



Report on National Forum on First Nations, Inuit and Métis Cancer Control

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Executive Summary

Cancer rates among Canada's First Nations, Inuit and Métis peoples are increasing faster in comparison to overall Canadian cancer ratesⁱ.

According to the World Health Organization, at least one-third of all cancer cases are preventable,ⁱⁱ yet awareness of cancer and its causes remains low among many First Nations, Inuit and Métis.ⁱⁱⁱ Early detection of cancer greatly increases the chances for successful treatment, yet First Nations, Inuit and Métis tend to present with later-stage cancers and have higher mortality rates from preventable cancers.^{iv,v} These findings suggest possible accessibility issues for cancer programs and services.

Broader determinants of health play a role. First Nations, Inuit and Métis in general continue to face critical housing shortages, high rates of unemployment and low levels of educational attainment - all of which affect the quality of life for First Nations, Inuit and Métis peoples. Social determinants of health are influenced by factors such as geography and access to basic health services.^{vi}

A number of programs across Canada are addressing these and other issues, from efforts in prevention to surveillance to screening to care. To build on these efforts, the Canadian Partnership Against Cancer (Partnership) convened a **National Forum on First Nations, Inuit and Métis Cancer Control** in March 2009. The Partnership's mandate is to advance Canada's cancer control strategy - this includes facilitating ways to minimize gaps in knowledge and leverage the best available knowledge, as displayed through promising or emerging practices. Being culturally responsive to the needs of First Nations, Inuit and Métis peoples is an important priority within this work.

Guided by a Planning Committee consisting of First Nations, Inuit and Métis organizations, cancer agencies, Health Canada's First Nations and Inuit Health Branch, the Public Health Agency of Canada and the Partnership, the Forum represented a first step in building on opportunities in cancer control and identifying areas where the Partnership could add value. Sixty-five (65) representatives from the cancer community and from First Nations, Inuit, and Métis organizations across the country shared information across the cancer control continuum.

Major themes emerging from the Forum included:

1. **Prevention and early detection:** a strategy based on community-led, grass-roots programs is needed to drive awareness of cancer, its prevention and the importance of early detection; smoking is one of the most important issues in prevention;
2. **No one-size-fits all solution:** initiatives must be adaptable to diverse communities and specific First Nations, Inuit and Métis approaches are needed;

3. **Social determinants of health:** the social determinants of health and risk factors for chronic diseases must be integrated into a holistic, person-centred approach to health and cancer control;
4. **Cultural sensitivity:** culturally relevant educational materials and health services are needed across the cancer control continuum;
5. **Geography:** remote and underserved communities present challenges that require innovative approaches to provision of cancer control services and education;
6. **Research and surveillance:** research and surveillance are critical to building community profiles of cancer and to measuring the impact of cancer control interventions; also, the capacity of communities to understand and apply research findings must be strengthened;
7. **Partnership's role:** focus on those initiatives where the Partnership can either lead or support within its mandate of advancing Canada's cancer control strategy; link to existing Partnership initiatives, as appropriate.

Going forward, the Partnership will continue to engage First Nations, Inuit, Métis and cancer control communities. This includes developing an action plan to address immediate and long-term priorities identified by Forum participants. These may take the form of First Nations, Inuit or Métis-specific activities within existing Partnership initiatives or new activities where the Partnership can either lead or support the work of others.

The Partnership will work towards the following timelines for action planning:

Action	Timing
Synthesize discussion points and provide the Forum report to participants	June 2009
Working with the First Nations, Inuit, Métis and cancer control communities - and based on recommendations by Forum participants - identify opportunities to link to existing Partnership initiatives (as appropriate). Examples include: <ul style="list-style-type: none"> • A First Nations, Inuit and Métis stream within the Partnership's new portal Cancer View Canada to foster increased networking and knowledge transfer • Supplementing an initial environmental scan on cancer care programs/initiatives with learnings from the Forum and further networking • Engagement with First Nations, Inuit and Métis organizations in the Partnership's primary prevention Coalition Linking Action and Science for Prevention (CLASP) strategic initiative 	May 2009 onwards
Concurrently with the work above, solicit participant feedback on selection criteria for 'working group' to develop action plan	May 2009
Working with the First Nations, Inuit, Métis and cancer control communities, recruit membership and orient working group	June - September 2009
Guided by working group, develop concrete action plan within the Partnership for implementation 2009-2012.	Fall 2009

The Partnership deeply appreciates the time, energy and insights that were generously shared by all of the delegates to the National Forum and is committed to working together to advance First Nations, Inuit and Métis cancer control efforts.

ⁱ Cancer Care Manitoba; “Aboriginal Cancer Care Progress Report”, 2008.

ⁱⁱ www.who.int/cancer/prevention/en/

ⁱⁱⁱ See Introduction for references

^{iv} Marrett, L and Chaudry, M. “Cancer incidence and mortality in Ontario First Nations, 1968-1991 (Canada).” *Cancer Causes and Control*, vol. 14, no. 3, pp.259-268, 2003.

^v Alvi, RA. *Breast, Cervical and Colorectal Cancer Survival Rates for Northern Saskatchewan Residents and First Nations*. Thesis (M.Sc.). University of Saskatchewan, 1999.

^{vi} National Aboriginal Health Organization; *Broader Determinants of Health in an Aboriginal Context*; 2007.



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“Cover photo: Elders Dr. Fred Shore, Margaret Lavallee, and Bernadette Niviatsiak”

A Message from Jessica Hill, CEO of the Canadian Partnership Against Cancer



We are pleased to provide this summary of key discussions and outcomes of the National Forum on First Nations, Inuit and Métis Cancer Control.

We consider the Forum an important first step in fostering better understanding of the challenges in cancer control faced by First Nations, Inuit and Métis peoples.

As host of the Forum, the Canadian Partnership Against Cancer (the Partnership) is especially grateful to the Elders who so generously shared their wisdom and whose participation has informed all aspects of this meeting. Going forward, their knowledge will continue to be the basis for all efforts to improve cancer control among First Nations, Inuit and Métis peoples.

This Forum epitomizes the Partnership's work: starting with the best in Canada in cancer control, no matter where the local base of this understanding, and bringing together the people and resources necessary to transfer this knowledge into meaningful and widespread solutions.

The Partnership is respectful of federal, provincial and territorial health-care systems, while focused on furthering the exchange of ideas and evidence across those boundaries. In the role of facilitator, the Partnership does not deliver or fund services, and in keeping with our mandate, an overriding goal of the Forum was to identify opportunities for collaboration.

Indeed, this report references how we are advancing some immediate opportunities for change identified at the Forum. From a wider perspective, the Partnership is moving forward in developing a longer-term Action Plan. The Assembly of First Nations, Inuit Tapiriit Kanatami and Métis Nation of Canada are providing guidance on a proposed Working Group to oversee the development of this Action Plan, scheduled for completion in December 2009.

On behalf of the Partnership, I would like to express my gratitude to our remarkable Forum Planning Committee. This group gave generously of their time and provided invaluable guidance in the planning of this event

As we move forward, the Partnership will continue to seek input from those with a stake in its success and sustainability. In planning this event, we were keenly aware of the importance of strong participation by our partners in First Nations, Inuit and Métis communities. Now, the participants' list serves as the basis of a communications network that will allow us to keep communities involved in, and informed about ongoing developments in the work to advance cancer control.

While serious challenges remain to advancing cancer control among First Nations, Inuit and Métis, we believe we have made important strides and, with guidance from the meeting evaluation results (contained in the report) and continuing input from participants, we look forward to future discussions and the next steps

Thank you for the opportunity to play a role in this important work.

Yours in improved First Nations, Inuit and Métis Cancer Control

Jessica Hill

Part One

Summary Report of National Forum on First Nations, Inuit and Métis Cancer Control



Introduction

The Canadian Partnership Against Cancer (Partnership) oversees implementation of Canada's cancer control strategy. The Partnership works with governments, federal agencies, patient groups, provincial cancer agencies, professional associations, national cancer organizations and others to bring Canada's cancer control strategy to life and create a more coordinated and efficient cancer control system. Being culturally responsive to the needs of First Nations, Inuit and Métis peoples is an important priority within this work.

On March 19-20, 2009 the Partnership hosted the National Forum on First Nations, Inuit and Métis Cancer Control. This report summarizes the issues discussed, learnings, recommendations and next steps. Detailed reports from the breakout sessions are included in the appendices, together with copies of the presentations and the meeting evaluation.

Background: First Nations, Inuit and Métis Cancer Control

Cancer control is becoming a critical concern for First Nations, Inuit and Métis across Canada. Although research in this area is limited, existing studies invariably show that cancer incidence has risen dramatically in each of these populations over the past few decades.^{7,8,9} From being nearly unknown a few generations ago, cancer is now among the top three causes of death among First Nations, Inuit and Métis peoples.^{10,11,12}

Knowledge, attitudes and values

A number of cancer control challenges exist among First Nations, Inuit and Métis populations. At the community level, there is a general lack of awareness about cancer and successes in its prevention and treatment.¹³⁻¹⁵ Communities' experiences of poor cancer outcomes (largely due to lack of access to prevention and screening programs^{14,15}) have created barriers to open discussions about the disease.^{16,17} The lack of culturally relevant educational materials and expertise also contributes to this knowledge gap.^{18,19,20}

Determinants of health

Determinants that affect health status include: income and social status, food security, employment, education, housing and social support networks, among others.²¹ Many of these factors are worse, in general, for First Nations, Inuit and Métis. Determinants of health are influenced by factors such as geography and access to basic health services.²² In addition, experiences related to colonization, such as the residential school system and other forms of disempowerment, have caused serious intergenerational trauma which has resulted in low self-efficacy and poor coping mechanisms.^{23,24} It will be important to be cognizant of these historical realities in the development and implementation of strategic initiatives to improve cancer control. Another aspect of the determinants of health relates to First Nations, Inuit and Métis who are contending with urgent problems such as contaminated water or youth

suicide. Persons in this position may be preoccupied by these acute concerns and temporarily unable to address longer-term health needs such as cancer prevention or screening. This is an important consideration in setting expectations in the design and implementation of cancer control programs.

Access to services

At the interface between communities and the health system, access to screening and treatment services is difficult for many First Nations, Inuit and Métis.^{25,26,27} As noted, geographic obstacles exist for the large proportion of these populations living in remote communities. Significant historical, psychosocial and financial barriers also must be overcome.^{28,29,30,31}

In addition, within the health system, lack of cultural sensitivity and understanding of important cultural elements can reduce the effectiveness of treatment,^{32,33} while a lack of healthcare resources in communities and often poor coordination of care between hospitals and primary care providers can undermine follow-up and palliative care.^{34,35,36}

These challenges have been recognized by several organizations across Canada that have developed collaborative strategies to address the gaps in cancer control - from prevention to surveillance, screening and care. To build on these efforts, the Partnership hosted a national forum in Winnipeg, Manitoba, convening participants from First Nations, Inuit and Métis organizations and from the cancer community to share information across the cancer control continuum.

