CANCER CARE AND CONTROL IN INUIT NUNANGAT

PREPARED FOR THE CANADIAN PARTNERSHIP AGAINST CANCER
BY CORVUS SOLUTIONS

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Acknowledgements

The project team and Canadian Partnership Against Cancer would like to thank all of the Key Informants and cancer Survivor & Caregiver participants who contributed their knowledge and shared their time with us to make this report possible. We also want to thank all of the regional health sector personnel who assisted the project team throughout our travels to your communities.

Cover Photo: Arctic Cotton photo courtesy of André Perron

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EXECUTIVE SUMMARY

Cancer Care and Control in Inuit Nunangat presents the results of an Inuit-specific environmental scan of cancer care pathways; programs & services; promising initiatives; and challenges. The Inuit homelands, or Inuit Nunangat, are comprised of four regions: Nunatsiavut (in Labrador), Nunavik (in Northern Quebec), Nunavut, and the Inuvialuit Settlement Region (in Northwest Territories). The findings in this report are based predominantly on knowledge obtained through interviews with Key Informants (health sector personnel involved in design and/or delivery and/or management of cancer related services); and cancer Survivor & Caregiver participants.

The four regions of Inuit Nunangat are home to approximately 40,000 Inuit living in 53 communities spanning the Canadian Arctic and sub-Arctic. Communities are small, populations range from under 200 to the over 6,600 (in Nunavut's capital, Iqaluit). There is very little inter-community road infrastructure so most communities rely upon year-round air services and seasonal marine shipping as their primary (or only) transportation links. Provision of health care services to these small, isolated communities is challenging and expensive.

Cancer care in Inuit Nunangat follows the pathway built into the regions' general health care delivery systems. Primary health care is provided at community facilities by nurses and scheduled fly-in physicians. The regions face constant challenges to recruitment and retention of primary health care professionals which impacts continuity of care and provision of community services. Secondary and tertiary care requires air transportation of patients across vast distances to facilities in regional centres or southern Canada (which are often in other health jurisdictions).

To support referral management and the tracking and movement of patients, the regions have established various navigation and logistics services related to appointment coordination, travel and accommodations. From the patients' perspective, this is a familiar experience. Therefore, any cancer-specific patient navigation is experienced as an additional layer that may or may not be discernible to patients.

Key Findings: Cancer Related Programs and Services along the Continuum of Care

- **Prevention**
  - Public Health Education activities in communities are delivered by community health personnel.
  - Regional public health campaigns target broader issues such as tobacco reduction and healthy living.
  - All regions have an HPV Vaccination program in place.
  - Prevention activities are sporadic and inconsistent among communities.
  - Level of public awareness and health literacy are generally low.
  - There is a lack of culturally relevant materials and resources.

- **Screening**
  - Screening programs (partially organized) for cervical cancer and clinical breast exam are incorporated into Well Woman clinics (which are very well-established) in all regions.
  - Mammography screening programs are in place in Nunavik, Nunatsiavut and the Inuvialuit Settlement Region. Mammography is not available in the communities; it requires patient travel to secondary or tertiary site.
  - Colorectal and prostate screening is available based on clinician assessment or patient request in all regions. Mammography is available on this basis in Nunavut.
  - Only selected screening procedures are available in communities (i.e. Pap smears, physical exams, fecal occult blood, blood tests, x-rays in many, but not all, communities). For other screening procedures, patients are required to travel to secondary or tertiary sites.

- **Diagnosis**
  - Diagnostic testing requires patient travel to secondary or tertiary sites.
  - Patients experience at least one trip out of their community usually of duration of a week or more to undergo testing at secondary/tertiary sites.

- **Patient Navigation**
  - Cancer patients from Inuit Nunangat are all served by some degree of patient navigation at the secondary or tertiary sites.
  - Navigation services are either incorporated into or supplemented by the navigation components built into the system-wide navigation and coordination services.

- **Treatment**
  - **All** cancer treatment requires patient travel to tertiary or (some) secondary sites.
  - Chemotherapy and some surgery is available at the secondary sites serving patients from Nunatsiavut, the Kitikmeot region of Nunavut and the Inuvialuit Settlement Region.
  - All other treatment is provided at the tertiary cancer treatment sites.

- For patients, cancer treatment means repeated trips to treatment sites for weeks or months at a time for a year or more. In addition to the burden of the disease, they face long periods of separation from home, family, community and, often, financial hardship from loss of employment or income.
- Many patients are unaware of the numerous patient and caregiver support services available to them at the cancer treatment sites. However, these services are not necessarily culturally responsive or accessible.

- **After Care**
  - Basic after care services are available at: community health facilities or (if appropriate) at patients' homes through home and community care services and/or community health care providers. Complex after care is only available at the secondary or tertiary sites.
  - If after care is not available in their communities, patients face extended stays at the secondary or tertiary sites.
  - Patients and caregiver have a great need for emotional, psycho-social support.

- **Recovery – Survivorship Support**
  - There are no formal cancer support services, programs or groups in the communities.
  - Mental health and counselling services are extremely limited and not necessarily appropriate.
  - Community health care providers are largely unaware of the potential support services available to their patients through treatment centres or existing organizations.
  - Survivors and caregivers rely upon friends and family for emotional support. The need for support services is high.

- **Palliative Care**
  - If there is family support, communities make best efforts to palliate patients at home through collaboration between home and community care services and community health care providers.
  - The opportunity to spend the end of their lives at home is profoundly important to the patient and their families.

Key Findings: Pressure Points and Promising Initiatives

Efforts to improve cancer care and control in Inuit Nunangat are challenged by a set of pressure points affecting the system and the communities. At the same time, there are many promising initiatives underway that can or do improve the patient journey. These fall into four themes:

1. Access to Care – Physical

Pressure Points:

- The impact of vast physical distances separating communities and required cancer care services upon patients (numerous, lengthy medical trips; increased stress upon patients and families) and the health systems (complex logistics over multiple jurisdictions)
- The impact of certain cultural values and attitudes upon peoples' willingness and ability to seek care, services and information
- The impact of socio-economic stressors upon peoples' willingness and ability to seek care and their potential to mask symptoms of cancer

Promising Initiatives:

- The Tele-oncology program (Nunatsiavut) – Labrador Grenfell Health, Eastern Health and Nunatsiavut Government.
- Mobile Mammography services (Nunavik) – Institut National de Santé Publique du Québec.

2. Access to Care – Safety and Responsiveness

Pressure Points:

- The need for improvement of community level tracking and follow up of patient test results
- The need to resolve communications issues between tertiary sites and community level regarding discharge and patient orders
- The need for consistent, culturally and emotionally supportive protocols for delivery of initial diagnosis to patients

Promising Initiatives:

- Kivalliq Inuit Services in Winnipeg – Government of Nunavut.
- Cancer Patient Navigation – Oncology Pivot Nurse in Montreal – Nunavik Regional Board of Health and Social Services.
- NWT Cervical Cancer Screening program – Government of the Northwest Territories.
- Initial Diagnosis Delivery Process – Labrador Grenfell Health, Nunatsiavut Government.

3. Awareness (Provider and Patient)

Pressure Points:

- The need to raise levels of public awareness, health literacy and self-advocacy skills among the public
- The need to raise levels of community clinician awareness (prevention) and clinical education (assessment/early detection)
- The need to raise patient and community health care provider awareness of existing cancer care support services at secondary and tertiary sites

Promising Initiatives:

- The “Inuk to Inuk” prevention program – Nunavik Regional Board of Health and Social Services.
- The Provincial Cancer Committee, Eastern Health, Newfoundland and Labrador.

4. Culturally Responsive Resources and Services

Pressure Points:

- The need to improve provider cultural awareness and cross-cultural communications skills
- The need for culturally relevant public education materials and resources across the cancer care continuum (i.e. prevention through survivorship)

Promising Initiatives:

- The Palliative Care Project – Beaufort Delta Health and Social Services and Inuvialuit Regional Corporation.

Key Findings: Next Steps

Several options for actions are put forward to respond to the pressure points identified above.

- **Public Awareness Raising**
  - Facilitate the identification of health literacy gaps; the development of resources to address them; and strategies for incorporation in public education activities in the Inuit Nunangat region
  - Facilitate the development of public education materials about cancer that address attitudes and cultural values related to cancer; warning signs and symptoms for cancers to guide decisions about when to go to the clinic.

- **Patient Support Services**
  - Engage Inuit Nunangat regions and tertiary cancer care sites to support development of cancer pathway information kits for their patients. This should include an overview of the physical pathway; what to expect at the cancer treatment site; navigator contacts; and identify support services and where available.
  - Utilize the Partnership's network of partners and linkages to undertake an inventory of relevant survivor support networks and services that could be accessible to Inuit Nunangat cancer survivors and caregivers.

- **Building Primary/Secondary/Tertiary Site Communication Bridges**
  - Facilitate health sector communication linkages between the Inuit Nunangat regions and tertiary cancer sites
  - Support the development and/or delivery of cross-cultural orientation for tertiary cancer care sites

- **Clinical Education and Support**
  - Support development of clinical education tools to support community health care providers in cancer assessment and community level treatment preparation and procedures
  - Engage Inuit Nunangat regions to consider and provide guidance for health care providers for delivery of initial diagnosis to patients
  - Facilitate knowledge exchange relating to models or practical systems for patient results tracking and alerts

- **Remaining Inuit Pathway Knowledge Gaps**
  - Explore promising practices in circumpolar Inuit regions
  - Explore cancer care pathways among urban Inuit in Canada

INTRODUCTION

The Canadian Partnership Against Cancer (the Partnership) is a national level, non-profit organization established by the federal government to foster action on cancer control for all Canadians. Part of the Partnership's mandate is to shape and oversee implementation of a national cancer control strategy that will significantly reduce its impact across the country.

For the past two years, the Partnership has been working with an Advisory Committee on First Nations, Inuit and Métis Cancer Control (members include: Inuit Tapiriit Kanatami, Assembly of First Nations, Métis National Council, elders, cancer patients, Public Health Agency of Canada, First Nations and Inuit Health Branch, Canadian Cancer Society, Heart and Stroke Foundation and the Canadian Association of Provincial Cancer Agencies). Together, they developed a national strategy called the *First Nations, Inuit and Métis Action Plan on Cancer Control*.

Link: www.cancerview.ca/cv/portal/Home/FirstNationsInuitAndMétis

The Partnership's vision for the Action Plan is to support the reduction of rates of cancer and improve the quality of cancer control among Canada's Inuit, First Nations and Métis by implementing activities within their mandate—including working through partners to create and share new knowledge and convening stakeholders to discuss issues, plan and take action to address gaps. The ultimate goal of the action plan is to meet the distinct needs of Inuit, First Nations and Métis peoples by addressing priority cancer control gaps, including those related to cancer and chronic disease prevention, identified by each of the three peoples and by the health systems serving them.

As a first step in the implementation of the *First Nations, Inuit and Métis Action Plan on Cancer Control*, the Partnership needed to fill knowledge gaps about current cancer care pathways, promising practices and culturally responsive resources and services for these populations.

Corvus Solutions was hired by the Partnership to work with the Inuit Nunangat regions to undertake an environmental scan to fill Inuit-specific knowledge gaps about these issues and thereby build the foundation for future actions.

SCOPE AND OBJECTIVES

This report presents the results of an Inuit-specific environmental scan of cancer care and control in the Inuit Nunangat regions: the Inuvialuit Settlement Region (in Northwest Territories); Nunavut; Nunavik (in Northern Quebec); and Nunatsiavut (in Labrador).

The objectives of this project were to:

a) Describe typical cancer care pathways (focus on health care delivery system) for each of the Inuit Nunangat regions

b) Identify innovative or promising practices from across the continuum of cancer care

c) Identify culturally responsive cancer control (i.e. includes prevention) resources and services

The scope of this project was limited to an exploration of information about services, programs and cancer journeys of Inuit living within the Inuit Nunangat regions. The Partnership and the authors are aware that there are significant populations of Inuit living in urban centres in Canada (approximately 8400). Urban Inuit were outside of the scope of this project, therefore the knowledge gaps about cancer care pathways, programs and services remain to be addressed.

METHODOLOGY

The methodology developed for this project reflects our overarching commitment to operating in a respectful, collaborative manner with the Inuit Nunangat regions. Our approach was consultative, iterative and practical.

Recognizing that there is a known deficit of published literature relevant to the question of cancer care pathways, programs and services within or related to the Inuit Nunangat regions, the project methodology was based predominantly upon direct inquiry via semi-structured interviews.

Research Relationships:

The first step methodologically was to establish a working relationship with each Inuit Nunangat regional health jurisdiction and seek assignment of a lead regional contact to enable discussion about and adaptation as required of: information collection methodology; informed consent protocols; on-going communications; and results reporting.

Information Collection:

Questionnaires, interview guides and consent forms used to support information collection are included in the Appendix to this report.

1. ***Literature Review***

   A search for existing documentation related to Inuit-specific cancer care and control (systems, services, models, practices) was conducted using web-based and library-based databases and search engines.

2. ***Key Informant Interviews***

   A semi-structured interview guide was developed (with input from lead regional contacts) for use in conducting Key Informant interviews.

Working with lead regional contacts, lists of health sector personnel involved in design and/or delivery and/or management of cancer related services and programs were developed as potential Key Informants to be interviewed.

Key Informants included representation from territorial/provincial, regional and community levels of the health sector from each Inuit Nunangat region as well as personnel from tertiary cancer treatment sites.

Key Informant interviews were conducted in-person (except for three interviews conducted by telephone) as private, in depth conversational-style meetings. Verbal consent for permission to record interviews for note taking purposes and to quote anonymously was obtained and recorded during each interview. Interviews lasted from 2 to 3 hours each.

3. *Validation Consultations (Nunatsiavut, Nunavik, Nunavut)*

Preliminary findings were summarized in graphical format. These findings were presented to regional lead contacts and selected Key Informants for validation, discussion and incorporation into findings as required.

Preliminary findings for each region were summarized in graphical format and provided to selected Key Informants for participants for follow-up discussions via in-person or telephone meetings.

4. *Cancer Survivor & Caregiver Interviews (Nunatsiavut, Nunavik, Nunavut)*

Conversational style interviews with individual and/or family (as per participant choice). Written consent to participate, allow recording interviews for note taking purposes and to quote anonymously was obtained prior to the interview.

A semi-structured interview guide was developed (with input from lead regional contacts) for use in conducting Cancer Survivor and Caregiver interviews.

In order to protect survivors and caregivers privacy, lead regional contacts (or their designated staff) contacted and invited individuals who were cancer survivors and/or caregivers to ascertain their willingness to participate. The following generic script (developed with input from lead regional contacts) was used to support these initial conversations:

> *The [Inuit Nunangat Health Department/Division] is working with the Canadian Partnership Against Cancer on a project to improve cancer care pathways in the Inuit*

> *regions across the north. Part of this project is to get a better understanding of peoples' experiences with care as they dealt with cancer.*
>
> *Marianne Demmer, a consultant, is working with us on this project.*
>
> *Can you spare an hour of your time to speak with her? She would like to meet with you with/without your family or care giver - whatever you prefer. Please know that your conversation will be confidential.*
>
> *Your contribution will help to improve cancer care.*

Cancer Survivor & Caregiver interviews were conducted in-person as private, in depth conversational-style meetings. Verbal consent for permission to record interviews for note taking purposes and to quote anonymously was obtained and recorded during each interview. Interviews lasted from 3 to 4 hours each.

The following table indicates the number of interviews conducted for this project.

Region	Key Informant Interviews	Validation Sessions	Survivor & Caregiver Interviews
Nunatsiavut	14	3	4
Nunavik	12	3	4
Nunavut	25	3	13
Inuvialuit Settlement Region	13	0	0

Analysis:

The collected information was analysed using qualitative analysis techniques to identify themes and trends. Data coding and management for qualitative analysis was supported by the use of Nvivo 10 software.

Results Reporting:

Regions agreed that a comprehensive report would be submitted to the Partnership. It was understood that excerpts from and/or this entire report would be widely distributed and that the Partnership has permission to re-package it as required.

It was agreed that all lead contacts will receive copies of the comprehensive report. Further, all Key Informants and Survivor & Caregiver participants were to be offered a copy of the report.

Recognizing that the comprehensive report may, by its nature, not reflect all of the information collected for each region, the investigator offered to prepare region-specific reports for distribution to the respective regions if required.

Nunatsiavut requested digital copies of the Survivor & Caregiver interviews to be securely stored and committed to respect the terms of confidentiality agreed to between participants and researcher.

LIMITATIONS

1. There is a marked lack of published literature relevant to the question of cancer care pathways, programs and services within or related to the Inuit Nunangat regions.

2. Chronic challenges with under-staffing and turnover in the regions impacted information collection in several ways:
    - Key Informants and, in one case, lead contact had left their positions between the point of initial contact and the arrival of the investigator in their community
    - Delayed responses to requests for interviews (due to excessive workloads) impacted interview scheduling

3. Survivor & Caregiver participant discussions - time constraints:
    - Time available for validation was scheduled based on Focus Group timings. Significantly more time was required to conduct one-on-one interviews, reducing opportunities for additional potential Key Informant interviews (Survivor & Caregiver interviews were given priority).
    - A common phenomenon in the communities is that people want a sense of what kind of person a researcher is before they will step forward to take part. Often people wait for word of mouth about who the researcher is and how they conduct themselves. There were anecdotal reports from 5 of the 9 communities visited that more Survivor & Caregiver participants came forward after the investigator had left the community.

SECTION 1: INUIT NUNANGAT BACKGROUND

The Inuit homelands extend across the Arctic regions of Canada, Russia, Alaska and Greenland. In Canada, Inuit live primarily in communities within the four Inuit Nunangat regions of Canada: Inuvialuit Settlement Region (in Northwest Territories), Nunavut (the newest Territory), Nunavik (in Northern Quebec), Nunatsiavut (in Labrador). Community infrastructure is very limited compared to southern areas of Canada.

The delivery of health care services to these small, isolated communities is challenging and expensive. The pattern of health service delivery in the north has remained relatively unchanged for over 40 years. Primary health care is provided by community health care providers and scheduled fly-in visits by physicians. Access to secondary and tertiary care requires air travel either via scheduled medical travel or medical evacuation (medevac) to reach better equipped hospitals in regional centres and southern Canada. The costs associated with provision of health care coupled with difficulties faced in the recruitment and retention of community-based health care staff means that most governments face challenges to deliver comprehensive health care services.

The remainder of this section offers snapshots of the political, geographical and demographic factors impacting each region. It is meant to provide the reader with a glimpse of the socio-political context within which cancer care is being delivered by the health systems and experienced by the patients.

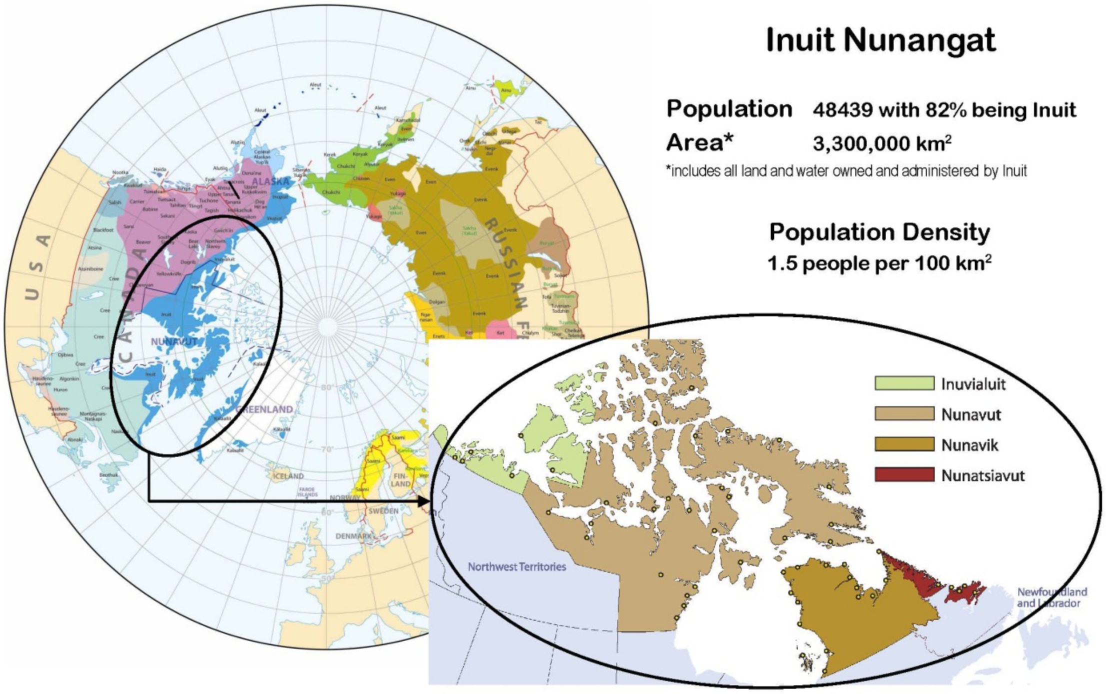
Data Sources for the snapshots are as follows:

- Statistics Canada. 2007. 2006 Aboriginal Population Profile. 2006 Census.
- Statistics Canada Catalogue no. 92-594-XWE. Ottawa. Released January 15 2008.
- Statistics Canada. Table 102-0704 - Mortality, by selected causes of death (ICD-10) and sex, five-year average, Canada and Inuit regions, every 5 years.
- Institut de la statistique du Québec
- NWT Bureau of Statistics

Inuit Nunangat

Population **48439 with 82% being Inuit**
Area* **3,300,000 km²**
*includes all land and water owned and administered by Inuit

Population Density
1.5 people per 100 km²



Language of the Inuit

It is widely accepted that language is the verbal expression of culture . The Inuit know their culture mostly through their oral history. Thus to understand the Inuit it is important to have some concept of the scale and scope of the Inuit language. The Inuit language is the most widely spoken of the Eskaleut languages. Western Canadian Inuktun and Eastern Canadian Inuktitut groups are comprised of 9 dialects and 20 sub-dialects spoken by over 50,000 people in a geographic area that stretches over 4500 kilometers from east to west.

Inuit culture has been shaped to a large degree by the natural world that the Inuit inhabit. Dialects have evolved from the need to explain the immediately observable world and belief systems about the supernatural world. The dialects allow for Inuit to convey their worldview as it fits their culture.

It is paramount to understand the importance of language to the Inuit so that we can reflect that in the cultural appropriateness of the medical care continuum.

Inuit Nunangat
"Inuit Homeland"

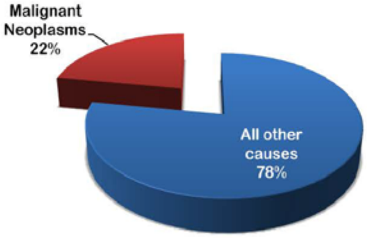
Inuit Nunangat is home to approximately 40,000 Inuit in 53 communities located in 4 land claims regions in the Canadian Arctic and sub-Arctic.

The region is typified by small communities separated by vast distances. Communities range in size from hamlets of under 200 people to the 6600 people that reside in Nunavut's capital, Iqaluit. There is very little inter-community road infrastructure with the majority of communities being served by year-round air services and seasonal marine shipping.

For the purposes of this study all of the communities can be considered to be isolated (isolated being defined as "a community without year-round road access")

Social Determinants of Health for Inuit

People who suffer from adverse social and material living conditions also experience high levels of physiological and psychological stress. Stressful experiences arise from coping with conditions of low income, poor quality housing, and food insecurity. Comprehensive recent data on Inuit health and socioeconomic indicators is scarce. Where reliable quantitative data exists, the salient social determinants of health for Inuit have been represented graphically in the regional snapshots in the following pages.



Mortality due to Cancers in Inuit Nunangat

Income

Income is perhaps the most important social determinant of health. Level of income shapes overall living conditions, affects psychological functioning, and influences health-related behaviours such as quality of diet, extent of physical activity, tobacco use, and excessive alcohol use. The resources of Inuit living in low-income households are further stressed by the high cost of living in the Arctic regions.

Food Insecurity

Food security (consistent economic access to sufficient, nutritious food) is a direct determinant of physical and psychological health. Food insecure households are more likely to have chronic health issues, depression and reduced abilities to learn than households with sufficient food.

Moderate food insecurity refers to compromised quality and/or quantity of food.

Severe food insecurity refers to reduced food intake and disrupted eating patterns.

Education

Education is an important social determinant of health. People with higher education tend to be healthier than those with lower educational attainment. Several studies have shown there is a relationship between higher levels of education and improved health in Inuit.

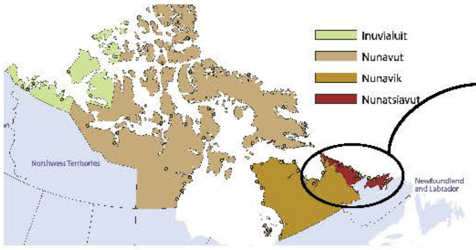
Housing

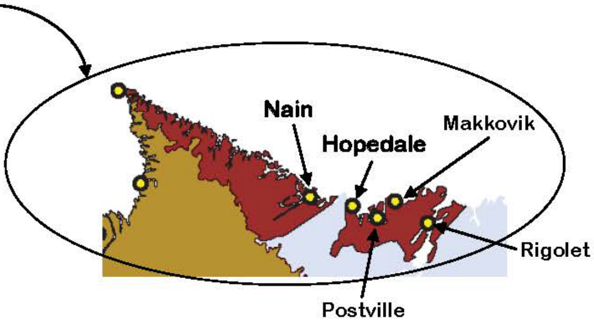
Housing influences health in many ways. People experience qualitatively different material environments depending on their housing quality.

The majority of Inuit live in social housing. Over 50% of those people in public housing live with overcrowding. Overcrowding and inadequate housing allows for transmission of respiratory and other illnesses as well as increased incidences of psycho-social events (i.e. spousal abuse, substance abuse and depression)

Age

Age in itself is not commonly cited as a social determinant of health. However, health determinants related to age such as acculturation for youth and the importance of health determinants in early childhood are magnified given the age distribution in Inuit regions which tends to be lower (younger) than the statistical normal.

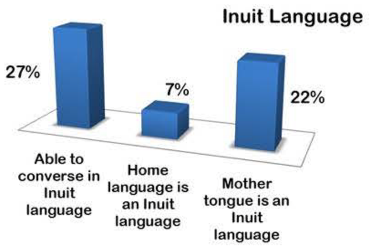




Nunatsiavut

Population	**2414 of which 90% are Inuit**
Area	**15,800 km^2**

Population Density
15 people per 100 km^2



Inuttitut

Written form – roman orthography

Labrador Inuttut
Labrador Inuttut (or Inuttitut) is the main dialect spoken in northern Labrador and Nunatsiavut. It consists of several dialect variations, as the Nunatsiavut communities are made up of Inuit originally from different nearby areas.

Rigolet Inuttut
Spoken in Rigolet with some speakers in Happy Valley-Goose Bay.

This dialect is facing language loss as the few speakers in the community are very elderly. Currently efforts are being made both within the community and in Happy Valley/Goose Bay to preserve some of the distinct characteristics of this dialect and to revive the speaking of Inuttitut.

The Nunatsiavut Government (NG) was established in 2005, born out of the Labrador Inuit Land Claim Agreement (LILCA). The LILCA was the last of the Inuit Nunangat Regions' land claims to be finalized and the first Inuit land claim to win the right to self-government.

The NG has (or shares) authority over many central governance areas including health, education, culture and language, justice and community matters. It is responsible for serving not only Inuit and non-Inuit residents of Nunatsiavut, but also Labrador Inuit living throughout Canada.

The NG operates at two connected levels: Regional and Community.

The Regional level of the NG is organized into seven departments including the Department of Health and Social Development.

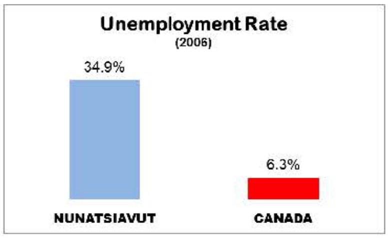
The Community level of NG is comprised of five Inuit Community Governments which are responsible for serving all residents of their communities.
The AngajukKâk of each Inuit Community Government represents his or her constituency in the Nunatsiavut Assembly.

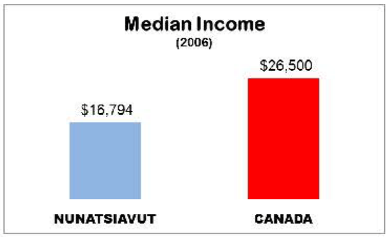
The community of Hopedale is the legislative capital of Nunatsiavut with Nain being the administrative capital.

All the communities in Nunatsiavut are isolated in that they are communities wthout year-round road access.

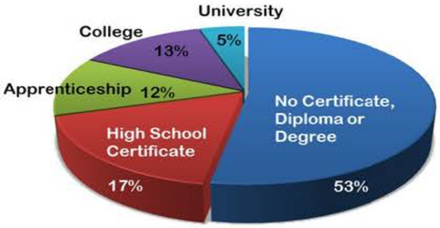
Nunatsiavut means 'our beautiful land' in Inuttitut.

Nunatsiavut Social Determinants

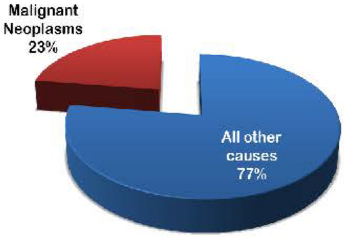




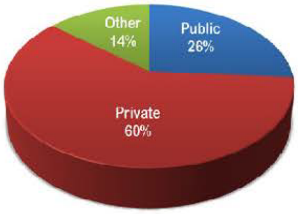
Food Insecurity



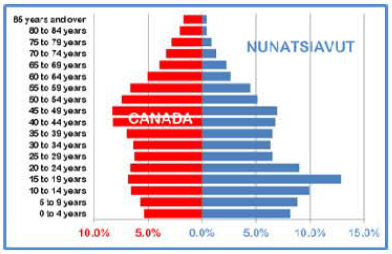
Education



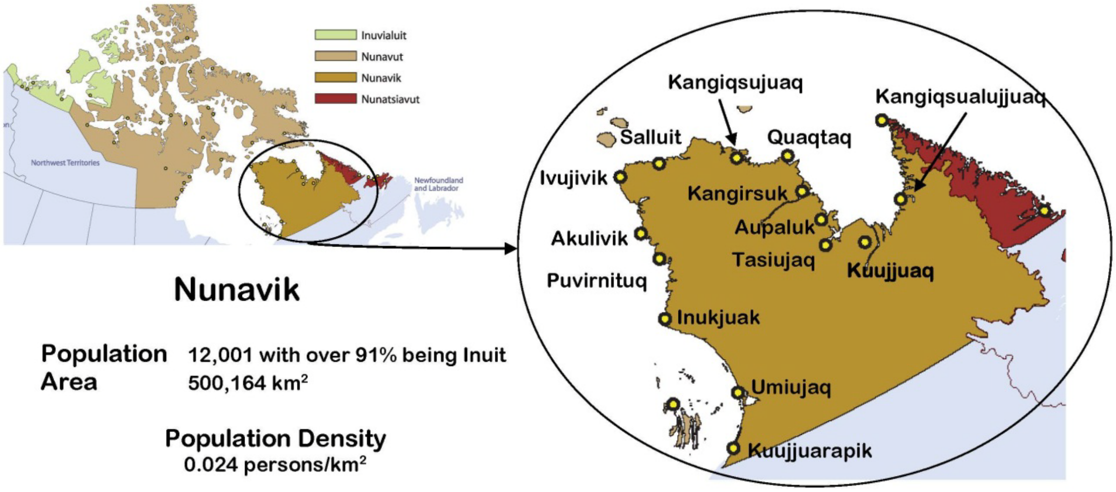
Mortality due to Cancers in Nunatsiavut



Housing



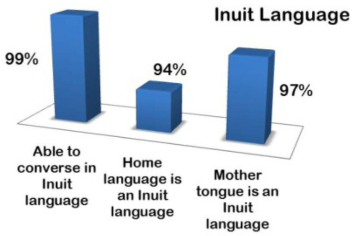
Age



Nunavik

Population	12,001 with over 91% being Inuit
Area	500,164 km^2

Population Density
0.024 persons/km^2



Inuktitut

Written form – syllabics (some roman orthography)

The Nunavik dialect of Inuktitut consists of two sub-dialects:

Tarramiut
The Tarramiut dialect is spoken in communities of the northeastern coast of Hudson Bay, Hudson Strait and Ungava Bay.

Itivimiut
Itivimiut is spoken primarily in the communities on the east coast of Hudson Bay.
It is also spoken in Sanikiluaq which belongs to Nunavut.
Several families relocated from the Inukjuak area to Grise Fiord and Resolute Bay in the 1950's took the Itivimiut dialect with them.

The Inuit of Nunavik successfully negotiated the first modern comprehensive land claims agreement with the signing of the James Bay and Northern Quebec Agreement (JBNQA) on November 11, 1975.

The Kativik Regional Government (KRG) was created in 1978 pursuant to the JBNQA to deliver public services to Nunavimmiut.

The Kativik Regional Government is responsible for the delivery of municipal services and infrastructure in the communities. Health services to Nunavik residents are managed by the Nunavik Regional Board of Health and Social Services.

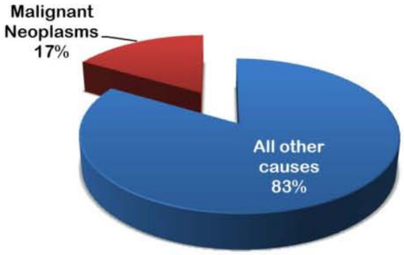
Formal "self government negotiations" with the province of Quebec and the Government of Canada began in 2002 and on December 5, 2007 the Inuit of Quebec, the Province of Quebec and the federal government signed the agreement-in-principle to formally create a new regional government in Nunavik.
The new Nunavik Regional Government represents all citizens of Nunavik.

The Inuit of Nunavik live in 14 communities above the 55th parallel. Kuujuaq is the largest community (pop. 2375) with Aupaluk (pop. 183) being the smallest.

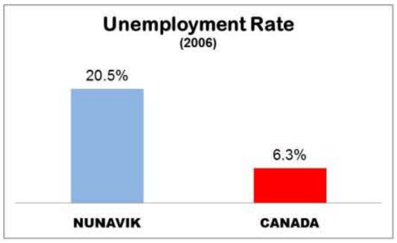
All the communities in Nunavik are isolated in that they are communities wthout year-round road access.

