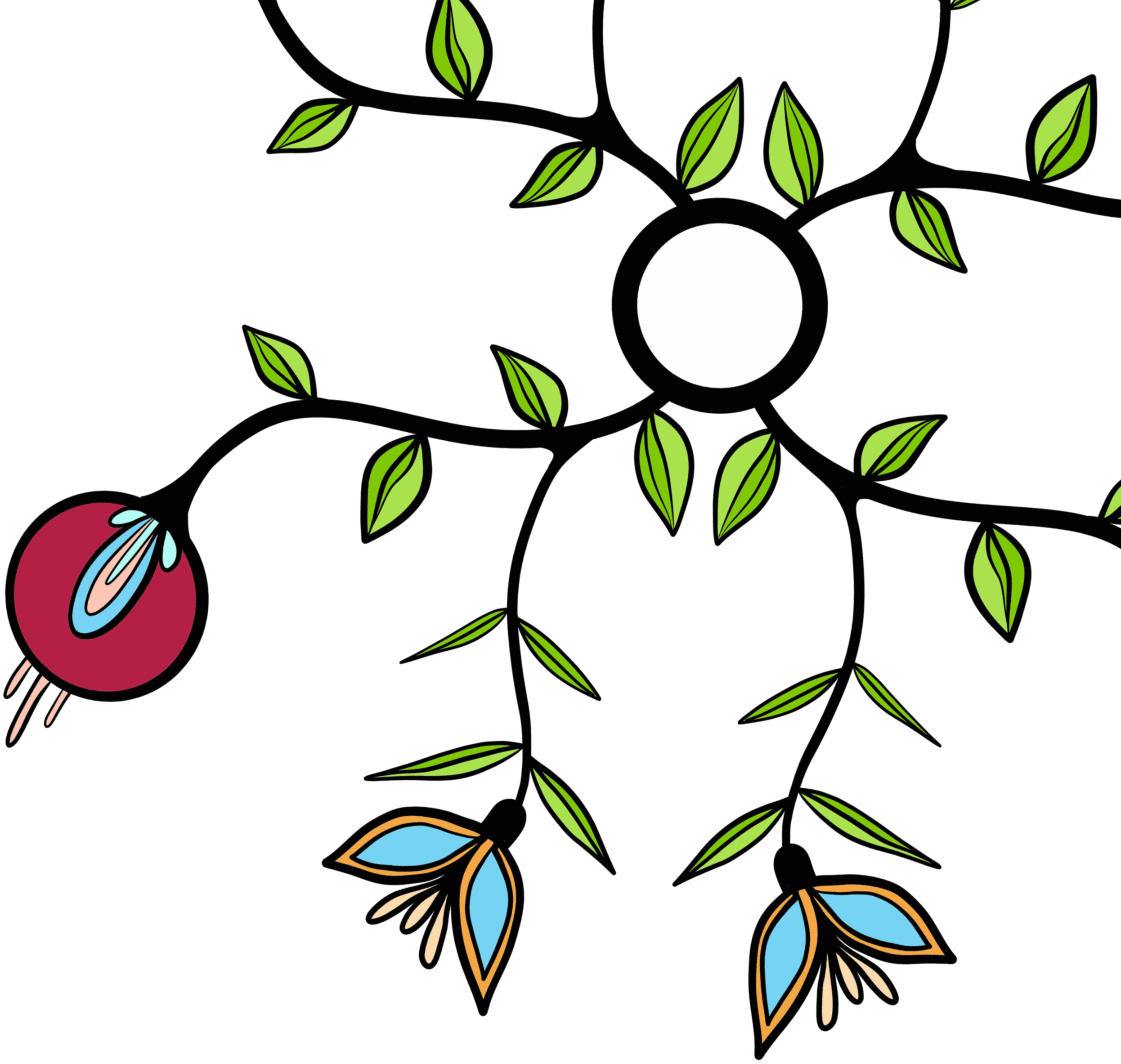

Indigenous Patient, Family and Community **Engagement Toolkit**

UPDATED: JANUARY 2024

INDIGENOUS PRIMARY HEALTH CARE COUNCIL

Purpose of Toolkit

This Indigenous Patient, Family, and Community Engagement Toolkit has been designed by the Indigenous Primary Health Care Council (IPHCC) to support and guide Indigenous Primary Health Care Organizations (IPHCOs) and all Indigenous communities and organizations involved in the *planning, design, delivery, and evaluation* of health services for Indigenous Peoples to partner, collaborate and engage in a good way.

This resource includes principles for engagement, protocols, and tools that can be used to consult with Indigenous patients, families, and communities to ensure health systems are designed by, with and for Indigenous populations. Co-designing and co-producing health care systems with input from the community, and those with lived/living experience is critical to advancing a patient-centred, safe, and effective health care system.

This resource may also serve as an informative resource for Ontario Health Teams (OHTs) to ensure meaningful engagement and consultation with Indigenous organizations, peoples, and communities is taking place as efforts are undertaken to create a more integrated and equitable healthcare system across the province. It is also important to recognize that consultation on a single topic, or with one person or group is not appropriate engagement. Ongoing, purpose-driven, and meaningful engagement is needed to create change that will result in improved outcomes. It must be more than an exercise to receive and document concerns and complaints. Engagement means a commitment to a meaningful dialogue, mutual understanding, and an open mind to consider all possible options, in good faith.

Evidence has shown that healthcare systems can be discriminatory and are not always the safest spaces for Indigenous Peoples. Health care partners want to engage with Indigenous communities but are not always sure how to do so. This toolkit has been created from an Indigenous lens, with specific attention, care, and focus on engagement with Indigenous communities in culturally safe and respectful ways.

Please note, this toolkit is not intended to replace existing relationships, practices and protocols organizations may already have in place, but is a tool offered to those who may require support with developing meaningful relationships and partnerships with Indigenous populations. The information in this Toolkit is provided for information purposes only and does not, constitute legal or professional advice, or define the only path for engagement.

Indigenous Health in Indigenous Hands

Indigenous organizations and communities must be equitably equipped and supported to plan, design, deliver, and evaluate their own healthcare systems. Health care must be Indigenous governed, positioning Indigenous leaders as the central authority for decisions about Indigenous health and well-being. While non-Indigenous health professionals often demonstrate compassion and empathy for their patients, it is not typical that they are able to comprehensively understand the full impact of Indigenous histories, worldviews, and cultural paradigms; all necessary to provide patient-centred care.

