

*Red River Métis Health Knowledge Authority*

# The Red River Métis Cancer Journey in Manitoba



**Winnipeg, Manitoba, Canada 2023**

**Manitoba Métis Federation**

**Health & Wellness Department**

**Authors:**

Chantal Perchotte

Olena Kloss

Julianne Sanguins

William Harrison

Wajihah Mughal

Bronson King

Bryce Gallant

A. Frances Chartrand

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Health & Wellness Department  
Manitoba Métis Federation  
150 Henry Avenue  
Winnipeg, Manitoba R3B 0J7  
Telephone: (204) 586-8474

# A Message from the Minister of Health & Wellness

## FOREWORD FROM MINISTER FRANCES CHARTRAND

*It is with immense gratitude and a deep sense of purpose that I address the resilient and vibrant Red River Métis Citizens, our esteemed staff, and our invaluable funders through these words. The idea of distinctions-based healthcare is crucial to the Manitoba Métis Federation. It recognizes the history and culture of Indigenous peoples, including Red River Métis Citizens, and acknowledges systemic inequalities. We aim to nurture a healthier and prosperous future for our community and create relevant programs and support for our Citizens. Our Red River Métis Citizens have shown time and again their commitment to the betterment of our community's health and well-being. Your voices, stories, experiences, and active participation in our research are the foundation upon which we build a future of improved health outcomes and holistic well-being.*

*To the remarkable staff from the Health & Wellness Department who facilitate research and program development for our Citizens I extend my deepest thanks. Your commitment to ensuring the success of our initiatives, and your unwavering dedication to the well-being of our Citizens is commendable. It is through your efforts that we have been able to gather meaningful data, provide a safe space for dialogue, and offer a platform for the voices of our Red River Métis Citizens to be heard. No endeavor of this magnitude can be achieved without the support of those who believe in our vision. To our esteemed funders, your commitment to our community speaks volumes. Your belief in our mission has enabled us to take strides toward implementing distinctions-based healthcare that not only acknowledges the unique needs of our community but also paves the way for equitable and accessible services.*

*In closing, I want to reiterate my deepest gratitude to each and every one of you. Your participation, dedication, and support have transformed research from a mere endeavor into a beacon of hope and progress. Together, we are shaping a future where the well-being of our Red River Métis Citizens stands as a testament to the strength of community, the power of collaboration, and the potential of compassionate healthcare.*

*With heartfelt appreciation,*

*Minister Frances Chartrand*



## **Acknowledgments**

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## **Disclosure**

The results and conclusions in this report are those of the authors, and no official endorsement by Canadian Partnership Against Cancer or other parties is intended or should be inferred. For the purposes of this study, we obtained approvals from the Manitoba Métis Federation to work with Red River Métis Citizens in various Regions.

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## Abbreviations

AHWC - Aboriginal Health and Wellness Centre  
CBPR - Community-Based Participatory Research  
CCDAP - Collective Consensual Data Analytic Procedure  
CCMB - CancerCare Manitoba  
CCPN - The Community Cancer Programs Network  
CCS - Canadian Cancer Society  
KI - Key Informants  
MAiD - Medical Assistance in Dying  
MCLD - Métis Community Liaison Department  
MMF - Manitoba Métis Federation  
MMF-HWD – Manitoba Métis Federation – Health & Wellness Department  
NACF - Never Alone Cancer Foundation  
PDP - Prescription Drug Program  
SGRIA - Self-Government Recognition and Implementation Agreement  
UNDRIP - United Nations Declaration of the Rights of Indigenous Peoples Act  
WRHA - Winnipeg Regional Health Authority



## Executive Summary

The underrepresentation of Red River Métis in cancer research is cause for immediate action, especially considering the finding that cancer is the leading cause of mortality among the Red River Métis population. In response, the Manitoba Métis Federation–Health & Wellness Department aims to bridge this knowledge gap through meaningful engagement with Red River Métis Citizens, generating evidence to inform culturally relevant health policies, programs, and resources to benefit Red River Métis Citizens and their families dealing with cancer.

Gaps in understanding of Red River Métis perspectives and needs regarding cancer care were identified through a review of current health policies, programming, and resources throughout the cancer care system in Manitoba. Then, utilizing a Community-Based Participatory Research approach, the experiences of Red River Métis Citizens going through a cancer journey and the perspectives of Key Informants working in the Manitoba cancer care system were investigated. Citizens participated in virtual discussion groups, and Key Informants were interviewed individually by a study team member.

Data analysis revealed 10 overarching themes from Key Informant interviews: Key Informant Roles and Responsibilities, Accessing Existing Supports, Addressing Community Needs, Barriers to Accessing Care, Cultural Awareness Training for Service Providers, Determinants of Health, Information Gathering and Shared Decision Making, Providing Red River Métis-Specific Care, Structural Barriers to Adequate Care, and Successes and Failures in Patient Communication.

Discussions with Red River Métis Citizens revealed the following 11 overarching themes: Existing Level of Knowledge, Discrimination in Healthcare, Community Supports, Experience and Perception of Treatment Options, Connection with Healthcare Providers, The Role of the MMF in the Cancer Journey, Experiences in Accessing and Navigating CancerCare Manitoba, Cancer Information and Self-Education, Individual Prevention Efforts, Barriers to Care and Resources, Impact of Cancer on the Individual and the Family. The findings are presented in detail in Section 4.

The findings and recommendations presented in this report not only guide the future work of Manitoba Métis Federation–Health & Wellness Department to support Citizens dealing with cancer, but also establish the National Government of the Red River Métis as a trailblazer in developing evidence-based policy. This study serves to amplify Red River Métis voices and perspectives, contributing to a distinctions-based Red River Métis Cancer Strategy that includes culturally grounded policy recommendations and proposed cancer care programming. The study and ensuing Strategy will provide guidance to entities such as CancerCare Manitoba and Regional Health Authorities as they fulfill their obligations under the United Nations Declaration on the Rights of Indigenous Peoples and increase support for Red River Métis Citizens facing challenges related to the cancer journey.

# Section 1: Introduction

## 1.1 Project Context

A notable lack of Red River Métis-specific research contributes to shortfalls in culturally relevant policies, supports, and resources throughout the cancer care continuum for Red River Métis Citizens going through a cancer journey in Manitoba. To address these concerns, this project aims to engage with Red River Métis Citizens to understand their lived experiences and identify their needs and concerns around the cancer journey.

## 1.2 The Red River Métis

The Red River Métis have a distinct identity and share a common history, entirely our own, in the great western plains centered in the Red River Valley of West Central North America. It is the Indigenous collective - made up of Citizens and individuals entitled to be Citizens - located within Manitoba and elsewhere inside and outside of Canada. In this regard, it transcends the common meaning of on-site specific “brick and mortar” community such as a village or a settlement. The Red River Métis are comprised of a common identity, culture, and history and, among other things, interconnected political, social, entrepreneurial, economic, and kinship networks.

In 1869, the National Committee of the Red River Métis, led by President John Bruce and Secretary Louis Riel, rightly asserted Métis People’s jurisdiction and authority over the whole of the Métis Homeland in what was then commonly referred to as the North-West Territory. Through negotiations with Canadian representatives, the Territory entered Canada. In 1870, the Red River Métis became the Founder of the province of Manitoba and Canada’s negotiating partner in Confederation.

After governing the province peacefully, the Métis People faced the Reign of Terror resulting in many being widely dispersed across the Homeland, mainly westward and northward in search of peace and security. To this day, the Red River Métis bear the consequences of the broken promise of the Manitoba Act, 1870, the Reign of Terror, and the dispersal as well as the Residential and Day Schools, and the Sixties Scoop. As a result, Red River Métis remain overrepresented in the foster care system and among the unemployed, the incarcerated, and the chronically ill. In Figure 1.2.1 we display the distribution of Red River Métis across the province.



**Figure 1.2.1** Artistic Rendering of the Red River Métis Homeland

### **1.3 The Manitoba Métis Federation**

Decades after the Reign of Terror and the dispersal, the Red River Métis began to regroup and reorganize with the aim of improving the lives of Red River Métis Citizens historically treated unfairly. Nearly 100 years after the National Committee of the Red River convened to assert jurisdiction, the Red River Métis used the only available avenue for representation and incorporated the Manitoba Métis Federation (MMF) as a non-profit in 1967. The current Governance structure is pictured in figure 1.3.1.

In 1981, MMF launched a court case on behalf of the Red River Métis claiming that the federal government had failed to implement the land grant provision set out in section 31 of the Manitoba Act, 1870, as per the honour of the Crown. Thirty-two years later, in 2013, the Supreme Court of Canada determined that the federal government was constitutionally obligated by section 31 to fulfill its promise to the Red River Métis. Responding to this decision, in 2016, Canada and MMF signed a memorandum of understanding as well as the November 15, 2016, *Framework Agreement for Advancing Reconciliation to advance exploratory talks on reconciliation*.

In 2021, Canada and the MMF signed the *Manitoba Métis Self-Government Recognition and Implementation Agreement (SGRIA)* to “recognize, support, and advance the exercise of the Manitoba Métis’[also known as the Red River Métis] right to self-determination, and its inherent right to self-government recognized and affirmed by section 35 and protected by section 25 of the Constitution Act, 1982, in a manner that is consistent with the United Nations Declaration on the Rights of Indigenous Peoples, through a constructive, forward-looking, and reconciliation-based arrangement that is premised on rights recognition and implementation.” This same year, Canada’s *United*

*Nations Declaration on the Rights of Indigenous Peoples Act* (UNDRIP; the Act, 2016) received royal assent and came into force. Both the Act and the SGRIA commit Canada to working with the MMF to implement the UN Declaration, to advance reconciliation with the Red River Métis, and to advance the Red River Métis right to self-government and self-determination.

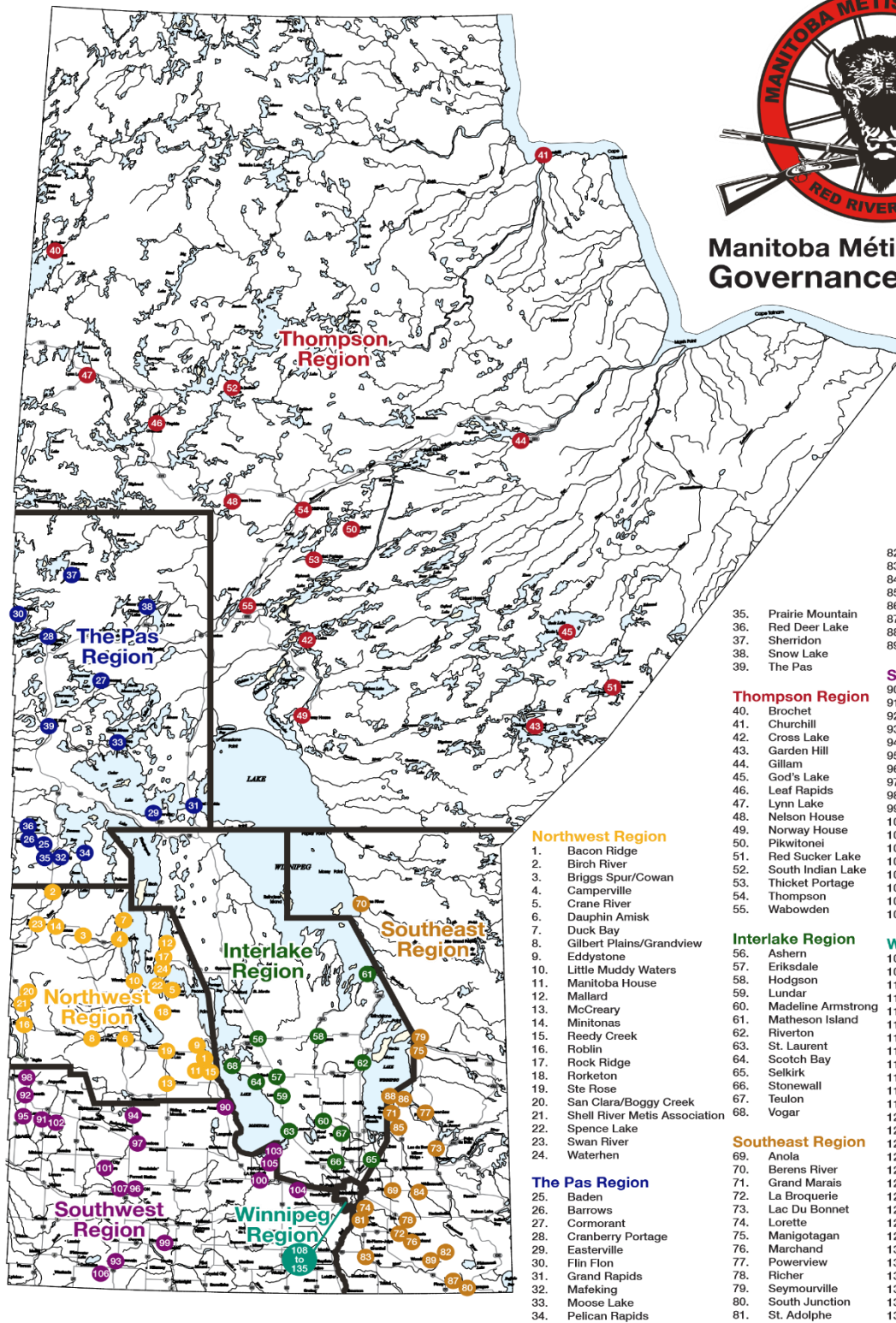
Today, to be a Citizen of the MMF one must:

- 1) Self-identify as Red River Métis.
- 2) Show an ancestral connection to the Historic Red River Métis Community; and
- 3) Be accepted by the contemporary Red River Métis Community.

Further, the Canadian endorsement of the UN Declaration on the Rights of Indigenous Peoples serves as a significant step that highlights Indigenous people's entitlement to self-determination, culture, and health. This declaration stresses the importance of their participation in health decisions. Despite these advancements, Canada's fragmented healthcare system has historically yielded inconsistent services for Red River Métis, a situation further exacerbated by a lack of distinction-based health legislation. To bridge this gap and honour Indigenous rights, a dedicated focus on creating distinctions-based health legislation to support Red River Métis health is crucial. These historical reasons result in the creation and persistence of the Manitoba Métis Federation–Health & Wellness Department (MMF-HWD).



