

“Walk a Mile in My Moccasins”

Foundations For Action in First Nations Cancer Control



April, 2012

An environmental scan and related analysis of cancer care pathways and leading models of cancer care in rural, remote and isolated First Nations communities, and leading culturally responsive cancer control resources originating from those communities.

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EXECUTIVE SUMMARY

Cancer is the leading cause of death in Canada. First Nations are at increased risk for cancer and experience poorer outcomes. Creating positive change is everyone's responsibility. This report builds an improved understanding of the current cancer pathways for First Nations (FNs) in reserve communities¹ across Canada. It also identifies promising/leading practices and models of cancer care and culturally appropriate resources that can be used to guide future efforts. This information will lay the foundation for sustainable partnerships that can work to make a difference. Funding for this work was provided by the Canadian Partnership Against Cancer.

This report represents the findings from data collection that included the following: review of the literature; provincial scans; e-survey for FN community health care managers/providers; sharing sessions; e-survey for Cancer Control organizations; and key informant interviews. The report reflects the voice of over 250 people across nine provinces and Yukon Territory and provides rich information on the current realities for First Nations affected by cancer. The project approach ensured full and meaningful engagement of FNs in the identification of the issues, gaps, and barriers in cancer control as well as the identification of opportunities for action to improve cancer control for First Nations².

FINDINGS

THEMES

The data revealed that the issues, gaps and barriers to cancer care fall into three themes: **Access**, **Partnerships**, and **Jurisdiction**. These themes not only resonate through all of the data collected, they are also present in the promising/leading practices and models of care that are working to make a difference.

Access

At present, less than 50% of FN communities have any cancer programs or services available on reserve. Cancer care access is hampered by inconsistent transportation coverage (NIHB) and distance. The high turnover of health staff makes accessing primary care providers difficult and accessing specialists complicated. Although some communities have good access to cancer screening, access is not consistent or available for all communities. Access is also an issue when it comes to palliative care. Almost half of the respondents indicated that their community or Tribal Council provides palliative care, however, in reality there is no formal palliative care program. Health care providers working in FN communities identify the need for evidence based cancer care education, decisional support, information systems, and culturally appropriate resources.

“Cancer care is one thing that is forgotten in our First Nation communities, there is no palliative care training, to allow us to provide adequate care for the terminally ill cancer patients...if we had more First Nations trained in palliative cancer care, our people could have their wish and remain in the comfort of their own home until their time.”

¹ The term ‘FN communities’ in this report includes rural, remote, and isolated reserve communities, unless otherwise indicated.

² Quotes from participants are identified by quotation marks and are italicized.

Partnerships

Partnerships are essential to support improvement in cancer pathways for FNs. The data revealed a clear want and need from communities to partner more effectively with provincial cancer agencies. These partnerships have the potential to address gaps related to the access of prevention, screening, care and treatment and survivorship. Jurisdictional and privacy issues need to be addressed to support the continuity of care for cancer patients as they move between treatment centres and their home communities.

“The gap I experience the most is the follow-up for the client, the (discharge) information is given to the client with little to no information for the nursing station to co-ordinate follow-up care.”

Jurisdiction

The data demonstrated that jurisdictional boundaries (FN, federal, provincial, and health authority) complicate cancer pathways for FNs. Changes to access and partnerships will not be effective or sustainable without the corresponding jurisdictional change (policy) and cooperation.

CURRENT REALITY: CANCER PATHWAY

Results of the data analysed show that cancer care for FNs is more similar than different regardless of geographical location, proximity to treatment centres, or type of cancer. The data highlights that cancer pathways in FN communities are burdened by the long lasting effects of historical trauma and the negative effects of the social determinants of health. This history has imbedded a “fear” and “mistrust” of the health care system. Gaps and barriers related to Access, Partnerships, and Jurisdiction hinder access to existing cancer care, which leads to populations that are under-screened, and diagnosed with advanced cancer. When cancer is diagnosed, options are too often linked to isolation away from home communities. Existing technology is not effectively used to link patients to families and health systems to FN health centres. Patient navigators are rare. The lack of formal palliative care programs places burdens on the patient, family, community, and the community health providers. Too often the diagnosis comes so late, that a funeral precedes viable treatment.

“Going for cancer treatment out of the community is like a death sentence. You may as well have died on the plane, because you won’t be back except for your funeral.”

MOVING FORWARD: OPPORTUNITIES FOR ACTION

The opportunity to improve access by strengthening partnerships across jurisdictions is a collective responsibility necessary to create positive change. Promising/leading practices and models of cancer care in e-technology, outreach, and patient navigation highlighted in the report demonstrate the power of effective partnerships and can be used to guide the efforts necessary to improve cancer care for FN communities.

E-Technology

The Mustimuhw Community Electronic Medical Record (cEMR), is a computer program that provides health professionals with quick access to secure patient information such as blood test results and medical history. Mustimuhw was developed by the Cowichan Band in British Columbia and offers solutions designed around FN health centre needs. It is currently being used in more than 50 communities in BC and has recently expanded from six to nine communities in Manitoba. Electronic records will allow communities to track disease incidence, information that is useful for program planning and evaluation.

The second leading practice is the @YourSide Colleague® Cancer Care Course. The SK Cancer Agency partnered with Saint Elizabeth, (the not-for-profit charitable health care organization that developed the @YourSide Colleague® online e-learning tool) and First Nations and Inuit Health to use the course and the e-platform to help introduce the new colorectal screening program. Although, the @YourSide Colleague® learning program is available to all FN communities free of charge, data revealed that program awareness could be enhanced. The program currently has 10 online courses available; this is a great opportunity to bring evidence base culturally appropriate resources to the doorstep of every FN community. Resources are developed in partnership with FNs with a goal of reaching community based health care providers. The @YourSide Colleague® has the potential to address gaps related to education and overcome barriers of distance and travel.

The final promising practice uses basic technology. Teleconferences link Aboriginal communities in Saskatchewan to the provincial cancer agency and a network of chronic disease groups. This integrated chronic disease approach supports chronic disease groups to work together with FNs to collectively improve communication, support education, and address challenges. This approach can be replicated in any region, it is a low cost, low technology option that is a first step to improving access and communication.

Existing e-technology has the potential to improve communication across jurisdictions, support education, and establish sustainable links to cancer experts, however, to date, the technology is underutilized. Formal relationships between jurisdictions need to establish policy around information sharing that supports continuity of care as patients move between the cancer care system and their communities.

Outreach

Mobile breast screening is an outreach program that demonstrates the positive effects of collaboration between provincial cancer agencies and FNs. Access to screening is improved by bringing the service closer to home. Community ownership evolves through the collaborative process, which creates a culturally safe environment and decreases the fear and mistrust associated with cancer and the health care system, resulting in increased screening participation. Efforts to expand mobile outreach will ensure more equitable access to screening.

In Northwestern Ontario, the Breast Screening Mobile Program is maximizing effectiveness by promoting an integrated chronic disease approach. The major chronic diseases (cancer, heart disease, lung disease and Type 2 Diabetes) share common risk factors. Individuals at risk for one chronic disease are often at risk for other chronic diseases. FNs understand the connection, it is consistent with a FNs holistic view of health. Breast screening is well accepted in communities; therefore it makes sense to promote prevention and screening for all major chronic diseases at the same time.

An integrated chronic disease approach is also key to the second example of outreach. The HEY project is a Saskatchewan-Manitoba partnership that uses a train the trainer model to bring a FN specific chronic disease curriculum to communities. This project has the potential to address the current FN health human resource gap.

The third outreach example comes from rural Saskatchewan (File Hills Qu'Appelle Tribal Council). Access to cancer care is improved by the hiring of a nurse practitioner at the Tribal Council level that provides outreach to seven communities. Outreach consists of women's wellness including cancer screening. TCs across the country may view this as a viable option to improve screening for their communities.

Patient Navigation

Patient navigators (PN) touch the human side of cancer directly, reaching out to vulnerable patients and families to assist and advocate on their behalf in a complex and confusing health care system. Although few FN communities have access to PNs, the data reveals an awareness of the role and support for the integration of PNs. An Aboriginal Patient Navigator (APN) program in Hamilton Ontario was recognized as a best practice by Accreditation Canada in 2010. Aboriginal Patient Navigators need the support of all jurisdictions, since their work will cross jurisdictional boundaries as they help patients and their families.

Partnerships that work collaboratively across jurisdictions are key to improving cancer pathways for FNs. The report highlights promising / leading practices and models of care examples that promote e-technology, outreach, and aboriginal patient navigation and hold potential for adoption or adaptation regionally to improve access to cancer care and outcomes.

The issues surrounding the NIHB program and the lack of a formal palliative care program remain. Knowledge translation with Health Canada will inform the need for change.

RECOMMENDATIONS

Based on the work of this report four broad recommendations for consideration and action are presented:

1. Promote and support meaningful engagement of First Nations.
2. Enable partnerships to establish infrastructure that improves access to cancer care for First Nations.
3. Promote and support use of electronic technology that enhances cancer control for First Nations.
4. Support knowledge translation with Health Canada.

Our findings indicate that FN reserve communities are ready, willing, and able to undertake the collaborative work required to address and improve the cancer pathways. This is an environment ready for action.

By honouring the past with recognition and acknowledgement of the present we can work together to plan a tomorrow that will improve the cancer pathways of First Nations.

ACKNOWLEDGMENTS

We would like to acknowledge the participation of the over 200 people living and working in First Nation communities, who took the time to share their experience and wisdom to support the development of this report. All of these people have been touched by cancer in some way, and collectively we are working to make a positive difference in the cancer pathways of First Nations.

We also wish to acknowledge the partnership with CancerCare Manitoba (CCMB) and First Nation communities. The environmental scans used in this work are the result of collaborative efforts of all three parties.

This work led to the development of a unique data-sharing agreement between Alberta First Nations and Saint Elizabeth. We wish to acknowledge Alberta First Nations and the Alberta First Nations Information Governance Centre (AFNIGC) for their dedication to improving cancer outcomes and their willingness to establish a data-sharing agreement that can support future collaborative efforts.

Finally, a special thank you to Eleanor Carriere, a breast cancer survivor who asked to share her personal pathway, which reminds us all of the purpose of this report and the impact of its action.

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ABBREVIATIONS AND DEFINITIONS

Action Plan – The First Nations, Inuit and Métis Action Plan on Cancer Control
(Canadian Partnership Against Cancer)

ADI – Aboriginal Diabetes Initiative

AFN – Assembly of First Nations

AFNIGC – Alberta First Nations Information Governance Centre

AFNQL – Assembly of First Nations of Quebec and Labrador

AHAC – Aboriginal Health Access Centre

AMC – Assembly of Manitoba Chiefs

APN – Aboriginal Patient Navigator (Program at Juravinski Cancer Centre in
Hamilton, Ontario – recognized by Accreditation Canada as a best practice)

BCAFN – British Columbia Assembly of First Nations
CAPCA – Canadian Association of Provincial Cancer Agencies

cEMR – Community Electronic Medical Record

CBE – Clinical Breast Exam

CBHCP – Community-Based Health Care Provider

CCMB – CancerCare Manitoba

CCS – Canadian Cancer Society

CHC – Community Health Centre

CHN – Community Health Nurse

CHR – Community Health Representative

CHW – Community Health Worker

CLASP - Coalitions Linking Action & Science for Prevention

COPS – Community Oncology Programs

CYFN – Council of Yukon First Nations

FIT – Fecal Immunochemical Test

FN – First Nation (used as both noun and adjective)

FNHIB – First Nations and Inuit Health Branch (Health Canada)

FNIM – First Nations, Inuit and Métis

FNQLHSSC – First Nations of Quebec and Labrador Health and Social Services Commission

FOBT – Fecal Occult Blood Test

F/P/T – Federal/Provincial/Territorial

FSIN – Federation of Saskatchewan Indian Nations

HCA – Health Care Aide

HCC – Home and Community Care Program (Health Canada)

HCP – health care professional

HCW – health care worker

HPV – Human Papilloma Virus

INAC – Indian and Northern Affairs Canada

ITK - Inuit Tapiriit Kanatami

MKO - Manitoba Keewatinowi Okimakanak

Network - Aboriginal Communities and the Saskatchewan Cancer Agency Network

NIHB – Non-Insured Health Benefits Program

NITHA – Northern Intertribal Health Authority

NP – Nurse Practitioner

NS – Nursing Station

OCAP – The First Nations Principles of OCAP (Ownership, Control, Access and Possession)

PN – patient navigator/patient navigation

PSA Test – Prostate-Specific Antigen Test

PSW – Personal Support Worker

PTO – Provincial/Territorial Organization

RCC – Regional Cancer Centre (Hamilton)

RHA – Regional Health Authority

RN – Registered Nurse

SCA – Saskatchewan Cancer Agency

SCO – Southern Chiefs Organization

TC – Tribal Council

Definitions

‘Leading’ refers to models/practices/resources that have been shown to be at the forefront of change and that address important barriers or gaps. Evidence indicating leadership may include formal evaluation and peer-reviewed publication, however, a lack of formal evaluation will not exclude a practice from being considered as ‘leading’.

‘Culturally responsive’ is defined as: a holistic perspective on health, literacy and language, imagery, perspectives on medicine, psychosocial barriers of fear and beliefs about cancer. For the purposes of this work, this definition does not include traditional models of care, which allow for on-site healers and healing facilities (such as sweat lodges) within mainstream health centres, and the administration of traditional medicines as part of cancer treatment.

‘Model of care’ refers to the way health care services are organized and delivered. This is where the patient touches (and receives care by) the system.

“Practice” is the actual activity, or group of activities, that is employed to provide a program or service. The term can also be used to refer to the work of a group of practitioners, i.e. nursing practice.

‘Resources’ refers to information-based entities such as educational materials (printed, video, oral or web-based content), support networks (e.g., talking circles) or linkages to other organizations.

‘Rural’: a community with road access to medical services (primary care, diagnostic and treatment services) within 20-90 km.

‘Remote’: a community with road access to medical services (primary care, diagnostic and treatment services) greater than 90 km distance

‘Isolated’: a community without year-round road access. The community can be reached by scheduled or non-scheduled flights or winter roads and has telephone and/or radio services.

INTRODUCTION

Overview

The work included in this report was made possible by a contract awarded by the Partnership, through a request for proposal process. This project is one component of the Partnership's *First Nations, Inuit and Métis Action Plan on Cancer Control (Action Plan)*. The Saint Elizabeth First Nations, Inuit and Métis (FNIM) Program worked in partnership with FN communities across Canada to understand the gaps and barriers for FN community members (Status and Non-Status) in cancer control as well as to identify leading models of cancer care programs/services and culturally responsive resources.

The goal of the project was to build a comprehensive understanding of the reality of cancer care pathways for FN communities across Canada. The Northwest Territories and Nunavut Territory were not part of the scope of this work. As such, the report represents a strong initial understanding of the cancer care pathways for FNs but cannot be generalized to all of Canada.

Both secondary and primary data collection methodologies were employed. Secondary data collection and analysis included a comprehensive Canadian and international literature review (peer-reviewed and grey literature) and provincial environmental scans of FN communities in the context of geographical and jurisdictional influence, including provincial health systems and cancer care organizations. Primary data collection included two e-surveys, two provincial / territorial sharing sessions (Manitoba and Yukon), key informant interviews, and interviews to document gaps and barriers to care, promising and leading practices, and existing culturally appropriate resources originating from FN communities. Validation and knowledge exchange were built into the primary data collection process. The First Nations principles of OCAP were acknowledged and respected resulting in the meaningful engagement of FNs that was acknowledged by the national FNs advocacy group the Assembly of First Nations (AFN) and several provincial / territorial organizations (PTOs).

Triangulation and analysis of data reveal the complexities of cancer care for FN communities, identify the gaps and barriers to care, and help to shape recommendations for consideration.

Introduction

Background

The Canadian Partnership Against Cancer

The Partnership was established by the federal government to shape and oversee implementation of a national cancer control strategy that will significantly reduce the impact of the disease on all Canadians. The Partnership works with provincial/territorial governments, provincial cancer agencies and programs, federal agencies, patient groups, 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. Identifying promising and leading practices and being culturally responsive to the needs of First Nations, Inuit and Métis is an important priority within this work.

The Partnership recently facilitated the development of the *Action Plan*, in collaboration with First Nations, Inuit and Métis patients and organizations involved in cancer control and chronic disease prevention. Implementation of the *Action Plan* is now underway with the 2011/2012 focus being on gathering information (data and resource/program collation) to provide a knowledge development foundation that will enable longer-term collaborative work in the Partnership's second mandate, by addressing identified priorities and facilitating the adoption of promising and leading practices that are culturally responsive.

Work conducted by various jurisdictions across the country indicates that FNs residing in rural, remote, and isolated communities experience barriers to optimal cancer care because of challenges in accessing health services and discontinuity of care. Awareness of existing infrastructure and pathways of cancer care in rural, remote, and isolated First Nation communities is needed to understand the context for potential transformative system change (www.partnershipagainstcancer.ca).

Saint Elizabeth

For more than 11 years, Saint Elizabeth has been working in partnership with FNs to positively impact health care delivery at the local level. From action-based research to knowledge exchange and mobilization, the Saint Elizabeth FNIM Program is focused on enhancing and supporting the capacity of communities to understand and solve complex health care issues, improve access, and address barriers to care. Combining leading practices and innovative technologies with meaningful involvement of FN partners has been the foundation of their success to date.

Saint Elizabeth is committed to ensuring meaningful FN involvement, which includes incorporating various data collection methods (e-survey, in-person survey, phone interviews, key informant interviews, sharing sessions (focus group) participation), respecting the FNs principles of OCAP, integrating FN validation and knowledge exchange, and ensuring the final report is available to all FNs (<http://fnim.atyourside.ca/about-us>) to help create meaningful solutions.

Introduction

Contract Timeline

Secondary Data Collection

Literature Review (September 2011– January 2012)

Descriptive Context of Health Care Delivery (September 2011 – January 2012)

Primary Data Collection

E-survey (Health Care Providers): August 11, 2011 – December 14, 2011 (October 15, 2011 - January 31, 2012 for Alberta)

E-survey (Health Managers): Oct. 2011 – December 14, 2011 (October 15, 2011 - January 31, 2012 for Alberta)

Sharing Sessions (Focus Groups): Manitoba-September 7 & 8, 2011; Yukon Territory- October 27 & 28, 2011

Key Informant Interviews and Promising / Leading Practices and Models of Care Interviews: November 15- January 2012

Cancer Control Sector E-survey (Joint Saint Elizabeth and CancerCare Manitoba Initiative) and related Key Informant Interviews: June – November 2011

Validation of Draft Final Report: February 2012

Preliminary Report Knowledge Exchange Presentation: December 1 & 2, 2011

Final Report Submission: March 31, 2012

METHODOLOGY

Secondary Data Collection

Secondary data collection included a comprehensive Canadian and international literature review (peer-reviewed and grey literature) and provincial descriptions of FN communities in the context of geography, jurisdictional influence, health care services, leadership, and the organization of cancer control.

Literature Review

The purpose of the literature search and review was to identify current information from both peer-reviewed and grey literature regarding four areas of cancer care for FNs people living on reserve in rural, remote, and isolated areas in Canada, the United States, New Zealand, and Australia. These include: context of cancer care; cancer care pathways, including screening, diagnosis, treatment, survivorship, and palliative care as well as barriers / gaps in the cancer care pathway; promising and leading models of cancer care; and culturally responsive cancer resources and services.

A primary literature search was conducted using the Pub Med database and the key words: cancer, oncology, neoplasm, tumour, carcinoma, Aboriginal, Ojibway, Cree, Métis, First Nation, Inuit, and Native American. As well, citation snowballing was employed, and the University of Victoria library journal database from JSTOR, SAGE, EBSCO, and UpToDate was searched with the key terms: leading models, cancer care, First Nation, Métis, Aboriginal, and Indigenous. Literature was sorted based on English language, publishing date (must be less than 25 years old), and literature review relevance. Once references were obtained, all abstracts were read and categorized as: Canadian or international; prevention/ recruitment and screening/ diagnosis and treatment/survivorship/palliation; case reports/transformation; or epidemiological/ those unattainable.

The first literature search was conducted through PubMed:

- 856 results; almost entirely peer reviewed articles (Removed the 89 results that were more than 25 years old; could not obtain full text for 42 articles, and 550 did not directly address objective—these were not reviewed beyond the abstracts)

A second peer-reviewed article search was conducted for three years of literature from Scopus (professional journal literature):

- 78 articles (approximately half of these had already been found in the first literature pull)

Methodology

Search for grey literature on University of Manitoba library website with the key terms Aboriginal cancer and Aboriginal tobacco

- 119 articles
- 54 articles were obtained from team members working on environmental scans; roughly 30 of these were grey literature
- Additional white literature sources were gathered by bibliography mining/citation snowballing
- Additional grey literature was gathered by using Google, and Google Scholar to search for reports, articles, and organization websites

Descriptive Context of Health Care Delivery

In order to conduct a systematic environmental scan for each province and Yukon Territory, a template was created to provide consistent data collection on key areas such as geography (reserve location, road access, distance to local health and cancer care), demographics (on/off reserve population, health care access), and political (Tribal Council (TC) Affiliation and PTO affiliation) information. The descriptive context documents also include health-care related information such as FNs health care and provincial structure, and provincial regional cancer care. Context data was gathered through website searches using search engines such as Google and key First Nations, government and health-care related websites. In some instances direct contact was made with provincial/territorial contacts in order to validate demographic and health structure information gathered. Descriptive contexts documents are located in the Appendix (see Appendix A-1 – A-7).

Primary Data Collection

Primary data collection included six different collection methods.

- 1) E-survey for Health Care Providers (see Appendix B-1) –Opened August 11 2011-December 14, 2011 (October 15 2011 - January 31, 2012 for Alberta)
 - E-survey was available on a FluidSurvey site (FluidSurvey provides an analysis tool that allows data to be examined through established filters, such as rural, remote, isolated, and province-specific filters.) Links were accessed from the @YourSideColleague® website www.atyourside.ca.
 - Separate FluidSurvey access was established for Alberta FNs (see OCAP section).
 - Survey consisted of 19 questions related to: community information (non-identifiable), cancer care journey across the cancer care continuum, leading practices, culturally responsive resources, coordination gaps, and barriers to access.
 - Combination of closed- and open-ended questions (participants had the option of providing additional written information).
 - Participants had the option to identify themselves for further follow-up.
 - Participants had the option to identify others for further follow-up.

Methodology

- 2) E-survey for Health Managers (Tribal Council / Provincial Territorial Organizations) (see Appendix C)-Opened Oct. 2011 – Dec. 14, 2011 (Oct. 15 - Jan. 31, 2012 for AB)
 - E-survey was available on a FluidSurvey site. Links were available from the @YourSideColleague® website www.atyourside.ca.
 - Separate FluidSurvey access was established for Alberta FNs (see OCAP section).
 - Survey consisted of 19 questions (closed and open ended).
 - Followed the same format as the e-survey for HCPs.
 - Allowed differentiation between HCPs and health managers or responses representing TCs or PTOs.
- 3) Sharing Sessions (focus groups) Manitoba (MB) (September 2011) and Yukon Territory (October 2011) (see Appendix D-1 – D-2)
 - Sharing sessions brought together community HCPs from rural, remote, and isolated FN communities from MB and Yukon Territory.
 - Process maps of current cancer pathways were produced.
 - Challenges and opportunities in navigating the cancer pathways were discussed and recorded.
 - Changes required to support ideal cancer pathways were identified.
 - Promising and leading practices were identified and discussed.
 - Recommendations for consideration were developed.
- 4) Key Informant Interviews (see Appendix E) –Conducted November – January 2012
 - Key informants were identified from e-surveys, sharing sessions, promising and leading practices, and networks.
 - Informants provided verbal consent to participate; their identity and that of their community is assured.
 - Informants were interviewed over the phone using a questionnaire template of 19 open-ended questions. Questions were built on the trends that were becoming evident in the e-surveys and aimed to strengthen the data.
 - In addition to categories investigated in the e-surveys, key informants were asked to comment on:
 - the difference in cancer pathways for rural, remote, and isolated communities;
 - the presence of surveillance systems to identify and track clients with chronic disease;
 - availability of specific types of cancer care (screening, diagnosis, treatment) on and off reserve;
 - transportation coverage for travel related to screening;
 - wait times between suspicion and diagnosis;
 - wait times between diagnosis and treatment;
 - access to follow-up, survivorship, support programs, patient navigation, outreach, and palliative care; and

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- connection with provincial cancer agencies.
 - Informants were also asked to identify promising and leading models of cancer care or culturally responsive resources.
- 5) Promising / Leading Practices and Models of Cancer Care Interviews (see Appendix F-1 & F-2)- Conducted November – January 2012
- Informants for promising and leading practices were identified from e-surveys, sharing sessions, and key informant interviews.
 - Informants provided verbal consent to be interviewed and written consent to allow their contact information to be shared.
 - Informants were interviewed over the phone using a questionnaire template of 18 open-ended questions. Questions helped to identify key information regarding the promising or leading practices.
- 6) Cancer Control Sector, E-Survey and Selected Follow-up Interviews (see Appendix G-1 & G-2)- Conducted June – November 2011
- Cancer control sector data collection was conducted as a joint initiative between Saint Elizabeth (SE) and CancerCare Manitoba (CCMB).
 - List of potential recipients of the e-survey was developed to capture First Nation / Métis, provincial and national level organizations (see Appendix G-1).
 - E-survey was emailed to identified recipients (n=305), professionals working in various roles within the broad cancer control sector.
 - E-survey goal was to identify:
 - cancer care programs and services for First Nations and/or Métis populations living on- or off-reserve in rural, remote or isolated areas across Canada.
 - culturally responsive cancer control programs, services and resources for First Nations and Métis populations, especially those originating from First Nations reserves across Canada.
 - E-survey consisted of 14 questions, both closed and open-ended (participants had the option of providing additional written information).
 - Participants were asked to identify their organization and had the option of identifying themselves for further follow-up.
 - Participants had the option of identify others for further follow-up interviews.
 - Responses to the e-survey were reviewed to identify potential candidates for interview requests.

Cancer Control Sector

Saint Elizabeth and CancerCare Manitoba (CCMB) partnered to develop and distribute an e-survey focused on identifying cancer control programs, services and resources for First Nations on and off reserve and Métis. CCMB was contracted by the Partnership to conduct a similar environmental scan with a focus on First Nations (off reserve) and Métis in rural and remote communities. Saint Elizabeth and CCMB recognized that both projects would require information from the cancer control sector and determined that a joint e-survey would avoid duplicate contact of the same organizations and people within the sector. The e-survey was distributed to 305 individuals representing provincial and national organizations as depicted in Appendix G-1.

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Culturally Responsive Resources

Culturally responsive resources were identified through a mix of secondary and primary data collection methods (see Appendix H).

Defining Rural, Remote, and Isolated Communities

Historically, Health Canada has been responsible for providing health care services to FNs who live on reserve (Health Council of Canada, 2005). First Nation communities generally have either a community health centre (CHC), which provides community health programming to the community, or a nursing station (NS), which provides primary care services plus community health programming.

The definitions used by Health Canada to define rural, remote, and isolated FN communities have been adopted in this project. These definitions influence funding and services available within communities; however, political influences inside and outside of the FN communities often alter the services. For example, Health Canada does not generally fund NSs in rural communities, since they are close (less than 90 km) to acute care/medical services. If a rural hospital closes or downsizes, this can have a direct effect on a FN community that relied on its service. Therefore, it is not uncommon to see a rural FN community with a NS; this does not necessarily mean that Health Canada is funding the NS. It may indicate that the community or TC is supporting a nursing station related to an identified need.

Rural- a community with road access to medical services within 20-90 km

Remote- a community with road access to medical services greater than 90 km

Isolated- a community without year-round road access, it can be reached by scheduled or non-scheduled flights or winter roads and has telephone and /or radio services.

Target Population

The target population for the primary data collection was HCPs or Health Managers working in FN communities.

Recruitment strategies

The Saint Elizabeth FNIM Program provides an award winning, secure, web-based learning and knowledge-sharing program entitled @YourSideColleague® at no cost to health care providers working in FN communities across Canada (www.atyourside.ca). This program has developed networks into many FN communities, and these networks were invited to participate in the e-survey for HCPs. Other professionals from existing networks were also invited via email to participate in the survey. In October 2011, natural gatherings (meetings, conferences, etc.) were used to help increase survey participation and to identify key informants and leading or promising practices. Participants at these natural gatherings were given an invitational card as a reminder to participate in the surveys (see Appendix I).

Survey respondents had the option of identifying themselves as well as others they would recommend to be interviewed. Respondent information was considered and a list of potential key informants was developed. These informants were contacted by phone or email for interviews.

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Survey respondents, key informants, and network contacts helped to identify promising and leading practices and models of cancer care and culturally relevant resources (see Appendix F & H).

Confidentiality and Privacy

Participation in the e-surveys and/or key informant interviews was voluntary and anonymous. Consent was implied with the decision to participate. Participants were informed that “all survey responses will be confidential and individual responses will not be shared.” Final reports of the work will be available on Cancer View Canada’s website:

<http://www.cancerview.ca/>. Participants had the option to identify themselves at the end of the survey. Some of these individuals were later contacted for key informant interviews.

The privacy of individuals and their communities is assured.

The participants of the two sharing sessions (focus groups) are listed in the respective reports (see Appendix D-1 & D-2), with their awareness and permission. Reports reflect aggregate data and do not refer to individual comments or communities.

Key informants who agreed to share promising or leading models of cancer care information are aware that their identity will be shared for the purpose of highlighting their practice, which also includes identifying their province and their community or TC (written permission obtained) (see Appendix F).

First Nations Principles of Ownership, Control, Access, and Possession (OCAP)

First Nations have an inherent right to govern FN data, and in an attempt to assert and protect this right, the First Nations Principles of OCAP were formalized. The principles provide a frame of reference when dealing with the collection of any FN information or data. “Respecting cultural diversity across Canada, the First Nation community whose data or information is at stake decides what these principles really mean. Compliance with OCAP is determined by First Nations (Assembly of First Nations, 2007)”.

Saint Elizabeth recognizes and respects FNs’ right to govern FNs data. A validation and knowledge exchange process was built into the Pathways Project. The final report reflects aggregate data that has been validated by FNs in the provinces and Yukon Territory.

In addition, a unique arrangement for this project was undertaken in Alberta in accordance with the First Nations Principles of OCAP as determined by Alberta FNs. In January 2010, the Alberta Assembly of Treaty Chiefs passed a resolution for the establishment of an Alberta First Nations Information Governance Centre (AFNIGC). The AFNIGC has a direct mandate and accountability process as defined and structured in conjunction with the National First Nations Information Governance Centre. Saint Elizabeth approached the AFNIGC as part of the regional focused approach undertaken in this project and met with the AFNIGC Board of Directors to inform and seek approval for this particular project. Once approval was received, development of the data-sharing agreement between both parties began. A copy of the data-sharing agreement can be found in Appendix J (Note: An unsigned copy of the report has been provided, however, signatures were provided on behalf of both parties.)

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In order to maintain the principles of OCAP as defined by AFNIGC, the project did not have access to community-level data but rather to aggregate data provided by AFNIGC to Saint Elizabeth. In order to ensure AFNIGC possessed the community-level data, Saint Elizabeth purchased a separate license agreement for an online survey account to be held by the AFNIGC and created separate surveys for Alberta First Nation Tribal Councils or Provincial Territorial Organizations Health Managers/Coordinators and First Nation Community Health Care Providers, as well as a separate listing of on-line surveys on the SE FNIM announcement page. The Alberta First Nations Information Governance Centre then exported aggregate level data to Saint Elizabeth.

On behalf of our FNIM Program team, we would like to extend our sincere gratitude and appreciation to the Alberta First Nation Leadership, the AFNIGC Board of Directors and AFNIGC Interim Operations Manager Ms. Bonnie Healy, for ensuring this project was conducted in Alberta in a manner that respected and honoured Alberta-specific protocols and processes. Inquiries about the AFNIGC should be referred to the Interim Operation Manager Ms. Bonnie Healy at bhealy@afnigcab.ca.

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Secondary Data Collection

Literature Review Summary

Full literature review is located in Appendix J.

First Nation People Living On Reserve

According to the 2006 census, just under 1.2 million persons in Canada or almost four percent (4%) of the Canadian population report Indigenous identity. First Nations represent the largest of three constitutionally recognized Indigenous groups in Canada, which includes 615 Nations and 60 languages. Nearly one million or 62 per cent of First Nations people live in 633 communities in urban, rural, remote and isolated areas. Of this group, 60 per cent live in a remote community with less than 500 residents (CPAC, 2009), and 51 per cent are fluent in a First Nation language (Statistics Canada, 2008).

A long history has predicated today's situation for First Nation communities. The federal and provincial governments removed First Nations onto reserve, and in tandem ended fishing, hunting, trapping and gathering on First Nations traditional lands. Adding to this, First Nation children were removed to residential schools causing psychological trauma for survivors, and in turn, their children and generations afterward. In addition to the physical and sexual abuse that many children suffered at these schools, the complete absence of parental love and guidance caused suffering and an "inability to make choices" (Manitoba First Nations Patient Wait Time Guarantee, 2009; Loppie & Wein, 2009).

