

Talking together to improve health
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Gathering and Sharing Learning with First Nations Communities

January 2020

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Acknowledgements

The Project Team gratefully acknowledges the First Nation communities who participated in the Gathering and Sharing Learning phase of this project: Dokis First Nation, M’Chigeeng First Nation and Serpent River First Nation. We sincerely thank the community leadership for supporting their community’s participation in the research project, the community research assistants who provided support and coordination along the way, the community advisory committees who guided this work at each stage, and the focus group and interview participants who openly shared their perspectives on principles and practices for respectful engagement between public health and First Nations communities.

The Project Team thanks Mariette Sutherland who played a key role in the recruitment of communities, in the development of community research agreements, and in the facilitation of focus groups and interviews. The Project Team would also like to acknowledge the contributions of Donna William and Susan Underhill from Keesic Health Strategies for preparing this report.

Finally, the Project Team would like to thank the Indigenous Circle for their commitment and guidance which ensured project activities were culturally appropriate and led to respectful engagement with First Nations communities.

This research project was supported with funding from Public Health Ontario’s Locally Driven Collaborative Project (LDCP) stream. The views expressed in this report are those of the research team and do not necessarily reflect those of Public Health Ontario.

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Citation

Talking Together To Improve Health Research Team. (2020). *Talking together to improve health: Gathering and Sharing Learning*. Sudbury, ON: Locally Driven Collaborative Projects.

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Introduction

The term “First Nations community” is utilized throughout this report as a respectful alternative phrase for the term “reserve”. It refers to a community which is officially recognized and administered on land that was set aside under the Indian Act or under a treaty agreement, and which is governed by a band council. Because engagement in this phase of the project was conducted with and in First Nations communities, the term “First Nations” is used although individuals living in First Nations communities may identify as First Nations, Indigenous, Métis, Inuit or non-status.

Public Health promotes and protects the health and well-being of people and communities as well as prevents disease and injury. Public health also works to examine and address unequitable health experiences across different populations. This is particularly important for First Nations communities and people whose legal and constitutional recognition, complex history, and shared experiences of colonialization have contributed to poorer population health outcomes compared to other Ontarians.

In Ontario, the public health system has established legislation (Health Promotion and Protection Act, 1990) and standards (Ministry of Health & Long Term Care, 2018) that legislate requirements for the public health system in Ontario. There are 35 public health units that operate across Ontario, 21 of which intersect with the boundaries of 133 First Nations communities (Chiefs of Ontario, n.d.). Northeast Ontario is home to about 60,000 Indigenous people, approximately 11% of the total population in the North East Local Health Integrated Network catchment area (Local Health Integrated Network, 2016).

First Nations communities are “tracts of land... that have been set apart by Her Majesty for the use and benefit of a band” (Indian Act, 1985, p. 5). As a result, First Nations communities have historically been considered to be under the jurisdiction of the federal government. The multi-jurisdictional health system for First Nations at times creates gaps, discontinuity of care and inadequacies in services. Current programs to address public health problems are often developed independently by one or more of the provincial, federal or First Nations’ partners resulting in well-intentioned initiatives that create overlaps, duplications or gaps. The result is evidenced in poor health outcomes that are exacerbated by determinants of health such as increased poverty, poor housing, racism, language barriers and cultural differences.

These inequities in health outcomes have also been well documented in national and international publications. The UN *Declaration on the Rights of Indigenous Peoples* became part of international law when it was adopted by a majority vote of the United Nations (UN) General Assembly on September 13th, 2007. One of the drivers behind the UN *Declaration* was the

persistent denial of basic human rights of Indigenous people, resulting in the marginalization of Indigenous people (Hartley, Joffe, & Preston, 2010). In response, the UN Declaration has recognized the need for Indigenous self-determination. In 2015, Canada's Truth and Reconciliation Commission (TRC) released its final report and called for reconciliation and the creation of a more equitable and inclusive society. This would be achieved by closing gaps in health and other areas between Indigenous people and other Canadians. It is recognized that First Nations communities and peoples have begun to reclaim control of their health and well-being, asserting their aims in self-determination, and revitalizing cultural and community strengths and resiliency (Public Health Sudbury & Districts, 2018). As part of self-determination, First Nations are leading and developing health programs and services that are based on community needs and priorities. Indigenous Services Canada funds several public health programs and through health transformation efforts, First Nations communities are taking ownership in the planning and delivery of these programs in their communities.

Recently, *Ontario Public Health Standards* (2018) were revised and direct boards of health to strengthen relationships with Indigenous communities and organizations and to ensure it is done in a culturally safe way (MOHLTC, 2018). In light of this direction, public health units in Ontario are in need of further guidance on how to strengthen these relationships with Indigenous communities and organizations. This project is premised on understanding this unique context as an important starting point for meaningful engagement between public health units and Indigenous communities (comprised of First Nations, Métis, and Inuit people). The focus of this project is engagement with First Nations communities in Northeastern Ontario.

Why multi-agency engagement and collaboration are important

Because of the complex historical relationship Canada has had with First Nations communities, a number of public health issues persist and will require resources and collaboration across federal, provincial and First Nations governments. A comprehensive review of current data and health-related literature reveal a many systemic deficiencies within public health services to First Nations (Adelson, 2005). Among these are:

- Obstructive jurisdictional layout;
- Lack of essential resources and services;
- Lack of surge capacity in the clinical and public health systems;
- Absence of protocols for data or information sharing among levels of government;
- Uncertainties about data ownership;
- The role of personal identifiers;
- Inadequate capacity for epidemiologic investigation of an outbreak;
- Lack of coordinated business processes across institutions and jurisdictions for outbreak management and emergency response;
- Inadequacies in chronic disease programming and infectious disease surveillance; and

- Cultural and social barriers that exist between First Nations and health-service providers both in community and urban centres (Adelson, 2005).

An effective public health system is essential to preserve and enhance the wellness of First Nations, to reduce the amount of disease, premature death, and pain and suffering in the population. In the area of public health, the greatest need is in First Nations communities. The fact is, almost without exception, those characteristics, which are identified as necessary to a well-functioning health system, are under-funded, under-resourced and even non-existent in these communities. For example, basic public health measures that have been recognized since the 19th century as fundamental to health, i.e., water treatment, sewers and sanitation, and food security are still issues that many First Nations have to deal with in the 21st century. There are also issues related to the potential outbreak of infectious diseases in remote and isolated communities, where communities are only accessible by air and do not have resident physicians, diagnostic equipment and other key resources. As examples, recent news headlines inform us of the following public health related concerns:

- Rheumatic fever rates in some Ontario First Nations are 75 times higher than rest of Canada. This recently published report indicates that *the incidence rate among First Nations in northwestern Ontario is related to late diagnosis, overcrowded housing and inadequate public health response* (Gordon & Kirlew, 2015).
- A recently published study revealed that First Nations communities in northwestern Ontario have the highest rates of community-associated Methicillin-Resistant Staphylococcus Aureus (MRSA) in Canada leading to 23 cases of sepsis and pneumonia during a two-year period – attributable to overcrowded housing, a lack of clean water and inferior health care delivery (Gordon & Kirlew 2015).

Project objectives

There is a need for guidance for public health units in Ontario on effective principles and practices that can promote meaningful engagement with First Nations communities.

In response to this identified gap, the overall intent of this research project was to answer the following research question:

“What mutually beneficial, respectful and effective principles and practices of engagement between First Nations communities and public health units in Northeastern Ontario can be identified, as an important step in working toward improved opportunities for health for all?”

Specifically, the objectives for this project were to:

- Identify existing guidance on engagement with Indigenous populations in Canada [and possibly other jurisdictions].
- Describe the current state of engagement across Ontario First Nations communities and public health units.
- Explore selected examples of engagement in the Northeast that can form the basis for principles and practices.

- With guidance and community-driven direction from an Indigenous Circle (comprised of Indigenous community representatives or those with significant Indigenous community engagement experience from across the Northeast) and in partnership with First Nations, the project was designed to:
 - Enhance relationships between participating First Nations and health units.
 - Identify promising strategies, principles and practices for engagement of First Nations and local public health and can be a foundation for guidance that will be available to all of Ontario’s 35 public health units.

The project was structured in phases.

- The first phase of the project involved scoping what is already known on principles and practices for engagement from existing research and experience, through a literature review. Four themes emerged from the literature review: respect, trust, self-determination, and commitment (Talking Together to Improve Health Project Team, 2017). The literature review findings helped develop and inform phase two of the project which involved a survey of Ontario public health units.
- The second phase of the project focused on understanding public health units’ perspectives on current principles and practices of engagement between First Nations communities and health units, as well as perceived successes and challenges (Talking Together to Improve Health Project Team, 2018a).
- The third phase of the project involved key informant interviews with health organizations that have existing Indigenous health-focused strategies (Talking Together to Improve Health Project Team, 2018b).
- The fourth phase of the project was called the Gathering and Sharing Learning phase and consisted of gathering and sharing information via focus groups and interviews with individuals from First Nations communities in northeastern Ontario. The information accumulated from all four phases contributed to the identification of principles and practices that have been utilized or recommended for fostering effective engagement between First Nations communities and public health that will be highlighted in this report.

