Patient-Oriented Research (POR)

Best Practice Recommendations

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1. Best Practice Recommendations for Patient-Oriented Research

The purpose of this document is to provide Patient-Oriented Research (POR) Best Practice Recommendations for researchers undertaking research in Northwestern Ontario. The goal is to contribute to building a sustainable, accessible, and equitable process, which can support clients and community stakeholders to be fully engaged in the creation of knowledge that can inform health services and maximize therapeutic outcomes. Ultimately, these recommendations can be used by researchers with the aim to strengthen the therapeutic alliance between clients and health professionals and improve healthcare systems, services, and health outcomes.

2. Unique context of Northwestern Ontario

Hospitals (16)

- St. Joseph's Care Group (Thunder Bay)
- Thunder Bay Regional Health Sciences Centre
- Sioux Lookout Meno Ya Win Health Centre
- Red Lake Margaret Cochenour Memorial Hospital
- Lake Of The Woods District Hospital (Kenora)
- Geraldton District Hospital
- Atikokan District Hospital
- Riverside Health Care (Fort Frances)
- Dryden Regional Health Centre
- Mary Berglund Community Health Centre (Ignace)
- Emo Health Centre
- Rainy River Health Centre
- Nipigon District Memorial Hospital
- Manitouwadge District Hospital
- McCausland Hospital (Terrace Bay)
- Marathon Wilson General

Community Primary Care Health Providers (6)

- Health Canada
- Sioux Lookout First Nations Health Authority
- Shibogama First Nations Council
- Windigo First Nations Council
- Independent First Nations Alliance
- First Nation Community Health Directors

Regional Research Organisations (4)

- Lakehead University
- Northern Ontario School of Medicine
- Confederation College
- Thunder Bay Regional Health Research Institute (TBRHRI)

North West LHIN - Sub-Region Boundaries

NORTH
WEST
LHIN

Northern
(21,800)

District of Kenora
(43,100)

District of
Thunder Bay
(17,800)

District of Rainy River
(20,400)

City of
Thunder Bay
(128,000)

Terrace Bay
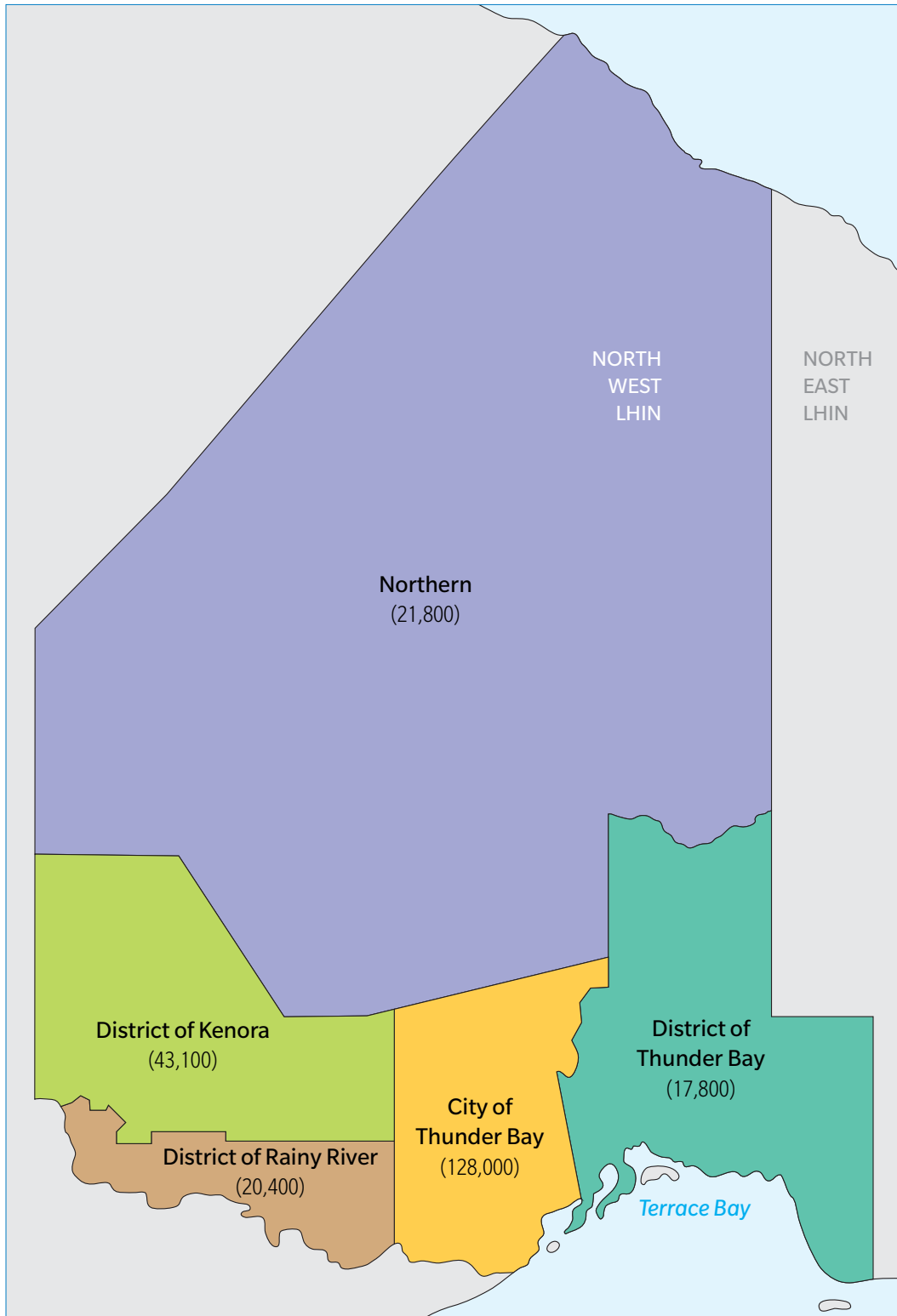
3. The District of Thunder Bay

Hospitals in Thunder Bay, Ontario are part of the North West Local Health Integration Network (LHIN), which consists of five sub-regions. Principles underlying client involvement as research partners align well with both the St. Joseph's Care Group (SJCG) and Thunder Bay Regional Health Sciences Centre (TBRHSC) Mission and Vision statements. These principles encourage collaboration with multiple stakeholders, including clients to achieve quality client-centred care.

St. Joseph Care Group (SJCG)

St. Joseph's Care Group (SJCG) combines tradition and innovation in responding to the unmet needs of the people of Northwestern Ontario since 1884. SJCG is here for our clients, offering a broad range of programs and services in Addictions & Mental Health, Rehabilitative Care, and Seniors' Health across eight sites in the City of Thunder Bay.	**Mission Statement:** St. Joseph's Care Group is a Catholic organization that identifies and responds to the unmet needs of the people of Northwestern Ontario, as a way of continuing the healing mission of Jesus in the tradition of the Sisters of St. Joseph of Sault Ste. Marie.
SJCG's vast service area and culturally diverse client population includes many remote and isolated communities where access to specialized health services is a challenge. To meet that challenge, SJCG finds new and innovative ways to deliver care through technology and strong partnerships, and are Northwestern Ontario's regional lead for Rehabilitative Care, Behavioural Supports, Seniors' Care, Rapid Access Addiction Medicine, and Palliative Care.	**Vision Statement:** A leader in client-centred care. **Core Values:** Care, compassion, and commitment.

Thunder Bay Regional Health Sciences Centre (TBRHSC)

TBRHSC's mission to *"deliver a quality patient experience in an academic health care environment that is responsive to the needs of the population of Northwestern Ontario"* will be advanced through efforts to learn from lived experience of clients.	**Mission Statement:** We will deliver a quality patient experience in an academic health care environment that is responsive to the needs of the population of Northwestern Ontario.
TBRHSC's values of *"Patients First, Accountability, Respect, and Excellence"* and SJCG's vision of being *"a leader in client-centred care"* are consistent with POR best practices, for example having clients play a key role in identifying research questions or topics, and giving them first priority and respect as research team members and partners.	**Vision Statement:** Healthy together **Values:** Patients First, Accountability, Respect and Excellence.

With Thunder Bay serving communities throughout Northwestern Ontario, involvement of clients may extend beyond the city of Thunder Bay. It may be challenging or impossible for researchers to effectively plan a POR or client engagement that will extend to the entire region of Northwestern Ontario. Researchers will need to refine POR approaches, depending on the context, health settings, and community needs, considering the transferability of findings to other communities, cities, or health settings.

4. Definition: What is Patient-Oriented Research (POR)?

A **patient** (or client) is a person with lived experiences concerning a particular health issue(s) or an informal caregiver, which include family and friends who have a level of understanding on the issue due to their relationship with the person.

Patient-oriented research (POR) is research that engages clients as active partners at various levels (governance, priority setting, conduct of research, summarizing, distributing, sharing, and knowledge application) to improve health and health care with a focus on client-identified priorities. Simply, clients as part of the research team are collaborating and co-building with researchers, health care practitioners, and decision-makers in the research.

POR refers to a research project that engages clients as **co-researcher** and focuses on priorities which are identified in collaboration with the client(s). To be classified as POR, a research project should include the following features: [1]

> For the purposes of these Guidelines, a *patient (or client)* is defined as a person with lived experience of a health issue, an informal caregiver, a family member, or a friend.

- The research team includes clients, researchers, health care providers, and decision makers.

- Research questions proposed by researchers must be co-developed with, and/or accepted by clients.

- Clients are involved at various levels of research: governance, priority setting, summarizing, distributing, sharing, and knowledge application.

- Researchers, health care providers, decision-makers, and policy-makers appreciate the value of partnering with clients and clients understand the value of these collaborations.

- Inclusion of explicit processes to build a trusting relationship and meaningful client collaboration throughout various stages of the project, such as developing POR protocols, defining the research question, designing the project, recruiting study participants, collecting data, data analysis, dissemination of study findings, and project evaluation, inform POR guidelines, and consultant for hospital research programs.

- Clear and explicit understanding of the purpose for the engagement and how the client partner(s) will contribute to the planning process.

Note: inclusion = kikinikewin

5. Principles: Values that guide Patient-Oriented Research

There are various core principles that govern client involvement in research. Guiding principles can be drawn from three sources: 1) Strategy for Patient-Oriented Research (SPOR) from the Canadian Institutes for Health Research (CIHR); 2) INVOLVE from the United Kingdom's National Health Service; and 3) Patient-Centered Outcomes Research Institute (PCORI) from the United States. Each set of principles is uniquely worded but there are overlaps across the principles in the spirit and intent of POR.

