive space. Over the two days, the ease with which participants shared their stories increased.

Participants shared their stories from their perspectives as patients, survivors, caregivers, and family members who remain behind when their loved ones pass on. The role of youth was recognized as very important not only because they are part of the caregiving team, but also because they will lead us toward community health and wellness in the future.

The participants revealed that they want to learn from past challenges and gaps in order to improve the cancer journey for NWT patients. Sometimes these challenges and gaps stem from cultural differences between patients and their health care providers. The health care professionals in the room were very open to hearing about some of these challenges and gaps,



and were eager to begin addressing them where they could. As lead facilitator Charlie Furlong explained, while there are many challenges we face today, as a group we are paving the way to make things easier for future cancer patients and their families.

During this initial discussion, three areas for improvement emerged:

1. Support for the cancer patient

- Support groups—or at least 24-hour access to telephone support—are needed.
- Patients should be able to receive a cancer diagnosis in the presence of their family, or other support persons they choose.
- Regardless of age or language, all cancer patients need someone to accompany them to appointments, especially when they must travel.
- Non-medical travel escorts need to be oriented on their roles and responsibilities.

2. Support for the family and/or caregivers

- Caregivers also need support to deal with their own emotions and stress. There should be support available particularly in the communities, at Stanton Territorial Hospital, and at Larga Boarding Home in Edmonton.

3. Sensitivity of health care professionals

- Broken trust between patients and health care providers is one of the biggest obstacles we see in small communities.
- While there are many health care professionals in the NWT who go above and beyond to help their patients, there are others who may be seen as insensitive and rushed.
- The individual who delivers a diagnosis should be sensitive and take the time to sit with the patient and family to answer any questions they may have.

The cancer sharing circle participants agreed that upon return to their respective communities, there is much they can do to provide support to cancer patients and their families.



There is strength in this room and I can feel it. It's a really nice feeling.

– Participant



Cancer in the Beaufort-Delta

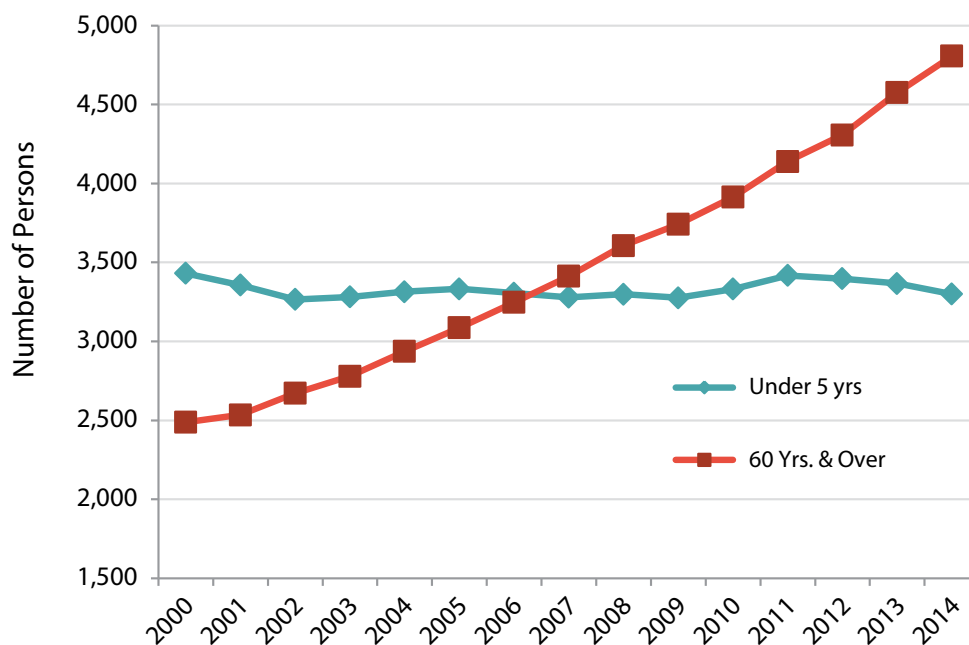
Dr. André Corriveau, Chief Public Health Officer of the Northwest Territories, presented information on cancer in the NWT and among Inuvialuit populations of the Beaufort-Delta. The following is a summary of his presentation.



