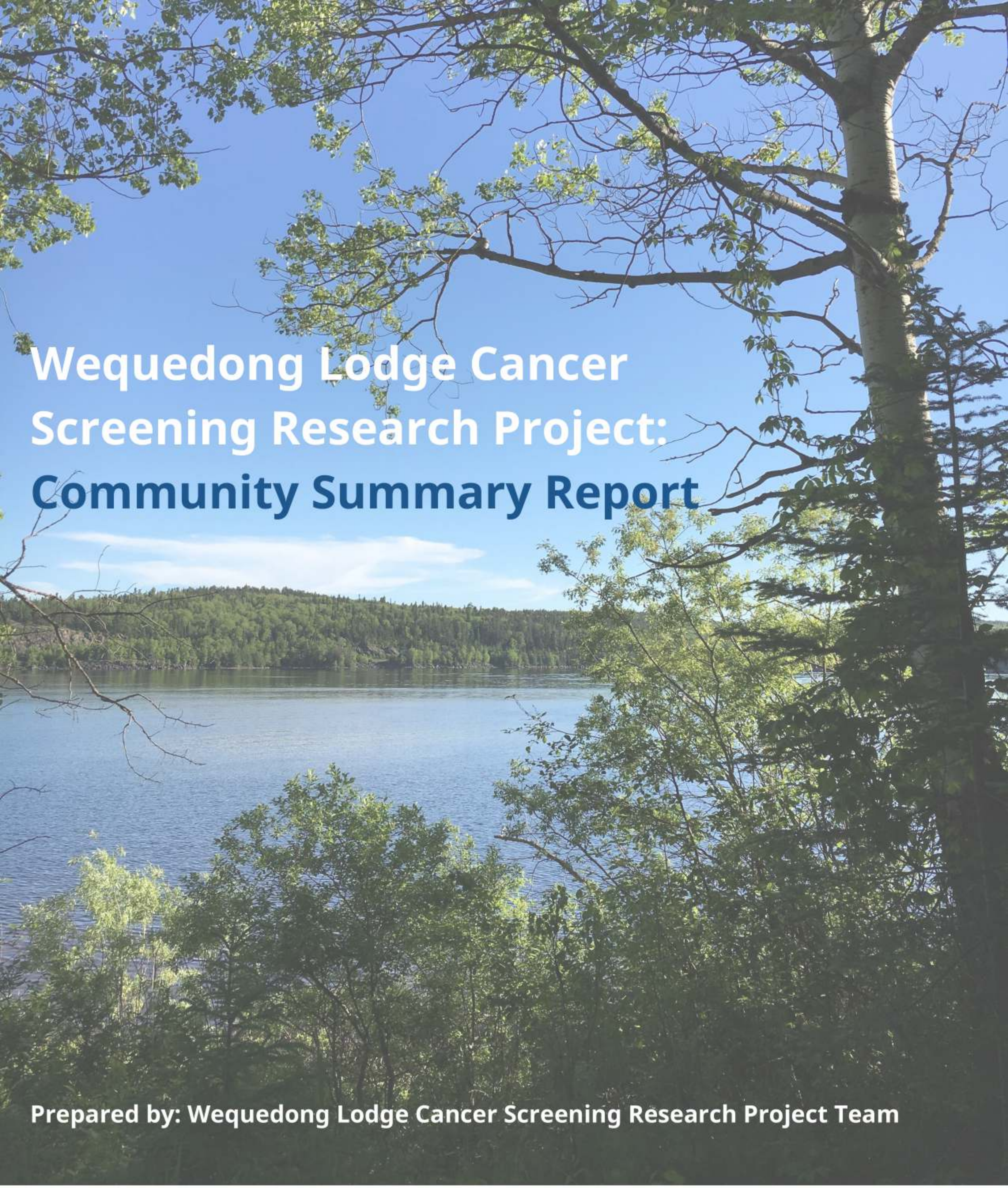


Wequedong Lodge Cancer Screening Research Project: Community Summary Report

Prepared by: Wequedong Lodge Cancer Screening Research Project Team

Wequedong Lodge Cancer Screening Research Project: Community Summary Report[1]

Background

Cancer is a growing health challenge in First Nations populations in Ontario. Research shows that the chance of getting many cancers is rising in First Nations populations and, in some cases, is higher than in other Ontarians, while the chance of surviving cancers appears to be lower in First Nations populations.[1, 2] Cancer screening is widely seen as an important strategy in addressing the challenges of some cancers by reducing the chance of getting and dying from cancer.[3-7] In Ontario, there are organized cancer screening programs for breast, cervical and colon cancer; an organized lung cancer screening program was recently launched in 2021.[8, 9] These organized screening programs aim to provide high quality screening to the entire target population in a coordinated and integrated way.[10] *However, cancer screening participation in First Nations populations in Ontario is lower than other Ontarians.*

In the Northwest region of Ontario, there is a large First Nations population and many First Nations community members live in remote communities located across the region. Among many other factors, this geographic context creates many challenges in providing health services, such as cancer screening.[11] There is a great need to better understand how First Nations communities in the Northwestern Ontario region experience cancer screening.

Project Governance and Approvals

Wequedong Lodge of Thunder Bay (WL) partnered with the Indigenous Cancer Care Unit at Ontario Health (Cancer Care Ontario) and Sunnybrook Research Institute on a research project focused on better understanding barriers to and supports for cancer screening for First Nations communities in Northwestern Ontario. As equal project partners, WL, Sunnybrook Research Institute and Ontario Health (Cancer Care Ontario) designed and ran the Wequedong Lodge Cancer Screening Research Project together, with ongoing leadership and direction from our Wequedong Lodge Community Advisory Group (WL-CAG). In line with the Ownership, Control, Access and Possession (OCAP®) principles, we developed a research collaboration agreement that makes clear that data collected as part of this research project is owned by WL, as the community partner. The WL-CAG, which included leadership and frontline staff from WL, the Wequedong Lodge Cancer Screening Research Project research coordinator, the Northwest Regional Indigenous Cancer Lead and Coordinator, guided all aspects of the project. The research team, which included the WL-CAG and team members from Ontario Health (Cancer Care Ontario) and Sunnybrook Research Institute, worked together to complete this project including developing interview guides, collecting, analyzing and interpreting data, and sharing project findings.

As an important part of the research team, the WL-CAG was actively involved in leading the project from start to finish, including our approach to asking for approval from communities and community organizations to participate in this project. Ongoing support and guidance from the Joint Cancer Care Ontario Indigenous Cancer Committee, a committee with representation from all provincial political and territorial organizations, Independent First Nations, Métis Nation of Ontario, Tungasuvvingat

---

[1] *This summary report provides an overview of the research and highlights key findings. Please refer to the* ***Wequedong Lodge Cancer Screening Research Project: Full Research Report*** *for further details.*

Inuit, the Aboriginal Health Access Centres), Ontario Federation of Indigenous Friendship Centres, Ontario Native Women's Association and other healthcare provider organizations, that provides guidance and direction for the work of the Indigenous Cancer Care Unit, was also important in shaping our approach to engaging communities.

Recognizing that permissions and approval processes are different depending on the community site (e.g., communities, tribal councils, community health service organizations), we worked with leadership at each community site to obtain the appropriate approvals for that particular site. Our engagement work was supported by the Indigenous Cancer Care Unit's regional engagement team between February 2015 and April 2016. One community organization wanted to formalize our relationship through a data sharing agreement before giving permission to invite community members to participate. We took direction from community sites and adapted research approaches and approval-seeking processes to follow community protocols. This allowed us to engage in a respectful, community-directed way.

In addition to community-based approvals, we obtained research ethics approvals for the project from the Sunnybrook Research Ethics Board, University of Toronto Research Ethics Board, and Health Canada and Public Health Agency of Canada Research Ethics Board. The research project was governed by the Chapter 9 of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – Research Involving the First Nation, Inuit and Métis Peoples of Canada*.

Research Objectives and Approach

This community-based research project aimed to explore how First Nations community members in Northwestern Ontario (NWO) actually experience cancer screening, so that we could identify and address the gaps in Ontario's cancer screening system that community members are experiencing, and how to address them. To meet this objective, we used a qualitative research approach and completed in-depth research interviews with three different participant sample groups:

1. First Nations community members
2. Community health workers (health directors and community health representatives)
3. Primary care providers (physicians, registered nurses, nurse practitioners)

We chose these three groups to provide different important perspectives on cancer screening in NWO. Within each sample group, we also selected participants whose perspectives on screening were expected to be different, to try to understand the diversity of screening experiences more fully. This included participants who lived in, or worked with, communities: from different geographic locations within NWO (north of Red Lake, mostly fly-in communities; south of Red Lake, mostly communities with road access)[2]; from different political territorial organizations (PTOs – Nishnawbe Aski Nation (NAN), Anishinabek Nation-Union of Ontario Indians (UOI), Grand Council Treaty #3 (GCT#3), and Independent First Nations communities); with different identity groups (Ojibway, Oji-Cree and Cree) and communities of different population sizes.

---

[2] The research team used Red Lake's geographical position (51°N latitude) to create a dividing line between north and south, throughout the NWO region. Most communities in the 'north' part of the NWO region must be accessed by flight or by winter roads. Most communities in the 'south' part of the NWO region are accessible by road and ferry.

We developed a different interview guide for each of the three participant sample groups. Interview guides focused on understanding participant understandings of, and experiences with, cancer screening. The guides were revised over several months, and then piloted with community members, community health workers and primary care providers to make sure they were clear and relevant; they were changed as necessary before interviews were started.