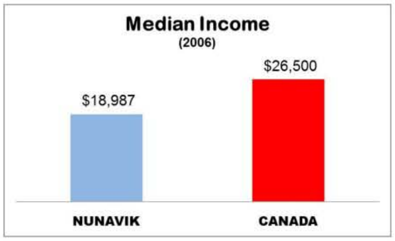
Nunavik means "place to live" in Inuktitut

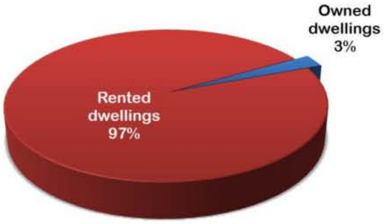
Nunavik Social Determinants



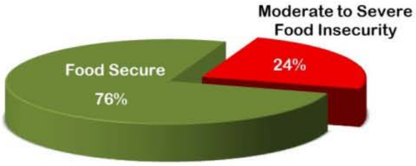
Mortality due to Cancers in Nunavik



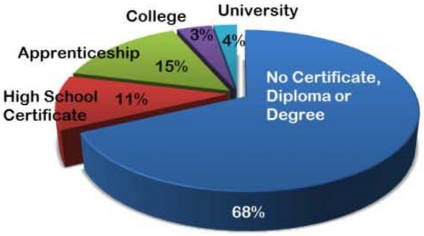




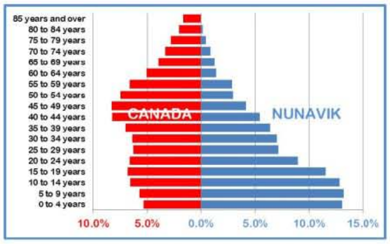
Housing



Food Insecurity



Education



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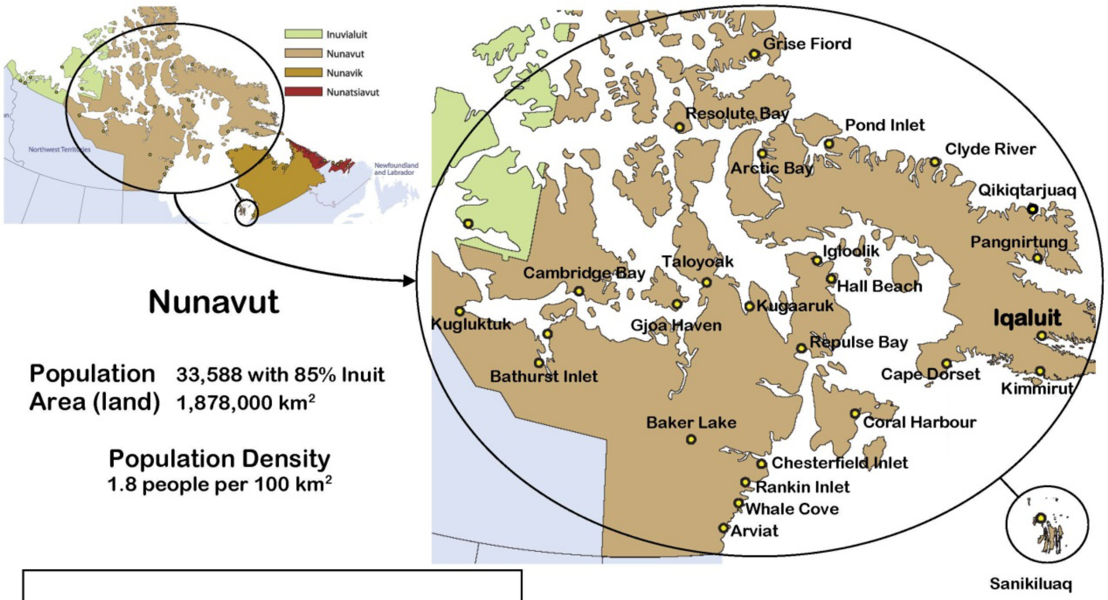
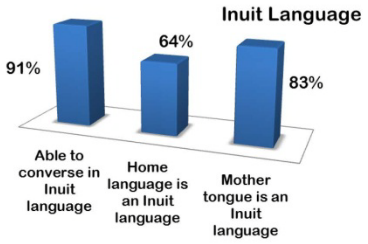


Nunavut

Population 33,588 with 85% Inuit
Area (land) 1,878,000 km²

Population Density
1.8 people per 100 km²



Inuktitut and Inuinnaqtun

As spoken in Nunavut there are nominally some 13 sub-dialects belonging to 5 dialects.

(Note: Inuit and many linguists would agree there is no consensus on the exact number and nature of dialects and sub-dialects of the Inuit language.)

Inuktitut
Spoken primarily in all but 2 of Nunavut's communities. Inuktitut is usually written in syllabics (also written in roman orthography).

Inuinnaqtun
Used in the communities of Kugluktuk and Cambridge Bay, there were approximately 300 Inuinnaqtun speaking Inuit as of 2006.
The language is written only in roman orthography.

In 1993, after negotiations that spanned 20 years, the Inuit of Nunavut signed the Nunavut Land Claims Agreement (NLCA). The NLCA was the largest transfer of money, resources, and power in Canadian history.

The NLCA is also the only aboriginal land claim or treaty in the world that resulted in the creation of a new territory and public government. The claim contained a commitment for the creation of the Nunavut Territory and government which came into existence on April 1, 1999.

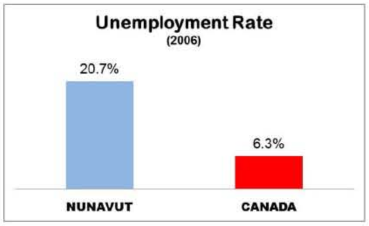
The Government of Nunavut is a public government with responsibility for providing services to all residents of the territory (Inuit and non-Inuit).
It is organized into 10 departments, including the Department of Health and Social Services which is responsible for providing health care services to all residents of Nunavut.

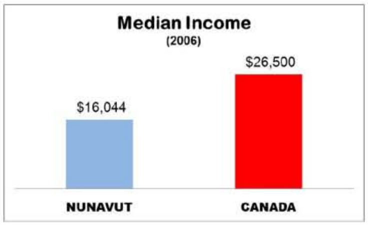
Iqaluit (pop. 7152) is the administrative capital and the largest community. The smallest community is Grise Fiord (pop. 157) which lies over 1500 kms to the north of the capital.

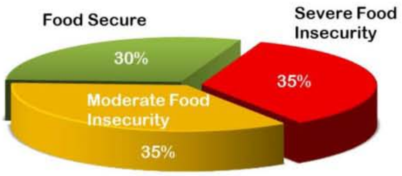
All the communities in Nunavut are isolated in that they are communities wthout year-round road access.

Nunavut means 'our land' in Inuktitut

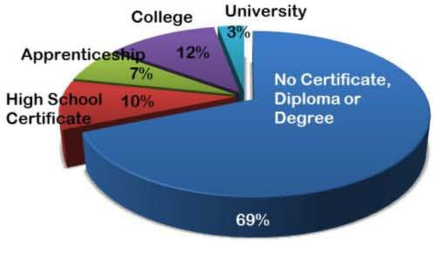
Nunavut Social Determinants



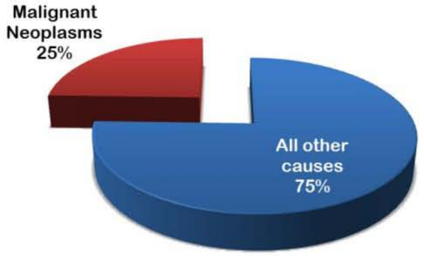




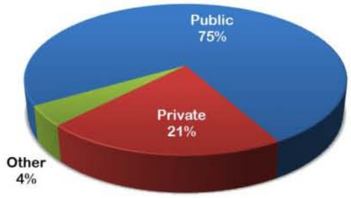
Food Insecurity



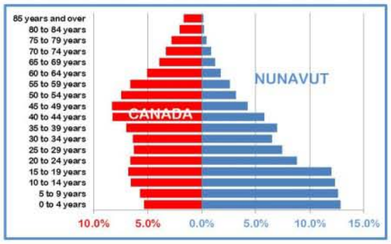
Education



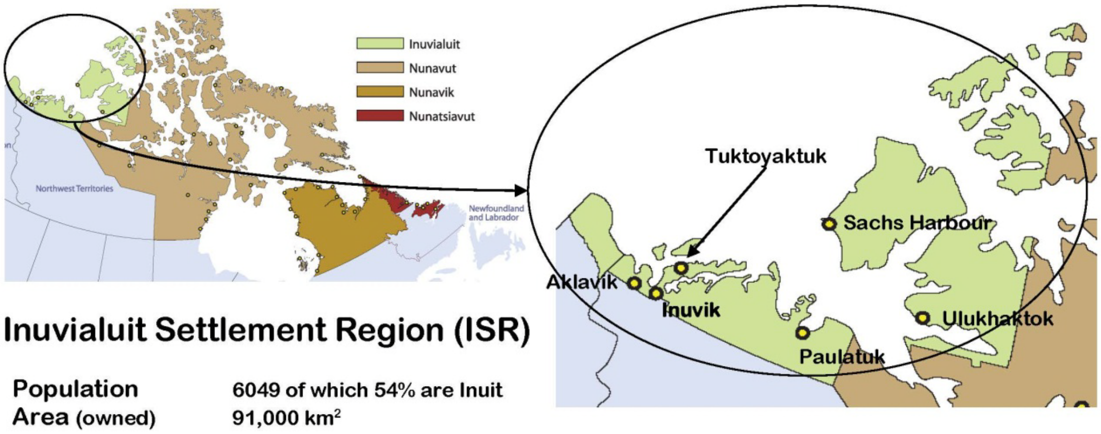
Mortality due to Cancers in Nunavut



Housing



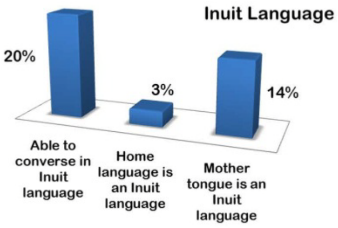
Age



Inuvialuit Settlement Region (ISR)

Population	**6049 of which 54% are Inuit**
Area (owned)	**91,000 km²**

Population Density
6.6 people per 100 km²



Inuvialuktun

Written form – roman orthography

Inuvialuktun, as spoken in the ISR, consists of 3 dialects:

Siglit
A dialect of the Western Canadian Inuktun group, Siglitun is spoken primarily in the coastal communities of Tuktoyaktuk, Sachs Harbour and Paulatuk.

Kangiryuarmiut
Essentially very similar to the Inuinnaqtun spoken in the westernmost communities in Nunavut, Kangiryuarmiut is spoken in the community of Ulukhaktok.

Uummarmiut
A subdialect of Inupiaq (spoken in northern Alaska) Uummarmiut is spoken in the communities of Inuvik and Aklavik.

The Inuvialuit Settlement Region is the result of a comprehensive land claim passed into law as the Western Arctic Claims Settlement Act in 1984.

The Inuvialuit share management responsibilities equally with the Federal and Territorial governments through a system of co-management bodies. The five co-management bodies deal mainly with environmental impact, wildlife and fisheries management.

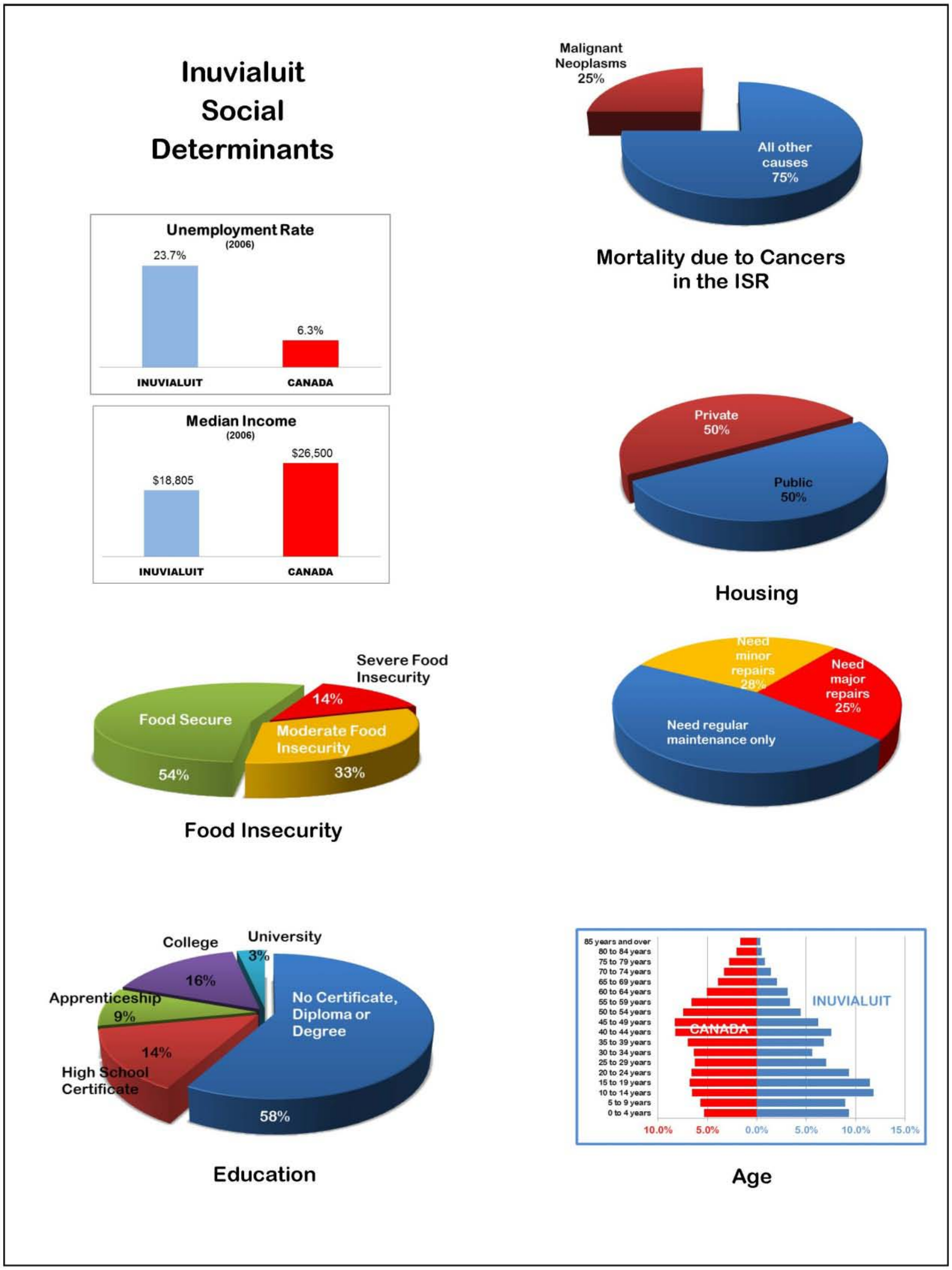
In 2007 Inuvialuit representatives reached an agreement with the Governments of Canada and the Northwest Territories outlining the timeline for negotiation of Inuvialuit Self Government.

Inuvik (pop. 3504) is the regional administrative centre and the only community with year round road access via the Dempster Highway. Although Inuvik technically has a "year-round road" it should be noted that the trip to Yellowknife is over 3700 kms on rough roads and takes over 72 hours of driving.

Tuktoyuktuk (pop. 935) and Aklavik (pop. 655) are linked with Inuvik by ice road during the winter.

The communities of Ulukhaktok (pop. 479) and Sachs Harbour (pop. 135) are on islands and are considered isolated for the purposes of this report.

Inuvialuit means 'the real people' in Inuvialuktun.


Inuvialuit Social Determinants
Unemployment Rate
(2006)
23.7%
6.3%
INUVIALUIT
CANADA
Median Income
(2006)
$18,805
$26,500
INUVIALUIT
CANADA
Malignant Neoplasms 25%
All other causes 75%
Mortality due to Cancers in the ISR
Private 50%
Public 50%
Housing
Need minor repairs 28%
Need major repairs 25%
Need regular maintenance only
Severe Food Insecurity
14%
Food Secure
54%
Moderate Food Insecurity
33%
Food Insecurity
College
University
3%
16%
Apprenticeship
9%
No Certificate, Diploma or Degree
14%
High School Certificate
58%
Education
85 years and over
80 to 84 years
75 to 79 years
70 to 74 years
65 to 69 years
60 to 64 years
55 to 59 years
50 to 54 years
45 to 49 years
40 to 44 years
35 to 39 years
30 to 34 years
25 to 29 years
20 to 24 years
15 to 19 years
10 to 14 years
5 to 9 years
0 to 4 years
INUVIALUIT
CANADA
10.0%
5.0%
0.0%
5.0%
10.0%
15.0%
Age

SECTION 2: INUIT NUNANGAT CANCER CARE PATHWAYS

The information presented in this section reflects the rich knowledge shared by the Key Informants (health sector personnel from territorial/provincial, regional and community levels in each Inuit Nunangat region as well as personnel from tertiary cancer treatment sites) and the cancer Survivor & Caregiver participants.

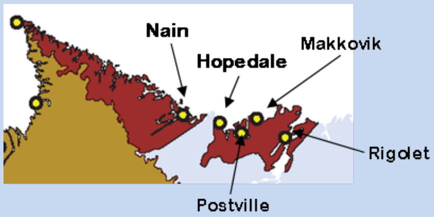
Unless otherwise noted, the reader should assume that Key Informant and Survivor & Caregiver participant interviews are the sources of the information.

HEALTH SERVICES DELIVERY SYSTEM

Cancer care services are received by patients in the context of the broader health service delivery system operating in Inuit Nunangat. This section provides a primer on the general health service system in place in each region, focusing on the system aspects that are most relevant to cancer. It is not meant to present the complete spectrum of health care services available in each region as those not directly related to cancer care are not discussed.

The responsibility for provision of insured health services for all residents within the Inuit Nunangat regions rests with the respective territorial or provincial governments. In the case of Nunatsiavut, certain health services are provided directly by the Nunatsiavut Government.

Nunatsiavut



Acute and Clinical Care:

Government of Newfoundland and Labrador, Department of Health and Community Services

- Ministry

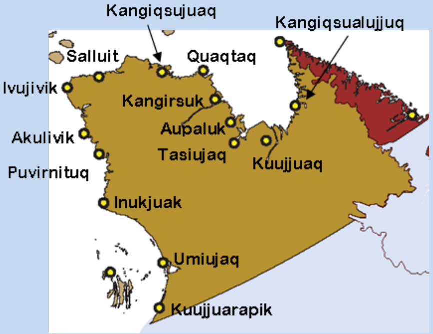
Labrador-Grenfell Regional Health Authority (LGH)

- Operational provision and administration of clinical services
- One of 4 Regional health authorities within the Newfoundland & Labrador health administration system
- Serves the 5 communities of Nunatsiavut and 17 other communities within its service area

Community Health Services:

Nunatsiavut Government, Department of Health and Social Development (DHSD)

Nunavik



Government of Quebec, Ministère de la Santé et des Services Sociaux (MSSS)

- Ministry

Nunavik Regional Board of Health and Social Services (NRBHSS)

- Operational provision and administration of services
- One of 17 regional boards of health and social services within the Quebec health administration system
- Serves the 14 communities of Nunavik

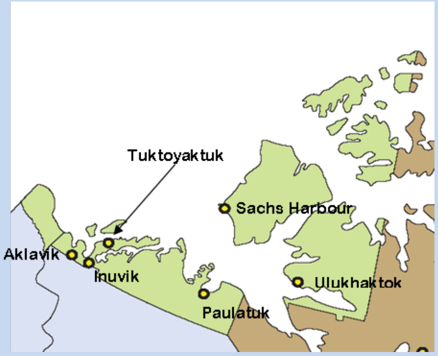
Nunavut

Government of Nunavut, Department of Health and Social Services (DHSS)

- Ministry

- Operational provision/administration of services via 4 administrative divisions:
    - Kitikmeot Regional HSS (west)
    - Kivalliq Regional HSS (central)
    - Qikiqtaaluk Regional HSS (east/Baffin Island)
    - Iqaluit HSS (Iqaluit and the Qikiqtani General Hospital)

Inuvialuit Settlement Region (ISR)



Government of Northwest Territories, Department of Health and Social Services

- Ministry

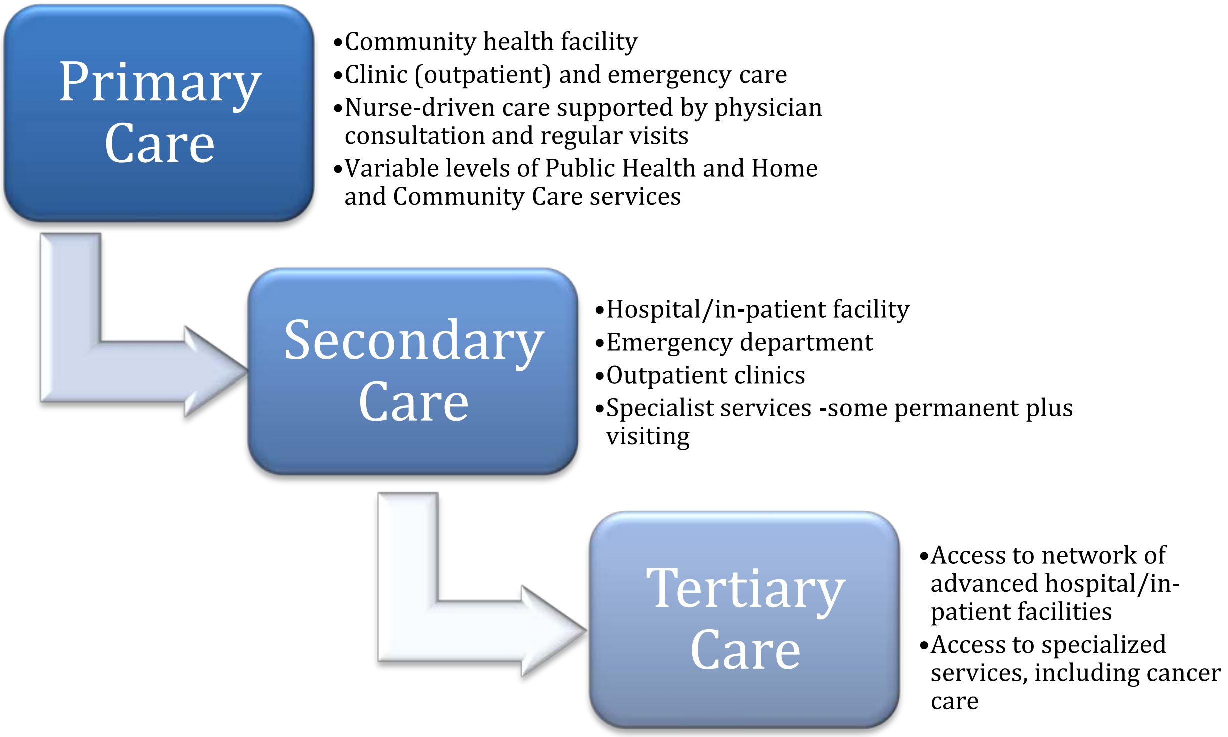
Beaufort Delta Health and Social Services Authority (BDHSSA)

- Operational provision and administration of services
- One of 8 health authorities in NWT health administration system
- Serves the 6 communities of the ISR plus 2 others within its service area

Therefore, with the exception of the set of community health services provided by the Nunatsiavut Government, health care services are provided to Inuit based on their residency within their respective territorial or provincial health jurisdictions, not as a result of Aboriginal status.

The provision of an additional set of non-insured health goods and services (i.e. those not insured by provinces, territories or other private insurance plans) are provided federally to Inuit (Nunatsiavut manages its own program for all beneficiaries in Canada). Health Canada's Non-Insured Health Benefits (NIHB) program covers costs for a specified range of drugs, dental care, vision care, medical transportation, medical supplies and equipment, and short-term crisis intervention mental health counselling for Inuit (and First Nations people). Those NIHB services most relevant to cancer care will be discussed in more detail in subsequent chapters within this report.

Provision of clinical care to Inuit Nunangat residents typically follows the pattern illustrated below:



PRIMARY CARE

Each of the communities of Inuit Nunangat has a health facility, usually centrally located in the community, through which primary care is provided. Generally, these facilities provide clinical and acute services on an outpatient basis. Services at the community facilities are delivered by nurses who are supported by visiting family physicians. Family physicians, usually based at secondary sites (or in the south) visit communities on a scheduled, rotational basis, usually every 4 – 6 weeks.

Staff complements for community health facilities vary based on the size of the community but generally range from 1 to 5 nurses per community health facility. In the larger regional communities, primary care is usually delivered through clinics located within or near the regional hospitals.

The regions face a constant challenge to recruit and retain health care professionals and turnover is high which impacts continuity of care and provision of community services.

What's in a name?

The regions used different terminology to describe their health facilities:

	Community	**Secondary**
Nunatsiavut	Community Clinic	Health Centre
Nunavik	"CLSC" (local community service centre)	Health Centre
ISR and Nunavut	Health Centre	Hospital

Kugluktuk Health Centre

Nain Community Clinic

SECONDARY AND TERTIARY CARE

In all cases, because of limited infrastructure, capacity and small populations within the regions, health delivery systems rely heavily upon referral to secondary and southern Canada tertiary sites for medical and health care services.

Inuit Nunangat Secondary and Tertiary Care Sites:

Nunatsiavut

Secondary Care:	**Happy Valley-Goose Bay** **Labrador Health Centre** 
Tertiary Care:	**St. John's, NL**

Nunavik

Hudson Coast Secondary Care:	**Puvirnituq (Nunavik)** **Inuulitsivik Health Centre** 
Ungava Coast Secondary Care:	**Kuujjuaq (Nunavik)** **Ungava Tulattavik Health Centre** 
Tertiary Care (both coasts):	**Montreal, QC**

Nunavut

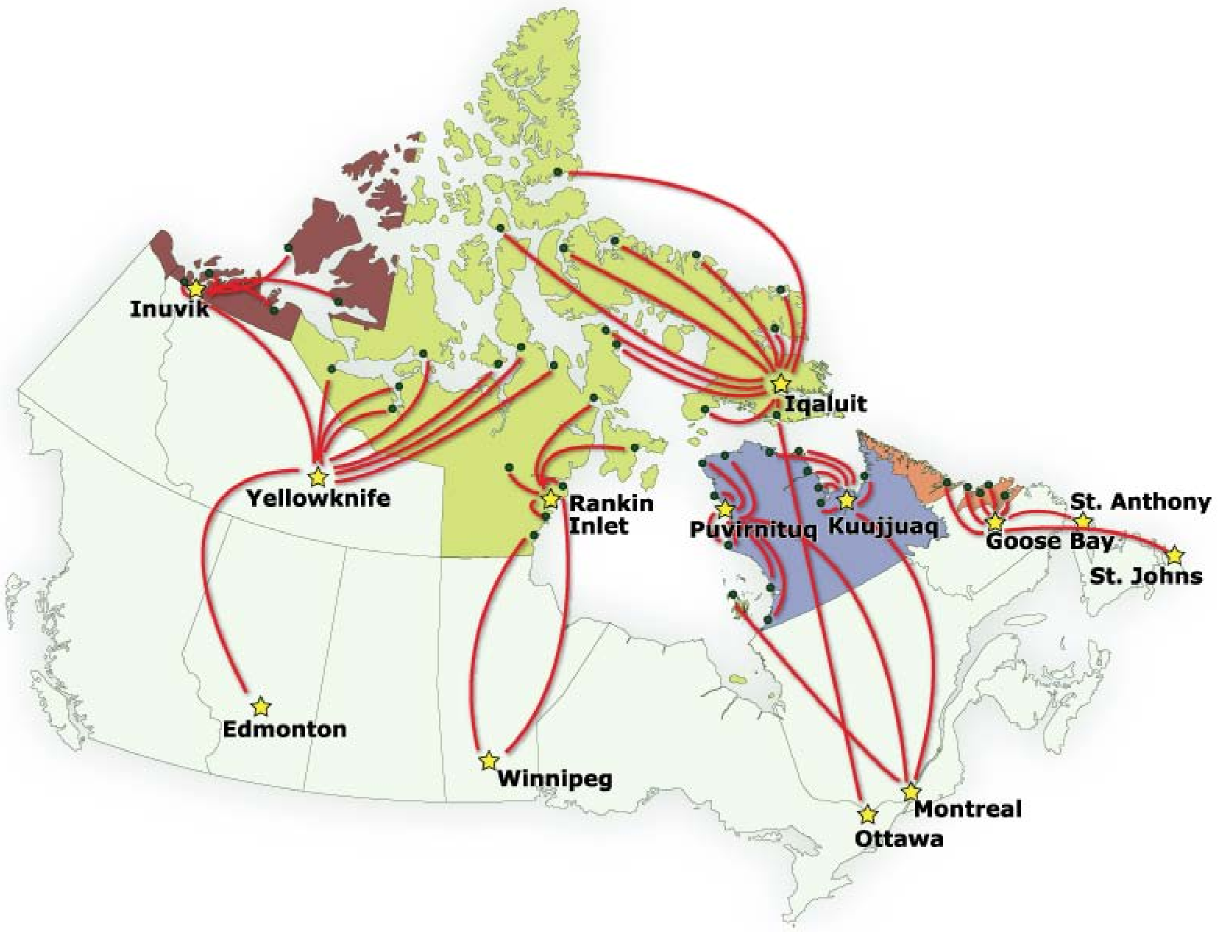
Qikiqtaaluk **Secondary Care:**	**Iqaluit (Nunavut)** **Qikiqtani General Hospital** 
Tertiary Care	**Ottawa, ON**
Kivalliq **Secondary Care:**	**Limited: Rankin Inlet (Nunavut)** **Kivalliq Health Centre (expanded service centre)**  **More common: Winnipeg, MB**
Tertiary Care:	**Winnipeg, MB**

Kitikmeot Secondary Care:	**Yellowknife, NT Yellowknife Stanton Territorial Hospital** 
Tertiary Care:	**Edmonton, AB**

Inuvialuit Settlement Region

Secondary Care:	**Limited: Inuvik (ISR) Inuvik Regional Hospital**  **More common: Yellowknife, NT Yellowknife Stanton Territorial Hospital**
Tertiary Care:	**Edmonton, AB**

The distances between communities and secondary/tertiary referral sites are vast. Inuit from the regions often have to embark on lengthy journeys to receive advanced or specialized health services. This is particularly true in the case of cancer, where, from the point of suspicion of cancer onwards, patients will have to make numerous and often lengthy trips to receive care. This is illustrated by the map below (provided courtesy of Inuit Tapiriit Kanatami) showing the referral patterns for the four Inuit Nunangat regions.



OUTREACH SERVICES

All of the regions seek to build outreach services into their health systems:

- Physicians and some specialists travel to communities
- Specialists travel from the tertiary sites to the secondary sites
- Telehealth systems are in place throughout the regions. At this time, Nunatsiavut is the only region that specifically uses it to support cancer care (i.e. tele-oncology)

Nain Community Clinic

SYSTEM-WIDE COORDINATION AND LOGISTICS

Because of the vast distances involved in providing health care to Inuit, and the necessity for inter-jurisdictional transfers of patients to secondary and tertiary sites, the regions have established various navigation and coordination systems to support the needs of patients requiring referrals out of their communities to receive health care (including, but not specific to, referrals related to cancer care).

These services fall into two categories: navigation & coordination; and medical travel related (through NIHB).

This is an important point to understand in the context of cancer care: patients from Inuit Nunangat who are referred to a secondary or tertiary site for medical care experience a set of navigation and logistics services related to appointment coordination, travel and accommodations. From the patients' perspective, this is a familiar experience. Therefore, any cancer-specific patient navigation is experienced as an additional layer that may or may not be discernible to patients.

SYSTEM-WIDE NAVIGATION & COORDINATION

System-wide navigation and coordination services linking regions to tertiary care sites are crucial for tracking and monitoring patients from the regions as well as for making appointments as efficiently as possible (i.e. coordinating a series of appointments to minimize the number of trips required).

Region	**System Navigation & Coordination**
Nunatsiavut	Labrador Grenfell Health & Eastern Health (St. John's) personnel • Medical referral coordination • Coordination/communication of patient information • Patient navigation (aboriginal navigator, non-nurse)

Region	**System Navigation & Coordination**
Nunavik	Northern Quebec Module - Montreal, QC • Medical appointment coordination • Accommodation coordination • Nursing case management • Coordination/communication of patient information • Inuktitut Interpreter services • Patient support

Region	System Navigation & Coordination
Nunavut – Qikiqtaaluk	Ottawa Health Services Network Inc. - Ottawa, ON • Medical appointment coordination • Nursing case management • Coordination/communication of patient information • Patient support • Coordination of specialist clinics for QGH • Inuktitut Interpreter services
Nunavut – Kivalliq	Kivalliq Inuit Services – Winnipeg, MB • Medical appointment coordination • Nursing case management • Coordination/communication of patient information • Patient support
Nunavut – Kitikmeot	Northern Health Services Network – Edmonton, AB • Nursing case management • Coordination/communication of patient information

Region	System Navigation & Coordination
Inuvialuit Settlement Region	Northern Health Services Network – Edmonton, AB • Nursing case management • Coordination/communication of patient information

The services for Nunavik, Nunavut and Inuvialuit Settlement Region provide navigation services through the nurse case managers. This includes direct services to patients while they are in the south, visiting patients in the hospitals as well as at the boarding homes or accommodations. For example, they accompany patients to the diagnosis and treatment planning appointments.

It was clear from Survivor & Caregiver participants and Key Informants, that the navigators in the south are some of the longest-term personnel in the system and provide a source of continuity to patient care that is not commonly experienced within the regions themselves.

> *"They do amazing work, they're conscientious and committed and we couldn't imagine it working without them."*
>
> Key Informant, Kivalliq
>
> *"Without them, we would not be able to function in Montreal…they are our heart line"*
>
> Key informant, Nunavik

MEDICAL TRAVEL (NIHB)

The other essential aspect of service coordination and logistics are medical travel related services. All regions have processes in place to coordinate and arrange patient travel for all medical needs including, but not specific to, cancer related needs.