Self-determination is generally accepted to mean that “human beings, individually and as a group, are equally entitled to be in control of their own destinies” (Dalee Sambo Dorough, 2011). The Truth & Reconciliation Commission (TRC) Calls to Action and Missing and Murdered Indigenous Women & Girls (MMIWG) Calls for Justice point to the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and Aboriginal and Treaty rights that form self-determination.

Empowering Indigenous Peoples and communities to have a voice in and control over the forces and solutions that affect their health and wellbeing is a critical factor to ensure self-determination over the planning, design, delivery, and evaluation of health care services.

Indigenous organizations must be equipped to design health systems which are wholistic, culturally safe, and free from discrimination and systemic racism, culturally relevant, encompass Two-Eyed seeing, and reflect coordinated health and social services which address all social determinants of health. The IPHCC has created this resource to empower organizations to amplify the voices and stories of Indigenous Peoples and communities.

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Engaging with Indigenous Patients, Families and Communities

Four Requisite Indigenous Engagement Approaches

COMMUNITY SPECIFIC

Community is a pillar of identity for Indigenous Peoples. Indigenous communities are not solely limited to First Nations on territory (reserve). Indigenous communities include First Nation, Inuit and Métis people, no matter where they reside. Indigenous communities are not a homogenous entity within Canada, but have many unique histories, languages, cultural practices and spiritual beliefs.

Indigenous community is an encompassing concept based in coming together for ceremony, for mourning, for celebration, for advice, for support, and for many other important events. For Indigenous Peoples, community is healing. It is important to support wellness for Indigenous Peoples through initiatives that reflect the community's unique lived/living experiences and that highlight culturally appropriate modes of enhancing wellness. The importance of diversity in communities needs to be recognized. Program development should support initiatives that follow the vision and needs of the specific community that is involved. Community-specific engagement will ensure that the needs of the community are met.

SPIRITUALLY GROUNDED

In developing culturally appropriate care, it is essential to understand the spiritual importance to Indigenous Peoples. For Indigenous Peoples, being spiritually grounded includes being connected to language and culture, Indigenous traditions, a wholistic view of wellness, connecting to the land and sustaining relationships with family and community members. Spirituality is a way of life and a way of knowing (worldview) and these ways inform the foundation of all beliefs and practices. A Knowledge Keeper refers to a person who holds Traditional knowledge and teachings. These gifted individuals have been identified by their respective communities as embodying physical, emotional intellectual and/or spiritual gifts that are unique. Knowledge Keepers refers to those that are identified as Elders, Métis Senators, Knowledge Sharers, Helpers or other culturally appropriate terms.

It is important to know **these exceptional individuals are diverse and their presence and service are just as distinct.** Some roles that Knowledge Keepers can do in healthcare settings include, but are not limited to leading openings and closings, smudging and diverse ceremonies, sharing circles, and providing advice, support, and guidance on how to share teachings, where appropriate.

TRAUMA INFORMED

It is important to understand that history has had a strong impact on Indigenous communities, individuals' identity, and their mental health. Healthcare organizations must consider the intergenerational impact of colonization and its associated negative impacts on the lives of Indigenous Peoples. From an Indigenous perspective, trauma informed care is a strength-based, person, family, and community centred approach.

To engage with a trauma-informed approach through an Indigenous perspective, **healthcare organizations need to familiarize themselves with the causes and effects history has created on Indigenous Peoples and understand the potential impacts this has on wholistic health.** They need to create principles that reflect an Indigenous worldview, create a healing environment that is culturally safe, educate clinicians and staff about residential schools and their impacts, and create the opportunity for the development of healthy, supportive relationships. Programs and services must be created in respectful ways that will not perpetuate systems that have alienated Indigenous Peoples or re-traumatize them.

As previously mentioned, this is one of the cornerstones to genuine engagement and/or collaboration, to ensure a culturally safe lens is incorporated and, to continue to build trusting, working relationships. Something that has been lacking when minimalistic engagement occurs for the sake of filling a checkbox.

STRENGTH-BASED

Individuals dealing with health concerns are not given the opportunity to take control of their lives to develop a care plan that is best suitable for them and their culture. A strengths-based approach attempts to identify resources an individual can access to positively address the issue. This approach focuses on developing assets and recognizes that Indigenous Peoples have mental, physical, spiritual, social, and emotional abilities that can be utilized. Indigenous Peoples tend to emphasize their problems and weaknesses rather than their strengths and capabilities. All social determinants of health must be considered such as employment, poverty, education, housing, geographic location, culture and language. Further, being subjected to Canadian colonial practices and policies has had, and continues to have, negative impacts on Indigenous Peoples' health and education. Therefore, colonialism and Indigeneity must be recognized as social determinants of health.

A strength-based approach recognizes that **Indigenous Peoples are strong, resilient, kind-hearted and connected with spirituality.** Evaluation should consist of what is going well and how participants are working to improve and maintain wellness. It is crucial to note that healthcare systems should be grounded in feedback. While it is important to take a strength-based approach to addressing Indigenous health care, it is also important to recognize the ongoing challenges in Indigenous communities because of colonization and ongoing racism.

Improved Outcomes from Appropriate Engagement

- Shows respect for Indigenous rights, self-determination, culture and identity
- Builds trust through relationships built upon love, care and humility
- Allows Indigenous Peoples to feel connected to their culture, land and traditions
- Allows Indigenous Peoples to fully embrace and embody every ounce of who they are
- Allows for healing of all aspects (physical, mental, spiritual and emotional)
- Ensures Indigenous Peoples are empowered to lead and inform all decisions impacting their health and wellbeing
- Enhances patient-centered, and culturally safe and appropriate care
- Safeguards Indigenous knowledge
- Values Indigenous self-determination

Struggles Indigenous Peoples Face in the Healthcare System

It is essential to take trauma-informed and strength-based approaches when providing health care services to Indigenous Peoples. Though a strength-based approach is needed to dismantle negative and sometimes false narratives about the health of Indigenous Peoples, it is important to recognize that intergenerational impacts of colonization, racism, and white supremacy are determinants of health. Some struggles that Indigenous Peoples face in the healthcare system include, but are not limited to:

Inequitable access to care

- Do not have timely and/or appropriate access, or any access, to a primary care provider
- Due to geographical barriers many rural and remote communities do not have access to comprehensive health care services, including access to specialist services and diagnostic testing, which means Indigenous Peoples must leave their communities to receive care
- No transportation or technology to access health care services
- Long wait lists and wait times for specialists and social services

