

# INCREASING CANCER SCREENING IN THE MÉTIS NATION OF ONTARIO:

Final Report from the Métis Cancer Screening Research Project

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#### Ontario Health (Cancer Care Ontario)

Ontario Health is an agency created by the Government of Ontario with a mandate to connect and coordinate Ontario's health care system. Cancer Care Ontario transitioned from a standalone agency to being incorporated into Ontario Health, an agency of the Ministry of Health that aims to provide an improved patient experience through improved health system integration. To reflect Cancer Care Ontario's incorporation into Ontario Health, we refer to this entity as Ontario Health (Cancer Care Ontario), or OH (CCO), throughout the document. OH (CCO) is committed to improving the performance of the cancer system by driving quality, accountability, innovation and value. Working with our many partners, OH (CCO) implements provincial cancer prevention and screening programs; develops and implements quality improvements, standards and accountability for cancer care; and uses electronic information and technology to increase accessibility to, and advance the safety, quality and efficiency of, Ontario's cancer services. OH (CCO) also develops multi-year system plans, including the Ontario Cancer Plan V and the associated First Nations, Inuit, Métis and Urban Indigenous Cancer Strategy IV, both of which run from 2019 to 2023, to ensure that the needs of current and future people with cancer will be met.

#### Sunnybrook Research Institute

The Sunnybrook Research Institute (SRI) is a research and teaching hospital affiliated with the University of Toronto. SRI spans three Toronto-based campuses, including the Sunnybrook Health Sciences Centre, Holland Centre and St. John's Rehab. SRI has more than 300 scientists and clinician-scientists. Their work is supported by approximately 1,400 research staff, around 5600 highly skilled biomedical and research personnel, and over 400 postdoctoral fellows and other trainees. SRI's main aims are to understand and prevent disease, and develop precise treatments that enhance and extend life and minimize adverse effects.

#### The Métis Nation of Ontario (MNO)

Founded in the early 1990's, the Métis Nation of Ontario (MNO) represents the rights, interests and aspirations of the Métis people of Ontario, embodied within MNO's Statement of Prime Purpose. MNO's role as the province wide, democratically elected Métis governance structure in Ontario is formally recognized in the Métis Nation of Ontario Secretariat Act (passed by the Ontario legislature in December, 2015) and through a series of bilateral and tripartite processes established with the federal and provincial governments, including the Ontario-Métis Nation Framework Agreement with the Government of Ontario, initially signed in 2008, which remains in place today.

Through its province-wide infrastructure, the MNO delivers culture-based programs services in health and wellness, labour market development, education, and housing to Métis clients across the province. In accordance with the goals outlined in the MNO Statement of Prime Purpose, the MNO Healing and Wellness Branch aims to provide culturally appropriate, supportive, self-directed health and wellness opportunities that address the emotional, spiritual, mental, physical and social requirements of citizens, families and communities. The MNO approach to healing and wellness is client and family centred, holistic in nature, and firmly rooted in Métis traditions, culture and values. Services are directly responsive to identified individual and community

needs, and MNO remains fully accountable to Métis program clients, citizens and communities as well as to its partners and funding agencies. The MNO has a proven track record of excellence in policy, program and service delivery.

#### **ACRONYMS**

CCC Colon Cancer Check CCO Cancer Care Ontario **FNIM** First Nations, Inuit, Métis **FOBT** Fecal Occult Blood Test **ICCU** Indigenous Cancer Care Unit **JOICC** Joint Ontario Indigenous Cancer Committee **MCR** Métis Citizenship Registry **MCSRP** Métis Cancer Screening Research Project MNO Métis Nation of Ontario **OBSP** Ontario Breast Screening Program **OCSP** Ontario Cervical Screening Program Ontario Health OH OH (CCO) Ontario Health (Cancer Care Ontario) **OHIP** Ontario Health Insurance Plan OTN Ontario Telemedicine Network SRI Sunnybrook Research Institute WG Working Group

# Contents

Ontario Health (Cancer Care Ontario)	2
Sunnybrook Research Institute	2
The Métis Nation of Ontario (MNO)	2
ACRONYMS	3
EXECUTIVE SUMMARY	7
INTRODUCTION	8
Background	8
Research Objectives	12
Ontario Health (Cancer Care Ontario) (OH (CCO)) and the Métis Nation of Ontario (MNO)	13
Project Governance Structure and Process	14
METHODS	16
Study Setting	16
Study Overview	17
Participant Characteristics and Data Collection	17
Group 1: MNO Healing and Wellness Staff Participants	17
Group 2: MNO Citizen Participants	19
Data Security: Data Storage, Transcription & Quality Assurance	20
Data Analysis	21
Survey Data	21
Focus Group Data	21
RESULTS	21
Part 1 Overview of Participants	22
Participant Characteristics - Age, Sex, Cultural Identity, Geographic Location	22
Healthcare Utilization – Access to Care and Information	23
Part 2 – Cancer and Cancer Screening – Survey Results	26
➤ Group 1 – MNO Healing and Wellness Staff Participants	26
➤ Group 2 – MNO Citizen Participants	28
Part 3 – Cancer Screening – Focus Group Results	31
Group 1 – MNO Healing and Wellness Staff Participants	31
Group 2 – MNO Citizen Participants	50
DISCUSSION	63
Summary of Key Findings	63

Interpretation of Results – Cancer Screening Pathway	64
Awareness and Perceptions (Pathway steps 1 and 2)	66
Access to cancer screening services (Pathway steps 3 and 4)	67
Cultural safety of cancer screening services (Pathway steps 3 and4)	
Results in Relation to Published Literature	
CONCLUSIONS AND RECOMMENDATIONS	70
ACKNOWLEDGMENTS	74
REFERENCES	75
Figures  Figure 4. Métic Concer Serecaring Research Project (MCSRR) Process	4.4
Figure 1: Métis Cancer Screening Research Project (MCSRP) Process	
Figure 3: MNO Regional Map	
Figure 4: Ontario Health (Cancer Care Ontario)'s "Ideal State" Cancer Screening Pathway.	
Figure 5: Locations that MNO clients access screening services	
Figure 6: Métis Cancer Screening Pathway	65
Tables	
Table 1: Ontario's Cancer Screening Programs	11
Table 2: Group 2 Characteristics – MNO Citizen Participants	
Table 3: Where MNO staff indicate that Métis clients access primary healthcare services	24
Table 4: MNO staff perceptions about degree of difficulty Métis clients experience when accessing healthcare services	24
Table 5: MNO staff perceptions about where Métis clients receive information about health	/
Wellness	
Table 6: Where MNO citizens typically access primary care services	
Table 8: Cancer Screening Uptake (as reported by MNO citizens)	
Table 9: Barriers identified by MNO Healing and Wellness Staff - limited access to healthca	
providers / screening services	
Table 10: Barriers identified by MNO Healing and Wellness Staff – lack of cultural competer	-
in healthcare system	35
reluctance to participate	38
Table 12: Barriers identified by MNO Healing and Wellness Staff – lack of awareness about	
screening / ineffective existing education approaches	40
Table 13: Barriers identified by MNO Healing and Wellness Staff – Basic needs take	40
precedence	42

Table 14: Facilitators identified by MNO Healing and Wellness Staff – Improve education
approaches and resources so they are specific to Métis community and grounded in culture43
Table 15: Facilitators identified by MNO Healing and Wellness Staff – Improve social support
throughout screening process
Table 16: Facilitators identified by MNO Healing and Wellness Staff – Improve access to cancer
·
screening services
Table 17: Facilitators identified by MNO Healing and Wellness Staff – Improve cultural
competency of healthcare providers49
Table 18: Barriers identified by MNO citizens – Limited of access to cancer screening services
51
Table 19: Barriers identified by MNO citizens – Lack of cultural competency/safety in cancer
screening services and healthcare system52
Table 20: Barriers identified by MNO citizens – Attitudes and / or perceptions about cancer /
cancer screening - fear, avoidance, and reluctance to participate55
Table 21: Barriers identified by MNO citizens – Lack of screening awareness and ineffective
cancer screening education approaches56
Table 22: Barriers identified by MNO citizens – Basic needs take precedence
Table 23: Facilitators identified by MNO citizens – improve education approaches and access to
resources so they are specific to Métis community and grounded in culture57
Table 24: Facilitators identified by MNO citizens – improve social support throughout screening
process
Table 25: Facilitators identified by MNO citizens – improve access to cancer screening services
60
Table 26: Facilitators identified by MNO citizens – improve cultural competency of healthcare
providers61
Table 27: Recommendations to improve cancer screening in the Métis Nation of Ontario71
Table 27. Recommendations to improve cancer screening in the webs Nation of Ontano7

#### **EXECUTIVE SUMMARY**

Cancer screening is widely recognized as an important strategy in addressing the burden of cancer by reducing cancer incidence and mortality.<sup>1-4</sup> In Ontario, there are well established organized cancer screening programs for breast, cervical and colorectal cancer.<sup>4</sup>

Research conducted by the Métis Nation of Ontario (MNO) and Ontario Health (Cancer Care Ontario) (OH (CCO)) in 2015 suggests that cancer risk factors are more prevalent, and the incidences of some cancers are higher, among the Métis than non-Indigenous people in Ontario.<sup>5</sup> Building on this work, MNO, OH (CCO) and Sunnybrook Research Institute (SRI) partnered on a community-based study that examined factors that impact cancer screening among Métis communities in Ontario.

The objectives of this study were to identify barriers and facilitators to cancer screening uptake and to improve access to culturally relevant cancer screening services for Métis in Ontario. The study combined focus group and survey methods to understand the perspectives of Métis communities throughout Ontario. Participants included 66 MNO frontline staff and citizens.

Key themes identified through collaborative analysis were examined in relation to OH (CCO)'s proposed 'ideal state' cancer screening pathway, which outlines how cancer screening is expected to proceed in order to maximize early detection rates and improve cancer treatment outcomes. Based on study findings, the pathway was streamlined into *four key steps* in cancer screening, as understood by Métis communities:

- 1. Knowing about cancer screening: education / awareness;
- 2. Deciding to get screened;
- 3. Taking Action: booking an appointment, getting to services or completing tests; and,
- 4. Following up: getting test results, completing further testing, or initiating screening again when appropriate.

Key factors that impede participation in cancer screening among Métis communities, as well as key supports, were identified in relation to this streamlined pathway. Key factors included: limited Métis-specific resources and supports; widespread lack of cultural competency among healthcare providers; limited access to screening services; and challenges with long-distance travel to access services. Key supports included: culturally specific information and programming; assistance with transportation; local screening services; Métis cultural training for providers; and integrated screening services

Drawing on these findings, the research team identified three overarching factors that are particularly important in understanding how Métis communities in Ontario experience cancer screening:

Awareness and perceptions (impacts screening steps 1 and 2 in particular);

- Access to cancer screening services (impacts screening steps 3 and 4 in particular);
   and,
- Cultural safety of cancer screening services (impacts screening steps 3 and 4 in particular).

These factors are interrelated with one another and can serve as barriers or facilitators to cancer screening.

This research identified key service gaps and culture-based strategies for improving cancer screening services among Métis communities in Ontario. Recommendations to improve cancer screening uptake for Métis communities in Ontario are summarized below:

- Support awareness and discussions about cancer screening at the community level;
- Support MNO frontline workers to provide cancer screening education and facilitate cancer screening uptake in Métis communities;
- Support healthcare providers to engage more effectively with Métis patients;
- Improve awareness and understanding of Métis health service experience with respect to screening among research community; and,
- Support policy and program development that promotes screening knowledge and uptake in Métis communities.

To date, approaches to understanding cancer screening behaviours in Indigenous populations have mostly been pan-Indigenous in nature, or predominantly First Nations-focused. Such approaches mask Métis-specific geographic, demographic, and sociopolitical factors that impact Métis screening rates. This project engaged community and policy partners in a collaborative, culture-based study of cancer screening among Métis communities in Ontario. Results provided insights into factors impacting Métis community screening rates specifically, not available from pan-Indigenous approaches. This study provides clear direction to policy makers and will help target resources to where they are more likely to be effective in increasing screening among the Métis people of Ontario.

#### INTRODUCTION

# **Background**

The Métis Nation is one of three Indigenous peoples formally recognized in Section 35 of Canada's constitution. Métis people are generally either poorly identified or under-identified, and consequently, generally under-represented in Indigenous research and statistics. According to Statistics Canada's most recent census, compiled in 2016, there are 587,545 Métis peoples in Canada (1.7% of the total population) of which 120,585 are in Ontario.<sup>6</sup> In contrast, the Métis

Nation of Ontario's (MNO) Métis Citizenship Registry (MCR) includes approximately 20,000<sup>i</sup> Métis citizens.<sup>7</sup> It is important to note that the difference in population estimate is attributable to the inclusion of self-identified Métis peoples in Statistics Canada's census, compared to MNO's MCR, which is comprised only of those who satisfy the *National Definition of Métis* as referenced on MNO's website (MNO, 2021).<sup>8</sup>

Métis, First Nations and Inuit populations are significantly younger than the non-Indigenous population, with proportionally more children and youth, and fewer seniors; however, the percentage of those 65 years of age and older is increasing and accounted for a larger share of each of the three populations in 2016 than in the past.<sup>6</sup>

Métis-specific health data and research is limited. Most Métis health data comes from research that Métis Nation governments themselves have conducted, often linking their own citizenship registry data with health administrative databases to provide estimates of disease incidence and prevalence. In Ontario, the MNO's Chronic Disease Surveillance Program, which was conducted in partnership with the Institute for Clinical Evaluative Sciences between 2010 and 2015, has provided much of the evidence on chronic disease rates among Métis in this province. The work completed to date in Ontario shows that Métis populations are experiencing disproportionately high rates of chronic disease and other conditions, and have less access to primary and specialist care, than non-Indigenous populations. Pegarding cancer, a study published in 2018 examined site-specific incidence rates and survival for the most common cancers among Métis adults in Canada and compared these with rates for non-indigenous adults from 1992 to 2009.10 Findings suggest that when data for all cancers and for both sexes were combined, cancer incidence was similar for Métis and non-Indigenous adults. However, the disease specific data showed that incidence of breast cancer and cervical cancer was significantly higher among Métis women compared to non-Indigenous women .<sup>10</sup> Lung, liver, larynx, and gallbladder cancers were also higher among Métis adults compared to non-Indigenous adults.<sup>10</sup> Métis men had significantly poorer survival rates for prostate cancer compared to non-Indigenous men. 10 The study suggests that these disparities may be attributed to a combination of lifestyle factors (including increased tobacco use and obesity) and lower participation in cancer screening, and provides evidence to support development of public health policy and healthcare services to address the cancer burden among the Métis people of Canada.

To shed light on the Métis-specific cancer experiences, MNO and the Canadian Partnership Against Cancer (CPAC) collaborated in 2011 on the qualitative research project called the *Métis Cancer Patient Journey*. <sup>11</sup> The objective of this project was to better understand Métis cancer patients experiences through their journeys and to explore what could be done to improve the continuity of care and ultimately result in healthier outcomes. Specifically, the project aimed to explore the experiences of Métis cancer patients and their families and what they would like decision-makers to know. These perspectives were gathered through a one-and-a-half day facilitated session that included group discussions, small group conversations and individual

<sup>i</sup> This figure is accurate as of January 16<sup>th</sup>, 2020. Citizens' applications are received in an ongoing basis and this estimate is changing in real time.

work. Participants created a cancer journey timeline graphic sharing their cancer journey, how they felt throughout their journey, and recommendations that could improve the cancer system. Some barriers throughout the cancer journey identified during this process included social barriers (e.g., reluctance to see physicians early on when experiencing problems attributed to complex circumstances), lack of identification resulting in difficulty to access cultural supports, fear of marginalization and health system barriers (e.g., lack of access to essential services in home communities; lengthy wait times and poor clinician communication).<sup>11</sup>

Furthermore, a 2015 study conducted in partnership by the MNO and OH (CCO) revealed cancer risk factors are significantly higher within the Métis population in Ontario as compared to the non-Indigenous provincial population.<sup>5</sup> Specifically, this study showed that:

- Métis people in Ontario have higher exposure to tobacco smoke than their non-Indigenous counterparts (including via smoking and exposure to second-hand smoke);
- Although the rate of smoking has declined over time, rates of smoking among Métis teens and young adults is double that of their same-age non-Indigenous counterparts (17% compared to 8% for Métis aged 12-19 years and 47% compared to 27% for Métis aged 20-29 years);
- More Métis adults exceed cancer prevention guidelines for drinking alcohol and a higher percentage of Métis adults both smoke and drink more than their non-Indigenous counterparts; and
- Métis adults are more likely to be obese than their non-Indigenous counterparts (with increasing obesity attributed to less physical activity).