Today, all First Nation communities endure overcrowding and inadequate housing (Adelson, 2005), with many suffering a lack of clean, running water and nutritious food (Manitoba First Nations Patient Wait Time Guarantee, 2009). Rates of economic disadvantage and poverty among First Nations in North America, are considerably higher than the rest of the population (Denny, Holtzman, Goins, & Croft, 2005; Adelson, 2005) and in 2006 the average income for the Indigenous population was under \$19,000 per year (Statistics Canada, 2008). This is due to high rates of unemployment, scarce economic opportunities and low literacy and educational attainment (Task Force on Aboriginal Languages and Cultures, 2005). An estimated 50 per cent of First Nation youth will drop out, or be pushed out, of high schools. This results in approximately 50 percent of First Nations 15 years of age and over who do not have a high school education as compared to 30 per cent for other Canadians (Cardinal, 2004; Adelson, 2005). The impact of some of these social factors on health is reflected in the responses to a NAHO and the First Nation Regional Health survey. Respondents earning \$30,000 or more annually were more inclined to rate their perceived health status as excellent or very good (50 per cent), as compared to respondents who earned \$30,000 and less (35 per cent). Similarly, 50 per cent of respondents with a high school or higher education reported their perceived health status as being excellent or very good, while only 36 per cent of those with less than a high school education did the same (First Nation Regional Health Survey, 2007; NAHO, 2003).

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Cancer in First Nation Communities

As identified in the CPAC National Forum report (2009), cancer control is becoming a critical concern for First Nations, Inuit and Métis across Canada. Existing studies show that cancer incidence has risen dramatically in First Nation population over the past few decades (Marrett & Chaudry, 2003; Cancer Care Manitoba, 2008)). A few generations ago, cancer was relatively unknown, but now it is among the top three causes of death among First Nations, Inuit and Métis peoples (The First Nations Regional Longitudinal Health Survey 2002/03; Cancer Care Manitoba; Health Council of Canada, 2005).

Common cancers such as cervical, breast, prostate, lung and colorectal have increased remarkably over the last several decades in many First Nations Communities, but gathering information on current cancer statistics remains difficult. In 1997, First Nations women had six times the rate of cancer of the cervix in Canada compared to other women (Grunfeld, 1997), yet today, cervical cancer among First Nations women appears to be the only cancer that has declined (AFN, 2009). Conversely, although breast cancer rates for First Nation women remain lower than for the general population, the incidence is rising among Ontario and Saskatchewan First Nations women (AFN, 2009; U of Saskatchewan, 2000).

Similar patterns are seen with colorectal and prostate cancer. Recent research has linked smoking to the development of colorectal cancer (Botteri 2008) and it is well documented that smoking rates among Canada's First Nations are much higher compared to the general population (AFN, 2009). This may be contributing to the fact that the incidence of colorectal cancer is now as high among First Nations men as for non-First Nations. As well, there is a higher mortality rate for prostate cancer for First Nations men living on-reserve compared to men in the rest of Canada (Health Canada, 2001). In some provinces, this may be compounded because doctors are the gate-keeper to prostate and colorectal screening.

Fortunately cancer mortality rates in First Nations are generally lower than in the Canadian population largely because the incidence of cancer is lower. However, First Nations with cancer tend to die from their disease faster than non-First Nations. For example, Ontario First Nations appear to have a statistically significantly lower rate of survival than other Ontarians for most cancers (Marrett, 2003). This may be due to the stage of disease at diagnosis (Sheppard, 2010; Alvi, 1999 cited in AFN, 2009), poor access to health care; co-morbidities; genetics; and lifestyle including diet, lack of exercise and smoking (AFN, 2009).

Cancer Care Pathways

All provinces and territories now offer organized screening programs through their health care systems (Young, Kliewer, Blanchard, & Mayer, 2000). Where no organized program exists, ad hoc or opportunistic screening takes place in doctors' offices or in specialized clinics (such as Well Women's and Well Men's Clinics) (AFN, 2009). As a result of constant turnover of health care providers, most care in First Nation's communities is episodic in nature with very little attention to screening and participation in these programs remains low (AFN, 2009). For individuals whose test results show abnormalities, referrals are made through their health services provider to a specialist for further diagnostic tests. Primarily, diagnosis and treatment is done outside of First Nation communities and coordination and communications between patients, family doctors and specialists can be problematic. For those where treatment is unsuccessful, palliative care for First Nation people is noticeably absent (Manitoba Health, 1992; Canadian Palliative Care Association,

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1997). Consequently, First Nations people, especially those from remote communities, in later stages of terminal illness are commonly referred for treatment and long-term care in urban tertiary care hospitals. They often die in health care centers, isolated from their families and community, and traditional rituals, customs and practices (Kaufert & O'Neil, 1995). This is despite the demand for palliative services to accommodate death at home. This is hampered by a lack of professional development related to palliative care, funding for twenty-four hour care, palliative care facilities (Verde et al., 2010) and home care (Hotson, Macdonald & Martin, 2004). In addition, the work schedule (i.e. hours from 9am to 5pm) for most local health care providers is inadequate to facilitate palliative care, and as fewer people die at home, doctors, nurses and community healers may lose their expertise and confidence in providing end-of-life care (Hotson, Macdonald & Martin, 2004). Resources such as adequate equipment and supports for the client and family are also missing.

Gaps and Barriers to Cancer Care

In addition to the lack of basic resources within First Nation communities, there are a number of gaps and barriers impacting cancer care delivery. Some of the gaps have been previously identified and include a lack of health human resources, research and surveillance, cancer care guidelines and standards and written care plans (CPAC National Forum Report, 2009; Cancer Quality Council of Ontario, 2009). As well, there is poor communication between community and tertiary centres, inconsistent processes such as specialist referrals, jurisdictional issues such as the availability of health care programs on reserve, medical supplies and transportation, rural location and a lack of culturally appropriate resources.

Of utmost concern for First Nation communities is a chronic shortage of staff in local health care facilities, as few providers want to live and work in remote rural communities, especially in the north (Curran & Rourke, 2004). This is compounded by a work environment that is made difficult due to lack of time, resources and funding, heavy workloads, and inconsistent health care knowledge (Manitoba First Nations Patient Wait Time Guarantee, 2009). Gaps in communication also put First Nations people's health at risk. Currently health care systems are not well connected and there is a lack of two-way communication between care providers in primary (community) and tertiary (hospital) care systems and/or jurisdictions. For the most part, there is no case management or follow-up system between on- and off- reserve First Nation care systems or surveillance within the community. First Nations people often 'fall through the cracks' by arriving back in their home community without the required information for care (Manitoba First Nations Patient Wait Time Guarantee, 2009).

There also appear to be gaps in health care processes such as referral processes to health care specialists. For example, in the Manitoba First Nations Patient Wait Time Guarantee, project, referral policies and procedures varied among (Manitoba) First Nation communities. Some community providers were able to refer directly to specialists (primarily northern nursing stations), while others relied on family physicians for access to specialist care. Strong relationships and connections between community providers and specialists (when present) helped to ensure timely referrals (Manitoba First Nations Patient Wait Time Guarantee, 2009). Currently, policy requires a referral from a community physician and often people have to wait until their condition develops into a medical emergency in order to access care (Manitoba First Nations Patient Wait Time Guarantee, 2009; AFN, 2009).

There also appears to be a gap due to jurisdictional issues including lack of health care programs on reserve, medical supplies, and transportation. Under the First Nations and Inuit Health (FNIH) program policy, health providers working in First Nation communities have limited access to medications and care supplies (Minore et al., 2002; Manitoba First Nations Patient Wait Time Guarantee, 2009; Adams, Hardwick, Embree, Sinclair, Conn, & Bishop, 2009). For example, nurses are unable to access specialized dressing supplies

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without a prescription, thereby delaying wound healing. In some communities, health centres are allocated a smaller stock of medical supplies under the Blue Card system (i.e. FNIH approval system for restocking) than the northern First Nation nursing stations (Manitoba First Nations Patient Wait Time Guarantee, 2009). As well, FNIH funding levels for medical transportation have not kept up with the increasing demand for primary and tertiary care services outside communities. The increasing cost of fuel and the population growth have resulted in reductions in transportation services and therefore a delay in keeping medical appointments (Manitoba First Nations Patient Wait Time Guarantee, 2009).

A systematic review of 36 studies related to people indigenous to their country, also found rural location and isolation contributed toward disparities in health care (Bramley, Hebert, Jackson, Chassin, 2004; Newbold, 1998; Chan, Hart, & Goodman, 2006). Due to location, many communities have limited access to ambulatory, acute and specialized health care (Shah, Gunraj, & Hux, 2003). In general, First Nations people living in non-isolated and semi-isolated communities, and large- and medium-sized communities reported easier access to health-care professionals than those living in isolated/remote and small communities (First Nations Regional Health Survey, 2007; NAHO, 2003). Specifically, First Nations people living in small communities reported more difficulty in getting appointments with health care providers than their counterparts living in medium- or large-sized communities, particularly with respect to access to family doctors and specialists (First Nation Regional Health Survey, 2007; NAHO, 2003). Often in remote, rural areas, service is provided by a resident community health representative and a doctor who flies in on a semi-regular basis. As a result, not all services can be obtained in the community and further care may involve evacuation to southern centres (Elliott & Foster, 1995).

Barriers to seeking care also include cultural differences such as varied perceptions of health between provider and person, language barriers and the desire to use Traditional Medicine. These have resulted in prior bad experiences with the health system and have undoubtedly contributed to the commonly reported pattern of patients not seeking medical attention until they are very sick (Kaufert & O'Neil, 1995; AFN, 2009). As a result, in many communities, there is a general lack of awareness about cancer, causative factors (Minore et al., 2002) and available screening and treatment programs (O'Brien, Mill & Wilson, 2009; Cancer Care Ontario, 2002; Jago, C., & Burghardt, 2006). This is compounded by a lack of open discussion about the disease (Loppie & Wein, 2005; O'Brien et al., 2009), and culturally relevant educational materials (Loppie & Wein, 2005; Calam, Norgrove, Brown, & Wilson, 1999).

Language barriers also present a formidable obstacle to accessing adequate health care and have been shown to be a serious barrier (Anderson, Scrimshaw, Fullilove, Fielding, & Normand, 2003). This may be further complicated by the fact that in some communities, the use of Traditional Medicine is an important part of the culture. While each First Nations group may have their own Traditional Healing practices, the common understanding is that *health is a holistic state of walking in balance*, and therefore, *healing is holistic, encompassing all dimensions of life – spiritual, emotional, mental, as well as physical*. Traditional healing is a distinct way of healing and should be complementary to or collaborative with other ways of healing (Manitoba First Nations Patient Wait Time Guarantee, 2009).

Finally, the model of current care delivery is a barrier to effective care. Cancer is now recognized as a chronic disease as it shares common risk factors with the other major chronic diseases such as heart disease, stroke, lung disease and diabetes. As such, an integrated chronic care approach is now suggested as a more holistic way of managing care across the continuum. All provinces have been moving toward a chronic disease model of care, and although the approach in each province may be somewhat different, case management is an integral feature. Currently, an Enhanced Chronic Disease Model is being suggested for First Nation communities. The key difference is the development of productive partnerships between health care providers, clients and their families and community partners. The model requires efforts to help clients manage their health, create a care team,

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base care on the best evidence and have the right data to manage client populations (First Nation and Inuit Health, Home and Community Care, 2011). As part of a change in care delivery system, some programs such as the Integrated Diabetes Health Care Service Program in Manitoba, have demonstrated good results, while increasing capacity for local providers and delivering care closer to home (Diabetes Integration Project, 2010).

Culturally Appropriate Resources

The review of the literature did not identify any new culturally appropriate resources.

Promising and Leading Practices and Models of Care

A number of promising and leading practices were identified in the literature review including:

- 1) Cape Breton Home Care Discharge Planning Program, a program designed to provide a home care discharge plan to First Nations clients who need one when they leave hospital and return to their reserve.
- 2) Feasibility of self-sampling and human papillomavirus testing for cervical cancer screening in First Nation women from Northwest Ontario, Canada; a pilot study designed to test the use self-sampling HPV tests to raise screening rates among Native American women.
- 3) Aboriginal Women's Cancer Care Project (AWCCP): an example of the Participatory Research Model in action; AWCCP was designed to increase understanding of the intersection of culture, identity, and health systems in Aboriginal and Native American women's experience of and access to cancer care by investigating health and cancer beliefs, decisions, and health care experiences of Canadian Aboriginal and Native American women with breast and gynecological cancer.
- 4) Indigenous Health Knowledge Transfer/ Translation Network (IHRKTN); The IHRDP aims to develop a cadre of researchers interested in Indigenous health in Ontario and attempts to recognize the diversity of Indigenous cultures and peoples in Ontario, both on and off reserve to a) improve the two-way flow of relevant and respectful information between Aboriginal health organizations and researchers, b) to evaluate best practices over time.
- 5) Cancer Care 101; Cancer education resource developed in collaboration with American Indian/Alaska Natives/Alaska Natives to improve cancer knowledge, action regarding cancer control in tribal settings, and survival rates for members of their communities.

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- 6) American Indian/Alaska Native/Alaska Native Cancer Information Resource Center and Learning Exchange; resource center providing cancer-related materials to health care and service providers involved in education, care and treatment of American Indian/Alaska Natives and Alaska Natives through the educational arm of the Spirit of Eagles.

See Appendix K for a full list of Promising and Leading Practices documented in the literature and through interviews.

Descriptive Context of Health Care Delivery

Documents describing the descriptive context of health care delivery (including geographic, demographic, political and health system dimensions) have been created for all provinces in Canada and Yukon Territory (see Appendix A-1 – A-7). Challenges were encountered compiling this information with regard to definitions for community categorization and the need to search multiple sources to create a single community profile. Information for the scans was obtained through public websites such as Indian and Northern Affairs Canada (INAC), Government of Canada, as well as provincial and FN organizations. In addition, direct contact was made when necessary to gather information not readily available through public websites. Information was found and compiled on the context of health care delivery, including rural, remote, or isolated geography, demographic and political context (including provincial /territorial and FN jurisdictions) and health system dimensions.

The Aboriginal population in Canada now exceeds 1 million, which represents 4% of the Canadian population. The term ‘Aboriginal’ includes individuals that are of First Nations, Métis, or Inuit descent. According to Statistics Canada (2006) (www.statscan.gc.ca) there are approximately 700,000 FNs; 400,000 Métis; and 50,000 Inuit (see Chart #i: Provincial Comparison-Descriptive Context of Health Care Delivery Summary). This Cancer Pathways Project focuses on FN people living on reserve land, who represent approximately 50% of all FNs people in Canada.

The descriptive context documents reveal the differences within and between FN communities. Of the 700,000 FNs, 53% identify themselves as being Status First Nations. Of those, 40% live on reserve, with the highest on-versus-off reserve population ratios found in Manitoba, New Brunswick, Saskatchewan, and Nova Scotia. The average age of the on-reserve population is young at 27 years of age (versus the average age of Canadians, which is 40). There are 50 FN languages, with various dialects spoken. Although Statistics Canada reports a decrease in the number of “Aboriginal people who identify a Mother Tongue language” there is evidence of Aboriginal languages increasing as a second language (www.statscan.gc.ca).

Each province presents a different picture in terms of the relationship between FN communities and the Federal/Provincial/Territorial (F/P/T) relationships. First Nation communities are primarily located in rural, remote, and isolated areas of Canada, and the collective (combined) data represents all three of these community locations. The population of FN communities has wide variation (less than 500; 500-1000; 1000-5000; more than 5000) and the data reflects each population category. Provinces/territories vary in their geographical distribution and size of FN communities, which has a direct influence on the health care delivery systems that have developed in each province.

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First Nations are moving toward a goal of implementing FN governments, as individual communities and as a collective national entity (www.afn.ca). First Nation political leadership organization varies from province to province. The AFN is the national advocacy group for the 630 FN communities (www.afn.ca). Some provinces have one or more provincial advocacy/political groups that represent the voice of FNs for the province, for example, Ontario has the Chiefs of Ontario organization, Manitoba has three provincial FN political groups, and Saskatchewan has the Federation of Saskatchewan Indian Nations (FSIN). Individual communities recognize elected chiefs, and the communities can decide to be represented by the provincial political organization or can choose to be independent. For example, in the Yukon, there is a FNs territorial organization called the Council of Yukon First Nations (CYFN), however only 11 of the 14 YT settlements are represented by this ‘territorial’ organization. A similar pattern is seen in TCs. A TC is formed when a group of FN communities work together and share resources, however, membership is not absolute; communities can opt to work independently or they can join another TC.

The national body for provincial cancer agencies is known as the Canadian Association of Provincial Cancer Agencies (CAPCA). Cancer Agencies are organized provincially, and some provincial cancer agencies are responsible for service provision (for example SK) while others manage provincial cancer services but are not direct service providers (for example ON). Not all provinces have a provincial cancer agency (for example AB). The BC Cancer Agency provides service to the province of BC and YT.

A summary of the descriptive contexts is presented in the chart below (Chart # i). For more details please refer to Appendix A1-A7.

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Chart # i: Provincial Comparison-Descriptive Context Summary (Key: Ab=Aboriginal; Comm=communities; FN=First Nation; On Res=On Reserve; Off Res=Off Reserve; Lang=language; Res=reserve; RHA=Regional Health Authority; Pop=Population,; tx=treatment)

| | National | YT | BC | AB | SK | MB | ON | QC | Atlantic Provinces |
|--|--|---|--|---|--|---|--|--|---|
| Population (2006) Ab=Aboriginal: (Ab=FN+Métis +Inuit) www.statcan.gc.ca FN includes: Status & Non-Status Ab pop is younger, median age 27 vs. 40 | CAN-34 M Ab-1.1 M (4%) On Res- 40% Off Res- 60% FN- 698,025 -Status (53%) -Non-Status (11%) Métis-389,780 (30%) Inuit- 50,480 (4%) | YT-34,984 Ab-7,580 (25%) FN- 6,280 Métis- 800 Inuit- 255 | BC-4.5 M Ab-196,075 (4.8%) On Res-38% Off Res-62% FN- 129,580 Métis- 59,445 Inuit- 795 | AB-3.8 M Ab-188,365 (5.6%) On Res-41% Off Res-59% FN- 97,275 Métis-85,495 Inuit- 1,610 | SK-1 M Ab-141,890 (15%) On Res-52% Off Res-48% FN- 91,400 Métis-48,120 Inuit- 215 | MB- 1.2 M Ab-175,395 (15%) On Res-62% Off Res-38% FN- 100,640 Métis- 71,805 Inuit- 565 | ON-13.3 M Ab-242,,495 (2%) On Res-30% Off Res-70% FN- 158,395 Métis- 73,605 Inuit- 2,035 | QC- 7.9 M Ab-108,425 (1%) On Res-51% Off Res-49% FN- 65,085 Métis-27,985 Inuit- 10,950 | NS PE NB NL- 2.3 M Ab-67,010 (3%) NS On Res-52% PE On Res-32% NB On Res-56% NL On Res-18% FN- 36,615 Métis-18,805 Inuit- 5255 |
| Communities Languages=Lang=L | 616 Ab Comm Rural- 306 (50%) Remote- 189 (30%) Isolated- 117 (19%) Undetermined- 4 (1%) | 14 Comm; Lang-8 Rural-4 (28%) Remote-9 (64%) Isolated-1 (7%) | 200 Comm; Lang-12 Rural-81 (41%) Remote-88 (44%) Isolated-27 (13%) Undetermined- 4 (2%) | 46 Comm; Lang-6 Rural-39 (85%) Remote-5 (11%) Isolated-2 (4%) | 68 Comm; Lang-5 Rural-50 (74%) Remote-18 (26%) Isolated-0 | 63 Comm; Lang-5 Rural- 25 (40%) Remote-15 (23%) Isolated-23 (35%) | 133 Comm; Lang-13 Rural- 66 (50%) Remote-31 (23%) Isolated-35 (26%) | 40 FN +14 Inuit; Lang-12 Rural- 18 (33%) Remote- 14 (27%) Isolated- 22 (40%) | 33 FN +5 Inuit; Lang-4 Rural- 23 (60%) Remote- 9 (22%) Isolated- 7 (18%) |
| Aboriginal Leadership Movement toward Self-Determination & FN governance. | National Advocacy Groups: AFN- 630 FN comm www.afn.ca Inuit Tapiriit Kanatami (ITK)- 55,000 Inuit. www.itk.ca | Each settlement has elected leadership. 11 of the 14 settlements have reached land claims & self-government agreements. CYFN: 10 of 14 belong. | BC Assembly of FN (BCAFN) is regional arm of AFN -Tripartite Agreement Oct. 2011 (1 st in Canada) -Most BC FNs did not sign treaties in past. Today, ~70% are negotiating treaties with Fed. Gov't. | 45 FNs in 3 Treaty Areas (Treaty 6,7,8) -Various Tribal Council / Organizational groupings. - AFNIGC | FSIN- political organization Northern Intertribal Health Authority (NITHA) (4 TCs) TCs-8 Independent Comm- 8 | 3 political org.: Assembly of MB Chiefs (AMC) represents 64 communities Manitoba Keewatinowi Okimakanak (MKO)- 27 northern FNs Southern Chiefs Organization (SCO)- 36 southern FNs) Regional Health Authorities-11 TCs-7 | Chiefs of ON 133 Chiefs of ON Federal & Provincial governments fund FN programs on & off reserve. TCs-16 | Assembly of FN of QC and Labrador (AFNQL)- mandated to represent Aboriginal interests at P/F level. Most FNs under Fed jurisdiction. Inuit are under the jurisdiction of QC institutions, not the Fed. Gov't. No treaties in QC. 61% of comm. have less than 500 people | Each province has an Aboriginal advocacy organization. FNIH provides funding to 33 FN comm. & to Inuit gov't in Labrador (Nunatsiavut). Tribal Councils: Numerous TCs in each province. |

Results

| | National | YT | BC | AB | SK | MB | ON | QC | Atlantic Provinces |
|-------------|---|---|--|--|--|--|---|---|--|
| Cancer Care | <p>Canadian Association of Provincial Cancer Agencies (CAPCA)</p> <p>Canadian Partnership Against Cancer (CPAC)</p> <p>Canadian Cancer Society (CCS)</p> | <p>CAN Strategy for Cancer Control BC Yukon Council</p> <p>Service delivered & funded by F/T/FN. No programs targeted for FNs.</p> | <p>BC Cancer Agency</p> <p>-Centralized cancer service through 4 regional centres, communication managed via website www.bccancer.bc.ca</p> <p>-Has northern strategy & Ab strategy</p> | <p>No Provincial Cancer Agency in AB</p> <p>-AB Health Services offers cancer programs & services. 2 Cancer Centres (Edmonton & Calgary) linked to 16 community sites offering cancer care.</p> | <p>SK Cancer Agency-</p> <p>2 Cancer Centres, (Regina & Saskatoon) link to 16 Comm Oncology Programs (COPS) to provide care & tx near home comm..</p> <p>-Ab comm. & SK Cancer Agency Network</p> | <p>CancerCare MB</p> <p>works with local Regional Health Authorities (RHAs), Comm Cancer Programs Network (multi-disciplinary teams use teleoncology for education, televisitation, consultations, www.cancercare.mb.ca</p> | <p>CCO, not responsible for service provision; manages all cancer services, through integrated cancer programs across the province</p> <p>-Ab Cancer Control Strategy, develops culturally appropriate materials</p> | <p>QC Cancer Care Organization</p> <p>Province organized into central, regional, & local levels.</p> | <p>Provincial Cancer Agencies</p> <p>NS-Cancer Care NS</p> <p>PE-PEI Cancer Tx Centre</p> <p>NB-NB Cancer Network</p> <p>NL-2010- Cancer control strategy</p> |

Results

Primary Data Collection

The majority of the primary data collected for this project comes from three provinces: BC, MB, and ON; however, these three provinces have the greatest percentages of FN people. It is important to keep in mind that some regions (Atlantic) are underrepresented in the current data and that the NWT and NU were not within the scope of this project³, therefore this report builds a strong initial understanding but should not be generalized to all of Canada.

Target Population

Although the e-survey (HCPs) did not identify the role of the HCP respondents, a review of the respondents that identified themselves revealed that a broad range of health care roles was represented. Identified respondent roles included but were not limited to: health care aides, mental health workers, home care nurses, home care coordinators, community health nurses, health directors, health managers, and a FN Chief. Based on written comments it was clear that some of these early respondents were providing information from a TC perspective, which is important since it strengthens the data by representing more FN communities.

Recognizing that the data from TCs, health managers, coordinators or higher level management positions offered a different level of information, a second survey (based on the initial survey) was developed to target ‘Health Managers / Coordinators of First Nation Tribal Councils and On-Reserve Provincial / Territorial Organizations’. However, this second survey had limited participation (BC-1; AB-10; ON-1).

The target population for the two sharing sessions (focus groups) was the same as the target population for the e-survey; however, the sharing sessions included community members outside of the health care realm. For example, a few individuals representing the political side of the communities were involved (band counselors, TC employees), and in addition Elders from the province/territory were involved at each sharing session. In both sharing sessions there were participants present who were cancer survivors and spoke of their personal journeys with the cancer care system. As a result the data was enriched with the reality of cancer survivors living in FN communities.

An additional cancer survivor from Manitoba, Eleanor Carriere, asked to share her cancer story to inform the data. An in-person interview was arranged with a Saint Elizabeth staff member. Eleanor’s story was recorded and transcribed and is highlighted in the discussion section of this report.

³ This information will be gathered from these two territories in 2012/2013.

Results

Primary data collection included six different collection methods:

- 1) E-survey for Health Care Providers (see Appendix B-1)
- 2) E-survey for Health Managers (Tribal Council / Provincial Territorial Organizations) (see Appendix C)
- 3) Sharing Sessions (focus groups) in Manitoba and Yukon Territory (see Appendix D-1 & D-2)
- 4) Key Informant Interviews (see Appendix E) and Eleanor Carriere Interview (see Discussion section)
- 5) Leading Models of Cancer Care Interviews (see Appendix F-1 & F-2)
- 6) Cancer Control Sector, E-Survey and Selected Follow-up Interviews (see Appendix G-1 & G-2)

E-Survey for Health Care Providers

The e-survey for HCPs reached the largest number of people, in terms of data collection, as a total of 179 responses were received. Below is a summary and analysis of the e-survey that follows the format of the questions of the survey, which can be viewed in Appendix B-1.

The e-survey for HCPs results are presented three ways:

1. Aggregate results question-by-question review (Summary and Analysis);
2. Provincial Comparison Chart #12 see Appendix B-3.
3. Rural, Remote, and Isolated Community Comparison Chart #13 see Appendix B-4.

E-Survey for Health Care Providers: Aggregate results question by question review (Summary and Analysis)

There were 179 responses to the e-survey and 50% of respondents (n=90) provided written responses. Note that not all respondents answered every question, which explains the discrepancy in some questions regarding the total response numbers.





Results

Q#1. What is the population of your First Nation Community? (169 Responses)

Each FN population category is represented.

Eight provinces/territories participated in the e-survey for HCPs. All population categories are represented in the survey results, other than YT, which only had one e-survey response. However, a sharing session was conducted in the Yukon, which brought together strong representation from the FN settlements of the YT (see Appendix D-2 for summary of YT sharing session).

Chart #1: What is the population of your First Nation community?

| Response | Chart | Percentage | Count |
|-----------------|--|------------|-------|
| less than 500 |  | 21% | 36 |
| 500 - 1000 |  | 24% | 41 |
| 1000-5000 |  | 30% | 51 |
| more than 5000 |  | 24% | 41 |
| Total Responses | | | 169 |

Discussion

Canadian FN communities are diverse in terms of population and vary from small communities of less than 500 people to large communities with populations that exceed 5000. Survey respondents represent each population category, which provides balanced information gathering. The survey is not able to determine if communities are independent communities (non-aligned) or part of a larger TC or FN health authority, however, written responses indicate that all categories are represented.

Results

Q#2. In what province / territory is your community located? (173 Responses)

Provinces and territories are not equally represented in survey responses.

Although survey responses represent eight provinces /territories, Atlantic Canada is under-represented. The majority (73%) of the responses come from three provinces (BC, MB, and ON). Although there is only one response from YT, a focus group was held in the Yukon that brought together strong representation from the settlements of the YT (see Appendix D-2 for summary of YT sharing session)

Chart #2: In What province / territory is your community located?

| BC | AB | SK | MB | ON | QC | NB | NS | PE | NL | YT |
|----|----|----|----|----|----|----|----|----|----|----|
| 44 | 22 | 10 | 40 | 42 | 9 | 0 | 5 | 0 | 0 | 1 |

Discussion

The AFNIGC worked with Saint Elizabeth to participate in the survey, and separate access to the e-survey was established (refer to OCAP section). Alberta FNs coordinated sharing of AB data with Saint Elizabeth, and AB data was combined with data from other regions for analysis.

Limitation

As stated previously, the NWT and NU were not included in the scope of this work and the Atlantic provinces are under-represented, placing a limitation on the degree to which results may be generalized.

Q#3. Using the definitions provided, is your community considered rural, remote, or isolated? (179 Responses)

Rural, remote, and isolated First Nation communities are represented in the survey.

Respondents represent rural (66%), remote (21%), and isolated (13%) FN communities. The percentages are reflective of the geographic locations of FN communities in Canada.

A survey filter was used to determine the occurrence of Community Health Centres (CHCs) and Nursing Stations (NSs) within the rural, remote, and isolated communities.




Results

Rural: 93% CHC; 22%NS. **Remote:** 73% CHC; 46% NS. **Isolated:** 52% CHC; 74% NS

Provincial Comparison

The provincial comparison reveals that BC, AB and SK responses do not include any isolated communities, although there are isolated communities in all three provinces. All five responses from Nova Scotia represent rural communities, however, this is consistent with the geography of the province (see also Provincial Comparison Chart #12 in Appendix B-3).

Chart #3: Using the definitions provided, is your First Nation community considered?

| Response | Chart | Percentage | Count |
|-----------------|---|------------|-------|
| Rural |  | 66% | 119 |
| Remote |  | 21% | 37 |
| Isolated |  | 13% | 23 |
| Total Responses | | | 179 |

Rural: a community with road access to medical service within 20-90 km

Remote: a community with road access to medical services greater than 90 km

Isolated: a community without year-round road access. The community can be reached by scheduled or non-scheduled flights or winter roads and has telephone and/or radio services.

Discussion

First Nation communities are located in rural, remote, and isolated areas of Canada. FN communities generally have either a CHC, which provides community health programming to the community or a NS, which provides primary care services plus community health programming. Location has a direct effect on access to medical services. When medical services are not available within the community, community members must travel to the service site. Travel for medical purpose (eg. to attend a doctor’s appointment) is covered under the NIHB program, coordinated through First Nations and Inuit Health Branch of Health Canada, for Status FN individuals. Health Canada carries the responsibility to ensure access to health care to Status First Nation individuals.

There is a unique mixture of CHCs and NSs that have developed in FN communities in response to geography, distance to major health centres, political influences, and jurisdictional issues. Assumptions regarding the presence or absence of CHCs or NSs cannot be made based on whether a community is classified as rural, remote or isolated.

Results

Q#3b. Do you provide health care services to more than one First Nation community? Yes / No

Limitation: Since the survey was targeted to HCPs the question can be interpreted in two ways: as a HCP do you personally provide health care services to more than one FN community, or does your FN community provide health care services to more than one FN community. Both possibilities exist and the survey is unable to determine how the question was interpreted. Therefore, the results were not included in the analysis.

Q#4. What types of health services are available in your First Nation community? (check all that apply) (178 Responses)

Community Health and Home Care are the most common health care services available in First Nation communities.








The majority (>80%) of FN communities have community health and home care services available in the community.

Provincial Comparison

Provincial comparison reveals that communities represented by Nova Scotia respondents (n=5), do not have any long term care facilities or hospitals. The YT focus group data only referred to long term care facilities and hospitals located outside of settlement land.

Results

Chart #4: What type of health care services are available in your First Nation community?

| Response | Chart | Percentage | Count |
|--|---|------------|-------|
| Community Health Centre/Office |  | 84% | 149 |
| Long Term Care Facility / Nursing Home |  | 26% | 47 |
| Hospital |  | 17% | 31 |
| Nursing Station |  | 34% | 60 |
| Home and Community Care Program |  | 88% | 157 |
| Health Promotion and Prevention |  | 72% | 129 |
| Other |  | 22% | 40 |
| Total Responses | | | 178 |

Other Responses (36):
Assisted Living complex /
program-3;
Diabetes programming-6;
Other-(mental health, maternal
health, doctors, visiting doctors,
adult day program, dental.

Discussion

Despite the fact that >80% of FN communities have home care services, only 72% indicate they have health promotion /prevention services. Respondents may define health promotion/prevention differently, which can account for the discrepancy, since traditionally both community health and home care provide promotion/prevention programming. 34% of the respondents indicate that their community has a nursing station, which generally provides primary care services. Less than 30% of communities have either a hospital or long term care facility, which impacts the community’s ability to care for individuals dealing with cancer.

Results

Q#5. What types of health care workers provide cancer care in your First Nation community? (check all that apply) (177 Responses)

Chart #5: What types of HCWs provide cancer care in your FN community?