- Cancer originates from the Greek word for crab. Cancer was thought of as a bug or a creature that infests the body. However, we have found that this is a misconception and does not reflect what cancer really is.
- Our bodies are made up of billions of cells that naturally divide and grow to repair any damage. These cells receive a signal from the brain to divide when something needs to be repaired—like a broken bone or a sunburn—and receive another signal from the brain when they need to stop dividing. Abnormal cells do not receive the “stop” signal from the brain and continue to divide without control. These are cancer cells. There are more than 200 types of cancer that are named for where in the body they start.
- There are still some mysterious aspects to cancer. For example, some cancers are aggressive while others are easy to cure, and some healthy people develop cancer whereas others with lifelong unhealthy habits do not.

- Because the population is older in high-income countries like Canada, cancer is the number one cause of death. However, in developing countries and overall worldwide, cardiovascular disease is the number one cause of death because the population is younger.
- We are starting to talk about cancer the way we talk about cardiovascular disease. This may start to lessen the fear and stigma around cancer. It is also important for health professionals to learn to talk to patients in simple yet accurate ways.
- NWT residents are getting older: the NWT Statistics Bureau has statistics that show the number of NWT residents aged 60 years and older almost doubled between 2000 and 2014. Our risk of developing cancer increases as we get older.
- Screening programs are highly recommended for people who are 50 years and older.

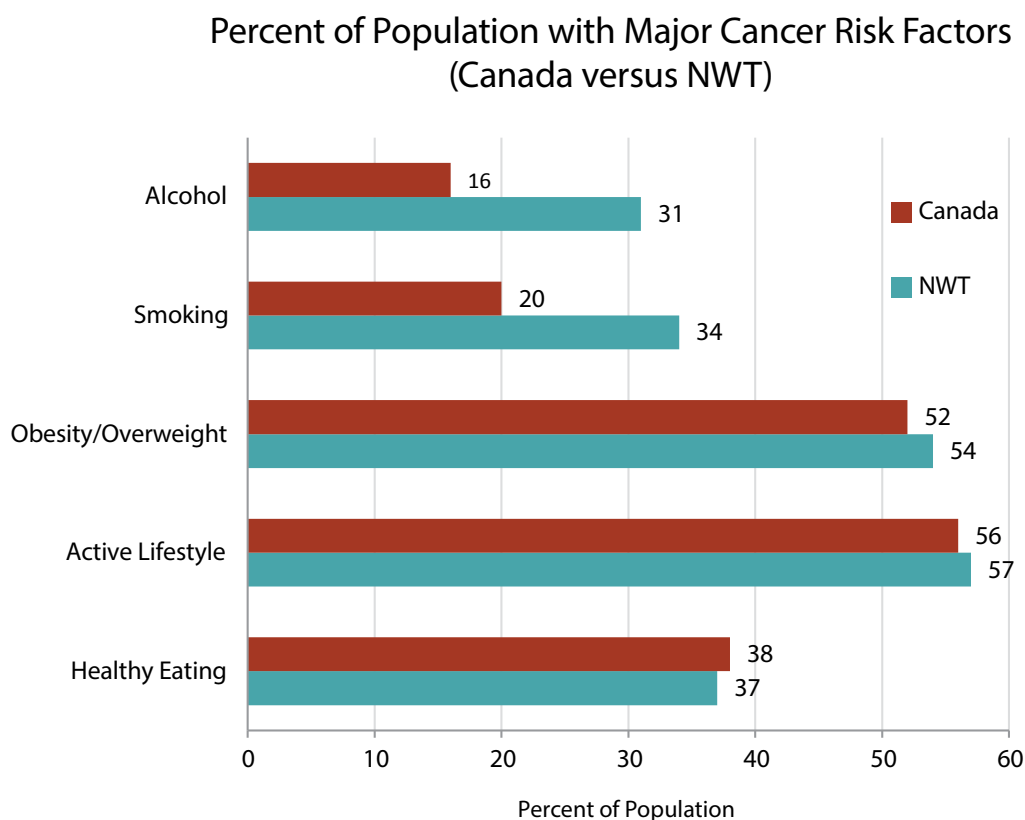
Number of NWT Residents: Children Under 5 and Adults 60 and Older (2000-2014)