Cancer screening is widely recognized as an important strategy in addressing the burden of cancer by reducing cancer incidence and mortality.<sup>1-4</sup> In Ontario, there are organized cancer screening programs for four types of cancer: breast, cervical colorectal and lung.<sup>4</sup> At the time of the study, the organized lung screening program was in development as a pilot program focused on those at high-risk.<sup>12</sup> As such, the lung screening experiences are not assessed by this study. OH (CCO) works closely with 14 Regional Cancer Programs (RCPs) throughout the province to lead the implementation of the screening programs within each region. Organized population-based cancer screening programs invite screen-eligible people who do not have any cancer symptoms to participate in screening tests at a regular interval. The purpose of cancer screening is to detect pre-cancerous changes or cancer at an early stage, when treatment is more effective. Ontario's cancer screening programs ultimately aim to promote prevention and early detection of cancer, and to reduce the number of deaths attributable to the targeted cancer. The screening guidelines are outlined in Table 1.<sup>4</sup>

The MNO-OH (CCO) research study found that Métis Ontarians are less likely to be up-to-date with cancer screening tests compared to non-Indigenous Ontarians.<sup>5</sup> Specifically, half of Métis adults aged 50–74 were overdue for colorectal cancer screening (i.e. they were in need of a fecal test, sigmoidoscopy or colonoscopy in order to be up to date with the recommended colorectal cancer screening guidelines). Métis peoples aged 50–54 are particularly underscreened, with over 60% overdue for colorectal cancer screening. Those Métis adults with the lowest income were the most likely to be overdue for colorectal cancer screening. Similarly, for

**Table 1: Ontario's Cancer Screening Programs** 

Program	Recommended Screening Test and Interval	Eligible Criteria for Screening
Ontario Breast Screening Program (OBSP) High Risk Ontario Breast Screening Program (High Risk OBSP)	Digital mammography provided at an OBSP screening location every 2 years  Digital mammography + magnetic resonance imaging (MRI) every year	<ul> <li>Women aged 50-74 who have:</li> <li>No acute symptoms</li> <li>No personal history of breast cancer</li> <li>No current breast implants</li> <li>Not had a mammogram within the last 11 months</li> <li>Women aged 30-69 and who:</li> <li>Have a physician's referral</li> <li>Have no acute breast symptoms</li> <li>Fall into one of the following risk categories: <ul> <li>known to be carriers of BRCA1 or BRCA2 gene mutation</li> <li>First-degree relative of a mutation carrier, has had genetic counselling and has declined genetic testing</li> <li>Previously assessed by a genetic clinic as having &gt;25% lifetime risk of breast cancer</li> <li>Received radiation therapy to the chest before age 30 and at least 8 years ago</li> </ul> </li> </ul>
Ontario Cervical Cancer Screening Program (OCSP)	Cytology (Pap) test performed at healthcare provider's office every 3 years	Women aged 21 and over, who are (or have ever been) sexually active. Screening can stop at age 70, if participant has had 3 or more negative tests in the previous 10 years.
Colon Cancer Check (CCC)	Fecal immunochemical test (FIT) completed at home every 2 years. Ordered by family physicians/nurse practitioners or by contacting Health Connect Ontario <sup>ii</sup> and mailed to participant	<ul> <li>Men and women aged 50-74 and who have:</li> <li>No first-degree relative who has been diagnosed with colorectal cancer</li> <li>No personal history of pre-cancerous colorectal polyps requiring surveillance or inflammatory bowel disease</li> </ul>

<sup>&</sup>quot;Health Connect Ontario (formerly known as Telehealth Ontario) is a free, secure and confidential service that Ontarians can call or access online at any time to get health advice from a registered nurse or to find health services or information. This tool is for non-urgent health care information, advice and referrals. Ontario Health (OTN) is a telemedicine network that uses secure virtual care technology to connect patients with their health care providers and can be accessed from the patient's home or from a nearby health care centre. However, some participants used the terms "OTN" and "telehealth" interchangeably.

Program	Recommended Screening Test and Interval	Eligible Criteria for Screening
CCC Increased Risk	Colonoscopy every 5-10 years	Men and women with a family history of colorectal cancer that includes 1 or more first-degree relatives who have been diagnosed with colorectal cancer, but do not meet the criteria for hereditary colorectal cancer syndromes.  Screening with colonoscopy should begin at age 50, or 10 years earlier than the age their relative was diagnosed, whichever occurs first.
Ontario Lung Screening Program (OLSP)	Low-dose computed tomography (LDCT) scan. Referred by healthcare provider to OLSP to confirm eligibility. Individuals can contact OLSP directly to confirm eligibility.	Initial referral is for men and women aged 55-74 and who have:  • smoked cigarettes every day for at least 20 years (it does not have to be 20 years in a row, which means there could be times when you did not smoke)  OLSP navigator confirms eligibility using a risk assessment based on factors such as:  • age  • cigarette smoking history  • body mass index  • education  • personal history of cancer and chronic obstructive pulmonary disease  • family history of lung cancer

breast cancer screening, only 49% of Métis women aged 50–74 had had a recent mammogram for breast cancer, compared to over 60% of non-Indigenous women. Métis women with less education or lower incomes were more likely to be overdue for breast cancer screening. Most Métis women (81%) were up to date for Pap test to screen for cervical cancer, which was similar to non-Indigenous women (80%). Métis women with the lowest incomes are less likely to be up to date with cervical cancer screening (68%).

While it is clear that Métis people in Ontario suffer disproportionately from a number of cancers, are at greater risk for several cancers, and are under screened for some cancers, the reasons for low participation in the provincial organized cancer screening programs among the Métis population are not well understood.

# **Research Objectives**

This study aims to address these knowledge gaps and ultimately, to help reduce the cancer burden in the Métis people of Ontario through improved health policy and programming that more effectively addresses Métis-specific cancer screening needs and priorities. The study builds on the research summarized in the previous section.<sup>5, 9-11, 13</sup> It also takes into account the stories that MNO elected leaders and MNO Healing and Wellness staff hear from across the province as they continually work to assist Métis clients in accessing cancer services, including

screening and diagnostic services as well as timely cancer treatments, in order to reduce cancer risk and support positive outcomes.

The study aimed to increase collective understandings of barriers and facilitators to cancer screening among MNO communities in Ontario. Specific research objectives included:

- Explore perceptions of and experiences with cancer screening in the Métis Nation of Ontario (citizens, families, and the community at large);
- Identify barriers and facilitators to effective cancer screening for the Métis Nation of Ontario; and,
- Identify gaps in cancer screening services for Métis Nation of Ontario and how to address them.

A key focus in addressing these research objectives was to examine the role of upstream health systems factors in shaping barriers and facilitators to cancer screening among the Métis Nation of Ontario. Importantly, the study also builds on a significant foundational partnership and continuum of work between OH (CCO) and MNO.

# Ontario Health (Cancer Care Ontario) (OH (CCO)) and the Métis Nation of Ontario (MNO)

In February 2015 – following several years of relationship building – OH (CCO) and the MNO signed a Memorandum of Understanding (MOU) to formalize their relationship and guide future work to reduce the burden of cancer in the Métis Nation. One mechanism that drove this work was the Joint Ontario Indigenous Cancer Committee (JOICC), through which MNO (and others) collaborate with OH (CCO) as it develops and implements strategies to improve the performance of cancer system with and for Métis, First Nations and Inuit people in Ontario. OH (CCO)'s Indigenous Cancer Care Unit (ICCU) and MNO have undertaken significant work to address the strategic priorities of OH (CCO)'s First Nations, Inuit Métis and Urban Indigenous Cancer Strategies. The most recent strategy (2019-2023) includes seven priorities that have been informed by MNO and other JOICC members throughout the duration of the partnership. Strategic priorities include building productive relationships; measurement, monitoring and evaluation; prevention; screening; palliative and end-of life care; education, and equitable access.

Starting in 2014, OH (CCO)'s ICCU and Sunnybrook Research Institute (SRI) collaborated on a Canadian Institutes for Health Research (CIHR)-funded program of research focused on improving cancer screening among Métis and First Nations communities in Ontario. The research program had four interrelated research aims that culminated in the development of a comprehensive knowledge translation action plan to improve cancer screening among First Nations and Métis communities in Ontario. The collaboration between OH (CCO), SRI and MNO, for the purpose of this study, focused on the second research aim: *conduct community-based analyses of cancer screening*. This study is referred to as the Métis Cancer Screening Research Project (MCSRP). MNO's participation in the MCSRP is in response to identified needs of Métis Nation communities, families and citizens across Ontario (for a detailed account

of the project – including a description of the other three research aims see <u>Appendix A: Project</u> <u>Partnership Agreement</u>).

## **Project Governance Structure and Process**

The SRI and OH (CCO) research team members approached the MNO about working together on this study in March of 2014 and completed the MNO Research Checklist for review and consideration by the MNO. Between 2014 and 2016, MNO, SRI and OH (CCO) team members worked together to develop our research partnership, define the study objectives and outline the study design. This process was guided by input and needs identified by Métis Nation communities, families and citizens throughout the province. In 2016, our working relationship on the MCSRP was formalized through a research collaboration agreement, a legal document that outlines the ways in which the research partners (MNO, SRI, OH (CCO)) have agreed to work together, as well as the research protocol. Importantly, this agreement makes clear that our partnership is based on mutual respect and a commitment by all partners to comply with the Métis principles of data access, ownership and governance. As such, the agreement formally recognizes MNO's role as the community custodian of all data and information collected and developed through the MCSRP. The agreement also makes clear that any reports or materials that result from the MCSRP must be developed collaboratively by the research partners and cannot be shared without written approval of all research partners. This commitment to respecting Métis collective and self-determined data management and governance is fundamental to the agreement, and to the MCSRP. This agreement was reviewed and approved by MNO Healing and Wellness Director and Chief Operating Officer (COO).

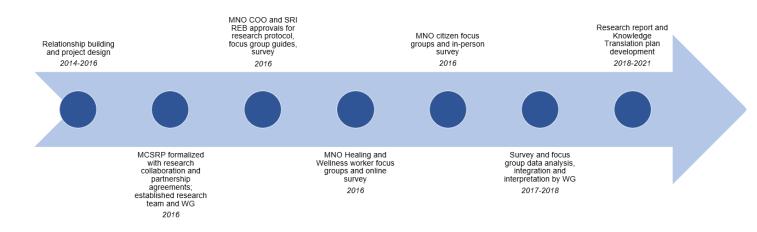


Figure 1: Métis Cancer Screening Research Project (MCSRP) Process

The research collaboration agreement also detailed our research funding arrangement and budget. Research funding was transferred from the CIHR grant held at SRI to MNO, in order to

support the implementation of the project at MNO. This included funding to support the hiring of an MNO-based research coordinator who played a vital role in implementing the research project and liaising between the research partners, as well as funding for other research-related costs which were administered by MNO.

The research partners also established the MCSRP Working Group (WG), which oversaw the implementation of the project, with ongoing direction from leadership within each of the project partners (See Figure 2). The WG was co-chaired by MNO and OH (CCO) and had representation from all research partners, including the MNO-based research coordinator, other MNO research and policy team members, with input from the broader OH (CCO)-SRI research team. Rooted in our equal research partnership, the WG worked collaboratively to implement the MCSRP, including revising the research protocol, developing data collection materials, conducting data collection, analyzing and interpreting results, and developing knowledge translation products (e.g., reports, education resources etc.) Approval was obtained at the outset of the project from the SRI Research Ethics Board and the MNO COO via the formal approval of the original project proposal and research collaboration agreement.

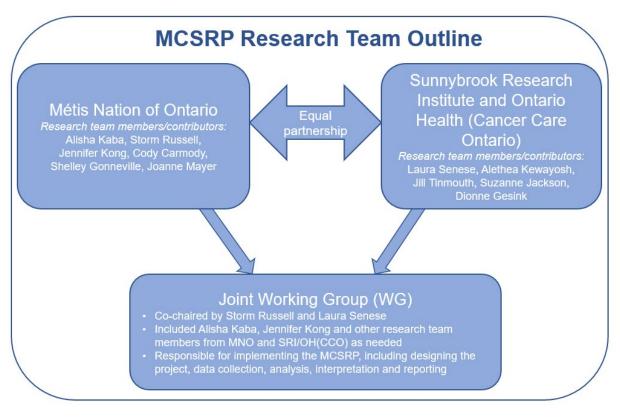


Figure 2: MCSRP Research Team Outline and Governance Structure

# **METHODS**

# **Study Setting**

The study focused on improving understandings of the diverse experiences of Métis communities across Ontario. The Métis are a distinct Indigenous people with a unique history, culture, language and territory that includes the waterways of Ontario, surrounds the Great Lakes, and spans into what is known as the historic Northwest. Distinct Métis settlements emerged as a result of the fur trade along freighting waterways and watersheds. In Ontario, these settlements were part of larger regional communities, interconnected by the highly mobile lifestyle of the Métis, the fur trade network, seasonal rounds, extensive kinship connections and a shared collective history and identity.<sup>7</sup>

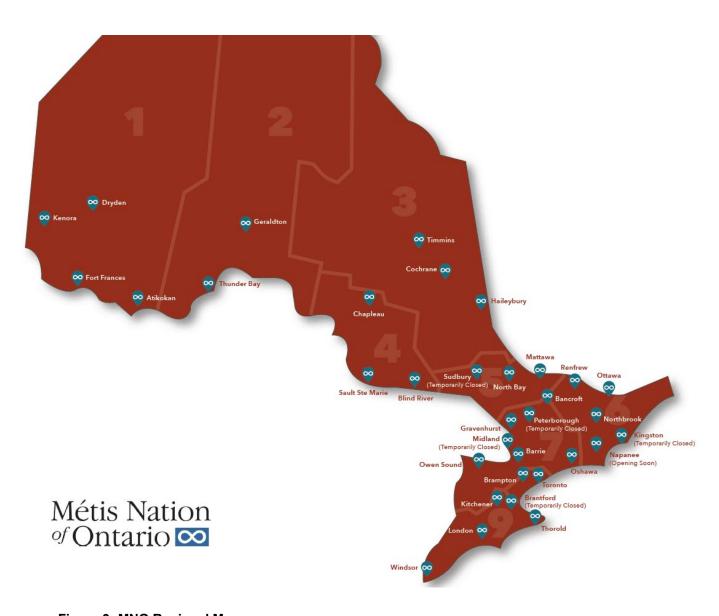


Figure 3: MNO Regional Map

The MNO has nine regions (see Figure 3), which span the province, covering a range of urban and rural settings. Each region has an MNO Chartered Community Councils, which represent Métis citizens at the local level.

The MNO delivers a range of programs and services in the areas of health, labour market development, education and housing to Ontario Métis and other Indigenous people. More than 300 people work for the MNO in 33 offices throughout the province. The MNO Healing and Wellness Branch employs over 100 staff most of whom work directly with Métis clients and families across the province in delivering a range of MNO programs and services. Some MNO Healing and Wellness staff are also Métis Nation of Ontario citizens. At the time of the study, MNO employed Healing and Wellness frontline staff in 31 MNO service centres located throughout Ontario. The number of MNO service centres has since increased to 33.

MNO Healing and Wellness staff from all nine regions across the province participated in the study. MNO citizen participants were from regions five and seven.

#### **Study Overview**

An exploratory mixed methods study design was used to learn about how cancer screening is understood and experienced by Métis communities in Ontario. Six focus group discussions were conducted with MNO Healing and Wellness frontline staff, many of whom also identify as Métis (Group 1) in January 2016 (n=45) and followed by an online survey in February 2017 (n=28). Focus groups and surveys were used to capture frontline staff perspectives on cancer screening among Métis communities in Ontario. MNO citizens (group 2) shared their perspectives about and experiences of accessing cancer screening through two facilitated focus group discussions and a follow up survey in November 2016 (n=21).

#### **Participant Characteristics and Data Collection**

#### **Group 1: MNO Healing and Wellness Staff Participants**

#### Participant Recruitment and Inclusion Criteria

In their role as MNO service providers, MNO Healing and Wellness frontline staff are rightly regarded as key informants who possess in-depth knowledge of Métis communities' health needs, and also their experiences in accessing the healthcare system – in this case, cancer screening services and supports. Many of the MNO staff are also Métis themselves, and are therefore well-positioned to provide both a service provider as well as a Métis community perspective, based on their own personal experience with the cancer care system.

As part of MNO's ongoing staff development and programming, MNO holds regular training and information sessions with MNO Healing and Wellness frontline staff throughout the year. At one such training session held with all staff in 2016 in Toronto, MNO set aside time for staff to participate in voluntary, facilitated focus group discussions, which formed the first part of the staff data collection.

Inclusion criteria for the focus groups and follow up survey included being 18 years of age or older and being an MNO employee who worked directly with Métis clients and community members.

#### Informed Consent and Data Collection

Prior to beginning the focus group sessions, participants were provided with a detailed introduction and overview of the study (written and verbal), including that the sessions would be audio-recorded. They were also informed that their decision to participate (or not) in the project would have no effect or impact whatsoever on their status or relationship with the MNO, OH (CCO), or SRI, nor would it affect their employment with MNO, or their access to or eligibility for, services and supports provided through either MNO or OH (CCO). Participants were encouraged to ask questions throughout the project overview presentation.

Once all participants' questions had been answered and any concerns addressed, they were then invited to review and sign the informed consent form (see <u>Appendix B: Staff Informed Consent</u>).

Consenting study participants were then divided into one of six focus groups based on the geographic area in which they worked. This geographic grouping was done in order to facilitate and encourage discussion, and to identify regional barriers and/or facilitators that might be specific to a particular region (e.g., northern versus more southern locations). As well, it enabled staff who were more likely to have similar experiences and perspectives to be grouped together to allow for more in-depth discussion of specific issues.

The six focus groups were facilitated by members of the research team using a common written discussion guide that probed participants' understanding of their own and their Métis clients' knowledge and awareness of OH (CCO) and MNO programming, resources, and service delivery in the area of cancer screening, prevention and treatment. A copy of the discussion guide is included in <u>Appendix C: Staff Focus Group Discussion Guide</u>.

All audio recordings of the focus group discussions were subsequently professionally transcribed and de-identified to provide anonymized verbatim reports of participants' comments and perspectives. Both the group facilitator and a designated note-taker also took detailed written notes throughout each discussion which were used to supplement the audio recordings and assist with transcription and interpretation.

Following the staff focus group discussions, the MNO distributed an online survey questionnaire to frontline staff. The questionnaire was designed to complement and supplement the qualitative data from the face-to-face MNO staff focus group discussions. It consisted of open-ended and closed questions that focused on Métis community access to healthcare services, as well as cancer screening education, supports, participation and experiences. A copy of the staff questionnaire is included in Appendix D: *Staff Survey Questionnaire*.

In total, 45 MNO Healing and Wellness Staff members participated in one of six focus groups and 28 MNO Healing and Wellness Staff members completed the follow up self-administered online survey.

#### **Group 2: MNO Citizen Participants**

#### Participant Recruitment and Inclusion Criteria

Under the direction and supervision of the Associate Director of MNO Healing and Wellness, MNO citizens living throughout Ontario were contacted by MNO frontline staff working in 31 MNO community centres across the province and invited to participate in the community data gathering. This method of communicating and engaging with MNO citizens is a long-time standard practice of MNO, and leverages the very close formal and informal networks, historic relationships, and province-wide connections that exist among the citizens and families of the large Métis Nation of Ontario. It also aligns with and is supported by MNO's province-wide governance structure.