Strategy for Patient-Oriented Research (SPOR) [2] Canada, 2011	INVOLVE United Kingdom, 1996	Patient-Centered Outcomes Research Institute (PCORI) [3] United States, 2010
Inclusiveness: Promote openness to client's perspective based on lived experience.	**Fairness of Opportunity:** All stakeholders in the research understand and give support to the principles of equality, diversity, and inclusion. Researchers and research organizations should ensure that public involvement opportunities are open to all and information is written in simple English and accessible in different formats.	**Reciprocal relationship:** The roles and decision-making authority of all stakeholders in the research team should be clearly outlined and maintained in agreement by all in the team.
Support: Needed support should be extended to participating clients to enhance their skills, understanding of the project, and involvement. Give clients necessary training, education, and financial support.	**Support:** Make sure all stakeholders, especially the client partners, have the needed support to learn and develop the skills required to be actively involved in the research. Provide researchers the knowledge needed to support public/client involvement in research. Make financial provisions to cover public members' expenses. Take advantage of infrastructure within research organizations to support public involvement in research.	**Partnership:** Clients and other stakeholders' time and contributions are valued, which is evidenced in equal financial compensation. Members of the research team expect diversity, are culturally competent and accommodate those with a disability.

Strategy for Patient-Oriented Research (SPOR) [2] Canada, 2011	INVOLVE United Kingdom, 1996	Patient-Centered Outcomes Research Institute (PCORI) [3] United States, 2010
Mutual Respect: All stakeholders acknowledge differences in expertise and respect one another's contributions.	**Respect:** All members of the research team (researcher, research organizations, and client) must respect one another's roles, perspectives, skills, knowledge, and experiences. **Transparency:** All members of the research team should have a good understanding of the research project and why they are involved. Researchers and other research partners should truthfully inform public members about the purpose, scope, and expectations of the research.	**Transparency, honesty, and trust:** Research team decisions are made inclusively with open and honest communications among all members at all levels.
Co-Building: Researchers, health practitioners, and clients collaboratively identify important health issues and develop appropriate measures.	**Responsiveness:** Give good attention and react well to the input of public members involved in research studies. Everyone involved in the research contributes to group decision-making. Researchers and research organizations committed to public/client involvement should act on the input of the public/client. **Accountability:** All stakeholders are accountable to one another. Researchers, research organizations, and public members evaluate the effect of public participation in the research.	**Co-Learning:** Provide helpful resources to stakeholders and clients involved in research, to help understand the research process and gain knowledge on client-centredness and engagement.

OCAP

Kaa kihtencikaatekin tepwewininan ihiweniwan Anishinini otepwewinan Tipinawewisiwin, Min ciminikewin, Tepinikewin, miina Tahkonikewin (OCAP), mii ihiweniwan tepwe enahtek Anishinini omihkikewin keyishi maamoonshakinikaatek, kanawencikaatek, aapatahk, miina wii ci aapacihcikaatek.	A valuable set of principles are the First Nations principles of Ownership, Control, Access, and Possession (OCAP), which are de facto standards for how First Nations data should be collected, protected, used, and shared.

The First Nations Principles of OCAP: [4]

Ownership: Refers to the connection of First Nations to their cultural knowledge, data, and information. The principle of Ownership states that a community/group owns information collectively as a person owns his/her private information.

Control: First Nations, their communities, and representative bodies have the right to seek control over all aspects of research and information management processes that concern them. This includes all stages of a research project from start to finish. This include the control of resources, review processes, planning, management of the information, and more.

Access: First Nations must have access to information and data that involve them and their communities irrespective of project location. First Nations communities and organizations have the right to manage and make decisions on access to their collective information.

Possession: While ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete: it refers to the physical control of data. Possession is the mechanism by which ownership can be asserted and protected.

Further to this, other Indigenous groups or communities may have their own protocols or standards when choosing to participate in research. When working with Indigenous populations, it is important to consult and collaborate at the onset of the research and on an ongoing basis to ensure the priorities, needs, and goals of the researchers and the communities are being met.

6. Rationale: Involving Clients as Co-Researchers

Client involvement in research is important as it enables clients with lived experiences to share their unique perspectives in the development of approaches, services, and policies that will help enact a change in Canada's national and provincial health systems. POR makes research more accountable and transparent and can bring about exceptional findings. To achieve better POR results, client partners need to be involved in the research project from the outset, helping to ask questions that are most relevant to clients and their experiences of health services and policies.[5] Ultimately, meaningful engagement of clients in health research leads to more effective health policies and health services.

In POR, clients engage in research as **research partners ("patient researchers" or PRs)**, bringing their lived experiences and unique understandings of health issues, illness, and health care. Client partners are valued research partners, because they bring a **unique perspective** that health care staff and researchers might not otherwise consider. Client partners will likely bring up issues, concerns, possible solutions and perspectives that other research team members do not possess.[6]

Key rationale for engaging clients in research is that they have **valuable knowledge** to contribute, and they have **the right to be involved** in shaping the services that affect them. More specifically: [7]

- Clients have unique expertise and experiences and have a vital role to play in defining the health, social, legal, and research policies that affect them.

    Wiicihaakanak paahpahkaan ishi okihkentamaawiniwak miina kiihpiishihsewak miina oka kihci wiicihtoonaawaa kekonen kaa icikaatek minoyaawin, wiitaatisiimiwewin, onaahkonikewin, mii na mahcihsewin kaa nanaantawencikaatek onaahkonikewinensan kaa naanta ishipinikoowaac.

- Clients have the capability and support to meaningfully contribute to and participate in research.

    Wiicihaakanak ci kahshkihtoowaac miina ci wiicihintwaa kwayahk ci pakitinikewaac miina ci wiicihtoowaac macihsewin kaa nanaantawencikaatek.

- Clients have the right to become involved in activities that affect their health and well-being.

    Wiicihaakanak omashkawisiiwiniwak ci wiicihtoowaac tootamoowinan ke wiicihikoc ominoyaa winink miina mashkawaatisiwin.

- Clients have the right to be able to make informed decisions about their health.

    Wiicihaakanak omashkawisiiwiniwak ci onentamiwaac ominoyaawiniwaa.

The following are key reasons why POR is valuable: [8]

Improved health: Clients help us understand, from an insider perspective, what leads to better health outcomes and how specific characteristics of health services have contributed (or not) to those outcomes. Client engagement deepens the understanding of clients' concerns and provides answers that will be meaningful to improve client health and the health system.

Improved access to the health care system: Clients help us understand the barriers and facilitators to accessing health services and resources.

The right treatment at the right time: The Ontario Ministry of Health and Long-Term Care (2015) aims "to successfully build a high-performing, better connected, more integrated, patient-centred health system," with access to care remaining a priority. [9]

Being an active and informed partner in health care: Establishing a client-oriented research team increases the client perspective in the research process. Ideally, the client perspective will enhance health professionals' understanding of how to deliver client-centred services.

Quality of life that is tied to client-oriented outcomes: When identifying therapeutic goals, client-oriented understandings of quality of life are essential. What health professionals identify as client goals may not be consistent with holistic aspects of quality of life that are important to clients.

Make a contribution to improving the cost effectiveness of the health care system: Ontario Ministry of Health and Long Term Care 2016-2017 espoused priority is "putting people and patients first and promoting evidence-based care."[10] When health services meet the needs of clients and engage them in culturally safe care, resources will be more effectively spent.

Mutual skills building: POR builds the skills and knowledge of clients, health researchers and health professionals. Clients, in particular, may gain confidence and new skills in research that can be transferable to other projects, increase confidence, and they may gain access to information they can understand and use.

7. Best Practices: Practical Strategies for Engaging Clients

These best practice recommendations are intended to help direct the course of action for POR projects. Without deliberately incorporating some of these best practices, it could be difficult for researchers to successfully engage clients as partners in designing and conducting research.[11]

Ideally, POR includes clients and all stakeholders in the entire research process.[12] When planning any POR in Canada, the research team should make thorough plans to enable client partners to have genuine involvement in all stages of the research, including: [13]
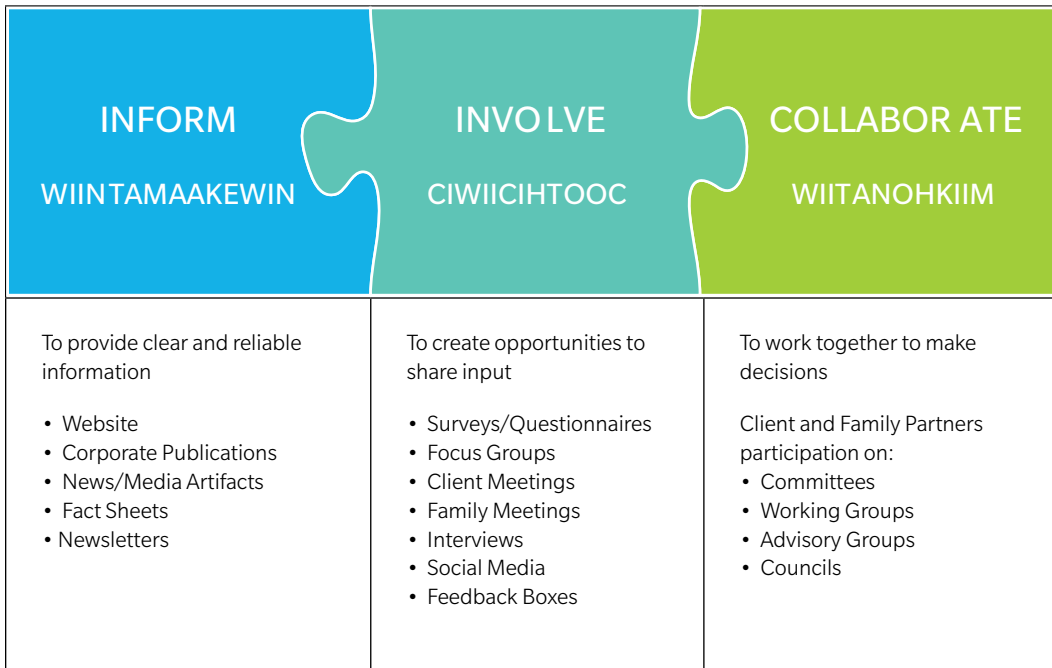
- developing the research question
- designing the study (overall methods, data collection tools, processes)
- collecting the data
- analyzing the data
- disseminating the findings
- evaluating the research

It is also important to understand that there are different levels of client engagement. A helpful framework is the International Association for Public Participation (2004) IAP2 Public Participation Spectrum, which depicts increasing level of input and decision-making impact as one moves from left to right of the spectrum.

