Courage, Compassion and Connection, and the Journey to Healing: Exploring Cancer Pre-Diagnosis for Nunatsiavut Inuit

By

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ABSTRACT

Cancer is a chronic disease that has become increasingly prevalent in Indigenous populations within recent decades in Canada. Many risk factors contribute to the high rates of cancer for Indigenous peoples. Indigenous peoples have endured a history of colonialism, loss of culture, and dispossession of land. Indigenous peoples in the country present with later-stage cancers. This project was led by the Nunatsiavut Government in collaboration with the other Indigenous governments and organizations in Labrador: NunatuKavut Community Council, Mushuau Innu First Nation, and Sheshatshiu Innu First Nation, and explored the journey one must undergo to be diagnosed with cancer in Labrador, called the pre-diagnosis journey. Culturally safe approaches to data collection were used. We adopted a decolonizing approach with qualitative methods. This thesis will focus on findings from Nunatsiavut communities. Sharing circles and interviews were conducted with n= 32 participants. Thematic coding resulted in six themes: 1) Access and Supports; 2) Prolonged Investigation; 3) Travel; 4) Communication; 5) Fear and Anxiety; and 6) Being your own Health Advocate. Patients discussed challenges they encountered during their pre-diagnosis journey, and ways to improve their experience. There is a need for cultural-safety training for healthcare workers, a local cancer support group, accessible mental health services and educational materials about cancer. This thesis can be used to inform policy recommendations to enhance healthcare, and increase awareness of useful resources that can improve the pre-diagnosis journey.

GENERAL SUMMARY

The majority of Inuit in Canada live in Inuit Nunangat, which is the arctic homeland consisting of four Northern regions. One of these regions is Nunatsiavut, Labrador. Labrador is considered a remote region, which is located thousands of kilometers from the province's most equipped hospitals. The Nunatsiavut Government identified the journey one must undergo to receive a diagnosis of Cancer in Labrador as a research priority. The current project aimed to explore the journey a person must undergo to receive a diagnosis of cancer for people living in Nunatsiavut. This project was Indigenous-led and involved a partnership with Memorial University. Sharing circles and interviews were completed to engage cancer patients, survivors, family members, and healthcare workers to explore the challenges and opportunities in the cancer journey for Nunatsiavut community members. Thirty-two participants took part in the study. Six core themes emerged from the discussions: 1) Access and Supports; 2) Prolonged Investigation; 3) Travel; 4) Communication; 5) Fear and Anxiety; and 6) Being your own Health Advocate. We describe the pre-diagnosis journey according to themes that emerged and identify ways to improve the patient experience, based on participant feedback. There is an urgent need for accessible mental healthcare in Labrador, a greater number of healthcare professionals, quality cultural-sensitivity training for healthcare providers, and increased awareness of resources and development of educational materials on cancer.

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CHAPTER 1: INTRODUCTION

Introduction

Cancer is the leading cause of death in Canada, and the rates amongst Indigenous populations are increasing (Gifford et al., 2019; Government of Canada, 2022a). Cancer care for Indigenous populations is a growing public health concern (Young, 2016). Newfoundland and Labrador (NL) has the highest incidence rates of Cancer in Canada (Statistics Canada, 2021). The current project aimed to explore the cancer care experience for Inuit patients, family members, and healthcare providers in Labrador. This topic was deemed an area requiring further investigation by the Indigenous governments across Labrador. This project was Indigenous-led and included the Nunatsiavut Government (NG), in collaboration with the other Indigenous governments and organizations in Labrador - the NunatuKavut Community Council (NCC), Mushuau Innu First Nation (MIFN) and Sheshatshiu Innu First Nation (SIFN). See Table 1 for common abbreviations used throughout the thesis and their meanings.

Table 1. *Common Abbreviations*

	Abbreviation	**Meaning**
Province	NL	Newfoundland and Labrador
Indigenous Governments or Organizations	NG	Nunatsiavut Government
	NCC	NunatuKavut Community Council
	MIFN	Mushuau Innu First Nation
	SIFN	Sheshatshiu Innu First Nation
	NCCIH	National Collaborating Centre for Indigenous health
University	MUNL	Memorial University

Cancer Organization	CPAC	Canadian Partnership Against Cancer
Form of Research	CBPR	Community-Based Participatory Research
Other	NIHB	Non-Insured Health Benefit

The thesis is organized into five Chapters. Chapter 1 provides an overview of the terminology used throughout the thesis, an introduction to the larger research project, and the research context. In Chapter 2, the epidemiology of cancer is summarized, along with an overview of access to and experiences of cancer care among Indigenous and non-Indigenous populations. This Chapter also discusses prior qualitative research on Inuit experiences in cancer care. In Chapter 3, the project's theoretical framework, objectives, and methods are described. Chapter 4 provides the results, and Chapters 5 includes the discussion and main conclusions.

Terminology

According to the Canadian Constitution (Government of Canada, 2022b), Indigenous peoples refer to the original residents of North America and their relatives, and consist of three main groups:

- Inuit: This Indigenous group represents the peoples of the Arctic (Government of Canada, 2021b). The majority of Inuit in Canada live in Inuit Nunangat. Nunangat comprises four regions: Nunatsiavut (Labrador), Nunavut, Nunavik, and Inuvialuit (Northwest Territories and Yukon). In 2021, there were an estimated 64,235 Inuit in Canada.
- Métis: The Métis are the mixed offspring of Indians and Europeans who possess a distinct culture, language, and nationhood (Métis National Council, 2023). In

2021, about 590,000 individuals self-identified as Métis (Government of Canada, 2021a).

- First Nations: ‘First Nation’ can describe a large ethnic grouping and it is synonymous with the term ‘band’ (Parrott et al., 2023). This group includes Indigenous peoples in Canada with a distinct culture, and language. Community members of specific nations or communities often define themselves as members of their respective community or nation.

‘Indigenous peoples’ is a collective term for the original peoples of North America and their descendants (Government of Canada, 2022b). ‘Aboriginal peoples’ has also been used. The 1982 Canadian Constitution used ‘Aboriginal’ as an umbrella term to describe First Nations, Inuit, and Métis. In recent years there has been a shift towards using the term ‘Indigenous’ instead of ‘Aboriginal’ (Indigenous Awareness Canada, 2023).

Overview of Journey in the Big Land: Enhancing Cancer Care Services for First Nations, Inuit and Métis in Labrador

In 2016, Eastern Health developed an initiative called Journey in the Big Land: Enhancing Cancer Care Services for First Nations, Inuit and Métis in Labrador to address the rising incidence of cancer diagnoses in Indigenous populations, and to improve health outcomes in Indigenous communities in NL. This project was funded by the Canadian Partnership Against Cancer (CPAC) and involved collaboration with the Indigenous groups in Labrador (NG; NCC; MIFN; SIFN), the Dr. H. Bliss Murphy Cancer Care Foundation, the Canadian Cancer Society, and representatives from the health authority. The project focused on three priority areas: Transitions in Care, Tele-oncology, and Cultural Safety. This project led to the implementation of the following efforts to improve care and patient experiences:

- Increased completion of cultural safety training by healthcare workers.
- Indigenous artwork and pieces placed inside the Health Science Center and the Dr. Bliss Murphy Cancer Centre.
- A tele-oncology working group, visuals, and guidelines.
- An infographic that included an overview of the main findings of the project.
- A body part diagram and cancer glossary booklets in English and Indigenous languages.
- Redesign of the patient passport.

Building on this initiative, in 2018, a meeting with stakeholders from the prior project with representatives from each Indigenous organization: NG, NCC, MIFN, SIFN, the P.I. from Memorial University (MUNL), community Co-Investigators, and the health authority, was held in Happy Valley-Goose Bay. In addition, Indigenous patients and nurses caring for cancer patients across Labrador discussed the depth of needs. One core theme that emerged from the session was the challenges during the pre-diagnosis journey for Indigenous patients. This theme is the focus of this thesis. The present study is an extension of the larger *Journey* project, and engages community members, healthcare leaders, cancer survivors, and family members to discuss their experience with cancer in Labrador. For the purpose of this thesis, I will focus on project findings involving the Nunatsiavut communities: Nain, Hopedale, Postville, Makkovik, and Rigolet.

The objective of the current study was to identify key challenges in the healthcare journey of cancer patients living in Nunatsiavut, Labrador and to develop and implement a plan to maximize use of tools and/or resources to make their experience more seamless.

Setting

Labrador

Labrador is a sub-arctic region in Eastern Canada that accounts for approximately 72% of land for the province of NL but has a population of only 27,200 people (Government of NL, 2018; NL Statistics Agency, 2021). Labrador has four regions: North Coast, South Coast-Straits, Central, and Western Labrador (Heritage NL, 2023). See Figure 1 for a Map of Labrador. The North Coast of Labrador includes the Torngat Mountains, Cape Chidley, as well as Natuashish, and Nain. Central Labrador includes Churchill Falls, Lake Melville, Happy Valley-Goose Bay, Sheshatshiu and North West River. Western Labrador includes Labrador City and Wabush and Southern Labrador stretches from Cartright to the Labrador Straits, which connects to the Québec border.

Figure 1. *Map of the Labrador Region. Note. Retrieved from Elections Canada (2023).*

In order to travel to NL, there is a two-hour ferry that runs between St. Barbe on the Great Northern Peninsula to Blanc Sablon, near the border between Québec and Labrador (Government of NL, 2023a). In addition, flights are available from Happy Valley-Goose Bay to all North Coast communities, Labrador to St. John's, Gander and Deer Lake. Flights from Labrador to St. John's are approximately three hours and are offered year-round. Although it can appear there are few limitations to entering and exiting Labrador, the ferry is only available in the summer months, there are no roads connecting Nunatsiavut communities, and all modes of travel require suitable weather conditions (MacDonald et al., 2015). Also, Labrador's troublesome weather conditions are well-documented (Harper et al., 2011; Nickels et al., 2005). Labrador regularly experiences poor weather conditions including high intensity and frequency of storms, changing rain and snow patterns, high temperatures in the summer and extremely low temperatures in the winter months. Weather-related issues in combination with the remote-ness of the region serve as significant barriers to travelling within, to, and from the area (Hippe et al., 2014).

Indigenous Populations in Labrador

The remote region of Labrador has been the home of Indigenous peoples for centuries. There are three main Indigenous groups in Labrador: the Nunatsiavut Inuit, the NunatuKavut Inuit, and the Innu (Michelin, 2019). In 2021, Census data revealed that approximately 9,115 people from Labrador identify as Indigenous (Statistics Canada, 2021). The majority of Indigenous residents in Labrador are members of one of following groups: 1) Nunatsiavut Government; 2) NunatuKavut Community Council, or the 3) Innu Nation.

In 1973, the Labrador Inuit Association (LIA) was formed to advance Labrador Inuit land claims with the provincial and federal government (NG, 2023c). In 2005, the LIA Land Claims agreement was finalized, and the NG was established. The NG was the first Inuit region in Canada to achieve self-government and represents the Beneficiaries of the Labrador Inuit Land Claim Agreement. The Inuit of Nunatsiavut primarily live in Nain, Makkovik, Rigolet, Hopedale, and Postville, Labrador. The Inuit in Nunatsiavut are also represented by the Inuit Tapiriit Kanatami (ITK), the National Representational Organization of Inuit in Canada (ITK, 2020). Nunatsiavut (northeastern Labrador) is also one of four regions in Canada known for where Inuit reside, called ‘Inuit Nunangat.’ The other regions include the western edge of the Northwest Territories (the Inuvialuit Settlement Region), the territory of Nunavut, and northern Québec (Nunavik).

The NG offers a variety of services to their members, such as interpreter and translator services, mental health and healing services, home and community care, communicable disease control, and programs such as healthy children and youth, and Non-Insured Health Benefits (NG, 2023b; Shea, 2018).

NunatuKavut meaning ‘Our Ancient Land,’ is the territory of the Inuit of Southern Labrador (NCC, 2023a). The NCC was originally formed in 1981 and represents approximately 6,000 Inuit (NCC, 2023b). The Innu Nation is an organization that represents the Innu of Labrador (Innu Nation, 2023). In 1976, Naskapi Montagnais Innu Association (NMIA) was organized, representing the Innu of Labrador. In 1990, the NMIA changed its name to the Innu Nation. Today, the Innu Nation represents approximately 3200 people, who primarily live in Sheshatshiu and Natuashish, Labrador. Sheshatshiu and Natuashish represent two of three reserves in the province, that are governed by separate bands called the Sheshatshiu Innu First Nation Band Council, and the Mushuau Innu First Nation Council, respectively (Michelin, 2019). However, both Council Chiefs are members of the Executive Council of the Innu Nation.

Health Services in Labrador

When this study was conducted, the province was divided into four regional health authorities, and the Labrador-Grenfell Regional Health Authority oversaw the health services in the Labrador region (Government of NL, 2023b). Now, there is one provincial health authority called ‘NL Health Services.’ This transition was made with the goal to reshape the healthcare-system in a way that can better support the health and health outcomes for people in NL (NL Health Services, 2023).

In Labrador, there are three hospitals: the *Labrador Health Center*, located in Happy-Valley-Goose Bay, the *Labrador West Health Centre* in Labrador City (Labrador-Grenfell Health, 2023d; Labrador-Grenfell Health, 2023f), and the *Charles S. Curtis Memorial Hospital* in St. Anthony (Labrador-Grenfell Health, 2023b). The Labrador Health Centre and Labrador West Health Centre provide emergency services, outpatient clinics, dialysis, diagnostic testing (i.e. ultrasounds, radiology, CT and mammography services), as well as physiotherapy, respiratory therapy, access to dietitians, mental health services, and occupational therapy. Other services include cervical screening, and health promotion education. The Labrador West Health Centre also offers surgery, maternity care and home care. However, the Labrador Health Center and Labrador West Health Center only has 25 and 28 beds, respectively. The Charles S. Curtis Memorial Hospital provides laboratory and diagnostic imaging (i.e. ultrasounds, CT, and mammography), social work, mental healthcare, oncology/chemotherapy services, diabetes education, nutrition and emergency services (Labrador-Grenfell Health, 2023b).

There are also two Health Centers in Forteau and Roddickton-Bide Arm, called the *Labrador South Health Centre* and the *White Bay Central Health Centre* (Eastern Health, 2015). These health centers offer primary healthcare, blood work, nursing mental healthcare, and diagnostic testing e.g., X-ray; (Labrador-Grenfell Health, 2023e; Labrador-Grenfell Health, 2023h). They also have holding, beds basic equipment, supply of essential medications, and care is provided by registered nurses and two physicians.

There are also community clinics across Labrador (Labrador-Grenfell Health, 2023c).

There are clinics in all of the Northern communities, as well as in the following Southern Labrador communities: Black Tickle, Cartwright, Charlottetown, Mary's Harbour, Port Hope Simpson, and St. Lewis. Each clinic on average has two healthcare providers, with sites staffed by nurses. These clinics offer point of care testing (i.e. blood glucose monitoring, pregnancy tests), medications, and laboratory testing. Approximately half of the clinics provide access to medevac for patients to reach appropriate referral centers.

Access to Cancer Care

The Labrador Health Centre and the Labrador West Health Centre are the central hubs for cancer care in the region due to access to primary care physicians, chemotherapy, and screening services (Labrador-Grenfell Health, 2023d; Labrador-Grenfell Health, 2023f). In February, 2023 the province opened a breast screening center at the Labrador Health Centre in Happy Valley-Goose Bay (Eastern Health, 2023b). The Charles S. Curtis Memorial Hospital in St. Anthony also offers oncology/chemotherapy services, and they employ a part-time patient navigator (Labrador-Grenfell Health, 2023b).

Radiation therapy, cancer screening (breast, cervical, colon) and diagnostic tests are also available in Hospitals in St. John's (Eastern Health, 2023a; Eastern Health2023c). The Dr. H. Bliss Murphy Cancer Centre, that is attached to the largest hospital in St. John's, the Health Sciences Centre, offers cancer screening, chemotherapy, radiation, and consultative services (Eastern Health, 2023c). Therefore, in order for Labrador patients to receive radiation services, temporary relocation to St. John's, Newfoundland is required for the duration of the treatment cycle.

Beneficiaries of the NG qualify for funding for travel for cancer care (NG, 2023b). NG's non-insured health benefits program can cover some or all costs associated with medical transportation, and medical supplies. The NG, through the Non-Insured Health Benefit's (NIHB) program also provides transportation to and from medical appointments in Upper Lake Melville (ULM) and St. John's, NL. For appointments outside of these locations, NIHB covers the cost of taxi fare and/or private vehicle mileage. Although certain Indigenous governments provide NIHB coverage directly to members, there is an option to submit claims to the Government of Canada (Government of Canada, 2023b). All that is required is proof of an identification card that demonstrates membership with your Indigenous organization, or proof of recognition from your land claim organization.

In the following Chapter, I provide an overview of the epidemiology of Cancer in Indigenous populations and non-Indigenous populations in Canada, and I discuss the impact of geographic location on the accessibility on health and specialty medical care.