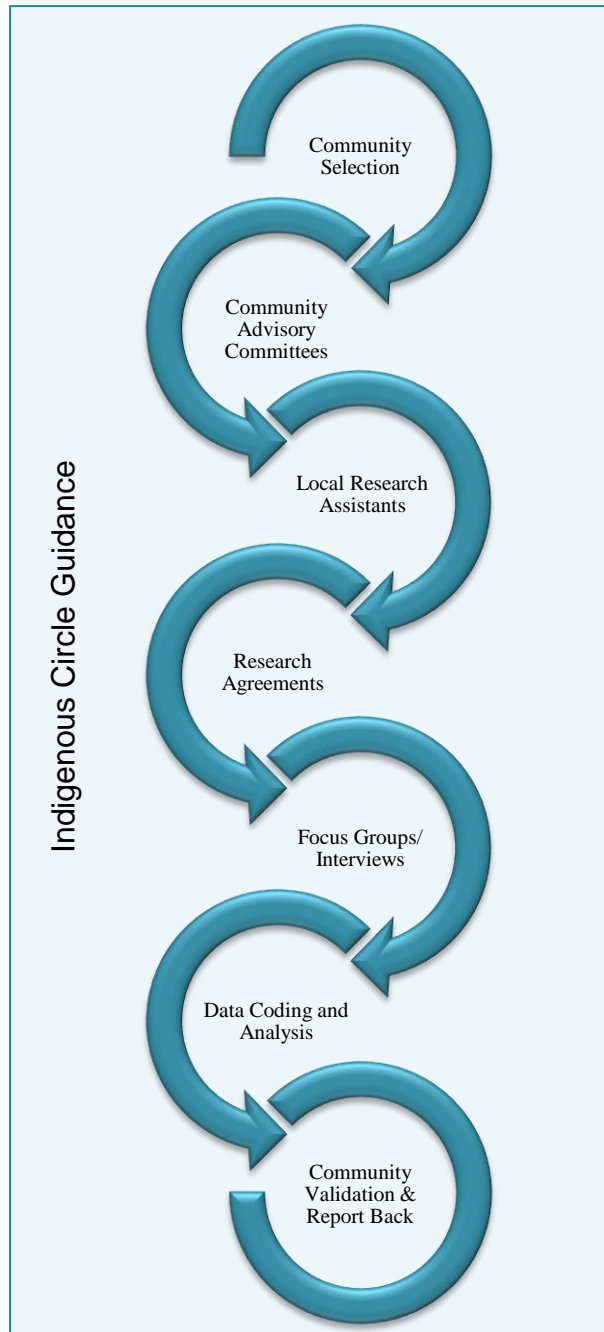
To ensure that the overall approach to this project is appropriately balanced, an Indigenous Circle comprised of representatives with expertise, experience and Indigenous perspectives from communities within the Northeast was established. The research team included six health units (with Public Health Sudbury & Districts as lead agency), academic partners (including an Indigenous scholar), and the Indigenous Circle.

The purpose of this report is to provide an overview of the fourth (and final) phase of the research project – the gathering and sharing learning phase.

Methodology

This section outlines the research team’s overall approach and methodologies used for the Gathering and Sharing Learning Phase of the project (depicted in the diagram below).

Figure 1: Overall Approach and Methodology for Gathering and Sharing Learning Phase



Description of the Research Process

The Gathering and Sharing Learning phase of the project consisted of engaging with interested First Nations communities and identifying focus group/interview participants to share perspectives about potential facilitators and barriers to engagement. The main objective of this phase was to identify principles and practices that have worked, and/or would be recommended, for mutually beneficial engagement between First Nations and public health units. Participatory research approaches and Indigenous research methodologies were applied throughout this phase, to ensure the process was mutually beneficial and respectful.

Specifically, this phase included a) the recruitment of select First Nations communities and within these, the recruitment of individual focus group and interview participants as well as b) the establishment of local research assistants and community advisory committees c) the development of collaborative research agreements d) the collection of data via focus groups and/or interviews and e) and validation sessions with each community advisory committee.

Community Engagement Process

To begin, the project team and Indigenous Circle members established two working groups to guide and shape the Gathering and Sharing Learning Phase: The *Community Selection Criteria Working Group* was responsible for recommending a process and criteria for selection of participant First Nations communities; and the *Gathering and Sharing Learning Working Group* was responsible for developing approaches, methods, and identifying data collection tools for gathering and sharing learning with participating communities with an emphasis on Indigenous methodologies.

Together, the recommendations from both working groups were used to identify and invite First Nations communities and potential participants for the focus groups and/or interviews.

The project sought to engage First Nations communities considering the following selection criteria:

- Regional: from a range of locations and health unit catchment areas throughout the Northeast
- Setting: from a mix of rural, remote, urban
- Community size: from small, medium, large sized communities
- Capacity: individual First Nations and/or regional health organizations that serve multiple First Nations
- Existing relationships: a mix of communities where partnerships are already established and also where they are not
- Interest: as previously expressed by community

Across Northeastern Ontario there are 40 First Nations and five public health units who operate in these First Nations territories. The research project initially aimed to include five or six First Nations communities in the Gathering and Sharing Learning Phase based on the criteria and selection process shared by the *Community Selection Criteria Working Group* (described above).

Public health unit project team members worked with their respective Indigenous Circle representative to determine which community(ies) in their service area would be approached based on these criteria. Based on these discussions, the project team, in consultation with the Indigenous Circle, identified numerous communities to be approached and invited to participate in the study. These were grouped according to first, second, and third choice. The respective public health unit project team members contacted the selected community and initiated dialogue with the community's Health Director to share background concerning the research project and determine interest. In instances where a First Nation community declined, the second choice (and if needed third choice) was approached to determine interest. In total, 10 communities were approached. Some communities who initially expressed interest received community approval to participate but were unable to accommodate the necessary activities in their community plans. These communities were open to receiving ongoing updates concerning the project and maintaining contact with their local public health unit partners.

The project team stopped recruiting in January 2019 and by this time, the following First Nations communities were recruited:

- Dokis First Nation – Rural (large); 1,236 total registered population, 177 living within the First Nation (Government of Canada, 2019); intersecting with the North Bay & Parry Sound District Health Unit service area
- Serpent River First Nation – Rural (large); 1,433 total registered population, 374 living within the First Nation (Government of Canada, 2019) ; intersecting with the Algoma District Health Unit service area
- M'Chigeeng First Nation – Rural (large); 2,639 total registered population, 944 living within the First Nation (Government of Canada, 2019); intersecting with the Public Health Sudbury & Districts service area

In some communities, the Health Director invited the project team members to share an overview presentation at their health and social services committee meeting and subsequently at Chief and Council meeting. This dialogue was extremely informative and provided learnings to the project team about community self-determination, jurisdictional concerns, community perceptions concerning public health and community wellness and certainly community priorities and capacity.

Equally important learnings were derived from instances in which First Nations declined to participate. Project team members learned that there are numerous other priorities at the community level that clearly take precedence over a public health research project. Community capacity is often constrained in terms of taking on new initiatives and jurisdictional concerns remain unclear when entering new relationships with provincial public health entities. It was also noteworthy that other environmental circumstances, community crises, and seasonal community events were also factors and impacted the participation of communities in any new initiatives.

Throughout the community engagement process, it was important for the project team to embrace flexible timelines. Though the research project anticipated moving forward according to certain planned project milestones, it was apparent that community communications and

decision-making protocols may operate on a different timeframe and needed to be respected. Beginning with initial outreach and throughout all of the participatory research steps noted in Figure 1, deliberate and respectful pacing driven by the community's cues and direction was required.

The local research assistant identified individuals and recruited participants via email (letter), telephone calls or in person. Participation in the study was completely voluntary and participants could choose to withdraw from the study at any time.

Community Advisory Committees

The community advisory committees included representation from First Nations community Health Directors, band council members, Elders, and other representatives from community health centres, education or the community at large.

The community advisory committees were responsible for representing their First Nations communities and ensuring that the overall research project implementation was conducted respectfully, appropriately and reflected community preferences and expectations. Each community advisory committee was accountable to the community leadership and advised the research team accordingly to help refine the interview questions for their community, determine appropriate gift giving protocol/process and determined how best to store and share the project data (see next section for details).

Community advisory committees provided participating communities with the opportunity to gain experience in community-driven research; customizing the research design for local community and cultural context.

Locally-hired Research Assistants

Locally hired research assistants were hired to provide support and coordination to their respective community advisory committee, the development of the research agreement, and the data collection process. The Health Director or the community advisory committee provided recommendations regarding recruitment of the local research assistants.

The hiring of the local research assistants ensured project approaches were respectful and reflective of community protocols and helped participating communities build their local research capacity.

Research Agreements

The research team and each of the First Nations community advisory committees developed research agreements in partnership. These research agreements were developed based on discussions held with the committee to ensure that each community had the opportunity to express their preferences and expectations of the research project.

Each research agreement outlined details concerning the research approaches, informed consent, privacy, confidentiality, data access and storage, roles and responsibilities, dissemination of the results, authorship, and honorariums and gift giving.

The project team customized the research agreements to reflect the wishes and needs of each participating First Nations community. Specifically, they ensured that privacy, consent, confidentiality, authorship and dissemination of research findings and data collection procedures were appropriately designed, communicated, and applied. In this regard, Ownership, Control, Access, and Possession (OCAP®) principles were discussed and ways to enact them were agreed to.

OCAP® Principles

Ownership, Control, Access, and Possession (OCAP®) is a set of principles that have been established to guide research processes within First Nations. The term has been trademarked by the First Nations Information Governance Centre (The First Nations Information Governance Centre, 2019); and is considered foundational to any research being done with First Nations. The OCAP® principles recommends that community-based and participatory research approaches are used. Participatory Action Research is research which involves all relevant parties in actively examining together current action in order to change and improve it (Wesley-Esquimaux, & Caillou, 2010). The participatory approach used to work with First Nations communities and Indigenous health and social services organizations, was carried out in a respectful and culturally informed way, and was crucial to the success of phase four of the project.

The project functioned under OCAP® principles ensuring that decisions impacting First Nations communities were made by the community representatives themselves. First Nations communities determined which approaches were most appropriate for them for the Gathering and Sharing Learning phase of the project. Activities that supported such engagement included participation and guidance from the community advisory committees, the community-led research agreements, the locally-hired research assistants, project team working groups, and the overall guidance from the Indigenous Circle.

Indigenous Circle

A research project about First Nations engagement must be led, guided and be responsive to First Nations voices as equal partners. Moreover, research and learning together about principles and practices in First Nations engagement must make space for and recognize that there are Indigenous approaches to undertaking research and making meaning about community engagement.

