

Improving the Accessibility of Research Ethics Boards for HIV Community-Based Research in Canada

HIV CBR ETHICS

Managing multiple roles and boundaries



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- 10 Learning about illegal, sensitive and stigmatized topics

We are a group of Canadian HIV researchers interested in community-based research (CBR) and research ethics. We conducted interviews with over 50 academic researchers and community service providers from across Canada involved in HIV CBR. They told us about the ethical issues they encounter in their daily work with communities affected by HIV. They also described how they work with their research ethics boards (REBs) to ensure participants will be protected from research related harms. In this series of 10 evidence-based fact sheets, we identify key ethical considerations when designing HIV CBR projects and seeking ethics review. We encourage HIV CBR teams to use these fact sheets to assist in project planning. They may also be useful for engaging REBs in a dialogue about the range of strategies employed by Canadian researchers for ensuring the protection of diverse individual and community needs.

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In this fact sheet, we discuss **four key issues:**

- Building discussions of power, roles, responsibilities and boundaries into partnership agreements
- Differentiating between programming and research in recruitment and data collection
- Managing multiple roles (clinician, researcher, community member) and blurred boundaries
- Identifying and managing conflicts of interest throughout the research process

Background

This fact sheet explores issues of managing multiple roles and boundaries on community-based research (CBR) teams. This includes the roles of academic researchers, clinicians and other staff members, and community members (for more information on peer researchers, see *Fact Sheet #8: Supporting peer researchers*). Based on strategies employed by Canadian HIV CBR teams, the following four issues are addressed:

- Building discussions of power, roles, responsibilities and boundaries into partnership agreements
- Differentiating between programming and research in recruitment and data collection
- Managing multiple roles (clinician, researcher, community member) and blurred boundaries
- Identifying and managing conflicts of interest throughout the research process

In most social and behavioural health research, the researchers and participants do not know each other and spend relatively little time interacting outside of the research process. This is an attempt to ensure ‘objectivity.’ The intent is to minimize the possibility that the researcher or the participants will be influenced by the relationship they have with each other. From a research ethics perspective, the concern is that personal relationships will result in a “conflict of interest” that makes it difficult to maintain personal and professional boundaries. For research participants, this may mean that they are not able to differentiate research from social services, healthcare, and personal relationships, and that they may be more likely to participate in research without fully understanding the ramifications (Beauchamp & Childress, 2009).

Another “conflict of interest” that research ethics boards (REBs) are concerned about is when researchers, or others in their personal and professional networks, may personally benefit from the research (e.g., a physician who is conducting research on a drug in which s/he has a financial stake) (Little, 1999; Thompson, 1993).

In CBR, there is a strong emphasis on partnership building, long-term relationships, and having representation from academic and community-based organizations. These relationships are understood to improve researchers’ understanding of community needs and increase the quality and usefulness of the research (Israel, Schulz, Parker, & Becker, 1998). As well, many researchers involved in CBR are committed to serving communities outside of research (e.g., membership on community boards), and may identify as members of the communities with which they research (e.g., gay men, Aboriginal peoples). However, most REBs will be unfamiliar with the approach taken in HIV CBR projects and will need to be assured that certain boundaries are maintained and that protections are put in place. In this fact sheet, we identify various approaches to thinking about managing multiple roles (e.g., clinician, researcher, community members). We describe the strategies employed by Canadian HIV CBR teams to balance competing interests.

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Issue 1: Building discussions of power, roles, responsibilities and boundaries into partnership agreements

“After we all came to the decision [to] move forward together, one of the first things we did was to start fleshing out a memorandum of understanding that helped to clarify the roles and responsibilities of each co-applicant, and it also acted as an important discussion piece and decision-making piece for us to refer back to anytime there is any type of confusion.”

The first step in addressing potential conflicts of interest is identifying and discussing the forms of power that exist within the team, between the team and the community, and within the partnering organizations. Regular meetings provide excellent opportunities to discuss power and develop partnership agreements (Hunter, Lounsbury, Rapkin, & Remien, 2011; Nation, Bess, Voight, Perkins, & Juarez, 2011). Comprehensive partnership agreements should be developed and implemented as part of the research partnership from the beginning. When submitting to their REB, CBR teams will need to explain the different roles of team members, where potential conflicts exist, and strategies for managing these conflicts. This is important not just for REB submissions, but in order to maintain roles and boundaries throughout the course of the project (see Issue 4).