## Manitoba Métis Federation Governance Structure



- |                        |                                   |
|------------------------|-----------------------------------|
| 35. Prairie Mountain   | 82. St. Labre                     |
| 36. Red Deer Lake      | 83. St. Malo                      |
| 37. Sherridon          | 84. Ste Rita                      |
| 38. Snow Lake          | 85. Stoney Point                  |
| 39. The Pas            | 86. Traverse Bay                  |
|                        | 87. Vassar                        |
|                        | 88. Victoria Beach                |
|                        | 89. Woodridge                     |
|                        | <b>Southwest Region</b>           |
|                        | 90. Amaranth                      |
|                        | 91. Assiniboine                   |
|                        | 92. Binscarth/Ste Madeline Birtle |
|                        | 93. Cherry Creek Metis Council    |
|                        | 94. Erickson/Wapiti               |
|                        | 95. Fort Ellice                   |
|                        | 96. Grand Valley                  |
|                        | 97. Les Metis                     |
|                        | 98. Pelly Trail/Russell           |
|                        | 99. Pembina River                 |
|                        | 100. Portage                      |
|                        | 101. Rivers                       |
|                        | 102. Snake Creek                  |
|                        | 103. St. Ambroise                 |
|                        | 104. St. Eustache                 |
|                        | 105. St. Marks                    |
|                        | 106. Turtle Mountain              |
|                        | 107. Westman                      |
|                        | <b>Winnipeg Region</b>            |
|                        | 108. Blueberry                    |
|                        | 109. Bosco                        |
|                        | 110. Catfish                      |
|                        | 111. Conseil Elzéar Goulet        |
|                        | 112. Dakota                       |
|                        | 113. Dumont                       |
|                        | 114. Fontaine                     |
|                        | 115. Gilbert Park                 |
|                        | 116. Heritage Proud               |
|                        | 117. Infinity                     |
|                        | 118. Keenleyside                  |
|                        | 119. Kinew                        |
|                        | 120. Liberty                      |
|                        | 121. Metis Elders                 |
|                        | 122. Michif                       |
|                        | 123. New Horizons                 |
|                        | 124. Point Douglas                |
|                        | 125. Prairie Buffalo              |
|                        | 126. Red River                    |
|                        | 127. Redboine                     |
|                        | 128. Riel                         |
|                        | 129. Seven Oaks                   |
|                        | 130. South Central                |
|                        | 131. Spruce                       |
|                        | 132. St. Norbert                  |
|                        | 133. St. Vital North              |
|                        | 134. Winnipeg North               |
|                        | 135. Winnipeg West                |
|                        | <b>Thompson Region</b>            |
| 40. Brochet            |                                   |
| 41. Churchill          |                                   |
| 42. Cross Lake         |                                   |
| 43. Garden Hill        |                                   |
| 44. Gillam             |                                   |
| 45. God's Lake         |                                   |
| 46. Leaf Rapids        |                                   |
| 47. Lynn Lake          |                                   |
| 48. Nelson House       |                                   |
| 49. Norway House       |                                   |
| 50. Pikitonei          |                                   |
| 51. Red Sucker Lake    |                                   |
| 52. South Indian Lake  |                                   |
| 53. Thicket Portage    |                                   |
| 54. Thompson           |                                   |
| 55. Wabowden           |                                   |
|                        | <b>Interlake Region</b>           |
| 56. Ashern             |                                   |
| 57. Eriksdale          |                                   |
| 58. Hodgson            |                                   |
| 59. Lundar             |                                   |
| 60. Madeline Armstrong |                                   |
| 61. Matheson Island    |                                   |
| 62. Riverton           |                                   |
| 63. St. Laurent        |                                   |
| 64. Scotch Bay         |                                   |
| 65. Selkirk            |                                   |
| 66. Stonewall          |                                   |
| 67. Teulon             |                                   |
| 68. Vogar              |                                   |
|                        | <b>Southeast Region</b>           |
| 69. Anola              |                                   |
| 70. Berens River       |                                   |
| 71. Grand Marais       |                                   |
| 72. La Broquerie       |                                   |
| 73. Lac Du Bonnet      |                                   |
| 74. Lorette            |                                   |
| 75. Manigotagan        |                                   |
| 76. Marchand           |                                   |
| 77. Powerview          |                                   |
| 78. Richer             |                                   |
| 79. Seymourville       |                                   |
| 80. South Junction     |                                   |
| 81. St. Adolphe        |                                   |
|                        | <b>The Pas Region</b>             |
| 25. Baden              |                                   |
| 26. Barrows            |                                   |
| 27. Cormorant          |                                   |
| 28. Cranberry Portage  |                                   |
| 29. Easterville        |                                   |
| 30. Flin Flon          |                                   |
| 31. Grand Rapids       |                                   |
| 32. Mafeking           |                                   |
| 33. Moose Lake         |                                   |
| 34. Pelican Rapids     |                                   |

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Figure 1.3.1 MMF governance structure within Manitoba, 2022

## **1.4 The Manitoba Métis Federation – Health & Wellness Department**

In 2005 after deliberation on the historical poor health of Red River Métis, the MMF-HWD. Today, the MMF-HWD continues the fight to improve the overall health and wellness of its Citizens. The organization is committed to developing and using culturally grounded, distinctions-based, holistic knowledge. This commitment aims to enhance the quality of life and well-being of Red River Métis through prevention, health service delivery, research, and innovation.

Health Research: Established in 2005, this team conducts qualitative research to grasp the viewpoints and encounters of Red River Métis Citizens. The aim is to generate culturally appropriate and safe Red River Métis-specific health insights by gathering lived experiences through consultations, group discussions, and individual interviews.

Clinical Services: This comprises of nurses, registered foot care nurses, registered dietitians and support staff that serve Red River Métis Citizens of Manitoba by implementing strategies developed by the Health Research and Policy & Health Information teams to improve their health.

Policy & Health Information: This was created in January 2022 to develop Red River Métis-specific information to support policies, programs, and services for our Citizens.

Community Programming: Formed in 2022, they empower the MMF-HWD to tackle Citizens' health requirements via diverse programs. Through community engagement and attentive listening, they customize health initiatives to ensure relevance, accessibility, and a positive impact on the overall well-being of all Citizens.

All these areas are overseen by our leadership & management team, consisting of Director, Olena Kloss, and Minister Frances Chartrand. Our commitment to collaboration with Red River Métis communities has led us to grow, acquire knowledge, and discover innovative ways to support the health of Red River Métis people.

## **1.5 Goal and Objectives of this Project**

The primary objective of this project is to understand the unique needs of Red River Métis individuals and families going through a cancer journey in Manitoba. The project does so by identifying gaps in existing cancer programs and policies in the province, collecting, and presenting insights from Red River Métis cancer journey experiences, considering perspectives of Key Informants (KIs) working in the cancer care system and creating culturally tailored tools and resources. The present project will contribute to the development of a Red River Métis Cancer Strategy that effectively supports and addresses the distinct needs of Red River Métis Citizens throughout Manitoba.

The specific objectives include:

- Identifying gaps in distinctions-based cancer programming and policy in Manitoba.
- Exploring experiences of Red River Métis individuals and families going through a cancer journey.
- Gathering perspectives of KIs working in the Manitoba cancer care system.

## **1.6 Overview of Sections**

Section 1 introduces the report and provides the reader with an overview of the MMF, who the Red River Métis are, the MMF–HWD and its holistic research approach.

Section 2 provides background information for the study through a review of current policies, programs, and resources related to cancer care in Manitoba.

Section 3 outlines the design of the Community-Based Participatory Research approach: recruitment; ethical considerations; data collection (interviews and discussion groups); data analysis process (Collective Consensual Data Analytic Procedure); and limitations of the study are communicated.

Section 4 presents the qualitative findings from Red River Métis Citizens discussions and Key Informant interviews with healthcare professionals.

Section 5 discusses key findings of the study, describing contributions of the present study to the larger body of knowledge on cancer journeys, while emphasizing knowledge gained about unique contextualized experiences of Red River Métis in Manitoba.

Section 6 offers recommendations based on key findings.

## Section 2: Background

### 2.1 Cancer Among the Red River Métis Population

The enduring effects of colonial policies and practices throughout Canada's history are evident in ongoing disparities in social determinants of health and health outcomes between Red River Métis and all other Manitobans. Generally, the self-rated health of Red River Métis is poorer than for all other Manitobans and Red River Métis experience higher rates of chronic disease (Martens et al., 2010). Regarding health-promoting behaviours, Red River Métis have lower consumption of fruits and vegetables, higher alcohol consumption, and higher smoking rates than all other Manitobans (Martens et al., 2010). These are concerning findings considering the correlation between these behaviours and increased risk of cancer (Cancer Care Society, 2023).

Until recently, little was known about cancer among the Red River Métis population. The 'Profile of Métis Health Status and Healthcare Utilization in Manitoba: A Population-Based Study' (Martens et al., 2010) revealed cancer as the leading cause of mortality for Red River Métis in Manitoba. To support policy and program responses, health information related to cancer among Red River Métis is vital. This report provides valuable insights into the lived experiences of Red River Métis Citizens navigating the cancer care system to identify their unique concerns and needs.

### 2.2 Cancer Care Services and Programming in Manitoba

When an individual consults with their doctor about a concern or suspicion of cancer, it will be followed by testing and diagnosis. If there is a cancer diagnosis, an individual may be referred to a specialist or CancerCare Manitoba (CCMB). If referred to CCMB, support is available from a clinical care team, including oncologists, surgeons, nurses, social workers, and other healthcare professionals. CCMB offers programming around cancer prevention, early detection, and research of cancer and blood disorders. Beyond CCMB, additional services related to cancer are available from the Canadian Cancer Society (CCS), the MMF, and other non-governmental agencies.

#### 2.2.1 Screening

CCMB has three organized Cancer Screening Programs: BreastCheck, CervixCheck, and ColonCheck. The programs provide screening tests and partner with healthcare providers to increase access to screening services in Manitoba. Each of the programs send letters to invite and remind Manitobans to get screened and notify them of results, work with healthcare providers to ensure individuals with abnormal screening results receive follow-up care, and provide information and resources to the public and to healthcare providers (CCMB, 2022a).

**BreastCheck:** Provides cancer screening mammograms in Manitoba.

- Operates four permanent screening clinics and two mobile clinics, offering year-round appointments at the permanent sites and travelling to approximately 90 rural and northern communities on a two-year rotation. They also facilitate group trips for communities to coordinate screenings.



- Open to Manitoban women eligible for breast cancer screening (CCMB, 2022b).

**CervixCheck:** Offers pap test clinics and involves family doctors in cervical cancer screening (CCMB, 2022c).

- Collaborates with numerous pap test clinics throughout Manitoba.
- Open to all eligible Manitoban individuals who need cervical cancer screening.

**ColonCheck:** Provides home screening tests for early detection of colon cancer.

- Offers home screening tests requested by phone or online delivered by mail.
- Open to all Manitobans eligible for colon cancer screening (CCMB, 2022d).

There are currently no routine screening programs in place for other types of cancer. Individuals are encouraged to speak with their healthcare provider if they have concerns about a particular type of cancer and their risk level (CCMB, 2022e). There is evidence to support screening high risk individuals for lung cancer, which would involve an annual low dose computed tomography for three years (Jonas et al., 2021). CCMB is currently working towards making this a routine screening practice for high-risk individuals in Manitoba.

CCMB also operates the Breast Health Centre, comprised of a multi-disciplinary team of experts who specialize in breast health. The Centre coordinates clinical assessments, diagnostic tests, treatment, education, and support through a variety of specialized programs (Shared Health Manitoba, 2022a). This includes diagnostic imaging, surgical consultation, lymphedema treatment, psychosocial counseling, nutrition services, education, genetics/hereditary breast cancer, and research.

## 2.2.2 Treatment

The type of treatment an individual receives depends on the type of cancer, the stage of cancer, the age of the individual, and their preferences (CCS, 2023). The most common types of conventional cancer treatment are surgery, radiation, and chemotherapy (CCS, 2023).

Surgery is most effective for cancer at an early stage when it is localized and has not spread (CCS, 2023). The goal of surgery is to completely remove the tumor or cancerous tissue (CCS, 2023). Chemotherapy uses drugs to treat cancer (CCS, 2023). It can be used alone or with other treatments, including surgery or radiation therapy (CCS, 2023). Radiation therapy destroys cancer cells and damages the DNA of cancer cells to stop them from growing and dividing (CCS, 2023).

## 2.2.3 Complementary Therapies

Complementary therapies do not directly target the cancer to eliminate it. Rather, their purpose is to support the patient's overall well-being by aiding in physical and emotional coping during conventional cancer treatment (CCS, 2022). It has been found that a patient's sense of control and involvement in their own healthcare increases when complementary therapies are used, and many individuals with cancer seek out these

options (CCS, 2022). CCMB provides a variety of complementary therapies, including support groups and programs on a variety of topics such as yoga, art therapy, and mindfulness practice (CCMB, 2022f). Other examples of alternative treatments include aromatherapy, Ayurveda, biofeedback, chiropractic therapy, energy therapies, guided imagery, hypnosis, massage therapy, medical cannabis and cannabinoids, meditation, music therapy, naturopathic medicine, tai chi, and traditional Chinese herbal remedies (CCS, 2022).

Services are also available to help individuals with cancer with body image and self-esteem challenges. The Look Good Feel Better Program is delivered by Cosmetics Alliance Canada, supported by CCMB. The program provides two-hour workshops to help individuals manage appearance related side effects of cancer treatment by teaching them about skin care, make-up and how to wear wigs/head coverings (Look Good Feel Better, 2017). In addition, CCMB runs the Guardian Angel Caring Room, which borrows out wigs, scarves, turbans, and hats for free (CCMB, 2022g). For individuals with concerns regarding body image, sexuality, or sexual functioning due to their cancer treatments, a sexuality counsellor is available by request (CCMB, 2022h).

## **2.2.4 Navigation Services**

Navigation Services are available to residents in each Regional Health Authority (RHA). Patients can contact the department directly or receive a referral from a healthcare professional. Each Regional Cancer Program “hub” has a navigation team that includes Nurse Navigators, Psychosocial Oncology Clinicians, and Community Engagement Liaisons. Nurse Navigators are Registered Nurses with specialized training in cancer care. They work closely with a patient’s healthcare team and provide information, support and guidance to the patient and their family to help them understand their diagnosis and care plan. Psychosocial Oncology Clinicians are counsellors available to help patients and their families cope with the range of emotions and changes that come with a cancer diagnosis. They also assist with practical issues such as work, finances, and transportation, and offer guidance to patients for speaking with children, family, and friends about their illness. Finally, Community Engagement Liaisons provide information about available cancer supports and services. The Liaison develops and distributes culturally appropriate information and works with communities to increase awareness about cancer prevention and early detection (CCMB, 2022i).

