

Community Engaged Research Practice: A resource for CTN members





This document is a living resource and is updated periodically.
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Introduction

Community engagement (including the greater involvement and meaningful engagement of people living with HIV [GIPA/MEPA]) are core values of the CIHR Canadian HIV Trials Network (CTN). These values coincide with CIHR's policy for citizen engagement in all of its funding programs, including its HIV/AIDS and CTN funded research. Successful community engagement helps to ensure that CTN health research:

- 🍏 Improves health outcomes for all, while attending to population differences;
- 🍏 Encourages productive collaboration based on mutual respect for talents, expertise and cultural distinctiveness;
- 🍏 Recruits research participants effectively and meets enrolment targets required to develop meaningful data;
- 🍏 Builds capacity of both community members and CTN investigators; and
- 🍏 Produces integrated and end of grant knowledge translation in comprehensible terms for all stakeholders by using publicly accessible lay language (especially important in basic science research).

As a resource for CTN members, this document provides some practical tips for successful integration of people living with HIV and other community members in research teams from all CTN Cores, identification of principles for mutual learning to improve research design and execution, and building trust and support for the research enterprise.

When should I engage community research team members?

Engage
community
as soon as
possible

Research teams can enlist community members at many stages of the planning and implementation phases of a research project, but engagement that starts during the conception phase of the research idea – prior to submission of protocols to funding agencies and/or the CTN – ensures that a range of voices are at the table to generate ideas that are useful for the practice of good science, and also ensures that resources are secured to support community participation at all stages of the work.



Which community members should I invite to participate on the research team?

Ideally, you will identify and invite individuals and community organizations that as a collective bring a comprehensive understanding of the health and social issues of the community under study, the principles of study design, and appreciation of the relevance and potential health impacts of the study. Often, investigators equate “community” with people living with HIV; however, there are also others who identify as community members. A potential list includes, but is not limited to:

- People living with HIV;
- Those from AIDS service organizations and other community-based organizations;
- Staff at community health centres and public health agencies/departments;
and
- People who identify with the population under study (e.g. caregivers, chosen/biological family, friends).

To uphold GIPA/MEPA principles, in HIV treatment studies, the majority of community team members should be people living with HIV; in prevention studies, the majority should be people comprising the target populations.

There are many perspectives within any community. To ensure a greater breadth of input, undertake broad outreach to different individuals, groups and agencies, and consider the social determinants of health (e.g., income, education, stigma and discrimination), and how these can influence health and perspectives on a research issue. In order to create a team that respects different perspectives, engage with community members and other investigators who are willing to be educated about different points of view that they themselves cannot represent.

Connect with individuals and organizations that understand and are connected to their communities

How do I engage the community?

Outreach should be purposeful

Community organizations may be national, provincial/regional and local. Many such organizations value research and have developed guidelines to engage with researchers. A number of people at risk for or living with HIV work as expert research consultants. Some investigators regularly attend community-based events and conferences in order to develop relationships with, and a deeper understanding of, the populations they work with and study. Conversely, you could consider inviting community members into your labs and centres to attend rounds or sessions, either as participants or as speakers.

Because research involvement is a commitment of time and energy, approach community members who are passionate about the topic at hand, and who would be willing to invest time and effort over the course of the study. Formally posting positions is one way to encourage new talent to come forward and apply to be part of a research team. You also could consider soliciting referrals from other researchers, conduct literature searches, or reflect on previous working relationships.

Coordination and time management

Academic timelines (particularly grant timelines) are often tight. Taking time to establish relationships before a specific grant call is an effective way to avoid a last minute scramble to find research partners. If possible, support community members to meet application deadlines by providing them with paperwork assistance, such as writing letters of support and completing ResearchNet or Canadian Common CV registrations.

In order to ensure team members understand what is expected of them, discuss and define different roles (e.g., knowledge user, peer researcher, advisory committee member) on the research team, including the responsibilities and time commitments associated with each role, and then ask how each person wants to be involved. Note that the research team's and funding body's terminology for roles may differ. If the role being taken on by a community member on a research team is a "peer" role, it is important to clarify issues of personal disclosure of HIV or other relevant personal characteristics status that are involved.

Roles and responsibilities

Dual-roles (e.g., researcher – physician or researcher – community support provider) can blur relationship boundaries with community members. Defining roles within the study context helps to maintain open lines of communication on the study team and help to address any real or perceived conflicts of interest. In addition, these dual roles need to be outlined for an REB application.

Consider potential conflicts of roles and conflict of interest

Questions to consider in determining possible conflict of interest:

- Could a dual clinician-researcher relationship make it awkward for a community member to decline to participate on a study team?
- Does interacting with a clinician-researcher confuse a care/provider relationship?
- Are community research team members free to speak their minds on a study (e.g., disagree with a clinician) without affecting their clinical relationships?
- Will participating on the study team have other implications for community members, including confidentiality or disclosure concerns?
- Is there a dependency in the interaction (i.e., financial dependence)?

Engaging Indigenous communities

Respectful engagement

The unique status of Canada’s Indigenous Peoples provides the context in which a research ethics framework has been developed for research involving the First Nations, Inuit and Métis Peoples of Canada (Chapter 9 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)). While these are similar to those for sound research engagement with other populations, there are historical and cultural realities related to colonization that create specific protocols and requirements for respectful research engagement with Indigenous communities, whether on or off reserve.

