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

HIV CBR ETHICS

Recruiting hard to reach individuals and communities in CBR

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HIV CBR Ethics Fact Sheet Series:

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 five key issues:

- What are some historical and contextual challenges with sampling and recruitment in CBR?

- How do we develop effective inclusion and exclusion criteria in CBR studies?

- What recruitment strategies and materials are useful?

- What ethical concerns emerge when we recruit through organizations and service providers?

- What are some of the ethical issues associated with recruiting through peers?

Background

This fact sheet explores issues related to reaching hard-to-reach and hidden communities in community-based research (CBR). We identify various approaches to thinking about sampling and recruitment and describe some of the innovative strategies employed by Canadian HIV CBR teams.

Most researchers who conduct social and behavioural health research have to make decisions about 'sampling' (who they want to hear from) and 'recruitment' (how they will reach them). Ethical concerns related to sampling and recruitment in research include: the unfair exclusion of some participants and the potential for researchers to misrepresent the purpose of their research.

Some groups have been historically excluded from research. One such group is pregnant and nursing women who have been defensibly excluded from biomedical research owing to health concerns for their foetuses and babies. However, this should not exclude them from participating in all research (e.g., a focus group discussion or filling out a survey). Researchers have also selectively recruited in ways that privilege particular groups, while excluding others. These exclusions are considered a 'justice' issue as the perspectives of whole groups may be excluded (Wendler, 1998). Further, some researchers have misrepresented their research to attract a greater number of participants than they would have been able to if they described the research in detail (e.g., recruitment materials that read "Do you want to make $20?").

In community-based research (CBR), our goal is to hear the perspectives of traditionally marginalized and 'hard-to-reach' groups to better inform programs, interventions and policy. Many HIV CBR projects aim to identify and describe the behaviours, attitudes and experiences of members of socially marginalized groups. People living with, or at risk for, HIV continue to experience various forms of discrimination (e.g. stigma directed at people who use injection drugs). As a result, many people at risk of, or living with HIV, are 'hard-to-reach' because they are difficult to find and do not readily respond to calls for participation. Sampling and recruitment may therefore require creative and innovative approaches. Some research ethics boards (REBs) have expressed concern about how HIV CBR projects undertake these two critical aspects of the research process.

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Issue 1: What are some historical and contextual challenges with sampling and recruitment in CBR?

"We have a lot of difficulty with recruitment, and I think a lot of that has to do with issues of colonialism, internalized racism, and homophobia. So, recruiting sometimes for research projects can be very difficult because people don't want to be exposed."

The term "community" has many meanings and is applied differently by community members, community-based organizations (CBOs), and researchers (Jewkes & Murcott, 1998). The communities that are known to shoulder the greatest burden of HIV infection also tend to have complex histories with the healthcare system and health researchers. In the past they have faced barriers to receiving healthcare and research has often failed to adequately represent their needs or improve their life conditions. In communities where participants have had negative experiences with forms of authority, it is important to ensure that they feel safe in the research process (Ogilvie, Burgess-Pinto, & Caufield, 2008). For these reasons, sampling and recruitment in CBR can be challenging and must be done with sensitivity to the history and context of particular communities.

While CBR recognizes communities and community networks as a source of strength and shared understanding, there may be complex power dynamics and imbalances within communities that research teams may not be aware of (Tiffany, 2006). Thus, not all community members will feel comfortable accessing community programs and making themselves visible to researchers. Some of the researchers we spoke with told us that so-called 'hard-to-reach' communities do not want to be found for good reasons, while others are easily accessible when approached in the right way. REBs may be unaware of these historical and contextual issues that may pose barriers when recruiting from communities of interest in HIV CBR projects. Research teams will need to explain why conventional approaches (e.g., putting up posters in public spaces) are not suitable (if that is the case) and offer alternatives (see discussion below).

"So, we've had to do some education with our ethics boards because, once again, they don't understand that the traditional ways of recruitment, advertising don't work. But also. . . particularly in terms of refugees. . . there's this whole fear of researchers."

Issue 2: How do we develop effective 'inclusion and exclusion' criteria in CBR studies?