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	Provide the public with balanced and objective information to assist them in understanding the problems, alternatives and/or solutions.	To obtain public feedback on analysis. alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision making in the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will Keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision. We will seek your feedback on drafts and proposals.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will work together with you to formulate solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

In Thunder Bay, St. Joseph's Care Group (SJCG) drew on IAP2 principles to conceptualize different levels of client engagement, from informing, to involving, to collaborating with clients and their families or caregivers. While **informing** is simply communicating decisions already made, involvement and collaboration allow clients to have input into those decisions. **Involvement** occurs when quick input from a diverse group is needed. Surveys, interviews and focus groups are common methods to gain input from clients/families. Involvement can also be done

informally and routinely by simply asking for input. **Collaboration** occurs when input on complex issues/topics that require long-term planning and decision-making is needed. Clients and families are involved in formal groups and processes responsible for organizational and strategic objectives. Clients and families commit to a specific level of responsibility and become partners in research, program or policy development.[14]

INFORM WIINTAMAAKEWIN	INVOLVE CIWIICIHTOOC	COLLABOR ATE WIITANOHKIIM
To provide clear and reliable information • Website • Corporate Publications • News/Media Artifacts • Fact Sheets • Newsletters	To create opportunities to share input • Surveys/Questionnaires • Focus Groups • Client Meetings • Family Meetings • Interviews • Social Media • Feedback Boxes	To work together to make decisions Client and Family Partners participation on: • Committees • Working Groups • Advisory Groups • Councils

Power dynamics is another factor that may impose challenges on a project as client partners may not feel comfortable or respected when they think that other team members have more authority than them. Hence, they may feel undervalued.[15] To effectively engage diverse groups of clients, the research team should ensure that the power dynamics between the facilitators and the PRs are addressed. If PRs should perceive the researcher or facilitator as too knowledgeable or having more social capital than them, it may affect their level of comfort and how they provide information to the study.[16]

Common client concerns[17]	Common researcher concerns
• Tokenism • Not being taken seriously • Time and financial commitments • Insufficient understanding of subject matter or of research methods • Discouragement • Insufficient resources to compensate clients • Low client literacy or language barriers • Poor understanding of clients' role • Poor client engagement strategy • Distrust • Lack of guidance or communication • Poor recruitment strategy • Lack of training opportunities • Daily responsibilities of a client partner such as care for family members • Inflexible employment schedules • Household and caregiver responsibilities • Lack of transportation • Insecure housing • Unpredictable schedules • Food insecurity • Coping with addiction or mental illness	• Additional time and resources necessary in POR • Recognizing clients' knowledge and contributions • Lack of clarity of client role • Lack of clarity for how to engage client • Need to facilitate access to resources typically required for research, such as computer, Internet, printer, scanner, fax • Need to distinguish between research participants (for data collection) and patient researchers (as partners), particularly for Ethics Review Boards • May need to negotiate mutually acceptable means for paying patient researchers with institutional financial services

There is no single strategy to overcome the challenges that come with a client partnership. In dealing with a sensitive population, it is very important to start by building a **trusting relationship** with the client partners and client researchers.[18] By building a trusting relationship, the clients involved will feel safe throughout the research process and their partnership will be meaningful and active.

8. Best Practices: Northwestern Ontario Context and Decolonizing Approaches

Below are some best practices in implementing a patient oriented research project.[19] Included here are recommendations specific to Northwestern Ontario and specific to engaging in research with Indigenous people and communities. Researchers have a responsibility to respect and honour all people and communities. The recommendations for engaging in research with Indigenous people and communities is based on current literature and principles, but they are not to be viewed as exhaustive nor definitive.

1. **Identify the research question and methodology:** Ideally, POR focuses on priorities identified by client(s) and health care provider(s) (not the researcher). With this in mind POR allows the client or health care provider to take the lead in pointing out the areas of health issues and healthcare concerns that are most paramount to them at the time. In cases where the research topic is generated by the researcher, client allyship needs to be secured to ensure congruency with POR principles.[20]

   Northwestern Ontario:
   - There is research capacity in Northwestern Ontario to engage in community-based research. Existing processes for inviting communities to identify research priorities can be built on.
   - We recommend that it become considered best practice for every health-related research team to include one or more patient researcher.
   - We recommend that research institutes and hospitals develop processes for clients to prioritise research needs and interests.

   Decolonizing research approaches:
   - Work collaboratively to develop a research question that reflects the needs of both patients and researchers.
   - Facilitate open dialogue regarding which methodology is suitable to address the research topic and culture.
   - There may be need for education about methodology for researchers and/or patient researchers. Researchers may be asked to consider methods outside their existing expertise.
   - "Two-eyed seeing framework" privileges Indigenous perspectives. It offers a framework where Indigenous and non-Indigenous worldviews can be seen as complementary.[21]

     Ci niikaanakintek onahcikewin "kaa niishoocaapi kanawaapancikaatek onahcikewin" wimihti kooshi miina anishinini kaashi kanawaapancikewaac ciishi waapancikaatek ewiicihitiimakahkin.
   - Understand and respect the 5 R's in the context of Indigenous research (relationship, respect, relevance, responsibility and reciprocity).[22]

     Nihsitohtaan miina kihtentan kaa niyaananowaac R's nehke onci Anishinini omacihsewin kaashi nanaantawentank (wiiciiwitiwin, kihtenimiwewin, kewinci wiicihiwemakahk, papaamisiihkanci kewin miina kwehkwehk keshi wiicihiwemakahk).

2. **Recruit wisely:** It is crucial that PRs be representative and engaged. Consider questions such as: Whose voices and experiences are most relevant to the conversation? What issues will be discussed? And how? The type and depth of engagement will help determine the PR outreach process. If possible, aim for a mix of people who are new to engagement and those who are experienced.

☐ Consider and meet the needs of a variety of clients, populations, and age groups
☐ Deliberately identify and engage under-represented client groups
☐ Support clients in their efforts to engage/reach out to underrepresented groups

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Northwestern Ontario:

- Northwestern Ontario covers vast geographical regions and includes a diverse population. Research teams will need to consider the population of interest and determine what is "representative" for the scope of the project.

- Researchers may consider the need for access to translators and interpreters to provide inclusive and diverse team engagement.

- Researchers will need to consider 'hidden' financial costs for prospective PRs (e.g., bus, parking, child care)

Decolonizing research approaches:

- As per OCAP principles and the TCPS-2 https://ethics.gc.ca/eng/tcps2-eptc2_2018_chapter9-chapitre9.html, research that involves Indigenous People must adhere to distinct processes of knowledge governance that extends beyond research team membership.

- Ensure members of the community you are partnering with during the research process are involved in recruiting participants should they wish to be so.

- Ensure recruitment procedures are collectively decided to ensure they incorporate local customs and traditions.

- Be mindful that, historically, relationships with research and health care systems have not necessarily all been positive, resulting in mistrust. An ongoing lack of appropriate and culturally suitable care has created tensions and reluctance for Indigenous clients to be willing to engage in health research (especially if it is within a health care system framework).

Three methods to identify/connect with clients for a POR project: [23]

a) A case-by-case basis where researchers identify clients with experience of a health condition or knowledge about a particular subject matter.

b) Researchers and clients seek each other out through the use of directories. Clients and researchers look for posted projects.

c) Researchers and clients are matched by a third party.

Four strategies for recruiting patient researchers: [24]

a) Social marketing: Advertisements on radio, TV, newspapers, social media and community spaces for example churches, schools, libraries, and waiting rooms.

b) Community outreach: Town hall meetings, reaching out to community leaders, booths at community events, fairs and festivals.

c) Health system: Health care providers or research staff approach prospective clients within the healthcare system to inform them of the project. Organisations may consider maintaining a list of interested clients (with consent), such as through Research Services or Peer Support Services.

d) Partners: Cooperation with an organization or group who have members or can reach out to community members based on previously established trusting relationships.

Northwestern Ontario:

- In Northwestern Ontario, there are no existing formal processes to connect researchers and clients. However, many hospitals have both Research Services and Peer & Family Advisory groups that may support these types of connections.

Decolonizing research approaches:

- Engagement with local elders and leaders may direct researchers to knowledge-holders not otherwise considered.

3. **Give PRs the tools they need:** Provide PRs with accessible, relevant, and balanced resources and support to build their knowledge and skills and increase their confidence and capacity to engage. Provide the necessary capacity building and ensure that projects include a phase for adequate education, orientation, and training for clients, researchers, health care providers, and decision makers. Clients' ability to participate and comfort sharing their thoughts and experiences are additional factors to consider when engaging clients.

Northwestern Ontario:

- It may be advantageous to develop modules in multiple formats (e.g., online, written) about research and research processes. Research organisations and health organisations can work together to reduce duplication of resources.

- Ethics Boards and Research Services may review their processes to support involvement of patient researchers and remove unnecessary barriers.

- To successfully carry out a POR in NW Ontario more broadly, the research team may consider plans to accommodate the needs of the client partners and study participants, such as the use of distance technology. It is important to facilitate access to resources needed by patient researchers. Not all patient researchers will have ready access to phone, Internet, computer, scanner, fax, or videoconference capabilities.

Decolonizing research approaches:

- Researchers should be aware of the ways in which their research processes may need to be modified to suit the population they are working with (i.e., bringing in translators, including visuals, ensuring adequate time for explanation/consultation)

- Consulting local Indigenous Chief and Council to review and approve the research prior to commencing recruitment.

- Researchers should be aware of and leave room for understanding individual experiences within the context of family and community.

- Researchers should be aware of the concept of spiritual ecology and the role it may play in viewpoints of patient researchers.

4. **Consider a range of engagement methods:** Sometimes involvement of clients at all stages of research is not feasible. To engage clients at select stages, consider one-on-one interviews, focus groups, questionnaires/surveys, comment boxes, advisory councils/committees, meeting with client and family groups, storytelling, displays, or informally engaging clients/families. Remember, involvement of patients as research partners is distinct from data collection and requires distinct approaches.

