ᐸᐅᒃᑑᑎᑦ
ᐃᓄᐃᑦ ᐊᕐᓇᐃᑦ ᑲᓇᑕᒥ
PAUKTUUTIT
INUIT WOMEN OF CANADA

Pauktuutit Inuit Women of Canada

Inuit Cancer Project
Year One Final Report (March 2013)
Project Number: 6263-15-2011/10871068

Submitted to:
Brigitte Belanger
Centre for Chronic Disease Prevention and Control
Public Health Agency
785 Carling Avenue,
Ottawa, Ontario K1A 0K9

Submitted by:
Geri Bailey
Manager Health Policy & Programs
Pauktuutit Inuit Women of Canada
520 – 1 Nicholas Street
Ottawa, ON, K1N 7B7
Telephone: 613-238-3977 ext.227
Fax: 613- 238-1787
E-mail: gbailey@pauktuutit.ca

Content

Introduction

The Inuit population is very young and linguistically and culturally distinct from the rest of Canada. It is one of the most economically challenged, medically underserved, and remote populations in the country. Even cancer patterns are distinct from the general Canadian population — ranked as the second leading cause of death among Inuit, a rate nearly twice than for the total population of Canada (Inuit Tapiriit Kanatami 2009). The Inuktitut term for cancer lacks precision; it is broadly understood as a disease that lacks a cure. There is limited health literacy about cancer and a lack of culturally appropriate cancer awareness resources. For some, cancer is only diagnosed in its later stages when the long-term prognosis is less promising. These all reinforce a fear, stigma, and fatalistic attitude about the disease which, in turn, may discourage early screening for the disease.

Health service systems and cancer screening and diagnostic programs and services vary between the four regions of Inuit Nunangat (Inuvialuit Settlement Region, Nunavut, Nunavik, and Nunatsiavut). Generally, diagnostic services and cancer treatment facilities are limited or non-existent in the communities. There are no cancer clinics in Inuit Nunangat. Cultural barriers — language, lack of cultural sensitivity within the health care system, and a lack of culturally appropriate information resources — limit the ability of health care providers to meet the information needs of Inuit. To address these problems, Pauktuutit Inuit Women of Canada has undertaken the *Inuit Cancer Project*. With financial support from the Public Health Agency of Canada (PHAC), Pauktuutit has partnered with the Canadian Cancer Society, the Canadian Breast Cancer Network, the Canadian Partnership Against Cancer's Advisory Committee on First Nations, Inuit, and Métis Cancer Control, and the Government of Nunavut's Department of Health and Social Services to achieve the following objectives:

1. Increase Inuit knowledge (health literacy) about different cancers, about cancer screening and early detection, and about cancer care and treatment.
2. Increase the capacity of front line health providers working to explain and promote the importance of participation in cancer screening and early detection programs.
3. Increase the understanding among non-Inuit health professionals about their Inuit cancer patients, Inuit culture, and about Inuit attitudes about cancer and cancer treatment.
4. Increase the cancer language/terminology capacity of all front line health providers working with Inuit.

This report presents the results of Pauktuutit's work between April 2012 and March 2013. To date, the project has successfully met the requirements of a number of research ethics boards; undertaken an environmental scan which has included a literature review, key informant interviews, and a review of Inuit-specific cancer awareness material; conducted nine focus group sessions; conducted a cancer workshop during Pauktuutit's Annual General Meeting (AGM) in March 2013; and conducted a two-day meeting of the project's advisory committee to review the project's work to date and to discuss next steps.

Project Overview

The *Inuit Cancer Project* is a two-year initiative to develop culturally appropriate cancer awareness tools that will promote increased screening and early diagnosis of cancer among Inuit living in Inuvialuit, Nunavut, Nunavik, and Nunatsiavut. Increased awareness about cancer among Inuit will reduce the stigma associated with cancer screening and early detection, and reduce the health disparities among Inuit diagnosed with the disease.

The project's key activities include an environmental scan (literature review, Internet search, and key informant interviews); the development and undertaking of nine Inuit-specific Knowledge-Attitude-Behaviour focus group sessions; the undertaking of a terminology forum to develop an Inuktitut glossary of cancer-related terms; and the development, translation, and field testing of culturally and linguistically appropriate plain-language cancer awareness tools and complementary support material for use by Community Health Representatives/Workers (CHR/Ws) and non-Inuit health care providers. To this end, an advisory committee with cultural, regional, administrative, and subject matter expertise has been established to guide the cultural content, the project's methodology, and development of the final products.

The focus groups help to develop an understanding of Inuit knowledge, attitudes, and behaviours about cancer. They offer an opportunity to gain unique regional perspectives on how Inuit view the topic. This information will support the development of educational resources and tools that better target the Inuit audience. The assumption is that information campaigns are filtered through cultural lenses and therefore awareness products should be appropriate for the target culture. The focus groups provide an opportunity to gauge Inuit understanding of cancer in terms of what they know and feel about cancer and what behaviours and attitudes guide their reasons to participate in screening initiatives. The focus groups also help to identify the best formats and media to reach out to Inuit in order to raise awareness.

Developing linguistically appropriate cancer awareness tools is an important outcome of the *Inuit Cancer Project*. Before awareness tools will be developed, translated, and distributed, a terminology forum will be conducted with the participation of content and language experts. The forum is planned for the summer of 2013. It will make certain that technical and cancer-related terms have suitable Inuktitut-equivalent wording. This will contribute to the effective knowledge exchange of cancer information in each of the four Inuit regions.

The long-term goals of this project are to increase Inuit health literacy and engagement in cancer screening and early detection programs and to promote lifestyle changes that will reduce Inuit exposure to cancer risks. The intent is to overcome Inuit attitudes that cancer is a disease that cannot be cured or managed. Over time, this project will contribute to decreased health disparities, reduced cases of cancer among Inuit living in remote communities, and reduced treatment costs associated with Inuit living with cancer.

Research Ethics Board Reviews

Prior to the start of the focus group research, Pauktuutit was required to have the research methodology reviewed and approved by PHAC's Research Ethics Board (REB). Fortunately, Pauktuutit was provided the opportunity to make a presentation to the REB in July 2012, soon after it had signed a contribution agreement with the Agency. The timing, however, also proved onerous in that it required Pauktuutit to complete a number of REB application requirements and project components in a compressed timeframe. In particular, it was necessary to complete by the end of June 2012 the project's literature review, and the focus groups' discussion guide, facilitator's guide, note-taker's guide, consent form, and participant registration forms. Following a teleconference presentation in July 2012, Pauktuutit also was required to submit information about the project's planned key informant interviews.

Typically, Pauktuutit would present the material presented to the REB first to the project's Advisory Committee for review, assessment for cultural appropriateness, and approval. Pauktuutit's strategy for most projects is to build on community strengths and networks by assembling advisory bodies that solicit broad and comprehensive Inuit input and expertise. This strategy ensures that the differing socio-economic and regional circumstances of Inuit are captured and incorporated during program and project development. Unfortunately, the REB process pre-empted this strategy, making the Advisory Committee's cultural expertise and input secondary to that of REB members.

Pauktuutit's *Inuit Cancer Project* received PHAC REB approval in late August 2012, allowing the focus group research to proceed. However, a session was planned for Nunatsiavut and Pauktuutit was compelled to have the project reviewed by Health Research Ethics Authority (HREA) of Newfoundland and Labrador and approved through the Nunatsiavut Government Research Process. Applications, project descriptions, the literature review, and other supporting documents were submitted to this end. Both bodies approved the project though the HREA requested minor modifications to the facilitator's guide.

Despite the rigours of PHAC's REB review process, the governments of Newfoundland and Labrador and of Nunatsiavut were unwilling to accept the federal review process. The focus groups were allowed to proceed without having to undergo ethics reviews in the jurisdictions of Nunavik, Québec, Nunavut, Northwest Territories, and the Inuvialuit Settlement Region.

Literature Review

A somewhat more detailed literature review for the *Inuit Cancer Project* was prepared in advance of Pauktuutit's REB submission to PHAC. The review presented here is an abbreviate version that presents the key findings. The literature review relied on an Internet-based search of the PubMed database and the Arctic Science and Technology Information System (ASTIS) database and on additional published material that examines cancer and cancer awareness among Inuit. Primary interest is in literature and resource material that examines Inuit knowledge and behaviour about cancers. Overall, limited literature exists on the subject, and what does exist tends to focus on epidemiology of different types of cancer and less on Inuit attitudes and behaviour.

Cancer Among Inuit

At the turn of the last century, cancer among Inuit was thought to be nonexistent. During the 1970s, studies in the circumpolar region revealed the existence of distinctive cancer patterns characterized by high frequencies of cancers of the nasopharynx, salivary glands, esophagus, and low frequencies of tumours and such 'Western' cancers of the breast, skin, prostate, and hematological systems (Firborg and Hassler 2008; Carrière et al. 2012). Among circumpolar countries, the highest rates of cancer are reported in Greenland and in Nunavut. A key research challenge is that Inuit-specific data is limited. Both Nunavut and the Northwest Territories maintain cancer registries that allow for some degree of Inuit-specific data, but this is not possible with the Québec or Newfoundland and Labrador cancer registries.

Overall cancer rates among Inuit in the 1950s and 1960s were lower than the national rates, but they appear to have caught up. Lung cancer rates among Inuit in Canada, for example, are now the highest in the world. Recent data reveals that the incidence of cancer among Canadian Inuit women is higher than among men. Data from 1998 – 2007, indicate 14% of Inuit men have had some form of cancer whereas 29% of Inuit women have had cancer (Carrière et al. 2012). As Inuit life expectancies increase, so has the number of years in cancer prone years. As well, risk factors have changed (less traditional diet, less physical activity, and greater tobacco use) and cancer detection has improved. As a result, cancer has evolved into a major health problem in the Arctic (Firborg and Hassler 2008; Carrière et al. 2012).

In the NWT, the most commonly diagnosed cancers for Inuit women are breast (22%), colorectal (22%), trachea, bronchus, and lung (19%) (ITK 2008). In Nunavut, 'historical' cancers now are declining and the incidence of such 'modern' cancers as lung, breast, colon, and cervix cancer are increasing (McDonald and Trenholm 2010). Between 1992 and 2001, cancer of the lung, colon, breast, and nasopharynx were the most common invasive cancers diagnosed in the territory (Healey, Plaza, and Osborne 2003). Cancer rates for Nunavik and Nunatsiavut are not readily available.

Some cancers are linked to such modifiable risk factors as smoking and potentially to such socioeconomic factors as housing, income, and educational attainment levels. Educational attainment, for example, may be associated with health literacy and behaviours that are protective against cancer (Carrière et al. 2012). Of concern is that reduced engagement in cancer screening in Inuit regions may result in cancer rates being underestimated in these regions. Potential factors in reduced access to screening include remoteness, availability of specialised services and screening programs, and language barriers (ITK 2008; Tait 2008). Additionally, there may be an unwillingness to seek screening because the diagnosis and treatment of many cancers often requires travel outside of Inuit regions.