The National Forum on First Nations, Inuit and Métis Cancer Control, March 19-20, 2009, Winnipeg, Manitoba

The National Forum on First Nations, Inuit and Métis Cancer Control represented an important first step in further validating the known gaps and opportunities in cancer control—including those identified in previous submissions to the Public Health Agency of Canada from the national and regional Aboriginal organizations—and identifying opportunities and areas where the Partnership could add value.

Led by a Planning Committee consisting of First Nations, Inuit and Métis organizations, cancer agencies, Health Canada's First Nations and Inuit Health Branch (FNIHB), the Public Health Agency of Canada (PHAC) and the Partnership, 65 participants attended the March Forum. Participating individuals and organizations included: Elders; First Nations, Inuit and Métis organizations; cancer control agencies; provincial/territorial governments; researchers; Canadian Cancer Society as well as patient and professional organizations; Canadian Institute for Health Information; FNIHB; and PHAC, among others.

The Forum objectives were three-fold:

1. Share information about gaps across the cancer control continuum for First Nations/ Inuit/Métis people
2. Identify initiatives across Canada that are addressing gaps
3. Explore opportunities for improvement, building on current knowledge and ongoing work

The meeting agenda involved a mix of plenary and interactive breakout sessions, with the goal of exploring new possibilities in advancing First Nations, Inuit and Métis cancer control. The recommendations obtained from this meeting, together with best practices identified by participants, will inform the development of a concrete action plan within the Partnership.

Next Steps: the action plan

Guided by a working group, an action plan will be developed to address immediate and long-term priorities identified by Forum participants. The priorities will focus on deliverables the Partnership can either lead or support within its mandate to coordinate implementation of the national strategy for cancer control. These may either be new activities or linked to existing Partnership initiatives. This work will continue to reflect the Partnership's mandate - the organization adds value by working with partners to minimize gaps in knowledge and leverage the best available knowledge, as displayed through promising or emerging practices.

For More Information

National Forum participants will be kept informed of progress on the action plan by postings to the meeting website at: <http://www.partnershipagainstcancer.ca./Aboriginalcancerforum> (and later through Cancer View Canada, the portal supported by the Partnership).



Setting the stage: presentation summaries

The meeting was opened and closed each day by First Nations, Métis and Inuit Elders who shared with the audience their experiences with cancer and their prayers for a successful meeting.

Jessica Hill, Chief Executive Officer of the Partnership, welcomed attendees and discussed the role of the Partnership in advancing First Nations, Inuit and Métis cancer control. This was followed by presentations outlining priorities for cancer control from the national organizations: Assembly of First Nations, Inuit Tapiriit Kanatami and Métis National Council. (Full presentations are in Appendix 2.)

Canadian Partnership Against Cancer

Jessica Hill

Canadian Partnership Against Cancer

The Canadian Partnership Against Cancer began operations in April 2007 to oversee implementation of Canada's cancer control strategy. The Partnership's role is to work as a catalyst to advance cancer control efforts and to develop targets and measure performance. The organization brings a national perspective to a cancer system that is largely provincially funded and focused.

The Partnership is not a granting agency and does not deliver programs or services. Rather, it directs its funds toward orchestrating collaborative and pan-Canadian efforts that can be sustained and that will ultimately reduce cancer rates and deaths and improve patients' lives. This includes working with many partners across the country to generate new knowledge and share best-available knowledge and promising practices.

The Partnership's work focuses on the eight cancer control priorities of the strategy, from prevention through to palliative care:

Prevention	Guidelines	Research
Screening	Cancer Journey	Surveillance
Quality & Standards	Health Human Resources	

Central to success across priority areas is the need to be culturally responsive as it advances pan-Canadian cancer control initiatives. With involvement and direction from First Nations, Inuit and Métis groups, the goal of the National Forum is to explore how the Partnership can add value to First Nations, Inuit and Métis cancer control efforts. This may take the form of First Nations, Inuit or Métis-specific activities within existing Partnership initiatives or new activities where the Partnership can either lead or support.

First Nations & cancer: an emerging crisis

Melanie Morningstar and Tracy Tarnowski

Health and Social Development, Assembly of First Nations

First Nations is the largest of the three constitutionally recognized Aboriginal groups in Canada, including nearly one million citizens who live in 633 First Nation communities, as well as in rural and urban areas.

For First Nations who live on reserves, accessing health care is often difficult. Sixty-two per cent of First Nations people live on reserves; of these, 60 per cent are defined as remote and have less than 500 residents. This creates difficulties for residents who must travel to access all but the most basic services, and for healthcare providers who must travel to remote sites to deliver care. In addition, it is unclear where the boundaries of responsibility for providing primary care lie with respect to the federal and provincial/territorial governments. Cancer screening and cancer treatment follow-up, for example, are areas that are not well coordinated.

The cancer situation for First Nations is difficult to determine, since very little research has been done. Existing studies indicate that cancer incidence is rising faster in First Nations than in the general population and is now the third leading cause of death among Aboriginal people in Canada. Like every member in society, lifestyle-associated risk factors may contribute to cancer. First Nations are particularly vulnerable to these risk factors because of socio-economic conditions. All of these issues must be addressed as integral parts of cancer control.

Three priority areas have been identified by the Assembly of First Nations, through consultation with their regions:

1. Need for accurate and complete information on cancer and on the effectiveness of cancer control measures
2. Focus on patients and equitable access in a manner that respects First Nations culture
3. Population based screening and prevention

The Assembly of First Nations (AFN) is committed to addressing cancer control and seeks to do this through partnerships, linkages and participation of First Nations with key organizations at the national, regional and community levels.

Inuit and cancer

Cheryl Young and Soha Kneen

Inuit Tapiriit Kanatami

Approximately 40,000 Inuit live in 52 communities across four Inuit land claim regions—Nunavik (Northern Québec), Nunatsiavut (Northern Labrador), Inuvialuit (Northwest Territories) and Nunavut—and an additional 11,000 live in urban centres across Canada.

Cancer is the second leading cause of death among Inuit and some cancers occur at higher rates in Nunavut than in the rest of Canada—lung cancer incidence in particular may be linked to higher rates of smoking. In addition, inadequate housing and food security are major concerns for the Inuit and likely contribute to the rise in cancer incidence.

Cancer in the Inuit is diagnosed at a later stage, which is believed to be due in part to poor access to regular screening. The lack of culturally appropriate information on cancer is one reason why Inuit may not seek medical attention more promptly. In addition, most Inuit communities have understaffed health centres and people often need to travel great distances for specialized health services including cancer diagnosis and treatment.

Our understanding of how cancer affects the Inuit is hindered by the enormous gaps in identifying Inuit with cancer. There are no systemic and long term records documenting cancer in this population and thus research is extremely difficult to do.

The following are priorities for improving access to cancer care by the Inuit:

- Link and collaborate with key participants in Inuit health
- Advocate for better policies and practices
- Increased Inuit-specific resource material
- Establish and support community networks for those living with cancer
- Access to rehabilitation, supportive and palliative care
- Tele-health and video conferencing

Inuit Tapiriit Kanatami (ITK), the national Inuit organization, will continue to advocate for improved cancer programs and services.

Cancer in Métis People in Canada - the past, the present, the future

Marc LeClair

Métis National Council

The Métis are a constitutionally recognized Aboriginal group whose population is found throughout Canada. Métis communities exist largely in the West.

Little is known about the overall health of Métis people. From our ancestors we know that in the past little, if any, cancer was seen. Today, however, many of us can identify one, or several, Métis individuals who we know have been treated for cancer. Métis-specific cancer rates remain largely unknown. Métis people face lower levels of income, education, and access to resources—all important determinants of health and factors in cancer prevention and treatment.

Access to the cancer control system across Canada may be limited for the Métis population. Most Métis people have a family doctor but initial screening and follow up may be limited by satisfaction with the primary care they receive. Those in urban areas may not be able to afford public transportation. Many live in rural communities with limited access to public transportation and often incur out-of-pocket expenses. Those with low income jobs lack

health benefits and there is no Non-Insured Health Benefit (NIHB) program for the Métis population through Health Canada. [See Glossary for explanation of the NIHB program.]

To build knowledge, work is beginning in some Métis National Council Governing Member Organizations to determine rates of cancer in our populations. For example, in Manitoba a “Cancer in Métis in Manitoba” study (available in November 2009) will provide reliable information. Such information is essential to support future planning around cancer programs and services relating to the Métis population.

Our future priorities are to determine the burden of illness in Métis people, and to identify the most prevalent types of cancer to target prevention and treatment efforts.



Where are the gaps?

Participants worked in breakout groups to discuss the gaps in cancer control among First Nations, Inuit and Métis populations.

Sources of information

The cancer control gaps presented for discussion had originally been identified by the five national Aboriginal organizations in their submissions to the Public Health Agency of Canada (the submission was made prior to the formation of the Canadian Partnership Against Cancer in 2007):

- Assembly of First Nations
- Inuit Tapiriit Kanatami
- Métis National Council
- Native Women's Association of Canada
- Aboriginal People's Congress

A list of gaps, summarized from these submissions, was presented to the Forum delegates for discussion within the themes below. Many of the gaps, such as those related to “cultural sensitivity” and “access”, cut across these themes:

- Prevention and screening
- Cancer journey
- Health human resources
- Research and surveillance
- Guidelines, quality and standards

Participants were asked to identify which gaps were of the highest priority for their group/ area, and to provide comments that may be helpful to the Partnership in developing an action plan.

Output

The following summary of gaps in cancer control was discussed by participants. There was a general agreement that all of the gaps on the list were important, however some were noted as being more serious for certain groups (e.g., First Nations, Inuit or Métis; rural and remote communities; older or younger individuals; women and men). This input is captured in detail in Appendix 3.

The list of gaps presented below will undergo a further validation process before being used as a basis for developing an action plan. Since not all invitees were able to attend this forum, representative First Nations, Inuit and Métis organizations will have an opportunity to provide their input as a next step.