Source: NWT Statistics Bureau

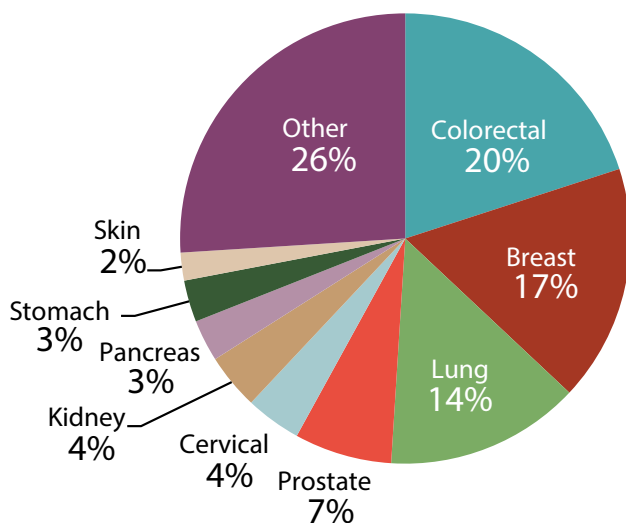
- A risk factor is something that increases our chances of getting cancer. These include things such as family history, lifestyle, or environment. For example, not all smokers will get cancer. However, 90% of people with lung cancer were smokers. Smoking is the biggest risk factor for many types of cancer.
- Family history is something we cannot control as a risk factor. However, there are ways to reduce your risk of cancer such as healthy eating and knowing healthy ways of cooking. For example, cooking at high temperatures and frying reduce the nutrients in food.
- Alcohol consumption is also a risk factor for many types of cancer. The NWT has higher rates of smokers and drinkers when compared to the rest of Canada, so the sooner people reduce their smoking and alcohol consumption, the better.

Source: Statistics Canada (2013)

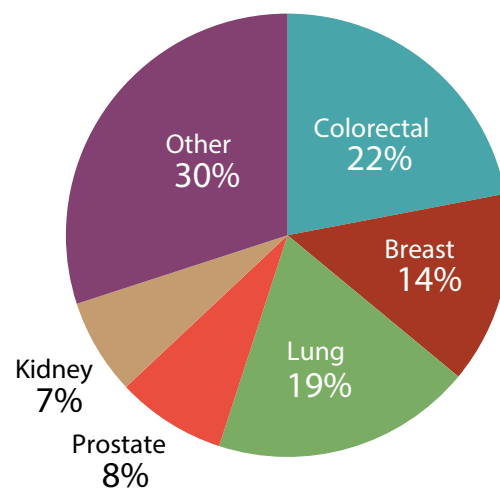


- Overall in the NWT, cancer is the leading cause of death: 30% of women and 22% of men in the NWT die from cancer.
- In the NWT, most cancer deaths are from lung and colorectal cancers because of smoking, drinking, and finding the cancers too late. Men tend to avoid seeing the doctor or getting screened, which may result in a cancer being found late.
- Between 2001 and 2010, the NWT had 1,107 new cancer cases; roughly 111 new cases per year. However, more people today are surviving cancer because we are able to find cancers earlier and provide quick access to treatment.
- Between 2000 and 2011, the Beaufort Delta had 256 new cancer cases. 117 of these cases were among residents of Inuvialuit descent.

**New Cancers in the Beaufort-Delta
(2000-2011)**



**New Cancers Amongst Inuvialuit
Populations in the Beaufort-Delta
(2000-2011)**



Source: NWT Cancer Registry, Department of Health and Social Services, Government of the Northwest Territories

- The Department of Health and Social Services is developing a new cancer strategy that will be presented in the Legislative Assembly in the fall of 2015. This strategy will focus on the whole cancer pathway. Resources are currently being developed to support the cancer strategy.
- Screening guidelines have been released for breast, cervical and colorectal cancers.

Cancer Screening in the NWT

BREAST CANCER			
WHO	WHAT TEST	WHEN	WHERE
Most women aged 50-74	Mammogram	Every 2 years	Yellowknife Hay River Inuvik
CERVICAL CANCER			
WHO	WHAT TEST	WHEN	WHERE
Most women aged 21-69*	Pap smear	Every year**	Community health centers
COLORECTAL CANCER			
WHO	WHAT TEST	WHEN	WHERE
Most men and women aged 50-74	Fecal immunochemical test	Every 1-2 years	Community health centers

* Or 3 years after becoming sexually active

** Until 3 consecutive normal Pap smears, then every 2 years

Questions and Answers with Dr. Corriveau

Q: What is the relationship between food and cancer?

A: It is not that some foods cause cancer as much as some diets do not provide enough vitamins and minerals needed to help the body repair itself. Certain foods are important to repair cells because they provide the necessary minerals and vitamins. If your diet lacks healthy foods, your body's cells may not be getting the help it needs to repair your body effectively.

Q: Do we know all the chemicals in cigarette smoke? Can these chemicals be removed from cigarettes to make a healthier product?

A: We do know all the chemicals in cigarettes. However, these chemicals cannot be removed. When the cigarette burns, the chemicals in tobacco are transformed to more than 4,000 chemicals. These chemicals include tar, formaldehyde, carbon monoxide, nicotine, and many more.