While Nurse Navigators are required to take cultural competency training, there are currently no Nurse Navigators designated to work specifically with Red River Métis patients in the province (CCMB, 2022i). The lack of this service is antithetical to UNDRIP and our SGRIA. Further, it impedes access to culturally safe, distinctions-based care, as well as opportunities to include spiritual and holistic traditions as part of the health journey for Red River Métis. In this regard, Manitoba and all other provinces should implement Red River Métis specific navigation supports for Red River Métis and look to provincial partners as a guide. For example, Cancer Care Ontario currently employs Indigenous cancer navigators who act as a medium for building and strengthening trust between Indigenous patients and their cancer care team (Cancer Care Ontario, 2021; Roberts et al., 2020).

## **2.2.5 Educational Tools and Resources**

CCMB operates a Patient and Family Resource Centre which offers educational materials and a lending library with books, CDs, and DVDs on cancer types and cancer-related information. Materials can also be sent by mail upon request (CCMB, 2022j).

CCMB and affiliate organizations host regular information sessions, courses, and webinars. Examples of recent topics include Treatment for Cancer Pain, Living an Active Life After Cancer, and Cancer and Sleep (CCMB, 2022j). CCMB also distributes a monthly newsletter, The Navigator, to share information about available supports and services (CCMB, 2022k).

## **2.2.6 Indigenous Health Services**

The Winnipeg Regional Health Authority (WRHA) provides Indigenous Health Patient Services for Indigenous people receiving medical care in Winnipeg. Services include language interpretation, resource coordination, discharge planning and coordination, advocacy, spiritual/cultural care, patient resources, and Indigenous medical transportation coverage (WRHA, 2022a). Traditional medicine is also available at the Traditional Wellness Clinic, located at Health Sciences Centre. The clinic offers Indigenous and non-Indigenous people access to traditional healing, and is open two days per month (WRHA, 2022b).

The Aboriginal Health and Wellness Centre (AHWC) offers similar services in Winnipeg. The AHWC cultural advisor provides guidance related to spiritual and traditional healing, connecting people with other traditional healers when needed (AHWC, 2021). Indigenous Liaisons and interpreter services are also available in Flin Flon, The Pas, and Thompson hospitals to address cultural and language barriers by ensuring individuals can ask questions and get answers in their own language (Northern Health Region, 2022a). They are also there to help people cope with the impacts of illness and hospitalization, provide spiritual and emotional support as well as help make connections with family members, Elders, and community organizations (Northern Health Region, 2022a).

To address challenges faced by Red River Métis Citizens in accessing healthcare, the MMF provides services and support geared specifically for their Citizens. The MMF MEDOCare Pharmacy offers a variety of free services including prescription delivery throughout Manitoba, medication review, blister and bubble packaging and pill-splitting for prescriptions, diabetes meter training, private consultations, expired drug disposal services, and prescription transfer (MEDOCare, 2022). The Prescription Drug Program (PDP) pays an individual's MMF calculated deductible throughout the year for Pharmacare-eligible prescription drugs. Additional supports are available for Citizens through the Métis Community Liaison Department (MCLD). MCLD workers assist Citizens on a case-by-case basis and can help individuals navigate supports offered throughout the province (MMF, 2022).

## **2.2.7 Palliative Care**

Palliative care supports life quality for those with life-threatening cancer, delivered by a team of professionals. Early palliative care is advised for advanced cancer patients and can be accessed through RHAs with different application processes (CCMB, 2022l). WRHA Palliative Care Program provides 24/7 support (WRHA, 2022c). Manitoba Health's Drug Access Program covers medications (CCMB, 2022l). Currently, there are no services that provide culturally appropriate support for Red River Métis Citizens.

## **2.2.8 End of Life Assistance**

Medical Assistance in Dying (MAiD) is an option through one's healthcare team or by direct contact with Shared Health Manitoba (Shared Health, 2022b). While federal legislation permits MAiD requests, there is a gap in Indigenous-informed, Red River Métis-specific policies (Government of Canada, 2023).

Research is crucial to help develop culturally sensitive MAiD policies that include Red River Métis viewpoints for respectful, accessible end-of-life care.

## **2.2.9 Travel and Accommodation**

Addressing transportation barriers remains a key priority for enhancing cancer care access and utilization (Ambroggi et al., 2015; Adunlin et al., 2019; Charlton et al., 2015; Chen et al., 2019; Jenkins et al., 2018 Longacre et al., 2020; Vetterlein et al., 2017) Travel to distant locations for cancer screening and appointments poses challenges. Limited transportation support services exist to improve cancer service accessibility.

The CCMB Community Cancer Programs Network (CCPN) collaborates with RHAs to bring cancer care services closer to residents outside of Winnipeg. CCPN operates outpatient units in community hospitals, as many cancer treatments can be delivered safely in regional or community-based settings. This service allows for patients to remain connected to family and community (CCMB, 2022o). Currently, CCPN consists of 7 Regional Cancer Programs, 8 Community Cancer Programs, Eriksdale's Community Cancer Resources and Support Program, and the Western Manitoba Cancer Center in Brandon, which specializes in radiation therapy (CCMB, 2022m).

The CCS provides the Wheels of Hope program, offering transport to and from cancer appointments (CCS, 2022). This service covers Winnipeg, Brandon and select rural areas. Through the Driver Program, volunteer drivers are paired with ambulatory patients needing rides to treatment appointments (CCS, 2022). Financial assistance for transportation is also available from CCS (CCS, 2022).

The Northern Patient Transportation Program aids residents living in the North with medical travel costs to the nearest facility, elective, or emergency (Government of Manitoba, 2022; Northern Health Region, 2022). Subsidies may cover escort costs. Eligibility includes Manitoba Residents north of the 53rd parallel (west side of Lake Winnipeg) and extends south to the 51st parallel with physician approval and no other coverage (Government of Manitoba, 2022).

Patients needing treatment in Winnipeg face limited accommodation choices. Some hotels provide patient discounts. Ronald McDonald House (RMH) is an option for child patients and their families, located near Health Sciences Center Children's Hospital (Ronald McDonald House Charities, 2022). Eligibility requires a referral and a minimum of 50km residence from the hospital. Staying costs \$10/night. Despite these options, expenses persist due to limited RMH availability and high hotel rates for multiple, extended stays.

Red River Métis Citizens, especially in rural areas, still struggle with cancer care service access (Horrill et al., 2019). Even with support, transportation, work commitments or childcare may hinder attendance (Horrill et al., 2019; Lavoie et al., 2016; Maar et al., 2013). Flexible health services, drop-in appointments, and innovative technology in remote areas could improve engagement (Black 2009; Cerigo et al., 2012; Decker et al., 2015).

## **2.2.10 Financial Supports**

The financial strain for individuals enduring a cancer journey is persistent (Guidry et al., 1998; Desai et al., 2020) and especially impacts underserved groups (Ahmed & Shahid, 2012). Socioeconomic disparities worsen outcomes and disease progression (Ahmed & Shahid, 2012). Rural patients face compounded burdens, influencing care choices (Mathews et al., 2009), underscoring the need for accessible care. Patients also worry about "out-of-pocket costs," indirect expenses and the financial burden on the family during the cancer journey.

CCMB's Home Cancer Drug Program provides eligible outpatient Citizens with supportive drugs at no cost, easing the financial burden of cancer treatment (Government of Manitoba, 2018; CCMB, 2022n). The Never Alone Cancer Foundation (NACF) provides focused help to Cancer patients, covering emotional, social, financial and education needs. They offer affordable lodging, grocery delivery, peer support, and potential tax receipts for medical expenses (NACF, 2022). Patients are advised to keep receipts for accommodations and transportation costs.

## **2.3 Conclusion**

This review presents cancer care services and programs available in Manitoba. Needs for support and resources span the cancer care journey, from screening to palliation and end-of-life. It was revealed that no Red River Métis specific cancer care programs are available in Manitoba. As most cancer care services are centralized in major hospitals, financial, emotional, and time burdens are imposed on remote residents.

Further, though culturally specific care is available for Indigenous people with cancer, many of these resources are centralized in Winnipeg and most are not specific to Red River Métis. This is another gap in the existing supports and one that must be addressed by the Red River Métis Cancer Strategy.

Despite these shortcomings, this investigation has shown that Manitoba has a wide-ranging suite of supports and resources for cancer care and has provided direction for

potential priorities for the Red River Métis Cancer Strategy. By identifying supports and agencies providing them we have identified existing programs that may be altered or extended to meet the specific needs of Red River Métis Citizens through future initiatives and partnerships.

## **Section 3: Community Consultation Research Introduction and Methods**

### **3.1 Introduction**

This section outlines the consultation methods for the present study. We employed a Community-Based Participatory Research (CBPR) approach, a collaborative method involving all partners in the research process to leverage their unique strengths. CBPR enables the MMF-HWD to meaningfully engage with and understand the distinct needs of Red River Métis Citizens. By harnessing the voices of Citizens, CBPR enables the development of policies, programs, and interventions that are precisely attuned to their needs. This approach involves integrating research insights directly from Red River Métis community members, resulting in effective interventions and well-informed policy adjustments. Further, CBPR fosters social change, builds trusting relationships, and empowers community partners. In line with CBPR, Red River Métis research participants were involved in all stages, including reviewing the reporting and sharing results.

### **3.2 Methods**

#### **3.2.1 Healthcare Professionals**

##### ***Sampling***

All KIs were recruited using purposive sampling. The central inclusion criterion was one year or more of experience working with or providing care to individuals with cancer or cancer survivors. Study staff solicited respondents whose contact information was provided to members of the CCMB Community Connector program.

##### ***Data Collection***

Interviews were conducted using a semi-structured interview tool developed by project staff. Respondents were asked questions related to their level of experience with delivering care to Red River Métis, their knowledge of Red River Métis specific tools and resources, community engagement techniques they use, and their observations on barriers to accessing health services. Prior to the interview, interviewers informed participants of the purpose of the study and how their responses would be used. Their consent to be interviewed and recorded was then obtained verbally. Interviews lasted from 30 to 90 minutes and were conducted on the Zoom videoconferencing platform. All KI interviews were transcribed and analyzed.

#### **3.2.2 Red River Métis Citizens**

##### ***Sampling***

To reach members of the target population during the COVID-19 pandemic, online discussion groups were held as part of a public outreach event held by the MMF, entitled *Health & Wellness Forum: Health Knowledge through a Métis Lens* (The Health Forum). The Health Forum was a two-day event, held remotely on the Zoom videoconferencing platform in September 2021.

Red River Métis Citizens were invited to attend the Health Forum through advertisements on MMF's social media, posts on the MMF website, and through the mobilization efforts of the MCLD and MMF cabinet ministers.

The result of this effort was a convenience sample of 85 Red River Métis Citizens who resided in Manitoba self-selected to participate in discussion groups. This sample was randomly separated into 8 discussion groups of 10 to 11 participants each. Demographic data indicated that the sample was majority female (80%) and over 40 years of age (~69%).

### **Data Collection**

Project staff began with a presentation concerning the aims of the projects and an update on its progress, after which attendees were randomly separated into discussion groups using the Zoom breakout room feature. At this point, participants consented to participate and be recorded and were asked to complete a poll to collect demographic data. This data is presented in Table 4.2.1.

Discussion groups were moderated by MMF-HWD staff, who structured discussion around a set of questions and prompts developed by project staff and reviewed by the MMF Engagement and Consultation Department. Questions covered participants' preferred methods of receiving cancer information, when they received information related to cancer and what they received, the distance they needed to travel to receive regular care and specialist treatment, as well as their thoughts on where programs and resources could be improved. Meetings lasted from 20 to 30 minutes. Discussion group sessions were recorded, transcribed, and analyzed. Due to a technical malfunction, the recording of one discussion group was lost. Therefore, the analysis to follow concerns a subsample of 75 Red River Métis Citizens and 7 discussion groups.

### **3.2.3 Analysis**

The Collective Consensual Data Analytic Procedure (CCDAP) was utilized to analyze the qualitative data (Bartlett et al., 2007). CCDAP is an Indigenous-led framework for decolonizing qualitative based analysis. CCDAP has been identified as well suited to qualitative analysis in Red River Métis health research (Bartlett et al., 2007) as it affords input into the analysis process by Red River Métis members of the research team to assist in the expression of the social, historical, and political contexts that shape Red River Métis experiences. A two-stage analytical process was performed. Stage one involved individual coding of qualitative data from transcripts to identify key statements. The COVID-19 pandemic led the project team to adapt the second stage of the process, which was conducted virtually through Microsoft Teams. Key steps involved in the second stage included:

**Step 1:** Key phrases and ideas identified from the transcript were placed in a table on a Word document.

**Step 2:** The coding was compared to ensure consistency through the following actions using the word document created in Step 1 and another word document to facilitate clustering of key phrases.



**Step 3:** The team identified similarities and differences in themes from KI interviews with healthcare professionals and discussion groups with Red River Métis.

**Step 4:** Interpreting the data.

### **3.3 Ethical Considerations**

Principles of Red River Métis-focused research (ownership, control, access, and stewardship) (Martens PJ, et al, 2010) were negotiated and respected throughout the research process. Red River Métis data is held in trust by the National Government of the Red River Métis, the MMF, who controls access to this data, and everything produced through it. The MMF is committed to using the research to benefit the Red River Métis. This research was completed in accordance with the principles of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada 2022).

## Section 4: Findings

### 4.1 Healthcare Professional Perspectives

The goal of interviewing KIs working in healthcare was to discover a) how their Red River Métis clients access information and resources; b) barriers to accessing those information and resources; c) how to overcome those barriers; d) how to better support Red River Métis specifically; and e) their perceptions on the impact of gender for service access and utilization.

The following themes emerged from the interviews:

- 1) KI Roles and Responsibilities;
- 2) Accessing Existing Supports;
- 3) Addressing Community Needs;
- 4) Barriers to Accessing Care;
- 5) Cultural Awareness Training for Service Providers;
- 6) Determinants of Health;
- 7) Information Gathering and Shared Decision Making;
- 8) Providing Red River Métis-specific Care;
- 9) Structural Barriers to Adequate Care;
- 10) Successes Failures in Patient Communication.

