



Pauktuutit Inuit Women of Canada

Inuit Cancer Project: Know Your Risk Focus Group Report June 2013

About the Inuit Cancer Project

Cancer is the second most common cause of death among Inuit living in Canada. The rate is nearly twice as high as the rest of the country. There is a need to provide Inuit with more information about the disease. In 2012, Pauktuutit Inuit Women of Canada began a two-year project to increase Inuit knowledge about cancer and to promote the importance of cancer screening and early detection.

With financial support from the Public Health Agency of Canada, Pauktuutit is working with the Canadian Cancer Society, the Canadian Breast Cancer Network, and other national, provincial, and territorial governments and organizations. The goals are to develop the tools and resources to help Inuit learn more about different cancers and to improve the care and support for cancer patients in Inuit communities. It is hoped Inuit will talk more about cancer, talk to their nurse or doctor about their cancer risks, and will get the testing they deserve to live healthy lives.

This report describes the results of nine focus groups conducted by Pauktuutit during the first year of the *Inuit Cancer Project* as well as a brief summary of the cancer workshop conducted during Pauktuutit's Annual General Meeting (AGM) in March 2013. During the focus group sessions, a facilitator introduced different topics and asked questions and participants were invited to discuss their views and ideas. There were no right or wrong answers. Together with the workshop, the intent was to get a better understanding of the knowledge, attitudes, and the things Inuit do when cancer touches their lives. This information will help Pauktuutit design and deliver better tools and resources that meet the needs and values of Inuit.

About the Focus Group Participants

A total of 64 people participated in nine cancer focus group sessions. These took place between September 2012 and March 2013. The sessions were conducted in Nunatsiavut (Rigolet), Nunavik (Kuujuuaq and Puvirnitug), Nunavut (Rankin Inlet and Pangnirtung), Inuvialuit (Inuvik), and in Ottawa. A total of three

sessions took place in Ottawa — one at Baffin Larga and two during Pauktuutit's March 2013 AGM among Inuit women visiting from across Inuit Nunangat. Only the Pangnirtung session and one of the AGM sessions were conducted in Inuktitut though some participants spoke in Inuktitut in the other sessions as well.

About 70% of the focus group participants were women. This is because all the AGM participants were women and because it is difficult to get Inuit men to talk about their health. Most participants were over the age of 45 years and three-quarters of them have children. Over 60% indicated they speak Inuktitut at home though many indicated they also speak English. In terms of education, about 35% have not completed high school, another 20% have at least a high school education, and 35 percent indicated they have more than a high school education. Before the sessions began, most participants ranked their knowledge of cancer as being fair to good. Participants from Rigolet and Puvirnituaq ranked their knowledge the highest. Though participants tended to agree that cancer is a problem in their community, they tended to rank their personal risk as medium. Participants in Ottawa ranked their risk as very low, whereas those in Rankin Inlet and Inuvik ranked their risk as very high.

Inuit Knowledge and Attitudes about Cancer

Personal History of Cancer: All of the cancer focus group sessions included people who have had cancer or have family members or friends who have had cancer. These experiences and the limited testing and support for cancer in Inuit Nunangat may help to explain why so many Inuit view cancer as an incurable or fatal disease. Even though some people in the focus groups had personally experienced cancer and probably knew more about the disease, the discussions in the groups tended to be in general terms, with only limited discussion about different types of cancer.

Inuktitut Terminology: The focus group participants often stated that the Inuktitut word for cancer needs to be changed. The word promotes fear and discourages people from seeking treatment and fighting the illness. As a result, some participants viewed cancer as an incurable disease. Others recognized that cancer can be treated and managed and they commented that the Inuktitut meaning for the word is not correct. Participants in most sessions spoke about the lack of Inuktitut terminology for different types of cancers.

“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: In most focus group sessions, at least one participant would refer to cancer as an incurable disease. However, most sessions also included people who had survived cancer or knew someone who had been cured or treated. Participants described how they feared cancer, how it was a death sentence, and how they would give up hope if they found out they had cancer.

