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

HIV CBR ETHICS

Supporting Peer Research Assistants (PRAs)

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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 four key issues:

- benefits of a PRA approach

- training PRAs

- supporting PRAs during the project

- planning for study closure.

Background

Peer research assistants (PRAs) are members of a research project's target population who are trained to participate as co-researchers or research assistants (Guta, Flicker, & Roche, 2013). A PRA is "a person who shares in common at least one lived experience with …[research] participants, such as… gender, race/ethnicity, or HIV-positive serostatus" (Logie, James, Tharao, & Loutfy, 2012, p. 11). In some cases, peer researchers partner in all facets of a research project. In others, peer research assistants are instrumental in one or more aspects of a research project (e.g., participant recruitment or data collection).

This fact sheet explores ethical issues related to supporting PRAs in the context of community-based research (CBR) projects. Based on strategies employed by Canadian HIV CBR teams, the following four issues are addressed:

- benefits of a PRA approach
- training PRAs
- supporting PRAs during the project
- planning for study closure.

In most social and behavioural health research, data is collected by experienced researchers, or researchers-in-training, with specialised skills and instruction. Once in the "field," researchers work to develop trust and gain access into community spaces to document community practices. There is a long tradition in the social and behavioural sciences of discussing strategies for building rapport. The concern from a research ethics perspective is that researchers need to be able to anticipate, manage, and mitigate research-related harms. As well, in some jurisdictions, specific research ethics and data management training is required for any project members and staff who have access to sensitive data. Most research ethics boards (REBs) ask about the training and experience of researchers to conduct sensitive research. This is meant to ensure that everyone on a research team will have a common understanding of research ethics and what is required when collecting data, analysing it, and disseminating it. HIV is considered a particularly sensitive topic to research because of the stigmatized nature of sex and substance use practices that put individuals and communities at greater risk.

In CBR, many researchers (despite their training and experience) are understood to lack lived experience. Not having a *lived* understanding of some community practices and norms means some researchers will always be outsiders; they will likely not be privy to certain kinds of community conversations (particularly if community members fear judgement or retribution). They may also risk offending research participants with questions that are seen as uninformed and insensitive. For these reasons, a growing number of CBR projects are involving community members as peer researchers (PRs) or peer research assistants (PRAs). Ideally, there ought to be opportunities for reciprocal capacity building among team members – where those with lived experience are provided with an opportunity to both share their expertise and learn from others on the team with different capacities.

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The PRA approach involves recruiting, hiring, and training members of the community who are living with, or at risk of, HIV to assist in designing projects, developing research instruments (e.g., survey and interview questions), and collecting, analyzing and disseminating data (e.g., conducting interviews and facilitating focus groups). The PRA approach has become popular to engage community members in HIV/AIDS research (Greene et al., 2009; Logie et al., 2012); some see it as aligning well with the Greater Involvement of People Living with HIV/AIDS (GIPA) principles (Travers et al., 2008). Nevertheless, the term "peer" remains difficult for others, particularly in relation to HIV status; some may prefer to define themselves through different dimensions of their identity or may not want to disclose their HIV status by taking on the peer label. Other terms that are used to refer to PRAs include "community consultants" or simply "research assistants." Project teams may wish to discuss the pros and cons of using different labels and to work with staff and members to come up with the most suitable language for their given contexts.

In this fact sheet, we identify various approaches to thinking about engaging peer researchers and describe the strategies employed by Canadian HIV CBR teams to balance these competing interests.

Issue 1: Benefits of a PRA approach

"I think that the peer research idea is one that is very useful in terms of how we're bringing lived experience, bringing different ways of understanding evidence, into our work. It is also important that people who have been unable to work for one reason or another, but are capable of doing this kind of work, that they be given these opportunities because it's a way of providing income, it's a way of giving people something to put on their resume that might lead to something else, right. So it can be an end in itself for people who want it to be that, but it can be a way of starting on something else."

The researchers we heard from told us that there are many benefits to this approach for the PRAs, the research project, and the larger community. First, PRAs benefit individually by having their knowledge and experiences validated. Their lived experience is recognized as an important form of knowledge to help guide the research. PRAs are involved in CBR projects in different ways and take on different roles. In some projects, PRAs are central members of the research team and participate in project decision-making, in other cases, they are hired for specific tasks (for a discussion of the benefits of different approaches see Roche, Flicker, & Guta, 2010). Being meaningfully involved in a CBR project can increase access to community resources and programming and help alleviate the social isolation that some people living with HIV experience. When compensated properly, PRA positions can provide PRA with an income or a meaningful income supplement (for a discussion of different payment approaches in PRA initiatives see

Guta, Flicker, & Roche, 2010). For some PRAs, being involved in research can be an important form of capacity building and a transition avenue into other, more permanent, forms of work.