#### 4.1.1 KI Roles and Responsibilities

The KIs work in diverse areas of the provinces including the Winnipeg, Northern, Prairie Mountain and Southern Regional Health Authorities. The KIs come from several different career paths and have different job titles, including Social Worker, Peer Connector, Community Engagement Liaison, Indigenous Health Executive, Nurse Navigator and Psychosocial Oncologist Clinician.

Social Workers describe their positions as assisting patients and their families in finding supports and securing funding for unexpected costs (including transportation and accommodation). Another KI noted their work focuses on safe discharges and assisting patients with managing the transition from in-patient care to home care.

*“I assist cancer patients and their families with all the things that come up that you don’t think you’re going to have to deal with when you have a cancer diagnosis.”*

Peer Connectors describe their work on screening and prevention, as well as community engagement and outreach. They also noted their position and program are new and still in active development. As such, their responsibilities are fluid and may be subject to change.

*“My big thing right now is screening and prevention and early detection.”*

A Community Engagement Liaison focuses on distributing educational materials and developing new, Indigenized methods for outreach, in addition to managing a team of Peer Connectors and other providers.

*“My program’s focus is to educate communities, schools, healthcare regions and nursing stations about cancer Programs, cancer screening and the resources that can be accessed without leaving the community.”*

Indigenous Health Executives deliver cultural proficiency and cultural safety training. Along with developing strategies for combatting racism in health, they also serve on several steering committees for health and Indigenous health governance.

Nurse Navigators characterize their role as supporting patients who are not yet fully immersed within the cancer system (still waiting on diagnosis) to “fill gaps” in the initial stage. The first point of contact occurs after basic investigations have caused suspicion of cancer. Nurses listen to patient concerns and connect them and their families with resources to support them on their cancer journey.

*“She guides and provides resources, teaching around the cancer diagnosis, the cancer, just reiterating what the cancer community is doing or before when there’s fears and stuff coming up, she provides those resources and guidance.”*

Psychosocial Oncologist Clinicians deliver support, resources, and guidance to patients across the cancer journey. These include referring to resources as well as delivering coping skill development workshops and counselling supports.

#### **4.1.2 Accessing Existing Supports**

Providers were eager to share many of the resources they found useful, including governmental supports through the CCS, CCMB, and the MMF. Several non-profits were also mentioned including the Never Alone Foundation and Safe Families Steinbach.

During the interviews, KIs were keen to focus on the programs that their clients could use to defray costs related to treatment, especially transportation. Other programs mentioned included support for nicotine replacement therapy combined with traditional and cultural supports.

##### **i. Screening Services**

Mobile screening services were identified as an important initiative to overcome barriers related to distance and challenges involved with travelling for care. One KI wondered aloud if similar methods could be used to deliver other services.

*“...going for a mammogram, my understanding is that it’s not a fun thing to do and people are unlikely to want to make the trip into a city or a larger center to get that done... So, the fact that it’s coming out to their home communities or at least closer to their home communities, I think that’s huge.”*

##### **ii. Referring to Resources**

KIs noted they often referred patients to resources and other providers rather than delivering care themselves. Some mentioned few resources can be accessed without a referral from a healthcare provider. One KI working as a Nurse Navigator noted their work

was restricted to a specific portion of the cancer journey and their involvement with the patient ended after referring them to the clinical oncology team.

*“And we are an interim support service so what that means is once we have a diagnosis and once a patient is connected to an oncologist then we do typically transfer our care and support over to the oncology clinical team.”*

### **4.1.3 Addressing Community Needs**

#### **i. Community Engagement in Practice**

KIs working in public facing roles reported they attempted to engage with the communities that they serve to learn about their needs and priorities, with the aim of addressing these concerns by identifying complementary programs and tailoring existing ones.

*“... I wanted to know what the community felt they needed. So, I did a lot of calls.”*

These KIs reported that obtaining this information was difficult but they found success in face-to-face interactions and in harnessing existing networks, such as churches.

*“I did station myself outside [the post office] and did some, a survey, like we did a survey to find out, you know, what people wanted. So that was a good way of getting information.”*

#### **ii. Service Provider Connection to Community**

Many KIs noted that having staff with an existing connection to a community was important for engaging with the community, building trust, and improving uptake of services. One KI specifically mentioned that this connection was a major strength of the CCMB Community Connector program.

*“It’s a little bit more scary or intimidating if you know, there’s just the nurse there all of a sudden trying to find someone, but you get that immediate sense of trust because you have the community connector by your side.”*

*“...we couldn’t get any work done up North without [the Community Connector] support and their help.”*

### **4.1.4 Barriers to Accessing Care**

#### **i. Distance to Care**

Most KIs identified distance from healthcare services as the most common barrier to care and information for their clients. Many of the following sub-themes describe barriers that are aspects of this larger issue.

*“Oh, for sure transportation. That’s like the biggest one across the board, no matter who you are, where you live in the province, it’s always transportation.”*

## **ii. Reduced Mobility**

For those with reduced mobility, the issues of distance and access were magnified.

*“You know, I’ve seen elders carried to a nursing station because they couldn’t walk, they don’t have any way of going in their wheelchair because the roads are so bad and so muddy and so this or so that, and they have to be carried.”*

## **iii. Navigating New Cities for Treatment**

Many KIs recognized that travelling to a new city was often an overwhelming and exhausting experience for their clients. These appointments could also be frustrating when their clients were forced to endure a lengthy period of travel for a trivially short meeting with a healthcare provider.

*“It’s really hard for people to leave their community and go to a place that’s – you know, maybe it’s fascinating because it’s got a lot of people and a lot of bells and whistles and a lot of places to go, but culture shock is huge.”*

*“...for people coming in from the city, traveling eight, nine hours for a ten-minute appointment, it’s frustrating for people.”*

## **iv. Financial Impacts of Transportation**

KIs indicated that costs associated with travelling for cancer treatment were a major financial burden for their clients. This included wear on vehicles and the cost of fuel. In some cases, this burden interfered with their treatment.

*“There’s a lady that came to see me just before Christmas. She was diagnosed with stage two Breast Cancer. She did have the surgery and now she had to have radiation for six weeks. She’s a senior, her husband is as well and he’s not like medically well, like he’s diabetic. So then financially she couldn’t afford it and he couldn’t drive her so that was the problem. So, then she decided you know what, I’m not having the treatments.”*

## **v. Accommodations When Travelling for Care**

KIs reported that the logistics of organizing accommodations, coupled with the high cost of those accommodations add to the client’s financial burden.

*“The cost associated with that, whether that, I mean imagine having to stay in a hotel for six weeks, just the hotel cost alone is unbelievable it’s hard for people to get there and to figure out the logistics of where you’re going to stay.”*

Community Connectors can only try to reduce this burden by carefully scheduling appointments to reduce time spent away from home.

*“What we try to do for people is we try to get all their appointments set up so that they’re not there for as long.”*

## **vi. Childcare During Treatment**

For families, arranging for childcare presents an additional burden:

*“... and now you add, you have six children at home, or let’s even say you only have two children, however many children you have, now you need a trusted person in your family who has enough in place to be able to then take on your children while you’re away.”*

KIs noted that this is particularly burdensome in the North, where they worked with many single mothers. KIs also shared that many women are reluctant to access childcare services that would require them to create a file with Child and Family Services.

## **vii. Other Financial Impacts of the Cancer Journey**

In addition to travel, KIs reported that many other components of the cancer journey had financial impacts on clients. Those without insurance, or those without significant savings were at risk of falling into poverty, or forgoing medication due to an inability to pay.

*“I’ve had patients say they couldn’t afford some medications.”*

A KI reported that financial barriers complicate preventative care as well, as many patients cannot afford nicotine replacement therapies.

Another reported that many patients have to resort to fundraising to cover costs of living while seeking treatment, and that this barrier is not an experience unique to Red River Métis.

*“It is so sad that people have to have Chase the Ace or Duck Race or this race or 50/50s or all kinds of fundraisers, to support people going through cancer.”*

*“Yeah, it is a big barrier and yeah I don’t think it’s unique to Métis...pertains to the general population as well.”*

## **viii. Technology as a Barrier**

KIs mentioned technology as a powerful way to access care and information at distance but noted that many areas don’t have reliable access to internet or computers and that elders are often uncomfortable using technology.

*“This [videoconferencing] to me is fine, but elders don’t like it.”*

## **4.1.5 Cultural Awareness Training for Service Providers**

### **i. Experiences with Cultural Awareness Training**

Several KIs indicated they had participated in cultural awareness training programs, either as coordinators or participants, and provided descriptions of the activities taking place during these trainings. One KI responsible for coordinating trainings reported that Red River Métis content is now being emphasized in her work.

*“And we’ve really modified the blanket exercise... northernizing the blanket exercise and bringing in Métis content. And so we are, blanket exercise has the Métis resistance fighters... ..we also would acknowledge Métis and First Nation in when the history reflects is part of that as you walk through the exercise. And so, we did build those things in.”*

## **ii. Building Cultural Awareness among Service Providers**

Multiple KIs mentioned that cultural safety training is a compulsory part of their education or licensing process. The KIs identified two companies Saint Elizabeth Distance’s @yourside and San’Yas Indigenous Cultural Training that most have completed training with. However, upon investigation they do not offer specific Red River Métis culture safety training.

Several KIs considered cultural training a useful way to better address the needs of their Red River Métis clients.

*“And while we work with individuals from different cultural backgrounds, it’s important to take the time to listen so that we can better understand each person’s perspective and individual needs.”*

Another expressed that while training is useful, practicing cultural safety is complicated by the diversity of human cultures and traditions.

*“What one person needs and wants isn’t going to be necessarily the same as the next person even if they come from the same background.”*

## **iii. Perceived Effects of Cultural Awareness Training**

One KI mentioned that during the trainings, a space emerges where social hierarchies are relaxed and where relationships can grow and change.

*“CEO, janitor, whomever you are - it doesn’t matter on the day on the land, and that is clear. You can’t tell who’s who unless you know who people are.”*

*“It just creates a balance and creates relationships. People always talk about the relationships that are built and oh, wow, we’ve said hi to each other for all these years, and I didn’t know this, or I didn’t know that, or oh, we had good laughs or good times.”*

The provider who often delivered these trainings mentioned these sessions are often emotionally charged and that eliciting strong emotions is an important mechanism for turning participants into agents of change.

This provider also testified that even individuals who only take the training to fulfill a job requirement often found it rewarding.

*“We get good evaluations from them at the end of the day. So, you can break through to people who even don’t want to be there.”*

#### **iv. Recommendations for Cultural Awareness Training**

The same KI further noted that a successful cultural training required facilitators who are emotionally healed enough to effectively manage conflict and deal with the emotionally charged atmosphere.

*“So, and that I don’t think there’s any matrix or anything like that, you just have to have relationships, and know and trust that these are people who can teach and learn and be open to people who may be at the beginning stages of their learning or their healing, you know?”*

To account for diversity present within and between Indigenous peoples, one KI noted that cultural safety training programs should include different content and involve different peoples in different parts of Manitoba.

KIs also expressed concern that workshops do not happen often, are not always available and may be easily missed by people who would benefit most by attending.

*“We have 1900 employees and then Lucy here doesn’t – always manages to be sick, every time it’s offered, so then you don’t get to Lucy, because it’s only offered four times a year. And well, she’s managed to miss it for eight years, and she’s the one who needs to go.”*

#### **4.1.6 Determinants of Health**

Though not specifically related to cancer, many of the KIs told stories regarding the clients they serve and spoke of other factors that influenced the health of those clients.

##### **i. Nutrition**

Food security and quality of nutrition was identified as an issue, especially for populations in Manitoba’s North and those recovering from illness. One KI advocated for Indigenous people to return to traditional gardening practices to improve access to fresh foods and nutrition. Another mentioned that they conceived of food broadly, as a medicine and as a part of one’s heritage.

*“[Food is a] part of your way of life, your ancestry. Food is medicine.”*

##### **ii. Affordable and Accessible Housing**

Affordable housing that is also accessible to people with mobility issues stemming from cancer treatment leads to financial insecurity and stress. One KI indicated the lack of options available means that people with medical needs are often put in substandard or inappropriate housing situations.

*“We’ve ended up putting a lot of younger people in assisted living and oftentimes personal care homes when they’re not really at that level because there’s no other housing options for them.”*



### iii. Impact of COVID-19

KIs mentioned the wide-ranging impacts of COVID-19 on service delivery. At the time of interviews, transportation support programs were disrupted having an impact on communities: their clients still required regular care but had minimal or no access to Community Connectors. Events had to be made virtual or adjusted to have fewer participants. KIs noted that these changes in format impacted the effects of consultation and outreach events.

*“And it’s meaningful, small groups are different than large groups. And so it’s important.”*

One KI perceived COVID-19 to have positively impacted wait and travel times for appointments by forcing a shift to virtual appointments.

*“I think, our primary care because of COVID, this might be a bit of a positive, our waits for appointments, it used to be something like 17 or 24 days, it was a long time, like any given day to get an appointment. We’re down to days, two or three days, or something.”*

### iv. Gaps in Patient Knowledge

KIs noted that their clients do not know all the resources that are available to them, and that part of their work was dedicated to addressing this issue.

*“People don’t know that we [peer connectors and nurse navigators] even exist most times. They don’t know that we’re here.”*

One KI implied that this issue might stem from relying on the first meeting with the primary care provider to connect the patient to supports and resources. Another KI spoke to the presence of cancer misinformation in small communities.

*“There’s some people who think it’s contagious [laughs] especially in small communities that have, you know, not quite as much education as we would like them to have.”*

### v. Impact of Gender

When prompted, KIs spoke to gender matters and most indicated fewer men access their services and there is less information and support available for men in comparison to women.

*“The women will at least go to a breast screening van that comes to the community, but a man will go to a trap line because, Well I’ll be fine, I’ll just walk it off.”*

On the topic of psychosocial support, several KIs suggested that men were unwilling to talk about health issues. One reported that she knew of men in the community she served who had been diagnosed but did not seek support from her.

*“I do know there is a few males that have been diagnosed with cancer since I’ve been here, and they’ve not contacted me at all. And one has already passed, like he just died just before New Years.”*

Because of this, one KI recalled the men they worked with tended to be diagnosed in later stages of their cancer in comparison to women.

In terms of female centred issues, one KI noted that many women she has worked with want to re-evaluate their life and career goals in survivorship.