The research team established an Indigenous Circle comprised of representatives with expertise, experience and Indigenous perspectives from communities within northeastern Ontario to ensure that the overall approach to this project was appropriately balanced. The Indigenous Circle members were a part of the Project Team, and ensured that the work of the overall project was

framed with “two-eyed”¹ seeing, by providing community context and a culturally appropriate lens to the planning and implementation of the project.

The Indigenous Circle was also responsible for guiding the project team and informing important decisions about the project’s design, direction and implementation. This included providing feedback on the research methodologies, data collection tools, data analysis, reports and other project outputs; assisting as equal partners in the selection of communities to participate in the research project and interpretation of results; as well as advising on and supporting knowledge exchange activities.

Indigenous Circle members were involved in all aspects of the project including working groups, project team meetings, and collaborative face to face meetings involving all project team members. Additionally, three Indigenous Circle meetings convened at critical junctures in the project to reviewing and discussing data collection tools, project outputs, overall project direction, interpretation of results, as well as advising on and supporting knowledge exchange activities. While Indigenous Circle members were involved in all phases of the project, during the Gathering and Sharing Learning phase, they were particularly engaged in advising and guiding the project team’s activities to ensure culturally appropriate and respectful engagement with First Nations communities.

Ethics Certification

The research team obtained ethics approval for this study from Public Health Sudbury & Districts’ Research Ethics Review Committee on March 22, 2018 and Laurentian University’s Research Ethics Board on March 23, 2018.

Data Collection and Analysis

This section outlines how the focus groups and interviews were conducted and how the research team coded and analyzed data from the focus groups and interviews.

Focus Groups and Interviews

Local research assistants in collaboration with a member of the research team worked with the participants and the researchers to arrange a mutually convenient date, location and time for the focus groups, and/or interviews. The project team provided participants with a copy of the focus group/interview questions and consent form prior to their session to ensure they had an adequate amount of time to review the documents, felt comfortable, and could prepare (see Appendix A).

¹ “Across Canada, researchers and Aboriginal communities are beginning to work together in a new research model known as “two-eyed seeing”. This approach combines the strengths of both traditional scientific methods and Aboriginal ways of understanding health. Together, these teams are hoping to create a more collaborative and comprehensive way to study health issues.” (Canadian Institutes of Health Research (CIHR), Institute of Aboriginal Peoples’ Health. (2013). Two-Eyed Seeing: Bringing Aboriginal Perspectives to Health Research)

One consistent person from the research team conducted the focus groups and two researchers shared the responsibility of conducting individual interviews. The researchers confirmed permission to audio record the focus groups/ (or interviews) in advance to ensure that all of the information was captured. In all cases, participants granted permission. In addition, others were on hand to assist the focus groups/ (or interviews) as per each research agreement, such as an Indigenous Circle member, a locally hired community research assistant, and/or a representative from the local health unit.

The focus groups required approximately two to three hours to complete. Interviews required approximately one hour. These time frames ensured that participants had an adequate amount of time to provide their input and discuss their experiences engaging with public health. The project team provided all participants with an honorarium or a gift for their contribution to the study as identified in the community’s research agreement.

Data Coding and Analysis

To analyse and interpret the focus group and interview data, research notes were typed and audio recordings were transcribed. An analysis working group was struck with Indigenous Circle, project team and academic representation. The first focus group was analysed separately by two researchers and consensus was reached. The analysis was presented to the focus group facilitators and the analysis working group for their validation and interpretation. This analysis framework was then used for subsequent interviews and focus groups. Subsequent interviews and focus groups were analyzed by one researcher, reviewed by the second researcher, and also presented to the focus group facilitator and working group for their validation and interpretation.

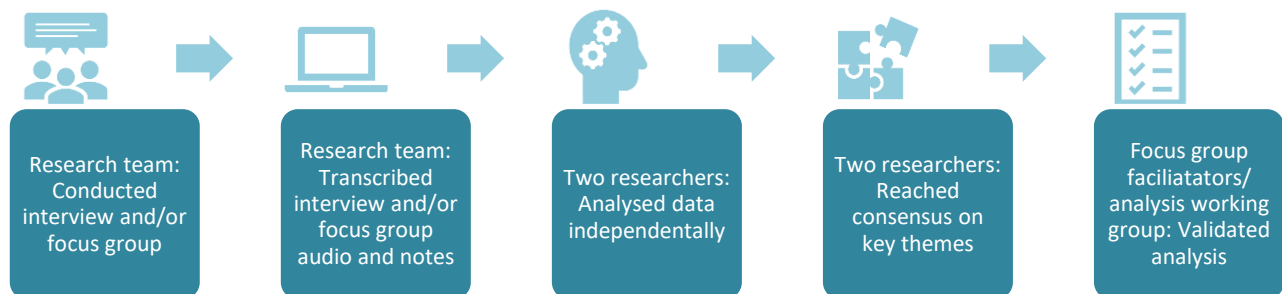


Figure 2. Process for Data Coding and Analysis

Validation

The analysis was presented to the focus group facilitators and analysis working group for validation and interpretation. The analysis, including themes and sub-themes, their description and quotes, were then presented to all three community’s advisory committees for validation and interpretation.

Transcripts and field notes did not contain the participant's name but rather an assigned ID number and the project team stored these in a locked filing cabinet at Public Health Sudbury & Districts. Only the project leads, co-investigators, research assistant, principal and academic investigators had access to these recordings.

Results

This section describes preliminary project results for the Gathering and Sharing Learning Phase.

Participation

A total of ten First Nations communities were invited to participate in the research project, three of which were willing/able to engage at this time including Dokis First Nation, Serpent River First Nation and M'Chigeeng First Nation. A total of 32 individuals participated in this phase of the project (see table below).

Community	Number of Focus Group Participants	Number of Interviewees
Dokis First Nation	7	4
Serpent River First Nation	10	2
M'Chigeeng First Nation	9	0
TOTAL	32	

Dokis First Nation

Dokis First Nation community is located on the boundaries that separate the Districts of Parry Sound, Sudbury and Nipissing, approximately 16 kilometers South-West of Lake Nipissing on the French River. The community is accessed by a 25-kilometer gravel road from Highway 64, leading to the two nearest urban centers of North Bay via Highway 17 and Sudbury via Highway 69. Both centers are approximately 120 kilometers from the community.

The First Nation lands are composed of two large islands which are nestled within the flows of the historical French River. The main settlement or community is located on the northern island called "Okikendawt Island" (meaning Island of the Buckets/Pails). The name is derived from several bucket formations in the rock due to centuries of water flows to these areas. The buckets were often utilized for tobacco offerings for safe passage through the territory.

The second island is a large Southern Peninsula which is generally utilized for traditional purposes such as hunting, fishing, camping and hiking. Many locals have private hunting and fishing camps throughout this First Nation territory. In total, the First Nation land base is in excess of 39,000 acres.

The total membership of the community is steadily climbing with over 1071 members with a residential population of approximately 200. In the summer months, the population increases. The community has a growing population and a commitment to sustain and improve the quality of life for all its members, both on and off-reserve.

Dokis also provides a wide range of health, employment and administrative services to its members as well as a sustainable lifestyle based on the richness of the natural resources under its care.

Sources: Community Profile from Dokis First Nation Official Website; Population numbers differ from INAC profiles and reflect community definitions.

A total of 11 individuals participated in interviews (4) and focus groups (7) from Dokis First Nation. Participants included a mix of community members and representatives from the health sector, band council/ band administration, and education sector.

Serpent River First Nation

The Serpent River First Nation is part of the unceded lands retained by the Ojibway who traditionally inhabited the North Shores of the St. Mary's River and the Georgian Bay.

Serpent River First Nation is part of the Robinson Huron Treaty, which was signed on September 5th 1850. The Serpent River First Nation is also known as Cutler or in the recent past as Kenabutch [sic]. For the past three decades, traditionalists have preferred the Ojibway titles as Genaabaajing and Chi Gebebek Ziibibg Anishnabek.

The reserve has always been a relatively small community; however, recent years have showed a rapid development of community infrastructure and community services. In addition, the community population has shown a definite increase.

The Serpent River First Nation is located approximately 160 kilometers east of Sault Ste. Marie, or approximately 140 kilometers west of Sudbury. It is located 30 kilometers east of the Town of Blind River on the Trans-Canada Highway 17. Two small communities flank the community: Town of Spanish to the east and the Township of the North Shore (Serpent River) to the west. Serpent River First Nation is a twenty-minute drive from the retirement (nee mining) community of Elliot Lake. It is also bounded by the Serpent River and Grassy Lake to the north, Whalesback Channel and Lake Huron to the south and west.

The reserve consists of a land base of 26,947 acres along the north shore of Georgian Bay. It is located on the Precambrian Shield and consists primarily of outcropping igneous and metamorphic rock containing large areas of granite. This type of steeply rolling topography and its effects on groundwater limits the types and locations of developments in the community. Mining, Forestry and Commercial Fishing have been the main employment areas.

The residents are of the Ojibway Nation and have traditionally always inhabited the area. They continue to use the Ojibway language and pursue traditional ways. The total population as of January 23, 2015 is 1,381 members of which 359 live on-reserve and 1,022 band members live off reserve. The large number of band members living off reserve is due to the number of reinstated registered members under the Bill C-31 process of 1985. There are 160 households.

Sources: Community Profile provided by Serpent River Community. Population numbers differ from INAC profiles and reflect community definitions.

A total of 12 individuals participated in interviews (2) and focus groups (10) from Serpent River First Nation. Participants included representatives from the health sector and education sectors.

M'Chigeeng First Nation

The M'Chigeeng First Nation is located on beautiful Manitoulin Island in Lake Huron in the Province of Ontario. It is situated in one of the highest elevated terrains in the area giving it an advantage for Wind Farm Development projects. The community has a total population of 2,437 band members and is located within the boundaries of 3,094 square hectares. The community is recognized as a progressive community supporting local Governance, Education, Local Business development, and Community infrastructure Projects.