CHAPTER 2: LITERATURE REVIEW

Epidemiology of cancer

Canada

Cancer is the leading cause of death in Canada and worldwide (Government of Canada, 2022a; World Health Organization, 2023). In addition, Cancer is responsible for approximately 28.2% of deaths in Canada (Canadian Cancer Society, 2023b). In 2022, it was estimated that there would be about 233,000 new cancer cases and that 85,000 people would die from cancer. The most common cancers affecting Canadians include colorectal, prostate and lung cancer, and these account for about half of all new cases. In 2022, it was estimated that about 29,000 women would be diagnosed with breast cancer and that breast cancer would account for 14% of cancer deaths in women (Canadian Cancer Society, 2023a). Atlantic Canada has the highest rates of Cancer across the country (Canadian Cancer Society, 2023b). Specifically, NL has the highest rates of cancer of all provinces and territories.

Indigenous Populations

There are approximately 1.8 million people who self-identify as Indigenous, comprising about 5% of Canada's total population (Statistics Canada, 2022b). A number of factors contribute to the increasing rates of cancer amongst Indigenous populations. First Nations, Métis and Inuit disproportionately experience poverty, poor living conditions, limited access to healthy foods, and low socio-economic status (Ahmed et al., 2015; Rahman et al., 2019). Individuals of lower socio-economic status experience greater incidence rates of cancer and lower survival rates following a cancer diagnosis. In addition, colonization has resulted in generations of marginalization, cultural genocide, intergenerational trauma, and social disadvantages for Indigenous peoples that impact their health status (CPAC, 2023e; Sheppard et al., 2019).

Indigenous peoples are also at a higher risk for cancers associated with modifiable risk factors, such as tobacco use and the consumption unhealthy foods (Beckett et al., 2021). Indigenous peoples also experience poorer cancer outcomes than non-Indigenous people (CPAC, 2023b). Disparities in cancer rates, stage of cancer when it is detected, and incidence of cancer between Indigenous and non-Indigenous populations is well-documented (Ahmed et al., 2015; Sheppard et al., 2010). Indigenous peoples in Canada are diagnosed with the most common cancers at higher rates than non-Indigenous peoples and they are more likely to receive later-stage diagnoses of cancer (McGahan et al., 2017; Métis Nation of Ontario and Cancer Care Ontario, 2015; Sheppard et al., 2010). For example, cervical cancer among First Nations and Inuit is 2.3 times higher than non-Indigenous Canadians (CPAC, 2023f). Also, even though cancer incidence rates for lung cancer are similar to the general population, First Nations and Métis are about 35% less likely to survive lung cancer five years following a diagnosis (CPAC, 2023d). Mazeereeuw et al. (2018) used Long Form Census data to compare cancer incidence rates in First Nations adults in Canada to non-Indigenous adults in Canada. Responses from individuals 25 and older between 1992 and 2009 showed that First Nations had a higher incidence of colon, rectum, cervix, and liver cancers. Also, incidence rates of stomach and gallbladder cancers were higher in First Nations who lived on-reserve. In 2021, data from the Canadian Cancer Society showed that the aged-standardized incidence rates of the four most common cancers in NL (colorectal, breast, prostate, and lung) have been increasing among Indigenous populations, and these rates are continuing to rise in contrast to non-Indigenous peoples.

Cancer Among Inuit

Inuit experience substantial disparities in risk factors and health outcomes compared to non-Indigenous populations, and also experience a higher burden of cancer morbidity and mortality than First Nation and Métis populations (Jull et al., 2021; Young et al., 2020). People living in Nunangat are more than twice as likely to be diagnosed with lung cancer than the general population (CPAC, 2023e). Also, cancers of the nasopharynx, bronchus, colorectal, stomach, kidney and pelvis have shown to be elevated in the Nunangat population compared to the rest of Canada (Carrière et al., 2012).

Young and Colleagues (2016) assessed age-standardized incidence rates of cancer between 2000 and 2009 and found that Inuit populations in Alaska, the Northwest Territories and Greenland were at an extremely high risk for developing lung and colorectal cancer compared to the international average. Also, the rates of cervical cancer amongst Inuit are about two to three times higher than the national average (Gamelin et al., 2022; Kelly et al., 2008). There has been an increasing trend in female breast cancers, lung and colorectal cancers (Gamelin et al., 2022). More recent studies have found that Inuit populations have the highest lung cancer mortality rates in the world (Tungasuvvingat Inuit and Cancer Care Ontario, 2017) and the rates of morbidity for other cancers is increasing among Inuit (Jull et al., 2021; NCCIIH, 2019).

Given the epidemiological patterns of cancer, Inuit require increased access to primary and specialized health services. However, many studies indicate that access and quality of care often does not meet community needs for Inuit or other rural and northern populations.

Access to Healthcare

Access to Health Services for Rural Populations

Rural areas refer to all territory lying outside of population centers, and including census metropolitan areas (Statistics Canada, 2022a). Canadians living in rural communities experience various challenges to accessing healthcare (Bosco et al., 2006). Approximately 18% of Canadians live in rural areas who are served by only 8% of healthcare professionals (Canadian Institute for Health Information, 2016; Wilson et al., 2020). Rural communities lack physicians, mental healthcare professionals and nurses (Huot et al., 2019; Mew et al., 2017; Oosterveer & Young, 2015). In addition, healthcare clinics in rural and remote communities report lower access to specialty medical care, specific medications, prevention programs, medical equipment, and disease screening (Cerigo et al., 2012; Walker et al., 2021). Therefore, rural populations are also more likely to have to travel greater distances to access healthcare and experience worse health outcomes compared to urban populations after services are accessed (Jull et al., 2021; Rural Health Information Hub, 2022).

Rurality has shown to play a role in disparities in cancer screening and diagnosis follow-up in Canada (Vahabi et al., 2015). Further, remoteness can impact the rates of preventable and treatable mortality in Canada (Subedi et al., 2019).

Access to Health Services Among Indigenous Peoples

Globally, Indigenous peoples have comparatively poorer access to health services (Beckett et al., 2021; Gracey & King, 2009). Approximately 40% of all Indigenous peoples in Canada live on reserves, and about 14% live in rural or remote regions (Government of Canada, 2020). Indigenous peoples are less likely to have a family physician, a health card, or transportation to appointments (Logan, 2017 as cited in Sheppard et al., 2019). Also, Indigenous peoples living on-reserve or in remote locations have to rely on non-resident health professionals to travel to remote communities for short periods of time (Nelson & Wilson, 2018; Oosterveer & Young, 2015). In order receive either primary or tertiary health care, Indigenous patients often have to travel thousands of kilometers from home to urban areas (Jull et al., 2021). As a result, they are less likely to receive timely and culturally appropriate care and their medical and mental health needs may not be met (NCCIH, 2019).

Inuit Access to Healthcare

About 73% of the Inuit population in Canada live in Nunangat (NCCIH, 2019). Most Inuit in these regions live in northern coastal communities that are only accessible by air year-round (Beckett, 2021; Enuaraq, 2021; Jull et al., 2021). Also, these regions experience varied and challenging weather conditions, and lack inter-community infrastructure (Beckett, 2021). Low population density and limited services often make it difficult to attract healthcare professionals to northern regions, which then in turn further entrench inequities in health care access (Huot et al., 2019). These factors also pose barriers to accessing health treatment and negatively impact the ability for residents to look after their own well-being (Huot et al., 2019; Thibeault, 2002).

In 2012, the Aboriginal People's Survey showed that only 23% of Inuit who lived in Nunangat had a regular medical doctor and 14% stated they had unmet health care needs (NCCIH, 2019; Wallace et al. 2014). About one quarter of Inuit who completed the survey stated that the reason for having unmet health needs was because the health service was not offered in their area. In contrast, 74% Inuit living outside of Inuit Nunangat in Canada reported having access to a regular medical doctor, and only 10% felt they had unmet health care needs.

Inuit can opt to seek secondary care, which involves commuting to regions with larger health centers, or tertiary care, which requires further travel to major Canadian cities, such as St. John's (Beckett et al., 2021; Chan et al., 2019). The alternative is to opt not to seek healthcare (Jull et al., 2021). Therefore, in order to access health services, Inuit often must navigate complex health systems, make decisions about their employment, leaving family members, their home, and community and, in the mean-time, attempt to look after their own health.

Literature Review of Cancer Care

Cancer Care for the General Population

There are five main approaches to cancer prevention and treatment. In high-income nations, often, governing bodies make recommendations regarding cancer care (Kisling & Das, 2023). Recommendations are based on advancements in cancer research, innovation in screening and treatment methods, resulting in improved healthcare outcomes (Ahmed et al., 2015). Governing bodies often use the different stages of disease and preventative health measures to target prevention at each stage of the disease (Kisling & Das, 2023). Primordial, primary, secondary, tertiary and quaternary prevention. Primordial prevention includes government policies and the built environment affecting access to healthy foods and safe neighborhoods. Primary prevention can include the use of immunizations and tobacco cessation programs. Secondary prevention can include early detection using screening services, and health testing. Tertiary prevention can include treatment and rehabilitation, and quaternary prevention can include actions taken to protect individuals from medical interventions that can do harm (i.e. over-treatment; Martins et al., 2018). Inequities can take place at various levels of cancer prevention. Despite Canada and other high-income countries having well-developed healthcare systems, inequities in cancer care exist, and many of these approaches to prevention are not reaching Inuit (Ahmed et al., 2015).

Differences in cancer care can result in varied presentations of cancer, especially among older age groups (Ahmed et al., 2015; Sheppard et al. 2010). In 2006, a Canadian Strategy for Cancer Control was created to improve the cancer experience in individuals across Canada (CPAC, 2023e). In 2019, the Canadian Strategy for Cancer Control was updated and a 10-year action plan to achieve equitable access to cancer care in Canada was launched. This strategy included input from across all provinces and Indigenous communities to identify the different priorities. The strategy focuses on four main goals: 1) decrease the number of people who develop cancer; 2) increase the number of people who survive cancer; 3) increase equitable access to quality cancer care; and 4) enhance quality of life for cancer patients. According to CPAC (2023c), since the launch of the Canadian Strategy for Cancer Control in 2006, the burden of cancer on Canadians has been reduced. Access to preventative health care services has increased, there has been an increase in cancer screening and development of tools and resources related to cancer, and the needs of Indigenous peoples has been better recognized in cancer care.

Cancer Care for Indigenous Populations

Having access to timely and equitable health services can facilitate early detection, and improve health outcomes (Canadian Cancer Society, 2023c; Lavoie et al., 2016; NCCIH, 2019; Sheppard et al., 2009). Access and uptake of cancer screening can find cancer before it spreads when it is easier to treat, and if it is found in its early stages, the better the chances are of survival (Canadian Cancer Society, 2023c). However, Indigenous peoples are significantly less likely to complete cancer screening and are more likely to have cancers that are preventable, and detectable by screening (Garvey & Cunningham, 2019; Moore et al., 2015; Sheppard et al., 2010). Previous research has shown that cancer-screening is often not accessible in Indigenous communities (Lavoie et al., 2016). In addition, although First Nations and Inuit have funding for medical transportation, it is sometimes not provided for screening purposes (CPAC, 2013; Lavoie et al., 2016). A retrospective review that investigated cancer care and treatment in Inuit living in Nunavut revealed about 70% have to travel to urban regions for cancer care (Asmis et al., 2015; Jull et al., 2021).

Provincial, national, and international governing bodies have recognized a need to target cancer control strategies for Indigenous populations (Garvey & Cunningham, 2019). For example, Cancer Care Ontario created an Indigenous cancer strategy that honors Indigenous path of wellness (Garvey & Cunningham, 2019; Kewayosh et al., 2015). The Australian government's approach to cancer control involved a high degree of stakeholder consultations and collaboration with Indigenous organizations and community members to develop the *National Aboriginal and Torres Strait Islander Cancer Framework* (Cancer Australia, 2015; Garvey & Cunningham, 2019). Also, in 2015, there was a call to action by the Truth and Reconciliation Commission of Canada for a partnership between the CPAC and the Indigenous peoples of Canada to advance their cancer care priorities (CPAC, 2023b). CPAC supported the health-related calls to action that aim to close the gap in health outcomes between Indigenous and non-Indigenous populations by increasing the use of Indigenous ways of healing in healthcare, improving cultural competency of all healthcare workers, and increasing the number of Indigenous healthcare professionals.

Inuit Experiences of Cancer Care

Qualitative data on cancer care experience among Inuit can provide important insights into the different dimensions of health status, the social determinants of health, and healthcare

(Young et al., 2020). Prior research has incorporated qualitative study designs to gain a more-in-depth look at cancer care for Inuit populations (Carr et al., 2020; Ceriago et al., 2012; Jull et al. 2021). Jull et al. (2021) in collaboration with an Indigenous-led organization in Nunavut and Ontario, investigated the experiences and decision-making of Inuit in Canada who travel from remote regions for cancer care. The study found that Inuit patients often lack support during their cancer treatment. Patients reported finding it difficult to engage in decision making about cancer, and they lack knowledge about the impacts of engaging in decision-making about their health. Also, this study showed that Inuit patients believe that there is a duty to keep their family and community in mind when making decisions about their health care.

Cerigo et al. (2012) investigated women's attitudes and experiences toward cervical cancer and prevention strategies in Nunavik, Québec. About 200 Inuit women were involved in focus groups where barriers and facilitators to Pap smear attendance, use of safe-sex practices, awareness of cervical cancer, purpose of Pap smears, perceptions about HPV vaccination, and ways to promote vaccine use were discussed. They also completed a survey to explore personal experiences, attitudes and beliefs about cervical cancer. The results showed that most participants believed early detection would increase chances of a cure, however, about 40% of women did not think screening would make a difference. In addition, women lacked knowledge of the HPV vaccine. Further, about 40% of participants were reluctant to complete screening due to embarrassment during the screening process.

Gamelin et al. (2022) conducted an ethnographic study on the barriers and facilitators to implementing HPV self-sampling as a screening strategy for cancer care among Inuit women in Nunavik. With an aim to decrease the high risk of cervical cancer among Inuit, Gamelin and colleagues (2022) interviewed Inuit women to determine their perceptions of the barriers and facilitators to self-sampling. Despite evidence demonstrating the effectiveness of self-sampling, they found that the Inuit women doubted the effectiveness of this method. Through effective information diffusion, and culturally sensitive adapted information strategies, there is potential to increase uptake of self-sampling cervical cancer screening. Barriers included costs and limited resources for HPV testing.

Previous research has also investigated the use of knowledge-translation to promote shared-decision making in Inuit cancer care (Jull et al. 2018). In collaboration with a primarily Inuit Steering Committee and advisory groups with Inuit cancer care providers, a shared decision-making strategy was developed. A workshop took place and a training booklet was created about cancer care decision-making. Interviews with community members revealed that the strategy was useful and feasible for use.

Prior work has also aimed to explore the meaning of culturally safe cancer survivorship care for Inuit, and the barriers and opportunities to receiving care in urban regions (Enuaraq et al, 2021). Through the use of focus groups with Ontario cancer survivors and their family members, three core themes emerged. Access to traditional ways of life, communication and family involvement were deemed essential to receiving culturally safe cancer care. In addition, having family support, access to patient navigators, and designated spaces were facilitators to culturally safe cancer care. According to participants, culturally safe care strives to honour the cultures of Indigenous peoples, allows them to access traditional ways of life, patient navigators, and trauma-informed approaches (Enuaraq et al., 2021). Inuit also identified one overarching barrier in interviews and focus groups: the financial burden of receiving care in urban settings.

End-of-life (EOL) care for Inuit cancer patients in Nunavik has also been researched to support the development of a sustainable model of care (Hordyk et al, 2017). Interviews were completed with community member’s healthcare professionals and administrators. They found that patients often receive end-of-life care outside of their communities and away from their family members. Patients wish to spend EOL care in their home communities. In addition, they found that having access to interpreters as well as trust in healthcare providers is essential. Participants believe that there is a lack of healthcare training on the historical and cultural realities for Inuit, and a lack of knowledge of how to build trusting relationships. In addition, collaboration with Inuit communities was recommended to inform care practices.

Galloway et al. (2020) also explored the perspectives on cancer end-of-life experiences of Inuit patients and families from Nunavut using in-depth interviews. In interviews, participants revealed that efforts to improve communication and enhance culturally appropriate care among health care providers, as well as the recruitment of health care providers with strong ties to the community can improve the healthcare experiences of Inuit patients and family members. Participants identified difficulties they have faced in cancer care and end-of-life care, such as extensive medical travel, and a lack of healthcare services, and culturally appropriate care within their hometown community. These qualitative designs allowed for insights into the cancer care experience for Inuit peoples.

The current project sought to address a lack of patient-oriented research that evaluates the cancer care experience of Inuit peoples in Nunatsiavut, Labrador. The NG identified the pre-diagnosis cancer journey for Inuit patients, families, and health care providers as a research priority. This thesis explores the challenges in the pre-diagnosis cancer journey for Inuit in Nunatsiavut and recommendations to improve their pre-diagnosis journey.

In the following Chapter, I discuss the decolonizing methodology, my positionality, and the objectives of this work. In addition, I present the study design, participant recruitment procedures, as well as the data collection methods and the framework used for data analysis for the current project.