Gaps in cancer control

<p>Primary Prevention and Screening</p>	<p>Awareness</p> <ul style="list-style-type: none"> • Education about cancer is lacking (importance of cancer, types of cancers, smoking as a cause of cancer, prevention and treatability, examples of success, relationship of social determinants of health to cancer, knowledge of screening guidelines) • Lack of culturally relevant materials about cancer (adapted to: holistic perspective, literacy and language, imagery, perspectives on medicine, psychosocial barriers of fear and beliefs about cancer, lack of focus on successes) • Communication channels (pamphlets are not enough, local media - radio and TV - not utilized to its full advantage) <p>Support for screening</p> <ul style="list-style-type: none"> • Geographic and financial barriers to access • Non-Insured Health Benefits (NIHB) policies (for eligible registered First Nations and Inuit) do not pay for travel for screening, unless included in other eligible medical travel • No regular examinations due to doctor shortages • Residential school experience makes people reluctant to be examined • Lack of resources and funding to promote prevention and screening at the community level • Need for culturally sensitive health services <p>Other</p> <ul style="list-style-type: none"> • Holistic approach to care is needed • Creative approaches are lacking
<p>Cancer Journey</p>	<ul style="list-style-type: none"> • Medical transportation is inadequate in remote/rural areas • Families cannot afford to accompany/visit the patient, so the patient lacks emotional and advocacy support during their treatment stay - some may choose not to go • Circumstances force some patients to relocate for treatment, requiring them to maintain the cost of two homes • Gaps in coverage: drugs, accommodation, travel; some drugs are not covered, patients cannot afford to pay and be reimbursed later, wait times for approval are too long (through Non-insured Health Benefits) • Access issues: palliative care; family physicians and specialists • Lack of culturally sensitive materials • Wait times (pre-diagnostic, imaging)

<p>Health Human Resources</p>	<ul style="list-style-type: none"> • Severe shortages of health professionals in remote areas • Community Health Representatives are overworked - there is a need to have professionals at the community level who address cancer needs • Lack of culturally sensitive services across the cancer continuum
<p>Research and Surveillance</p>	<ul style="list-style-type: none"> • Lack of cultural identifiers in existing databases • No surveillance systems that identify First Nations, Inuit and Métis • FN/I/M-specific data not available or extremely limited (incidence, mortality, morbidity, etc.) • Need for research on occupational and environmental risk factors • OCAP is not always respected [see Glossary] and this creates reluctance of communities to participate in research studies • No central database of existing information (research, surveillance studies) • Lack of capacity at community level for interpretation and translation of research findings into practice
<p>Leadership</p>	<ul style="list-style-type: none"> • First Nations and Métis leadership needs to be aware of the importance of cancer as an issue (at national and local levels); Inuit leadership has already initiated work at the national and regional levels • Formal and informal leaders need to drive awareness of cancer in the communities, the importance of screening and understanding that cancer is not a death sentence - leadership needs to be educated as to the importance



Work being done to address cancer control gaps

Following the discussion on gaps in cancer control, the subsequent breakout sessions were focused on work being done to address these needs.

Breakout discussions

Meeting participants were asked to come prepared to share information about ongoing projects in their area, both within and among the breakout groups. Due to the large number of initiatives, the time available for discussion of each one was necessarily limited. An additional opportunity was provided the following morning. A ‘marketplace’ of booths featuring descriptions of projects, printed materials and internet-based programs was set up to allow attendees to review projects in greater depth and to meet the project leaders.

Output

More than one hundred projects, initiatives and programs were presented. The following summary outlines the categories of projects and gives examples of each.

Prevention and Screening

Region	Initiative
Culturally relevant materials:	
Alberta	The Alberta Breast Cancer Screening Program developed an Aboriginal Breast Cancer Education Toolkit to help Aboriginal health workers provide information about cancer screening to First Nations and Métis women.
Ontario	<p>Cancer Care Ontario’s Aboriginal Cancer Strategy Team provided samples of materials (pamphlets, playing cards, posters, videos, calendars, radio PSA’s, teaching wheels etc.) developed by and for Aboriginal communities. These are aimed at increasing awareness of cancer in general and to address specific topics such as tobacco use and overcoming barriers to cancer prevention and screening.</p> <p>CCO also manages a website www.tobaccowise.com tied to educating about traditional versus commercial uses of tobacco.</p>

First Nations/Inuit/Métis community-based activities:

Labrador	The Blue Light Campaign of the Nunatsiavut Department of Health and Social Development is creating community awareness about smoking by placing a blue light outside every home that is smoke free.
Nunavut	The Quit to Win! challenge, funded by Health Canada, provides incentives for youth to stop smoking.
Ontario	<p>A Community Coordinator position is funded by the Canadian Cancer Society - Ontario Division as part of the Screening Saves Lives project. An Aboriginal nurse, responsible for the Manitoulin Island area, conducts educational programs and trains lay health educators to promote cancer screening and prevention in the communities.</p> <p>Cancer Care Ontario's Aboriginal Cancer Strategy Unit provides small-scale community capacity building grants to First Nation, Métis communities for tobacco cessation pilots. The unit works with the communities to customize the intervention based on community need.</p> <p>Ontario has a video called "In Our Own Words" based on First Nation, Métis and Inuit experiences in the cancer system.</p>
Manitoba	The Aboriginal Health Transition Fund adaptation project Norway House is piloting a community engagement model in Manitoba. Among its various projects, the community's working group is developing a navigation system to help address the gaps between diagnosis and treatment.
Saskatchewan	The Saskatchewan Cancer Agency's Breast Screening Program, in collaboration with First Nations and Inuit Health and First Nations tribal councils, has added one community with low participation rates each year as an area of focus. Working with Community Health Representatives to educate and recruit eligible women, participation rates have increased dramatically. The Agency has also developed a breast screening navigation program in communities for women who need to receive further diagnostic testing.

Cancer Journey

Region	Initiative
Quebec	The First Nations of Quebec and Labrador Health and Social Services is an autonomous organization that provides primary care to communities and coordinates with provincial services, resulting in seamless care for patients.
Nova Scotia and Ontario	Aboriginal patient navigation programs have been established by the Juravinsky Regional Cancer Centre in Hamilton, Ontario and by Cancer Care Nova Scotia. The Nova Scotia program also includes a video describing the patient journey.
Northwest Territories	NWT provides Breast Health Patient Navigation and Cancer Patient Navigation. Regionally, there is currently a pilot project underway focusing on the implementation of Traditional Practitioners with land medicines in a community health care center. Territorially, an Aboriginal Wellness Program is being implemented which will offer access to Traditional Practitioners, medicines, traditional foods, and appropriate ceremonies.
National	The Canadian Hospice Palliative Care Association produced a handbook supporting First Nations patients and caregivers, plus an inventory of resources and tools for palliative care for use by First Nations and Inuit communities. The association also sponsored a roundtable meeting to identify key issues in palliative care.

Health Human Resources

Region	Initiative
National	Saint Elizabeth Health Care successfully piloted @YourSide Colleague with 35 First Nations across Manitoba. The program includes a web-based learning component and self-directed courses on cancer, screening and treatments. The program has since been shared with First Nations communities and health authorities across Manitoba, British Columbia and Saskatchewan.
Nova Scotia	Nova Scotia has developed a program Partners for Interprofessional Cancer Education which includes cultural sensitivity and safety training.
Manitoba	As part of its First Nations, Inuit and Métis Cancer Control Strategy, Cancer Care Manitoba has implemented mandatory two-day cultural safety training for all employees.

Research and Surveillance

Region	Initiative
Manitoba	Manitoba's Centre for Aboriginal Health Research program: "Access to Quality Cancer Care and Control of Cancer for Manitoba First Nations" is a partnership between the Centre, First Nations and governments. The program includes a surveillance system which uses data linkage to capture cancer information on over 90% of First Nations populations living on reserves. The project will also identify a framework for a culturally appropriate knowledge translation process that will allow research findings to be applied to the communities, and will increase capacity for health-related decision making by all parties.
Ontario	Cancer Care Ontario is working with two Regional Cancer Centres on a pilot project, funded by the Ministry of Health and Long-Term Care, which asks a cultural identifier question for the Ontario Cancer Registry. This small-scale model will be evaluated and, if successful, may be applied to the remaining cancer programs in the region."

Guidelines, Quality and Standards

Several organizations are developing Aboriginal Cancer Control Strategies that are aimed at ensuring quality cancer care at the standard expected by Canadians.

Region	Initiative
Alberta	Alberta is currently developing an Aboriginal Cancer Strategy, including an environmental scan and needs assessment.
Ontario	Ontario has a 5 year strategy developed for Aboriginal Cancer Control. The strategy will be renewed in 2009-2010.
Other Provinces	Cancer control strategies for First Nations, Inuit and Métis exist in various forms in Manitoba and British Columbia.
National	Inuit Tapiriit Kanatami (ITK) developed a Discussion Paper and Fact Sheets on Inuit cancer control. Based on the priorities identified in these documents, ITK is developing a cancer control advocacy platform.

Snapshot of ongoing work in advancing Canada's cancer control strategy

Lee Fairclough, Vice President of Knowledge Management at the Partnership, provided a snapshot of some of the ongoing work in advancing Canada's cancer control strategy. (Presentation is available at www.partnershipagainstcancer.ca/Aboriginalcancerforum). For more detail on the full range of initiatives underway in advancing the strategy, please visit Cancer View Canada: www.cancerview.ca.

Cancer View Canada, a new initiative of the Partnership, is an ever-evolving portal connecting Canadians to online services, information and resources for cancer control. As it further develops and expands capacity, with input from partners, the portal will bring together resources for cancer prevention, screening, treatment, and supportive, palliative and end-of-life care.

Following discussion at the Forum, the Partnership has commenced the development of a First Nations, Inuit and Métis stream within Cancer View Canada to foster increased networking and knowledge transfer.



Themes, learnings and recommendations

The following themes and learnings emerged based on input from participants. These are potential areas of focus for the action plan. The themes and learnings highlighted below are followed by a summary of recommendations for action. Details of these inputs are available in Appendix 3.