Nurses are the most common type of HCW providing cancer care in FN communities.

| Response | Chart | Percentage | Count |
|---|-------|------------|-------|
| Community Health Nurses | | 77% | 137 |
| Home Care Nurses | | 76% | 134 |
| Nurse Practitioners | | 33% | 58 |
| Community Health Representatives/Community Health Workers | | 58% | 103 |
| Health Care Aides/Personal Support Workers/home support | | 63% | 112 |
| Physicians | | 50% | 88 |
| Traditional Healers | | 42% | 75 |
| Home and Community Care Coordinators | | 49% | 86 |
| Wellness Workers | | 27% | 47 |
| Health Directors | | 39% | 69 |
| None | | 3% | 6 |
| Other | | 3% | 6 |
| Total Responses | | | 177 |

Data reveals that all regions that participated in the survey have representation of the health care workers listed working in their communities.

Nurses (CHNs, HCNs, and NPs) work with community based health care providers (CHRs, CHWs, HCAs, PSWs) to provide cancer care.

Physicians (50%); Traditional Healers (42%); and Wellness Workers (27%) are less likely to provide cancer care.

Results

Q#6. Please indicate if these cancer care programs and services are available in your community. (127 Responses)

Respondents were asked to follow a drop-down menu to provide details. If the program or service was not available or they were not aware they were directed to the next question asking them to indicate the estimated distance the community member must travel to receive the program or services. (Loops 1-9)

Less than 50% of FN Communities have any cancer programs or services available.

Chart #6: What types of cancer programs and services are available in your First Nation community?

| | Yes | No | Not Aware | Total |
|---|----------|----------|-----------|-------|
| 1. Prevention | 60 (48%) | 42 (33%) | 24 (19%) | 126 |
| 2. Screening and Early Detection | 60 (47%) | 50 (39%) | 17 (13%) | 127 |
| 3. Treatment | 22 (17%) | 94 (75%) | 10 (8%) | 126 |
| 4. Survivorship (health and life of a cancer survivor) | 18 (14%) | 67 (53%) | 41 (33%) | 126 |
| 5. Support Programs or Sharing Circles | 15 (12%) | 75 (60%) | 36 (29%) | 126 |
| 6. Care Giver Support | 44 (35%) | 52 (41%) | 30 (24%) | 126 |
| 7. Palliative Care | 59 (47%) | 49 (39%) | 18 (14%) | 126 |
| 8. Outreach (example: services coming into the community) | 49 (39%) | 52 (41%) | 25 (20%) | 126 |
| 9. Patient Navigator | 21 (17%) | 70 (56%) | 35 (28%) | 126 |
| 10. Pharmacy Services | 57 (45%) | 54 (43%) | 15 (12%) | 126 |

Provincial Comparison

Provincial comparison reveals that the following services are not available on reserve:

Treatment not available in NS (n=5)

Survivorship not available in SK

Support program not available in SK, QC

Patient Navigation not available in-SK, MB, NS

(see Provincial Comparison Chart, Appendix B-3)

If the listed programs and services are not available in the community, what is the average distance travelled to access the service? The majority of FNs travel more than 90 km or via plane to access cancer care programs and services. The only exception is pharmacy service travel, which is closer.

Discussion Despite the closer proximity of pharmacies, written responses reveal that there are gaps regarding consistent access to pain medications and guidelines for palliative care clients.

Results

Q#6. Please indicate if these cancer care programs and services are available in your community. (cont'd)

Discussion

Terminology around prevention, screening and early detection, and treatment of cancer is confusing and inconsistent, which may have influenced the results. Only 48% of respondents indicate that there are programs or services focused on prevention. It is likely that this low percentage is related to the use of the term 'cancer' in the prevention realm. The concept of cancer as a chronic disease is new, and as such most communities do not link general prevention programs (diabetes prevention including ADI [Aboriginal Diabetes Initiative], early childhood development, school nutrition programs, food security programs, or exercise programs) to cancer prevention. Chronic diseases, including cancer, have common risk factors, therefore any programming that addresses these risk factors is also helping to prevent cancer.

As expected, cancer prevention and screening programs are more likely to be available than treatment in FN communities. A review of the written responses reveals that breast cancer and cervical cancer programming are the most well established programs in FN communities. There is indication of some mobile screening for both breast and cervical cancer, which is evidence of links to provincial cancer agencies. In communities where screening is not available a *"huge gap"* is evident. There is inconsistent coverage of travel from the NIHB program. Non-Insured Health Benefits is a Federal (Health Canada) program that is defined regionally (provincially); therefore some provinces provide coverage for women to attend screening and others do not cover costs (Health Canada, 2011a). Colorectal cancer screening is the newest organized screening program in Canada. (There are three organized cancer screening programs: Breast, Cervical, and Colorectal). There is strong awareness of the colorectal cancer screening program in the written responses, although some problems with *"missing the FN communities in the mail out"* were revealed in MB responses.

The majority of FN communities have no in-community cancer survivorship or support programs available. Less than 40% have caregiver support programs available. Palliative care, when mentioned, is linked to the HCC program, home care nurses, and PSWs (or HCAs). It is a clear struggle to manage the needs of a patient dying of cancer within the community. According to one respondent, *"Palliative care is particularly difficult to provide when all the home care nurse can provide is support for the care given by family members. A client with a desire to remain in his home community must have family committed and unafraid of providing 24-hour care to a loved one."* *"Respite care is desperately needed and not adequately funded."*

Although 39% of respondents indicate their community receives outreach programming, the written responses reveal that much of the outreach is one-time offerings from organizations that come out to the community: *"The regional palliative care nurse came to our community once in 2010, it was more of a learning experience for the nurse than support for the family. The nurse was just as uneducated to First Nations as the First Nations are uneducated to cancer."*

In the written responses, over 35 respondents mention Patient Navigation specifically as a gap or as a potential solution. The concept of PN is always referred to positively. There is little evidence of PN services reaching FN communities. It is considered by many respondents to be a promising practice that holds potential to address some of the major issues revealed in the survey results. Although 45% of respondents indicate that the community they work in has pharmacy service available, it is unclear the role this service has with cancer care.

Results

Q#6. What types of cancer care programs and services are available in your community? (Combined written responses)

Chart #7: Cancer Programs/Services

(Key: R=responses; Educ=workshops, pamphlets, posters, awareness campaigns, health fairs; Well= Well ♂♀ Clinics; Mamm=mammography; Supp=support)

| | Breast | Colorectal | Prostate | Lung | Cervical | Other | All |
|--|---|---|--|--|--|---|--|
| Prevention | R=36 Educ-8 Mamm-22 Mamm mobile-14 Mamm travel-11 | R=26 Educ-12 Stool testing-8 | R=23 Educ-4 Prostate-Specific Antigen (PSA) test/Digital exam-7 Well ♂-5 | R=22 Educ-14 Assessment off reserve -5 | R=29 Educ-10 Pap tests-15 locally HPV vaccine-5 Well ♀-10 | R=9 Sun safety-2 Brain tumor-1 Cancer clinic-1 Wellness- 2 | R=12 Educ.-5 Work with RHA or cancer agency-3 |
| Screening & Early Detection | R=36 Educ-3 Mamm-30 Well ♀-7 | R=21 Stool test-9 Screening clinic-5 Specialist visit-3 | R=19 Educ-1 PSA/Dig-11 Blood Work-1 | R=14 No screen avail-7 x-rays / CT scans-6 | R=27 Educ-4 Pap test-17 (mobile) BC Cancer Agency-TT-1 | R=10 Large centers-3 Lab on site-1 | R=11 |
| Treatment | R=6 PN-1; Supp. group-2 Mamm-3 Local doctors.- 1 | R=4 PN-1; Supp group-1 Colonoscopy-1 Chemotherapy-1 | R=5 PN-1; Supp group-1 Blood work-2 Chemotherapy-1 | R=4 PN-1; Support group-1 Physical-2 Xray/CT-2 | R=4 PN-1; Supp group-1 Paps-1 Local doctors- 1 | R=2 Screening in hospital-1 Local doctors- 1 | R=3 Work with RHA-1 Home & Community Care program-1 |
| Survivorship | R=7 Supp group-5 Well♀+Elder-1 | R=5 Palliative care-2 Mental Health-3 | R=5 Palliative care-1 Mental Health-3 | R=3 Palliative care-1 Mental Health-2 | R=3 Palliative care-1 Mental Health-2 | R=4 Palliative care-1 Mental Health-2 | R=5 Mental Health-2 Support-2 |
| Support Programs or Sharing Circles | R=6 | R=5 | R=5 | R=5 | R=5 | R=4 | R=6 |
| | Little differentiation from Survivorship; *Cut & Paste theme (see next page) responses-Support groups-3; Cultural camps-1; Health care workers support-3 | | | | | | |
| Care Giver Support | R=10 | R=9 | R=9 | R=9 | R=9 | R=7 | R=12 |
| | *Cut & Paste Theme (see next page) Care giver support is organized through Home Care; 1 mention of Cancer Agency ; Hospice-1; RHA-4; Respite psychologist-1 | | | | | | |
| Palliative Care | R=16 | R=15 | R=16 | R=16 | R=15 | R=15 | R=21 |
| | *Cut & Paste Theme-Palliative care coordinated & managed by Home Care Nurses & Personal Support Workers. 1 mention of Cancer Agency. 1 mention of hospital | | | | | | |
| Outreach | R=8 | R=5 | R=4 | R=4 | R=7 | R=2 | R=5 |
| | Mobile Mammography most common example of outreach; Pap clinics-2; Mental health / Social Worker-1 Can. Cancer Society-1 | | | | | | |
| Patient Navigation (PN) | R=4 | R=2 | R=3 | R=3 | R=3 | R=3 | R=8 |
| | Examples of PN provided, no detail, i.e. "We have a PN to cover Kelowna & Vernon". "Local nurses or social workers work with clients." | | | | | | |
| Pharmacy Services | R=15 | R=12 | R=13 | R=13 | R=12 | R=13 | R=16 |
| | Responses refer to basic pharmacy services not cancer related: "Dispensing medications only" "Pharmacy in local community" "Med delivery 2X/wk" | | | | | | |

Results

Q#6. What types of cancer care programs and services are available in your community? (Combined written responses)

Discussion / Limitation

*Cut and paste themes: Sections of the e-survey that incorporated loops, for example asking the same questions nine times (for prevention, screening, treatment, survivorship, support programs, caregiver support, palliative care, outreach, patient navigation, and pharmacy services) had decreased participation as the loops progressed. In addition, there was a tendency to cut and paste a response from one category and repeat the same response for subsequent categories. The looped questions were described by respondents as “*repetitive*”. Pharmacy service responses did not reflect pharmacy service related to cancer care, they only indicated if communities have access to pharmacy services.

Q#7. Do you have designated human resources to operate cancer programming? Yes / No (0-52 Responses)

Q#8. Do you have designated financial resources to operate cancer programming? Yes / No (0-52 Responses)

First Nation Communities lack human and financial resources to operate cancer programming.

Less than 30% of respondents replied to questions regarding human and financial resources. Since the survey was targeted to ‘Health Care Providers’, this broad role description captures individuals that might not have knowledge regarding the human and financial resource allocation. Individuals with knowledge would be more inclined to respond to the question.

There are a few responses (< 3% of all respondents) that indicate they have human and financial resources to operate any cancer programming. Written comments reflect on the fact that diabetes has dedicated funding, but there was no dedicated funding to address chronic disease broadly or cancer specifically. “*No designated human resources or palliative care in communities.*” “*Sustainable long term budget required for chronic disease in communities to assist in prevention, promotion, and treatment follow-up.*”

Lack of human and financial funding to operate cancer programming may seem inconsistent with the fact that respondents indicated that ~45% of their communities have prevention, screening and early detection, and palliative care services. However, these services are funded under other broad programming, for example community health or HCC, and would not be specifically designated as ‘cancer care programming’.

Palliative care deserves special mention since approximately 50% of respondents indicate that their community provides palliative care services. Written comments reflect that “*Palliative care is not listed as an essential service by Home and Community Care*” or simply that there is “*no funding for palliative care service or supplies.*” This sentiment extends to all provinces and territories that participated. First Nation communities are piecing together palliative care as required to meet the needs of community members in the absence of formal programming, minimal or no funding, lack of palliative care guidelines, and less-than-optimal communication with hospitals and treatment centres. Communities recognize the need for help and guidance for family members providing care, as well as for health staff providing and coordinating care. Communities also understand cancer as a chronic disease.

Results

Q#7. & Q#8. Do you have designated human or financial resources to operate a cancer control program?

Chart #8: Human and Financial Resources

First Nation communities lack human and financial resources to operate cancer programming.

(53 Responses)

| | 7. Human Resources | | 8. Financial Resources | |
|-------------------------------------|--------------------|------|------------------------|------|
| Prevention | Y-5 | N-47 | Y-4 | N-49 |
| Screening & Early Detection | Y-2 | N-24 | Y-1 | N-22 |
| Treatment | Y-0 | N-4 | Y-0 | N-4 |
| Survivorship | Y-0 | N-1 | Y-0 | N-1 |
| Support Programs or Sharing Circles | Y-0 | N-1 | Y-0 | N-1 |
| Care Giver Support | Y-0 | N-9 | Y-0 | N-9 |
| Palliative Care | Y -0 | N-9 | Y-0 | N-9 |
| Outreach | Y-0 | N-4 | Y-0 | N-4 |
| Patient Navigation | Y-0 | N-0 | Y-0 | N-0 |
| Pharmacy Services | Y-0 | N-4 | Y-0 | N-4 |

Discussion

Respondents were more likely to answer the first two loops (prevention, screening) and less likely to answer subsequent loops. Written comments confirm that FN communities have little to no resources (human and/or financial) to operate cancer programming.

Results

Q#9. Are you aware of any cancer programs in your First Nation community that are leading practices? Yes / No (Yes=6; No=52)

If yes, please provide a brief description.

(Leading refers to practices that have been shown to be at the forefront of change and that address important barriers or gaps to care.)

Q#10. Are you aware of any cancer programs in other First Nation communities that are working well? Yes / No (Yes=12; No=104)

If yes, please provide a brief description and contact information if available.

Q#11. Has your community developed any culturally responsive cancer information resources (see definition above) Yes / No (Yes=9; No=110)

If yes, please describe the information resource?

Questions #9,10, and 11 have been combined since the concepts of leading practices and culturally responsive resources are naturally linked.

There is a lack of promising / leading practices and culturally responsive cancer information resources in FN communities.

Discussion

Less than 10% of respondents were able to identify a promising/leading practice or a culturally responsive resource.

The resource that is mentioned most often as a leading, culturally responsive resource is the Colorectal Cancer Screening Kit, developed by the Aboriginal Cancer Care Ontario unit. This resource is described as “*holistic*” and “*culturally sensitive*”, and it can be used as an example for future resource development. Effective resources need support to ensure all FN communities have access to the resource. Despite the lack of dedicated sustainable funding for cancer care programming, communities were able to provide some examples of leading practices and models of care. Positive responses in this area refer to initiatives where collaborations with external groups were established. This is important since one of the major gaps identified is the need to link cancer organizations with FN communities. For example, mobile mammography is a partnership established between provincial cancer agencies and FN communities or TCs to bring breast cancer screening to the communities. First Nations work to ensure information, invitations, and format are culturally safe, appropriate, and meaningful at the community level. This collaboration increases screening participation and helps to decrease fear and mistrust around screening. Often communities use the opportunity to host a health fair, which helps create excitement in the community and brings a holistic approach to screening and health.

A scan of culturally responsive resources is located in Appendix H.

Promising and leading practices and models of cancer care were investigated further with key informant interviews. Definitions for promising/leading practices and models of care were provided by the Partnership. Please see the list of definitions and acronyms. Descriptions of the practices/models and contact information are listed in Appendix F-1 and select models/practices are highlighted in the Discussion section of this report.

Results

- Q#9** Are you aware of any cancer programs in your FN community that are leading practices? If yes, provide a brief description.
Q#10 Are you aware of any cancer programs in other FN communities that are working well? If yes, provide a brief description
Q#11 Has your community developed any culturally responsive cancer information resources? If yes, describe the resource.

Chart #9: Leading Practices and Culturally Responsive Resources (Combined written responses)

| | 9. Leading Practices | | Examples |
|-------------------------------------|-------------------------------------|-------|--|
| Prevention | Y-6 | N-52 | Aboriginal Cancer Care Ontario- Colorectal Screening Program; <i>Other responses do not offer relevant info.</i> |
| Screening & Early Detection | Y-4 | N-22 | “Linkage of traditional healing program as a treatment supplement for cancer patients” <i>Other responses do not offer relevant information.</i> |
| Treatment | Y-0 | N-6 | |
| Survivorship | Y-0 | N-1 | |
| Support Programs or Sharing Circles | Y-0 | N-1 | |
| Care Giver Support | Y-0 | N-9 | |
| Palliative Care | Y-1 | N-8 | No example provided |
| Outreach | Y-1 | N-4 | No example provided |
| Patient Navigation | Y-0 | N-0 | |
| Pharmacy Services | Y-1 | N-4 | No example provided |
| | 10. Other FN Leading Practices | | Norway House-pilot cancer care program; Gitxsan Health Society-Cancer Awareness; Chemotherapy in Haida Gwaii (Queen Charlotte Islands)-100 km away; Six Nations-Brantford-resources; Liaison with Palliative Care Coordinator to address needs of individual clients & community; Colorectal Screening Program; Men’s Wellness-Stellaten Band, Fraser Lake, BC (contact Cynthia Munger, CHR); Oncology Patient Navigator in QC; Six Nations & surrounding communities coordinated ‘Big Colon’ Tour together; Women’s Health Days- promote Pap tests. |
| | Y-14 | N-118 | (12 written responses) |
| | 11. Culturally Responsive Resources | | Cultural Camp-responds to family needs; Good Minds Program; Traditional Medicine; Eagle Moon Health-Regina (two year breast cancer project); Collecting herbal medicines for “those who don’t take medicine from non-natives.”; Pamphlets on cervical cancer (How, why, when, where); Breast & Cervical Cancer Toolkit (AB Cancer Board & FNIH)- Community Health Representatives use this to teach clients. |
| | Y-9 | N-110 | (8 written responses) |

Results

Q#11. Has your community developed any culturally responsive cancer information resources (see definition above) Yes / No (Yes=9; No=110)

If no, then what information resources would be helpful for you to have? (84 Responses)

First Nations identify the need for culturally responsive cancer information resources that are evidence based.

Chart #10: Required Resources Q#11b. What information resources would be helpful for you to have? (Combined written responses)

| Resource Type (84 Written Responses) | Overriding Themes Relevant to All Resource Types |
|--|--|
| Oral Based Resources: Video-22 Talking Circles-18 Radio Ads-9 Workshops-11 | Culturally Appropriate / Culturally Sensitive Translation-Material needs to be easy to understand & easily translated. Easy to Understand Content, visual (include pictures) Linked to other organizations (i.e. provincial cancer agencies); Based on Best Practices; Evidence Based Partnerships with external organizations to promote Knowledge Exchange Support Networks (for Health Care Workers (HCW)- linked to cancer professionals, i.e. cancer agencies) Support Networks (for patients & families-linked to others living with cancer & local HCWs for support) Include Traditional Medicines, Traditional Diet, Traditional Healers (support research on traditional practices) Patient Navigators to support understanding for patient & family. |
| Web Based Resources: Oral (Telehealth, Podcasts)-5 E/Print-14 | |
| Print Based Resources: Pamphlets/Posters/Handouts-21 Palliative Care Manuals/Guidelines-7 | |

Discussion

Respondents clearly identified the lack of culturally appropriate/sensitive cancer resources, with less than 10% of respondents responding yes to this question. Requests for oral, web-based, and print material that is best practice- or evidence-based recognizes the need to link with cancer organizations. There is a preference for orally based resources: “*short videos*”, “*talking circles*”, “*community workshops*”, that are easy to understand and visual. Development of resources needs to be a collaborative process of knowledge exchange, or as one respondent stated, not a “*one-way-street*”. Support networks for health care workers, patients and their families are required to help address the emotional burden of cancer care.

Results

The development of FN-specific resources is an area that will require strong links across all jurisdictions. Respondents recognize the need for community-based support for patients, families, and healthcare workers. Support in these areas will help address the underlying *fear* associated with cancer.

- Coordination Gaps: Q#12. What coordination gaps exist in cancer care between the First Nation community and cancer care centres? (92 Responses)
- Q#13. How could the coordination gaps be addressed? (90 Responses)
- Q#14. Are there other gaps that impact the cancer pathway / journey for First Nation community members? (86 Responses)
- Barriers to Access: Q#15. What are the barriers to accessing cancer care for community members? (95 Responses)
- Q#16. How could access to care be improved? (85 Responses)
- Q#17. Do you have any other comments? (53 Responses)

Analysis for questions 12-17 was combined, there was significant overlap in the responses, and content analysis revealed 3 themes: Access, Partnerships, and Jurisdiction.

CHART #11: TRENDING THEMES: ACCESS, PARTNERSHIPS, JURISDICTION (Questions 12-17; Content Analysis)

| ACCESS | |
|---------------------------|--|
| Transportation | Gaps -rigid NIHB policy (not coordinated with cancer agencies, escorts not covered, meals need support, city housing depressing), screening not covered |
| | Barriers -(distance, roads, travel time, weather), cost, low mileage reimbursement rates, jurisdictional issues, poverty, many do not have phones |
| | Improve - ↓medical transport red tape (NIHB), ensure accommodation in city is non-smoking & not depressing, cover in-city taxi costs, meal & escort costs |
| | |
| Health Care Professionals | Gaps -no links to cancer agencies; need culturally competent cancer education for all HCWs; need support personnel; need palliative guidelines for communities |
| | Barriers -no primary doctor (use walk-in clinics); doctors booked with chronic clients; high turnover nurses & doctors ; too much bureaucracy to get tested or see specialist |
| | Improve -↑number of doctors & nurses & NPs; support a system of primary care providers; create certificate program for all levels of HCWs on cancer care; ↓time to see specialist |
| | |
| Education | Gaps -lack of culturally appropriate, easy-to-understand resources; need resources for patients / family & for HCW's (all levels); ↓educational attainment; language |
| | Barriers -fear & mistrust of the medical system; historical trauma infiltrates all aspects of life (↑stress, ↓trust, ↓self-worth); cancer carries stigma (cancer=death) |
| | Improve -FN specific teaching resources; FN leadership role models for change; self-responsibility; system change, so that cancer is not viewed as death sentence |
| | |
| Prevention | Gaps -lack of knowledge of common risk factors linked to cancer (nutrition, exercise, smoking); lack of FN-specific prevention initiatives (speak to local realities) |
| | Barriers -Poverty (disparity in access to fresh food); cheap cigarettes; FN leaders need to be role models; need mental health support; less access to outreach |

Results

| | |
|--------------------|---|
| | Improve -FN specific, locally appropriate prevention programs; improve access to nutritious foods; target children with healthy living programs |
| | |
| Screening | Gaps -cancer screening not available on reserve; need community level input & approach; community not aware of what is available |
| | Barriers -distance is a barrier; cost not covered to attend screening; fear associated with outcomes; screening off reserve not culturally sensitive |
| | Improve -link with cancer agencies to bring culturally sensitive screening close to home (on reserve); education to ↓ fear; education for HCPs; NIHB travel coverage |
| | |
| Care and Treatment | Gaps - need palliative care education for HCWs & families; need support programs for patients/ families; no funding for respite; need palliative care system; available HCWs |
| | Barriers - Jurisdiction (NIHB ≠ Provincial coverage for pain medications & supplies); cancer management not funded; reliable access to pain medication when discharged from hospital & when pain worsens; caregiver burnout; no prevention of other cancer for survivors; lack of communication between programs |
| | Improve -Jurisdictional change- funded formal palliative care program available in FN communities, including end of life care, & respite; NIHB to cover palliative care supplies (pain medications & supplies -same as province); palliative training for HCWs & families; care guidelines from cancer agencies to ensure safe, quality care |

CHART #11: TRENDING THEMES: ACCESS, PARTNERSHIPS, JURISDICTION cont’d. (Questions 12-17; Content Analysis)

| PARTNERSHIPS | |
|-----------------------|---|
| Cancer Agencies | Gaps -lack of formal links between FNs & cancer agencies; limited communication or collaboration; need Cancer Certificate program; need to work with FN communities to support cancer research |
| | Barriers -cancer agencies do not have contact information for FNs & FNs do not know how to contact cancer agencies; lack of culturally appropriate resources; |
| | Improve -need to establish formal links btw cancer agencies & FNs; knowledge exchange to build two-way understanding; share educational opportunities with FN staff |
| | |
| Hospitals | Gaps -lack of discharge planning; restricted information sharing with FN Health Centre; lack of communication with FN communities; no team meetings; no follow-up |
| | Barriers -lack of discharge planning; translators not always available; lack of FN navigators; waiting for results takes too long; poor communication |
| | Improve -jurisdictional knowledge sharing agreements; standard discharge planning protocol; work with FN communities to plan pt. care; |
| | |
| Aboriginal Navigators | Gaps -limited number of Navigators; Navigators need to be hired locally (understand FN remote/ isolated reality); no advocates for patients; lack of coordination |
| | Barriers -lack of funding for Navigators (Navigator examples are all positive); need a link between hospital and community workers; |
| | Improve -Aboriginal Navigator to assist FN patients & families to understand the system, options, tx.; work across jurisdictions to improve access issues & advocate & coordinate care |
| | |
| Technology | Gaps -existing technology not used (patients travel 10 hours for a 10-minute appt.); not using Telehealth to communicate with doctors, specialists, hospitals, cancer agencies, etc. |

Results

| | |
|--|---|
| | Barriers -ensure technology in FN communities is working and that staff know how to manage technology; Create system that uses existing technology (doctor visit, family visit, discharge) |
| | Improve -jurisdictional, technical, time issues to create system change that uses existing technology to address gaps and barriers. |
| | |
| Research | Gaps -not able to identify who is FNs; no surveillance system; unable to identify who has cancer in the community; need to be able to track screening |
| | Barriers -still working with paper-based charts; need an electronic health record; there is mistrust of the mainstream health care system & data collection |
| | Improve -respect OCAP principles; build an electronic health record that can be owned by FNs; work with FNs to identify environmental cancer related issues; |
| | |
| JURISDICTION | |
| FNs, Federal / Provincial Health Authorities | Gaps -discharge planning bureaucracy (catchment areas); information sharing / privacy issues; access to primary care doctor; lack of cultural awareness; disjointed system |
| | Barriers -no funding to support FNs to work with cancer agencies; trust; language ; cultural sensitivity; poor access to traditional medicines & healers; poverty |
| | Improve -jurisdictional system change to support cooperation & information sharing; support funding for screening, escorts, food security, chronic disease prevention |

The road to improving cancer pathways for FNs must address Access, Partnerships, and Jurisdictional Issues.

The e-survey focuses on health services as they related to FN communities. Access to health services is one of the determinants of health, however, there are many other determinants of health that influence health outcomes (www.phac-aspc.gc.ca). FNs continue to deal with the effects of residential school, and this historical trauma has a negative effect on social support. Educational attainment is lower for FN populations, and high unemployment and poverty are detrimental to health and wellbeing of communities (www.afn.ca). The impacts of the determinants of health are very evident in the responses in this section implicitly (transportation is the most common listed gap/barrier) and explicitly (*“poverty is a barrier”*). The three themes identified must be considered in the context of the broad determinants of health. Below is a summary of the combined comments.

ACCESS

Transportation is the most commonly cited gap and barrier to accessing cancer care. The majority of FN patients need to travel more than 90 km to access cancer services. The NIHB system is described as *“rigid”* and having *“too much red tape”*. These issues create frustration and delay in an overburdened system. The Non-Insured Health Benefits program is described as *“suspicious”* of transportation claims made by exhausted cancer patients.

Health Care Professional access issues are linked to high turnover and lack of consistency of a primary care provider. These gaps lead to inconsistent, untimely care, which patients try to avoid. Add this to a FN population that has *“fear”* and *“mistrust”* of the health system and the result is poorer cancer outcomes.

Education that is culturally sensitive is identified as a need at all levels (patients, family, community, and HCPs). Many respondents refer to the need to link to the cancer organizations to share workshops or *“create a certificate program”* for HCPs. Knowledge exchange needs to support reciprocal learning.

Prevention should focus on common risk factors of all chronic disease, including cancer, and provide flexibility to address local realities including poverty and historical trauma.

Screening efforts need to focus on bringing screening to the community level in a culturally sensitive, locally meaningful approach. Local screening increases *“ownership”* and helps to break down existing *“fear and mistrust”*.

Care and treatment needs community level education to create a system that can support palliative and respite care in the community. Jurisdictional system change should allow patients to seamlessly move from the FNs system to the provincial system and back. Palliative care needs to be funded, and links with Cancer Agencies will ensure evidence-based care is provided regardless of the patient’s location.

PARTNERSHIPS

Cancer Agencies (and other cancer organizations) need to build formal sustainable links with all FN communities. Knowledge exchange and collaboration can address the educational and resource issues that exist.

Hospitals need to support an information-sharing agreement that allows patient information to be shared with their FN health centre to support safe, quality-based continuity of care.

Aboriginal Navigators can work as liaisons between the cancer care system and FN communities, and navigators need to be able to cross jurisdictional boundaries.

Technology can help bridge distance and can support education and communication. Virtual appointments with specialists may improve quality of life for cancer patients and their families.

Research regarding cancer rates in FN populations will require identifiers that meet the needs of FNs, cancer organizations, and provincial, territorial, and federal jurisdictions. Respect for OCAP will build the trust required to gather surveillance data.

JURISDICTION

There are jurisdictional boundary issues between FNs, the federal government, provincial governments, and Health Authorities. The boundaries create gaps and barriers in the cancer pathway for FNs. Change in ACCESS and PARTNERSHIPS will not be effective unless there is corresponding jurisdictional system change.

Discussion

The three themes (Access, Partnerships, and Jurisdiction) were consistent across provinces and the Yukon. The themes were further supported and clearly evident in both sharing sessions and key informant interviews.

Q#18. May we contact you with follow up questions? Yes / No

If yes, please provide contact information.

66 Respondents identified themselves and agreed to follow-up contact.

Results

Discussion

A comparative analysis was conducted to compare the responses of those that chose to identify themselves (n=66) and those that did not include identifying information (n=91). The two groups are similar in responses and rates provided. For example, identified respondents come from all provinces listing responses, represent all population size communities, and offer similar statistics in terms of types of health care services available and types of cancer programming and services available. Written responses were also compared to determine if responses from identified respondents were different from non-identified respondents, and no significant differences were noted. Respondents that identified themselves were more likely to provide written responses and offer contact information of others they recommended to be surveyed. The Alberta region had 22 respondents, and, as stated previously, separate access to the survey was established for this region. Although data was integrated for analysis, the identity of the respondents remains with Alberta FNs.

Q#19. Is there anyone else in your community you feel we should speak to? Yes / No

If yes, please provide contact information.

37 Additional contacts were identified by survey respondents.

Provincial Comparison Chart: E-Survey Health Care Providers (HCP) Summaries (and *Yukon Focus Group* data integrated):

Chart #12, located in Appendix B-3, presents the e-survey for HCP data in a provincial comparison format. The Yukon sharing session (focus group) was integrated (where applicable), since there was only 1 e-survey response from the Yukon. The Manitoba sharing session (focus group) data is not integrated into this provincial comparison chart, since there were 40 Manitoba responses to the e-survey. The Manitoba sharing session (focus group) data is consistent with the Manitoba data revealed in the e-survey for HCPs. The data from the two sharing sessions (MB and YT) can be viewed in full in Appendix D-1 and D-2 or summarized in Charts #15-16.

Commentary on provincial collective data is documented in the E-Survey for HCPs: Aggregate results question by question review (Summary and Analysis) section.

Discussion of the provincial comparison is found in the discussion section.

Results

Rural, Remote, and Isolated Community Comparison Chart: E-Survey HCPs Summaries:

Chart #13, located in Appendix B-4, presents the e-survey for HCP data in a format that allows comparison across rural, remote, and isolated FN communities. The Yukon Territory sharing session data is not integrated into this chart, however, the YT has communities that fit the rural, remote, and isolated descriptors. When the YT sharing session data is compared with rural, remote, and isolated issues, the gaps and barriers regarding access to cancer care are similar. Differences are commented on in the Provincial Variation section (see Discussion).

E-Survey for Health Managers (Tribal Councils / Provincial / Territorial Organizations): Aggregate Results

The e-survey for HCPs did not identify the role of the respondents, and it became clear that some respondents were providing information from a TC or provincial organization level. In an attempt to differentiate data, a separate e-survey was developed and targeted to health managers. However, by that point, many health managers had already completed the e-survey for HCPs. The e-survey for health managers mirrored the survey for HCPs, however areas that were proving to be repetitive and decreasing responses were revised. In total twelve (12) responses were obtained from the e-survey for health managers from the following regions: BC-1; AB-10; ON-1. Alberta had more responses, since both e-surveys opened later in Alberta (see OCAP section).

Chart #14, below, presents the aggregate data for the responding regions. A copy of the e-survey for health managers can be viewed in Appendix C.