The services most relevant to cancer care include:

- Escorts
- Coordination and provision of air transportation
- Ground transportation to/from airports and to/from appointments
- Accommodations
- Meals
- Interpretation services

These are non-insured services. For Inuit, the costs of these services are covered through the federal government's NIHB program. For non-Inuit, these services are subsidized by the jurisdictions, but patients are required to pay a portion of the costs either directly or through third party insurance. According to Key Informants, this is the only difference between Inuit and non-Inuit along the cancer care pathway.

The provision of medical travel is another layer of coordination which necessarily interacts with medical appointment coordination. Medical travel clerks, community nurses, tertiary referral coordinators relay required information until all arrangements are in place at which time the patient is notified of their appointment, flights and accommodation.

Accommodations, meals, interpretation services and ground transportation to shuttle Inuit patients to and from the airport and their appointments are also provided.

Region	Accommodations
Nunatsiavut	Happy Valley-Goose Bay (Labrador) • Various - Organized by Nunatsiavut Government medical travel personnel St. John's, NL • Various - Organized by Nunatsiavut Government medical travel personnel

Region	Accommodations
Nunavik – Hudson Coast	Puvirnituq (Nunavik) • Transit house Montreal, QC • Organized by Northern Quebec Module • Westmount YMCA residence
Nunavik – Ungava Coast	Kuujjuaq (Nunavik) • Transit house Montreal, QC • Westmount YMCA residence
Nunavut – Qikiqtaaluk	Iqaluit (Nunavut) • Tamaatavit Boarding Home Ottawa, ON • Larga House Baffin boarding home
Nunavut – Kivalliq	Winnipeg, MB • Kivalliq Inuit Centre boarding home
Nunavut – Kitikmeot	Yellowknife, NT • Larga Kitikmeot boarding home Edmonton, AB • Larga Home Edmonton boarding home
Inuvialuit Settlement Region	Yellowknife, NT • Vital Abel Boarding Home Edmonton, AB • Larga Home Edmonton boarding home

Survivor & Caregiver Voices:

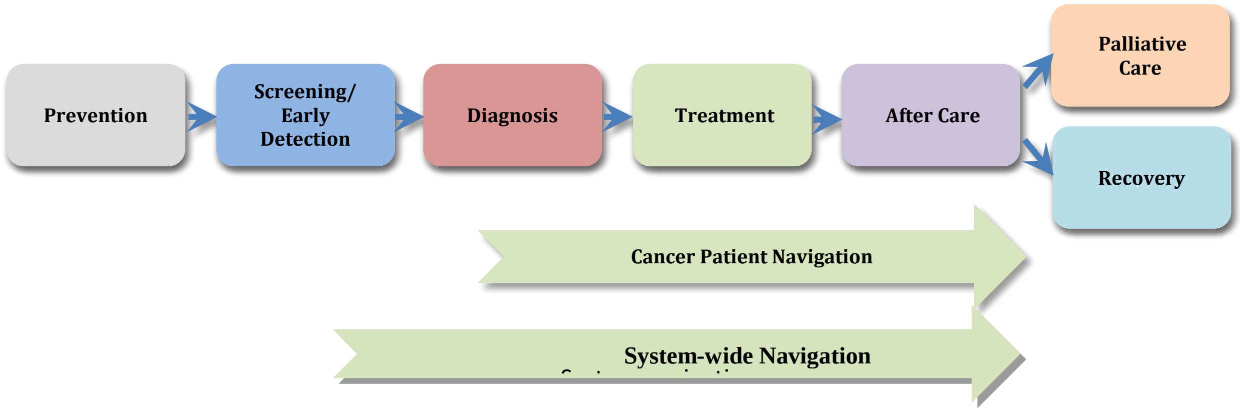
"The people at the boarding home were like a second family for me, they cared about me. They tried hard to get country food, which meant a lot to everyone there."

The boarding homes serving Inuit patients and their escorts make best efforts to provide culturally appropriate services and environment for their clients, including the provision of interpreter services and access to country foods. The importance of these efforts to Survivor & Caregiver participants who had stayed at boarding homes was clear. They all included the staff of the boarding homes in their comments about feeling well cared for and looked after.

CANCER CARE PROGRAMS AND SERVICES

This chapter follows the cancer care pathway to present the knowledge gained about cancer care programs and services in place throughout Inuit Nunangat. It is based primarily on the interviews with Key Informants and Survivor & Caregiver participants.

The Cancer Care Continuum



As the reader explores the information to follow, they should bear in mind that, for cancer patients from Inuit Nunangat, cancer-specific navigation services are, in practice, layered on top of existing system-wide coordination & logistics services (provided to all patients).

PREVENTION

Snapshot – Prevention

Public Health Education:

Activities delivered by community health personnel including:

- Periodic information sessions at schools/community events (e.g. sun health; cervical cancer; breast health awareness)
- Individual education (i.e. during well-woman appointments)
- Displays (health promotion boards)
- Tobacco Reduction initiatives

HPV Vaccination:

Immunization program in place

Community Journey

- Prevention activities sporadic and inconsistent
- Low levels of health literacy
- General lack of culturally relevant materials and resources

The interviews examined prevention along two axes: Public Education and HPV Vaccination.

Public Education:

Each region engages in public education at the community level periodically.

This usually falls under the purview of community nurses and or community health workers or Public Health Nurses (where they exist) who will engage in various health promotion activities throughout the year utilizing techniques such as displays in public areas or community events; visits to schools as well as one-on-one consultations with clients usually associated with particular clinics at the health centre (e.g. Well Woman, Moms & Tots, Well Man).

Tobacco Reduction

A crucial cancer-related issue, tobacco reduction has been the focus of a growing range of public education initiatives across the regions. Largely supported by federal program funding, regions have been able to develop initiatives and materials and intensify their efforts to promote tobacco reduction education activities.

Two cancer-specific prevention campaign projects from 2008/2009 were brought to light: a breast health awareness program from Nunatsiavut; and a colorectal screening education program in Inuvialuit Region. These initiatives were funded for a specified period of time and enabled these regions to engage in focused education activities. Among other things, these projects enabled both regions to develop culturally relevant materials, resources and promotional items. Some of those materials still exist and, where the information is still relevant, have been incorporated into the supplies and resources offered to community health centres for prevention work.

While some Key Informants were aware of the above activities, others – notably individuals from the community clinical care level – were themselves unaware. They believed that there was no cancer related public health education at all.

Key Informants who were aware of public education activities (including individuals involved in delivering public health education) felt that cancer-related education efforts are sporadic, inconsistent and, therefore, not likely to be very effective.

Cancer is only one issue on a long list of health concerns. In part, because these jurisdictions are small and their public education budgets are very tight, they tend to focus on root causes and also upon diseases that are driving the system harder – are more prevalent in their incidence and impact on peoples' health. Public health strategies in the regions tend to reflect these realities. To make best use of scarce human and fiscal resources, and align with regional public health strategies, this multi-disease approach to public health education is necessary, but the net result is that there are no dedicated and continuous cancer-specific prevention educational activities. There is also a shortage of culturally relevant cancer-related prevention material to use – either to provide to the public or to use as background materials to make displays. That is, there is a shortage of adapted or culturally relevant material.

Key Informants expressed a need for more readily accessible and available material to support them in their work and more direction and education for health providers with respect to appropriate prevention material.

HPV Vaccination

All of the regions now offer an ongoing HPV Vaccination program aimed at Grade 6 females. The programs were initiated within the past five years beginning in 2008 (in Nunatsiavut) to 2010 (in Nunavut). All regions utilize a similar protocol, where community level health sector staff (Public Health nurses where those positions exist or else community nurses) go into schools to perform immunizations.

Where information about uptake was available, it was variable. In Nunatsiavut, Key Informants indicated there is very high uptake (100% in their first year) while Nunavut Key Informants felt the uptake was not high, estimating it at less than 50% overall.

***Health Literacy:**

Key Informants unanimously felt public awareness and general health literacy was very low among residents of the regions and that investment in this area should be a high priority in terms of cancer prevention.

> *"An important aspect of prevention is to educate the public about warning signs and symptoms as well as providing information about diet, healthy choices, tobacco reduction and so forth."*
>
> Key Informant

*Note: Health literacy, for the purposes of this report, refers to a general understanding of health issues; signs and symptoms, ways to engage more fully in one's own health care, personal responsibility for health, etc.

Survivor & Caregiver Voices:

Lack of awareness was evident during participant interviews. In spite of having experienced the cancer journey, 25% of the participants were still clearly dealing with a low level of comprehension and awareness about cancer.

Awareness among the other participants was quite high, as one participant put it, "thanks to a forced education program". This lack of public awareness was apparent to them and was a concern. They see cancer rates rising in their communities and want to find ways to help raise peoples' awareness. Three participants specifically said they wanted to find ways to 'give back' to their communities – to share their stories, promote healthy living and emphasize the importance of taking care of one's own health.

SCREENING/EARLY DETECTION

Snapshot – Screening

Programs:	**Region**
Cervical	All
Clinical Breast Exam	All
Mammography	Nunavik Nunatsiavut ISR
Clinician Assessment or Patient Request:	
Colorectal	All
Prostate	All
Mammography	Nunavut, ISR
X-Ray	All

Snapshot – Early Detection

- Many cancers being found at late stages
- Concerns about inconsistent tracking and/or follow up of abnormal results
- Inconsistent clinician awareness and responsiveness

Patient Journey

Screening:

- In community = visits to local health centre
- Mammography = travel to secondary site, several days minimum away from home, work, family

Undefined Symptoms:

- Numerous visits over extended period to local health centre
- May face impacts of non-responsive service, social stressors, fear
- Waiting for results

Note: Very few of these screening procedures are available in communities (i.e. Pap smears, physical exams, fecal occult blood, blood tests, x-rays in many, but not all, communities). For all other screening procedures, patients are required to travel to designated sites. Rates of uptake for screening programs are largely unavailable as standardized tracking systems are not in place within the regions. Where estimates were offered by Key Informants they have been included.

Cervical Screening:

All regions offer cervical cancer screening as part of their well-established Well Woman clinics. There is a long tradition of well woman clinics in the community clinics, spanning at least 20 years. Key Informants were very positive about these clinics and, in general, they feel there are high participation rates. Each regional authority has its own checklist for well woman clinics which are provided to health centre nurses. A sample from Nunatsiavut is attached in the Appendix.

In 3 of the 4 regions, cervical cancer screening is a partially organized program meaning the regional health authority/system provides standardized clinical protocols for conduct of screening including follow-up. Nunavut is the only region providing cervical screening on a spontaneous basis, meaning they do not provide standardized territorial clinical guidelines, instead relying upon individual nurses to adopt the guidelines from their original jurisdictions. However, they are poised on the brink of implementing a partially organized program based on adaptation of NWT guidelines.

In Nunatsiavut, all Key Informants indicated high participation in cervical cancer screening (that is, well woman clinics generally).

> *"One benefit of having small communities is that we've got a captive audience, our patients aren't going anywhere."*
>
> Key Informant

According to the 2011 NWT Health Status Report (NWT Health and Social Services, August 2011), the NWT cervical cancer screening program is said to enjoy a 91% participation rate – which would make it the highest participation rate in Canada.

Breast Examination:

In terms of screening for breast cancer, all regions include clinical breast exam as part of Well Woman clinic checklists. However, recommendations for breast self-exam are changing and are no longer promoted in all regions. Key Informants indicated they are likely to be phased out due to new thinking nationally around efficacy of breast self-exam.

Mammography:

Nunavik is the only region with a mobile mammography screening program. It is part of Quebec's provincial program and is led by the Institut National de Santé Publique du Québec. On a regularly scheduled basis, a mobile mammography unit travels by ship or by air to the main air transportation hub communities along both coasts. Eligible women are notified and travel is arranged for them to receive a mammogram at the closest community to which the mobile program is traveling.

In Nunatsiavut and the Inuvialuit Settlement Region, health care providers follow provincial/territorial mammography program guidelines. However mammograms are only available at the secondary sites so eligible women have to travel to Happy Valley-Goose Bay or Yellowknife if they wish to have a mammogram.

In Nunavut, mammography is only used for screening for high risk patients or based on client request and clinician approval. In these regions, mammography is only available at secondary or tertiary sites.

Colorectal Screening:

At this time all regions offer **colorectal** screening either as part of their Well Man/Well Women clinics or as part of their general clinical protocol or upon request of a client. In Nunatsiavut and the Inuvialuit Settlement Region, FIT testing is now being used instead of fecal occult blood testing (FIT tests give less false positive results for individuals with high levels of red meat consumption). Nunavut intends to switch to FIT testing in the near future. In the Hudson Coast region of Nunavik, colonoscopy is used for preventive screening as they have elevated rates of colorectal cancer.

Nunatsiavut will at some point benefit from the implementation of a new provincial, population-based colorectal program which is presently being rolled out in selected health jurisdictions within the province. According to discussions with the lead coordinator for the program, implementation in Nunatsiavut is likely several years away.

Targeting Men:

All regions attempt to offer Well Man Clinics during which they would offer colorectal and prostate screening. Unfortunately, Key Informants were unanimous in their statements that Well Man clinics are not well attended. When asked for their opinions as to why this is the case, Key Informants were unsure. Several ventured that men (Inuk and non-Inuk alike) seem to be an elusive group, difficult to engage in preventive health care of all kinds.

> *"Men are quite resistant to going to the Health Centre when they're sick…getting them in there for a checkup? Well, that's nearly impossible.."*
>
> Key Informant

Early detection

Asking Key Informants their opinions about early detection revealed/led to some of the most passionately expressed and urgent concerns of Key Informants who worked at or closer to the community level. They felt they are not finding cancers early enough. Their speculation about why this is the case fell into three major themes:

- Clients waiting too long to present with symptoms
- Challenges with tracking and follow-up of abnormal results
- The need to raise clinical awareness and education

Clients waiting too long to present with symptoms:

> *"Drug and alcohol problems can overshadow peoples' lives, so indistinct or undefined chronic symptoms are way lower on their list of immediate problems"*
>
> Key Informant

Key Informants felt that clients often don't realize there is anything wrong with them. They also said that, even when people do know there is something wrong, clients delay going to the community health centre. Key Informants were careful to say they could only speculate on the reasons. But their observations were that lack of health literacy and awareness are contributing factors. Fear (of cancer) and denial were also mentioned. Cultural values (i.e. stoicism) were also mentioned. The fact that people know they will have to leave home to receive treatment, and associated hardships for them and their families were also raised. Finally, many Key Informants believe that high degree of socio-economic stressors that affect the communities plays a role. The health impacts of addictions, substance abuse, poverty, overcrowding, etc. are likely to mask early symptoms of cancer.

> *"This needs to be said…in the communities, there is a moderate risk of follow up of abnormal results being missed. In communities with high staff turnover, that risk is high. "*
>
> Key Informant
>
> *""We send tests and x-rays and referrals out and all these reports come back and they can get lost and they often do, it's part of the challenge of long distances and multiple providers."*
>
> Key Informant

Challenges with tracking and follow-up of abnormal results

All Key Informants recognized that lapses do occur in their systems for tracking and follow up of abnormal results. However, Nunavut Key Informants were particularly concerned about this as an issue impacting early detection of cancer.

Clinician awareness:

Community health care providers are working in an environment of constant staffing challenges combined with high demand for emergency and acute care. Key Informants feel that this situation may make it more difficult for clinicians to 'switch' from an emergency to a preventive mindset when facing a patient with undefined, chronic symptoms. They felt that support in the form of clinical education and protocols related to cancer assessment would be useful.

Survivor & Caregiver Voices:

Participant experiences with screening and early detection reflected the full range of possibilities from swift, efficient assessment, follow-up and detection to disturbing accounts of non-responsive clinicians, lost test results and (in their opinion) delayed detection.

Several participants also shared their views about why people delay going to their health centres: people don't think it will help. Their reasons focused on the impact of lack of responsiveness combined with lack of continuity of health care personnel. As one participant put it:

"The nurses are rotating, the doctor's a locum – they read the history but apply their own perspective. Everything's always starting over and you're no closer to an answer so, after a while, if you're not in too much pain, you give up and stop going back."

DIAGNOSIS

Snapshot – Diagnosis

Region	Service Availability
Nunatsiavut	Happy Valley-Goose Bay
Nunavik	Some: Kuujjuaq, Puvirnituq All: Montreal
Nunavut – Qikiqtaaluk	Some: Iqaluit All: Ottawa
Nunavut - Kivalliq	Limited – Rankin Inlet All: Winnipeg
Nunavut – Kitikmeot	Yellowknife
Inuvialuit Settlement Region	Some: Inuvik All: Yellowknife

- Lack of protocols for delivery of initial diagnosis to patients

Patient Journey

- One or more trips to secondary/tertiary site
- Stays of a week +
- Home waiting for results

Initial News of Diagnosis:

- Sometimes at home
- Sometimes at health centre
- Sometimes at secondary site
- Sometimes alone
- Always a time of shock and fear

Once the nurse/physician suspect cancer, the patient's journey away from home and family begins. The community physician (directly or through consultation with community nurses) will refer the client for diagnostic tests to the secondary or tertiary site that serves their region.

All of the regions are able to provide some diagnostic tests at their secondary sites. According to Key Informants, efforts to expand the capabilities of these secondary sites, which are closer to home for patients, is a priority for all regions.

In terms of secondary sites, the Labrador Health Centre (serving Nunatsiavut) and Yellowknife Stanton Hospital (serving Inuvialuit and Kitikmeot region of Nunavut) are the most advanced in terms of their ability to provide a nearly complete range of diagnostic testing for cancer. According to Key Informants, the majority of suspected cancer patients can undergo all required diagnostics at these secondary sites and only rarely have to travel further to the tertiary care sites for diagnosis. This is an important accomplishment – while the distances are still vast, and the time away from home still significant, at least these patients are in city environments that are more familiar to them and somewhat similar to their homes. It is a concrete step towards bringing care closer to home.

For Nunavik and the rest of Nunavut (i.e. Kivalliq and Qikiqtaaluk), progress continues towards enhancing capacity at their respective secondary sites. In these areas, the vast majority of suspected cancer patients are able to undergo initial diagnostic testing at their secondary sites. However, certain diagnostic services may not be available at certain times (based on visiting specialist schedules and staff capacity). In those cases, patients are sent straight to the tertiary sites. In any case, Key Informants said that patients will still have to travel to the tertiary sites for additional testing in about half of the cases.

From the patient perspective, it's at this stage that the coordination and logistics systems become more visible – health centre staff and/or medical travel staff are contacting them directly with dates and travel and accommodation arrangements. Once they arrive at the secondary/tertiary site – the system-wide layer of navigation is activated, with nurse case managers following their progress and navigating as required during their stays. And, in the regions where they exist, it is upon formal diagnosis and treatment planning that the cancer patient navigators become involved.

Delivery of Initial Diagnosis to Patient:

Survivor & Caregiver Voices:

All of the survivors said the day they received the initial news that they had cancer was devastating. The shock and fear and disbelief they felt was profound.

The manner in which they were told was quite varied. For some, it was a carefully handled meeting with family present and a health care team including a navigator. For others, it was a phone call when they were alone at home. Other times, it was a call to come to the health centre where they were told they had cancer, again, alone. In the most painful cases, it was another solo trip to the secondary/tertiary site where the client assumed they were going for another test - only to be told they had cancer. For all of them: it was the worst day of their lives.

They went on to talk about their inability to comprehend what they were being told. Even participants who are educated and speak English fluently, said they couldn't absorb any of the information they were given, "That whole day is all a blur to me", was how one participant put it.

The investigator shared these experiences with Key Informants and learned that none of the regions have protocols or policies related to ensuring cultural and emotional support for patients during delivery of initial diagnosis.

Nunatsiavut comes the closest in that it is their informal practice to a) ensure that patients have an escort to receive a cancer diagnosis and b) they increasingly and systematically employ telehealth and tele-oncology to support diagnosis delivery. To deliver the initial news, often the surgeon or specialist will either arrange video conference with patient & family and nurse at community clinic OR will arrange to have patient and an escort brought to LHC to tell them. To deliver the full diagnosis and treatment options, patients will usually choose to return to LHC to meet in person with medical personnel there (including the patient navigator) and be linked via tele-oncology videoconference with specialists from the St. John's Cancer Centre.

All Key Informants expressed heartfelt and deep compassion for patients and the best of individual intentions, but they recognized that inconsistent diagnosis delivery is a reality in a system where clinician-patient relationship building is challenged by high staff turnover, staff shortages and the nature of fly-in rotational services.

PATIENT NAVIGATION

Snapshot: Cancer Patient Navigation

Region	Cancer Patient Navigation	System Navigation
Nunatsiavut	• Patient Navigator at Labrador Health Centre	Labrador Grenfell Health & Eastern Health (St. John's) personnel • Medical referral coordination • Coordination/communication of patient information • Patient navigation (aboriginal navigator, non-nurse)
Nunavik	• Oncology Pivot Nurse at Montreal General • Supported by NQM case managers	Northern Quebec Module (NQM), Montreal, QC • Medical appointment coordination • Accommodation coordination • Nursing case management • Coordination/communication of patient information • Inuktitut Interpreter services • Patient support
Nunavut - Qikiqtaaluk	• Supported by OHSNI designated oncology case manager • NEW: QGH nurse case managers	Ottawa Health Services Network Inc. (OHSNI) - Ottawa, ON • Medical appointment coordination • Nursing case management • Coordination/communication of patient information • Patient support • Coordination of specialist clinics for QGH • Inuktitut Interpreter services
Nunavut - Kivalliq	• Supported by KIS case managers	Kivalliq Inuit Services (KIS) – Winnipeg, MB • Medical appointment coordination • Nursing case management • Coordination/communication of patient information • Patient support
Nunavut – Kitikmeot & Inuvialuit Settlement Region	• NEW: Patient Navigator at YK Stanton Hospital • Supported by NHSN case managers	Northern Health Services Network (NHSN) – Edmonton, AB • Nursing case management • Coordination/communication of patient information

All patients from Inuit Nunangat who are referred out of their communities to a secondary or tertiary site for medical care experience a set of navigation and logistics services related to appointment coordination, travel and accommodations. From the patients' perspective, this is a familiar experience. Therefore, any cancer-specific patient navigation is experienced as an additional layer that may or may not be discernible to patients.

As the snapshot shows, cancer patient navigation for patients from Inuit Nunangat is either incorporated into or supplemented by the navigation components built into the system-wide navigation and coordination services.

For Nunatsiavut patients, cancer patient navigation is at the secondary level at the Labrador Health Centre through a half-time navigator who becomes involved at diagnosis. This is a well-established program which is now being integrated into the provincial navigation program under the provincial cancer care umbrella.

> *"(For community health care providers the navigator) is central to cancer care – we call anytime for patient information and she either knows the answer or gets it and calls right back. The system would fail without her."*
>
> Key informant

In Nunavik, there is also a well-established Oncology Pivot Nurse who is embedded at the tertiary site (Montreal) and navigates for clients from Nunavik.

These navigation programs are considered to be very effective. Key Informants who were health care providers from those regions spoke emphatically about how valuable these navigators are to them and to the care of their patients.

Survivor & Caregiver Voices:

Participants from Nunatsiavut and Nunavik knew these nurses, by name (but not by title). They knew these people were looking after things for them and were people they call anytime. To the participants, the navigators were constant and recognizable figures who were accessible and contributed greatly to their sense of being well cared for.

Nunavut has launched a new initiative for the Qikiqtaaluk region where they are piloting an expansion of case management linkages with the tertiary navigation services in Ottawa and the community health centres. While this is a new program and has yet to be defined and developed, there is an indication that at least one of these nurse case managers will have a special focus on cancer patients. In Kivalliq, navigation is generally built into the model of Kivalliq Inuit Services based in Winnipeg. The nurse case managers in that system dedicate special attention to cancer patients. Again they are considered pivotal by the Key Informants from that region as their eyes, ears and advisors in terms of patient care, tracking and management.

In the NWT there is a new cancer patient navigator at the Yellowknife Stanton Territorial Hospital, the secondary site for both Inuvialuit and Kitikmeot region of Nunavut. The position is still being defined and forming linkages but is actively engaging with the navigators at the Cross Cancer Institute in Edmonton and the general navigation services of Northern Health Services Network on behalf of NWT and Kitikmeot clients.

Key Informants involved with the new navigation programs in the Qikiqtaaluk region and Yellowknife Stanton both indicated enthusiasm for resources and advice about the best methods to implement their mandates.

TREATMENT

Snapshot – Treatment

Region	**Secondary Site (chemotherapy, some surgery)**	**Tertiary Site (complex chemotherapy & surgery, all radiation therapy)**
Nunatsiavut	Labrador Health Centre Happy Valley-Goose Bay	St. John's Cancer Centre, St. John's
Nunavik	None	McGill University Health Centre Montreal
Nunavut – Qikiqtaaluk	None	The Ottawa Hospital Ottawa
Nunavut - Kivalliq	None	CancerCare Manitoba Winnipeg
Nunavut – Kitikmeot & Inuvialuit Settlement Region	Yellowknife Stanton Territorial Hospital	Cross Cancer Institute Edmonton

Patient Journey

- Multiple trips with an escort over period of a year + to secondary/tertiary site
- Stays of several weeks to months at a time
- Facing long periods of separation from home, family, community and impacts upon patient and caregiver employment
- Lack of awareness of patient support services at cancer treatment sites

All of the Inuit Nunangat regions rely upon tertiary cancer treatment sites outside of their borders to provide treatment for cancer patients.

At this time, the Labrador Health Centre (LHC) which serves Nunatsiavut and Yellowknife Stanton Hospital (serving Inuvialuit and Kitikmeot region of Nunavut) are the only secondary sites that provide some cancer treatment services (surgery and chemotherapy).

The LHC is a satellite program of the St. John's Cancer Centre. They have surgical capacity and some chemotherapy capability but no oncology onsite therefore they receive orders from St. John's oncology; on site patient medical conditions overseen by community physician in consultation with St. John's.

Because of their use of tele-oncology for virtual consultations with St. John's Cancer Centre (e.g. for treatment planning; assessment and monitoring) it is now possible for some patients to undergo their entire treatment process at LHC (closer to home).

> *"It's a lot better than having to go to St. John's and wait around in hotels between treatments and such. Generally speaking, from my experience, it's faster here – if they're diagnosed here and we have capability to do the surgery here, they'll have it within a week and that's a maximum."*
>
> Key informant

The Yellowknife Stanton Territorial Hospital is affiliated with the Cross Cancer Institute (the Cross) in Edmonton, Alberta. Through this relationship, based on the Cross's community cancer centre model, Stanton can offer certain surgical and chemotherapy services in collaboration with the Cross. Upon diagnosis, all cancer patients must travel to the Cross for treatment planning and usually to receive their first course of treatment. At that point, if the chemotherapy is within Stanton's capability they will receive the rest of their treatments in Yellowknife under the direction of the Cross.

Survivor & Caregiver Voices:

The value of receiving treatment closer to home for patients is significant and was revealed by comments by the participants.

Those who received care at a secondary site were aware that this was not possible a few years ago and were very grateful they did not have to 'go south' for treatment. While they still had to travel long distances and be away from home for weeks at a time, they were more familiar with their environments and, often, had friends or even family in those cities.

Those who had to go south for treatment all expressed a strong wish that they could get treatment closer to home.

For patients from Inuit Nunangat communities, cancer treatment always means repetitive cycles of travel, often for lengthy stays at the boarding homes near the treatment centres associated with their respective regions. Cancer patients are always entitled to an escort throughout each stay. The lengths of stays vary depending on treatment plan but ranges from 2 – 3 weeks at a time up to months at a time going on for a couple years. There is no denying the enormous strain that this places on the patients and their escorts as well as their children and family members back home who all have to make accommodations for these lengthy absences from home and work and community.

On the positive side, with respect to medical care, there is no question that the referral arrangements made by their jurisdictions mean those residents of Inuit Nunangat are receiving exceptionally good medical care.

Patient and Caregiver Support:

Each of the cancer treatment centres have numerous services and programs to support cancer patients under their care. All Key Informants at cancer treatment centres indicated they make best efforts to ensure culturally relevant services, however with respect to Inuit, their ability to ensure culturally relevant and accessible services are somewhat limited.

Survivor & Caregiver Voices:

Unfortunately, discussions with participants revealed a general lack of awareness of the existence of these support services and the fact that they can access them.

Although all participants were quite clear that they felt very well cared for and respected at the treatment centres, only 2 participants were aware of the various support services (psychosocial support, social workers, art and peer support therapy, etc.) available to them. Only 1 participant was aware that she could draw upon those services when she was at home by the simple means of using the telephone.

The lack of awareness extends to health care providers in the regions. When discussing some of the services available at the treatment centres with Key Informants from the regions, they were surprised, extremely interested and very willing to learn more. They expressed a desire to know more about these services so they can use them as tools to support their patients. They also expressed frustration because, in general, they don’t know who to contact to get this information.

Interviews with Key Informants from treatment centres made it extremely clear that in all cases, they are eager and willing to find ways to extend their services and include their patients from Inuit Nunangat but they, too have a limited knowledge of who they should communicate with in the regions and how they could accomplish their goal of increasing patient awareness.

AFTER CARE

Snapshot – After Care

Basic After-Care Services:

- Available in community
- Provided by home and community care services and/or community clinical staff

Complex After-Care Services:

- Available at secondary or tertiary sites only

- Communities experience some communication issues with respect to discharge notification/after-care instructions

Patient Journey

- May face extended stay at secondary or tertiary site if after care services not available in community
- A time where the need for emotional, psycho-social support for patient and caregiver can be great

The type and complexity of after-care services for patients in between treatment cycles or following treatment varies widely. All regions endeavor to provide after-care for patients in their home communities but are generally limited by their capacity to providing minor services.

It is at this point along the cancer journey that Home and Community Care services are brought into play. To the extent possible, communities make best efforts to bring patients home for after-care. Based on the orders received from the tertiary site, home and community care will collaborate with clinical staff to decide how best to provide the care needed for the patient.

Key Informants involved with home and community care were deeply committed to doing everything possible to enable people to receive after care at home. They felt this was particularly important for cancer patients given the long, difficult treatment path these patients must endure.

> *"Our motto is always train for everything and never say 'no' to patient care. We always want to bring them home as soon as possible and care for them here as much as possible."*
>
> Key informant

For more complex after-care, follow-up diagnostic testing and examinations, patients must travel to the secondary or tertiary care sites.

Nunatsiavut is seeking to enhance their ability to serve patients in their communities through their telehealth & tele-oncology model which is being diligently applied to enhance their community clinics' ability to monitor patients through virtual consultations with specialists.

Survivor & Caregiver Voices:

All participants greatly and deeply appreciated the opportunity to go home between treatments. And those who received/needed home care praised the nurses and support workers highly. It clearly meant a great deal to these people to be home and be looked after.

System Coordination - Communication

Discussions about this phase of the cancer care pathway exposed some challenges to communications between tertiary, secondary sites and communities in terms of discharge plans and orders. Essentially, there can be breakdowns in communications between the treatment site discharging or sending the patient home and the community clinicians receiving the information.

Based on Key Informant interviews, these challenges fell into two areas:

a) Delays along the chain of communication to the extent that the patient is already home and sometimes has been for several days before the community health centre receives notification and instructions for their care

   Key Informants described system communication issues associated with breaks in processing information along the information pathways between the tertiary site, secondary site and the final community level destination. Efficient system communication is another aspect of care affected by staff shortages and high turnover. Tied into the issue of delays is the effect of slight differences in pathways used by tertiary sites based on whether a patient was discharged (i.e. in-patient) versus completing a treatment course as an outpatient at the cancer treatment centre.

b) Orders or instructions that assume availability of supplies or medications that are not kept in stock in the community and are not received with enough lead time for the community to secure what's needed before the patient is home

   Key Informants said it was not uncommon to receive orders that assume the availability of certain supplies, medication or infrastructure which are, in fact, not available in the community. They felt this was a reflection of a lack of awareness on the part of the tertiary sites who assume levels of capacity and infrastructure that do not apply to northern towns and villages of Inuit Nunangat.

These issues were of most concern to Key Informants in Nunatsiavut and Nunavut and steps are being taken in those areas to address the problems:

- Eastern Health in St. John's, who administers the provincial Cancer Care program, has set up a provincial cancer quality committee to foster communications with all partners in cancer care. The committee meets regularly and includes direct and routine communication between personnel from the cancer services in St. John's; the Regional Health Authorities (including Labrador Grenfell Health); the Nunatsiavut Government; aboriginal associations and patients. Key Informants from Nunatsiavut believe this committee will be a valuable mechanism for raising awareness among the primary, secondary and tertiary levels of the health care system about each other; the full spectrum of services available; and the limitations to services being experienced by the various partners involved in cancer care.

- In Nunavut, they've launched a pilot project to incorporate 2 nurse case managers based at the Qikiqtani General Hospital to complement their Ottawa-based patient navigation and coordination services and support improved communication to the community level.

Survivor & Caregiver Voices:

Whether between treatments or following treatment, it was clear that for most participants after care can be a lonely time for survivors and their caregivers.

Participants and caregivers expressed a need for someone to talk to – for emotional support, for counselling, for advice about the many aspects of their lives and relationships impacted by their cancer journey.

RECOVERY: SURVIVORSHIP SUPPORT

Snapshot – Recovery & Survivorship Support

Community Level

- No formal cancer specific services
- Mental health and counselling services extremely limited and not necessarily appropriate

Regional or Territorial Level

- Limited services (i.e. non-government organizations; survivor support groups)

Patient Journey

- Reliance upon friends and family for emotional support
- Need for emotional and psycho-social support is high
- Little awareness of potential services available through treatment centres or existing organizations

No Key Informant or Survivor & Caregiver participant was aware of any survivorship support in any of their communities. Only 4 Key Informants (excluding those from the cancer treatment sites) were aware of any regional or provincial/territorial level support services. These tended to be individuals involved at that level of the health system and the services they were referring to were primarily prosthetics, wigs, etc.

Survivor & Caregiver Voices:

Participants – both survivors and caregivers – indicated a keen desire for survivorship support, either for themselves or on behalf of others. Two of the participants had tried to start support groups or networks with limited or no success. Four participants asked specifically where they could get advice about how to successfully start and maintain a support group.