The community is Governed by an 11 member Chief and Council elected for two year period terms. Advisory Groups appointed by Chief and Council provide advisory services. M'Chigeeng is well known as an accountable and well governed community with leadership remaining in office for as many as Five (5) terms at a time.

Managing the First Nation with the Chief and Council is a Management Team consisting of a CEO and Eight (8) Department Managers managing departments that include Education, Health Services, Economic Development Social Services Capital Works, Finance, Ontario Works and Child and Family Services. Annual Budgets and Work plans are submitted and approved by the Department and Management staff accordingly.

Sources: Community Profile from M'Chigeeng Community; Population numbers differ from INAC profiles and reflect community definitions.

Seven individuals participated in a focus group from M'Chigeeng First Nation. Participants included a community member, an Elder and representatives from band council/ band administration and the health sector.

Strengths and Limitations of Methodology

The goal of qualitative research is to deepen researchers' understanding of phenomena such as human behaviour, cultural or social organizations and is intended to describe complex social and or cultural dynamics and individual perception. While the project aspired to get input from more communities, the total sample size of 32 is ample in the context of the broader study to understand engagement with First Nations communities. While the views of individual participants cannot be generalized, they provide insights into the literature review, survey results and key informant interviews from previous phases and deepens our understanding of First Nations experiences of engagement with public health units.

While the project team wanted to engage with and hear from a wider array of communities, the tone of the meetings and stories differed across the three participating communities reflecting

each community's unique history, culture and experiences. For example, some communities had more interaction with outside agencies while other communities had less. These experiences were reflected in the kinds of encounters they experienced and the stories that they shared. Further, most, if not all of the First Nations communities would have been unaware of the new public health guideline around engagement because it is a relatively new guideline for Public Health (MHLTC, 2018). Prior to this guideline, there was no explicit mandate for boards of health to engage with First Nations communities. Many participants shared stories that reflected their experiences going back ten or fifteen years and would not yet reflect this new mandate. This context provides insight and deepened understanding on the current state of engagement amongst First Nations communities and public health units in the Northeast.

The Gathering and Sharing Learning phase of the research provides insight into the experiences of First Nations community members first hand and is critical to answering the project research question: *What mutually beneficial, respectful and effective principles and practices of engagement between First Nations communities and public health units in Northeastern Ontario can be identified, as an important step in working toward improved opportunities for health for all?* The adherence to the OCAP® principles further strengthened the entire research process.

What We Heard

Four key overarching themes emerged from discussions with the First Nations communities. The first theme, *(1) Positive Experiences and Ways of Working*, pointed to where engagement and collaboration was working well. The experiences and stories shared under the first theme provide examples of engagement that can form the basis for principles and practices. The second theme, *(2) Opportunities for Collaboration*, provides specific, practical examples of where there may be opportunities for collaboration.

The additional themes, *(3) Barriers to Collaboration* and *(4) Solutions to Effective Engagement* provide specific experiences and historical context that create barriers to collaboration and participants' advice on how best to overcome these barriers (shown in Figure 3 below).

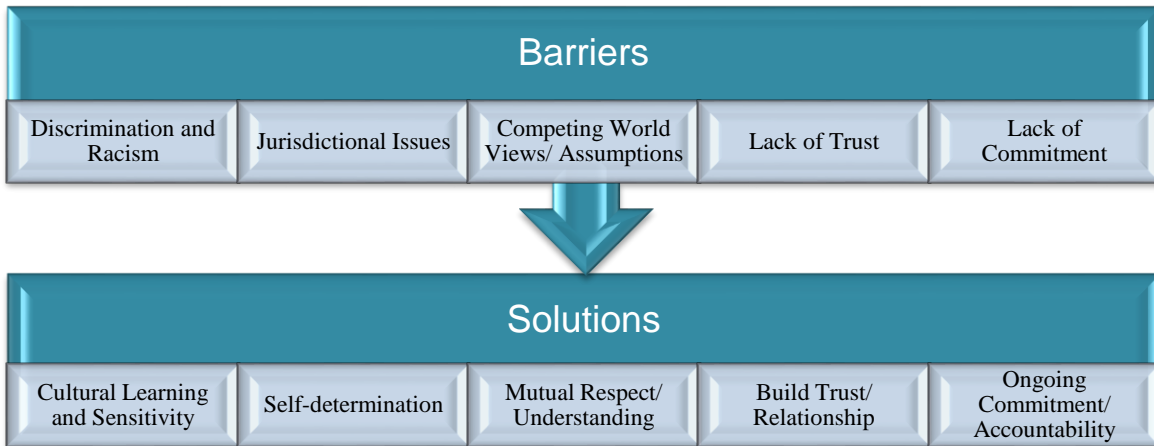


Figure 2: Overview of Findings Regarding First Nations View of Barriers and Solutions to Engagement

(1) Positive Experiences and Ways of Working

Participants reflected on examples of positive interactions or relationships and what worked well in these interactions. Key principles that emerged included:

- Representatives are respectful of their culture and value the opinions of those in the community
- Open and frequent communication - including face-to-face interactions
- Committed to and contributing to the community
- Collaboration is mutually beneficial

When staff or representatives are respectful of the First Nations culture and valued the opinions of those in the community, participants reported that the relationship was positive. One participant described it as follows,

“Our opinion was taken seriously, so that’s what I liked. It wasn’t, like, every First Nation was the same, like, they understood that we are all unique.”

Positive relationships required meaningful and frequent communications. Participants appreciated when public health workers checked in and asked questions noting the importance of face-to-face interactions. As one participant put it,

“What worked well was...that there was a lot of communication, whether it was through email, telephone, and a lot of face-to-face interaction. I think face-to-face interaction is very important.”

Consistently, when participants reflected on positive inter-agency collaboration, they emphasized the importance of coming to the community and contributing to the community. For example, one public health worker provided a healthy eating workshop and provided food as well as a hands-on experience. Participants noted that she even provided individuals with a slow cooker. This gesture demonstrated commitment to the community which was considered important to ongoing collaboration. Participants also shared examples that demonstrate other positive ways of working such as: being resourceful, understanding how services are provided in First Nations communities, and the importance of consistent follow-up.

“They have been resourceful when I needed resources, or an explanation... When she came out to do the fridge check, she went through that whole process with me.”

“They would also provide us with our STI results...I always found that they were very good at following up. They would ensure those results went to Health Canada...and they would always follow up with me to make sure that individual was treated.”

Participants also indicated that collaboration worked well when the focus was on client needs and the collaboration was mutually beneficial.

“I think we are one of the First Nations that's fortunate to have a very good relationship with public health. We are always looking at, you know, if it's going to be beneficial to our First Nations members. Absolutely utilizing those partnerships.”

(2) Opportunities for Collaboration

When participants reflected on specific opportunities for collaboration, they often spent time educating the interviewers on what and how services are provided in the community. While participants identified specific areas for collaboration, an important first step to collaboration is a mutual understanding of each other's programs and services.

“And I think there is very little interaction because I think the public health units don't know enough about First Nations and how we do things, or what we do provide or what we could utilize assistance with, like we do have prevention programs but sometimes it's to get the professionals to come in and assist with those programs which would really be a bonus to the First Nations also.”

Developing a mutual understanding of each other's programs and services extends to developing an understanding of how program's and services are organized and who in the community or at public health units are providing programs. For example, the comment below makes specific reference to resources that were hired for the community,

“Other than that, working with the public health unit wasn't on top of our priority list. These programs like the prevention and health promotion, was done right at the health centre, that's what these workers were hired for.”

The following quote speaks to the community's openness and willingness to explore partnerships,

“I think I would like to see more of a commitment from public health. Just being the only health promotion worker in our community...there is a lot of health promotion topics and a lot of things that need to be covered with our community members. I look at public health a lot, even the website...so it would be nice to have a respectful and committed relationship with them where we could work together to provide more information.”

Participants also described potential areas for collaboration with Public Health Units, such as:

- Food handlers training
- Client navigator and advocate
- Smoking cessation workshops
- Healthy eating, diabetes management
- Screening for students and curriculum support in schools
- Sexual health services
- Immunization
- Child and family health
- Support with communications around pandemics
- Dental health and screening
- Dog bites
- Needle exchange program
- Naloxone training
- Environmental health and safe housing

One participant described a successful collaboration between their community and public health in regards to dental health,

“Other instances that we have utilized public health, again one of the ones that's been very successful is the dental. [He] has been coming to our community for a number of years and providing dental screening in elementary school. And we have actually assisted in trying to get [him] into other First Nations because he was having some struggles being accepted or being allowed to go into schools in some other First Nations. So, we worked with [him] to try and smoothen that transition. So, it was good, it was very positive, and the bottom line is that it assisted our young students in oral health.”

Collaborating on service delivery could lead to further engagement and create an opportunity to collaborate on policy issues.

(3) Barriers to Engagement

Participants shared several negative experiences accessing or engaging with public health providers. Participants indicated that there can be hesitancy to engage because of preconceived notions and barriers to collaboration due to historic experiences of public health unit staff being authoritative, condescending and discriminating. Many participants talked about the systemic

barriers related to jurisdictional mandates. These experiences have contributed to a general lack of trust of public health units and other mainstream agencies and doubts regarding the commitment that public health units have around engagement and service delivery.

Discriminatory Behaviors and Practices

One community provided examples where the local public health unit displayed an attitude in which they felt they held superior knowledge, protocols and practices. Participants described instances where they were not treated as professional equals by public health staff, despite providing public health services to their First Nations communities.

For example, one participant described challenges around immunizations and ordering and storing vaccines as follows,

“I find immunization the least effective working in First Nations communities. There are several things, but one they come and check the fridge, really they are mandated to supply the vaccine first, that’s it, we let them check the fridge, but they actually insist on them doing.”

Another participant described their relationship with a public health unit as follows,

“I just find that, it seems like there is so many barriers with policies, almost like they think they are the only health organization that’s ever been and none of us really know how to think or do our work.”

