

Project Title: Dialogue and Storywork in Support of First Nations, Inuit, and Métis Cancer Patients throughout Oncology and Primary Care Transition Experiences

Primary Care and Cancer Care Integration Initiative

The Canadian Partnership Against Cancer (CPAC) is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. The Partnership aims to achieve a focused approach that will help prevent cancer, enhance the quality of life of those affected by cancer, lessen the likelihood of dying from cancer, and increase the efficiency of cancer control in Canada. One particular area of concern surrounds best practices and policies for the transition between cancer treatment and follow-up, particularly in relation to care at the interface between primary care and oncology care during the survivorship period.

Dialogue and Storywork is a CPAC-funded project designed to improve the transitions and outcomes of First Nations, Inuit, and Métis patients during the cancer journey. The Government of the Northwest Territories Department of Health and Social Services and Cancer Control Alberta, Alberta Health Services, are the lead implementing partners working with CancerCare Manitoba, the British Columbia Cancer Agency Centre for the North, and Saint Elizabeth Health Care, as well as First Nations, Inuit, and Métis communities in the Northwest Territories, British Columbia, Alberta, and Manitoba. The project aims to improve patient transition experiences from screening through survivorship, increase the availability of resources for patients and care providers, and enhance primary and oncology care provider knowledge about the care needs of First Nations, Inuit, and Métis cancer patients, their families, and communities.

Project Summary

Dialogue and Storywork will emphasize trust and relationship building between First Nations, Inuit, and Métis cancer patients and communities, primary and oncology care providers, and other stakeholders. Individual cancer journeys will be documented with multimedia and used not only to create informative resources for other cancer patients and their families, but also to generate understanding between patients and care providers of their unique needs and perspectives. This innovative use of dialogue through stories, compatible with oral traditions, will reveal many of the underlying values, beliefs, hopes, and needs of cancer patients, communities, and care providers by providing opportunity to recognize similarities as well as to explore and interpret differences.





Anticipated Outcomes

1. Improved cultural awareness and understanding across the primary and oncology care systems and among project participants;
2. Trusted working relationships among First Nations, Inuit, and Métis communities and primary and oncology care systems;
3. Increased awareness, understanding, and knowledge of the transition phases between primary and oncology care services and FNIM communities and a variety of community-based services and care;
4. Increased system efficiencies; and
5. Increased availability of culturally safe and relevant resources to assist and support the transition of First Nations, Inuit, and Métis people from the point of diagnosis, through treatment and care, and upon return to primary and community-based services and care.

Approach

Over three years, the project will roll out in three interdependent phases. Phase One is focused on building trusting relationships with participants while finalizing the ethical processes to be carried out in each jurisdiction and 11 communities (three each in the Northwest Territories, British Columbia, and Manitoba, and two in Alberta), ensuring respect and cultural safety for all participants. Phase Two will use storytelling and dialogue in safe environments to produce audiovisual and written support resources and tools for sharing and refining with First Nations, Inuit, and Métis communities and health care professionals from community, primary, and oncology care systems. Phase Three will focus on the distribution of the support resources and tools among First Nation, Inuit and Métis communities, health care networks, and health care providers in the Northwest Territories, British Columbia, Alberta, and Manitoba.

Starting in the spring of 2014, First Nations, Inuit, and Métis community members will have the opportunity to tell their cancer journey stories. These stories will be recorded on video and viewed by their primary and oncology care providers, whose responses will also be recorded on video and in turn viewed by the initial community members.

Using video as a means to broker communication and dialogue builds on First Nations, Inuit, and Métis storytelling traditions and ways of knowing. Rough cuts and written materials will be piloted and refined within the communities, allowing all participants the opportunity to provide input on the content and feel of the final products. The final audiovisual and written support resources and tools will be made available to First Nations, Inuit, and Métis communities across the country in 2016.

We expect that open, continuing discussions will improve mutual understanding between First Nations, Inuit, and Métis cancer patients and their health care providers. Reduced fear, fewer misconceptions, and a greater appreciation of the other's values and traditions, should lead to positive change in attitudes, perceptions, and behaviours—and, ultimately, improved patient outcomes.

Participation & Rights

All project partners recognize and respect the right of participants to assume ownership, control, access and possession (OCAP™) over information in the course of, and resulting from, project activities. The activities will facilitate community learning around improving cancer care transitions within both the cancer care and primary health care settings. We will ensure at all times that OCAP™ principles will govern our interactions with project participants including cancer patients, survivors, families, caregivers, and health care providers.

Ownership: This principle asserts that a community or group owns information collectively in the same way that an individual owns his or her personal information.

Control: This principle asserts that communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes that impact them, and includes all stages of a project from conception to completion. This principle extends to the control of resources and review processes, the formulation of conceptual frameworks, and data management.

Access: This principle asserts that a community or group has access to information and data about themselves, and has the right to manage and make decisions regarding access to their collective information.

Possession: This principle refers to the physical control of data. Although not a condition of ownership, possession is a mechanism by which ownership can be asserted and protected.

Contact Information

**Dr. André Corriveau, MD, MBA,
FRCPC**

(Project Co-Lead)
Chief Public Health Officer
Department of Health and Social Services
Government of the Northwest Territories
Phone: 867-920-6204
Andre.Corriveau@gov.nt.ca

Pam Tobin, M.A

(British Columbia Team Lead)
Director, Regional Operations
BC Cancer Agency, Centre for the North
Phone: 250-645-7300
PTobin@bccancer.bc.ca

Dr. Angeline Letendre, RN, PhD

(Project Co-Lead)
Provincial Coordinator, Community Oncology
Alberta Health Services, Cancer Care
Phone: 780-643-4483
Angeline.Letendre@albertahealthservices.ca

Kali Leary, BSc, MBT

(Manitoba Team Lead)
Director of Development
First Nations, Métis and Inuit Cancer
Control
CancerCare Manitoba
Phone: 204-787-4982
Kali.Leary@cancercare.mb.ca

Christina Leeson, BBA, CAPM®

(Project Manager)
Cancer Projects Officer
Department of Health and Social Services
Government of the Northwest Territories
Phone: 867-920-6350
Christina.Leeson@gov.nt.ca

Paul Holyoke, PhD

(Research & Evaluation Lead)
Director
Saint Elizabeth Research Centre
Phone: 905-968-6551
PaulHolyoke@saintelizabeth.com