The most poignant illustration of the need for survivor and caregiver support occurred during a participant interview. This participant thought the investigator was a counsellor and that the invitation to speak about their experience was also an opportunity to seek counselling. Upon realizing this was not the case, the participant broke into tears.

At the end of every single Survivor & Caregiver interview (including the one above), participants expressed deep gratitude for the opportunity to talk to someone about their experiences. In several cases, the participants were surprised by their own emotions.

One couple (one the survivor and the other the caregiver) learned things about each other's experience they had never discussed. All of them commented that they felt better, 'lighter' for having a chance to talk about what their journey had been like for them.

As one participant admitted, "I almost cancelled on you coz I was tired and nervous to come here, but now I feel energized. Hey, I should go dancing tonight!"

The experiences shared by the Survivor & Caregiver participants clearly highlighted the need for support throughout the Inuit Nunangat regions. It was very clear that participants need someone to talk to beyond family and friends, whether that be psycho-social services or just a sense of support with people going through the same journey.

PALLIATIVE CARE

Snapshot – Palliative Care

IF family support:

- At home via collaboration between Home and Community Care program and community health care providers

IF no family support (or patient chooses):

Region	Palliative Care Site
Nunatsiavut	Happy Valley-Goose Bay
Nunavik Hudson Coast	Puvirnituq or Montreal
Nunavik Ungava Coast	Kuujjuaq or Montreal
Nunavut – Qikiqtaaluk	(unlikely) Iqaluit or Ottawa
Nunavt – Kivalliq	(unlikely) Rankin Inlet or Winnipeg
Nunavut – Kitikmeot	Yellowknife
Inuvialuit Settlement Regions	Inuvik or Yellowknife

Patient Journey

At home:

- Reliance upon Home and Community Care for palliative care
- Reliance upon friends and family for palliative care support
- opportunity to spend end of life surrounded by loved ones

At palliative care site:

- Separation from loved ones, from community
- Spend end of life in strange surroundings

The commitment and passion that Key Informants felt about being able to provide palliative care to patients in their home communities was overwhelming. The phrase that came up repeatedly was: 'we do whatever it takes to make it work'. And they do. Collaboration and cooperation among all levels of health care providers within the region is the key. Health care providers in each region share equipment and, sometimes, personnel to meet a need for palliation in a community.

> *"It's hard on the head, hard on the heart…I don't know how to describe it. See, a lot of people becoming palliative are my grandparents' friends and family…other people you just know because it's a small community where everybody knows everybody…I am almost crying just trying to talk about it.*
>
> *But I am so glad I give them the option to die at home – I remember the first time I had to palliate someone here who I've known all my life…it was…really…a peaceful feeling. A really good feeling – of course everyone was sad he had passed on but, there was a sense of peace that came with it…it was 'right' somehow.*
>
> Key informant,
> Inuk Home Care Nurse

According to Key Informants, there are, in fact, no palliative care programs in any of the regions. What communities do is to make best use of resources and services available through Home and Community Care programs which are active to varying degrees in the communities of Inuit Nunangat. Health care providers make extreme efforts to compensate for the shortfalls in capacity and infrastructure.

However, they cannot do it alone. No community can formally offer 24/7 nursing home care, so health care providers rely heavily on the involvement and engagement of family members in a palliation plan. In fact, family support is essential. It the family is unable for any reason to support palliation, there is often no option but for the patient to stay in one of the secondary or tertiary hospitals.

Survivor & Caregiver Voices:

Several of the participants had experienced palliation of a loved one at home. They were overwhelmingly grateful that their loved one was able to be home, in their own community during their final time.

Three participants had experienced the death of a loved one who had not been able to come home to die. In two cases, this was because their loved ones cancer occurred before the existence of the Home and Community Care program. In the other case, the tertiary site physicians felt the extent and complexity of the patient's needs were too complex to be provided in the community.

These participants spoke movingly of how painful that experience was for everyone involved. They described the sense of fear and frustration of various family members constantly calling the hospital for updates while searching for ways to raise the thousands of dollars needed to allow at least a few of them to travel to see their loved one.

The impact on the patient's escort was particularly disturbing. Having traveled with the patient on a trip that began as treatment but turned into palliation, the escort (who was one of the patient's adult children), was now alone and quickly became emotionally exhausted. This story illustrated – again – the lack of awareness of tertiary cancer site support services since it seems no one in the family was aware that the escort could have drawn upon extensive psycho-social and caregiver supports available through the cancer treatment centre.

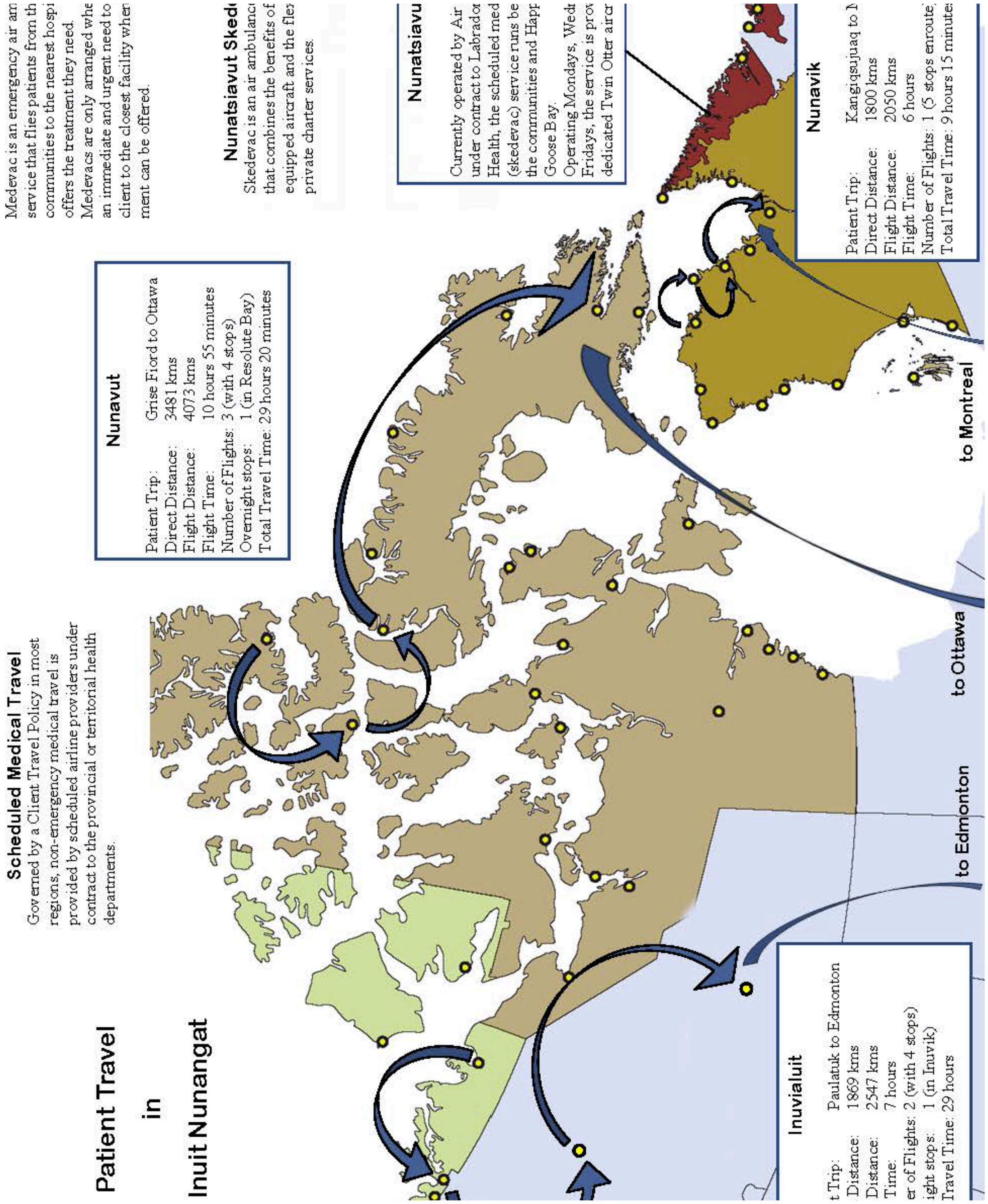
MAPPING THE PATIENT JOURNEY

The illustrations on the following pages offer some insight into the typical cancer care journey experienced by community residents from the regions of Inuit Nunangat.

The map on the next page illustrates the reality of the time and travel required for patients from Inuit Nunangat to receive secondary and tertiary health care services.

The set of graphics that comprise the remainder of the chapter map the typical cancer care journey for community residents according to the referral patterns followed by each Inuit Nunangat region. They are based on review and discussion with Key Informants and represent best efforts to present the most common, or most likely pathway – as several Key Informants noted, there is never anything 'typical' about cancer, so there will be many readers who will know of variations to the journeys mapped here.

PATIENT TRAVEL IN INUIT NUNANGAT



Scheduled Medical Travel
Governed by a Client Travel Policy in most regions, non-emergency medical travel is provided by scheduled airline providers under contract to the provincial or territorial health departments.

Medevac
Medevac is an emergency air am
service that flies patients from th
communities to the nearest hospi
offers the treatment they need.
Medevacs are only arranged whe
an immediate and urgent need to
client to the closest facility when
ment can be offered.

Nunatsiavut Sked
Skedevac is an air ambulanc
that combines the benefits of
equipped aircraft and the flex
private charter services.

Nunavut

Patient Trip:	Grise Fiord to Ottawa
Direct Distance:	3481 kms
Flight Distance:	4073 kms
Flight Time:	10 hours 55 minutes
Number of Flights:	3 (with 4 stops)
Overnight stops:	1 (in Resolute Bay)
Total Travel Time:	29 hours 20 minutes

Nunatsiavu
Currently operated by Air
under contract to Labrador
Health, the scheduled med
(skedevac) service runs be
the communities and Happ
Goose Bay.
Operating Mondays, Wedn
Fridays, the service is prov
dedicated Twin Otter aircr

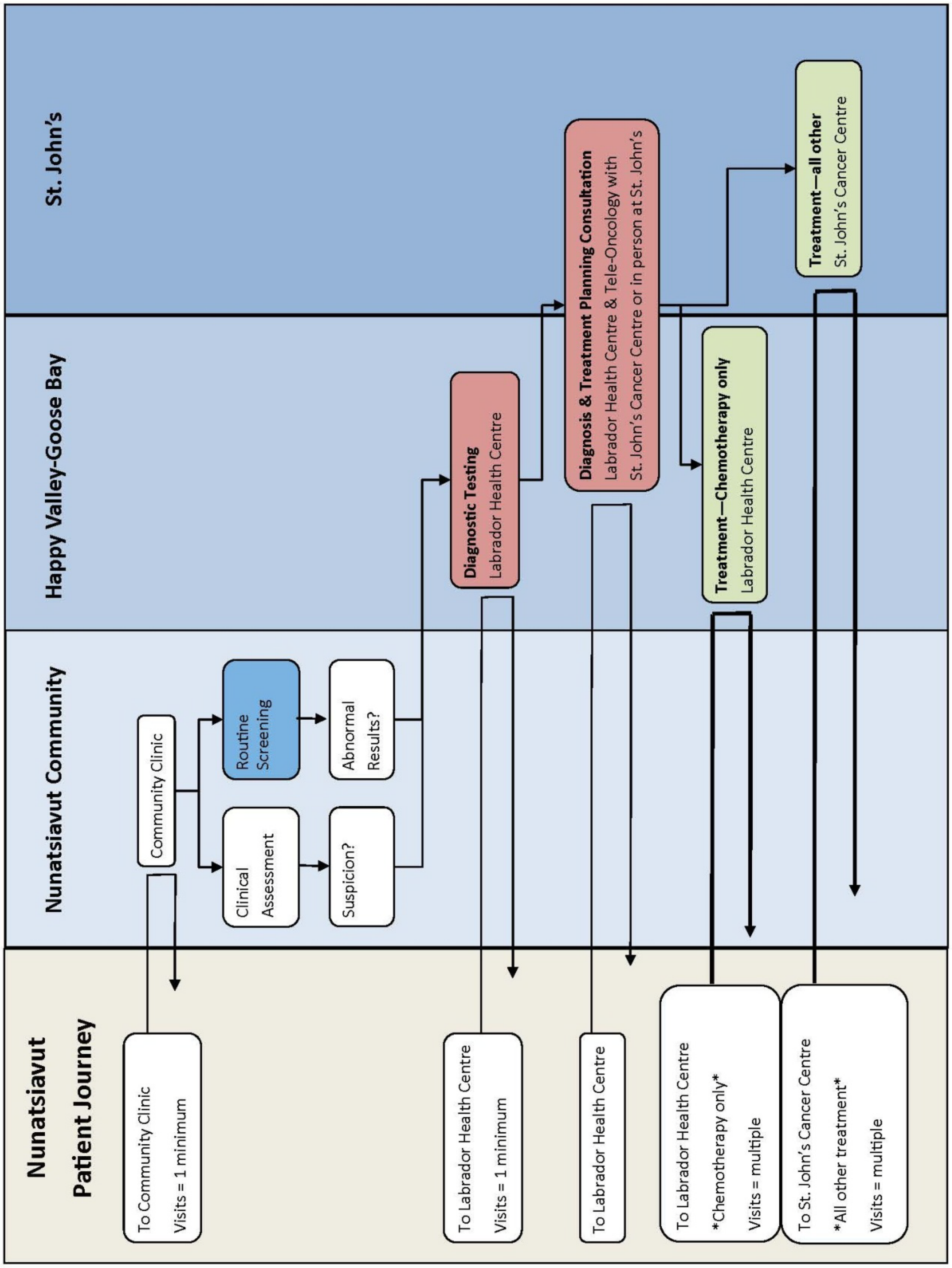
Inuvialuit

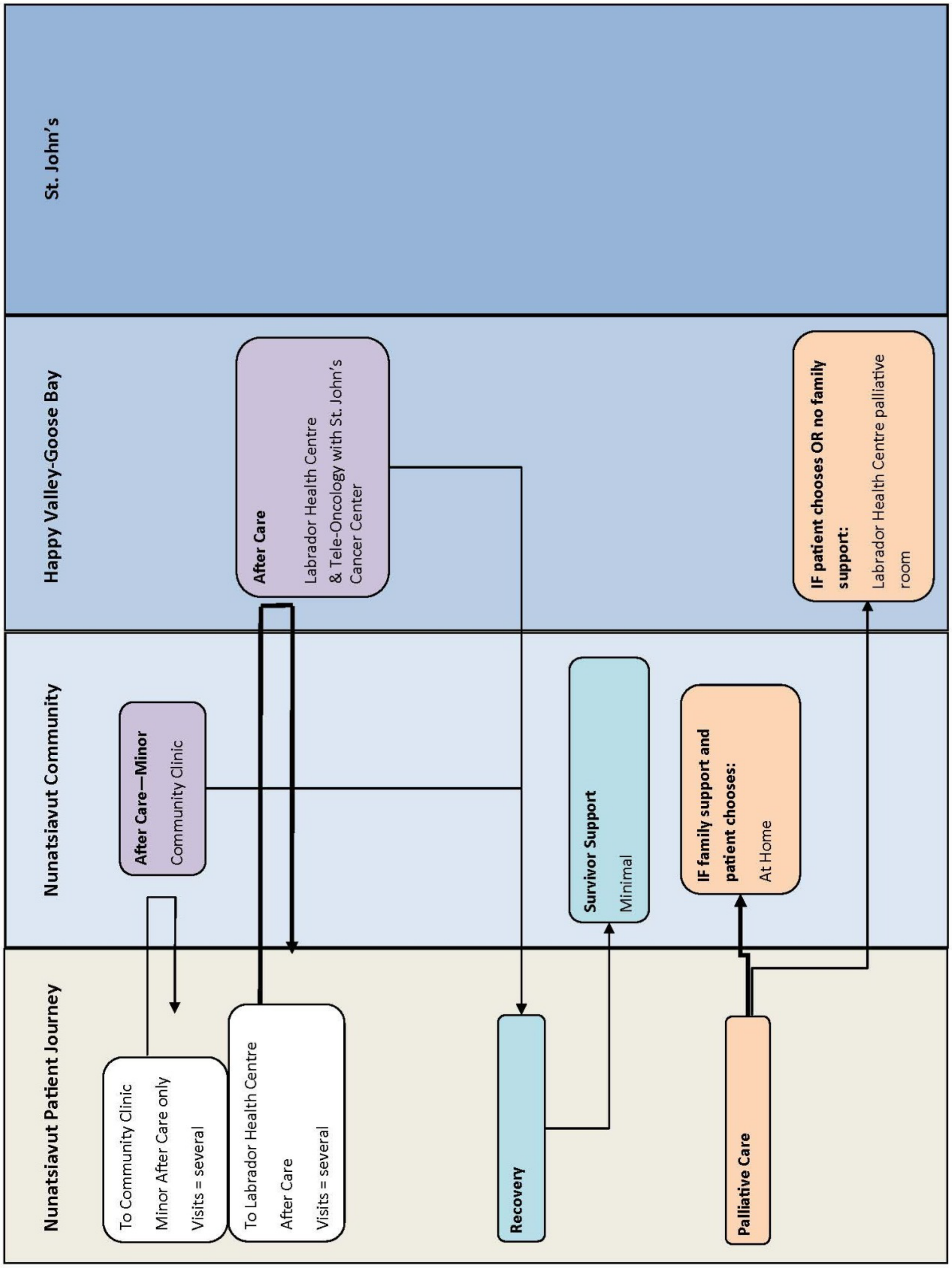
t Trip:	Paulatuk to Edmonton
Distance:	1869 kms
Distance:	2547 kms
Time:	7 hours
er of Flights:	2 (with 4 stops)
ight stops:	1 (in Inuvik)
Travel Time:	29 hours

Nunavik

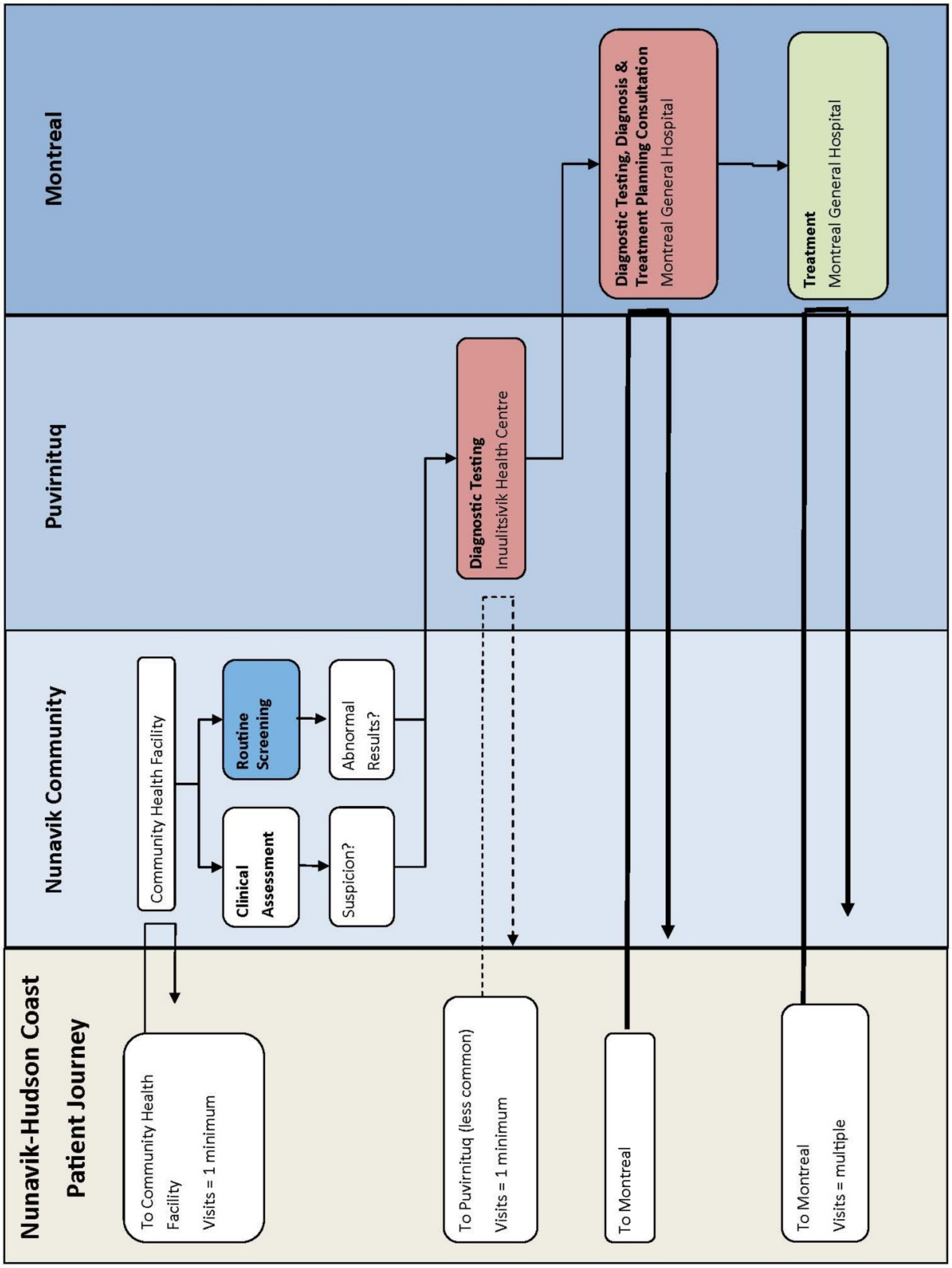
Patient Trip:	Kangiqsujuaq to M
Direct Distance:	1800 kms
Flight Distance:	2050 kms
Flight Time:	6 hours
Number of Flights:	1 (5 stops enroute)
Total Travel Time:	9 hours 15 minutes

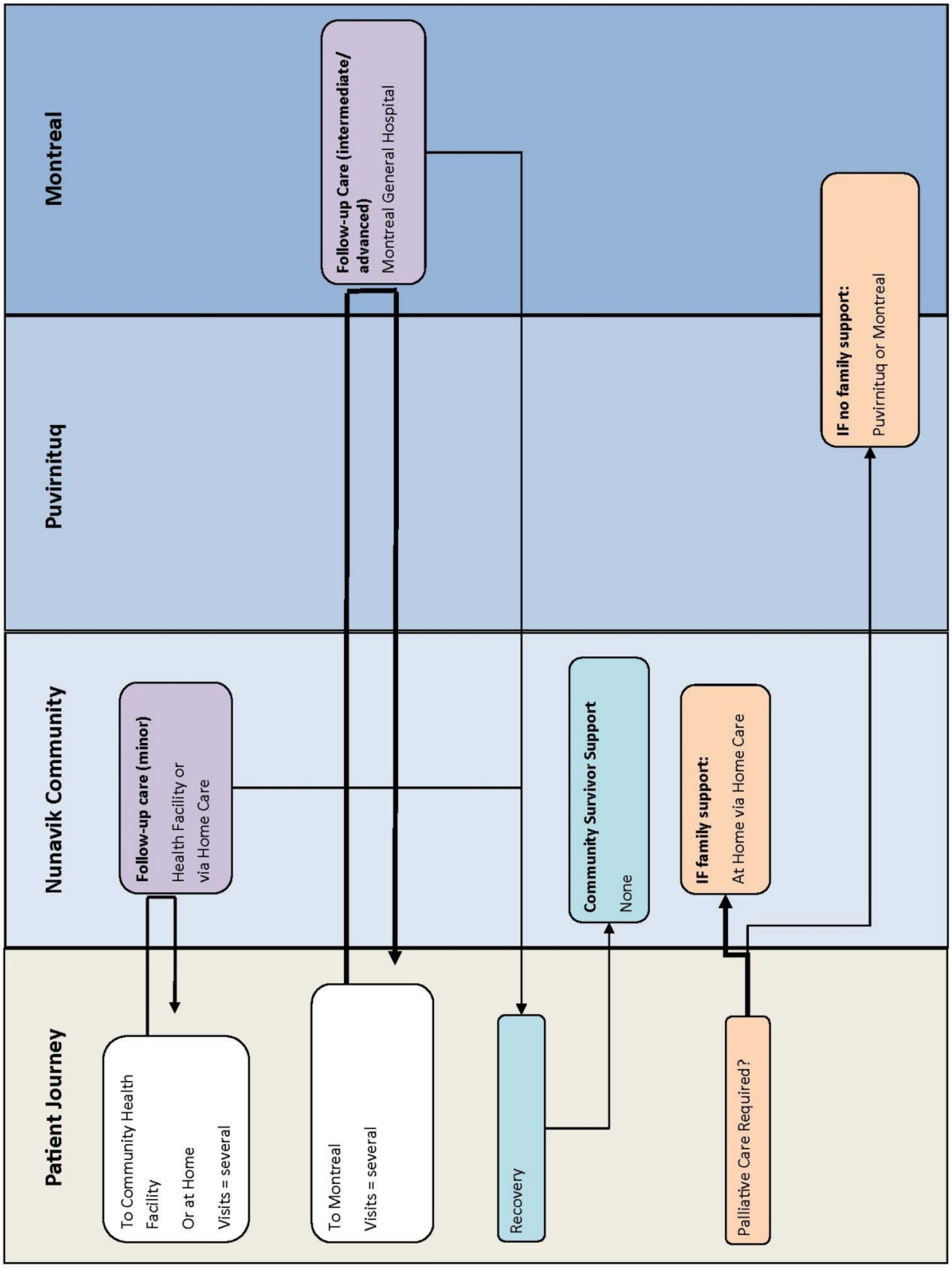
NUNATSIAVUT PATIENT JOURNEY



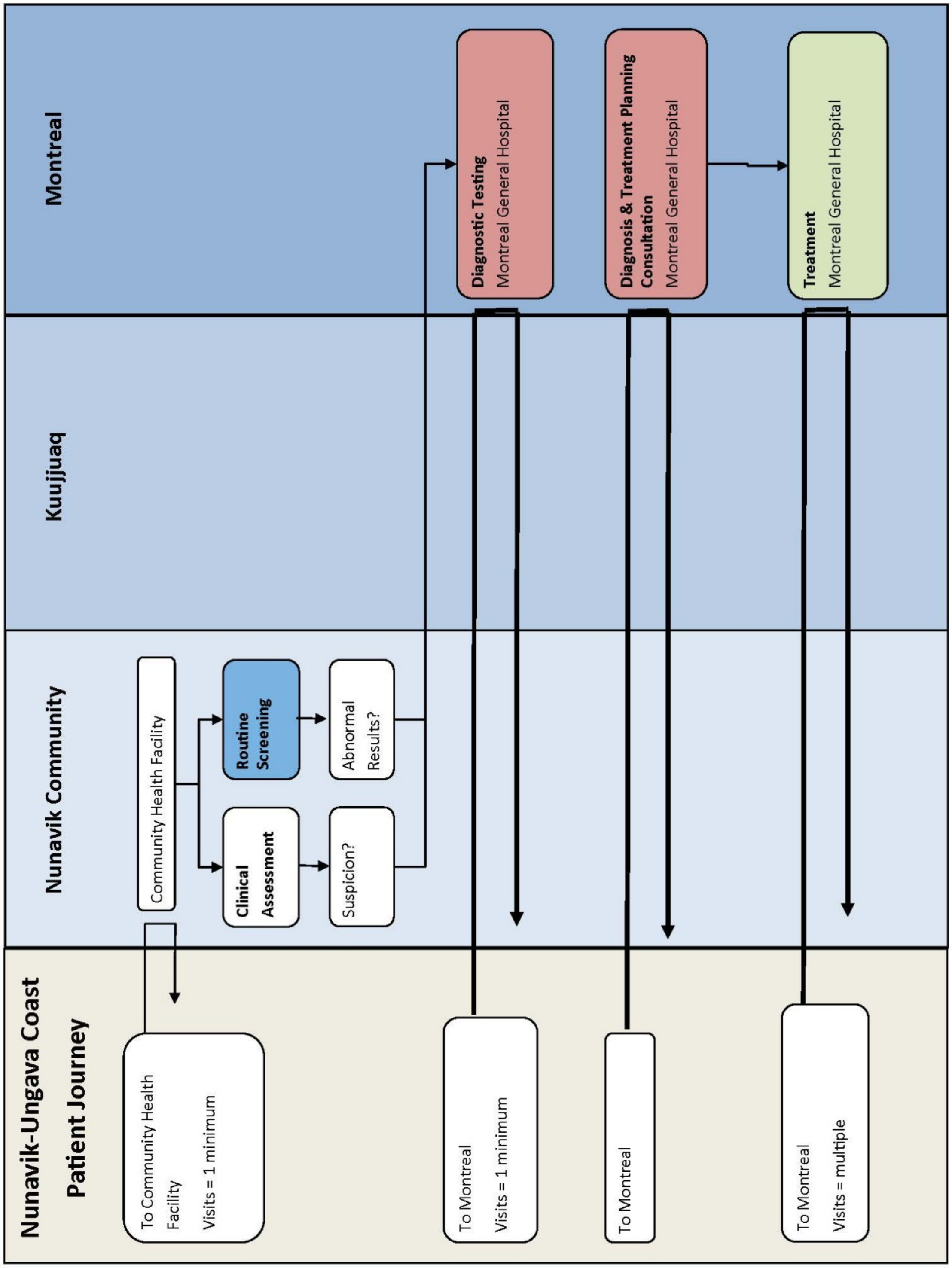

Nunatsiavut Patient Journey
Nunatsiavut Community
Happy Valley-Goose Bay
St. John's
To Community Clinic
Minor After Care only
Visits = several
To Labrador Health Centre
After Care
Visits = several
Recovery
Palliative Care
After Care—Minor
Community Clinic
Survivor Support
Minimal
IF family support and patient chooses:
At Home
After Care
Labrador Health Centre & Tele-Oncology with St. John's Cancer Center
IF patient chooses OR no family support:
Labrador Health Centre palliative room

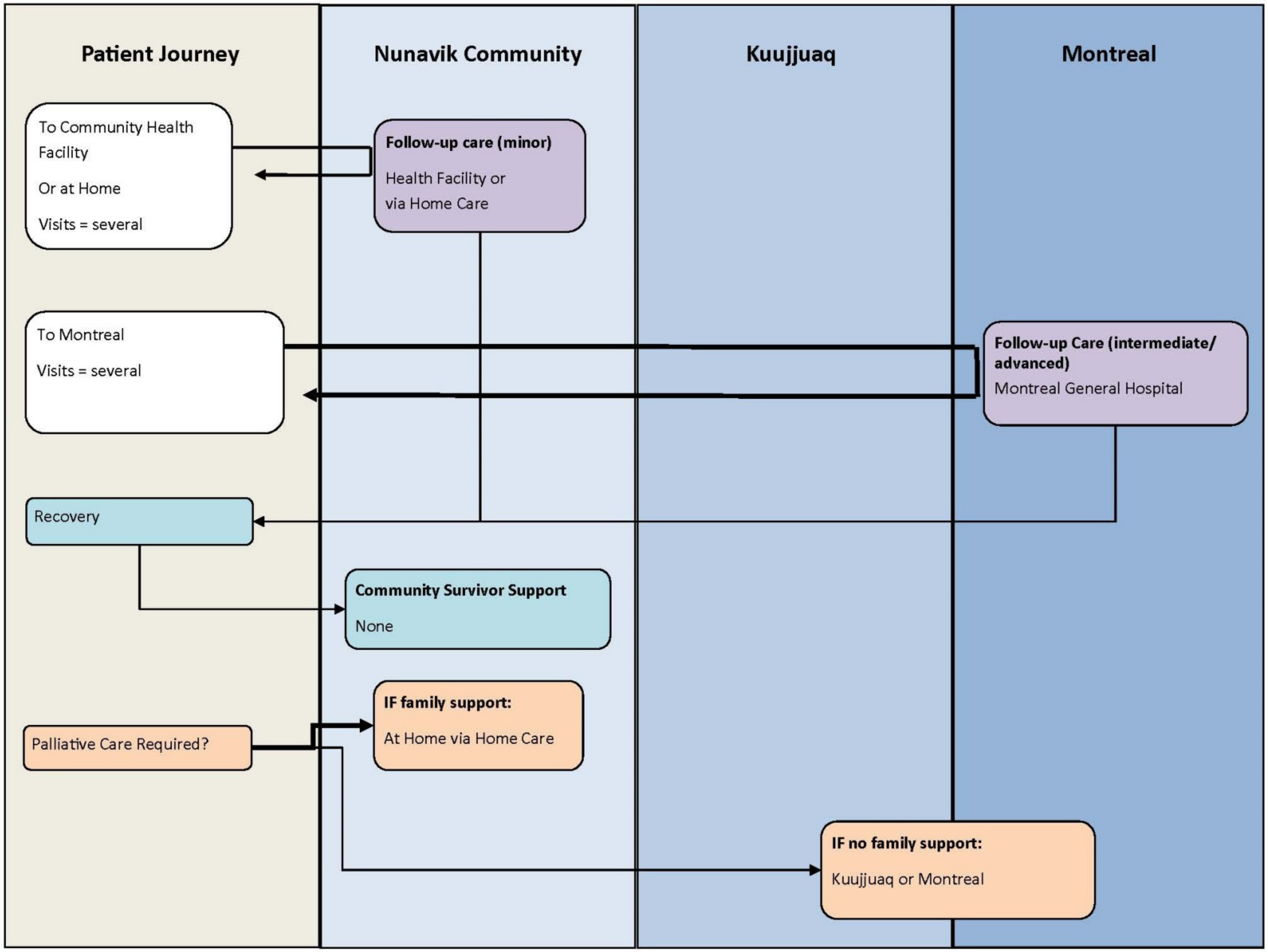
NUNAVIK-HUDSON COAST PATIENT JOURNEY



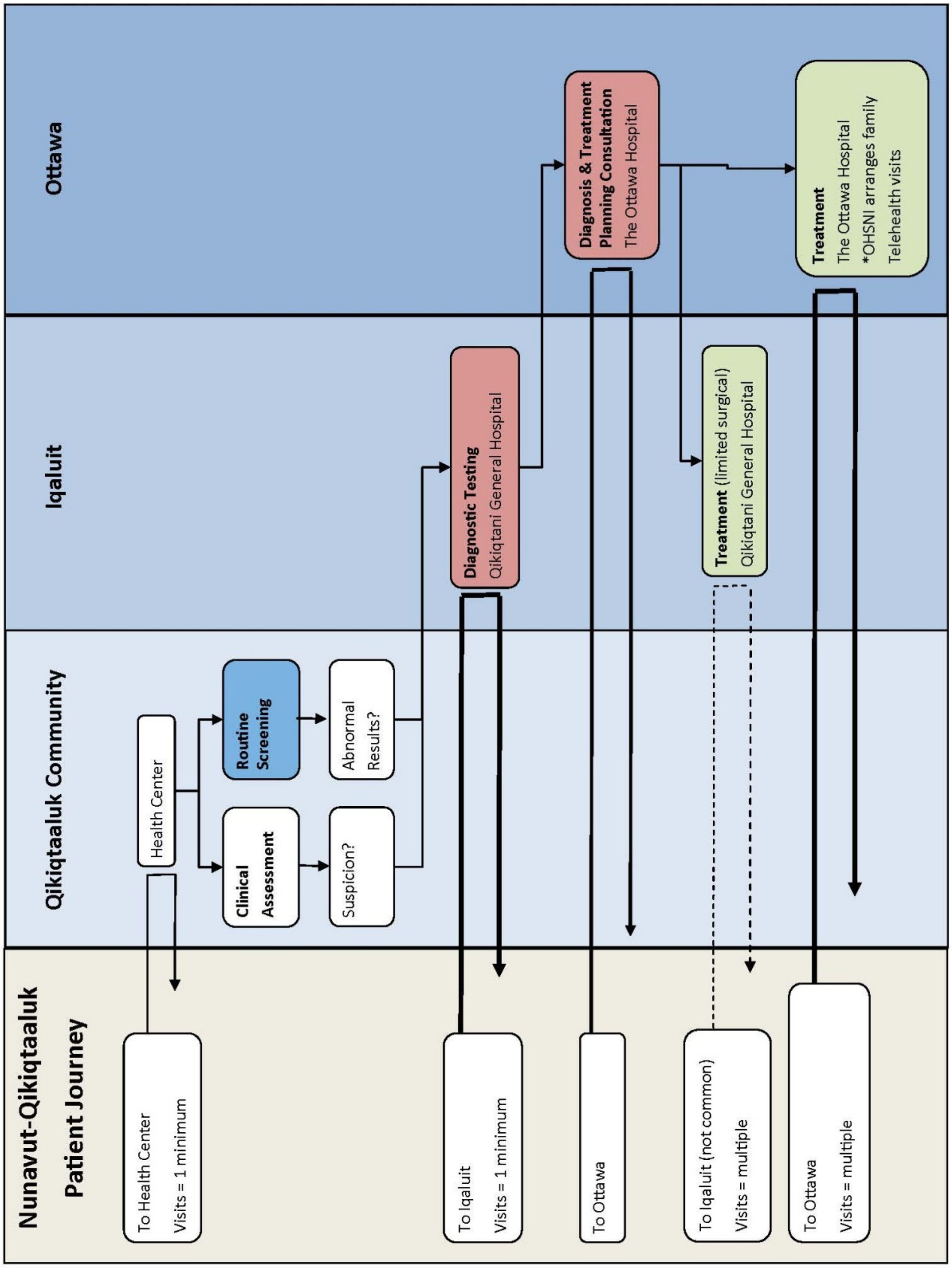

Patient Journey
Nunavik Community
Puvirnituq
Montreal
To Community Health Facility
Or at Home
Visits = several
Follow-up care (minor)
Health Facility or via Home Care
To Montreal
Visits = several
Follow-up Care (intermediate/ advanced)
Montreal General Hospital
Recovery
Community Survivor Support
None
Palliative Care Required?
IF family support:
At Home via Home Care
IF no family support:
Puvirnituq or Montreal