Community member interviews were led by the Wequedong Lodge Cancer Screening Research Project research coordinator, a multi-lingual First Nations woman from NWO. Participants had the option of completing the interview in the language that they felt most comfortable in. Twenty-nine community members participated in an interview (21 interviews completed at WL and eight interviews completed at five community sites). All but two community members chose to be interviewed in English. Community health worker and primary care provider interviews were completed by a member of the research team who has a lot of experience with Indigenous health research and leading in-depth research interviews. Interviews with nine community health workers from 6 different communities and 10 primary care providers from five different health service provider groups/organizations were completed in English.

In addition to the community approvals, we also received individual informed consent from all interview participants. All interviews were audio recorded and notes were taken. Interviews lasted between approximately 30-90 minutes. Participants were recruited on a rolling basis between May 2015 and July 2016. Data collection ended when the sample groups were well represented with participants and the research team agreed that limited new information about how cancer screening is understood and experienced was learned from additional interviews.[12]

Data analysis was done collaboratively by the research team. Once we came to an agreement about the initial research results, we presented them to, and discussed them with, seven of the community sites that had participated in the interviews, including all five communities and community organizations where the team had travelled to do interviews. We also presented and discussed initial research results with other community and health service providers groups (e.g., Joint Cancer Care Ontario Indigenous Cancer Committee, health service providers working with First Nations communities in NWO, Indigenous healthcare providers and community health workers throughout Ontario).

For each community site, we approached the community health leadership who had supported participant recruitment and asked how they would prefer to review and discuss the initial results. The review sessions varied from, for example, a formal presentation and discussion with Chief and Council or leadership, to an open community presentation and discussion, to attendance at a community health fair. Detailed notes were taken throughout the community review sessions. Data were re-examined based on some points raised in these sessions to make sure that key factors had been fully understood and explored in our analysis. Instead of altering the analysis, these sessions increased the research team's confidence that project findings had accurately represented key perspectives on, and experiences with, cancer screening among First Nations communities in NWO.

Results Summary

Project Participants

An overview of the three participant sample groups is included in *Table 1*. The 29 community member participants were from 19 different NWO First Nations communities, mostly in remote areas north of Red Lake, Ontario. Nine community health worker participants were from six different NWO First Nations communities, covering all three PTOs in the NWO region. Among the 10 primary care provider participants, there were four physicians, one nurse practitioner, three nurse managers and two nurses. The primary care providers worked with communities throughout the region, which were associated with all regional PTOs.

Context – Community Perspectives on Health and Cancer

To provide better background understanding of First Nations community members' perspectives on cancer screening, we asked participants about how they think about health and cancer more generally. Consistent with common Indigenous understandings of health, community members described

Table 1. Overview of participants

	Sample 1 – First Nations Community Members	Sample 2 – Community Health Workers	Sample 3 – Primary Care Providers
Total number of participants	**29**	**9**	**10**
Location within NWO*			
North	22	3	5
South	7	6	5
PTO*			
NAN	14	1	4
GCT3	2	2	2
UOI	5	4	3
Independent	3	2	1
No PTO affiliation - urban	5	0	0
First Nations Groups			
Ojibway	13		
Oji-Cree	15		
Cree	1		
Age			
21-30	2		
31-40	4		
41-50	5		
51-60	10		
61-70	5		
≥71	3		
Gender			
Women	20	7	7
Men	9	2	3
Role/Occupation			
Health Director		3	
Community Health Representative (CHR)		5	
Other community health role		1	
Nurse			2
Nurse Manager/Nurse in Charge			3
Nurse Practitioner			1
Physician			4

**For Sample 1, refers to place of residence. For Samples 2 and 3, refers to place of work. The research team used Red Lake's geographical position (51°N latitude) to create a dividing line between north and south, within the NWO region. Most communities in the 'north' of the NWO region must be accessed by flight or by winter roads. Most communities in the 'south' of the NWO region are accessible by road and ferry.*

health in terms of their relationships with their family, friends, community and environment. Being healthy meant having strong positive relationships, taking care of oneself, feeling good and being able to live as one wants. Many community members also noted that eating healthy food, being active, and spending time out on the land and engaged in traditional activities (e.g., hunting, fishing) made them feel healthy. In addition to these positive understandings of health, many community members also spoke about health as the absence of disease.

There was a strong sense among First Nations community members that cancer is common in communities in their region and that there is a lot of fear about cancer, because it often results in death. Many participants shared stories about friends and family members passing away from cancers that were caught too late for effective treatment. One participant shared that:

> "a lot of people get it late, you know, where we come from – the reserves…[a] lot of people get it in when it's already in the late stages, and most people die…. Almost everyone that I've known or heard about that gets diagnosed with cancer, it's already spread all over." (CM6)[3].

Many community members also expressed a lot of fear around cancer and the sense that the whole community feels the impact of cancers among community members.

> The emotional toll of cancer on communities was explained by a nurse who was also a community member – "most families will keep quiet until it's, they're in palliative state and they go home and that's when the whole community feels it..." (PCP5).

Other participants explained that cancer was sometimes kept secret in communities, in order to spare others the pain of the experience. As one community member explained "… the person that may have cancer may not want the family to know what it's about…So that they don't have to go through the same thing." (CM3).

When asked to share what they knew about cancer and where it comes from, many community members explained that behavioural-lifestyle factors (e.g., eating habits/access to healthy food, physical activity, smoking) and damage to their physical environments, noting pollution and toxins in the water, local plants and animals in particular, impact their cancer risk. In line with the wholistic ways of understanding health shared by several community members, some participants explained that cancer was the result of being out of balance in one's life. Some community member participants felt that too much stress, trauma and negative emotions were linked to cancer. A community health worker who was also a community member explained that: "[we] don't have time to get over a death, and the next one happens…that takes a toll on your body…that's how we get these diseases…It's how we deal with our stresses and griefs." (CHW5). Another community health worker, who was also a community member, used the Medicine Wheel to explain cancer:

> "…our Medicine Wheel… keeping that balance and, you know, how cancer can… if we don't take care of our physical, how cancer can set in… if we don't have, like, a good mental or emotional

---

[3] Participant codes are used throughout the report to replace the name of the participant and protect their right to privacy. CM refers to community member; CHW refers to a community health worker (health director or community health representative); PCP refers to a primary care provider (nurse, nurse practitioner or doctor). Other acronyms in participants quotes include community health representative (CHR) and community health nurse (CHN).

> outlook on everything, you know. And all the stressors, you know, how that can affect any kind of sickness… not just cancer, but anything, you know?" (CHW6).

A few community members offered perspectives on cancer that had been shared with them by their Elders. One community member shared that: "In my language, 'ga-moog-gwi-ang' means 'the eating disease'…It eats you inside out. That's, that's what they call it." (CM1). Another community member's Elder referred to cancer as "a bug…because he said it eats away at you" (CHW5). Several community members also shared traditional and spiritual approaches to managing or treating cancer.

Overview of Main Results

Key Factors Impacting Cancer Screening Perceptions and Experiences among First Nations communities in NWO

Our analysis of the 48 in-depth research interviews with First Nations community members, community health workers and primary care providers identified six key interconnected factors that affect the ways that First Nations community members understand and experience cancer screening in NWO:

1. Basic *life circumstances and competing priorities*
2. *Relationships* between patients and healthcare providers
3. Cancer screening *knowledge and awareness*
4. *Attitudes* and *feelings* about cancer screening
5. *Access* to cancer screening services
6. Cancer screening *processes*

Participants explained that ***basic life circumstances*** and competing physical and mental health priorities make participating in cancer screening difficult and a low priority for some community members. Participants explained that ***poor patient-provider relationships*** are also an important barrier to screening. They identified many issues that harmed these relationships: lack of cultural competency, poor communication and discriminatory behaviours among healthcare providers; healthcare provider turnover, staff shortages and limited time with patients; and power imbalances that limit patient voice and make it difficult for them to play an active role in their healthcare experience. Participants described ***limited knowledge and awareness about cancer screening*** among community members and providers, linked to limited and ineffective education strategies and poorly targeted screening education resources. They also explained that many community members have difficulty talking about personal health matters, which makes cancer screening education among community members challenging. Commonly held ***attitudes and feelings*** about screening among community members, including fear, avoidance, discomfort and distrust, were also often described as barriers to cancer screening participation.

Participants described ***challenges in access to screening***, which focused on limited availability of healthcare providers and screening tests in communities. They also identified many challenges with the travel needed to complete screening tests, including the danger and disruption of travel and discomfort in larger urban areas where screening services were available. Non-Insured Health Benefits (NIHB) travel policy, which participants explained does not support a patient-centered approach to care, and the lack of clarity and consistency in the way the policy is put into action, were also identified as key access barriers. Finally, many overall and cancer ***screening step- specific process challenges***, including poor coordination and data sharing between providers involved in cancer screening, were identified as barriers to screening participation.

These factors are outlined in *Table 2*, along with a few participant quotes that help to explain the barrier-related themes. For more details and participant quotes, please refer to *Wequedong Lodge Cancer Screening Research Project Full Research Report*.