Access to culturally safe and appropriate care

- Indigenous Peoples may experience challenges with access to culturally safe and appropriate care due to gaps in Indigenous-led health care services (e.g., currently gaps in access to Indigenous Primary Health Care Organizations in communities due to inadequate funding)
- Many individuals are unwilling or reluctant to go to hospitals because of previous negative experiences resulting from stereotypes, and systemic anti-Indigenous racism
- Many Indigenous Peoples do not receive adequate or appropriate care due to their race and complex health care needs, resulting in ongoing health issues and in some cases, unnecessary deaths
- Traditional Medicines and culture-based services are not understood, and therefore not offered for treatment or understood by Western health care service providers

Systemic discrimination and barriers

- Lack of awareness, resources and/or action in the healthcare system to uphold Joyce's Principle, Truth & Reconciliation Commission Calls to Action, Missing & Murdered Indigenous Women & Girls Calls to Justice, commitments within the *Connecting Care Act, 2019*, to "recognize the role of Indigenous Peoples in the planning, design, delivery, and evaluation of health services", United Nation Declaration on the Rights of Indigenous Peoples (UNDRIP), and the Canadian Constitution - Section 35
- Lack of accountability for Indigenous cultural safety training in healthcare settings

- Language and cultural barriers
- Lack of Indigenous-led healthcare system navigation supports, including navigating Non-Insured Health Benefits (NIHB) and jurisdictional challenges/barriers with navigating/receiving care both on and off territory (reserve)
- Disproportionate number of Indigenous children in foster care combined with the lack of Indigenous foster homes

Public Health concerns

- Lack of clean drinking water
- High evacuation rates
- Overcrowded housing, which can cause easy exposure to second hand smoking and spreading of airborne illnesses
- Unemployment causes lack of money for food and medical expenses

Root causes to mental health and wellness

- Many individuals are unwilling to go to hospitals due to previous negative experiences with healthcare systems, stereotypes and racism
- High rates of depression, suicide, Post Traumatic Stress Disorder (PTSD), and mental health conditions due to past trauma from Residential schools, racism and stereotypes

> “My mother was sent to a Residential School and spent many years there. When she was released, she joined the army. From these experiences, she was wounded and traumatized. She had no support or help. This caused her to self-medicate with alcohol. She was scared to talk about her feelings. The addiction part took over her life. This caused my mother to raise her children as an alcoholic. My mother ended up getting diagnosed with diabetes, which caused her to lose both of her legs. She also experienced strokes and spent many years in the hospital. She was institutionalized and ended up passing away.
>
> This experience has taught me to respect everyone even if they are struggling and dealing with personal issues. It taught me to be non-judgmental and to help those who are wounded with nothing in place to help them. I have learned how to listen well to others and look for the strengths in everyone. Negative experiences can sometimes have positive impacts. Overall, this experience has strengthened me as a person and made me who I am today.” - *Adele Madigan, IPHCC Storytellers Circle Member, 2023*

How Ontario Health Teams can support Indigenous health care needs

- Become educated about the original inhabitants of these lands and waters. Learn about Indigenous laws and teachings, and the First Nation territories, Treaties, and unceded (never surrendered) territories across Ontario and within your local geography.
- Acknowledge the inherent rights of Indigenous Peoples that must be upheld based on provincial, national and international laws and understand that health system transformation efforts must be led and informed by Indigenous communities or their representatives.
- Be clear on why you or your organization is asking for Indigenous involvement. Does your OHT have a focussed plan to meaningfully include the Indigenous community? Is the plan led and informed by representatives endorsed by the Indigenous community?
- Understand that Indigenous communities are not homogenous and be prepared to highlight gaps in your engagement efforts, including openly outlining limitations. Identify who you have (and have not) engaged with (e.g., Chief and Council, Health Directors, or staff from Indigenous Primary Health Care Organizations (IPHCOs), Friendship Centres or leadership from other FNIM organizations) and don't assume that participation/collaboration equates to consent and support.
- Acknowledge Indigenous Peoples' inherent rights to lead their own health system transformation efforts and do not assume that OHT efforts and defined priorities are the same priorities for Indigenous communities. Is your OHT prepared to partner and engage with First Nation, Inuit and Métis communities as true and equal partners?
- Is your OHT committed to ensuring accountability to enforce Indigenous cultural safety training and anti-Indigenous racism education and training for health care providers in your region, with guidance from First Nation, Inuit and Métis partners?
- Does your OHT have plans in place to prioritize trauma-informed, culturally respectful, and Indigenous-led care and does your OHT have relationships with Indigenous-governed health service providers in your region?
- Understand that Indigenous populations face greater rates of chronic disease at earlier ages resulting from the effects of colonization. Mainstream health care service providers measure population health from a Western lens and Indigenous organizations are well positioned to engage in the dialogue about solutions and supports needed to

affect change. Do not assume or expect your OHT has all the solutions and humbly respect and support Indigenous-led approaches.

- Does your OHT understand the barriers that exist for Indigenous populations living in rural and remote communities? And is your OHT willing to partner with Indigenous organizations to ensure accessible mobile health clinics, adequate technology and emergency services are available?
- Work with Indigenous organizations to discuss the importance of ensuring supports and appropriate care pathways are developed for Indigenous patients and clients in your region, including awareness and supports with accessing Indigenous-led health services and Indigenous Patient Navigators.
- Focus on strength-based models rather than deficit-based models. Western approaches tend to be more deficit-based, whereas using a strength-based approach will help recognize that **Indigenous Peoples are strong, resilient, kind-hearted and connected with** spirituality. Following a strength-based model will reduce the risk of stereotyping and empower spiritual and cultural knowledge.

"In October of 2019, I noticed a lump in my breast and went to the doctors. I then found out it was cancerous. The way the news was relayed to me was uncomfortable. The surgeon wanted to put a surgery date on the calendar right away. It felt very cold and impersonal, like I was just another patient they wanted to get done with and out of the way. I was still trying to process this news and was in no place to start thinking about surgery dates. As an Indigenous woman, the Western approach felt uncomfortable. Treatment was put on hold as COVID hit. I then decided to switch hospitals and see a new surgeon. This time, I wanted to be more engaged and vocal in decisions about my treatment. I was very open about my concerns and having an Indigenous Patient Navigator on site.