CHAPTER 3: THEORETICAL FRAMEWORK, SETTING, AND OBJECTIVES

Theoretical Framework

For this thesis, I used a theoretical framework that drew on several theoretical and methodological frameworks including the decolonizing methodology, patient-oriented research, and community-based participatory research (CBPR). These approaches have been used in prior research involving Indigenous groups, and they were deemed culturally appropriate by the project Steering Committee members.

Decolonizing Methodology

Colonialism has resulted in substantial negative consequences for Indigenous peoples (Limmena, 2021; Shea et al., 2013). Indigenous peoples have been victims of countless forms of abuse, discrimination, and cultural erasure by powerful institutions (Limmena, 2021). Indigenous peoples inhabited North America for thousands of years prior to the arrival of European settlers (Government of Canada, 2017). Following their arrival, Europeans aggressively took lands from Indigenous peoples and eventually displaced them, forcing a disconnection between Indigenous peoples and their land, culture, and their communities (The Canadian Research Institute for the Advancement of Women, 2016). Eventually, they were forced to relocate to inadequate lands (i.e. the reserve system) and to attend residential schools (Limmena, 2021). Children suffered various forms of abuse at these schools, and today, many suffer from intergenerational trauma.

Indigenous peoples have also been victims of oppression by western researchers (Datta, 2018). As a result, it has been questioned whether it is possible to conduct research without doing further damage. Western research practices can be seen as extensions of colonialism (Absolon & Willet, 2005). Further, previous research involving Indigenous peoples often involved ‘parachute’ researchers; individuals who collect the data they are looking for from the Indigenous community and then exit quickly without sufficient communication throughout the process with those involved (Castellano, 2004; Castleden et al., 2012). Prior research involving Indigenous populations has also been conducted without consent, which has resulted in communities being misrepresented, and the benefits of the research conducted have not extended to the Indigenous community (Ball & Janyst, 2008; Battiste & Henderson, 2000; Castleden et al., 2012).

Smith (1999) challenged researchers to increase their ethical standards, and to adopt a new approach when involving Indigenous participants. Decolonization means challenging traditional research practices, acknowledging the impact of colonial history, and ensuring that research is wanted by and benefits Indigenous communities (Shea et al., 2013). Indigenous scholars (Denzin et al., 2008), have stated that decolonization honours Indigenous approaches about the world, and not considering decolonization in research that involves Indigenous peoples causes harm (i.e. by displacing them, results in economic inequality, and the loss of culture; Datta et al. 2018; Lavallée, 2009).

The current project adhered to a decolonizing approach. A decolonizing methodology begins to address the damage created through colonization, and as a research paradigm, allows for a different way of thinking about how data is collected (Shea et al., 2013; Wilson, 2008). Decolonizing methodologies aim to shift the focus from communities being researched to members being equal partners in the research (Edwards et al., 2008). Furthermore, the adoption of this methodology can have a positive impact on the health of communities through the understanding and honouring of different perspectives of health between Western and Indigenous models (Sherwood & Edwards, 2006).

Patient-Oriented Research

‘Patients’ can refer to individuals with a health issue, those who receive healthcare, as well as informal caregivers, such as family and friends (Manafo et al., 2018; Sundergi et al., 2019). Patient-oriented research entails creating partnerships with patients, and involving them throughout all or the majority of the research process (Sundergi et al., 2019). They can help to set research priorities, determine the research question, assist in the analysis and interpretation of data, and help to distribute the research findings. There are a variety of benefits that can result from conducting patient-oriented research. Patient-involvement in health services research can increase the likelihood that research will respond to community needs (Canadian Institutes of Health Research, 2014). Also, patient-oriented research can lead to the development of interventions that are more accessible and beneficial to communities (Kendall et al., 2018). Further, it can lead to greater study participation, interest in the project, as well as for data to be owned and acted on by local community members (Kendall et al., 2018; Wright et al., 2016). The ‘Spectrum of Engagement' model adapted by Sunderji et al. (2019), shows that open dialogue that is bi-directional with stakeholders, continuous efforts to engage with stakeholders, shared decision-making and power balances represent high levels of patient engagement. According to this model, this project involved high levels of patient engagement.

It is important to consider the challenges of patient-engagement prior to conducting research. For example, it can take time a substantial amount of time and resources to build relationships, gain a patient’s trust, and for them to feel comfortable to contribute to the project (Gonzalez et al., 2023; Panel on Research Ethics, 2022). In addition, they may lack knowledge of and experience in research. Also, it can be difficult to maintain engagement over time, and learning how to collaborate as a team is essential. It requires effort on behalf of the research team to effectively conduct patient-oriented research and to observe the benefits of this approach.

The current project involved multiple aspects of patient-oriented research. Cancer patients, cancer survivors, family members, as well as health-care providers from Nunatsiavut participated in the project. Partnerships were established and relationships were built with the Indigenous government, community members, and patients, and they were involved in every step of the research process. Taking the time to establish relationships that can promote mutual trust, communication, and collaboration has been identified as a central feature to research involving Indigenous peoples according to the Tri-Council Policy Guidelines (Panel on Research Ethics, 2022). The NG determined the research question, completed data collection, and owns all data collected from the study. Also, multiple community gatherings, meetings, and conversations took place with the different community partners and patients throughout the course of the project which facilitated engagement.

Positionality

I am an Inuk who currently lives in St. John’s, NL. My family's roots are within the Nunatsiavut regions of Labrador. Throughout my Bachelor of Science (Honours) degree, I had learned the importance of health promotion, accessibility to health services and health education. In addition, my work experience as a Research Assistant, focused on patient-oriented research and improving health outcomes. My education and research background piqued my interest in wanting to work to overcome existing barriers in healthcare and to improve the well-being of individuals of this province. Also, I had known about the poor healthcare experiences my family members who currently live in Labrador had endured. I wanted to transition to my key interest of working on health issues related to Indigenous health in my province. After reviewing potential

Supervisors from the Faculty of Medicine, at MUNL, it was evident that Dr. Jennifer Shea was the researcher I wanted to complete my Master's research with. I learned of Dr. Shea's extensive research background on health services for Indigenous communities, as well her long-term and strong relationships with Indigenous communities. After connecting with her, she offered me the opportunity to be involved with a few Indigenous focused projects, and after mentioning the current one, I jumped at the opportunity. I am honored to be able to work with her, the Indigenous governments, the research partners, and the Indigenous community members for this project and highlight areas for improvement to the cancer experience of Indigenous patients in Labrador and solutions to identified issues. The current thesis focused on the Nunatsiavut communities: Makkovik, Nain, Hopedale, Rigolet, and Postville.

Rationale

The current study is amongst the first to investigate the journey Indigenous peoples must undergo to receive a diagnosis of cancer in Labrador, also referred to as the pre-cancer diagnosis journey, of Indigenous peoples in Labrador. This study sought to identify challenges and areas for improvement along the continuum of the pre-diagnosis phase of a cancer journey for Indigenous peoples, and make it easier for governments, policymakers and healthcare providers to step in and take action to address identified issues. Therefore, this project can lead to effective solutions and ultimately the development of tools and resources to address challenges identified by Indigenous cancer patients, and thereby, lead to improvements in the coordination of care. The NG shared concerns of community members relating to challenges involved for Indigenous peoples to receive a diagnosis of cancer. Therefore, the NG deemed this topic a research priority. This project involved a partnership between NG and MUNL to explore this topic.

Despite the abundance of evidence highlighting that cancer is being detected in later stages in Indigenous peoples (Ahmed et al., 2015; Sheppard et al., 2011), along with the increasing rates of cancer and poor survival rates among Indigenous peoples (NCCIH, 2019), there is a lack of patient-oriented research that explicitly evaluates the cancer care experience of Indigenous peoples in Labrador. Specifically, limited attention has been paid to investigating challenges in the healthcare experience of Labrador's Indigenous peoples, and the potential solutions and resources to challenges identified by this population.

Objectives

The research question guiding the study was: What challenges and solutions will cancer patients and survivors identify to improve the cancer care experience of Nunatsiavut cancer patients? The objective of this study was to identify key challenges in the pre-diagnosis journey of cancer patients living in Nunatsiavut and to develop and implement a plan to maximize use of tools and/or resources to make their experience more seamless. Improvements in the coordination of care during the pre-diagnosis cancer journey and enhancements to information sharing will advance the patient care priority area.

Study Design

The study used a qualitative design to investigate the pre-diagnosis journey for Indigenous cancer patients from Nunatsiavut. Community members were engaged using a community-based participatory approach. Data was collected through a series of sharing circles and interviews conducted in Nunatsiavut.

Community Based Participatory Research

The current project used a community-based participatory research approach for this project. Community-based participatory research (CBPR) is a process that fosters engagement among communities, and community-research collaboration (Jull et al., 2016). This approach prioritizes the development and maintenance of strong and positive partnerships with all of those involved (Collins et al., 2018; Minkler & Wallerstein, 2008). CBPR values the voices and knowledge of community members, stakeholders, and participants, and this involvement is recognized as a strength of the research (Collins et al., 2018). Communities are involved in decision-making throughout the research project and share ownership of data.

This approach was considered a good fit, as similar to the Inuit tradition of emphasizing community, CBPR differs from traditional research methods that focus on the individual (Anang, 2021). The CBPR approach emphasizes the importance of creating equitable partnerships with those engaged in the process and seeks to eliminate injustices or power differentials within the research (Jull et al., 2017; De Sayu et al., 2015). CBPR entails co-learning and co-creation of knowledge and capacity building among all partners that can result in mutual benefits for those involved (Jull et al., 2017; Minkler & Wallerstein, 2008). For example, CBPR can lead to social change and knowledge generation (Minkler &Wallerstein, 2008). In addition, this approach is increasingly being recommended and used in research involving Indigenous communities, and compliments a decolonizing approach (Dadich et al., 2019; Kovach et al., 2015).

Despite the benefits of this approach, CBPR must be considered with specific limitations in mind. Creating and building relationships with communities, and engaging community members throughout the research process, requires considerable time, flexibility, and energy from all involved (Minkler & Wallerstein, 2008). In addition, trying to balance power differentials and inequities among partners can be difficult (Minkler & Wallerstein, 2008). Also, community timelines can vary from the research institutions (Collins et al., 2018). These are all challenges associated with CBPR. However, CBPR has the potential to change and improve community-researcher relationships amongst Indigenous communities, it can empower participants to discuss community health issues so that they can be addressed, and it can lead to reduced health disparities (Collins et al., 2018; Wallerstein et al., 2017).

The current study adhered to the CBPR approach as strong relationships were formed and built upon between all members of the Steering Committee and the community. Relationships between the Co-PIs, Co-Investigators, and community liaisons had already been established prior to the project, due to involvement in prior research projects, and attendance at various community gatherings. Decisions relating to the project involved input from all partners with the project (i.e. the Steering Committee). In addition, feedback from all partners and participants has valued and documented using feedback forms at community gatherings and note-taking by students. Input from the feedback forms and discussions with all partners has been used to make decisions relating to the data collections methods, to plan the next steps in the research process, to assess the accuracy of our findings, and make changes to tools developed to improve the pre-diagnosis journey (larger project).

I became involved with this project an Indigenous master's student in September 2021, as my Supervisor had approved for me to focus my thesis on this project. I was soon introduced to the NG project team members, however, the COVID-19 pandemic and my late involvement with the project hindered my ability build strong relationships with the project team members and community members. Once restrictions were lifted, I was able to attend a project gathering where I was introduced to the other Steering Committee members, members from the other Indigenous groups, and community liaisons in Happy-Valley Goose Bay. Here, I was able to connect with them and hear their feedback on project findings that I would later integrate into this thesis.

In my role, I have analyzed data and summarized findings, and completed a thesis focused on this project, and have done my best to honour Nunatsiavut community member perspectives. I collaborated with the NG partners to complete this thesis, and I have implemented all of the feedback I have received. I have learned a significant amount about the pre-diagnosis cancer journey from the Nunatsiavut participants, and in line with the CBPR approach, as an Indigenous person with family in Nunatsiavut, and a student involved with this project, it is my aim for these findings to lead to social change. In particular, it is my plan to share this thesis and other knowledge-translation materials that are created based on the project with decision-makers, leaders, and health care workers so that changes can be made to improve the pre-diagnosis journey for people living in Nunatsiavut, and the rest of Labrador.

Partnerships and Patient Involvement

Relationship building is vital to collaboration and the decolonizing approach. See Table 2 for an overview of the partners that were involved in the design, planning, and methods for the current project.

Table 2. *Key partners in the project.*

Individual	Role	Occupation	Affiliation
Co-Principal Investigators			
Sylvia Doody (S.D.), BN, RN, MPH	Project planning and oversight, data storage (Lead for NG)	Director of Health Services	NG
Tina Buckle (T.B.), BN, RN	Project planning and oversight	Community Health Nursing Coordinator	NG
Darlene Wall (D.W.)	Project planning and oversight (Lead for NCC)	Department of Health and Community Services	NCC
Dr. Jennifer Shea (J.S.), PhD	Student Supervisor and Co-project planning, research and data analysis	Assistant Professor of Indigenous Health, Division of Community Health and Humanities	MUNL
Co-Investigators			
Kathleen Benuen (K B.)	Lead for MIFN	Health Director	MIFN
Anastasia Qupee (A.Q.)	Lead for SIFN	Social Health Director (Previous)	SIFN
Project Coordinator			
Kathy Michelin, (K.M.), BSc	Project Coordinator, Co-Investigator, project advisor, data collection, analysis	Senior Policy Analyst	NG
Students			
Jennifer Bent (J.B.), BSc	MSc student, data analysis, thesis development	Student (NG analysis)	MUNL
Rebecca McQuaid (R.M.)	MAHR student data collection, analysis, thesis development	Student (Evaluation of overall project) & research assistant	MUNL
Jessica Pelley (J.P.), MPH, MD	UGME Research project, – Transcription and analysis of interviews and sharing circles	MD student (completed June 2023) & research assistant	MUNL
Community Liaisons (NG)			
Carly Blake (C.B.)		Community Health Aide	Rigolet

Joan Goudie (J.G.), RN	Community Research Planning	Home care nurse	Postville
Kim Andersen (K.M.)		Team Leader	Makkovik
Sophie Pamak (S.P.), RN		Home care nurse	Hopedale
Dawn Michelin (D.M.), BN, RN		Health promotion	Nain

This project was led by the NG. The journey to implementing this project involved the creation of a Steering Committee for the larger project, composed of membership from the NG, NCC, MIFN, SIFN, the research lead from MUNL, along with membership from the health authority. Also, community liaisons assisted with the recruitment of participants, advertising of the study, and planning. This project involved multiple meetings, conversations, trips to Indigenous communities, group planning sessions, and activities. Steering committee meetings were held at least quarterly (more frequent then needed). Below is a summary of gatherings held throughout the project (note: there was a pause between 2019-2021 due to COVID-19):

- In July of 2019, a partner engagement session was hosted in Happy Valley-Goose Bay, NL. At this meeting, a Steering Committee was formed. Furthermore, patients and families were invited to be members of the Steering Committee, Working Groups and stakeholder meetings. At this meeting, community liaisons were identified to aid with the project.
- In December of 2019, a gathering was held in Happy Valley-Goose Bay. Community engagement strategies were discussed, and a discussion guide was developed.
- In March 2020, a stakeholder gathering was held in St. John’s (co-hosted in partnership with Eastern Health (two separate projects funded by CPAC).
- In August 2021, a gathering took place in Battle Harbour to plan next stages of the research project.

- In September 2023, a gathering was held in Happy Valley-Goose Bay to discuss findings and complete member-checking.

Research Ethics and Community Approvals

Prior to conducting any in-person research, ethics applications were submitted to the Health Ethics Research Board for the province, and to the Nunatsiavut Government Research Advisory Committee (NGRAC). The ethics applications outlined the details of the research, such as the number of participants, locations of sessions, recruitment, research methods, discussion questions, and incentives. Ethics approvals were received from the Health Ethics Research Board on December 20, 2019, and the NGRAC on December 16, 2019 (See Appendix A).

Study Population

This project engaged cancer patients, survivors, family members and healthcare providers from 14 communities across Labrador. However, the focus of the current thesis was the Nunatsiavut Communities: Nain, Postville, Makkovik, Rigolet, and Hopedale. Nunatsiavut was selected to scale-down the scope of the project and to provide a more in-depth analysis of findings for the purposes of my thesis.

Nunatsiavut is located in the northern region of NL and covers about 15,000 kilometers of coastline along the Labrador Sea and about 72520km^2 of land (CIRNAC, 2005; Kourantidou et al., 2021; Snook et al., 2018). In 2021, there were approximately 2300 residents living in Nunatsiavut (Statistics Canada, 2022b). In addition, about 90% of the Nunatsiavut population identified as Inuit.

Eligibility Criteria

Cancer patients, survivors, family members, community members, and healthcare providers who were over the age of 16 were eligible to participate. This age range was selected due to the sensitivity of the topic. Participants who spoke English or Inuktitut were eligible, as language translation services were provided. Participants were recruited across the following five Nunatsiavut communities: Hopedale, Postville, Rigolet, Nain, and Makkovik. Based on the knowledge of the Nunatsiavut Co-PIs and liaisons, it was estimated to connect with approximately 60 individuals. This estimation was based on the small population sizes of the communities, and the aim to have a minimum of three, up to a maximum of 10 people per sharing circle.