Chart #14: E-survey for Health Managers (Tribal Council / Provincial Territorial Organizations): Aggregate Results

| Question | British Columbia (n=1) | Alberta (n=10) | Ontario (n=1) |
|---|---|---|------------------------------------|
| Respondent's Role | Health Coordinator | Manager / Director / CEO-7 Nursing-3 | Health and Family Services Manager |
| Number of communities represented by your Tribal Council? | 1 community | 1 to 10 communities- 7 responses 10 to 20 communities- 2 responses 45 communities- 1 response | 39 communities |
| Population of your FN community? Rural, remote, or isolated? | Population-400 Rural | Population Rural- 8 responses Remote-2 responses | Population-900 Rural |
| Designated resources (human or financial) to operate cancer programs / services? | No | No | No |
| Screening services available in your community? If not, is there coverage for individuals to attend screening? | Breast Screening available on reserve through mobile outreach. No coverage through NIHB for travel related to screening. | Mobile breast screening=7 Yes = 8 (Travel screening is covered by NIHB) No=1 (individuals cover cost) | No cancer screening in community. |
| Leading practice examples of cancer care? Culturally relevant resource examples? | No | No=8 Yes=1 (Tipi model, recognizes cultural and traditional practices) | No |
| Palliative care costs covered? | Yes- NIHB, HCC program, and FN band in collaboration with Northern Health Palliative care and hospital care. | No=5 Yes=4 (NIHB, HCC, family, hospital) | No |

Chart #14: E-survey for Health Managers (Tribal Council / Provincial Territorial Organizations): Aggregate Results cont’d.

| Question | British Columbia (n=1) | Alberta (n=10) | Ontario (n=1) |
|--|--|---|---|
| <p>Gaps & Barriers Content was applied to existing themes.</p> <p>ACCESS Transportation Health Care Professionals Education Prevention Screening Care and Treatment</p> <p>PARTNERSHIPS Cancer Agencies Hospitals Patient Navigators Technology Research</p> <p>JURISDICTION</p> | <p>ACCESS “NIHB patient travel program is a barrier along with weather and geography.” “Teaching regarding how to advocate for self.” “Access to screening for breast and prostate cancer is an issue.”</p> <p>PARTNERHIPS “Increase mobile screening outreach.” “Access to diagnosis and doctors that will refer in a timely manner.”</p> <p>JURISDICTION “No access to screening or diagnosis without a doctor’s referral (requires policy change).” “Too many patients are given or repeatedly treated for other symptoms without a diagnosis. By the time they are diagnosed they have end-stage cancer.” “Government legislation needs to spell out what ‘portability’ is and how it applies to provincial health services. Regardless of federal/provincial services a mechanism needs to be put in place for equitable health service delivery regardless of race! Too many health authorities are getting away with using the ‘jurisdictional’ issue.” “Jurisdictional policy level change is required to support the social determinants of health.”</p> | <p>ACCESS “Transportation and access is always a barrier.” “Staff need cancer education (chemotherapy, palliative care).” “Need community-based education and culturally responsive resources related to cancer and screening; role of nutrition and physical activity; how traditional ways can prevent chronic disease; how to develop support groups or talking circles in communities.” (Resources need to describe that cancer treatments would not hinder or affect FN spirituality.) “Accessible care closer to home.” “Palliative care needs to be funded at the FN community level.”</p> <p>PARTNERSHIPS “Lack of communication with cancer centres. There is no information, people don’t know if they have cancer or not. There is a lack of follow up, related to access (social determinants of health, i.e. no ride available).” “Use of a common assessment tools (RAI-HC) and surveillance tools would help communication and support FN statistics.” “Need follow-up and grief counselling, support.” “Patient navigator positions funded by province/federal governments to support access, continuity, and follow-up.” “Need to use Telehealth to support learning.”</p> <p>JURISDICTION “The Tipi Model is an administrative model for health service delivery (supported by the work of Elders). The model supports partnership of FNs with F/P government.” “Need federal /provincial resources for FN programs/services.” “Need a chronic disease approach.” “Systemic racism needs to be addressed at all levels.”</p> | <p>ACCESS</p> <p>PARTNERHIPS “Need FN-specific research.” “FN-specific data is lacking, tends to be combined with regions or with other rural areas (including non-FNs).”</p> <p>JURISDICTION “Need statistical information to advocate to government for services and support.” “Data will help support strategic direction for communities.”</p> |

Sharing Sessions

The Manitoba sharing session (focus group) was held Sept. 7 and 8, 2011 in Winnipeg, MB. Twenty-one people participated in the two day session. The full report of the sharing session was validated by the MB participants and is available for review in Appendix D-1. A summary of the sharing session is listed in the chart below (see Chart #15).

The Yukon Territory sharing session (focus group) was held Oct. 27 and 28, 2011 in Whitehorse, YT. Nineteen people participated in the two day session. The full report of the sharing session was validated by the YT participants and is available for review in Appendix D-2. A summary of the sharing session is listed in Chart #16.

Chart #15: Key Informant Data: Sharing Session (Focus Group) Manitoba Summary (Key: CHC=Community Health Centre; CHW=Community Health Worker; Hosp=Hospital; FN= First Nation; HCP=Health Care Professional Provider; NIHB = Non Insured Health Benefits; NS=Nursing Station; HCC=Home & Community Care; Comm=community; Dx=diagnosis; tx=treatment)

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|--|--|---|---|---|
| <p>MB-Focus Group-21 participants</p> <p>Difference between Rural, Remote, and Isolated- Rural- more likely to have initial cancer screening & diagnostic workup in larger city setting. Isolated communities concerned about delays in receiving test results and lost results.</p> <p>Surveillance System-</p> <p>Transportation coverage-No -FN community coordinates medical transportation. -NIHB provides limited funding for transportation, accommodation, & food. -NIHB does not cover travel costs for escorts.</p> <p>Link to Cancer Agency- “CancerCare Manitoba’s (CCMB) role is not clear.” Need education on cancer care (including palliative care) for front line workers and families. Need research to support change.</p> | <p>On Reserve-CHC, NS (varies) Internet connectivity & Telehealth availability is an issue. Off Reserve-Hosp, medical services, pharmacy</p> <p>Wait time (suspicion-diagnosis)-Delayed diagnosis is complicated by inadequate access to primary care services & poor communication systems. Too many late-stage diagnoses.</p> | <p>Breast-Via mobile or in large centre Pap- In comm, local HCP or large centre Colorectal- FOBT kits mailed out, CCMB Colonoscopy-hosp, in large centre</p> <p>Factors influencing screening: Cancer is a ‘taboo’ subject; language & literacy barriers; shame, fear & misconceptions; mistrust of health care system; historical trauma related to residential school; loss of traditional teachings; turnover of health care staff; lack of self-care; lack of culturally safe care; poverty; isolation; struggle to motivate for self-care;</p> <p>↑ Screening Participation: Consistent health promotion messaging; promotion of wellness, mental health, self-love, self-pride, Elder involvement; include traditional healers & Elders in messaging; include men; electronic health records; NIHB coverage of transportation; education using @YourSide Colleague; promote screening through technology, radio, & social media; support self-worth & self-esteem campaigns (Dove); pair youth with Elders to bring back traditional teachings; bring screening close to home; support integrated chronic disease approach & healthy living</p> | <p>Dx received- Doctor’s office Test results- Process is ‘flawed’ too many delays, too many contaminated samples Late stage dx-Complex, complicated system with multiple barriers, including inadequate access to HCPs, a flawed transportation support system for a population that due to the determinants of health are struggling with poverty. Linkages between FNs & the cancer care system are weak which impedes communication. All these factors lead to late stage dx.</p> <p>Navigators- Navigators needed to support culturally safe care. Focus group recommends cancer care coordinators at the tC level & community based cancer care workers.</p> | <p>Where- Large centres: Winnipeg, some available in The Pas</p> <p>Wait for tx-Varies, access to doctor influences process Follow-up-Lack of discharge planning from hosp./tx centre to home community CHC Survivorship-No survivorship programs in comm</p> <p>Palliative Care-Palliative care not recognized as one of the essential service elements of the HCC Program, critical gap. Many communities provide palliative care (despite lack of program & funding), Nurses train family to provide care. No respite for family. NIHB- gap in coverage of supplies (i.e. pain medication, dressing supplies) Permanent funding required to support palliative care program. Where-Home, hosp or care centres- limited supply of beds.</p> <p>Comm Supports-Varies from comm to comm Outreach-varies from comm to comm (i.e. Mobile breast screening reaches some comms But not all comms, not consistent.</p> |

Results

Chart #16: Key Informant Data: Sharing Session (Focus Group) Yukon Summary (Key: CHC=Community Health Centre; CHW=Community Health Worker; Hosp=Hospital; FN= First Nation; HCP=Health Care Professional / Provider; NIHB = Non Insured Health Benefits; NS=Nursing Station; HCC=Home & Community Care; Comm=community; Dx=diagnosis; tx=treatment)

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|--|---|--|--|--|
| <p>YT- Focus Group 19 participants</p> <p>Difference between Rural, Remote, and Isolated-More similar than different. Person living in an isolated comm less likely to have the option of dying at home.</p> <p>Surveillance System- No cancer research or surveillance.</p> <p>Transportation coverage- NIHB covers travel outside of territory but does not cover escort costs.</p> <p>NIHB-Complicated, frustrating, bureaucratic system, increases anxiety & stress on vulnerable people.</p> <p>Link to Cancer Agency- Need training for front-line staff & community members on palliative care.</p> <p>Need jurisdictional change to support clinical care provision in Home Care.</p> <p>Need research regarding environmental carcinogens from mines & dumps.</p> <p>Need FNs Cancer Control Strategy for YT.</p> <p>Need surveillance data & research data to support change.</p> | <p>On Reserve-CHC, NS, Telehealth 1 Nurse often covers Comm Health & Home Care for 1-4 communities.</p> <p>Off Reserve-Hosp, medical services, pharmacy</p> <p>Wait time (suspicion-dx)- Long (6 months-5 years) just to get a first appointment-Dr. shortage makes it difficult to get a dx. Family doctors not taking new patients, walk-in clinics are closing. Many inexperienced doctors, results in misdiagnosis. Doctors often ignore symptoms in clients with FASD (Fetal Alcohol Spectrum Disorder) or substance abuse problems due to racism & stereotyping.</p> | <p>Breast- > 90 km or plane Whitehorse, hosp.</p> <p>Pap-In comm., local Health care professional</p> <p>Colorectal- > 90 km Whitehorse, hospital</p> <p>Colonoscopy- > 90 km Whitehorse, hospital</p> <p>Factors influencing screening: Lack of awareness, education, fear, sense of hopelessness, misconceptions, mistrust, historical trauma of residential schools, nurses too busy reacting to crises, Telehealth available but underutilized, language barriers, no YT-specific cancer strategy, travel, time away from community, NIHB, racism, stereotyping, no mental health services, loss of traditional ways.</p> <p>↑ Screening Participation: Community wide cancer education; support empowerment & hope; implement a YT Cancer Care Coordinator; promote understanding & compassion in HCPs; strengthen partnerships with Cancer Agency; decrease wait times; promote self-care; need FN advocates; empower existing informal support groups such as women’s groups in comm; forge partnerships between health organizations & FNs; screening closer to home; permanent primary care providers; increase human and financial support for screening; electronic health records; chronic disease approach that promotes prevention & screening across all chronic diseases.</p> | <p>Dx rec’d- Whitehorse, hospital</p> <p>Test results- There is a communication gap between doctors & community HCPs. Test results therefore are delayed.</p> <p>Late stage dx-Fear; misconceptions; lack of awareness; mistrust of the health system; known barriers related to transportation, NIHB, access to Drs,</p> <p>Navigators- Citizen’s advocate works out of the Whitehorse hosp. Cancer patients and their families need emotional support.</p> | <p>Where- > 90 km or via plane Whitehorse, Vancouver, Edmonton</p> <p>Wait for tx- Long-too long</p> <p>Follow-up- Specialists & doctors & community health care professionals (Follow-up is often poor due to communication barriers)</p> <p>Survivorship- No survivorship programs.</p> <p>Palliative Care-No organized program for palliative care. Nurses do not provide clinical care such as dressing changes or medication administration (due to jurisdictional issue involving insurance coverage expected to be paid by FNs). Inadequate human resources.</p> <p>Where-Home-limited support. Care provided by family with instructions from doctors and registered nurses. Issues with NIHB regarding access to required pain medications and supplies.</p> <p>Hospice- in Whitehorse</p> <p>YT Continuing Care Homes-long waiting lists.</p> <p>Comm Supports- No mental health services.</p> <p>Outreach- No outreach programs.</p> |

Key Informant Interviews

Key informant interviewees were identified through the e-survey responses and through various networks. Each key informant was chosen specifically for their knowledge and expertise of issues related to FN cancer care. All of the key informants are Health Care Workers that deal directly with FN individuals and families as they journey through their cancer pathways. In order to protect the identity of the key informants, only a brief description of their role is listed in the first column (i.e. Nurse). Some of the key informants work for FN communities or FN health organizations, while others work for cancer organizations or provincial health groups. The key informant interviews were conducted by Saint Elizabeth personnel, and each interview took approximately 30 minutes to complete. There are two key informant interviews listed on each page, and below each interview is a direct quote that summaries the feel of the interview. The quotes bring the data to life. Eleven key informant interviews were conducted.

Chart #17: Key Informant Data: Individual Interview Summaries (Key: CHC=Community Health Centre; CHW=Community Health Worker; Hosp=Hospital; FN= First Nation; HCP=Health Care Professional / Provider; NIHB = Non Insured Health Benefits; NS=Nursing Station; HCC=Home & Community Care; Comm=community; Dx=diagnosis; tx=treatment)

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|--|---|---|---|--|
| #1. BC-Rural-Single Comm Watson Lake, closest comm Health Director Surveillance System- No (just purchased new electronic database) Paper charts-Yes Transportation Covered- No (case by case) Links with Cancer Agency- Yes for info | On Reserve CHC, with CHWs (no cancer training); Telehealth Off Reserve- Hosp+pharmacy in Watson Lake Wait time (suspicion-dx): Serious issue, doctors disregard symptoms, or misdx., dx late stage, complete system failure. | Breast- >90 km Whitehorse hosp.(500 km) Pap- (20-90 km) Watson Lake hosp. Colorectal- (20-90 km) Watson Lake hosp. Colonoscopy- >90 km Whitehorse or Vancouver Factors influencing screening: Family history; t.v. information; fear & stigma ↑ Screening Participation: Education & awareness | Dx received- Watson Lake, HCP Test results- 2-3 weeks Late stage dx- Fear, stigma, doctors ignore signs and symptoms; problem with misdiagnosis; ↓ education; lack of trust in system Navigators- Yes, Whitehorse hosp. Social Worker in Vancouver FN Liaison Worker in Watson Lake | Where- Chemotherapy- >90 km Whitehorse hospital Radiation-via plane Vancouver hospital Wait for tx- <1 month Follow-up- Specialist +Local doctor +HCC Survivorship- None Palliative Care “No funding for palliative care” Where- Home (HCC+ family) RN visits from Watson 2Xmonth.; Hosp- if 24 hour care required Community Support- Church based Outreach- Specialist visits yearly; Telehealth cancer care (pending); mobile mammography; RN from Watson Lake 2Xmonth |
| <i>“Services are not available here, therefore people disregard what they see/feel.” “Communities here are like Third World countries.” “Challenges in the north are huge.” “Cancer education must come to the communities.”</i> | | | | |
| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
| #2. BC-Rural-Single Community 45 minutes from health services Surveillance System- No Electronic database- Yes | On Reserve- CHC + NS + medical service (no cancer training) Off Reserve- Hospital +Pharmacy + Telehealth 4 km from reserve | Breast- 20-90 km mobile to hosp, yearly (Cancer Agency) Pap- <20km Hospital off reserve Colorectal- <20km in community (Hospital) Colonoscopy- <20km (Hospital) | Dx received- Hospital, doctor’s appointment Test results- Very long, lack of specialists Late stage dx- Fear | Where- Chemotherapy->90 km Hospital Radiation-via plane Wait for tx- 1-4 months Follow-up- Specialist Vancouver & local doctors; Specialist visits local hosp. 3X/year |

Results

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|---|---|--|---|--|
| Paper Charts-Yes Transportation Covered -Yes by FN & NIHB Links with Cancer Agency -Yes for information. Linked to local hospital or northern health online | Wait time (suspicion-dx): Very long; little communication between health care professionals and patients; late diagnosis; lack of coordinated services | Factors influencing screening: Values, beliefs, people talking about it ↑ Screening Participation: Education, honoraria for attending | Navigators -Not locally; yes in Prince George & Vancouver Aboriginal Navigator- Yes at local hospital for Elders. | Survivorship -Church based (Off Reserve~4km) Palliative Care Where - Terrace Hospital (1.5 hrs) Home- not generally Community Support -Social & Mental Health workers through hosp; educational workshops; community cancer walks Outreach -Specialist 3X/year; Telehealth education on cancer; mobile mamm yearly; |
| See also Leading Models: ‘Cancer Support Group’. “There is a lack of coordination of services & communication between multiple doctors. People are passing away waiting for tx.” | | | | |

Chart #17: Key Informant Data: Individual Interview Summaries cont’d. (Key: CHC=Community Health Centre; CHW=Community Health Worker; Hosp=Hospital; FN= First Nation; HCP=Health Care Professional / Provider; NIHB = Non Insured Health Benefits; NS=Nursing Station; HCC=Home & Community Care; Comm=community; Dx=diagnosis; tx=treatment; NP=Nurse Practitioner; TC=Tribal Council; RN=Registered Nurse)

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|---|--|--|--|---|
| #3. SK-Rural -Yes (7 comms) Nurse Each comm has a health centre & Registered Nurse (RN) + HCA (communities may share RN + HCA) Surveillance System -No Transportation Covered -No (some communities have a medical van) Links with Cancer Agency -Not aware, we do have pamphlets. | On Reserve - CHC (Nurse Practitioner (NP) works for TC- ♀ health outreach 0.5, Clinical Breast Exams (CBE) & Paps) Off Reserve -Hospital Wait time (suspicion-dx) :- few weeks -Dr. shortage affects screening→ later stage diagnosis. | Breast - >90 km Regina (100 km) Pap - In community (TC, NP) Colorectal -In community (Fecal Immunochemical Tests (FIT) - Cancer Agency) Colonoscopy - >90 km Regina Factors influencing screening: Available NPs; culturally sensitive care, respectful non-judgemental care; HCPs: encouragement & dispels fears ↑ Screening Participation: ↑ Awareness of screening & NP; Navigator; mobile screening; work more closely with Cancer Agency | Dx received - Regina Test results - Days Late stage dx - ↓ awareness on screening & mobile; doctor shortage; travel; screening is low on their priority list; stereotyping Navigators Access-No ‘Native’ counselling service at Regina Cancer Clinic. | Where - >90 km Regina, Cancer Agency staff Wait for Tx - <1 month. Follow-up -Cancer clinic in Regina Survivorship -Not in community at cancer clinic in Regina Palliative Care Where - Local Hospital or at home supported by HCC Community Support -Mental health workers, Traditional Healers Outreach -Nurse Practitioner for ♀ health from TC |
| See also Leading Models: ‘ Tribal Council NP’. “Care is reactive not preventative.” “Avoidance of health care system, people don’t want to be scolded, i.e. ‘If you didn’t smoke, you wouldn’t have gotten cancer’”. | | | | |

Results

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|--|--|---|--|--|
| #4. SK-Rural-No Nurse Difference between Rural, Remote, and Isolated- States that remote & isolated communities have lack of community-based services and knowledge, lack of access to medication & dressing supplies, & lack of competence. Surveillance System- Yes Nurses informally pass information along. Transportation coverage- No Link to Cancer Agency- No | On Reserve- CHC, Telehealth Off Reserve- Medical service centre, pharmacy Wait time (suspicion-dx):- Variable, many barriers (access to health care professionals, weather, medical transportation available but there may be no gas). May take 5 trips to Regina to get a diagnosis. | Breast- >90 km (Cancer Agency) Pap- 20-90 km, local health care professionals Colorectal- 20-90 km, local HCPs Colonoscopy- >90 km, hospital Factors influencing screening: Socioeconomic factors; awareness; desire; self-respect; encouragement by RN. There is no money put toward cancer for FNs, very aware of diabetes...but little else. Medical model does not promote prevention, provides episodic care only. ↑Screening Participation: Address above factors. | Dx received- Doctor's office Test results- 3-6 weeks Late stage dx- Addictions & mental health issues, little cancer in the comm, lack of awareness of screening, lack of follow-up tx. Navigators- No (there is a Patient Navigator at the regional cancer centre, but they do not deal with FNs only) | Where- >90 km (Cancer Agency) Wait for tx- 1-4 months Follow-up- Through cancer centre &/or family doctor with local HCPs & traditional healer Survivorship- Nothing available Palliative Care- Where- Home or local hospital (20 miles away) or city hospital (50 miles away) Home- If not complicated &requiring 24 hr care HCC + Family (provides the majority of care) Community Supports- Ssocial & mental health workers Outreach- None |
| <i>“Often by the time the cancer is identified they are already at stage 3 or 4.”</i> | | | | |

Chart #17: Key Informant Data: Individual Interview Summaries cont’d. (Key: CHC=Community Health Centre; CHW=Community Health Worker; Hosp=Hospital; FN= First Nation; HCP=Health Care Professional / Provider; NIHB = Non Insured Health Benefits; NS=Nursing Station; HCC=Home & Community Care; Comm=community; Dx=diagnosis; tx=treatment)

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|--|---|---|---|---|
| #5. ON-Rural-Yes (7 comm) Aboriginal Health Access Centre (AHAC) Executive Director Surveillance System- No (Tracking on Electronic Health Record- used for high-level reports) Electronic Health Record- Yes Transportation Covered- Yes (FNIHB + Northern Grant + AHAC for 55+) Links with Cancer Agency- Yes -For info- Yes- CCO + Canadian Cancer Society (CCS) -To contact- Yes | On Reserve- CHC , CHW no cancer training Off Reserve- Hospital + Pharmacy + Telehealth + medical service Wait time (suspicion-dx):- Not aware of any gaps or barriers. | Breast- Sudbury > 90 km (Province) Pap- In comm (partnership AHAC & local family health team) Colorectal- pilot Fecal Occult Blood Test (FOBT) kit CCO (local Health care workers) Colonoscopy- > 90 km, hospital (cancer agency staff) Factors influencing screening: Personal choice; awareness; media; lay educators are champions. ↑Screening Participation: Reach men; need male role models | Dx received- Health care professional Test results- 2-3 weeks Late stage dx- Fear, denial; need to normalize screening Navigators- Sudbury Regional Cancer Program (Northeast Cancer Centre) - Supportive Care Program team, helps patients/families to navigate the system. | Where- > 90 km (Sudbury or southern ON), Province, cancer agency staff Wait for tx- 1-4 months (varies with severity) Follow-up- Specialist with primary care provider (also include psychologist & traditional healing) Survivorship- No formal program, people access traditional healers & psychologist Palliative Care Where- Hosp, Home, Nursing Home In comm-HCC +PSWs + Long term care nurses Community Support- not cancer specific, general, i.e. mental health, Traditional Healers |
| <i>“Need to focus on chronic disease prevention.” “Mental health is a gap.”</i> | | | | |

Results

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|--|---|---|---|---|
| #6. ON -Isolated-Yes (6 comms) Regional Hospital Difference between Rural, Remote, and Isolated- Rural more access to screening. Difference between status & non-status -No difference in service delivery; Difference linked to NIHB coverage (travel & medications) Surveillance System -No (paper=yes) Transportation Covered - No (yes, if linked to doctor’s appointment) Links with Cancer Agency - Yes & they have our contact info. | On Reserve - CHC, NS, Telehealth CHW-limited cancer training Off Reserve -Hosp, pharmacy (Telepharm), Telehealth Wait time (suspicion-dx) :- Varies...go to Kingston, may get bumped off plane for a higher priority. | Breast - Moose Factory <20 km (via plane for other comm) Telemammography Pap -In comm, local HCPs Colorectal -In community, local HCP Colonoscopy - Via plane-Timmins or Kingston Factors influencing screening: Access, other health priorities; no transportation or childcare; react when something is wrong; awareness & education ↑Screening Participation: Education solve transportation issue NIHB, mobile breast screening. | Dx received - Timmins or Kingston Test results - Varies (many patients do not have phones- delay) Late stage dx -Lack of access to screening; beliefs are reactive Navigators - No | Where -Via plane- Kingston or Sudbury, hosp Wait for tx -Unsure Follow-up -Poorly coordinated; need to leave comm; should use Telemedicine (NIHB + treatment hospital + referral hospital) Survivorship - Canadian Cancer Society phone support (difficult to access with no phone) Palliative Care Where - Home (HCC) or Hospital Comm Support -Social & Mental Health workers; Traditional Healers Outreach -Yes Telehealth cancer care education sessions; mobile mammography every 2 years |
| <i>“No funding for escorts, they need to leave the community, it is often very scary & unfamiliar for the patient.” “Good news: Sudbury Cancer Program just posted a position for a Cancer Prevention Worker for NE Region.”</i> | | | | |

Chart #17: Key Informant Data: Individual Interview Summaries cont’d. (Key: CHC=Community Health Centre; CHW=Community Health Worker; Hosp=Hospital; FN= First Nation; HCP=Health Care Professional / Provider; NIHB = Non Insured Health Benefits; NS=Nursing Station; HCC=Home & Community Care; Comm=community; Dx=diagnosis; tx=treatment)

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|---|--|--|---|--|
| #7. ON -Rural, Remote, Isolated- Yes (50-60 FN comms) Health Canada employee Difference between Rural, Remote, and Isolated- Cancer care more accessible in south. Surveillance System - No Transportation coverage -No (only if linked to another doctor’s appt.) Status vs. Non-Status Non-Status not covered by NIHB (no transportation & medication); screening same for both groups. | On Reserve - CHC, NS, Telehealth Off Reserve - Hosp, pharmacy Telepharmacy (Curve Lake) Northern ON- high # later stage diagnosis (especially♀) Wait time (suspicion-dx): People are not being screened, then it is too late | Breast - In comm for rural & some remote mobile, or by plane for isolated communities (ON Breast Screening Program) Pap -In community by local RN, or hospital or at provincial sites Colorectal -FOBT in community Colonoscopy - Hosp (distance depends on community location) Factors influencing screening: Family history, fear, access, education, transportation, child care ↑Screening Participation -Provide incentives | Dx. received -Hospital Test results -? Late stage dx - Fear of diagnosis, if they leave the comm, they will never return home; access, education. Navigators - Depends where they go for treatment (linked to hospital not FN community); some PNs are aboriginal. | Where -Depends where they live in the province. Large centre (hospital & Cancer Agency) Wait for tx. - Not aware Follow-up - Not aware Survivorship -Not aware Palliative Care Where - Depends on the community Health Canada is light on palliative care funding- HCC coordinates Community Supports - Not aware Outreach - Telehealth on cancer care; mobile mammography Northwestern ON |
| <i>“Giant Colon effective education.” “NIHB is tx focused, not prevention focused.” “Diabetes is the only chronic disease funded by Health Canada.” “Need surveillance data to support change.”</i> | | | | |

Results

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|---|--|--|--|--|
| #8. QC- Isolated- Yes (2 comms) Nurse Navigator- Oncology Difference between Rural, Remote, and Isolated- None Surveillance System- No Transportation coverage- Yes, by QC government. Link to Cancer Agency- Not aware | On Reserve- CHC, NS ,Hosp, Pharm, CBHCP (no training in cancer care) Off Reserve- Telehealth (videoconferencing) Wait time (suspicion-dx): 2-3 weeks (isolated communities deal with weather delays)s | Breast- In community, local HCP Pap- In community, local HCP Colorectal- In community, local HCP Colonoscopy- Via plane (1,940 km to Sept Îles), hospital Factors influencing screening: Lack of information on available screening; staff turnover ↑Screening Participation- Innu language information on screening. | Dx. received- Havre St-Pierre or Sept îles Test results- 2-3 weeks Late stage dx- People do not take information seriously, unable to attend appointment related to i.e. hunting Navigators- Yes, RN in Sept-Îles will refer patients to a Patient Navigator (no Aboriginal PN) | Where- Via plane Sept îles, hosp Wait for tx- <1 month Follow-up- Patient’s doctor sends care protocol to oncology centre & HCP in the comm Survivorship- Social workers in community; no formal programs for cancer survivors Palliative Care Where- Home (usually) HCC coordinates service, there are doctors & nurses that can visit palliative care patients, advice also available by phone. Comm Supports- Yes, i.e. social & mental health Outreach- Mobile mammography & visiting specialists on a yearly basis. |
| See also Leading Models: ‘DSIE’ (Demand for services between institutions) a Lotus Notes application, promoting information sharing. “Support service should be available in Innu language.” | | | | |

Chart #17: Key Informant Data: Individual Interview Summaries cont’d. (Key: CHC=Community Health Centre; CHW=Community Health Worker; Hosp=Hospital; FN= First Nation; HCP=Health Care Professional / Provider; NIHB=Non Insured Health Benefits; NS=Nursing Station; HCC=Home & Community Care; Comm=community; Dx=diagnosis; tx=treatment; RN=Registered Nurse)

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|--|---|--|---|---|
| #9. QC- Isolated- No (however, provide service for people that come to the area to work) Nurse in Charge, NS Difference between Rural, Remote, and Isolated- Not aware Surveillance System- No Electronic database– Yes Transportation coverage- Yes, by the community. Link to Cancer Agency- No comment | On Reserve- CHC, NS, medical service Off Reserve- Hospital, pharmacy, Community-Based Health Care Provider (CBHCP), Telehealth Wait time (suspicion-dx):- Not long | Breast- In comm, mobile, by provincial agency Pap- In community, by local HCP Colorectal- In community, by local HCP Colonoscopy- Via plane (500 km to Sept Îles) hospital Factors influencing screening: No comment ↑Screening Participation: No comment | Dx received- Out of comm (Sept Îles) Test results- 4-6 weeks Late stage dx- Not a problem here, due to guaranteed access to HCPs; need organized screening program. Navigators- No | Where- Chemotherapy & radiation in Sept Îles, hospital Wait for tx- 1-4 months Follow-up- Care coordinated-liaison at hospital & community & community doctor Survivorship- None Palliative Care-Where- Home Community clinic (dispensary sends in workers) Community Supports- Social & Mental Health workers & Traditional Healers Outreach- Visiting specialists, however, not cancer specialists; mobile mammography q2 years |
| “Cancer is a big problem. Health Canada needs to take charge...we need nurse navigators in communities, specialized cancer care personnel to work on prevention. Families need health care providers who will provide care & follow-up.” | | | | |

Results

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|---|---|---|---|---|
| <p>#10. QC-Rural-No Head Nurse Difference between Rural, Remote, and Isolated- Access to specialized service complicated for isolated comms (weather, transportation). Difference btw Status & Non-Status: Non-Status do not have NIHB coverage for transport & medications. Surveillance System- Yes, electronic database tracks all chronic diseases Transportation coverage-Yes, NIHB (justification letter required for plane, otherwise 12 hour bus ride) Link to Cancer Agency-No (they do contact First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC))</p> | <p>On Reserve-CHC, NS, Pharmacy (standard prescriptions) Off Reserve-Hosp, Pharmacy, Telehealth, CBHCP</p> <p>Wait time (suspicion-dx):~1 month, Gap is that people put off going to doctor related to fear.</p> | <p>Breast-20-90 km, Havre St-Pierre, hosp Pap- In comm, local HCP Colorectal-20-90 km, Havre St-Pierre, hosp Colonoscopy- >90 km, Sept îles, hosp</p> <p>Factors influencing screening: Fear; other priorities; people do not take action until well after they know they have health problems.</p> <p>↑Screening Participation: More collaboration with doctors to promote screening.</p> | <p>Dx received-Havre St-Pierre or Sept îles hosp Test results-Not long (by phone &/or mail) Late stage dx-People do not want to leave the community for health care. Palliative patients, want to die at home.</p> <p>Navigators-No</p> | <p>Where->90 km or via plane (~50% have to go to Quebec City), hospital Wait for tx-<1 month Follow-up-Complicated- Hospital Liaison RN links with HCP in community, but sometimes information gets rerouted to provincial health department Survivorship-None in community (members not interested in services outside comm) Palliative Care- Where- Home (HCC coordinates, care often provided by families, social services offers domestic help i.e. house cleaning) Community Supports-Social & mental health, traditional healers, Outreach-No</p> |
| <i>“Organized provincial breast screening program has increased screening rates for FN communities.”</i> | | <i>“Hospital not well informed about what services patients have access to in communities.”</i> | | |

Results

Chart #17: Key Informant Data: Individual Interview Summaries cont’d. (Key: CHC=Community Health Centre; CHW=Community Health Worker; Hosp=Hospital; FN= First Nation; HCP=Health Care Professional / Provider; NIHB = Non Insured Health Benefits; NS=Nursing Station; HCC=Home & Community Care; Comm=community; Dx=diagnosis; tx=treatment; RN=Registered Nurse)

| Province | Available Cancer Care | Screening | Diagnosis | Treatment |
|---|---|--|---|---|
| #11. NB-Rural-No Surveillance System- No Paper-based charts-Yes Transportation Coverage -NIHB (not sure) Links with Cancer Agency -No | On Reserve -CHC, CHW (no cancer training), Telehealth Off Reserve -Hosp, medical service, pharmacy Wait time (suspicion-dx): Unsure, poor, depends on doctors. | Breast -<20km- hosp Pap -In community, local HCP Colorectal -In community, FOBT, local HCP Colonoscopy - <20km- hospital Factors influencing screening: Cancer not talked about; intimacy of screening is embarrassing. ↑Screening Participation: More peer support; role models. | Dx received -Doctor’s office or hosp Test results - Not long Late stage dx -Social determinants of health, intimacy of screening, lack of HCPs is huge problem. Navigators - No (CHC staff help clients) | Where - > 90 km Halifax (5 hrs away), hosp Wait for tx -1-4 months. Follow-up - Care coordinated-oncology unit @ hosp & primary HCPs & extramural RN services Survivorship -No formal in comm; CCS outside community. Palliative Care Where - Home or hosp or hospice In community-HCC + family + RN extramural Comm Supports -Social & mental health workers (not cancer specific) Outreach -Psychiatrist & toll-free provincial health line |
| <i>“Need Nurse Practitioner to promote & conduct cervical screening.” “The biggest barrier is poverty.” “There is no support for Home and Community Care Registered Nurse, this is an extremely demanding position.”</i> <i>“ Need increased access to health care providers.”</i> | | | | |

Promising / Leading Practices and Models of Cancer Care Interviews

A total of 20 interviews were conducted by Saint Elizabeth staff to catalogue 20 promising / leading practices and models of care from across the country. In addition one international interview was conducted to gain information regarding an Australian Aboriginal Cancer Care Coordinator position. Contact information and an overview of each practice / model is presented along with a copy of the questionnaire guide (see Appendix F-1 & F-2).