Having this Navigator felt like I was supported and had someone on my side who would be there for me. The Navigator came to appointments and meetings with me and helped me determine my course of treatment. It was very comforting having him there with me. When speaking to doctors, I didn't understand the terms being used. The Navigator helped me understand these terms and made sure I understood my treatment plans. Without the Navigator, I probably wouldn't have showed up to my appointments. He was there for me mentally and emotionally and made me feel comfortable when showing up to appointments. I was able to walk in and out of my appointments with dignity. Through this experience, I realized that I was the medicine for the Western system and showed them how to respectfully treat Indigenous Peoples." - *Vicky auf der Mauer, IPHCC Storytellers Circle Member, 2023*

How to use this Toolkit

STEP 1: Assess level of community impact

STEP 2: Select appropriate type(s) and method(s) of community engagement

STEP 3: Develop an engagement plan

STEP 4: Develop a data sovereignty plan

STEP 5: Implement the engagement plan

STEP 1: Assess level of community impact

Assessing the level of community impact will help determine the effect that a specific action or change will have in the community. Engage early with Indigenous patients, communities, and organizations to develop your assessment. A fair procedure for engagement includes well-informed and substantive sessions, not just the ability to comment on final products. This precludes that Indigenous consultation needs to be embedded in the design process to ensure legitimate engagement, and the relationship building process.

To assess the level of impact on the community, work with your organization(s) to identify the communities or patients/clients that would be affected. As mentioned, Indigenous communities and peoples are not homogenous. There are distinct and diverse differences, including variations in worldviews and rights across cultures that must be understood, respected, and upheld as engagement efforts are undertaken. Before assessing the level of community impact, organization(s) must learn about these inherent rights and self-governance of Indigenous communities that may be impacted. Further, OHTs seeking to engage must ensure Indigenous patients, families, and organizations are equal partners and must be supportive during the process for developing solutions. In other words, Indigenous partners at any level must be empowered and enabled to plan for and evolve Indigenous-led health systems.

Level of Community Impact Criteria

Level of Impact	Criteria	Examples
Level One: High Impact on whole community	o High impact across community o Results in significant changes to environment or the health and safety of all residents o High degree of interest across community	o Building a new hospital/facility that serves the whole community
Level Two: High impact on select area or group	o High impact on a <u>specific</u> group or community	o Relocation of a health centre
Level Three: Moderate impact on whole community	o Moderate impact across community o Adequate degree of interest across the community to call for public engagement	o Need for more physicians and nurses at a hospital o Proposed improvements to a community wide service such as health clinics
Level Four: Moderate Impact on select area or group	o Moderate impact on a <u>specific</u> group or community o Small change to a localized facility or service	o Change hours of operation for clinics, hospitals, programs etc., to better suite the availability of the community

STEP 2: Select appropriate type(s) and method(s) of community engagement

Once you have assessed the level of impact, the next step is to select the most appropriate type and method of community engagement. This is related to **communication** methods, **community-driven** methods, and/or **direct participation**.

The following offers a brief description of the engagement types and subsequently the chart below can be used to help decide the most suitable engagement method. For improved relationship building and fostering genuine engagement all methods should be informed by, and where possible led by, Indigenous individuals, communities, and organizations as early in the process as possible.

COMMUNICATION: Communication may seem like a basic element for engagement but is essential to tie together all types of community and patient relationship building and collaboration. As the first point of contact with individuals, groups, and other stakeholders, communication is intended to lay the foundation and provide understanding around the intended work and goals. The goal of communication should be to reach as many individuals as are necessary for the scope of the work and to deliver as much information as possible, must be delivered in way that is easily understood. Ultimately, this will help ensure the community is aware of the health care services and programs that are available to them, and should provide a means for asking questions and raising concerns where appropriate.

Key Initial Communication Questions: How can we become transparent to the people who want to know about our services? How can we enable people to fulfill their roles and responsibilities and enable them to take part fully? How do we make ourselves fully accountable to all our members/patients? How can we communicate more clearly and effectively for our members/patients? How do we gain a better understanding of our patients wants and needs? How can we make it easier for people to communicate with us? What measures can we use to assess the effectiveness of our methods?

COMMUNITY-DRIVEN: The goal of community-driven engagement is to seek the opinions and suggestions of Indigenous Peoples and communities. Community-driven processes, like implementing feedback/concerns from Indigenous patients, families, and organizations into the internal decision-making process is key to building and fostering a trusting relationship. This may be done through focus groups, sharing circles, community input sessions, workshops, surveys, or storytelling. Allow patients to provide their feedback and opinions about how health care for Indigenous Peoples can be improved. It is essential that Indigenous health care systems are determined/designed from feedback. Community-driven engagement should also seek actionable feedback, advice, and recommendations that can be taken back to stakeholders and support the concerted efforts of working towards improved health outcomes for Indigenous individuals. This will ensure improvements are made to best suit the specific community or culture.

Key Initial Community-Driven Questions: How will engagement processes ensure communities are made aware of opportunities to become involved in providing input into solutions and decision-making and ultimately kept informed? How will processes ensure the broader group do not become excluded? Was all feedback taken into consideration? Were decisions made for the betterment of the community?

DIRECT PARTICIPATION: This is an important part of the engagement process and can lead to better decisions and outcomes. Sharing in the decision process and empowering the community or organization improves trust and transparency. Public participation allows freedom of expression and a safe space for sharing ideas. Indigenous patients and communities will have a say in decision making. This is essential to design a healthcare system that highlights Indigenous Peoples' needs.

Key Initial Direct Participation Questions: How have Indigenous-governed organizations and communities been engaged as true and equal partners to inform the planning, design, delivery and evaluation of health services for their communities?

Community Engagement Methods

ENGAGEMENT METHOD	WHY/WHEN TO USE IT	EXAMPLE
Communication		
Phone call	When in person contact might not be available. A quick method for members to contact each other and express their opinions and concerns	Have a contact number available to the public