Inclusion criteria for this group required participants to be 18 years of age or older and to have some knowledge of or experience with cancer or cancer screening (either personally, or through a family member or friend). Age-eligibility for cancer screening was not used to exclude participants from the study on the understanding that while participants who fell outside the age-eligibility criteria were not themselves be eligible for certain types of screening, they may well have knowledge of the perspectives and experience of their friends, family and/or other community members in making choices around cancer or cancer screening, and could therefore contribute substantially to the discussion. Care was also taken to attempt to ensure a balance of perspectives from MNO citizens living in different regions, of differing ages and genders, and with differing perspectives and experiences.

#### **Informed Consent and Data Collection**

Two MNO citizen focus groups were held in Toronto in November 2016. Following an opening prayer provided by an MNO Senator, focus group participants were then provided with a detailed introduction and overview of the study (written and verbal), including the fact that the sessions would be audio-recorded. They were also informed that their decision to participate (or not) in the project would have no effect or impact whatsoever on their status or relationship with the MNO, OH (CCO), or SRI, nor would it affect their access to or eligibility for, services and supports provided through either MNO or OH (CCO). Participants were encouraged to ask questions throughout the presentation. Once all participants' questions had been answered and any concerns addressed, they were then invited to review and sign the informed consent form (see Appendix E: Community Consent Form).

Travel and accommodation for participants was paid for by the research project and participants were provided with a \$75 honorarium to acknowledge their contribution to the study.

The two half-day community focus group discussions were facilitated by an independent consultant, an experienced Métis facilitator and MNO citizen, with support from the WG. Along with the Métis Senator and MNO staff who were also present to support, she was able to provide a comfortable and culturally safe environment for the discussion. The session was structured around a written discussion guide and set of probe questions (see <a href="Appendix F: MNO Citizen Facilitator Guide">Appendix F: MNO Citizen Facilitator Guide</a>).

The two MNO citizen focus group discussions followed the same general format as the staff focus group discussions. Both sessions were audio recorded (with written participant consent)

and later transcribed verbatim to ensure accuracy. Notes were taken by designated note takers throughout the focus group discussions to supplement the audio recordings and assist with both the transcription and interpretation of results.

Following each group discussion, the participants were also invited to complete a brief self-administered questionnaire which was collected at the completion of each session by members of the WG (see <u>Appendix G: Community Survey Questionnaire</u>).

In total 21 MNO citizens participated in one of two half-day focus group sessions. All 21 participants completed a written, follow-up survey to allow for additional input, which in this case was administered immediately following the focus group discussions. The surveys consisted of open-ended and closed questions that focused on access to healthcare services, as well as cancer screening education, supports, participation and experiences.

# Data Security: Data Storage, Transcription & Quality Assurance

All qualitative and quantitative data (i.e., survey responses, focus group audio recordings and transcripts) were securely stored at all times and were password protected, with data accessible only to MNO research team members directly involved in the data management and analysis. Data security was maintained during all transfers, including during the transcription process and during the data cleaning and analysis. All files were stored in a secure environment managed by the MNO project lead (Storm Russell).

To ensure the quality of the focus group transcripts, a series of quality assurance tests were conducted that consisted of playing random sections of each audio recording to verify that the recording corresponded to the text provided by the transcription service. This assured that the transcripts accurately reflected the comments and perspectives of all focus group participants. All identifying information was removed from transcripts.

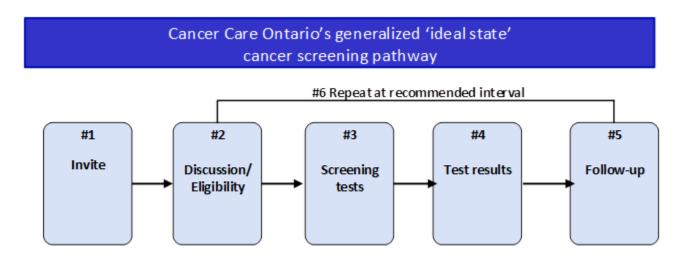


Figure 4: Ontario Health (Cancer Care Ontario)'s "Ideal State" Cancer Screening Pathway

## **Data Analysis**

#### **Survey Data**

Quantitative data from both the MNO staff and citizen follow-up surveys, including those distributed online to frontline staff and those administered in person to citizens, were analyzed separately by the WG using Microsoft Excel and *Survey Monkey*<sup>iii</sup>, in order to assess any differences between MNO front line service provider and MNO citizen perspectives. Frequencies are reported in the results section.

In both the staff and citizen surveys, respondents had the opportunity to also provide openended responses to a number of questions and to offer unprompted comments and feedback. These qualitative survey data were analysed thematically and are presented separately for each group of participants in the relevant results section.

#### **Focus Group Data**

The qualitative focus group data were also analyzed separately for staff and citizen participants. Specifically, after verifying the accuracy of the transcribed data against the audio recordings, all focus group transcripts were uploaded into *NVivo*iv, a software program designed to facilitate the organization and analysis of qualitative data. Once entered, data were analyzed by the WG using an iterative process that involved first reviewing transcripts line by line, and then using an open-coding methodology to identify emergent themes. The emergent themes were grouped initially into 'barriers' and 'facilitators' of cancer screening in order to organize and understand the data. Themes were then further refined and regrouped into key sub-themes within each overarching category, and this process continued until it was determined that the resultant conceptual models adequately captured and represented focus groups participants' perceptions and experiences with cancer screening.

Key themes and survey findings were then integrated and examined in relation to the primary research objectives, and in the context of OH (CCO)'s proposed 'ideal state' cancer screening pathway which outlines how cancer screening is expected to proceed in order to maximize early detection rates and improve cancer treatment outcomes. This 'ideal state' cancer screening pathway is displayed in Figure 4. The focus for this analysis was to identify individual, community and systemic level barriers and facilitators to cancer screening as they present themselves through various stages of the cancer screening pathway. The WG worked together collaboratively throughout all stages of the data analysis and in the interpretation of results to ensure the reliability and validity of the results.

#### RESULTS

The results from the focus groups and surveys with the MNO Healing and Wellness staff and MNO citizen groups are presented below. Results are presented in three parts:

SurveyMonkey is a tool that allows users to create their own surveys using question format templates. https://www.surveymonkey.com/

NVivo software package that is specifically designed to assist in organizing qualitative data through categorization of emergent ideas into themes. https://www.qsrinternational.com/nvivo/what-is-nvivo.

**Part 1** presents an overview of the study participants, based on the self-administered questionnaire responses provided by both groups of participants. Age, sex, cultural identity, geographic location and healthcare utilization are included. These results provide important context for the cancer screening-focused results presented in subsequent sections.

**Part 2** presents participant perspectives on and experiences with cancer screening, based on the self-administered questionnaire responses.

**Part 3** presents participant perspectives on and experiences with cancer screening, based on the thematic analysis of focus group data.

All results are presented separately for each group of participants (Group 1 - MNO staff and Group 2 - MNO citizens). Differences between MNO staff and MNO citizens' responses and perspectives, as well as regional differences are highlighted in the Discussion section.

# **Part 1 Overview of Participants**

#### Participant Characteristics - Age, Sex, Cultural Identity, Geographic Location

#### **→ Group 1 – MNO Healing and Wellness Staff Participants**

In total, 45 MNO Healing and Wellness frontline staff participated in one of six focus group discussions and 28 MNO Healing and Wellness frontline staff completed the follow up survey. Staff participants included MNO Community Service Coordinators, Métis Community Wellness and Métis Family Well-being program staff, and staff who worked in the MNO Aging at Home program, Métis Mental Health and Addictions programs. The majority of staff participants had worked for MNO for three or more years. Staff from all nine MNO regions participated in the study; region 6 had more staff participants than any other region (See Figure 3).

#### Group 2 – MNO Citizen Participants

Altogether 21 MNO citizens participated in one of two separate citizen focus group discussions and completed the follow-up survey. Group 2 consisted largely of older MNO citizens, with 86% of participants over the age of 50. Almost 60% of participants were female. Most participants were from MNO regions 5 and 7 (See Figure 3). Being an MNO citizen was one of the inclusion criteria for participation in the community member portion of the study. Group 2 participant characteristics are outlined in Table 2.

Table 2: Group 2 Characteristics - MNO Citizen Participants

Characteristics	Total number of participants (n=21)
Age	
18-20	1
21-30	0
31-40	0
41-50	2
51-60	9
61-70	5
71-74	3
75+	1
Sex	
Male	9
Female	12
Place of residence – geographic location	
Region 5	8
Region 7	12
All other areas (Regions 1-4, 6, 8-9)	0
Did not specify	1

Note: the same people participated in the survey and focus group, so the characteristics of this group are not shown separately for survey and focus group participants.

#### **Healthcare Utilization – Access to Care and Information**

#### **→ Group 1 – MNO Healing and Wellness Staff Participants**

The majority of staff who responded to the survey estimated that more than 50% of their clients had regular access to a family doctor and primary care services. Participants shared that most of their clients had an Ontario Health Insurance Plan (OHIP) card. Staff reported that their Métis clients were accessing primary healthcare services through a variety of means, including primarily, their family doctor or family health team, hospitals/emergency departments, and walkin clinics. Detailed responses about where MNO staff indicate clients access primary healthcare services are outlined in Table 3.

Table 3: Where MNO staff indicate that Métis clients access primary healthcare services

Primary care service location	Number of times selected
Hospital / emergency	20
Local family doctors' clinic	19
Walk-in clinic	16
Family health team	14
Community health organization	7
FNIM health organization	6
Telehealth	4
Other ("health access centre")	1
Other ("medicine man")	1

Note: In addition to the pre-determined categories that respondents were able to select from, they were provided the option to choose "other" and indicate something different; these "other" responses are reflected with the use of quotations throughout the Results section.

Approximately three quarters of MNO staff reported that their clients experienced at least a moderate degree of difficulty in accessing primary health care. Approximately 85% of staff reported that their Métis clients experienced at least moderate difficulty in accessing specialist care. All responses are outlined in Table 4.

Table 4: MNO staff perceptions about degree of difficulty Métis clients experience when accessing healthcare services

	Very easy	Easy	Moderate level of difficulty	Difficult	Very Difficult	Total number of respondents
Primary care	1	6	11	6	2	24
Specialist services	1	3	9	8	5	26

MNO staff reported that their Métis clients got most of their information about health / wellness from their family doctor and/or family health team. Information online, from family / friends, and from the MNO were also frequently selected. Detailed responses are outlined in Table 5. Most MNO staff were not aware of whether their clients were regularly receiving OH (CCO) cancer screening correspondence letters in the mail for any of the cancer screening programs.

Table 5: MNO staff perceptions about where Métis clients receive information about health / wellness

Source of Information	Number of times selected
MNO (offices / staff)	19
Family doctor	18
Online / social media	15
Family	14
Family health team	11
Friends	10
Community centre	5
TV	5
Radio	4
Telehealth	4

# **➢ Group 2 – MNO Citizen Participants**

Over 90% of MNO citizen participants reported that they had regular access to a family doctor or nurse practitioner. All participants reported that they had an OHIP card.

When asked to report where they typically access primary health care services, local family doctors' clinic / family health team was selected most times. All MNO citizen responses are outlined in Table 6 (totals are greater than number of participants, as each participant was asked to "select all that apply").

Table 6: Where MNO citizens typically access primary care services

MNO Citizen Responses	Number of times selected
Local family doctors' clinic	18
Hospital / emergency	10
Family health team	6
Community health organization	4
Walk-in clinic	3
Nurse practitioner / community nursing	2
FNIM health organization	1
Other ("Barrie")	1
Other ("Pain clinic")	1
Other ("traditional method")	1

# Part 2 - Cancer and Cancer Screening - Survey Results

#### Group 1 – MNO Healing and Wellness Staff Participants

MNO staff participants reported that cancer was among the top five health concerns facing Métis people. Approximately two thirds of staff reported speaking to their clients about cancer screening (18/26 participants who answered this question) and over three quarters of staff reported supporting their clients in connecting with cancer screening services (14/18 participants who answered this question). This support included:

- providing information about screening;
- helping to set-up and remind clients about screening appointments;
- helping to get clients to screening appointments; and,
- following up on screening test results.

MNO staff participants reported the locations that their MNO clients accessed screening services including pap tests, mammograms, FOBTs and colonoscopies; responses are displayed in Figure 5.

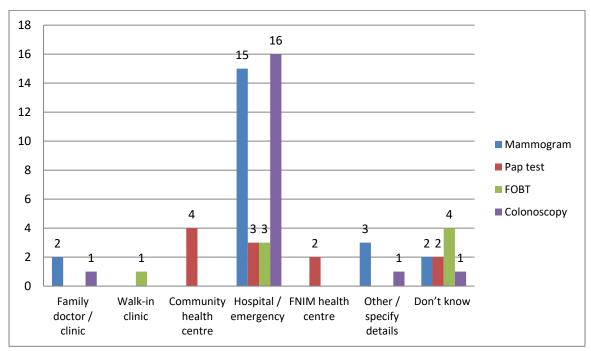


Figure 5: Locations that MNO clients access screening services

The most frequent responses were 'hospital/emergency' for mammogram and colonoscopy. In the 'other' category, three participants noted that they participated in mammography on a cancer screening coach bus.

#### **Barriers to Screening**

In the open-ended survey questions, MNO staff participants shared their perceptions about major barriers preventing Métis individuals, families and communities from getting screened for

cancer. Complete participant responses are provided in <u>Appendix H: Survey Results</u> (Table H1). Key perceived barriers are summarized below:

- Accessibility issues related to
  - Lack of transportation and access to health providers / screening services outside of urban centers (in rural areas);
  - Lack of childcare;
- Denial and / or fear of receiving a positive cancer diagnosis;
- Communication issues attributed to the lack of a regular home address (e.g., they may not receive OH (CCO) screening letters), language barriers, and shyness about asking for these types of services;
- Lack of awareness / information about the screening services available or who to talk to;
   and,
- Lack of trust in /comfort with healthcare providers.

#### **Supports for Screening**

MNO staff participants suggested various supports and sources of motivation that encourage screening among Métis citizens, families and communities. Complete participant responses are provided in <a href="Appendix H: Survey Results">Appendix H: Survey Results</a> (Table H2). The broader themes identified by staff participants are summarized below, they include:

- Good communication and educational supports e.g.:
  - MNO (e.g., Community Support Services (CSS) coordinator providing information);
  - Métis specific information
  - Health professionals;
  - OH (CCO) screening reminder letters);
  - Visual aids (e.g., posters);
  - o Consistent messaging (e.g., same message from multiple sources); and,
  - Information about treatment plans and options
- Culturally relevant advocacy/supports (e.g., Métis specific care supports, MNO CSS coordinator attending appointments with client to help advocate and ask difficult questions)
- Having a family history of cancer;
- Seeing or learning about friends or family participating in screening;
- Accessibility supports (e.g., improved transportation options and supports, short wait times for appointments; and child care supports);
- Group screening events; and,
- Healthcare providers respecting patient decisions about care (e.g., not pushing specific treatment options on patients).

One participant noted that a focus on prevention, rather than screening, was needed.

## **MNO-Specific Supports for Screening**

Finally, MNO staff shared what they would find most useful in order to further support their Métis clients with cancer screening. Their complete responses are provided in <u>Appendix H: Survey Results</u> (Table H3). Broader themes that they identified are summarized below:

- Métis-specific information and services;
  - More targeted/relevant screening information to share with Métis clients (e.g., how screening works, where to get screening in their region);
- More information and training for MNO staff about screening and related concerns (e.g., training on how to explain benefits of screening to clients, information on alternative methods to cancer treatment such as naturopathy, information about prevention);
- More specific screening participation details about their clients, so that they can remind/follow up with them as necessary; and,
- Resources (time and funding) to support:
  - o Clients in getting to appointments e.g., transportation assistance; and,
  - o Accompanying clients at their appointments with cancer screening services.

#### Group 2 – MNO Citizen Participants

Over half of MNO citizen participants reported that cancer screening was a high priority for them (10 of 16). Participants most often selected *family / friends, family doctor / family health team, media* and *internet / social media* as their primary sources of health information and information about cancer screening. All responses are outlined in Table 7.

Table 7: Where MNO citizens receive information about health and cancer screening

Source of Information	Number of times selected
Family doctor	15
Family	13
Friends	9
Internet	9
TV	7
Radio	5
MNO service centre	5
Other social media	4
Family health team	3
Community centre	2
Telehealth	1
MNO website	1
MNO social media	1
Other (speakers from hospitals)	1
Other (Grand River cancer centre)	1
Other (traditional healer)	1
Other (LHIN, Mescape)	1
Other (cancer navigator)	1

Eleven of 21 participants reported having received a letter in the mail from OH (CCO) informing them about cancer screening, when to get screened, or about test results; the other 10 people responded *no* to having received a letter in the mail. Eleven of 17 participants reported that it was easy to find time to get screened for cancer. MNO citizens also reported on their participation in organized cancer screening. All responses are summarized in Table 8.

Table 8: Cancer Screening Uptake (as reported by MNO citizens)

Type of test / screening	Males screened	Females screened
Pap Test (cervical cancer)	N/A	10 (of 12 age eligible)
Mammogram (breast cancer)	N/A	10 (of 10 age eligible)
Fecal Occult Blood Test or Colonoscopy (colorectal)	5 (of 7 age eligible)	10 (of 10 age eligible)

#### Barriers to Screening

MNO citizen participants provided open-ended responses about barriers that prevented their participation in screening and supports that would increase their participation in screening. Complete participant responses are included in the <a href="Appendix H: Survey Results">Appendix H: Survey Results</a> (Table H4); broader themes are summarized below, they include:

- Fear of cancer screening, cancer and treatments (such as chemotherapy);
- Lack of information about screening and what options are available;
- Lack of transportation, long distances to travel and / or costs associated with transportation;
- Lack of health care practitioners and / or lengthy wait times to access practitioners / receive appointments; and,
- Other economic costs (taking time off work).