The following cancers are of particular concern among Inuit:

- **Lung cancer** rates have increased in all Inuit populations since the 1960s. Between 1992 and 2001, lung cancer accounted for 39% of the invasive cancer cases in Nunavut — 3.2 times the national average for men and 5.3 times the national average for women. Currently, it is estimated that 36% of the cancers among Inuit men and 27% among Inuit women are cancers of the lung and bronchus. Given the latency of several decades between smoking and cancer development, the lung cancer epidemic among Inuit (especially among women) may not have reached its peak.
- **Breast cancer** rates have traditionally been low among Inuit but rates began to increase in the 1970s. About 16% of all cancers suffered by Inuit women are breast cancer. In Nunavut, rates are about 40% that of Canada as a whole. Extended breast-feeding and the traditional Inuit diet may have offered protection against the disease (Carrière et al. 2012). The increase in breast cancer rates is consistent with increasing prevalence of obesity and type II diabetes in Inuit populations (Firborg and Hassler 2008).
- **Colorectal cancer** rates have increased significantly among Inuit since the 1970s (Carrière et al. 2012). Currently, it is estimated that 21% of all cancers among Inuit men and 16% among Inuit women is colorectal cancer. It is now the second most common invasive cancer in Nunavut with most cases (70%) occurring among individuals under the age of 70 years in contrast to the typical occurrence after 70 years of age in the rest of Canada. The dietary transition among Inuit and less physical activity are likely contributing factors (Firborg and Hassler 2008).
- **Cervical cancer** rates are generally three times higher among Inuit, though the rates are declining as a result of increased screening and increased use of condoms. It is estimated that cervical cancer constitutes about 4% of all cancers suffered by Inuit women. Certain types of HPV are linked to cervical cancer. Aggravating factors such as smoking, diet, and the number of times a woman has given birth may influence the acquisition and persistence of the HPV infection and its progression to the invasive cancer. Research has identified certain factors that may limit cervical cancer screening among Inuit women, including a lack of knowledge about Pap smears and their importance, feelings of embarrassment, and a lack of continuity of care due to a high turnover of health professionals (Cerigo et al. 2012).
- **Nasopharyngeal cancer** varies widely by geography and ethnic group. It is 25 to 40 times more common among Inuit compared with Caucasians (Firborg and Hassler 2008). It constitutes about 5% and 4% of all cancers among Inuit men and women, respectively.
- **Salivary gland cancer** is relatively rare in most populations. Compared to Europeans, it is five to 10 times more common among Inuit though the rates are stable. Salivary gland cancer may share genetic and/or environmental factors with nasopharyngeal cancer though little is known about risk factors in the Arctic (Firborg and Hassler 2008).
- **Esophageal cancer** continues to be a public health concern. Smoking and alcohol are confirmed risk factors. However, rates of the cancer among Inuit have not followed the increasing trend of lung cancer and therefore other risk factors may be relevant. Among Alaskan natives, for example, human papillomavirus (HPV) has been found in a high proportion of esophageal cancer patients.
- **Stomach cancer** rates are increasing, especially among Inuit in Greenland and Alaska. While smoking is known to increase the risk of stomach cancer, the large increase in rates among Inuit men is not paralleled among Inuit women. The increase in stomach cancer rates remains largely unexplained. Among Inuit men in Canada, stomach cancer constitutes about 5% of all those with cancer.
- **Prostate cancer** rates among Inuit men are the lowest in Canada, constituting about 6% of all cancers suffered by Inuit men. However, dietary changes among Inuit and the tendency

towards less physical activity are risk factors for the disease and there is concern prostate cancer rates may start to increase (Firborg and Hassler 2008).

Cancer and Inuit Behaviour

Limited research was identified that has examined Inuit cancer-related behaviour. Ethnicity, however, is an important determinant of other health-related behaviours among Inuit and other northern residents. According to McDonald and Trenholm (2010), only 31% of Inuit live within 50 kilometres of a hospital and this geographic isolation may be a factor in the low levels of early medical diagnosis among Inuit and the relatively low levels of access to general practitioners. The researchers suggest the legacy of evacuations for pregnant women and the prospect of medical evacuations to southern centres for cancer treatment may act as barriers that keep Inuit from seeking early diagnosis and treatment.

Using data from the 2000-2001 and 2004-2005 Canadian Community Health Survey, McDonald and Trenholm (2010) found that Inuit with a high school or post-secondary education are more likely to consult with a doctor and nurse, have lower smoking rates, and have a lower prevalence of obesity. Further, those living closer to a hospital are more likely to consult with a doctor rather than with a nurse. In general, after controlling for differences in remoteness, socio-economic status, and demographic factors, Inuit remain significantly less likely to have consulted with a physician and Inuit women are significantly less likely to have had a Pap smear test or a mammogram than are non-Aboriginal individuals in the same region. The researchers conclude these differences may be due to unobserved factors that are specific to Inuit themselves, their communities, and their historical and current interactions with Western culture and modern health system.

The research reported by Cerigo et al. (2011 and 2012) describes the results of a survey of Inuit women in Nunavik about their knowledge, attitudes, and beliefs about HPV, cervical cancer, and their self-perceived risk of sexually transmitted infections (STIs). The researchers note this is the first study of its kind among Canadian Inuit women and that worldwide, very little published literature exists on Aboriginal women’s knowledge, attitudes, or experiences about cervical cancer and its prevention. The researchers conclude there is a low awareness of cervical cancer and HPV among Inuit women but this level differs little from non-Aboriginal populations. The key distinction is that there is a higher prevalence of HPV in Canadian Inuit populations. Higher awareness is linked to education levels and knowing someone with cervical cancer. The researchers note, however, that Inuit are often modest about their knowledge and may understate their knowledge unless they are confident about it. As such, the study may underestimate the true level of knowledge held by Inuit women in Nunavik.

Cerigo et al. (2011 and 2012) note that cervical cancer rates are declining among Inuit women in Canada but the burden remains about three times higher than the Canadian average. Though almost all the women surveyed had had a Pap smear, less than half understood that it was for cervical cancer screening and about a third linked it to screening for STIs. Almost 40% reported feeling embarrassed during Pap smear exams and 60% reported experiencing pain. Sixty percent also indicated they preferred female practitioners and having the nurse or doctor explain each step of the procedure.

Among survey participants who identified Pap smear tests with cervical cancer screening, multiple sexual partners were commonly identified as a risk factor. About 45% of the women considered themselves at average risk of developing cervical cancer though the rates were higher among older Inuit women. Almost 60% recognized that early detection would increase the chances of being cured.

Cerigo et al. found that 27% of the survey participants had heard of the HPV vaccine, with the majority of these women linking it to cervical cancer prevention. For many, their health practitioner is considered their key source of information about HPV and critical in their decision to receiving the vaccination. However, the researchers note that there is a high acceptance of vaccines in general in Nunavik and this is likely influenced by the role of nurses. Though the media is an important source of information, the researchers suggest discussion-based learning may be a useful avenue for greater awareness. Focus group participants expressed a desire for more information about HPV and the researchers conclude that further education about cervical cancer is needed.

Kemberling et al. (2011) examined the knowledge, attitudes, and perceptions of 79 Alaskan Native adolescents (females aged 11 through 18) about cervical cancer, HPV, genital warts, and the HPV vaccine through interviews conducted in four Alaskan communities. The study did not report on any Inuit-specific results. The researchers conclude that participants knew very little about HPV and cervical cancer. When asked about cancer in general, the participants were more informed about lung cancer. In a related study among parents, the researchers found that adults had heard of the HPV vaccine but were not aware of the link to cervical cancer screening.

When asked about the cause of cancer, Kemberling et al. (2011) report that the Alaskan Native adolescent females tended to respond that they did not know. Drugs, alcohol, tobacco, sexual intercourse, STIs, HPV, environmental factors, and poor health were other responses. Some participants did not think that cancer was preventable while others proposed vaccines, medicine, healthy lifestyle, safe sex, and abstention from sex, drugs, alcohol, and tobacco. More participants answered that cancer was curable than those who answered, they did not know or that there was no cure.

The Alaska Native teens commonly received health information from school, health providers, family, television, the Internet, and magazines. Newspapers and the radio were less commonly cited. Posters and brochures were less common sources among younger people. When asked about their preferred type of media, the most common response was television, followed by the Internet, brochures, and posters.

Walker et al. (2010) report on a representative telephone and Internet survey among Canadians about awareness of risk factors associated with lung cancer, COPD, and sleep apnea. The survey included a sample of First Nations, Métis, and Inuit people (115 of 3,036 people surveyed). The researchers note that tobacco use is a generally known cancer risk factor but that awareness of obesity, low physical activity, and poor diet are less widely known. In terms of Canada's Aboriginal population, the researchers note a higher prevalence of smoking compared with the general population. However, they report no significant difference with the Canadian population in awareness of risk factors and symptoms for the three lung diseases under study and no statistical difference in terms of attitudes toward health care. No specific statements were offered about Inuit awareness.

Both the Cerigo et al. (2011 and 2012) and Kemberling et al. (2011) research are unique in their focus on knowledge, attitudes, and behaviour about cancer in northern Aboriginal populations. Similar research on the broader topic of cancer in general among Inuit could not be located in the search of recent studies using the PubMed database. Nonetheless, the two studies described above lend some insight into how Inuit populations may perceive topics other than cervical cancer and HPV. If these studies are any indication, knowledge about other cancers is equally limited, perhaps with the exception of lung cancer and the link to tobacco use. It is reasonable to assume their findings with respect to preferred media for disseminating cervical cancer and HPV awareness material extends to other cancers as well.

Cancer Awareness in Inuit Regions

As part of the literature review for the *Inuit Cancer Project*, a search was undertaken to identify relevant public awareness resources suitable for Inuit audiences. Though broader topics of tobacco cessation, diet, and exercise are relevant to cancer prevention, interest was in cancer-specific resources. In general, such resources are not common.

Northwest Territories

The Government of the Northwest Territories' Department of Health and Social Services has published a series of 10 cancer fact sheets about cancer. The fact sheets were produced in 2004 and are available in English and French. Most are very short plain language information pamphlets. They are general statements that do not focus on any specific cancer. They are organized under the following titles:

- Key Findings from Cancer in the NWT
- What is Cancer?
- Cancer Incidence
- Cancer Survival
- Cancer Control - Preventing Cancer
- Cancer Control - Detecting Cancer
- Cancer Treatment
- Continuing Care
- Cancer Support
- NWT Action Plan on Cancer Control

In addition, a single English language online audio file (mp3 format) about colorectal cancer is available that provides a more detailed description of the disease, risk populations and factors, screening procedures, and NWT screening policies.

The IRC and Nunatsiavut Government have partnered in a publication that describes a collaborative cancer screening initiative in the two Inuit regions (Inuvialuit Regional Corporation and Nunatsiavut Government: nd). The publication provides examples of regionally specific and culturally appropriate cancer awareness posters, information brochures, display boards, and breast self-exam shower cards. The document provides an overview of cancer in each region and the regional colorectal, cervical, and breast cancer screening initiatives. The document is not directed to the general public. Notably, the report suggests too much information on posters and in brochures can be counter-productive.

The report describes the Beaufort-Delta Health and Social Services Authority and IRC partnership to develop an Inuit-specific colorectal cancer screening project for the Inuvialuit region. It describes the procedures for soliciting samples (screening coordinator, training of CHRs, poster campaigns, letters placed in mailboxes, and promotion at weekly Games Night), reporting test results, and the means patients access more advance diagnostic and treatment services. The report notes that the use of a visual display of a giant colon in Inuvik was an effective learning tool. Barriers to the uptake of the colorectal screening project included high staff turnover that limited trusting relationships between community members and health care providers, lack of information about colorectal cancer which fosters fear of positive results, a lack of awareness of risk factors, and the requirement to travel to Inuvik to undergo colonoscopies.