Indigenous communities welcome meaningful research engagement. From an Indigenous perspective, good starting points include approaching in a good way, being respectful, and walking with humility. Approaching with active and respectful listening ensures hearing the areas the community identifies as important for research. By connecting with the leadership and with Elders and traditional knowledge holders, important and relevant research areas will be identified, and natural leaders will emerge to champion these issues.



Seeking
permission
and study
engagement

Indigenous communities seek meaningful, long-term relationships with researchers; “research-and-run” relationships should be avoided. While there is much diversity among Indigenous communities and cultures, generally there is a formal authority (e.g., Band Council) or organizations that represent a particular community’s interest (e.g., an urban Friendship Centre), and there are also knowledge holders who have moral authority (e.g., Elders and traditional knowledge holders). Where possible, approaching these different types of authorities for approval for a study with an Indigenous Community is a TCPS 2 requirement; in many cases, involvement of a representative of each of these authorities on the study team, along with other community members, is beneficial. Elders and traditional knowledge holders take on a special role within a research team, provide guidance for all team members, promote positive team functioning, and assist researchers to better understand Indigenous worldviews and appropriate research actions and cultural protocols.

Because there is still a large degree of unfamiliarity with research and historically based mistrust of the health system among many Indigenous people, communication about health research with Indigenous community research team members may require additional efforts. Research teams may need to use multiple communication methods dependant on population (e.g., youth may prefer text messages or videos; older adults may prefer in-person interactions and want to see examples or hear stories).

The Canadian Aboriginal AIDS Network (CAAN) has excellent resources for researchers and an Aboriginal Research Strategy called FEAST.

Developing roles

Community members bring their skills and expertise to the study team

Community team members can ensure development of educational materials, develop public knowledge translation and exchange (KTE) plans, assist with drafting informed consent materials, organize recruitment plans, assist in data analysis and interpretation, plan logistical arrangements for the conduct of the research, and provide information about health beliefs, cultural norms, and practices.

If community team members are not familiar with expectations and boundaries in research environments, it is important to offer mentorship. It is also important to provide training in research ethics and information on the research methods being used. Encourage and support education and training to obtain online certifications such as GCP (Good Clinical Practice) and TCPS 2. Many institutions require these for research team members. Training on how to read and draft protocols is widely available online.

KTE is an integral part of the research process, and is especially crucial when results are available. Community members can help guide the research team on how to frame messages, and provide advice on venues for communication of results (e.g., meetings, newspapers, video postings, etc.) and contribute to expanded public research literacy.

Capacity building for CTN investigators and community members

Capacity building and training is necessary for community members just as it is for students, junior investigators or more senior researchers moving into a new area of inquiry. Through an iterative learning process, community team members share insights and skills with their research counterparts, while trained researchers reciprocate by helping community members build particular research skill sets. Consider assigning a more experienced team member as a “research buddy” or mentor, so community members and junior researchers can listen, respond and react together in meetings or in ongoing discussion.

Compensation

During budget development within the protocol design stage, include reasonable compensation for community members. Where possible, it is helpful to provide an honorarium for time spent developing protocols and funding proposals as well as time spent in training. Keep in mind that while your time and the time of your research staff is compensated as part of your regular duties, the community team member may be participating with no compensation. There may be implications for receipt of compensation (e.g., some people may find their insurance or benefits payments affected), so it is important to discuss compensation expectations and income reporting requirements prior to engaging individuals on a research team.

Determine compensation during budget development

Hourly wages or honoraria paid to community experts vary across the country and throughout institutions. Individuals should expect to be paid on par with the hourly wage of a research associate or research coordinator. More experienced consultants may have a higher set hourly fee. Aim to provide compensation commensurate with experience and responsibility.

Individual experts

Release time, at equivalent wage, should be negotiated with community organizations for their employees' time spent on the research project, and, if possible, provision should be made to compensate for administrative and office space, if applicable. As noted earlier, many organizations have guidelines to engage in research partnerships and these may include compensation requirements.

Organizational experts

It is appropriate and respectful to compensate traditional knowledge holders such as Indigenous Elders. Some organizations will have an Elders/knowledge keeper policy, which will outline respectful engagement (e.g., in some territories, offering a gift or tobacco), and an appropriate way of compensating their time (e.g., providing honoraria, or travel expenses and accommodation).

Traditional knowledge holders

Funding bodies increasingly allow for community partner remuneration. At the institutional level, consider including community partner remuneration and expenses by building in release time, creating part-time positions, and advocating for sharing of direct and indirect funds with partner agencies and organizations.

Institutional responsibilities

If you would like more information on engaging community in research, please contact the CTN National Centre at ctninfo@hivnet.ubc.ca.

This document was created by the CTN PVP Community Engagement Resource Working Group, including members Patrick Cupido, Troy Grennan, Shari Margolese, Kevin Pendergraft, Sherri Pooyak, Robert Reinhard and Cathy Worthington, with support from Chavisa Horemans (PVP Core Research Associate).



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