Q: Does the environment cause cancer?

A: Certain activities such as mining can expose you to dusts that increase your risk of developing cancer. However the environment poses a very low risk of cancer. Even a weekend spent in a big city with air pollution is very low-risk compared to smoking a cigarette.

Q: Will heavy drinking earlier in life affect you later, even if you no longer drink?

A: Heavy drinking damages your body, but the longer you've been away from drinking, the better.

Q: I heard about a 21 year old woman who got breast cancer. She would keep her cell phone in her bra. Might this have caused her cancer?

A: There are many things we do not know about this. This young woman could have had a family history of cancer or been exposed to something else that caused her to develop



cancer. The research so far has not shown a significant impact of wireless technology on cancer. Cell phones do give off some waves that make cells vibrate, but this is very little compared to radium, for example.



Q: In your presentation you mentioned *reportable* cancers. When you receive your reports, do you share this information with the patient's community health nurse?

A: The reports we receive are actually copies of what the patient's health care provider already has. But you raise a good point that we need to look more into sharing information and communicating better.

Q: I have heard of a project in Aklavik that treats *H. pylori* infection. Will this project extend to other communities?

A: This research project is led by the University of Alberta. The DHSS and the IRC are key partners in this project. So far they have focused on the communities with the highest *H. pylori* infection, which is why places like Aklavik have received more health promotion and education on this issue. Other communities within the Inuvialuit Settlement Region have expressed their interest to be involved, and they will be included once they set up their community steering committees. Whether or not a community is involved in this particular research project, all communities have access to *H. pylori* testing and treatment through their local health centres.

Q: What do you do to raise awareness of cancer screening? Do you train your staff at all levels on signs and symptoms of cancer so that they know when to screen for cancer?

A: Screening is a priority in the new cancer strategy. Health care professionals are trained to recognize signs and symptoms of cancer when they are students. Also, we share promotional materials with all communities about screening. We are especially concerned by low screening rates among men, and hope that communities can advise us on how to get more men in for screening.

Support in the cancer journey

Participants discussed challenges and possible solutions or opportunities with regard to the support available to patients and families in the cancer journey. Overall, the participants said that cancer patients and families need information, escort and travel services, and caregiver and community support.

- We need to break the silence and talk about cancer. To make progress in creating supports for cancer patients, communities need the support of their local politicians/government.
- Cancer patients need more information. The more knowledge one has, the less stressful the journey. Information is needed to guide patients and caregivers toward financial support, and there needs to be an improvement of cross-cultural awareness and education within the system. It would be best for there to be a single one-stop shop (for example, a website) where cancer patients and others can access information about care and support services.
- The current review of medical travel and escort policies should not be isolated from the upcoming territorial cancer strategy. Non-medical escorts need more knowledge about cancer, surgery, and after care. Community wellness plans could integrate training workshops to establish pools of non-medical escorts in each community. As well, extra time should be allowed for patients and their escorts to travel a few days in advance of medical appointments during seasons when weather delays are likely.
- Nurses on a short rotation do not have enough time to form relationships with their patients. These relationships are important to know how to respect a patient's comfort zone. Patients also need to feel comfortable around those taking care of them. It is helpful when health care providers use plain language and take the time to explain concepts to their patients. Health care providers would benefit from cultural orientation and sensitivity training before working in the NWT.



You can't just be on an assembly line.

– Participant



- A cancer patient navigator or liaison worker at Stanton Territorial Hospital (STH) would provide invaluable help to cancer patients and their families as they navigate the cancer journey. The hospital should also make audio recorders available to their patients to record conversations with their care providers.
- Cancer patients would benefit from massage and other personal care services.
- Caring for someone with cancer can be stressful. It can also be difficult emotionally, especially if caring for a family member or a close friend. Caregivers need spiritual, emotional, and bereavement support while they are caring for a cancer patient, and in the case of a death. STH would be an ideal location for caregivers to access counsellors or other support services. However, elders, youth, or community wellness workers could also be trained to provide various kinds of support, including bereavement support, within their community.
- Finding ways to bring people together, including recreational opportunities, will contribute to improvements in a cancer patient's quality of life while creating opportunities for community members to support one another.

“ *My doctor would phone me every morning from Yellowknife on his own.*

That really touched my heart and kept me going on. ”

– Participant



Our vision for cancer and community health

Participants brainstormed what actions contribute to the emotional, mental, physical, and spiritual health of a community. The group acknowledged that there is much overlap between each category.



