

TAKING STEPS TOGETHER

Regional Cancer Program Gathering

March 27-28, 2019
Ottawa, ON

Tungasuvvingat Inuit



This event was made possible through funding provided in partnership with the Canadian Partnership Against Cancer and Health Canada

Introduction

In February 2019, Tungasuvvingat Inuit submitted a proposal to the Canadian Partnership Against Cancer (CPAC) in order to receive funding to host a regional partnership meeting, modelled after the Partnership meeting hosted by CPAC in Happy Valley, Goose Bay, Labrador in early December.

Upon receiving a successful short-term funding agreement for the purpose of hosting a partnership event, our vision was to create a space and an opportunity to connect with our potential regional cancer program partners, partner organizations and urban Inuit community members who have been affected by Cancer in the South. In each stage of our planning process, it was a top priority that our gathering demonstrates the uniqueness of Inuit culture and community, acknowledging the precedence of Inuit often being overshadowed or grouped together with First Nations and Metis. We wanted to ensure that this event captured the essence of Inuit understanding and tradition, as well as celebrate Inuit culture, all meanwhile focusing on the topic at hand: cancer.

Our purpose in wanting to host an event of this nature was multi-faceted. As mentioned, we wanted to create a space where we could connect with potential partners in relation to our cancer project over the next three years and allow for community members to share their stories with those who work in the field and with each other. We also wanted to use this gathering as an opportunity to gain insight and collect data from a variety of perspectives related to three key themes that our project is organized around: cancer prevention, cancer screening, and patient experience.

Overall, over the course of two days, we were able to host over 60 individuals who shared their experiences, knowledge and insights on cancer prevention, screening and patient experience. We were able to capture a plethora of information related to those topics, much of which will be included here. We wanted to record the event through a variety of mediums, therefore, we have a graphic that was created based on our group discussions, photo images, and a video that captured all aspects of the event as well as participant perspectives on cancer.

The following report will discuss our findings, the successes and the challenges in relation to our Taking Steps Together gathering.

Findings

Prevention and Screening

The findings of our group discussions on cancer prevention and screening identified the areas of access, education and patient support as key items in improving prevention and screening outcomes for Inuit.

The following are taken directly from the discussions of the participants at Taking Steps Together:

- Inuit need more support and counselling, including spaces for healing, when it comes to receiving a cancer diagnosis.
- There is fear surrounding cancer prevention and screening for Inuit – specifically about the potential of a negative outcome (cancer diagnosis), leaving the community for treatment, and intergenerational/historical trauma.

- Challenges related to cancer screening including a lack of access to certain screenings, lack of access outside urban areas, lack of trust towards health care providers, lack of equitable treatment and health centres being closed in Nunavut due to staff shortages (this equates to late detection, more severe diagnosis).

The area of education related to cancer prevention and screening was broadly discussed among all groups. It was suggested by participants that more education and knowledge is needed on a variety of levels including, but not limited to:

- self-examinations,
- what happens after a positive cancer screening
- the fear surrounding cancer screening processes
- proper diet/healthy eating (in an Inuit-specific context)
- knowledge of Inuit-specific understandings of health, culture and history for health care professionals
- Significance of self-identification within the health care system

In this regard, it was also suggested that the social determinants of health play a significant role in the current conditions and/or experiences of Inuit within the Ontario cancer care system. By acknowledging and addressing the social determinants of health among Inuit, we will subsequently also be addressing many of the issues or challenges Inuit face prior, during and after a cancer diagnosis and treatment.

In addition, providing information, education and knowledge in a way that is understood well by Inuit is very important. This can include ensuring that the content and information is culturally-relevant and speaks to the distinct needs of Inuit as well as using approaches of dissemination that are interactive, visual, community-based and in Inuktitut.

During group discussions, the specific areas of smoking cessation and healthy eating were addressed as subcategories of cancer prevention. Below are a few observations and recommendations made by participants on how to best address smoking cessation and healthier eating within Inuit communities.

Smoking Cessation

- Take a phased-in, strength-based approach to smoking cessation
- Socially, when young people start smoking, it's sometimes seen as "growing up" or a sign of maturity – this social understanding needs to be changed and interventions/education should start early amongst youth.
- Provide incentives through prevention campaigns – and celebrate attempts, reductions and progress.
- Provide role models and community-based messaging without shame

Healthy Eating

- Support opportunities for traditional food and education around healthy eating
- Encourage healthy eating as eating food that makes you feel better
- Create an Inuit-specific food guide and include the cultural components of health – consider investing in Inuit-led research about dietary consumption amongst Inuit.

Finally, we asked participants to share innovative or effective ways to address challenges related to cancer prevention and screening. Of these suggestions, a few stood out as ideas that we are interested in possibly pursuing and integrating into our project as effective ways to address the disparities between Inuit and the general population:

- Health promotion workshops
- Hosting a cancer-screening day for Inuit – inviting community members to attend a screening day together
- Creation of a community garden as a tool to knowledge-share about healthy eating/behaviour/activities.
- Creating a cancer toolkit (i.e. treatment options, how cancer works, what to expect, etc.)