"So, in our research with gay men for example, who are we recruiting? Because we always, you see, when we use the term MSM (men who sex with men), we are sort of opening it up and we are saying, you know, MSM could be homosexual men, bisexual men, straight men, transmen... but who in fact are we recruiting?"

CBR attempts to redress history by implementing more inclusive practices that involve various stakeholders in the research process. While this has been very effective in engaging community members and service organizations in CBR projects, difficult project decisions face teams, including: 1) who do we need to hear from most? 2) what perspectives have been missing in past research? 3) what can we do with available resources (e.g., time, money, staffing)? Projects may choose to focus on one group within a larger community that is in greatest need, or is most under resourced. The researchers we heard from raised two concerns about inclusion and exclusion criteria in their research projects: 1) that they weren't always reaching the right people, and 2) that they had to exclude some people, which can create conflict.

a) *Who is the community?* – Our understanding of communities often relies on definitions that may not reflect realities and practices within those communities. These definitions have come from research that failed to capture the nuance of culture, or they are based on those used in community programs that or-

ganizations have already identified as inadequate. Such definitions may be antiquated or premised on a fixed understanding of practices (e.g., that people's sexual behaviours correspond to how they identify on an intake form). It can be very difficult in some communities (e.g., people who use injection drugs), to accurately define the population or to obtain a representative sample (Scott, 2008).

HIV CBR teams will need to rely on their community partners to define who the community is and how to reach its members during the project planning phases. Consultation with community investigators at all stages (and possibly a community advisory team) will be important to ensure that the team understands community norms, language, and culture.

b) *Ensuring the right people are engaged* – Once a definition of community has been developed, it will be important to establish clear inclusion criteria for the study. Excluding individuals who want to participate can be challenging because it may reproduce other forms of exclusion they experience and can create conflict when some community members appear to be chosen over others. However, it is important that time and resources (including participants' time) are not wasted collecting data that won't be useful for the team's goals. Community partners can offer important knowledge about accessing specific subgroups in a community (Anderson, 2010; Remple, Johnston, Patrick, Tyndall, & Jolly, 2007). CBR teams need to carefully balance inclusion and exclusion to avoid inadvertently excluding subgroups they want to hear from (Sadler, Lee, Lim, & Fullerton, 2010; Simon & Mosavel, 2010).

"There's a possibility that some of the people we're interviewing were not injection drug users but they're people who've just come in from the shelters to pick up some money. . . . .And so now what we do is, most of our recruitment is done now through front-line workers handing out recruitment cards to people that they know for sure smoke crack or know for sure inject, and that seems to have helped considerably."

Issue 3: What recruitment strategies and materials are useful?

"So, recruitment is challenging and it flies in the face of what's seen as this is what you do to recruit: you put up the coloured piece of paper with the little phone number slips at the bottom and you pin it all around the university and get university students to agree to do something for ten minutes and get ten bucks. It's different; it's about people being sure that they're not going to be hurt and/or exploited and that takes time and it does mean that we're looking for people with a certain view of life."

REBs are especially interested in how research teams recruit, who is doing the recruiting, and the means they are using to solicit participants. The researchers we spoke with told us that traditional recruitment approaches such as, fliers and posters often fail to reach the people they are interested in and that they can sometimes raise unanticipated ethical issues.

a) **Process:** Participant recruitment in CBR studies needs to be thought of as a process that can take time and multiple iterations, depending on the community and the recruitment context. Traditional passive approaches like posting information or more active approaches like speaking directly to potential participants may be equally inappropriate. In many communities, being exposed to information from unknown sources or being approached by an unknown researcher, may be regarded with mistrust. Participants need to be reassured that researchers understand the community. Recruitment may require multiple interactions and a long-term presence in the community. Some projects have recruiters spend extended periods of time in community-based organizations to be available to promote their study with potential participants.

b) **Materials:** Many of the researchers we spoke to had developed innovative recruitment materials, using community-relevant symbols and language to engage participants' attention. This reflects growing changes to recruitment, where researchers are providing potential participants with additional materials and information (i.e. condoms, HIV prevention information, etc.) as part of the recruitment process (Remple, et al., 2007). This can demonstrate a commitment to the community beyond just obtaining data. CBR teams are increasingly using multiple strategies with different materials that would appeal to a range of individuals within a community (e.g., YouTube clips and Facebook pages). However, REBs will need to be informed as to why these methods of recruitment are appropriate for the community you are working with.