“We know it can’t be cured. We understand that. It scares us. It’s a scary topic.”

“We see so many people — Inuit — die from cancer so it scares me.”

Basic Knowledge of Cancer: When asked about their knowledge of cancer, participants often spoke in general terms that it was a disease or illness. The spoke less about specific types of cancers. 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 home community. Those with a personal or family history of cancer seem to know more and indicated they tended to undergo regular tests. Several people stated that there is little awareness about cancer in the North.

“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.”

“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.”

Quality of Care: 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 more caring service providers, and the challenges associated with treatment outside of home communities.

Causes of Cancer: Discussions about the causes of cancer varied between focus groups. In general, the most common causes discussed were: (1) the environment and contaminants; (2) smoking and second hand smoke; (3) changes in the diet and store bought foods; and (4) having a genetic or family history of cancer or having cancer dormant in the body. Participants also suggested stress, alcohol, too many sex partners, mould and mildew, dry Arctic air, and old age as possible causes for cancer. Though lung cancer was linked to

tobacco smoke, air pollution, and dust from carving stone, most participants did not link other types of cancer to any of the possible causes they mentioned.

“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?”

In all nine focus groups, there were discussions about contaminants and their link to cancer. The chemicals used to purify drinking water and to preserve food along with pesticides and industrial contaminants were listed as possible causes of cancer. In terms of diet, eating too much store bought food often mentioned as causes of cancer. Some participants mentioned smoked fish and meat. Country food, however, was often described as a cure.

Knowledge of Different Cancers: Overall, lung and breast cancer were the most commonly discussed cancers. When participants described different types of cancers, they usually mentioned them in the context of their personal or family history and usually did not discuss what caused the cancer. The exception was lung cancer and the link to cigarettes. These people discussed being diagnosed with cancer, the treatment they received, and where they went to get treatment. Some participants described different cancers in terms of those that are deadly and those that people survive. Often the focus group sessions involved asking the facilitator questions about different types of cancers.

“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.”

Knowledge about Testing: It was common for some focus group participants to state that they had never been tested for cancer and as a result, some were unsure what was involved and where they should go for tests. In some groups, there was very little discussion about the topic. Men seemed to be less engaged in testing and in fact, this was a point of discussion in some sessions. Inuit men may deny or hide that they are sick. Women who have had cancer before are more likely to have regular breast exams, and to a lesser extent, Pap smears. In almost all sessions, there were discussions about the difficulty of getting screened for cancer within Inuit communities.

Some focus group participants were unsure what was involved in testing. Some were concerned that accurate testing was available only in the south because the doctors who work temporarily in the North are more likely to misdiagnose people or because high staff turnover makes it hard to learn about the test

results. Some participants also described the challenges of language. It was suggested that those who can speak English are more likely to get better medical attention. Participants indicated they wanted more information about cancer testing.

Knowledge of Cancer Treatment: The focus group participants did not discuss cancer treatments in great detail. Many stated they had heard about chemotherapy and radiation treatment and they discussed which one was considered the worst or most difficult. The general view is that they “kind of work” but not really, that they control the disease rather than cure it. Discussion about surgery was less common. Some participants suggested that Inuit learn about cancer treatments only after they have been sent south for tests or treatment.

“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.”

Participants were aware that treatments vary depending on the type of cancer and many felt that traditional medicines could be effective. Participants in most groups were interested in the topic of traditional therapies and medicines. Various teas were described and recommended as well as the benefits of living off the land. Often participants stated that lifestyle changes — better diets, less tobacco, and more exercise — were important ways to cure cancer.

Attitudes about Cancer: When compared to other illnesses, focus group participants considered cancer the worst disease because they felt there was no cure. A common reaction was to describe cancer in terms of fear. 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 some to believe that cancer is a terminal illness. Some fear dying alone in the south with no one at home knowing what happened.