The report notes that in 2009, the GNWT launched a territory-wide HPV vaccination program. Similarly, a breast cancer screening program is in place at the Inuvik Regional Hospital. Four clinics are scheduled per year with 125 clients per clinic.

Nunatsiavut

As noted, the Nunatsiavut Government (Department of Health and Social Development) entered into a partnership agreement with IRC with respect to breast, cervical, and colorectal cancer screening initiatives. Nunatsiavut was tasked with developing an enhanced breast health promotion strategy. A “Be Breast Aware" promotion program was developed that targeted Inuit audiences. The products were consistent with the services available in Nunatsiavut. Two posters, two pamphlets, one bookmark, and one shower card were developed. Key guidelines used during product development included:

- Messages and concepts originating from Inuit organizations.
- Products that target Inuit only.
- Messages that were first written in Inuktitut and then translated to English.
- Use of Inuit imagery.
- Emphasis of visual messages over written messages.
- Limited use of technical terms.

The IRC and Nunatsiavut Government report (Inuvialuit Regional Corporation and Nunatsiavut Government: nd) describes the cervical cancer screening initiative started in 2007 by the Labrador Grenfell Health. The screening is integrated into the Well Woman clinics. As well, Newfoundland and Labrador now have a province-wide Cervical Cancer Screening Initiative Program. Inuit-specific data are not available about cervical cancer rates in the province.

Typical barriers to cervical cancer screening are the invasive, awkward, embarrassing, and painful nature of Pap smear tests. The lack of knowledge among clients about the purpose of the test and the lack of female health care providers are additional barriers. None of these barriers are linked specifically to Inuit though the research described by Cerigo et al. (2011 and 2012) about Inuit women in Nunavik are consistent with these conclusions. To better engage Inuit women, after-hour clinics (one evening per week) with female health care providers in Happy Valley - Goose Bay has proved effective. The report notes that male receptionists at the Labrador Health Centre may act as a barrier to women booking appointments. As well, male nurses in some clinics in coastal communities are not comfortable performing the test and are a barrier to testing.

The most common cancer in Newfoundland and Labrador is colorectal cancer which is linked, in part, to an aging population. The IRC and Nunatsiavut Government report outlines the colorectal screening guidelines for Nunatsiavut and offers limited Inuit-specific information about the cancer and barriers to screening. For coastal residents, for example, advanced screening procedures requires travel to Happy Valley-Goose Bay which is stressful for those who have began screen preparations before departing home. The lack of statistics about colorectal cancer among Inuit in Nunatsiavut has acted as a barrier to developing Inuit-specific strategies. Anecdotal evidence, and trends in Nunavut, suggests the incidence of the cancer is on the rise.

The Nunatsiavut contribution to the cancer screening report notes that breast cancer among Inuit is consistent with the increasing prevalence of obesity and Type 2 diabetes and potentially, to shortened extended patterns of breastfeeding. However, rates remain lower than the general Canadian population. In Nunatsiavut, Inuit-specific data are not available. A mammography screening program is now established in Newfoundland and Labrador. The report notes that Inuit women should be encouraged to discuss breast screening with their health provider and should learn to become more breast aware. This requires culturally appropriate education and advertising material.

Nunavut

A search of the of the Government of Nunavut, Department of Health and Social Services Internet site did not identify any cancer awareness material. At best, cancer was mentioned in a hepatitis B fact sheet. Other documents were related to policy statements, legislation, general health status statements, and documents about tobacco reduction, STIs, and chronic diseases, etc.

A similar search of the entire Nunavut government Internet site identified few additional documents. Notably, the 2012-2013 Budget Address states the government will act to reduce tobacco consumption in light of high lung cancer rates.

The Qulliit Nunavut Status of Women Council has undertaken and renewed the Nunavut Cancer Project, an initiative to build community capacity and advocacy for improved health practices for women in Nunavut with breast and other cancers. The project involves:

- Dialogue with educators and health representatives on ideas for effective use of a Breast Health Education Kit, and additional resource educational mail-out kit;
- Strengthening the Nunavut Breast Cancer Advocacy and survivors group;
- Increasing human resources through educational workshops or training of college or high school students about cancer, healthy body, early detection, and breast self-examination.

The objectives of the project are to build an information network on breast cancer, to better support cancer survivors, to help survivors reach out to inform community members, and to expand the cancer information about breast, lung, and cervical cancers. The project further aims to develop the user guide for the information kit on breast health by having it translated into four languages and to develop a Nunavut breast cancer information website. The user guides will be mailed to all communities and training will utilize the Nunavut Telehealth teleconference system.

Currently, Nunavut does not have a breast cancer screening program. Mammography in Nunavut only is available at the Qikiqtani General Hospital and access is through referrals.

Nunavik

A search of the Nunavik Regional Board of Health and Social Services and the Kativik Regional Government Internet sites failed to locate public health resources about cancer. No cancer-related information was located on the Nasivvik Centre for Inuit Health and Changing Environments located at the Université Laval. The Québec's Breast Cancer Foundation has provided resources for two travelling mammography machines operated by the province's breast Cancer Screening Program. The machines can be shipped to Nunavik communities

The scan suggests there is a lack of readily available public health resource information about cancer in Nunavik. Public health initiatives exist for breast cancer screening and Pap smears, but information resources geared for the general Inuit population are not easily located.

National Inuit Cancer Awareness

During Pauktuutit's 2000 Annual General Meeting (AGM), a women's health workshop was organized during which participants were asked to identify what they thought were the three most important health issues facing Inuit women in their community or region. Participants from all regions identified cancer and cancer screening as the most common concern. Recommendations from the workshop included more information on lung, cervical, and breast cancer. As a result, in 2002, Pauktuutit published Inuit-specific information on aging, cancer, and healthy hearts. *Cancers: Actions I Can Take to Reduce My Risks of Developing Cancer* (2002) describes breast cancer, cervical cancer, and lung cancer. The document discusses causes, symptoms, prevention, and treatment of breast cancer, cervical cancer, and lung cancer. The document is available in English, Inuktitut, Inuinnaqtun, and Labradorimiut.

Inuit Tapiriit Kanatami has published the English-language *Inuit and Cancer Fact Sheet* (2009) and the *Inuit and Cancer Discussion Paper* (2008) in English and Inuktitut. The discussion paper is intended to open dialogue on the unique needs and issues relating to cancer among Inuit in Canada. It provides recommendations to improve:

- Inuit access to cancer services, resources, and treatment.
- To support the development of policies, plans and programs at the federal and provincial/territorial level.
- To help guide the Canadian Strategy for Cancer Control.

The barriers to treatment described in the discussion paper include language and the social isolation many Inuit face when they receive cancer treatment in southern centres. There are also federal, provincial, territorial, and regional administrative issues, problems of geographical isolation, limited support facilities in Inuit regions for cancer patients, and an overall lack of Inuit-specific cancer data from all Inuit regions.

The Canadian Cancer Society hosts a Nunavut-specific Internet page that is available in both English and French. The Canadian Cancer Society does provide a select number of information publications in the First Nations languages of Cree, Ojibwe, and Oji-cree but none is suitable for an Inuktitut-speaking audience. Significantly, a 1-800 telephone Cancer Information Service is offered by the society that is available in over 100 languages including Inuktitut.

Literature Review Conclusions

Overall, the literature on Inuit knowledge and behaviour with respect to cancer is limited. Little specific research has been conducted in terms of knowledge-attitudes-behaviour. Notably, the available resources developed for public awareness campaigns vary widely between Inuit jurisdictions. Little in the way of plain-language material translated into regional dialects was located. However, the guidelines for developing cancer resources identified by the Nunatsiavut Government are an important contribution for future efforts.

There is a need to ensure that screening and treatment services for Inuit are supported with cancer awareness resources that are appropriate for Inuit. Awareness about smoking, alcohol, diet/obesity, physical activity, and protection from the sun offer multiple health benefits and through the years, several Inuit-specific campaigns have been undertaken at either the regional or the national level. However, there is a need for culturally appropriate, plain-language, Inuktitut-language resource material that will specifically contribute to cancer awareness, greater health literacy, and informed cancer-related health decisions.

Profile of Inuit Cancer Services

> *"It's a big problem up North because as soon as you hear of someone having it, you know it's probably too late to cure. Most people only find out they have it when it's too late to cure. Often times the only way to cure it is to go down south and we don't like that. Being alone, going to get treatment is not fun."* (Kuujjuaq Focus Group Participant)

To help provide context for discussions about Inuit cancer rates, available cancer services and resources, the focus group results, and the *Inuit Cancer Project's* next steps, it is useful to provide an overview of medical and cancer services available within Inuit Nunangat. The following table summarizes the location of the primary, secondary, and tertiary medical facilities used in each of the Inuit regions and sub-regions. Primary care facilities exist in all communities under different titles. Secondary sites are located in all regions and/or sub-regions though some may have limited capacity and therefore partner with other facilities (see, for example, Inuvialuit and in the Kivalliq region of Nunavut). All tertiary facilities are located in southern urban centres. These arrangements are well established but can involve great distances and high medical travel costs, especially when the cost for patient escorts are factored in.

Table 1:
Organization of Primary, Secondary, and Tertiary Medical Services in Inuit Regions

Facilities	**Inuvialuit**	**Nunavut**			**Nunavik**		**Nunatsiavut**
		Kitikmeot	**Kivalliq**	**Qikitaaluk**	**Hudson**	**Ungava**	
Primary Care	Health Centres	Health Centres			CLSC (Local Community Service Centres)		Community Clinics
Secondary Facilities	Inuvik Regional Hospital Yellowknife, NT	Yellowknife Stanton Territorial Hospital	Kivalliq Health Centre (Rankin Inlet) Winnipeg, MB	Qikiqtani General Hospital (Iqaluit)	Innulitsivik Health Centre (Povirnituq)	Ungava Tulattavik Health Centre (Kuujjuaq)	Labrador Health Centre (Happy Valley-Goose Bay)
Tertiary Facilities	Cross Cancer Institute (Edmonton)	Cross Cancer Institute (Edmonton)	Cancer Care Manitoba (Winnipeg)	The Ottawa Hospital (Ottawa)	McGill Univ. Health Centre (Montreal)	McGill Univ. Health Centre (Montreal)	St. John's Cancer Centre (St. John's)

Source: Adapted from Corvus Solutions (2012). *Cancer Care and Control in Inuit Nunangat*. Prepared for the Canadian Partnership Against Cancer.

Limited preventative care for cancer is available within Inuit communities (see Table 2). All regions offer HPV vaccinations for girls in grade six and public health education is offered by CHR/Ws. Delivery of the latter, however, may vary between communities. Multiple health concerns can result in conflicting priorities among health service providers and can shift attention and resources to competing priorities and emergencies. The environmental scan undertaken for the *Inuit Cancer Project* identified limited cancer awareness resources geared for

Inuit audiences. Research conducted by Corvus Solutions for the Canadian Partnership Against Cancer confirms this finding (Corvus Solutions 2012).

Table 2 also summarizes what cancer screening programs are available in the four Inuit regions. The table indicates that clinical breast exams and cervical cancer programs have been established in all Inuit regions. Generally, these screening programs are conducted at Well Woman clinics. As well, mammography screening programs have been established in Inuvialuit, Nunavik, and in Nunatsiavut. These programs involve contacting and arranging for women at risk to travel to secondary or tertiary facilities for regular tests. For example, in Nunavik, all women aged 50 to 69 years receive a mammogram every two years using mobile services. The participation rate is one of the highest in the province. In Nunavut, mammography services are available in Iqaluit but are based on referrals by nurses or physicians. A client can request a mammography but the test requires a clinical assessment before approval. This type of client assessment or patient requested testing also is available in Inuvialuit.