Emotional Health

- Honouring those who have survived cancer and acknowledge those who supported them at community events
- Encouraging strong and open communication practices between patients, families, doctors and nurses
- Creating a circle of care that includes professionals, patients, family, friends, and caregivers
- Promoting and enhancing community partnerships between families, agencies, and organizations
- Facilitating workshops on care and needs of cancer patients for caregivers and families

Mental Health

- Sharing information, knowledge, and experience with others by breaking the silence and talking openly about cancer
- Developing community volunteer groups that comprise youth, elders, and other community members
- Organizing and conducting cancer sharing circles in every community
- Facilitating sing-a-longs during community gatherings
- Believing that cancer can be conquered
- Encouraging patients, family, friends, and community members to have fun and live life
- Setting up an information hotline that provides clear information in all appropriate languages

Physical Health

- Promoting exercise and active lifestyles
- Promoting healthier lifestyle choices and addressing risk factors
- Increasing access to affordable, healthy foods
- Encouraging regular check-ups and providing reminders
- Increasing access to services
- Organizing more home visits by community health representatives (CHR) and wellness workers
- Promoting screening guidelines and information
- Building on existing community strengths to implement community initiatives such as those run by the Aklavik recreation department

Spiritual Health

- Recognizing and promoting being on the land
- Facilitating communication between ministers or pastors and patients and families
- Promoting strong spirituality



How do we achieve our vision?

Cancer Prevention and Healthy Living

Health professional turnover in communities is a problem. New staff may have different approaches to healthy living that do not incorporate Inuvialuit culture. To ensure the continuity of care despite turnover of health care professionals, new staff should receive culture and compassion training. Additionally, funds need to be allocated to respite workers and counselling services.

Groups of individuals such as CHRs, community wellness workers, youth, and elders can work together to educate community members about cancer prevention and healthy living. Information can be shared via the radio, Aboriginal Peoples Television Network, fact sheets, workshops, public meetings, surveys, and online. Public meetings, workshops, and radio call-in shows also give people the chance to share their concerns. Specific ideas that were discussed to promote cancer prevention and healthy living include:

- Create posters for survivors in all communities as a “Hall of Fame”
- Have resources such as video testimonials and posters available in health centres and online
- Create fact sheets on each cancer
- Disseminate information via newsletters and postcards
- Communicate information to the community on local radio stations
- Use telehealth for questions about lifestyle and diet changes
- Promote patient self-advocacy
- A liaison worker in the clinic or hospital can help provide information
- Community members and health care professionals can work together to promote regular check-ups and screening



- Provide affordable healthy foods in all communities and educate community members about the differences between processed and traditional, natural foods.
- Have experienced community members host workshops and act as community role models
- Train CHRs on presentation skills to share information with different groups in the communities such as schools

Early Detection and Screening

Doctors and nurses need to take patients seriously. If a patient is repeatedly coming into the clinic with the same complaints, the issue should be examined further. People know their own bodies well, and know when something is wrong.

It is important that communities have access to the appropriate screening tools. As well, community members should be educated about early detection and screening. Specific ideas that were discussed include:

- Local male champions should encourage other men to get screened
- Encourage regular screening, especially for those who have a family history of cancer
- Local health care providers should contact those with a family history of cancer to suggest screening



Participants suggested that in cases where a second medical opinion is necessary, there be a clear process to ensure associated costs are included under territorial health coverage.

Screening results need to be shared with patients in a timely manner to reduce anxiety. Other ways for patients to reduce anxiety around early diagnosis and screening include:

- Accepting the possibility of cancer—don't stay in denial
- Getting emotional support from family or friends

Support to Navigate the Cancer Journey

Local community members could be trained to offer support to others, and health care providers can be trained to effectively communicate with patients in remote northern communities.

Cancer patients currently do not know what to expect in the cancer journey. Improved community access to information about cancer would help cancer patients advocate for themselves. The IRC and GTC could partner to organize information sessions that align with bingo nights to get as many people as possible in attendance. The IRC and GTC could begin with an assessment of community knowledge to determine where gaps exist and how to fill those gaps.

A cancer patient navigator in each region of the NWT would help the patient to navigate between community health centres and hospitals. This position would help to orient patient and caregivers on what to expect in the cancer journey. The cancer patient navigator could also go to appointments with patients, if needed, to advocate for the patient. Virtual video tours of treatment facilities would help the patient and their family.