*“I just want to add – and I don’t know if it’s me or – in survivorship, in cancer survivorship, moving forward sometimes, well I would just say women because that’s what I work with and that’s where I’ve experienced this, feel like they need to re-evaluate their lives and their goals and the jobs they do.”*

Another KI expressed concerns about access to birth control for women in the North when dealing with socially conservative doctors.

*“Because if you end up with a bunch of physicians that have perspectives on women, that are different than what’s accepted in Canada or in Manitoba, it creates inequity for women. So, if you have a bunch of physicians who don’t believe in birth control, it becomes a whole lot harder to access it.”*

#### **vi. Patient’s Emotional Needs**

KIs working as or with patient navigators saw emotional support as a critical part of their role, especially in the early stages before a formal diagnosis. One KI mentioned that psychosocial supports were the second most requested after travel resources. Some KIs reported that clients were often reluctant to discuss their feelings and worked hard to mask their distress in public.

*“Those people that I am helping with, you could never tell that they’re struggling with this because they’re so well kept, look good and try to maintain some sort of control and self-esteem ... by the way they keep themselves or present themselves to the public because they won’t share that.”*

One KI working in the North mentioned they considered emotional wellness to be a part of a holistic model of health.

*“Now if you understand the concept, you have the physical way and then you have the mental way, you see. So, you have to develop the fact that you have all four directions of healing. So, you need your body to heal, you need your physical aspect to heal; you need your mental aspect to be able to heal.”*

#### **4.1.7 Information Gathering and Shared Decision Making**

KIs shared their worries about their clients’ ability to advocate for themselves and take an active role in understanding and influencing their care. KIs suggested that the passivity of some clients results from feeling like they are not allowed to question their doctors and service providers.

*“Well, we’re still trying to make people understand that they have a right to question their diagnosis or their outcome. They have a right to question their prognosis and/or any treatment that they have to take without feeling like it’s a terrible thing.”*

These KIs further noted that clinicians must provide a safe space where clients feel empowered to ask direct, personal questions, but that creating this environment is difficult.

*“Where somebody might be able to make a connection where if they have a question, a very personal question, that they feel safe to ask it. And there’s where our falling is, nobody has that safe, nobody knows how to make it. We’re still in the process of figuring out how to do that.”*

They also suggested that solving this issue will require care providers to begin by asking probing questions and actively listening to the patient.

#### **4.1.8 Providing Red River Métis Specific Care**

##### **i. Identifying Red River Métis Clients**

When asked how many Red River Métis clients they serve, many KIs reported that they did not know, saying that most clients do not explain how they identify and that KIs do not ask them to. One KI reported that inquiries on Non-Insured Health Benefits often prompted people to reveal their Red River Métis Citizenship. Otherwise KIs identified Red River Métis clients when their identity came up in conversation or by drawing on their existing knowledge of the Community.

Another KI reported that since their initial contacts with clients were over the phone, asking how they culturally identify was a difficult subject. Another KI working as a Psychosocial Oncologist Clinician reported that they did not ask because they did not think it would impact the care they provide to their clients.

Conversely, another KI working as a Peer Connector thought that self-identification could be used to connect people with Indigenous supports.

*“If people were identified if they are Métis, we could then... direct people to those resources.”*

##### **ii. Demand and Availability of Red River Métis-Specific Cancer Resources**

None of the KIs were aware of any existing Red River Métis-specific cancer resources in Manitoba. Another KI noted that most Indigenous resources are written from a pan-Indigenous perspective.

*“You’ll notice I keep using term the term Indigenous, because we haven’t, as a Northern Health Region, to my knowledge, and I am still learning. We haven’t really zeroed in on Métis specific, First Nations specific, it’s been Indigenous.”*

KIs identified the lack of Red River Métis-specific resources as a problem that needed to be addressed. However, when asked, several KIs noted that client requests for Red River Métis-specific resources were also rare.

*“I can think of maybe three times in five years.”*

In one case, a KI reported that a request for Red River Métis-specific resources came from the family, rather than the client themselves.

One KI suggested that the reason for this apparent lack of interest may be due to clients suspecting that such resources do not exist, and another wondered if clients did not ask for such supports because they felt it was inappropriate to do so.

*“You know, I think if there was a resource available then maybe it would be requested. Right now, nobody asks because nobody thinks about it, nobody expects it. Expectations are pretty low.”*

Another KI recommended that any Red River Métis-specific materials should have symbols and graphic design that will appeal to Red River Métis people.

### **iii. Lack of Trust in Healthcare Due to Discrimination**

Two KIs noted that uptake of supports among Indigenous people, including Red River Métis, is impeded by an overall lack of trust in the healthcare system, rooted in colonialism and reinforced through experiences of racism within healthcare.

*“[A Doctor might think] ‘Maybe they’re seeking a prescription; maybe this, maybe that.’ And so, there’s not that same automatic referral that may happen if you didn’t appear Indigenous, you might not have those same questions and barriers to get through from the provider. So no, again, no easy answer for that issue.”*

Going further, one KI spoke of a disconnect between the care providers they knew and worked with, the general attention paid to racism and the examples of racism in healthcare that have been shown in the Canadian media.

*“Sometimes I’m optimistic and I feel like this anti-racism strategy and just the global attention to racism... And then you have healthcare systems saying, Oh, my goodness, things are getting revealed. Joyce [Echaquan] videoed her, as Dr. Barry Lavallee says, her murder.”*

### **iv. Characteristics of Red River Métis Culture**

Some KIs shared their understandings of Red River Métis culture, usually when speaking on how they attempted to deliver services to Red River Métis people.

KIs were careful to note that Red River Métis are a distinct people from First Nations, and that they are also diverse in perspectives, particularly as it relates to spirituality and ceremony.

*“To me, that’s a Métis experience and Métis culture is to be out on the land, and it’s not connected to ceremony.”*

*“It shouldn’t be forgotten, because not everybody follows the church and or a combination of.”*

*“It would depend really on how they were raised; do you understand what I’m saying by that?... Not everybody has been raised traditional Métis.”*

KIs further note that Red River Métis culture influenced the way they interacted with people and received or solicited services. In particular, KIs noted that interpersonal interaction and humour helped Red River Métis people open up about their health, while personal pride prevented many from asking others for help.

*“Sometimes that’s the icebreaker and then the more serious stuff does come out. You know giving them that time to joke around first.”*

#### **v. Combining Traditional Healing with Western Medicine**

One KI noted that traditional Red River Métis healing was not available through their RHA, but that Métis often people access that kind of support from outside the purview of the RHA.

One KIs understanding of traditional healing extended beyond access to practitioners of traditional medicine, to providing holistic care, including providing space for family members to be involved a person’s care.

*“It doesn’t have to be a gigantic circle with 40 people; it needs to be a personalized sharing circle built on what that person needs at the time that they need it so that all four directions are cared for. So, we need to do something like that.”*

*“Acknowledging family connections and creating space for that in the system, I think is - would be a biggie.”*

KIs also noted existing difficulties with getting access to some traditional First Nations supports and using them in an effective and timely manner.

*“I mean we can’t even have a smudge in a hospital without making a four-hour recommendation, you know, for alarms and bells and whistles to be turned off and so on and so forth... Yeah. You have to set that up and it takes almost half a day before it actually can transpire.”*

KIs made several recommendations regarding access to traditional healing, including employing a traditional healer at CCMB in Winnipeg and ensuring that access to traditional medicine is sustained throughout the cancer journey and incorporated with western medicine.

*“So that would be something to make those links in our system. That it’s not just kind of something on this side that you do when you do yoga or something.”*

#### **vi. Reclaiming Red River Métis Identity**

When discussing Red River Métis identity, many KIs mentioned identity and preserving culture as important parts of Red River Métis people’s well-being.

*“When you bring back something as important as somebody’s culture, you’re bringing back the pride. You’re bringing back the historical references, the pride, the importance of the person, OK. Their soul basically, you know. How different is it when somebody is proud to walk the walk as opposed to, you know, hiding.”*

#### **4.1.9 Structural Barriers to Adequate Care**

##### **i. Gaps in Service Provider Knowledge**

Several KIs noted they were lacking in knowledge in some areas relating to care. While the authors do not expect all service providers to maintain complete knowledge of all resources and treatments, some omissions may be instructive to highlight to identify gaps that could be address by further supports or trainings for service providers.

One KI noted that they did not know if any practicing oncologists in Manitoba identified as Red River Métis and noted that would be helpful information to direct Red River Métis clients. Another noted they were not aware of all of the resources and support provided by the MMF, its Regions and its Locals. Another KI working in administration did not have firsthand experience of cancer or even a family member with cancer. Finally, one KI noted that the healthcare system is fragmented, and many healthcare providers do not understand the services available, nor employ them adequately. They further noted that trainings to improve this are often not well attended, complicating efforts to improve this situation.

*“Even if it’s getting our own healthcare system to understand and use the services adequately can be a challenge for them, for anyone.”*

##### **ii. Busy/Overworked Healthcare Providers**

KIs noted that care providers are overworked and the resulting pressure and stress effects the care they can deliver. In particular, the KIs noted that care providers are under pressure to deliver care quickly and move on to the next patient, the consequence being that they talk quickly and often do not leave enough time for patients to understand the information they have been given.

*“I mean the oncologists are busy, we know that. We know they’ve got a backlog of people that they’re trying to get in touch with.”*

##### **iii. Limited Healthcare Resources**

Peer Connectors reported that their positions were precarious and funding dependent, and they couldn’t provide the resources that their clients needed.

*“I can’t provide [mobility support]. It’s just me.”*

The KI working as an Indigenous Health Executive lacked the human resources to provide cultural awareness training, respond to demand for services, cultural changes needed in their RHA.

*“We need positions within. The amount of times I get tapped on throughout our system. We could have indigenous specialists, First Nation, Métis throughout departments, not calling on one or two people, but in HR, in cancer, in emergency, in the care home.”*

Lack of resources was even more pronounced in the Northern RHA, one KI reported. These included staffing shortages for care workers and respiratory therapists and a lack of MRI equipment in Thompson, and the fact that many communities only have access to a nursing station rather than a doctor.

*“Right now, we even have to send them away to, you know, have an asthma test for God sakes because we have no RTs here.”*

#### **iv. Shortcomings in Existing Policies**

KIs noted that many current policies in healthcare institutions and systems are outdated, having been drafted in an earlier era of cancer treatment and unable to adequately respond to modern requirements. For example, changes in cancer treatment have made care last longer and forced a shift to outpatient care, however policy concerning family caregiver leave and financial support for healthcare related travel does not reflect these changes.

*“To find out that a policy only supports two days for your cancer appointment or that you don’t get an escort for this appointment or it just, to me doesn’t acknowledge the patient need.”*

*“I just put that as a disclaimer, but that policy was drafted in the 80s and hasn’t been updated. ...in the 80s, I would have been in the hospital, because you didn’t just go down for an appointment, you would be overnight, you would be an inpatient. So, you have to have an escort that you can share your hotel room with, that isn’t going to screw you over.”*

*“And there’s a family caregiver leave which is 15 weeks, but treatment is much longer than that.”*

Furthermore, another KI mentioned that current policies reflect a Euro-Canadian understanding of health and do not account for aspects of Red River Métis culture, such as family connections. This results in a disconnect between the health system and Red River Métis people that may contribute to the lack of trust described above.

*“And then we ask ourselves, well how do we get Indigenous people to be more engaged in the health system? Well, we need to have these policies match values.”*

Another KI suggested that changes in policy may be able to effect specific issues of health and the determinants of health, specifically citing the cost of milk in northern areas.

*“And again, I would say it’s based on bad policy of, I always say, if we can regulate the cost of a bottle of vodka, we should be able to do it for things that matter, like milk and healthier foods, it’s just, it’s a priority.”*

#### **v. Issues with Accessing Timely Care**

Wait times for specialist care is a perennial issue across the healthcare system, and this was noted by KIs. For cancer in particular, KIs noted that accessing palliative care was both critical for quality of life and difficult to achieve.

*“Like one of our Métis Elders who died of cancer, OK. His entire family was fighting for him, but nobody listened, and the man didn’t even get palliative care until the last week of his life. You can’t possibly tell me that palliative care shouldn’t have been sooner.”*

KIs identified healthcare navigators as a useful method for streamlining the process of accessing care and reducing gaps in care.

#### **vi. Healthcare System is Resistant to Change**

KIs explained changes they would like to see, noting that the healthcare system is difficult to change and, in their perception, has not changed much over the course of their careers.

*“I’ve been fighting the good fight on Highway 6 for some years now so it’s about time somebody else comes in here and starts helping me, my foot’s getting tired [laughs].”*

One KI placed part of the blame on healthcare providers becoming complacent over long, difficult careers.

*“I think it has a lot to do with not only education but the complacency that happens when you’ve worked in a system for as long as some of them have... No, people become complacent of the care that has been given because the system is really difficult to change, OK. It is.”*

Others were optimistic, having seen changes in attitudes toward issues like racism in healthcare.

*“It’s starting to align, and we may see people actually invest. I was just in a meeting where someone said, you know, 15 years ago, we weren’t even allowed to say the word racism at work.”*

Another noted that challenging the issues present in healthcare will mean honestly engaging with staff and patients to tackle the issues present.

*“I feel like we just have to be real with each other or else we won’t make the changes, and we all know they need to happen. They need to happen, so let’s be real with each other and figure out what we can do.”*

#### **vii. Jurisdictional Complexity**

KIs expressed frustration concerning the fragmentation of health services and benefits available to Indigenous people. One KI was pessimistic about the possibility of a Red River Métis-specific health system, having seen the failures of First Nations Peoples’ healthcare systems.



*“There likely won’t be a Métis system created. And I don’t even know if I’d advocate for that watching a First Nations system and the gaps that come out of that is this so hard to witness.”*

#### **viii. Partnerships between Healthcare and other Organizations**

KIs also noted that much of their work occurred through inter-organizational partnerships, which were often positive and important for challenging the partners to better support each other.

*“So, then you kind of along the First Nation arm of things, start referring to First Nation Inuit health branch or oh, we partner with First Nation Inuit health branch.”*

*“And I think once the training happens, people become more open. And those partnerships become embedded, and they become real, and people care about each other and start feeling that sense of responsibility or community.”*

However, KIs perceived critical partnerships, particularly between MMF Locals and health organizations and between health organizations and the community’s private sector to be non-existent or limited.