Sampling and Recruitment Procedures

Key participant recruitment categories were identified by the Steering Committee and consisted of cancer patients, family members of cancer patients, and healthcare providers. A community liaison from each community was identified who assisted with recruitment of these participants through physical posters and personal contact (in-person, by phone or both). The community liaison made the first contact to provide information about the study. Following the identification of participants, the researchers and community liaisons set dates in which sharing circles could be held in the community. The Project Coordinator, reviewed the consent process with participants and facilitated all sharing circles and interviews for the project. She also answered any questions about the study. Consent forms were written in the English language (Appendix B); however, participants had the option to have consent forms translated to their language. In addition, the Project Coordinator asked participants whether an interpreter would be needed for the study. If so, it was arranged for one to be present. Interested participants provided written consent.

Cancer is a sensitive topic, and it was anticipated that participants may find it difficult and emotional to talk about throughout the study. Patients were informed that they would be offered mental health support if needed. After consent was obtained, the Project Coordinator began facilitating the sharing circles or interviews. Mental health support was offered to participants in need after the study. There was also a follow-up plan in place to check in with participants at least twice following the discussion to see how they were doing and to refer them to additional supports if needed. Community liaisons also served as a part of the circle of care for patients, as all worked in the communities for NG in the department of Health & Social Development (DHSD) and live in the community.

Data Collection

The study used a qualitative study design with a common method of data collection used with Indigenous groups called sharing circles. According to Indigenous scholars, decolonizing research involves placing the voices of Indigenous peoples in the center of the research process (Datta, 2018). In sharing circles involving Indigenous patients, the discussion can be started and led by an Indigenous patient partner (Carr et al., 2020). Sharing circles incorporate the Indigenous methodology of story-telling and allow the flexibility to accommodate Inuit oral traditions (Carr et al., 2020). Therefore, this method was deemed beneficial, as it would allow for a deepened understanding of the experiences of Indigenous patients and survivors affected by cancer.

Sharing circles can take place in a culturally appropriate location selected by the participants, therefore participants feel comfortable in the environment where data collection occurs (Carr et al., 2020). The circle promotes support and respect, as individuals are seated in a circle and participants take turns communicating. An object (i.e. stone) can be passed around the circle in a clockwise or counter clockwise direction to signal when it is the next person's turn to speak. Therefore, people listen when others are speaking. Previous research has investigated Indigenous health using sharing circles, and this method in research has been increasing (Carr et al., 2020). Also, in a sharing circle, permission is given by participants to researchers to report on and assess discussions that occurred during the sharing circle (Nabigon et al., 2000).

The World Health Organization (2020) declared COVID-19 to be a pandemic on March 11th, 2020. Unfortunately, this was the same timeframe that data collection for the present study was planned to begin. The Government of NL (2022b) implemented public health measures to reduce the transmission of the virus such as travel restrictions and travel bans, COVID-19 testing, vaccination and mask mandates, social distancing, and closures of businesses and institutions. Also, flights were suspended in Labrador and there was now a significant concern for immuno-compromised participants, uncertainty surrounding when sharing circles and interviews could take place again, and sharing circles and interviews had to be rescheduled. However, the determination of the Steering Committee members and other project stakeholders resulted in the project to continue while abiding to the NL Governments public health measures. To reduce the risk of transmission, our project was modified to use one-on-one interviews instead of the sharing circles in the remaining communities. Also, due to the uncertainty regarding COVID-19, planning adjustments needed to be made, and approvals received from all research partners. Therefore, our project experienced delays.

When the appropriate approvals were granted to proceed with the study, sharing circles or one-on-one interviews were conducted by the Project Coordinator in the communities. One-on-

one interviews ranged between five to fifteen minutes and sharing circles ranged between one to two hours. Sessions were audio-recorded and transcribed by two Research Assistants from MUNL. Participants were invited to check transcripts for accuracy. Sharing circles or interviews took place in each of the Nunatsiavut communities identified. The Project Coordinator provided prompts to ensure the discussion was centered around cancer, such as, discuss your cancer experience, how you received a diagnosis of cancer, how long did it take after you started to experience your first symptoms of cancer did you receive a definite diagnosis of cancer, whether travel was required, and potential solutions that would make navigating the healthcare system simpler. See Appendix C for all questions.

The NG is the primary data holder for data collected from this project. As discussed earlier on in the Chapter, Indigenous peoples have been victims of oppression, disrespect, and significant harm by Western researchers (Datta, 2018). Research involving Indigenous peoples has involved ‘parachute’ researchers who have collected data without consent or sufficient communication, and exited the community, and eventually Indigenous participants would learn that the benefits of the research were not being extended to their Indigenous community (Ball & Janyst, 2008; Castleden et al., 2012). The ITK (2018) created the National Inuit Strategy on Research to put an end to this exploitative relationship. A core priority of this strategy includes Inuit access, ownership and control over data and information for research, and includes the following objectives: 1) ensuring ownership of Inuit data by Inuit appointed entities; and 2) investing in Inuit led data.

NG received copies of all data pertaining to their community. Paper files for the current project were secured in a locked cabinet in a secure office (3M118) in the Department of Health Services at NG headquarters. Electronic files were password protected and held on an encrypted device. The retention period of all data relating to this project is at the discretion of the NG. Electronic versions of the data have also been transferred to the NGRAC for housing in their data repository.

Data Analysis

Transcription of audio recordings and note-taking during sharing circles and interviews was completed by students from MUNL. Prior to data analysis, participants indicated they wanted to review the transcripts of their respective interview or sharing circle. No corrections were made to the transcripts. Following their review, thematic analysis was initiated according to Braun and Clarke's (2006) thematic coding framework. This form of analysis was appropriate due to the flexibility of content and the exploratory nature of the research question. See Table 3 for the thematic analysis approach.

Table 3. *Thematic analysis approach according to Braun and Clarke's (2006) framework.*

Step	Process
1	Audio-recordings and transcriptions were reviewed independently multiple times by the Co-PIs (MUNL), (the Project Coordinator; the sharing circle and interview facilitator), and students (MUNL). This allowed us to become familiar with the interview content and to assign preliminary codes to describe data content
2	A search for patterns and themes was then conducted across different interviews and similar text fragments were assigned codes
3	The frequency of codes between each sharing circle session was tracked and common themes relating to the Indigenous cancer patient experience were identified and combined to accurately depict data.
4	Themes were reviewed.
5	Themes were defined and theme names were determined.
6	A final report was provided to the Indigenous communities that identified which themes made meaningful contributions to understanding the meaning of the data. Member-checking was completed.

The Co-PI (MUNL) and Project Coordinator discussed themes at meetings and through discussion a consensus was reached on what themes made meaningful contributions to understanding the data. I quantified the number of themes from each respective Nunatsiavut community to assess the level of agreement and importance of themes between the communities. The most frequent themes across the five communities were deemed as the most pressing areas of the pre-diagnosis journey to be improved.

Member-checking is a tool used to check the credibility of the results (Birt et al., 2016). Data is returned to participants and it is checked for accuracy. This project involved-member checking in the form of two project gatherings. In August 2021, a two-day gathering took place in Battle Harbour, where stages of tool development (for the larger project) and initial findings from the current project were discussed. This gathering was attended by the Indigenous representatives, a community liaison and the Co-PI (MUNL). In September 2022, a one-day gathering took place in Happy Valley-Goose Bay, NL. Several community liaisons, representatives from the Indigenous groups, and Steering Committee members attended. At the gathering the results from the current project were presented and a roundtable discussion followed. Feedback was provided from all attendees on whether project findings were an accurate representation of their experiences. I attended this session and documented participant feedback and the next steps for the project.

In the following Chapter, I discuss the study's findings, the number of sharing circles and interviews, the core themes that emerged and descriptions of what these themes mean. I also identify and describe the recommendations that participants suggested to improve the pre-diagnosis journey, and the feedback participants provided on our results.

CHAPTER 4: RESULTS

Study Population

Thirty-two individuals across each of the five Nunatsiavut Communities took part in interviews or sharing circles. Participants were primarily female and middle-aged. Although translations services were offered for all interviews and sharing circles (only one community member availed of this service). No participants withdrew from the study post-data collection and all participants stayed until the end of their interview or sharing circle. Figure 2 shows the number of community members who participated from each community.

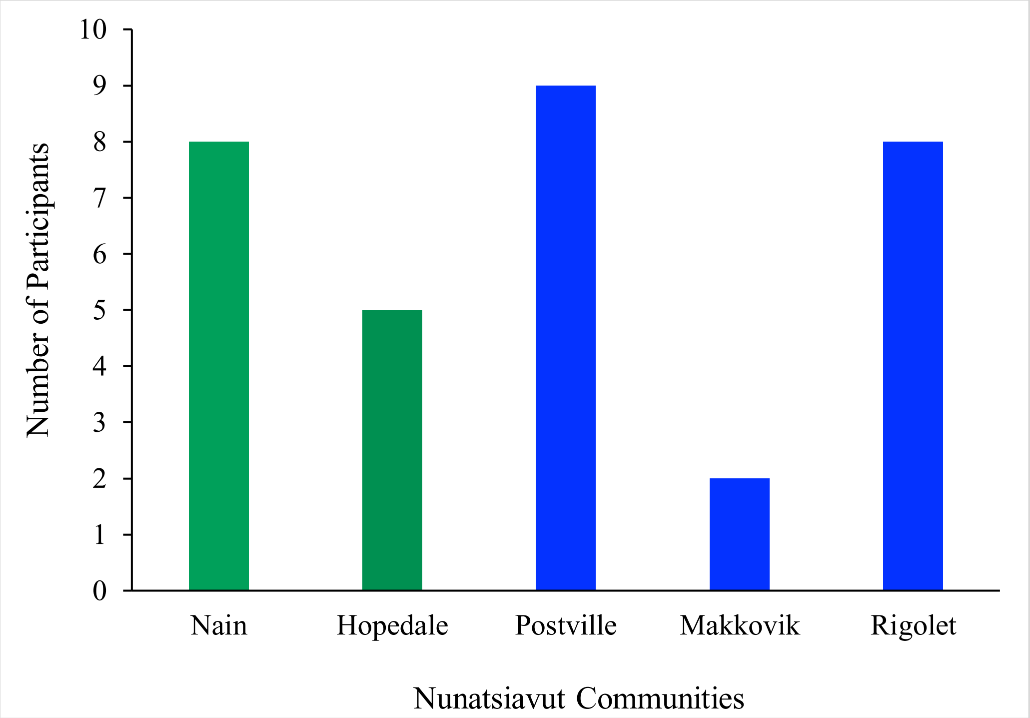

Figure 2: Number of sharing circles and one-on-one interviews, and participants in Nunatsiavut communities.

Note. The blue bars represent the number of participants who completed interviews and the green bars represent the number of participants who participated in sharing circles.

Overview of Results

All interviews and sharing circles were completed by the Project Coordinator and the Co-PI (MUNL) attended and assisted with the interviews in Makkovik. The dates and locations that the sharing circles and interviews took place along with the community and location of the sessions are reported in Table 4.

Table 4: *Nunatsiavut Community Engagement Sessions, Locations, and Dates*

Community		Date Completed	Method of Data Collection
1	Hopedale	November 10, 2020	Sharing Circle
2	Nain	November 11, 2020	Sharing Circle
3	Postville	June 15, 2021	9 Interviews
4	Rigolet	August 5, 2021	7 Interviews
5	Makkovik	October 7, 2021	2 Interviews

Core Themes from the Indigenous Participant Interviews

The following core themes were identified based on the content of sharing circles and interviews: 1) Access and Supports; 2) Prolonged Investigation; 3) Travel; 4) Communication; 5) Fear and Anxiety; and 6) Being your own Health Advocate. The core themes are ordered from most frequently mentioned to least frequently mentioned.

Access and Supports included discussion around healthcare service and provider access, as well as the availability of resources related to cancer, and knowledge of the pre-diagnosis journey. ***Prolonged Investigation*** was used to describe conversations on the length of time and the amount of effort that it took to receive a diagnosis of cancer. The theme ***Travel*** was used to describe conversations related to the method of transportation and the distance required to commute to medical appointments. Also, this theme covered reflections on participant experiences associated with these commutes. ***Fear and Anxiety*** was used to describe instances where patients spoke about their fear or anxiety for experiences related specifically to the pre-diagnosis journey (i.e. fear of traveling alone to receive a scan). ***Communication*** was used to describe experiences of verbal and non-verbal interactions with healthcare providers, as well as their comprehension of language used by healthcare providers. ***Being your own health advocate*** was used to describe participant experiences where they advocated for themselves in the healthcare setting, or when they encouraged others to advocate for themselves. See Table 5 for topics (sub-themes) of participant experiences that would be captured under their respective core themes.

Table 5. *Core Themes and Their Respective Sub-themes that Capture the Pre-diagnosis Journey*

Core Themes	Sub-themes
Access and Supports	• Access to Medical Escorts • Access to Doctors and Specialists • Cancer Resources
Prolonged Investigation	• Being Misdiagnosed • Receiving a Late-stage Diagnosis • Dismissal of Symptoms • Continuous Trips to the Health Clinic or Hospital
Travel	• Traveling Long Distances to Receive Care • Stress Associated with Travel • Navigation Services • Relocation for Treatment and Associated Costs
Communication	• Language Barriers • Lack of Understanding of Medical Terminology • Understanding and Comprehension • Verbal and Non-verbal Interactions with Healthcare Providers
Fear and Anxiety	• Perception of High Rates of Cancer in the Community • Family History of Cancer • Fear of being Diagnosed with Cancer • Fear of Hearing the Word 'Cancer'
Being Your own Health Advocate	• Experiences of Speaking Up to Healthcare Providers • Encouraging Others to Advocate for Themselves • Emphasizing a need to Trust your Body and your Ability to Tell When Something Isn't Right • Needing to Push for Investigation, Follow-up, and Healthcare Plans

The frequency of themes that emerged in sharing circles and interviews for each community was summed to compare the pre-diagnosis experiences between communities and to assess the importance of each of the themes. Refer to Figure 3 for the frequency of themes that were discussed in each of the five Nunatsiavut communities.

Figure 3. *The Frequency of Core Themes discussed across the Five Nunatsiavut Communities.*

Note. The total number of communities that discussed a topic related to a core theme is represented by 'n.'

Access and Supports

Access and supports were discussed in all five communities (n= 5). The majority of discussion related to access and supports focused on medical escorts. The need to have an escort to accompany patients on medical trips to other communities was emphasized in all five communities (n= 5). A medical escort is a person who is recommended by a healthcare provider to accompany a patient to travel for healthcare (Government of Canada, 2023c). A non-medical escort is a family member, friend, or another person recommended by a healthcare professional, that can accompany a patient that is unable to travel alone. A non-medical escort can be provided in any of the following situations: they are a minor, require additional assistance, they face a language barrier, they are pregnant, undergoing a medical procedure requiring anesthetic, or they have a medical condition that would require them to have assistance during the trip. Escorts can receive funding under the Non-Insured Health Benefits program to accompany patients for their medical appointments. In the current study, participants explained that escorts provide needed support to patients during uncertain and stressful times, and they can be important to a person's well-being. Below, one participant reflected on the importance of escorts, and how they should be provided upon request.

> "*If a person feels that they need an escort or anything, they should be allowed to have an escort, for their own wellbeing. You know like, even if it's just to Goose Bay or wherever, sometimes you need some support with you for whatever reason.*"

Individuals also spoke about the strict rules around being able to have an escort for medical trips. As a result of these rules, their requests to receive an escort are often denied. In Nunatsiavut, NIHB are provided directly through the NG (2023b), however, NG is bound by the Federal Government of Canada's policies when administering the NIHB program (i.e. medical escort policy). In the following quote, one participant reflects on the likelihood of receiving approval for an escort during the pre-diagnosis journey.

> "*The escorts, as far as for pre-diagnosis, that's not happening half of the time. They have escorts when they are diagnosed but pre-diagnosis? No. And that's because Nunatsiavut doesn't approve it. You're going for a mammogram? They're not going to approve that. If you're going for something that's suspicious? They're not gonna approve it unless you ask for it or until you're actually diagnosed. And that's when you see a doctor. After you see a doctor and get diagnosed, that's when the escort happens. I think when they suspect like, when cancer is suspected, a terminal illness like that, I think they should be provided an escort because it's, it's...You need the support*."

According to this quote, it is often only after you receive a diagnosis that approval for an escort is granted. Another participant explained that an escort is not allowed unless 'necessary.' Without access to the appropriate exploratory tests that are available at secondary or tertiary care centers, it can be difficult for local health care providers to distinguish if symptomology is consistent with a diagnosis of cancer. Therefore, the NIHB program is certainly not void of policy limitations.