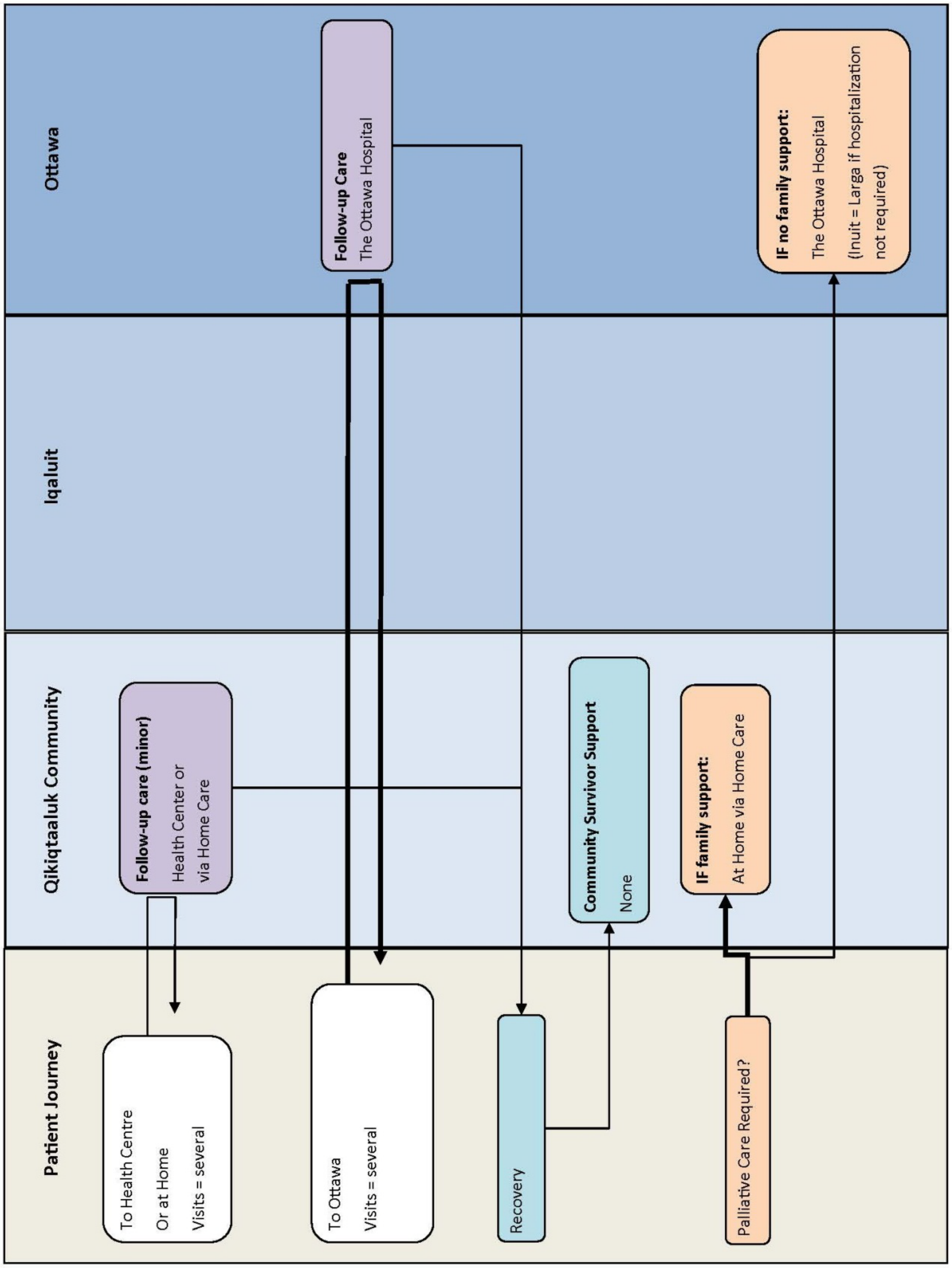
NUNAVIK-UNGAVA COAST PATIENT JOURNEY



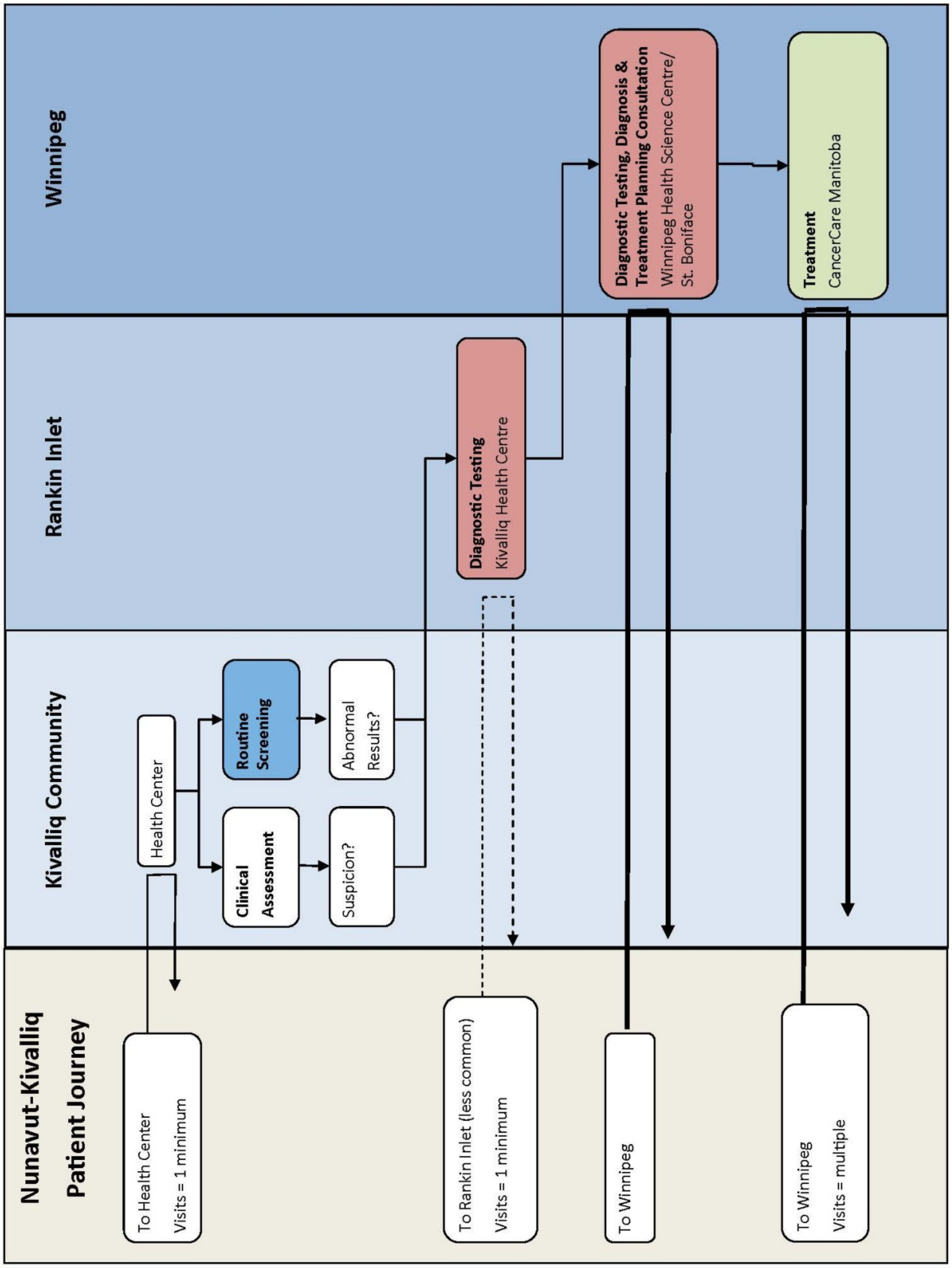

Patient Journey
Nunavik Community
Kuujjuaq
Montreal
To Community Health Facility
Or at Home
Visits = several
Follow-up care (minor)
Health Facility or via Home Care
To Montreal
Visits = several
Follow-up Care (intermediate/ advanced)
Montreal General Hospital
Recovery
Community Survivor Support
None
Palliative Care Required?
IF family support:
At Home via Home Care
IF no family support:
Kuujjuaq or Montreal

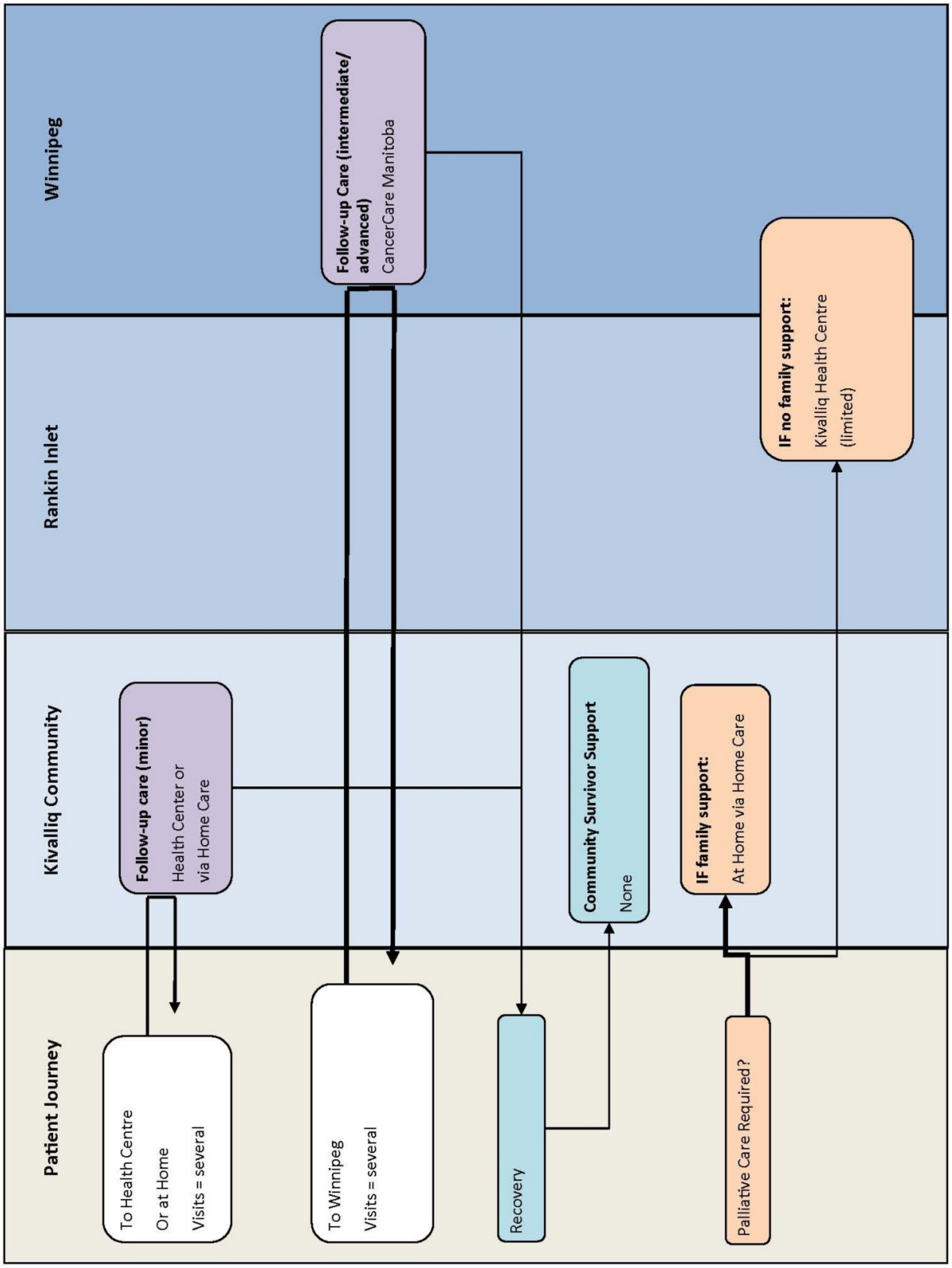
NUNAVUT-QIKIQTAALUK PATIENT JOURNEY



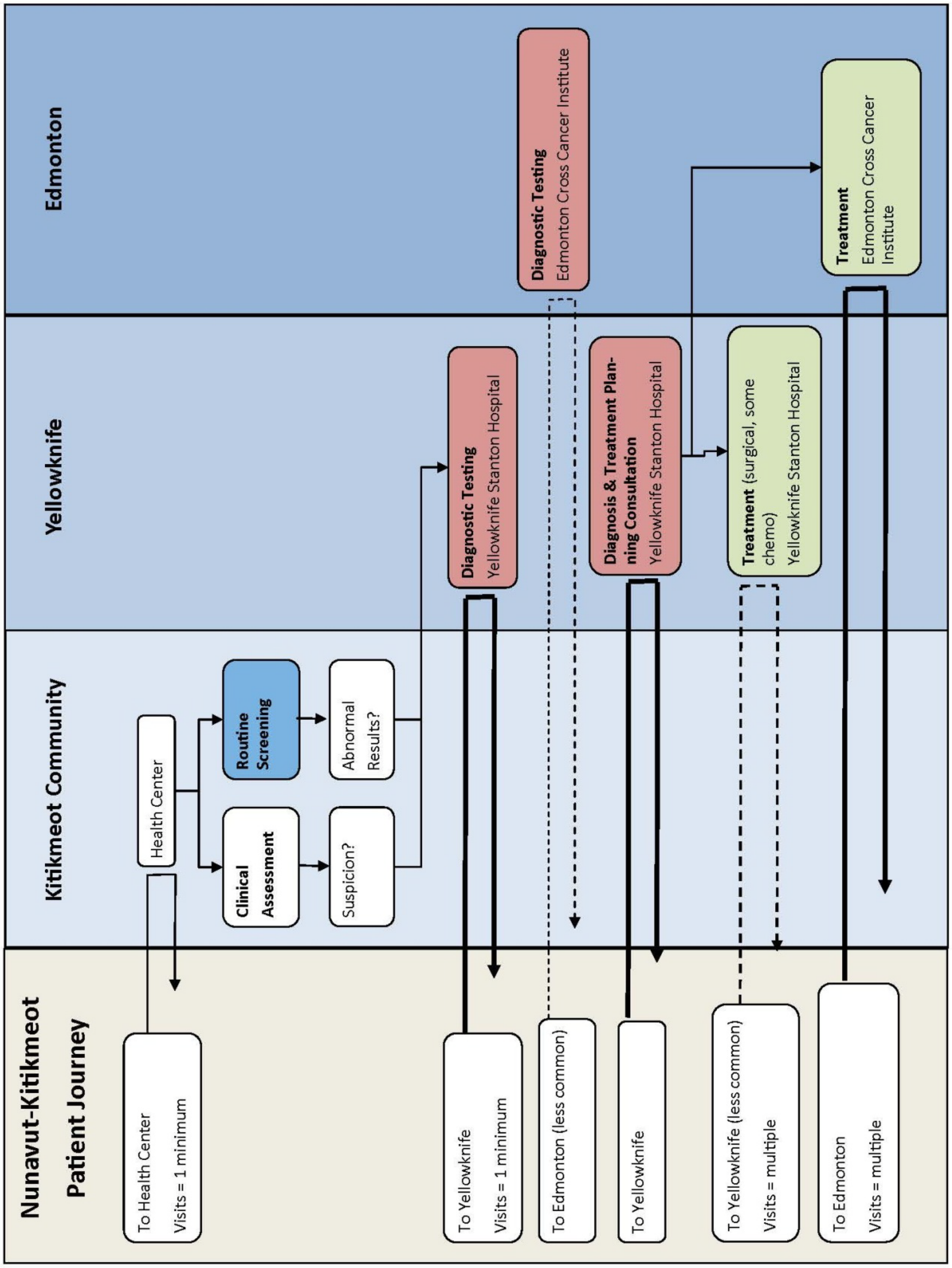

Patient Journey
Qikiqtaaluk Community
Iqaluit
Ottawa
To Health Centre
Or at Home
Visits = several
Follow-up care (minor)
Health Center or
via Home Care
To Ottawa
Visits = several
Follow-up Care
The Ottawa Hospital
Recovery
Community Survivor Support
None
Palliative Care Required?
IF family support:
At Home via Home Care
IF no family support:
The Ottawa Hospital
(Inuit = Larga if hospitalization
not required)

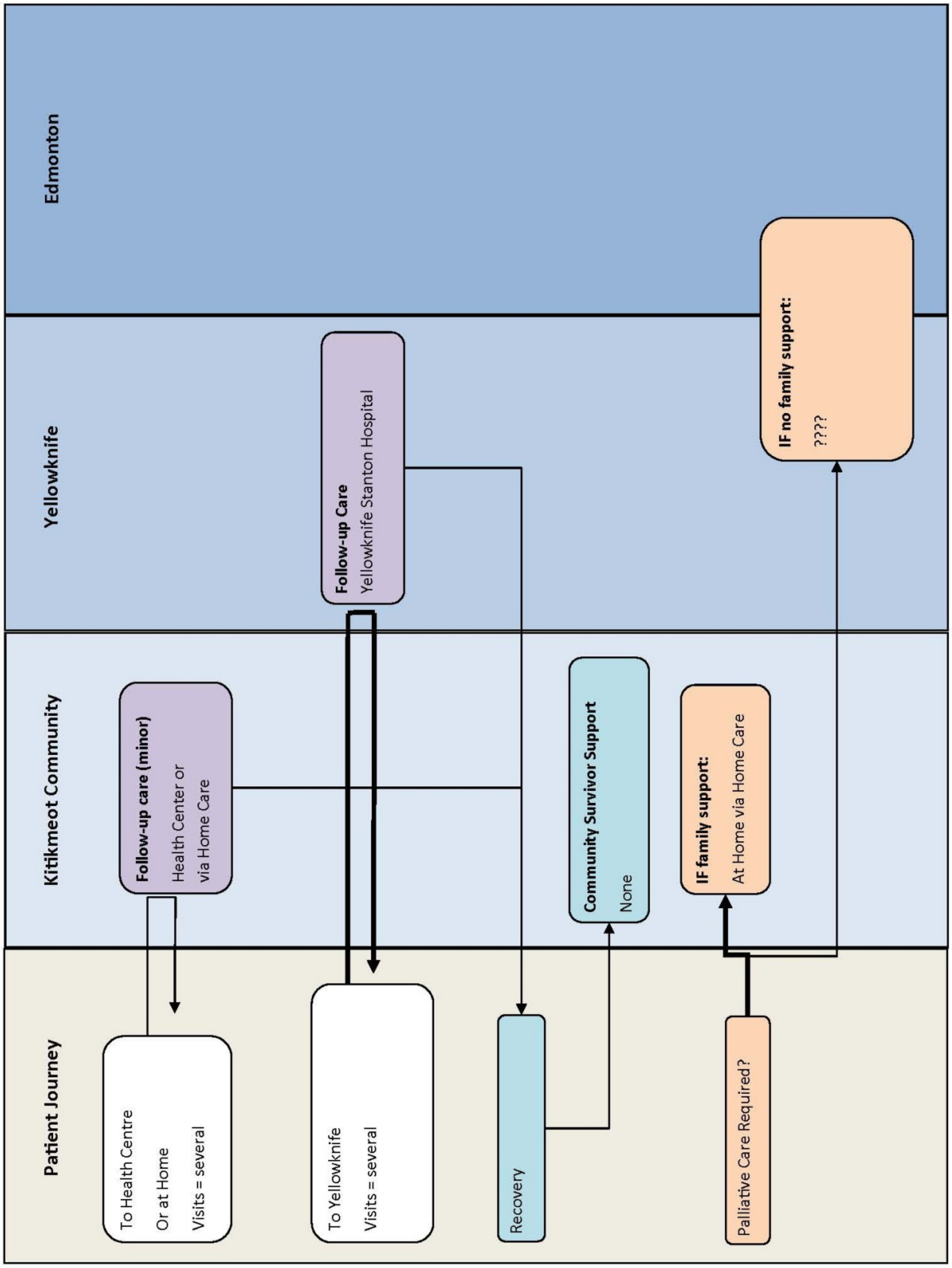
NUNAVUT-KIVALLIQ PATIENT JOURNEY



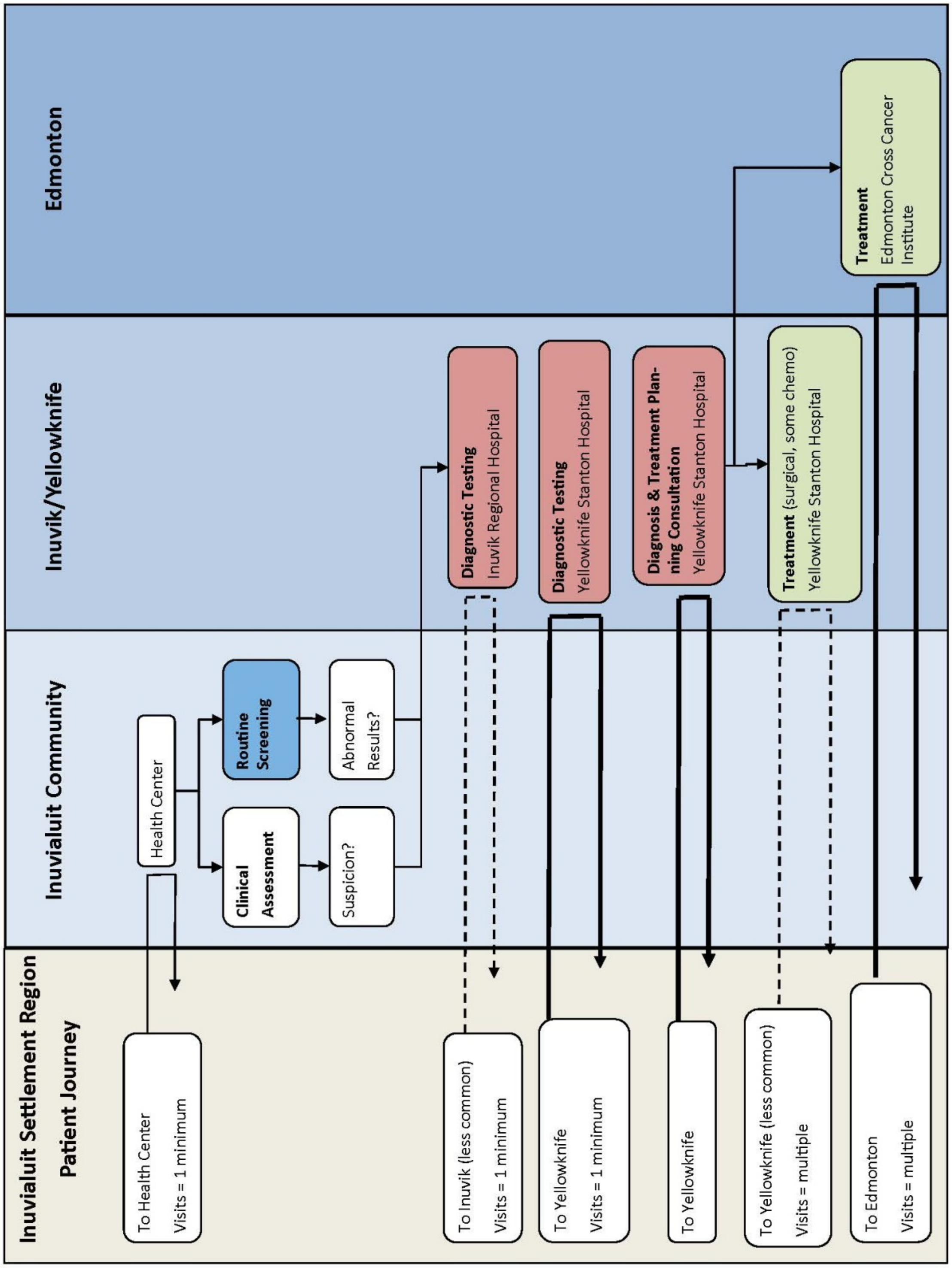

Patient Journey
Kivalliq Community
Rankin Inlet
Winnipeg
To Health Centre
Or at Home
Visits = several
Follow-up care (minor)
Health Center or via Home Care
To Winnipeg
Visits = several
Follow-up Care (intermediate/ advanced)
CancerCare Manitoba
Recovery
Community Survivor Support
None
Palliative Care Required?
IF family support:
At Home via Home Care
IF no family support:
Kivalliq Health Centre (limited)

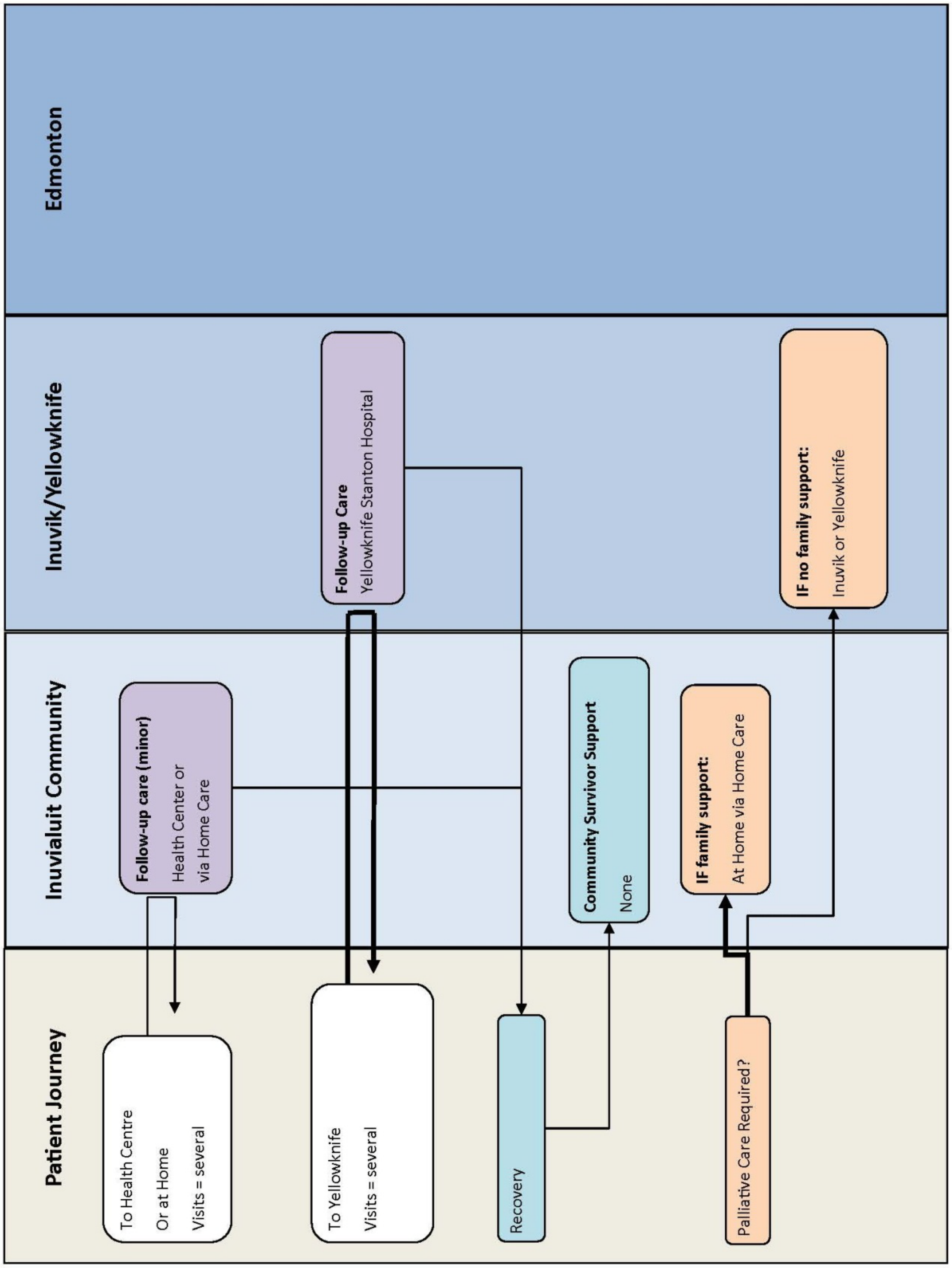
NUNAVUT-KITIKMEOT PATIENT JOURNEY




Patient Journey
Kitikmeot Community
Yellowknife
Edmonton
To Health Centre
Or at Home
Visits = several
Follow-up care (minor)
Health Center or
via Home Care
To Yellowknife
Visits = several
Follow-up Care
Yellowknife Stanton Hospital
Recovery
Community Survivor Support
None
Palliative Care Required?
IF family support:
At Home via Home Care
IF no family support:
????

INUVIALUIT SETTLEMENT REGION PATIENT JOURNEY




Patient Journey
Inuvialuit Community
Inuvik/Yellowknife
Edmonton
To Health Centre
Or at Home
Visits = several
Follow-up care (minor)
Health Center or
via Home Care
To Yellowknife
Visits = several
Follow-up Care
Yellowknife Stanton Hospital
Recovery
Community Survivor Support
None
Palliative Care Required?
IF family support:
At Home via Home Care
IF no family support:
Inuvik or Yellowknife

SECTION 3: PRESSURE POINTS AND PROMISING INITIATIVES

Pressure Points:

Initial analysis of Key Informant interviews revealed a series of challenges to the provision of cancer care being faced by each region. During validation, these ‘pressure points’ were probed further with interviewees to confirm or amend initial interpretations. During secondary analysis, the knowledge gained through Survivor & Caregiver participant interviews was added and a set of pressure points common to all of the regions was identified.

Promising Initiatives:

For the purposes of this study, ‘promising initiatives’ refers to unique approaches to providing services or resources that are deemed by Key Informants and Survivor & Caregiver participants to:

a) Be effective
b) Address a need
c) Has improved or is expected to improve cancer care

The promising initiatives presented in this section also meet the Partnership’s selection guidelines as being:

- Client or family-centred
- Creative and innovative
- Able to demonstrate positive impacts
- Potentially adaptable by other organizations

They do not meet the Partnership’s selection guideline of being regularly assessed.

Themes

The pressure points presented and promising initiatives described in this section are organized and prioritized thematically as follows:

1. Access to Care – Physical
2. Access to Care – Safety and Responsiveness
3. Awareness (Provider and Patient)
4. Culturally Responsive Resources and Services

ACCESS TO CARE - PHYSICAL

Pressure Point: Vast Geographic Distances between Communities and Cancer Care Services

From the point of diagnostic testing through diagnosis, treatment and, in some cases, after care and palliation, cancer care services can only be accessed away from home for Inuit Nunangat patients. Cancer patients from Inuit Nunangat have to make numerous and often lengthy trips over vast distances to receive care.

There is a need to consider all possible technologies, initiatives and processes that support enabling the provision of care closer to home.