Email	When in person contact might not be available. Used to send files and any form of update	Send automatic emails to remind members of engagement activities and events
Pamphlet	To reach a wide audience. For quick reminders/ summaries. Can include information about healthcare system improvement initiatives, events, etc.	Print publications to send out
Community-driven		
Storytelling	When patients, caregivers and health care staff are comfortable sharing lived experiences	Gather group of individuals with common shared experiences to tell their stories to the group
Sharing circles	Encourage open debate, opportunity for individuals to share their ideas	Compose group of 5-10 individuals to share ideas on how to improve patient complaints at a health centre
Workshops	To disseminate information about a topic or concern	Gather group of people to work through an issue
One-on-one Interview	To have an in-depth conversation about a particular concern or issue	Follow up phone interviews with patients one month after their

		discharge from a hospital, etc.
Surveys	To gain feedback on focused questions, and from many people quickly. Can be used for people in rural and remote areas who are not able to meet in person. Used to evaluate patient/client perspectives on health services in their community	A survey soliciting feedback on level of access and experience navigating the healthcare system – *See Appendix A as an example*
Anonymous Suggestions Boxes	For those who may not be comfortable sharing their opinions out loud. To hear feedback on sensitive issues	Include a suggestions box at an Elders home and ask members to comment on the quality of their experience
Online forum	Obtain individual feedback, create opportunity for those who are less vocal to share their thoughts and opinions	Create an online forum for the public to fill out about their thoughts on ER wait times
Direct Participation		
Citizens Jury	To include citizens input into policy decisions	Compose jury of 12-16 randomly chosen citizens. After deliberation

		and discussion, the citizens will provide recommendations in a citizen's report
Deliberative Polls	Engaging public in the deliberation on current issues or proposed policy changes	Conduct surveys before and after deliberation and allow for documentation of opinion change
Committees, Task Forces	When your organization requires patient and community perspectives for a project that requires ongoing commitment	Invite Knowledge Keepers, Elders, or individuals with lived/living experience to sit on a committee (e.g., to review ways to reduce unnecessary transfers from Long-term Care home to the ED)

STEP 3: Develop an engagement plan

In developing your community engagement plan, you should consider the following five processes:

1. **Research:** Gain an understanding and build relationships before engaging with Indigenous communities. This is a period of research, learning and reflection. During this time, spend time developing your knowledge in Indigenous content and conducting research about the histories, culture, and languages of Indigenous communities with whom you wish to engage. The work before engaging is a time to discuss how to contribute to the communities' requests.

2. **Inform:** Inform Indigenous patients, families, and communities about the ongoing issues or project. It is important the community has adequate information to make informed decisions. It is also important to promote where, when, and how the public can contribute to the process. Therefore, the public must be informed of the available avenues to contribute to the process. Once information has been disseminated, ensure participants are kept informed of outcomes and decisions.

3. **Engage:** Obtain feedback from Indigenous patients, families, and communities. This promotes trust and confidence that community voices have been heard. The consultation process should be designed to be as transparent as possible. Have clearly defined and realistic objectives. Share how the information and input will be used, supply feedback and updates of progress. Have accurate records and detail how input will be used.

    - Depending on engagement method used, consider preparing gifts. Gifting is a Traditional way to engage, and gifts can range from organizational swag and local crafts to sacred items such as tabaco and sweetgrass. It is recommended that your organization have a Memorandum of Understanding (MOU) with an Indigenous Primary Health Care Organization, Friendship Centre, or another FNIM organization to support with approaches to determine appropriate gifts and making payments to Knowledge Keepers, Helpers, and Elders. This MOU process would position these Indigenous organizations in a respectful place. Protocols around gifting are unique to the specific community and Indigenous organizations can provide support. For example, when offering tobacco, the preparation, type, and quantity are all unique and important considerations, and the significance and meaning of these sacred gifts should be understood.

4. **Involve:** Provide opportunities for thoughts, opinions, ideas, and vision. Indigenous Peoples participating should be acknowledged and incorporated in the project and activities. Address concerns and ensure they will be considered. Other Indigenous engagement practices include openings and closings, where prayers and songs, are commonly shared. Ensuring these practices are considered as part of your engagement efforts is not only respectful, but it also creates a safe and welcoming environment for participants.

5. **Collaborate:** Indigenous communities are active partners in each aspect of decision making. Assess the quality of the involvement to provide a better understanding and obtaining of data regarding the view or need of the community.

STEP 4: Develop a data sovereignty plan

Indigenous knowledge has historically been taken from Indigenous Peoples and exploited without consent. Indigenous Peoples are routinely not consulted about what information is collected from them, who gathers the information, who maintains it, and who has access to it. For example, Indigenous knowledge about plants and medicines continues to be exploited by non-Indigenous people and corporations for research, personal use, and profit.[1]

To ensure trust in your project, you must respect principles of Indigenous Data Sovereignty[2], which means:

(a) The right of First Nations, Métis, and Inuit Communities to own and govern their data regardless of where it is housed.

(b) The right of First Nations, Métis, and Inuit Communities to decide how their data is shared and with whom.

Indigenous data may include Traditional knowledge, self-identification information, community-wide health data, and population specific health Information.

Indigenous data requires protection like that of Personal Health Information (PHI). The key obligations and restrictions on use of PHI are set out in the *Personal Health Information Act, 2004.* One of the most important obligations is about consent. Consent is required for the collection, use, and disclosure of PHI, subject to certain exceptions (s.29). Consent must be of the individual, knowledgeable, relate to the Information sought, and not obtained through deception or coercion (s.18). Consent is "knowledgeable" if it is reasonable in the circumstances to believe that the individual knows the purposes of the collection, use or disclosure and that the individual may give or withhold consent (s. 18(5)). The right of

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[1] Report of the Royal Commission on Aboriginal Peoples: Gathering Strength*, vol 3 (Ottawa: Supply and Services Canada, 1996) at p 498; and Chidi Oguamanam & Christopher Koziol, "Biopiracy Flashpoints and Increasing Tensions Over ABS in Canada," in Chidi Oguamanan, ed, Genetic Resources, Justice and Reconciliation, (Cambridge University Press, 2018); Harriet V Kuhnlein & Nancy J Turner, Traditional Plant Foods of Canadian Indigenous Peoples: Nutrition, Botany and Use, (Philadelphia: Gordon & Breach Science, 1996).*

[2] Indigenous Data Sovereignty principles include:

- First Nations data sovereignty principles of ownership, control, access, and possession (OCAP)
- Métis data sovereignty principles of ownership, control, access, and stewardship (OCAS)
- Inuit data sovereignty principles of Inuit Qaujimajatuqangit (IQ)

Indigenous Peoples to determine what happens with their data also flows from the *United Nations Declaration on the Rights of Indigenous Peoples*.[3]

Any project that contemplates collecting Indigenous data must:

(a) Clearly identify the purposes for which you are collecting, creating, holding, or otherwise using the Indigenous data.

(b) Develop a plan to prevent misuse of Indigenous data, such as through cultural appropriation and inappropriate profit motives, and general unauthorized use.

(c) Develop procedures for Indigenous communities and organizations to own and govern the data collected as well as decide how that data is shared and with whom.

The policies and practices of many organizations do not adequately address (or address at all) Indigenous Data Sovereignty principles. It is therefore crucial that any plan start with an effort to understand these principles and the constraints and positive obligations they impose on all the parties involved.