#### Supports for Screening

MNO citizen participants identified supports that would enable them to *feel more comfortable / supported* when going for a screening appointment. Their complete responses are included in the <u>Appendix H: Survey Results</u> (Table H5); broader themes are summarized below, they include:

- Improved awareness and screening information (e.g., sharing information regularly, getting notices by mail);
- Transportation supports (e.g., providing transportation to appointments at no cost to patient, support for parking costs while at appointment, good road conditions);
- Having a support person attend screening with community member (e.g., family, friend attending appointment with them);
- Having friendly, respectful healthcare provider that patient trusts (e.g., good bedside manner, knows patient well, communicates well, respects patient choice); and,

Healthcare providers sharing patient health data/results with patient (e.g., shares
information in a clear way, provides test results, gives them access to their health
information).

MNO citizen participants were also asked about what *would make it easier for them to* participate regularly in cancer screening. Their complete responses are included in the Appendix H: Survey Results (Table H6); broader themes are summarized below, they include:

- Access to information (e.g., mail reminders);
- Improved access to screening services (e.g., transportation supports, services close to home); specific need for improved access for colonoscopy, more scheduling options)
- Autonomy over health care (e.g., access to medical records); and,
- Fear as a motivator.

#### **MNO-specific Supports for Screening**

MNO citizen participants shared their opinions about the MNO staff and volunteer supports and / or services most useful to them. These were broader in scope and less specific to cancer screening; nonetheless, they provide insight into mechanisms that MNO could further develop to promote cancer screening. Complete MNO citizen responses about useful MNO supports and services are include in the in <a href="Appendix H: Survey Results">Appendix H: Survey Results</a> (Table H7); broader themes are summarized below.

- Transportation assistance (e.g., providing rides);
- Specific programs (e.g., counselling and employment services, foot care);
- Workshops, seminars and events; and,
- Social / cultural supports (e.g., harvesting, sharing moose, emotional supports).

They shared that these MNO supports / services could be strengthened simply by providing more of them (e.g., more volunteer drivers to support transportation, further outreach/education sessions, more funding for existing programming, and further support groups). Please see <a href="#">Appendix H: Survey Results</a> (Table H8) for more details.

# Part 3 – Cancer Screening – Focus Group Results

Key themes identified in the thematic analysis of the focus group data were categorized into barriers and facilitators and are included below, for each participant group, separately. Representative participant quotes are included in tables throughout the section to explain themes.

#### **Group 1 – MNO Healing and Wellness Staff Participants**

#### **Key Barriers to Cancer Screening Participation**

MNO Healing and Wellness staff identified several important barriers to participation in cancer screening among Métis communities, focusing in particular on their Métis clients. Key barriers included:

- Limited access to healthcare providers /screening services
- Distrust of healthcare system and providers lack of cultural competence / respect for Métis culture and identity
- Fear about cancer and screening and resistance to screening
- Lack of awareness ineffective education materials and strategies
- Basic needs take precedence

Each key barrier is outlined further below with representative focus group participant quotations in Tables 9-13. Additional participant quotes are included in Appendix I: Focus Group Discussion (FGD) Results, Group 1: MNO Healing & Wellness Staff.

Participants described difficulty in accessing healthcare providers as a barrier to participation in cancer screening. Many shared that it is difficult for Métis community members to find a primary care provider, many do not have access to a consistent provider and that wait times to see providers were often long. This was attributed to their relative geographic isolation, as most Métis communities are in rural or small urban areas and to general primary care provider shortages. Participants explained that this made it difficult for community members not only to access screening, but to develop the kinds of trusting relationships with providers that some explained were a requirement for community members to feel comfortable participating in screening. The inconsistency in terms of the providers that community members had access to was attributed to both to the shortage of providers and to the mobility of Métis communities.

The relative geographic isolation experienced by many Métis community members also meant that the travel required to participate in screening was a significant barrier. In some cases, this was due to long trips in difficult road conditions that would be required to get to appointments. However, even for shorter trips, the limited public transit options and limited access to a personal vehicle among community members made travel for screening difficult. Participants also outlined that the costs for travel (e.g., bus fare, gas,

parking, rental, out of town accommodation) and limited transportation supports (e.g., no access to Non Insured Health Benefits supports, issues with Northern Health Travel Grant), prevented people from participating. Participants also described difficulty taking time off work or finding and paying for childcare that would allow community members to travel for screening.

Table 9: Barriers identified by MNO Healing and Wellness Staff - limited access to healthcare providers / screening services

Theme	Selected participant quotes
<ul> <li>Shortage of and lack of consistency among primary care providers:</li> <li>Few providers available, particularly of preferred gender;</li> </ul>	I know in Owen Sound, at least, there are not enough family doctors for the people. It's like a giant region that everyone comes into Owen Sound to do all of their stuff. So, a lot of the doctor's offices are there. And, they're servicing a massive population that's very spread out. (FG 4) <sup>5</sup>
<ul> <li>Long wait times for appointments;</li> <li>Limited time with provider during appointment;</li> <li>Limited consistency of providers; and,</li> <li>Difficulty developing patient-provider relationships.</li> </ul>	To get it [reminder letter] in the first place, you have to see a doctor. And where we are, it takes two months to get in. Or, it's a different doctor every time you see somebody. So nobody has a comfortable rapport. (FG 3)
	I mean I feel very rushed when I go to my doctorI feel like I can't ask whatand all of a sudden she's gone. (FG 2)
	I have heard of other people saying, you are only allowed to bring up two things. (FG 2)
	I actually have a lot of clients, uh, that have trouble having consistency. Like, they get a really good doctor, but then that doctor moves on. And then, they can never find another doctor. Part of it is maybe the doctor moves on. But, because the population is so transient, that they're moving from location to location, or back - back and forth. And then, the waitlist, you can't get back to see that good doctor that you've already developed a rapport, again, because the list is way too long. (FG 1)
	It's the shortage of doctors that's a challenge. Their times for other people that didn't get their results yet. (FG 5)
	I know one barrier I've heard from some people I've worked with, specifically with, the cervical screening, they don't feel comfortable if they have a male doctor. Or, if the

<sup>&</sup>lt;sup>5</sup> Throughout Part 3 of the Results section, participant quotes are identified by the focus group (FG) number. FG 1-6 are for MNO Healing and Wellness Staff and FG 7-8 are for the MNO citizens.

<u></u>	
	person performing the test is male, they don't feel comfortable. Um, so I find that's a huge, huge barrier, um, especially in our community. There are not a lot of female doctors. (FG 5)  We have no female OBGYN, or whatever. It's all males. (FG 6)
	The other thing is that, a lot of Métis don't have a regular doctor or healthcare provider.  And they are sometimes not accepted at some of the clinics. (FG 2)
	And getting the government on board.  To get them invested.
	You get this many hours to go and vote, so why don't you get this many hours to go for tests.  Yeah. Having it be, kind of normalized in that way.  Including men, like, that work 12-hour shifts. (FG 6)
Limited equipment/ services in more rural and remote communities	The CAT scan machine Midland doesn't work right anymore and, things like that. (FG 4)  So foryeah, and mammogram's hard because often that's really specialized equipment that you can't get everywhere. (FG 6)
	I also think that if you don't live in a large city, that the machines are, you know limited. You know, there's only so many per city. There's a longer wait time for smaller cities. (FG 2)
Difficultly with transportation to appointments:  • Geographic isolation;	I know in Owen Sound, at least, there are not enough family doctors for the people. It's like a giant region that everyone comes into Owen Sound to do all of their stuff. So, a lot of the doctor's offices are there. And, they're servicing a massive population that's very spread out. So, medical transport is huge. (FG 4)
<ul> <li>Limited access to public transportation or personal vehicles;</li> <li>High cost of travel / limited transportation supports; and,</li> </ul>	The isolation is humongous. And lack of transportation. (FG 3)  That's a huge barrier, is that geographical isolation for people as well as the transportation issue of how to get there. (FG 4)

• Difficult to secure childcare / time off work to travel to appointments.

It's not like the urban centre here where it's right downtown. And if you need to go from this doctor over here to get to see a specialist, it's just...hospital across the street or whatever. That's not the case. And then, often we have to travel. There aren't a lot of specialists in the Sault. So, we have to travel to Sudbury. (FG 5)

People in my area, have to go to Kingston for these appointments. And, the travelling is under 45 minutes. But I mean, the money, or, they don't have the vehicle, or anything like that - there's always those types of roadblocks. (FG 2)

Not all our people [MNO clients] have cars. And, we [MNO staff] did provide, I think - I can't speak out of turn - bus tickets. But see, Thunder Bay has [a mobile screening bus]. See, that's why to lump Thunder Bay in, like, [with people in Fort Frances who are]... more isolated [in Fort Frances]. I mean, we're isolated [in Thunder Bay], but they're more so [in Fort Frances]. They don't have [public transit] buses. (FG 3)

So, yes your doctor wants it. But then, how are you going to get to Barrie, because, again, that's a 40-minute drive. You have one bus in and out. Can you get a volunteer driver? Red Cross charges. We don't have a lot of cancer, um, drivers because they get paid less kilometres. (FG 4)

...when you have families, parents with children, whether they're single parents, or childcare is an issue. (FG 3)

Because if you have kids, you don't have a babysitter and then, well what? Who's going to sit at the doctor's office with four kids? You know? They won't go. They'll miss the appointment. (FG 5)

Another issue too, especially with some of our, our moms, is that they don't want to bring their children in. They may not have – they may be single parents – they may not have support systems around them. They don't want to bring their children into the examining room, especially if they have young children, while they're having that done. (FG 6)

The Northern Travel Grant is a joke because you can't get the money until after the doctor signs off when you come back. But it's, like, "well how do I get...I need money to get there." Right? And many people don't have money to travel. (FG 5)

Attach things to the monthly benefit that goes out to people, if going to the test, be able to call up Ontario Works and get a taxi (FG 5).

The lack of cultural competency in the healthcare system was identified as a key underlying barrier to cancer screening participation. Participants explained that their Métis clients did not feel that their cultural identities were respected or reflected in the healthcare system, making them reluctant to participate in screening. They noted a broad distrust in the healthcare system and in some cases, of Western medicine more specifically. Poor relationships between patients and providers, linked to a lack of cultural competency and poor communication skills among providers, were explained as key factors in community members' willingness to participate.

Table 10: Barriers identified by MNO Healing and Wellness Staff – lack of cultural competency in healthcare system

Theme	Selected participant quotes
Métis cultural perspectives on health/wellbeing not well respected in healthcare services:	They [providers] will dismiss you as a patient. And, I even know, even coming from a personal perspective. I was engaging in some research with my son. And, it was just – I mean I was looking into it [naturopathic treatments]. I hadn't even engaged in it. And my doctor said to me right way, if you go down this avenue you, you will be dismissed as a
<ul> <li>Limited acknowledgement of and dismissal of Métis approaches to health/wellness;</li> <li>Limited existing services and resources are First Nationsfocused; and,</li> <li>Screening guidelines do not reflect lived experience of community members (restrictive age guidelines).</li> </ul>	patient.(FG 6)  The cure sometimes is, you know, people look at the cure as beingthe Western way. And they discount it. Our medicines. A lot of doctors are easy to just give you a prescription for something, and there you go. And they discount it. Our medicines. Or see it as natural medicine. Our teas could benefit, or complement the the medications that are being given. I don't like pills myself, but if you would incorporate tea, what they or us, believe in(FG 3)
,	We need more doctors who are going to be understanding of the [Métis] culture, understanding identities maybe, a bit more, too. [Service providers who are]

amicable...like, people who are willing to work on relationship and rapport building, and, who are patient and can explain things. (FG 1)

That idea that the Western medicine isn't going to cure it, is history, again. It's having seen other family members or people in your community going through the Western treatment, and only seeing the devastation. You know, the cure is worse than the illness, in a sense, is what it is. If this is where I'm going to end up... so, I think education about the advances. Like, I know we're talking screening, but I think it's that whole perception of where that journey is leading us. And it's leading us away from the natural ways that a lot of us, as Métis people, practice. (FG 3)

We're not allowed because there's the age gap. I mean, I knew a 21 year old woman who had breast cancer, and they didn't test her for it because of her age. (FG 2)

If you think that a Western medicine isn't going to cure it, then you won't be interested in getting it identified [as Métis]. That's my understanding. (FG 3)

# Distrust of healthcare system and poor patient-provider relationships:

- Distrust in effectiveness of Western medicine;
- Past negative experiences with healthcare system/other institutions attributed to racism, discrimination, intergenerational impacts of historical trauma;
- Lack of understanding / awareness among health providers (e.g., about Métis peoples, culture, history, healthcare needs, which leads to stigmatization, stereotyping); and,
- Patient privacy concerns (e.g., asking too many questions over phone; everyone in community scheduled for screening on same day).

That idea that the Western medicine isn't going to cure it, is history, again. It's having seen other family members or people in your community going through the Western treatment, and only seeing the devastation. You know, the cure is worse than the illness, in a sense, is what it is. If this is where I'm going to end up... (FG 3)

Past history of trauma. So, [a Métis woman] having to show her body. It's like having your first Pap exam. You know, you're terrified. You don't want to do it. You think it's invasive. You're horrified by the whole experience. It's a horrifying experience and, um...but after you've got the first one, and, then, it's really no, no big deal, right? It's just getting them there. (FG 1)

I've actually been with clients and I've.. that have asked to, uh, attend doctor's appointments with them. And, as soon as I introduce myself to the doctor with my [business] card, I notice a whole different treatment towards my client. (FG 1)

We need more doctors who are going to be understanding of the [Métis] culture, understanding identities maybe, a bit more too. [Service providers who are] amicable...like, people who are willing to work on relationship and rapport building, and, who are patient and can explain things. (FG 1)

The other part is, I think you're right, the stereotypes. I have blond haired, blue eyed clients and they go in and they go, "why are you here? And they're like 'well I'm Métis, why are you here?" They don't all look like this. (FG 1)

Look at Toronto. The culture down here, people don't look at you in the eye. They're afraid of you. They don't say thank you. They never smile at you...but where we live you know, people will walk by; they smile, they say "good morning". (FG 3)

There is a mental health barrier with the screening. Uh, for some people that have been traumatized at, at the, um, the residential schools because there is a lot of sexual abuse. Um, and as...uh, and the last residential school closed in 1990 or 1992, whatever, right? So, it's really – it's actually recent. It's not just the great-grandparents that went through it. So, um, I would suggest that there's a mental health component, there. Post-traumatic stress disorder component, uh, that would be a barrier to screening. And, um, that needs to be addressed. (FG 2)

For some men and women; I've heard...if I go there, say for, um, you know a colonoscopy, well, everybody's going to know.

That's huge.

And it's an embarrassment...you can't just go down to St. Michael's and Sunnybrook, and here, and here. You've got one hospital. You know...

Everybody's scheduled on the same day. (FG 3)

That lady that answers the phone...she'll pick up and go, well, why do you want to see the doctor?

There would be many people that are not going to say...especially if it's your sister-in law. It's the whole process, I find it demeaning (FG 6)

# Poor communication between healthcare providers and Métis clients:

 Providers not providing clear explanations about what to expect/ results/how to follow up; How many doctors actually go through [it] with you? You know, what's your...what's all the hereditary illnesses? What's your background...they're supposed to, but they hardly do. My mother's doctor does. My doctor doesn't. I'm sitting there waiting for her to ask me all these questions that my mother's doctor in Winnipeg asks her, and they don't. (FG 2)

I can think of a couple of examples from my community where they've gotten the results from their doctors. And they just said, you now need to go to Sudbury, or you need to go to Toronto, and the specialist will tell you more. And so, they're waiting, you know, sometimes a couple of weeks, a month – whatever – until they get down to their appointment.

•	Patients assume doctors will alert them about when they are due for screening; and,	Worrying and you know, having this anxiety because their doctors are not providing the information, either because they don't know, or they don't have the information to explain it to the client, so then they're waiting again. (FG 6)
•	Patients find it hard to ask questions or advocate on own behalf.	I think they just think that it's expected, either when a physical comes, or just by, you know, what the doctor has in their chart about them. So, I think that they expect, or assume, yeah, on the doctors. They, they expect the doctors to know that issue (FG 3)  I think in my experience with my clientsa lot of them that have family doctors; they think that their family doctor will bring it up with them. (FG 2)
		Because another thing is too with the culture, is, they are afraid, sometimes, to say things and they can't advocate as much. So to have someone present that they feel comfortable with, to really support them through the system (FG 2)

Many participants explained that fear of cancer and of the screening tests themselves were barriers to participation among Métis community members. This fear was sometimes linked to community members having seen others in their family or community go through cancer. Denial that they might develop cancer or pre-cancer and overall reluctance to participate were also noted.

Table 11: Barriers identified by MNO Healing and Wellness Staff – fear, avoidance, and reluctance to participate

Theme	Selected participant quotes
Fear about screening tests, attributed to:	[Colonoscopy] is something that people fear. So, it's a joke about how people don't want to go. (FG 4)
<ul> <li>Previous traumatic experiences;</li> <li>Invasive screening tests;</li> <li>Family/community history of cancer – have seen impacts; expect worst; and,</li> <li>Fear of unknown / while waiting for results.</li> </ul>	They're afraid to get that, "you have cancer" diagnosis. (FG 6)  It's scary just to wait for the results. And, if they know there's going to be support for them, or what the support could look like if the test were positive before they go for the test, then they might not be as scared to go for the test. (FG 2)

In the context of something like cancer screening, you have to really put yourself in the position of the residential school survivor when, you know, a white doctor is saying, right, so we're going to do a breast exam right now. And, white doctors think, of course you want to get this done. Like, this is good for you and you need it. It's cancer screening. I'm, I'm here to help. And, you know, the First Nations or Métis female is saying, I'm not going anywhere near [you]... (FG 2)

There's you know, a high risk of, you know, clients that I work with who've experienced sexual assaults - um, sexual history of sexual abuse. Um, so, to go through a...something for a cervical screening, um, that can be a huge barrier for them. That can be very challenging. (FG 6)

Cancer has been an issue in our family. And it's almost a 50/50 split. It makes half the people want to go and be tested, and it makes the other half scared to death not to. (FG 3)

They don't want to be tested. Even if they are at the doctor and doctor says to him, "you know, you're old enough, you should be getting tested for this. Your father had prostate cancer." They don't want to know. (FG 3)

# Denial and reluctance, attributed to:

 pride, not admitting to weakness (particularly among men). I think the men are very resistant to even having that discussion, because, they're so proud and so private. Same with the prostate exams...it's a taboo topic – anything anal. (FG 1).