Further, participants questioned why they received different responses from one public health worker to the next and described feeling “let down” when there was no follow-up and have been left “waiting weeks or hanging”. One participant described their feelings,

“I do feel that it is a lack of respect, when I think about my relationships with other agencies that I work with, and I think even about personal relationships that, if I think a matter is important to another person and if I respect that person enough I am going to go the extra mile and make sure I call them.”

In another community, where the relationship with the local public health unit was described positively, participants still noted discriminatory practices around a Meningitis outbreak,

"I recall an incident back when they had the Meningitis scare in a high school in Sudbury. So, they were offering the medications for the students in the Sudbury area. So, I called public health, and I said why are you not offering that same thing to the students on Manitoulin? They said they thought it was kind of isolated, they said we are only worried about interactions with the students that are say playing football against each other or whatever. I said well we are part of the school district. I said our kids are playing against these kids. I said I think you guys missed the boat on this thing. I said our kids should be having that same access. ... Now we make sure Manitoulin is included."

Another barrier that participants described was where there was a hesitancy or lack of information sharing around patient care,

"I think when you have had a conversation with somebody that you are sharing the care of, that mutual respect says that the communication goes two ways and that's where I felt that very let down; on more than one occasion. So that was, like I understand they are very busy, but you know so are other people and it does leave you to feel not respected."

Jurisdictional Issues

All communities identified jurisdictional mandates as an issue, noting that the differences between provincial, federal and First Nations protocols and processes can lead to conflict and/or confusion.

One participant described the frustration felt when they come up against mandate issues,

“One of the most frustrating things to hear is “oh that’s a federal responsibility”, sorry you are on reserve so, that’s a federal responsibility, we can’t engage you on that. That’s probably one of the most frustrating things to hear as an administrator and so if the protocol can also clarify those lines and focus on how we can work around that.”

Two of the communities raised the challenges they have negotiating differences in protocols and standards between federal and provincial jurisdictions. First Nations communities are equally concerned about safety for their people and want to ensure that they are meeting high standards, but when federal and provincial codes are not aligned, they described feeling “*stuck in the middle*”.

“The public health world, they have their own standards and First Nations in this community, they have their own way of writing things and their standards but somewhere in the middle they are not meeting and it’s like, no, no, no. So, you are not getting what you need for your people.”

The third community focused on jurisdictional issues related to catchment definitions. For example, when a First Nations community is determined to intersect with a public health unit and then the community requests support from another public health unit, they would be told that they are “out of our district”. Participants noted that these experiences can serve to undermine their confidence in and commitment to building a relationship.

First Nations, federal and provincial governments are each funded according to specific mandates. These can create silos and participants noted how these silos can negatively impact access to services for First Nations clients. Examples include:

- Repeated entry to services may re-traumatize the client – for example when clients are asked to repeat their story several times to different providers
- Money driven services versus client-driven – such as where funding drives how services are provided as opposed to client need
- Being let down by inflexibility of public health unit services – this included times when individuals or communities tried to access public health unit services and told “no” for any number of reasons
- The impact that band membership has on accessing services – sometimes band membership can impact which services can be accessed such as access to health transportation

“I don't think there is that much, like I have been out of the system for a while but I don't know how much interaction there is in public health units and First Nations because we are always considered federal and public health never came into the community because they were provincial, that was always, always a big problem.”

Competing World Views/ Assumptions

Competing world views around health services and the way services are managed can also create barriers to engagement. The First Nations world view of health is much more holistic and does not necessarily distinguish between primary care, public health, mental health, etc. but rather comes from a balance of physical, emotional, mental and spiritual health. This competing world view can be apparent in the way services are provided. For example, the participant below referenced the protocols and hierarchy that exists within public health,

“They can't change their practice without having to go through managers and then through the chief medical officer. Whereas here because we are inter-professional or more of a team approach, we can make changes to programs much easier.”

Competing world views can lead to assumptions and misperceptions on both sides. In one community, participants noted that there was a lack of public health unit presence and engagement and voiced their perceptions of what might be driving this, speculating that perhaps public health units:

- Felt unwanted in the community
- Felt that First Nations communities do not want mainstream services
- Are worried about offending or being too intrusive
- Do not know how to engage or what works best in First Nations communities

“It seems like they have this preconceived notion that because First Nations are self-determined that, that means that they don't want any access to resources or help and they are almost afraid that they are going to offend, or they are afraid to engage because historically the relationships haven't been that good”

Lack of Trust

Participants in all the communities reflected on how historic racism, discriminatory practices and jurisdictional mandates have led to a lack of trust and undermined engagement. For example, one participant shared the following:

“So, all those outside agencies come in, they want to do studies and they want to use all our numbers... they did that and then when we wanted to send people there for services, they refused us, that's what. So that was a barrier then, then we get leery about where is all our information going and why can't we get service?”

All three communities shared similar experiences where information was gathered from their community but then the results of the study or report are not shared back with the community. Because of these negative experiences, participants described losing faith and questioning the motives of potential partner agencies.

“You almost feel, as a health care provider, hesitant to even pick up the phone and call for any reason as a result because you know almost the answer before you will ask the question and I can anticipate the barriers.”

Another participant shared how a lack of trust was evident while working with mainstream community partners as part of a coalition, and the effect it had their partnerships and the work they were trying to accomplish.

For our community diabetes program, it was really hard for us to get off the ground...we couldn't understand what was happening, what is this meeting about again...We weren't quite sure what exactly our goal was, it was never a clear understanding. There was a mistrust with the person who was leading it, because we didn't have any leadership or a First Nation navigator so that trust could be developed. With that committee, we had a lot of people around that table who were experts and I think there could be more happening with that program.

Lack of Commitment

Participants across all three communities consistently noted that inconsistent engagement with partner agencies signaled a lack of commitment to true partnership. Participants described the following issues:

- No consistent contact or communication with public health unit staff
- Inconsistent approaches among health unit teams, divisions and office sites
- Discontinuation of services
- Staff turnover and loss of contacts
- Services offered do not meet community needs and a lack of flexibility

For example, one participant described the following experience,

“I would also add that when you are starting a program, and then poof they are gone. You just start to build that trust and then they are gone. ... And then they talk about them in a good way and some of them said you know I wish we had continued on. They formed a little support group amongst themselves. So that's what I would like to say, keep it going, when you start something.”

Participants identified that there was a lack of understanding by the public health unit around First Nations services and the resources available to each community, noting that public health units have to understand that funding and resourcing differs in each community:

“Because you know when you compare to communities like ..., you know probably 10-15 times bigger than here. So, their population base and their funding are going to be different, way different. So yeah don't compare us all the same.”

Similarly, First Nations community members do not understand what public health units offer and how to engage with public health units:

“I haven't done any engagement. It's obviously more positive already, just through this and everything, but I don't know who to reach out for...I wanted to do smoking cessation workshop but like, do I just throw a random email to someone I see online? I don't know. That's why I'm interested in this.”

Another factor that created barriers to collaboration was the fact that, historically, there has been little interaction with the public health unit for several reasons including:

- Working with other public health agencies (for example Health Canada)
- First Nations communities delivering public health services themselves
- Jurisdictional issues
- Being unsure of public health unit services or who to call
- Being new to a role

For example, First Nations communities receive funding from Health Canada for public health programs and so tend to work more closely with Indigenous Services Canada.

“I don't have a lot of direct contact with the health unit, like even if there is a dog bit reported they don't contact me, it's Health Canada that contacts me.”

(4) Solutions for Effective Engagement

Participants offered suggestions for effective engagement between First Nations and public health units beginning with cultural sensitivity and safety training for public health staff and

managers such as training on the Seven Grandfather teachings² (Ojibwe. Net, 2019). At the conclusion of the each focus group and/or interview, participants reflected on the four principles that came out of the project’s literature review in phase 1: *respect, trust, self-determination, and commitment*. Most participants agreed these principles were important and provided advice related to how these principles can support effective engagement.

Cultural Learning and Safety Training

Participants reinforced the importance of public health units grounding their engagement in a clear understanding of First Nations culture and historical context prior to beginning any engagement. Participants suggested that staff receive training around First Nations culture. However, participants went beyond formal training and suggested ways in which public health unit staff can integrate their training. For example, getting involved with activities in their own communities (e.g., at the Friendship Centre) and exploring ways to acknowledge and celebrate Anishinaabe culture.

“From culture perspective you can introduce the practice, like utilizing an Elder, discussing things and medicine and opening prayer and what that signifies in terms of our commitment... and it speaks to all of those things about respect and trust. Those are almost like the Grandfather teachings there. And then if you put those forward first, people realize if I am going to get into relationship with you, I already know what to expect, I already know what is expected from me.”

Participants provided specific advice on how program resources such as brochures and information could be drafted to be more inclusive of a First Nations perspective (e.g., terminology and design). They noted that there can be language and comprehension barriers within First Nations communities, especially with Elders and that information needs to be presented in plain language and with a First Nations worker or nurse to provide clarification.

Participants also spoke about incorporating traditional concepts into public health programming.

² The Seven Grandfather Teachings are viewed by many Anishinabe as traditional knowledge that provide principles for living a good life. The teachings include: Minwaadendamowin – Respect; Zaagidiwin – Love; Debwebin – Truth; Aakodewewin – Bravery; Nibwaakawin – Wisdom; Miigwe’aadiziwin – Generosity; and Dibaadendiziwin – Humility. Source: Ojibwe.net. [The Gifts of the Seven Grandfathers](#).

“There are different parenting programs but sometimes you come from mainstream perspective but there is also First Nations approach to parenting and it ties into our teachings. Triple P parenting is a good program but if it's more culturally sensitive, it will be stronger.”

Self-determination

Participants indicated that it is important for public health units to understand where each community is with regard to their journey towards self-determination. In First Nations communities, the community has a say in the way services are provided within their own communities. Public health units need to understand the First Nations health system, the structure, and roles and come with a firm understanding that First Nations communities do not have the same services or funding.