Develop a *partnership agreement*¹ that outlines roles, responsibilities, and decision making structures for your team that delineates your collective:

- a) understandings of CBR, ethical practice, and boundaries (acknowledging that these can mean different things to different people).
- b) agreements about what protections will be put in place to prevent potential conflicts of interest from unduly influencing the research.

As a research project progresses, regular meetings between the research partners will help to determine courses of action and any potential tensions as roles and expectations shift. Clear communication with research staff helps to diminish a sense among them that they are accountable to multiple research partners with different agendas/priorities (Nation et al., 2011).

1 For some excellent examples of these types of documents, see sections 3.3.3 or 3.3.4 of the CBPR Curriculum at http://depts.washington.edu/ccph/cbpr/documents/cbpr_curriculum.pdf or CAAN's Principles of Research Collaboration: http://depts.washington.edu/ccph/pdf_files/MOU7%5B1%5D.pdf

Issue 2: Differentiating between programming and research in recruitment and data collection

The presence of researchers in a community-based organization (CBO) can help build community trust and improve recruitment and retention. When agency staff participate on the research team, it can improve the study design and ensure community relevance. However, this can also be confusing to service users who may not understand the difference between research and the services, programming, and supports they receive. For example, a focus group can resemble a group therapy session and participants may be disappointed when the group is not held the following week. While REBs will expect CBR teams to explain

the ways research and care are kept separate, on the ground, it can be a more challenging process that requires continual adaptation and discussion. Project materials and consent processes should address this, and it may be preferable to conduct data collection in spaces where care is not usually provided (e.g., the organization board room). However, as many researchers told us, they used data collection sessions to remind participants of the resources available at the host organization and gave them materials to take home. Doing so may encourage some to return for regular programming.

“I think you just have to be very clear. ‘At this point we’re gathering information, we’ve got the community agencies on board, because we want to make sure the information is the information they want to alter their programmes...We’re really just getting information at this stage,’ and that seems to work. But on the other hand, I do think the interview can sometimes act as an intervention and I’ve had people call me and say, ‘[the researcher] told me some really good stuff and I just want you to know that I’m doing what she said.’ And, we know that whenever we do interviews at different recruitment sites, they do have an increase in clients.”

Issue 3: Managing multiple roles (clinician, researcher, community members) and blurred boundaries

“I want to say, I think those lines are kind of artificial. Why has research been separated from advocacy? What’s the point of research? But I wouldn’t present it as a problem that those [lines] are being blurred, I think that’s what we want to do, but we need to put some more thought into what that really means.”

In CBR we often wear many “hats” and it can be challenging to keep our roles (e.g., researcher, clinician, service provider, community member) separate. While many of the researchers we heard from described the importance of maintaining boundaries in research to protect participants, these boundaries are sometimes contrary to the goals of CBR. CBR may result in different kinds of relationships than other forms of research. Spending months or even years working together may result in friendships between project team members, with peer researchers, and in some cases with participants. When researchers are part of the community they study, they may have pre-existing relationships with other team members or participants, and may encounter them in everyday settings on a regular basis. As well, researchers who work in community settings may be involved in both clinical care and research. These are some considerations when managing boundaries and relationships:

- a) Will the research roles affect other relationships (e.g., therapeutic, professional, community, etc.)? If the researcher is also a clinician, will there be confusion that the relationship is therapeutic?
- b) What are the personal circumstances of the individuals involved? If one party is dependent on the other (e.g., someone with very limited resources) the relationship may be too imbalanced.
- c) Will the relationship affect the process or outcomes of the research (e.g., if a researcher has a previous relationship with a participant, this may affect confidentiality or pressure to participate, etc.)?

There is no formula for how to negotiate these situations and contextual factors will need to be considered. Researchers may need to balance a desire to be accepted by the community with a need to maintain some distance to protect themselves and participants from harm resulting from raised expectations and possible exploitation. Participants also need to be given the choice of whom they want to speak with during data collection processes (e.g., with someone outside their community vs. within). Informed consent processes need to ensure participants are aware of their rights and do not feel undue pressure to participate based on previous relationships (e.g., personal, therapeutic) (for a more in-depth discussion of these issues, please see *Fact Sheet #5: Issues of informed consent*). It is important to note that while these are very real challenges, they can be managed ethically.