Table 2. Key factors that affect cancer screening experiences among First Nations community members in NWO

Key Factors	Selection of Participant Quotes
1. **Basic life circumstances and competing priorities** • Cancer screening not seen as a priority when struggling with socioeconomic inequities and competing health issues	"…we're used to, uh, being in crisis all the time and acting in crisis mode. Behaving in crisis mode. It's hard to go into prevention mode because we're busy dealing with all the crises and all the details that go with crisis." (CHW6) "I have patients that…[tell me]… 'I don't have running water and you're asking me to do something [screening] that might cause a problem in ten years?'" (PCP8) "If it happens that their life already is chaotic, they have, maybe they're not working, they don't have food for their children… they have huge bills and there's domestic abuse, things like that in the home, I think it's really hard for them then to focus on something like a mammogram…" (PCP3)
2. **Relationships between patients and healthcare providers** • Lack of cultural competency, poor communication and discriminatory behaviours among healthcare providers • Provider turnover and limited time with patients • Limited patient voice or agency in health care decisions/processes, including about cancer screening	"Yeah, that's how it is over there. Sometimes if you get sick, you get worse 'cause they don't really do, do anything right away…You have to wait and wait. In the community, I know some people get worse… can't do anything about it. That's how it is in northern communities." (CM13) "…medically speaking, sometimes vital information gets lost in translation… we had an Elder who was diagnosed – not diagnosed – but who was found to have, um, an abnormal test. Now what happened was this person who translated, this person told them…the way the Elder understood it was, 'you've got cancer, you're going to die'." (CHW2) "Well, they don't go through each test results, right. They kind of just tell them, 'everything's okay'. Or if they just tell them, abnormal…Like, if there is an abnormal value or something, then they'll just tell them what's wrong. But they don't go into full detail." (PCP1) "[T]he nursing station, you go over there and tell them you've got a headache, or whatever you say. They say, 'take aspirin, go home'. Next thing you know, a couple of months later they tell you that you have three months because you've got cancer… sometimes they don't want to go to the nursing station because they don't trust people over there." (CM5) "… one of our challenges is, it's always that… it's so difficult to recruit physicians, nurses…people often don't stay for a long period of time…so that's…recruitment and retention... relationship is so important… [a]nd that takes time… I've known [my patients] for ten years and they're only now just getting comfortable to tell me certain things… it's not a short-term thing." (PCP8)

Key Factors	Selection of Participant Quotes
	“I didn’t know and yet I was, I didn’t really understand everything because I didn’t want to be a burden to other people saying, ‘I don’t understand, like, what does that mean?’, you know?”(CM16) “And, uh, if the community doctor feels that I need to go out she’ll make an appointment. If she doesn’t I won’t be able to go. Yeah it’s hard to get an appointment out there…But if you think that you need to get a screening done yourself…You know, it doesn’t work like that.” (CM9) “I mean, it's the legacy of colonialism, even if I don't tell them they've got an appointment, if I don't see them, say I saw some result, like, oh a family member has confirmed colorectal cancer and I decide to send all the family members, people would just go. Like, most people wouldn't even ask why. They'd just say, ‘Oh, I have an appointment? Okay.’ And they'll go.” (PCP9)
3. **Cancer screening knowledge and awareness** - Lack of knowledge and awareness about cancer screening among community members and providers - Limited and ineffective education strategies and poorly targeted screening education resources - Difficulty talking about personal health matters, including cancer screening	“I don’t think there’s much information. Just probably only these, like, just pamphlets- type things that are in...like, nursing station clinics. But, I don’t know of anywhere else. Like, not, like, where you could actually go in and ask for advice, or even resources, or what to do. I don’t know any of those kinds of things on reserves.” (CM23) “Come to our communities and promote their program, provide the education…if they wanted the CHRs or CHNs [to support] screen, then they should be coming, you know, come and teach us…Come and show us what to do. So we could share [with] the people who are possibly in that range for screening and then start tracking them…” (PCP5) “We used to have a regional CHR coordinator in Ottawa…She had the information…she would have a tape or a pamphlet or something…But that's not happening anymore…right now there is no place I can go to, to pick up information on cancer. [CHR coordinator role] just disappeared.” (CHW1) “At this point. Sad but true… There’s just not, um, there’s just not enough manpower to get it all done…Ideally…when we’re up to a full, stable staff, that’s, you know, it’ll be a lot easier to do more radio shows, more education, possibly even doing workshops here, where that’s what we do for the afternoon.” (PCP7) “…I think the follow up [after a community member gets a screening letter from CCO] is where we need to…or the encouragement or support. That's a big area that we talked about here that we need to work on.” (CHW6) “… they can’t read the pamphlets, you know, it’s over-their-head… I get pamphlets in, and the words on there, like, ‘oh my God, they’re going to be Googling forever trying to find these words out.’ It has to be at their level. And I find none of the education’s at their level. And none of it’s in their language. You know, they’re more fluent here in their own language than English...” (PCP2) “It’s something that’s not talked about, you know? That, like, that sexual part of a person… when I was a kid, my mom never talked to me about that….It was my grandmother who did the explaining when I got my period; I stayed with my grandma... it was supposed to be like that a long time ago. It was, like, the grandmothers that took care of you. Like, even that’s lost…It’s not there anymore because of the language barrier, too… like my mom, she can’t even talk to my 14-year-old and my, um, 9-year-old because, well, they do understand but

Key Factors	Selection of Participant Quotes
	they just can't speak…Ojibway back to my mom, so that's really…It's hard for my parents." (CHW5) "I think that's a, an intergenerational thing. I mean you look at the '50s, the '60s, they would talk about cancer, it was like: 'Back! You know, I'm gonna catch it!' and whatever else and all the negative attitudes…Yeah, myths linger…It's OK, we're working on it…We'll get there, you know? It's not something we can just change overnight." (CHW3)
4. **Attitudes and feelings about cancer screening** - Reluctance to participate among community members due fear, avoidance, discomfort and distrust	"…most people, they prefer not [to] know if they are sick especially with cancer…. well I know some people that are feeling healthy don't want to get screened because even then they are afraid to hear any kind of negative results..." (CM27) "But I mean, you know, people, if they don't see it, you know, then there's nothing wrong. Or if you don't have the symptoms then there's nothing wrong." (PCP1) "Well, if somebody is scared like me…When they told me to [get screened], or something, very clearly. I just, I don't go. I didn't understand why, why he called me to go over there. Maybe I'm not going in. I have to know first." (CM10) "I think they're kind of shy about their bodies….I know I was but… I still went and did all that stuff for breast cancer. I think because of their shyness. They don't want to show their private parts." (CHW8) "you have to be cognizant of that, right?...you know, the rates of past sexual abuse are astronomically high. Um, and residential school abuse and other things that that can be a barrier for a number of people." (PCP8) "…you feel like as if everybody's looking at you. 'What if that other patient knows why I'm here?' …That's what prevents most ladies from coming, is…I don't know. Stigma, I guess. 'They're, they're going to know what I'm here for. They know that I got probed'…" (CHW5) "… certain policies put in place, that that serves as a barrier for people to accessing care…it sends a message to the population…I've had a number of times where I…you don't get escorts out for that appointment because the, the reason isn't enough of a medical justification...you start believing that that's how healthcare should work...like healthcare is not something that you feel comfortable with. It's something that's always uncomfortable. It's not something that, that can make you healthier, it's just something that brings uncomfort…" (PCP8) "the older women… most of them, they don't want to get tested because of what they went through in life…like…because if, uh…when somebody abuses you, you don't want people…you don't even want anybody to check you up…" (CM22) "Well, I mean, the sexual abuse, for years, I used to do a ton of 'Well-Woman' visits and Paps and deal with women who have been sexually assaulted and having a pelvic exam is very traumatic. And it can be…or the woman dissociates during it and… goes back to [the trauma] …the higher percentage of child sexual abuse and sexual assault that women, and men have experienced." (PCP9)

Key Factors	Selection of Participant Quotes
5. **Access to cancer screening services** • Limited access to screening in communities • Challenges with travel for screening tests (e.g., danger and disruption of travel, discomfort in larger towns/cities) • Non-Insured Health Benefits (NIHB) program-specific challenges	"Probably the nurse… a doctor [comes] very, once a month. And if the doctor comes in the community, the doctor's got a list to see…If you're not on the list that means you're not going to be seen in that visit. That's what's happening there." (CM13) "I mean it's really hard to get anything done on the reserves. So, basically, that's the biggest barrier. I mean, like, they don't offer it. They just have the nursing station and if you're sick you go in and get checked up." (CM6) "[O]ur nurses can't get the extended scope practice because we're so close to, they have a Norwest in [town name]. If we weren't close to… you have to be so far from a primary care facility…For us to have the extended scope so we can do those duties like Pap…And all those other kinds of things." (PCP5) "Probably in the last couple of months, we've slipped [with cancer screening] because we haven't had the staff….Too few nurses, too many male nurses, so…Not that that's a problem. I mean, they're great, but then I haven't had full staff, so we're just managing day to day." (PCP7) "…they have medical [van]…. But uh…[the] driver has limited... passengers on her vehicle…Even though she goes back and forth from time to time. The town flow is not very accurate. I mean, like it's slow….they have no time…miss appointments, in other words. Because of lack of…[space]…on the medical van…it takes time to reschedule" (CM28) "the people are worried about where they are going and where they'll be staying they get worried about leaving home and not comfortable having to leave for appointments…" (CM27) "…that's what the First Nations get right away. There's lot of that that comes in with healthcare so I think a lot of them have been used to not saying anything… a lot of them do see it as a burden having to come out of their communities because it's out of their comfort zone, they know they're going to be mistreated when they get over there so they, they, they just, you know like, 'I gotta go in again?, you told me I had to go in for this screening, ugh!'…I think it's just how they're treated when they get there… when they come in for the screens…"(PCP5) "So, like, if you're an Elder or if you're getting put to sleep, then you require an escort…And that's the only way. Like, you can't have someone there just for support." (CM25) "Like, for mammogram, unless you have bad arthritis and, you know, using a walker or a wheelchair. Then for a mammogram, you're on your own….I've had people who wouldn't go out because they couldn't get an escort." (PCP9) "And then my patient refuses to go. And then, if she refuses to go, then they won't book it again. So, Non-Insured takes that as 'No, you had an appointment. You chose not to go. You refused. We're not going to pay for your travel.'…We, we have to go through another whole process of arguing and fighting and saying, 'Oh, well, she's always gone to this doctor. She's more comfortable with…'. It doesn't matter." (PCP2) "…the people who are assessing that are not medical people… they're not regulated by any sort of college …they're given training by Health Canada but they're not regulated by any