Themes and learnings

<p>Primary Prevention and Screening</p>	<p>Awareness</p> <ul style="list-style-type: none"> • One size does not fit all: adaptation to the realities faced by a specific population is needed for a program to be successful • Successful initiatives include participation by communities, starting as early as possible in the process, and involving community-based health workers as project champions • Communication and education must be delivered in various ways; the best approaches include a combination of health counselling/ sharing circles, local news media, telehealth seminars, and visual media such as posters and videos made by and for First Nations, Inuit and Métis communities • Social determinants of health must be integral to the cancer awareness message (e.g., air quality in crowded homes; link between food insecurity, diet and cancer) • Messages need to be culturally sensitive (e.g., recognize traditional beliefs and fears about cancer, use meaningful terms for cancer, consider and respect the whole person) <p>Support</p> <ul style="list-style-type: none"> • Geographic barriers can be overcome by some communities through outreach screening programs and telehealth • Health services that are culturally sensitive tend to be much more successful in addressing cancer control gaps
<p>Cancer Journey</p>	<ul style="list-style-type: none"> • Navigation services are important to patients and families • Partnerships between First Nations, Inuit and Métis groups, First Nations and Inuit Health, provincial/ territorial government and non-governmental organizations can be effective in driving new initiatives to address important unmet needs for patients

Health Human Resources	<ul style="list-style-type: none">• Communities that have autonomy over health services can sometimes find innovative and collaborative ways of providing better services within fixed budgets• Cultural sensitivity/safety training builds awareness, respect and reflects the commitment of healthcare organizations to addressing the needs of First Nations, Inuit and Métis
Research and Surveillance	<ul style="list-style-type: none">• Successful surveillance and research programs require early and ongoing participation of First Nations, Inuit and Métis as full partners• There is a great need for further research and surveillance in order to understand the cancer profiles of First Nations, Inuit and Métis communities and to explore specific issues such as different types of cancer, environmental contamination, etc.• To have an impact on cancer control, First Nations, Inuit and Métis communities need the capacity to interpret, share and apply research findings in their communities
Guidelines, Quality and Standards	<ul style="list-style-type: none">• Measurement of the success of projects and cancer control programs is essential to their sustainability



Recommendations

The following summary list of recommendations was developed and shared by meeting participants as priorities for action.

Primary Prevention and Screening	<p>Community-Based Programs to Increase Awareness</p> <ul style="list-style-type: none">• Develop a community mobilization plan, including:<ul style="list-style-type: none">• best practices for leadership and collaboration• training programs• potential partners and resources• standards specific to First Nations, Inuit and Métis• methodology for conducting needs assessments, communication plans, focus groups/sharing circles• Support the development of education and communication programs<ul style="list-style-type: none">• materials that are easy to adapt to local needs• basic information on cancer• social determinants of health and healthy living• positive messages of success• culturally relevant messages• address emotional realities (fears, frustration)• tools and communications channels• Create facilities to share materials:<ul style="list-style-type: none">• high-speed internet access and telehealth• pan-Canada e-knowledge portal where culturally relevant cancer prevention, education and end-of-life tools and programs can be shared and posted <p>Leadership/Advocacy Support</p> <ul style="list-style-type: none">• Address social determinants of health, including food insecurity and smoking• Advocate for healthy public policy• Advocate for more community resources• Collaboration for all organizations to carry similar messages• Sustainable funding for screening
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<p>Cancer Patient Journey</p>	<ul style="list-style-type: none"> • Re-examine Non-Insured Health Benefits policies: <ul style="list-style-type: none"> o flights for screening o travel for family members o coverage for all Aboriginal peoples - Métis people do not receive health coverage through non-insured health benefits o asking patients to pay for medications and reimbursing them later is unfair o the sometimes lengthy approval processes result in patients in pain waiting for their medication to be approved repeatedly • Palliative care within communities is lacking and requires further supports • Share best practices in patient/family navigation • Advocate for screening services closer to home • Ask communities what they need - don't assume
<p>Health Human Resources</p>	<ul style="list-style-type: none"> • Address shortages of health workers and access to services in remote communities • Develop innovative, collaborative service delivery models <ul style="list-style-type: none"> o broaden scope to include community volunteers, Elders, corporate sponsors, governments, NGOs o use telehealth more o train primary healthcare providers to assess and promote healthy living in communities o use a patient-centred model to address risk factors for all chronic diseases o examine the prospect of patient navigators for regions and communities to help individuals steer through the sometimes overwhelming hospital care decisions, NIHB, etc. • Coordinate care between federal and provincial/territorial/First Nations jurisdictions • Improve cultural sensitivity and understanding <ul style="list-style-type: none"> o provide a standardized cultural sensitivity/safety training program and ensure that health care providers are mandated to participate in the training o cultural liaison support workers to educate national organizations and field health workers

<p>Research and Surveillance</p>	<p>Research Conduct</p> <ul style="list-style-type: none"> • Design geographically relevant projects that will demonstrate where sustainable funding should be placed • Collaborate with communities and build partnerships to strengthen research; apply OCAP principles (see Glossary for definition) • Coordinate existing research efforts <p>Surveillance</p> <ul style="list-style-type: none"> • Develop First Nations, Inuit and Métis identifiers for surveillance and research • Ensure that data collection is being done according to OCAP [see Glossary for definition] and research standards <p>Research Topics</p> <ul style="list-style-type: none"> • Broaden the focus of research to include prevention and complementary/traditional approaches • Be open to community and participatory based approaches • Causes of rising cancer incidence <p>Knowledge Translation</p> <ul style="list-style-type: none"> • Community profiles with health indicators for planning • Don't wait to act until all the data is in • Assist communities in understanding and applying research by building capacity and training
<p>Guidelines, Quality and Standards</p>	<ul style="list-style-type: none"> • Develop policies that set standards and measure access to services • Guidelines must include traditional medicine, traditional healers • Cultural sensitivity/awareness must be part of standard of care; more input from First Nations, Inuit and Métis groups • Increased funding of services is needed for equitable access to quality care



Next steps

In her closing comments, Leanne Kitchen-Clarke, Vice President of Strategy, Performance Measures and Communications at the Partnership, summarized the main themes emerging from the Forum and next steps.

She reiterated the Partnership's role as that of a catalyst and facilitator - to work together with existing organizations to share knowledge and promising practices that will advance cancer control efforts.

The Partnership will work towards the following timelines for action planning:

Action	Timing
Synthesize discussion points and provide the Forum report to participants	June 2009
Working with the First Nations, Inuit, Métis and cancer control communities - and based on recommendations by forum participants - identify opportunities to link to existing Partnership initiatives (as appropriate). Examples include: <ul style="list-style-type: none"> • A First Nations, Inuit and Métis stream within the Partnership's new portal Cancer View Canada to foster increased networking and knowledge transfer • Supplementing an initial environmental scan on cancer care programs/initiatives with learnings from the Forum and further networking • Engagement with First Nations, Inuit and Métis organizations in the Partnership's primary prevention initiative 	May 2009 onwards
Concurrently with the work above, solicit participant feedback on selection criteria for 'working group' to develop action plan	May 2009
Working with the First Nations, Inuit, Métis and cancer control communities, recruit membership and orient working group	June - September 2009
Guided by working group, develop concrete action plan within the Partnership.	Fall 2009

In closing, Leanne, on behalf of the Partnership, expressed her thanks to all participants for making the Forum a very productive meeting. The information and discussion will set the course for the development of a concrete action plan to advance cancer control among First Nations, Inuit and Métis communities across Canada.

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Glossary of Key Terms

Aboriginal	Collective term referring to the three constitutionally recognized groups: First Nations, Métis and Inuit
AHHRI	Aboriginal Health Human Resource Initiative Five-year program of Health Canada (since 2004). Areas of focus: <ul style="list-style-type: none"> to increase the number of Aboriginal people working in health careers; to adapt health care educational curricula to support the development of cultural competencies; and to improve the retention of health care workers in Aboriginal communities.
AFN	Assembly of First Nations <ul style="list-style-type: none"> National organization representing First Nations citizens in Canada. The AFN represents all citizens regardless of age, gender or place of residence.
Aboriginal Health Transition Fund	Program of Health Canada which seeks to improve the integration of Federal, Provincial and Territorial funded health systems, adapt existing health programs and services to better serve the needs of Aboriginal peoples (Inuit, First Nations and Métis). This program further seeks to improve access to health services and increase the participation of Aboriginal peoples in the design, delivery, and evaluation of health programs and services.
Communities	Refers to groups of First Nations, Métis and Inuit (not necessarily a place of residence). May also be used as an alternative term for reserves (First Nations) and municipalities (Inuit).
CPAC	Canadian Partnership Against Cancer <ul style="list-style-type: none"> Formed in November 2006 by the federal government for a 5-year term as an independent, arm's-length organization to implement the Canadian Strategy for Cancer Control
FNIHB	First Nations and Inuit Health Branch <ul style="list-style-type: none"> Branch of Health Canada responsible for ensuring that eligible registered First Nations and Inuit receive health services at the standard available to other Canadians, as agreed by treaties
FOBT	Fecal Occult Blood Test Standard screening test for colorectal cancer.
Healthy public policy	Refers to the coordination of public policy to achieve improvements in social, economic and environmental determinants of health.

Indian	Legal term referring to First Nations (as in the Indian Act). Not in modern use.
ITK	Inuit Tapiriit Kanatami <ul style="list-style-type: none"> National organization representing Inuit
IAHP	Institute for Aboriginal Peoples' Health <ul style="list-style-type: none"> One of 13 Institutes under the auspices of the Canadian Institutes for Health Research (CIHR) Provides research funding and coordinates/encourages research through its Network Environments for Aboriginal Health Research (NEAHRs)
MNC	Métis National Council <ul style="list-style-type: none"> National organization representing Métis
NAHO	National Aboriginal Health Organization An Aboriginal-designed and -controlled body committed to influencing and advancing the health and well-being of First Nations, Inuit and Métis Peoples
NIHB	Non-Insured Health Benefits <ul style="list-style-type: none"> Health benefits plan available through Health Canada's First Nations and Inuit Health Branch to eligible registered First Nations and Inuit Covers drugs, medical travel and medical supplies (with certain policy restrictions)
OCAP	Ownership, control, access and possession. <ul style="list-style-type: none"> Formal principles governing the collection and use of data about First Nations
Pap test	Short form for 'Papanicolaou test'. Standard screening test for cervical cancer.
Partnership	Canadian Partnership Against Cancer <ul style="list-style-type: none"> Formed in November 2006 by the federal government for a 5-year term as an independent, arm's-length organization to implement the Canadian Strategy for Cancer Control
PTO	Political Territorial Organization <ul style="list-style-type: none"> Organizations representing some or all First Nations within a province or territory
Registered or Status	Refers to the legal status of First Nations, under the terms of the Indian Act. First Nations who are registered with Indian and Northern Affairs (INAC) –as well as Inuit—are eligible for certain rights, including certain health care benefits.