Individuals also spoke about the lack of doctors, specialists, mental healthcare, and healthcare equipment at local community clinics, in all five communities (n= 5). Participants explained that due to this shortage of health professionals, they often have to travel to access healthcare. In the quote below, one participant reflects on the healthcare equipment at local community clinics and the burden of having to travel for an X-Ray:

> "*And the resources really need to be visited though because when you go away and there's everything right there, and I know we're isolated but we don't have enough services. You got to go so far away even just to get an appointment for X-Ray. You can go days and days without your family and your work. People can go and get an X-Ray and be off for half an hour. We go away and we're gone for three days, maybe longer. [inaudible]. How come there are no resources on the ground and in the communities, and we are having to go away. Very important. Healthcare services alone.*"

This quote provides a strong depiction of the absence of medical supplies, and technology in Nunatsiavut communities. This quote also indicates that clear inequities in healthcare services between remote and urban regions exist, and the resistance patients feel to have to travel for basic healthcare. Despite the lack of certain medical-imaging equipment, participants in three communities (n= 3) stated they had access to preventative healthcare services in their communities. These findings suggest that there is a need for greater information sharing on available medical equipment, and services offered in communities.

A recurring issue discussed amongst four communities (n= 4) was a lack of knowledge about cancer, resources, supports, their rights as patients, rules about escorts, funding, and medical topics. Patients emphasized that they should be informed that they can request a second opinion regarding their health, the rules surrounding escorts to accompany patients on trips, the next steps after receiving a diagnosis of cancer, and of cancer symptoms and prevention. In the following quote, one participant explains their experience with being misinformed by a health-care provider:

> "*But that's one thing, when my husband was going through cancer, and he tried to get a second opinion, he was told that if he did get a second opinion and went to Goose Bay for it, he would have to pay for it on his own. So, why should we have to… so, how can you get a second opinion if you're being told something like that?"*

In this case, being mis-informed about the healthcare system resulted in them not seeking further medical advice. Patients are frustrated with the lack of information they have regarding the pre-diagnosis journey, and it is clear that they would like this lack of knowledge to be addressed.

Prolonged Investigation

The second theme identified was Prolonged Investigation. Five communities (n= 5) spoke about receiving late diagnoses and being misdiagnosed was spoken about in four communities (n= 4). One individual spoke about a family member who had to travel three times to get biopsies to eventually be sent to St. John’s, NL for testing. It then took four months for them to receive a diagnosis of cancer.

Also, a shared experience across all five Nunatsiavut communities (n= 5) was having to travel ‘back and forth’ to the clinic for extended periods of time before receiving answers about their health. In two communities, having to travel back and forth to community clinics was mentioned in two separate interviews. In the following excerpt, a participant refers to their experience of having to make repeated visits to the clinic, and their dismissal of symptoms followed by a misdiagnosis.

> “*My diagnosis initially was all kind of messed up. They weren't sure. I got picked up through a well women’s clinic and they said it was nothing. And I got pregnant with my youngest one and carried her to term…and I still was not properly diagnosed. There was a lot of going back and forth, back and forth…So, it was three years before I had my surgery…And after that, there was not really a whole lot they did for me. Because it was so isolated here.*”

These findings indicate that patient symptoms and signs of cancer are continuously being dismissed by local healthcare providers, in cases when actions should have been taken to further investigate these symptoms. Early detection is crucial to the effectiveness of treatment and healing from cancer.

Furthermore, participants from three communities (n= 3) spoke about the long wait-times to see a doctor in their community. One individual mentioned how there had only been one doctor visit in the community in the last two years.

> Participant: “*I know like we don’t have a doctor here, well there’s been one, doctor visited once, was November 2019. You know like in..*”
>
> Interviewer: “*Two years almost.*”
>
> Participant: “*Yeah, we had one doctor since this visit. She came in November 2019, there was one doctor back. Now there’s a doctor in Goose Bay that’s responsible for Makkovik but they don’t come out. It’s like, it’s crazy.*”

This is a troubling result, as resident healthcare workers may not have the expertise to detect cancer symptoms, the ability to provide appropriate treatment, or the power to arrange for patients to travel to other more equipped hospitals.

Travel

Travel for medical appointments, operations, treatments and/or medications was discussed in three communities (n= 3 communities). The majority of conversations on travel involved air travel and centered on the challenges associated with this type of travel. In the following quote one participant reflects on the thoughts that run through their mind when they learn they need to travel for medical care.

> Participant: "*But anyway yeah so you know, that that was the - those stressors like that, away from your family, worrying about [name omitted] with three kids and no husband, and wintertime, and you know. And getting around on skidoo. And our other daughter while we were - because [name omitted] helps them a lot to fill up their machines*."
>
> Interviewer: "*Right.*"
>
> Participant: "*Yeah there was lots of –* "
>
> Interviewer: "*Personal and financial*."

This quote highlights that there are many factors patients take into account when deciding whether they will travel for medical care. Patients discussed the struggles of needing to take time off work, worrying about their family members, and the finances associated with travel.

Also, certain participants had to pay to travel or visit family members in the hospital. One participant stated they spent $10,000 of their own money travelling between St. John's, NL and their hometown community in Nunatsiavut to visit their family member for medical appointments. In contrast, another participant had their trip fully funded by the NG, including hotel costs, and air-travel. Patients and families who received NIHB administered by the NG for their medical trips requiring air travel stated that the funding helped to alleviate stress associated with their travel experience and they expressed their appreciation for this funding.

In addition, participants spoke about the need for and benefits of patient navigators, especially when relocation was required for medical appointments. Although many patients had not known that patient navigation was a service offered in St. John's, NL, those who did said they were helpful, and recommended that navigators are informed of patients arriving in St. John's.

Overall, patients disliked having to leave their community and family, travelling long-distances, and they would like to see more services offered in their communities. In the three communities, most participants reflected on the complex decision-making involved when relocation is required, and shared in the stress that comes with the experience. For example, participants mentioned having to worry about their family, their finances, and they had to think about whether they could take the time off of work to attend their medical appointment.

Fear and Anxiety

Numerous patients spoke about the fear and anxiety experienced throughout their pre-diagnosis journey. Individuals in three communities (n= 3) spoke about family members or themselves being reluctant to go to their community clinic or to see a healthcare professional. Individuals explained that prior experiences of them not being believed when speaking about their health, and damaged patient-physician relationships are a cause of their resistance to go to the clinic.

Also, many patients spoke of their fear of hearing the word 'cancer,' as they are aware of the high cancer rates in their communities. Having a family history of cancer was spoken about in three communities (n= 3). Patients expressed their concern for cancer, especially if they had a family member who had been diagnosed with cancer, and that this is a major reason for their fear of cancer. In the following quote, one participant reflects on the high rates of cancer in their community and how location can impact cancer morbidity.

> "*I think everyone here's got a relative with cancer. Cancer is high on the coast…And where you're living, where you're to. I mean, I was living in St. John's and thankfully it wasn't cancer, but I was like holy crap. All I kept thinking was, what if I was home on the coast? I'm thinking it wasn't cancer at the end of it, but that whole "how much more would've gone wrong" if I wasn't in St. John's and I was living on the coast, even with the diagnosis I had and the wait and all that was like.*"

Another participant mentioned how they had individuals on both sides of their family die from cancer and that there is no support for processing a terminal cancer diagnosis. Furthermore, patients and family members spoke about the anxiety associated with leaving their home and travelling to a different place (alone or with an escort). In the following quote, a patient discusses the anxiety and stress associated with attending medical appointments in unfamiliar locations:

> "*Like I find like I went to St. John's say for you know, an appointment but not like anything with cancer but it's very frightening when you go out there that like there's nobody there to meet you to show you where you have to go. Like at the airport you have to pick up this phone and call and say you're here. You know, all those things that has to take you to your appointment. Should be, you know, you should have somebody there saying, "OK yes you're in the right place". If it's your first time in St John's, you're not gonna know where you're going. You could get lost, get sidetracked, miss your appointment. All those things are playing on your mind.*"

These results indicate that a major source of fear and anxiety for Nunatsiavut community members is related to attending medical appointments. Unfortunately, previous negative experiences with healthcare providers, stress associated with navigation in unfamiliar hospitals, and a fear of being diagnosed with cancer may result in a reluctance to attend medical appointments. These findings are concerning, as early detection is vital to prevent poor health outcomes from cancer.

Communication

Communication was identified as a core theme, as many patients spoke about their healthcare experiences being negatively impacted by miscommunication or a lack of effective communication by healthcare professionals. Language barriers to understanding healthcare professionals when discussing the patient's health were mentioned in three communities (n= 3). For example, individuals spoke about a lack of understanding of medical terminology used by healthcare workers and a lack of effort on behalf of the healthcare provider to enhance their understanding.

One patient reflected on the need for interpreters for healthcare provider-patient discussions, especially when it is relating to a life-altering health condition.

> "*And with the severity… when it's imminent that you get the right translation, especially with cancer being that it's a terminal disease, can be a terminal disease. And to ensure that the patient clearly understands what they're going to face and what they're facing. I don't think there should be a question whether that patient understood. If they didn't understand, the interpreter should have been provided or should be provided because I like I said, technology now these days, you just have to pick up the iPad, iPhone and have it translated there. Or even video conference like they have set up in the hospital, if they're not comfortable with the other avenues that you have.*"

This quote demonstrates that language barriers and a lack of effort to translate the information on behalf of the healthcare providers, is preventing patients from understanding critical health information. Patients also discussed struggling to comprehend complicated health terminology. Being able to effectively communicate with patients is an essential skill for healthcare workers, and it is necessary for patients to be able to improve their wellness. Patients ask that measures are taken by healthcare workers to allow for them to understand what is being communicated to them.

Additionally, participants discussed a lack of culturally safe care by local health providers and a need for cultural sensitivity by healthcare providers:

> Participant: “*Formal orientation for staffing that’s coming up too. Not just the infrastructure of the community and the people and the patients. Some people skills. Not judging people when they come and go to the visit. A lot of people don’t want to go over there because all they ask is, “How much do you smoke, how much do you drink?” You know, because don’t be drinking too much. You’re supposed to be really looking at why they’re having those symptoms. Not automatically think just because [Nunatsiavut community name omitted] has a real sense that a lot of people are drunk all the time and are heavy drinkers. Don’t automatically assume that that is what it is.”*
>
> Participant: “*There’s a lot of judgement in there, for sure.”*
>
> Participant: “*That's how my cousin, my cousin had cancer for a while. I mean suddenly they’re by the phone because she drank too much and smoked too much and won’t stop drinking and smoking. But all that time she had cancer, and it was too late by the time they caught it. Really judging her for drinking and smoking*.”

Based on this information, patients are being subject to discrimination in a setting that is supposed to improve health status and do no further harm. In situations where care is based off of stereotypes or judgement, the patient’s concerns are being ignored, and they are not being treated based on their health situation. By neglecting the needs of patients, and subjecting them to discrimination, healthcare providers are causing harm to patients.

Additionally, individuals spoke about a lack of communication from physicians in two communities (n= 2). For example, individuals spoke about how it is often left unclear what a patient's next steps are following a cancer diagnosis, and that physicians do not take sufficient time to explain their diagnosis. On one occasion, a patient was told to ‘google’ their condition. As a result, patients often leave their appointments with a lack of understanding of their condition, and they either need to return to the clinic to follow-up, or they are left to research their questions on their own. Patients should be receiving all of the information they need to know about their health status from their healthcare provider. Not taking the time to inform patients of their condition and the next steps in their pre-diagnosis journey, can delay patients from accessing the care they need. In contrast, one patient reported a positive experience with their physician who made an effort to video call them and were pleased with the care they received from doctors.

> Participant: **“***Yeah. They video called him and as soon as he – they saw him on the screen, they said ‘you lost weight!’ Yeah, so. Went back with her again after that.*”
>
> Interviewer: “*Right.*”
>
> Participant: “*Yeah.*”
>
> Interviewer: “*So they were keeping good track of him.*”
>
> Participant: “*Oh yes, yeah.*”
>
> Interviewer: “*I heard the doctors - almost everybody when I ask about what was good, everyone says the doctors were fantastic out in St. John’s. Yeah. They have really good care.*”

Based on these findings, efforts to improve verbal communication and respect by healthcare providers can significantly improve the Indigenous patient care experience.

Being Your Own Health Advocate

Advocating for yourself was a core theme as it was spoken about in four of the communities (n= 4). Patients spoke about how self-advocacy is a requirement to get appropriate tests, to be sent to see specialists, and to be correctly diagnosed. Although many Indigenous participants emphasized how self-advocacy was necessary, certain individuals spoke about how they did not feel safe doing this, and the negative consequences that can result from doing so (i.e. coming off as aggressive and the police getting called).

In the following quote, one individual explains that if you do not advocate on behalf of yourself, you are sent home with Tylenol, or you are not taken seriously.

> "*like he said, he had to learn to ask to see a doctor. People don't know that. They don't know that they can request to see a doctor when there's no answers coming. Whether you're being sent back and forth from the hospital, brought home, like to home [inaudible] sometimes. A lot of times, they give Tylenol. People have different kinds of symptoms of many different illnesses and they're just sent home with Tylenol. And until our people can start to stand up and if they gotta call for help to see the doctor, like my husband had to.*"

According to this quote, patients need to request medical care. After patients present their healthcare situation to local healthcare providers, patients are not being provided with appropriate or effective treatment plans or medical care plans to investigate or potentially resolve their healthcare concern. As a result, many Nunatsiavut patients have to take their medical care into their own hands by 'standing up' or 'speaking up' to receive medical care.

In the following quote, one person reflected on a similar experience where their mother was sent home from the clinic despite having concerning symptoms.

> "*Same thing happened with my mom. Just not long after she passed away from aneurysm, they kept sending her home with Tylenol. And then she passed away from aneurysm like a couple days later. They just send them home with Tylenol. Tylenol, Tylenol. Like I think we need some kind of campaign about what you can do if they're sending you home from the hospital with Tylenol. Like you can call 811 or ask to see a doctor, you know?....I think there are too many people that we lost through the cracks and the gaps because they've been sent back home. Tylenol, Tylenol. So, people don't end up going there because they just keep sending you home. And when you try to raise your voice so they can hear you, and they say we don't tolerate that, I guess we'll call the RCMP when you try to speak up for yourself, so your voice is silenced again."*

This quote demonstrates that advocating for yourself to local healthcare providers to receive adequate medical care, can result in negative consequences. This situation demonstrates the lack of concern and care patients are receiving at their local community clinic. Although patients are reporting concerning symptoms, healthcare workers are not fulfilling their duty to provide acceptable standards of healthcare. In the situation above, local healthcare workers would rather threaten a patient to convince them to leave, than to take measures to further investigate their healthcare concern.

Unless patients ‘speak up’ and push for further investigation in their communities, their problems will go un-investigated and unaddressed. Therefore, the approval required for local-health care providers to take action and investigate patient’s healthcare concerns poses a significant barrier in the pre-diagnosis journey for patients.

Key Recommendations

Based on the interviews and sharing circles, the following recommendations were identified by Nunatsiavut community participants to improve the pre-diagnosis journey: 1) Cultural Safety Training; 2) Education and Resources on Cancer; 3) Increased Awareness of Navigation Services; 4) Enhanced Mental Health Services; and 5) Support Groups.

1. ***Cultural safety training for healthcare professionals***. There is a need for improvements to cultural safety training. Patients reported instances of discrimination for being Indigenous, and that they were receiving medical advice and treatment plans from healthcare providers based on Indigenous stereotypes (i.e. being told to stop drinking and smoking), and not on what they were communicating to healthcare providers (i.e. their cancer symptoms). Cultural safety training should educate healthcare providers about Indigenous culture, respect, and the harms of stereotyping and negative patient experiences.

As a part of the earlier project, ‘*Journey to the Big Land*,’ cultural sensitivity training was also identified as a necessity for healthcare workers. In order to address this need, cultural safety and sensitivity training was developed by the Government of NL in partnership with the health authority and Indigenous organizations (Power et al., 2016). This training is offered for Eastern

Health employees and provides education to healthcare professionals regarding the challenges faced in Indigenous communities and the complexities associated with traveling to access healthcare. The aim was to increase cultural safety among healthcare professionals so that Indigenous patients will feel more comfortable interacting with healthcare professionals and will better understand aspects of their diagnosis journey and treatment plan. Cultural safety training sessions were offered in-person between April 2016 and December 2016. Surveys revealed that the majority of participants (82.4%) had not completed a similar course before, and that their healthcare organization had not provided them with information relating to the different Indigenous groups in the province. However, it is unclear if this training or similar training is being offered to healthcare workers in NL.

The First Light St John's Friendship Center (2023b) offers Indigenous cultural diversity training that provides education on the different Indigenous groups in the province, their history, and why this information can be beneficial to know. They offer one-hour, three-hour, and eight-hour training sessions that include increasing levels of knowledge, and participation as levels increase. Sessions explore cultural humility, improve self-awareness, and can serve as an opportunity to enhance professional development for any professional working with Indigenous people.

Further, the Royal College of Physicians and Surgeons of Canada (2023) has strived to commit to Reconciliation in medical education. They have sought to implement Indigenous health education in the medical curriculum, provide cultural safety resources for practicing specialists to incorporate into their practice, and seek to include cultural safety training into all residency programs. In addition, they share online cultural training services to their website. An online training module is available in NL, additionally medical students at MUNL complete the module as part of their curriculum in addition to dedicated teaching on Indigenous health.