“Yeah, it’s really tough... you know meeting people in a research space...I might meet them on the street, or I might meet them in a bar, and then that relationship’s going to continue. I want it to continue. But there’s a demand on both of us to be ethical.”

Issue 4: Identifying and managing conflicts of interest during the research process

“Having front line staff or managers of the organization [involved in analysis means] some of them will know who the person is no matter what, so it has been difficult. Most people have been very upfront and say, ‘Oh, I know this person: I’m not going to make any comments about the analysis,’ ...It’s difficult, but you know nobody [was] breaching confidentiality.”

In CBR, team members often come to a project with competing needs, priorities, and wearing different “hats.” In fact, it is usually ties to the community that form the backbone of a successful CBR project. Research partners should have open and transparent conversations about roles, expectations, and any potential conflicts of interest at the outset of a project. Any perceived or actual conflicts of interest should be discussed as soon as they are identified, and strategies should be developed for how to manage them (Nation et al., 2011; Ross et al., 2010). Not all conflicts of interest are problematic, or unresolvable.

Conflicts of interests manifest in a variety of ways. For example, an executive director or other staff member, in the course of her doctoral studies, decides to nest her dissertation in an evaluation of a program she is running at an agency. Another example might be when participation in a process may breach confidentiality. For instance, staff members may not want management, who are involved as research team members, to know that they participated or the content of their interviews. When a clinician is also acting as a researcher, it may be difficult to remember where information was obtained, and where it may be shared.

Stakeholder involvement can also influence recruitment. For example, when a program is being evaluated in a CBO, there will likely be individuals who have an interest in showing that the program is successful, and who have relationships with the program participants. This may create a situation in which community members will feel uncomfortable participating if they believe staff will have access to their interview. In contrast, staff members at a CBO might feel pressured to participate if the request comes from management. Managing these roles or potential conflicts ahead of time, and as they arise, is important to doing ethical research.

Teams may wish to think about conflict of interest through the lens of moderating the potential for coercion. The following are areas where enforcing boundaries and re-thinking roles may be necessary:

- a) **Recruitment:** REBs prefer if someone without previous relationships with participants recruits. However, this may not always be possible in CBR (see *Fact Sheet #2: Recruiting hard to reach individuals and communities in CBR*). One strategy that some researchers use when recruiting through known peer networks is to separate the recruitment from the consent process. This way, perceived coercion is minimized, and people can confidentially opt out.
- b) **Data collection:** In CBR, individuals with connections to the community (sometimes referred to as peer researchers) are often involved in data collection. However, in some cases having an academic partner (or graduate student) collect the data may be preferable. This may limit the chance of confusion over the purpose of the research (e.g., programming vs. research). Where peer researchers, service providers or other community partners are involved directly in data collection, it is important to reiterate the purpose of the encounter and roles and responsibilities (see *Fact Sheet #8: Supporting peer research assistants*).
- c) **Analysis:** Research teams may want to consider team members’ different roles and the way access to raw data may affect people’s roles outside the research (e.g., clinical roles, therapeutic relationships, community roles). For example, information obtained through research could affect a therapeutic relationship between a clinician and a participant outside of the research. Teams may want to limit who has access to raw data (data which has not been stripped of identifiers). Once the data has had names and certain details removed, it can be shared with the larger team and other stakeholders. However, some data will always be identifiable because of its unique attributes (e.g., an interview with stories that could only belong to one person at the organization). In these cases, it may be necessary to discuss this with a participant after the interview and determine what they are comfortable sharing, remove entire parts of their interview, or use strategies where data are blended together.

Questions for consideration:

The following questions may be useful for HIV CBR teams to reflect on when deciding how to manage multiple roles and maintain boundaries. Thinking about these issues in advance may help facilitate the research process and maintain positive relations with individual participants and the community.

1. What are the different roles and responsibilities that team members bring to the project? How might these change over the course of the research collaboration?
2. Do team members have any pre-existing relationships or conflicts of interest (perceived or actual) that need to be discussed? What is the plan to manage these conflicts of interest?
3. How will your team differentiate programming from research?
4. What infrastructure will your team put in place to manage ethical issues as they arise? What supports will you put in place to help team members navigate challenges related to negotiating boundaries?

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