Case Example

An Indigenous organization plans to build a certified training course for Traditional Healers and approaches a non-Indigenous health organization for partnerships and funding. Both organizations agree that they want to support the project and the non-Indigenous health organization prepares a funding contract.

The contract has standard form Canadian law copyright and intellectual property terms that say that the non-Indigenous organization will have the right to license, use, translate, adapt, record, or reproduce the data that is collected over the course of the project in exchange for providing funding.

The Indigenous organization is internally committed to principles of data sovereignty and cannot agree to the contract because there is no way for them to gather knowledgeable consent from Indigenous participants in the project when they cannot tell them how their Information will be used.

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[3] United Nations Declaration on the Rights of Indigenous Peoples, Articles 3, 23, 24, 25, and 26, available at: https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf

This is an example of where what seems like a standard term to non-Indigenous organizations can turn out to be a deal breaker for their Indigenous partners. To avoid this kind of outcome, early engagement about Indigenous Data Sovereignty is essential to any successful collaborative project. There must be a clear understanding on how data will be used and processes for obtaining further consent if other uses are desired.

STEP 5: Implement the engagement plan

Once you have a clear community engagement implementation plan, the final step is to do the work. Based off your key pre-planned questions, prioritize the next steps of the plan. This is where you can partner up and build a stronger network through identifying your team(s) and members of the community and organize your resources and time effectively.

It is important to evaluate and monitor your approach as community engagement contains many variables. This will help your team/organization to understand what was done and how to improve in the future.

This is a great tool to help in the connection, communication, and collaboration process; although I am always cautious about initiatives such as this, as it can also be used as a tick box so to speak, to explain away why genuine collaboration did not take place. For example, this toolkit should not, in any way, absolve OHTs or any healthcare organization from thorough communication, relationship building, and ongoing partnership because a situation was deemed to have a low-level of community impact. Consistently revisiting commitments to partnership and relationship building are critical to foster trust and improve relationships.

- Natalie Paavola, Director of Health, Dilico Anishinabek Family Care

This toolkit has been developed to offer guidance and support for engaging with and supporting diverse Indigenous communities and peoples throughout the province. Understand engagement is an ongoing process, and if you have not engaged or realize that you may have not engaged in a good way after using this toolkit, starting over or backtracking to take a more comprehensive approach is possible. Using the engagement protocols and best practices above may lead to more positive results and more positive health outcomes for everyone.

Planning tools and resources

Pre-Planning Community Engagement Checklist

1. **Why do you want to involve patients/providers/others?**
    - ☐ What is the purpose of engagement?
    - ☐ What does success look like?
    - ☐ What are the desired outcomes of engagement?

2. **Who do you need to involve?**
    - ☐ Have you considered who will be affected by the decisions you make?
    - ☐ How will you ensure the community is kept involved?
    - ☐ What community partners should be involved?
    - ☐ Have you considered all options for who should be involved in engagement?

3. **What type of engagement are you looking for?**
    - ☐ To consult
    - ☐ To communicate
    - ☐ To participate in decision-making

4. **When will you involve others?**
    - ☐ What are the timelines?
    - ☐ Do you have an accessible location secured?

5. **How will you engage with others?**
    - ☐ What method of engagement will be used? (i.e., One-on-one, emails, storytelling, small groups, sharing circles, etc.)

6. **How will you ensure you have been successful?**
    - ☐ Are measures defined to evaluate your success?
    - ☐ How will you inform members of your success?
    - ☐ How will you deliver feedback to the community?

7. **Did you complete any Indigenous Cultural Safety Training prior to engaging?**

8. **Do you have enough background knowledge about the Indigenous community you are engaging with?**

9. **Did you complete any research about how to engage in a culturally respectful way?**

10. **Have you considered how Indigenous data will be used, stored and protected?**

Post Engagement Checklist

1. **Who was involved in your engagement process?**
   - ☐ What stakeholders were included?
   - ☐ What organizations were included?
   - ☐ What groups do you feel should have been included but were not?

2. **Were there any challenges?**
   - ☐ What step did you find the most challenging?
   - ☐ Were all your goals met?
   - ☐ If your goals were not met, what prevented you from doing so?
   - ☐ Were there any barriers?

3. **Did you report feedback to the community?**
   - ☐ Did you perform an evaluation of the engagement process?
   - ☐ How was your feedback reported?
   - ☐ Was all feedback taken into consideration?

4. **How did you ensure a sense of cultural sensitivity, awareness, and safety was included in your engagement process?**
   - ☐ What cultural safety methods were used?
   - ☐ Did you provide an option for including Knowledge Keepers?
   - ☐ Did you ensure a safe environment was created?

5. **What did you learn from the engagement process?**
   - ☐ What were your key successes?
   - ☐ Would you do anything differently?

6. **What are the next steps?**
   - ☐ How will you ensure Indigenous concerns are met?
   - ☐ How will you keep the Indigenous community involved?

Additional Resources:

The Indigenous Primary Health Care Council (IPHCC) is an Indigenous governed, culture-based, and Indigenous-informed organization. Its key mandate is to support the advancement and evolution of Indigenous primary health care services throughout Ontario.

The IPHCC has developed several resources and supports for its Indigenous Primary Health Care Organization members, other Indigenous organizations, and communities, as well as Ontario Health Teams engaged in broader provincial health system transformation efforts. Resources, including IPHCC's Anishinaabe Mino'Ayaawin, Foundations of Indigenous Cultural Safety (ICS) can be found at iphcc.ca, including on the resources tab.

Ontario Health Teams can contact oht@iphcc.ca to be connected with a member of the IPHCC's Health Systems Transformation Team to learn more about resources that have been completed and/or that are in development.