I think men are notoriously known not to go to a doctor. They have to be at death's door before they will agree to see a doctor, or even a nurse practitioner. They just stay away from that, so often, in my experience, their condition is advanced, and uh, some are very stoic. And even if they have pain, or whatever, they don't let on. (FG 2)

They're terrified so they go into magical thinking okay. And, I don't care how old you are, you'll go into magical thinking immediately. And, the reason I know is because I do it. When I'm hit with a crisis – a really bad crisis right – I will go into magical thinking mode until my brain is ready to take it on and deal with it. (FG 1)

And they don't say the 'cancer' word. They just say, I'm not well. (FG 1)

Denial is a big thing. If somebody's not feeling well, they're very fearful that it's cancer, and
they know how deep down that it is. But they just don't want to know (FG 5)

Participants described limited awareness about what cancer screening is and how to go about participating as a key barrier to community member participation. This was rooted in limited education resources, resources not being appropriately tailored to Métis communities, and ineffective screening education initiatives. In particular, participants explained that the OH (CCO) screening correspondence letters were not clear and could easily be misinterpreted.

Table 12: Barriers identified by MNO Healing and Wellness Staff – lack of awareness about screening / ineffective existing education approaches

Theme	Selected participant quotes
Unclear perceptions/understandings of cancer and cancer screening (e.g., benefits of early detection; how to go about participating; what to expect; confusion about screening/guidelines).	The other thing, too, is, like, my dad, he's a smoker. Um, his aunt died of lung cancer. She didn't smoke. So, he's, like, 'ptt. Had nothing to do with that." You know, like, and whatever. So now he's got the whole mentality. Like, "oh, you're going to get it, you're going to get it." Right? It has nothing to do with it. So it's that whole education too(FG 3)  Even if you get a follow up from Cancer Care Ontario saying, you know, you had abnormal normal cells or something, you need to have this test again in three months. There'sin the community there's a sense that you have to pay for that one. (FG 6)
Issues with existing education resources and initiatives:	I think another issue that's not necessarily Métis specific, but is something that's really, is important to all of our clients, is that there's a lot of mixed information I would say. (FG 4)
<ul> <li>Not clear/not easy to understand/too long;</li> <li>Mixed information;</li> <li>Not relatable/does not speak to Métis – too impersonal, not inclusive of</li> </ul>	And, like, even things like, I struggle with. Like, oh, it's two years for a Pap smear, now it's three. And then, you hearbut really, like, that's not good. You should have it every year. (FG 4)
<ul> <li>Métis (First Nations-focused);</li> <li>Negative messaging (e.g., horror stories; adds to fear);</li> </ul>	And then, you hear things like, you shouldn't get mammograms before you're 50. But, if you have problems you should go. Like, there's a lot of mixed information about that. (FG 4)
OH (CCO) screening letters (e.g., impersonal, too long, not clear, hard to understand, often discarded);	Even if you get a follow up from Cancer Care Ontario saying, you know, you had abnormal normal cells or something; you need to have this test again in three months.

- Limited access to resources (e.g., cable/internet limitations, inability to access programs / services due to lack of benefits / funding supports that are often available to First Nations only);
- Lack of awareness about existing education resources (e.g., unaware of Indigenous Patient Navigator); and.
- Health care providers (identified as a key education resource) not relaying screening information effectively (e.g., communication challenges with medical practitioners).

In the community there's a sense that you have to pay for that one... [lack of clarity] (FG 6)

Forms that you send in the mail to people 50 and over, you've got to change the font; you can't read them.

- -I got my invitation, right, and I'm looking at it going, yeah, younger people did this.
- -And there's too much information.
- -They don't bother, most of them throw it out.
- -Keep it very, very plain like Grade 3.
- -Like very precise.
- -Keep it simple. Just keep it simple. (FG 1)

I think we all want that same relationship from our doctor. Because, it's all...all of our personal, medical ailments are sensitive. And, we have one person, one person in our lives to help us...help guide us through those things, right? So, if I'm getting a letter from Cancer Care Ontario, that feels very non-personal, right? (FG 4)

I think that the impression or the misconception can be very different. So, it can be very scary for people to get a [screening correspondence] letter from you guys [OH (CCO)], and think, oh, my God. I have cancer. (FG 4)

We were told there's a navigator for that and there's a navigator for this. I have been going through everything with my father, um from the time, actually prior to him being diagnosed...not once has this navigator gotten a hold of us. Not once has the nurse, the doctor. But, not once has anyone identified that this navigator is available. (FG 5)

Let us know these people exist so we could bring them to our workshops instead of using someone from mainstream. (FG 5)

Nine times out of ten, unless it's something to do with harvesting, men aren't attending. (FG 5

Finally, MNO Healing and Wellness staff explained that for many of their clients, cancer screening was not a priority because they were focused on attending to more pressing life concerns. They explained that for many clients, focusing on trying to meet their everyday needs meant that participation in cancer screening was not feasible.

Table 13: Barriers identified by MNO Healing and Wellness Staff – Basic needs take precedence

Theme	Selected participant quotes
Socioeconomic priorities (e.g., daily living related – rent, groceries) make it hard for community members to invest time on other health services/issues/ including cancer screening.	The clientele that we work with is low income. They're in survival mode. They are, you know, getting through each day. (FG 4)  So, where, where is cancer screening in the priority list of things that that they needQuite a ways down. If it's not affecting their livelihood, firstand then, their family, and, then, their socialthen it doesn't exist. (FG1)  You can't afford to take your family for them to sit beside your bed. (FG 4)  Everything that we do comes out of our own pocket. And I don't thinkOHIP coverstransportation (FG 2)  They other daily priorities that are more important such as "how am I going to pay other appointment tomorrowwhat am I eating tomorrowI'm behind in rent". (FG 5)

# **Key Facilitators that Support Cancer Screening Participation**

MNO Healing and Wellness staff also identified several factors that could be improved in order to support Métis community members in participating in cancer screening. These included:

- Improve education approaches and resources so they are specific to Métis community and grounded in culture
- Improve social supports throughout screening process
- Improve access to cancer screening services
- Improve the cultural competency of healthcare providers

The key themes and representative quotes are outlined below in Tables 14-17. Further participant quotations are included in <u>Appendix</u> <u>I: Focus Group Discussion (FGD) Results</u>, Group 1: MNO Healing & Wellness Staff.

MNO Healing and Wellness staff offered many suggestions about ways that cancer screening education material and approaches to sharing information could be strengthened to function more effectively for the community. A key point was that education approaches that were grounded in Métis culture and communication preferences (e.g., including Traditional knowledge, inviting Elders to develop messaging, use of storytelling), would help considerably. They also explained that simple, positive messaging and materials that specifically explained common points of confusion about screening in the community, would facilitate learning about screening. MNO staff also explained that further screening education support for them would help them to be able to better support their Métis clients with screening education, explaining that they are well positioned to provide this education, as they have strong relationships with the community.

Table 14: Facilitators identified by MNO Healing and Wellness Staff – Improve education approaches and resources so they are specific to Métis community and grounded in culture

Theme	Selected participant quotes
Culturally grounded screening education:	Predominantly [the Métis] culture is a very shy, soft spoken culture. And you'reand you are reallyYou own your body and that's your spirit, right? So,
<ul> <li>Engage Métis Senators, Elders, community leaders and champions to adapt or develop more culturally appropriate education approaches and</li> </ul>	like, you can explain, this modern medicinethis testing is a little invasive, but we're going to go through every step to tell you what's going to happen, first. (FG 3)
resources (linked to importance of screening information coming from community members);	Do you have cable? Not all the time. Do you have internet access? Not all the time. It's in and out. Like, you don't have those even me living in Coldwater. Like, I'm still in a little community but I don't have internet all the time. It's in and
Use storytelling, family experiences and humour to share screening information;      Dair agreening adjusting with cultural.	out. So, the system and the information stage, has to go back to educating people. Like, you're going to have a better rapport with people like us. (FG 4)
<ul> <li>Pair screening education with cultural activities that are popular (including events / workshops with meals / other incentives); and,</li> </ul>	We'll [Staff] do a beading workshop or a moccasin-making workshop. But we're pushing something else. That's the draw-in. That's going to get you there. (FG 5)
<ul> <li>Include information about culture-based/ Traditional approaches to health.</li> </ul>	Say "I'm going to a dinner, and oh, there's this cancer thing going on in the background." Really, people are interested. They do want to hear it. It's like, it is important, but if you have that kind of excuseit's like when we were talking

about anything that's difficult to talk about...we do beading or something like that. Like, it's just easier to access. (FG 4)

If you'd had history of cancer in your family, you do become more aware of the risks. (FG 3)

I think people become aware when it happens. So, if you have a family member, then it's like, they pass it down. Did you know you're supposed to get screened at 40, or whatever? (FG 6)

I think women are more likely to get the screening done, or to go to their doctor...or, to ask about it because their friend had it done, and, well, maybe I should get it done, too. (FG 2)

That [MNO video telling the] story of Tim [the Métis man with prostate cancer]] is the kind of thing [we need]. We're story telling people. As soon as you see that's one of ours [i.e., he is Métis]. And he's telling his story. People listen. (FG 2)

I think getting input from an Elder on what would be useful as a written brochure or a fact sheet with culturally appropriate pictures and ways of wording things, would be useful. And descriptions of knowing what the screening involved ...(FG 3)

When it comes to our brochures, I totally agree. Things that are going out publicly and to the Peoples need to have clear symbolism... It's a better reflection of the population, because it's Métis. (FG 1)

That [MNO video] story of Tim [active MNO citizen who had prostate cancer]] is the kind of thing [that is needed]. We're story telling people. As soon as you see that's one of ours [i.e., Métis]. And he's telling his story. People listen. (FG 1)

I do think that with the media, we are bombarded with all negative horror stories. Especially about illness and, you know, things being missed, and all that kind of stuff. That if there was a way to put a positive spin, even on negative things like having the diagnosis of cancer, but saying, my God, this is 98% treatable. (FG 4)

# Improved and better-targeted communication/ messaging:

- Use appropriate wording/style health literacy;
- Use more positive/supportive rather than fear-based/negative messaging (e.g., screening is a way to stay healthy, benefits of early detection, survival stories);
- Address points of confusion among community (e.g., lack of clarity that screening is covered by OHIP, about screening guidelines, about what to

expect in completing screening procedures);

- Use more television and social media promotion – better engage younger people; and,
- Improve OH (CCO) screening correspondence letters; continue this program.

We don't...when you see a commercial, it's, you know, this treatment. You don't see, you know the end. Like, Tim Pile's video where it says he's now cancer free. Like, you don't see that... (FG 4)

Well, what's actually going to happen to them? They don't need a clinical view of what's going to happen. They need to know what's going to happen. You need to make sure you don't put deodorant on, and body cream...(FG 1)

-And, another thing that screening...like, forms that you send in the mail to people 50 and over – you've got to change the font. You can't read them.

I got my invitation, right. And, I'm looking at it going, yeah, younger people did this.

- -And, there's too much on it.
- -There's too much information.
- -They don't bother. Most of them throw it out.
- -Keep it very, very plain. Like, Grade 3.
- -Like, very precise.
- -Keep it simple. Just keep it simple. (FG 1)

I think they're pretty good, because not everybody wants to take the time to go see their doctor. I like the mail-out. (FG 5)

I remember there were lots of individuals who liked it. Because after they went and had their screening done, they received another letter. (FG 6)

# Further training and support for MNO to provide screening education:

- Support MNO Healing and Wellness staff with further outreach, allowing them to reach Métis who are not accessing services;
- Connect MNO Healing and Wellness staff with existing screening education resources to share with clients; and

We're the ones that are going in, um, getting a plan of care together for the family, doing an assessment. And then, doing the resourcing out to whichever service supports that they may need within our community. So, we have to be well-versed as to what's out there, who the best person is for them to reach out to. And, that includes, um, anything dealing with their health concerns. (FG 1)

You guys bring the information and bring some of the cultural sensitivity with partnering with somebody. But now that we've got someone there, I think, utilize people and frontline workers to work with that person to get them ready, and get the knowledge from you guys and have that support right next to them. (FG 3)

<ul> <li>Contributing to MNO's capacity to host</li> </ul>	One of the things that we have done is well within our programs is that we do, do
more screening events.	presentations or workshops or things like that on health issues. And so, that
•	information is provided through our events or our health fairs and things like that.
	Or we'll have, uh, health professionals come in and talk to our communities. So,
	usually, you know, offer a meal and then there's health education. (FG 6)

MNO Healing and Wellness staff highlighted the importance of providing social supports throughout screening, to improve community members' experiences with screening and willingness to participate. They stressed the importance of peer supports through the screening process, the value of offering screening combined with a positive social activity (e.g., a trip to the city in a group for screening that also included shopping). Participants also explained the key role that they play, as MNO Healing and Wellness staff, in supporting community members with screening, and the need for further resources to expand that support.

Table 15: Facilitators identified by MNO Healing and Wellness Staff - Improve social support throughout screening process

Theme	Selected participant quotes
Increase social supports available to Métis community members:	So go out, good, good, passing on the information. But, the hook was - and she knew there had to be a hook, okay; two hooks - lunch being offered. And, two, the gift card. (FG 1)
<ul> <li>Set up screening appointments in peer groups;</li> <li>Combine with a fun social activity/incentive (e.g., a spa day, to take fear out and make it fun); and</li> <li>Allow/facilitate a support person to attend screening appointments with patient.</li> </ul>	They did the integrated cancer screening, but partnered it with a Spa day. (FG 1)  So, if a, if a front line worker could be thereand we have staff that, um, that — like, our CSS [Community Support Services] workers - they do medical transportation. So, they can set up the medical transportation for the clients. They can also go with the client for that specific treatment, or, for that exam, whatever. And, you're hoping that the front line worker that's with them is going to be that worker, that's going to be sitting there explaining the process, breaking it all down for them, uh, being there in that supportive role. (FG 1).  Making sure when you're giving somebody the bad news that you're telling them, "bring in your support system. Bring in your worker. Bring in your daughter. Bring in your son." Or maybe you're not ready to have your family know yet, but bring in your worker; if you have a worker. Or have one of their workers ready to work with you. Have them in the room so it's not just you and the doctor, who is

an authority figure who you're not going to want to talk to. Because a lot of our people are still challenged by that authority figure. And a doctor is one. (FG 5)

Automatically schedule a one-week or two-week follow up [after seeing the doctor]. Because you go home; you absorb that information and then you've got a long list of questions, and where so we go from here? I think it would be ideal to have the follow up and that's when you can bring your support with you and make sure to get those questions [answered]. (FG 5)

I've had clients...there's a certain hospital in our area, that when they go for their screening there's a volunteer waiting for them, to navigate them through the hospital. And, they say, you know what? I wouldn't go if I didn't have that volunteer. (FG 1)

# Further support for MNO staff to navigate and support Métis community members through screening process:

- Help get to appointment travel/transportation support;
- Help take notes/listen to health professionals and explain information;
- Emotional support during testing; and,
- Link people to OH (CCO) Indigenous Cancer Navigator and other support resources.

We need to provide transportation. We've got people, especially our OW [Ontario Works] people. They don't get bus fare...(FG 1)

I'm just sitting there, at that point. Just sitting there and supporting her. I'm in the room. She feels safe because I'm there. (FG 1)

Let us know these people [Indigenous Patient Navigator] exist so we could bring them to our workshops instead of using someone from mainstream. (FG 5) So, we're [MNO frontline staff] the friendly visitors. We're the ones that are going in, getting a plan of care together for the family, doing an assessment. And then, doing the resourcing out to whichever service supports that they may need within our community. (FG 1)

I'd often go [to the screening] with them and [accompany them] home. And write them a letter when I got back to the office [explaining]. And mail it to them, so they know exactly what happened. (FG 1)

Participants suggested several ways in which access to screening for Métis community members could be improved, including providing more screening options closer to communities and integrating screening tests together, so that you could complete them all in one visit. They suggested that further access to options like the mobile screening coach, which travels to communities and offers

all three types of cancer screening, would help to improve participation. Improved access to healthcare service providers was also highlighted as an important facilitator. Finally, they explained that improved access to transportation and transportation supports would help to improve participation in cancer screening.