   It is essential to consider factors to support collaboration, such as location and times of meetings, teleconference or videoconference options, and spoken language.

   ### Northwestern Ontario:

   - When engaging patient researchers in communities at a geographical distance from the lead researcher, distance technology may provide a means to engage clients. Distance technology can also provide a means to facilitate engagement of a broad range of clients, such as people with mobility challenges and primary caregivers, and during times of year when weather is unpredictable.
   - Open-ended drop-in times that span a day may be helpful, particularly when engaging people who experience substance use or pain, have family or community obligations, or are employed.

   ### Decolonizing research approaches:

   - Research processes should be collaborative and decided upon at the onset of the research. Tailoring engagement methods and location to suit the clients' needs are essential.
   - Should you be engaging in Indigenous communitybased research, an advisory committee should be formed to collaborate on engagement methods suitable for that community.
   - Researchers should be aware of the Euro-western underpinnings of the research approach and explore alternative versions that acknowledge different ways of knowing and being. Acknowledge and consider the potential influence and use of Indigenous knowledge paradigms.

5. **Choose the best timeframe for meaningful input:** Choose the best duration and frequency of meetings for gathering input for the project, purpose, or initiative. For PRs to provide input into a complex issue/topic, they may need considerable time to gain background knowledge to enable full participation. Generally, factors to consider in shaping an engagement process include its purpose, the resources and supports available, the level of commitment from PRs, the complexity or specialized focus of the project or initiative, and the urgency of the issue.

   ### Northwestern Ontario:

   - While it is ideal to include patient researchers throughout all stages of research, this may not be realistic, depending on factors such as institutional processes, timelines, funding, and/or patient researcher availability. It is recommended that teams carefully consider minimum standards for involvement and avoid tokenism.

   ### Decolonizing research approaches:

   - Building relationships prior to engaging in any research process is necessary. Researchers should consider historical contexts that may influence the relationship building process and engage in critical reflexivity in relation to the groups they are working with during the research process

6. **Be clear about your purpose and objectives:** From the start, give PRs a clear understanding of the engagement's purpose, objectives, indicators of success, and of the level of involvement you expect from them. Let them know that things may evolve but not beyond their comfort level. Questions to consider include: How will the engagement advance the goals for improving care or service? How will the PR's input be sought for decision-making, especially as the engagement evolves? Will the engagement connect to policy change, program design, service delivery, or a combination thereof? If so, how?

Northwestern Ontario:

- Be conscientious of peoples' roles in their communities and discuss potential risks or conflict of interest.

- Particularly when integrating critical perspectives or addressing highly sensitive topics, a patient researchers' position and reputation in the community needs to be protected.

Decolonizing research approaches:

- Collaboration and decision making at the onset of the research ensures engagement expectations are outlined from both sides to ensure a respectful and productive research relationship

- Creating a research agreement (written or oral) relating to the purposes and objectives collectively decided should be created and shared openly with both researchers and community members

- Co-constructing important research documents (such as consent forms) ensures the purpose and objectives are properly translated to participants.[25]

7. **Be clear about the level of commitment needed:** By agreeing to participate as patient researchers, people accept that they are ready to devote their time and energy because they understand the importance of the project and the value they bring by participating. Consider the time, location, method, and facilitator(s) of the client engagement sections.

Northwestern Ontario:

- There can be high community mobility among people in rural and remote communities in order to access health, education, employment, and other services. Be clear about expected length of commitment and establish a means to maintain or re-establish contact if there are lulls in the research process (e.g., awaiting Ethics approval).

Decolonizing research approaches:

- Due to historical contexts of Indigenous peoples being over-researched with little to no benefit to the community itself, researchers should outline the level of commitment needed at the onset and be transparent about purposes and intentions. It is the right of the community to decide whether they wish to be involved.

- Knowledge exchange may have unique customs and expectations attached. Explore the needs and expectations surrounding this. Researchers need to understand that the findings may not be permitted to leave the community (e.g., for publication, presentation) if the community so chooses.

8. **Be clear about the scope of influence:** Be clear with the PRs what level of influence or authority the group has to implement changes, and explain the scope and limits from the start. Establish decision-making processes within the POR team, with clear and transparent methods, and explicit ways of ensuring contributions from all team members are heard and valued.

Northwestern Ontario:

- Health and social systems of Northwestern Ontario are often complex and convoluted, especially in the context of service delivery. Establishing strong local contacts can be essential to make sure the "big picture" is captured and that understanding of structures and processes are not lost.

- Capacity building may be valuable and applicable.

Decolonizing research approaches:

- Knowledge sharing and dissemination strategies should be decided upon collectively.

- Consider alternative methods to research dissemination and determine the scope to which this research will be shared (in an academic journal, within the community, at a government meeting, in an academic journal).

- Discuss partnerships and provide credit to community co-researchers/partners as consulted and as is due. Preference will vary (e.g., authorship on manuscripts; sharing finding in various ways that protect and respect Indigenous culture).

9. **Decide on a code of conduct together:** By facilitators and PRs agreeing on rules together, solidarity, trust, and commitment are enhanced. The approved code should set an understanding of the importance of the confidentiality and privacy of all of the PRs, and a shared commitment to protecting it.

Northwestern Ontario:

- Be realistic about privacy in small communities when discussing involvement of patient researchers. While confidentiality of information can be more closely managed, privacy can be challenging to ensure.

Decolonizing research approaches:

- Ensure cultural contexts are considered when developing a code of conduct.

- Confidentiality and privacy should be considered in relation to OCAP or other community frameworks or guiding principles

10. **Have an exit strategy in place:** In the course of a long-term engagement, it can be expected that some people will leave. The engagement may not be a good fit for them, or they may have to leave because of personal or medical issues. Consider whether an exit interview or survey would help to understand reasons why PRs leave an initiative.

Northwestern Ontario:

- At the onset, timelines, including termination of the research partnership, should be collectively decided and understood.

Decolonizing research approaches:

- Researchers should be aware of historical contexts in relation to communities they partner with, and capacity building should be incorporated to ensure research findings and data can be effectively utilized by the community long after the partnership ends.

11. **Give PRs the recognition they deserve:** Extending gestures of appreciation helps in recognizing the valuable contribution and impact that PRs make. It is also important to acknowledge the contributions of PRs when reporting to the public and other audiences. Public recognition must be negotiated with all research partners, as some people prefer their contributions to be confidential.

Northwestern Ontario:

- Discuss the desired recognition of the PRs and the community at the onset of the research to mitigate misinformation and disagreement.

Decolonizing research approaches:

- Discuss appropriate recognition strategies in relation to cultural customs (e.g., tobacco, food, gifts). Gestures that are culturally appropriate may differ widely and one's culture and traditions cannot be assumed based on ethnicity. Asking, showing humility, and allowing room for learning can be helpful.

12. **Report back:** Commit to a communication feedback loop at the beginning of the project, and follow through to its conclusion. Include time during meetings to discuss the progress and achievements of the work that PRs are involved in.

Northwestern Ontario:

- Become familiar with local processes already in place when the time comes to share the knowledge collected.

Decolonizing research approaches:

- Explore strategies that allow for better communication and progress dissemination.
- Consider the first-language of the community members.
- Develop a plan for consulting times throughout the entire research project that do not overburden the participants. This plan should include collaboration on suitable locations, appropriate formats, and a timeline.

13. **Be prepared for times of less intense work:** Tell PRs to expect lulls in the activity and intensity. Give PRs advance notice that their role may be put on hold, reduced, or shifted during some phases of the project. Keep communication open during lulls and, if possible, offer relevant alternative activities.

14. **Be aware—and mindful—of people's emotions:** Empathy will be needed if memories of sadness, anger, or trauma are elicited at any time during the project. As much as possible, be aware of issues that trigger people's emotions and be sensitive to individual needs. Have a plan in place to support the psychological safety and wellbeing of all research team members and study participants and provide resources as required.

Northwestern Ontario:

- In Northwestern Ontario, researchers are encouraged to integrate a trauma- and violence-informed lens into collaborative processes.

Decolonizing research approaches:

- Facilitators should be aware of and acknowledge strong emotions surrounding colonial history and may have to navigate tensions arising from the engagement process. If the issues explored are particularly sensitive, having access to a traditional healer may be appropriate.

- Emotions may be expressed differently within different cultures, so researchers should educate themselves and utilize reciprocal knowledge sharing to understand the contexts in which they research.

15. **Carry it forward:** When engagement initiatives come to a close, act as a bridge for PRs. Encourage them to join other groups or engagement opportunities if they wish to continue.

16. **Evaluate efforts:** Assess and adapt initiatives to ensure they are as effective as possible. Evaluation can help identify areas for improvement and ultimately help realize goals more efficiently. For a longer-term initiative, evaluation may be conducted at a few points during the journey. Examples of evaluation forms are provided in the Appendix.

Decolonizing research approaches:

- At the onset of the research, consult and agree upon appropriate evaluation methods that ensure applicability and utilization to all partners (researchers and clients/patients/communities). This may include co-developing evaluation methods that respect cultural norms, values and traditions.

- There may be alternative ways of evaluation that include artistic or creative approaches, and ways to explore internalizing knowledge.

Information for Patient Researchers: Things to consider before joining a research team

Questions to ask the researcher	Personal considerations **Is this the right fit for you?**
How many clients will be involved? Is there an experienced patient researcher on the team?	Is peer mentorship essential for me? How comfortable am I to work with researchers?
What area of "expertise" am I being asked to bring?	Is the research topic important to me? Do I have some knowledge about the topic?
What issues will be discussed? And how?	Do I feel comfortable sharing my thoughts and/or experiences?
Who will be on the research team?	Do I feel able to collaborate well with the other team members?
Where will meetings be held?	Is the location convenient for me? Are there various ways to join meetings that might be better for me (e.g., teleconference, videoconference)? How long will it take me to travel to meetings?
Will costs for travel to meetings be paid?	Are there additional costs for me to be a member of the team? (e.g., if driving, will gas and parking be covered?)
Is this a paid position? What is the rate of pay? (How does it compare to the rate of pay for a Research Assistant?)	Do I feel the rate of pay is fair? Will the pay negatively impact my income tax or benefits programs?
How will I be paid?	Will pay be in the form of gift cards? Honorariums? Am I expected to have a chequing account for direct deposit? (Do negotiate these details with the lead researcher)
How many hours am I expected to work? Will hours fluctuate?	Do I have the time to commit to the project? How flexible am I with my time?
How will my confidentiality and privacy be respected on the team?	What are my personal boundaries regarding what I am willing to share on the team?
What is the style of meetings? If there is a particular style, will I be taught about the "rules"?	Does the style of meeting work for me? Does it allow space for me to contribute meaningfully?
What time of day/evening will meetings occur? How long are meetings?	Do the hours work for me? Is there flexibility in meeting dates and times in case I have other obligations or priorities (e.g., work, child care)?