Second, PRAs can help improve the quality of the research by working with research teams to decide on appropriate methods and questions, and flag any concerns and community sensitivities that the researchers may not be aware of (e.g., questions that are likely to offend participants or create conflict in a focus group). PRAs are often able to enter community spaces where other researchers would not be able to go and to build rapport with participants because of their shared experiences. For example, a PRA who injects drugs entering a space where drugs are consumed will likely be treated differently from a graduate student who does not have a history of drug use and is not known to community members who run or use the establishment. Beyond the data collection, PRAs can help inform the analysis by providing examples from their own experience to give context and meaning to participants' accounts.

Finally, PRA involvement can have broader effects for the entire community. PRAs can help with dissemination by providing input into the design and development of knowledge products aimed at service providers and community members. Their involvement can help translate complex research findings in useful ways targeted at community audiences. Findings that reflect community knowledge and are delivered in respectful ways are more likely to be taken up and to produce tangible improvements in the health of communities. When PRAs take up leadership roles in their communities, they can become important resources beyond the life of a single project, and may encourage others to become involved in social change work. Overall, employing community members is an important component of a broader strategy of community engagement and partnership between CBR teams and the larger community (Remple, Johnston, Patrick, Tyndall, & Jolly, 2007; Simon & Mosavel, 2010).

"We piloted the questionnaire with our peer research assistants when they're here in training and ... if we need to make changes, we'll make changes then. But the PRAs all gave lots of good feedback and we incorporated their changes."

Issue 2: Training PRAs

"We really had to redesign the training program based on the needs of the PRAs and to do this we worked with the different ASOs around the province, and they had recruited the PRAs and then they worked one on one with the peer research assistant coordinator [to make them] aware of all the different circumstances and different challenges and successes that each PRA was coming with. So we were able to really tailor the training to those needs of the PRAs."

For PRAs to be effective in research settings, their lived experience needs to be complemented with appropriate training to prepare them for the realities of conducting research and to help differentiate research from routine experiences of their everyday lives. In some cases, PRAs may also benefit from learning more about the expectations associated with "professional" environments. REBs may not understand the role of PRAs and confuse them with participants. Research teams need to differentiate them by describing the PRA role (as they define it) and detailing the training process. Formalized training can provide opportunities for PRAs to augment and share their current skills and build capacity in areas in which they lack experience.

a) **Research methods:** PRAs should be trained in any methods they will be required to use (e.g., introduction to survey methods if they will be administering a survey). Research teams need to balance content with accessibility and not overload PRAs with too much information. It can take years to learn the nuances of data collection, and PRAs should not be expected to learn everything in a day or a week.

b) **Ethical standards:** PRAs should be trained in research ethics standards and especially the importance of informed consent and confidentiality. PRAs need to be assured that conducting research ethically is more important than collecting data. There are a number of resources to help familiarise PRAs with research ethics, including the TCPS online tutorial. Teams can then role-play different scenarios they might encounter in the field.

In addition to core methods training, training can include discussions of relevant legalities and self care (Remple et al., 2007). Some teams may want to consider how to develop training processes that lead to the development or enhancement of "transferable skills" that may assist PRAs in their search for future work. Training can be given at the beginning of a project; however, ongoing training throughout the research, including close supervision, feedback, and opportunity for reflection, is ideal (Simon & Mosavel, 2010). Team members may want to encourage PRAs to lead training sessions on the research context and community so that their in-depth knowledge of the "on the ground realities" can be shared with the larger team.

"I'm hardly convinced that they had enough training. I just didn't have enough money to train them for longer."

The complexity of many PRAs' lives requires that training be flexible, with opportunities to catch up later for sessions missed, or for new peer researchers to be integrated and brought to the same level as the others if someone has to leave the project. Training can be expensive and time consuming. Many of the researchers we heard from said they wished they had budgeted more time and money for this important step in the research process.

Issue 3: Supporting PRAs during the project

"When you think about HIV and it being an episodic illness and these periods of potential wellness and illness, I mean there may be periods of time where individuals need to step away um and then periods of time where they may be able to engage more."

While PRA approaches have many positive benefits, the nature of HIV CBR necessitates that PRAs discuss sensitive topics while managing their own personal health and wellness issues (Greene et al., 2009). We heard from many of the researchers we spoke to that PRAs needed supports that were additional to the ones usually offered to paid research staff. They stressed the importance of recognizing PRAs personal limitations related to their health and implementing practices and policies to support and accommodate them. First, the research process can be stressful for even the most experienced researchers. While PRAs will have an intimate knowledge of their community, it does not mean they will not encounter stressful research situations (Logie et al., 2012; Simon & Mosavel, 2010). When the research process is not going as anticipated (e.g., difficult or slow recruitment), it can have a very negative impact on PRAs' morale (Robinson et al., 2006). Lulls in the research or extended gaps (e.g., delays in obtaining research ethics) can leave PRAs feeling like they are not needed and cause them to question their role in the project (Guta et al., 2013). In addition, PRAs may not be prepared for the (positive and negative) impacts that their new role may have on their social circles and the resulting shifts in power and their relationships to their community.