Emotional Support and Quality of Life

Cancer is less scary when you know what you are dealing with—in other words, cancer patients and their families need access to information and support. Participants agreed that they would like more education about cancer and cancer risk factors, starting with youth in the schools. CHRs were identified as the appropriate link between the health system and communities. The participants suggested that the profile and mandate of the CHRs be assessed and adapted to ensure that CHRs take on more health promotion and outreach than administration.

It takes a community to support a cancer patient and their family. Communities can come together to form committees or support groups that address care needs for those living with cancer. The following services are examples of what communities can provide.

- Rides to and from the hospital, clinic, grocery store, and other locations
- House cleaning or simple chores
- Cooking or food preparation
- Non-medical escorts

- Linking patients with traditional medicine or healers
- Preparing traditional foods
- Taking them for a trip out on the land
- Working with the hamlet or other community organizations to host monthly activities or events with traditional food and games
- Fundraising for events, escorts, or other needs of those living with cancer in the community

Organized support groups could meet every two weeks to share experiences and support one another. Volunteers could seek training to learn physical and emotional support skills to bring back to the community. More emotional and navigational support is needed at STH and the boarding homes in Yellowknife and Edmonton. Support is needed not only for cancer patients and survivors, but also their caregivers. Caregivers need to remember to care for themselves as well as the patient, and may be very stressed while on the receiving end of much anger and negative expression.

It is important to have grief and mental health services available right away for those who have lost a loved one. Communities need immediate and ongoing access to grief counsellors.



Suggestions to increase community capacity to deal with grief include:

- Have grief counsellors visit communities more than once a month;
- Offer training for community members to provide emotional support and one-on-one services to help others deal with grief;
- Have a grief counsellor available in communities rather than putting people on a waiting list for counselling in Yellowknife.

Community organizations can work together to facilitate cancer sharing circles. When you break the silence on cancer, it makes the community stronger. These sharing circles should also take place frequently, determined by community need.

Survivorship care, also called aftercare or follow-up care, is needed in small communities. Health care centres can follow up with patients—even after they are cancer-free. Friends, family or health care providers can also check-in with patients regularly in the morning or evening. Additionally, health care centres could provide fresh produce or healthy foods to patients most in need. We need to make sure patients are well taken care of: eating healthy and doing mentally-stimulating or strength-building activities to stay on a healthy and positive path.

“

I think this is the first time I've ever sat through something like this for cancer, and I've really enjoyed it.

– Participant

”



[illegible]

Appendix A: *Agenda*

Breaking the Silence:

Cancer Sharing Circle in the Inuvialuit Settlement Region

Ingamo Hall, Inuvik, January 20 & 21, 2015

AGENDA

January 20, 2015

- | | |
|-------|---|
| 9:00 | Opening prayer |
| 9:15 | Welcome from the Inuvialuit Regional Corporation |
| 9:30 | Introductions |
| 10:00 | Participant expectations and stories |
| 10:30 | Break |
| 10:45 | Cancer in the Beaufort-Delta
NWT Chief Public Health Officer Dr. André Corriveau |
| 12:00 | Lunch |
| 1:30 | Support in the cancer journey |
| 2:30 | Break |
| 2:45 | Small groups: What is our vision for cancer and community health? |
| 4:00 | Reflections |
| 4:30 | Close |

January 21, 2015

- | | |
|-------|---|
| 9:00 | Opening prayer & welcome |
| 9:30 | Reflections from Day One |
| 10:30 | Break |
| 10:45 | Small groups: How do we achieve our vision? |
| 12:00 | Lunch |
| 1:00 | Video presentation |
| 1:30 | Small group presentations |
| 2:30 | Break |
| 3:30 | Tree of hope |
| 4:00 | Close |

Appendix B: *Glossary*

Caregiver	In this document, a caregiver is defined as a spouse, adult child, other family member or friend who provides unpaid care to someone living with cancer, allowing them to remain in their home and community.
Cancer journey	The cancer journey is the full experience of cancer in all its stages, either first-hand or through a loved one.
Circle of care	The circle of care is a model where the patient is at the center of care and a team of health professionals works collaboratively toward the patient's holistic health and wellness.
Community health representative	A community health representative is a community member who links the community with the formal health system through the delivery of health promotion, treatment, and surveillance programs.
Continuum of care	The continuum of care is a concept to describe the delivery of health services throughout all stages of an illness from diagnosis to the end of life.
Cultural competence	Cultural competence is the individual ability to interact and communicate with people of other cultures and backgrounds in a way that is effective and respectful.
Cultural capabilities	Cultural capabilities refer to an organization or system's ability to provide services that are equitable and respectful of other cultures and practices.
Cultural safety	Cultural safety is a concept to describe when a health care provider combines cultural competence with inquiry about an individual patient's preferences, resulting in an atmosphere where the patient feels no fear or judgment.