Key Factors	Selection of Participant Quotes
	sort of…medical body or medical association…[But they are m]aking [medical] decisions...” (PCP8) “As long as Non-Insured is in control there is no easier way of doing it…There will always be the nightmare of dealing with Non-Insured. They’re not very, very, uh, supportive, receptive, [to] our way. There is no other way.” (CHW2) “I was, I was supposed to go for that [breast] screening this week…I went…But that had been canceled…And they rescheduled it to April. But nobody told me here, so I went… for nothing… I went to the x-ray department…They don’t have a, a lot of reliable communication with the nursing station to the hospital, I don’t think…Yeah. They should’ve known that they, they have to let them know early, because my, my flight is booked for the day before… my appointment was canceled, but they didn’t cancel my, my flight….And then that, and then you get blacklisted… They should know these things.”(CM22)
6. **Cancer screening processes** • Poor coordination/ communication and data tracking/sharing among providers involved in cancer screening • Discomfort and difficulty completing the screening tests • Inconsistent and unclear communication of test results • Confusion about follow up steps	*Overall process/integration challenges* “community health nurses are outside of the [Aboriginal Health Access Center]. I don’t know what their role and whether they look at prevention, preventive care but...Those roles often turn over fairly quickly…so there’d be an RN that would be associated with, you know, one of the reserves, that they’re there for blood pressure screening, questions of how to access care, so I’m not clear what their role is...And then whether they see prevention or cancer detection as part of their role, I don’t know.” (PCP4) “…who's job is it to keep track of all this stuff and come back to it?...I mean, it's m[y job], I assume, but I don't feel like I have the system support and the skills to do it at the moment. Like, and the staffing that it would require.” (PCP9 - physician) “… between the government and the band…It’s kind of like, they have different funding than us, and…We can’t use their funding, they can’t use ours. So, we try to kind of sneak through the process.” (PCP2) “The problem is, it all takes time to do the education. And physicians are not really given time in their 7 minute appointments to do any teaching whatsoever… physicians don’t tend to do it...[be]cause they’re not funded to do it. They’re funded to see as many patients as they can, it doesn’t matter about the quality of the care they provide…[The health organization is] really worried about the numbers. They don’t understand about acuity and all of the challenges that many of the patients have…many of the patients I do see, have multiple complex issues, and, education is the secret to work around all those challenges...And education takes time so, we’re now pushed more for numbers…we really, have to be sensitive to where the patient is at that moment, and not be looking just at numbers…they’re not cattle.” (PCP3 – nurse practitioner) “I think it would have to take...the leadership, our health authorities, like our health directors to be involved more [in running nursing station].” (CHW5) “…I think a lot of problems that we have would be solved if we were given that…give us the opportunity to do the things that we need to do to make it work… for example, this cancer thing. You want to make it work, work with us. We have an equal partnership in it. That’s the only way it’s going to work. Just because it works down in southern Ontario doesn’t

Key Factors	Selection of Participant Quotes
	mean it’s going to work here. Like I said, we do things differently but yet the result is the same. But there is a sense of being an equal partner is what makes it work. Don’t come in here and say, okay, here’s your cancer screening program, this is how it’s going to be done.” (CHW2) “…I need to get a list of everybody who hasn't been screened. So there can be some targeted interventions for those people…We have no way in our EMR [electronic medical record] to, kind of, easily pull that data, that's the problem….[we need something that] kind of triggers the discussion…That's not there.” (PCP8) “When I see that the mammogram is normal, I will flag in the EMR [electronic medical record] that in two years’ time they need a new one…And in two years’ time there’s a system in my…the way I flag it is that in two years’ time it will come up that I need to reorder the mammogram…But you have to input it yourself. It’s not automatic…So, the only way it works well is because I’m diligent about it, right. If I wasn’t diligent there would be no record…There would be no way of it coming back up.” (PCP10) “Like, if it’s just for a regular screening…Um, to be honest, I don’t know how often [routine screening has] happened…I honestly don’t know… I have no idea…[how often patients complete the FOBT kits the nursing station distributes]. I know I’ve seen some results coming back, so I know we’re getting them back. Yeah. But I have no idea how many …” (PCP7 – nurse in charge) “But, I don't know, honestly, how often those letters are getting to people, and I haven't had anybody come in and say, ‘here's the letter. I'm due for my mammogram,’ right?” (PCP9) “[Community health nurses don’t have access to past screening records]… that’s why I said we rely on the CHRs in figuring out who’s, who’s potential in that age group, kind of thing. But unless the client shares that information, you know, the nurse goes the extra step, ‘well when do you need to be screened again?’…It would be nice if they would tell our nurses here in saying, ‘OK you’re at [health team name], is it OK if we send it to your community health nurse, you know, kind of thing?’…And then at least the nurse can go and say an educational part of it too and tell what their follow up, what that means… If we were involved we would ensure they see follow up with the doctor, they follow up with somebody…” (PCP5) “We’re not allowed to due to the Privacy Act. We’re not allowed to do that…So that could be the big stumbling block about letting us know and then talking to them.” (CHW3) “The communication between the health care provider and say, the nurse…say, their family doctor and then myself trying to…there’s no communication there at all. So, and if they’re not effectively relaying, like, healthcare communication, then there goes something that could fall between the cracks, you know? Then I wouldn’t be…I wouldn’t know about it unless [the patient] told me.” (PCP1) *Difficulties with specific parts of screening process* “They’re not treated with a friendly face, they’re not treated with, you know, ‘how are you today?’ and if it is a mammogram or anything like that, they’re very rough with them and, you know, First Nations are very private about their bodies, kind of thing, so it’s very hard

Key Factors	Selection of Participant Quotes
	when they say, you know, when my mum went for her first mammogram, my mum says she felt like she was raped [chuckling]. She was so rough, she didn't explain that she was going to do that to her…She said, she's pushing me harder, my breast against the [machine]…She said, 'I was embarrassed cause I felt dirty, I felt ashamed after' [chuckling] and…So it was, it wasn't a very good experience, kind of thing." (PCP5) "that did the Pap [laughing]. It's kind of embarrassing when a guy doctor does it… Pap test was very embarrassing….Gross. Well, I'm being honest." (CM18) "[N]o results were given to me, I don't understand why they do test and people don't get results back..." (CM27) "Sometimes or it can get missed and then, then you call in and get, oh it's OK, don't worry about it. And meanwhile you've been on edge for like, you know, waiting…Sometimes they have to call and get it and that's not good, especially if it's negative because then you feel like nobody gives a crap." (CHW3) "Unless they call me and say, you know, 'What was the result?' I'll tell them then, but…I should, but there's not enough hours in the day to call every single person about their labs. There's just not. There's not enough manpower." (PCP7) "So, I think we could really improve on increasing accessibility of the screening and the results of the screening; so it's not just doing it, cause there's, so the other, the hard stuff, behind the scenes, is the getting the results and sharing it with the patient and making a plan of what to do next." (PCP3) "At that time the nurse said, 'oh it's abnormal' and then she says, 'oh mostly these Pap tests are abnormal'… So I kind of figured it wasn't a big thing until later on when the doctor told me, 'OK your numbers are growing and we'll have to do a biopsy.'...And I finally started doing my research on, like, the procedure, what will be happening, like, what to expect...[the nurse] made it sound as if it was nothing, like, everybody has this...when they said that 'you have to do the biopsy' that's when it finally hit home… I'm thinking, like, do I have cancer, like you know?" (CM16) "I was kind of scared when they, you know, when they told me, when they sent me a letter saying that I have to go in and get another test." (CHW8)

Supports for Cancer Screening Participation among First Nations communities in NWO

Our analysis also identified many ways to address or improve these factors to better support participation in cancer screening in First Nations communities in NWO. Key groups of supports that address one or more key factors that make cancer screening participation challenging are summarized in *Table 3*. Taken together, these supports can be grouped into the following broader themes:

- addressing underlying determinants of health;
- improving cultural safety of cancer screening services (patient-provider interactions, service integration, navigation/supports);
- improving access to screening (offering community screening options, travel supports, NIHB program changes); and

- supporting community screening education and discussion.

Participants explained that support with underlying ***determinants of health***, including the intergenerational impacts of colonialism, would be needed before some community members are able to consider participating in cancer screening. There was a strong focus on improving the ***cultural safety of cancer screening services***, including the capacity for healthcare providers to interact with community members in culturally safe ways and shifts in the way that screening services were provided that would support culturally safe healthcare visits. They suggested, for example, improving healthcare provider staffing levels and integration in communities to allow for relationship development between community members and providers, and offering screening navigation supports.

Table 3. Supports that address key factors serving as barriers to cancer screening participation among First Nations community members in NWO

Key Factors / Supports	1 Competing priorities	2 Relation-ships	3 Knowledge and awareness	4 Attitudes and feelings	5 Access	6 Process
Address underlying determinants of health *(e.g., support community self-determination; enhanced resources to deal with socioeconomic challenges; create socioeconomic opportunities in communities; provide supports to contribute to underlying healing that could make screening feasible)*	x	x	x	x	x	
Enhance cultural safety in patient-provider interactions *(e.g., effective communication; supporting patient voice)*		x	x			
Improve health system capacity to support culturally safe interactions *(e.g., increase consistency and length of time in clinical encounters; support space for relationships and shared decision making)*		x		x	x	x
Improve coordination of providers supporting screening and screening processes *(e.g., clarify respective roles and collaborate; integrate screening data/tracking to avoid patients falling through cracks)*					x	x
Improve navigation supports throughout process *(e.g., First Nations screening navigators; support from family/friends)*				x		x
Improve access to screening in/close to community *(e.g., mobile screening options, extended scope of practice for nurses; reduce need for travel via integrating screening with other medical trips; improved use of telemedicine)*					x	x
Improve support for travel, when necessary *(e.g., address NIHB challenges; additional funding supports for screening)*	x				x	
Culturally relevant prevention and screening education approaches and resources for community members *(e.g., rooted in community; visual; encouraging)*			x	x		
Support community discussion about screening *(e.g., screening community champions, encourage family/friend/Elder conversations to help normalize)*			x	x		

Note: 'x' and dark shading indicates a key factor (1-6) that is addressed by the support noted by row.