Screening for colorectal and prostate cancers is available in all Inuit regions. These tests are conducted on the basis of a clinician assessment of the client's risk for the cancer or upon a client request for the tests and a supporting clinician assessment approving the test.

Table 2:
Comparison of Cancer Prevention, Screening, and Diagnostic Services in Inuit Regions

Prevention	**Inuvialuit**	**Nunavut**	**Nunavik**	**Nunatsiavut**
HPV vaccination (grade 6 students)	X	X	X	X
Public health education [1]	X	X	X	X
Screening Programs	**Inuvialuit**	**Nunavut**	**Nunavik**	**Nunatsiavut**
Clinical breast exam	X	X	X	X
Mammography screening program [2]	X		X	X
Cervical screen program [3]	X	X	X	X
Screening based on Client Assessment or Patient Request [4]	**Inuvialuit**	**Nunavut**	**Nunavik**	**Nunatsiavut**
Mammography as required	X	X		
Colorectal [5]	X	X	X	X
Prostate	X	X	X	X
X-Ray	X	X	X	X
Diagnostic Tests	**Inuvialuit**	**Nunavut**	**Nunavik**	**Nunatsiavut**
Secondary care sites	X	X	X	X
Tertiary care sites	X	X	X	X
Telehealth	**Inuvialuit**	**Nunavut**	**Nunavik**	**Nunatsiavut**
Basic telehealth	X	X	X	X

Tele-oncology				X

1. Conducted by Community Health Representatives/Workers. Education varies between communities.
2. Programs require travel to secondary/tertiary sites for tests.
3. Cervical cancer screening conducted as part of Well Woman clinics located in each community.
4. Tests are based on clinician assessment or client request with clinician approval. Tests require travel to secondary/tertiary sites.
5. Inuvialuit and Nunatsiavut utilize the fecal immunochemical test (FIT). The Hudson Coast region of Nunavik conducts colonoscopies due to high rates of colorectal cancer.

Source: Adapted from Corvus Solutions (2012). *Cancer Care and Control in Inuit Nunangat*. Prepared for the Canadian Partnership Against Cancer.

Table 2 indicates that diagnostic cancer tests for Inuit can only be conducted in the secondary and tertiary medical facilities. The location of these facilities varies by Inuit region and sub-region (see Table 1, above). Patient navigation services have been established in all regions to support Inuit cancer and non-cancer patients travelling to these facilities. Though all regions also employ telehealth technology, only Nunatsiavut offers a tele-oncolgy system that allows communication between physicians and other cancer specialists with cancer patients and their health providers located in more remote and/or isolated communities.

Table 3 provides a comparison of the cancer treatment facilities utilized in each of the Inuit regions and the capacity of these facilities to provide cancer treatment. The Yellowknife Stanton Territorial Hospital provides some chemotherapy and some surgical procedures for Inuit cancer patients living in Inuvialuit and the Kitikmeot region of Nunavut. Nunatsiavut's secondary medical facility in Happy Valley-Goose Bay (Labrador Health Centre) also provides some chemotherapy services and some surgical procedures. Otherwise, Inuit cancer patients must travel to medical facilities in Edmonton (Inuvialuit and Kitikmeot) Winnipeg (Kivalliq), Ottawa (Qikiqtaaluk), Montreal (Nunavik), or St. John's (Nunatsiavut) for cancer treatment.

Table 3:
Comparison of Cancer Treatment Facilities Utilized in Inuit Regions *

		Nunavut			**Nunavik**		
Treatment	**Inuvialuit**	**Kitikmeot**	**Kivalliq**	**Qikiqtaaluk**	**Hudson**	**Ungava**	**Nunatsiavut**
Secondary care facilities	Chemo-therapy / some surgery	Chemo-therapy / some surgery					Chemo-therapy / some surgery
Tertiary care facilities	All others	All others	All treatment	All treatment	All treatment	All treatment	All others

* See Table 1 for the location and names of secondary and tertiary medical facilities.

Source: Adapted from Corvus Solutions (2012). *Cancer Care and Control in Inuit Nunangat*. Prepared for the Canadian Partnership Against Cancer.

In terms of after care, all Inuit regions provide Home and Community Care (HCC) programs that can provide basic support to cancer patients who have returned to their home community following treatment. CHR/Ws are also available to provide basic after care support. A key challenge is the effective communication of medication and hospital discharge and after care instructions to either family caregivers or HCC workers and CHR/Ws. For some Inuit, their return home after treatment may not be possible or may be delayed if the after care services are not available or are not yet in place. Those Inuit patients who require complex after care support must remain close to either the secondary or tertiary medical services. Complex after care is not available in most Inuit communities.

A critical support element for Inuit undergoing diagnostic tests or treatment for cancer is patient navigation services. As noted, these are established in all regions to support patients requiring medical services outside their home community. For patients living in Inuvialuit and Kitikmeot, a patient navigator is available at the Yellowknife Stanton Territorial Hospital. The Northern Health Services Network provides support for patients travelling to Edmonton for medical treatment. This includes discharge planning, the coordination of appointments with doctors, nurses, and other health providers, information about medical treatments and procedures, and coordination with Larga House in Edmonton to arrange patient transportation and boarding.

Kivalliq Inuit Service supports to Inuit patients in travelling to Winnipeg for medical care. Services include medical appointment coordination, nursing case management, the coordination and communication of patient information, and arrangements for patient travel. Accommodations in Winnipeg are provided at the Kivalliq Inuit Centre and are available to Nunavut Land Claim Beneficiaries and their escorts for approved medical travel.

Patients from the Qikiqtaaluk region of Nunavut receive support from the Ottawa Health Services Network Inc. (OHSNI) when travelling to Iqaluit and Ottawa for specialist and tertiary care. The OHSNI coordinates medical care, nursing case management, social work support, medical records management, and interpretation services. In Ottawa, accommodations are arranged through Larga Baffin.

Nunavik patients travelling to the McGill University Health Centre in Montréal are supported by the Nunavik pivot nurse in oncology (Infirmière pivot en oncologie (IPO)). The nurse maintains contact with the patient throughout their stay with support from Inuit interpreters when required. The IPO collaborates with nurses in the Nunavik communities and ensures they understand the treatment plans needed for cancer patients when they return to their communities. In addition, the IPO is supported by the Northern Quebec Module which provides accommodation, transportation, and the services of nurses and interpreters to support the stay of Inuit from Nunavik who are receiving care in Montréal.

Nunatsiavut patients are supported by the Aboriginal Patient Navigation program at the Labrador Health Centre. The program provides interpretative services, navigation to appointments, assistance with transportation and accommodations, discharge planning, liaison services, and education and information support.

Key Informant Interviews

A number of key informant interviews were conducted to round out the picture of cancer-related program delivery in Inuit Nunangat and to help identify some of the challenges that are faced by Inuit. There were difficulties engaging informants during this phase of the project. Fortunately, the *Cancer Care and Control in Inuit Nunangat* document prepared by Corvus Solutions (2012) for the Canadian Partnership Against Cancer — a partner in the *Inuit Cancer Project* — undertook a large number of key informant interviews. By and large, the key informant interviews conducted for this project and by Corvus Solutions confirm the findings of the focus group sessions. There is limited awareness among Inuit, limited awareness resources, challenges with regards to screening and diagnosis, and logistical challenges getting patients to secondary and tertiary care facilities.

The key informants were generally health care providers either working in Inuit Nunangat or working in southern centres supporting Inuit cancer patients. They were first contacted by email and asked if they were willing to engage in a telephone discussion about cancer services and the challenges they witness. Often the key informants did not respond to the inquiry.

Suitable cancer information was commonly cites as a problem. Though readily available for cancer patients receiving care in southern secondary and tertiary facilities, these are commonly in English and are not brought back home by Inuit cancer patients. In the communities, information is limited and informants expressed a desire for more resources. Corvus Solutions (2012) notes that northern community health providers are largely unaware of the patient support services provided by treatment facilities and other organizations. For example, the CCS offers a 1-800 information support service in over 100 languages including Inuktitut and offers a peer-to-peer services that can connect Inuit cancer patients with volunteer Inuit cancer survivors. The CBCN works to establish networks to support women with breast cancer.

In terms of messaging, informants stressed the importance of “basic, simple stuff.” Visual resources are effective. One informant described an APTN advertisement about breastfeeding. The use of local people in the ads resonated better. The challenges of engaging Inuit men were discussed by some. Using role models was recommended, such as having Inuit men explain to others their experiences and reassuring them that it is OK to go for screening and testing. This grassroots approach will help to overcome elements of Inuit traditional views of privacy and silence about difficult topics.

Some informants described the challenges of medical consent when dealing with Inuit, especially in the context of receiving medical tests and explaining the results of those tests. For example, an elder Inuk who has travelled to a southern facility may not understand the need to provide formal consent for various procedures. For them, their very presence is their consent. Why else would they be there? The role of family members as escorts and translators can be challenging. Diagnostic results may be difficult to explain or translate. Some family members may wish to hear the test results before informing the patient, indicating that they want to shield the patient from the bad news and the worry or that the patient does not want to know the results. This is something doctors and nurses cannot do.

Inuit patients may be unwilling to immediately consent to cancer treatment. Patients first may want to discuss options with their families, seeking buy-in and agreement about the support this may require. To do this the patient may want to travel back home which is an added financial burden to the system. One informant noted that when a patient hears the word ‘cancer’ they do not hear much after that. This is true of tuberculosis as well.

Informants agreed that it is hard to get Inuit to talk about cancer. They noted that older Inuit also are less likely to ask questions and are less likely to advocate for themselves. Some noted that Inuit returning home following treatment are better informed. There are cases, however, when there has been a breakdown in communication at the secondary and tertiary levels. An informant described how some Inuit are not always aware that their cancers have progressed to terminal stages. An example was given of a patient returning home to Nunatsiavut from St. John’s with hospital discharge instructions for palliative care, something unbeknownst to the patient. Informants discussed the role of patient navigators and their importance in the system. Language remains a huge issue, not just in terms of the complex and technical language of cancer, but also in terms of Inuktitut translations. Older Inuit prefer hearing things in Inuktitut.

Some of the challenges and gaps in services identified by the key informants include the need for formal cancer support services, programs, or groups. These are not common or are completely absent in Inuit communities and regions. In addition, existing mental health and counselling services are limited and may not be suitable for cancer patients and their families. Though support services are available to patients receiving care in southern facilities, Inuit patients may not be aware these are available to them. Once home, there is a heavy reliance on family caregivers. There is a need for stronger patient support services. Informants also stressed the need to ensure strong communication channels between secondary/tertiary care facilities and home communities with respect to hospital discharge and patient treatment instructions.

The results of the key informant interviews readily support the objectives and outcomes planned for the *Inuit Cancer Project*. It is clear that the project activities will fulfill a broadly recognized need for Inuit-specific messaging about cancer awareness and that resources that can be used by health providers are needed. Much of what the key informants have state about Inuit awareness and understanding about cancer are echoed in the focus group findings.