Cancer Control Sector, E-Survey and Selected Follow-up Interviews

A total of 67 responses were received to the joint SE/CCMB e-survey, representing a response rate of 22% (see Appendix G-1 for list of survey recipients and G-2 for a copy of the e-survey). Provincial breakdown of respondents to the e-survey are listed in the chart that follows.

| BC | AB | SK | MB | ON | QC | NB | NS | PE | NL | YT | NWT |
|----|----|----|----|----|----|----|----|----|----|----|-----|
| 15 | 4 | 8 | 8 | 17 | 1 | 4 | 7 | 1 | 1 | 0 | 1 |

Of the 67 responses 13 respondents indicated that they had knowledge of on reserve patient journeys (8 of these respondents also indicated knowledge of on/off reserve transition) and a further 4 had knowledge of the transition points only. Saint Elizabeth attempted to contact 8 of these individuals for further key informant interviews and was able to arrange for 3 key informant interviews (the other 5 individuals did not respond to requests for interviews). The results of the 3 key informant interviews have been integrated into the key informant data (see Chart #17) and associated analysis. The key informant data also includes further interviews with other key informants within the cancer control sector identified outside of this joint survey.

The collective data from the two sharing sessions, the eleven key informant interviews, and the cancer control sector e-survey results and follow-up interviews are consistent with the e-survey data. Using a variety of data collection methods helps to enrich and inform the process. The issues regarding the cancer pathway are very similar in all communities, regardless of their locations. Outreach programming that is continuous is most likely linked to screening and specifically breast screening. Late-stage cancer diagnosis is not uncommon and is linked to a combination of the impacts of historical trauma and barriers to HCPs and screening. Communication between treatment centres and FN health centres is often lost or absent. Despite the fact that there is no formal palliative care programming in FN communities, the majority of communities are piecing together support for community members who want to die in their own communities.

DISCUSSION

Triangulation

Triangulation employs different methods of data collection to inform an area of study. In addition to a literature review and descriptive contexts of provincial health care delivery and FN communities, the cancer pathways project employed six different methods of data collection to build a beginning understanding of the reality of cancer pathways for FN people living in FN communities. Chart #18 summarizes the data collection methods and participation rates across Canada. The identified target population was health care providers or managers working in FN communities. The joint SE/CCMB e-survey also captured data from health care professionals in the broad cancer control sector.

Provincial breakdown of the e-survey responses are found in Appendix B-3 (Chart #12).

As part of the data collection process, two sharing sessions were hosted by Saint Elizabeth staff. The first was held in Winnipeg, MB and the second took place in Whitehorse, YT. Both sharing sessions brought together individuals that work and or live in FN communities in MB or YT. In addition, 11 key informant interviews were conducted with individuals identified through the e-survey or other networks (Nov. 2011-Jan. 2012), to enrich the data. Sharing session summaries and key informant interview summaries are detailed in Charts #15-17. Participation in the focus groups and the key informant phone surveys was voluntary, and individual and community anonymity is assured.

One of the goals of the project was to identify culturally responsive resources and services and promising/leading models of care and practice. In situations where promising / leading practices or models of care and practice were identified, interviews collected information about the model/practice, including contact information with the FN community's awareness and permission. A total of twenty (20) interviews on promising /leading practices and models of care were conducted (see Appendix F-1).

Saint Elizabeth collaborated with CancerCare Manitoba to conduct an e-survey of the broad cancer control sector. A total of 305 professionals working in cancer control across the country were emailed the survey and invited to participate. Responses to the e-survey (n=67) represented eleven provinces / territories. Responses were reviewed to identify individuals for follow-up interviews.

Discussion

Chart #18: Triangulation: Primary Data Collection Methods (Key: Ab= Aboriginal; comm=community; HCW=Health Care Worker; TC=Tribal Council; NS=Nursing Station; RN=Registered Nurse)

| | BC | AB | SK | MB | ON | QC | NB | NS | PE | NL | YT/NWT |
|--|---|---|---|---|--|--|--|----|----|----|---|
| E-Survey Health Care Professionals n=155 (see Chart #2 for provincial breakdown) | 44 | 22 Separate Access Coordinated with AFNIGC | 10 | 40 | 42 | 9 | 0 | 5 | 0 | 0 | 1 |
| E-Survey TC/PTO Health Care Managers n=12 | 1 -Health Coordinator of 1 FN | 10 -Managers, Health Directors, CHNs, Policy Analyst | | | 1 -Health & Family Service Manager of more than 30 FN communities. | | | | | | |
| Focus Groups (2) n=21+19=40 (see Charts #15-16 for Sharing Session Summary) | | | | Sept. 7 & 8, 2011 n=21 representation from rural, remote, isolated | | | | | | | YT-Oct. 27 & 28, 2011 n=19 representing 11 of the 14 FN settlements in YT (rural, remote, & isolated) |
| Key Informant Interviews (n=11) (see Chart #17 for Key Informant Interview Summary) | 2 -Health Director, rural FN -HCW, rural FN | | 2 -RN TC comm, rural -RN independent rural comm | | 3 -Executive Director Aboriginal Organization -HCW, regional hospital -Health Canada | 3 -RN Navigator -RN Manager of Isolated NS -RN Manager (rural) | 1 -Health care worker, rural FN comm | | | | |
| Leading / Promising Practice Interviews n=20 (see Appendix F for contact information & description) *International-1 Australia Aboriginal Cancer Care Coordinator | 2 -Cancer Support Group (church based) -Mustimuhw cEMR | | 4 -HEY project -TC NP, Women’s Health -Colorectal Screening -Aboriginal Communities and the SK Cancer Agency Network | 3 -HEY project -Norway House Aboriginal Journey Facilitator -Sagkeeng FN Breast Check Program | 8 -Ab Patient Navigator -Miles to Go (Support) -Ab Health Promotion -Ab Breast Health -Screening Saves Lives -NWON Breast Mobile -Telepharmacy -Telemedicine | 1 -DSIE (Demand for services between institutions) | | | | | 1 -Hospital Liaison Worker |
| Saint Elizabeth / CancerCare Manitoba E-Survey Cancer Control Sector n=67 | 15 | 4 | 8 | 8 | 17 | 1 | 4 | 7 | 1 | 1 | YT=0 NWT=1 |

Provincial Variations

All data sources point to the fact that despite provincial /territorial variations, cancer care for FNs living in reserve communities is more similar than different across surveyed regions.

One of the limitations of this project was that although the intent was to cover all provinces and the YT, data was received from a total of nine provinces and the Yukon. Some areas have minimal or no responses. Specifically, Atlantic Canada is under-represented (and NWT and NU were not part of the scope of this project). Despite this fact, the data collected provides a good initial understanding of the reality of cancer pathways for FN communities. Participating regions vary in terms of the numbers of FNs people that live in FN communities, the location of the communities, health services available, and the political organizational structures.

Change in any part of the cancer care continuum requires an understanding of the federal/provincial/territorial/FNs health and governance structure. Historically, Health Canada was responsible for providing health care services to FNs in FN communities. The health care coverage consisted of public health, health promotion, and disease prevention, and the service provision was provided by the First Nations and Inuit Health Branch of Health Canada. Since 1978, there has been a movement towards the transfer of health services (in whole or in part) to FN control. Over half of all FNs have opted for health transfer. Provinces vary in their degree of health transfer, and there can be great variations within provincial boundaries. For example, in SK health transfer is represented in the north with the formation of the Northern Intertribal Health Authority , however, there are other communities in SK that receive all of their health services from Health Canada. Health transfer is consistent with the FNs movement toward self-determination and FN governance (www.afn.ca; www.hc-sc.gc.ca).

In Oct. 2011, the first Tripartite Agreement was signed in the province of British Columbia. “Over the next two years, the federal government will transfer all of its responsibilities, resources and infrastructure for Aboriginal health in BC to a new First Nations health authority under the British Columbia Tripartite Framework Agreement on First Nations Health Governance” (Health Canada, 2011b). The agreement is between the federal government, the Province of British Columbia, and BC First Nations and is meant to support better health for BC FNs. This agreement paves the way for other provinces and FN groups to move toward full transfer.

The Canadian Association of Provincial Cancer Agencies is the national body for cancer agencies across the country, however, there is significant variation with relation to FNs on a provincial/territorial level. For example, CCO has a dedicated Aboriginal Cancer Strategy. Survey responses from across the country recognized the work of CCO, especially their culturally relevant resources such as the colorectal cancer educational package. Despite the various organizational models of the provincial cancer agencies, there is a consistent gap between cancer agencies and FN communities in all regions surveyed. First Nation communities do not feel connected to their provincial cancer organizations, they referred to “*a lack of coordination*” “*a lack of communication and collaboration*” and working relationships that are “*unclear*” or “*non-existent*”.

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However, all of the surveyed FN communities in the provinces and YT report access to organized provincial cancer screening programs (breast, cervical, colorectal), that are coordinated by the provincial cancer agencies. There are many positive examples of outreach screening programs reaching communities across Canada, most notably the mobile mammography units that successfully increase screening rates in under-screened populations, including FNs. Although there is clearly room to improve screening outreach, it is likely that the frustration expressed in the “*lack of communication and collaboration*” comments is not only directed to cancer agencies, but to the broader reality of cancer care for FNs: a reality that is witness to inconsistent access to screening; inconsistent transportation coverage; a bureaucratic and complicated benefit program (NIHB); strained access to primary care providers and specialists; no formal in-community palliative care programs; language and cultural barriers; impaired communication between treatment centres and FN health centres; the lack of use of available technology; and jurisdictional boundaries. These realities are present in all of the regions surveyed.

As stated, the regions surveyed are more similar than different. Across all regions gaps and barriers can be categorized into issues around Access, Partnerships, and Jurisdiction. Below is a summary by province and YT highlighting ways each area is different from the others (refer to Chart #12 in Appendix B-3, Chart #14-15, and Appendix D-1 & D-2 for detailed summaries).

Yukon (E-survey HCPs n=1; Sharing session n=19; Leading practices n=1)

Participants at the Yukon sharing session expressed frustration in the fact that there is not a separate YT cancer agency or FNs cancer control strategy; they feel that cancer issues of the YT are not being adequately addressed through the BC Cancer Agency. The group identified the need for northern-based environmental research to link health issues, like cancer, to environmental pollutants (related to mining and dump sites). Although participants at both the MB and the YT sharing sessions talked about the negative effects of racism and stereotyping, those at the YT sharing session drew special attention to vulnerable sections of the population, such as those living with FASD (Fetal Alcohol Spectrum Disorder) or substance abuse problems, where cancer symptoms are too often ignored by doctors. Problems with delayed diagnosis and misdiagnosis were mentioned at both the MB and YT sharing sessions, however, the YT was the only region to link inexperienced doctors to these issues. Yukon participants expressed frustration over the fact that their home care nurses are restricted from providing clinical care (i.e. dressing changes, medication administration). and explained that this is due to a jurisdictional issue involving insurance coverage that is expected to be paid by FNs. As a result, at-home palliative care is provided by families, with guidance from HCPs, in the absence of a palliative care program. The Yukon was the only region to state that palliative care patients from isolated communities are less likely to have the option of dying at home. Remaining YT sharing session data is consistent with collective data.

British Columbia (E-survey HCPs n=44; E-survey managers n=1; Key informant interviews n=2; Leading practices n=2; E-survey cancer control sector n=15)

There was no representation from isolated communities in BC in the survey responses or in the key informant interviews. However, interview data was consistent with survey data, and key informants identified the process of getting a diagnosis as “*a serious issue*” that takes a “*very long time*”. This “*lack of coordinated service*”, is linked to late-stage diagnosis and is further aggravated by the fact that there is no formal palliative care program. Both key informants identified existing links to the provincial cancer agency as an informational source. The e-survey health manager indicated that palliative care costs are coordinated by efforts of NIHB, the HCC Program, the FN band and the Northern Health Palliative care program, which is evident of a high degree of collaboration from all partners. One of the key informants indicated that their community has an electronic database

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and the other informant indicated that their community just purchased an electronic database. Remaining BC data is consistent with collective data.

Alberta (E-survey HCPs n=22 ; E-survey managers n=10; E-survey cancer control sector n=4)

The responses from AB represent rural and remote FN communities, and there is no representation from isolated communities. Alberta has the highest participation in the e-survey for health care managers of any region, which is likely due to the later start date for AB region linked to the agreement with AFNIGC (see Appendix J). E-survey health manager's comments represent over 65 FN communities, and content analysis of the aggregate comments reveals that existing gaps and barriers fall into the same three themes of Access, Partnerships, and Jurisdiction. Remaining AB data is consistent with collective data.

Saskatchewan (E-survey HCPs n=10; Key informant interviews n=2; Leading practices n=4; E-survey cancer control sector n=8)

There were only 10 responses from SK, and no responses from isolated SK communities. Of note, 100% of SK respondents reported active HCC programs in their communities. In contrast, responses indicate no available cancer programming in communities in terms of survivorship, support, or patient navigation. Difficulty accessing a primary care provider is viewed as a factor in delaying the process of diagnosis. Determinants of health, specifically poverty, education, addictions and mental health issues are also identified as barriers to cancer care, and "*screening is low on the priority list*". Remaining SK data is consistent with collective data.

Manitoba (E-survey HCPs n=40; Sharing session n=21; Leading practices n=3; E-survey cancer control sector n=8)

Sharing session responses are consistent with MB survey data. Manitoba is the only region that specifically identified internet connectivity and Telehealth availability as an ongoing issue. Like SK survey responses, MB's sharing session addressed the influence of the determinants of health in FN communities (poverty, isolation, historical trauma, residential school, loss of traditional teachings, literacy). The group described CancerCare Manitoba's role as "unclear". Manitoba participants want palliative care to be recognized as part of HCC's essential elements, to be eligible for permanent funding and to bring culturally relevant palliative care education to front line health care workers and family members in need. Remaining MB data is consistent with collective data.

Ontario (E-survey HCPs n=42; E-survey managers n=1; Key informant interviews n=3; Leading practices n=8; E-survey cancer control sector n=17)

Cancer Care Ontario's Aboriginal Cancer Strategy is reaching FN communities; respondents demonstrate an awareness of CCO and know that CCO has their contact information. Despite this fact, there is still a need for "*improved communication between cancer centres and FN communities*". Although wait times to diagnosis and treatment are not listed as issues, late stage diagnosis is recognized as a problem, especially with women in northern ON. This is likely linked at least in part to NIHB not covering transportation costs related to screening. The NIHB program is described by one of the key informants as, "*treatment focused not prevention focused*". Remaining ON data is consistent with collective data.

Quebec (E-survey HCPs n=9; Key informant interviews n=3; Leading practices n=1; E-survey cancer control sector n=1)

Although QC only had nine respondents to the e-survey, the responses represent a high percentage of isolated communities (two of the QC key informants were also representing isolated communities). The survey indicates that QC communities are the most likely to have physician services available in the community (78%), and perhaps this explains why a

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key informant from QC stated that there is not a problem with late diagnosis in the community, since there is “*guaranteed access*” to HCPs. In contrast, QC was the least likely to have Traditional Healers (22%). Quebec is the only region where provincial rates for prevention, screening, treatment, survivorship, caregiver support, palliative care, patient navigation, and pharmacy service are higher than the combined rates as indicated in Chart #12 (see Appendix B-3). Despite the fact that Quebec has a DSIE (Demand for Services between Institutions), an electronic data-sharing system (see Appendix F-1), respondents still highlighted the need for sharing of discharge information from hospitals with FNs health centres. Remaining QC data is consistent with collective data.

Nova Scotia (E-survey HCPs n=5; E-survey cancer control sector n=7)

There were only five e-survey responses from Nova Scotia and they all represent rural communities. Nova Scotia was the only region to indicate that no cancer treatment service is available in their FN communities, which may be related to the proximity of the communities to larger treatment centres. Remaining NS data is consistent with collective data.

New Brunswick (Key informant interviews n=1; E-survey cancer control sector n=4)

There was only one key informant interview with a health care worker from a rural NB FN community. Access to primary care providers was identified as an issue affecting cancer care. Remaining NB data (although limited) is consistent with collective data.

There are some provincial variations in the cancer pathways of FN communities, however, overall the picture is more similar than different. Despite the similarities, caution must be taken not to over-generalize or create a one-size-fits-all solution. First Nation communities are unique entities, and even within provincial boundaries, there are variations that will make some activities meaningful and others ineffective. Knowledge exchange and meaningful collaboration is the key to identifying actions that will promote positive change. Respondents caution against a “*cookie cutter approach*” and identify the need for “*two-way*” partnerships.

Difference between Rural Remote and Isolated Communities

Rural, remote, and isolated FN communities are more similar than different regarding access to cancer care and cancer pathways.

Logic would suggest that communities located in closer proximity to cancer care facilities would have easier access to cancer programs and services. However, when the triangulated data for FN communities is categorized according to community type (rural, remote, and isolated) the data is so similar that it is difficult to differentiate between the categories. This is consistent with the literature, which reveals that living in a rural location is a barrier to adequate health care for communities, regardless of race (Chan, et al., 2006). Non-urban sites have more difficulty recruiting and retaining HCPs and often operate in understaffed situations that worsen with the degree of isolation (Curran & Rourke, 2004). As expected, isolated communities are more likely than rural or remote communities to have nursing stations, however, they are actually less likely to have nurse practitioners. In the data collected, Traditional Healers were found in rural (47%), remote (39%), and isolated (22%) communities, but the percentage is least in isolated communities. Isolated communities report the lowest percentage (48%) of communities having health promotion programming available. This may be related to the tendency for nursing stations to have more of a primary/acute focus. Often nursing stations are busy centres where immediate/acute needs are dealt with first and prevention and promotion

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activities are often forced to take a back seat. The literature reveals that most health care being delivered in FN communities is based on a “treatment” orientation. This tendency is linked to staff turnover and community expectation (Minore, et al., 2002).

Rural, Remote, and Isolated Screening

Collective data revealed that there is minimal to no human or financial resources allocated to FN communities to operate cancer programming. The rural, remote, and isolated comparison reveals the same. As expected, women from isolated communities are more likely to have to travel outside of the community for mammography screening. There are examples of organized screening for isolated communities, where women are flown in to a site (usually a northern mobile site) where screening takes place on a two-year cycle. Both the rural and remote FN communities have examples of mobile mammography reaching their communities, either in-community or close by. Although all regions, except the Yukon, report having mobile mammography service, this does not mean that all FN communities are covered by this outreach service. Provincial cancer agencies are making strides in mobile outreach, and this success is a model that will help pave the way for other outreach programs related to cancer and chronic disease. The written responses highlight that provincial cancer agencies involve communities in the planning of screening days and events, which is part of the ongoing success of this program.

Rural, remote, and isolated communities all demonstrate an awareness of colorectal screening, and they all comment on the need to involve FNs in the planning of the delivery of kits and the collection of samples. All community types indicate that PSA testing is occurring in their communities, either by drawing of blood in the community or by doctors ordering the test on an as-needed basis. Since prostate screening is not an organized screening program, there tends to be more variability with this screening. There is mention, from the MB sharing session, of the need to include men in talks about cancer and chronic disease prevention. Rural, remote, and isolated communities all indicate concern over community smoking rates, in the absence of organized lung screening, and respondents commented on the fact that they try to maintain smoking prevention and/or cessation programs. There are various models evident to support cervical screening. The Yukon has recently started an organized cervical cancer awareness program via an October Cervical Cancer awareness week, and written responses indicate that some of the rural, remote, and isolated communities have participated in this awareness movement in an attempt to increase screening rates in their communities. All community types (rural, remote, and isolated) have community-based health care professionals that provide Pap tests in their communities and HPV vaccination in the schools. However, caution needs to be taken not to over-generalize the results, since this does not mean that all communities have the capacity to do Pap testing at the community level.

Rural, Remote, and Isolated Resources

When rural, remote, and isolated communities are asked what type of resources would be helpful, the answers are virtually the same (see Chart #10). There is a preference for oral-based resources that are evidence based with a clear need to link to cancer experts (cancer agencies). Knowledge exchange is important in the development of such resources, to ensure cultural appropriateness and local-level relevance. *“Most of the time, western health services offer their knowledge and resources to FNs. This is good, however, it’s like a one-way street...there should be a shared knowledge which could enhance overall care and prevention of cancer.”* Existing examples of outreach are often the result of a FN community or TC initiating contact with an organization (i.e. Canadian Cancer Society). The fact that the initiation occurs is an indication that the community has a level of capacity that may not be available in other communities due to staff turnover or available resources. As a result, even within the same province there can be great variation from

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community to community regarding outreach. Many of the organizations providing the outreach are also dealing with limited resources and the reality is that geography makes outreach to FN communities time-consuming and expensive. The bigger issue is that current outreach efforts do little to ensure that all FN communities are able to benefit from the outreach. As expected, outreach programs are more likely to reach rural communities (49%) than remote communities (29%) and it is not surprising that isolated communities receive the lowest percentage of outreach (18%). However, when outreach examples are reviewed, they refer more often to one-time offerings and less often to sustainable links.

“We had a regional palliative care program nurse come to the community once in 2010. It was more of a learning experience for the nurse than support for the client and family...the nurse was just as uneducated to First Nations as the First Nations are uneducated to cancer.”

This data underlines the need for resources to be developed in collaboration with FNs and available in electronic format, so that all FN communities have the potential to benefit from the resources. It also supports an integrated chronic disease approach, since collaboration of chronic disease groups collectively with FNs will be more productive. The practice of each chronic disease group (cancer, heart and stroke, lung, and diabetes) heading out to health fairs is an ineffective use of resources that benefits small numbers of people. Human and financial resources would be better spent to work collaboratively with FNs in developing programming that is accessible, sustainable, culturally appropriate, and locally relevant.

Rural, Remote, and Isolated Gaps and Barriers

Review of the gaps and barriers for rural, remote, and isolated communities reveals almost identical data (see Chart #13, Appendix B-4). This is interesting since some of the rural communities by definition are relatively close to treatment centres. Despite this proximity and in comparison with isolated communities that can be over 1000 km away from a treatment centre, responses point to frustration over the coverage or lack of coverage of travel costs. Non-Insured Health Benefits is the federal program that covers FN individuals who live on or off reserve. The program appears to create great frustration for rural, remote, and isolated communities alike, which indicates that the problem lies in the bureaucratic process rather than the actual travel or distance. Of course, individuals from isolated communities are more likely to be required to spend more time away from their home community when they are undergoing diagnosis and treatment. However, all community types (rural, remote, and isolated) report that the frustrations related to NIHB follow them to the cities, where NIHB “*dictate where we must eat and sleep*” and where accommodations are “*depressing*” and not health promoting. There are concerns expressed over the fact that NIHB has limited coverage for escorts, which are seen as important, especially for Elders and those that are unfamiliar with the city or do not speak the language.

In the written sections of the survey data collection, the sharing session data, and in the key informant interview data it becomes clear that biggest barrier to cancer care for FN communities is not distance and geography (although this clearly plays a part). The biggest barrier lies in the fact that these FN communities are living in situations of poverty, under-employment, limited educational attainment, and dealing with the impacts of historical trauma including the loss of traditions. These factors cause community stress that expresses itself in higher rates of mental health issues, addictions, and chronic disease. Furthermore, the literature suggests that even when socioeconomic status is taken into account, Indigenous populations in a publicly funded health care system have less access to and use of adequate and quality health care services (Newbold, 1998). For FNs living in rural, remote, and isolated communities, the negative outcomes of the determinants of health are further complicated by jurisdictional boundaries, which make access to health care systems, communication, and the development of effective partnerships with external organizations like cancer agencies more difficult.

Difference Between Cancer Types

Beyond screening the collective data did not reveal any differences in the cancer pathways for the various types of cancer.

There is little difference in the cancer pathways related to the type of cancer. The collective data reveals that when differentiating between the types of cancer and cancer pathways, the only point on the cancer continuum that is different is related to screening. Breast cancer screening requires mammography, and each region (except the Yukon) demonstrates active outreach programs to make breast screening more available to FN women living in communities. However, the fact that outreach exists does not mean that the outreach reaches every FN community. The data suggests that it is sometimes more difficult for FN women living in rural areas to access mammography, since there is no NIHB coverage for travel related to screening. In remote and isolated communities, there appear to be organizational attempts either through mobile outreach or FN medical van coverage to support women to attend screening.

The data reveals that cervical screening is often available in the community by a local HCP. Some communities make use of a NP hired at the TC level to provide women's health services to a group of communities (see Appendix F-1, Leading Models of Care). Many communities partner with local medical service providers to allow women to have a choice in where they have their Pap tests. There are comments regarding both breast screening and cervical screening, in terms of the sensitivity that links back to residential-school abuses. Not all FN communities have the capacity to make cervical screening available at the community level. Communities with nursing stations are more likely to be able to provide the service. However, some CHCs that have identified the need have worked to make screening available using different models of care.

Colorectal screening is a relatively new organized screening program. Since the screening itself is home based, the issue around the availability examines the collaboration between provincial cancer agencies and FN communities. Depending on the location of the FN community, attention to collection of samples, storage, shipping to the provincial lab, community awareness, and buy-in need to be considered. Manitoba participants commented on the need to communicate with FNs more effectively to ensure the screening program is effective.

Beyond screening the collective data did not reveal any differences in the cancer pathways for the various types of cancer. The issues regarding cancer care along the continuum are more often linked to problems accessing the services (transportation), a lack of communication between treatment centres and FN health centres, and the absence of formal palliative care.

Status versus Non-Status First Nations Living On Reserve

The difference for Status vs Non-Status FNs living in FN communities lies in the coverage of NIHB for Status FNs, which covers medical travel costs and medications.

According to Statistics Canada (2006), there are currently close to 700,000 First Nations people in Canada, this number includes both Status and Non-Status individuals. The majority of FNs people in Canada are Status FNs (82%), only 17% of FNs are Non-Status. Both Status and Non-Status FNs people live in FN communities. The term 'Status' means that an individual is recognized as registered in accordance with the rules of the Indian Act and is recorded in the Indian Register (www.cihi.ca). Non-

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Status FNs individuals refer to themselves as First Nations or Indians, however, they do not meet the criteria to be registered (<http://www.aadnc-aandc.gc.ca/eng/>).

Key informants were asked to explain the difference between Status and Non-Status individuals in the delivery of health/cancer care in FN communities. The content of the responses was the same regardless of the province. *“There is no difference with the actual services delivered to Status and Non-Status people living on or near reserves.”* According to the responses this includes access to cancer care for primary prevention and screening. The difference for Status vs. Non-Status is linked to the NIHB program. The NIHB program is a federal Health Canada program that is defined regionally to cover Status FNs living on or off reserve and is meant to fill the gap of services not insured by the province or territory. The NIHB program covers the costs of transportation to medical appointments and prescribed medications. However, NIHB does not cover Non-Status FNs, therefore, if a Non-Status FNs woman lives in a reserve community and is screened for breast cancer in the community, the costs of screening are covered by the province. However, if she needs follow-up diagnostics, her travel to the nearest medical service site is not covered nor are the costs of her medications (<http://www.hc-sc.gc.ca/>).

One respondent representing an isolated community provided the following example:

“For Non-Status people, travel is not covered. If they have appointments they must arrange and pay for their own travel. This would include a flight, which can cost from \$486 - \$1,452, and travel to and from the community by water taxi (\$15 each way). Then, travel from the docks to the hospital is available only for Status people. Therefore, Non-Status patients, including pregnant women and elders with canes or walkers must walk up the hill to the hospital.”

Within the services and programs available on reserve, including community based programming and outreach programming (i.e. Cancer screening), there is no differentiation between Status and Non-Status individuals. The difference becomes clear when transportation or medication needs are present. Non-Status FN individuals are eligible for provincial coverage equal to non-FNs people.

Culturally Relevant Resources and Promising / Leading Practices and Models of Cancer Care

There is a need for the development of culturally relevant resources that are meaningful at the community level.

Promising / leading practices and models of cancer care improve access by developing partnerships that cross jurisdictions.

An environmental scan of available culturally relevant resources is listed in Appendix H. The responses regarding culturally relevant resources in the e-surveys and in the interviews revealed few examples. Less than 10% of respondents were able to identify a promising/leading model/practice or a culturally relevant resource. This is likely due to the fact that communities have little to no resources (human/financial) to extend to resource development. In addition, existing links with external agencies have not been developed to a point to support extensive resource or program development that is culturally appropriate. Despite the fact that FN communities have little or no funding for cancer programming, a number of promising/leading practices and models of care are highlighted in Appendix F-1. The promising /leading practices and models of care were identified by survey participants, sharing session participants, and key informants. Each practice/model was investigated through a phone interview with an individual who is involved directly with the

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practice/model. Promising/leading practice/model informants provided written permission to allow the practice to be shared with identifying contact information. One of the barriers across FNs nationally is a platform to share information regarding these resources so that other communities can benefit from success stories. Future efforts to support e-copies of resources will increase availability nationally. Sites such as www.cancerview.ca should be used to support sharing of resources.

Language and cultural safety must be integrated into health care delivery, including cancer care, through the development and implementation of culturally appropriate resources, programs, and services. When the promising/leading practices are viewed collectively, the common theme that runs through each example is that the practices work to improve access to cancer care across jurisdictional boundaries through the development of sustainable partnerships. For example, mobile mammography is a partnership established between provincial cancer agencies and FN communities or TCs to bring breast cancer screening to the community. First Nations work to ensure information, invitations, and format are culturally safe, appropriate, and meaningful at the community level. This collaboration increases screening participation and helps to decrease fear and mistrust around screening. It is no coincidence that the three themes of Access, Partnerships, and Jurisdictions are present not only in survey responses, but also in the examples of leading practices and models of care.

Cancer Control Sector

Collective data from the cancer control sector is consistent with the collective report data, in the identification of the gaps and barriers and the resulting themes of access, partnerships, and jurisdiction.

Saint Elizabeth and CancerCare Manitoba (CCMB) partnered to develop and distribute an e-survey focused on identifying cancer control programs, services and resource for First Nations on and off reserve and Métis. CCMB was contracted by the Partnership to conduct a similar environmental scan with a focus on First Nations (off reserve) and Métis in rural and remote communities. Saint Elizabeth and CCMB recognized that both projects would require information from the cancer control sector and determined that a joint e-survey would avoid duplicate contact of the same organizations and people within the sector. In total 67 cancer control sector professionals responded to the e-survey from eleven provinces / territories. Responses were reviewed and ten interviews were completed to enhance the data. The interview participants were from the following sectors: Canadian Cancer Society (ON Division) n=1; Ontario Regional Cancer Program Staff n=4; Manitoba Provincial Cancer Agency Staff n=2; Saskatchewan Provincial Cancer Agency Staff n=3. The data collected from the cancer control sector demonstrated consistency with the collective data, the gaps and barriers, and the resulting themes.

The following quote is from a provincial cancer agency staff member it is reflective of the data collected from the cancer control sector and demonstrates consistency with the collective data. *“I understand there is a need to raise awareness of increasing rates of cancer among Aboriginal people across the province. More needs to be done to heighten this awareness and reach the population. This is an area that our department has not had much involvement in and we may need to reevaluate this. Other departments may have stronger involvement so I can't speak to that. However, creating linkages may be an option to ensure Aboriginal people have access to culturally appropriate services, know what the services are (a scan may be needed and a resource tool could be developed for communities to know what is out there). Jurisdictional issues between provincial and federal*

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health care systems are also an issue to ease the continuum of care particularly if clients are sent back home to remote and isolated communities. If cancer rates are increasing, this survey and findings can help to raise this awareness and encourage governments to recognize this as a priority.”

Cancer Pathways: Gaps and Barriers

“Walk in my moccasins and you will feel the barriers.”