<p>Risk factors for chronic diseases</p>	<p>Several modifiable and non-modifiable risk factors have been shown by researchers to increase the likelihood of developing chronic diseases, such as cancer, diabetes and heart disease:</p> <ul style="list-style-type: none"> • Non-modifiable risk factors include genetics and environmental pollution • Modifiable risk factors, which have recently been shown to potentially reduce the risk of cancer by one-third, include: smoking, obesity, lack of physical activity, low consumption of fruits and vegetables, infection, sun exposure and excessive alcohol intake
<p>Social determinants of health</p>	<p>Social determinants of health are linked to health outcomes: physical conditions (overcrowded housing with poor ventilation and mould, contaminated drinking water), economic status (unemployment, poverty), social status, support networks, education levels and health literacy, access to health services, early childhood care, food security. Social determinants may have more influence on health status than the risk factors cited above.</p>
<p>Tribal Councils</p>	<p>Political organizations representing a number of individual tribes or First Nations within a region.</p>



Part Two Appendices

Appendix 1	Meeting agenda Participating organizations
Appendix 2	Presentations
Appendix 3	Outputs from breakout sessions: Gaps, recommendations and what is needed
Appendix 4	Meeting evaluation
Appendix 5	Further information: Planning Committee members Meeting website link Partnership contact information

Appendix 1

Meeting Agenda and Participating Organizations

National Forum on First Nations, Inuit and Métis Cancer Control

Winnipeg Fairmont Hotel, 19-20 March 2009

AGENDA

Wednesday March 18		
6:00 - 9:00 pm	Conference registration	East Foyer (conference level)
Thursday March 19		
7:00 - 8:00	Continental breakfast Conference registration	East Ballroom
8:00 - 8:45	Welcome and opening ceremonies Jessica Hill CEO, CPAC <u>Elders:</u> <i>Margaret Lavallee (First Nations)</i> <i>Bernadette Niviatsiak (Inuit)</i> <i>Fred Shore (Métis)</i>	
8:45 - 8:55	Review meeting agenda <i>Facilitator</i>	
8:55 - 9:15	Introduction <i>Jessica Hill</i>	
9:15 - 9:35	First Nations perspectives <i>Melanie Morningstar and Tracy Tarnowski,</i> <i>Assembly of First Nations</i>	
9:35 - 9:55	Inuit perspectives <i>Cheryl Young and Soha Kneen, Inuit Tapiriit Kanatami</i>	
9:55 - 10:15	Métis perspectives <i>Marc LeClair, Métis National Council</i>	
10:15 - 10:35	Break	East Foyer
10:35 - 10:45	Introduce Breakout #1 <i>Facilitator</i>	East Ballroom
10:45 - 12:15	Breakout #1: Validate needs/issues for your region	Breakout Rooms
12:15 - 1:15	Lunch	East Ballroom

1:15 - 2:30	Breakout #2: Review current work in your region	Breakout Rooms
2:30 - 2:50	Break	East Foyer
2:50 - 4:00	Breakout #3: View and discuss other regions' initiatives	Breakout Rooms
4:00 - 4:45	Day 1 closing ceremonies <i>Elders</i>	East Ballroom
6:30 - 9:00 pm	Evening event	Midway Ballroom
Friday March 20		
7:30 - 8:30	Continental breakfast	East Ballroom
8:30 - 9:10	Opening ceremonies <i>Elders</i>	East Ballroom
9:10 - 9:20	Welcome to Day 2; Introduce Marketplace <i>Facilitator</i>	
9:20 - 10:00	Marketplace: Display of projects and initiatives	West Ballroom
10:00 - 10:45	Breakout #4 <i>Identify remaining gaps</i>	Breakout Rooms
10:45 - 11:00	Break	East Foyer
11:00 - 12:00	Breakout #4 (continued)	Breakout Rooms
12:00 - 12:45	Lunch	East Ballroom
12:45 - 2:00	Breakout group presentations (10 min each)	East Ballroom
2:00 - 2:20	Next steps <i>Leanne Kitchen-Clarke, VP Strategy, Performance Measures and Communication, CPAC</i>	
2:20 - 3:00	Closing ceremonies <i>Elders</i>	

Participating Organizations

Attendees

Abegweit First Nation, PEI
Aboriginal Council of Manitoba
Aboriginal Nurses Association of Canada
Alberta Cancer Board
Assembly of First Nations
BC Cancer Agency
Canadian Cancer Society (National, BC/Yukon and Manitoba Divisions)
Canadian Hospice Palliative Care Association
Canadian Institute for Health Information
Canadian Institutes of Health Research
Canadian Partnership Against Cancer
Cancer Care Manitoba
Cancer Care Ontario
Centre for Aboriginal Health Research, University of Manitoba
Council of Yukon First Nations
Department of Health and Social Services - Nunavut
Elder, First Nations
Elder, Inuit
Elder, Métis
First Nations and Inuit Health Branch, Health Canada
First Nations and Inuit Health, Alberta
First Nations and Inuit Health, Atlantic
First Nations and Inuit Health, Ontario
First Nations Health Council, British Columbia
First Nations of Quebec and Labrador Health and Social Services Commission
Government of Nunatsiavut
Inuit Tapiriit Kanatami
Inuvialuit Regional Corporation
Manitoba Métis Federation
Métis National Council
National Aboriginal Health Association
New Brunswick Cancer Network
Public Health Agency of Canada
Saskatchewan Cancer Agency
Stanton Territorial Health Authority
Teslin Tlingit Council
Thunder Bay Regional Health Sciences Centre
Tungasuvvingat Inuit
Union of Nova Scotia Indians
University of Toronto
Urban Circles, Winnipeg
Western Cree Tribal Council Treaty 8

Regrets

Due to the timing of the meeting and staff shortages, a number of organizations were unable to attend but expressed interest in remaining part of the action planning process.

Assembly of Manitoba Chiefs
Canada Health Infoway
Canadian Cancer Research Alliance
Canadian Public Health Association
Cancer Care Nova Scotia
Chiefs of Ontario
Congress for Aboriginal Peoples of Canada
Eastern Health (Newfoundland & Labrador)
Federation of Saskatchewan Indian Nations
First Nations Health Council
Indigenous Cancer Care Resource Research Network
Indigenous Physicians Association of Canada
National Association of Friendship Centres
National Indian & Inuit Community Health Representatives Organization
Native Women's Association of Canada
Pauktituuit Inuit Women of Canada
Quebec Ministry of Health and Social Services
Queen Elizabeth Hospital, PEI
Yukon Health & Social Services

Appendix 2 Presentations

To view the presentations, please visit the meeting website at:

<http://www.partnershipagainstcancer.ca./Aboriginalcancerforum>

Appendix 3 Outputs from breakout sessions: Gaps and Recommendations

The following charts contain verbatim comments recorded during the breakout sessions.

The breakout groups were organized according to geographic location and contained cross-sectional representation of First Nations, Inuit and Métis (FN-I-M) delegates and participants from the cancer community (cancer agencies, healthcare funding organizations, health policy and research organizations). Although many of the comments noted are consistent among the various breakout groups, their origins are identified in each case to preserve the granularity of the discussion since this document will form the basis of discussions by the Working Group in developing an action plan. Where a comment has relevance to only certain groups, this is also noted.

<i>Primary Prevention and Screening - Awareness</i>	
Gaps	Recommendations / What is Needed
<p>Communication - cultural relevance</p> <ul style="list-style-type: none"> Existing differing levels of literacy levels need to be recognized. Creative solutions are needed in prevention information - pamphlets are not enough. - BC / YT FN/I/M often do not respond to the medical model of health. We have to very careful how we deliver the message, not just what we say. - BC / YT More collaboration with Canadian Cancer Society to avoid duplication. More cultural awareness related to holistic health approach is needed. Mainstream info not always appropriate for the communities. - BC / YT Cultural translation of medical info - cancer information is not getting out to the populations. Networking needed. Links need to be established. Cultural translation of medical information needs to be more accessible. - BC / YT Lack of culturally appropriate materials - ON/NU Cultural responsiveness of cancer communications materials ...psychosocial barriers...health literacy of groups not known...do we know what works for diverse groups in communities, need to learn this (need data) - ON/NU Accurate language translation, problem at some workshops southern language used and presentation styles, think about reaching local target audience, some materials not appropriate, make more simple - ON/NU 	<p>Communication - cultural relevance</p> <p>Recommendations</p> <ul style="list-style-type: none"> Consider application of FN/I/M indicators around community mobilization that are relevant to the population (smear the poop campaign) - NB / PEI / NS <p>What is Needed</p> <ul style="list-style-type: none"> Workshop adapted with plain language that makes it easy to report to the community. - QC/NL Health Canada pamphlets need to be made with plain language. There need to be focus groups specific to the needs of the Yukon. - BC / YT More information geared to families rather than the individual. For example, use of game cards for colorectal cancer awareness. - BC / YT Messages or campaigns to target this must address various audiences, generations, as well as geography, cultural context. - ON/NU Create culturally appropriate resources - ON/NU Create a pan-Canada e-knowledge Portal (Partnership) where cultural/relevant cancer prevention, education and end-of-life tools and programs can be shared & posted - ON/NU <ul style="list-style-type: none"> o 'Push' (Partnership actively maintains site) o 'Pull' (providers post their projects) o This would be real knowledge transfer. E.g. Cancer Word Book (Ojibway) o Inclusion of role of culture, tradition specific to FN/I/M, one size does not fit all

<p>Primary Prevention and Screening - Awareness</p>	
<p>Gaps</p>	<p>Recommendations / What is Needed</p> <p>Communication - cultural relevance</p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Give ‘cancer’ an Aboriginal name - ON/NU • Culturally sensitive consultation and dissemination of information. Direct communications by involving locals in their language or dialect. - ON/NU • Need for culturally relevant and effective (tested) communications strategy, with integrated FN/I/M outreach as part of implementation approach. (Relevant means responsive to psychosocial issues, demographic charts) - ON/NU • Means and resources in community need to be in place to accomplish effective communications campaigns (Inuit) - ON/NU • Regional Focus Groups - to understand the needs (example: don’t assume you’re communicating because you’re translating into the official language - many don’t read or write and need visual or auditory information) - AB/NWT • Needs assessment of where the community’s level of knowledge, attitude and beliefs are with respect to cancer - AB/NWT

Primary Prevention and Screening - Awareness	
Gaps	Recommendations / What is Needed
<p>Communication - content and channel</p> <ul style="list-style-type: none"> • Lack of specific information on types of cancers. Information is needed on Helicobacter pylori (H. pylori - bacteria that infect the digestive system) and its connection to cancer. There is a high priority of gastrointestinal cancers in First Nations in Yukon. - BC / YT <ul style="list-style-type: none"> o H. pylori is a major concern in the communities. Patients need help to make the connection to cancer. - BC / YT • More research/more information to be made available to the public. - BC / YT • Better access to information for interveners, knowledge management strategies. - QC/NL • Identify the fears associated with cancer and address them (holistic approach rather than mechanistic) - QC/NL • Psycho-social barriers of screening. Fear of death - ON/NU • More examples of success, information materials - SK / MB • Awareness of importance of cancer, value of prevention and screening (5) - ON/NU • Health literacy and health promotion resources (3) - ON/NU • Access to literature materials, information, etc. - AB/NWT 	<p>Communication - content and channel</p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Clearinghouse for materials, influence access to high-speed internet - Sask/Man <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Awareness - need to use community champions working at grassroots level. - ON/NU <ul style="list-style-type: none"> o Train them to bring cancer awareness to those they love - raises capacity and ownership. • Use appropriate communication tools - i.e. local radio. Many print materials not effective - ON/NU • Use local radio for promoting services - eliminate boxes of paper materials. - ON/NU • Use local people information/communications - ON/NU • Improve effectiveness of communication strategy - ON/NU • Workshops to just listen, history, cultural relevance training - Winnipeg Regional Health Authority in Manitoba has great programs - ON/NU • Social marketing initiatives - AB/NWT • Awareness - what treatments are available - AB/NWT