Participants also proposed supports that focused on ***access to cancer screening services***. These included making screening more easily available in communities, reducing the need for travel, and improving support for travel when it was necessary (e.g., changes to NIHB medical transportation policy and implementation). Finally, participants suggested that ***improving awareness about cancer prevention and screening*** was needed and that education efforts should include community knowledge and values, support community discussion about cancer screening, and involve community screening champions.

Table 4 outlines each of these themes with a limited selection of participant quotes. For more details and participant quotes, please refer to *Wequedong Lodge Cancer Screening Research Project Full Research Report*.

Table 4. Key supports for cancer screening among First Nations community members in NWO

Key supports	Selection of Participant Quotes
Addressing underlying determinants of health • support with challenges linked to intergenerational impacts of colonialism	"…I've seen people with very dysfunctional lives before, and it's like, within a blink of an eye [through the Suboxone program], their lives are so much better now…you know what increased our cancer screening rate? Treating people's addiction." (PCP8) "…now that they're in recovery, they're starting to recognize other things that are going wrong, kind of thing… so, they, kind of, make referrals to do…get more tests done. Or, uh, they [get] referrals to other doctors for whatever issue is going on… They're managing, like...I don't know where our community would be right now if we didn't push the issue of Suboxone…It's a management tool, and it's stabilized our community." (CHW6) "I think our best educational modules are going to fail…in some places and with some people, until there's more healing. So, some of it is just acknowledging to a person, 'okay, you're not ready to discuss this now. This isn't of interest to you. When can we come back to this?'" (PCP9)
Improving cultural safety of cancer screening services • Cultural safety in patient-provider interactions (e.g., effective communication, developing trust over time, shifting control to community members)	"…you have to really… take a step back and understand… we always talk about, in medicine, getting the history, but sometimes it's more important to understand people's stories… what is their… shared, collective experience? …what is that individual experience…like, you have to do that listening phase… As physicians and health care providers we always have an agenda… But we always have to take a step back for a moment and listen...if you come on too strong then it's going to be like, 'whoa, okay, you know, I'm not doing this'...I find, if you take that time to understand that experience… then you, kind of, learn some ways in which to bring things up… And it took me time to do that…Because you have you have all the evidence and you have all the best practices and you're kind of like, I want to do this…but it's kind of like, well, do you even know, like, what the experience of the people here in the region are? …how that can impact actual health outcomes, right? Are we taking that time to sort of listen…?" (PCP8) "I'm sure culture has a lot to do with it. Like, I've been told going in there when I first started, [as] an Aboriginal nurse, we've never had one here. So, that plays a lot in it. And I'll go in and I'll talk to them. I don't have my form and go what's this, what's this. I have a conversation. I get to know them, you know…We go off on tangents all the time. Just so that they know that I'm not only there just for whatever is on that piece of paper that I have to ask, right? … And not going in with, like, a presentation. Like, you know PowerPoint. It's the one-to-one contact, a conversation. That's what's most wanted." (PCP1)

- Culturally safe health service delivery models (e.g., greater and more consistent access to providers; supporting confidentially/privacy in screening process; team-based approach) - Navigation and screening supports	"I guess if I know more about the actual procedure, what's going to be happening." (CM16) "And we have to make that easier transition for them. Maybe the doctor comes out and talks to them at the house? Or they call one of us and said, bring them in and talk and, you know. I think that would be easier than a phone call. It's like if you've got someone off at war, right? As soon as you hear the knock at the door and they say, 'we, we regret to inform you'… well you automatically go into shock. Same thing over the phone, right? You haven't got [any]body sitting in front of you talking so I think, I think that needs to be handled better…More gently, you know? …And you're left dangling and sometimes you don't get your appointment for a week or 2, right, so it's like…" (CHW3) "I think the other ones will get there but it's just, it takes time [to warm to the idea of screening]. And I know what it is with First Nations but it just takes time. I think it's a lot of, you know, just seeing it and figuring it out for themselves, kind of thing. Over time, well even though time could be a factor for some families we, we still have to, to respect that… they don't want to jump in right… they keep listening, understand a bit more… Eventually do it. They're like, 'oh that's it? OK, well I'll come back again'…[it's a] culture of just… taking time to do things. You know the expression 'Indian time' doesn't mean being late but it just means taking time. Like, Indians, they take time to, you know, I just don't rush into anything…I got to think about it.'" (PCP5) "… with my parents I feel like I have to be responsible to go with them to all of their appointments in the community, like, even with, same with the nurse. The nurses are better, they take time…Some of them, they do take time and talk to the person but once I go, go the doctor's offices, like, when he's there, I have to be there and I'm the one that has to voice their concerns." (CM16) "I think if there, you know, there were regular meetings with the wellness worker and the physician and the nurse in charge and the CHR, you know, you could…we could become a wellness screening team machine. You know, like we could really set that as a priority and say, okay, you know, how…where will we focus this year, and how will we do it? And what's the best way to get the message out, right? And how will make sure nobody gets missed. Like, who's the safeguard here?" (PCP9) "… we had… a discussion with community leadership and our health director on different sort of strategies to improve things like, you know, our colorectal cancer screening rate. You know… community events or radio shows, those types of things, you know. Prizes worked really, really well…to help bring up the rates… It's important in all these things that you're community-centered… not me saying, 'what are my ideas?' It's going to the community and saying, 'this is…an issue, how are we going to work?'… 'What are some of your ideas?'… because I truly believe that's important…to making sure that it stays community-centred…" (PCP8) "The best tool would be to have an integrated health, electronic health record, that, irrespective of where you are in the province, that that information would be available. 'Cause a lot of people don't have a regular primary care provider and a lot of people change where they go according to convenience, so it should really follow the patient. And I guess, Cancer Care [Ontario]'s database is pretty good but, it doesn't integrate into my electronic record, but if it did, it'd be great." (PCP4) "No. I was alone. But, my wife came before, you know, before. She was there when I woke up….Because, somebody escorting me would be good….Yeah. Instead of being there alone." (CM24)

Key supports	Selection of Participant Quotes
Improving access to screening - offering community screening options and travel supports - NIHB program changes	"I just think it should be more accessible to people here…Without having to leave our own community…Having the screening bus right here, in the community…." (CM17) "Closer to home, I guess, would be, instead of going through all the trouble of going all the way to town…" (CM19) "… so having it available is, is probably something that needs to, needs to be…I know it's becoming more available but just to have it readily available for any of the healthcare providers around the communities, kind of thing." (PCP5) "So sort of, having screening, increase the screening accessibility by providing workers that can do that screening …don't have a physician who is over-qualified to do a Pap…What the heck are they doing that for? They should have trained workers to do these services, and also, I feel that the NPs should be implemented in roles, but more in those kind of programs..." (PCP3) "We have K-Net [Keewaytinook Okimakanak]. They have a K-Net over there. And we have that in [community name] and they do have access to all this information. And it really is a very, very nice tool..." (CM5) "Because there's the barrier of having to travel, like, having to travel to go to appointments and it would be nice if, for instance, if they were interested in screening, getting a screening and if they have an appointment down there, they can call there and say I have an appointment there and it could be arranged along with it…I mean that probably would be good." (CM16) "They are? Doing all three now?...That's going to be a benefit because they love the van [NW mobile screening coach]… I can speak for probably like four or five of our communities just right away they're like, 'when is it coming? Put my name on [the list]'…Seems to be a big event when the bus comes…" (PCP5) "So, I would want to see a system where Non-Insured is not a gate-keeper to care like how it is right now…Let [funding support for an escort] be to the patient and physician to determine that… Some will be fine…going for that screening by themselves… But, but some people are going to want to have that escort. Especially when we talk about knowledge translation. Especially when we talk about explaining. That needs to be a decision that has to be up to the patient and their healthcare provider. So Non-Insured has to take a step back… and not… insert themselves saying, if you fit criteria X, Y and Z, then you're going to get that particular provision. And I think that's where a lot of their policies fall short and are not patient-centred but are policy-centred policies…they insert themselves…into a relationship that they have no business being in… those policies need to be revisited because they serve as a complete barrier to care." (PCP8)
Supporting community screening education and discussion - Improving cancer prevention and screening education materials and	"She showed me some stuff, the [screening tool]kit and all that…It was very informative…like all the symptoms and stuff like that. It's very helpful." (CM6) "Posters, I do not have posters…Posters would be great…Some more pamphlets." (CHW3) "If something can be translated into the Oji-Cree, then [Elders] can go on the radio anytime they want to." (CHW1)