Pressure Point: Client Cultural Values and Attitudes

Certain cultural values may contribute to discouraging people from seeking care and demanding services/information.

- Ajungnarmut (it cannot be helped) is a powerful cultural value that enables an individual to accept a loss, difficult or unexpected situation, similar to fatalism
- Stoicism – to bear up against adversity and pain without complaining is a highly valued quality, particularly among men
- Fear of cancer (in Inuktitut, it is called 'the sickness which cannot be fixed'). For many patients, a diagnosis of cancer is still perceived as a death sentence.
- The fear and stress of separation. People know that to have a complex illness like cancer will mean separation from family and work for long periods of time.

There is a need to address these influences in health related public education initiatives.

Pressure Point: Impacts of Socio-economic Stressors

Socio-economic stressors are linked to high rates of addictions (alcohol and smoking), family violence, food insecurity, overcrowding, poverty, suicide, etc. these circumstances and behaviours contribute to:

- Increased risk of developing cancer
- Being assessed accurately (symptom masking)
- Discouraging people from seeking care (assume other causes for symptoms; assume they'll be criticized for behaviours)

There is a need to consider the impact of Socio-economic stressors in the development of cancer-related public and clinician education material

PROMISING INITIATIVE

Tele-oncology, Nunatsiavut Government, Labrador Grenfell Health and Eastern Health

Target Clientele: Residents of Nunatsiavut (and other communities within Labrador Grenfell Health service area)

Description: Tele-oncology is part of the utilization of the telehealth system in place in the primary, secondary and tertiary sites serving Nunatsiavut.

It is used to support consultations between patients (and family), health care providers, physicians and specialists as required. For example:

- Initial diagnosis delivery: Patient (and family) with health care team at community clinic connected to health care team at Labrador Health Centre to deliver initial diagnosis in a structured, safe and supportive manner.
- Formal diagnosis and treatment planning: Patient (and escort support) with health care team at Labrador Health Centre connected to oncologists and specialists at St. John's to reduce requirement for patient to travel to St. John's.
- Treatment and After Care: Sessions to connect patient and health care team at community clinic to Labrador Health Centre or St. John's as required for pre-treatment consultations and patient monitoring and assessment.

One of the key factors in their success is that it is system driven. A high priority is placed on maximizing the utilization of technology across the province. There are standardized policies for use of telehealth and training for nurses at community clinics is part of standard orientation. Community clinic maintenance & repair personnel are trained to trouble shoot and operate all equipment. IT personnel provide centralized (online) scheduling and technical support.

Background: Telehealth units have been in place since 2005 at each community clinic in Nunatsiavut as part of a strategic plan for telehealth led by Labrador Grenfell Health in collaboration with the Nunatsiavut Government. Utilization has been growing steadily since that time. Labrador Grenfell Health has also been involved in a pilot project using advanced clinical telehealth technology. Rosie the Robot (or the InTouch RP-7 Remote Presence videoconferencing Robot for short) has been part of the Nain community clinic since July 2010. This pilot project is being undertaken in partnership with the Nunatsiavut Department of Health and Social Development, Health Canada, First Nations and Inuit Health

Advantages: Provides clinical support which improves care.

Reduces travel for patients.

Time-efficient (for patient).

Cost-efficient.

Disadvantages: Relies on stable, high speed internet access to be most effective

Inuit Engagement: Highly supported and promoted by the Nunatsiavut Government.

Phase of Cancer Continuum Addressed: Diagnosis, Treatment, After Care

Adaptability: High

Contact: Labrador Grenfell Health

PROMISING INITIATIVE

SOPHIE - Mobile Mammography, Institut National de Santé Publique du Québec

Target Clientele: Residents of Nunavik

Description: The mobile mammography program serving Nunavik is part of the Québec Breast Cancer Screening Program (PQDCS) led by the Institut National de Santé Publique du Québec (INSPQ). As part of this provincial program, women aged between 50 to 69 years are offered mammography exams every two years.

SOPHIE, the name of the portable mammography unit, travels by ship or air to the main air transportation hub communities along each coast to provide mammography services to women from Nunavik as well as to communities along the North Shore, Lower North Shore and James Bay region. Working with the Nunavik Regional Board of Health and Social Services, eligible women are notified and travel is arranged for them to receive a mammogram at the closest community to which SOPHIE is travelling.

A second unit, CLARA, is installed in a bus which travels to locations with either road or rail access and provides mammography services to communities in northern Québec, North Shore and Abitibi-Témiscamingue.

As part of a provincial program, data tracking and management are coordinated by the INSPQ and held in a provincial cancer registry (i.e. data are not Nunavik-specific).

Background: These mobile mammography services have been available to Nunavik residents since 2004 as part of the provincial breast cancer screening program.

Advantages: Provides access to regular screening to support early detection and improve care.

Reduces travel for patients.

Time-efficient for patients.

Disadvantages: Requires human resource capacity to centrally administer and operate program.

Cost efficiency is affected by locations of regional communities and respective air transportation hubs.

Inuit Engagement: Collaboration with Nunavik Regional Board of Health and Social Services.

Phase of Cancer Continuum Addressed: Screening, Early Detection

Adaptability: Moderate

Contact:

Hamado Zoungrana
Research Officer, Public Health Department
Nunavik Regional Board of Health and Social Services
hamado.zoungrana@ssss.gouv.qc.ca

ACCESS TO CARE – SAFETY AND RESPONSIVENESS

Pressure Point: Tracking & Follow up of Test Results

Lack of health system-driven, standardized tracking and alert systems at the community level in each region impacts health care providers' ability to ensure consistent, reliable tracking and follow-up of all reports and results.

Pressure Point: Communications Issues – Discharge and Patient Orders

There are gaps in communications between the tertiary site discharging or sending patient home and community health care providers receiving the patient.

Gaps are either:

- Breaks or delays in transmission and receipt of information
- Tertiary site lack of awareness of community/regional capacity and infrastructure

Pressure Point: Delivery of Initial Diagnosis to Patient

While best efforts are made to ensure language, emotional and family support for patients throughout the diagnosis and treatment planning phase, there are no formal protocols or policies in place.

Particularly in an environment of high turnover among health care providers, this can result in inconsistent approaches to diagnosis delivery.

There is a need for system-supported guidance with respect to cancer diagnosis delivery to ensure cultural and emotional support for patients during this extraordinarily stressful event.

PROMISING INITIATIVE

Kivalliq Inuit Services, Winnipeg, Government of Nunavut

Target Clientele: Patients from Kivalliq

Description: Kivalliq Inuit Services (KIS) provides referral coordination, patient navigation and track and report patient information for Kivalliq patients in Winnipeg for medical care. The staff of KIS are employed by the Government of Nunavut and reside within the Inuit patient boarding home in Winnipeg (Kivalliq Inuit Centre).

Their services include:

- Medical appointment coordination
- Nursing case management
- Coordination/communication of patient information
- Patient support
- Arrangement of return patient travel

Their approach is practical and labour intensive: they tap into the network of Winnipeg health services to ensure swift and efficient scheduling of appointments; accompany patients to appointments (when needed); maintain direct contact with physicians to collect patient summaries and monitor follow up; inform patients of the outcome of their appointments; send weekly patient reports to health centres. They are also involved in coordinating specialist services to Kivalliq. Specialists from Winnipeg traveling to Kivalliq receive travel kits from KIS which include a digital tape recorder. KIS transcribes the physician notes, flag the follow up instructions in their own system and forward them as required to Kivalliq.

KIS 'flags' cancer patients for particular attention. They accompany the patient and their escorts to the diagnosis and treatment planning session (ensuring interpreter support is present if they feel it's required). They monitor and support the patient and escort throughout treatment. This applies even if patient does not stay in the boarding home.

Background: KIS was initiated approximately 15 years ago, prior to the creation of Nunavut. It was adopted by the Government of Nunavut in 1999. It was created to solve coordination gaps and improve patient care for Kivalliq patients traveling between the communities and Winnipeg for medical care.

Advantages: Improves patient care.

Provides stable, efficient system coordination and communication between tertiary site and secondary/primary sites in the region.

Supports and monitors patient progress in Winnipeg.

In conjunction with Kivalliq Inuit Centre, it provides a safe, culturally responsive environment for patients.

Disadvantages: Labour intensive

Inuit Engagement: Part of the Kivalliq Regional HSS, Government of Nunavut.

Interaction with patients. Well known and respected

Phase of Cancer Continuum Addressed: Diagnosis, Treatment, After Care

Adaptability: Moderate

One of the key elements of their success is their physical integration into the patient boarding facility. Adaptability in the absence of that system of lodging for a population would compromise the model.

Contact:

Sharon Hunting
Nurse Manager, KIS
Government of Nunavut
shunting@gov.nu.ca

Note: The Northern Quebec Module serving Nunavik operates a similar model that is equally effective.

PROMISING INITIATIVE

Cancer Patient Navigation – Oncology Pivot Nurse, Montreal

Nunavik Regional Board of Health and Social Services

Target Clientele: Cancer patients from Nunavik

Description: The Oncology Pivot Nurse (OPN) is a navigator in Montreal at the tertiary cancer treatment hospital. Her role is fourfold:

- Evaluation and assessment/discussion of diagnosis for patient
- Patient (and caregiver) teaching
- Patient (and caregiver) support
- Patient information tracking/communication with Nunavik health care providers
- Supports coordination of treatment and follow-up appointments

The OPN meets the patient in the hospital upon diagnosis and maintains a direct relationship with them for the rest of their cancer journey. The OPN is the patient's contact person in the system – lines of two way communication are always open between them, whether the patient is in Montreal or back home.

The OPN maintains a close relationship with the Northern Quebec Module case managers, through their collaboration, the OPN gets advance notice of a cancer patient's arrival in Montreal. This is particularly valuable to ensuring the OPN is aware of the diagnosis and treatment planning session – the first time they will meet the patient.

Background: This service began in 2007. It was spearheaded by the Director of Nursing and Hospital Services in Nunavik to take advantage of a provincial initiative to implement OPN positions to support cancer care throughout Quebec. Initially, they tried placing a position in Nunavik to navigate for patients in Montreal, but it proved ineffective (information access and coordination problems).

To solve the coordination and communication problems, and enable direct contact between the OPN and patient, they placed the Nunavik OPN position directly in the Montreal hospital.

Advantages: Improves patient care.

Contributes to stability and efficiency for cancer care coordination and communication between tertiary site and secondary/primary sites in the region.

Supports and monitors patient progress throughout their cancer journey

Disadvantages: Relies on tertiary site and jurisdictional collaboration to enable positioning of navigator within tertiary care site.

Inuit Engagement: Driven by the Nunavik Regional Health and Social Services Board.

Interaction with Nunavik patients. Well known and respected

Potential Phase of Cancer Continuum Addressed: Diagnosis, Treatment, After Care

Adaptability: High

Contact: Nunavik Regional Health and Social Services Board

PROMISING INITIATIVE

NWT Cervical Cancer Screening Program

Government of Northwest Territories

Target Clientele: Eligible women throughout the territory.

Description: The NWT Cervical Cancer program employs a standard set of guidelines adapted to suit the population and geography of the territory (predominantly small remote or isolated communities, largely aboriginal population). Cervical cancer screening is integrated into the protocols for the Well Woman clinics offered at all community health centres throughout the territory.

This is a partially organized program in that it does not include territorial tracking and recall systems or program databases.

In the communities, including those in the Inuvialuit Settlement Region, tracking and recall are handled by the health centres. However, the small community populations combined with the well-established and familiar Well Woman clinics make this an effective and stable program. According to sources within NWT and Nunavut, their participation rates are high (between 79% and 83%).

Judging this program to be a best practice for their purposes, the Government of Nunavut has adapted the NWT Guidelines (with their collaboration) and is in the process of implementing their own Cervical Cancer Screening Program.

Advantages: Designed to suit the delivery of primary care through community clinics with limited human resource capacity.

Disadvantages: Does not include standardized patient tracking systems to support community health centres' ability to ensure consistent, reliable tracking and follow-up of all reports and results.

Inuit Engagement: Interaction with Inuvialuit clients. Well known and respected

Phase of Cancer Continuum Addressed: Screening

Adaptability: High

Contact:

Dr. Andre Corriveau
Chief Public Health Officer
Department of Health and Social Services
Government of Northwest Territories
Andre_Corriveau@gov.nt.ca

PROMISING INITIATIVE

Initial Diagnosis Delivery Process, Labrador Grenfell Health, Nunatsiavut Government

Target Clientele: Residents of Nunatsiavut (and other communities within Labrador Grenfell Health service area)

Description: While not a formalized protocol, personnel at Labrador Health Centre (LHC) and Nunatsiavut Government NIHB managers strive to follow an informal practice to support delivery of a cancer diagnosis to patients in a manner that: a) ensures the patient has an escort (is not alone) and b) receives diagnosis as close to home as possible.

To deliver an initial diagnosis, the attending surgeon or specialist will work with staff from LHC and the community clinic to arrange a telehealth videoconference with the patient and their family at the community clinic. Alternatively, they will arrange for the patient and an escort to be brought to the LHC to receive the initial diagnosis in person. In those cases, the LHC staff will also endeavor to set up telehealth videoconferences with family back in the patient's home community.

In both cases, patients usually choose to receive their full diagnosis and treatment planning session(s) at the LHC where they meet in person with medical personnel, including the patient navigator, and be linked via tele-oncology videoconference with specialists from the St. John's Cancer Centre.

Background: Telehealth units have been in place since 2005 at each community clinic in Nunatsiavut as part of a strategic plan for telehealth led by Labrador Grenfell Health in collaboration with the Nunatsiavut Government.

Since that time, the informal development of this protocol for delivery of the initial diagnosis to cancer patients is a reflection of the system-driven priority (for Labrador Grenfell Health and the Nunatsiavut Government) to bring care closer to home. It also reflects the commitment to maximise levels of cultural and emotional support for patients.

Advantages: Provides clinical support which improves care.

Provides increased cultural and emotional support for patients during an extremely stressful period.

Reduces travel for patients.

Makes best use of existing telehealth network and system.

Cost-efficient.

Disadvantages: Relies on stable, high speed internet access to be most effective.

Relies on a pre-existing tele-oncology network and system.

Inuit Engagement: Highly supported by the Nunatsiavut Government.

Phase of Cancer Continuum Addressed: Diagnosis

Adaptability: High

Contact:
Kathy Elson
Clinical Nurse Manager
Labrador Health Centre
katherine.elson@lghealth.ca

AWARENESS (PROVIDER AND PATIENT)

Pressure Point: Public Awareness, Health Literacy and Self-Advocacy

Low levels of public awareness, general health literacy including concepts of self-advocacy reduces peoples' ability to:

- Make informed decisions
- Understand health information
- Demand or facilitate access to services and information

There is a need to raise public awareness of cancer risks, signs & symptoms (i.e. warning signs to guide decisions to go to health centre).

There is a need to improve health literacy. Health literacy refers to comprehension of health information, health care systems and personal responsibility for health. An aspect of health literacy is promotion of self-advocacy within the health system.

Pressure Point: Clinician Awareness and Clinical Education

Community health care providers work in an environment of constant staffing challenges, high turnover rates, and high demand for emergency and acute care. With respect to assessment and early detection of cancer, these pressures may affect community clinicians' ability to 'switch' from an emergency to a preventive mindset when facing a patient with chronic, undefined symptoms (as is often the case for cancer).

There is a need for clinician education and/or protocols to support earlier detection of cancer.

There is a need to address patient experiences and perceptions of clinicians being non-responsive to patients presenting with chronic or undefined symptoms.

Pressure Point: Patient and Provider Awareness of Existing Cancer Care Support Services

Lack of communication linkages between tertiary cancer sites and regional/community health care providers reduces their ability to facilitate access for Inuit Nunangat patients to existing support services.

PROMISING INITIATIVE

"Inuk to Inuk Prevention Program, Nunavik Regional Board of Health and Social Services

Target Clientele: Inuit of Nunavik

Description: "Inuk to Inuk" is a novel, culturally responsive public education model used to raise public awareness and support prevention of diabetes.

Each year, a nurse with diabetes training and an Inuk speaker who is a person with diabetes travel as a team to a number of communities for one week each to deliver the program. Their activities are supported by a coordinator at the board who oversees the scheduling, preparation, and advance liaison work and promotion for each trip.

In each community, the team directly engages communities in diabetes prevention through presentations by the speaker to the community. She shares her personal experiences, and facts about the challenges, and consequences of living with diabetes. Building on this foundation, she delivers information about diabetes; its causes and prevention; and a Q & A session. She is supported by the nurse, displays, visual tools and handouts.

They arrange four presentation opportunities in each community:

1. Meeting with an assembly of secondary students in collaboration with the local school.
2. A live phone-in show on the local radio
3. Hosting of a community feast in collaboration with the Municipality. The whole community is invited but special efforts are made in advance to invite diabetics in the community.
4. A support and information meeting with diabetics in the community. This meeting is arranged in collaboration with the chief nurse at the local clinic and/or a member of the local Wellness Committee

Background: Inuk to Inuk was launched approximately five years ago. It is an ongoing program run by the department of Public Health, Nunavik Regional Board of Health and Social Services. Funding to operate the program comes through Nunavik's budget from the federal Aboriginal Diabetes Incentive program.

Advantages: Feedback from communities is extremely positive. They attract large audiences in every community.

The delivery of information about diabetes by a diabetic Inuk to other Inuit creates credibility and trust.

The emphasis on sharing knowledge in person resonates with the traditionally oral culture of Inuit.

The partnership between the speaker and the diabetes nurse (who is not necessarily Inuk) facilitates rapport between the community and health care professionals.

Disadvantages: The program relies upon identification of a motivated, committed speaker.

The speaker is not an employee of the health system, she schedules these activities around her existing work and life commitments.

The advance planning, costs and time commitments required mean only a few communities per year are visited.

Inuit Engagement: Very High

Potential Phase of Cancer Continuum Addressed: Prevention, Screening & Early Detection, Survivor Support

While the model is being applied to diabetes at this time, it has significant potential to be applied effectively to cancer care.

Adaptability: High

Contact:

Sylvie Dénommé
Diabetes Program Coordinator,
Nunavik Regional Board of Health and Social Services
sylvie.denomme@ssss.gouv.qc.ca

PROMISING INITIATIVE

Provincial Cancer Committee, Eastern Health, Newfoundland and Labrador

Target Clientele: Cancer patients and health care providers including Nunatsiavut

Description: The provincial cancer quality committee fosters linkages between partners and stakeholders involved with cancer care to improve services, programs and processes within the health system.

Membership includes at least one representative from:

- Cancer patients throughout the province
- Each type of cancer service (e.g. pediatric oncology, surgical oncology, hematology, etc.)
- Executive of each Regional Health Authority and the Department of Health and Social Development, Nunatsiavut Government
- Senior leadership of aboriginal associations
- Executive of key partners including the Canadian Cancer Society, Dr. H. Bliss Murphy Cancer Foundation and Young Adult Cancer Canada

The committee meets regularly with a structured agenda that begins with a patient story; includes an education session from one of the groups represented on the committee (for members to learn about each other); discussions about standards; and discussions of issues of concern related to cancer services.

Background: Initiated approximately a year ago by Eastern Health, who administers the provincial Cancer Care program for Newfoundland and Labrador.

Advantages:	Feedback from a committee member survey was very positive. Members valued the linkages and see specific improvements in system coordination and communications issues.
Disadvantages:	Sustainability relies on individual commitment of members and strong leadership
Inuit Engagement:	Nunatsiavut Government
Potential Phase of Cancer Continuum Addressed:	All This initiative fosters communication and problem solving between all partners involved with cancer care throughout the jurisdiction, including cancer patients
Adaptability:	Moderate Scale and composition of committee would depend on cancer care partners involved.
Contact:	Katherine Chubbs Chair of the Provincial Cancer Committee Vice President and Chief Nursing Officer Eastern Health Katherine.Chubbs@easternhealth.ca

CULTURALLY RESPONSIVE RESOURCES AND SERVICES

Pressure Point: Provider – Cultural Awareness & Cross-Cultural Communications

Lack of cultural awareness among health providers at all levels reduces their ability to recognize and address the needs of their patients.

It reduces their ability to:

- Accurately assess the quality of their communications with patients (i.e. do they understand each other)
- Recognize patient 'cues' about pain and distress
- Build trust relationships with patients

There is a need for cultural orientation/education for health care providers

Pressure Point: Culturally Relevant Public Education Materials and Resources

There are very few culturally relevant, cancer-specific materials and resources for Inuit across the cancer care continuum.

There is a need for adaptation of existing resources and/or development of culturally relevant materials to support public education efforts in Inuit Nunangat

PROMISING INITIATIVE

Palliative Care Project

Beaufort Delta Health and Social Services,
Inuvialuit Regional Corporation

Target Clientele: Inuvialuit and First Nations Communities and Health Professionals

Description: The Palliative Care project was an initiative to develop palliative care guides for health professionals and communities based on community consultation within the service area of the Beaufort Delta Health and Social Services region (which includes the Inuvialuit Settlement Region).

The ability for patients to spend their final days in their home communities is extremely important to Inuvialuit and First Nations communities. This project was a response to the regional board's need to find out what they could do to enhance their ability to provide palliative care in a culturally respectful and collaborative way.

A team traveled to each community to learn about their culture and traditions, past and current beliefs about palliative care and death. They also consulted residents about respectful communications and the needs of the families.

Based on these consultations, two community-specific sets of guides were produced and are in use today:

- *Palliative Care: Education Guide for Health Professionals*. This guide assists the health care provider(s) by presenting the traditions, beliefs, needs and expectations of that community based on the project consultations.

- *Comfort for Those in Need: Caring for the Terminally Ill*. This guide is for the patients and their families to assist them in understanding the role of the health provider, options for care and what to expect throughout the process.

Advantages: Culturally responsive and respectful approach to enhancing palliative care in aboriginal communities.

Supports relationship building and engagement of communities in health care.

Inuit Engagement: The project was undertaken in collaboration with the Inuvialuit Regional Corporation and the Gwich'in Tribal Council. Each community was directly engaged in defining the scope and content of their community's guides.

Phase of Cancer Continuum Addressed: Palliative Care

Adaptability: High

Contact:
Jane Smith
Director of Client Services
Beaufort Delta Health and Social Services
jane_smith@gov.nt.ca

SECTION 4: NEXT STEPS

This environmental scan was part of a first step in the implementation of the *First Nations, Inuit and Métis Action Plan on Cancer Control*. The information gathered is intended to provide a foundation for future action by the Partnership. It is also intended to promote the sharing of ideas and possible actions for all jurisdictions and partners involved with cancer care and control among Inuit, First Nations and Métis.

To support these goals, this section presents some options for actions for the Partnership and its partners to consider. These options for action address the pressure points identified in this report and outstanding knowledge gaps with respect to cancer pathways for Inuit.

The options for action to address pressure points for Inuit Nunangat have been developed by Corvus Solutions based on analysis of the information and on initiatives offered by Key Informants and Survivor & Caregiver Participants.

OPTIONS FOR ACTION: PRESSURE POINTS

Awareness

- Facilitate the identification of health literacy gaps; the development of resources to address them; and strategies for incorporation in public education activities in the Inuit Nunangat region

- Facilitate the development of public education materials about cancer that address attitudes and cultural values related to cancer; warning signs and symptoms for cancers to guide decisions about when to go to the clinic.

Pressure Points:

Public Awareness, Health Literacy and Self-Advocacy

Client Cultural Values and Attitudes

Impacts of Socio-economic Stressors

Culturally Relevant Public Education Materials and Resource

Patient Support Services

- Engage Inuit Nunangat regions and tertiary cancer care sites to support development of cancer pathway information kits for their patients. This should include an overview of the physical pathway; what to expect at the cancer treatment site; navigator contacts; and identify support services and where available.

- Utilize the Partnership's network of partners and linkages to undertake an inventory of relevant survivor support networks and services that could be accessible to Inuit Nunangat cancer survivors and caregivers.

Pressure Points:

Culturally Relevant Public Education Materials and Resources

Patient and Provider Awareness of Existing Cancer Care Support Services

Build Communication Bridges

- Facilitate health sector communication linkages between the Inuit Nunangat regions and tertiary cancer care sites
- Support the development and/or delivery of cross-cultural orientation for tertiary cancer care sites

Pressure Point:

Pressure Point: Patient and Provider Awareness of Existing Cancer Care Support Services

Pressure Point: Communications Issues– Discharge and Patient Orders

Provider Cultural Awareness & Cross-Cultural Communications

Clinical Education & Support

- Support development of clinical education tools to support community health care providers in cancer assessment and community level treatment preparation and procedures
- Engage Inuit Nunangat regions to consider and provide guidance for health care providers for delivery of initial diagnosis to patients
- Facilitate knowledge exchange relating to models or practical systems for patient results tracking and alerts

Pressure Point:

Clinician Awareness and Clinical Education

Delivery of Initial Diagnosis to Patient

Tracking & Follow up of Test Results

OPTIONS FOR ACTION: PARTNERSHIP KNOWLEDGE GAPS

This project was a first step by the Partnership to fill Inuit-specific knowledge gaps about current cancer care pathways, promising practices and culturally responsive resources and services.

While much has been learned through the environmental scan undertaken for this survey, two knowledge gaps remain and are presented here for future consideration.

Explore Promising Practices within Circumpolar Inuit Regions

- Undertake an environmental scan of promising practices for cancer care and control within the Inuit Circumpolar Regions.

  The Inuit homelands extend beyond Canada across the Arctic regions of Russia, Alaska and Greenland. Inuit communities in the circumpolar regions face similar geographic, demographic and socio-economic challenges as Canadian Inuit. A scan of promising practices in cancer care in those areas may reveal highly relevant and transferable initiatives.

Explore Cancer Care Pathways among Urban Inuit in Canada

- Undertake an environmental scan of cancer care pathways, programs and services for Canadian Inuit living in urban centres.

  According to 2006 Census data, there are approximately 8,400 Inuit living in Canada's urban centres, predominantly in St. John's, Montreal, Ottawa, Winnipeg and Edmonton. At this time, there is a knowledge gap with respect to the cancer journey they experience.

Appendix

CONTENTS

DEFINITIONS

Beneficiary	Refers to an individual who qualifies as a beneficiary of an aboriginal land claim. Criteria for determining eligibility are defined within each land claim.
Cancer Care Pathway	Refers to the physical and medical pathway experienced by a cancer patient
Culturally Responsive	A holistic perspective on health, literacy and language, imagery, perspectives on medicine, psychosocial barriers of fear and beliefs about cancer.
Health Literacy	Refers to a general understanding of health issues, signs and symptoms, personal responsibility for health and how to self-advocate.
Inuit Qaujimajatuqangit	Inuit traditional knowledge and information passed down through oral history, customs and traditions. It encompasses all aspects of traditional Inuit culture including values, world views, language, social organization, knowledge, life skills, perceptions and expectations.
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.
Navigation	A navigator works with patients, families and health care providers to track, monitor and support the patients needs throughout their cancer journey.
Promising Initiative	Refers to unique approaches to providing services or resources that are effective, address a need and have improved or are expected to improve

	cancer care.
Remote	A community with no road access to medical services (diagnostic and treatment services) greater than 90 km distance.
Resources	Refers to information-based entities such as educational materials (printed, video, oral or web-based content), support networks or linkages to other organizations.
Telehealth	The use of telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration. Technologies include videoconferencing, the internet, store-and-forward imaging, streaming media, and terrestrial and wireless communications.
Tele-oncology	The use of telehealth to support clinical consultations and patient care for cancer diagnosis, treatment and after care

KEY INFORMANT QUESTIONNAIRE

Inuit Nunangat Cancer Care: Environmental Scans of Pathways, Promising Practices and Models

Management Health Sector Interview Guide

Corvus Solutions is pleased to have been chosen by the Canadian Partnership Against Cancer* to work with Health Authorities in NWT, Nunavut, Nunavik and Nunatsiavut to identify:

- Cancer care programs and services for Inuit in the Inuit Nunangat Regions
- Culturally responsive cancer control (including prevention) programs, services and resources for Inuit
- Gaps and barriers faced by community members to accessing cancer care and control

This project is part of CPAC's efforts to improve cancer care for Inuit in Canada by seeking information about the current situation with respect to cancer care and control for Inuit and to identify current leading practices and models that can be shared and leveraged to improve cancer care for Inuit. Your perspectives and expertise are vital to ensuring that the information being compiled is complete and accurate. We would be very pleased if you would participate as a key informant in this work.

We request your permission to record this interview to ensure accuracy. Please note that your responses will be confidential and individual responses will not be attributed, nor any part of this recording used without seeking your prior permission.

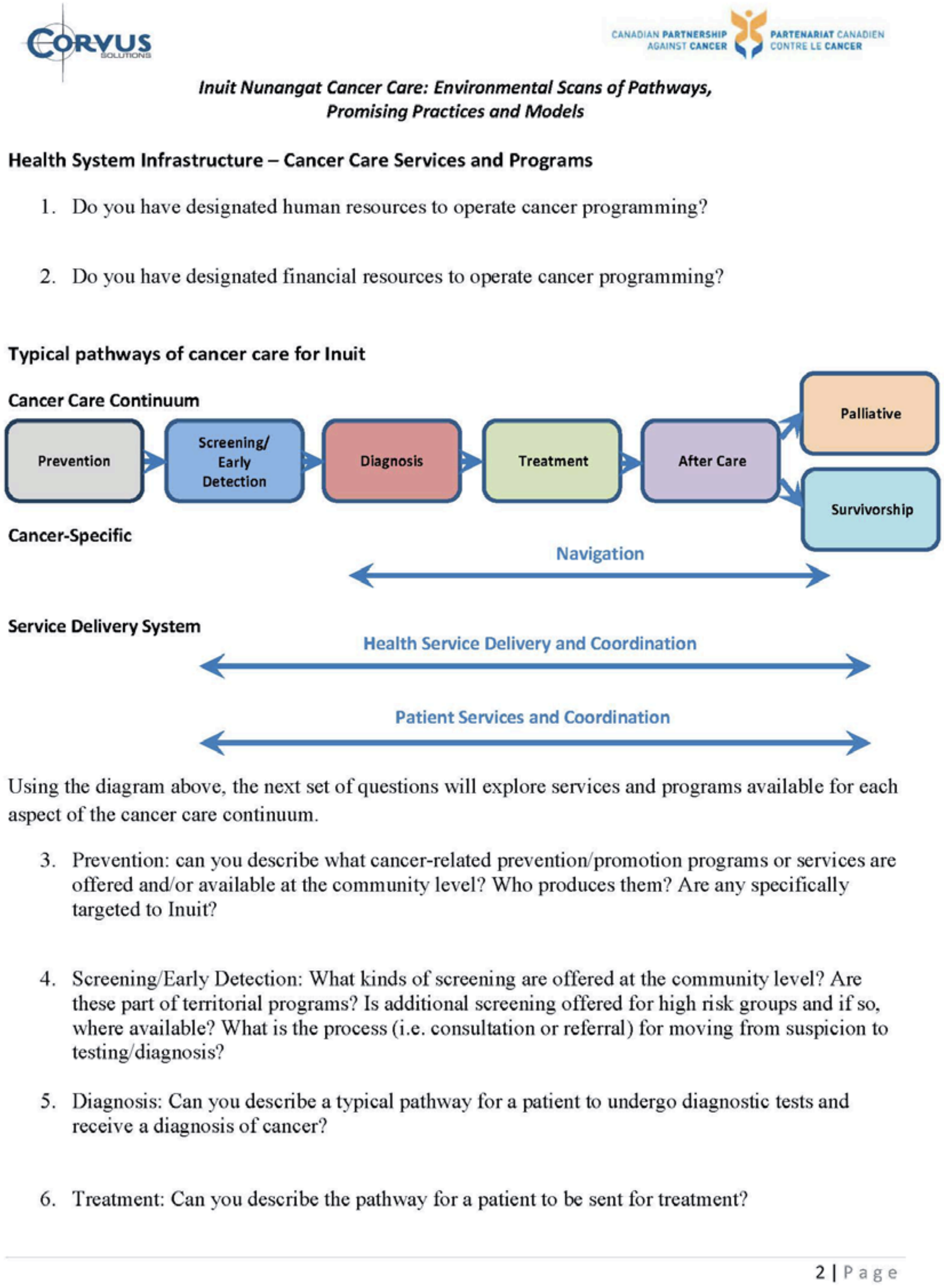
**The Canadian Partnership Against Cancer (CPAC) recently facilitated the development of the First Nations, Inuit and Métis Action Plan on Cancer Control, involving Inuit, First Nations and Métis representatives involved in cancer control and chronic disease prevention. The Action Plan is posted on the Partnership's Web site at this link:* http://www.partnershipagainstcancer.ca/node/resources/.