Secondly, people living with HIV are likely to experience episodic illness that may limit their ability to actively participate in the project for short or extended periods. PRAs who are marginalized and lack basic resources like stable housing will likely encounter significant barriers and require considerable support to get to data collection sessions and team meetings and events (Guta et al., 2010). The researchers we heard from described aiding their PRAs in a range of personal issues, including obtaining access to public services and even in court proceedings. This is not uncommon, and the literature has examples of researchers supporting PRAs through personal challenges such as drug relapse (Remple et al., 2007). PRAs support needs may range from emotional care, to assistance with navigating health and social service systems, to financial challenges. Identifying relevant supports and referrals at the outset of the study is important, particularly if some of these supports are outside the expertise of team members. Having these resources on hand can also open lines of communication with PRAs so that crises can be averted through early intervention. Using reflection sessions to talk through challenges and suggesting possible solutions can be an effective way to address some issues (Simon & Mosavel, 2010). Before adopting a PRA approach, researchers should consider whether they have the time, expertise, and budget to properly support PRAs. If the answer is no, then community members should be engaged in less demanding ways, such as through an advisory committee.

"During our training, um, one woman didn't have her medications with her, so we had to take her to get a new prescription... it's sort of all of these support systems that are needed for people to be able to function in a job, so it's not just that they just show up and do a job we need to help enable them to be able to show up."

Issue 4: Planning for study closure

"I think what ends up happening, is communi-ty-based research takes longer, often, than people expect and so they run out of money by the time they get to that dissemination."

Several researchers we heard from told us they had concerns about what happens to PRAs who lose their income and support networks when projects end. Unfortunately, some PRAs may find it difficult to transition out of a research project, especially when a strong support network has developed (Flicker, Roche, & Guta, 2010; Northway, 2000), and, worse, some may feel abandoned after a project ends (Boynton, 2002). Many of the researchers we heard from struggled with how best to end a project and whether they had ongoing responsibilities to PRAs. While research teams cannot commit to supporting PRAs beyond the life of the project, they can take certain steps to ease the transition. Plans for end-ing the project should be made from the beginning and "the end" should not come as a surprise to PRAs – they should be warned of this inevitability.

While there is some literature about creating closure for research participants when a project ends, there is little discussion in the literature about supporting PRAs through this process (Iversen, 2009; Morrison, Gregory, & Thibodeau, 2012). Where possible, CBR teams should include PRAs in decision-making about how their relationship with the researcher(s) will change or end when the project wraps-up. When writing grants that include a PRA ap-proach, CBR teams should think ahead to study closure by bud-geting in funds to help PRAs transition and by including capacity building opportunities that will be useful for other projects and paid work. Researchers often have large networks and should explore the possibility of work opportunities for peer researchers with other community/research projects (Boynton, 2002). At the very least, researchers should be available to provide ongoing re-ferrals and reference letters. Ideally, one CBR project will be used to leverage future funds and turn into subsequent projects that PRAs can continue to be involved in, if they so choose. CBR teams cannot ensure that additional funding will materialize, but should commit to keeping open lines of communication with PRAs to en-sure they understand where they stand in relation to the project and whether additional opportunities are possible.

"We bring people into a study [and when] the study ends...they no longer have a job, it's a problem right? It's a big problem, and it gets repeated every time. Hopefully, by the time that that project ends another [opportunity] has shown up; otherwise, everybody gets laid off...even though we may have this idea that we're equal partners and we share decision making, in the end it's very clear that they're dependent, it's very uncomfortable"

Questions for consideration:

The following questions may be useful for HIV CBR team to reflect on when designing a study to ensure it ends as well as it began. Thinking about these issues in advance may help facilitate the research process and promote positive relations with individual participants and the community.

1. What benefits might accrue (for whom?) from adopting a PRA approach in your particular project? How might benefits be maximized?

2. Has your team defined the multifaceted roles and responsibilities for PRAs in your project? What language has your team decided to adopt to refer to PRAs?

3. Has your team considered the range of labour practices appropriate for PRAs in your project (e.g., working conditions, salary)?

4. Has your team fully considered the range of PRA support needs necessary and developed strategies to address these needs?

5. How might involvement in the project affect a PRAs position in the community? Has your team considered ways to address or mitigate any potential challenges that may compromise a PRAs relationship to his/her community?

6. Has your team considered how the budget can support the degree of training, capacity-building, and support warranted for PRAs?

7. Has your team developed a plan for project wrap-up that takes into consideration the goals and needs of the PRAs?

8. Are there mechanisms that would support a community member being in a compensated leadership/project decision making role?

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