Key supports	Selection of Participant Quotes
approaches in communities - Education approaches based on community knowledge and values	“They should have more, more education on cancer, whether it's something simple, or something that's fast, you know.” (CM3) “[M]ore public awareness….More pamphlets not just in the, in the medical clinic…Like this is the Ontario Works and Education building so, you know, we’ve got people flowing through these doors on a daily basis and a lot of them at the end of month so even that’s a good opportunity to get pamphlets out there, pamphlets that are created in words that people will understand…With a simple question and answer: what should I do if; what should I do if; who should I call if? With just very down to earth, practical information.” (CM17) “… a nurse would do well in it, just getting the community members out there. So, you know, establishing linkages with the community health reps or the health director would be one of the main things.” (PCP1) “But it's community run. And I do think it's more powerful because of that…So when the communities, which, I think, are increasingly getting this, and interested in it, and I think the [Screening Activity Report] will help to promote that interest and say, ‘wow, look, you know, compared to the dominant culture, we're doing great.’… or, 'oh, my God, compared to the dominant culture, you know, we're 30% less [screening participation]… Like, we've got to step up’ and then let the Chief and Counsel get the community rallying around that…” (PCP9) “…they’re all different, the culture is so different. You know maybe similarities in some of the, you know, how they understand things but it’s totally different perspective on how they, how they take things in… one thing I think would work…with understanding the communities is sitting down with the CHRs…I always see the CHRs cause they have so much knowledge doing, getting a community profile. So if you’re going in for any kind of education or screening kind of thing, sit with your CHRs.” (PCP5) “…we show them everything. You know, ‘This is what a speculum looks like, this is what it does, this is how you put the light on,’ you know, everything like that...If you can demonstrate it, like I said, like, demonstrating it, how it’s going to be done or what’s going to happen, kind of what you’re going to feel, you know?” (PCP2) “I think the most effective would be one-on-one….a sit down conversation...I think…it should be recommended…And then have a conversation…if you’re talking to a nurse the nurse should be able to explain to you, ‘because of this there’s the potential this could happen’… Or, they could make a referral to somebody else and say ‘have a chat with this person’…you know, if the doctor can refer to, let’s say a CHR.” (CHW2) “… those population-level interventions like pamphlets and programs, those are very important and I firmly support them. But you're going to have to have a way of people…in feeling connected….And it's very hard to connect to a population base. And it's very easy to connect with, you know…with a person, a friend, a colleague… (PCP8) “She came by about a week later [after a cancer screening education session that offered information without being directive]; she came and dropped in. And she, you know, mulled through all that information. And she said, ‘you know, I've been thinking about this. Do you think this would work’? You know, and just passing…just using us as a sounding board.” (CHW6)

Key supports	Selection of Participant Quotes
	"Some of them, you know, may want time to think about it; some of them still want to ask well 'I'm gonna ask my sister, I'm gonna talk'… they may want to look, talk to somebody else about it, kind of thing." (PCP5) "… you can go to Internet but I would rather have person, in-person to talk about cancer…So we can, where we can answer questions, things like that." (CM15) "…just getting out there into the community…getting to know the community and talking to people, just on a personal level, right. Like 'how are you, how many kids you got?' – that kind of thing. I think that could be a major thing to gaining the whole community's trust. Because once you gain the community trust, then it's easier to set up these types of [screening education] visits, like the bus, or whatever." (PCP1) "'Let's talk about…There's stuff that you can do to empower yourself so that you'll live a longer life.' And, and a lot of that's psychological. A lot of that's spiritual, a lot of that's emotional. But, like, for some of the physical stuff, I was speaking at the…and this is one of them, right?...Maybe it's better coming from that person than from the healthcare provider." (PCP8) "If I was asked to get screened I would probably do it right away. I want to still live for my, for my family's sake. I would probably want to get screened right away. Because of all the…I'm starting to get to that age where life is important to me now. Like, coming to my 30s and going into my 40s." (CM1) "...hiring somebody from the community like even one of the staffs there…Teaching them about all this and giving them the information and going around to schools, talking about it or going to the radio or even doing visits with Elders or the ones are, they have mobility challenges and stuff…I think that would be very good because, their own, the person from their community is teaching them…Because sometimes when it's a stranger it's kind of like, 'yeah, OK, OK.' Like when they talk to somebody, they act like they understand everything…[but they don't]… Like that's how I find myself. When I'm talking to somebody familiar…I'm able to talk to them and…ask questions…" (CM16) "…if you had somebody that just concentrated on cancer, I think you'd reach more people. And also, I think you would also be able to…what does a person need to do to take preventative measures?…CHR can do part of it. But can't do all of it." (CHW2) "… what's going to work in one is going to work…it's going to work everywhere else…people…they have a lot of good ideas for screening that are in the community. How can we support the good ideas that are there? Than trying to take ideas that work outside, somewhere else and fitting the square peg in the round hole." (PCP8)

Adapted Cancer Screening Pathway

Based on these Wequedong Lodge Cancer Screening Research Project findings, the research team developed an adapted cancer screening pathway that reflects important factors that would support cancer screening participation First Nations community members in NWO (see *Figure 1*). The adapted pathway highlights the key roles of context and broad determinants of health in shaping the ways that First Nations community members consider screening, in addition to the key roles of education, awareness and ongoing discussion throughout the screening pathway. The adapted pathway also makes clear how important community members' decisions about participating in cancer screening are. The adapted pathway also separates receiving screening test results (step #5), following up on results (step #6) and completing follow up testing (if necessary; step #7), to make the difference between these important parts of the screening pathway, where community members often fall through the cracks, clearer. Finally, the adapted screening pathway is represented as a cycle, to highlight the importance of ongoing participation in screening for it to be effective.

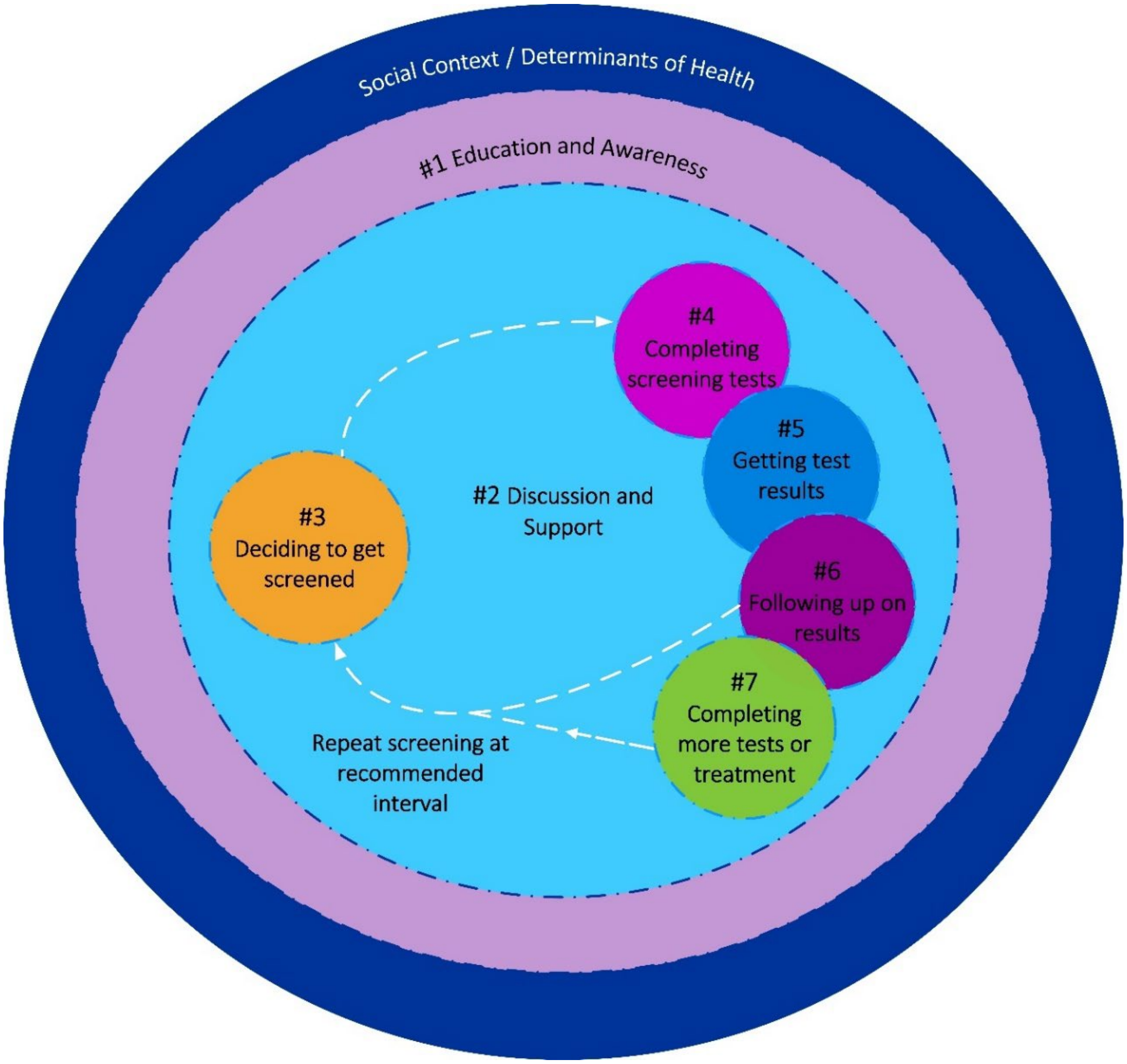


Figure 1: Adapted cancer screening pathway for First Nations communities in NWO

Using the adapted screening pathway presented in ***Figure 1***, our analysis suggests that to be effective, cancer screening efforts must be:

- Community driven and engaged
- Patient-centred and relationship-based
- Effectively integrated and streamlined
- Accessible and feasible

Efforts to improve awareness about screening and participation in screening must meaningfully engage community and community health leadership and be adaptive to the particular community context (see outer layer and all-encompassing steps #1 and #2 in the adapted pathway). The diversity and uniqueness of communities in NWO means that a 'one size fits all' approach within the region will not be effective. Partnerships with communities, and effectively aligning the efforts of community health providers and other health providers working in the community, are essential (e.g., the team-based approach to screening outlined in Table 4). This is also important in approaches to education about cancer preventions and screening, which must be tailored effectively to the community and involve community and community health leadership.