Table 16: Facilitators identified by MNO Healing and Wellness Staff – Improve access to cancer screening services

Theme	Selected participant quotes
Provide further supports for transportation required to participate:	And sometimes our agency can help with some of the travel expenses or maybe a hotel or a room when they get there, whatever. But they still need to eat. (FG 5)
<ul> <li>Funding to cover costs;</li> <li>Access to driving supports; and,</li> <li>Better public transit.</li> </ul>	You know, if you're going for your yearly test, be able to call up OW [Ontario Works] and have a taxi paid for. You know, like, I got my yearly exam. I got my transportation. (FG 5) Not all our people have cars. And, we did provide, I think - I can't speak out of turn - bus tickets. But see, Thunder Bay has bus. We don't. (FG 3)
Make screening accessible closer to communities and improve integration of screening into other healthcare visits (to reduce need for travel):  Facilitate screening participation and addressing other health issues in one	Was it Thunder Bay where they had this van [Mobile Screening Bus], or something? This travelling van that does mammograms, and stuff; I think that's fantastic. Because, you're going right to the person. And, you're there, the van's there. Well, I might as well - I can just walk in and get it done - it's not like you have to make an appointment, and you have to think about it, and you have to try and get to the appointment. And then, you just don't show up. But, yeah, having that, I think, is really fantastic. (FG 2)
<ul> <li>location/one health visit;</li> <li>Arrange for all screening test to be done on one trip and support/integrate with transportation;</li> </ul>	[Local accessibility to screening]. And then, you're not changing people's lifestyles. So, they have to take time off work three times. (FG 4)
<ul> <li>Expand capacity and range of mobile screening coach/options to visit more rural areas; and,</li> <li>Improve access to healthcare providers.</li> </ul>	Rainy River has their own hospital with doctors, but the doctors are filled with we have two that basically fly in and out. They spend, I don't know, how many days each there? And then, every now and then we get a locum. So, yes, you can make clinic appointments and things like thatand follow ups. The [screening buses] coaches come once a year, I'm assuming. So maybe that's the thing we need to look at, is offering those screening services more often in

the more isolated areas...and making sure that those things are advertised well, by promoting within...our Healing and Wellness branch. (FG 3) They actually went and got a bus. Picked up all the women for the day, did integrated screening. So, they did bloodwork in the morning, so they all fasted that night. They did blood work, they did Paps, they did, uh, breast screens for the women who qualified. They did the FOBT kit for them, and, if they wanted. their partner, also. And, they did health education and provided lunch. And then, they did...allowed them time to go shopping. Because, a lot of these women it was big for them. (FG 1) I just think that with cervical cancer and screenings...to do the Pap smear, if it could be done...the same time maybe as the...mammograms and all that kind of stuff. That it was being done all together...would, would save on some stuff. (FG 4) I would love to have a female that is there doing that [cervical cancer screening]. So, if they had someone who was doing those sorts of things, and it was, kind of, done in and out and just taken care of. (FG 4) Our [local community] health team does Pap screening, as well, so if you don't have a family doctor there's that option. (FG 6)

Finally, MNO Healing and Wellness staff identified improved cultural competency of the screening programs, including cultural competency training for healthcare providers, improved communication skills among providers, as an important facilitator for cancer screening. They focused on respect for Métis culture and identities (e.g., openness to Métis cultural perspectives on health and healing), as well as improved communication with Métis patients in particular.

Table 17: Facilitators identified by MNO Healing and Wellness Staff - Improve cultural competency of healthcare providers

Theme	Selected participant quotes
Cultural competency among healthcare providers – improved communication and relationships:	Although we are educators for our clients, I think there are service providers that need to be educated on our culture. (FG 1)
•	[Improve providers'] bedside manner. Part of cancer screening would be talking to the patient. So, how do you talk to the patient in a sensitive away?

- Cultural competency training for healthcare providers;
- Improve communication skills with Métis patients (e.g., improve dialogue and help Métis patients to more questions, challenge providers when necessary, ask for second option); and,
- Develop openness to/respect for traditional approaches to wellness.

How do you identify possible barriers that the patient might have? How do you let go of an assumption? You know, like, there's all kinds of soft skills that doctors don't get to practice when they're in med school, because they're so focused on the content. (FG 2)

When you [go] in for your mammogram...and then, also, they're calling you back in. You've got to go in for a second one. Explain why. It's the same session. Like, you're not done, yet. (FG 1)

Aboriginal families should be able to choose which way [reference to biomedical vs. traditional approaches to health], or both, if that's what they want. And, there shouldn't be any problem with that. (FG 4)

Automatically schedule a one-week or two-week follow up [after seeing the doctor]. Because you go home; you absorb that information and then you've got a long list of questions, and where so we go from here? (FG 5)

Because another thing is too with the culture, is, they are afraid, sometimes, to say things and they can't advocate as much. So to have someone present that they feel comfortable with, to really support them through the system (FG 2)

# **Group 2 – MNO Citizen Participants**

#### **Key Barriers to Cancer Screening Participation**

MNO citizen participants identified several important barriers to cancer screening that they had experienced in their communities, including:

- Limited access to cancer screening services
- Lack of cultural competency/safety in cancer screening services and healthcare system
- Attitudes and / or perceptions about cancer / cancer screening fear, avoidance and reluctance to participate
- Lack of screening awareness and ineffective cancer screening education approaches
- Basic needs take precedence

Each key barrier is outlined further with representative focus group participant quotations in Tables 18-22, below. Additional participant quotations are included in <u>Appendix I: Focus Group Discussion (FGD) Results</u>, Group 2: MNO Citizens.

MNO citizens explained that limited access to healthcare service providers (e.g., long wait times, limited time with providers) and geographic access challenges served as key barriers to their participation in screening. They noted that lack of public transportation and poor road conditions were contributing factors.

Table 18: Barriers identified by MNO citizens - Limited of access to cancer screening services

Theme	Selected participant quotes
Not enough providers – long wait times; feel cannot get a second opinion;     Not enough time with provider to get into	Even to get into a doctor's appointment, in my doctor's office is three months. From the day I walk in therefrom the day I make my request to the time I get in there. So within that three months and a couple of days you feel better and you think screw it, I'm not going, you know? (FG 7)
complex health issues/discussion; and,  Needing a referral from a physician is a barrier.	Now, if my health fails or my wife's we have a walk-in clinic. Now, they won't take you in Orillia unless you do have a family doctor. So if you don't have a family doctor, you just strictly go to Emergency. I was visiting my wife when she was in there and that place is just jammed full of people waiting to see a doctor. So, you're going to be there for a long time. (FG 7)  Well, there is [a barrier] if you have to get to see your doctor first.  -Okay. If you need the referral from your doctor for a screening such as a colonoscopy because then you have difficulty getting into your doctor just to
	get the referral? Is that why? -Right. (FG 8)  You're treated like a piece of meat and it's just like bang, bang, bang and there's no information passed to the family, to the patient all the way through
	that whole process and it's just like it's just so rushed. (FG 7)
<ul> <li>Geographic isolation/transportation challenges</li> <li>Poor/unsafe driving conditions/poor weather;</li> <li>Cost for travel too high;</li> <li>Lack of public transportation options;</li> <li>Limited budget for MNO to support travel; and,</li> <li>Limited services in rural / remote areas.</li> </ul>	A huge barrier in the north, and I hear time and again, it keeps coming up, it's transportation, believe it or not. For the Métis. They can't just hop a bus and get to this. They can't just take a taxi and anybody rural and also, we're almost relegated, some of us, to our homes in the winter because of the weather conditions or if you have to cancel. Like, there's so many things that impact in that way that's not the same. (FG 8)

Even when you go to the hospital to do some of the testing, you have to pay the meter so much. And, now parking at hospitals is getting a little pricey. Not everybody on a fixed income or senior's income can really afford to keep doing that for all those different appointments they're making. So, I saw that as prohibitive. (FG 8)

I know transportation is a big issue...the Métis council in North Bay itself, they can't even meet the needs of the people that require medical transportation...it's a huge component. (FG 8)

Where people live geographically from the services. As you go further north people are further apart. When you're down in the city; the bigger cities, they may have more access points but they may not always have the right service close by. They may have to go further to get to where they want to go. (FG 8)

MNO citizen participants explained that their distrust in the healthcare system and in healthcare providers made participating in cancer screening difficulty and served as barriers to their participation. Poor relationships and communication with providers, including experiencing a lack of understanding about and respect for their culture, were related factors. Participants also explained that their distrust or skepticism about screening and the healthcare system stemmed from having experienced healthcare system breakdowns/challenges (e.g., poor data sharing integration between providers, old equipment in hospitals), which made it hard for them to believe that recommendations from healthcare providers, for example, about participating in screening, were actually intended to support their health.

Table 19: Barriers identified by MNO citizens – Lack of cultural competency/safety in cancer screening services and healthcare system

Theme	Selected participant quotes
Lack of cultural competency / safety among healthcare providers and poor patient-provider relationships  • Poor communication with patients – not enough information shared; poor follow up communication after; providers do not listen;	None of that was explained to us, nothing. We didn't know better to take him to the hospital or whatwe didn't know nothing. Like, it was just, it was a lack of information. (FG 7)  She was after her doctor. I need, I got a lump in my breast, I need to get checked. I've got something wrong like and it was just bypassed. Like half the time I think it's your family doctor that just doesn't listen, you know, so it's too late. (FG 7)

- Lack of trust/ discomfort with providers cannot share your trauma/context that informs your health;
- Power dynamic with health care providers positions patients below healthcare providers; hard to question/challenge providers;
- Poor treatment by health care providers (particularly specialists) – racism; discrimination; lack of empathy;
- Lack of awareness/respect for Métis approaches to health (e.g., patients 'fired' for suggesting alternative approaches to treatment/ wanting a second opinion); and,
- Lack of Métis-specific supports and culturally relevant screening services (Métis on the fringe because not FN, not mainstream).

I did the smear test too and I found it very ineffective...because it was like it'd come back and it was like six months later I got my results back. And, they're like well the test didn't go through properly. (FG 7)

I went to the hospital and as I said I spoke to the doctor and she's talking about consent form. Well, I'm upset sitting with the shirt and it's stuck to my body and I'm not happy. So, I'm walking out of there and I went to my Métis [worker at MNO in Kingston] and I'm balling my eyeballs out and all of them come out to me and said, "what can we do? (FG7)

I also know that there's discrimination that's still alive for the Métis and the First Origin people. Discrimination...they're still being discriminated because the fact that the old beliefs. (FG 8)

We live in a society where the ownership for our health has been taken away from us and somebody else is the expert in our health, and that's not true. (FG 8)

Some doctors don't necessarily see it as a joint deal with their patients so they don't want you to be leading your own healthcare. They're going to tell you who you're going to see, what you're going to do. And, if you veer outside of that, you risk losing them as a doctor. (FG 8)

My quest, or my comment is on the fact that we're Métis and we've already been identified as higher risk in certain cancers and things. Why is the medical community not aware of that? (FG 7)

The Aboriginal Spiritual Centre [in Sudbury Hospital], there was nothing specific to Métis. I actually educated her; the woman who had just started there, about some of...who we were. And then, when I went again a couple of years later I'd been up there and I noticed they have...they had a sash. That was about it. (FG 8)

# Distrust of institutions / healthcare system

• Distrust that screening is truly about patient health;

A lot of problems with the government decisions to segregate the services. Down in the Niagara region, they're taking the colonoscopy in one area and they're going to put the pre-natal services in another hospital. All the hospitals; each individual hospital used to have all the services combined. But

- Question relevance of screening guidelines for Métis community; and,
- Distrust that the healthcare systems involved in screening are functional (e.g., old/outdated equipment; poor communications processes – results get lost; poor integration of healthcare services within systems).

being...raising the cost to the taxpayer, I guess, is the natural inclination for the government to try and cut the costs. But, I find they're doing it the wrong way. (FG 7)

It would be so nice to see that nothing is cut back. But, a lot of screening programs are cut back, too. (FG 8)

In Midland, our CT machine is so old. So, there's no surgeon that will accept our scans outside...like, if you have scans done in Midland and then your doctor sends you to a specialist in Barrie, they then send you for new scans because they don't accept them. (FG7)

If you get transferred from one doctor to the other, in most cases your records; your medical records are lost...(FG 8)

Well, we have a young girl, at home... and she's only 30. I'll say 35. She was after her doctor. I need, I got a lump in my breast, I need to get checked. And I guess he kept putting it off. Well now this young lady is going through chemo and has to have both breasts removed. Like why... I've got something wrong like and it was just bypassed. Like half the time I think it's your family doctor that just doesn't listen, you know, so it's too late. (FG 7)

My quest, or my comment is on the fact that we're Métis and we've already been identified as higher risk in certain cancers and things. Why is the medical community not aware of that? (FG 7)

I have a girlfriend who actually is battling breast cancer and her mother passed away from breast cancer. And, she had her daughter's tested. Like, she was the one pushing for this and one of her daughter's does carry that gene. So that's why I was saying like if that was maybe pushed more on the medical system then, you know, we'd be diagnosed sooner, better outcomes...(FG 7)

MNO citizen participants described fear about the screening tests and denial about the possibility of getting cancer, which was related to fear about cancer, as common barriers to screening.

Table 20: Barriers identified by MNO citizens – Attitudes and / or perceptions about cancer / cancer screening - fear, avoidance, and reluctance to participate

Theme	Selected participant quotes
<ul> <li>Fear about cancer, about screening tests</li> <li>Cancer equated with death;</li> <li>Emotional challenge of waiting for results/ anticipating negative results; and,</li> <li>Fear that mammogram will increase chances of developing cancer (squishing cells will stress them; rooted in cultural conceptions of health).</li> </ul>	Another thing for me personally for getting retested is the biggest fear that I'm going to have to go through chemo again. (FG 7)  First thing that comes to my mind is death because when you think back even 20 years ago, somebody had cancer it was pretty much a death sentence. (FG 7)  We had this conversation in the house the other day where like one of the young lads said, "I don't want to get tested because I'd just rather not know". And we're just like, well, no it's not like that anymore. (FG 7)  I will not go for a mammogram. You know, and it's just my own studies, my own knowledge. I have an alternative healthcare background. But, I justI would prefer a thermograph because to me, if someone is pushing and pushing and pushing that hard on my breastsit's like [name of another focus group participant] said, is that we all have latent cancer cells and I figure something's going to come up, you know, just doing that mammogram. I know people who do it and they're fine. It's just for my own belief and where I stand, I won't do it. (FG 8)
Denial and reluctance linked to: Reluctance (rather not know, tests are unappealing – e.g., FOBT).	We had this conversation in the house the other day where like one of the young lads said, "I don't want to get tested because I'd just rather not know". And we're just like, well, no it's not like that anymore. (FG 7)  I think it's fear of the unknown when it comes up and I also think it's often a wake-up call. And, I think leading into some of what you've spoken about it's about, we get little signals to listen to our bodies and we have opportunities to act on them and become conscious of what is actually happening. (FG 8)

MNO citizens noted that there was limited information about cancer screening available and explained that the existing resources that they were aware of were too long and complex and were not Métis-specific.

Table 21: Barriers identified by MNO citizens – Lack of screening awareness and ineffective cancer screening education approaches

Theme	Selected participant quotes
Lack of education resources / poor education strategies  Limited screening information available – it is not being talked about, information not shared	I went for the cancer, they gave me a pamphlet like all the books. I'm not reading through all that. I'm totally distraught; I think I'm dying here. I'm not reading a book. (FG 7)
in a way that is accessible to community	Use the Kiss program. Keep it simple. (FG 7)
Lack of Métis specific information	Well, communication. Not everybody has Internet. (In response to barriers to screening). (FG 8).
	We didn't know nothing. Like, it was just, it was a lack of informationif there was somebody like you say like an Aboriginal advisor or somebody that could say, you know what, when this is going ongiving you your outcome and your possibilities and whatthat information's not there for you. (FG 7)
	The Aboriginal Spiritual Centre [in Sudbury Hospital], there was nothing specific to Métis. I actually educated her; the woman who had just started there, about some ofwho we were. And then, when I went again a couple of years later I'd been up there and I noticed they havethey had a sash. That was about it. (FG 8)

Finally, MNO citizens explained that for some, participating in screening was not a priority, given their focus on attending to more pressing essential needs and socioeconomic priorities.

**Table 22:** Barriers identified by **MNO citizens** – Basic needs take precedence

Theme	Selected participant quotes
Socioeconomic priorities (e.g., daily living related – rent, groceries) make it difficult for community members to invest time on other health services / issues including cancer screening	I find that going to get screening, it cuts into your work week. And even getting to a hospital, you have to take one day off for travelling and then one day for an appointment and then another day for travelling back. (FG 8)  I know Midland it's \$45.00 for the [PSA] test. And like I said, it might not sound like a lot to some people, but to some people it means their groceries. (FG 7)

### **Key Facilitators that Support Cancer Screening Participation**

MNO citizen participants outlined several facilitators that would help to support participation in cancer screening, including improving:

- education approaches and (access to) resources so they are specific to Métis community and grounded in culture.
- social support throughout screening process.
- · access to cancer screening services
- cultural competency of healthcare providers.

Each key facilitator is outlined further with representative focus group participant quotations in Tables 23-26, below. Additional participant quotations are included in <u>Appendix I: Focus Group Discussion (FGD) Results</u>, Group 2: MNO Citizens.

MNO citizen participants explained that screening education and awareness could be improved by grounding education efforts in Métis culture. They suggested that Métis community leaders and members, should be engaged in developing screening education materials and education efforts should be targeted to Métis communities (e.g., paired with Métis cultural activities, address points of confusion or concern for the community). Finally, they noted that supporting MNO Healing and Wellness works in providing screening education efforts would help to improve awareness in the community.

Table 23: Facilitators identified by MNO citizens – improve education approaches and access to resources so they are specific to Métis community and grounded in culture

Theme	Selected participant quotes
Culturally grounded screening education     engage Métis Senators, Elders, community leaders and champions to adapt or develop more culturally appropriate education approaches and resources (linked to importance of screening information coming from community members);	Having your Elders come in and give that spiritual counselling and guidance and just talk and listen to them. You know, what? Yeah, we had one Elder come in for us and heor, actually sheshe came in and she said, you know what, guys? I want you guys just to kind of expand your wings. Just talk about stuff that has hurt you or stuff that's very painful, too. And, you know what? Being in that circle is powerful. (FG 8)
<ul> <li>pair screening education with cultural activities that are popular (including events / workshops with meals / other incentives);</li> <li>include information about culture-based / traditional approaches to health;</li> </ul>	That circle that came was very powerful. You know, there was the healing blankets made and, you know, people came forward. We had men come forward and even speak about their issues. And, again, sitting in this is extremely powerful. Look what it's done with me because of what I'm going through. (FG 8)
<ul> <li>raise awareness via existing community communication processes (e.g., MNO Voyageur publication, health promotion at MNO Annual General Assembly); and,</li> </ul>	Be aware of the alternatives [to biomedical treatments] and to know that we have choices. (FG 8)

 engage via family/friends, motivation and supports (e.g., Especially wives nudging husbands, Being personally impacted in your family, Motivation from thinking about the next generation, not for you). The Healing and Wellness branch of the Métis Nation of Ontario that should certainly maybe be a once or twice yearly workshop to get the Métis people out. Make them aware of the types of screenings and who to contact. (FG 7)

My grandmother, mother and several aunts and they all passed with the cancer. So, my mother bore six girls. So, we were going for the mammograms yearly even though we weren't 50 yet. I was still in my late thirties. (FG 7)

# Improved and better-targeted communication / messaging

- use appropriate wording / style health literacy;
- use more positive / supportive rather than fear-based messaging / negative (e.g., screening is a way to stay healthy, benefits of early detection, survival stories);
- improve relevance of screening education messaging and promotion
  - o address points of confusion;
  - Bring screening education resources together so they are easier to find;
- improve OH (CCO) screening correspondence letters; continue this program;
- develop resources appropriate for children and youth; and,
- increase awareness among community about available MNO supports.