Questions to ask the researcher	Personal considerations **Is this the right fit for you?**
What type of training and/or mentorship is available for me?	How much training or mentorship do I need? How much do I already know? If I am expected to be a mentor, will I have additional training in leadership skills?
What is the process for me to bring concerns and/or feedback to the team?	What would support me to be comfortable to provide feedback to the team or lead researcher?
What resources will be needed to fully contribute (e.g., Internet, printer, phone, computer)? What resources can be provided to me or how can I access what I need?	What resources do I have or have access to? What resources do I need? How will I tell the lead researcher about my needs, if they assume I already have these resources?
What roles will I have on the research term?	Are these roles of interest to me? How much support/mentorship do I need to do these roles? Am I interested in learning new roles? Or am I more comfortable being part of only select roles?
Will I be expected to travel?	Am I available to travel? Are there any hidden costs (e.g., child care, missed work)? Do I want to travel? Am I able to travel?
How will my contributions be acknowledged (or kept private)?	Do I want my contributions publicly acknowledged or kept private? Will my name be included on all work at the same level as the other researchers?
How will I be supported if sensitive topics arise?	At meeting, if sensitive or uncomfortable topics come up, how can I bring this up to the team? How might being a part of the project impact my physical and mental health? Do I have adequate support systems outside meetings?
What are the expected goals and outcomes of the research?	Are these goals important to me? Am I able to provide input to create goals? Am I willing and able to support these goals? Or to what extent can I support the goals?
What is the expected length of my involvement on the team?	Will there be fluctuations in the amount of work over time? If needed for health or family reasons, is it possible to take break(s) in my level of involvement?

Involving Under-served, Vulnerable, Stigmatized, and/or Marginalized People in Research

It is important to involve people who are considered to be in some way(s) vulnerable, stigmatized, and/or marginalized in research.

It is important to remember that *patient researchers are not research participants/informants*. When designing a research project, it is important to distinguish the role of the patient researcher as a team member who is contributing to the research process, not a person who will be providing data.

> **Example:** A research team exploring access to Opioid Agonist Therapies (OAT) in rural communities might involve a researcher, a health professional from a rural community who practices in this area, and a patient researcher who has had personal experience with attempting to access (OAT treatment).
>
> This team would collectively decide on the research question and methods, and undertake data collection, analysis, and data sharing. The patient researcher role is to inform *decision making* about the project.
>
> As part of the project, the team may collect data from research participants. The patient researcher has unique insights that can strengthen the project and participant engagement, such as appropriate wording of research questions and underlying meaning of data. Patient researchers may be skilled interviewers or facilitators of focus groups, building rapport and trust with participants. *The patient researcher is a source of information for the research process; the research participants are a source of direct information about the research topic under exploration.*

The Council for International Organizations of Medical Sciences (CIOMS) defines **vulnerable persons** as "those who are relatively (or absolutely) incapable of protecting their own interests. More formally, they may have insufficient power, intelligence, education, resources, strength, or other needed attributes to protect their own interests."[26]

Stigmatization refers to negative attitudes, values, and beliefs that impact how people are viewed and treated. Areas where stigma is prevalent include ethnicity, poverty, homelessness, level of education, social class, sexual orientation, and experiences such as substance use, mental illness, sexually transmitted infections, and obesity.

Marginalization is defined as "Marginalization is the process by which individuals and groups are prevented from fully participating in society. Marginalized populations can experience barriers to accessing meaningful employment, adequate housing, education, recreation, clean water, health services and other social determinants of health." [27]

To exclude people who are in some way(s) considered vulnerable and/or stigmatized from engaging as patient researchers can result in further marginalization. Aldridge (2015) observed,

> "people who may be defined as vulnerable or marginalised… are often overlooked or denied full participation in research, either because they are considered 'hard to reach'… or because the ethical considerations and procedures involved in doing so are seen as problematic, challenging, or even insurmountable. The result is that certain vulnerable or marginalised individuals or groups (specifically, for example, those who may be defined as multiply vulnerable) may be left out of studies altogether, and thus our knowledge and insights about their experiences and needs remains limited." [28]

Involvement of PRs is especially important when those clients are marginalized due to their socio-economic status. It is especially important to hear from PRs in order to understand their experiences of stigma within the health care system, and how their access to respectful and supportive health services has been impacted. PRs can help us understand, for example, how health care providers' responses to substance use by hospital clients influences their engagement in care for physical health problems.

POR offers a socially just approach to inclusion and diversity in knowledge creation. At the same time, researchers and the research team are faced with the added responsibility of creating and maintaining safe, trusting, and ethical collaborative processes that afford power sharing. Some strategies for this are discussed in more detail in Section 7 of this document.

9. Assessment: Successful Implementation of POR

How do we know that a client engagement in POR is successful? In a nutshell, a successful POR is a research project that encourages **client engagement at all levels of the research**. Below is a more detailed checklist that all members of the POR team should independently consider: [29]

☐ There was adequate **orientation, education and training** to ensure that all members of the team had the capacity to provide input at all phases of the research project.

☐ There was transparent and regular **communication** among all stakeholders.

☐ The **roles and responsibilities** of all stakeholders in the team were clearly defined. Every member of the team understood what was expected of them.

☐ Stakeholders experienced mutual **respect** and **honest dialogue** within the research team.

☐ First-hand knowledge from client partners was **valued**, interpreted, and incorporated with the goal of informing research outcomes and improving future healthcare.

☐ All stakeholders **effectively collaborated** to improve the quality of research, with measures put in place to communicate progress to client partners.

In addition to the checklist above, there are more extensive evaluation tools that can be used to rigorously evaluate a POR project. Patients Canada has developed Patient/Caregiver and Researcher Surveys that are designed to document the actual experience of research partners and to identify behaviours that support productive partnerships. Each type of survey (Patient/ Caregiver and Researcher) is to be administered three times in order to track the relationship over the duration of the project: 1) initial - to be delivered in the early stages of the partnership; 2) mid-project - to be delivered half-way through the research project; and 3) end of project - to be delivered after the research is completed and while it is in the knowledge translation phase. These surveys can be found in Appendix A.

Evaluating client engagement is an important phase in research as it allows us to know what worked well and what needs to be improved on for future purposes. Evaluating client engagement involves looking at different stages of the research with a focus on how client partners informed the project and its impact on client care and health outcomes. The research team will consider a client engagement in POR successful if the clients' partnership, experiential knowledge, and input made a difference in the project and positively impacted health services and health outcomes.[30] The evaluation section should look to identify ways the client partnership influenced the project because client involvement makes POR projects stand out from non-POR projects. The evaluation should also look to see if respectful collaboration and the POR principles were maintained throughout the research process. Standard evaluation methods that could be used to evaluate POR success are surveys, interviews, and focus groups.

10. Effectively Responding to Challenges and Barriers

Alongside the numerous benefits attached to POR, there are various challenges that may confront clients, researchers, health care providers, and decision makers involved. It is important to anticipate and mitigate potential barriers and challenges that can emerge during POR. These challenges are a result of the research team's diversity and may act as potential barriers to client engagement success.

During the planning phase of any POR, the research team should devote some time to proactively address these potential challenges. Doing this will increase the team's success, reduce time wastage, and increase the quality of the research process.

Involving clients as partners makes the research process more complex because most client partners do not have existing **skills or knowledge specific to research**.[31] To meaningfully and successfully carry out POR, the research team needs to know the population of interest and have an in-depth knowledge of what they need to participate. Doing so is the first step to reducing possible barriers to participating in client engagement.[32]

To minimize potential barriers involved in working with client partners or PRs, researchers can **partner with community-based agencies**. Many clients feel safe working with community-based agencies due to previously established trust with using the services they provide.[33] Community-based agencies have connections to clients who may not be seen frequently or do not use health services. Therefore, if researchers collaborate with such agencies, they may be able to recruit PRs more successfully. Also, if researchers should collaborate with a community-based agency, the agency may be a valuable resource for planning the recruitment strategy as they already have in-depth knowledge of the target population. If such an agency should extend an invitation to participate, the PRs may find trust with the agency. If clients are personally invited by someone they can identify with, they may believe they have the capacity required to participate.[34]

Working with such agencies that people trust and feel contented with may reduce the worry or distress that PRs may have regarding client engagement.[35] Community-based agencies may also help plan meeting times with the study population to align with regular group services or activity times. They may also have resources, such as space and childcare facilities that clients are accustomed to and comfortable visiting. The agency can help to reduce barriers, such as childcare and transportation costs.[36] The agency can also provide guidance on effective ways to present the engagement opportunity and may be able to help conduct the recruitment of PRs.[37] The agency may be able to facilitate client engagement or teach the facilitators and research team the methods through which they can effectively engage with the populations they serve.