### **4.1.10 Successes and Failures in Patient Communication**

#### **i. Methods of Communicating Service Information**

KIs mentioned a wide array of methods they employed for connecting with their community and communicating information about health and their services. These included, brochures, posters, Facebook (including making and posting videos), and newsletters. Facebook was the only social media platform mentioned by name. One KI working as a Peer Connector notes that she made her resources available in English and French. Some community-based KIs also mentioned attending events, such as health fairs, and engaging with local newspapers and news websites.

*“We also hit every health fair we could attend, community events and back then like 2015/16 it was just an opportunity to engage with the public to educate them about navigation services.”*

#### **ii. Ideas for Improving Communication of Service Info**

KIs offered many suggestions to improve the delivery of information about health. One KI in social work suggested that social media was still an untested area in their work, while another suggested combining use of social media with print materials to compensate for the weaknesses of each medium. Another suggested that patients should be able to access information through dialogue with real people.

When commenting on the style of communication, one KI noted that lectures and other traditional methods of transmitting information remain common and are rarely “user-friendly” for their clients, implying that that modern, diverse audiences require modernized and diverse approaches education. Another KI argued that print media needs to appeal to its audience visually and signal that its information is relevant to its audience’s interests

and tailored to their purposes and level of understanding. Yet another KI mentioned they were hoping to employ a “two-eyed seeing” approach to their work. This refers to the practice of blending western and Indigenous ways of knowing, pioneered by Mi’kmaw Elder Albert Marshall (Bartlett et al., 2012).

*“So, you really have to make literature people friendly.”*

### **iii. Effectiveness of Communication Methods**

KIs were keen to report on how their different outreach methods succeeded or failed in reaching their target audience. Several reported that posters and brochures were ineffective and were often thrown away before they were read.

*“I think posters and brochures often just get kind of glanced at or tossed aside.”*

Others reported that phone contact could be unreliable, as many people in the area they served did not have cell phones or had disconnected landlines.

Many KIs reported that they found the most success in reaching people in-person and getting them to pass on information through word-of-mouth.

*“Probably truthfully word-of-mouth is the easiest and the most consistent and reliable.”*

One KI who worked extensively with virtual outreach reported that virtual approaches make connecting with clients more difficult.

*“The only thing with virtual though, there’s a disconnects there too. You know, you don’t feel the connection and personally I feel the same way.”*

Finally, another KI noted that if workshops and trainings are delivered without following up and continuing learning, many people do not retain critical information over the long term.

*“And again, you know what lessons are, lessons are something they learn for the hour and is gone the next hour. Right, there’s no contingency, there’s no follow-up, there’s not any of these.”*

### **iv. Patient Self-directed Information Seeking**

When discussing information and cancer resources, KIs mentioned how their client’s accessed information. Interestingly, many noted that family members of clients often reached out to KIs to find support and information on the client’s behalf.

*“Like she was a very good advocate for her mom. Mom had cancer and nothing was being done so she came and said where can I go and who can I talk to?”*

Others reported that patients contact them after finding their telephone number on the CCMB website or by word-of-mouth through friends and family.

*“So, I think that like that experience, that’s actually interesting because the gentleman who I’m working with MMF to help with Murray House, he called me on his own... because he has a relative, I think who had worked with me and said why not MMF?”*

#### **v. Barriers to Doctor/Patient Communication**

KIs perceived that communication between healthcare providers and patients are often ineffective and identified issues that their clients have faced when receiving care or information about their illness. One KI reported that they perceived providers to assume a level of knowledge and English proficiency that many patients, including Red River Métis, may not have.

*“Métis people because of their language and stuff they, you know, it takes a little longer for them... ..And it’s not registering for them you know? They’re not kind of getting it because of maybe the language you know?”*

However, another KI argued that providers should not insult the intelligence of their clients or judge them and yet another KI working as a Peer Connector noted that none of their clients have requested materials in Michif or French.

*“When somebody isn’t feeling well or when they’ve been diagnosed with some sort of terrible disease, they’re not willing to be open to peoples condescending ways.”*

Another KI in social work noted that hour long appointments to discuss psychosocial supports and resources for transports were well received, remarking clients “just want the time to talk,” and that being judgemental in these appointments impedes trust and communication.

A KI working as a Nurse Navigator noted that their most fruitful conversations with clients occur when they ask patients to tell them anything they feel is important about themselves or their treatment.

*“I think that is just a good question to, that we should all be remembering to ask patients because you never know how someone is going to answer it, right, and sometimes that becomes the most meaningful part of the whole conversation.”*

#### **vi. Interpreters in Telehealth Appointments**

One KI working as a Peer Connector mentioned that they had been asked to attend a telehealth conference between a Red River Métis client and their oncology team to help clarify technical terms and speech and to translate English to Michif. They also mentioned that they would stay with the client after the conference had finished to make sure they understood what was said during the meeting.

*“Sometimes they’ll say well this, you know the doctor said this, what does that mean? So, they’ll need you know, and I make it very plain. I will say it in Michif, and I’ll say it in you know, more simple English.”*

## 4.2 Red River Métis Voices

Each cancer journey is unique, as are the perspectives of our Citizens. The discussion group participants shared similar challenges and barriers while accessing, navigating, and utilizing Manitoba's cancer care system. The information presented in this section is an aggregation of the Red River Métis voices participating in virtual discussion groups held at the 2021 Health & Wellness Department Health Forum. Throughout these discussion group sessions, the following topics emerged as important themes related to Red River Métis cancer journey experiences:

- 1) Existing Level of Knowledge;
- 2) Discrimination in Healthcare;
- 3) Community Supports;
- 4) Experiences and Perception of Treatment Options;
- 5) Connection with Healthcare Providers;
- 6) The Role of the MMF in the Cancer Journey;
- 7) Experiences in Accessing and Navigating CCMB;
- 8) Cancer Information and Self-Education;
- 9) Individual Prevention Efforts;
- 10) Barriers to Care and Resources;
- 11) Impact of Cancer on the Individual and the Family.

**Table 5.2.1 Demographic Data on Discussion Group Sample**

	Count	Percentage (%)
<b>Gender</b>		
Male	13	15.29
Female	68	80
Non-binary/ Other	4	4.71
<b>Total</b>	<b>85</b>	<b>100</b>
<b>Age</b>		
< 16	0	0
16-29	20	23.53
30-39	6	7.06
40-49	13	15.29
50-59	20	23.53
60-69	18	21.18
70+	8	9.41
<b>Total</b>	<b>85</b>	<b>100%</b>

## 4.2.1 Existing Level of Knowledge

### i. Knowledge of Cancer Screening Methods

Red River Métis Citizens shared what they know about cancer screening methods, reflecting on their own experiences or those of family members. Participants discussed specific screening tests they had gone through to diagnose certain types of cancer. Many Citizens mentioned blood tests as a common method of cancer screening and inquired if regular blood tests taken at the doctor could be used for cancer diagnosis.

*“I think for certain cancers they can check your elevated white blood cells and I think that’s what they do.”*

### ii. Gaps in Knowledge

Our group discussions revealed gaps in Citizens’ knowledge and awareness surrounding available cancer care services. Participants shared they are unaware of nearby cancer screening services and assistance programs that aid with travel or finances. Participants noted they are aware of services and programs offered in larger cities, but little is known about services available in rural or remote communities.

*“Well, cancer care services that I know about are the ones that are in urban centers. There’s not that much I know about in rural centers in northern communities.”*

### iii. Recommendations for Bridging Gaps in Knowledge

In response to the knowledge gaps identified, participants contributed ideas for improving cancer education and awareness of available programs and services. Some participants indicated it would be helpful to receive educational materials on the basics of cancer and ways to detect signs or symptoms of cancer in its early stages. Additional suggestions included an increase in advertising and/or communication of services and supports available in communities.

*“I think it would be really helpful to educating people on the basics of cancer.”*

## 4.2.2 Discrimination in Healthcare

### i. Existing Indigenous Health Services Exclude Red River Métis

There was plenty of discussion surrounding the perceived lack of Red River Métis-specific health services available and offered to our Citizens. Participants highlighted existence of Indigenous Health Services departments in healthcare facilities, yet there are few, if any, resources specifically designed and distinctions-based for Red River Métis. Although a focus on First Nations traditions exists in current healthcare, many shared a common concern that no distinctions have been made between Indigenous groups, the services offered and continuous exclusion of our Citizens.

*“What we don’t have available is anything that complements Métis people.”*

## **ii. Need for Red River Métis-Specific Resources**

A major topic of discussion was a need for Red River Métis-specific resources in the current provincial healthcare system. Participants shared they would like to see a Red River Métis-specific department in healthcare facilities, more Red River Métis health practitioners, and culturally appropriate safe spaces for Red River Métis.

*“We really need to push for a Métis-specific department ... where it’s run by our staff, that we know what our patients, what our Citizens need, is support.”*

## **iii. Racism and Discrimination**

Red River Métis shared their experiences with racism and discrimination within the healthcare system. Participants had experienced these instances themselves or with a family member. One participant shared:

*“I think culturally again, it all depends on your doctor. I had an English doctor. He wasn’t concerned at all about any of the health problems that Métis women especially with arthritis. He was like I don’t know about you people.”*

## **iv. Ageism**

Our Citizens experience age-based discrimination while using the healthcare system. Participants felt their needs were not addressed or taken seriously because they were young or old. Age requirements used for cancer screening guidelines was identified as a barrier; a few participants said they could not access screening because they were not old enough or were deemed too old to benefit.

*“And no one really listened to me because I was a youth.”*

## **4.2.3 Community Supports**

### **i. Community Supports**

Participants mentioned community supports they are aware of and/or have used include mobile cancer screening units. Participants largely agreed that mobile units are an effective way to provide cancer screening services in communities. It was mentioned that the best way to enhance screening service usage would be to increase community outreach, especially in rural and remote communities.

*“As far as resources, I mean that’s what I’m thinking like the bus or the CancerCare bus or whatever the – the breast screening I think is huge. But it’s not just breast screening because there are your pap smears, your skin cancer detection, lung cancer, like there’s a whole slew of it, right?”*

### **ii. CCMB Quit Smoking Program**

A few participants shared their experience with the CCMB Quit Smoking Program. Their experiences were positive, and they cited the availability of free cessation products and information as strengths of the program.

*“They actually give you information, plus they also give you the free quit smoking methods. Like they will give you patches, or they’ll give you the inhaler. Whatever you feel comfortable using.”*

#### **4.2.4 Experience and Perception of Treatment Options**

##### **i. Cancer Treatment Options**

In sharing stories of their personal cancer journeys, participants shared their knowledge of different cancer treatment options and their treatment experiences. Many were aware of chemotherapy and radiation therapy as common treatment options. Participants shared their experiences with alternative treatments including experimental medications and surgery.

*“They tell you that if it’s treatable, they tell you your options and that’s usually chemo, radiation.”*

Speaking of their experience with experimental drugs, one participant shared:

*“This doctor pushed experimental treatment so much it was like being used as a guinea pig.”*

##### **ii. No Accommodation for Alternative Treatment**

One common experience was if participants had chosen an alternative treatment route or opted out of treatment, they had difficulty in accessing different resources or supports. Two participants said of their experiences:

*“... with my brother, he did have trouble accessing any care when he opted out of chemotherapy. So that was difficult. And that is still a problem that he’s dealing with.”*

*“Once he decided that he didn’t want to do treatment, CancerCare did just sort of, kind of washed their hands and said, ‘well if you want treatment, call us.’”*

##### **iii. Delays in Treatment and Diagnosis**

The time it took for diagnosis or for treatment to commence varied between participants. While some found their cancer journey to move quickly, some experienced delays in care. Responses from participants included:

*“Everything moved really, really quickly with CancerCare.”*

*“They wasted three weeks of his life that he had, that he couldn’t get the treatment for his cancer.”*

##### **iv. Alternative Treatment Experience**

One participant shared stories of their family member who chose to leave Canada to receive an alternative cancer treatment. They did not identify what this treatment involved but credited their family member’s survival to it and expressed frustration with the care they received in Canada.

*“...This person is still living because he chose another option, which is not available in Canada.”*

## **4.2.5 Connection with Healthcare Providers**

### **i. Job Descriptions**

Some discussion group participants also worked in healthcare, which influenced their perspectives on the cancer care system. Healthcare providers included nurses, social workers, and community support workers.

*“Being a cancer survivor, I retired from the emergency medical services of Manitoba, and I became a CancerCare employee.”*

### **ii. Doctor-Patient Relationships and Communication**

It was generally agreed that the relationship between a doctor and a patient can impact a patient’s cancer journey. Participants said it was imperative for doctors to be attentive and listen to patients without judgement. While some shared positive experiences with primary care providers, others mentioned they do not have a regular family doctor. This can create difficulties in sharing their concerns with a new doctor, especially if a relationship has not been established.

*“Thankfully, I had a really good care team, and they were very caring and kind.”*

*“If you don’t have a good relationship with your doctor, it’s hard to just walk into a walk-in and tell them your concerns.”*

### **iii. Poor Coordination of Care**

Citizens shared common experiences of seeing several doctors, specialists, and other healthcare providers throughout the cancer journey: from the first time they present symptoms to their family doctor to seeing an oncologist for further assessment and/or treatment. This complex process can become overwhelming for patients, foster miscommunication, and confusion. It can also hinder trust in relationship building and open communication between patients and healthcare providers. As one discussion group participant said:

*“Because a lot of times you’re going from family care into oncology, and then you’re going into specialties, and then you’re going to another one. And then by the time you’re done, you have five doctors for your one diagnosis.”*

*“Sometimes, especially with older people, by the time they get the answers, they’ve had to go through four people, and they have no idea where or what is going on.”*

Poor coordination and inadequate synergies are also demonstrated at the healthcare system level: between departments in healthcare facilities and health authorities. For example, discrepancies between guidelines for screening ages:



*“CancerCare wants people to have screening every six months if they’re high risk, but Manitoba Health and their family doctor may not give them screening because they have their own idea of when someone should have it done.”*

#### **iv. Continuity of Primary Care**

One identified barrier to adequate care was fragmented continuity of primary care. Some participants expressed challenges they experience in accessing a family doctor, keeping the same family doctor long-term, and the transfer of medical records when they start seeing a new doctor.