Inuit Cancer Focus Groups

To effectively target Inuit audiences with cancer awareness resources, Pauktuutit undertook a total of nine focus group sessions to gauge Inuit knowledge, attitudes, and behaviours about cancer. They offered an opportunity to gain unique regional perspectives on how Inuit view the topic. The research has provided Pauktuutit with a firm baseline from which to develop tools and resources. The focus groups probed general knowledge about different types of cancers, about cancer screening, treatment, and prevention in order to provide insights on how best to raise the health literacy of Inuit.

Focus groups provide an opportunity for a small number of people who share common interests or concerns to share their opinions on a given topic in a comfortable, non-coercive environment. The group format of the sessions promotes an atmosphere of disclosure in which people can exchange their ideas, experiences, and attitudes. Respondents can qualify responses or give contingent answers to questions. The researchers have an opportunity to interact directly with respondents, to seek clarifications, to ask follow-up questions, and to probe further for responses. As well, it is possible for researchers to observe non-verbal responses that can supplement verbal response.

Methodology

Focus Group Sessions

In order to gain a cross-Canada sense of Inuit knowledge, attitudes, and behaviours about cancer, Pauktuutit planned to conduct focus group sessions in Nunatsiavut (Rigolet), Nunavik (Kuujjuaq and Puvirnituq), Nunavut (Cambridge Bay, Rankin Inlet, and Pangnirtung), Inuvialuit (Inuvik), and in Ottawa. The Cambridge Bay event was cancelled so Pauktuutit opted to take advantage of the Inuit women from across Inuit Nunangat attending its March 2013 AGM to conduct additional focus groups in English and Inuktitut. These two sessions increased the overall participation rate of the focus group research. In total, 64 individuals participated in nine focus group sessions.

In the communities, participants were selected from the general Inuit public using convenience sampling. Pauktuutit used either a radio public service announcement and/or its contacts in the communities to solicit participation. Each participant signed a consent form and completed a brief registration form that garnered limited demographic data.

Focus group sessions last from 45 minutes to about three hours, depending on the number of participants. A facilitator guided the discussions and a note taker took notes and made an audio recording of the sessions.

To ensure consistency between focus group sessions, facilitator and note taker guides were developed. These outlined the roles of the facilitator and note taker, outlined the anticipated sequence of events for each session, and provided a sample introductory statement, provided guidelines about questions and topics, explained the post-session debriefing process, and provided a basic glossary of terms and concepts in anticipation of questions and issues that may be raised. The intent was to ensure a consistent and systematic approach to each session in order to garner consistent and comparable focus group results.

When logistically possible, the discussions were supported with a PowerPoint presentation to help guide the discussions and questions. Each slide was supplemented with notes for the facilitator that described the reason for the questions and what information was being solicited. These supplemental notes also include alternative or more probing questions to stimulate discussions. The key topics of discussion included:

- What does the word cancer mean to you?
- What do you know about breast cancer, melanoma, cervical cancer, lung cancer, colorectal cancer, prostate cancer?
- What do you know about the causes of cancer?
- What do you think are the most common causes of cancer among Inuit?
- What would be your reaction if you found out you had cancer?
- What do you know about getting tested for cancer?
- What do you think of when you hear about surgery, radiation, chemotherapy, hormone therapy, traditional healing?
- Do you think you are at risk of cancer?
- In your opinion, do the people you know have enough information about cancer?

Methodological Challenges

The logistics of undertaking several focus group sessions on a given topic across the North are challenging. In addition, the topic of cancer is not one to readily engage Inuit. The disease carries negative connotations. Those who have been the most affected by cancer are the most likely to speak out and to attend a focus group session. Those who are least informed are not inclined to talk about it. The following methodological challenges should be noted:

- Women made up the vast majority of participants, in part because the AGM sessions were all women. Inuit men are difficult to recruit and tend to be silent on topics concerning their health. Without a much more aggressive and systematic recruitment of Inuit men, this bias is difficult to overcome.
- It is difficult to recruit Inuit to discuss cancer, especially if the project budget does not include an honorarium. Cancer is an emotional and troubling topic, and offers of light refreshments do not encourage participation.
- Many of the participants are cancer survivors or have a family history of cancer. Engaging the broader Inuit public proved difficult.
- Most of the focus group participants are over the age of 45 years. A financial honorarium would likely have helped to engage younger participants.

Focus Group Participants

Prior to each focus group session, participants were asked to sign a consent form and to complete a short registration form that solicited information about age, gender, family, language use, Internet use, and how each person rated cancer in terms of personal knowledge, sense of urgency in the community, and in terms of their own personal risk. For all questions, the participant had the option to decline from answering.

Overall, the male-female mix was disproportionate, with 88% of the participants being female. This bias was introduced, in part, by conducting focus groups among those attending Pauktuutit's March 2013 AGM. Only the Rigolet session had an equal share of men and women. Over 70% of the participants are over the age of 45 years, three-quarters of all participants were married, and almost 90% had children. Though most of the focus group sessions were conducted in English, over 60% indicated they speak Inuktitut at home, though not necessarily exclusively. Seventy-five percent indicated English is spoken in the home. Not surprising, those living in the Inuvialuit and Nunatsiavut regions favoured the sole use of English. The use of Inuktitut is much stronger in Nunavut and Nunavik and this was reflected in the in the responses about language provided by the focus group participants.

When asked about the highest level of education achieved, the breakdown was fairly balanced. Thirty-five percent of focus group participants indicated they had less than a high school education, 20% indicated they had at least a high school education, and 35 percent indicated they had more than a high school level of education. Ten percent declined to answer. When asked about Internet access, almost 77% indicated they have access from their homes. Internet access from work was the second most common site (43%) followed by access from friends in a distant third (8%). Ten percent indicated they do not use the Internet.

Using a five-point scale, the focus group participants were asked to rank their knowledge of cancer (1 = Poor, 2 = Fair, 3 = Good, 4 = Very Good, 5 = Excellent). The mean average response was 2.6 or between fair and good. Participants in Rigolet and Puvirnituq ranked their knowledge the highest, rating their knowledge of cancer as good. Elsewhere, the personal ratings tended to fall in the range of having a fair knowledge of cancer. The ranking of the AGM participants is consistent with the mean average of 2.5 out of 5.

When asked to rate the extent cancer is a problem in their community (1 = Strongly disagree, 2 = Disagree, 3 = Neither agree nor disagree, 4 = Agree, 5 = Strongly agree), the mean average response was 4.1 out of 5. Forty-three percent agreed with the statement and 41 percent strongly agreed. A much smaller number either disagreed or were not sure and this brought the mean average down.

When asked to rate their personal risk of cancer on a scale of one to five (1 = Low Risk and 5 = High risk), the average rating was 3.3 out five, or a medium risk. Participants in Ottawa ranked their risk as very low, whereas those in Rankin Inlet and Inuvik ranked their risk as very high.

Cancer Knowledge, Attitudes, and Behaviours

Personal History of Cancer

> *"All my kids, husband – they were affected when I had lung cancer. The word cancer scares everyone. It's a scary topic. Even when we hear it's only a possibility."*

All of the cancer focus group sessions included individuals who have personally suffered from cancer or have a family history of cancer. The link to past experiences with terminal cancer likely has fostered a view that cancer is an incurable or fatal disease. Participants in Nunavut and in Nunavik were most likely to offer statements that cancer is incurable. The late diagnosis of cancer among Inuit probably has reinforced the perception of cancer as an incurable or fatal disease.

Having experienced specific cancers personally, having a family history with certain cancers, or knowing someone who has suffered from cancer seems to be a factor in what people know about the disease. Even so, cancer was often referred to in general terms, with no reference to a specific type.

Inuktitut Terminology

> *"There should be a different name. When we hear the word cancer, we automatically think of the worst; that it's incurable."*

There was widespread recognition that the current Inuktitut term for cancer ("…cannot be fixed or healed") needs to be changed. The term invokes fear and discourages people from seeking treatment and fighting the illness. As a result, some participants viewed cancer as an incurable disease. Others, however, recognized that cancer can be treated and managed and they commented about the inaccuracies of the Inuktitut meaning for the word cancer. The Pangnirtung session was conducted in Inuktitut and the participants were most engaged in discussions about language and terminology. Participants in most sessions spoke about the lack of Inuktitut terminology for different cancers. It was suggested that those who cannot read or understand English need to learn about cancer verbally using Inuktitut.

> *"For me, when I hear the word cancer I automatically assume it's something that's going to kill you. Even if it's not a deadly cancer, I still think it's going to kill you. I know it's a disease in the body but I also know often times, it's a deadly one."*

Cancer as an Incurable Disease

> *"We know it can't be cured. We understand that. It scares us. It's a scary topic."*

In most focus group sessions, at least one participant would refer to cancer as an incurable disease. As noted, however, most sessions also included individuals with a personal or family history of cancer thus some discussed how cancer can be cured or treated. Besides fear, participants equated a cancer diagnosis with death, some expressed that they would be devastated, would give up hope, and would accept their fate.

> *"We see so many people — Inuit — die from cancer so it scares me."*

Basic Knowledge of Cancer

> *"It's a problem in the North, it's a problem everywhere, but the awareness is very limited here. So much can be prevented if they knew about cancer."*

When asked about their knowledge of cancer, there was generally mixed opinions. Statements were somewhat generic in nature in that individuals spoke in broad terms and less about specific cancers. Some simply equated it as a disease or sickness. Some indicated that it lacks a cure and that the causes are unknown. For some, cancer was defined in terms of the need to seek treatment outside of their community.

> *"Sickness – we know it can't be cured or fixed in Pangnirtung and if anyone has it, we know they have to leave town."*

Those with a personal or family history seem to know more and indicated they tended to undergo regular tests. Several commented about limited cancer awareness in the North.

> *"We don't randomly talk about it. We talk about it when we know someone is infected with it or when we know of family members who have it."*

Many expressed frustration with the quality of health services in the North. Some noted the lack of information, the lack of local support services, the language barriers with southern doctors, and the challenges of finding out about test results. Common concerns included the need for better terminology, the need for better support and caring service providers, and the challenges associated with treatment outside of home communities.

Causes of Cancer

> *"And we know soapstone carving is a cause. Before they wore masks, we lost lots of men from the dust. Lots of Inuit men died."*

When asked about the causes of cancer, focus group discussions varied widely. Some participants indicated that cancer is dormant in the body or in the cells, something that was waiting to breakout, perhaps triggered by environmental factors like contaminants, bad diet and diet change, stress, or smoking and/or second hand smoke. With the exception of lung cancer, participants tended not to link specific cancers to specific causes. Lung cancer was linked to tobacco smoke, air pollution, and to stone dust from carving.

> *"For the longest time, I thought only people who smoke were the only ones at risk of lung cancer but I have heard of people who have never smoked and have lung cancer. I find that odd. What other factors can lead to lung cancer?"*

Some stated that there is a genetic link. In many of the sessions, cancer risks were linked to a person's family history with cancer. In Puvirnituq there was some discussion of the fact all Inuit share common ancestors and were genetically related. It was suggested intermarriage was leading to abnormal cells and genes and this was leading to the spread of cancer among Inuit or the simple fact that cancer was in everyone.

> *My mother had cancer that is why I got it. I was told that my ancestors used to get cancer so I may get cancer myself. I prayed to God to help me and I got healed.*

In all nine sessions, there were discussions about contaminants and their link to cancer. The chemicals used in drinking water filtration and other contaminants found in water were mentioned in Nunatsiavut, Puvirnituq, Pangnirtung, and Inuvik. Pesticides, food preservatives, industrial air pollutants, and chemicals on toilet paper were mentioned in some sessions.