Overall, these findings on cancer prevention and screening will allow us to target specific sub-topics, and we intend to incorporate the recommendations included in this report into our resource development process and approach to addressing the areas of prevention and screening amongst Inuit. As the project continues, our findings in this area will broaden and continue to influence what steps we take next, with the support of our Kaggutiq Advisory Group.

Patient Experience

The findings of our group discussions on patient experience identified the areas of language, cultural understanding and decision-making as the areas in most need of attention.

The following findings are based on the direct experiences of participants:

- Qikiqtani Hospital had misdiagnosed a participant with a heart condition. It was put on heart medication and sent to Ottawa's Heart Institute for treatment. After three rounds of testing and assessments were done, the participant was transferred to the cancer department and diagnosed with colon cancer. There were no Inuktitut services available to them (circa. 2000).
- Interpreters (when available) do not know the feeling of physical pain the patient is experiencing, making communication, especially when there is a language barrier, very challenging.
- As a doctor, even when a patient is diagnosed with advanced-stage cancer, we still send the patient to Ontario without considering other factors. As the doctor, we try to save their life, forgetting to consider the patient's cultural or language appropriate needs.
- Cancer diagnosis is often accompanied by feelings or experiences of shame, blame, having a curse, hurting others, turning to prayer and turning to healing. Diagnosis can potentially re-traumatize Inuit.
- Many Inuit patients are dying away from their home and families when treatment doesn't work or diagnosis is too severe.
- Lack of trust in the government, church, or institutions like hospitals.
- Health care providers need to be comfortable with silence and space in conversation. This gives patients time to reflect and formulate plan -> health care providers need to listen.
- Terminology in regards to cancer is extremely complex
- Exposure of physicians to Inuit and their culture will lead to better understanding of their challenges and strengths.

- There is a sentiment that environmental factors could be contributing to the increasing prevalence of cancer amongst Inuit.

In our discussions, we asked participants directly what they felt worked well or was most important when it came to patient experience. The following are recommendations and observations provided by health care providers, organizational representatives and Inuit community members:

- Communication must remain open between provider and patient – the patient must have the final decision.
- There needs to be collaborative effort among all moving parts of the current health care system for Inuit and clearly defined roles – GN – OHSNI – Government of Ontario
- Long-term Inuit patients sent to Ontario for treatment should have end-of-life and discharge planning in place before leaving and support to do so.
- Patients need to be able to lead the decision-making
- There are many health care professionals that become an ally in advocacy for their patients
- There is an ongoing improvement in creating safe spaces and sharing responsibility of the process
- Navigators are an excellent resource – Inuit navigators would be even better.
- Cancer Care Ontario is doing good work with Inuit.
- Pauktuutit Glossary and Cancer Care Ontario demonstrate patient-centered resources and support better communication and simplifying terminology

In general, it was acknowledged that incremental changes are occurring within health care spaces, but there are still many areas that require attention and need improvement. The areas that were identified as in need of improvement were the following:

- Language – hospitals and health centres do not always have interpreters and the majority of people in health care do not have the language skills to be able to communicate effectively with Inuit patients.
- Knowledge sharing – health care providers in Ontario need to be better trained, knowledgeable and experienced in providing care to Inuit and those from the North
- Government needs to improve policies related to cancer prevention and education
- There cannot be a blanket approach to Indigenous people’s care – Inuit are distinct and unique in their understandings and needs
- Shared Decision Making - Inuit need to be included in all stages of planning care and stability should be a priority in treatment plan process
- Navigators – there is a need for nurse navigators who speak Inuktitut and share cultural connections
- There must be plans for discharge to avoid re-admission or further sickness.
- Delays in diagnosis, appointments and/or test results are affecting patient’s ability to get better or treated
- Significant need for cultural safety training and competency – need to recognize the continuation of patient’s journey (i.e. trauma, what happens after treatment)
- Lack of follow-up practices and after-care support for other barriers (i.e. homelessness, further health issues, etc.)

Ultimately, it was determined that there is much work to do in the area of patient experience when it relates to Inuit within the Cancer Care system. Over the course of the next three years, we will be working in collaboration with community members, Inuit organizations and community partners to address many of these needs. In FY2021/22, patient experience will be our primary focus, however, until that point, we will continue to integrate the experiences and knowledge of our many partners in the programming that we do and continue to support, within our capacity, Inuit who have been or are currently being treated for cancer in Ontario.

Conclusion

In closing, Tungasuvvingat Inuit's Taking Steps Together event fulfilled all our intended objectives, including creating a space for Inuit community members to share their experiences with cancer, bringing health care professionals, organizations and Inuit community members together to share and work together on how we can address the disparities between Inuit and the general population in cancer care, and establishing relationships with potential partners to support our work over the next three years.