> "My name is Sierra Drodge, and I am 20 years old from Sault Ste Marie Ontario. I am currently completing my Bachelor of Science in Biology degree at Algoma University. After obtaining my Bachelor's degree, I plan on applying for my Masters with hopes to work in the medical field. I am bilingual in both French and English and have always had a passion for medical science. My favourite course is human anatomy and physiology as I enjoy learning about the different body systems and how our bodies function. I have always been very athletic and have played multiple sports such as hockey, soccer, volleyball, and track and field. As an Indigenous woman this project was very important to me as it will help create a more integrated and equitable health care system. I strongly believe that everyone deserves the right to access safe, patient-centered, and appropriate health care."
>
> - *Sierra Drodge, IPHCC Research & Writing Student Intern, Ontario Health Teams*

References

Algoma Ontario Health Team. (2018). Ad Hoc Engagement Evaluation Form. https://www.algomaoht.ca/

Cauchie, L. (n.d.). Social Determinants of Health. https://www.nccih.ca/28/Social_Determinants.nccah

Spark BC. Community Engagement Toolkit. (2013, July). https://cdn2.hubspot.net/hubfs/316071/Tamarack_New_Website/A_CE_toolkit.pdf?hsCtaTracking=759875b6-7ecc-4d0c-b242-7024c9bbc798%7C17cb1027-9871-439e-b2e3-571db04b5752

FNIGC. (n.d.). First Nations Regional Health Survey. https://fnigc.ca/wp-content/uploads/2020/09/520754778360d9f56c3fc4aba9fa64f0_RHS-Adult-Phase-3_Final.pdf

FNIGC. (n.d.). *FNIGC*. Strengths-Based Approaches to Indigenous Research and the Development of Well-Being Indicators. https://fnigc.ca/wp-content/uploads/2021/05/FNIGC-Research-Series-SBA_v04.pdf

Government of Canada, D. of J., & Sasakamoose, J. (2022, September 15). Exploring Indigenous Approaches to Evaluation and Research in the Context of Victim Services and Supports. https://justice.gc.ca/eng/rp-pr/jr/eiaer-eaame/appendixd-annexed.html

Government of Ontario, Ministry of Health and Long-Term Care. (2018). Relationships with Indigenous Communities. https://www.health.gov.on.ca/en/pro/programs/publichealth/oph_standards/

Health Quality Ontario. (n.d.). Choosing methods for patient and Caregiver Engagement: A guide for Health Care Organizations. https://www.hqontario.ca/Portals/0/Documents/qi/choosing-methods-pce.pdf

HSPN. (n.d.). Ontario Health Team Patient Experience Survey. https://hspn.ca/wp-content/uploads/2022/02/HSPN-OHT-Patient-Experience-Survey-EN-1-02-2022.pdf

Macaulay, A. C. (n.d.). Improving aboriginal health- How can health care professionals contribute. https://www.cfp.ca/content/cfp/55/4/334.full.pdf

Our health, our community: Health & Wellness Survey. (n.d.). https://redcap.viha.ca/redcap/surveys/index.phps=URHSpfs8gmXhybqz&__prevpage=1

Public and Patient Engagement Evaluation Tool (PPET). (2018, August). https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf

Reading, J., & Halseth, R. (2013). Pathways To Improving Well-Being for Indigenous Peoples. https://www.nccih.ca/495/Pathways_to_Improving_Well-being_for_Indigenous_Peoples__How_living_conditions_decide_health_.nccah?id=102

Saskatchewan Health Authority. (n.d.). Engagement planning worksheet. https://www.saskhealthauthority.ca/sites/default/files/2022-11/SHA-Engagement-Planning-Worksheet%20Fillable.pdf

University of Manitoba. (2020, May). Methods of patient & public engagement. https://umanitoba.ca/centre-for-healthcare-innovation/sites/centre-for-healthcare-innovation/files/2021-11/methods-of-patient-and-public-engagement-guide.pdf

University of Manitoba. (n.d.). A pathway for Indigenous Community engagement. https://umanitoba.ca/sites/default/files/2021-05/a-pathway-for-indigenous-community-engagement-infographic.pdf

View of Miýo-Pimātisiwin Developing Indigenous Cultural Responsiveness Theory (ICRT): Improving indigenous health and well-being. (n.d.). https://ojs.lib.uwo.ca/index.php/iipj/article/view/7527/6171

Appendix A - Sample Indigenous Community Driven Survey

Boozhoo / Aanii / Atelihai / Wâciye / Hello!

Thank you for your interest in participating in this survey. This project is being led by the Indigenous Primary Health Care Council (IPHCC) in collaboration with our collective membership of 23 Indigenous Primary Health Care Organizations in Ontario. Empowering Indigenous Peoples and communities to have a voice in, and control over, the forces and solutions that effect their health and wellbeing is a critical factor to ensure self-determination over the planning, design, delivery, and evaluation of health care services. This survey has been created by an Indigenous-led and governed organization, to collect the stories and perspectives of Indigenous communities and peoples to effect positive change in our health care system.

What is Required if I Participate?

The survey is voluntary. You are also free to stop the survey at any time by closing your browser. If you decide to participate in this survey, you will complete a survey asking you about your experiences accessing health services, as well as your preference and views regarding how health services should be delivered/improved in your community. The survey takes approximately 30-40 minutes.

Risks & Benefits

We do not anticipate you will experience any harm by completing this survey. Some survey questions may seem sensitive or personal; you can choose 'Prefer not to answer' for these questions.

Notice of Collection of Personal Information

The IPHCC is internally committed to safeguarding Indigenous data, which will inform the way data is collected and used through this community research. It is important to the

IPHCC that decisions and actions regarding the data it collects remain in line with the values of Indigenous self-determination.

The need to move beyond existing protections for Indigenous knowledge is reflected in Canada's ongoing efforts to modernize legislation, like the *Privacy Act,* to acknowledge the uniqueness of Indigenous interests in relation to personal information, and to bring Canadian laws in line with principles of Indigenous data sovereignty and the United Nations Declaration on the Rights of Indigenous Peoples.[4]

While the survey does not collect direct identifiers such as your name, address, or identification numbers, it does ask for your postal code. We are asking for your postal code to understand the differences in perception of health service delivery and health and wellness priorities across the province. While your specific responses in relation to your postal code will not be shared outside of the IPHCC team, there is a risk of re-identification when collecting full postal codes. You can select 'Prefer not to answer' in response to the question asking for your postal code. Additionally, to protect your privacy, you should not share your name or any personal information in the text boxes (including 'Other: please specify' fields) that could identify you or anyone else in the survey.

Data Access & Storage

Data will be stored in IPHCC's secure network. Survey responses will be entered into a secure database called [enter database] by [IPHCC staff] and stored on a secure IPHCC network. Access to survey data will be restricted to only approved project team personnel. Of the project team members, the [Insert Role], and [Insert Role], [Insert Role], and [Insert Role] will have access to all survey responses and will have the ability to transfer data from [enter database] to IPHCC's secure network. The other project team members will only have access to de-identified survey responses.

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[4] Government of Canada, "Privacy Act Modernization: Engagement with Indigenous Partners–What We Have Learned (So Far) and Next Steps" Part One: Context and Summary.

Your de-identified responses from the survey will be kept indefinitely to carry out planning and advocacy efforts. Responses from the survey may be used for future research purposes.