> *Back in the day, when Inuit only ate country food, I'm sure even if there were tests back then the rates of cancer among Inuit were probably at zero. Now, with Inuit not eating as much country food and eating only canned food from the stores, this increases the risks. Think about it, how much contaminants are in a tin can. That's probably more than half of peoples' diets now, canned food. That must put people at a greater risk."*

Diet was often cited as a cause of cancer as well as a cure. For some, the rapid change in diet was a root cause of cancer, for others it was the heavy reliance on processed and store bought foods. A few participants indicated they knew people who ate a lot of smoke fish and then succumbed to cancer.

> *“As well the food that is produced in the factories, and the food that we eat and the food that we buy from the store that come from the factories, they aren’t always clean and the things they use are different, what they cook it with, they have things that can kill, bugs….”*

In general, the most frequently cited causes for cancer were the environment/contaminants, smoking/second hand smoke, and diet/change in diet. These were identified in all nine focus group sessions. References to a personal/family history of cancer, to genetics, to heredity, or something dormant in the body were the next most common causes cited. Other causes of cancer cites during the focus groups included stress, alcohol, too many sex partners, mould and mildew, dry Arctic air, and simply old age.

Knowledge of Different Cancers

> *"We would like to know what they are and what they mean. What the sickness is and how it affects our bodies.”*

Participants recognized that there were different types of cancers but this knowledge may be guided by personal experience — their own history of cancer, their family history with cancer, or from the people they know who have had cancer. References to specific cancers were usually in the context of their personal or family history. The exception was reference to lung cancer where participants readily referred to it among Inuit.

> *"Lung cancer is the one cancer we know about the most because it is the most talked about and the rest we don't know so much why they happen. Lung cancer we know smoking."*

Though a wide range of different cancers were mentioned and discussed, generally only limited details were offered about them. Often the focus group sessions involved asking the facilitator questions about different types of cancers. The Pangnirtung session was conducted in Inuktitut and some discussion was devoted to the lack of Inuktitut terminology for different kinds of cancers.

For some participants, cancer survivability is what distinguishes one cancer from another. Not all people die from cancer. This contrasts with those participants who stated that cancer is a deadly illness. The contradiction may be linked, in part, to the late stage diagnosis of cancer experienced by Inuit and the resulting lower chances for recovery. Those who know cancer survivors or are survivors themselves may have a broader, more balanced perspective. Those who only are aware of those who have died because they were diagnosed too late or were reluctant to leave their home communities for treatment (or who sought treatment too late), may hold more fatalistic views.

> *“No, not all are the same but I do think most times they have the same outcome. I know not all cancers are deadly but I do assume it once I hear someone has cancer because of the deaths I know of from cancer.”*

Overall, lung and breast cancer were the most commonly discussed cancers. Though references were made to colorectal and prostate cancer, comments were more passing in nature, referring to someone with the disease. This was true of cervical and stomach cancer as well. References to melanoma were often in terms of seeking clarification about what it was. Mention of throat cancer and leukemia were made only in a few sessions.

Knowledge of Testing

> *“We need to know the knowledge so we better protect ourselves, in the future. We need to know how to get tested.”*

When the focus group participants were probed for knowledge about cancer screening and testing, it was not uncommon for some participants to state that they had never been tested. In all likelihood, this is true of all the sessions. This limited experience with testing suggests limited knowledge about the topic. As well, the level of discussion about testing varied widely with the Rigolet, Rankin Inlet, Kuujjuaq, Inuvik, Ottawa, and the Inuktitut session at the AGM offering few comments.

> *"Men up North it is different. In my grandfather's day, men were men. They were the hunters, the supporters. They still have their pride even though they aren't hunting like they used to. Men think it is unmanly to go to the nurse and they don't want to go for personal intimate things. When they go, it is too late. I know one man who would not go until the people he lived with told him they would no longer take care of him and he went and died three months later."*

It was common for female participants with a history of cancer to state they have had regular breast examines, and to a lesser extent, Pap smears. Men seemed to be less engaged in testing and in fact, this was a point of discussion in some sessions. In almost all sessions, there were discussions about the difficulty of getting screened for cancer and the availability of tests within communities.

> *"I knew something was wrong and the nurses wouldn't take me seriously. Finally, I kept going to the nursing station to make a point. Then I was sent to Iqaluit and Even though the Doctor told me I had cancer, I knew my body and knew I had it before he told me. I knew I had to be sent away. I was back and forth for two years. So discouraging always being away but we go through it."*

Some focus group participants were unsure what was involved in testing and where they could go for tests. Some participants suggested that accurate testing was available only in the south. Either because doctors working temporarily in the North tend to misdiagnose people (not just for cancer) or the turnover of staff made it difficult to follow through with test results. Some participants also described the challenges of language. It was suggested that those who can speak English are more likely to get medical attention.

> *"I feel like you get tested more if you can speak English. Sometimes it's hard to get nurses or doctors to listen when you have concerns if you can't communicate in English."*

The participants in the Inuktitut session in Pangnirtung were particularly engaged in to the topic. They expressed a need for more information about cancer and testing. They felt that there was not enough information about the different types of cancer or about the treatment.

Knowledge of Cancer Treatment

> *"Yes, I've heard of all the procedures. Radiation and chemotherapy scare me. I think they're the scariest ones. I know they do a lot of damage to the body. I hope there's a cure. It's hard to see people go through it. Your whole life revolves around it."*

Though some participants in most focus group sessions indicated they had personally undergone some form of cancer treatment or knew someone in the family who had, the discussions about treatment tended to be limited. Participants indicated they had heard about chemotherapy and radiation treatment and tended to discuss which one was considered the worst or most difficult. The general consensus is that they "kind of work" but not really, that cancer treatment controls the disease rather than cure it. One participant in Pangnirtung noted that cancer treatments destroy abnormal cells. Often the participants discussed chemotherapy and radiation together, describing how they, or people they know, have undergone both treatments together. Discussion about surgery was less common.

> *"We hear about it when we're sent down south. We should hear about it from people we're comfortable with. We hear about it from doctors down south. It's hard. We would like more knowledge about this topic, on the different types. We hear about it only when someone else is experiencing cancer."*

Participants in all the focus group sessions were particularly engaged in the topic of traditional therapies and medicines. Various teas were described and recommended as well as the benefits of living off the land. Those in Puvirnituq described the benefits of fresh water off the land and the benefits of fermented meat. Often participants stated that lifestyle changes — better diets, less smoking, and more exercise — were important dimensions to overcoming cancer.

Attitudes About Cancer

> *"We know it can't be cured. We understand that. It scares us. It's a scary topic."*

Compared to other illnesses, cancer is consistently considered the worst disease. A common reaction was to describe cancer in terms of fear. For some, this fear was linked to the difficulties people faced by people with cancer.

> *"I'd be scared because most people I know who have had it have went through a hard time beating it or have died. It's not easy."*

Discussions linked cancer to a fear of death, to concern about their families, and to concerns that every ache, pain, mole, or wart is a sign of cancer. A cancer diagnosis "would be devastating" and considered a "death sentence." The late diagnosis of cancer and the difficulties of getting treatment have led to a perception that cancer is a terminal illness. Some fear dying alone in the south with no one being told what happened.

> *"When my mom died, they just said she died. There was no letter, no information; no one said how it happened. My mom wanted me here [Ottawa] with her and by the time my flight was arranged, she passed away. I know my mom wanted me to be there with her."*

For some participants, cancer appears to be becoming more common and more inevitable. In Puvirnituq, participants agreed that having cancer was "like being dead" and was a death sentence. A few participants noted that some people give up hope and consider suicide after they are diagnosed with cancer. In Inuvik, Pangnirtung, Puvirnituq, some participants were willing to accept the prospect of a cancer diagnosis, accepting that there was no point in worrying about it. When asked about their personal risks, participants commonly cited contaminants, poor diet, and smoking as risk factors.

As noted, the focus group sessions indicated Inuit women are more willing to seek testing and engage in discussions about cancer than Inuit men. Inuit men are more likely to deny they are sick, to express stoicism, and to avoid seeking medical support. This is a common attitude not limited to cancer.

> "*It is us who have to be aware. Many people go too late to be checked. They wait and wait and wait. It is going to go away, it is nothing bad. Especially men.*"

Many participants expressed frustration with getting tested and finding out about the results of the tests. Some expressed frustration trying to convince health providers to refer them for diagnostic tests when they felt sick but were not deemed a high-risk candidate. More than one focus group participant stated they knew they had cancer before the health system confirmed the condition. Others provided stories of insensitive young doctors who inform someone they have cancer and then just leave the room.

> *"When a person is told they have cancer by the doctor they need support. Even if they do not understand English, they understand the word cancer. Doctors tell you have cancer – and then that's it – they leave and the person is left on their own."*

> *My brother felt so alone when the doctor told him that he walked the streets of Ottawa for a long time with no one to talk to. That still makes me cry today thinking he felt so alone.*

Behaviour Towards Cancer

> *"Women get tested more than men. Men need to start getting tested more. Women get tested for breast cancer but men do not get tested for specific cancers."*

In terms of behaviour, participants discussed their exposure to contaminants, the foods they eat, and the consequences of smoking and second hand smoke. Country food was widely cites as a way to avoid cancer and as a way to cure cancer as was a healthy lifestyle. In both Rigolet and Puvirnituq, participants identified the benefits of fresh water off the land instead of municipal water and water from trucks as a means to avoid illnesses.

> *"In my opinion, everyone is at risk. You can try to be healthy to reduce those risks, eat healthier food, no canned food, don't smoke, get checkups, and maintain a healthy lifestyle but you never know who will get it. I worry about all the cancers but I try not to think about it."*

Maintaining a healthy lifestyle was identified as both a way to reduce one's risk of cancer and as a possible cure if one is diagnosed with the disease. However, it was noted in some sessions that people often do not want to change their lifestyle.

> *"My first reaction would be, if I work hard, change my lifestyle, maybe I can exercise, change, and do more physical activities and tell yourself to think positive and fight. That's how we were taught."*

With the exception of smoking, second hand smoke, and stone dust, focus group participants did not necessarily link their discussions of cancer risk behaviour to specific forms of cancer.

As noted, the focus group findings suggest Inuit women are more likely to seek cancer testing than Inuit men. There is a cultural component behind this reluctance among men to go to a doctor or to request a test. One participant suggested, "They are scared of needles, they are scared of everything. And shy."

> *"Men up here will not go for an annual exam. They won't go for routine tests. They will go if they are sick and the doctor will take the opportunity to do the tests. Women are called to go for a pap test every year."*

Breast cancer screening and Pap smear programs are well established in all Inuit regions and the focus groups suggest many Inuit women are actively engaged in cancer screening. In Nunavut, mammography is offered only after clinical assessments support the request and some focus group participants described the difficulties they faced convincing community nurses that they should be tested. In Puvirnituq, however, the participants discussed the tendency, especially among Inuit men, not to seek testing. Their concern was that people wait until it is too late.

> *"We need to get tested early to cure it but we don't have the resources. We always have to leave our communities to get the proper screening, testing, knowledge, and information."*

Cancer Education

> *"My mother who is going to be 80 years old, she's 79 years old, yes she's quite old. For me, I am 50 years old and I am capable of using the computer and I read and understand and can ask in English, so I would understand more about this then her."*

When asked how best to inform Inuit about cancer prevention, screening, and treatment the focus group sessions offered a range of suggestions. Participants agreed there was limited information available to them about cancer. Some noted there was plenty of information at the cancer clinics in the south, but far less in the north. Some however, expressed concerns about information for those who do not speak English and those who do not read. Though pamphlets were recommended, it was noted that those that are too long will not be read.