Besides these, the research team should have meet and greet meetings with food as an opportunity to meet, develop trust, and build the relationship needed for the research to be successful.[38] If the meeting setting is too formal such as a research environment or in locations that may trigger negative experiences like law enforcement offices, patient researchers may not feel safe, or comfortable, and the setting may impact their contributions and health negatively.[39]

To mitigate POR barriers, the research team should also make information created for the population of interest user-friendly by making it simple and translated into the target population's languages for non-English speaking clients.[40]

In addition to the above strategies, below is a useful list of the practical Do's and Don'ts of POR:[41]

DO'S	DON'TS
Do invite several people Kakwecim naanta awiyak ci piishaawaac	Don't invite just one client
Do select people who can represent various perspectives Ontin awiyak paahpahkaan kaa inentamiwaac	Don't always hand-pick the same person you know and are comfortable with
Do consider a wide variety of client experiences (e.g., active illness, recovered, remission, managed/unmanaged symptoms) Naanaakatawentan mishiinwayek paahpahkaan wiicihaakanak otishihsewiniwaa	Don't rely on stereotypes or over-simplify the client experience
Do hold a meeting or consultation in low-key settings or in a setting where clients already spend time Maawacihitiwinihken naanta kakwetwewin aasha wiicihaakanak kaa tashi ayaawaac	Don't hold meetings in a government building
Do provide a variety of options for involvement (e.g., in person, teleconference, videoconference) Onahtoon paahpahkaanayek ciwinci wiicihtoowaac (taapishkooc., ci ishaac, kitoowinink, pawaahtesicikaninink)	Don't only include people who are able to attend in person
Do provide everyone with the resources and support we need to participate fully. Kahkina awiya ci miininc aapacihtaakanan miina keshi antawentank minsiwe ci wiicihiwec	Don't assume that we have easy access to a computer, telephone, scanner, fax, Internet, etc.
Do provide pay at a rate commensurate with research assistants or minimum wage Ci tipahamawinc omohtanohkii peshikwan macihsewin onanaantawi kihkencike owiiciwe kaa ontisic	Don't assume that we don't need an honorarium or dictate how the money can be spent
Do pay for time in cash Shooniyaa tipahikaaken kaa aapacihac	Don't write us a cheque, or give us a gift card to spend money the way you think we should
Do come to us, if possible Pinaasihkawishinaam, kiishpin ishihsek	Don't ask us to come and meet you in another city
Do guarantee confidentiality Kehcinaac kaawin awiya wiintamaw	Don't identify what a particular client said in proceedings of the meeting

DO'S	DON'TS
Do listen to our opinions and make efforts to use our input Pisintawihshinaam kaa inentamaank miina aapacihtoon kaa ihkitoyaank	Don't just ask the question because it is politically correct to ask us
Do show flexibility with meeting styles Naakohtoon ekaa ci mashkawahcikeyan kaa ishi maawacihitiwinihkeyan	Don't hold a meeting or consultation just the way you are used to
Do show flexibility with meeting times aakohtoon ekaa ci mashkawahcikeyan kaa ishihsec kiishihsohkaan maawacihitiwinihkewin	Discuss the time of day that is most suitable. Consider other priorities through the week/month
Do minimize the length of meetings and workshops Tahkwaahtoon kaa ahkwaak ki maawacihitiwin miina kihkinwahamaakewin	Don't expect us to have the endurance for full-day meetings
Do ask us what we need Kakwetwen kekonen entawentamahk	Don't be afraid to ask
Do acknowledge that you, too, may have needs and that unfamiliarity may make you uncomfortable Kihkentan kekiin, kekoon ci antawentaman miina kaa pahkaanentaman ekaa ci minohshkaakoyan	Don't assume that I am the problem and the only one who needs to learn
Do assign mentorship or provide training (if you ask us to be on a research team)	Don't run your meetings without acknowledging that it may be the first time for us to be on research team
Do consider training for yourself and other research team members specific to the issue of client involvement; ask clients to participate Maamitonentan ci kihkinwahamaakooyan miina pahkaan macihsewin nanaantawikihkencikewin kaa wiicihtoo waac ihimaa maayaam ciwiicihtooc wiicihaakan; kakwecim wiicihaakanak ci wiicihtoowaac	Don't think that you can't learn how to involve me better
Do protect confidentiality Kwayahk kanawentan ki wiintamaakoowin	Don't require disclosure of health status
Do consider our participation in specific roles as a start, with the potential to do more Maamitonentan keniinawint ci wiicihiweyaank paahpahkaanayek ani maacihcikaatek, kaye kiyaapic cikii too tamaank	Don't think that we cannot do more

DO'S	DON'TS
When travel is involved: **Kiishpin maacawin aapatahk:**	
Do help with arranging for access to medication (if applicable) Wiicihiwen ci ontinikaatek mashkihki (kiishpin inahtek)	Don't invite us at the last minute and assume we can deal with this alone
Do provide accommodation close to the meeting space Pehshonc kaa ishi maawacihitinaaniwank ishi kapeshihiwen	Don't just leave us on our own in cities we don't know
Do have a physician on call Ayaaw mashihkiiwinini ke ahsho kanooninc	

11. Conclusion

Regional capacity development to support the involvement of clients as research partners may further inform organizational policy and improve client care outcomes. Education and resources may improve capacity for health professionals, researchers, and clients to form genuine research partnerships. We propose that health care organisations and researchers consider initiatives to further involve clients, health care providers, researchers, community-based agencies and health decision-makers in refining context-specific research principles. Organisations can develop and refine best practice research processes that contribute to contextually relevant outcomes with the support of client involvement.

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Appendix A: Sample Information Pamphlet for Prospective Patient Researchers

see attached document

About Patient-Oriented Research

Who can be a Patient Researcher?

A **patient** (or client) **researcher** is:

- a person with lived experiences of a particular health issue
- an informal caregiver (family and friends who understand the health issue)

A patient researcher is an equally valued member of a research team.

YOU could be a patient researcher!

What is research?

Research involves asking an important question and finding a way to answer that question.

For instance:

- How can access to inexpensive and nutritional food be improved?
- What are the out-of-pocket cost for patients in rural communities who access specialist services?
- What helps build a positive client-doctor relationship?

What is Patient-Oriented Research?

Patient-oriented research (POR) involves clients as co-researchers.

- This means research is done with clients as team members.
- The research is not ABOUT the individual client. Instead, the client brings expertise to help create important research projects.
- Your voice and perspectives are very important. You can help make sure that research is relevant to you, your family, and your community.

Be an active partner in health research!

You are a valued research partner!

- You have unique perspectives to share.
- You have lived experiences that make you an "expert" in those areas.
- Your voice will help make sure that the research being done matters.
- You know important areas for research.
- You understand what is needed to improve health services and policies.
- You have the right to shape research that will affect you, your family, and your community.

Appendix A: Sample Information Pamphlet for Prospective Patient Researchers

What to expect

Successful POR encourages **client engagement**

- Access to **orientation and mentorship**
- Opportunities to **learn** research skills
- Clients help decide on **research topics**
- Transparent, regular **communication**
- Clients are a part of **decision-making**
- Clearly defined **roles and responsibilities**
- Mutual **respect**
- Clear and honest **communication**
- Knowledge of client partners is **valued**
- Effective **team collaboration**
- Researchers work to build **trust**

Inclusiveness: You are an important member of the team.
Your experiences and perspective are valued.

Support: You should be provided the training, education,
and financial support you need to do this work.

Mutual Respect: Every team member brings special expertise.
It is important to respect what each person brings to the team.

Co-Building: Your voice matters.
Your opinions and perspectives are included.

Research roles

Clients can be involved in any and all stages of the research:

- Asking the research question
- Designing the study
- Collecting research information
- Helping to understand the meaning of the information collected
- Sharing the findings publicly
- Evaluating the research and research team

*Knowledge
is in your
hands!*

Appendix A: Sample Information Pamphlet for Prospective Patient Researchers

ᐅᑕᑯᔾ ᖄᐃᔪᐱᒀᐃᐧᒥᐣᐃᐦ ᓄᓇᑕᐃᐧᖅᒋᖅᒀᐃᐧᐳ

ᐊᐁᐧᓂᐳ ᖅᐱᐃᓇ ᓂᐳᐸᐧᐳ ᐅᑕᑯᔾ ᖄᐃᔪᐱᒀᐃᐧᒥᐣᐃᐦ ᓄᓇᑕᐃᐧᖅᒋᖅᒀᐃᐧᐳᐧ?

ᐊᐁᐧ· **ᐅᑕᑯᔾ** (ᓇᐳᑕ (ᑲᐊᓄᕆᑕᐃᐧᐧᐧ) **ᐅᓄᓇᑕᐃᐧᖅᒀᕆ** ᑲᐃᐊᑲᓄ⁻:

- ᐊᐃᐧᔾ ᑲᕆᐱᖅᖢᑲᐧ ᐱᑯ ᖅᑯᐳ ᐃᐊᐱᔪᐃᐧᓂ
- ᐊᐃᐧᔾ ᑲᕆᐱ ᑲᓇᐁᐧᓂᒥᐁᐧ⁻ (ᐅᐊᑐᓪᑲᓇᐳ ᓇᐳᑕ ᐅᑐᐤᒪᐳ ᑲᓂᔾᑕᐁᐧᑕᒥᓂ⁻ ᐊᑯᔾᐃ· ᖅᑯᓂ)

ᐊᐁᐧ· ᐅᑕᑯᔾᐃ· ᓄᓇᑕᐃᐧᖅᒀᕆ ᒪᐊ⁻ ᖃᕆ<ᐱᔾ ᐃᒪ ᓄᓇᑕᐃᐧᖅᒀᕆᖅᐃᐧᓂ` ᑲᒪᒪᐊᐧᓄᑲᑐᐊᐧ⁻.

ᖅᐱᐳ ᖃᖅ ᑐᑕᐳ ᒥᓇᓄᖅᔾᐳ ᐅᑕᑯᔾᐃᐧᐧᐧᐧ ᓄᓇᑕᐃᐧᖅᒀᕆ!

ᖅᑯᓂᐳ ᐃᐁᐧ· ᓄᓇᑕᐃᐧᖅᒋᖅᒀᐃᐧᐳᐧ?

ᑲᓄᓇᑕᐃᐧᖅᒀᑲᓄᐊᐧ` ᑲᖄᐧᐃᐧᓇᓂᐊᐧᓄᐳ ᑲᕆᕆᖅᑲ` ᑲᖄᐧᐃᐧᐃ ᒥ ᓄᓇᑕᐃᐧᖅᒀᑲᐤ ᕆᖅᒀᕆᑲᐤ` ᑲᕆᑲᖄᐧᐃᐧᓇᐊᐧᐳ`.