It's got be consistent. I get the electronic version [of the Métis Voyageur] as most of you do here and also the paper version. I go through the electronic version because, you know, like there's a limit. [name of another focus group participant] said, "how much can you read?" If you're going to get on with your life... we can sit at home with the manuals on how to do this and do that and how to cook a turkey and how to skin a moose and whatever. You're kind of limited in what you want to absorb. So like they used to say, "use the Kiss program. Keep it simple". (FG 7)

I think that's an important message to know... like we were saying before is that we know now that there are success stories. You know, we have to promote those success stories as well, right. (FG 7)

I would probably, I would turn to the Métis and just say, "hey, we have to go here, I can't drive or whatever". Like, you know, but I think by and large we don't know how to access the services. I think there should be better directions or certainly something you can put on your wall if this happens boom, here's where you call. (FG 7)

I'm on the breast screening and I go every year so they send me a letter for that. (FG 8)

Kids are bulletproof and maybe it needs to be more in the curriculum that they're being taught in the school programs. (FG 7)

On a positive note, when MNO first started delivering their health programs, they were bringing the Elders and the families and that, people

	were getting together more often so you did get to know who your Métis community was, even in the city. And, that was really good but then as things evolved, and again, funding became an issue; government funding, so things got cut back so you don't see that happening the way it used to. And, it went on quite often. Now, I don't remember the last time I was told to go to something, or invited. (FG 8)  They've gotten a lot better results since they started some of the programs and started sending cards as reminders. And, it's not like we don't know. But, they're not allthey're not all at the same time. And, they're not all operating under the same umbrella and they require different things. And, it's like a lot of programs that are available, like so, the Government of Ontario may offer 60,000 programs. There's no one individual can know all of them. So, where do we go for one-stop shopping, is one thing, in regards to our health? (FG 8)  When I got my letter this year I went okay, I'm going to do that
	[mammogram]. So, I thought hey, I'm almost due for my colonoscopy. I'm going to ask for that. Oh, no, you can't do it [colonoscopy] through us. You have to go to your doctor. (FG 8)
Further training and support for MNO to provide screening education:  • support MNO Healing and Wellness workers with further training / outreach, allowing them to reach Métis who are not accessing services.	I think we've got to start with our frontline people get them some education. (FG 7)

Participants also highlighted the key role of social support and navigation in encouraging cancer screening participation. They noted the important role of MNO staff in supporting access to screening (e.g., through transportation supports that they provide).

Table 24: Facilitators identified by MNO citizens – improve social support throughout screening process

Theme	Selected participant quotes
Increase social supports available to MNO	Maybe give a prize to the family that goes together. Anything. But, do
citizens	something promotionally and gather it in a central location. And, I think,

<ul> <li>set up screening appointments in peer groups;</li> <li>combine with a fun social activity/incentive (e.g., a spa day, to take fear out and make it fun); and,</li> </ul>	too, sometimes it could be done not necessarily with the doctors themselves. Some of the screening can be done with nurse practitioners. (FG 8)
<ul> <li>allow/facilitate a support person to attend screening appointments with patient (e.g., Indigenous Navigator support, peer support).</li> </ul>	If there was somebody like you say like an Aboriginal advisor or somebody that could say, you know what, when this is giving you your outcome and your possibilities(FG 7)
Further support for MNO staff to navigate and support MNO citizens through screening process:  • help get to appointment – travel / transportation support.	-If they [clients] don't have any family supports and they are Métis and they are aware of the programs and services at the [MNO] office, they phone, they get transportationYeah. I got driven to Sudbury a couple of timesBut there's a budget for that transportationAnd there's a budget and don't go more than two times a month. (FG 7)

MNO citizen participants explained that improved access to screening services would support improved participation in screening. They explained that improving the existing transportation supports and providing screening closer to home would help. They also noted that access to healthcare providers more broadly would support screening participation.

Table 25: Facilitators identified by MNO citizens – improve access to cancer screening services

Theme	Selected participant quotes
Provide further supports required to participate:  • funding to cover transportation costs;  • access to driving supports;	It was my Métis family that asked me if I was aware for the radiation I went 25 times. They asked me if I was aware that through the Cancer Society if I paid a fee of \$100.00, they have volunteer drivers that would come and pick me up at my farm, bring me in. (FG 7)
Make screening accessible closer to communities and improve integration of screening into other healthcare visits (to reduce need for travel):  • facilitate addressing screening and other	Maybe give a prize to the family that goes together. Anything. But, do something promotionally and gather it in a central location. And, I think, too, sometimes it could be done not necessarily with the doctors themselves. Some of the screening can be done with nurse practitioners. (FG 8)
<ul> <li>health issues in one location;</li> <li>arrange for all screening test to be done on one trip and support / integrate with transportation;</li> </ul>	They've gotten a lot better results since they started some of the programs and started sending cards as reminders. And, it's not like we don't know. But, they're not allthey're not all at the same time. And, they're not all operating under the same umbrella and they require different things. And, it's like a lot of

	programs that are available, like so, the Government of Ontario may offer 60,000 programs. There's no one individual can know all of them. So, where do we go for one-stop shopping, is one thing, in regards to our health? (FG 8)
<ul> <li>Improve access to healthcare providers:</li> <li>Better use of telemedicine to support discussion around/follow up after screening</li> </ul>	Well, one thing that I have not used, but I know that there's a Telehealth phone number. I think that is a great resource. I haven't used it myself too much, but if there was a more cancer content on that. If there were questions or if I could ask questions. If I could phone and ask questions, I would. (FG 8)

Finally, MNO citizen participants explained that improving cultural competency skills among healthcare providers would be an important means of improve screening participation among Métis communities. They focused on how this would improve communication and strengthen relationships between Métis patients and their providers. They highlighted the need for providers to demonstrate that they were open to, and had respect for, Métis approaches to health and healing. They also noted the need for improved dialogue between Métis patients and providers (e.g., supporting MNO citizens in asking more questions, challenging providers when necessary, asking for second opinion, recognizing screening as patient's choice, advocating for one's self and family in interactions with providers).

Table 26: Facilitators identified by MNO citizens - improve cultural competency of healthcare providers

Theme	Selected participant quotes
<ul> <li>Improved communication and relationships:         <ul> <li>improve communication skills with Métis patients;</li> <li>develop openness to / respect for traditional and / or alternative approaches to wellness; and,</li> <li>support improved dialogue between Métis patients and providers (e.g., help Métis</li> </ul> </li> </ul>	I would have preferred that my doctor's office called me with the results then me have to wait. And then, I have tried and get in touch to see, because basically the standard answer would be, 'if you don't hear from me everything's fine.' I felt, because it's my health, I want to speak to somebody and I want to hear them say, 'these are your results and it's okay.' Not that if you don't hear from me, because there are cases when they haven't gotten in touch and it wasn't okay. (FG 8)
patients in find their voices to communicate more with providers and take ownership of their care by asking more questions, challenge providers when necessary, ask for second option)	I also went to see another health practitioner. He was a medical doctor but he was practicing natural therapies. He had two licences and his specialty was critical illness. So, I went to see him and we talked about it and he looked at my records and he said, "yeah, I think you better go through with

it." So, I had a better frame of mind going into it because I knew that it was my best option even though it seemed like overload. (FG 8)
You know you try to explain it to the doctor what's going on. Oh no, you're too young for this. I have osteoporosis and I had it since I was 25 years old, you know what I mean? Like yes it's young, but it happen. And, they should listen to what we have to say. We know our own body. We know our ache and pain. If something is different they should take notice of that. (FG 7)

### **DISCUSSION**

# **Summary of Key Findings**

There was considerable agreement among the two groups (MNO Healing and wellness staff and MNO citizens) and the two types of data collected (survey and focus group data) regarding perspectives on healthcare utilization, health priorities, cancer and cancer screening. These similarities are particularly noteworthy given the differences in geographic distribution in each group – with a greater proportion of MNO citizens coming from central Ontario relative to staff and greater breadth of geographic representation among staff. The MNO citizen (n=21) and MNO Healing and Wellness staff (n=28) survey participants indicated that most Métis community members have an OHIP card and have a primary healthcare provider. However, MNO staff suggested that their clients have at least moderate difficulty accessing primary and specialist healthcare services (MNO citizens were not asked this question). MNO citizens and MNO staff suggested that primary care and family/friends were the top sources of health information for community members. Cancer was identified as a priority health concern among Métis community members by both groups.

While an effort was made to engage a diversity of perspectives from MNO frontline staff and MNO citizens throughout the province, the citizen group was not as geographically representative as the staff group. This may have skewed our MNO citizen findings, as this small group is not representative of the diversity of screening perspectives and experiences among MNO citizens in Ontario. For example, the self-reported screening participation rate among community members was very high, which may not be the case for the Métis community as a whole. As such, the study findings may have missed some community perspectives.

Despite the somewhat limited geographic representation in the citizen group, there was considerable consistency among the more geographically representative staff group and the MNO citizen group, in their descriptions of barriers and facilitators to cancer screening in the survey data. Fear of receiving a positive screening test result was flagged by both groups as a key concern. Both staff and citizens also highlighted the need for more and better targeted screening information, more culturally relevant information specific to Métis needs and circumstances, more culturally competent screening service provision, and the need for support people (family, friends, community members) to accompany community members to appointments and during the screening process, including any follow-up that might be required. Differences were more a matter of emphasis than substantive in nature. Distance from services, limited local availability of healthcare providers and services, lack of transportation, and the associated financial and other costs of having to travel long distances to access services were common concerns. Both groups identified the key role of MNO and MNO Healing and Wellness staff in supporting cancer screening in Métis communities.

The key themes identified in the MNO staff focus groups (n=45) and MNO citizen focus groups (n=21) were very similar to one another, and, not surprisingly, overlapped considerably with the barriers and facilitators to cancer screening that participants outlined in the surveys. Participants identified important barriers to cancer screening participation among the Métis Nation of Ontario:

- Limited access to cancer screening (i.e., to healthcare providers and to screening services) among Métis communities
- Lack of cultural competency/safety among healthcare providers and healthcare institutions
- Distrust of healthcare institutions / healthcare system among Métis communities
- Lack of screening awareness among Métis communities ineffective and poorly targeted screening education materials and strategies
- Fear about cancer and screening among Métis community members and reluctance to participate
- Lack of socioeconomic supports make screening challenging for Métis community members

Relatedly, participants in both groups identified facilitators that align quite well with the identified barriers:

- Improve access to screening increase availability of screening services and supports in traveling to/accessing screening
- Improve cultural competency/safety among healthcare providers respect for Métis culture and identities; communication skills; support Métis patient voice/decisions in screening process
- Improve education strategies and increase availability of screening education resources
   culturally grounded, Métis-specific approaches to screening education and supports
- Improve social supports throughout screening process navigation supports, role of family/friends as key motivators and supports

# **Interpretation of Results – Cancer Screening Pathway**

In an effort to address our research objectives, the key themes identified through our collaborative thematic analysis were examined in the context of OH (CCO)'s proposed 'ideal state' cancer screening pathway, which outlines how cancer screening is expected to proceed in order to maximize early detection rates and improve cancer treatment outcomes (see Figure 4). In doing so, the working group first revised the cancer screening pathway to better reflect the meaningful steps in cancer screening from the perspective of Métis community members. The pathway was streamlined into four key steps in screening, as understood by the community, and emphasized both the community member as a central driver of progress through the pathway (rather than a passive recipient or disengaged participant in cancer screening) and the important considerations prior to actually completing a cancer screening test (see Figure 6).

- 1. **Knowing** about cancer screening: education / awareness
- 2. **Deciding** to get screened
- 3. Taking Action: booking an appointment, getting to services or completing tests
- **4. Following up**: getting test results, completing further testing, or initiating screening again when appropriate



Figure 6: Métis Cancer Screening Pathway

While the proposed Métis-specific cancer screening pathway outlined in Figure 6 provides a useful means of organizing and making sense of the results, it quickly became clear in examining the key barrier and facilitator themes from the results that many of these themes are not restricted to one stage along the screening pathway, but rather act as barriers/facilitators at several, and in some cases, all stages and throughout the cancer pathway more generally. Further, as noted above, the tightly linked barriers/facilitator pairs suggest that the cancer screening experiences of the Métis community members might be best understood as key factors that impact experience, which often serve as barriers to screening participation, but can be shifted in order to support or facilitate participation in cancer screening.

Taken together, our data suggest that three overarching factors are particularly important in understanding how the Métis community in Ontario experiences cancer screening:

- Awareness and perceptions (impacts screening steps 1 and 2 in particular)
- Access to cancer screening services (impacts screening steps 3 and 4 in particular)
- Cultural safety of cancer screening services (impacts screening steps 3 and 4 in particular)

These factors are interrelated with one another, can serve as barriers or facilitators to cancer screening, operate throughout the cancer screening pathway at multiple steps (see numbers in brackets, above) and are rooted in deeper determinants of health and health system factors. For example, lack of access may impact the decision to initiate screening while also impacting the

ability to undergo follow-up testing; as such, it is essential that future policies consider how these factors are related in order to effectively impact screening uptake among the Métis community. Improving methods of education / awareness will not impact screening uptake if parallel solutions for geographic isolation are not identified. These key factors are consistent with what is already known about cancer system experiences among the Métis in Ontario from previous work and firsthand, frontline experience of MNO, but they give us further insight into how best to intervene to improve access to cancer screening.<sup>11</sup> Each key factor is outlined in greater detail below, both as a barrier and facilitator. The order in which they are presented is not intended to reflect the relative importance of the key factors, but instead was chosen for alignment with the pathway outlined in Figure 6. The subsequent section outlines a set of recommendations that stem from this analysis.

#### Awareness and Perceptions (Pathway steps 1 and 2)

Participants identified a need for culturally relevant, clear, and user-friendly information at every stage of the cancer screening pathway, be it information about when to get screened, the actual process of screening, follow-up testing or available treatments. While these factors are particularly impactful in steps 1 and 2 of the Métis screening pathway, it is clear that they also have implications for the ways that Métis community members experience subsequent steps in the pathway, as discussed further in the following section.

Limited knowledge about, or trust in, the benefits of biomedicine, paired with the failure of healthcare providers to accept/support the use of alternative treatments, proved to be challenging for people who were wary of biomedical advances often perceived to be "the Western way". Along with lack of healthcare provider cultural competency, limited time with healthcare providers also hindered cancer screening education efforts. The provider role is especially important given that many MNO citizens and MNO staff reported that healthcare providers were clients' primary source of health and wellness information.

Increased awareness through education is necessary to reduce fear and distrust among Métis community members and help increase screening uptake among Métis communities. Identified challenges with existing approaches to screening education experienced by the Métis include education resources poorly designed for the Métis community, because for example, they were too long and detailed, used exclusively First Nations terminology and symbolism, and included negative and fear-inducing depictions of cancer (e.g., "horror stories").

Misconceptions about cost and recommended frequency of screening were apparent. Some MNO citizen participants in the study reported that after receiving a screening reminder letter, they thought they would have to pay for screening in order to participate. In addition, people felt unprepared when they were getting screened. They were not told what to wear (or what not to wear) or properly informed about what the actual process entailed. The follow-up process after participating in a screening test also provoked anxiety among many people who preferred that they be contacted even if their results did not warrant additional testing / treatment.

Engaging and involving friends, family and other Métis community members in raising awareness about cancer screening was seen as vital for increasing cancer screening uptake. Family and community members, including older family and community members, appear to

play an important role in encouraging individuals to undertake screening. As well, MNO staff and MNO citizens both called for a more positive approach to messaging around Métis cancer screening, one that focused on the value of screening in terms of cancer prevention and in optimizing outcomes should treatment be required, compared to the negative messaging that some community members explained that they often encountered. They suggested that screening outreach should be tailored to the needs of Métis men and women, noting that some men preferred more privacy when engaging with health matters, while women preferred sharing events or group information sessions.

Both MNO staff and MNO citizens also reported that they found MNO workshops and events to be extremely useful vehicles for transmitting information and increasing awareness of screening options and procedures, and suggested that more be conducted. Métis-specific resources provided in a variety of media (e.g., the Métis cancer video co-developed by MNO and OH (CCO)) were also identified as being useful for prevention efforts and the promotion of cancer screening.

Because healthcare providers were also regarded as a key source of information, cultural competency training was suggested us an essential support in improved screening awareness among Métis communities. This training should target better communication approaches and seek to instill a sense of respect for Métis conceptions of health, in providers.

Written education resources should be revised or developed with Métis communities, including Knowledge Keepers and Senators, to ensure that they align with Métis cultural perspectives. They should include Métis imagery, symbolism, be reflective of Métis perspectives on health and healing. Further support for MNO staff so that they felt adequately prepared and supported in providing the information on cancer screening to community members was also identified as an important screening facilitator. Where these supports do exist, more outreach is necessary to increase awareness that these resources are available to Métis community members and MNO staff. For example, the Regional Cancer Program Indigenous Patient Navigators were regarded useful supports; however, many people were not aware of this service.

#### Access to cancer screening services (Pathway steps 3 and 4)

Access to cancer screening among the Métis community was affected by limited access to healthcare providers/screening services, geographic challenges, and socioeconomic challenges. These barriers operated mainly in the second half of the screening pathway (steps 3 and 4), but it is easy to see that if the access challenges appear to be insurmountable, engagement with the earlier steps in the pathway (1- learning about, 2 - considering your choice and deciding to participate) would be much less likely. Many participants described challenges due to limited availability of healthcare providers, particularly in more rural and isolated areas, which meant that accessing a primary care provider was difficult. Without a regular primary care provider, it was challenging to develop patient-provider relationships and the kind of trust that is important when discussing and participating in cancer screening (linked to and explored further in the following section). The limited availability of providers also meant that there were long wait times to see healthcare providers and participants described being rushed through

appointments, which also negatively impacted patient-provider relationships. These barriers were greater in more rural and geographically isolated areas.