Culturally appropriate	A culturally appropriate care or service aligns with the characteristics, preferences, and values of a particular cultural group.
Emotional safety	Emotional safety is a concept to describe when an individual feels that his or her thoughts and feelings will be respected for what they are.
End-of-life care	End-of-life care is care for patients with advanced and incurable disease.
Fecal immunochemical test	The fecal immunochemical test (FIT) is a simple stool test that is used as the primary colorectal cancer screening test in the Northwest Territories for individuals aged 50-74 years who are at average risk of the disease. The test is available in all health centers, can be done at home, and does not have any dietary restrictions.
Health promotion	The Ottawa Charter for Health Promotion defines health promotion as the process of enabling people to increase control over, and to improve, their health.
Holistic care	Holistic care focuses on all aspects of an individual's life, including his or her physical, emotional, spiritual, and social needs. Healing the person as a whole is the goal of holistic care.
Incidence	Cancer incidence refers to the number of new cancers that occur in a specific population in one year. Cancer incidence is usually expressed as the number of cancers per 100,000 individuals at risk in the population.
Mammogram	A mammogram is a specialized x-ray of the breast that is used as the primary breast cancer screening test in the Northwest Territories for women aged 50-74 years who are at average risk of the disease. Mammograms are available in Yellowknife, Hay River, and Inuvik.

Mortality rate	A cancer mortality rate is the number of deaths due to cancer that occurs in a specific population in one year. Cancer mortality is usually expressed as the number of deaths due to cancer per 100,000 individuals in the population.
NWT Cancer Registry	The NWT Cancer Registry is the collection of data on tumours and cancer screening tests among NWT residents. It is an important tool for evidence-based, data-driven decision making.
Oncology	Oncology is the field of study and medicine devoted to cancer.
Palliative care	The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering and pain, and other physical, psychosocial, and spiritual challenges. Palliative care includes, but is not limited to, end-of-life care.
Papanicolaou test	A Papanicolaou (Pap) test is used as the primary cervical cancer screening test in the Northwest Territories. Women should have an annual Pap test starting at age 21 years or three years after becoming sexually active, whichever comes earlier. Following three consecutive tests with normal results, the Pap test can be taken every two years.
Primary prevention	Primary prevention of disease includes actions to reduce or avoid disease before it occurs. Examples of primary prevention include maintaining a healthy diet, exercise, and not smoking.
Risk factor	A risk factor is any behaviour or thing that increases the likelihood of developing a disease. Risk factors that we can control, such as smoking and exercise, are referred to as modifiable risk factors.
Screening	Cancer screening involves simple tests that are used to find early signs of cancer. Screening is for healthy people who do not have any symptoms of illness.

Secondary prevention	Secondary prevention of disease includes actions to detect and treat a disease early, prior to the appearance of symptoms. Cancer screening is an example of secondary prevention.
Self-advocacy	Self-advocacy is a term to describe the actions of individuals or groups to represent their own needs or interests.
Social determinants of health	The social determinants of health are the economic and social conditions that influence the health of individuals or groups.
Survivorship care	Survivorship care involves regular medical check-ups to identify and monitor changes in a person's physical and psychosocial health after completing cancer treatment. Survivorship care may also be called follow-up care, after care, or discharge care.
Telehealth	Telehealth is the use of communications technology to connect remote patients with health care, removing the need for travel
Tertiary prevention	Tertiary prevention of disease includes actions to reduce the damage of disease through rehabilitation and treatment. Surgery and palliative care are examples of tertiary prevention.
Traditional medicine	The World Health Organization defines traditional medicine as the sum of knowledge, skills, and practices based on the theories, beliefs, and experiences of Indigenous cultures that are used to maintain health and treat illness.

Appendix C: *Cancer Resources*

Choose NWT

<http://choosenwt.com/>

Choose is the public face of the Healthy Choices Framework, a GNWT-wide initiative to encourage and support NWT residents to make healthy and safe choices, consistent with the 17th Legislative Assembly's goal of fostering healthy, educated people. The site contains written and video resources.

NWT Breast Health/Breast Cancer Action Group

<http://www.breasthealthnwt.ca>

For nearly two decades, the NWT Breast Health/Breast Cancer Action Group has worked to improve breast health and breast cancer information, services, and support available to NWT women. They implement a number of initiatives such as *Healing Through Art* workshops, survivor retreats, and a project to determine survivorship care planning needs.