The cancer pathway, gaps and barriers for FNs living in FN communities identified from all data sources can be woven together to reveal three central themes: Access, Partnerships, and Jurisdiction (see Chart #11, Appendix B-2). Analysis revealed that there is little variation between the participating regions (nine provinces and the Yukon Territory) in terms of these gaps and barriers. Despite distance from cancer centres there also is little difference between those that live in rural, remote, or isolated FN communities. The realities of the gaps and barriers must be examined in the context of the adverse effects of the social determinants of health that affect the daily lives of FNs. According to the AFNs National Chief, Shawn A-in-chut Atleo, FNs, “suffer exponentially the poorest socio-economic conditions of all people in Canada...with the highest youth suicide rate in the world...chronic health condition (rates) not seen anywhere else in the country...and an education gap that will take over two decades to close” (www.afn.ca). Respondents identified in the data collection process that social determinants, the legacy of historical trauma (including colonization and residential schools) create fear and mistrust of the health care system. These factors result in an under-screened population, later-stage diagnosis of cancers, and poorer outcomes. Palliative care facilities are not available in FN communities, and there are few long term care facilities (26%) and fewer hospitals (17%). Despite the fact that there are no formal palliative care programs in FN communities, almost 50% of communities indicate that they piece together care with the help of family members and health care workers to support those who want to die at home. In the end the picture of cancer in FN communities is bleak, further perpetuating the fear and mistrust of the system (see Diagram #1).

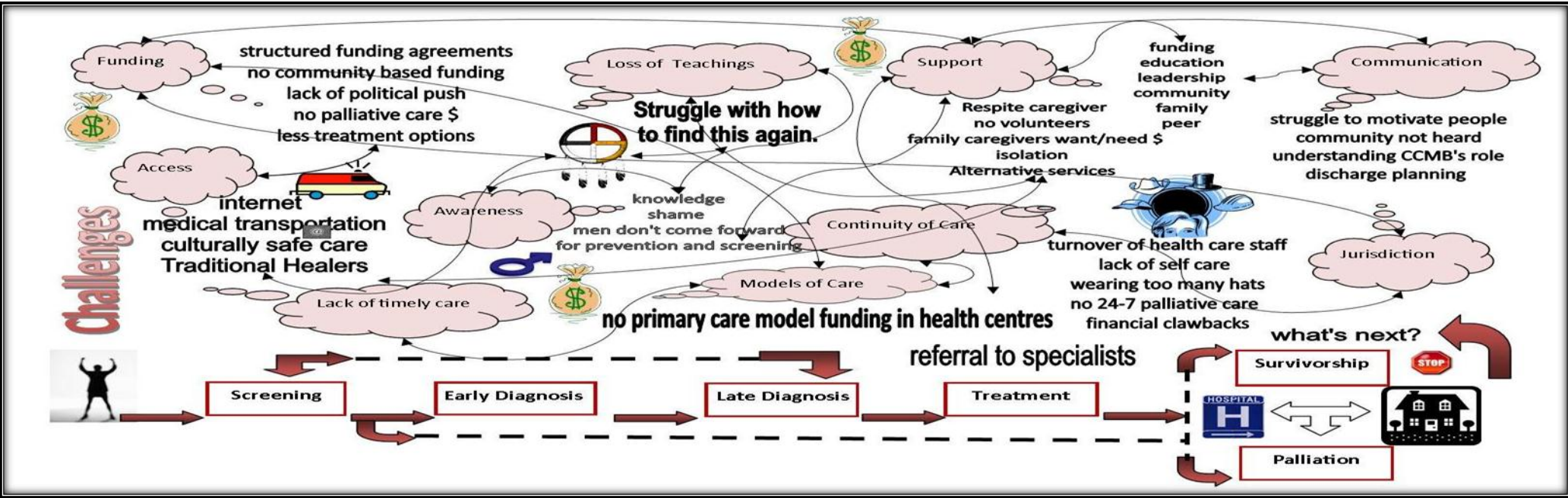
Diagram #1 presents the current reality of cancer pathways as they are depicted in the combined data from all regions. Although the themes of Access, Partnerships, and Jurisdiction are evident in every responding region, there are slight variations in regional experiences or priorities.

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Manitoba Sharing Session Cancer Pathway (data from MB Survey respondents also integrated)

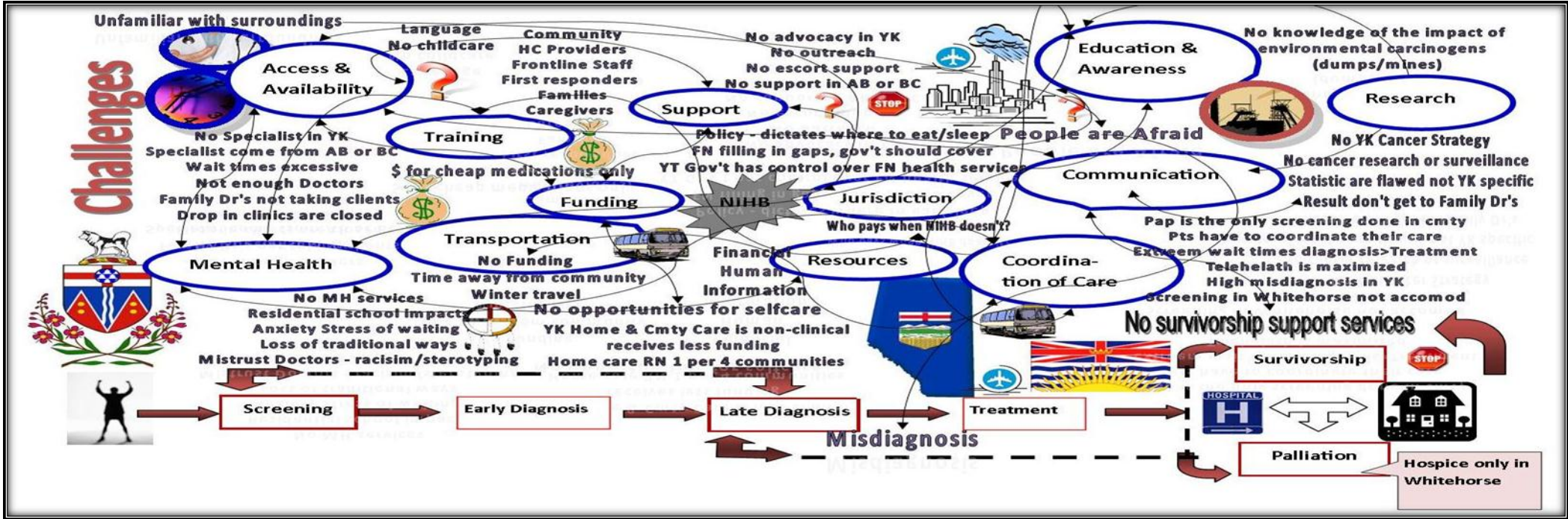
The Manitoba sharing session visual cancer pathway is displayed in Diagram # 2 (see also Appendix D-1). The main message is that impaired access and ineffective jurisdictional partnerships lead to late diagnoses for FNs (see also Chart #15).

In Manitoba, there is no travel support for FN women to attend cancer screening outside of their community. Although mobile screening is available in many communities, it is not available to all communities across the province. Communities have identified the need for stronger links to the provincial cancer agency to support community-based cancer awareness, prevention, and screening and to support clinical decision-making for HCPs working in communities. Manitoba FNs would like to partner with CCMB to support the development of culturally appropriate resources. Manitoba FN communities are providing palliative care to dying community members without the support of a formal palliative care program, which places stress on health care workers who are asking for palliative care programming and guidelines to support their care. Strengthening jurisdictional partnerships and communication will help improve cancer pathways for FN people living in reserve communities in Manitoba.



Yukon Sharing Session Cancer Pathway

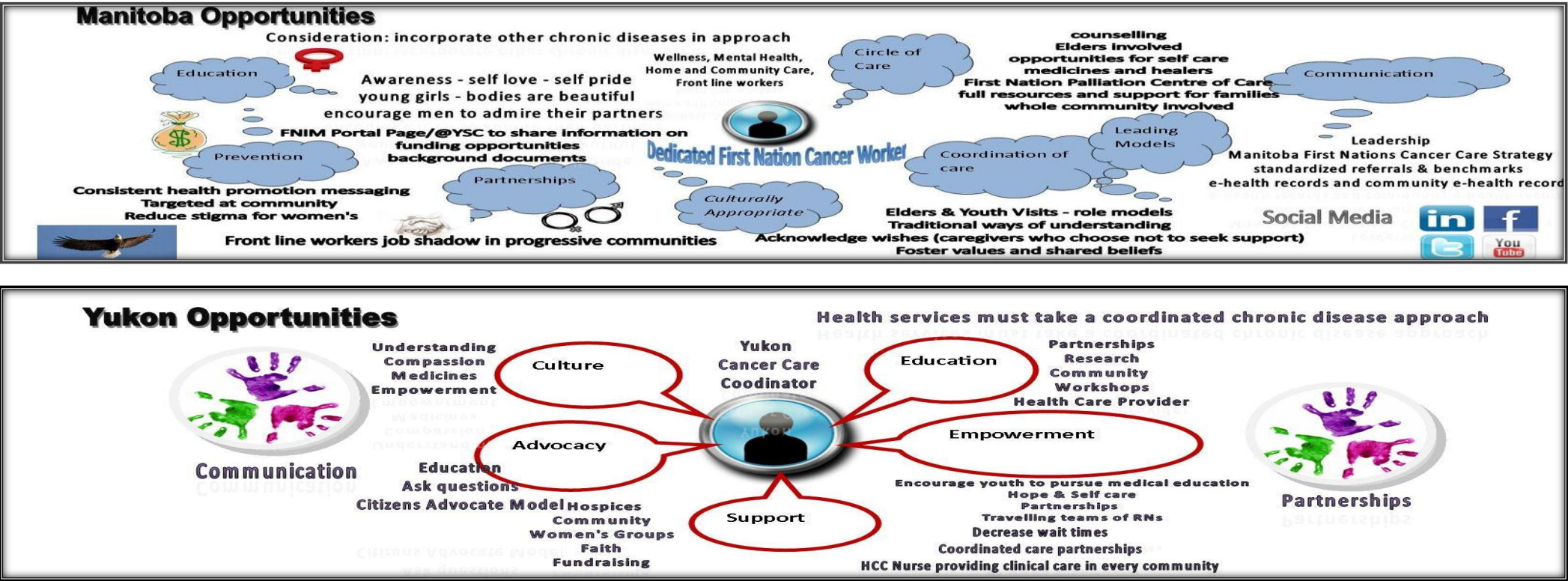
The Yukon sharing session visual cancer pathway is displayed in Diagram #3 (see also Appendix D-2) and the data collected (see Chart #16) demonstrate issues related to Access, Partnerships, and Jurisdiction. In the end, the participants reflect on a pathway that is distinguished by too many late diagnoses and misdiagnoses. The cancer pathway is a symptom of a larger, system-based problem. Access to care is hindered by problems with NIHB coverage and difficulty finding support for escorts. Many of the cancer patients have language and cultural barriers that make it more difficult to access care, especially if they are faced with racism or stereotyping. When primary care providers are difficult to access, there is a tendency to wait with questionable symptoms. The wait can be extended when screening is not close to home. Health care providers are overburdened and working in a system that has less than optimal communication, which can lead to miscommunication and misdiagnoses. Existing technology is underutilized, however, it has the potential to link cancer experts with FN communities to support knowledge exchange and client-centred case management, to help ensure patients do not get lost in the system. Jurisdictions need to work together to promote use of technology to support palliative care in FN communities, in a manner that respects cultural beliefs, is safe, and is affordable.



Opportunities for Change (Sharing Sessions - Manitoba and Yukon)

Participants at the Manitoba and Yukon sharing sessions documented their vision in terms of the opportunities for change to the current reality of their cancer pathways (see Diagram #4). Participants at both sessions indicated the need to take a chronic disease approach to cancer care, that they view cancer as a chronic disease, and they believe that efforts to address the cancer pathways will have implications on the pathways of other chronic diseases such as heart disease and stroke, diabetes, and lung disease. Partnerships that support two-way communication are seen as the key to addressing the existing gaps and barriers. Participants at both sessions identified the need for culturally relevant and locally meaningful resources that address not only the disease processes, but the issues of self-worth and self-care. Community-based workers that can assist patients to navigate the health care system and advocate on their behalf hold promise for communities.

Diagram #4



Improving Cancer Pathways: Addressing Gaps and Barriers

The road to improving cancer pathways for FNs must address Access, Partnerships, and Jurisdictional Issues, in the context of the determinants of health.

Cancer is a chronic disease and shares common risk factors with most other common chronic diseases, such as heart disease and stroke, diabetes, and lung disease. An integrated chronic disease approach is recommended by participants at both sharing sessions (Manitoba and Yukon), and is also mentioned in the survey written responses: *“Need to focus on chronic disease broadly.”* The expanded chronic care model offers a framework for an integrated chronic-disease approach that works across the care continuum (see Appendix L) (http://www.improvingchroniccare.org/index.php?p=Model_Elements&s=18, http://www.primaryhealthcarebc.ca/resource_eccm.html).

From an examination of the Access, Partnership, and Jurisdictional gaps and barriers it is easy to see that other chronic diseases share similar gaps and barriers for FNs.

ACCESS

The first theme of the gaps and barriers is Access. The term defines the essence of the category and is divided into six subthemes: Transportation, Health Care Professionals, Education, Prevention, Screening, and Care and Treatment. Each subtheme will be discussed in terms of addressing the issue and improving the pathway.

Transportation

The federal NIHB program provides coverage for medical travel for all Status FNs living on or off reserve. Therefore, it is surprising that the number one issue identified in all of the data sources is *“medical transportation”*. Issues with NIHB are well documented in the Patient Wait Times Guarantee Project (2009). One Health Canada employee describes NIHB as having a focus on *“treatment”*, not prevention. This is evident in the comments that indicated *“transportation to screening is covered if it is linked to a doctor’s appointment”*, which creates an environment waiting for creative solutions. There is inconsistent coverage from region to region regarding transportation to screening (i.e. mammography). Transportation coverage varies from no coverage (ON), to full coverage (Northern SK). The AB e-survey for health managers revealed that eight (8) of the managers indicated that travel for screening is covered by NIHB, and only one manager indicated that travel related to screening is not covered by NIHB. Some FN communities cover the costs of this transportation while others partner with the province to support coverage (QC) (see Key Informant Interviews Chart #17).

Transportation to screening is not the only problem. The NIHB system is described as *“bureaucratic”* and *“full of red tape”* by HCPs responsible for coordinating the paper work. One of the issues linked to cancer care is described by a survey respondent, *“Travel is established by a separate organization than those providing the cancer care. There is often a disconnect in coordination, if we have to send a patient to an appointment the travel arrangements (financial) may not be in place by the required time and the appointment is often delayed.”* Delays in a cancer pathway that is already burdened with late diagnosis are frustrating for everyone involved.

The issues with NIHB continue past screening and initial appointments long into treatment: *“Travel for a lengthy treatment, such as a series of radiation treatments, is very difficult to obtain and arrange through NIHB. Clients have found meals unavailable at the provided accommodations, for instance. It is hard for a client weakened by the treatment to get to and from appointments on foot, even if the accommodation is close, and NIHB is reluctant to provide taxi services. Some accommodations have stairs or allow*

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smoking, which a cancer patient may be unable to tolerate. Requests to accommodate these limitations are met with suspicion by NIHB travel assessors.” There was an example provided by a sharing session participant in the Yukon whose daughter was undergoing cancer treatment in Vancouver. The treatment was extensive and lasted longer than three months. At the three-month mark, they received word from NIHB that they would have to return to the Yukon for one week until the NIHB funding could be reinstated: *“I had to fight every step of the way for my daughter.”* In the end, logic prevailed and coverage continued for the length of the required treatment.

In the context of life in FN communities, where unemployment rates can be as high as 80%, transportation is always an issue (www.afn.ca). Many families do not have the option of taking their own vehicle, and in many isolated communities the only way out is by air. Of course geography and weather also play a part in the access equation. There is a definite preference for screening or other programs that can be community based. Provincial cancer agency partnerships with FN communities need to be strengthened to promote aspects of cancer care that can be delivered or organized in communities, ensuring quality and safety. The potential of existing technology needs to be explored to link FNs with provincial cancer experts, to decrease required travel, and to promote education for health care workers and communities. Jurisdictional partners (F/P/T/ FNs) need to view cancer pathways for FNs and identify required travel parameters, and these parameters should be used to revise existing NIHB protocol to make the system less bureaucratic, more logical, and timely.

Health Care Professionals

Combined e-survey data reveals that less than 50% of respondents indicated that they have access to doctors in their FN community. The only exceptions are QC (78%) and Nova Scotia (60%). Even this access tends not to be consistent access, as it is often provided by rotating doctors on a part-time (i.e. 2 days per week) basis. As one respondent indicated, *“Doctors are overwhelmed with the acute needs of chronic clients,”* and there is little attention paid to prevention, screening, or long-term case management. Additionally, other HCPs (nurses) tend to have high turnover rates. The literature identifies that this lack of continuity of HCPs is often linked to low screening participation rates and cancer diagnosed in later stages (Minore, et al., 2002). Difficult access to a primary care provider forces visits to hospital emergency rooms or walk-in clinics, where as one respondent commented, *“doctors dispense prescriptions to cover up the [problem], rather than find out what the problem is.”* This tendency toward acute episodic care is well documented in situations where high staff turnover is present (Minore, et al., 2002). As a result, these visits often result in disjointed care that does not get followed up, and may lead to poorer outcomes.

There are various successful practices that have been demonstrated to address recruitment, retention, and coordinated care delivery. Various provinces have incentives targeted to HCPs, and ensuring these incentives extend to those that work in FN communities is one step to addressing turnover. Incentives may include relocation support, sign on and retention bonuses, or educational assistance. Evaluating the effectiveness of such incentives specifically for areas that have high turnover or are difficult to staff would be beneficial information for all jurisdictions. First Nation communities have been actively trying to encourage youth to pursue health careers (www.afn.ca). Existing staff and the community members would benefit from a case-management approach to ensure people do not get lost in the system. Patient navigators can help support patients within the health care system, and they can also act as a bridge between jurisdictions. Technology and partnerships that link urban health centres (i.e. cancer treatment centres) with FN health centres will help promote continuity of care, and support the ongoing educational needs of HCPs.

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Education

All data collected indicates that cancer educational opportunities in FN communities are limited for both HCPs and community members. One exception is the Saint Elizabeth @YourSide Colleague Cancer Care Course and Education Series, a program that received positive praise from those respondents that were aware of the program. However, respondents indicate that the overall awareness of this online educational series for health care providers, available at no cost to communities, needs to be increased. The program was developed in partnership with FNs and is a model of the integration of current guidelines and practices into a format that is readily accessible, “Anytime, anywhere” (www.atyourside.ca). The e-format allows easy content review and updates and helps to ensure consistency.

Most respondents indicate that they have cancer resources in their community, although they are generally not able to identify where the resources come from: “*we have pamphlets from somewhere*”. Perhaps this is because they also indicate that resources received are generally not culturally appropriate or locally meaningful. Community educational levels, literacy, and language can build additional barriers to the utilization of existing resources. There is a recognized need for culturally appropriate, locally relevant, cancer-specific information and cancer information as it links to chronic disease. The concept of cancer in the prevention realm is one that needs to be emphasized along with the recognition of the common risk factors for chronic disease (broadly).

Respondents also identified the need for education targeted to “*all levels*” of HCPs. One respondent suggested a “*cancer certificate*” program. Education around palliative care, for families and health care workers, is a need echoed across the regions, and this will be discussed further in the palliative care section.

Regardless of the type of education required (community or professional), the need to partner with experts is clear. Partnerships between provincial cancer agencies (and other chronic disease groups) and First Nations will help promote culturally relevant, evidence based information. Using a platform like @YourSide Colleague will ensure accessibility to all FN communities across the country.

Prevention

When respondents were asked if they have ‘cancer prevention programs or services’ in their community less than half (48%) indicated that they have activities related to cancer prevention. Terminology regarding cancer prevention can be inconsistent and confusing, even the concept of cancer being preventable is not well understood. The common risk factors linked to chronic disease (inactivity, overweight and obesity, smoking, and unhealthy diets), are often not recognized as also being linked to cancer. The data revealed that the most common examples given in terms of prevention programs deal with activities targeted toward Type 2 diabetes prevention and healthy child development. This is not surprising, since there are long-standing dedicated funds and programs in both of these areas in FN communities.

Promoting a holistic integrated chronic disease approach will help communities recognize that prevention of one chronic disease, like Type 2 Diabetes, will have protective effects against other chronic diseases like cancer and heart disease. The sharing sessions provided more opportunity for dialogue. Given this forum, participants discussed the need to strengthen “*self-worth*” and “*self-care*” concepts that have suffered the negative effects of historical trauma including residential school. The need to identify self-worth is consistent with the findings of the Manitoba First Nations Patient Wait Times Guarantee Project (2009). Communities gave examples of trying to reconnect with “traditional ways”

Discussion

and “holistic” approaches to health. Historical trauma continues to haunt FN communities and expresses itself in higher rates of mental health issues, including addictions and suicide. It is difficult to focus on prevention when social determinants of health create conflicting priorities.

Respondents indicated that cancer is generally not perceived as having any link to prevention. Increasing awareness of the common risk factors for all chronic disease would help spread the word that there is something communities can do to decrease their risk of cancer and other chronic diseases. This holistic integrated message is one that all chronic disease agencies need to support.

Screening

Currently in Canada, there are three organized cancer screening programs: breast screening, cervical screening and colorectal screening. The data clearly demonstrates that all three types of screening are reaching FN communities; however, access is not consistent.

Mobile mammography breast screening is a positive example of outreach that is reaching many FN communities across the country. Provincial cancer agencies work with FN partners to organize screening and wellness days. Community-based screening promotes partnerships and builds cultural safety into the process. Communities express with pride how breast cancer screening rates have increased in their communities since access to mobile screening has been available. Many respondents referred to the effectiveness of screening that is closer to home (see Leading Practices, Appendix F-1 & F-2). However, the reality is that not all communities have access to mobile screening; for example, there is no mobile screening available in the Yukon. In other areas, the mobile may set up at a small local hospital and invite eligible FN women to participate. This is where the transportation coverage through NIHB becomes an issue, in some areas transportation is covered in other areas there is no coverage for transportation linked to ‘prevention’. Some communities try to work around the NIHB issue of transportation coverage for breast screening by organizing a community “*medical van*” to take women to the screening site, while others arrange cost sharing with the province. Cancer agencies and FN communities/organizations need to continue to work together to track which communities currently have access to screening and where efforts need to concentrate to reach under-screened communities.

The data indicates that many communities organize cervical cancer screening at the community level by having local health care professionals conduct the Pap testing for eligible women. One FN community that is part of a TC in SK is finding that a NP, hired at the TC level, is an effective way to support women’s health, including regular Pap testing (see Leading Practices, Appendix F-1). A number of respondents mentioned that they try to promote Pap testing in October during Cervical Cancer Awareness week. All provinces indicated involvement in the HPV immunization programs. Communities with nursing stations were more likely to have local health care professionals completing Pap tests for women in the community. However, there are also health centres that have determined local need and have coordinated local Pap testing. Provincial cancer agencies could improve cervical screening rates by working with FN communities to develop and organize outreach programming that brings Pap testing to communities, especially those that do not have the capacity to provide the service. This outreach will require close collaboration with FN communities, since access is only part of the screening equation. Many respondents talked about the influence of a history of sexual abuse and other trauma that influences women’s comfort level with cervical screening.

Colorectal screening is the newest organized screening program in Canada (it is not yet available in YT). Responses indicate there is a high level of awareness regarding colorectal screening. Although the screening method is different than breast or cervical screening it is equally important to involve FN communities in the planning of the outreach. Some

Discussion

frustration was expressed in MB, where planning did not involve FNs and as a result there were problems with the initial roll out of the MB screening program in FN communities. The Saskatchewan Cancer Agency (SCA) engaged FNs with the colorectal cancer screening rollout, and this practice had a positive outcome and demonstrated above-average uptake of FIT (fecal immunochemical test) testing (see Appendix F-1 Colorectal Screening: A model to engage FNs in FIT testing). First Nations engagement included high level activities such as the Vice President of the SCA meeting with RHAs and FN leaders, as well as grassroots initiatives such as the SCA partnership with Saint Elizabeth, and First Nations and Inuit Health collaboration to bring educational sessions to northern SK (in person and virtually). The educational sessions highlighted the new colorectal screening program and the @YourSideColleague® Cancer Care Course.

Although prostate cancer and lung cancer do not have organized screening programs, the data illustrated an awareness of the screening conducted for both types of cancer. For example, rural, remote, and isolated communities indicated that they have the capacity to coordinate PSA (prostate specific antigen) testing. In terms of lung cancer, respondents expressed frustration regarding recent Health Canada cuts to smoking-related programming (ie. Cessation programming).

Provincial cancer agencies have demonstrated success with outreach programs like mobile breast screening. This outreach should expand to reach more FN communities. The established relationships can further cultivate links to support knowledge exchange that can be used to build ongoing educational programming for health care workers and culturally appropriate resources that will work at the community level. Screening too often takes a back seat to acute care needs. The current lack of an electronic database in the majority of FN communities makes it time consuming to identify and track community screening needs. Screening eligibility and participation rates should be available at the community level in an e-format that respects the FNs principles of OCAP. Screening participation goals could be set in collaboration with cancer agencies.

Care and Treatment

Once a cancer diagnosis is made and the cancer patient returns to their FN community, there is little evidence of support for the client or their family. Access to cancer treatment in communities is low (17%) and there is little evidence of survivorship (14%) or support programming (12%) in FN communities. However, the issue of greatest concern regarding care and treatment is the lack of formal palliative care programming. In the absence of formal programming almost half of communities (47%) indicate that they provide services for those community members who want to spend their last days at home. Respondents shared stories of families providing around-the-clock care to dying loved ones. In the Yukon this is done without the hands-on assistance of HCWs, due to jurisdictional issues that require FNs to cover the costs of insurance. In other regions palliative program financial support is described as “*light*”, “*limited*”, or “*not available*”. Participants at the MB sharing session were vocal about the need to fund palliative care as one of the essential elements of the HCC program.

All respondents point to the need to partner with provincial cancer agencies to ensure that cancer education regarding palliative care is available to families and HCWs. Health Care Professionals identify the need to have access to palliative care guidelines in community health centres. A number of respondents mentioned that there is a need to examine the current practice of the availability of pain medications for palliative care patients (recognizing that there are community concerns regarding narcotics in the community). Health

Discussion

Care Professionals have clearly had experience dealing with palliative care patients that have been discharged to their FN communities, only to discover that medication coverage through NIHB is not equal to the medications they were receiving in the hospital or treatment facility. Communication within the circle of care needs to improve to support safe, continuous, and quality care, no matter where the circle of care extends. Palliative care patients deserve seamless care, and concern over the availability of required pain medication is not reasonable.

Treatment centres need to be able to identify FN cancer patients and their home community locations. Policy must support communication with FN health centres prior to discharge. Discharge must ensure continuity of medications and care supplies for cancer patients. Non-Insured Health Benefits program plans for FN individuals must, at a minimum, provide coverage equal to provincial plans. Flexibility for exceptional cases should be supported by a process that allows effective, timely communication between the required parties (NIHB, treatment centre, FN health centre). Palliative care needs to be recognized and supported through human and financial resources in all FN communities. Links with provincial cancer agencies need to be strengthened to extend palliative care training to FN HCWs and families in a format that is flexible and available on an ad hoc basis. Collaboration between cancer agencies and FNs can build culturally appropriate resources that are meaningful at the community level to support the continuum of cancer care.

PARTNERSHIPS

Partnerships are essential to support improvement in cancer pathways for FNs living in FN communities. The subthemes of partnerships includes: Cancer Agencies, Hospitals, Aboriginal Navigators (Patient Navigators), Technology, and Research.

Cancer Agencies

Organized screening programs have connected cancer agencies with FN communities across Canada. There is evidence of positive collaborations with FNs related to mobile mammography outreach programs and cancer awareness strategies such as the Cervical Cancer Awareness Week. Despite these connections, there is a distance evident in the comments citing that *“there is a lack of communication and collaboration”* with provincial cancer agencies. Respondents recognize the expertise of the cancer agencies and their comments demonstrate a willingness to work with cancer agencies to develop culturally appropriate resources, bring prevention and screening closer to home, provide cancer and palliative care education to community members and health care workers, and support a system of seamless care. Ontario is the only province where key informants indicated a connection with the provincial cancer agency that included contact-information sharing. In the MB sharing session, participants described the role of CCMB as *“unclear”*. In the Yukon sharing session, participants stated that they felt the British Columbia Cancer Agency could not meet the needs of FNs in the YT, and participants expressed the need for a YT-specific cancer agency and at a minimum a YT-FNs Cancer strategy. Participants at the YT sharing session also revealed a keen interest in working with the cancer agency to collect FN-specific data around cancer rates and felt that environmental mining and dump sites should be tracked for possible links to cancer.

Cancer agencies have existing educational programming for communities and health care providers. They also have palliative care educational material. These resources can help connect cancer agencies to FN communities. Working in collaboration with FNs, resources can be adapted to meet the cultural needs of FNs. Effort must be taken so that resource development is available to all FNs. Website access would allow sharing and updating of resources. Cancer agencies need contact information of FN reserve communities and

Discussion

communities need cancer agency contact information. This will allow a starting point for relationship-building and communication. However, token communication is not enough, for FN health centres rely on the cancer experts to guide them through some of the most stressful cases they encounter. Partnerships with cancer agencies need to address hard issues, such as information sharing, discharge planning, decisional support, and consultation.

A promising/leading practice from SK is highlighted: The development of the Aboriginal Communities and the Saskatchewan Cancer Agency Network (Network) is an example of a low-cost, flexible method to strengthen partnerships. The Network was established in 2007, and although the evolution has been slow, there are positive signs of improved communication. One of the first objectives of the Network was to establish sharing of contact information. The Network is in the process of expanding by inviting other chronic disease agencies to join, an action that is consistent with the data indicating that issues evident with cancer access are likely also issues with other chronic diseases. The health care organizations work with communities to identify and develop solutions collaboratively.

Hospitals

Hospitals and cancer agencies are closely linked when it comes to cancer care. Depending on how provincial cancer agencies are organized, there may be significant overlap. Hospitals are listed here as a subtheme, because in the content analysis hospitals emerged as a separate theme. The largest gap and barrier with regard to hospitals is the lack of communication with FN health centres. This is not a new issue and it is not limited to cancer care. There are jurisdictional and privacy issues that need to be addressed to allow seamless care to become a reality. However, there are provisions in privacy legislation to share information within the ‘circle of care’. Hospitals need to be able to identify which patients are of FN ancestry and which FN community they will go to on discharge. As one respondent commented: *“The gap I experience the most is the follow up for the client, the information is given to the client with little to no information for the nursing station to co-ordinate follow up care.”* Relying on weakened patients and stressed families to relay information is not an effective practice.

In Quebec, a Lotus Notes e-application connects care centres (hospitals, treatment centres, FN health centres). It allows for sharing of essential information between care givers, but does not allow access to the full scope of the client’s history (protecting privacy) (see Appendix F-1, Leading Practice-DSIE). This type of data sharing is essential to support patients as they move from one system to another. Policy change to ensure consistent information sharing will help fill the communication gap with hospitals.

Aboriginal Navigators

Over 80% of respondents to the e-survey for HCPs indicated that there are no PN programs or services available in their FN community. In order to access PN services the majority (55%) of FN patients need to travel more than 90km by road or further via plane. (Note that respondents may be grouping PN services with cancer treatment services, since the response rates are very similar. The assumption that PN services are available where cancer treatment is available may be optimistic). Further, it is more likely that if PN services are not available, patients generally do without the service versus travelling to access this service. The majority of key informants and the sharing session participants (MB and YT) also indicated that patient navigation services are rare.

Discussion

There is no evidence in the collective responses (e-surveys, sharing sessions, key informant interviews, or leading practice interviews) of any human and/or financial resources available in FN communities to support PN.

Combined responses reveal that the PN role is well recognized, and it is identified as a current gap in the system and as a solution to many of the existing communication problems. There is clear support for ‘Aboriginal’ PNs. Respondents indicate that this distinction will help bridge the communication gap and the cultural gap, while promoting cultural safety for patients and their families. The MB sharing session envisioned a model of PN that would include coordinators or navigators at the TC level that would link to community-based workers at the community level. The YT sharing session also supported the concept of PN, and they felt that for their territory PN would be most effective working at the territorial level as a FNs ‘Yukon Cancer Coordinator’. Different models will work for different regional locations, and the common factor is that the concept of PN is always referred to positively. There is a clear need for a link between the cancer care system and patients (and their families) who live in FN communities. The PN role must be able to work across jurisdictional boundaries and should be involved with transportation and appointment coordination as well as supporting cross-jurisdictional communication, including the use of available technology to support ongoing links.

An Aboriginal PN role is highlighted as a leading practice from Ontario and was recognized as a best practice by Accreditation Canada (see Appendix F-1).