Following our Taking Steps Together event, a feedback form was sent out to participants, and we received overwhelmingly positive reviews. The meeting structure (open group discussion), organization of the event, the integration of Inuit-specific elements, and the opportunity to socialize and network with new people were highlighted as the best components of the conference. For future events, feedback suggested that the conference be longer (2 full days), that there be more community members, and that there be more time for people to socialize with each other.

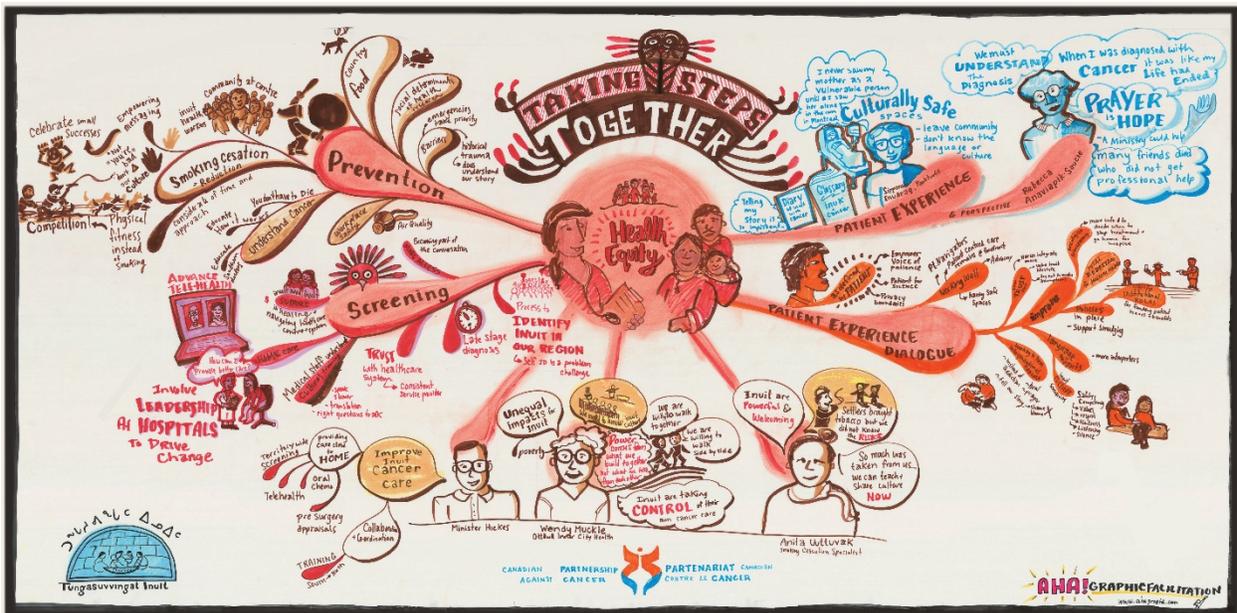
From an organizational perspective, after evaluating the lead up and execution of our event, the Regional Cancer Program team identified a few areas where, given the opportunity to host again, we would improve the Taking Steps Together event. First, this event was a significant workload on the capacity of a two-member team and if we were to do it over, we would want to have a bigger team to assist with the preparation and execution of the conference. Second, we would hope to have more time to prepare for the event so that we can do more work in inviting and having more community members attend. It is a challenging topic, and so it requires a lot of outreach and communication in trying to find Inuit who have had experience with cancer and who may want to attend, especially from outside of Ottawa. Finally, we would consider hosting the workshop at a different venue, due to a variety of issues related to the location of Wabano Centre for Aboriginal Health. A venue at the same hotel of participants or a more central location with on-site parking would better accommodate our needs and the convenience of guests.

Conclusively, the Taking Steps Together event was able to capture a plethora of data, insights and experiences related to our key themes of cancer prevention, screening and patient experience, and to our overall conversation on addressing the cancer-related health disparities that exist between Inuit and non-Inuit in Ontario. The event was engaging and relevant, and organized in a way that left every participant taking something home with them, and in many cases, wanting more time, space and information. It was evident that this was the first stride in *Taking Steps Together*.

“The setting was safe for me as an Indigenous person. I felt comfortable being in a space supported by other indigenous people.”
 - Participant, Taking Steps Together, 2019

“My overall experience was absolutely amazing. I was so grateful to be a part of the day and to learn from all of the different Inuit and non-Inuit presenters and participants... I plan to use what I have learned in my current role.”
 -Participant, Taking Steps Together 2019

“The event had a great focus and a clear objective, so it was easy to participate.”
 -Participant, Taking Steps Together, 2019



Graphic capturing the findings of Taking Steps Together in March 2019, by Aha! Graphic Facilitation