> *"No, there will never be enough information about cancer but especially in the North. Now that you mention, I can't even think of any information provided to the public about cancer."*

Participants specifically identified the need for information about different types of cancers, information about cancer risks, information about testing, diagnosis information in Inuktitut for use by interpreters, and information about treatment. The need for appropriate Inuktitut information and terminology was mention in all the sessions.

Focus Group Conclusions

Overall, it is difficult to engage Inuit on the topic of cancer. Inuit women are typically more inclined to be engaged in their state of health and are more inclined to have regular contact with health care providers. This proactive approach to personal health likely extends to those willing to participate in cancer-related focus groups. Research suggests higher awareness about cancer is linked to education levels and having a personal or family history with cancer (see Carrière et al. 2012). This too seems to be reflected in who attended the focus groups.

From the focus groups, knowledge about cancer seems to be fairly generic. With the exception of lung cancer and to a less extent breast cancer, discussions tended to be in broad terms with only limited reference to different types of cancer. Knowledge also linked to personal or family histories with cancer. Those with personal experiences could speak about the cancers they were familiar with. This, however, did not necessarily extent to understanding cancer risks (with the exception of smoking).

Regular comments were made about contaminants, processed foods, and unhealthy lifestyles but not necessarily with a specific link to any type of cancer. Potentially, the reports stemming from the Northern Contaminants Program which began in 1991 may be at the root of the heightened awareness about contaminants. Nonetheless, the value of country foods and life on the land were often cited as a preventative and curative measure for cancer.

Though most recognize that different cancers have different outcomes, there is a strong fear of the disease that is likely rooted in what has been witnessed personally and in the community as a terminal illness. There is a need to provide information about different types of cancers and information about the screening, diagnosis, and treatment of each of them. As well, more needs to be done to engage Inuit men in screening and diagnostic tests.

Advisory Committee Meeting

The first face-to-face meeting of the *Inuit Cancer Project* Advisory Committee took place in Ottawa on March 6th and 7th, 2013. The committee's role is to provide cultural, regional, administrative, and subject matter expertise to guide the cultural content, the project's methodology, and development of the final products. Partnerships with the Canadian Cancer Society (CCS), the Canadian Breast Cancer Network (CBCN), the Canadian Partnership Against Cancer's (CPAC) Advisory Committee on First Nations, Inuit, and Métis Cancer Control, and the Department of Health and Social Services, Government of Nunavut have been established to advance the project's outcomes. The project's Advisory Committee is complemented with the participation of representatives from Inuit Tapiriit Kanatami (ITK), the Inuvialuit Regional Corporation (IRC), and frontline health providers working in different Inuit regions.

The March 2013 meeting was attended by the following committee members:

Geri Bailey	Manager Health Policy and Programs, Pauktuutit (Ottawa)
Phillip Bird	Consultant for Pauktuutit (Ottawa)
Heather Chappell	National Director, Canadian Cancer Society (Toronto)
Gogi Greeley	Executive Director Population Health, Department of Health and Social Services, Government of Nunavut (Iqaluit)
Ethel-Jean Gruben	Inuvialuit Regional Corporation Representative (Inuvik)
Sophie Keelan	Community Health Representative, Nunavik Regional Board of Health and Social Services (Kangiqsualujjuaq)
Jenn McNeil	Director of Operations, Canadian Breast Cancer Network (Ottawa)
Looee Okalik	Project Coordinator, Health and Social Development, Inuit Tapiriit Kanatami (Ottawa)
Sophie Pamak	Home Care Nurse, Department: Health and Social Development, Nunatsiavut Government (Hopedale)
Melissa Santoro Greyeyes-Brant	Note taker for Pauktuutit (Ottawa)
Joelle Walker	Canadian Cancer Society (Ottawa)
Sally Webster	Elder and Inuit urban representative (Ottawa)

Regrets were offered by the representative from the Canadian Partnerships Against Cancer Advisory Committee on First Nations, Inuit, and Métis Cancer Control and by the Project Officer from PHAC.

The two-day meeting of the *Inuit Cancer Project* Advisory Committee was structured first to inform the participants about the role of each partnering organization and then to provide a review of the research Pauktuutit has conducted to date. The Advisory Committee members then reviewed existing cancer awareness resources. This background provided the basis upon which to brainstorm about what new resources are needed and would be effective among Inuit. The second day of the meeting was devoted to planning for the cancer terminology forum scheduled for Inuvik in June or July 2013. The Advisory Committee members considered a range of key terms and concepts that need to have plain language definitions that can be translated into various Inuktitut dialects. The development of this glossary will support the development of better Inuit-specific cancer awareness resources.

Heather Chappell, the CCS National Director of Cancer Information and International Affairs, gave a detailed PowerPoint presentation about the structure of the organization and the range of resources at the disposal of the *Inuit Cancer Project*. The organization's research and cancer content specialists and its team of plain-language specialists are available to adapt scientifically accurate, Canadian-specific information into a format suitable for Inuktitut translation. The CCS has a 3,500 page Cancer Encyclopedia and an online Cancer Glossary of 1,200 terms can serve as the basis for the Inuktitut glossary content. Heather Chappell also described other CCS services that Inuit can take advantage of including a 700-page website, a Cancer Information Service (a 1-800 telephone service) that offers simultaneous translation in over 100 languages including Inuktitut, and a Peer Support Service which offers one-to-one matching of cancer survivors. The CCS considers the *Inuit Cancer Project* as a great opportunity to further develop CCS resources for prevention, early detection, screening, and support.

Jenn McNeil gave a PowerPoint presentation about the Ottawa-based CBCN as an organization that promotes information sharing and advocacy by putting a face and story to the breast cancer experience in an effort to influence the decisions of governments and policy-makers. CBCN works with federal and provincial governments, other national cancer organizations, local breast cancer organizations, non-breast cancer NGOs, patient groups, and other professional organizations. The vision is to have the best quality of life for all Canadians affected by breast cancer. It was suggested that the CBCN newsletter would be a good vehicle to advocate for Inuit women and promote awareness of the challenges face by Inuit women with breast cancer. Besides the newsletter, it was noted that face-to-face meeting are considered the best way to convey information but webinars are practical for those living in rural or remote locations with fewer available resources than in urban centres.

In terms of the *Inuit Cancer Project*, the CBCN will share its breast cancer resources to see if they are appropriate for an Inuit audience, will help disseminate some of the products developed during the project, and will help raise the voices of Inuit women on the national level. Jenn McNeil also encouraged Inuit women to consider representing northern Canada on its Board of Directors to ensure that a northern perspective is heard and respected.

Pauktuutit presented the Advisory Committee members with a detailed review of the cancer focus group research (see above). The Committee then reviewed the results of Pauktuutit's AGM workshop on cancer conducted the previous day. AGM participants had first been divided into English and Inuktitut language groups to participate in two focus group sessions. Following this, the participants were presented a summary review of the focus group research to date. AGM participants had the opportunity to discuss and probe the results of this research. Following this plenary session, participants were encouraged to review a number of cancer awareness resources and to offer their comments. As part of the *Inuit Cancer Project* Advisory Committee meeting, the feedback provided by the AGM participants about the cancer awareness resources was reviewed. Overall, the responses from AGM participants were very positive. Some of the material had been developed by IRC and the Nunatsiavut Government Department of Health and Social Development in a shared project to develop resources on colorectal and breast cancer screening. Products included posters, pamphlets, shower cards for self breast exams, and large visual displays. Workshop participants liked the Inuit-specific nature of the awareness resources and products like fridge magnets.

The Committee members discussed what types of cancers should be listed in the glossary and agreed the five most common cancers among Inuit should be included: nasopharyngeal cancer, colon/rectal cancer, breast cancer, lung cancer, cervical cancer, and stomach cancer. As well, there was agreement to include common terms for treatments and side effects in order to help families prepare for cancer recovery at home.

The CCS was tasked with assembling the proposed cancer terms and topic areas and developing a list of relevant terms for review by the Advisory Committee. The CCS would rely upon its Cancer Encyclopedia and Cancer Glossary to draw up the first master list of terms and definitions. These would be organized in terms of the major forms of cancer and the associated screening, diagnosis, and treatment procedures. Appendix One provides a draft listing of the terms developed by the Advisory Committee and the CCS.

Communication Plan

Though the availability of Inuktitut print material was recommended by focus group participants, it was commonly suggested that information that targets older Inuit should be in Inuktitut and be verbal. Information sessions and the use of radio shows were widely recommended. Elders listen to the radio. On the other hand, younger people speak English and use the computer and it was suggested that they know more about cancer because of their Internet access. This is true of many Inuit in the fifties. For some, cancer education should begin with younger people, starting in the schools, and using social media (Facebook), pamphlets, and posters. In Kuujjuaq, it was suggested information was needed in Inuktitut, English and French, that posters should be placed in all the stores in town, and doctors should inform people when they go to the clinic. Notably, for many Inuit, their health practitioner is considered their key source of health information and the basis for health-related decisions.

Of relevance is the research conducted by Kemberling et al. (2011) about cervical cancer awareness among Alaskan Native adolescents. The researchers found that these teens commonly received health information from school, health providers, family, television, the Internet, and magazines. Newspapers and the radio were less commonly cited. Posters and brochures were less common sources among younger people. When asked about their preferred type of media, the most common response was television, followed by the Internet, brochures, and posters. Much of this research is consistent with the results of Pauktuutit's focus group research.

The following table summarize the information needs, the preferred media, and the sub-audiences identified by participants during the focus group sessions.

The Advisory Committee meeting in March 2013 also addressed components of a communication strategy. The Committee discussed the idea of video and audio recordings of the stories of cancer survivors for use on websites. The stories could also be used in newsletters. There is a need to hear good news and messages of hope. It was noted there were not a lot of these stories about Inuit. There was agreement that messaging must shift away from the negative to the positive — "don't do this" to "this is what you can do."

Table 4:
Communication Needs, Preferred Media, and Target Identified in the Focus Group Sessions

Information Needs	Inuktitut Language Needs	Preferred Media	Target Audiences
• Information for Health Providers • Risk factor Information • Diagnosis / treatment Information	• Need for Inuktitut Information • Inuktitut terminology • Information sessions • Inuktitut language	• Pamphlets • Posters • Fact sheets • Internet / New Media • TV	• Elders • Young people • Gender specific • Health providers • Schools

• Information on testing • Information on types of cancers • Information on available services	radio		

A plain-language booklet was recommended that details the questions that newly diagnosed patients should ask oncologists and doctors. The booklet could be used by escorts, could be brought home, and could be helpful to start the dialogue between patient and health care provider.

The final development of the terms and concepts is scheduled for the 2013 - 2014 fiscal year. The content of the awareness tools and resources will rely on the expertise of the CCS and the work undertaken during the upcoming language forum. Drawing on the advice and experience of the Nunatsiavut Government (see Inuvialuit Regional Corporation and Nunatsiavut Government: nd), the final messages and content should originate from Inuit organizations and only target Inuit. Though it is recommended that the messages be first written in Inuktitut and then translated to English and that messages avoid technical terms, this is very difficult given the complexity of the subject matter. The content and plain language expertise offered by the CCS will help to ensure that messages are technically correct and easy to understand prior to being translated into Inuktitut. The Nunatsiavut Government also recommends the use of Inuit imagery in the resources being developed and an emphasis on visual messages.