Develop Mutual Respect and Understanding

When reflecting on the four principles, participants indicated that there is a need for both the public health unit and First Nations communities to develop a mutual understanding of each other's services, mandates and way of working in order to come up with solutions and ideas of how they might work together.

“I am just thinking about all the issues that were brought forth just now, and maybe having a partnership with a memorandum of understanding, so that way you have some paper backing, saying yeah we have a partnership, at least you have all the outlines described in it, so that way everybody is on the same page, public health and First Nations.”

For example, one community described a positive partnership where the service partner came to the community and asked questions about how the community currently provided services and their local protocols. This was viewed as respectful to their customs and traditions and they were able to identify where the service provider could address gaps in service and/or knowledge. The service was seen to be mutually beneficial.

Communities agreed that the Health Director should be the point of contact for any incoming requests from the public health unit and that clear ground rules need to be established up front. Participants also underscored the importance of coming to the community and meeting face-to-

face to discuss services and explore opportunities to work together. Participants advised public health units to be honest about what they can commit to and to ensure any partnership is mutually beneficial.

“Respect, respect is a two-way street. They respected cultural ways, for us here which was very good. They knew that we had our own traditional food, they know what we eat. They did not try and take that out of the menus we were trying to develop. So, respect was a two-way street - we got respect, they got respect also.”

Participants also shared their ideas around how First Nations communities and public health units could come together to develop this mutual understanding. Ideas included:

- Hold a meeting to clarify roles and responsibilities, policies and procedures
- Discuss and understand barriers
- Work together to identify solutions (and include front-line staff)
- Identify gaps in service and potential partnership opportunities
- Develop a memorandum of understanding
- Hire a First Nations navigator to advise and build trust

Build Relationships and Trust

Building relationships and trust takes time and commitment. There was broad agreement across all communities that relationship building needed to happen face-to-face so that people could get to know each other, begin to understand roles, and learn about each other’s programs. Participants noted that the partner organization’s willingness to come to the community was noticed by community members and helped to build respect and trust.

One participant, when reflecting on the four principles noted the following,

“I think it sounds like a domino effect. If you have respect, then you will gain trust and there is more commitment from all parties involved and as time progresses maybe self-determination can happen more readily. So those four attributes are all intertwined.”

Participants also wanted to see that partner organizations were open and willing to go above and beyond to build the relationship, noting that food was an effective way of bringing people together.

“Just having a consistent person, but I mean, that goes for both sides as well, the First Nations community has their turnover as well. Coming in to the community as well, having that contact within the health centre, and then if you’re doing a community presentation, food is a good thing to bring people in.”

Participants also wanted to see more of a visible presence by the public health unit in the community and wanted public health units to ensure that when First Nations visited public health units that they are welcomed and are made to feel comfortable. Overall, participants were optimistic that with time and commitment, public health units and First Nations communities could begin to build connections and trust between them.

Ongoing Commitment and Accountability

Commitment was seen by participants as key to building trust and effective engagement. Participants describe the importance of commitment and accountability to their community members. This means that if the organization has said that they are going to do something, then the organization must follow-up. Public health professionals providing services in the community, including the Health Director, are accountable to their community members. If an external provider does not follow through on a commitment, it reflects on the individual who engaged the external provider. Public health unit commitment means that as an organization, you understand that health professionals working in the community are *professionals* and are accountable to their community.

“Commitment is absolutely essential too, if one leaves the other hanging and when you work for your own community, every single day everybody knows each other there is an expectation and if that expectation has been broken then the trust with the community has been broken with those service providers”

Participants were aware that because they are both involved in public health activities that learning and resource sharing could be mutually beneficial,

“I think I would like to see more of a commitment from public health. Just being the only health promotion worker in our community...there is a lot of health promotion topics and a lot of things that need to be covered with our community members. I look at public health a lot, even the website...so it would be nice to have a respectful and committed relationship with them where we could work together to provide more information.”

Examples of mutually beneficial engagement that demonstrated commitment needed to be ongoing and could include:

- Regular meetings with a standing item to discuss partnership opportunities
- Invitations from public health professionals on both sides
- Ongoing sharing of materials, handouts, and information
- Working meetings to improve protocols and processes
- Use of community newsletters to share information and events
- Open up networking/ training opportunities to each other
- Build off positive experiences
- Attend events such as high-school luncheons

Discussion

The research team shared the results of the Gathering and Sharing Learning Phase with the Indigenous Circle for discussion and input. Their insight and experience provided a deeper interpretation of the qualitative data that was collected in the communities. The following section organizes the input from the Indigenous Circle by the specific project objectives.

Current State of Engagement across Ontario First Nations Communities and Public Health Units

The Indigenous Circle and Project Team agreed that while there are many opportunities for collaboration, the barriers to collaboration identified and the examples provided by participants can be seen as evidence of systemic discrimination for First Nations communities in engaging with and accessing mainstream public health. Upon reflecting on these findings, Project Team members acknowledge the public health system's role in maintaining the underlying structures and attitudes that have resulted in institutional racism and, in turn, contributed to systemic racism. Public health has been complicit in eliminating policies, practices and procedures that appear neutral but have the effect of disadvantaging racialized groups.

Further, focus group and interview participants identified significant barriers related to jurisdiction that require systemic policy, legislative and mandated solutions in order to address. They also provided further insight and direction on solutions and next steps particularly on building capacity of front-line community health staff that address public health issues within First Nations communities.

Systemic Racism and Discrimination

The Ontario Human Rights Commission defines systemic discrimination as follows:

“Systemic discrimination can be described as patterns of behaviour, policies or practices that are part of the structures of an organization, and which create or perpetuate disadvantage for racialized persons.”

Source: Ontario Human Rights Commission.
Racism and Racial Discrimination (fact sheet).

Systemic racism is like systemic discrimination but is present when the discrimination occurs on the basis of race:

A system in which public policies, institutional practices, cultural representations, and other norms work in various, often reinforcing ways to perpetuate racial group inequity. It identifies dimensions of our history and culture that have allowed privileges associated with whiteness and disadvantages associated with colour to endure and adapt over time. Systemic racism is not something that a few people or institutions choose to practice. Instead it has been a feature of the social, economic, and political systems in which we all exist.

Source: Aspen Institute

Specifically, the Commission notes that formal and informal policies, practices and decision-making processes can result in barriers for and exclusion of racialized persons. The experiences shared such as public health units not allowing vaccines to be stored in communities because the refrigerators do not meet provincial standards, or the example of the Meningitis scare in the Sudbury high school where the Manitoulin students were not initially offered a vaccine are clear examples of where policies, practices and/or decision-making resulted in barriers for First Nations communities. The ongoing jurisdictional conundrum of who is responsible for public health services has also been allowed to continue, resulting in a two-tiered public health system, with First Nations receiving inadequate services when compared to other Ontario citizens.

Another form of systemic racism and discrimination occurs in organizational culture where practices and approaches of the dominant culture are valued over other styles or approaches. Whether conscious or not, First Nations communities perceived that their way of doing things were not valued by public health staff.

The Indigenous Circle noted the importance of naming the issue of systemic racism and discrimination from a human rights perspective and a recognition of its impacts in the delivery of public health services. The Ontario Human Rights Commission cautions that it is not acceptable for an organization to remain unaware of systemic discrimination or to fail to act when a problem comes to its attention.

Jurisdictional Roles and Responsibilities

The sense of discrimination is further sustained through the ongoing lack of clarity around jurisdictional roles and responsibilities. First Nations public health services are typically under the mandate of Indigenous Services Canada (ISC) and operate independently from other systems such as local public health agencies and Public Health Ontario. Indigenous Services Canada either provides public health services directly or supports, funds and oversees First Nations to deliver these services. The research showed that First Nations community health professionals had limited knowledge of the provincial system and felt that public health staff lacked an

understanding of how services were provided in First Nations communities. This separation of services is rooted in the government's interpretation of Treaty rights and the Indian Act. The United Nations Declaration and the Truth and Reconciliation Commission recommendations encourage all levels of government to reconsider these silos in order to address health equity.

The most well-known Canadian example of jurisdictional silos is Jordan River Anderson, a young Norway House Cree Nation boy, impacted by a payment dispute between the Federal and Provincial government about who should pay for services. Jordan was born in 1999 with multiple disabilities and stayed in hospital from birth. When he was two years old, doctors said he could move to a special home that could care for his medical needs. However, the federal and provincial governments could not agree on who should pay for this home-based care and Jordan passed away in hospital at the age of five (Government of Canada, 2018).

In 2007, the House of Commons passed Jordan's Principle in memory of Jordan and committed that First Nations children would get the products, services and supports they needed when they need them, and payments would be worked out later at a bureaucratic level.

While Jordan's Principle is specific to children and children's services, the concept behind the gap persists across health services. Participants clearly expressed frustration around jurisdictional issues and who is responsible for what. The Indigenous Circle noted that with a public health crisis in many First Nations communities, disputes around who is responsible for what leaves communities with limited capacity to address these issues without the benefit of established standards, legislation, professionals and resources available for other citizens in Ontario.

The Ministry of Health published the *Relationship with Indigenous Communities Guideline* in 2018 which is intended to assist boards of health in implementing the requirements to engage in *fostering and creation of meaningful relationships starting with engagement through to collaborative partnerships with First Nations and Indigenous communities striving to reconcile jurisdictional issues* (Ministry of Health and Long-term Care, 2018). This begins to clarify that there is a role and responsibilities of public health units to engage First Nations communities.

While this guideline is a positive step towards recognizing the challenges related to jurisdiction by providing a clearer mandate to boards of health, the Indigenous Circle members noted that there are many issues around jurisdiction that remain unclear including legislative coverage. Most First Nations communities lack the resources to meet provincial standards and through appropriate engagement would embrace the opportunity to access training and support. The power imbalance persists with public health units having access to more resources, support and training. Because of this imbalance, the responsibility for outreach rests with public health rather than the communities.