Screening should be patient-centred and relationship based, meaning it must be adaptive to individual community members' contexts and preferences, and must support community members' own voices in the screening process (see steps #2 and #3 in the adapted pathway). As outlined ***Table 4***, it is important that when a provider brings up screening with a community member, they are mindful and respectful of where the community member is with respect to screening (i.e., respecting their current perspective, without pushing screening on them or judging their possible reluctance to participate). Cancer screening can only be participated in safely when the community member is actively engaged in the decision to participate and the process that follows. This requires strong and respectful patient-provider relationships, improved communication, and efforts to reduce power imbalances in these relationships. This will require more training to help providers better understand when and how to approach discussions about cancer screening with First Nations community members; specific challenges that community members may experience when they consider participating in cancer screening (so they understand key barriers from community members' perspectives and ways to address them) and how to build trusting relationships. It will also require more support for community members in using their voices in healthcare interactions, to make sure they are actively engaged in the screening process. Full and stable healthcare provider staffing in communities is also essential to allow more time for providers to engage with their patients in these more effective ways. Further, trusted community-based screening education and navigation supports (e.g., hiring and training community screening educators and navigators to support community members in learning about and participating in screening) are also needed to provide ongoing support and make sure that community members' voices are heard and respected throughout the screening process (see step #2).

Screening processes must be effectively integrated and streamlined, to better support access to screening among community members (see steps #4 to #7 in the adapted pathway). This would involve providers working together through an integrated, team-based approach that centres around community-based providers and leadership. Streamlined screening data tracking and sharing is also central to this key principle of effective screening. Improving access to screening services in, or closer to, communities and improving support for travel when it is necessary, including significant adjustments to the way that NIHB medical transportation policy works in the screening process, is essential. Ultimately, improving access to screening would also contribute to improved trust in the healthcare system, and in particular, trust that cancer screening is actually intended to support the health of community members.

Finally, working to address the deeper challenges that keep community members from participating in screening must also be a part of any effective effort to improve cancer screening participation (see outer context layer in adapted pathway). That is, efforts must be made to make it easier for community members to get screened, by supporting the healing necessary to make participating in screening (and other preventative health priorities) possible in the lives of community members. For exampling, improving socio-economic conditions in communities, providing mental, emotional, spiritual health supports to begin to address some of these underlying challenges.

By calling attention to components of cancer screening processes that are meaningful to the experiences of First Nations community members in NWO, the adapted pathway can serve as a guide in developing specific recommendations to improve cancer screening experience and participation in this population, as outlined in the next section. For further information about the development of the adapted pathway and the identification of the key principles of effective approaches to cancer screening, please refer to the *Wequedong Lodge Cancer Screening Research Project Full Research Report*.

Recommendations and Conclusion

Based on our project findings, the research team proposed several concrete recommendations and deliverables that aim to improve cancer screening participation and experience in the region in relation to three main objectives:

1. Improve cultural safety of cancer screening services (e.g., NIHB medical transportation program improvements; training, integration and coordination among healthcare providers; sufficient and consistent staffing)
2. Support understanding and awareness about cancer screening in communities (e.g., support community discussion about screening; community screening educators and champions)
3. Support community engagement and partnership in managing screening services (e.g., community health leadership involved in planning and management of screening in communities; support community members in using their voices in cancer screening process)

Table 5 provides further details about the overarching objectives, as well as corresponding recommendations and deliverables.

Table 5: Recommendations to Improve Cancer Screening in First Nations Communities in NWO

Outline of objective	Recommendations and deliverables
1. **Improve cultural safety of cancer screening services** • Improve cultural safety in patient-provider relationships ○ Improve providers' abilities to provide culturally safe screening (e.g., build trust, respectful,	*Patient-provider interactions* ➢ Support healthcare providers in providing anti-racist, trauma-informed, culturally safe care (e.g., by providing training and support to integrate this into the way they provide care)

Outline of objective	Recommendations and deliverables
effective communication, understanding of screening challenges) o Support community members to use their voices in, and engage actively with, screening process and decisions o Increase and stabilize healthcare provider staffing to support relationship building • Improve integration and coordination among providers involved in screening to streamline process o Clarify providers' roles and support collaboration o Screening data tracking • Improve navigation supports for community members participating in screening throughout whole process • Improve access to cancer screening services in/close to communities • Improve support for travel, when travel is required	➢ Promote cultural safety training course completion (e.g., "Indigenous Relationship and Cultural Awareness" courses) and hands on cultural safety learning among healthcare providers and medical trainees (e.g., medical students, residents and fellows) ➢ Develop a screening- focused "Indigenous Relationship and Cultural Awareness" course module ➢ Develop shared decision making tools to support community members making their own decisions about cancer screening ➢ Develop a process that supports community members who experience racism/discrimination in healthcare services to report concerns to an independent body, which includes a strong mechanism to hold providers and healthcare organizations accountable. (e.g., patient ombudsman) *Staff communities appropriately* ➢ Address healthcare provider staffing challenges to support full and consistent nursing, physician staffing in communities ➢ Expand training/scope of practice for more nurses to provide screening *Improve access to screening services, including community member supports* ➢ Re-evaluate, clarify and improve NIHB policy on medical transportation for cancer screening with input from community and medical experts, including making sure that: o Healthcare and community health providers shape the way NIHB medical transportation policy is implemented (e.g., provide funding to support a medical escort when provider recommends this is necessary) o NIHB medical transportation policies are implemented fairly and consistently by stable and well-trained staff ➢ Expand reach of mobile screening options ➢ Improve clinical infrastructure and supplies in communities to support safe screening services ➢ Provide emotional supports for community members throughout screening process ➢ Increase use of Ontario Health (OTN) or other telemedicine networks (e.g., K-Net)

Outline of objective	Recommendations and deliverables
	Streamline screening process ➢ Create and fund community cancer screening navigator roles ➢ Improve discussion between community, regional, provincial and federal health leadership to support a regionally coordinated screening efforts and clarification of screening roles ➢ Improve screening data tracking and sharing among healthcare providers ➢ Support consistent patient and escort check-in with healthcare provider before/after travel for screening ➢ Revise OH (CCO) screening correspondence letters for cultural relevance ➢ Combine screening appointments with other health appointments to reduce travel burden on community members
2. **Support understanding and awareness about cancer screening in communities** • Support education and discussion about cancer prevention and screening in communities • Improve cultural relevance of education materials, strategies and supports by basing them on community knowledge/values • Support communities in developing education resources	*Community education materials, strategies and supports* ➢ Develop and share community cancer prevention and screening education resources (e.g., share existing Cancer and Screening Toolkit, develop additional resources) ➢ Develop cancer screening pathway and access guide for community members and community health workers ➢ Create and fund community-based cancer and screening health educator roles ➢ Support lay health education/screening champion roles ➢ Develop and provide optional cancer screening training for community health representatives (CHRs) and other community health workers
3. **Support community engagement and partnership in managing screening services** • Support community health leadership involvement in managing and providing community screening services • Engage community members actively in cancer screening and decision making	*Community-driven and engaged screening services* ➢ Support community health leadership efforts to plan and deliver cancer screening services in communities (e.g., Sioux Lookout Screening Activity Report program) ➢ Support team-based approach to cancer screening, which centres around community-based providers ➢ Support community members' decisions about screening participation and follow up (e.g., using shared decision making tools)

The research team and partners have already developed and acted on some of these recommendations. For example, a screening pathway and access guide for community members and community health workers was developed (Please see *Appendix 1* for additional cancer screening education resources and tips from participants). In 2018, Ontario Health (Cancer Care Ontario) worked in partnership with Sioux Lookout First Nations Health Authority and Indigenous Services Canada to develop and implement a cancer Screening Activity Report. This monthly report supports many physicians and nurses working in the Sioux Lookout region to track, monitor, and ultimately aims to improve, cancer screening participation among First Nations community members. Detailed feedback about the ways that the NIHB medical transportation policy acts as a barrier to screening participation was included with Ontario Health (Cancer Care Ontario)'s contribution to the Assembly of First Nations-led revision of NIHB policy. Finally, additional research funding has been secured to work with First Nations communities to revise the Ontario Health (Cancer Care Ontario)'s screening correspondence letters and develop shared decision making resources to support community members throughout the cancer screening process.

Importantly, the recommendations outlined in ***Table 5*** have also shaped 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 *First Nations, Inuit, Métis and Urban Indigenous Cancer Strategy IV (2019-2023).*[7] These documents inform and guide the work of the Indigenous Cancer Care Unit and other groups within Ontario Health (Cancer Care Ontario) with First Nations communities throughout the province.

Research Team Members

Community summary report developed by Wequedong Lodge Cancer Screening Research Project research team members: *Laura Senese, Fred Sky, Colleen McKay, Susan Bale, Alethea Kewayosh, Suzanne Jackson, Dionne Gesink & Jill Tinmouth.*

Past members of the research team who contributed significantly to this research include: *Jacqueline Gagnon, Charles Morris, Shannon Wesley, Crystal Hardy, Betsy Ledger.*

Acknowledgements

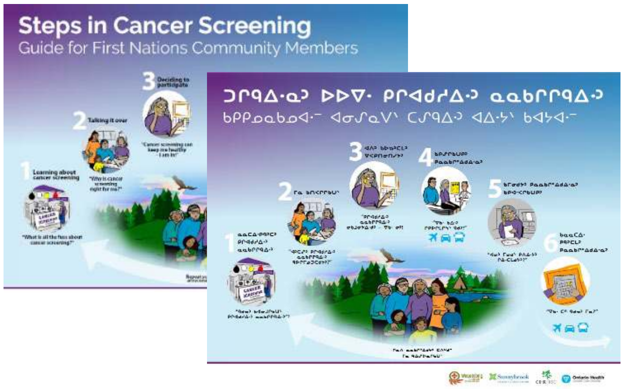
We would like to thank all the First Nations community member, community health worker and healthcare provider participants who generously shared their perspectives and experiences with us. We would like to thank the First Nations communities and community organizations that welcomed us into your communities and supported this work, including the Kenora Chiefs Advisory.