Primary Prevention and Screening - Awareness

Gaps

Social determinants of health

- Focus is on social determinants, not prevention - SK / MB
- Increase understanding of the social determinants and especially the impact of education and acculturation. - QC/NL
- Systemic issues are a factor - creates stressors - AB/NWT

Recommendations / What is Needed

Social determinants of health

Recommendations

- Social determinants need to be addressed: establish collaboration among all the organizations carrying the same message - QC / NL
- Healthy public policy - income, education, social support networks, etc. are all contributors to health - interventions to improve these will improve health - AB / NWT
- Focus on food security - BC / YT
 - o The Partnership should work with FN / I / M to increase access to traditional and healthier foods
 - o E.g. The Partnership has focused on anti-smoking, healthy eating, etc. (prescriptive in nature) - (e.g. why buy a shrivelled up apple that's more expensive than a bag of Cheesies that's cheaper, or why harvest healthy seaweed when the water is polluted, etc.).

What is Needed

- Reduce stressors re: living conditions, nutrition, hopelessness / psychological state - AB/NWT
- Understand the conflict between healthy living messages and the reality of life (example: foods espoused by healthy living are prohibitively expensive in the North. Rather than being helpful it just creates stress because you're either not eating healthy, or you're spending too much to try to buy that food) - AB/NWT
- Integrate the messages for healthy living across chronic diseases - AB/NWT

Primary Prevention and Screening - Awareness	
Gaps	Recommendations / What is Needed
<p>Anti-smoking strategy</p> <ul style="list-style-type: none"> • # 1 Problem is a lack of a commitment to smoking prevention as a cancer cure which would have the most impact on health/cancer reduction. - BC / YT • Tobacco use a major health concern. - BC / YT • Smoking cessation is not a priority in FN/I/M societies because of all the things they have already survived - abuse, alcohol, marginalism - BC / YT 	<p>Anti-smoking strategy</p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Include FN/I/M tobacco issue in Partnership strategies or create a new one - Sask/Man <ul style="list-style-type: none"> o Empowerment of the community for change o Share effective educational strategies, adapt tools o Focus on positive aspects o Connect to social determinants; culturally based o Sustainable change through policies o Connect to reasons for addictions; build pride o Partner with other groups who can advocate (for better housing, etc.) o Focus on change-leaders (grandmothers with a dream) o Who are the other partners (Canadian Cancer Society, etc.) o Face-to-face work in the communities (not a DVD or teleconference) o Partnership role to help with evaluation tools • Tobacco strategy - Need for an integrated broad approach that involve community leaders and health care providers (including dentists) - QC / NL • Tobacco - systematic strategies - should afford incentives to quit smoking - AB / NWT <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Tobacco control - ON/NU

Primary Prevention and Screening - Awareness	
Gaps	Recommendations / What is Needed
<p>Other</p> <ul style="list-style-type: none"> • Leadership awareness - cancer as an issue on the map - AB/NWT • Informed consent decisions - AB/NWT • A knowledge base is lacking that needs to be addressed regarding causes and prevention - AB/NWT • Pockets of awareness about cancer but not prevention - AB/NWT • Effects of uranium mining on cancer - ON/NU • Overlap of risk factors (2) - ON/NU • The political will needs to support the people not just the policies. The top down approach of the past and current government is not working in the communities. - BC / YT • Political will and leadership buy-in regarding cancer awareness & importance - ON/NU • Act locally, local wisdom - SK / MB • Focus on impact of prevention dependent of geography, locality - ON/NU • Everyone should have in mind to put the client first. It would change everything and avoid working in silos. - QC/NL 	<p>Other</p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Kinship training - AB/NWT • Concept of public health - AB/NWT

Primary Prevention and Screening - Support	
<p>Gaps</p> <p><i>Geographic barriers to support</i></p> <ul style="list-style-type: none"> • Testing takes too long in the North. Access to screening and getting results needs to be improved. - BC / YT <ul style="list-style-type: none"> o There is a lack of screening programs in Yukon and a lack of culturally relevant information. o Travel / accessibility a concern o Mobile screening units are needed in Yukon. o Central based screening facilities within regions to be shared • Geographical barrier (FN/M) - SK / MB • Medical transportation policies for screening - ON/NU • Lack of limited screening programs is unacceptable and should be a priority for Health Canada & Non-Insured Health Benefits to address. (See Glossary for information about NIHB). Ask for input from those affected to determine the need. - ON/NU 	<p>Recommendations / What is Needed</p> <p><i>Geographic barriers to support</i></p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Increase use of telehealth - adaptation of funding. - QC / NL <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Medical transportation: Advocate for change and policies, to reflect in particular fly-in communities. Make the ‘trip out’ more value added - for example, an integrated screening day - breast, Pap, FOBT, education - ON/NU • Speedier intervention for those with cancer (tied to culturally appropriate awareness for cancer care and treatment) (FN) - ON/NU • Use lay workers, Elders & volunteers who have a desire to help. Provide financial incentives - e.g. phone cards, food vouchers or gas vouchers, hunting equipment. Partner with industry to provide these incentives, e.g. Coca Cola - ON/NU • Need more mobile units - AB/NWT • Screening closer to home - AB/NWT • Mobile cervical screening programs - if going into FN communities, have FN nurses offer the service - AB/NWT

Primary Prevention and Screening - Support

Gaps	Recommendations / What is Needed
<p>Health care professionals</p> <ul style="list-style-type: none"> Late stages cancers are a result of masking by health care professionals (e.g., alcoholism). - BC / YT <p>Psychological barriers</p> <ul style="list-style-type: none"> Intimidation / embarrassment of needing certain tests in small communities/lack of privacy. - BC / YT Attention to residential school victims in terms of adult medical care (e.g. issues about authority figures examining them) - BC / YT 	<p>Health care professionals</p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> Manitoba has excellent workshops on Aboriginal cultural awareness for health care providers - ON/NU Better equipped interveners, offer them the possibility to share and exchange information among themselves but keeping in mind that they are very busy people with little time to train. - QC/NL Training of local individuals, programs must be community based. - QC/NL Evidence based assessment tool for primary care provider, research, collaborative strategy to promote healthy living, need to move beyond awareness, training for care workers on health promotion strategies. - QC/NL Provide more training through telehealth and phone conferencing - ON/NU Liaison workers in hospitals - AB/NWT Community trained people - AB/NWT

<p>Primary Prevention and Screening - Support</p>	
<p>Gaps</p>	<p>Recommendations / What is Needed</p> <p><i>Partnerships and Coordination</i></p> <p><u><i>What is Needed</i></u></p> <ul style="list-style-type: none"> • Health Canada to partner early on in the development of new resources with Aboriginal groups to provide input on language, culture & effective distribution - ON/NU • Build and strengthen scientific research and community collaborations - ON/NU • Coordination of efforts - AB/NWT • Clarification of jurisdictional issues regarding prevention and public health - AB/NWT • Ask FNs what they need, don't assume what is best for FNs, get Elder/youth input - ON/NU • FNIHB for on-reserve cancer programs - AB/NWT <p><i>Psychological barriers</i></p> <p><u><i>What is Needed</i></u></p> <ul style="list-style-type: none"> • Psychosocial barriers include residential school effects <ul style="list-style-type: none"> - these people don't know self love and just accept cancer diagnosis - training on how to deal with these intergenerational effects - ON/NU

Primary Prevention and Screening - Support	
<p>Gaps</p> <p>Other</p> <ul style="list-style-type: none"> • Attention to the whole person is lacking for FN, I, M. - BC / YT • Collaborative approaches need to create economies of scale, use of technology. - QC/NL • More localized services focus on importance of family in healing process - BC / YT • Translator must be seen as essential service. - BC / YT • Support services are lacking - ON / NU • Need best practices specific to Aboriginal cancer control - ON/NU <p>Funding</p> <ul style="list-style-type: none"> • More funding - SK / MB • Tele-health: fee structure: there is no compensation for telehealth consults. - QC/NL • Lack of resources - ON/NU 	<p>Recommendations / What is Needed</p> <p>Other</p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Develop policy to address gaps in access - ON/NU • Important internal structure raise awareness, educate own FN people, include successes for survival too - FN - ON/NU • Tele-health will address human resources, costs of doing business & time with family for support - ON/NU • Appoint resources to local councils or health authority for public service announcements - ON/NU • Knowledge translation of cancer terminology - AB/NWT • Policy - AB/NWT • Basic health literacy - AB/NWT • Medical terminology needs to be coherent with traditional conceptualizations of health - AB/NWT • Sustainable funding for screening activities (coordinator in NWT) - AB/NWT

Cancer Journey	
<p>Gaps</p> <p><i>Cultural safety and sensitivity</i></p> <ul style="list-style-type: none"> • Cultural differences, cultural safety, cultural proficiency for different groups - ON/NU • You can't serve a population if you don't understand the population you serve - ON/NU • Language barriers - ON/NU • Interpreter - AB/NWT • Education for communities on cancer control in their languages - ON/NU • FN and Inuit communities have been caring for their dying forever - why different now? - ON/NU 	<p>Recommendations / What is Needed</p> <p><i>Cultural safety and sensitivity</i></p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Educate the local Elders on the meaning of palliative care, define it in their language and relevant to their culture - ON/NU • Enhance home care services available in community - palliative care is a minimal piece of the federal Home and Community Care program - ON/NU • Create the Aboriginal (First Nations) Patient, Family & Community Centered Care Institute - much like the centre in Augusta, GA. The centre will host 'anglo' system administration and physicians and help with cultural sensitivity training - ON/NU • Escorts - in the North escorts are provided for cultural continuity/language/support. The problem is that it's hard to get the time off work. A national escort system should fund this service. - AB/NWT <p><i>Local support and training</i></p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Go back to community development roots. Mobilize. - ON/NU • Palliative care training in the community - ON/NU • Kinship training - AB/NWT • Re-orient service delivery - ON/NU • Create support groups - AB/NWT