There appears to be an increase in implementation and development of cultural safety modules in the last decade. This training should be a requirement for all healthcare workers, despite the location in which they live. Recent research involving Inuit has shown that culturally safe cancer care involves providing access to traditional ways of life (i.e. traditional foods, being able to take part in Indigenous crafts), access to family support, and efforts are made by healthcare workers to communicate clearly with patients (Enuaraq et al., 2021). Therefore, it is important that cultural safety training is re-assessed on a regular basis, and that organizations collaborate with Indigenous groups to provide culturally safe care. In addition, this training can be completed by healthcare workers every few years to ensure they have the most up to date knowledge, and thereby have the maximum positive impact on Indigenous patients.

2. ***Education and Resources on Cancer***: Patients explained that they lacked knowledge of cancer (i.e. cancer symptoms) and next steps following a diagnosis. Educational materials and resources should be shared with patients prior to and following a diagnosis of cancer to inform them about cancer, cancer services, and next steps.

Cancer Care Ontario offers a variety of different cancer education resources and opportunities for patients. For example, they offer a virtual certified cancer self-learning course, free of charge, as well as Indigenous relationship and cultural awareness courses (Cancer Care Ontario, 2023a). In addition, they offer a cancer patient and family member education program with the aim of improving the patient experience (Cancer Care Ontario, 2023b). This program focuses on advancing the quality of cancer patient and family education, and aims to enhance patient and family knowledge of cancer care providers, and provides information and tools for support across the cancer continuum. It is offered virtually and is available to anyone interested. They also host events and provide opportunities for healthcare providers and medical students to broaden their cancer education.

In addition, the NL Health Services authority offers a variety of education materials and resources online for patients and families to help them understand their health condition (Eastern Health, 2022b). Of the resources advertised, are tools created as a part of the earlier ‘Journey to the Big Land’ project, such as the body part diagrams (translated into the different Indigenous languages), a booklet identifying common steps in the cancer patient healthcare journey, a patient passport (for cancer patients to organize their medical information for healthcare clinics or hospitals), and a community and clinic profiles booklet, that provides an overview of each of the community and clinic profiles in the province. There is also cancer screening resources, cancer symptom management resources, advanced care planning, and Canadian Cancer Society resources. These resources can be shared by (or printed by) healthcare providers for patients in their pre- and post- diagnosis journey and their family members.

3. ***Navigation Services***: Many patients were unaware that Indigenous patient navigation services were available in St. John’s. Those who were aware of the navigation program thought they were extremely helpful. It was recommended that the navigators are informed of patients traveling to St. John’s, and that the navigators should make the first contact with the patient. Participants explained that patient navigators can reduce their stress by helping them navigate an unfamiliar hospital. Participants also explained they had difficulty navigating communities following their arrival at the airport. A potential solution is to expand the navigator roles to include community navigation or transportation. Further, advertisements or posters can be

created and posted around the Health Science's Center in St. John's so that more people learn about the patient navigators and where they are located.

Patient navigators became the norm for healthcare systems in Canada in 2011 (Walkinshaw, 2011). Navigators can provide a measure of security for patients. They connect patients with the appropriate healthcare professionals, and a host of available services. Also, they can serve as a personal guide for patients.

In NL, the 'Aboriginal Patient Navigator' program was created by the First Light St. John's Friendship Center (2023a) in collaboration with the health authority. They are a registered-non-profit organization that serves urban and rural Indigenous peoples. Under this program they provide support and assistance to patients who have traveled for medical appointments. Navigators can also advocate for patients to ensure access to healthcare options, provide navigation and escort services to appointments, they can arrange translation services in Innu and Inuktitut if needed, and can assist patient access to meals, transportation, accommodations, and medical supplies.

Healthcare providers can also complete various virtual courses on patient navigation to better support patients in navigating the healthcare system (De Souza Institute, 2021; York University, n.d.).

4. ***Enhanced Mental Health Services***: Patients in three communities expressed that there is a lack of any mental health support. In addition, they emphasized that individuals suffering with cancer and their family members are in desperate need of mental healthcare. They called for an urgent increase in mental health specialists and services within the community. Based on these findings, there is an immediate need for increased awareness of mental health services that are accessible for Indigenous peoples.

The provincial Government has recognized this need for accessible mental health and launched the *'Towards Recovery: The Mental Health and Addictions Action Plan'* with the goals to address service gaps, increase support for successful mental health and addictions initiatives, and to provide direction for mental health policies and programs to better address the needs of communities (Government of NL, 2022a). This plan involved 54 recommendations that were all successfully achieved in March, 2022. In addition, the *'Our Path of Resilience: An Action Plan to Promote Life and Prevent Suicide in Newfoundland and Labrador'* was also launched. This plan involved the Indigenous Health Team, collaboration with people with lived experience with suicide loss, and other Indigenous partners. An action item under this plan included socially equitable prevention, intervention, and follow-up. The government committed about $4.5 million to this plan over the next four years.

The following mental health services are funded under local Governments.
The health authority offers free mental healthcare in the form of in-person and virtual appointments in multiple locations across the province (Bridge the Gap, 2023). Through the NIHB program, the NG (2023b) offers up to 22 hours of mental health counseling by a registered provider on a fee-for service basis. Also, their mental wellness and healing division offers a continuum of services for anyone with mental health issues, substance use issues, gambling and smoking issues, or for those considered to be at high-risk (NG, 2023a). Again, there is a need for increased advertising of these services amongst Indigenous communities.

5. ***Support Groups***: Patients spoke about a need for a support group within their community for those suffering with cancer, and a separate group for family members of cancer patients. Cancer patients and family members wish to speak with others in their situation, to reflect on their experience with individuals who are not in their family, and check-in with each

other. Cancer survivors, family members, and healthcare providers identified essential recommendations to be implemented to improve the pre-diagnosis journey.

Courage Compassion and Connection Project Gathering

On September 13th, 2022, a stakeholder gathering was hosted in Happy Valley-Goose Bay and was attended by 15 participants. Steering committee members, members from all of the Indigenous groups, and community liaisons attended. At the gathering, the Co-PI (MUNL). presented a PowerPoint that provided an overview of our project, our approach to data analysis, as well as the core themes identified, and suggested recommendations to address issues identified based on findings from all of the Indigenous groups. Findings specific to only one Indigenous group were not discussed. Next, a roundtable discussion involving all attendees took place.

During the discussion, all attendees agreed that the project's core themes accurately reflected their communities' pre-diagnosis cancer experience. Attendees also spoke about what they liked and disliked about participating in the project. They explained that although it was difficult at times, overall participants found it nice to have people come together to talk about their experience. In addition, participants felt validated when they learned of others having similar experiences. Participants wished they had more time to participate. Attendees explained that there was more interest in participating in the project once the word of the project spread throughout the entire community. However, at that point sharing circles and interviews had already happened. Attendees stated that they want findings from this project to be put to use and acted on. In addition, many attendees stated that they would participate in research projects again in the future.

In the following Chapter, I provide an overview of our main findings, and discuss the similarities and differences with existing literature on cancer care for Inuit communities. I also discuss the strengths, limitations, meaning, and implications of the study. Also, I summarize the core themes that emerged from sharing circles and interviews and provide an overview of the recommendations to improve the pre-diagnosis journey.

CHAPTER 5: DISCUSSION AND CONCLUSIONS

The study outlined in this thesis sought to identify key challenges in the healthcare journey of Indigenous cancer patients living in Labrador, and to maximize the use of resources to improve the Indigenous cancer experience. Culturally safe and appropriate research methods were used to investigate the reality of the journey one must undergo to receive a diagnosis of cancer in Labrador. The current thesis investigated the experiences of cancer patients, family, community members and healthcare providers in Rigolet, Nain, Postville, Makkovik and Hopedale. In particular, this thesis addressed a gap in the literature, regarding the challenges in the healthcare experience of Nunatsiavut's Indigenous communities. Patients expressed their opinions on how their community's healthcare experience can be improved. Despite the diversity in the participants' cancer diagnosis, and their location within Labrador, shared themes emerged in the interviews. Core themes included 1) Access and Supports; 2) Prolonged Investigation; 3) Travel; 4) Communication; 5) Fear and Anxiety; and 6) Being your own Health Advocate.

Although there were some male participants in the current study, there was an over-representation of female participants. One potential explanation for this may be due to the fact that men are less likely to seek healthcare and visit doctor's offices and hospitals, and are more reluctant to ask for help when needed compared to women (Neville, 2008; Pinkhasov et al., 2010). Therefore, it is possible they chose not to participate as they would have fewer healthcare experiences to speak about during interviews and sharing circles. Other potential reasons could be that men are less likely to participate in health promoting activities, are more likely to have cancer, and to die prematurely compared to women (Baker & Shand, 2017; Neville, 2008). Therefore, similar to some participants in the current study, they may be avoiding the healthcare clinic due to fear of receiving a life-altering diagnosis or find the topic to be too sensitive to speak about with others. Future research should investigate this gender discrepancy and explore male healthcare seeking and health-related research participation in Nunatsiavut.

Overall, there were similarities in our findings compared to previous research exploring cancer patient experiences of Indigenous patients in Canada (Carr et al., 2020; Jull et al., 2021; Enuaraq et al., 2021; Lavoie et al., 2016). For example, Carr et al. (2020) conducted an Inuit-led project involving the culturally appropriate data-gathering method of sharing circles to explore cancer care. Consistent with our study protocol, their research process was guided by Indigenous partners, participants were recruited through community liaisons, and the sharing circle was facilitated by an Indigenous community member. Also, similar to our findings, participants expressed interest in receiving second opinions from healthcare providers, mistrust in their local medical system and feared cancer experiences.

Our findings demonstrated that due to a lack of healthcare professionals in Indigenous communities, participants often had to travel long distances or they had to commute to other communities to receive cancer care. They reported the need to advocate for themselves, otherwise they would be sent home with a treatment plan for a condition they did not have. Eventually, after significant effort, when they received testing, they were diagnosed with late-stage cancers. Also, participants found it difficult navigating unfamiliar healthcare systems, and they lacked knowledge of cancer and the next steps following a diagnosis.

These findings are consistent with Jull et al. (2021) and Galloway et al. (2020) who found that Inuit patients from Nunavut are often dismissed by their community healthcare providers and eventually, when they receive approval for medical travel outside of their community, they receive a cancer diagnosis. Patients from this study also emphasized a need to be persistent to get attention for health issues and discussed needing to fly to receive cancer care. They shared the same feelings of Nunatsiavut patients who do not want to be alone when traveling outside of their communities. In addition, they found that patients identified a lack of knowledge about cancer care to be a barrier, negatively impacting their decision-making throughout their cancer experience.

Research by Lavoie et al. (2016) found that Indigenous patients in Ontario make multiple attempts to seek care locally, however, it wasn’t until they were transferred to an urban center that a cancer diagnosis was received. Similarly, Indigenous communities in Ontario face a critical shortage of clinical support. Therefore, it appears Indigenous patients in Canada share in the experience of Prolonged Investigation. Patients in this study also emphasized a need to ‘speak up’ and to be assertive in requesting care, and that traveling long distances alone while sick, and accessing support for these trips are challenges to accessing cancer care. These challenges relate to our themes of Being Your Own Health Advocate, and Access and Supports.

Consistent with our findings, previous research involving Inuit has found that ineffective communication from healthcare professionals at local hospitals is a persistent issue (Enuaraq et al. 2021; Galloway et al., 2020). As result, healthcare needs go unaddressed. Similar to our findings, patients discussed experiences where healthcare providers rushed communication, failed to listen, and spoke about how language barriers and use of medical jargon impacted their ability to understand their healthcare providers (Galloway et al., 2020). The experiences described above match those of the Indigenous peoples in Nunatsiavut.

There are also similarities in recommendations Indigenous patients make to address challenges identified in the cancer care journey in Canada (Enuaraq et al., 2021; Hordyk et al., 2017; Jull et al., 2021; Lavoie et al., 2016; Sheppard et al., 2019). Our findings showed that patients believe healthcare providers working in Indigenous communities should complete cultural-safety training (Enuaraq et al 2021; Hordyk et al., 2017), and that educational resources on cancer care, medical escorts for medical trips, cancer groups, mental healthcare and navigation services are necessary to improve the patient experience. Previous work has also revealed that patients value the support they receive from medical escorts on medical trips (Galloway et al., 2020; Jull et al., 2021; Inuvialuit Region Corporation, 2019). Further, patient navigators have been deemed helpful by Indigenous peoples, as they can assist with language translation, and navigation (Lavoie et al., 2016).

Inuit cancer patients in Saskatchewan have also recommended Indigenous cancer patient support groups to combat fear and increase support (Carr et al., 2020). They believe that coming together to share knowledge of any kind to other Indigenous cancer patients can help keep spirits strong. Overall, it appears that Indigenous peoples in other rural and remote regions in Canada share the same challenges to receiving culturally safe and accessible cancer care and have similar recommendations to improving their care.

Our findings revealed that although a few patients spoke about the financial burden associated with travel to attend their appointment, the majority of participants received funding as a part of their government’s NIHB program. For the most part, patients received funding to cover the costs for medical appointments requiring travel. These findings contradict previous work that shows Indigenous peoples experience difficulty getting their personal costs approved under NIHB for medical trips (First Nations Information Governance Centre, 2018). A potential reason for this is that in the present study the NIHB program was administered by NG on behalf of the Government of Canada, therefore, NG directly oversaw the NIHB program. This likely removed some of the delays that Inuit patients are encountering elsewhere. Therefore, the NIHB program can play a role in how timely patients receive care that requires travel to other regions.

NG's role within the NIHB program can help to facilitate and improve patient's healthcare journeys that require travel.

Prior research that has focused on Indigenous populations has found that patient delays in seeking medical advice, and a low-awareness of early cancer symptoms were barriers to receiving cancer care (Condon et al., 2006; Minore et al., 2005). Our findings suggest that this is not the case for the majority of Nunatsiavut patients. Four out five communities shared stories of advocating to receive the appropriate care, screening, or medical travel. In most cases, patients knew something was wrong, and fought to receive the care they believed they needed. They also emphasized the need to not be afraid when speaking on behalf of yourself and to trust your body. Further, individuals in all communities described experiences of making trips back and forth to the community clinics. It was only after an extensive period of time and negative interactions with healthcare providers, when participants began to lose hope and became reluctant to visit the clinic.

Although medical escorts were deemed essential for appointments requiring travel, patients explained there are strict rules for receiving approval for an escort, and often, they are denied this service. This was surprising as previous research has also outlined the importance of escorts for Indigenous patients requiring travel, and that escorts are often provided when requested (Enuaraq et al., 2021; Jull et al., 2021; Oosterveer & Young, 2015). One reason for this is likely a difference in access to funding for healthcare by Indigenous governments as well as the amount of funding set aside for this service. Also, it may not be considered necessary for patients to be accompanied by escorts if it is for a medical appointment. However, these appointments can entail receiving a diagnosis of cancer, therefore, having an escort for all medical trips is something the Federal Government should consider when making policies regarding the NIHB program.

Our findings showed that fear of cancer experiences has contributed to the hesitancy to visit the community clinic. However, research by Carr et al. (2020) found that although patients discussed fear associated with their cancer care experiences, the majority spoke optimistically about fear. They explained that it was important to experience fear as fear makes people human, and not weak. In addition, it was emphasized that it was important to fight fear with hope. One reason for this discrepancy in mindset could be the difference in incidence and morbidity rates of cancer in NL compared to Saskatchewan. The majority of individuals from communities in Nunatsiavut who discussed having a fear of cancer also discussed having family members who had cancer or knowing others who had died from cancer. However, similar to the Nunatsiavut participants, Inuit participants from Saskatchewan recommended the formation of an Indigenous cancer group to improve patient's mentality about cancer.

According to CPAC (2023f), predominantly Inuit Regions in Canada lack access to cancer screening programs. However, in the majority of sharing circles and interviews, participants stated they had access to preventative health services, such as cancer screening. Throughout the past decade there has been a variety of initiatives to improve cancer screening access. According to the CPAC's (2023e) Strategy for Cancer Control, there was a call to focus on existing screening programs and to eliminate barriers to participate in screening, particularly in under-screened communities. In 2003, CPAC, in collaboration with Eastern Health, launched a cervical cancer screening program in NL, and in 2012 a colorectal screening program was also launched (CPAC, 2023a). CPAC is also in the planning stages for a lung cancer screening program for NL, which is the most common cancer affecting Inuit in Canada (CPAC, 2023d).

In 2010, the Government of NL (2022a) released their cancer control framework called: '*Gaining Ground: A Provincial Cancer Control Policy Framework for Newfoundland and Labrador Opens in new window.'* This framework led to the launch of the colon cancer screening program, and in 2014, this program was extended to include people from Labrador (Labrador-Grenfell Health, 2023g). Individuals can receive at home screening tests if they contact the health authority, and it is recommended that everyone between the ages of 50 and 74 who are at an average risk of colon cancer to complete the screening (Eastern Health, 2022a). The NL framework has also promoted the uptake of cervical cancer screening. Individuals can receive pap tests across 21 community clinics and health centers in Labrador (Labrador-Grenfell Health, 2023a).