Name:

Organization, Position and Title:

Location:

How long have you worked for this organization:



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CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

Inuit Nunangat Cancer Care: Environmental Scans of Pathways, Promising Practices and Models

Health System Infrastructure – Cancer Care Services and Programs

1. Do you have designated human resources to operate cancer programming?

2. Do you have designated financial resources to operate cancer programming?

Typical pathways of cancer care for Inuit

Cancer Care Continuum

Prevention → Screening/ Early Detection → Diagnosis → Treatment → After Care → Palliative / Survivorship

Cancer-Specific

Navigation

Service Delivery System

Health Service Delivery and Coordination

Patient Services and Coordination

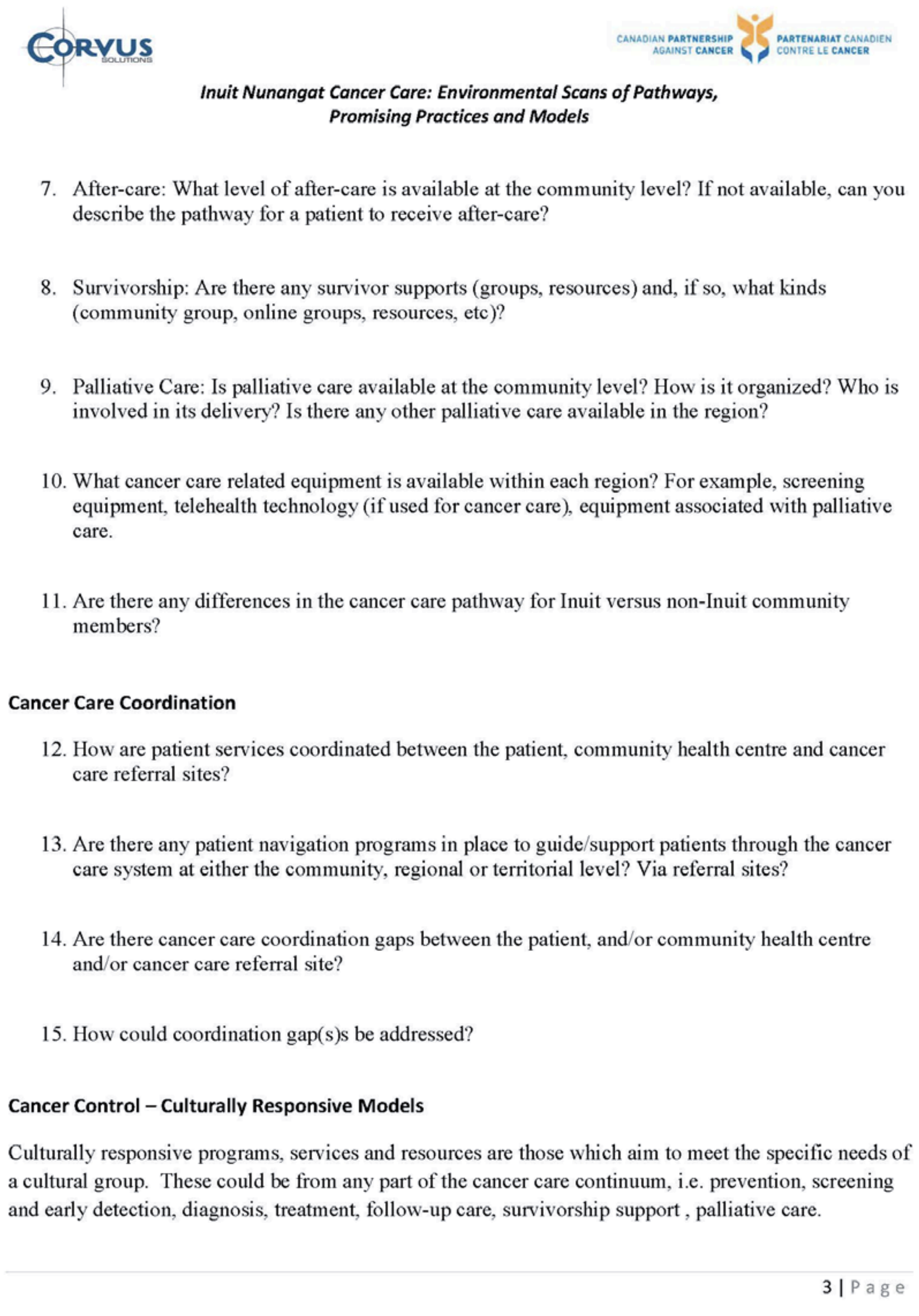
Using the diagram above, the next set of questions will explore services and programs available for each aspect of the cancer care continuum.

3. Prevention: can you describe what cancer-related prevention/promotion programs or services are offered and/or available at the community level? Who produces them? Are any specifically targeted to Inuit?

4. Screening/Early Detection: What kinds of screening are offered at the community level? Are these part of territorial programs? Is additional screening offered for high risk groups and if so, where available? What is the process (i.e. consultation or referral) for moving from suspicion to testing/diagnosis?

5. Diagnosis: Can you describe a typical pathway for a patient to undergo diagnostic tests and receive a diagnosis of cancer?

6. Treatment: Can you describe the pathway for a patient to be sent for treatment?



7. After-care: What level of after-care is available at the community level? If not available, can you describe the pathway for a patient to receive after-care?

8. Survivorship: Are there any survivor supports (groups, resources) and, if so, what kinds (community group, online groups, resources, etc)?

9. Palliative Care: Is palliative care available at the community level? How is it organized? Who is involved in its delivery? Is there any other palliative care available in the region?

10. What cancer care related equipment is available within each region? For example, screening equipment, telehealth technology (if used for cancer care), equipment associated with palliative care.

11. Are there any differences in the cancer care pathway for Inuit versus non-Inuit community members?

Cancer Care Coordination

12. How are patient services coordinated between the patient, community health centre and cancer care referral sites?

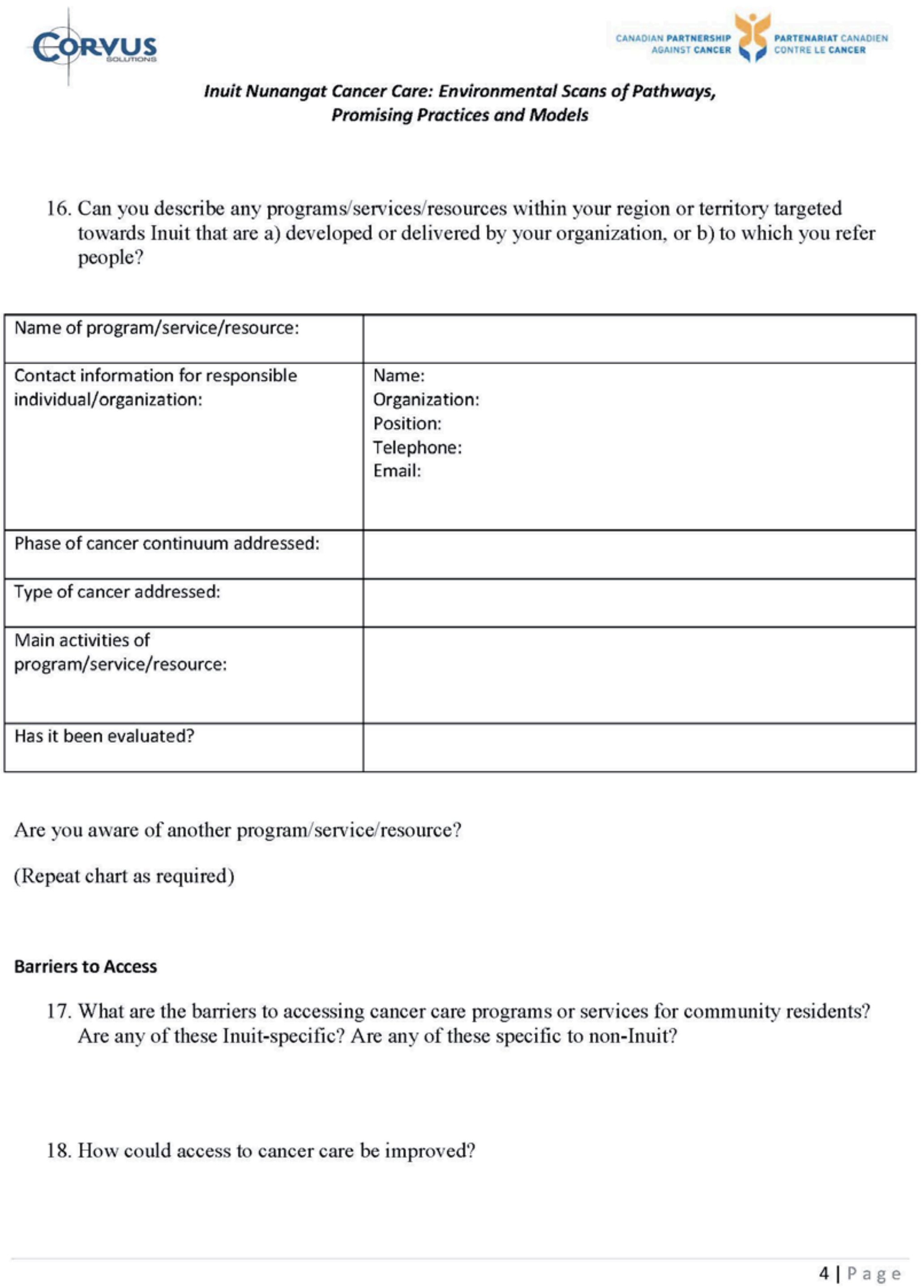
13. Are there any patient navigation programs in place to guide/support patients through the cancer care system at either the community, regional or territorial level? Via referral sites?

14. Are there cancer care coordination gaps between the patient, and/or community health centre and/or cancer care referral site?

15. How could coordination gap(s)s be addressed?

Cancer Control – Culturally Responsive Models

Culturally responsive programs, services and resources are those which aim to meet the specific needs of a cultural group. These could be from any part of the cancer care continuum, i.e. prevention, screening and early detection, diagnosis, treatment, follow-up care, survivorship support , palliative care.



16. Can you describe any programs/services/resources within your region or territory targeted towards Inuit that are a) developed or delivered by your organization, or b) to which you refer people?

Name of program/service/resource:	
Contact information for responsible individual/organization:	Name: Organization: Position: Telephone: Email:
Phase of cancer continuum addressed:	
Type of cancer addressed:	
Main activities of program/service/resource:	
Has it been evaluated?	

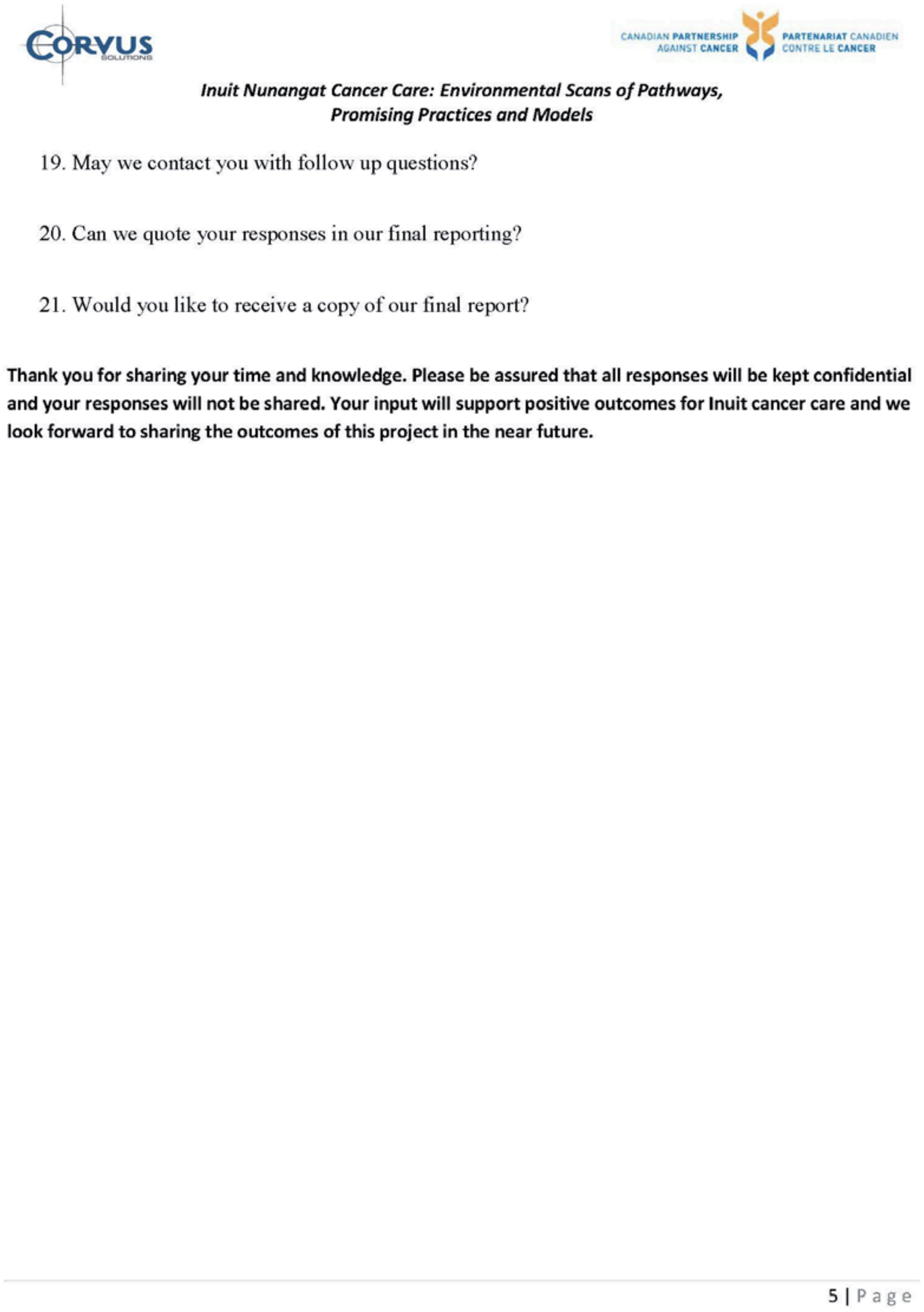
Are you aware of another program/service/resource?

(Repeat chart as required)

Barriers to Access

17. What are the barriers to accessing cancer care programs or services for community residents? Are any of these Inuit-specific? Are any of these specific to non-Inuit?

18. How could access to cancer care be improved?



Inuit Nunangat Cancer Care: Environmental Scans of Pathways, Promising Practices and Models

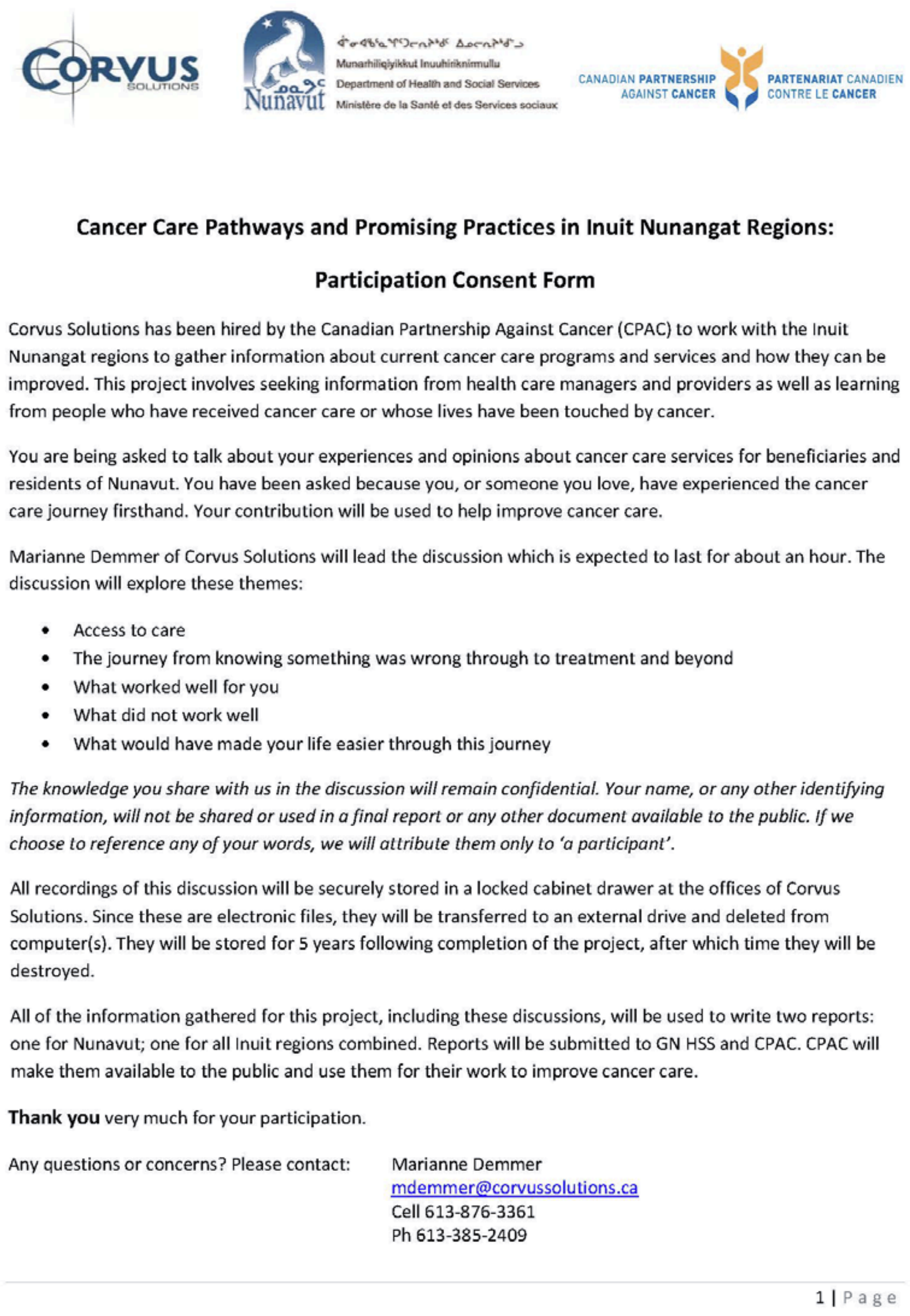
19. May we contact you with follow up questions?

20. Can we quote your responses in our final reporting?

21. Would you like to receive a copy of our final report?

Thank you for sharing your time and knowledge. Please be assured that all responses will be kept confidential and your responses will not be shared. Your input will support positive outcomes for Inuit cancer care and we look forward to sharing the outcomes of this project in the near future.

SURVIVOR AND CARE GIVER CONSENT FORM (SAMPLE)



Cancer Care Pathways and Promising Practices in Inuit Nunangat Regions:

Participation Consent Form

Corvus Solutions has been hired by the Canadian Partnership Against Cancer (CPAC) to work with the Inuit Nunangat regions to gather information about current cancer care programs and services and how they can be improved. This project involves seeking information from health care managers and providers as well as learning from people who have received cancer care or whose lives have been touched by cancer.

You are being asked to talk about your experiences and opinions about cancer care services for beneficiaries and residents of Nunavut. You have been asked because you, or someone you love, have experienced the cancer care journey firsthand. Your contribution will be used to help improve cancer care.

Marianne Demmer of Corvus Solutions will lead the discussion which is expected to last for about an hour. The discussion will explore these themes:

- Access to care
- The journey from knowing something was wrong through to treatment and beyond
- What worked well for you
- What did not work well
- What would have made your life easier through this journey

The knowledge you share with us in the discussion will remain confidential. Your name, or any other identifying information, will not be shared or used in a final report or any other document available to the public. If we choose to reference any of your words, we will attribute them only to 'a participant'.

All recordings of this discussion will be securely stored in a locked cabinet drawer at the offices of Corvus Solutions. Since these are electronic files, they will be transferred to an external drive and deleted from computer(s). They will be stored for 5 years following completion of the project, after which time they will be destroyed.

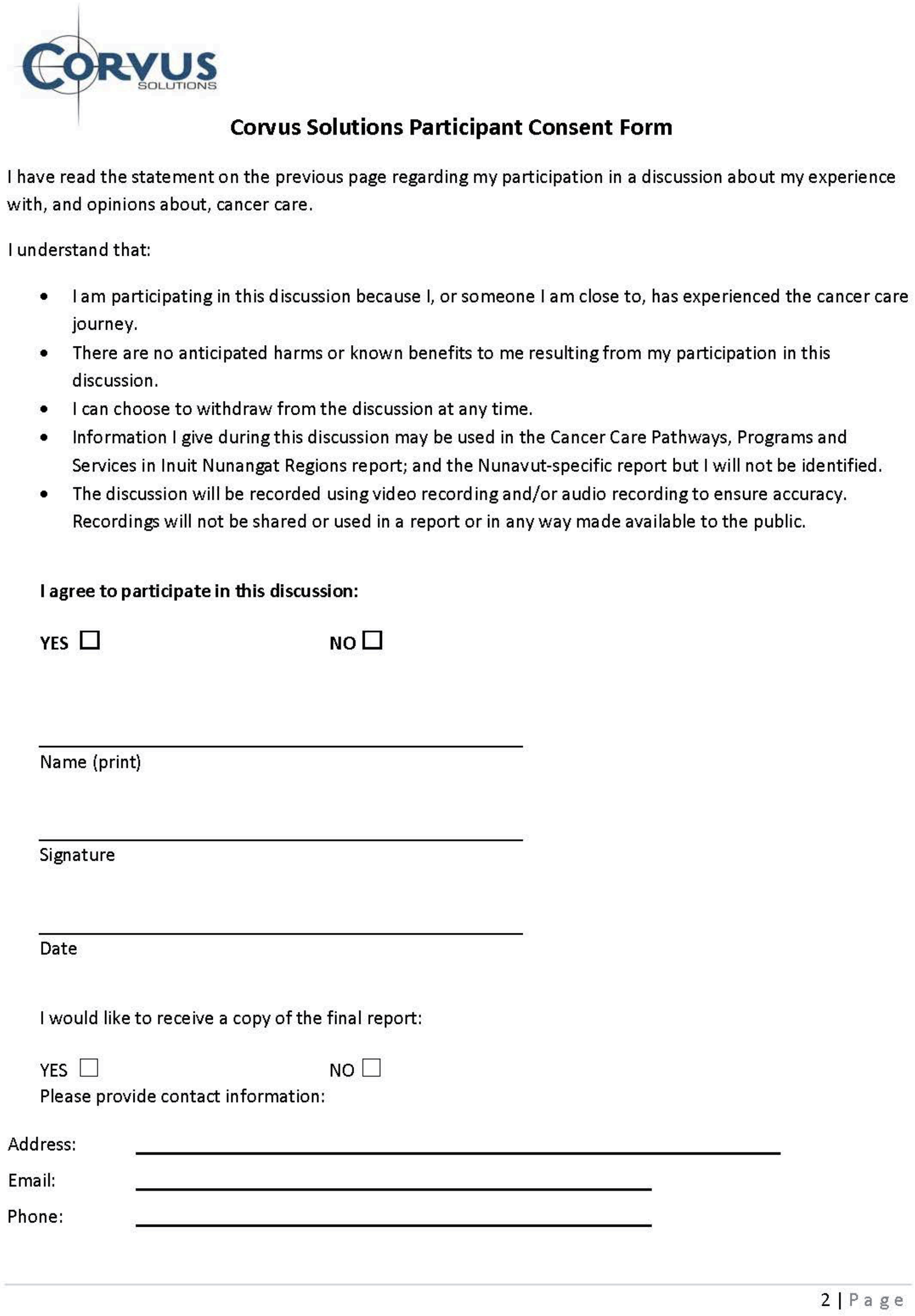
All of the information gathered for this project, including these discussions, will be used to write two reports: one for Nunavut; one for all Inuit regions combined. Reports will be submitted to GN HSS and CPAC. CPAC will make them available to the public and use them for their work to improve cancer care.

Thank you very much for your participation.

Any questions or concerns? Please contact:

Marianne Demmer
mdemmer@corvussolutions.ca
Cell 613-876-3361
Ph 613-385-2409

1 | Page



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Corvus Solutions Participant Consent Form

I have read the statement on the previous page regarding my participation in a discussion about my experience with, and opinions about, cancer care.

I understand that:

- I am participating in this discussion because I, or someone I am close to, has experienced the cancer care journey.
- There are no anticipated harms or known benefits to me resulting from my participation in this discussion.
- I can choose to withdraw from the discussion at any time.
- Information I give during this discussion may be used in the Cancer Care Pathways, Programs and Services in Inuit Nunangat Regions report; and the Nunavut-specific report but I will not be identified.
- The discussion will be recorded using video recording and/or audio recording to ensure accuracy. Recordings will not be shared or used in a report or in any way made available to the public.

I agree to participate in this discussion:

YES ☐ **NO** ☐

____
Name (print)

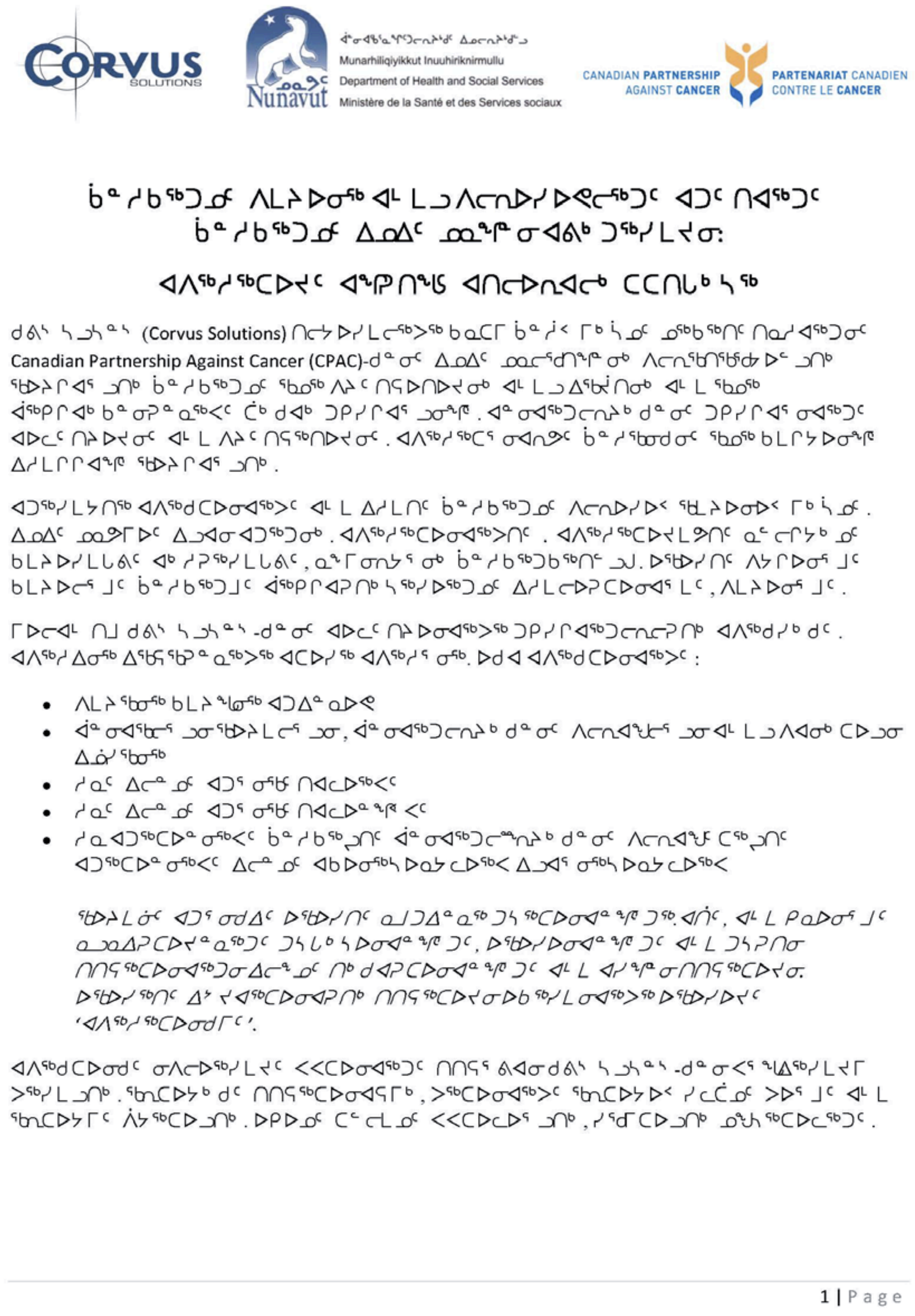
____
Signature

____
Date

I would like to receive a copy of the final report:

YES ☐ NO ☐
Please provide contact information:

Address: ____
Email: ____
Phone: ____



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Department of Health and Social Services
Ministère de la Santé et des Services sociaux

CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

ᑳᓐᓱᑲᖅᑐᓄᑦ ᐱᒪᔨᐅᓂᖅ ᐊᒻᒪᓗ ᐱᓕᕆᐅᓯᐅᕙᓕᖅᑐᑦ ᐊᑐᑦ ᑎᐊᖅᑐᑦ ᑳᓐᓱᑲᖅᑐᓄᑦ ᐃᓄᐃᑦ ᓄᓇᖏᓂᐊᕕᒃ ᑐᖅᓯᒪᔪᓂ:

ᐊᐱᖅᓱᖅᑕᐅᔪᑦ ᐊᖕᑭᑎᖓ ᐊᑎᓕᐅᕆᐊᓕᒃ ᑕᑕᑎᒐᒃᓴᖅ

ᑯᕙᔅ ᓴᓗᓴᓐᔅ (Corvus Solutions) ᑎᓕᔭᐅᓯᒪᓕᖅᐳᖅ ᑲᓇᑕᒥ ᑳᓐᓲᑉ ᒥᒃᓵᓄᑦ ᓄᖅᑲᖅᑎᑦ ᑎᓇᓱᐊᖅᑐᓂᑦ Canadian Partnership Against Cancer (CPAC)-ᑯᓐᓂᑦ ᐃᓄᐃᑦ ᓄᓇᓕᖅᑯᑎᖏᓂᒃ ᐱᓕᕆᖃᑎᖃᕐᑐᐅᓪᓗᑎᒃ ᖃᐅᔨᒋᐊᕐᓗᑎᒃ ᑳᓐᓱᑲᖅᑐᓄᑦ ᖃᓄᖅ ᐱᔨᑦᑎᕋᐅᑎᐅᔪᓂᒃ ᐊᒻᒪᓗ ᐃᖃᔫᑎᓂᒃ ᐊᒻᒪ ᖃᓄᖅ ᐋᖅᑭᒋᐊᒃ ᑲᓐᓂᕈᓐᓇᖅᐸᑦ ᑖᒃᑯᐊᒃ ᑐᑭᓯᒋᐊᕐᓗᓂᖏ. ᐊᓐᓂᐊᖅᑐᓕᕆᔨᒃᑯᓐᓂᑦ ᑐᑭᓯᒋᐊᕐᓂᐊᖅᑐᑦ ᐊᐅᓚᑦᑎᔨᐅᔪᓂᑦ ᐊᒻᒪ ᐱᔨᑦᑎᕋᖅᑎᐅᔪᓂᑦ. ᐊᐱᖅᓱᖅᑕᕐᓂᐊᕆᕗᑦ ᑳᓐᓱᖃᓂᑯᓂᑦ ᖃᓄᖅ ᑲᒪᒋᔭᐅᓂᖏ ᐃᓱᒪᒋᒋᐊᖏ ᖃᐅᔨᒋᐊᕐᓗᑎᒃ.

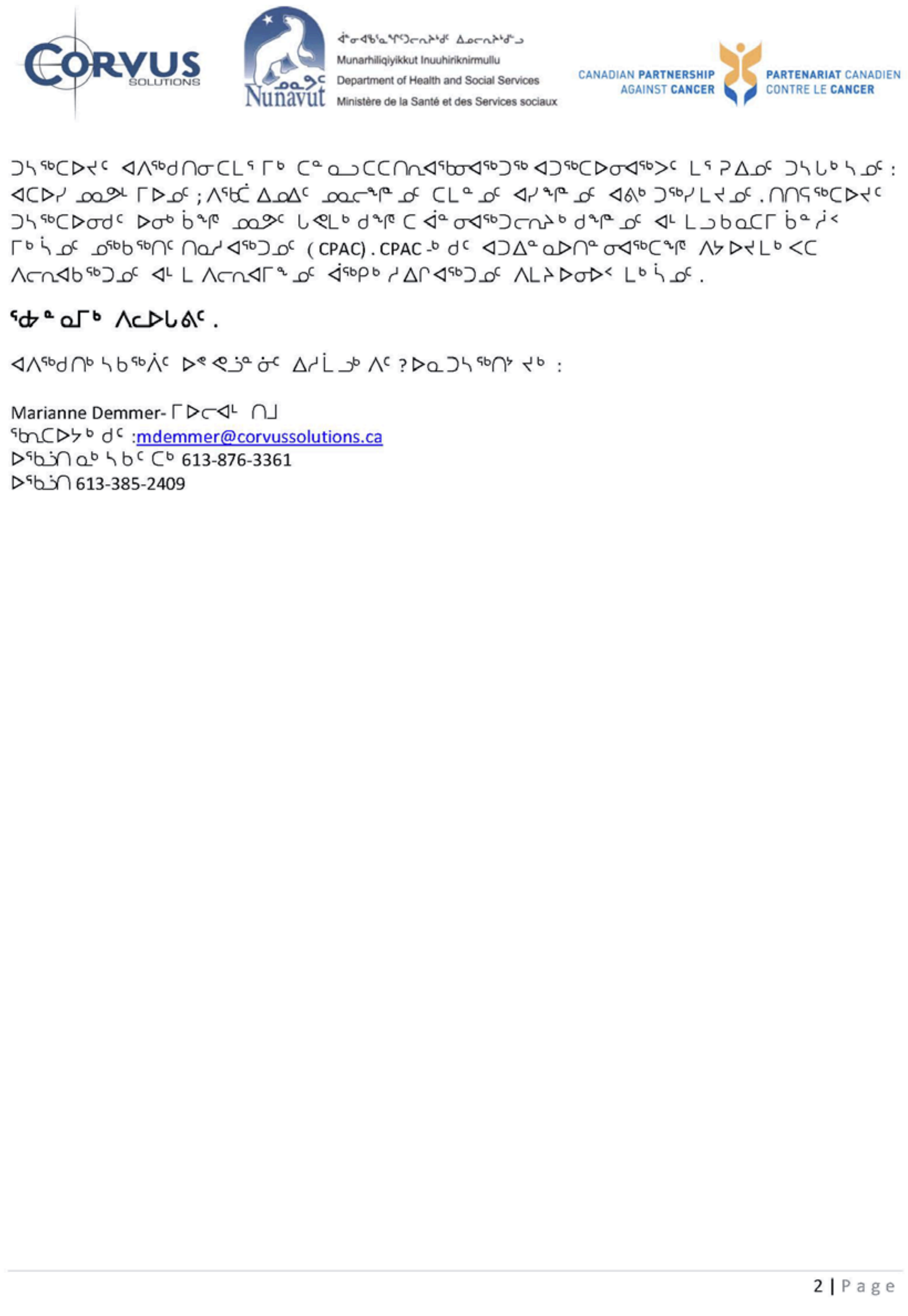
ᐊᑐᖅᓱᒪᔭᑎᖅ ᐊᐱᖅᑯᑕᐅᓂᐊᖅᐳᑦ ᐊᒻᒪ ᐃᓱᒪᑎᑦ ᑳᓐᓱᑲᖅᑐᓄᑦ ᐱᓕᕆᐅᓯᐅᑉ ᖃᓪᓚᐅᓂᐅᑉ ᒥᒃᓵᓄᑦ. ᐃᓄᐃᑦ ᓄᓇᒍᒥᐅᑦ ᐃᓗᐊᓂ ᐊᑐᖅᑐᓂᒃ. ᐊᐱᖅᓱᖅᑕᐅᓂᐊᖅᐳᑎᑦ . ᐊᐱᖅᓱᖅᑕᐅᔪᒪᒍᑎᑦ ᓇᓪᓚᒋᔭᒃᓄᑦ ᑲᒪᔨᐅᓯᒪᒍᕕᑦ ᐊᒃ ᓱᕈᖅᓯᒪᒍᕕᑦ, ᓇᖕᒥᓂᕆᔭᕐᓂᒃ ᑳᓐᓱᑲᖅᑐᑲᖅᑎᓪᓗᒍ. ᐅᖃᐅᓯᑎᑦ ᐱᔭᕆᐅᓂᕐᒧᑦ ᑲᒪᔨᐅᓕᕐᒧᑦ ᑳᓐᓱᑲᖅᑐᒧᑦ ᐋᖅᑭᒋᐊᕈᑎᒃ ᓴᖅᓯᐅᖅᑐᓄᑦ ᐃᓱᒪᓕᐅᕈᑕᐅᓂᐊᕐᒪᑦ, ᐱᒪᔨᐅᓂᕐᒧᑦ.