Participants felt that health centres / hospitals in some smaller towns also lacked sufficient medical equipment; in some cases, people were required to travel considerable distances to larger urban centres to undergo testing or, follow-up testing. As a result, many services were rendered inaccessible given that travel is not always feasible, especially when family and work commitments may not allow for extended absences, and the costs that this travel typically involves (e.g., costs for gas, parking, overnight stays), are considered. Limited access to a personal vehicle and poor public transportation options in small urban, rural and isolated communities also made travel for screening challenging. For those with access to a personal vehicle, the long drives that were required, often without a support person to come with them (as this would require another person taking time off from work and would likely make childcare even more challenging), were stressful, particularly in poor weather conditions, and served as a deterrent to participating.

Limited supports for Métis community members, who are not eligible for Non-Insured Health Benefit travel supports that status First Nations have access to, meant that these travel-related challenges were insurmountable for some. Participants also described the financial supports that some Métis community members do have access to – Northern Health Travel Grant and Ontario Works travel supports – as inadequate.

Clearly, limited socioeconomic resources among some community members intensified these barriers. Beyond travel-related challenges, some participants described competing socioeconomic priorities (e.g., daily living related – rent, groceries) meant that cancer screening was not practically accessible, as they were focused on more pressing needs.

In order to address these considerable barriers to access, participants offered several suggestions. Help with transportation was one of the most frequently reported needs by participants. MNO's system of volunteer drivers who assist with community members' medical transportation needs was mentioned multiple times during both the survey and the focus group discussions and was universally regarded as a valuable resource in fostering cancer screening uptake among Métis. Others suggested that amendments to the way that provincial travel supports, such as the Northern Health Travel grant, are administered and funded would help. For example, some noted that it would help if the Grant could be accessed without a doctor's sign off ahead of time and instead get this sign off after the appointment, because the initial out of pocket costs were prohibitively high for some community members. This issue was particularly important given the limited access to primary care providers (who could ideally provide the sign off required before the travel) described by many participants.

Other initiatives such as the OH (CCO) mobile cancer screening coach bus, which visits some rural communities (but not all), were cited as examples of ways in which to address the issue of geographic isolation and distance from services that serves as a barrier for many Métis. Participants also suggested that streamlining screening services (e.g., arranging for multiple medical appointments or specifically multiple types of screening) in one healthcare centre/hospital visit to reduce the amount of travel require, would be helpful.

Finally, participants suggested that improving access to primary care services more broadly would help to support access to cancer screening.

# **Cultural safety of cancer screening services (Pathway steps 3 and4)**

Participants described several barriers to cancer screening that can be understood as lacking cultural competency/safety among providers, and within healthcare services involved in cancer screening. They described experiences with screening services that were indifferent or unwelcoming to them and to their identities as Métis peoples; discomfort with screening tests and poor support in accessing them; and poor treatment from, and relationships, with healthcare providers. This was linked to an overall distrust of the healthcare system, which is also rooted in ongoing colonialism and related trauma.<sup>14, 15</sup>

MNO staff explained that many of their clients do not feel comfortable when speaking to their health care providers, who often rush through appointments, fail to explain processes or procedures in a comprehensible manner, and undermine alternative – or more naturopathic (as opposed to biomedical) – approaches to treatment.

Past trauma associated with residential school abuse further impacts people's willingness to engage with the health system. As such, establishing and building trust is essential for Métis community members who will disengage when trust is lacking. For example, some participants highlighted that the inability to see the same healthcare provider consistently served as a barrier because they were not able to develop these trusting relationships. Participants also pointed to a lack of access to female healthcare providers as a deterrent to cervical cancer screening participation.

In addition, participants explained that Métis community members often do not feel represented in healthcare service settings, which contributes to people's disengagement or distrust. To combat these issues and maintain consistency, social and culturally relevant supports are necessary. Ensuring that healthcare providers have a good understanding of, and demonstrate respect for, Métis culture and perspectives on health and healing, was important.

This study revealed that one important facilitating factor is having access to a support person who can provide social support and also potentially serve as an advocate if need be. This includes allowing people to be accompanied to their appointments, screening tests and or follow-up appointments by a support person (a friend or family member) whom they trust. MNO staff (frontline workers) were identified as essential support persons who not only accompanied staff to appointments, but also compiled written notes for later reference to help their clients with any questions or concerns they might have about their appointments or test results – questions they may not have felt comfortable addressing at the time of the appointment.

Relatedly, community members would like to be supported should they choose naturopathy or any alternative to "the Western approach" (in reference to biomedicine). Participants reported feeling dismissed or feared they would not be further assisted if their health provider knew they were considering alternative treatment or also seeing a traditional healer. While health practitioners may be hesitant to condone alternative methods of treatment it is important that Métis people feel respected and supported in making decisions regarding their

own health and well-being. This was identified as a way that healthcare providers could show respect for Métis approaches to health and healing.

#### **Results in Relation to Published Literature**

While cancer screening experiences among Métis community members in Ontario have not been well documented in previous literature, we can consider our findings in relation to other related literature. The numerous barriers to participation in cancer screening found in this study align well with previous research led by MNO and OH that found lower participation in cancer screening among Métis people in Ontario compared to other Ontarians.<sup>5</sup> Our findings help to illuminate some reasons that may underly lower screening participation rates. The barriers related to competing socioeconomic priorities and lack of sufficient socioeconomic supports that we identified also align well with previous research findings regarding lower participation in colon, breast and cervix screening among Métis community members with lower incomes compared to Métis community members with higher incomes.<sup>5</sup>

There is considerable overlap between the cancer screening barriers and facilitators identified in our study and those of the *Métis Cancer Patient Journey* project that MNO undertook with CPAC, which focused on the entire cancer journey.<sup>11</sup> For example, lack of access to cultural supports, poor healthcare provider communication with Métis patients, and long wait times/limited access to healthcare services, were identified as important barriers in both studies. Both studies also identified the important role of family, friends, and community programming in overcoming these barriers.<sup>11</sup>

In CPAC's larger baseline report, in which the *Métis Cancer Patient Journey* project findings were included, the main cancer screening barriers among Métis communities throughout Canada were identified as "personal fears and beliefs, geographic isolation, economic factors, and health system capacities". Our results reinforce and extend these findings, detailing/exploring the importance of screening service accessibility, poor experiences with, and lack of trust in, the healthcare system and the lack of Métis-focused, culturally safe screening and health education services. The historical roots of these barriers and the need to support culturally safe healthcare services that engage the Métis community specifically, rather than taking a pan-Indigenous approach, is well recognised in Métis health research. 15, 16, 17

#### **CONCLUSIONS AND RECOMMENDATIONS**

To date, approaches to understanding cancer screening behaviours in Indigenous populations have mostly been pan-Indigenous in nature, or predominantly First Nationsfocused. Such approaches mask Métis-specific geographic, demographic, and sociopolitical factors that impact Métis screening rates. This project engaged community and policy partners in a collaborative, culture-based study of cancer screening among Métis people of Ontario. Results provided insights into factors impacting Métis community screening rates specifically, not available from pan-Indigenous approaches.

Based on our research findings, the following strategies and or supports are recommended to help increase cancer screening uptake and enhance the cancer screening pathway for Métis communities in Ontario. These recommendations centred around improved

cancer screening education and training. The recommendations aim to provide information and resources to Métis citizens and communities in order to reduce fear and stigma associated with cancer screening as well as to empower citizens to engage in cancer screening and seek support when needed. The MNO aims to build on the established relationships its frontline workers have in communities and provide them with knowledge about cancer screening to be effective liaisons / cancer screening navigators for Métis citizens. Finally, the MNO aims to facilitate cancer screening in its communities by increasing the understanding of the Métis community and culture among healthcare workers.

Table 27: Recommendations to improve cancer screening in the Métis Nation of Ontario

#### 1. Support awareness and discussions about cancer screening at the community level

#### **Key Message:**

Provide information and resources to Métis citizens and communities in order to reduce fear and stigma associated with screening as well as to empower citizens to engage in screening and seek support when needed

#### **Recommendation to MNO and ICCU:**

- Develop workshop in a box for MNO frontline workers including MNO specific cancer screening information, a cancer screening facilitation guide, videos about cancer screening, cancer screening
- Increase use of Ontario Health (OTN) for discussions around cancer screening
- · Identify community champions for cancer screening
- Develop region (and / or community specific) resource guide to inform Métis citizens of cancer screening programs / services in their vicinity, the process for accessing these and other information to support navigating the cancer screening pathway

#### Stakeholders:

- Métis individuals & families
- MNO citizens & clients MNO
- > ICCU / OH (CCO)

#### **Dissemination Suggestions:**

- MNO frontline worker engagement at community gatherings, other client touch points, linked with other wellness priorities
- Screening promotion at existing MNO events
- Health Hub on MNO website
- Métis hub on CCO website
- Social media
- Métis Voyageur newspaper article

# 2. Support MNO frontline workers to provide cancer screening education and facilitate cancer screening uptake in Métis communities

#### Kev Message:

Build on the established relationships that MNO frontline workers have in communities and provide them with knowledge about cancer screening to be effective liaisons / screening navigators for Métis citizens

#### Recommendation to MNO:

• Support MNO frontline workers with training workshops on cancer screening for outreach with community members (e.g., best practices for bringing up prevention and cancer screening during broader health discussion and; how to run Workshop in a Box for cancer screening/training with cancer screening resources)

- Share existing OH (CCO) provider-focused cancer screening resources with MNO frontline workers
- Continued integration of MNO frontline workers in cancer screening support for MNO citizens and clients

#### Stakeholders:

- MNO frontline workers
- MNO staff and management
- ➢ ICCU / OH (CCO)

# **Dissemination Suggestions:**

- Email communication with MNO Healing and Wellness staff
- Healing and wellness staff training sessions
- Workshop in a Box resources on MNO staff Healing and Wellness Portal
- OH (CCO) screening courses/resources available on OH (CCO) website

# 3. Support healthcare providers to engage more effectively with Métis patients

### **Key Message:**

An understanding of the Métis communities and culture will inform how best to approach and support screening in Métis communities

#### Recommendation to MNO and ICCU:

- Develop a Métis specific slide deck with respect to cancer screening (consider seeking Continuing Medical Education accreditation or integrating into Indigenous Relationships and Cultural Awareness (IRCA) courses via a new cancer screening module)
- Support completion of IRCA courses and Métis specific slide deck

#### Stakeholders:

- MNO staff and management
- ➢ ICCU / OH (CCO)
- Healthcare providers and public health practitioners
- > OH (CCO) RICLs and RPCLs

#### **Dissemination Suggestions:**

- Continuing Medical Education days and activities
- MNO website
- Métis hub on CCO website

# 4. Improve awareness and understanding of Métis health service experience with respect to screening among research community

#### **Key Message:**

By sharing research project process and findings with broader research community, we support the development of an evidence base around equity and determinants of health with respect to screening in Métis communities. ('Sharing what we've learned' or 'Socializing the results')

#### Recommendation to MNO and ICCU:

- Develop a final research report/ executive summary, briefing deck and research project information fact sheet
- Develop journal articles and conference presentations

#### Stakeholders:

- MNO staff and management
- > ICCU / OH (CCO)
- > Health researcher community

# **Dissemination Suggestions:**

- Conferences
- Academic rounds
- Media / social media / popular press

# 5. Support policy and program development that promotes screening knowledge and uptake in Métis communities

# **Key Message:**

Improved understanding/awareness of Métis cancer screening access challenges is needed among health system stakeholders involved in policy development and program delivery. Evidence-informed recommendations are needed to improve policies and programs so that they better meet the needs of the Métis community.

#### **Recommendation to MNO and ICCU:**

 Develop resource packages (final research report/ executive summary, research project information fact sheet; MNO videos; Briefing deck/Métis 101 deck for external partners/healthcare provider) for key stakeholders, including targeted recommendations for each stakeholder:

#### o For MNO:

- Frontline staff training on screening/to support Workshop in a Box outreach with community
- Continued integration of MNO frontline staff in screening support for MNO citizens
- Use of Ontario Health (OTN) for discussions around screening
- Identifying/supporting community champions for screening

### For OH (CCO)/ Regional Cancer Programs (RCPs):

- Promote IRCS courses and Métis specific screening resources
- Develop Métis-specific screening correspondence content and delivery methods
- Integrate and streamline screening services (e.g., multiple screening tests in a visit, ensure data is shared appropriately between providers and with patients)
- Expand mobile screening options (e.g., screening coach)

#### For Health Canada and Ontario Ministry of Health (MOH):

- Integrate and streamline screening services (e.g., multiple screening tests in a visit, ensure data is shared appropriately between providers and with patients)
- Expanding use of Ontario Health (OTN) to support appointments around screening
- Expanding mobile screening options
- Improved medical transportation supports (e.g., funding to MNO to support drivers, increase to Northern Health Travel Grant, funding to support Métis specific transportation)
- Improved access to primary care providers

# Stakeholders:

- MNO staff, management, leadership
- ICCU / OH (CCO) and RCPs, Ministry of Health
- Health Canada and MOH

# **Dissemination Suggestions:**

#### MNO

- MNO KT dissemination pathways
- PCMNO
- Community councils
- MNO Citizens
- Annual general assembly

### OH (CCO)/RCPs

- CCO research day, lunch and learns, other internal meetings
- JOICC

Health Canada and MOH
Standing meetings
<ul> <li>Ad hoc meetings and presentations</li> </ul>
Policy briefings
Urban Indigenous health table
Other relevant tables

These recommendations are situated within the broader areas of individual and community level supports, improvement to the health care system, and health and social policy considerations. They provide clear direction to policy makers and will help target resources to where they are more likely to be effective in increasing screening among the Métis people of Ontario. These recommendations have informed the development of a Knowledge Translation Action Plan focused on improving cancer screening among Indigenous peoples in Ontario and Ontario Health (Cancer Care Ontario)'s <u>First Nations</u>, <u>Inuit</u>, <u>Métis and Urban Indigenous Cancer Strategy IV (2019-2023).</u><sup>18</sup>

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# **REFERENCES**

- 1. Canadian Task Force on Preventive Health Care. Recommendations on screening for breast cancer in average-risk women aged 40–74 years. CMAJ: Canadian Medical Association journal = journal de l'Association medicale canadienne. 2011;183(17):1957-8.
- 2. Canadian Task Force on Preventive Health Care. Recommendations on cervical cancer screening. CMAJ: Canadian Medical Association journal = journal de l'Association medicale canadienne. 2013;185(1):13-4.
- 3. Canadian Task Force on Preventive Health Care. Recommendations on screening for colorectal cancer in primary care. CMAJ: Canadian Medical Association journal = journal de l'Association medicale canadienne. 2016;188(5):340-8.
- 4. Cancer Care Ontario. Ontario Cancer Screening Performance Report 2016. Toronto, Ontario: Cancer Care Ontario; 2016.
- 5. Métis Nation of Ontario, Cancer Care Ontario. Cancer in the Métis people of Ontario: Risk Factors and Screening Behaviours. Ottawa, Ontario 2015 [Available from: <a href="http://www.metisnation.org/media/653628/mno-cco-report-screen.pdf">http://www.metisnation.org/media/653628/mno-cco-report-screen.pdf</a>.
- 6. Statistics Canada. 2016 Census of Population. 2017.
- 7. Métis Nation of Ontario. The Facts: MNO Citizenship 2020 [Available from: <a href="https://www.metisnation.org/news/the-facts-mno-citizenship/">https://www.metisnation.org/news/the-facts-mno-citizenship/</a>.
- 8. Métis Nation of Ontario. Citizenship 2021 [Available from: <a href="https://www.metisnation.org/registry/citizenship/">https://www.metisnation.org/registry/citizenship/</a>.
- 9. Métis Nation of Ontario. Chronic Diseases in the Métis Nation of Ontario: Chronic Disease Surveillance Program. Ottawa, Ontario 2012.
- 10. Mazereeuw MV, Withrow DR, Nishri ED, Tjepkema M, Vides E, Marrett LD. Cancer incidence and survival among Métis adults in Canada: results from the Canadian census follow-up cohort (1992–2009). Canadian Medical Association Journal. 2018;190(11):E320.
- 11. Canadian Partnership Against Cancer. Métis cancer control in Canada baseline report Toronto, Canada: Canadian Partnership Against Cancer; 2014 [Available from: <a href="https://content.cancerview.ca/download/cv/fnim/documents/metisbaselinereportpdf?attachment=0">https://content.cancerview.ca/download/cv/fnim/documents/metisbaselinereportpdf?attachment=0</a>.
- 12. Cancer Care Ontario. Lung Cancer Screening Pilot for People at High Risk Toronto, Ontario: Cancer Care Ontario; 2017 [Available from: <a href="https://www.cancercareontario.ca/en/guidelines-advice/cancer-continuum/screening/lung-cancer-screening-pilot-people-at-high-risk">https://www.cancercareontario.ca/en/guidelines-advice/cancer-continuum/screening/lung-cancer-screening-pilot-people-at-high-risk</a>.
- 13. Canadian Partnership Against Cancer. First Nations, Inuit and Métis Action Plan on Cancer Control. Toronto, Ontario; 2011.
- 14. Reading CL, Wien F. Health inequalities and social determinants of Aboriginal peoples' health. Prince George, BC: National Collaborating Centre for Aboriginal Health; 2009.
- 15. Dyck M. Social Determinants of Métis Health. Ottawa, Canada: National Aboriginal Health Organization; 2009.
- 16. Monchalin R, Monchalin L, editors. Closing the health service gap: Métis women and solutions for culturally-safe health services2018.
- 17. Smylie J, Firestone M. The Health of Indigenous Peoples. In: Raphael D, editor. Social Determinants of Health: Canadian Perspectives. 3rd ed. Toronto, ON: Canadian Scholars' Press Inc.; 2016. p. 434-66.
- 18. Ontario Health (Cancer Care Ontario). First Nations, Inuit, Métis and Urban Indigenous Cancer Strategy IV (2019-2023). Toronto, ON; 2020.