Under the theme of Prolonged Investigation, numerous patients discussed being misdiagnosed. Patients explained that they do not feel heard or believed when discussing their health status at local community clinics. Often, they are sent home, told to stop drinking and smoking, and eventually, they have to return back to the clinic when their symptoms do not improve. Communication and listening are core skills that all competent healthcare professionals and staff should possess (Jahromi et al., 2016). Not listening to patient's concerns can actually cause significant harm to patients (Leonard et al., 2004). In addition, communication has been deemed imperative in prior research involving Indigenous patients, and for achieving culturally safe cancer care (Enuaraq et al. 2021). In order to improve cultural safety and communication skills, patients believe that healthcare workers in Nunatsiavut should complete cultural safety training focused on education of their culture, respect, and communication skills. According to Sheppard et al. (2019), positive encounters within the healthcare system are not only important for receiving an early diagnosis, but the point-of-contact with healthcare providers sets the tone for the overall experience, and those going forward.

Under the theme of Access and Supports, the majority of participants discussed a lack of healthcare professionals, medical equipment, and mental healthcare in their communities. Also, similar to Jull et al. (2021), Indigenous patients lacked knowledge of cancer, the next steps following a diagnosis, and cancer resources. One reason for this could be that Northern healthcare systems face the challenge of provider recruitment and retention, high caseloads, and resource constraints, and therefore, lack the time required to effectively debrief patients (Jull et al., 2021; McDonnell et al., 2019). Also, a lack of quality internet access can impede patients from conducting online searches for resources. Despite these challenges, patients should be informed of all of the relevant supports they can avail of (i.e. cancer booklets, free mental healthcare). In order to address these issues, participants from our study recommended the creation and sharing of educational materials on cancer, next steps following a diagnosis, accessible services, and patient rights. Further, increased advertising of cancer resources that exist was suggested.

The theme Fear and Anxiety was created as patients explained their fear of hearing the word ‘cancer’, their fear of being diagnosed with cancer, and anxiety when traveling to unfamiliar communities alone. Patients explained that these factors have contributed to their reluctance to go to the community clinic. Screening and early detection are crucial to receiving appropriate treatment, and reducing the risk of mortality from cancer (NCCIH, 2019). Sheppard et al. (2010) investigated the rates of cancer screening uptake in Indigenous peoples in Ontario, and emphasized the importance of increasing knowledge of the benefits of cancer screening. They found that Indigenous patients who were not screened were more likely to present with late-stage cancers, and have untreatable cancers. By enhancing knowledge around cancer screening, they believe there is a greater likelihood that screening rates will increase, and cancer will be detected in stages that are treatable. Therefore, over time, it might be possible to improve health outcomes for Indigenous patients who are diagnosed with cancer, and reduce fear of cancer experiences in the community. Also, patients explained that having access to medical escorts and/or patient navigators can help reduce the anxiety and fear they experience when traveling to unfamiliar areas for medical appointments.

Strengths of the Study

There were several strengths to the current study. First our study was Indigenous-led (NG) and guided by a Steering Committee composed of proposal partners (NCC, MUNL), other Indigenous group partners, and representation from the health authority who together, provided direction and input regarding the project. Their contributions provided valuable information and support to the team. In addition, strong relationships between the Steering Committee and Indigenous partners allowed for project outcomes and goals to be achieved, despite being in the midst of a global pandemic. The team provided support to one another, and was determined to complete this project, which contributed to its success. Also, member-checking was completed at community engagement sessions, and attendees affirmed our findings were an accurate representation of their community perspectives.

Culturally sensitive and community-specific data collection methodologies were used for the current study. This Indigenous-approach likely aided in creating a welcoming atmosphere for participants, facilitated the data collection process, and helped to repair prior damaged relationships between University/Western institutions and Indigenous communities. Finally, this is the first study to provide an in-depth investigation into the pre-diagnosis journey of the

Indigenous cancer-patient experience in Labrador. These findings can be used by patients, policy-makers, researchers, and leaders to make improvements to the Indigenous cancer patient experience.

Limitations of the Study

The present study must be considered with limitations in mind. First, the current study's timeline took place amidst the COVID-19 pandemic. Therefore, travel restrictions and levels of participation affected the depth of engagement of the project. In addition, due to changes in our timeline and schedule, data collection, analysis and member-checking was delayed. Also, our plan involved engaging partners throughout the entire project (e.g., multiple community visits and meetings; opportunities to participate in working groups; newsletters and other communications, creation of knowledge mobilization materials). Finally, the Steering Committee was going to spend a few days in each community to facilitate cultural land-based activities in each community (i.e. ice-fishing, boil-ups, and berry-picking). Due to schedule changes and COVID-19, the process to engage partners was prolonged and cultural land-based activities involving the Steering Committee members were unable to take place.

Reflexivity

Reflexivity involves continual critical evaluation of the researcher's positionality and acknowledgement that their positionality can affect the research (Berger; 2015; Bradbury-Jones, 2007). It enhances the quality of research by allowing researchers to think critically about who they are and how this can both assist and hinder the research process (Lietz et al., 2006). It has been deemed imperative for researchers to participate in reflexivity when conducting Indigenous research (Russell-Mundine, 2012). In addition, understanding the researcher's world-view and personal factors that can impact the research has been considered integral to the Indigenous research paradigm.

As mentioned in Chapter 3, I am an Inuk Master's student with family from Nunatsiavut, Labrador. I completed data analysis, attended a project gathering, and wrote the current thesis based on the project. The Project Coordinator is a Nunatsiavut beneficiary, who completed most of the data collection, was involved in data analysis, and planning for the project. The Co-PI (MUNL) is non-Indigenous, but a long-term Indigenous health researcher and partner with the NG, and conducted data analysis, data collection, project planning, and supervised me throughout thesis development. The Co-PIs (NG) played lead roles in planning and oversight. The Co-PI (NCC) also assisted with project planning.

Having personal connections to the research topic, and involvement of a Steering Committee with members from Labrador allowed for the majority of the research team to have an 'insider' role. This offered multiple advantages to the study, as Co-Investigators and Committee members had a head start of knowing about the research topic and community members which facilitated project planning, data collection methods, and recruitment strategies (Padgett, 2008). In addition, the cultural knowledge of the Steering Committee and project Co-investigators helped to ensure that project methods and decisions made about the project were culturally respectful. For example, they selected the data collection methods, and helped to plan community engagement activities. Also, community liaisons consisted of health care workers from each of the Nunatsiavut communities. As a result, most of the participants that were contacted by the liaisons were receptive to the project, and showed interested in being and were cooperative throughout the research process. It is important to note that the gender of all community liaisons were female and this may have impacted the over-representation of female participants in our study.

The Project Coordinator's 'internal' position helped to ensure that interviews went smoothly, as she knew how to ask questions, when to probe more, and she was aware of potential sensitivities (Berger, 2015). Also, having someone from the same community lead the interviews/sharing circles along with the Co-PI's (MUNL) long term relationships with Nunatsiavut community members, could have helped to combat potential power-differentials during data collection, compared to if an 'outsider' or unknown researcher led data collection (Berger, 2015; Pillow, 2003).

The Co-PI's (MUNL) research background is focused on Indigenous health and health care service improvement across the province. In addition, she has built long-term and strong relationships with the included Indigenous groups. Her knowledge aided project planning and data analysis, as she was familiar with culturally appropriate research processes to follow and appropriate research methods to use. Also, she was familiar with the health care setting in Labrador, and all community clinics, and hospitals that participants discussed. Further, being an Expert in her field, allowed her to effectively supervise and guide me throughout thesis development, as she able to provide me with insight into relevant topics and topics I should discuss in my thesis.

Reflexivity also involves monitoring the impact researcher biases, beliefs and experiences (Berger, 2015). Due to the fact that the interviewer was from Labrador, it is possible that the results could have been subject to an interviewer bias, as participants could have known the interviewer and as result, altered their responses. However, being of the same culture of some participants' and having a common goal to improve healthcare services within Nunatsiavut communities, participants may have felt more comfortable during data collection compared to if an ‘outsider’ conducted data collection. Also, data analysis and collection was more challenging for the Project Coordinator as she had to separate her prior knowledge of people’s healthcare experiences within Nunatsiavut from the experiences of participants. I also had to separate the experiences of my family members from those of participants during data analysis. This required making a conscious effort to ensure the themes I was identifying were specific to only the interviews conducted. However, it is possible that my knowledge could have influenced my interpretation of the data (Berger, 2015).

In line with the CBPR approach, other strategies to increase reflexivity were implemented in the current project, such as prolonged engagement, efforts to maintain strong relationships, co-creation of knowledge, and member-checking (Berger, 2015; Brad-bury Jones, 2007; Jull et al., 2017; Padgett, 2008).

Overall, I believe our diverse and knowledgeable research team contributed to the success of this project. I strongly valued the opportunity to complete a thesis on this project, and I believe my personal connection to Nunatsiavut, and knowledge of my family's healthcare experiences further motivated me to do the best job that I could in my role. I wanted to learn of other Nunatsiavut community member experiences within the healthcare system and be a part of the process to help make improvements to their experiences.

Implications for Community Clinical Care

This study explored the challenges associated with the pre-diagnosis journey for Indigenous patients in Nunatsiavut. Participants were asked about their cancer care experiences, or those of family members, friends, or patients. Participant feedback and recommendations are summarized in the current study and can be particularly useful for health-leaders, healthcare professionals, and hospital staff located in Indigenous communities who wish to improve the quality of care for Indigenous patients. Patients identified ways to improve patient-provider interactions, such as being respectful, patient, and making efforts to listen and communicate effectively. Also, the results from the current study can be used to develop or enhance a learning module or curriculum for Labrador healthcare providers to improve cultural safety and relationships between Indigenous peoples and the healthcare system.

The following resources and tools are currently being created by the Steering Committee in collaboration with Indigenous partners as a part of the larger project. These tools are being developed with an aim to address a lack of knowledge related to the pre-diagnosis journey, to share study findings, motivational quotes, and images of cancer patients and their family members in hospitals and clinics across Labrador They are still in progress as feedback from Indigenous partners is still being implemented to improve them. See below for a description of each resource:

Maps

Maps were created to demonstrate the distance and time it takes for Labrador Inuit to travel from their communities for medical appointments and testing. A map was created specifically for Nunatsiavut and these will be placed in clinics and hospitals in Labrador.

Posters

Posters with images of Indigenous patients and family supports at different points of their cancer journey were created to help people in communities feel as if they are not alone. The posters included quotes from each patient that was pictured, demonstrating different points in their healthcare journey. Posters will be placed at different clinics and healthcare centers.

Infographics

Infographics were created to provide the communities with an overview of the findings of the cancer research project. Infographics will be shared with all communities in Labrador and the different Indigenous organizations.

Once completed, the following resources and tools can be shared with and used by patients in the pre-diagnosis phase of the cancer journey, their family members, and health care providers.

Implications For Policy

The Canadian Health Act states that all Canadians should have reasonable access to healthcare that is equitable, accessible, and promotes or restores physical and mental wellbeing of residents, without financial or other barriers (Government of Canada, 2023a). Our findings suggest that Nunatsiavut community members lack accessibility to quality healthcare that is culturally appropriate, and face numerous barriers to receive a diagnosis of cancer. Nunatsiavut community members are concerned about the absence of healthcare professionals, medical equipment and mental healthcare across their communities. Patients often reported being misdiagnosed or having received diagnoses of late-stage cancers. Government officials, healthcare leaders, and policy-makers can work to address the shortage of healthcare professionals in the community by allocating funding to incentivize healthcare professionals to work in Nunatsiavut communities.

In 2017, the Collaborative Task Force, composed of the College of Family Physicians of Canada and the Society of Rural Physicians of Canada developed the Rural Road Map of Action with an aim to address the health disparities faced by rural and remote populations (Soles et al., 2017). The social accountability framework includes 20 recommendations with an aim to improve access to rural healthcare. One of these recommendations is to implement policies within health service delivery areas that require acceptance of timely transfers and appropriate consultations between rural, secondary, and tertiary hospitals. Another recommendation is to develop specific resources, infrastructure, and networks of care within local and regional health authorities to address access issues for healthcare (College of Family Physicians of Canada and the Society of Rural Physicians of Canada, 2017). Actions taken to achieve these recommendations have the potential to improve the cancer care experience for Inuit in Labrador.

Also, greater investments in cancer care services, medical equipment, virtual and in-person mental health services, and the required bandwidth to use this technology are needed in Labrador. By reducing the need for patients to travel to urban regions for care, there is an opportunity to alleviate some of the fear, anxiety, and stress that Indigenous patient's experience. The provincial and federal governments are in a crucial position to assist in improving the healthcare experience for Labrador's Indigenous communities.

Implications for Future Research

Based on the findings from this study, future research should investigate:

1. The quality and uptake of cultural safety and/or cultural sensitivity training completed by healthcare providers in NL.

2. An investigation of effective strategies to recruit and retain healthcare professionals in Indigenous communities in Labrador.
3. Effective methods to increase awareness and uptake of resources and supports that are available in remote Indigenous communities.
4. The out-of-pocket costs for Indigenous patients from Labrador to receive cancer care.

Summary of Main Findings

A concern for the cancer care experience by the Indigenous governments in Labrador prompted the initiation of the current study. We summarized the challenges Indigenous patients face in the pre-diagnosis journey and recommendations to improve this journey. The research question that guided this work was 'What challenges and solutions will cancer patients and survivors identify to improve the cancer care experience of Labrador's Indigenous cancer patients?

Six core themes that represent areas for improvement emerged from sharing circles and interviews with the 32 participants: 1) Access and Supports; 2) Prolonged Investigation; 3) Travel; 4) Fear and Anxiety; 5) Communication; and 6) Being your own health advocate. Themes identified were topics that participants discussed during sharing circles or interviews in a minimum of three different communities. Our results demonstrated that the most important themes to target improvements in the patient experience are 'access and supports', and 'prolonged investigation'. Individuals from all five communities discussed topics that fell under these themes. Recommendations to improve the pre-diagnosis journey included: 1) Cultural Safety training; 2) Education and Resources on Cancer; 3) Increased awareness of Navigation Services; 4) Enhanced Mental Health Services; and 5) Support Groups.

This research project was Indigenous-led (NG), and involved the Co-PIs, a Steering Committee with Labrador-Grenfell Health Authority representatives, as well as community liaisons and community members throughout the course of the project. This was a strength of the current study. These partnerships allowed for individuals who would be impacted by the research, to lead the research. In addition, their perspectives ensured that the research objectives were targeted to best address community needs, and that the methods of data collection were culturally appropriate. Using a strength-based approach allowed for the current project to be a success, amidst a global pandemic. Sharing circles and interviews took place in all of the identified Nunatsiavut communities and allowed for cancer patients, family members and healthcare providers to identify issues in the pre-diagnosis cancer journey and recommendations to address issues identified.

The current thesis can be used by government officials, healthcare care workers, and patients to 1) inform policy recommendations to enhance Indigenous healthcare 2) improve patient-provider interactions; 3) increase awareness and uptake of resources and supports for patients; and 4) improve Indigenous patient health outcomes and experiences.

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APPENDIX A – ETHICS APPROVALS

Research Ethics Office
Suite 200, Eastern Trust Building
95 Bonaventure Avenue St.
St. John’s, NL

A1B 2X5

December 20, 2019

Dear Dr Shea:

Researcher Portal File # 20201068
Reference # 2019.227

RE: Courage, Compassion and Connection - The journey to healing: exploring cancer pre-diagnosis for Indigenous peoples in Labrador

Your application was reviewed by the Health Research Ethics Board (HREB) at the meeting held on November 7, 2019 and your response was reviewed by the Co-Chair on December 20, 2019 under the direction of the HREB and the following decision was rendered:

X	Approval
	Approval subject to changes
	Rejection

Ethics approval is granted for one year effective December 20, 2019. This ethics approval will be reported to the board at the next scheduled HREB meeting.

This is to confirm that the HREB reviewed and approved or acknowledged the following documents (as indicated):

Application, approved
Research proposal, approved
Revised recruitment script, approved
Revised consent, approved

Signed MOU - NG, NCC & MUN, approved
Discussion guide, approved
Information letter, approved
Poster, approved
NG Map, approved
NCC Map, approved
Map - Innu Land, approved
NG Support Letter, acknowledged
SIFN Support Letter, acknowledged
NCC Support Letter, acknowledged
MIFN support letter, acknowledged
Funding agreement (including budget), acknowleged

Please note the following:

This ethics approval will lapse on December 20, 2020. It is your responsibility to ensure that the Ethics Renewal form is submitted prior to the renewal date.
This is your ethics approval only. Organizational approval may also be required. It is your responsibility to seek the necessary organizational approvals.
Modifications of the study are not permitted without prior approval from the HREB. Request for modification to the study must be outlined on the relevant Event Form available on the Researcher Portal website.
Though this research has received HREB approval, you are responsible for the ethical conduct of this research.
If you have any questions please contact info@hrea.ca or 709 777 6974.

The HREB operates according to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2), ICH Guidance E6: Good Clinical Practice Guidelines (GCP), the Health Research Ethics Authority Act (HREA Act) and applicable laws and regulations.

We wish you every success with your study.