*“I find that the majority of the complication is continuous care. Family care. When you’re not – when you don’t have a doctor that you’ve had for a long period of time, like you have a doctor today but, you know, next week you don’t.”*

### **4.2.6 The Role of the MMF in the Cancer Journey**

#### **i. Suggestions for MMF Cancer Resources**

An objective of our Cancer Strategy is to identify measures the MMF and its partners can take to support Red River Métis throughout their cancer journey. Discussion group participants shared suggestions for new programs and ways to build on existing ones. Our Citizens said they would like to see health information available at MMF Mobile Units that travel to communities, as community outreach was identified as a preferred method of information sharing. Participants proposed that the MMF hire counsellors, doctors, nurses, and community liaisons who can support Citizens. Some suggestions include:

*“...The Métis Federation does have the mobile ability to get around to different communities with their mobile units. And I think that would be one way to get out some health information in person to people.”*

*“So, what about having like an 800 number that a client can call, or a patient can call? Just like the mental health line, maybe having something like that.”*

#### **ii. The MMF Has my Back**

Citizens shared their knowledge of current MMF programs and supports, and their experiences utilizing them. Participants indicated using the MEDOCare Pharmacy for their prescriptions, as well as the PDP. Participants mentioned while they may not use a specific support, they are aware of it and acknowledge the benefits of having such programs and supports available for Red River Métis Citizens. Notably, many expressed and emphasized their trust in the MMF, its staff and programs.

*“We trust the MMF. We know we can phone, and someone will try to help us. We might not get all our answers but it’s nice to know we have some kind of support.”*

*“The MMF offered support through a phone line, which I thought was good, but I didn’t call because I had support at home.”*

## 4.2.7 Experiences in Accessing and Navigating CCMB

### i. Accessing and Navigating the System

Participants had varying experiences related to navigating the cancer care system in Manitoba. Numerous people commented that once they entered the system, there was more information available about programs and services. However, some individuals found the system difficult to navigate, both as caregivers and patients. To assist with navigation, people found Nurse Navigators to be helpful resources. When accessing cancer care services, those travelling from small communities to larger cities expressed feeling overwhelmed by the lack of accessibility.

*“...once you’re in the system, things are great, because then you’ll get all this knowledge about all the services. But if you’re not in this, if you’re not in the system, then you don’t know as much about them.”*

### ii. Perception of CCMB

While some participants told us CCMB was helpful during their cancer journey, others had negative experiences regarding the healthcare institution. Employees of CCMB also shared they are understaffed causing them to become overwhelmed with their workloads and feeling burnt out.

*“[at CancerCare] they were actually quite helpful.”*

*“But what I’m telling you is, it’s a bad experience with CancerCare.”*

## 4.2.8 Cancer Information and Self-Education

### i. Printed Media for Cancer Information

Some participants told us they prefer to receive cancer information in a print format such as pamphlets or brochures. It was mentioned that not everyone has access to technology, so there is still a demand for print media. However, several disadvantages were discussed. Mainly, mail-out information may be seen as junk mail and thrown out before it is read. Suggestions to improve print media included using plain, simple language and eye-catching visual imagery, as well as directly personalizing mail-out resources to individuals so it is not mistaken for junk mail.

*“So just having something available for people that doesn’t come in just a little piece of paper that comes through the mail. Those things get missed, and I mean if it gets tucked in with the junk mail, like it’s all going out.”*

*“Because of the elders and some of our remote communities, I think mail-out information is very important, because the social media and the technology isn’t always there for everybody.”*

## ii. Barriers to Accessing Information About Care

Various barriers to accessing individualized information about cancer and cancer care were discussed. Multiple participants experienced challenges accessing their own medical records or those of family members. Participants also told us that communication with their doctor was challenging, and they did not feel their healthcare providers were being clear and direct when discussing their medical condition or care plan. Finally, many participants told us they were not offered information or resources in print form from their doctor and had to find it on their own.

*“I found it was really difficult navigating what I had with ovarian cancer and having a hysterectomy myself without having that accessibility to the [medical] records.”*

*“... communication is an issue, and that transparency was an issue. You can’t – you’re there asking the question and you can’t necessarily get the right answers.”*

## iii. Interpreters for Patient Information

A common discussion point during our sessions was a call for interpreters to be present during doctor’s appointments. Many participants identified a lack of medical knowledge to be a barrier to understanding diagnosis, treatment options, and care plans. While some wanted family members to be present to act as a liaison, others expressed a desire for Nurse Navigators or other healthcare professionals to act as interpreters in appointments.

*“And it was very difficult because my father has no medical terminology background at all. So, for him to relay to us what was going on with mom and her treatment plan and so on, he actually didn’t have much knowledge coming out of there.”*

*“... have a liaison to translate the medical terminology that is often used. I am a practical nurse, so a lot of the language I understand. So, to have somebody there that could translate and make it more clear for them once they stop listening to a liaison person could continue to listen about able to tell them later on after the appointment is over whatever – what was meant by certain terminology. I think that’s a very good idea.”*

## iv. Popular Mediums for Accessing Information

Participants were eager to share their preferred methods of receiving cancer information. Overall, it was agreed a variety of mediums should be used to adequately reach community members to effectively communicate information. Some preferred online mediums (such as virtual information sessions, emails, and online forums) while others expressed interest in more in-person meetings and workshops. An identified communication method was word-of-mouth that may be enhanced by visiting communities and providing health information in high traffic areas. Some participants also suggested TV advertisements for communicating cancer information.

*“I think on TV would be the best ... so public service announcements.”*

*“A lot of people, they won’t – they can’t travel and so you can go into the community they would – be more inclined to go to the workshop or not everybody has a computer or a phone with service to be able to get on Zoom.”*

## 4.2.9 Individual Prevention Efforts

### i. Cancer Screening Behaviours

Participants reported a wide range of screening behaviours, reflecting their sex, age, and personal health seeking behaviour. Some participants mentioned they go for cancer screening tests regularly while others expressed they schedule screening tests when their doctor addresses it in an appointment. Some participants said they receive screening reminders in the mail which may prompt them to schedule an appointment.

*“Maybe there’s something more I should be doing in screening. But unless, you know, it comes up to the doctor ... I’m not really thinking a lot about on the day-to-day.”*

*“Myself, I get my yearly checkup, physical checkup every year.”*

### ii. Reluctance to Start Regular Check-Ups

Many participants believed they should go for regular check ups with their doctor but neglect to do so. Some shared their own behaviours, and others shared their observations about others in their communities. A few said that they do not go to the doctor unless there is something wrong while many stated the importance of promoting regular doctor’s visits.

*“... if it could be somehow normalized those regular check-ups once a year or that sort of thing then early catching of cancer is huge too because there’s a lot of people who just regularly don’t go to the doctor.”*

*“I basically just do the regular check ins with my physician, you know, every few years.”*

## 4.2.10 Barriers to Care and Resources

### i. Travelling for Cancer Care and Screening

Throughout a cancer journey, an individual and their family may have to travel multiple times, experiencing financial strain along with emotional and physical exhaustion. A very common experience, especially for those in remote and rural areas, was the challenge of having to travel to another city for cancer care or screening services. Depending on where they live, many do not have a choice in where to go for cancer care services and must travel to a larger city such as Winnipeg.

*“They have to travel in for chemo, for everything. It’s exhausting. And it’s exhausting for the family as well.”*

*“... put something further North, so at least those people don’t have as far to travel and can access all the services and supports that they need.”*

## **ii. Financial Cost of the Cancer Journey**

Many commented on the high cost associated with a cancer journey, particularly when individuals must travel for treatment. Others mentioned financial assistance programs may help, but generally do not cover all costs.

*“The financial piece of it all definitely is a huge thing.”*

*“They have to come down to Winnipeg, you know, [consider] the affordability of that.”*

## **iii. Few Health Resources in Rural Communities**

A major concern and the main reason Citizens must leave their communities for cancer care is the lack of adequate health resources available in remote and rural areas. Citizens who live in small communities recognize the limitations of the health resources available, pointing out many communities do not have regular doctors and residents have trouble accessing supports.

*“There’s barriers in multiple communities where they don’t have the services available.”*

*“The doctors up North are limited, so that’s a problem.”*

## **iv. Technological Barriers**

When asked about preferred methods of receiving cancer information, participants pointed out people may not have access to internet or the computer literacy to use it. In this regard, Citizens suggested using alternative methods to provide cancer information such as pamphlets or in person workshops and seminars. Technological barriers were also brought up in the context of telehealth, which has increased in use since the onset of the COVID-19 pandemic.

*“... there’s people out there who don’t have access to internet or – you know, some of them don’t even have cell phones.”*

*“Telehealth – sometimes they can do telehealth, but not always.”*

## **v. Barriers to Accessing Cancer Screening**

Multiple barriers to accessing screening tests were touched on. One was the requirement for a doctor referral to go for screening. Another was lack of knowledge of where to go for screening and in some cases, a lack of physical ability to go to screening locations. Age requirements were also cited as a barrier, as some participants wanted to go for screening because of a family history of particular cancers but were unable to access screening due to their age (as set by healthcare regulations).

*“I can talk to my doctor until I’m blue in the face. And unless I get that permission from them, I can’t go for my own health screening.”*

*“... it’s a barrier for a lot of people that are in my particular age group and just want to ensure their own health and safety and can’t.”*

## **vi. Impacts of COVID-19**

The impact of the COVID-19 pandemic on the cancer journeys of Citizens and the healthcare system could not be overlooked. Participants acknowledged that due to the pandemic, services and supports were cancelled or limited in capacity. The impacts of COVID-19 on the healthcare system have also resulted in delays in diagnosis and treatment.

*“But most importantly for the fact that we’re not getting people diagnosed quickly because of this pandemic.”*

*“It’s becoming complicated for sure during this time of COVID. It is playing havoc on a lot of our healthcare system across the board.”*

## **vii. Cost of Medications**

Participants suggested that a financial barrier potentially impacting their cancer journey was the cost of their medications. Some mentioned they do not meet the age requirements to qualify for certain support programs, while others said they do receive financial support, but it is not enough to cover all costs.

*“I live on a fixed income of CPP Disability ... so my \$943 a month doesn’t cover everything, like my pills a month are like 500 and some dollars.”*

*“My Pharmacare has kicked in. So that’s – but there are some of the medications that I’m taking that is not covered.”*

## **4.2.11 Impact of Cancer on the Individual and the Family**

### **i. Cancer can be Scary**

The fear that comes with a cancer diagnosis is an important point when discussing supports needed throughout a cancer journey. Many acknowledged that even hearing the word “cancer” while in a medical context invokes fear, for both the patient and their families. This can cause barriers in communication between doctors and their patients, resulting in misunderstandings and further miscommunication regarding care and treatment plans. Participants suggested that interpreters should be present for diagnostic appointments because patients are likely to be in shock and unable to retain the information initially given to them.

*“You don’t know if this is a death sentence or not, if you’re going to survive.”*

*“And that’s for anything; that’s not just cancer but that’s across the board. When somebody gets a diagnosis, you know, it’s scary; they stop listening once they hear the word, and somebody needs to be there to support them and help them understand what’s happening.”*

## ii. Emotional Impact of Cancer on Family

It was recognized that patients are not the only ones experiencing fear and emotional strain when diagnosed with cancer. Family members and caregivers also feel the emotional impact of a cancer diagnosis when a loved one is going through a cancer journey. It was pointed out that there are insufficient supports available for caregivers and caregivers can become burnt out without such supports. Family members acting as interpreters in appointments can also be ineffective due to the emotional nature of a cancer diagnosis.

*“Same thing for the caregivers. They’re getting burnt out because they’re running people to all these appointments.”*

*“... sometimes family get very emotional about it too, so it’s hard for them to comprehend everything too.”*

## iii. Importance of Family

Participants expressed that they felt there was a lack of recognition of the importance of family during their or a loved one’s cancer journey. Participants said that particularly in Red River Métis culture, people respond to stressful life events as a family unit. Challenges included healthcare policies limiting the number of people allowed in a room with a patient. This was recognized as being culturally unsafe and a barrier to supporting each other.

*“And I would say the other challenge that we encountered is that we went with her as a family, there was lots of us in the room. And I’m not sure that all medical professionals ... sometimes they feel intimidated by that and don’t know how to deal with multiple people at once.”*

*“So, I think that, from a cultural standpoint, that is how we are, how we respond as families.”*

## iv. Cancer Journeys

During our discussions, participants explored their thoughts and feelings by sharing their own stories of going through a cancer journey. Some of what they told us includes:

*“So, my story is back in 2012, through self-examination, I found a lump.”*

*“My husband was diagnosed with cancer – Brain Cancer – in 2019. He passed in 2020.”*

## v. Family History of Cancer

Some participants shared mentioned their families have a history of cancer that can influence their healthcare decisions. For example, it is well known and widely accepted that if you know there is a history of cancer in your family, you should go for cancer screening tests earlier than the recommended guidelines.

*“Normally, and as far as doctors go, if you have family history and/or whether you have generations of it and/or 55 plus is when they start to actually focus on cancer care and preventions.”*

*“But for young people that do, like myself, I have a high risk with my family.”*



## Section 5: Discussion

The research question structuring this analysis was: how do Red River Métis experience cancer and navigate the Manitoba cancer care system? To fully answer this question and compile the results previously discussed, we will evaluate the perceived quality and relevance of existing programs and supports for Red River Métis going through a cancer journey by comparing key findings from the themes identified against dimensions of healthcare quality.

The identified dimensions of healthcare quality are as follows: *Effectiveness, Timeliness, Safety, Patient Experience, Efficiency, Equity, Sustainability, and Access.*

For each dimension, we will break key findings down further into two categories: i) barriers and weaknesses; and ii) opportunities and strengths. From these, recommendations will be made in the subsequent section. This process will allow us to identify barriers to quality care, opportunities and strengths in these areas that can be used and expanded, and recommendations made by research participants and authors. In so doing, this discussion will show both the negatives and positives of Red River Métis cancer experiences and serves as the foundation for the Red River Métis Cancer Strategy.

### 5.1 Key Findings

#### 5.1.1 Effectiveness

Interventions should be beneficial, timely and appropriate to the individual.

##### *Barriers and Weaknesses*

- A Red River Métis Citizen felt like a “guinea pig” due to the doctors insisting on experimental treatment, which caused delays in accessing palliative care.
- Both KIs and Red River Métis Citizens indicated that a pan-Indigenous approach to care and resources does not allow for culturally appropriate care for Red River Métis.
- KIs suggested that Red River Métis do not trust the healthcare system because of discrimination, which leads to delays in seeking care.
- Discrimination can lead to gaps in care. For example, a Red River Métis Citizen reported pain to their doctor but was treated as drug seeking behaviour and a diagnosis of hepatitis B was missed.