Technology

Technology is advancing at an astounding rate, yet the majority of FN communities are still working from paper-based charts. Providing simple counts of community members with chronic disease, including cancer, is too often a time consuming, labour-intensive task. Tracking health indicators or screening eligibility and outcomes is generally beyond community capacity, without electronic means, especially for large communities. First Nation communities are looking for electronic health records that allow them to collect and control their own data and respect the FNs principles of OCAP. Many communities have purchased or constructed databases to meet their needs at the community level. One example that is highlighted as a leading practice is the Mustimuhw Community Health Record system. This system is owned and operated by the not for profit Cowichan FN Band in BC. The community-electronic medical record (c-EMR) allows collection of personal health information, is flexible enough to meet various community needs, and has the capacity to integrate a case-management approach that is consistent with chronic-disease management systems. The success of the Mustimuhw cEMR is evident in that it has now expanded to over 50 FN communities in BC and is also being used in other provinces (see Appendix F-1). There is movement on the national front and the provincial/territorial front to implement electronic health records. First Nations look forward to being able to identify FN data as it links to cancer and other chronic diseases. Respect of the FNs principles of OCAP will be critical to success in this area (Assembly of First Nations, 2007).

Respondents expressed significant frustration over the fact that current available technology is not being used: *“Telehealth and Skype are not being used to link”* FNs with cancer organizations. Respondents see tremendous potential for the use of technology in terms of doctor-patient interactions, HCPs –Cancer Agency interactions, HCP and community education, patient-family interaction, and patient-patient support groups. One respondent stated that typically cancer patients from their community travel *“10 hours (return) for a 10 minute appointment”*, and these are patients who are weakened by treatment and illness. Technology can and should be used to support virtual appointments when appropriate. Provincial health systems need to coordinate payment schedules that provide compensation for HCP e-appointments.

Discussion

There are promising practices incorporating technology, specifically telepharmacy and telemedicine. The telepharmacy practice is outlined in the Promising/Leading Practices/Models section (see Appendix F-1) and is located in Curve Lake FN in ON. Only 43% of communities indicated that they have pharmacy services available on reserve, and for the communities that do not have available pharmacy services, acquiring medication is a complicated process. Some communities coordinate medication pick-ups, while others require community members to coordinate their own medication needs. As expected, NIHB travel coverage becomes an issue if a doctor's appointment is not part of the travel.

The telemedicine project highlighted in the Promising/ Leading Practice/Models section (see Appendix F-1), describes a First Nations- owned ON initiative, Keewaytinook Okimakanak Telemedicine (KOTM), that has been operational for four years. Jurisdictional cooperation is essential to support telemedicine, but the advantages to the system and patients are clear.

Saint Elizabeth @YourSide Colleague® was recognized by respondents as a good example of e-technology reaching FN communities. This e-platform promotes access and flexibility and allows education to target various levels of need from community-level information to HCPs. This type of programming should be expanded, since it has the potential to address a number of the gaps and barriers identified. For example, the platform could be used to connect cancer agencies with FN communities to support collaboration in the development of culturally appropriate resources. It could also be used to inform HCPs of new evidence-based practices through live webinars or by posting existing guidelines, such as those for screening and palliative care. The use of technology has the potential to bridge a number of existing gaps, and the possibilities are endless.

Research

First Nations recognize the power of statistics and want to be able to identify FN numbers as they link to cancer and chronic-disease rates. One ON health manager stated: *“FN specific data is lacking, it tends to be combined with regional data or rural data (including non-FNs). We need statistical information to advocate [for our needs], data will help support strategic direction for communities.”* In the YT sharing session there was keen interest for research that would be able to identify Yukon and Yukon FNs people specifically and not see their numbers combined with data from BC. Having this knowledge will provide direction for programming and support evaluation to ensure there is movement toward positive outcomes. The YT sharing session also identified the need to have research related to current mining operations and dump sites, to subsequent cancer rates. Respect for FN principles of OCAP will build the trust required to integrate FN identifiers and gather surveillance data that can be used to promote positive change. A recent (2010) pilot study in ON worked to develop and implement protocol that enabled two cancer centres to apply Aboriginal identifiers, with patient awareness and consent . The study points to the need for “strong project governance and accountability structure; cultural sensitivity, awareness and engagement; a strong underlying survey methods framework; and a strong communications plan” to support success” (Cancer Care Ontario, 2011). Identifiers are important for research, however, they are also important for coordination of services. Jurisdictional agreements need to support Aboriginal identifiers in a manner that respects FNs principles of OCAP and provides for FNs data that can be used to identify needs, set priorities, plan services, and monitor outcomes.

JURISDICTION

First Nations communities are historically linked to the federal government for the provision of health care coverage. Even though many FN communities or TCs are now responsible for the provision of their own health care (commonly referred to as ‘transferred’), the NIHB program creates an ongoing jurisdictional relationship with all FN individuals and all FN communities. The coordination of provincial health care through RHAs creates another jurisdiction, which may be complicated by the fact that FN community boundaries do not necessarily coincide with RHA boundaries, therefore, it is not uncommon to see an independent FN community or TC that is located across two or more RHAs. There are also FN communities or TCs that not only cross RHA boundaries, they also cross provincial boundaries. Provincial organizations like cancer agencies and chronic disease agencies provide care to everyone within the provincial boundaries. Needless to say, the system is complicated and full of potential barriers. There is also a cultural boundary that deserves respect, and the discussion of FNs principles of OCAP is an example of this boundary in practice. FNs are working to preserve their cultures. Collaboration with external organizations is essential to ensure FNs culture is integrated and respected, and that resources, programs and services are meaningful to FNs at the local level.

First Nations indicate in the data that they need access to FN-specific statistics for effective planning and health care delivery. However, FN --specific surveillance data is not readily available for cancer or chronic disease statistics. For example, screening eligibility for FNs too often involves an antiquated process of attempting to identify FN communities by postal code, which results in a time-consuming process for cancer agencies and FN health care workers. Hospital and treatment centres are also often not aware of a patient’s ancestry or that they will be discharged to a FN community with a health service system that might be different from that available in urban centres. The development of a system of Aboriginal-identity indicators must respect the FNs principles of OCAP and will require full collaboration of jurisdictional partners, including FNs, the federal government, the provincial government, and RHAs in each region.

Jurisdictional issues generally revolve around authority, money, resources, and culture. Respondents comment on the frustration of “*artificial*” barriers that are constructed as a way to offset responsibility. According to a health manager from BC, “*A mechanism needs to be put in place for equitable health service delivery regardless of race. Too many health authorities are getting away with using the ‘jurisdictional’ issue.*” To improve cancer pathways for FNs, the various jurisdictions need to agree to work toward this common goal. Changes to access and partnerships will not be effective or sustainable without corresponding jurisdictional change and cooperation. First Nation communities need dedicated funding to support cancer programming across the continuum. These efforts should encompass a broad chronic disease focus and include the major chronic disease agencies. Aboriginal patient navigators need to be able to work across jurisdictions to identify ways to improve cancer pathways. Information sharing agreements need to be clear and integrated into policy so that FN cancer patients are not discharged to their home communities without prior collaboration with the local health centres to ensure availability of care, including educated providers, available pain medications and supplies, and coordinated follow-up and support.

Discussion

Improving cancer pathways for FNs will require efforts to address Access, Partnerships, and Jurisdiction, and action on these fronts will create more positive outcomes for communities. It is not surprising that the promising/leading practices and models of care identified all work to improve access by creating partnerships that cross jurisdictions. The data in this report is specific to FN communities, however, the findings are consistent with the expanded chronic care model, which identifies the need for communities and health care systems to work together to support improved population-based health outcomes and functional clinical outcomes (see Appendix L) (British Columbia Ministry of Health, 2011). The expanded chronic care model can be used to guide action plans to address the gaps and barriers identified in this report around the broad concepts of access, partnership, and jurisdiction.

Eleanor Carriere's Cancer Pathway, "My voice was not heard."

Transcript of Recorded Interview, January 31, 2012

Preamble:

Eleanor (Eli) Carriere is a FNs breast cancer survivor from Nelson House Manitoba. When she learned of the cancer pathway work, she asked if she could share her story to help inform the project. Her story helps remind us of the true intent of the report and the actions that will follow. Eli's story is presented in her own words and was recorded and transcribed with her permission and consent. We respectfully acknowledge Eli's willingness and openness to share her story. Along the right-hand side of the page, key concepts are highlighted that reflect back to the collective data results of the report. Eli's story brings the cancer pathway to life and reminds us that this work will impact real people, their families, and their communities.

My name is Eleanor Carriere, I'm age 55. I work with NCN Child and Family as a case manager. I'm a social worker by profession. My cancer ordeal started in 2007. Well at age of 49 I started taking those mammograms tests, there were like the mobile ones that came. I was working at Nelson House at the time, I used to travel from Thompson to Nelson House which is an hour away and these mobile units would come and they do the mammograms. So I signed up for the program.

In 2007, I felt okay and normal and then one day like I was laying down and then my partner Herman was reaching over for something and he just grabbed my breast and squeezed it and I just screamed out in pain and I grabbed my breast because the pain was just vibrating. I touched my breast and was holding it until the pain subsided. When I pressed on my breast to try ease the pain I felt a lump there and then I said "Oh, my God", to make sure it was a lump and I felt that lump and I said "Oh, my God, Herman I got a lump". So anyway, I forgot about it the next day and working with child and family you're so busy that I completely forgot about it.



Outreach

Mobile mammography is available in most regions across Canada. A successful example of partnership established between provincial cancer agencies and FN communities.

Competing priorities

The social determinants of health create stress in FN communities.

I had a mammogram in August and I received a letter from the Cancer Care Breast Clinic in September and it said that I had an appointment for a mammogram and it made an appointment for Winnipeg that's all it said. I thought, what, I already had a mammogram in August, why are they asking me to go for a mammogram and I just threw that envelope in my desk and I forgot about it.

Communication and Follow-up Gap
Communication between the provincial cancer agency and the FNs health centre needs to be strengthened to ensure people do not fall through the cracks.

It was in February that I went to work one day. Herman wasn't feeling well and he had a sore back and I told him that I would come back from work if he'd phone me if he wasn't feeling well that I would take him to the hospital. So it was about 4:40pm, I came home and went walking toward the bedroom and he was propped up against the wall, he was just pale and I touched him and he was clammy and cold. I phoned the police. So I went to the hospital, we followed the ambulance and he died on the way to the hospital. I was traumatized by finding my partner dead in my apartment.

Eli's partner dies.

It was the next day after Herman died that I received a call from the Nelson House Nursing Station telling me that there was an anomaly in my mammogram and there was an anomaly on my breast and I had to go to the Breast Clinic right away. I said "no I can't because I just lost my partner yesterday and I'm grieving right now and I just can't go". So they called me back and so I went to the clinic on April 4th.

Communication Gap
Seven months after the August letter, the FNs health centre contacts Eli. What protocol does the cancer agency follow in terms of required follow-up? Need to improve communication with FN health centres.

They gave me this test where they, it was just like a needle but it's not, it has a little clamp at the end so he injected that into my breast and took a sample. Then the nurse came and said you have cancer and I said "no I don't because you never sent that sample to the lab so how could you tell me that I have cancer". She said because the doctor by just looking at it she can tell. I was devastated because they said I had breast cancer and I was overwhelmed with this and I couldn't believe this and I was crying. I phoned my sister-in-law to let her know but I still didn't believe it.

I went back home to Thompson from Winnipeg and I wouldn't believe that I had cancer and I said I don't know why they are telling me I have cancer when they didn't even send that thing to the lab. So anyway, they phoned and they did confirm that I had cancer. They made an appointment for me to go to the hospital on May 28th I was going to have a lumpectomy at the Hospital.

I did have a hard time because I have small veins and they were just poking me so finally they had to put ahh...I don't know what it was...it was plastic so that they can put in an I.V. they put that in my arm and I had the operation. So I'm there for two weeks and they took some samples from my lymph nodes and they found two that had cancer they took about 42 out, the rest were okay. I was on morphine and Tylenol #3 because it was painful after that operation. So I'm at the Hospital and it's so far away so people couldn't come to visit me. My sister Lyna came to visit me and my niece but people that came from north they said "Oh, it's too far, I wanted to go visit you but you're so far". I was so lonely I was there about a 3 weeks. I was still draining from under my armpit. My lymph nodes were draining into this container that was like a little rubber balloon and it had a little cap at the top and I had to drain that.

Diagnosis

Diagnosis delivered away from home, adds stress and isolation to the patient.

Access / Travel

Cancer diagnosis and treatment involves significant travel and time commitment for the majority of FNs.

Follow-up phone call a positive step to connect with cancer patients.

Surgery

Treatment far from home creates feelings of loneliness and isolation.

One thing that really concerned me was why the doctor let me out so early and the nurse was concerned and said I never in my experience witnessed a doctor discharging a patient with that tube still under their armpit. I was discharged with that thing and that nurse was so overwhelmed that the doctor was actually discharging me with that thing still stuck in my armpit and he didn't even tell me to go back or anything and he just discharged me like that. And I think it had to do with the hospital bed that they needed it for someone else.

So I just pinned it on my shirt and I went to my Mother's and that thing was bugging me and he told me I had to drain it all the time. So I was draining it, so it was two nights and then my arm swelled up so I phoned the doctor and he said, "Oh just take your Tylenol, so I took the Tylenol and my sister Lyna said, "If your arm is still swollen up tomorrow I'm going to take you back to the hospital". It was still swelled up so I went back to the hospital and they said that I had an infection.

So when I got to the hospital the doctor who operated on me wasn't there, this doctor from the emergency started me with that saline solution and he said add penicillin in there and I said "No, I'm allergic to Penicillin" and he said try it and the nurse put that thing in there and I said "I'm allergic to Penicillin" but they didn't listen and I broke out. I had that Steven Johnson Syndrome and my skin was all red and peeled off. I was in the hospital longer because of that and my doctor had to do a report to the Poison Control and they came to see me because he had to report that doctor for doing that. So I stayed in the hospital for three more weeks because of that. I was very lonely. I think I shouldn't have been let out with that tube stuck in my arm and I didn't feel good and I was discharged, I wasn't ready!

Discharge

There was no one to advocate on Eli's behalf. Eli was discharged without follow-up instructions. Was the discharge information shared with the health centre in Nelson House?

Infection

In the face of adversity, Eli demonstrated strength. As a social worker, Eli felt comfortable contacting the hospital.

Readmission-System Breakdown

Why did the health care workers not listen to Eli when she told them she was allergic to penicillin? Was Eli a victim of racism?

No one to advocate on Eli's behalf.

The incident was reported, but it sounds like it could have been avoided. Treatment away from home creates feelings of loneliness.

In May the doctor told me to take a year off and he gave me a letter and I took it to work. I was in the city May and June. I had my last pay cheque in May. In June they raised money in a yard sale so they made \$900 my sister-in-law gave it to me so I was able to pay my rent for May and in June they came to give me \$200 again so I was able to survive in May and June. In July, I was getting worried because I didn't have no money, no income. I did manage somehow to pay for July's rent. In July I'm sick and still in Winnipeg and I couldn't drive, they told me not to drive for six weeks so I didn't go back home to Thompson.

I stayed (in Winnipeg) and then my Mother was sick and she ended up in the hospital and this time she died so we had to come back (Thompson) for her funeral so I talked to the bank because I had my pension there so they released it. That Monday I went to get it and that Tuesday morning we left back to Thompson for the funeral.

I had to apply for that "Sunlife" benefit when they gave me a year off it was a such challenge because the finance worker in Nelson House didn't even look at my application, it was in her mailbox for 3 weeks because she was so busy and so I did fill out that form. After 3 months went by I never got any money for five months and I never got any cheques from SunLife for five months. It was frustrating for me to try get that money, the wait and filling out forms and them saying that that's not the right form. It was so awful and finally getting the money but what helped me too that time was I had gotten my residential school money so that was what I was living on.

Sick Time

Time away from work creates additional stress when living in situations of poverty.

Community support demonstrated to help Eli.

Eli's mother dies.

Survivorship

Survivorship support is generally absent in FN communities.

November comes around and they started me on chemo in Thompson. They told me my immune system was down and I couldn't have contact with people, so I isolated myself, people respected that. One friend of mine, when I was in the city cleaned out my apartment every day until it was spotless and when I came back home my house was clean. While I was on that chemo I was so weak that I would go on the computer and play on the computer maybe half an hour and then I would get so tired I would go to the couch and lay down and I would fall asleep then I would wake up a couple of hours later. A lot of the time I was sleeping because I was so effected by the chemo it made me so weak that I had to limit my TV time and my computer time and lay down to rest. I was always resting. I was so weak, I would have music playing and I would try to dance but I couldn't even move that I would start sweating and then I would have to go sit down. "I can't even do anything". And all I did through that, when I was alone was I would watch TV, watch movies and shortly after my chemo I would be so weak for four days then I would perk up a be a bit normal and then I had that thing in my arm and I had to take these pills and blood thinners so that it wouldn't clog up in that plastic tube that was inside my vein.

When I would eat my food would taste funny. It would taste like I was eating coal oils. I remember that taste from when I was a young child because I had taken this plastic tumbler and getting a cup of water and drinking it and there was some coal oil in there and I remember that taste and that's how my food tasted. I knew I had to eat so I would take another bite and it would taste normal and I would take another bite and it would have that taste and I would spit that one out.

I took a drive to The Pas and would do one visit and come back (Thompson) for two weeks because I had to do my chemo.

Chemotherapy

Exhausted, Eli tries to heal between chemo appointments in Thompson.

The next thing it was January, I had to go for my radiation so I stayed in this hotel room and I had this letter from the doctor that Medical Services had to put me in a hotel room because my immune system was so low and they couldn't put me in the boarding homes. I had to really fight all the time, every time I went, even on the plane I had this doctor's note that I had to go on the plane because of my immune system.

In Thompson they have a transport patient unit, northern transportation. So you go in there and you tell them you have an appointment, they make the arrangements but they will try send me by bus and I'd tell them no I can't I have a letter that I have to go by plane because of my weak immune system. So they would put me on the plane and I'd arrive in Winnipeg then I'd phone that 983-0911 then I would have to deal with the person that is on the line from medical services unit. I usually arrived on Sunday so there was weekend staff that was on and it seemed that they didn't have the information that they needed for me. If it was during the week they did but on the weekend they say "I have no information on you, Thompson did not phone". Thompson would say "yes we did" and they would say "no they didn't, we have no information on you, and which receiving home do you want to go to or which boarding home?" I would say I can't be put in a boarding home, I have a weak immune system and I have a letter here that states that I need to be put into a hotel and then they would say "Well we have to follow policy, we have to fill up the boarding homes first and once they're full then you could go to a hotel". They would try to put me in a boarding home and I would argue with them so they would finally put me in a hotel, I would go to the hotel and I would have to fax them the information because they didn't have it, then I would fax them that letter. Every time that I came in for an appointment I'd have to fax them that letter, all the time because they were always trying to put me in a boarding home where there

Radiation

Exhausted and immuno-compromised, Eli is forced to battle NIHB for travel coverage and accommodation.

Treatment Continues

Although Eli's treatment is ongoing and the issues and patterns repeat, each time she travels, she is caught in the bureaucracy of the NIHB system that is meant to support FNs.

is sick people and there was a lot of them. I could pick-up anything, viruses and it seemed like they were not very professional those people I had to deal with when I came. They would be so gruff and ignore that I had a weak immune system and they would try to insist that I go to a boarding home. I would have to fight and argue I was always arguing, arguing and arguing. It was a time when they had these vans that I have to phone the van and I'd have to wait half an hour to an hour before they would pick me up after my appointment. Then an hour would go by and they wouldn't pick me up and I'd be phoning, sometimes I wouldn't get picked up for about an hour and a half. That was before they had Duffy's taxi, so it was a long wait after appointments. In the van there was this one man who just had an operation and that van was just bouncing and he was just in pain and I felt sorry for him. Every bump would hurt him. It's better now that they have the Duffy's Taxi that comes to pick you up. It's better this way I believe.

I had Arthritis and I got that letter from the rheumatologist so it was good for one year, then after one year they told me that that letter was no more good so they started sending me on the bus and so I would be put in boarding homes even though my immune system was still low. It was the cheapest, cost efficient for Medical Services. Even though I protested my voice was not heard.

Through my radiation I was sweating at night and I would wake up sweating and I was so tired that I would just cover up. So I had this draft in my neck from all that sweat and then I had a stiff neck and so I'm walking around with this stiff neck because I got a chill. I can't hardly move my neck and I'd go back to Thompson and I'm like that. It took about two months before I fully recovered from that stiff neck and when I got back to Thompson then I would be so lonely so I would go play slots but I was lucky and I would and it was like someone was looking after me, you know, and I would win \$900, \$600. It was just awesome but that is how I overcame my loneliness, to be around people, I would go play slots because I was

Multiple Chronic Diseases

Co-morbidities are common with chronic disease. Multiple chronic diseases complicates the NIHB process.

Discussion

lonely and I really needed to be around people but not to be really with them and I had that hand sanitizer.

I wanted to share something with you when Herman died and I was going through my grieving I told myself that I'm a social worker and I have to try remedy this and fix this so that I can go through the grieving process faster and I won't be crying so much. So one day I was crying and then I heard this voice (Sings song) "That was what got me through my grieving and through my grieving for my life and that's my story".

Eli is a cancer survivor and role model.

PROMISING / LEADING PRACTICES AND MODELS OF CARE: HIGHLIGHTED EXAMPLES

Promising and leading practices and models of care are catalogued in Appendix F-1. Contact information and an overview of each practice is presented. Each practice/model demonstrates effort directed to improve access by developing partnerships that cross jurisdictions. These positive examples can help inform future efforts to improve cancer pathways for FNs. The data revealed that the issues related to FN's access to cancer care are complex, there is no single solution. A multi-pronged approach will help address the issues from different angles. FNs caution against “*cookie-cutter*” approaches that paint all FNs with the same brush. Solutions must include meaningful involvement of FNs and include partnerships that can support best practices and sustainability, and are flexible enough to embrace local realities.

Current promising and leading practices and models of care address: E-technology, Outreach, and Patient Navigation as strategies to improve cancer care pathways.

E-technology

There are six promising/leading practices that use the power of e-technology to support FNs: Curve Lake, Telepharmacy; Keewaytinook Okimakanak, Telemedicine; Demand for Services between Institutions; Mustimuhw, Community Electronic Medical Record; Saskatchewan Cancer Agency/ Saint Elizabeth/ First Nations and Inuit Health Partnership; and the Aboriginal Communities and the Saskatchewan Cancer Agency Network. The last three practices will be highlighted since they have success reaching the largest number of FN communities to date, and employ different types of existing technology that impacts at the health-system level by supporting information systems and linking health centres to the educational resources and chronic disease agencies required to provide safe quality care.

Outreach

Eight of the promising/leading practices are examples of how outreach efforts can improve access to cancer care. All of the examples involve successful partnerships that cross jurisdictional boundaries. Since breast cancer is the oldest organized screening program, it is not surprising that five of the eight outreach practices involve breast screening. Three outreach practices are highlighted, and each employs a population health approach that impacts at the community level. The first is the provincial Northwestern Ontario Breast Screening Mobile Program, run out of Thunder Bay, ON, which has been operational since 1992. The second is the HEY program, a FN specific integrated chronic disease curriculum that aims to promote positive holistic health for individuals and communities. The third is a SK- based TC program that uses a nurse practitioner at the TC level to promote well-women clinics in seven rural communities.

Patient Navigation

There are five examples of PN initiatives that work to improve access to cancer care for patients and families dealing with cancer. Patient navigators work across jurisdictions and advocate on the patients' behalf, having a direct impact on patients and their families. Their positions are evidence of jurisdictional recognition and support. One of the examples has been recognized by Accreditation Canada as a best practice. The Aboriginal Patient Navigator (APN) program from the Juravinski Cancer Centre in Hamilton, Ontario will be highlighted.

Conclusion

E-Technology Leading Practice #1- Mustimuhw Community Electronic Medical Record (cEMR) (British Columbia)

| | |
|--------------------------|--|
| Organization- | Ts'ewulhtun Health, Cowichan Tribes, Cowichan First Nation Band (250-286-0091) |
| Practice / Model- | Mustimuhw, Community Electronic Medical Record (cEMR) (www.mustimuhw.com) |
| Key Informants- | Tammy Johnston, eHealth Engagement Coordinator, tammy.johnston@mustimuhw.com Tempest Deptuch, Mustimuhw Liaison, tempest.deptuch@mustimuhw.com |

Description of the Product / Service

“Mustimuhw Community Electronic Medical Record (cEMR) is a computer program that provides health professionals with quick access to secure patient information such as blood test results, medication history and allergies. Developed by First Nations to offer solutions designed around First Nation Health Centre needs” (<https://www.infoway-inforoute.ca/about-infoway/news/news-releases/811>).

History

The Cowichan Band in BC operates a large health centre that was using a non-user friendly health record system called Tribe. The system did not meet the community's needs, which led to a search for a user friendly electronic system. A needs assessment was conducted, which included each area of health care, to identify the collective requirements for recording, reporting, surveillance, and case management. This led to the development of a windows based software program called 'Mustimuhw'. The Mustimuhw's confidentiality policy enabled shared access to patient's files across users and departments, within the circle of care. The ability of the program to develop reports, for example the number of people under the age of 24 with Type 2 Diabetes, and manage surveillance, proved very useful.

Mustimuhw was developed as a not-for-profit entity of the Cowichan Band. The FNs principles of OCAP are integrated in the system, since file information is stored on the community server owned by the FN. Mustimuhw is FNs owned and operated.

Implementation

Education is an important part of the implementation process. Health care providers received education on the system, and clients were introduced to the system by nursing staff who demonstrated how the computer system works and how their personal information would be protected. This was identified as an important part of the implementation process, since there are often privacy concerns in small communities, where everyone knows everyone and relationships are close. Clients sign a letter of agreement that indicates they understand and agree with the cEMR. The need to have ongoing support and training became evident and a project manager position and help desk were established.

Impact

Community owned and driven health information is imperative to the overall health of the community. There is a sense of pride and ownership at the community level of this

Conclusion

grassroots movement. Clients see the benefits of information that is collected and are secure in the fact that their privacy is protected. The system can work for single independent communities or across TCs, where a group of communities can share a central server with data-sharing agreements in place to protect clients.

First Nation communities often deal with high turnover rates of health care staff. The Mustimuhw cEMR provides continuity, and decreases the chance of someone getting lost or forgotten in the system. As one of the managers explained, “*Remember, in isolated communities it is the health staff that are the transient population and not the community members.*” The system also has the potential to save money, through the streamlining of required reporting, which is easily produced by the program, versus the hand counting of paper files done in the past.

Mustimuhw cEMR is currently being used in more than 50 FN communities in BC. It was also introduced to six Manitoba First Nations as part of the Manitoba First Nations Patient Wait Time Guarantee Pilot Project (2006-2009), a joint initiative of the Assembly of Manitoba Chiefs and Saint Elizabeth. Effective relationships are key to success when Mustimuhw is implemented in new communities. Mustimuhw trainers work with new communities to identify their own specific community needs, which builds ownership and ensures prioritized needs are addressed. For example, the community of Bella Bella identified the need to track health related travel, Mustimuhw staff were able to build in a tracking application, which now is available to all communities. The system can be used in rural, remote, and isolated communities and has built-in flexibility that promotes adaptation at the local level. Mustimuhw staff provide ongoing training and support to health centre staff as they implement the new software into their health centres.

Next Steps

On January 26th, 2012 the Assembly of Manitoba Chiefs announced plans to expand the use of Mustimuhw in MB from six to nine communities with a “goal to establish compatibility with clinical EMR systems in nine First Nation communities, so patient information can be shared more easily amongst authorized care providers both on and off reserve”. “The \$3.4 million program includes a \$1 million investment by Canada Health Infoway, the federally-funded organization investing in electronic health record systems across Canada” (<https://www.infoway-inforoute.ca/about-infoway/news/news-releases/811>). The partnerships established in this project will improve access across jurisdictions (FNs, federal, provincial), and since all provinces and territories across Canada are faced with similar challenges, there will be great interest in the outcomes of this innovative leading model that has the potential to expand even further.

Replicate

Health centre staff can be trained as a trainer to pass on the learning; good relationships between trainers and trainees on an ongoing basis are important; computer equipment that can store the data and operate the software; buy-in from the community, leadership and health staff; needs to be community owned and driven.

Conclusion

E-Technology Leading Practice #2- @YourSide Colleague® First Nations Cancer Care Course (Saskatchewan Cancer Agency/ Saint Elizabeth/ First Nations and Inuit Health Partnership)

| | |
|--------------------------|--|
| Organization- | Saint Elizabeth First Nations, Inuit and Métis Program (not-for-profit charitable health care organization) |
| Practice / Mode - | @YourSide Colleague® is a secure web-based learning program, the First Nations Cancer Care Course is one of ten courses available. |
| Key Informants- | Tracy Scott, Knowledge Liaison, Saint Elizabeth First Nations, Inuit and Métis Program, Suite 200, #5 Donald St. Winnipeg, Manitoba, R3L 2T4 Phone- 204-253-3560 Email-tscott@saintelizabeth.com Sandra Meeres, Manager, Colorectal Screening Program, Saskatchewan Cancer Agency Phone: 306-359-5606 Email-Sandra.Meeres@saskcancer.ca |

Description of the Product / Service

The @YourSide Colleague® Cancer Care Course is an innovative online professional development opportunity for health care providers working in FN communities. The course offers 24/7 access to an evidence-based, self-directed e-learning opportunity to build skills, knowledge and confidence among HCPs. In addition, it provides continuous access to a virtual support network of peers and cancer specialists and may thus reduce feelings of isolation that HCPs working in small, rural, and remote communities experience. One of the benefits of the online e-learning course is that community HCPs can hone their skills and knowledge without leaving their communities for continuing education purposes, which enhances continuity of care for their patients.

The content of the @YourSide Colleague® Cancer Care Course is specific to FN people. All promotional and learning materials feature photos of FN people and communities, and the course content has been developed with and for HCPs working in FN communities through a FNs lens.

History

Saint Elizabeth developed the @YourSide Colleague® online e-learning tool in 1999. In 2000, a First Nations and Inuit Health authority approached Saint Elizabeth about using the @YourSide Colleague® to support FN-driven health programs and services at the local level. Being early adopters of the e-learning program, FNs have helped to shape the @YourSide Colleague® program by providing input on the learning content and adapting the program to the needs of FN communities.

Currently, the @YourSide Colleague® program offers 10 courses in total, at no cost to health care providers working in or with FN communities and organizations. Drawing on the e-learning expertise of the program developers and their long-term partnership, FNs and Saint Elizabeth developed the @Your Side Colleague® Cancer Care Course for FNs

Conclusion

health care providers. The Cancer Care Course is a joint initiative by Saint Elizabeth Health Care and the Canadian Partnership Against Cancer to provide cancer care education to FN communities with the content developed for and with HCPs working in FN communities.

The SCA was working with FNIH to create a network to link with FN and Métis communities. As the Network began to meet, the communities identified the need for basic cancer information to inform health care workers working in remote and isolated areas. The SCA became aware of the development of the Cancer Care Course and offered their content expertise to review the course. The SCA was impressed with the content and worked to promote the course through the Network and through their established relationship with FNIH.

Implementation

The @YourSide Colleague® Cancer Care Course was launched in January 2009 and offers cancer care knowledge enhancement using a secure, web-based e-learning platform. It also provides interactive learning opportunities, with learning being facilitated through communities of learning and e-learning events such as webinars and study groups. Participants have unlimited access to information related to clinical health care and health care management, with a comprehensive library of resources to supplement learning, tools and templates to use during care, web resources, moderated discussion areas, and help and support. Practice quizzes and a final knowledge test assess progress and learning. Supervisors can track the learning progress through knowledge testing and detailed metrics. The content of the @YourSide Colleague® Cancer Care course is updated monthly; it provides an overview of the fundamentals of cancer, and is presented through the lens of FNs. The curriculum is evidence-based, and the course topics were developed by content experts working in oncology and in FN communities. All content is reviewed for clinical accuracy as well as the FNs context before the new material goes live on the website. The FNs context is critical because it considers the realities of working in FN communities (e.g. how social determinants such as inadequate housing or availability of running water affects health status and care delivery). The SCA, Saint Elizabeth, and FNIH continue to partner to support the cancer care course. For example, this collaboration has resulted in live national webinar sessions on cancer (prevention, screening, and treatment) and chronic disease hosted by provincial leaders of the SCA, chronic disease experts from FNIH and supported by SE staff. This partnership helped support the roll out of colorectal screening, by supporting education outreach to FN communities in SK.

Impact

The @YourSide Colleague® Cancer Care Course has brought new knowledge about cancer care to many health care providers in the communities. Surveys done early in the course found that while 85% of learners had no prior education or training in the area of cancer care, 77% of them provided weekly care to patients with cancer in their communities. Training and education in cancer care were clearly needed, and the Cancer Care course fills this gap. Launched in January 2009, the First Nations Cancer Care Course continues to demonstrate significant uptake and reach. The course consistently trends highest in utilization of all the courses available within the Saint Elizabeth web-based professional development program @YourSide Colleague (aYSC). Utilization patterns indicate consistent utilization over the past three years with more than 1600 visits to the course, more than 600 learning assessments completed (quizzes and Knowledge Tests) and over 1000 hours of learning. In addition to the course being available for self-paced learning anytime and anywhere, the Saint Elizabeth FNIM Program offers a number of e-learning events to complement the learning content in the course and connect community-based workers in communities of learning across the country.