In the months to come, the Inuit Cancer Project Advisory Committee will continue to meet regularly and as products and tools are finalized, a more systematic communication plan will be developed.

Conclusions

The work completed to date on Pauktuutit's *Inuit Cancer Project* confirms cancer as a very real health issue in Inuit communities. It is not necessarily one identified by Inuit as a preventable disease or one that can be cured or controlled. Inuit are not fully aware of different cancers and many hold beliefs that it is an inevitable or unavoidable illness that too often results in death. Cancer rates and awareness can be linked to many of the determinants of health. Education and literacy in general and health literacy in particular, the quality and availability of health services, contaminants and the physical environment, personal health practices and such lifestyle choices as smoking, diet, and exercise, the role of gender, and the importance of Inuit language, culture, and history interact in ways that help to explain the trends and the challenges.

Despite the growth in some cancer rates, there are Inuit values and behaviours, and gaps in knowledge that reduce the full engagement in prevention and screening programs. On the other hand, there are limited awareness resources about cancer available to Inuit. Without theses resources the trends will persist.

This project has worked to assemble data about cancer rates in Inuit Nunangat in a manner that can help inform the development of tools and resources that will improve cancer health literacy. There are, however, gaps in the data since the cancer registries in some jurisdictions do not offer Inuit-specific data. This project also has broken new ground by undertaking broad-based focus group research on the larger subject of all cancers among Inuit. This knowledge-attitude-behaviour research has not been without its challenges. Nonetheless, it has clearly identified the level of knowledge about cancer and risk behaviour, the level of awareness of different cancers and their causes, the attitudes held by many Inuit, the challenges they see in cancer screening, diagnosis, and treatment, and the best ways to disseminate cancer awareness messages. The project's Advisory Committee has worked to develop a very comprehensive draft listing of terms and concepts that will be refined into plain language text suitable for translation in to Inuktitut and ultimately, integrated into cancer awareness tools and resources that target the general Inuit public as well as health providers to help in their knowledge translation work.

The next steps are to conduct a language forum, develop cancer awareness resources, field test these resources, and then produce and disseminate them across Inuit Nunangat. To this end, Pauktuutit and the project's Advisory Committee will rely on the generous financial support of PHAC's Centre for Chronic Disease Prevention and the skills and resources provided by the project's partners and the Inuit organizations and frontline health providers who are providing important advice and guidance.

References

Carrière, G., M. Tjepkema, J. Pennock, and N. Goedhuis (2012). Cancer patterns in Inuit Nunangat: 1998-2007. *Int J Circumpolar Health* 2012, 71.

Cerigo, H., M. E. Macdonald, E. L. Franco, and P. Brassard (2011). Awareness and Knowledge about Human Papillomavirus Among Inuit Women in Nunavik, Québec. *J Community Health* (2011) 36:56–62.

Cerigo, H., M. E. Macdonald, E. L. Franco, and P. Brassard (2012). Inuit women's attitudes and experiences towards cervical cancer and prevention strategies in Nunavik, Québec.

Corvus Solutions (2012). *Cancer Care and Control in Inuit Nunangat*. Prepared for the Canadian Partnership Against Cancer.

Friborg, J. and S. Hassler (2008). Cancer. In *Health Transitions in Arctic Populations*, T.K. Young and P. Bjerregaard (eds). Toronto, ON: University of Toronto Press. pp. 308-33.

Healey, S., D. Plaza, and G. Osborne (2003). *A Ten-Year Profile of Cancer in Nunavut (1992-2001)*. Iqaluit, NU: Government of Nunavut, Department of Health and Social Services.

Int J Circumpolar Health 2012; 71(1): .

Inuit Tapiriit Kanatami (2008). *Inuit and Cancer: Discussion Paper*. Ottawa, ON: Inuit Tapiriit Kanatami.

Inuit Tapiriit Kanatami (2009). *Inuit Cancer Fact Sheet*. Ottawa, ON: Inuit Tapiriit Kanatami.

Inuvialuit Regional Corporation and Nunatsiavut Government (nd). *Cancer Screening: Inuvialuit and Nunatsiavut*. Inuvik, NT: Inuvialuit Regional Corporation.

Kemberling, M., K. Hagan, J. Leston, S. Kitka, E. Provost, and T. Hennessy (2011). Alaska Native adolescent views on cervical cancer, the human papillomavirus (HPV), genital warts and the quadrivalent HPV vaccine. *Int J Circumpolar Health* 2011; 70(3):245-53.

McDonald, J.T. and R. Trenholm (2010). Cancer-related health behaviours and health service use among Inuit and other residents of Canada's north. *Soc Sci Med*. 2010 May;70(9):1396-403.

Pauktuutit Inuit Women of Canada (2002). *Cancers: Actions I Can Take to Reduce My Risks of Developing Cancer*. Ottawa, ON: Pauktuutit Inuit Women of Canada.

Tait, H. (2008). *Aboriginal Peoples Survey, 2006: Inuit Health and Social Conditions*. Catalogue No. 89-637-X-No.001. Ottawa, ON: Statistics Canada.

Walker, S., D.L. Saltman, R. Colucci, L. sli Martin (2010). Awareness of risk factors among persons at risk for lung cancer, chronic obstructive pulmonary disease and sleep apnea: A Canadian population-based study. *Can Respir J* 2010; 17(6): 287-94.

Appendix One: Draft List of Cancer Glossary Terms

General Cancer Terms and Definitions
Definitions for Cancer Terms that are Not Specific to a Particular Cancer

Prevention	Early Detection & Screening	Symptoms	Treatment	Side Effects
Blood pressure	Bacteria	Anemia	Ablation	Acute pain
Body mass index (BMI)	Biopsy	Asymptomatic	Active surveillance	Adverse reaction
Carcinogen	Cell	Benign	Adjuvant therapy	Allergic reaction
Dietitian	Computed tomography(CT) scan	Fatigue	Alternative therapy	Anaphylaxis
Medical history	Congenital	Fever	Amputation	Chronic pain
Nutrition	Diagnosis	Grade	Analgesic	Dehydration
Physical activity	False-negative	Inflammation	Anesthesia	Diuretic
Teratogen	False-positive	Lump	Antibiotic	Fatigue
Toxin	Family history	Malignant	Antibodies	Fluid retention
	Familial	Nausea	Anti-emetic	Hair loss
	Gene	Platelets	Antigen	Immune system
	Gene mutation	Shortness of breath	Anti-inflammatory	Infertility
	Genetic testing	Stage	Biological therapy	Insomnia
	Hereditary	Staging	Chemotherapy	Nausea
	Magnetic resonance imaging(MRI) scan	Swollen lymph nodes	Chemoradiation therapy	Neuropathic pain
	Precancerous	Tumour	Clinical trial	Pain diary
	Ultrasound		Combination therapy	Palliative care
	Virus		Conventional therapy	Phantom limb pain
	X-ray		Donor	Phlebitis
			Dose	Pneumonia
			Drug therapy	Radiation sickness
			Experimental drug	Rating pain
			Follow-up	Side effect
			Informed consent	Somatic pain
			Injection	Survivor
			Inoperable	Visceral pain
			In situ	Vomiting
			Intravenous (IV)	
			Invasive	
			Narcotic	
			Non-invasive	
			Oncology	

Prevention	Early Detection & Screening	Symptoms	Treatment	Side Effects
			Operable	
			Pathology	
			Physiotherapy	
			Prognosis	
			Radiation therapy	
			Recurrence	
			Remission	
			Risks	
			Steroids	
			Surgery	
			Targeted therapy	
			Transfusion	
			Vaccine therapy	

Terms and Definitions by Cancer Type

Cancer type	Prevention	Early Detection & Screening	Symptoms	Treatment	Side Effects
Breast	• Birth control pill • Body mass index (BMI) • Hormone replacement therapy (HRT)	• BRCA gene mutations • Clinical breast exam (CBE) • Dense breast tissue • Genetic testing • Mammogram	• Lump • Skin change	• Breast-conserving surgery • Breast reconstruction • Hormonal therapy • Lumpectomy • Mastectomy	• Treatment-induced menopause • Osteoporosis • Rehabilitation exercise
Naso-pharyngeal	• Epstein-Barr virus (EBV) • Nasal passage • Occupational exposure • Pharyngeal • Pharynx	• Nasal endoscopy • Nasoscope	• Nosebleed • Sinus pain	• Neck dissection • Rhinectomy • Wide local excision	• Dry eye syndrome • Dry mouth • Prosthesis • Reconstructive surgery

Cancer type	**Prevention**	**Early Detection & Screening**	**Symptoms**	**Treatment**	**Side Effects**
Colorectal	• Aspirin • Body mass index (BMI) • Colon • Dietary fibre • Inflammatory bowel disease	• Colonoscopy • Coloscope • Digital rectal exam (DRE) • Enema • Fecal immunochemical test (FIT) • Fecal occult blood test (FOBT) • Flexible sigmoidoscopy • Occult blood • Polyp • Stool test	• Abdominal discomfort • Constipation • Diarrhea	• Colectomy • Polypectomy	• Colostomy • Ileostomy
Lung	• Arsenic • Asbestos • Occupational exposure • Radon • Second-hand smoke	• Bronchoscopy • Thoracotomy	• Hoarse voice • Pneumonia • Wheezing • Shortness of breath	• Lobectomy • Photodynamic therapy • Pneumonect-omy • Transplant	• Esophagitis • Neutropenia
Cervical	• Gynecology • Human papillomavirus (HPV) • HPV vaccine	• Colposcopy • Dysplasia • Pap smear • Pelvic exam • Pre-cancerous cells • Reproductive system • Uterus	• Abdominal discomfort • Cyst	• Cone biopsy • Hysterectomy • Trachelectomy	• Bowel obstruction • Infertility • Treatment-induced menopause

Cancer type	**Prevention**	**Early Detection & Screening**	**Symptoms**	**Treatment**	**Side Effects**
Stomach	• Aspirin • Body mass index (BMI) • Epstein-Barr virus (EBV) • *H. pylori* infection	• Fecal occult blood test (FOBT) • Stomach lining • Ultrasound • Upper gastrointestinal (GI) endoscopy • Upper gastrointestinal (GI) series	• Indigestion • Polyp • Ulcer	• Gastrectomy	
Oral	• Human papillomavirus (HPV) • Oral cavity	• Endoscopy	• Erythroplakia • Leukoplakia	• Neck dissection	• Reconstructive surgery
Bladder	• Arsenic • Occupational exposure	• Cystoscopy • Urinalysis • Urine culture • Urine cytology	• Bladder spasm • Dysuria • Hematuria	• Cystectomy	• Incontinence • Infertility • Ostomy
Skin	• Indoor tanning • Sunscreen • Ultraviolet (UV) radiation	• Excisional biopsy • Incisional biopsy • Punch biopsy • Shave biopsy • Skin exam	• Melanoma • Mole	• Excisional skin surgery	• Skin flap • Skin graft
Liver	• Aflatoxin • Cirrhosis • Hepatitis	• Angiography • Laparoscopy • Tumour marker • Ultrasound	• Belly pain • Jaundice	• Ablation therapy • Hepatectomy • Transplant	• Ascites • Hepatic encephalopathy • Jaundice