ᐊᓄᑲ ᑐᑲᐳ:

- ᐊᓂᐳ ᖅᐱᐅᕆᐅᐧᐱᑲᑲᐤᑲᐤ<ᐳ ᐁᐧᑲ ᑲᐊᐱᐳᖅᐳ ᑲᒥᓄᖅᑲᒀ ᑲᑭᐳ` ᒥᕆᒪᐳ ᐊᐊᐧᔾ ᖅᐱᐅᕆ ᐃᕆᕆᑲᐅᕆ<ᐳ?
- ᐊᓂᐳ ᒥᓄᑲᐤ` ᐅᑕᑯᔾᐳ` ᐃᐱ<ᐧᐊᒧᐊᐧ⁻ ᐅᓗᐱᕆᐃ· ᐃᒥᐁᐧᑕᐃᐧᓂᐊᐧ ᐁᐧᑲ ᐁᐧᔪᐤ` ᐅᓇᑲ` ᑲᑲᐁᐧᓴᐊᐧ⁻?
- ᐊᐁᐧᐳᐧ` ᐁᐧᐅᕆᐊᐧᐃ·ᐃᕆᑐᐤ⁻ ᒥᒥᐳᓇᓴᐤ` ᐅᑕᑯᔾ ᒪᖅᐱᐃᐧᓂᐊᐧᓄᐳ` ᑲᕆᐃᔮᕆ ᑲᓇᐊᐧ<ᕆᑐᐤ⁻?

ᖅᑯᓂᐳ ᐃᐁᐧ· ᐅᑕᑯᔾ ᖄᐃᔪᐱᒀᐃᐧᒥᐣᐃᐦ ᓄᓇᑲᕆᕆᖅᐃᐧᐳ?

ᐅᑕᑯᔾ ᖄᐃᔪᐱᒀᐃᐧᒥᐣᐃᐦ ᓄᓇᑲᕆᕆᖅᐃᐧᐳ (**POR**) ᓇᑐᒪᐊᐧ` ᑲᐊᓄᕆᑕᐃᐧᐧᐃᐧᐧᐊ ᕆᖅᕆ·ᐊᐃ⁻ ᓄᓇᑕᐃᐧᖅᐃᐧᐳᓂ`.

- ᐅᑲᐊᓄᑲᓇᐊᐧᐳ ᑕᑯ ᕆᖅᕆ·ᐊᐃ⁻ ᑲᐊᓄᕆᑕᐃᐧᐧᐃᐧᐧᐃᐧᐧᑲ ᕆᒪᒪᐃ· ᐊᓄᑯᐊᐧ⁻.
- ᐅᐁᐧ· ᓄᓇᑕᐃᐧᖅᒀᐃᐧᐳᐧ` ᑲᐊᔾ ᐃᑯ ᐁᐧᑕ ᐁᐧᔪᐤ` ᑲᐊᓄᕆᑕᐊᐧᑲᓄᐅ⁻. ᐃᐁᐧ· ᐱᑯ ᕆᐅᕆᐱᕆᑕᖅ⁻ ᑲᐊᔾᐧᑲᖅᒀᑲᐤ` ᖅᑯᐳ ᕆᐅᕆ ᐃᐣᐃᒀᐁᐧ⁻ ᕆᐅᑲᕆᑲᐤ` ᑲᕆᕆᖅᑲᐤᐧᐳ` ᓄᓇᑕᐃᐧᖅᒀᐃᐧᐳᐧ· ᒪᕆᕆᖅᐃᐧᓇᐳ.
- ᖅᐃ·ᑕᒀᐃᐧᐳ` ᒥᓇ ᖅᐣᐁᐧᑐᒪᐃᐧᓇᐳ` ᖅᕆᖅᑲᐤᓄᐳ. ᖅᐱᐅᕆ ᖅᕆᓇᐁᐧ·ᑕᒪ` ᐅᐁᐧ· ᓄᓇᑕᐃᐧᖅᒀᐃᐧᐳᐧ` ᐁᐧᐅᐅᕆᑲᐤ` ᖅᐃ·ᑕᒀᐃᐧᓂᐊᐧ`, ᖅᐣᐁᐧᕆᖅᐃᐧᓂᐊᐧ`, ᒥ ᖅᒪᐃᐧᐱᑕᐃᐧᓂᐊᐧ`.

ᖅᐱᐳ <<ᕆᔾᐳ` ᐅᒪ ᒪᖅᐱᐃᐧ· ᐃᕆᐣᐁᐧᐃᐧᐁᐧ·ᐃ· ᓄᓇᑕᐃᐧᖅᒀᐃᐧᐳᐧᐧᐃᐧᓂ!

ᖅᕆᖅᖅᑕᑯᔫ ᐅᒪ ᑲᐃᐧ·ᑕᓄᕆᒥᐁᐧ·ᔾᐳ ᓄᓇᑕᐃᐧᖅᒀᐃᐧᐳᐧᓂᐧ!

- ᖅᐳ ᑲᐃᐊᔪᐤᐁᔾᐳᐳ ᕆᐣᐁᐧᑐᑲᔪᐃᐧᓇᐊᐧ ᕆᖅᔾᐳ ᖅᐱᐃ·ᑕᒀᔾᐳ.
- ᖅᕆᐱᐊᐧ·<ᑕᓇᐊᐧ` ᖅᑯᓇᐳ` ᑲᐱᐊᐧᐃᐣᔾᔾᐳ` ᐁᐧᑲ· ᑕᐤ ᕆᓇᐧᐅᖅᒀᑲᓄᐊᐧ` ᐃᐧᓂᐧᐅᐊᐧᐳ` ᖅᑯᓇᐳ`.
- ᖅᐃ·ᑕᒀᐃᐧᓇᐧᐳ ᑕᐧᐅᕆ ᖅᕆᓇᐁᐧ·ᑕᑲᐤᐧᐳ` ᕆᐧᐊᖅᑲᐤ` ᐅᒪ ᓄᓇᑕᐃᐧᖅᒀᐃᐧᐳᐧᓂᐧ`.
- ᖅᕆᖅᑕᓇᐳ` ᑲᐃᐧᖅᒀᑲᐤᐧᐳᐳ` ᖅᑯᓇᐳ` ᖅᓄᓇᑕᐃᐧᖅᒀᑲᐤᕆᐳᐳ`.
- ᖅᕆᖅᑕᐤᐧ` ᖅᑯᓂᐳ` ᓇᑲᐁᐧ·ᑕᑲᐤᐧᐳ` ᕆᒥᓄᔾ` ᐊᑯᔾ <ᐃᐦᐃᐃᐧᐃᐧᐃᐧᓇᓇᐊᐧ` ᒥ ᐅᓇᓄᑲᓇ`.
- ᕆᑕᔾᐳ` ᒪᐧᑲᐃᐧᔾᐃᐧ·ᔾᐳᐳ` ᕆᐧᐊᔾᕆ <<ᕆᔾᐳᐧ` ᖅᐃᔪᐅᐧᑲᕆᑲᐤᐧᐳᐃᐧᐧ` ᖅᐃᔾ ᐃᕆᒥᐃᐧᓇᔾᐳ`, ᖅᐊᑐᓪᑲᓇᐤ` ᒥ ᐃᒪ ᕆᒪᐃᐧᐱᑕᐃᐧᓂᐊᐧ`.

ᑫᐃᑦ ᐊᑲᐧᑖᕐᑫᕉ

ᑲᑲᖁᑭᖀᒧᐧ POR ᑕᖀᖁᑫᑲᕌᑕ **ᑲᐊᓴᑭᑕᐃᐧᐸᐧ ᒥᕒᕒᐸᕒᐊᐧ**

- ᒥᒥᓯᐸᐧ **ᖀᑭᓇᒪᖁᐃᖁᐊᐧᕉ ᒦᓇ ᒍᑭᐧᑲᖁᐃᐧᐧ**
- ᖪᖪᐃᐧᓇᒫᐊᐧᐊᐧᖮ **ᒥᖀᑭᓇᒪᖀᐊᐧᐸᐧ ᐸᖁᖁ ᑲᐧᑭᐧᐃᐧᐸᐧᐊᐧ**
- **ᑲᐊᓴᑭᑕᐃᐧᑕᐸᐧ ᑕᐃᐧᒥᑕᐧᐊᐧᖮ ᖀᐸᖮᑭᑲᐅᕉᐧ ᖀᑰᓇᐧ ᖀᓇᓇᑕᐃᐧᑲᖀᑭᑲᐅᕉᐧ**
- **ᑕᐧᖭᐅᑕᑰᐧ ᐱᒦ ᐊᖭᒥᐧᐧᐃᐧᑐᐃᐧᐧ**
- ᑕᐊᑖᒥᐊᖮ **ᑲᐊᓴᑭᑕᐃᐧᑕᐸᐧ ᐊᐱ ᑲᐸᖮᑭᑲᐅᕉᐧ ᖀᑰᐧ**
- ᑕᐧᖭ ᓂᕒᑕᐃᐧᓇᑲᐧᓇᐧ **ᐃᓇᐧᕉᐃᐧᓇᐧ ᒦᓇ ᐸᐸᕒᐃᐧᓇᐧ**
- ᑕᐃᐧᕒᖭᑕᒍᕒᖮᐧᓇᐧᐊᐧ **ᕒᑌᓇᕒᑐᐃᐧᓇᐧ**
- ᑕᐧᖭᐅᓇᑲᐧ ᒦᓇ ᐅᐱᐧᐃᐧᓇᐧ **ᑕᐱᖁᐊᖭᒥᐧᐃᐧᐧᐧᓇᐧᐊᐧ**
- ᑲᐃᖁᐅᖀᑲᕌᑕᐧᓇᐧᐊᐧᖮ ᑲᐃᖮᑲᐅᕒᒥᖮ ᑲᐊᓴᑭᑕᐃᐧᖮ **ᕒᑌᖮᑭᑲᐅᓇ**
- ᒥᐧᖭᓇ **ᑲᖪᖪᐃᐧᐧ ᐃᖮᑕᐧᕒᑐᐊᐧᖮ**
- ᓇᓇᑕᐃᐧᖀᕒᖀᐊᐧᐧ ᑲᐊᐧᖁᑲᖮᑐᐊᐧᖮ ᐊᐧᖁᐊᐧᖮ ᕒᑕᑲᐧ **ᖭᐸᖀᓂᕒᑐᐊᐧᐧ**

   ᐊᖮᑕᕒᕒᑐᐊᐧᐧ: ᖀᕒᖭᑕᑯᐧ ᐅᒪ ᑲᑕᕒᖭᐧ ᐃᖮᑕᐧᕒᑐᐊᐧᐧᖮᖮ.
   ᑲᕒᐱᖮᓇᕒᖮᑲᒪᐧ ᖀᑰᐧ ᒦᓇ ᑲᐃᖮᑕᖮᒪᐧ ᕒᑌᖮᑭᑲᐅᐊᐧᐧ.