ᒥᐅᓕᐊᒻ ᑎᒧ ᑯᕙᔅ ᓴᓗᓴᓐᔅ-ᑯᓐᓂᑦ ᐊᐅᓚᑦᑎᔨᐅᓂᐊᖅᐳᖅ ᑐᑭᓯᒋᐊᖅᑐᓕᕆᓕᕈᑎᒃ ᐊᐱᖅᑯᓯᒃᑯᑦ. ᐊᐱᖅᓱᐃᓂᖅ ᐃᑲᕐᕋᕈᓐᓇᖅᐳᖅ ᐊᑕᐅᓯᖅ ᐊᐱᖅᓱᕐᓂᖅ. ᐅᑯᐊ ᐊᐱᖅᑯᑕᐅᓂᐊᖅᐳᑦ:

- ᐱᒪᔨᖃᓂᖅ ᑲᒪᔨᖑᓂᖅ ᐊᑐᐃᓐᓇᐅᕙ
- ᐋᓐᓂᐊᖃᓕᕐᓗᓂ ᖃᐅᔨᒪᓕᕐᓗᓂ, ᐋᓐᓂᐊᖅᑐᓕᕆᔨᒃᑯᓐᓂᑦ ᐱᓕᕆᐊᖑᕐᓗᓂ ᐊᒻᒪᓗ ᐱᐊᓂᒃ ᑕᐅᓗᓂ ᐃᓅᓯᖃᓂᖅ
- ᓱᓇᑦ ᐃᓕᓐᓄᑦ ᐊᑐᕐᓂᖁ ᑎᐊᓚᐅᖅᐸᑦ
- ᓱᓇᑦ ᐃᓕᓐᓄᑦ ᐊᑐᕐᓂᖁ ᑎᐊᓚᐅᓐᖏᐸᑦ
- ᓱᓇ ᐊᑐᖅᑕᐅᓐᓂᖅᐸᑦ ᑳᓐᓱᑲᖅᓗᑎᑦ ᐋᓐᓂᐊᖅᑐᓕᕆᔨᒃᑯᓐᓂᑦ ᐱᓕᕆᐊᖑᕗᑕᖅᓗᑎᑦ ᐊᑐᖅᑕᐅᓐᓂᖅᐸᑦ ᐃᓕᓐᓄᑦ ᐊᑲᐅᓂᖅᓴᐅᓇᔭᓚᐅᖅᐸ ᐃᓗᐊᕐᓂᖅᓴᐅᓇᔭᓚᐅᖅᐸ

> *ᖃᐅᔨᒪᓃᑦ ᐊᑐᕐᓂᑯᐃᑦ ᐅᖃᐅᓯᑎᑦ ᓇᒧᑐᐃᓐᓇᖅ ᑐᓴᖅᑕᐅᓂᐊᓐᖏᑦᑐᖅ. ᐊᑏᑦ, ᐊᒻᒪ ᑭᓇᐅᓂᕐᒧᑦ ᓇᓗᓇᐃᕈᑕᐅᔪᓐᓇᖅᑐᑦ ᑐᓴᒐᒃᓴᐅᓂᐊᓐᖏᑦᑐᑦ, ᐅᖃᐅᓯᐅᓂᐊᓐᖏᑦᑐᑦ ᐊᒻᒪ ᑐᓴᕈᑎᓂ ᑎᑎᕋᖅᑕᐅᓂᐊᖅᑐᓂ ᐃᓕᖕᓄᑦ ᑎᒃᑯᐊᕈᑕᐅᓂᐊᓐᖏᑦᑐᑦ ᐊᒻᒪ ᐊᓯᖏᓂ ᑎᑎᕋᖅᑕᐅᔪᓂ. ᐅᖃᐅᓯᖅᑎᑦ ᐃᔾᔪᐊᖅᑕᐅᓂᐊᕈᑎᒃ ᑎᑎᕋᖅᑕᐅᔪᓂ ᐅᑲᖅᓯᒪᓂᐊᖅᐳᖅ ᐅᖃᐅᓯᐅᔪᑦ 'ᐊᐱᖅᓱᖅᑕᐅᓂᑯᒥᑦ'.*

ᐊᐱᖅᑯᑕᐅᓂᑯᑦ ᓂᐱᓕᐅᖅᓯᒪᔪᑦ ᐸᐸᑕᐅᓂᐊᖅᑐᑦ ᑎᑎᕋᕐᕕᐊᓂ ᑯᕙᔅ ᓴᓗᓴᓐᔅ-ᑯᓐᓂᐸᕐᖕᐃᖅᓯᒪᔪᒥ ᐳᖅᓯᒪᓗᑎᒃ. ᖃᕆᑕᐅᔭᒃᑯᑦ ᑎᑎᕋᖅᑕᐅᓂᐊᕋᒥᒃ, ᐳᖅᑕᐅᓂᐊᖅᐳᑦ ᖃᕆᑕᐅᔭᐅᑉ ᓯᓚᑖᓄᑦ ᐳᐅᕐᒧᑦ ᐊᒻᒪ ᖃᕆᑕᐅᔭᒥᑦ ᐲᔭᖅᑕᐅᓗᑎᒃ. ᐅᑭᐅᓄᑦ ᑕᓪᓕᒪᓄᑦ ᐸᐸᑕᐅᓚᐅᕐᓗᑎᒃ, ᓱᕐᕈᑕᐅᓗᑎᒃ ᓄᖑᓴᖅᑕᐅᓚᖅᑐᑦ.



CORVUS SOLUTIONS

ᐋᓐᓂᐊᖃᕐᓇᙱᑦᑐᓕᕆᔨᒃᑯᑦ ᐃᓄᓕᕆᔨᒃᑯᓪᓗ
Munarhiliqiyikkut Inuuhiriknirmullu
Department of Health and Social Services
Ministère de la Santé et des Services sociaux

CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

ᑐᓴᖅᑕᐅᔪᑦ ᐊᐱᖅᑯᑎᓂᑕᒪᕐ ᒥᒃ ᑕᓐ ᓇᓗᑕᑕᑎᓐᐊᖅᑲᓂᐊᖅᑐᖅ ᐊᑐᖅᑕᐅᓂᐊᖅᐳᑦ ᒪᕐ ᕈᐃᓄᑦ ᑐᓴᒐᒃ ᓴᓄᑦ : ᐊᑕᐅᓯ ᓄᓇᕗᒻ ᒥᐅᓄᑦ ; ᐱᖃᑖ ᐃᓄᐃᑦ ᓄᓇᓕᖕᒥ ᓄᑦ ᑕᒪᓐ ᓄᑦ ᐊᓯᖕᒥ ᓄᑦ ᐊᕕᒃ ᑐᖅᓯᒪᔪᓄᑦ . ᑎᑎᕋᖅᑕᐅᔪᑦ ᑐᓴᖅᑕᐅᓂᑯᑦ ᐅᓂᒃ ᑳᖕᒥ ᓄᓇᕗᑦ ᒐᕙᒪᒃ ᑯᖕᒥ ᑕ ᐋᓐ ᓂᐊᖅᑐᓕᕆᔨᒃ ᑯᖕᒥ ᓄᑦ ᐊᒻ ᒪᓗ ᑲᓇᑕᒥ ᑳᓐ ᓲᕐ ᒥᒃ ᓵ ᓄᑦ ᓄᖅᑲᖅᑎᑦ ᑎᓇᓯᐊᖅᑐᓄᑦ (CPAC) . CPAC -ᒃ ᑯᑦ ᐊᑐᐃᓐ ᓇᐅᑎᓐ ᓂᐊᖅᑕᖕᒥ ᐱᔭᐅᔪᒪᒃ ᐸᑕ ᐱᑕᕐᓇᐊᑲᖅᑐᓄᑦ ᐊᒻ ᒪ ᐱᑕᕐᓇᐊᒥᖕ ᓄᑦ ᐋᖅᑭᒃ ᓱᐃᓕᐊᖅᑐᓄᑦ ᐱᒪᔾᐅᓂᐅᑉ ᒪᒃ ᓵ ᓄᑦ .

ᖁᓐ ᓇᒥᒃ ᐱᓚᐅᒐᕕᑦ .

ᐊᐱᖅᑯᑎᒃ ᓴᑲᖅᐲᑦ ᐅᕝ ᕙᓘᓐ ᓅᑦ ᐃᓯᒫᓗᒃ ᐱᑦ ? ᐅᓇᑐᓴᖅᑎᔾ ᔪᒃ :

Marianne Demmer- ᒥᐅᓕᐊᒻ ᑎᒍ
ᖃᕆᑕᐅᔭᒃ ᑯᑦ :mdemmer@corvussolutions.ca
ᐅᖃᓘᑎ ᓇᒃ ᓴᑦ ᑕᒃ 613-876-3361
ᐅᖃᓘᑎ 613-385-2409

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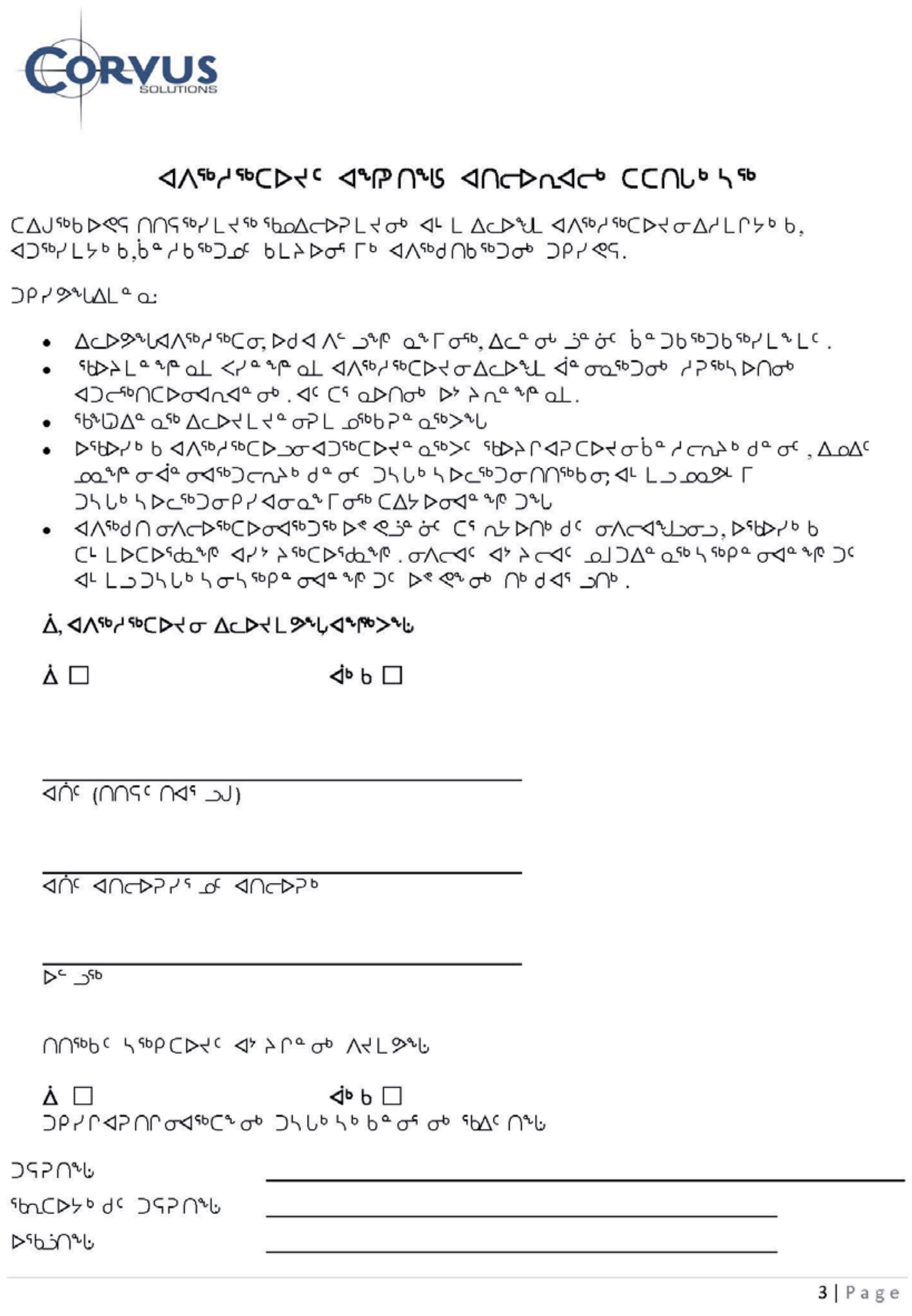

ᐊᐱᖅᓱᖅᑕᐅᔪᑦ ᐊᖏᕈᑎᖓ ᐊᑎᓕᐅᕆᐊᓕᒃ ᑕᑕᑎᒐᒃᓴᖅ

ᑕᐃᒍᖅᑲ ᐅᕙᖓ ᑎᑎᕋᖅᓯᒪᔪᖅ ᖃᓄᐃᓕᐅᕈᒪᔪᓂᒃ ᐊᒻᒪ ᐃᓚᐅᖕᒪ ᐊᐱᖅᓱᖅᑕᐅᔪᓂᐃᓱᒪᒋᔭᒃ ᑲ, ᐊᑐᖅᓯᒪᔭᒃ ᑲ,ᑳᓐᓱᑲᖅᑐᓄᑦ ᑲᒪᔩᐅᓂᕐ ᒥᒃ ᐊᐱᖅᑯᑎᑲᖅᑐᓂᒃ ᑐᑭᓯᕙ.

ᑐᑭᓯᕗᖓᐃᒪᓐᓇ:

- ᐃᓚᐅᕗᖓᐊᐱᖅᓱᖅᑕᓂ, ᐅᑯᐊ ᐱᑦ ᓗᖏ ᓇᖕᒥᓂᖅ, ᐃᓚᓐ ᓂᒃ ᓘᓐ ᓃᑦ ᑳᓐᑐᑲᖅᑐᑲᖅᓯᒪᖕᒪᑦ.
- ᖃᐅᔨᒪᓐᖏᓇᒪ ᐸᓯᓐᖏᓇᒪ ᐊᐱᖅᓱᖅᑕᐅᔪᓂᐃᓚᐅᖕᒪ ᐋᓐ ᓂᓇᖅᑐᓂᒃ ᓱᕈᖅᓴᐅᑎᓂᒃ ᐊᑐᓕᖅᑎᑕᐅᓂᐊᕆᐊᓐ ᓂᒃ. ᐊᑦ ᑕᕐ ᓇᐅᑎᓂᒃ ᐅᔾ ᔨᕆᓐ ᖏᓇᒪ.
- ᖃᖑᐃᓐ ᓇᖅ ᐃᓚᐅᔪᒪᔪᓐ ᓂᕈᒪ ᓄᖅᑲᕈᓐ ᓇᖅᐳᖓ
- ᐅᖃᐅᓯᒃ ᑲ ᐊᐱᖅᓱᖅᑕᐅᓗᓂᐊᑐᖅᑕᐅᔪᓐ ᓇᖅᐳᑦ ᖃᐅᔨᒋᐊᕈᑕᐅᔪᓂᑳᓐ ᓱᓕᕆᔪᒃ ᑯᓐ ᓂᑦ, ᐃᓄᐃᑦ ᓄᓇᖏ ᓂᐋᓐ ᓂᐊᖅᑐᓕᕆᔪᒃ ᑯᓐ ᓂᑦ ᑐᓴᒐᒃ ᓴᐅᓚᖅᑐᓂᑎᑎᖅᑲᓂ; ᐊᒻ ᒪᓗ ᓄᓇᕗᒻ ᒥ ᑐᓴᒐᒃ ᓴᐅᓚᖅᑐᓂᑭᓯᐊᓂᓇᖕᒥᓂᖅ ᑕᐃᔭ ᐅᓂᐊᓐ ᖏᑐᖓ
- ᐊᐱᖅᑯᑎ ᓂᐱᓕᐅᖅᑕᐅᓂᐊᖅᑐᖅ ᐅᕝ ᕙᓘᓐ ᓃᑦ ᑕᕐ ᕆᔭᐅᑎᒃ ᑯᑦ ᓂᐱᓕᐊᖑᓗᓂᓗ, ᐅᖃᐅᓯᒃ ᑲ ᑕᒻ ᒪᐅᑕᐅᖁᓇᖏ ᐊᓯᔾ ᔨᖅᑕᐅᖁᓇᖏ. ᓂᐱᓕᐊᑦ ᐊᔾ ᔨᓕᐊᑦ ᓄᒧᑐᐃᓐ ᓇᖅ ᓴᖅᑭᓐ ᓂᐊᓐ ᖏᑐᑦ ᐊᒻ ᒪᓗᑐᓴᒐᒃ ᓴᓂᓴᖅᑭᓐ ᓂᐊᓐ ᖏᑐᑦ ᐅᕝ ᕙᖕᓂᒃ ᑎᒃ ᑯᐊᕐ ᓗᑎᒃ.

ᐄ, ᐊᐱᖅᓱᖅᑕᐅᔪᓂ ᐃᓚᐅᔪᒪᕗᖓᐊᖏᖅᐳᖓ

ᐄ ☐ ᐋᒃᑲ ☐

____

ᐊᑏᑦ (ᑎᑎᕋᑦ ᑎᐊᕐ ᓗᒍ)

____

ᐊᑏᑦ ᐊᑎᓕᐅᕈᓯᕐ ᓄᑦ ᐊᑎᓕᐅᕈᒃ

____

ᐅᑦ ᓗᖅ

ᑎᑎᖅᑲᑦ ᓴᖅᑭᑕᐅᔪᑦ ᐊᔾ ᔨᒋᓐ ᓂᒃ ᐱᔪᒪᕗᖓ

ᐄ ☐ ᐋᒃᑲ ☐

ᑐᑭᓯᒋᐊᕈᑎᒋᓂᐊᖅᑕᖓᓂᒃ ᑐᓴᒐᒃ ᓴᒃ ᑲᓐᓂᕐ ᓂᒃ ᖃᐃᑦ ᑎᖓ

ᑐᕋᕈᑎᖓ ____

ᖃᕆᑕᐅᔭᒃ ᑯᑦ ᑐᕋᕈᑎᖓ __________________________________

ᐅᖃᓘᑎᖓ __________________________________

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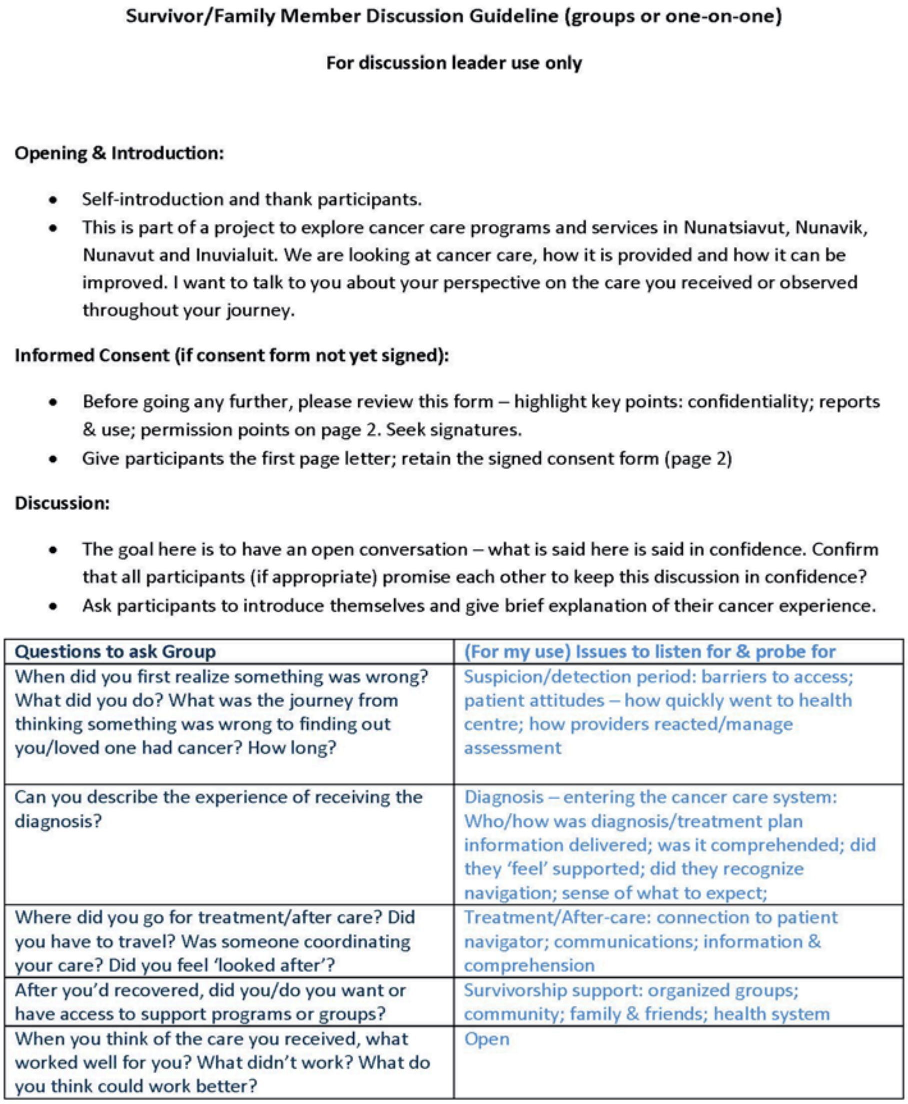
SURVIVOR AND CAREGIVER INTERVIEW GUIDE



Survivor/Family Member Discussion Guideline (groups or one-on-one)

For discussion leader use only

Opening & Introduction:

- Self-introduction and thank participants.
- This is part of a project to explore cancer care programs and services in Nunatsiavut, Nunavik, Nunavut and Inuvialuit. We are looking at cancer care, how it is provided and how it can be improved. I want to talk to you about your perspective on the care you received or observed throughout your journey.

Informed Consent (if consent form not yet signed):

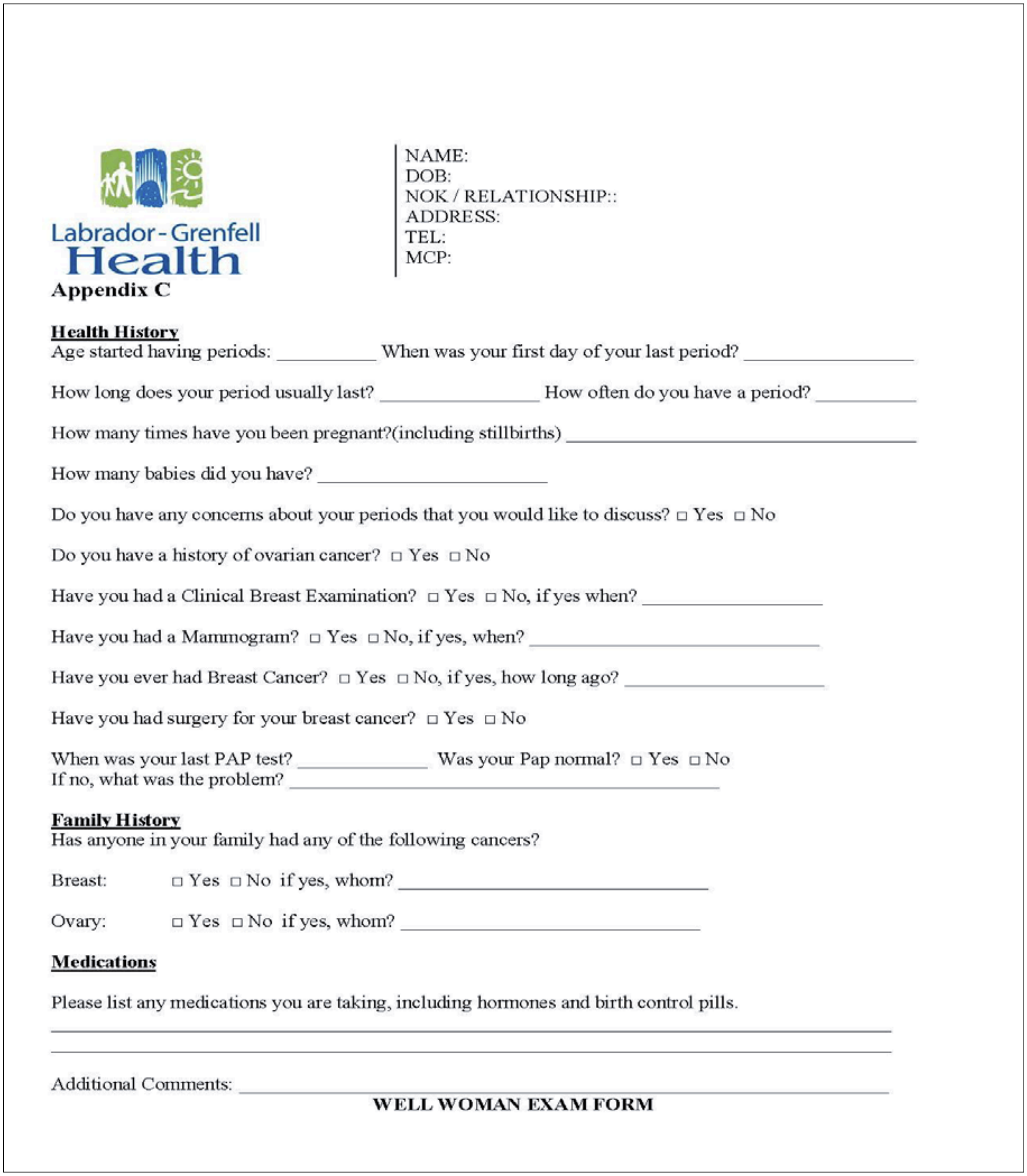
- Before going any further, please review this form – highlight key points: confidentiality; reports & use; permission points on page 2. Seek signatures.
- Give participants the first page letter; retain the signed consent form (page 2)

Discussion:

- The goal here is to have an open conversation – what is said here is said in confidence. Confirm that all participants (if appropriate) promise each other to keep this discussion in confidence?
- Ask participants to introduce themselves and give brief explanation of their cancer experience.

Questions to ask Group	**(For my use) Issues to listen for & probe for**
When did you first realize something was wrong? What did you do? What was the journey from thinking something was wrong to finding out you/loved one had cancer? How long?	Suspicion/detection period: barriers to access; patient attitudes – how quickly went to health centre; how providers reacted/manage assessment
Can you describe the experience of receiving the diagnosis?	Diagnosis – entering the cancer care system: Who/how was diagnosis/treatment plan information delivered; was it comprehended; did they 'feel' supported; did they recognize navigation; sense of what to expect;
Where did you go for treatment/after care? Did you have to travel? Was someone coordinating your care? Did you feel 'looked after'?	Treatment/After-care: connection to patient navigator; communications; information & comprehension
After you'd recovered, did you/do you want or have access to support programs or groups?	Survivorship support: organized groups; community; family & friends; health system
When you think of the care you received, what worked well for you? What didn't work? What do you think could work better?	Open

WELL WOMAN CHECKLIST (SAMPLE)



Labrador-Grenfell
Health

Appendix C

NAME:
DOB:
NOK / RELATIONSHIP::
ADDRESS:
TEL:
MCP:

Health History

Age started having periods: __________ When was your first day of your last period? __________________

How long does your period usually last? ________________ How often do you have a period? __________

How many times have you been pregnant?(including stillbirths) ___________________________________

How many babies did you have? _______________________

Do you have any concerns about your periods that you would like to discuss? ☐ Yes ☐ No

Do you have a history of ovarian cancer? ☐ Yes ☐ No

Have you had a Clinical Breast Examination? ☐ Yes ☐ No, if yes when? __________________

Have you had a Mammogram? ☐ Yes ☐ No, if yes, when? ______________________________

Have you ever had Breast Cancer? ☐ Yes ☐ No, if yes, how long ago? ____________________

Have you had surgery for your breast cancer? ☐ Yes ☐ No

When was your last PAP test? _____________ Was your Pap normal? ☐ Yes ☐ No
If no, what was the problem? ____

Family History

Has anyone in your family had any of the following cancers?

Breast: ☐ Yes ☐ No if yes, whom? _______________________________

Ovary: ☐ Yes ☐ No if yes, whom? ______________________________

Medications

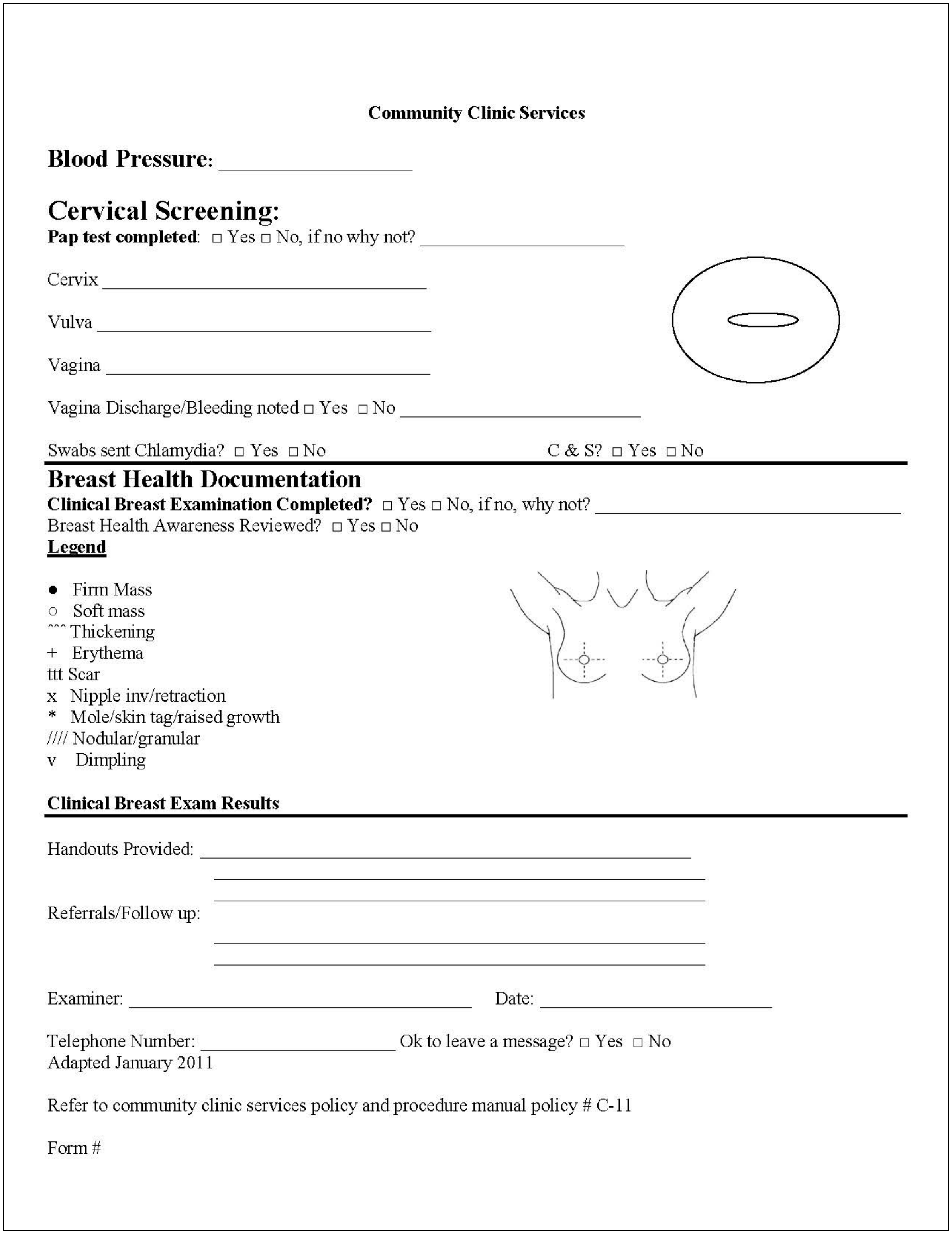
Please list any medications you are taking, including hormones and birth control pills.

____

____

Additional Comments: ____

WELL WOMAN EXAM FORM



Community Clinic Services

Blood Pressure: ____________________

Cervical Screening:

Pap test completed: ☐ Yes ☐ No, if no why not? _____________________

Cervix _________________________________

Vulva _________________________________

Vagina _________________________________

Vagina Discharge/Bleeding noted ☐ Yes ☐ No _________________________

Swabs sent Chlamydia? ☐ Yes ☐ No

C & S? ☐ Yes ☐ No

Breast Health Documentation

Clinical Breast Examination Completed? ☐ Yes ☐ No, if no, why not? ________________________________

Breast Health Awareness Reviewed? ☐ Yes ☐ No

Legend

- ● Firm Mass
- ○ Soft mass
- ^^^ Thickening
- \+ Erythema
- ttt Scar
- x Nipple inv/retraction
- * Mole/skin tag/raised growth
- //// Nodular/granular
- v Dimpling

Clinical Breast Exam Results

Handouts Provided: ____

Referrals/Follow up: ____

Examiner: ________________________________ Date: _________________________

Telephone Number: _____________________ Ok to leave a message? ☐ Yes ☐ No

Adapted January 2011

Refer to community clinic services policy and procedure manual policy # C-11

Form #