Further, it was noted that the responsibility for sorting out any jurisdictional uncertainties should not be borne by the First Nations.

Enhance Relationships between Participating First Nations and Public Health Units

The public health challenges facing First Nations communities in Ontario and the difficulties in providing adequate services will require system-level commitment and nation-to-nation negotiations and agreements that the Indigenous Circle noted, are beyond a local public health unit's mandate. The Ministry of Health and Long-term Care published the *Relationship with Indigenous Communities Guideline* in 2018 which is intended to assist boards of health in implementing the requirements to engage in *fostering and creation of meaningful relationships starting with engagement through to collaborative partnerships with First Nations and Indigenous communities striving to reconcile jurisdictional issues* (Ministry of Health and Long-term Care, 2018). This begins to clarify that there is a role and responsibilities of public health units to engage First Nations communities and the guideline underscores the importance of engaging in a way that honours a traditional view of health (described earlier in the document) and the right to self-determination.

This report provides examples of First Nations' experience of engagement with public health which are both positive and negative that can form the basis for principles and practices. The following section outlines these principles and practices in more detail.

Wise Practices

The advice that was provided by First Nations participants was relatively consistent and provides a clear roadmap for further engagement as illustrated in the following diagram.

Principles of Engagement: *Respect, Commitment, Trust and Self-Determination*
Linked to: *Deepened Understanding, Stronger Relationships, Systems Change, Increased Accountability*

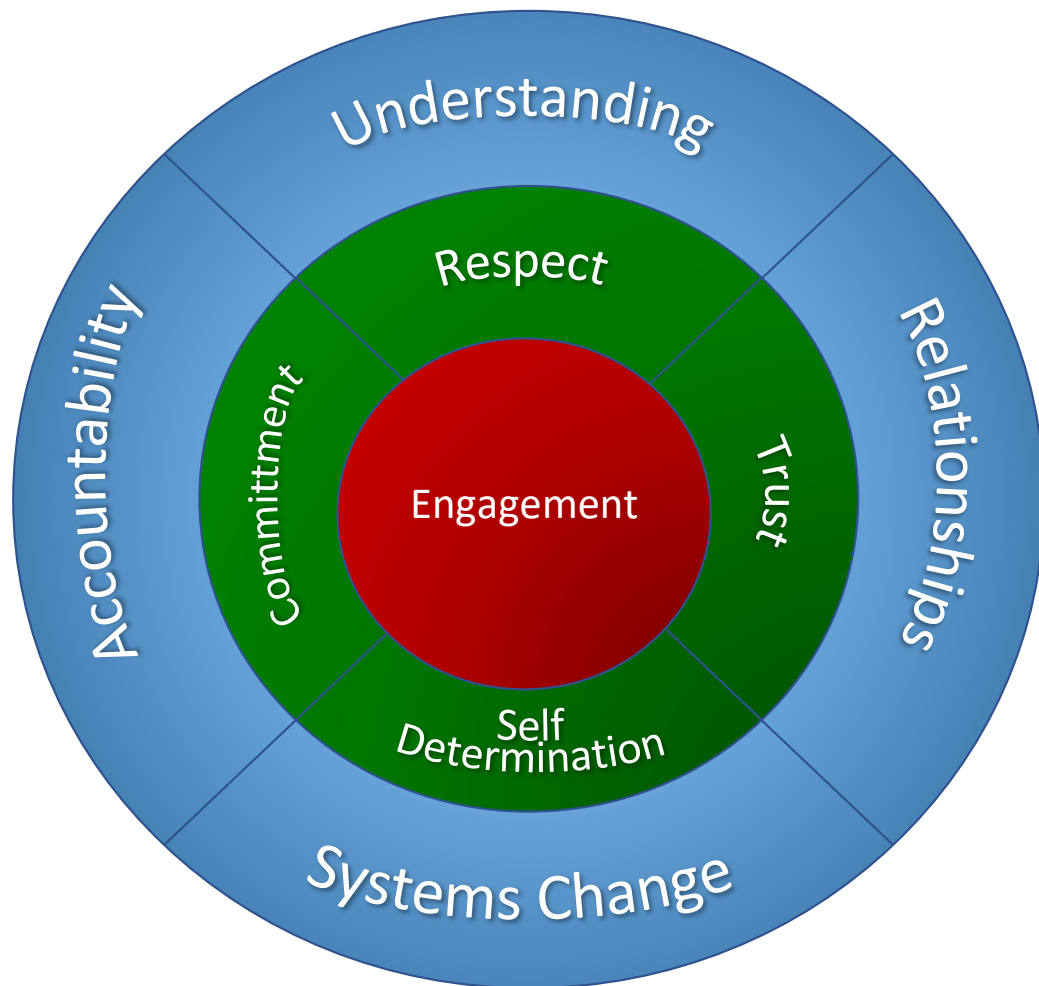


Figure 3. First Nations and Public Health Engagement Framework

The above framework shows engagement in the middle as the goal. The four core principles of engagement: Respect, Trust, Self-Determination and Commitment form the middle circle or “core” of the circle. Along the outside are four outcomes that participants consistently identified as elements of effective engagement. The circle suggests a connection and fluidity between each of the concepts in the diagram. While the following section describes individual principles being linked to specific outcomes, the reader should understand that these concepts are not mutually exclusive or linear and that the principles can and do link to more than one of the outcomes.

Respect – Linked to Deepened Understanding

Engagement with First Nations communities begins and ends with respect. The concept of respect “mnaadendamowin” is one of the Seven Grandfather teaching and is represented by the buffalo. *The buffalo, through giving its life and sharing every part of its being, showed the deep*

respect it had for the people. This sustainable and mutual relationship with the buffalo resulted in a relationship that was true expression of respect (Empowering the Spirit, 2019).

This is a fundamental underpinning of all interactions with First Nations and means understanding that no one stands above or in superiority of anyone else and that relationships are reciprocal and self-sustaining when they begin with *respect*.

While systemic discrimination is an issue that governments must address, public health agencies also have a responsibility to look internally and identify practices and policies that can be discriminatory. This organizational awareness links to the concept of “no one standing above or in superiority of anyone else” and could support a deepened understanding of how the relationship between First Nations communities and public health could be reciprocal and self-sustaining.

The following are “wise practices” which participants identified that can support a deepened understanding of First Nations communities.

Cultural Learning and Safety Training

Prior to any engagement, public health unit staff need to have a firm grasp and understanding of First Nations history, culture, and protocols. Understanding begins with an understanding of the Seven Grandfather teachings. These are foundational teachings and learning needs to be internalized into true understanding.

“I think one of the things that public health can do when you are going out to First Nations looking at partnerships is having your own staff go through an awareness program of First Nations... it gives that staff member an understanding of you know where they are going in to and it's going to help with the acceptance of the First Nations. You know somebody comes in already knowledgeable of their community, knowledgeable of their culture, you are already building that trust on that first step because first impressions are so important right.”

Many participants had suggestions on how individuals can deepen their understanding by getting involved with activities in their own communities (e.g., at the Friendship Centre) and exploring ways to acknowledge and celebrate traditional culture.

Staff could also research the First Nations communities in their catchment area to get a base understanding of the history of that community from the community’s own perspective.

Engage Elders

In considering how public health can strengthen engagement with First Nations, seek out the wisdom of Elders who are knowledgeable about protocols, traditions and teachings of their respective First Nations communities.

Mutually Beneficial Interactions

Participants provided many examples of successful interactions. Successful interactions were mutually beneficial, recognized the expertise on both sides and were ongoing.

Participants saw potential for collaboration with public health units and provided a list of potential areas for further discussion and partnership, including:

- Additional food handlers training
- Client navigator and advocacy
- Smoking cessation workshops
- Healthy eating, diabetes management
- Screening for students in the schools
- Sexual health
- Immunization
- Child and family health
- Other health promotion topics
- Support assistance with communications around pandemics
- Dental screening/ health
- Dog bites
- Needle exchange program
- Naloxone training
- Student presentation, health curriculum, more presence in the school

It is important to understand and align opportunities for collaboration with the public health priorities of the community with whom public health is engaging.

Trust – Linked to Stronger Relationships

Participants shared experiences they had with public health and other mainstream organizations which influence their openness and willingness to engage. Trust is something that is earned over time through sustained effort. Participants provided some suggestions of what can be done to encourage trust and what to avoid that could undermine trust. Respect and trust are the foundations for building a relationship between public health units and First Nations.

Face-to-face meetings

Once there is some openness around engagement, suggest a face-to-face meeting in the First Nations' community. All participants emphasized the importance of face-to-face meetings in developing trust and signaling a commitment to building a lasting relationship.

If the engagement is focused around training or program delivery, look for ways for activities to happen in First Nations communities and/or facilities.

Welcoming and Culturally Safe Environment

Seek advice on how to make public health unit space culturally safe. Identify local interpreters who can interpret materials. Ensure materials and brochures are written in accessible language and translate materials, whenever possible.

Identify Opportunities for Collaboration

First Nations see many practical benefits of working with public health units. Many examples were provided of positive interactions for example, a public health staff providing a slow cooker demonstration and providing participants with a slow cooker after the event; dental screening in the schools; support and assistance with pandemic communications; and sharing information on health promotion topics. Discussions on programs and services can provide a forum for identifying opportunities for collaboration. Collaborating on the delivery of a program can set a foundation for building a stronger relationship and developing trust over time.

Self-determination – Linked to Systems Change

The other piece that emerged as critical in the Gathering and Sharing Learning phase was the importance of recognizing the right to self-determination in any engagement. The recent guideline underscores the importance of engaging in a way that honours a traditional view of health and the right to self-determination:

It has also been cited that self-determination is the most important determinant of health among Indigenous People. Self-determination influences all other determinants including education, housing, safety, and health opportunities. Research has shown that community initiatives, cultural pride and the reclamation of traditional approaches to health and healing have helped to improve and promote mental, physical, emotional and spiritual health within Indigenous communities. Raising awareness among health practitioners of Indigenous cultural practices, histories and worldviews particular to the region in which they work are key to bridging gaps of misunderstanding among public health practitioners and the Indigenous People they serve.