Cancer Journey	
Gaps	Recommendations / What is Needed
<p><u>Funding and Support</u></p> <ul style="list-style-type: none"> • Medical transportation support in remote/rural areas - ON/NU • Disparity in the access to medicines (across FN/I/M but also across all Canadians). Some people get better access to better medicines and treatments - depends on provincial boundaries, employment, etc. - AB/NWT • Housing - patients are sent alone to the city- they may choose not to go for treatment - AB/NWT • Resources to support families - ON/NU • Funding and support - ON/NU • NIHB support is only for 4 months when still under treatment - ON/NU • Palliative care services - ON/NU • Ability to die in the community - ON/NU • Non-Insured Health Benefits - AB/NWT 	<p><u>Funding and Support</u></p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Access: Use Norway House example to understand patient journeys and the gaps - Sask/Man <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Build an understanding of traditional approaches among practitioners of western medicine (mutual learning) • Shift to a person-centred model • House and share information on navigation. Enhance home care services available in community - palliative care minimal piece of the federal Home and Community Care program - ON/NU • One stop shop for all tools/resources - like a “marketplace” portal - ON/NU • Linkages to other health programs is valuable - ON/NU • Canadian Cancer Society advocates and lobbies for equality of access to medications and services - AB/NWT • Housing for families of patients - AB/NWT • More doctors to visit the communities - AB/NWT • First Nations and Inuit Health Branch needs to fund palliative care programs - AB/NWT • Infrastructure for physical activity - AB/NWT • Housing - need to consider what type of housing is realistically helpful for FN/I/M - AB/NWT • Access to Non-Insured Health Benefits should be available to all Aboriginal people with a chronic disease - Aboriginal people have a lower health status than other Canadians - AB/NWT

Cancer Journey	
Gaps	Recommendations / What is Needed
<p>Other</p> <ul style="list-style-type: none"> • First intervention is way too late - hence, people die within 2 to 3 weeks. - ON/NU • Awareness of insurance schemes (public/private) - ON/NU • Right of every Canadian to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice - ON/NU 	<p>Other</p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Why not FN/I/M community advocacy? - ON/NU • Develop policy to address gaps in access - ON/NU • Examine models of integrated service delivery from a risk factor approach that addresses obesity, physical activity, healthy eating - ON/NU • Become servant leaders - ON/NU • Could connect people with their communities using technology - YouTube, Telehealth. Need connectivity in the North for this. - AB/NWT • Home care training - AB/NWT • Televisitation - AB/NWT • Tell the stories - AB/NWT • Recognition of non-medical aspects of health - AB/NWT

Health Human Resources	
Gaps	Recommendations / What is Needed
	<p><i>Cultural safety and sensitivity</i></p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Implement cultural liaison support workers who educate the national organizations and field workers. E.g. cross-cultural awareness officer, Elder advisors. - ON / NU <ul style="list-style-type: none"> o Orientation training programs (e.g. traditions, such as eye contact, to avoid misinterpretation) o E.g. Morrisberg - heavy equipment operator - general manager included a cross-cultural awareness section - delivered by a matron well versed in Inuit culture - ON / NU <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Blending traditional approaches to modern clinical services will decrease costs and improve collaborations - ON/NU • Extend cultural awareness to healthcare system - ON/NU • Human resources deployed according to the community's request as their priority - train new staff with cancer focus and broad/holistic health promotion across lifespan - ON/NU • Cultural competency should be regulated - AB/NWT • Invest in Aboriginal workforce - more Aboriginal providers - AB/NWT • Aboriginal person to lead the national FNIM cancer control strategy - AB/NWT

Health Human Resources	
Gaps	Recommendations / What is Needed
<p>Other</p> <ul style="list-style-type: none"> • High Priority: the severe shortage of health care professionals. In Nunavut brand new hospitals are not being utilized due to the lack of healthcare professionals and lack training to provide any kind of advanced health care - patients have to be flown to the south - ON/NU • Retention and recruitment of nurses and other medical attendants is an issue (including incentives for long term retention) - ON/NU • There are underused facilities because of lack of nurses and medical attendants - ON/NU 	<p>Other</p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • To identify required competencies to assist community workers to be involved in cancer control - NB / PEI / NS • Address the health human resources issues in isolated communities - ON / NU <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Consider use of other health professionals beyond primary care providers for screening, etc. - ON/NU • Expand telehealth - ON/NU • Family supports in supportive care services: end of life, palliative, respite - ON/NU • Training in hospice palliative care by the community not necessarily outsiders - ON/NU • Lobby for more funding, particularly for remote communities that have no road access - ON/NU • Maintain and diversify the Aboriginal Health Human Resource Initiative - ON/NU • More health care provider training development for FN/I/M - ON/NU • There needs to be trained health care professionals/ care-givers to ensure that our people in Nunavut have the option to stay in Nunavut to obtain health care. No other Canadians in southern Canada need to travel so far for health care. - ON/NU • Education/training incentive packages - AB/NWT • Funding for capacity training - AB/NWT

Research and Surveillance - Data	
Gaps	<p style="text-align: center;">Recommendations / What is Needed</p> <p>Partnerships</p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Research design - include academic institutions, FN/I/M groups, etc. - design geographically relevant projects that will demonstrate where sustainable funding should be placed - AB / NWT • Collaborative approach required - BC / YT <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Build and strengthen scientific research and community collaboration - ON/NU • Build partnerships (internships, practicum placements, apprenticeships) - ON/NU • Negotiate with Indian & Northern Affairs Canada (INAC) re: access to Indian Register to do data matching with provincial databases; privacy issues need support and partnership with FN/I/M organizations for this project - ON/NU • Create (at one of Winnipeg Regional Health Authority, Thunder Bay, other) Partnership-sponsored/supported Aboriginal Cancer Facility Design Centre - where new cancer centre/ remediation project leaders can source relevant information about design to meet Aboriginal peoples needs - ON/NU • Coordinate - governments, educational institutions & Aboriginal organizations - AB/NWT • Work collaboratively - AB/NWT • Partner with epicentre in Alberta - AB/NWT • Partnership with Canadian Institutes for Health Research/ Canadian Cancer Society - AB/NWT • Data sharing agreements to address jurisdictional and privacy issues - AB/NWT

Research and Surveillance - Data	
Gaps	Recommendations / What is Needed
<p>Cultural identifiers</p> <ul style="list-style-type: none"> • Cultural identifier questions in vital statistic registries - FN/I/M - ON/NU • Surveillance systems lacking for FN/I/M - ON/NU <p>Inventory of existing research</p> <ul style="list-style-type: none"> • Knowledge of what exists in: cancer prevention, screening, treatment, supportive care - ON/NU • Community profiles - ON/NU 	<p>Cultural identifiers</p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Identifiers for Inuit/Métis/Function - QC / NL <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Ethnic identifiers are absolutely necessary. - ON/NU • Extend Métis registry health records initiatives - ON/NU • Extend surveillance systems to Métis - ON/NU • Identify system to identify populations - AB/NWT <p>Inventory of existing research</p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Use existing data sources where possible - while other methods are being investigated. They may not be perfect, but they may give a sense of, in particular, FN information - ON/NU • Use existing surveillance data to identify priorities for programs, strategies, etc. around prevention, screening, access to care and research - ON/NU • Analyse existing data - ON/NU

Research and Surveillance - Data	
Gaps	Recommendations / What is Needed
<p>Other</p> <ul style="list-style-type: none"> • Data - ON/NU • Research Surveillance: Need action - move beyond interest/willingness to actual action - ON/NU • Capacity building for surveillance and research - ON/NU 	<p>Other</p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • More cancer research required - BC / YT <ul style="list-style-type: none"> o E.g. In Yukon research on current programs is needed for data collection to be used for evaluation purposes - BC / YT • Ability to provide good statistics - identify the various groups - there will be differences in how to do this between FN/1/M - AB / NWT • Statistics often needed to drive action (“show me the numbers and we’ll show you the cash”) - BC / YT • Data collection not being done properly in Quebec (geo zones) - QC / NL • Look at the Karelia project in Sweden as a model - AB / NWT • Research needs to broaden - we’ve been in the same treatment mode for 4 decades - we need to explore efficacy, cost, safety of other modes and put public dollars into this (traditional, complementary) - AB / NWT • Health Canada release Knowledge Transfer information to public - AB/NWT • Research Ethics Boards training - AB/NWT

Research and Surveillance - Research Topics	
Gaps	<p style="text-align: center;">Recommendations / What is Needed</p> <p>Topics</p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Research project: food as a medical intervention - governments support provision of fresh foods/ traditionally preserved foods (community gardens and greenhouses) and study the impact of that (health benefits, cost-benefit analysis) - AB / NWT • Consider and account for the interactions between cancer strategies and other chronic disease strategies - what benefits one may benefit all - AB / NWT <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Colorectal cancer research is needed: why is this cancer increasing so rapidly on FN? Is it increasing in all Aboriginal groups? Why or why not? - ON/NU • Research: why is cancer survival poorer in FN? Surveillance findings need to be known to research projects - ON/NU • Do not expend huge resources in creating FN registries when all we need to know is broad trends to help set targets/priorities - ON/NU • Develop community profiles with health indicators to be used for planning of cancer series - ON/NU • Examine models of integrated service delivery from a risk factor approach that addresses obesity, physical activity, health eating. - ON/NU • Research topics knowing Aboriginal view of cancer/ health will help us plan and deliver more effectively in prevention and screening - ON/NU • Research topics need to include an objective review of alternative and traditional medicines and approaches to cancer treatment - AB/NWT

Research and Surveillance - Use of Scientific Data	
Gaps	<p style="text-align: center;">Recommendations / What is Needed</p> <p>Research to Action</p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Don't wait to act until all the data is in (may take years) - BC / YT <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Need to translate results of surveillance and research <ul style="list-style-type: none"> - what they mean (and don't mean), how they can be used (or not), and what actions would be capacity building for surveillance and research - ON/NU • Using data to assist program planning/policy development is a means, not an end - ON/NU • Need action to move beyond interest/willingness to actual action - ON/NU <p>Building Local Capabilities</p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Data in aggregate form, training on how to use the data, community can translate the data better than we can at the national or provincial level, etc. - ON / NU • Will require training/infrastructure/support so that technology does not stay "in the box" - ON / NU <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Build data capacity - ON/NU • Better sharing of scientific data - ON/NU