"I definitely think we had to make a strong rationale for the fact that we were not going beyond urban centres. [It] was not something folks understood. That you can't go to a reserve community and then advertise for people who are HIV positive to be involved in research because there's so much stigma against HIV within the Aboriginal community, and because of the real need to make sure people were anonymous."

Issue 4: What ethical concerns emerge when we recruit through organizations and service providers?

A popular approach in HIV CBR is to have community-based organizations recruit community members who have been typically excluded from research (Anderson, 2010). This can enhance trust among community members and help to ensure that participants who meet inclusion criteria are recruited. However, REBs may be concerned that the involvement of service providers in recruiting could adversely impact service experiences (Anderson, 2010; Marshall et al., 2012). Researchers are advised to make it clear in their recruitment materials (and to reiterate verbally) that participating (or not participating in a CBR study will not influence the community member's ability to access services from the agency recruiting.

CBR teams should be mindful of extra stressors placed on community partner organizations involved in recruiting.

"I think sometimes we just got overwhelmed with the number of people that were coming. ...We did it on a first-come- first-served basis. Some of the agencies would get just so full of people and... they were crowding the waiting room, they were hanging around. I think there was some disruption to the program just by sheer volume. And people wouldn't go away. We'd say 'Come back in an hour,' and people would say, 'Well, I'd rather stay here.' So we tried giving out numbers; we tried all sorts of things."

It is important to remember that staff in community-based organizations have other commitments and responsibilities and may not be able to prioritize recruitment or have the time to do it effectively (Anderson, 2010).

"If I wanted to recruit people for a study, I couldn't just put something in the newspaper. Because, you know, there are some communities that have not been well-served by research and researchers and therefore people might be suspicious of what researchers are up to, but if they know, I mean, if they've received this information from what you might call a trusted intermediary, then they'll say, 'Ah, okay I can do this, it's okay,' rather than sort of just responding to some anonymous ad in a corner of the [newspaper] or something like that."

Issue 5: The role of community members in recruitment

"Well, we did go back to the ethics board because we were changing our approach and looking at this peer model and so, again, we did have to think through. It's interesting because the friendship model of recruitment thing, the ethics board didn't question us. I guess we were able to explain it in a way where we had covered or thought through some of the challenges that might arise.

Another popular means is using peer-based approaches, where members of the community (e.g., people who use injection drugs) recruit others from their own community. This "peer-driven recruitment" (PDR) facilitates access to populations who are often excluded from research (Remple, et al., 2007). It is important to ensure that peers do not pressure or coerce other community members to participate, especially if their pay is based on numbers recruited (Scott, 2008; Simon & Mosavel, 2010). Finally, it is important to ensure that peer recruiters have access to the resources (e.g., cell phones and access to email) they need to ensure they can be effective in their roles (Simon & Mosavel, 2010).

"I didn't realize how much time the peer research assistants were going to be spending involved in recruitment, so one of the great assets of involving peer research assistants is a slight snowball sampling where they ask their friends who ask their friends and then you're accessing the community but it takes a lot of time for the peer research assistants to contact people and that's why they need the phone."

Questions for consideration:

The following questions may be useful for HIV CBR team to reflect on when deciding on appropriate recruitment strategies. Thinking about these issues in advance may help facilitate a smooth research process and maintain positive relations with individual participants and the community.

1. Think about the people who will be doing the recruitment and outreach in your study? Do they have credibility with the community? Are they representative of the community? Will the community trust them? Do they have lived experience of the issue under study?

2. Do your recruitment materials and strategies reflect community language and values? What about the images that are used in your materials? Are they community-appropriate?

3. How will you ensure that the people who participate in your study meet the inclusion criteria established by your team? How will you ensure that community members don't feel excluded if they don't meet inclusion criteria?

4. How could community leaders be involved in your outreach and recruitment?

5. If recruiting through service providers (or others who hold power), what strategies will you put in place to avoid undue influence? What rationale will you provide to your REB for this approach to recruitment?

6. How will you communicate through your outreach and recruitment materials the risks and benefits to the community beyond participation?

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