NWT Quitline

1-866-286-5099

The NWT Quitline is a toll-free, confidential telephone helpline for people who want to quit smoking. Services include:

- Tobacco cessation counselling;
- Personalized call-back program;
- Information material;
- Translation services for all NWT languages; and
- Telephone helpline 24 hours a day, every day.

Canadian Cancer Society

<http://www.cancer.ca>

The Canadian Cancer Society is a community organization that supports cancer research, provides information on all cancer types, organizes community programs, and leads initiatives in cancer prevention. The Canadian Cancer Society website contains information about the following services and more:

- Cancer Information Service (1-888-939-3333 or info@cis.cancer.ca)
- Peer Support Service (1-888-939-3333 or info@cis.cancer.ca)
- An online community at cancerconnection.ca
- Smoker's Helpline (www.smokershelpline.ca)

CancerControl Alberta

<http://www.albertahealthservices.ca/cancer.asp>

CancerControl Alberta is the agency within Alberta Health Services responsible for cancer care. The majority of NWT cancer patients end up receiving care at the Cross Cancer Institute in Edmonton, run by CancerControl Alberta. The agency is involved in cancer prevention, diagnosis, treatment, survivorship and palliative care, and research.

Northern Health Services Network

1-780-735-5761

The Northern Health Services Network helps NWT residents to coordinate their care and support while in Edmonton. They have significant experience coordinating treatment and discharge care as well as access to equipment and supplies for cancer patients, and liaises with the Cross Cancer Institute, Stanton Territorial Hospital, and the patient's community health center. All staff members have nursing experience in Canada's north and can advocate on behalf of northern clients to meet their linguistic, cultural, and spiritual needs.

CancerView Canada

<http://www.cancerview.ca/cv/portal/Home/FirstNationsInuitAndMetis>

CancerView Canada is a site that connects Canadians to cancer services, information and resources. There is a *Community of Information* page with resources on cancer control for First Nations, Inuit, and Métis peoples. On this page, there are videos where people share their personal cancer journeys as well as a knowledge circle with links to publications and research on cancer prevention, testing, treatment, and living with cancer.

@YourSide Colleague


www.atyourside.ca

One of the key initiatives of the Saint Elizabeth First Nations, Inuit, and Métis Program is @ *YourSide Colleague*, a secure web-based learning and knowledge-sharing program that provides many internet-based health courses (including *Cancer Care*) to First Nations communities. All of the courses were developed in collaboration with community-based health care providers from participating First Nation communities and are offered at no cost to the communities.

Appendix D: NWT Cancer Posters


CANCER SCREENING

Saves Lives!



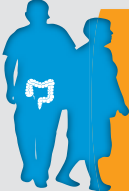
BREAST CANCER

WHO Most women age 50 - 74	WHAT TEST Mammogram	WHEN Every 2 years	WHERE Yellowknife Hay River Inuvik
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CERVICAL CANCER

WHO Most women age 21 - 69* <small>* Or 3 years after becoming sexually active</small>	WHAT TEST Pap test	WHEN Every 2 years** <small>** After 3 consecutive annual normal pap tests</small>	WHERE Community Health Centres
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COLORECTAL CANCER

WHO Most men & women age 50 - 74	WHAT TEST Fecal immunochemical test	WHEN Every 1-2 years	WHERE Community Health Centres
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CANCER SCREENING

- Is for people with no symptoms of cancer
- Helps to find cancer early and improve your chances of full recovery

You could be eligible for a different screening test, or screening at an earlier age. If you have family cancer history, personal cancer history, or are experiencing any unusual signs or symptoms, see your health care provider.

If you would like this information in another official language, call us at (867) 920-3367
Si vous voulez ces informations dans une autre langue officielle, téléphonez-nous au 867-920-3367



Let's Talk About Cancer
For more information, talk to your health care provider
or visit www.cancer.ca

10 WAYS TO REDUCE YOUR CANCER RISK



QUIT TOBACCO



MAINTAIN
HEALTHY DIET



BE SUN SAFE



GET SCREENED



GET VACCINATED



BREASTFEEDING



LIMIT ALCOHOL



ACHIEVE HEALTHY
BODY WEIGHT



BE PHYSICALLY
ACTIVE



KNOW YOUR
FAMILY HISTORY

If you would like this information in
another official language, call us at
(867) 920-3367

Si vous voulez ces informations
dans une autre langue officielle,
téléphonez-nous au (867) 920-3367

Choose 


A Program of the
Northwest
Territories

Let's Talk About Cancer

For more information, talk to your health care provider
or visit www.cancer.ca