This research was funded by a Partnerships for Health System Improvement Canadian Institutes of Health Research grant.

Appendix 1 – Cancer Screening Education and Awareness for First Nations Communities

First Nations-specific resources that have already been developed:

Steps in Cancer Screening: Guide for First Nations Community Members in Northwestern Ontario


Steps in Cancer Screening

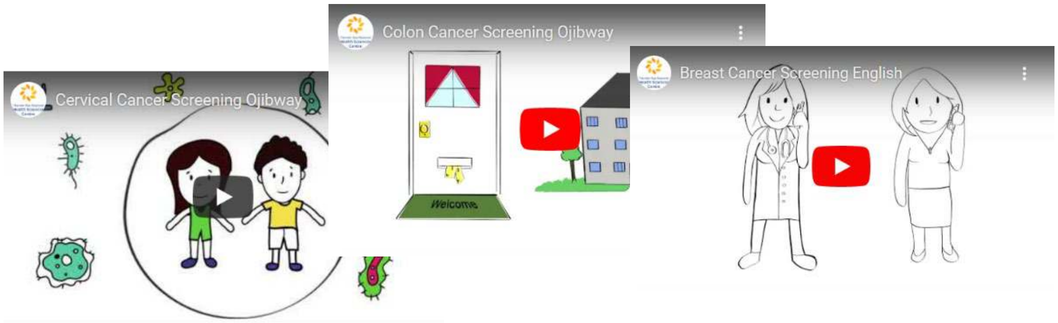
Guide for First Nations Community Members

First Nations Cancer Screening Posters and Postcards


Cancer screening is about helping you live a good life

Andooshkigaadeg amogowin giwiiji'igon ji-mino-bimaadiziyan

Northwestern Ontario Cancer Screening Videos (Breast, Cervix, Colon)



Cancer and Screening Toolkit – *for community and health care providers*


Cancer and Screening Toolkit

Ontario Health Cancer Care Ontario

First Nations Cancer Screening Fact Sheets (Breast, Cervix, Colon)

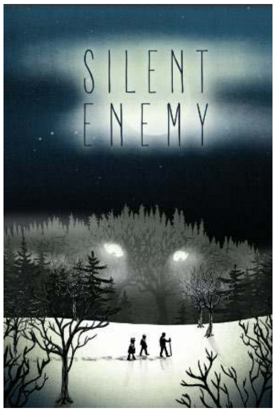

Honouring the First Nations Path of Well-being

Honouring the First Nations path of well-being

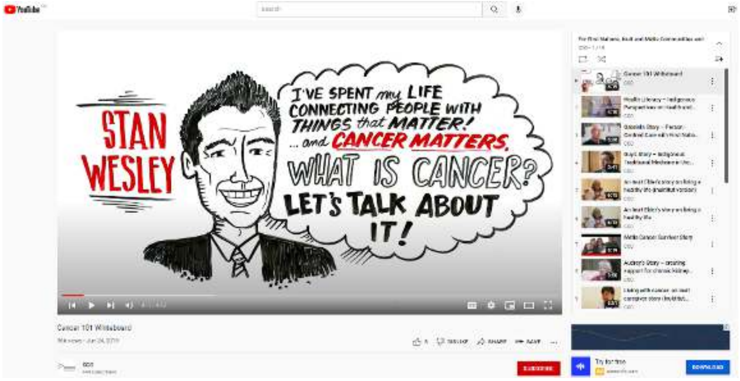
Honouring the First Nations path of well-being

First Nations Cancer 101 Toolkit brochures, Q&A

‘Silent Enemy’ - comic about cancer diagnosis, treatment and recovery

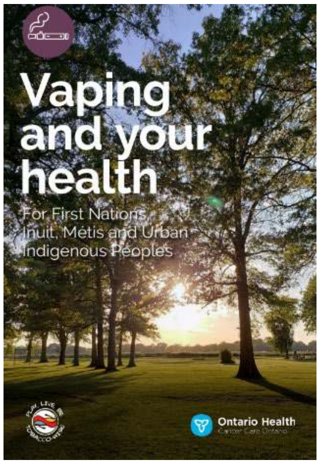


Cancer 101 Whiteboard Video



First Nations Be Tobacco-Wise Brochure

Vaping and your Health Brochure



Trustworthy websites with more information:

https://www.cancercareontario.ca/en/resources-first-nations-inuit-metis
https://www.cancercareontario.ca/en/get-checked-cancer
https://tbrhsc.net/programs-services/prevention-and-screening-clinical-services/screening/
https://tbrhsc.net/programs-services/prevention-and-screening-clinical-services/screening/gallery-and-media/
https://cancer.ca/en/cancer-information/find-cancer-early

Tips and ideas from for First Nations communities in Northwestern Ontario from the *Wequedong Lodge Cancer Screening Research Project*

First Nations community members, community health representatives, health directors, nurses and doctors in Northwestern Ontario shared some tips and ideas about how to raise awareness about cancer prevention and screening in First Nations communities…

Approaches to consider when DEVELOPING screening education resources:

- Use simple words or layman's terms – no medical jargon
- Resources should be short/not too detailed
- Translations into Ojibway, Oji-Cree, Cree
- Incorporate community knowledge and values into messages about cancer screening – how does cancer screening fit within more traditional ways of thinking about health and wellbeing?
- Use visuals (pictures, videos)
    - Show basic anatomy
    - Show what to expect – e.g., what the screening equipment and clinic look like
    - Use pictures that reflect community experience – e.g., include images of community members
- Positive and encouraging – e.g., sharing stories of cancer survivors, sharing positive experiences with screening
- Clarify common misconceptions about screening that may create reluctance to particiapte

TYPES of education resources to consider (what participants said would be useful):

- ✓ Posters, pamphlets, flyers
- ✓ Video or audio recordings (can be used repeatedly – particularly to support community health workers in sharing information)
- ✓ Pathway or map of screening process
- ✓ Handbook with details about how to access cancer screening (e.g., screening guide with space to add community-specific contacts/details)
- ✓ Screening toolkit
- ✓ Cancer and screening presentations

Approaches to consider when SHARING screening information with community members:

- Through conversation and discussion…
    - With trusted family, friend, provider

    - Providers getting to know patients, learn how/when to bring up screening effectively/respectfully, including when appropriate to include their support people in the conversation
    - Encourage community members to talk to each other about screening – hits home more when comes from peers; people listen to Elders; normalizing screening helps with stigma
- Supportive and directed
    - Invite people to learn about and talk about screening, without forcing people when not ready to engage with information or participate
    - Don't just share information passively – get out to talk to people, because some community members may be reluctant to initiate the conversation
- Repeat teachings/reminders (without badgering) – people will engage when ready
- Work with other groups of providers/workers, including community leadership –
    - Health information is best when it comes from multiple people (e.g., community health workers, other healthcare providers, peers)
    - Key to involve community leadership – support/guidance is important and influential
- Use many different approaches because people learn differently – e.g., group learning/sharing sessions and one on one discussion
- Build on what already works in your community – incorporate a bit of information about cancer screening into a community event or program that community members are already engaged in (rather that holding an event just on screening) – e.g., at an Elders lunch, at suboxone programming

Specific ideas for WAYS TO SHARE screening information:

- ✓ Add information to community Facebook page
- ✓ Put up posters/pamphlets in community places where people gather regularly, not just at the health centre
- ✓ Ask community school to have a screening session – important to learn age-appropriate cancer screening information, kids might share with screen-eligible parents, grandparents, helps to normalize screening from a young age
- ✓ Share information on the local community radio – older people still listen
- ✓ Buddy bingo with prizes – fun way to learn and reinforce information after a talk/presentation
- ✓ Screening champion – training a community member about cancer screening – help to spread the word/share information
- ✓ Hold a workshop or health fair
- ✓ Informal lunch/discussion/questions

What works in your community might be different – maybe you have another idea that has worked well that you would like to share?

References

1. Chiefs of Ontario, Cancer Care Ontario, Institute for Clinical Evaluative Sciences. Cancer in First Nations People in Ontario: Incidence, Mortality, Survival and Prevalence. Toronto, ON; 2017.
2. Nishri ED, Sheppard AJ, Withrow DR, Marrett LD. Cancer survival among First Nations people of Ontario, Canada (1968-2007). Int J Cancer. 2015;136(3):639-45.
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. 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.
5. 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.
6. Cancer Care Ontario. Aboriginal Cancer Strategy III Toronto, Ontario2015 [Available from: https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=345455.
7. Ontario Health (Cancer Care Ontario). First Nations, Inuit, Métis and Urban Indigenous Cancer Strategy IV (2019-2023). Toronto, ON; 2020.
8. Cancer Care Ontario. Lung Cancer Screening Pilot for People at High Risk Toronto, Ontario: Cancer Care Ontario; 2017 [Available from: https://www.cancercareontario.ca/en/guidelines-advice/cancer-continuum/screening/lung-cancer-screening-pilot-people-at-high-risk.
9. Ontario Health (Cancer Care Ontario). Screening for Lung Cancer Toronto, ON2021 [Available from: https://www.cancercareontario.ca/en/types-of-cancer/lung/screening.
10. Miles A, Cockburn J, Smith RA, Wardle J. A perspective from countries using organized screening programs. Cancer. 2004;101(S5):1201-13.
11. Minore B, Boone M, Cromarty H, Katt M, Kinch P, Power M. It's just so different up here: continuity of care for cancer patients in Northwestern Ontario First Nation Communities. Thunder Bay, Ontario: The Centre for Rural and Northern Health Research, Health Sciences North, Lakehead University 2002.
12. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant. 2018;52(4):1893-907.