##### *Strengths and Facilitators*

- KIs noted they had trust in clinical staff and their technical competency and many of their clients reported good experiences.

## 5.1.2 Timeliness

Healthcare systems should work to prevent illness and ensure that harmful delays to receiving care do not occur.

### *Barriers and Weaknesses*

- Some Red River Métis Citizens reported significant delays in treatment and diagnosis, while others recalled a swift and easy navigation through their cancer journey.
- KIs reported that hospital policies can be challenging or impossible to accommodate traditional healing or cultural practices like family gatherings.
- Both KIs and Red River Métis Citizens had observed difficulties accessing palliative care while an individual would still benefit from it.
- Citizens felt isolated from cancer care services when they decided not to have typical treatments like radiation or chemotherapy.
- Citizens often experience long wait and travel times for specialists, especially in Northern communities.

### *Strengths and Facilitators*

- KIs reported that Nurse Navigators can help achieve timely care by assisting with scheduling appointments.
- Services and supports that can be accessed within the community, such as mobile breast cancer screening, make it easier to access care in timely manner.

## 5.1.3 Safety

Interventions must involve active management of risk and minimization of harm.

### *Barriers and Weaknesses*

- One Citizen reported that their oncologist's insistence on experimental treatment delayed palliative care.
- KIs noted the limited supports for individuals who are suffering from decreased mobility due to cancer treatment, which often results in moving into less-than-optimal accommodations just to access affordable and accessible areas.
- Both Citizens and KIs noted that discrimination in the healthcare system leads to both emotional trauma and poor clinical outcomes. Several Red River Métis complained of a lack of cultural safety and outright racism in the healthcare system. One Citizen said it contributed to a misdiagnosis that led to her brother's death. KIs stated that clinician's preconceptions about Red River Métis people can affect the care they provide.

## 5.1.4 Patient Experience

Patients should be the core of healthcare services. Culture, work, family, and life beyond illness should be honoured. Addressing concerns about time, shared decisions, tailored information, and treating both physical and psychosocial symptoms.

### *Barriers and Weaknesses*

- Citizens expressed they felt that the Pan-Indigenous approach to care delivery ignores specific aspects of Red River Métis culture.
- Both KIs and Métis Citizens recognized that print resources, programs, or supports for the cancer journey targeted specifically to Red River Métis do not exist and that this was a problem.
- Citizens from smaller communities are not often equipped or supported to cope with staying in a city for treatment.
- KIs noted that Citizens are often frustrated to travel for many hours for very short appointments and meetings.
- KIs and Citizens remarked that the fear and panic resulting from receiving a cancer diagnosis makes it difficult to communicate and absorb information related to care and next steps.
- Citizens feel detached from providers which limits their involvement in decision making. A KI highlighted the unchecked power imbalance, especially with doctors.
- Rural Citizens are forced to travel or otherwise forgo treatment. This does not respect patient preferences and use of time.
- KIs stressed that one training can not cover all Indigenous diversity. They noted that the current cultural competency training lacks Métis specificity.
- CCMB's Underserved Population program is limited in scope and funding and provides supports on a case-by-case basis.

### *Strengths and Facilitators*

- The KIs had positive experiences with cultural competency trainings and were optimistic about their ability to challenge preconceived notions of others.
- All KIs had completed a cultural competency training.
- CCMB's Underserved Populations program is a useful program with existing ties to the MMF, creating a relationship that can be built upon to support Red River Métis.
- A KI working as a Community Connector in a Southern Manitoba Red River Métis community has made good use of psychosocial oncology resources offered by CCMB.

## 5.1.5 Efficiency

Care should make the best use of limited resources and avoid waste.

### *Barriers and Weaknesses*

- Some Citizens believed that they should receive regular check-ups, and others wanted to continue to receive mammograms while over the age of 74. This contrasts with current research and best practices that advise against these practices (van Ravesteyn et al., 2015, Birtwistle et al., 2017).
- Pressure for more localized services challenges conventional wisdom that healthcare services should be centralized to reduce duplication and expense.

### *Strengths and Facilitators*

- KIs saw opportunities for further collaboration with the MMF, which could potentially reduce expense as the MMF takes on responsibilities and delivers programs formerly under the purview of provincial health authorities.

## 5.1.6 Equity

Patients should be able to determine what high-quality care means to them and care should be equally available to all.

### *Barriers and Weaknesses*

- Healthcare services in rural communities are limited, forcing people with cancer to travel long distances or care, or in some cases forgo care entirely.
- Both KIs and Citizens agreed that the biggest barrier to accessing screening and treatment is distance from healthcare services.
- Distance from healthcare also greatly increased the cost of accessing care. Some KIs reported that their clients avoided treatment because the costs of travel were too high.
- Poor care coordination creates problems for transportation arrangements. Citizens may have multiple appointments in the city, which can add extra costs for accommodations due to the gaps in between appointments.
- Medications can be expensive, and current Red River Métis supports falls short. Some are not eligible due to age, and those that do say its not enough. Out-of-pocket costs, even for later reimbursement can be prohibitive. KIs mentioned that high drug prices cause treatment avoidance.
- Various costs (like parking, meals etc.) impact Red River Métis Citizens negatively. KIs emphasized that specific costs, like pricey prevention aids like nicotine replacement therapies are out of budget.
- Citizens, especially single mothers, face added costs and stress in finding childcare if travel for care or caregiving is needed. KIs mentioned some

support requiring Child and Family Services, which many are reluctant to engage with.

- Elderly Citizens felt dismissed as hypochondriacs or complainers by doctors. Other remember not being taken seriously during younger cancer experiences. Ageism affects some, as they feel their care decisions are being controlled.
- Citizens and KIs recognize that interacting with physicians is stressful due to their busy schedules. This lack of time restricts Citizens from getting answers to all their questions and participating fully in their care.

#### *Strengths and Facilitators*

- KIs and Citizens were positive about mobile screening, which could be used to improve equity in access to care.
- KIs reported that investments in telehealth infrastructure resulting from the COVID-19 pandemic have improved accessibility for their rural clients.
- Citizens reported positive experiences with the MMF's PDP and credited it with improving access to medications.

### **5.1.7 Sustainability**

The ability to deliver quality in other domains over the long term and at the population level.

#### *Barriers and Weaknesses*

- Equity seeking programs and cultural competency trainings will require long term funding and increased staff to remain effective.
- A KI felt that the people they train in cultural competency quickly forget the lessons of a single training.
- Some KIs working in client-facing roles have had clients request supports in excess of what should be expected of them: one example is client requests for personal rides to appointments.

### **5.1.8 Access**

Patients should be able to easily access primary care and information about their own health and care.

#### *Barriers and Weaknesses*

- Citizens expressed concern about locating and retaining family doctors to access primary care.
- Many Citizens did not know what care and supports existed for them. These Citizens were particularly curious about screening services, financial assistance programs, and supports available in rural areas.
- A KI indicated that misinformation about cancer exists in some Red River Métis communities.

- KIs and Citizens agreed that while print media has a place in conveying information about care, mail-out information may be seen as junk mail and thrown out before it is read.
- Citizens noted that many people, especially Elders, do not have cellphones, computers, or stable internet access, and are unable to access information and care that rely on these technologies. Many rural and remote locations do not have libraries or places where people can access technology easily and for free.
- One KI noted that it was difficult to keep healthcare staff apprised of all the resources available, noting that uptake of voluntary training is poor.
- Multiple Citizens experienced challenges accessing their own medical records or those of family members.
- Citizens find it challenging to communicate with healthcare providers. Medical terminology can be difficult to understand, creating a barrier for many Red River Métis Citizens. KIs also reported that some healthcare providers misjudge a patients' understanding which causes frustration.

### *Strengths and Facilitators*

- Both KIs and Citizens suggested that interpreters for appointments have helped to clarify information both during and after the appointment.
- KIs noted that word-of-mouth in the community is a vital way for people to access resources.
- There are many well received and widely used governmental and non-profit organizations and supports that could be partnered with or expanded to suit Red River Métis needs.
- Citizens suggested using diverse media for sharing cancer information, including virtual sessions, emails, in-person meetings, workshops, and radio announcements. KIs shared that they utilized all modes except TV, suggesting the potential for further educational campaigns.

## **5.2 Summary of Participant Insights**

KIs and Citizens shared insights about challenges tied to distance to care and treatment related financial stress. These profoundly affected equity and access, worsened by policy weaknesses in programs like NPTP.

Another barrier was obtaining care details with doctor-patient confusion, prevalent post-diagnosis due to heightened emotions. Noted by KIs and Citizens was that there are inadequate resources and cultural training, along with unaddressed power imbalances between patients and doctors. These concerns heavily influenced patients' experiences and wellness in relationships. Consultations highlighted a mismatch between Red River Métis needs, values, and healthcare policies, particularly regarding family roles during the cancer journey. Participants told important stories about how discrimination based on Indigenous identity and age can have life-altering consequences for Red River Métis that effects their willingness to seek care in the future. KIs emphasized the need to improve

existing support to maintain and ensure equity programs like cultural competency training and the community connector program over the long term.

Findings highlighted troubling trends in treatment stigma and resulting ability loss. KIs noted lower care-seeking behaviours among male clients, demonstrated by limited male participation in our Citizen discussion groups.

Discussions revealed widespread support among Citizens for the MMF, trusting it to advocate and offer valuable support. KIs viewed partnering with the MMF as a logical progression to enhance services for Red River Métis.

### **5.3 Limitations**

The Red River Métis population extends beyond Manitoba's borders. However, our research focused solely on participants from Manitoba's seven MMF Regions due to the provincial administration of cancer-related healthcare. As a result, the direct applicability of these findings to Red River Métis individuals outside Manitoba might be limited. It is crucial to acknowledge this limitation, especially considering the Beyond Borders Taskforce's emphasis on diverse healthcare beyond the province, aligned with UNDRIP principles. Future research should encompass participants from across the Red River Métis Homeland, transcending colonial borders. Our Citizens are spread nationally and internationally, with the MMF acting as the National Government, with the MMF-HWD playing a pivotal role.

The research findings are constrained by the composition of the discussion group sample. The shift to online discussions during the COVID-19 pandemic resulted in a convenience sample that might not fully represent the broader Red River Métis population. Overrepresentation of females and an inadequate representation of youth and individuals under 40, possibly due to scheduling conflicts, further impact the generalizability of our findings. Despite these limitations, the online format facilitated participation for geographically isolated individuals, offering unique advantages.

This pioneering study serves as an initial exploration of the Red River Métis cancer journey, with the recognition that further research is imperative. Gaining a deeper understanding of experiences is essential to shape the development of culturally tailored, distinctions-based programming and resources, aligning with the aspirations of the Red River Métis population.

## Section 6: Recommendations and Future Directions

The culmination of the present research points to a recurring theme of rectifying policy inadequacies. In light of this research, paramount revisions must entail grounding programs and services within the tenets of reconciliation, rights recognition, and respect for our governing institutions, particularly the National Government of the Red River Métis. At the core of this endeavor lies the resounding principle of "nothing about us without us." Major themes that the present study identified through a review of literature and consultations with Citizens were:

- Equitable funding anchored in rights recognition.
- Supporting patient escorts within the Northern Patient Transport Program.
- Amending hospital policies for family participation.
- Enhanced access for traditional treatment seekers.
- Comprehensive compassionate care leave.
- Collaborative cultural safety protocols.
- Distinctions-based Indigenous cultural training.
- Advocating cultural safety training for physicians.
- Strengthening telecommunications and mobile clinics.
- Augmented Red River Métis-specific resources.

Specific system-focused recommendations derived from the study findings include:

- Healthcare professionals should have opportunities to continue education on topics relating to Red River Métis culture, health, and cultural safety.
- Targeted efforts must improve awareness of the diversity that exists within Red River Métis culture.
- Healthcare and educational institutions should collaborate with the MMF to research, design and evaluate programs and services.
- Red River Métis leadership, MMF-HWD, and regional MMF Representatives should be involved in healthcare planning, policy, and governance.
- Red River Métis practitioners should be hired and retained to connect with Red River Métis patients and address their social, cultural, and linguistic needs.
- Health promotion materials should use Red River Métis-specific and culturally appropriate language and clear messaging that avoids technical jargon.
- Barriers to care, including structural barriers such as jurisdictional complexity and the social determinants of health should be addressed.

To enhance culturally appropriate care for Red River Métis, specific directives for healthcare providers and caregivers include:

- Care should be holistic and include family and community, and respect the connection with land, tradition, and the Red River Métis Way of Knowing as being essential to healing for our Citizens.
- Support and education should be provided to family and community to address stigma and misinformation.



- Places like hospitals and Cancer Centres should include Red River Métis art and interior design.
- Healthcare staff and support team should coordinate with primary care providers to promote healthcare initiatives and patient education incorporating Red River Métis specific care.
- Healthcare should integrate western and traditional Red River Métis healing practices when treating Red River Métis Citizens.

Individual Red River Métis educated healthcare workers should champion cultural safety within their institutions, practicing it consistently and promoting it with colleagues.

The quest to enhance cancer care for our Citizens necessitates complementary initiatives to address geographical challenges. Expanded investments in telecommunications can significantly enhance access to care for rural and remote Red River Métis, while preserving the efficiency of the centralized healthcare model. Notably, the MMF-HWD's investment in mobile clinics could be leveraged to disseminate pertinent cancer care information. Similarly, the exploration of an informational phone line, akin to the Red River Métis Mental Health line, could further bolster healthcare information dissemination.

This study further underscores the need for Red River Métis-specific cancer resources that cater to varied preferences and learning styles. Special care must be taken to ensure that print materials are not discarded unread, with increased avenues for face-to-face interactions and word-of-mouth communication explored to augment resource dissemination.

In conclusion, while this research provides a comprehensive overview of various issues, its scope remains limited, necessitating expansion to comprehensively fathom the Red River Métis cancer experience. This entails an inclusive examination of male and youth concerns in the cancer journey, as well as deeper ethnographic exploration for an enhanced understanding of the lived experience. Moreover, the boundaries of childcare support and comprehensive research into accessibility challenges warrant dedicated inquiry. By adopting these recommendations, we aspire to usher in an era of culturally appropriate and distinctions-based care that profoundly impacts the lives of Red River Métis Citizens in Manitoba and beyond.

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