Conclusion

Next Steps

The @YourSide Colleague® program in general and the @YourSide Colleague® Cancer Care course specifically are both applicable to the Canadian context, given Canada's vast geography. There have been expressions of interest in the @YourSide Colleague® Cancer Care course from health authorities and non-FN communities across Canada. With the growth of the information sources on the internet, there is a need, with many opportunities to fill this need, for courses such as the @YourSide Colleague® Cancer Care course. Such courses can provide learners with a trusted resource to obtain accurate and relevant information. This type of learning platform can address the call from FNs for cancer education for communities and all levels of community health care workers. Partnerships integrating provincial experts help to further build bridges to communities and lend credibility and local reality to educational sessions. E-learning can also help the implementation of new programs, such as palliative care, by supporting partnerships that cross jurisdictions, such as cancer agencies, the HCC Program and FN health centres.

Replicate

The experience and infrastructure of Saint Elizabeth is difficult to measure, it has helped support the success of the @YourSide Colleague ® program. Not an easy program to replicate, significant technology, health care expertise and FN partnerships have been developed over time. The program is a sustainable model as it provides significant cost savings to traditional in person training and workshops. Currently models of education and professional development often require health care providers to leave their communities which has greater financial, personal and human resource costs (cost to backfill staff). In some communities this also disrupts care continuity or provision as the provider leaving the community may be the only person providing care. FN partnerships are critical to support meaningful context and participation.

Conclusion

E-Technology Promising Practice #3- Aboriginal Communities and the Saskatchewan Cancer Agency Network (name change pending to reflect integrated chronic disease approach)

Organization-Saskatchewan Cancer Agency (SCA – Co-chair) and Federation of Saskatchewan Indian Nations (FSIN – Co-chair)

Practice / Model-Virtual network that meets quarterly via teleconference.

Key Informant- Cheryl Whiting, Provincial Leader Cancer Prevention, Population Health Division, SCA, cheryl.whiting@saskcancer.ca

Description of the Product / Service

Established in 2008, this virtual network meets quarterly via teleconference and has established a communication network between communities and the cancer system that strengthens and supports First Nation and Métis communities and care providers who care for people living with cancer. The network started by establishing the sharing of contact information. Currently the network builds capacity through knowledge exchange in areas of cancer control including prevention, early detection, treatment, and supportive care. The goal is to identify and solve problems / challenges by collaborating in areas of mutual interest. Collaboration strives to be open, honest, and flexible based on need. Membership does not require participation in the teleconferences, minutes are shared with communities and members, the goal is to share information to improve access across jurisdictions.

History

In 2007, the SCA recognized that they were not well connected with the FN or Métis communities. There were calls from communities with issues of not knowing who to speak to or how to connect to the cancer system. SCA contacted FNIH and flagged this communication gap. In 2007, FNIH and SCA reached out to the RN's working in FN communities with a survey that confirmed a disconnect to the cancer system. Together the SCA and FNIH built a network of RN's which eventually expanded to include other FN health care providers that began to open lines of communication and funnelling of information between communities and the SCA. The Network began meeting on a quarterly basis to talk about the needs in communities. As the network started to evolve other key SCA areas such as treatment were invited into the network. Letters were sent to FN Health Directors to inform them about the network. This was done to make the Health Directors feel welcome to participate but also to foster their support of key community people participating in the network. Currently the network has approximately 30-40 members, however, participation is voluntary, as community capacity is always an issue. Each network member receives a copy of detailed meeting minutes and follow-up information to keep informed and stay connected.

Implementation

Change takes time. This is a very slow process, building relationships and trust. There is no instant gratification, but long term benefits for making the effort. Communities require a key point of contact to help them navigate the cancer system. The SCA has patient navigators to help alleviate some of the issues identified around access to care and medications and transportation. Despite the existence of many SCA services as well as resources and services in rural and remote areas, there has been no coordinated effort to bring these

Conclusion

resources together to enhance local capacity, to build community partnerships, and to increase awareness of local resources for cancer patients and their families. Such coordination would allow gaps in care, local issues, and needs to be addressed. The SCA is working towards creating a Community of Practice (CoP) within the province of Saskatchewan to meet this need. The CoP approach ensures that all stakeholders are aware of all services available as well as the manner in which to link them all to improve the patient and family experience.

Impact

E-evaluation was completed in 2010, revealed improved communication and identified that future efforts should be action focused. The benefits of the partnerships established through the network include: information sharing and knowledge exchange; partnerships and collaboration; network is flexible and able to respond to changing needs; network helps build relationships and trust between FN, Métis, and health service agencies; culture based, engaging and involving Elders in the network; members see value in the network and want to participate. It has been difficult to evaluate the impact of the network as it evolves; it requires long term vision to support collaboration. Capacity in communities is a limited, therefore flexibility is key. At times different communities will join in when they are dealing with an issue that they feel the network may be able to provide support. There is no funding to support collaboration, each agency envisions the advantage and supports participation internally. The SCA recognizes that the success of creating a Community of Practice rests on the coordination and facilitation of the collaborative process mentioned previously. For this reason they are working toward the creation of Provincial Coordinator for this purpose.

Next Steps

The network was originally chaired by SCA, recently the Federation of SK Indian Nations (FSIN) agreed to co-chair.

The SK-MB CLASP project provided an opportunity for chronic disease agencies to work together. The existing network collectively saw the opportunity to invite the other chronic disease agencies to the table to support communities through information sharing and strengthening capacity. As a result the network is now expanding to include other chronic disease agencies and will establish an integrated chronic disease approach.

Replicate

This network is a low cost method to connect FN and Métis communities to provincial cancer agencies and other chronic disease groups. One agency needs to take the lead role to start the network, set meetings, provide dial in numbers, record and distribute / post minutes. Flexibility is key to enable communities dealing with capacity issues to participate when they are able. Integration of Elders helps to create vision and secure cultural competence. All partners must see the value of the network to continue participation.

Outreach Leading Practice #1- Northwestern Ontario Breast Screening Mobile Program

| | |
|--------------------------|--|
| Organization- | Ontario Breast Screening Program |
| Practice / Model- | Mobile, digital mammography breast screening |
| Key Informant- | Alison McMullen, Director of Preventive Oncology, Regional Cancer Care Email- mcmullea@tbh.net |

Description of the Program / Service

The mobile unit travels to over 55 locations and visits more than 30 communities from April to October and an additional 26 locations around Thunder Bay from November to March. Equipment sensitivity does not allow the mobile to travel gravel roads, therefore sites are coordinated and the program works with FN communities to coordinate access and transportation (including fly-in from isolated communities). Financial costs are significant (mobile coach, screening equipment, operating expenses, human resources, and travel costs), support for the program comes from a partnership between Health Canada and the Thunder Bay Regional Cancer Program.

History

Outreach started in 1992 to increase access to breast screening in rural, remote, and isolated areas and to increase screening participation. An Aboriginal Cancer Care Committee advises to ensure programs and services are culturally competent and an Aboriginal Health Promotion Planner position was established to support the outreach efforts.

Implementation

Effective outreach to FN communities requires culturally competent staff who recognize the benefit of working with communities to identify strategies to increase screening participation rates. Each community is different and what works in one will not work in another. The use of technology such as videoconferencing helps to maintain communication with communities. These partnerships address access issues to increase screening participation. Recently the program started to work with FNs to identify opportunities to integrate other screening and prevention messaging to reduce duplication with other chronic diseases. This work is in line with an integrated chronic disease approach. The program collects and shares with FNs screening participation rates, retention rates, and cancer detection rates to demonstrate positive outcomes.

Impact

Community involvement increases participation in screening. Result letters are sent to participants and their primary care provider within two weeks, and if they do not have a primary care provider the program can assist. Women with abnormal results are referred to a PN. Working with FNs enables the mobile screening program to provide a culturally safe and locally relevant environment for FN women in or near their own community. The coach is available in the evenings and on weekends to accommodate schedules and further increase accessibility.

Conclusion

Next Steps

The mobile breast screening outreach model has proven success over 20 years and continues to provide outreach with high level of engagement and collaboration with FNs, the provincial cancer program, and community HCWs.

Replicate

Financial costs are significant, mobile coach, screening equipment, operating expenses, human resources, travel costs. The model has proven success with over 20 years of service; it requires high level of engagement & collaboration with FNs, Cancer Program, HCPs. Health Canada & Thunder Bay Regional Cancer Program work together to sustain the practice. An Aboriginal Cancer Care Committee advises to ensure programs & services are culturally competent. A dedicated liaison position within the Regional Cancer Program for the TBRHS this is the Aboriginal Health Promotion Planner, who works to ensure effective prevention and screening outreach to FN communities.

Conclusion

Outreach Promising Practice #2- HEY (Health Empowerment for You) Saskatchewan and Manitoba

| | |
|-------------------|---|
| Organization- | Federation of Saskatchewan Indian Nations (FSIN) (Lead Agency) |
| Practice / Model- | First Nation specific, holistic, integrated chronic disease community curriculum, targets youth (16-30), using train the trainer model. |
| Key Informant- | Alvin Delorme, Project Manager, (FSIN), Email: alvin.delorme@fsin.com, Phone: 306-956-1049 |

Description of the Program / Service

The HEY project is a FN inclusive prevention of cancer and chronic disease community curriculum that targets youth aged 16-30 with culturally appropriate content and resources to promote overall health and well-being. FNs in SK and MB partnered with cancer and chronic disease agencies to promote primary prevention using a FN holistic view. Community role models are identified to take the HEY training and then return to their home communities to deliver the curriculum and assist in motivating change based on needs that are defined and meaningful at the local level.

History

In 2009, funding was received from the Canadian Partnership Against Cancer (CPAC) through a proposal process that partnered 19 FN organizations, cancer and chronic disease groups, provincial and federal governments, and post-secondary institutions across SK and MB. Key partners include: Canadian Cancer Society; CancerCare Manitoba; Saskatchewan Cancer Agency; Heart and Stroke Foundation of Canada (Saskatchewan and Manitoba Divisions); The Lung Association (SK and MB divisions); Kidney Foundation (SK and MB divisions); SK Ministry of Health; MB Ministry of Health; Red River College; SK Indian Institute of Technologies; and Health Canada (SK and MB regions).

The project was completed over a period of 2.5 years. This required significant cross cultural work to achieve a level of understanding around internal protocols to ensure meaningful engagement of FNs, including elder and community consultations and ongoing validation processes. A curriculum plan was developed in collaboration with Red River College (MB) and First Nation Institute of Technology (SK). The FN focused curriculum reflects traditional holistic values of health and promotes evidence based integrated chronic disease content. The curriculum underwent a full language assessment to ensure the content was at a grade 10 reading level.

Implementation

FNs in SK and MB were informed about the HEY project and communities / Tribal Councils submitted their interest. Communities were asked to identify role models to take the HEY trainer level curriculum (4.5 days). Following completion of the training, the HEY trainers returned to their home communities to deliver the curriculum to various youth groups. The intent of the curriculum goes beyond content, community groups individually and collaboratively work to identify ways to create balanced healthy environments that support active healthy lives. The cultural realities of FN communities are woven throughout the curriculum. There is flexibility in the curriculum to allow groups to focus on areas that are meaningful at the local level.

Conclusion

HEY is delivered using train the trainer and community based approaches. The train the trainer portion is 4.5 days for 5-15 participants, with 10 being the ideal. During this time, trainers learn how to facilitate a healthy living message to youth. The community based approach includes workshops on healthy living for youth as way to promote individual and community health. HEY consists of 7 modules: Vision of Health – Personal and Community; Prevention of Cancer and Chronic Diseases; Healthy Eating; Active Living; Healthy Body for Me; Tobacco Reduction; and Substance Misuse. The HEY curriculum includes printed materials, electronic resources and a training video.

Impact

To date 103 individuals from 78 bands (in SK and MB) have been trained. The next round of training is planned for Nov. 2012. The project has been well received from FNs groups that have participated. Collaborative partners (The SK Cancer Agency, the Canadian Cancer Society, and the Heart and Stroke Foundation of Canada [SK and MB divisions] participated in the HEY training to help their organizations attain an understanding of the current realities facing FNs. The partnerships have been a way to identify how business can be done more effectively. As a result there has been an increase in coordination between agencies in outreach efforts to FN communities. Partners in SK have linked to an existing group (Aboriginal Communities and the SK Cancer Care Network) to form a sustainable link with FN communities.

Reaching remote and isolated FN communities is expensive. Though successful, the HEY project was not able to reach every FN community that wanted to participate. Support for trainers was limited to the distribution of a Participant Manual for use in community sessions. The HEY program is not currently able to capture the outcomes at the community level that result from the training.

Next Steps

The HEY project funding will support efforts up until September 2012. Currently FSIN and the project partners are examining ways to sustain the success of the project. There has been interest expressed from other provinces and other groups across Canada.

Replicate

Partnerships are key, with the inclusion of key provincial partners, the HEY program can be replicated in any province or territory. The built in flexibility allows for local community needs to be integrated into the curriculum in a meaningful manner. The holistic perspective resonates across cultures.

Conclusion

Outreach Leading Practice #3- Tribal Council Nurse Practitioner (Saskatchewan)

Organization- File Hills Qu'Appelle Tribal Council
Practice / Model- Nurse Practitioner at the TC level provides outreach to 7 FN communities that belong to the TC.
Key Informant- Charlene Horsman, File Hills Qu'Appelle Tribal Council, Email: chorsman@fhqtc.com

Description of the Program / Service

A nurse practitioner hired at the TC level provides outreach to the seven communities that belong to the TC. Outreach consists of women's wellness including cancer screening.

History

The maternal and child health program identified that prenatal clients and women in the community were not going for medical check-ups. Leaving the community for care was recognized as a barrier. Competing priorities for women in the community resulted in an under-screened population.

Implementation

A NP was hired at the TC level to address women's health. The NP travels to the seven communities to provide screening (Pap tests), to encourage breast screening for eligible women, and to provide education regarding colorectal screening. In addition, the NP provides a holistic wellness approach, by completing health histories and physical examinations. The relationships established appear to help build trust and decrease fear of screening.

Impact

There is currently only one NP. The position is very effective, however the informant cautions that success can be linked to the effectiveness of the individual in the position. Networking with the provincial cancer agency and local doctors has proven effective. The NP is able to deliver culturally competent care. The NP takes client charts out of the community, a practice which is felt to increase feelings of privacy and confidentiality. The informant is unaware if the program has been formally evaluated.

Next Steps

The NP position requires financial support for the position and the buy-in from the community and other health care workers. Evaluation would help direct future efforts and help spread the practice to other communities.

Replicate

Model of care can be replicated to other communities. Requires multidisciplinary collaborative approach. Strong relationships established with specialist care. Networks with Provincial Cancer Agency and local doctor.

Patient Navigation Leading Practice #1- Aboriginal Patient Navigator Program (Accreditation Canada-Best Practice)(Ontario)

Organization- Juravinski Cancer Centre, Hamilton, Ontario
Practice / Model- Aboriginal Patient Navigator (APN) Program
Key Informant- Lee Styers Loft, Hamilton Health Sciences Regional Cancer Centre (RCC) Email: Lee.Styres-Loft@jcc.hhsc.ca

Description of the Program / Service

The Aboriginal Patient Navigator program started as a one year pilot project in 2006 funded by Cancer Care Ontario and subsequently supported by the Hamilton Niagara Haldimand Brant, Local Health Integration Network through a transfer of funds to the Juravinski Cancer Centre. The Aboriginal Patient Navigator is a staff member in the Supportive and Palliative Care Program, Juravinski Cancer Centre, Hamilton Health Sciences. In 2010, the Aboriginal Patient Navigator Program was identified as a leading best practice by Accreditation Canada. Cultural community consultations and Aboriginal cancer care networking committee involvement guides the principles of the Aboriginal Patient Navigator program to ensure strong cultural connections and holistic perspectives, and that the highest integrity of the work is maintained. Partnerships that have been established include the following groups: The Aboriginal Health Access Centre; Hamilton Regional Indian Centre, Fort Erie Native Friendship Centre; Native Women’s Centre; Wellwood Resource Centre; Six Nations Health Services; Public Health; the Ontario Breast Screening Program; ColonCancerCheck Program; and the Canadian Cancer Society. APN also will deliver cultural competency training to various groups upon request.

Purpose

Helps clients / families understand what to expect during various aspects of the cancer journey. Provides advocacy and support for access and accommodation, for example facilitation for consultation with the traditional cultural healing community practitioners. Assists in coordination of care to help ensure patient/family satisfaction. Health promotion for cancer prevention and screening is also a vital aspect of the role.

Limitations

The Aboriginal Patient Navigator is only one position, with service available during work hours from Monday through Friday. Possessing only limited medical knowledge, and at times being without immediate access to resources aiding in understanding medical jargon and terminology can be challenging to the Aboriginal Patient Navigator.

Conclusion

Learnings

Aboriginal people respond to holistic services offered that are sensitive to individual needs. An educational virtual tour video was produced and made accessible on YouTube by Hamilton Health Sciences. Outreach is required at provider level to increase cultural understanding and at the community level to reduce the fear & misconceptions. (Please remove all within brackets: With the support of, and accommodation from Six Nations Health Services, the Aboriginal Patient Navigator has provided supportive services and consultation with patients and their families in on-reserve professional settings where requested. Community and Cancer Centre endorsement is critical to the success of the Aboriginal Patient Navigator program. The Aboriginal Patient Navigator contributed to curriculum development and delivery training for the award winning Aboriginal Breast Health Train the Trainer Project; as well as the Colon Cancer Prevention Event which included the Giant Colon presentation and display on Six Nations; and the components of healthy eating public lectures, and cultural sensitivity training for OBSP (Ontario Breast Screening Program) at four regional sites.

Next Steps

Future outreach may be a possibility. Possible model for adaptation in other provinces/territories building on cross-jurisdictional support.

Replicate

An established relationship with the First Nations and surrounding Aboriginal communities that is founded on trust and respect. The Cancer Centre must be on board with addressing the needs of Aboriginal communities. A formalized Aboriginal advisory body or council to guide APN program; strong cultural connections and holistic perspective. Funding to support informational resources for the APN.

Conclusion

Promising / Leading Practices and Models of Care Discussion

Despite the fact that FN communities have little to no funding for cancer care programs or services, there are promising and leading practices and models of care that can be used as examples to guide future efforts to address the existing gaps and barriers. E-technology will have impact at the health system level, by supporting information systems and linking health centres to the educational resources they need and the decisional support required to provide safe care. Outreach efforts impact the community as a whole and promote a population health approach across the care continuum. Although patient navigation crosses jurisdictions, its impact is felt at the individual level. Patients and their families will feel the support of patient navigators as they help them in their cancer journeys.

E-Technology

The development, implementation, and expansion of the FN-owned and operated Mustimuhw Community Electronic Medical Record (cEMR) is a good news story. This is not the only example of a FN-specific electronic health record system, there are many, however, Mustimuhw has gained significant attention since receiving support from Canada Health Infoway for further expansion in Manitoba with the goal to establish compatibility with clinical EMR systems, so patient information can be shared more easily amongst authorized care providers, both on and off reserve. The project is expected to also demonstrate the benefit of cross-jurisdictional (FNs, federal, provincial) collaboration. “All other provinces in Canada face similar challenges in serving the health care needs of the First Nations population by multiple jurisdictions, but still need to ensure that information systems and interoperability be implemented in such a way that is respectful of First Nations governance and requirements” (<https://www.infoway-inforoute.ca/about-infoway/news/news-releases/811>).

Similarly, @YourSide Colleague® is not the only example of a web-based learning program, however, Saint Elizabeth has well-established relationships with FN communities and their FN-specific on-line programs, including the cancer care course, have proven effectiveness in addressing identified needs through collaborative partnerships such as the one undertaken by the SCA, Saint Elizabeth, and FNIH-SK Region.

The Aboriginal Communities and the Saskatchewan Cancer Agency Network is a low-technology (teleconference), low-cost example of how partnerships can work to identify gaps and barriers and work to create locally meaningful solutions. The Network is expanding to integrate other chronic disease agencies, and this integrated approach is in line with the data which indicates FNs’ preference for an integrated chronic disease approach.

Although not specifically highlighted, the Keewaytinook Okimakanak Telemedicine project in Ontario is worthy of discussion (see Appendix F-1) The data across the country indicates that existing technology is not being used to capacity, and the practice of virtual appointments like those conducted via KOTM holds promise for all FN communities. This practice, once established, has the ability to cross over the geographical barriers and jurisdictional boundaries, and eliminate the issues related to medical transportation. Not all appointments can be conducted virtually, however efforts to identify which appointments can occur safely closer to home will benefit all parties.

When the list of gaps and barriers is examined in the context of the three themes (Access, Partnerships, and Jurisdiction), e-technology holds potential power to address many of the identified needs. For example, partnership between provincial cancer agencies and FN communities could support educational needs of communities and HCPs at all levels

Conclusion

through the use of existing e-technology. The development and distribution of culturally responsive resources could be supported by e-technology. Sharing of such resources to benefit all FN communities should be posted on public sites such as www.cancerview.ca. The development and implementation of palliative care programming for FNs could be coordinated via e-technology. Data shows that respondents are asking for cancer and palliative guidelines to be available at the community level. Movement toward e-technology is inevitable, and this requires secure, reliable internet access and IT support, which is still not available in all FN communities. Electronic health records will help ensure continuity of care across jurisdictional boundaries, however, data-sharing agreements that respect the FN principles of OCAP need to be secured to promote data sharing within each province. Such agreements will help pave the way for virtual appointments, which have tremendous potential across the care continuum.

Outreach

There are examples of mobile breast screening outreach across Canada, and this type of outreach has been successful because it addresses access head-on, by bringing screening closer to home. The partnerships established between provincial cancer agencies and FNs support a culturally safe environment to which communities respond. Together, cancer agencies and FNs have established sustainable working relationships that cross jurisdictional boundaries. However, not all FN communities have access to mobile screening. There is a need provincially for cancer agencies and FNs to work together to map access to screening and work to increase access for all FN communities. The Northwestern Ontario Breast Screening Program has illustrated innovation. Building on the success of mobile outreach, they are working to integrate a more holistic and integrated chronic disease approach. Based on the data, FNs see the benefit of an integrated chronic disease approach across prevention and screening efforts. This holistic approach is evident in the HEY project and the third example of outreach from Saskatchewan, where a nurse practitioner works from the TC level to provide outreach locally to seven FN communities.

Patient Navigation / Aboriginal Patient Navigation

Patient navigators touch the human side of cancer directly, reaching out to vulnerable patients and families to assist and advocate on their behalf in a complex and confusing health care system. Although few FN communities have access to PNs, the data reveals an awareness of the role and a positive outlook on the integration of PNs into the FN cancer pathway. The APN program in Hamilton can be used as an example for future positions. The Manitoba and Yukon sharing sessions envisioned the APN roles differently, and flexibility needs to allow provinces to work with FNs to determine the best regional strategy for integration. Aboriginal Patient Navigators need the support of all jurisdictions and the ability to cross jurisdictional boundaries to assist patients and their families.

Recently, the Minister of Health, the Honourable Leona Aglukkaq, emphasized the importance of relationships with FNs to create positive change. The Minister identified the need for efforts that benefit multiple communities, with a collaborative common purpose, practical and realistic expectations, that respond to the needs and priorities as they are identified by communities (http://www.hc-sc.gc.ca/ahc-asc/minist/speeches-discours/2012/2012_01_24-eng.php). The leading practices highlighted meet the objectives of the Minister. E-technology, outreach, and patient navigation are a few approaches that will help address the gaps and barriers to cancer care that exist in FN communities. However, there is also the need for jurisdictional policy level change that will ensure communication between treatment centres/hospitals and FN health centres as FN patients move between the systems, and a formal palliative care program that provides care to the dying in their home communities. In addition, NIHB policy requires review, with a goal to realistic and practical solutions that support patients and their families.

CONCLUSION

Although this report illustrates a burdened cancer pathway, more importantly it clearly articulates the readiness and desire of communities to address the work necessary to improve the cancer pathway for FNs. This path cannot be changed in solitude; it must be grounded in meaningful partnerships that are both realistic and respectful.

The negative effects of the determinants of health are well documented in FN communities and FNs people carry a disproportionate burden of chronic disease including cancer. The voices of the communities represented in this report illustrate a cancer pathway that is more similar than different when compared across geographical locations, including provinces and Yukon Territory, as well as rural, remote, and isolated communities. There is also little difference in the pathway when compared against the different types of cancer. The gaps and barriers revealed fall into three themes: Access, Partnerships, and Jurisdiction. These themes not only resonate through all of the data collected, they are also present in the solutions as evidenced by the leading practices, which demonstrate improved access to cancer care by creating partnerships that work across jurisdictions. Communities consistently report a *“fear”* and *“mistrust”* of cancer and the health care system that can be linked back to the enduring effects of historical trauma. The lack of culturally safe programs and resources further complicates the situation, resulting in too many cancers diagnosed at advanced stages.

Programs meant to support access to health care (NIHB), instead create bureaucratic barriers with a treatment, rather than a prevention focus. The high turnover of health care professionals working in FN communities is a long standing problem well known to remote and isolated areas of the country. These workers identify the need for formal links to provincial cancer agencies to support the communities’ need for cancer information. They also recognize a need for cancer information and support for all levels of health care providers working in FN communities.

Cancer is a chronic disease; the data reveals that the issues related to cancer care extend to other chronic diseases, such as heart disease and stroke, lung disease, and diabetes, which helps explain why that data also demonstrates that FNs are looking for an integrated chronic disease approach. The expanded chronic care model provides a framework that brings together the health system and the community to ensure high quality chronic disease care and better health outcomes for FNs. Existing leading practices work to promote health system change with the use of e-technology, support community outreach to bring care closer to home, and advocate for patients and their families through APNs.

Electronic technology is seen as one method to help bridge the gaps. Two leading practices of e-technology are highlighted:

- The first is an FNs-owned and operated community electronic medical record (cEMR) system from the Cowichan tribe of British Columbia called Mustimuhw that has recently been supported with funding through Canada Health Infoway to expand into Manitoba. Mustimuhw cEMR promotes a case management approach that helps to ensure continuity of care in the face of health care staff turnover. Surveillance data allows FN communities to track trends, monitor success, and plan for future needs.

Conclusion

- The second example of e-technology that is highlighted as a leading practice highlights a cross-jurisdictional partnership that employs an e-platform to reach FN communities to provide culturally relevant education regarding cancer care for front line health care workers. The @YourSideColleague® First Nations Cancer Care Course was developed for and with health care providers working in FN communities.
- The final example of e-technology uses the most basic form of technology (teleconference), to bring together Aboriginal communities and the Saskatchewan Cancer Agency in a network that meets quarterly to determine ways to improve communication and offer support to communities and care providers. The Network is expanding to include other chronic disease agencies. The integrated approach will provide benefits for the communities and the agencies as they determine more efficient and effective ways to work together.

Outreach programming, such as mobile breast screening, is available in many regions; this type of outreach has demonstrated success in creating effective partnerships between provincial cancer agencies and FN communities, reaching under-screened populations, and increasing screening participation rates. Three outreach leading practices are highlighted:

- The Northwestern Ontario Breast Screening Mobile Program has been operational for over 20 years. The model's success is being expanded beyond breast screening to establish a more holistic integrated chronic disease focus to maximize efficiency.
- The HEY (Health Empowerment for You) project is a FN specific, holistic, integrated chronic disease curriculum. This SK-MB partnership promotes the collaboration of FNs with cancer and chronic disease agencies, and the federal and provincial governments to bring positive health change to FN communities using a train the trainer model.
- In Saskatchewan, the File Hills Qu'Appelle Tribal Council has experienced success reaching women and increasing screening participation, by creating a nurse practitioner position that travels to the seven TC communities to provide culturally safe information and screening.

Patient navigation is generally not available to the majority of FN cancer patients and their families. However, the practice is well known and there is positive support for the role, since it is viewed as a practice that can make a positive difference at the patient level. The APN program in Hamilton, ON has received recognition from Accreditation Canada as a best practice.

- The APN program assists self-identifying Aboriginal patients and their families through the complex cancer care system. The APN advocates on the patient's behalf, provides education and support, and works to build cultural competency within the health care system.

Promising / leading practices and models of care can help guide future efforts; however there is a need for jurisdictional support. First Nations, provincial and federal governments must work together to improve cancer care pathways for FNs. Information sharing agreements and policy, that respect the FNs principles of OCAP, will ensure that discharge

Recommendations

information from hospitals and treatment centres is shared with FN health centres, to support the safe continuity of care and pave the way for virtual appointments using telemedicine. Efforts to continue to bring prevention and screening closer to home in a culturally relevant and locally meaning way will lead to better outcomes. The development and support of a FN palliative care program will formally recognize a gap which FNs are trying desperately to address.

Collaboration to create a seamless system must move forward. First Nations expressed their gratitude for the work underway and look forward to working collaboratively to establish realistic, practical, and sustainable solutions.

RECOMMENDATIONS

Recommendations come from the collective data and represent collaborative ways to increase FN access to cancer care through the strengthening of partnerships across jurisdictions. Reference to promising / leading practices and models of care are highlighted in **green**.

1. Promote and support meaningful engagement of First Nations.

Ensure all FNs have access to the report.

Ensure that work that results from the report consistently includes meaningful engagement and collaboration with FNs.

Establish a system check that monitors and evaluates activity related to the report and the outcomes as they impact the cancer pathways of FNs.

2. Enable partnerships to establish infrastructure that improves access to cancer care for First Nations.

Present report findings provincially. Ensure the following groups are represented: First Nations, P/F/T government, cancer agency and major chronic disease agencies (Heart and Stroke Foundation, Lung Association, Diabetes Association).

Recommendations

Based on the findings present the need for jurisdictional partnerships between FNs and P/F/T governments to establish information sharing agreements and policy that respects the FN principles of OCAP to support:

- Aboriginal identity indicators;
- Hospital discharge sharing information with FN health centres;
- FN specific surveillance data; and
- FN specific screening eligibility. (See E-Technology Promising / Leading Practice #1)

Based on the findings present the need for the establishment of collaborative partnerships between FNs, the province, cancer and chronic disease agencies to ensure:

- Continuity of care (including sharing of discharge information and patient care plans within the circle of care)
- FN health care workers have access to an on-line information system including up to date chronic disease guidelines, continuing education, and decisional support. (See E-Technology Promising / Leading Practice #2 & #3)
- Cancer and chronic disease agencies work together with FNs to promote integrated chronic disease prevention and screening outreach supported by the development of culturally appropriate resources that are meaningful at the community level. (See E-Technology Promising / Leading Practice #2 & #3 and Outreach Leading Practice #2)
- Assess existing provincial mobile breast screening outreach to FN communities, identify ways to increase outreach and integrate a holistic chronic disease approach. (See Outreach Promising / Leading Practice #1 & #3)

Based on the findings, recommend the establishment of Aboriginal Patient Navigator positions that work across jurisdictions and are determined provincially through the partnership and collaboration of FNs and the cancer agencies with the support of FNs, federal and provincial governments. (See Patient Navigation Promising / Leading Practice #1)

3. Promote and support use of electronic technology that enhances cancer control for First Nations.

Support FN efforts to implement electronic health/medical record systems. (See E-Technology Promising / Leading Practice #1)

Support integration of case management capacity and a disease surveillance system within all electronic health databases. (See E-Technology Promising / Leading Practice #1)

Ensure that leading practices and culturally relevant resources are posted on sites such as www.cancerview.ca to ensure equitable access for all FN communities.

Increase awareness and use of e-platforms, such as @YourSideColleague® to support continuing education and decisional support. (See E-Technology Promising / Leading Practice #2)

Use e-platforms to deliver cancer and palliative care education to community members and health care workers in FN communities. (See E-Technology Promising / Leading Practice #2)

Nationally support and promote initiatives that use e-technology to conduct virtual appointments.

4. Support knowledge translation with Health Canada.

Present report findings to Health Canada.

- Highlight issues related to the Non-Insured Health Benefits (NIHB) program:
 - Travel support for organized cancer screening and follow-up diagnostics.
 - Need for streamlining of the NIHB application process.
 - Advantages of supporting screening in reserve communities.
 - Advantages of working with chronic disease agencies to understand cancer and chronic disease pathways.
- Highlight issues related to palliative care on reserve:
 - There is no formal organized palliative care program on reserve.
 - Palliative care is being provided in almost half of the communities that participated in the report in the absence of formal funding/supports.
 - There is a need for policy to support the sharing of discharge information of palliative patients and ongoing decisional support for health care workers.
 - There is a need to ensure continuity of care from treatment centres to home community in terms of medications and medical supplies.
 - There is a need for palliative care education for health care workers (all levels).
 - There is a need for palliative care education for community members that help care for palliative family members.
 - Advantages of established partnerships with cancer and chronic disease agencies to ensure safe quality care.
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AT-A-GLANCE SUMMARIES

For ease of reference, at-a-glance overviews of the data, including gaps and barriers and culturally appropriate resources, as well as leading/promising practices and models of care that currently exist to address specific gaps and barriers are provided in Appendix M. The charts also identify recommended actions to address gaps and barriers that exist in the current pathways.

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