Excerpt from: Ministry of Health and Long-term Care (2018). Relationship with Indigenous Communities Guideline, 2018. Population and Public Health Division, p. 7.

This recognizes that self-determination is not only an essential right of First Nations people but also that there are inherent health benefits to self-determination. The Indigenous Circle provided further insights and advice on the importance of recognizing the differing world views around health noting that traditional views of health are more holistic and as highlighted in the quote above encompasses mental, physical, emotional and spiritual well-being. As noted previously in this document, Western medicine makes a distinction between primary care, public health, mental health, etc. which does not align with the more holistic view. In First Nations communities, health services are provided in an inter-professional team-based approach which has less silos and is less hierarchical than Western approaches. Breaking down silos and incorporating traditional world views into First Nations health services requires system-level change.

Systems change is well underway with First Nations communities taking control over the delivery of health services in their communities. While First Nations communities in Ontario are on a journey towards self-determination and health transformation, it is important to understand that each community is at a different stage of transferring services to communities. Each community is unique and has its own history and experiences which influence community governance and capacity to delivery.

Building Capacity

It is important to understand what services and programs are provided in each community and how they are provided. In some communities, the Band may be fully responsible for delivering public health services with funding from Indigenous Services Canada. Others may be in the process of transitioning services to the community with some shared responsibility for delivering services with Indigenous Services Canada. Capacity is an issue in many communities and there are opportunities for public health to engage with First Nations communities on how they can support building capacity in the communities.

Participants recommended that the Health Director be the first point of contact for public health engagement. Sharing information about the programs and services offered in the communities and listening to what community health professionals identify in terms of capacity can help guide further engagement. There was significant interest in most communities around opportunities for professional development and exploring ways to enhance or supplement existing programming.

Hire Indigenous Staff

Hiring Indigenous staff within the public health unit or an Indigenous navigator was another recommendation from communities. This could assist the organization with outreach and Indigenous engagement. A diverse staff that reflects the community it serves can also help to create a more culturally safe environment.

Commitment – Linked to Accountability

Commitment from public health units was an important predecessor to engagement. Many participants provided stories of service providers coming to their communities once and then not returning, collecting information and not providing feedback, or starting a program and then losing funding and the program ceases. Participants explained that within their communities, they were personally accountable to community members. A lack of commitment by a potential partner can reflect poorly on them and impact their credibility within the community. In addition, starting a program and then stopping it because of lack of funding or shifting prioritizing also has a significant impact on clients. Because of this, it is important that public health is clear and transparent around whether there is funding or senior level support for engagement and whether and how engagement can be sustained.

Participants provided ideas on how to demonstrate commitment to engagement and be accountable to one another.

Outreach Protocol

With a base understanding of the First Nations community with whom the public health units intend to engage, initial outreach should begin with the Health Director of that community. Public health units must be clear on the purpose of the proposed engagement and whether any

money or resources are attached. The Health Director can provide further direction on protocols for engagement within their community. They may recommend a letter to the Chief and Council.

Recognize that building trust takes time and commitment. First Nations communities are under-resourced with many competing priorities. There may be many reasons why First Nations communities may be hesitant to engage and the public health unit should not assume that the door is closed forever. Keep learning and keep trying.

Policy Development

First Nations communities recommended clearly identifying roles, responsibilities and expectations through formal documentation (e.g., joint protocol, memorandum of understanding) to support long-term, sustainable collaboration. These documents serve as a formal record of the partnership and can be used to hold parties accountable to one another.

As mentioned at the beginning of the Discussion section, collaboration and policy development requires nation-to-nation collaboration. Indigenous Services Canada is primarily responsible under the *Indian Act* to fund health services in First Nations communities. The Ministry of Health and Long-term Care also has a role to play in ensuring equitable access to health services for First Nations communities and supporting self-determination. This includes setting expectations for public health units to engage with First Nations communities and clearly outlining legislative responsibilities (e.g., for the Chief Medical Officer of Health) in communities.

Conclusion

The results from the Gathering and Sharing Learning phase of the project provide a First Nations perspective on findings from the other three phases. Participants provided their views and perspectives on the primary research question:

“What mutually beneficial, respectful and effective principles and practices of engagement between First Nations communities and public health units in Northeastern Ontario can be identified, as an important step in working toward improved opportunities for health for all?”

Specifically, this phase contributed to the following objectives of the project:

- Describe the current state of engagement across Ontario First Nations communities and public health units
- Explore selected examples of engagement in the Northeast that can form the basis for principles and practices
- With guidance and community-driven direction from an Indigenous Circle (comprised of Indigenous community representatives from across the Northeast) and in partnership with First Nations, the project will:
 - Enhance relationships between participating First Nations and health units.
 - Identify promising strategies, principles, and practices for engagement of First Nations and local public health and can be a foundation for guidance that will be available to all of Ontario’s 35 public health units.

The Gathering and Sharing Learning Phase provided a First Nations perspective of the current state of engagement. Participants shared their experiences of where engagement with public health was effective noting successful engagement included:

- Representatives were respectful of their culture and valued the opinions of those in the community
- Communications were open and frequent and included face-to-face interactions
- Demonstrated commitment to and contributions to the community
- Collaboration was mutually beneficial

The principles for engagement identified in the literature review (i.e., respect, trust, self-determination and commitment) were brought to participants and seemed to resonate with participants and some identified alignment with the Seven Grandfather teachings which should be considered as well. The Indigenous Circle pointed out that there are differing interpretations of these teachings which reflect a way of being in the world. Thus, the four principles form a good foundation to guide public health engagement with First Nations communities.

The framework presented in the discussion section was endorsed by the Indigenous Circle which ties the four principles to specific wise practices suggested by communities.

Results obtained from the overall project will contribute to the development of promising strategies, principles and practices for mutually beneficial engagement with First Nations and public health units. Such findings may serve as a foundation for guidance that will be available to First Nations communities and Ontario's 35 public health units as well as other organizations and partners.

Next steps

Next steps include validating the overall results from the Gathering and Sharing Learning phase with the community advisory committees, the Indigenous Circle and the research team. In keeping with the principles of engagement and knowledge exchange, a summary report will be shared with the participating First Nations communities and public health units will continue to engage with participating First Nations communities to discuss how to move forward together to strengthen their relationship and action the findings of this research project. During the validation process, it will also be important to identify how the teachings and recommendations presented in the Gathering and Sharing Learning document and overall study are shared. Target audiences will need to be identified and confirmed as well as the ideal methods of reaching these groups. Some of these groups will include other First Nations, other public health units, provincial governments and perhaps others. Some of the questions that need to be answered:

1. What are the key messages/recommendations of the study?
2. Who needs to hear them?
3. How can we convey these teachings collaboratively?
4. How do we “action” the study together?
5. What tools are going to help us mutually in this process?

A final overall report for all phases of the study will also be developed and disseminated. Knowledge exchange strategies and approaches that are utilized will consider different target audiences, be versatile depending on the type of presentation, and facilitate culturally-appropriate ways of sharing the findings. For example, findings could be shared at a local event within the communities. Public health could work with Health Directors to identify a meeting or other event (e.g., a Health Directors meeting or a Chiefs Meeting) where a presentation and discussion of the findings could be shared.

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Appendix A – Interview Guide for Gathering and Sharing Learning Phase

INTERVIEW GUIDE

Study title: Talking together to improve health



(Prior to starting, the facilitator is to verify that participants have consented to participate and participants receive their own copy of the consent form)

Facilitators [please read to the focus group/sharing circle participants]

- Thank-you for agreeing to participate in today’s focus group/sharing circle or one-on-one interview.
- Participation in the study is completely voluntary and you can make an independent decision as to whether or not you would like to participate. The focus group/sharing circle process will last approximately 2-3 hours and will involve participating in an audio-recorded group interview. (For interviews: the interview will last approximately 1 hour).
- This focus group/sharing circle is not meant to be stressful. There are no right or wrong answers. We would like to hear your input with the objective to identify promising principles and practices for engagement between First Nations communities and public health units.
- Feel free to ask any questions at any point during the interview. You can choose to answer some or all of the questions and withdraw your participation at any time without consequence.
- All participants are asked to keep confidential any information shared during a group interview. However, an individual participant may choose to disclose their identity if they have noted this on their individual consent form

Before we begin the interview, I would like to provide a brief overview of what the public health system has to offer.

Public health is committed to: improving health outcomes in the community, promoting healthy living and behaviours, reducing social inequities, addressing social determinants of health, preventing the onset of diseases/ infections, a focus on protective factors and enhancing the development of evidence which improve overall community health.

Public health offers programs and services such as: health promotion, immunizations, sexual health screenings and services, promoting a healthy diet and balanced nutrition, smoking cessation, healthy babies/children education and family planning, air/water quality testing, environmental weather warnings, food inspections, needle exchange programs, emergency planning and outbreak investigations/monitoring, health data collection, community health assessments, and evaluations.

- Do you have any questions or comments about public health or the interview process before we begin?

(Wait for a response and respond to any questions)

1. Please describe your experiences engaging with a public health unit?
 - a. If you have not had engagement opportunities with a public health unit, please describe your experiences engaging with non-Indigenous health agencies?
2. What approaches, considerations and ways of working were important throughout the process of engagement?
 - a. We found in the literature review four principles that may help the process of engagement which are trust, commitment, self-determination and respect. What are your thoughts?
 - b. Any other thoughts?
3. Describe the outcome of engagement between your community and the public health unit(s) or non-Indigenous agencies?
 - a. What was successful about the engagement?
 - b. How would your First Nation community like to be engaged?
 - c. What was not successful about the engagement?
 - d. How could future engagement be structured to be most beneficial to First Nation communities?