Sharing of Survey Results

A summary of the survey results will be shared with the Indigenous Primary Health Care Council (IPHCC) Board and Council members, Indigenous organizations, and Indigenous community partners. Your de-identified and aggregated responses (e.g., your responses combined with those of other participants) from the survey may be shared publicly through a report or presentation. Your specific responses in relation to your postal code will not be revealed in any shared results. Survey results will be used to inform federal, provincial, and regional health care planning and advocacy efforts.

By proceeding with this survey, you are consenting to participate in this survey and acknowledging that your responses from this survey could potentially be used for advocacy and research.

Who Should I Contact if I Need More Information or Help?

For questions or concerns about this survey and/or your rights as a participant in the survey, please contact [*contact name]*. You can also contact info@iphcc.ca with the subject line Indigenous Patient, Family & Community Engagement Toolkit and your inquiry or concern will be triaged to the appropriate contact.

Some of the questions in this survey may evoke unease or feelings of distress. The IPHCC recognizes the need for access to culturally safe and appropriate Mental Health resources and supports. Please see IPHCC's Mental Health Resource Guide for contact and support information.

Consent

As Canadian laws develop, the IPHCC acknowledges that Indigenous data needs protection in a way like Personal Health Information (PHI). For PHI, there are key obligations and restrictions imposed by the *Personal Health Information Protection Act,* *2004*. One of the most important is consent. Consent is required for the collection, use, and disclosure of PHI.[5]

A guiding principle for collection, use, or disclosure of Indigenous data, such as Traditional knowledge, is informed consent. Consent is informed when individuals who share their data know the purpose of the collection, use or disclosure and that they may give or withhold their consent.

The survey will not affect any primary health care or community services you receive. The project team is not able to withdraw any data after it has been submitted through the survey. This is because we are not collecting contact information and therefore are unable to identify your specific responses after they are submitted.

By proceeding to the survey, you are consenting to participate in this survey.

1. What is your age? Please enter your age as a number (e.g, 20, 55, 73)

2. What is your postal code?
   - _________
   - Do not have a postal code/choose not to answer

3. I Identify as:
   - First Nation (Status/Non-Status)
   - Metis
   - Inuit
   - Chose not to respond.
   - Other (Provide details, for example, do you prefer to self-identify according to your nation or other description? If so, please specify (Examples may include but are not limited to: Anishnawbe, Cree, Haudenosaunee, Ojibway, Inuk, Cree Metis):

4. Do you have a primary health care provider?
   - Yes
   - No
   - I don’t know

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[5] Personal Health Information Protection Act, 2004, s. 18.

5. Do you currently receive primary health care services at an Indigenous Primary Health Care Organization?
   - ○ Yes
   - ○ No
   - ○ I don't know

If you responded yes to question #4, please skip to question #7

6. Where do you go to access primary care services when needed?
   - ○ Emergency department
   - ○ Walk in clinic
   - ○ I don't go anywhere
   - ○ Other (Please specify): _______________

7. How would you rate the quality of the health care services that are available in your community?
   - ○ Excellent
   - ○ Good
   - ○ Fair
   - ○ Poor
   - ○ Choose not to answer

Option to expand on response to question #4:

8. In the last 12 months, did you use Traditional Medicine?
   - ○ Yes
   - ○ No
   - ○ Choose not to answer

9. Have you experienced any of the following difficulties when trying to access Traditional Medicine?

○ Not interested in the use of Traditional Medicine	○ I am not educated enough about Traditional Medicine
○ No difficulties	○ Not available in health care settings
○ Do not know where to get it	○ Not covered by health benefits
○ Restrictions or Regulations	○ Was not offered by my health care provider
○ Cannot afford it	○ Don't know
○ Too far to travel	○ Primary care provider would not approve it
○ Concerned about side effects	○ Other:

10. In the last 12 months, have you experienced any of the following health care barriers?

Access Barriers	**Yes**	**No**	**Don't know**	**N/A**
Doctor or nurse not available in my area				
Indigenous Primary Health Care Organization not located in my area				
Health facility not available in my area				
Unable to find transportation				
Difficulty in getting Traditional care (Healer, Elder, Medicine Person)				

Access Barriers	Yes	No	Don't know	N/A
Services and treatment not covered by Health Benefits				
Could not afford direct cost of care/services				
Could not afford transportation costs				
Felt health care provider did not know me as a person and did not consider all the factors that affect my health				
Felt health care provider was not culturally respectful and care did not feel appropriate or safe				
Did not feel comfortable asking questions about my health care				
Chose not to see health care provider				
Wait list to become a patient/client at a primary care clinic was too long				
Wait times to see primary care provider, when services were needed, was too long				

Access Barriers	Yes	No	Don't know	N/A
I did not feel equipped and supported to navigate the health care system				
I did not receive all required necessary care				
Open ended section to expand on responses:				

11. The last time you were concerned about a health problem, how many days did it take to see your regular healthcare provider?
    - ○ Same day
    - ○ Next day
    - ○ 2-9 days
    - ○ 10-19 days
    - ○ Over 20 days
    - ○ Other (Please specify):
    - ○ I don't know

12. Do you have a connection to an Indigenous Patient Navigator?
    - ○ Yes
    - ○ No
    - ○ I don't know

13. When you see your regular healthcare provider or someone else in their office, how often do they involve you as much as you want to be in decisions about your care and treatment?
    - ○ Always
    - ○ Often
    - ○ Sometimes
    - ○ Rarely
    - ○ Never
    - ○ Choose not to answer

14. When you see or speak with nurses, doctors, physicians, specialists, and others in the healthcare system, in what language are you most comfortable?
    - ○ English
    - ○ Ojibway
    - ○ Cree
    - ○ Oji-Cree
    - ○ Dene
    - ○ Montagnais (Innu)
    - ○ Nuxálk/Bella Coola
    - ○ Halkomelem
    - ○ French
    - ○ I am most comfortable in another language. (Please specify): _________
15. Thinking about your most recent visit, how well did the organization respect Indigenous Peoples, Cultures, and Traditions?
    - ○ Very well
    - ○ Somewhat well
    - ○ Not very well
    - ○ Not at all well
    - ○ Choose not to answer
16. Healthcare plans were developed with regards to my strengths and needs.
    - ○ Strongly agree
    - ○ Agree
    - ○ Neither agree nor disagree
    - ○ Disagree
    - ○ Strongly disagree
17. Do you feel that your healthcare provider spent enough time with you at each visit?
    - ○ Yes
    - ○ No
    - ○ Choose not to answer