Research and Surveillance - Use of Scientific Data	
Gaps	Recommendations / What is Needed
	<p>OCAP (See Glossary for definition)</p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Data sharing agreements needed based around OCAP principles (FN) - ON/NU • OCAP must be used to facilitate not hinder dissemination of research results to benefit FN people - ON/NU • Must follow OCAP, code of ethics, data sharing protocols, etc. - BC / YT • Provide a safe place (OCAP (for FN not I/M) compliant) for all to access data - ON / NU • Educate non-Aboriginal researchers about OCAP - AB/NWT <p>Other</p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Never forget ‘human’ aspects in all policy work - ON/NU • Specific strategies to specific Aboriginal groups (FN/I/M) and, total buy-in - ON/NU

Guidelines, Quality and Standards	
<p>Gaps</p>	<p>Recommendations / What is Needed</p> <p><i>Cultural safety and sensitivity</i></p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Traditional medicine was a family-based knowledge system. Community based health workers need to regain or obtain a knowledge of preventive local medicines in their training and be able to share that in their communities rather than administering it - AB / NWT • Provide clarity for cancer control agencies in understanding the difference and distinct issues for rural First Nation and remote First Nation - NB / PEI / NS • Build awareness of concepts and distinction of concepts (like culturally aware/culturally safe/ culturally sensitive/ cultural competency)- when working with FN/I/M - NB / PEI / NS <p><i>Partnerships and Consultation</i></p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Develop a separate advisory group to help inform the Partnership - Aboriginal-specific (to outreach to FN/I/M) - ON/NU • Develop shared process with Aboriginals to achieve new culturally respected guidelines • Online communities of practice and networks - ON/NU • More input from FN to address guidelines regarding geographic - AB/NWT • National working group - AB/NWT

Guidelines, Quality and Standards	
Gaps	Recommendations / What is Needed
	<p>Research and Evaluation</p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> • Comprehensive analysis of impacts on health care, people, families and society - ON/NU • Partnership survey on perceptions regarding what causes cancer, what can the government do, etc. • Create a Centre Of Excellence for Best Practices. The centre can be a virtual centre to develop/share/ identify - ON/NU • Survey FN/I/M to build better prevention and screening programs, training for primary care • Use internet capabilities more broadly (reach) - ON/NU • Create evaluation systems to identify best practices, promising practices - ON/NU • Review medical incentive systems - are they effective for all regions/ territories/provinces - recruitment, retention - ON/NU <p>Other</p> <ul style="list-style-type: none"> • Alberta Cervical Cancer Screening/Breast Health outreach - AB/NWT • Ensure program sustainability - AB/NWT • Surveillance capacity of all Aboriginal streams - AB/NWT

Domain-wide	
Gaps	Recommendations / What is Needed
	<p>Partnerships / CPAC</p> <p><u>Recommendations</u></p> <ul style="list-style-type: none"> • Organized network - structured, coordinated, maintained, detailed - AB / NWT • Huge role for Partnership to play in gathering and maintaining all this information about programs / initiatives / services / organizations and making it available to everyone - AB / NWT • Partnership's role should be to support its partners by establishing information clearing houses - Partnership doesn't need to become the repository but work with partners who will - AB / NWT • Partnership should include the 3 territories in their presentations and mindset - the territories are not an "add on" to the provinces - AB / NWT • More engagement required - BC / YT <ul style="list-style-type: none"> o Partnership should continue to engage FN/IM representatives o We would prefer that the Partnership do this via a series of regional meetings, rather than via a national meeting o This will help uncover many short-term wins, in addition to ways to close longer-term gaps • Partnership Advisory Group - BC / YT <ul style="list-style-type: none"> o Permanent focus on FN/IM cancer control o Fully funded, inclusive and power to facilitate change • Partnership - we don't have a clear idea of what we can ask for in terms of resources/budget. - ON / NU <ul style="list-style-type: none"> o Of the \$50M per year what is available for FN/IM? o Be clear on timelines of funding - provide ballparks on what can be requested of the Partnership and how the money will be spent and when. o Be clear on the process and criteria for allocation of resources (Partnership) o How do we fit into existing initiatives (e.g. CLASP, P.L.A.N.E.T.?) • The need for strategic alliances with FHIHB/FNIH, provincial cancer agencies to explore avenues for the introduction of strategies/tools within an existing system (weaving) - NB / PEI / NS • Clarify the role of National Aboriginal Health Organization (NAHO) and what is their potential role with the Partnership - ON / NU

Domain-wide	
Gaps	Recommendations / What is Needed
<p>Cultural sensitivity training</p> <ul style="list-style-type: none"> Fundamental need for cultural sensitivity training. Without this, every approach and offering we develop will fail because it will not meet the local needs and be adopted by our audience. No one can speak for FN / I / M - no “expertise” - ON/NU 	<p>Cultural sensitivity training</p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> Winnipeg Regional Health Authority in Manitoba has great workshops - ON/NU Culturally relevant training for systems professionals. The Partnership can lead this. - ON/NU <p>Other</p> <p><u>What is Needed</u></p> <ul style="list-style-type: none"> Address the housing issue for clients leaving their northern communities for lengthy amounts of time during treatment - availability, appropriateness, inclusion of housing for families, access for those without health benefits - AB / NWT Health costs that fall under Non-Insured Health Benefits needs to be addressed - AB / NWT Funding needed (across the board) - BC / YT <ul style="list-style-type: none"> For screening in communities, awareness campaigns, prevention, etc To carry out an FN/I/M inventory with criteria and that this is validated by a peer review group. (Partnership can lead) - NB / PEI / NS To not lose sight of the influence and impact of leadership (formal and informal) in the policy development (such as tobacco) - NB / PEI / NS Our action plan has to capture the “heart” and not just the “intelligence”. (the documents that come out of this meeting have to capture the culture of FN/I/M which is holistic) - NB / PEI / NS To recognize that different regions are at different levels of engagement and involvement - NB / PEI / NS Streamline the process and save resources - A lot is going on - basics of offerings is the same. Lots of time spent duplicating effort - lever and customize existing work. - ON / NU <ul style="list-style-type: none"> Need an effective way of consolidating an inventory of resources at the Partnership - perhaps not broken down by FN/I/M. Need a coordinating point. Integrate information sharing / coordination Better diffusion of success stories - QC / NL AHAA! (Awareness, Holistic, Advocacy, Action, Access) - Sask/Man

Appendix 4

Meeting evaluation

Meeting evaluation results - National Forum on First Nation, Inuit and Métis cancer control

Question 1.

How clear were the objectives of this meeting?

- 32% of respondents said they were completely clear
- 53% of respondents said they were somewhat clear
- 5% of respondents said they were neither clear nor unclear
- 10% of respondents said they were somewhat unclear

Comments provided generally focused on the networking opportunity and the extent of the cancer control challenge.

Question 2.

How clear were you on the preparation required from you for this meeting?

- 26% of respondents said they were completely clear
- 58% of respondents said they were somewhat clear
- 5% of respondents said they were neither clear nor unclear
- 11% of respondents said they were somewhat unclear

Question 3.

What percentage of information/dialogue on FN/I/M cancer control was new to you?

- 16% of respondents said 60%
- 37% of respondents said 40%
- 21% of respondents said 20%
- 21% of respondents said 0%
- 5% of respondents did not answer this question

Respondents' most important learnings focused on the extent of the cancer control challenge, strategies currently in place in other regions, and opportunities for partnership.

Question 4.

Do you agree that the content discussed will be helpful in advancing FN/I/M cancer control?

- 63% of respondents said they totally agree
- 21% of respondents said they somewhat agree
- 11% of respondents said they neither agree nor disagree
- 5% of respondents said they totally disagree

Respondents noted need to discuss funding sources and focus on action plan, and also mentioned ambitious agenda and involving more community participants in meeting.

Question 5.

Do you feel that clear next steps have been identified?

- 27% of respondents said they totally agree
- 42% of respondents said they somewhat agree
- 5% of respondents said they neither agree nor disagree
- 21% of respondents said they somewhat disagree
- 5% of respondents did not answer this question

Respondents' comments focused on need to further clarify next steps, validate items with FN/I/M leadership, and ensure cross cultural training moving forward.

Question 6.

How would you rate the opportunities for participant feedback/input in breakout sessions?

- 47% of respondents said excellent
- 26% of respondents said very satisfactory
- 16% of respondents said satisfactory
- 11% of respondents said poor

Comments focused on the ambitious agenda and need for more time to provide feedback and identify clear actions.

Question 7.

How would you rate your overall satisfaction with this meeting?

- 53% of respondents said excellent
- 21% of respondents said very satisfactory
- 16% of respondents said satisfactory
- 10% of respondents said fair

Respondents valued the opportunity to hear the elders share their wisdom, the networking, and information exchange.

Question 8.

What was the most valuable aspect of this meeting for you?

Comments focused on: the learning (extent of the challenge, existing programs, and successes), networking and dialogue, and partnership opportunities; format of event (inclusive of FN/I/M issues).

Question 9.

What issues were unaddressed at this meeting, or what issues would you like to see addressed in the future?

Issues identified included: FN/I/M voice from Eastern Canada; funding opportunities in different regions; specifics re: activities CPAC can lead; and housing and palliative care.

Question 10.

Please give further suggestions as to how we can improve meetings like this in the future. Suggestions focused on: ensuring greater representation (e.g., Métis, Saskatchewan, clinical staff) and better gender balance; setting concrete objectives; and more time for networking/breakout sessions.

Other feedback

Comments included reference to the key role of Health Canada given its fiduciary responsibility, as well as the importance of continued networking (post-forum); a number of participants said they view the Forum as a positive step forward in facilitating knowledge exchange and progress in FN/I/M cancer control.

Appendix 5

Further information

Planning Committee members

- Melanie Morningstar (Assembly of First Nations)
- Tracy Sarazin (Inuit Tapiriit Kanatami)
- Cheryl Young (Inuit Tapiriit Kanatami)
- Soha Kneen (Inuit Tapiriit Kanatami)
- Barbara Van Haute (Métis National Council)
- Donna Turner (Cancer Care Manitoba)
- Kimberly Morrisseau (Cancer Care Manitoba)
- Michael Power (CCO, Thunder Bay Regional Health Sciences Centre)
- Alison McMullen (Thunder Bay Regional Health Sciences Centre)
- Caroline Lidstone-Jones (Cancer Care Ontario)
- Lianne Vardy (Public Health Agency of Canada)
- Carol Milstone (First Nations and Inuit Health Branch, Health Canada)
- Nicolette Kaszor (FNIH Ontario)
- Joanne Lucarz Simpson (Canadian Partnership Against Cancer)
- Leslie Greenberg (Canadian Partnership Against Cancer)
- Kris Atterbury (Canadian Partnership Against Cancer)

Meeting website:

<http://www.partnershipagainstcancer.ca./Aboriginalcancerforum>.

Contact the Partnership:

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