For some participants, cancer is starting to become more common. It was suggested that some people give up hope and may consider suicide after they find out they have cancer. Others are willing to accept the news and believe that there is no point in worrying about it. The focus group sessions suggest Inuit women are more willing to seek testing and are willing to talk about cancer. Inuit men are more likely to deny they are sick — to be tough and avoid seeking medical support. This is a common attitude not limited to cancer.

Many participants expressed frustration with getting tested for cancer and about learning the results of the tests. Some described how hard it was to convince health providers to refer them for diagnostic tests when they felt sick. Some participants stated they knew they had cancer before it was proved by medical tests. Others mentioned stories about young doctors who inform people they have cancer and then just leave the room without providing support.

Behaviour towards Cancer: 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, fresh water off the land, and healthy lifestyles were mentioned as ways to avoid cancer and as ways to cure cancer. Some stated that everyone is at risk of cancer and you will never know who will get it. In some sessions, it was mentioned that people often do not want to change their lifestyle and old habits and this is a problem. Though lung cancer was commonly linked to tobacco use and dust from carving stone, there was not always a clear link between other types of cancers and the lifestyles and activities that may place people at risk.

In terms of testing, the focus groups suggest Inuit women are more likely to get tested for cancer. Inuit men do not like to go to see doctors or nurses or to request a medical test. One participant suggested, “They are scared of needles, they are scared of everything. And shy.” Some participants expressed concern that Inuit wait until it is too late before getting tested.

Cancer Education: Focus group participants agreed that there is a need for more information available about cancer prevention, screening, and treatment. Some said there was plenty of information at the cancer clinics in the south, but not very much in the North. Participants in all the sessions talked about the need for information for Inuit who do not speak English.

“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.”

Pamphlets were recommended, but it was noted that if they are too long people will not read them. Information sessions and the use of radio shows were widely recommended because elders listen to the radio. Some participants suggested cancer education should begin with younger people, starting in the schools, and using social media (Facebook), pamphlets, and posters.

Focus Group Conclusions: Overall, it is difficult to get Inuit to talk about cancer. Because Inuit women see their doctors and nurses more often, they are more willing to talk about their health and cancer. The focus groups suggest

Inuit knowledge about cancer is fairly general. With the exception of lung cancer and breast cancer, discussions tended to be in broad terms with few comments about different types of cancer. Participants with personal experiences with cancer spoke about them in more detail.

Though most participants recognize that different cancers have different outcomes, there is a strong fear of the disease. This may be linked to what people have witnessed in their communities when people are diagnosed with cancer, become very sick, and sometimes die. There is a need to provide information about different types of cancers and information about the screening, diagnosis, and treatment for each of them. As well, more needs to be done to engage Inuit men to talk about cancer and to get regular tests.

AGM Cancer Workshop

Pauktuutit's AGM in March 2013 included a Cancer Workshop. It provided an opportunity to (1) presented an overall description of the *Inuit Cancer Project*, (2) present a summary of the focus group research to an Inuit audience, and (3) an opportunity for participants to comment on the research and suggest cancer terms that should be translated into Inuktitut.

During the Cancer Workshop, participants wondered why so many people now have cancer. Participants discussed the danger of contaminants in the North and the problem of cleaning up the DEW line sites. The participants also discussed whether Inuit carvers were using dust masks to protect their lungs. It was noted that most carvers probably know the dust is dangerous but it is too expensive to buy proper equipment. The participants also talked about the value of information pamphlets. There was agreement that messages need to be positive. The messages should tell people what they can do, not what they should not do. There was a suggestion that using Inuit cancer survivors as role models would be a good way to raise awareness. Finally, the workshop participants discussed Inuktitut terminology, the differences between regional dialects, and the need for greater clarity for explaining cancer to Inuit.

The results of this workshop and the focus group research will help Pauktuutit develop better tools and resources to help Inuit understand cancer and reduce their risks. During the second year of the project, Pauktuutit will organize a language forum in order to translate cancer terms and concepts into Inuktitut. A glossary will be developed to help health providers explain cancer to Inuit. It will also help Pauktuutit to develop the pamphlets posters, and other resources that Inuit have recommended.