Sincerely,

Dr Joy Maddigan, Co-Chair, Non-Clinical Trials
Health Research Ethics Board
You Have Received Ethics Approval, Now What?: HREB Reporting Requirements

Once a study has received ethics approval from the Health Research Ethics Board (HREB), there are still associated reporting requirements. In the conduct of approved research researchers are required to report to the HREB, in a timely manner, proposed changes from approved research that affect participants at any stage of the process. This includes, but is not limited to, changes to the consent form, changes to the tasks or interventions involved in the research, or changes to measures to protect privacy and confidentiality.

Any substantive change to the research should not be implemented prior to documented approval by the HREB, except when necessary to eliminate an immediate risk(s) to the participants. Below are examples of post approval documentation that must be submitted to the HREB:

Amendments

Any proposed change in the conduct of a study must be submitted to the HREB, and approved, before the change may be implemented. Such changes might include modification of recruitment procedures, inclusion or exclusion criteria, revised sample size, addition or deletion of study sites, changes to an intervention, consent forms, questionnaires or scripts, etc. If there are changes in project team members or changes to funding source(s)/sponsor(s), there are specific forms to complete to report this to the HREB.

Adverse Events

Serious and unanticipated adverse events that occur within Newfoundland and Labrador are required to be reported to the HREB. Such events may occur in both clinical trials and in other types of research, e.g. collapse during a rehabilitation program, emotional breakdown requiring follow up care during an interview, or breach of privacy during correspondence. Serious adverse events that are fatal or life-threatening are required to be reported to the HREB as soon as the research team is aware of the event.

Protocol Deviations

Deviations from an approved study protocol must be reported to the HREB. Changes that eliminate immediate hazards to participants do not require prior approval, but must be reported soon as reasonably possible.

Safety Reports

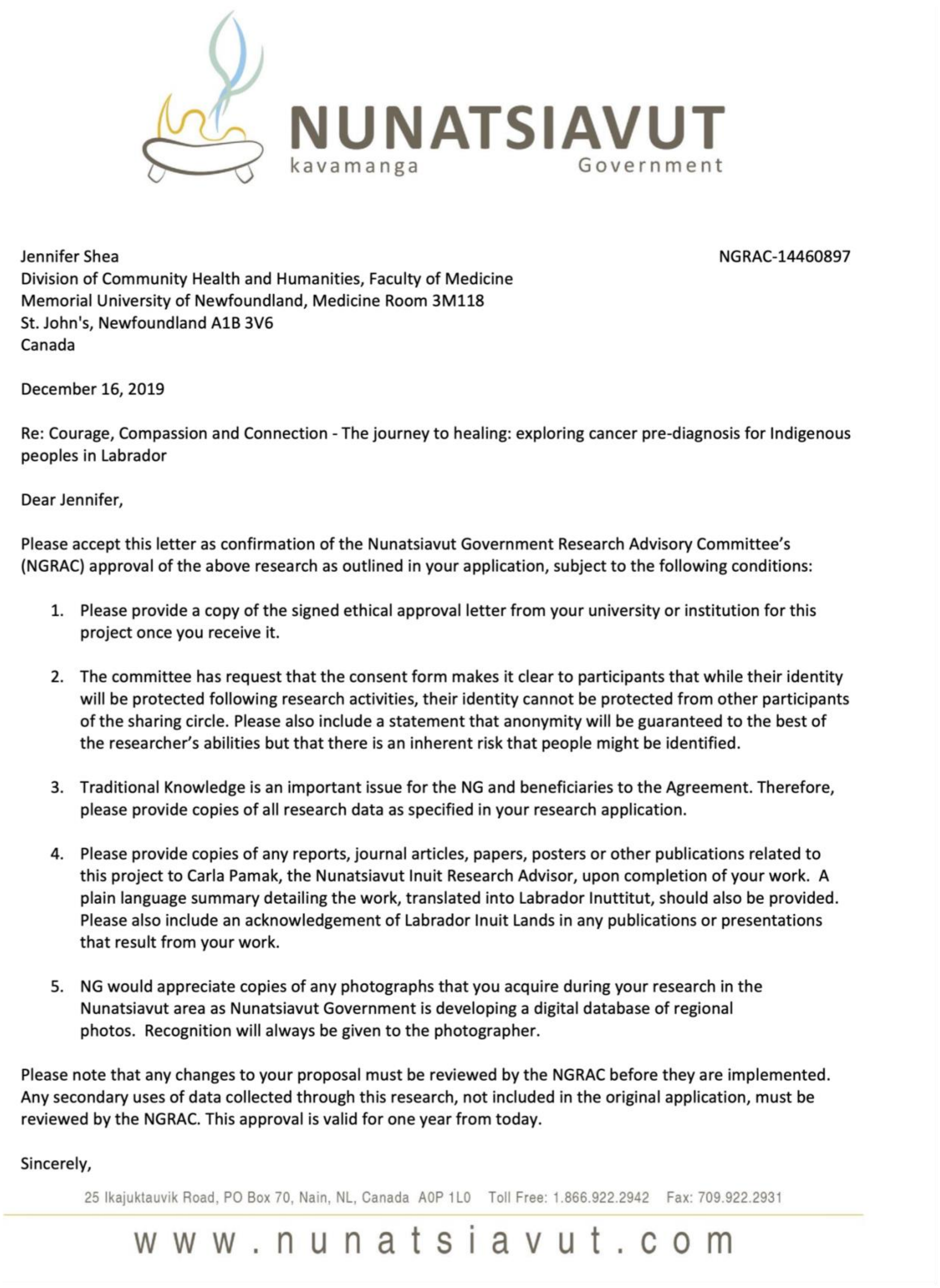
Safety reports providing information on all serious adverse events (SAEs) occurring in a clinical trial must be provided by the sponsor to the HREB, normally on a three or six monthly basis (i.e. in accordance with the specified reporting timelines that were outlined in the approved ethics application).

Investigator Brochure (IB) and Product Monograph (PM)

Throughout the course of a clinical trial, changes may be implemented to study documents. All revisions to approved study documents must be submitted to the HREB to ensure the record is up to date. If the revisions include new risk or safety information there may be a requirement to notify research participants.

Ethics Renewal/Study Closure

Ethics approval lasts for one year. Ethics renewal is required annually, on the anniversary of the date of the HREB notification of approval. Once data collection is no longer ongoing, a study closure form is required to be submitted to the HREB for the study to remain active or to be closed in good standing.



NUNATSIAVUT
kavamanga Government

Jennifer Shea
Division of Community Health and Humanities, Faculty of Medicine
Memorial University of Newfoundland, Medicine Room 3M118
St. John's, Newfoundland A1B 3V6
Canada

NGRAC-14460897

December 16, 2019

Re: Courage, Compassion and Connection - The journey to healing: exploring cancer pre-diagnosis for Indigenous peoples in Labrador

Dear Jennifer,

Please accept this letter as confirmation of the Nunatsiavut Government Research Advisory Committee's (NGRAC) approval of the above research as outlined in your application, subject to the following conditions:

1. Please provide a copy of the signed ethical approval letter from your university or institution for this project once you receive it.

2. The committee has request that the consent form makes it clear to participants that while their identity will be protected following research activities, their identity cannot be protected from other participants of the sharing circle. Please also include a statement that anonymity will be guaranteed to the best of the researcher's abilities but that there is an inherent risk that people might be identified.

3. Traditional Knowledge is an important issue for the NG and beneficiaries to the Agreement. Therefore, please provide copies of all research data as specified in your research application.

4. Please provide copies of any reports, journal articles, papers, posters or other publications related to this project to Carla Pamak, the Nunatsiavut Inuit Research Advisor, upon completion of your work. A plain language summary detailing the work, translated into Labrador Inuttitut, should also be provided. Please also include an acknowledgement of Labrador Inuit Lands in any publications or presentations that result from your work.

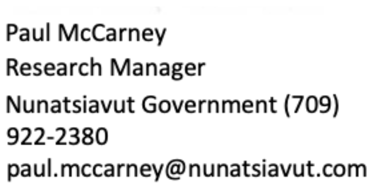
5. NG would appreciate copies of any photographs that you acquire during your research in the Nunatsiavut area as Nunatsiavut Government is developing a digital database of regional photos. Recognition will always be given to the photographer.

Please note that any changes to your proposal must be reviewed by the NGRAC before they are implemented. Any secondary uses of data collected through this research, not included in the original application, must be reviewed by the NGRAC. This approval is valid for one year from today.

Sincerely,

25 Ikajuktauvik Road, PO Box 70, Nain, NL, Canada A0P 1L0 Toll Free: 1.866.922.2942 Fax: 709.922.2931

www.nunatsiavut.com



Paul McCarney
Research Manager
Nunatsiavut Government (709)
922-2380
paul.mccarney@nunatsiavut.com

APPENDIX B - CONSENT FORM

Informed Consent Form for Qualitative and Community Based Research

Title:
Courage, Compassion and Connection - The journey to healing: exploring cancer pre-diagnosis for Indigenous peoples in Labrador

Researchers:
Jennifer Shea, Faculty of Medicine, Memorial University
Sylvia Doody, Nunatsiavut Government Department of Health & Social Development (NG DHSD)
Tina Buckle, NG DHSD
Darlene Wall, NunatuKavut Community Council (NCC)
Kathy Michelin, Policy Analyst, NG DHSD
Jennifer Bent, Master of Science Student, Faculty of Medicine, Memorial University
Jessica Pelley, Medical Student, Faculty of Medicine, Memorial University

You are invited to take part in our project "*Courage, Compassion and Connection – The journey to healing: exploring cancer pre-diagnosis for Indigenous peoples in Labrador*."
This is a standard consent form. It will give you a basic idea of what this project is about and what will be involved if you wish to take part. To decide, you should understand enough about the potential risks and benefits, this is the informed consent process.

Take time to read this form carefully and to understand the information given to you. Please contact the researcher before you consent if you have any questions or want more information about the study.

Introduction/ Background to the study

My name is Jennifer Shea and I am a researcher at Memorial University. I have worked with communities in Labrador since 2009. Sylvia Doody, Tina Buckle, Kathy Michelin (NG DHSD), Darlene Wall (NCC), and Jessica Pelley (medical student) are also researchers for this project. As a team, we developed the study together to learn more about the pre-diagnosis cancer journey in Indigenous communities in Labrador and to help identify what is working and improvements that need to be made. This continues the work of the "Journey in the Big Land" project with a continued focus on community consultation.

Purpose of study
In the sharing circle with community members, we will speak about and learn more about the journey before and during a cancer diagnosis in the community. The main objectives of the study are:
(1) To gain insight into the pre-diagnosis journey for Indigenous patients in Labrador;
(2) To improve connections between Indigenous partners and cancer organization partners in order to improve and advance community specific changes and improve the cancer experience for First Nations, Inuit and Métis people affected by cancer.

What you will do in this study
You will participate in a sharing circle with other community members.

Length of time
The sharing circle will be about 1.5-2 hours in length.

Withdrawal from the study
It is entirely up to you to decide whether to take part in this research and you can withdraw at any time. If you choose to not take part, or to drop out it will not affect your access to health care, or any services provided by your health care provider. You may stop answering questions at any time. If you change your mind about taking part we will eliminate as much information contributed to the group discussion as possible, keeping in mind it is a group conversation and it may be impossible to eliminate all of the conversation.

Possible benefits
There is no known benefit to the study.
Possible risks
Due to the sensitive nature of the topics of cancer and health some participants may feel shy, upset or uncomfortable. The name and contact information for a counsellor will be given to all participants (free of charge) if they wish to talk to a professional about any issue talked about. This information will be given to participants at the start of the project. Researchers will also check in with each participant at least twice following the sharing circle to ensure they are doing well and to refer to supports if needed.

Privacy and Confidentiality
Confidentiality means ensuring that identities of participants are only known to those allowed to have access. All paper and electronic files will be stored in a locked filing cabinet and/or secure computer in Jennifer Shea's or Sylvia Doody's office.
Anonymity

Anonymity means not sharing participant names or descriptions of physical appearance. There is a difference between anonymous participation and anonymous data. Every reasonable effort will be made to ensure participants anonymity, and that they will not be named in any reports and publications without their permission.

Although quotations from the sharing circle may be reported, if you wish you will be given a pseudonym (a pretend name) to help keep your identity private. All identifying information will be removed. The sharing circle will be audio taped. You may ask to have the recorder turned off at any point. You do not have to answer any questions you do not wish to answer. After participation in the sharing circle you will be offered the opportunity to review and comment on preliminary analyses from the sharing circles.

Storage of Data

Paper files will be kept in a locked cabinet in Jennifer Shea's secure office. Electronic files will be password protected and held on a secure device. Both Jennifer and Sylvia will have a copy of electronic files. Data will be kept for the standard 5-year period, then destroyed by a private shredding company and all electronic files will be deleted using a computer program.

Reporting of Results

The findings of this study will be shared with First Nations, Inuit and Métis communities of Labrador. It will potentially be in reports, presentations or publications. Findings from the study may be used to apply for future research funding and grants. And maybe used to respond to cancer in the community, and for health planning efforts.

Sharing of Results with Participants

All participants will be encouraged to ask questions throughout the research process. A written report of the findings will be given to all participants nearing the completion of the study. We will work with participants and the community to develop plain language materials to share information about the study, (such as posters). The researchers (and other community coauthors) may present at an academic conference, publish or share report with decision makers.

Conflict of Interest

No conflicts of interest to report.

Questions or problems

If you have any questions about taking part in this study, you can contact the researcher who is in charge of this study. Jennifer Shea can be reached at 709-864-3374.

You can also talk to someone not involved in the study but who can advise you on your rights as a participant in this study.

This person can be reached at:

Ethics Office
Health Research Ethics Authority
709-777-6974 or by email at info@hrea.ca

If you sign this form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

A copy of this Informed Consent Form will be given to you for your records.

Signature Page

Your signature on this form means that:

- You have read the information about the research.
- You have been able to ask questions about your involvement in this study.
- You are comfortable with the answers to all your questions.
- You understand what the study is about and what you will be doing.
- You understand that you are free to leave the study at any time, without penalty.
- You understand if you change your mind about taking part we will eliminate as much information contributed to the group discussion as possible, keeping in mind it is a group conversation and it may be impossible to eliminate all of the conversation

Your signature:

[ ] I have read what this study is about. I understand the risks and benefits. I have had enough time to think about taking part.
[ ] I have had the opportunity to ask questions and my questions have been answered.
[ ] I understand that this project will involve taking part in a sharing circle discussion.
[ ] I grant permission to be audio taped during the sharing circle.
[ ] I agree to participate in this research project. I understand the risks and what I would be asked to do. I also know that my participation is voluntary, and that I may stop participating at any time.
[ ] A copy of this form has been given to me for my records.

Signature of Participant		Date (DD-MM-YYYY)

To be signed by the researcher or person obtaining consent:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study and potential risk. And they have freely chosen to be in the study.

Signature of researcher Date (DD-MM-YYYY)

Assent of minor participant:

To be signed by the minor participant IF APPLICABLE (16-18 years of age)

Your signature on this form means that:

- You have read the information about the research.
- You have been able to ask questions about your involvement in this study.
- You are comfortable with the answers to all your questions.
- You understand what the study is about and what you will be doing.
- You understand that you are free to leave the study without having to give a reason. It will not affect you now or in the future.
- You understand if you change your mind about taking part we will eliminate as much information contributed to the group discussion as possible, keeping in mind it is a group conversation and it may be impossible to eliminate all of the conversation

Signature of minor participant Date (DD-MM-YYYY)

Name printed Age

Signature of parent/guardian Date (DD-MM-YYYY)

To be signed by the researcher or person obtaining consent:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study and potential risk. And they have freely chosen to be in the study.

Signature of researcher Date (DD-MM-YYYY

APPENDIX C - DISCUSSION GUIDE FOR INTERVIEWS AND SHARING CIRCLES

DISCUSSION GUIDE

This is an informal discussion guide. Questions will be further identified and refined with input from community contacts. Questions vary slightly based on patients, family/caregiver and health care professionals.

Patient Questions

Patients will asked to share their journey. Below are some questions to begin discussions.

Have you ever participated in any screening initiatives before?
Are you aware of any screening tests available in your community?
How did you enter the healthcare system?
Were you happy with the services and communication that were provided?
What two (2) things worked well and you were happy with?
What two (2) things would you have changed to help make the process better?
What supports were available to you? (e.g., stress, uncertainty etc…)
Is there anything else about your pre-diagnosis cancer journey that you would like me to know?

Caregiver/Family Questions

We are interested in learning about the impacts of the journey on loved ones, caregivers and the larger community.

Do you (or have you) help care for someone with cancer?
Are you aware of the patient's journey to diagnosis?
How were you involved with the patient leading up to a diagnosis?
What two (2) things worked well and you were happy with?
What two (2) things would you have changed to help make the process better?
Please tell me about the journey? Include what you felt as well.
Is there anything else that you would like me to know?

Health professional Questions

Health care professionals in the community play a key role in the pre-diagnosis of patients and community health generally.

What is your role in a patient's cancer journey?
Are there any experiences you would like to share regarding in caring for a cancer patient?
What are two (2) things that you think works within the system?
What are two (2) things you would change to make the process better?
Is there anything else about your pre-diagnosis cancer journey that you would like me to know?