   ᐊᕒᖮᑲᐃᐧᐊᐧ: ᐃᕒᖭ ᒥᕒᓇᖮᖭᐧ ᐊᐧᖁ ᖀᑭᓇᒪᖀᐊᐧᐧᖮ,
   ᖀᑭᓇᒪᖀᐊᐧᐧᖮ ᒦᓇ ᓇᐧᖮᖭᐧ ᐃᕒᖮᐃᐧᖮᖮᐊᐧᖮ ᖀᐸᐅᕒ ᑲᖮᑐᖭᐧ ᐅᐸᐧ ᐊᐧᖁᐊᐧᐧᖮ.

   ᒪᒪᖁ ᕒᑌᖮᕒᑐᐊᐧᐧ: ᑲᑕᕒᐱᐧᖮᑯᖮ ᐅᒪ ᐊᐧᖁᐊᐧᖮ ᐅᑕᖭᐧ ᖀᖀᖭᐧ.
   ᕒᑌᖮᖮᑲᐧ ᑕᐅ ᕒᑕᐧᖮᕒ ᑲᐃᖁᐧᐱᖮᑯᖮ ᐊᐧᐃᐧᖭ ᑲᐱᖀᕒᐧ ᐅᒪ ᐃᖮᑕᐧᕒᑐᐊᐧᐧ.

   ᒪᒪᐃᐧ ᐊᐧᖁᐊᐧ: ᕒᑌᖮᖮᑲᐧ ᕒᖀᕒᑐᐊᐧᐧ.
   ᒦᓇ ᐱᐧᖮ ᑲᐊᐃᐧᖭᑲᒪᐧ ᒦᓇ ᑲᐃᖀᕒᑲᕌᑕᐧ.

ᓇᓇᑕᐃᐧᖀᕒᖀᐊᐧ ᐃᓇᐧᕉᐃᐧᓇᐧ

ᑲᐊᓴᑭᑕᐃᐧᑕᐧ ᐊᖮᖮᑯ ᑕᖀᐃᖮᖭᐃᐧᐧᐸᕒᐧᐊᐧᖮ ᒦᓇ ᒥᕒᖭᐧ ᑲᐃᖁᐃᖮᕒ ᓇᓇᑕᐃᐧᖀᖀᑰᐊᐧᖮ ᖀᑰᐧ:

- ᒥᑲᖀᐅᐧᐊᐧᖮ ᓇᓇᑕᐃᐧᖀᕒᖀᐊᐧ ᑲᖀᐅᐧᐃᐧᓂ
- ᒥᐅᖁᑐᖮ ᖀᐃᖭᖁᑲᖮᐧ ᓇᓇᑕᐃᐧᖀᕒᖀᐊᐧᐧ
- ᒥᒪᐊᐧᐧᑐᖁᐧ ᐃᐧᑕᐃᐧᖀᐃᐧᓇᐧ
- ᒥᖮᒥᖮᐧᐃᐧᖭᐧᖮ ᒥᓂᕒᑐᕒᑲᐅᖮᐧ ᖀᑰᓂ ᑲᐅᕒ ᒪᐧᑐᖁᑕᑲᐅᕉᐧ ᓇᓇᑕᐃᐧᖀᕒᖀᐊᐧ ᐃᐧᑕᐃᐧᖀᐊᐧᐧᐊᐧᖮ
- ᒥᐊᖭᐸᖮ ᐊᐧᐃᐧᖭᑕᖀ ᑲᐃᖮᐃᖭᕒᖀᑲᕌᑕᖮ ᓇᓇᑕᐃᐧᖀᕒᖀᐊᐧᓇᐧ
- ᒥᖀᐧ ᓇᓇᑲᕒᑐᐊᐧᐧᖮ ᓇᓇᑲᕒᖀᐊᐧᐧᓂ ᒦᓇ ᑲᖀᒪᒪᐃᐧ ᐊᐧᖁᑲᕌᑕᐧᖮ

                                         ᖀᐧ ᖀᐱᖮᖮᐧ
                                         ᖀᖀᖮᑕᐃᐧᖮ!

Recherche axée sur le patient

Qui peut être patient chercheur?

Un **patient** (ou client) **chercheur** est :

- une personne ayant une expérience vécue d'un problème de santé particulier
- un aidant naturel (proches et ami-es qui comprennent le problème de santé)

Un patient chercheur est un membre à parts égales de l'équipe de recherche.

VOUS pourriez être patient chercheur!

Qu'est-ce que la recherche?

La recherche consiste à poser une question importante et à trouver une façon d'y répondre.

Par exemple :

- Comment peut-on améliorer l'accès à des aliments nutritifs et peu coûteux?
- Quels sont les coûts directs pour les patients qui ont recours à des spécialistes en région rurale?
- Quels facteurs contribuent au développement d'une bonne relation client-médecin?

Qu'est-ce que la recherche axée sur le patient?

La recherche axée sur le patient (RAP) implique des clients à titre de co-chercheurs.

- Ces clients participent à la recherche en tant que membres de l'équipe.
- La recherche ne porte pas SUR le client, mais ce dernier apporte une expertise à la création de projets de recherche importants.
- Votre voix et vos perspectives ont une grande importance. Vous pouvez faire en sorte que la recherche soit pertinente pour vous, votre famille et votre communauté.

Soyez un partenaire actif de la recherche en santé!

Vous êtes un partenaire précieux de la recherche!

- Vous avez des perspectives uniques à partager.
- Vos expériences vécues font de vous un « expert » du domaine.
- Votre voix contribuera à la réalisation de recherches qui importent.
- Vous connaissez les domaines importants de la recherche.
- Vous comprenez les améliorations requises aux services et politiques de santé.
- Vous avez le droit de participer aux recherches qui auront un impact sur vous, votre famille et votre communauté.

À quoi s'attendre

Une RAP fructueuse favorise **l'implication des clients**

- Accès à des services d'**orientation et de mentorat**
- Occasions d'**acquérir** des compétences de recherche
- Les clients aident à définir les **thèmes de la recherche**
- **Communication** transparente et régulière
- Les clients participent aux **prises de décisions**
- **Rôles et responsabilités** clairement définis
- **Respect** mutuel
- **Communication** claire et franche
- Les connaissances des partenaires clients sont **valorisées**
- **Collaboration** efficace **de l'équipe**
- Les chercheurs travaillent à bâtir la **confiance**

Inclusion : Vous êtes un membre important de l'équipe.
Vos expériences et vos perspectives sont appréciées.

Soutien : Vous devriez recevoir la formation, l'éducation et
l'aide financière nécessaires à accomplir ce travail.

Respect mutuel : Chaque membre de l'équipe possède une expertise
particulière. Il est important de respecter l'apport de chacun.

Codéveloppement : Votre voix importe,
y compris vos points de vue et vos perspectives.

Rôles dans la recherche

Les clients peuvent s'impliquer à toutes les étapes de la recherche :

- Question de recherche
- Conception de l'étude
- Collecte des données
- Interprétation des données recueillies
- Communication des résultats au public
- Évaluation de la recherche et de l'équipe de recherche

*Le savoir
repose entre
vos mains!*

Appendix A: Sample Information Pamphlet for Prospective Patient Researchers

Appendix B: Patients Canada Evaluation Surveys

https://ossu.ca/wp-content/uploads/EvaluationSurveysPatient_2016.pdf

https://ossu.ca/wp-content/uploads/EvaluationSurveysResearcher_2016.pdf

Appendix C: Ontario SPOR Support Unit

https://ossu.ca/for-patients/resources/

Notes

1   CIHR, 2014; McGavin, 2017; Mallidou, et al, 2018

2   CIHR, 2014; Vat et al, 2017

3   Vat, Ryan, & Etchegary, (2017)

4   https://fnigc.ca/ocap

5   CIHR, 2014; McGavin, 2017

6   Fraser Health, 2013

7   Adapted from: Canadian HIV/AIDS Legal Network. (2005). "Nothing about us without us": Greater, meaningful involvement of people who use illegal drugs: A public health, ethical, and human rights imperative. Retrieved from http://www.aidslaw.ca/site/wp-content/uploads/2013/04/Greater+Involvement+-+Bklt+-+Drug+Policy+-+ENG.pdf

8   CIHR's SPOR Patient Engagement Framework; Fraser Health, 2013

9   http://www.health.gov.on.ca/en/common/ministry/publications/plans/ppar16/

10 http://www.health.gov.on.ca/en/common/ministry/publications/plans/ppar16/

11 Bishop, Elliott, & Cassidy, 2018

12 Mallidou et al., 2018

13 CIHR, 2014; Mallidou et al., 2018; McGavin, 2017

14 SJCG Guide for When to Involve Client and Family Partners in Engagement.

15 Fraser Health, 2013

16 Fraser Health, 2013

17 Fraser Health, 2013; Bishop et al, 2018; Patrick, Kebbe, & Aubin, 2018; Vat et al., 2017

18 Fraser Health, 2013

19 SJCG Guidelines for Client Engagement Initiatives; Fraser Health, 2013

20 CIHR, 2014; McGavin, 2017

21 Martin, 2012

22 Kirkness & Barnhardt, 2001; Restoule, 2008

23 Vat et al., 2017

24 Vat et al., 2017

25 Basile, Asselin, and Martin. 2018

26 https://cioms.ch/wp-content/uploads/2016/08/International_Ethical_Guidelines_for_Biomedical_Research_Involving_Human_Subjects.pdf

27 https://www.publichealthontario.ca/-/media/documents/faqs-on-marg.pdf?la=en

28 https://ikhsanaira.files.wordpress.com/2016/09/participatory-research.pdf

29 Manafo et al., 2018; CIHR, 2014; Fraser Health, 2013

30 CIHR, 2014; Fraser Health, 2013

31 Bishop et al., 2018

32 Fraser Health, 2013

33 Fraser Health, 2013

34 Fraser Health, 2013

35 Fraser Health, 2013

36 Fraser Health, 2013

37 Fraser Health, 2013

38 Fraser Health, 2013

39 Fraser Health, 2013

40 Fraser Health, 2013

41 Adapted from: Canadian HIV/AIDS Legal Network. (2005). "Nothing about us without us": Greater, meaningful involvement of people who use illegal drugs: A public health, ethical, and human rights imperative. Retrieved from http://www.aidslaw.ca/site/wp-content/uploads/2013/04/Greater+Involvement+-+Bklt+-+Drug+Policy+-+ENG.pdf