

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

HIV CBR ETHICS

Learning about illegal,
sensitive and stigmatized topics



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HIV CBR Ethics Fact Sheet Series:

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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:**

- Supporting participants following the disclosure of sensitive and illegal information
 - Research vs. therapy
 - Professional and legal considerations (e.g., duty to report)
- Protecting the well-being of participants and whole communities
- Working with REBs to develop strategies to protect sensitive data
- Framing sensitive research findings

Background

This fact sheet explores the issue of researching illegal, sensitive and stigmatized topics in the context of community-based research (CBR). Based on strategies employed by Canadian HIV CBR teams, the following issues are addressed:

- Supporting participants following the disclosure of sensitive and illegal information
 - Research vs. therapy
 - Professional and legal considerations (e.g., duty to report)
- Protecting the well-being of participants and whole communities
- Working with REBs to develop strategies to protect sensitive data
- Framing sensitive research findings

Sensitive research can be defined as research that could result in harm to participants (e.g., emotional costs, legal consequences) or risk to researchers (e.g., legal costs) (Lee & Renzetti, 1993). Social and behavioural health research often entails collecting sensitive personal information about attitudes, practices, and behaviours that can be difficult for participants to share (Lee & Renzetti, 1993). Individuals' health practices may conflict with medical knowledge and social standards about health (e.g., smoking, using drugs, and having unprotected casual sex). Research participants are likely to be aware that their practices and behaviours conflict with established norms and may feel embarrassed discussing these issues with researchers. People living with, or at risk of, HIV often experience stigma and discrimination because of social attitudes about drug use and 'high risk' sexual behaviour. Unfortunately, this may come from friends, family, their communities, and society at large (Logie & Gadalla, 2009).

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While research can help identify and address some forms of stigma, it can also unintentionally reproduce others. For example, information obtained through research with people living with HIV may describe illegal activities (e.g., selling drugs or failing to disclose one's HIV status). The concern from a research ethics perspective is that participants may be caused distress by certain kinds of research and lines of questioning. Research on sensitive, stigmatized or illegal activities may be of critical importance, as it has the potential to reduce stigma, challenge injustice and create platforms for advocacy initiatives that may require an objective evidence base. An important legal concern is that data may be subpoenaed by police looking for incriminating information. While the threat of subpoena is generally remote, it has happened more than once in the Canadian context (Canadian Association of University Teachers, 2013; Lowman & Palys, 2000).

In CBR, teams often strive to challenge forms of stigma and discrimination which contribute to negative health outcomes for communities (Zanjani & Rowles, 2012). For example, HIV is related to sensitive issues by virtue of 'risk' activities and transmission routes (e.g., drug use and sex). In HIV research, this may involve soliciting stigmatized experiences and contextualizing them to help understand their roots and meaning in the lives of people living with, and at risk for, HIV (e.g., drug injecting practices among street-involved youth). Furthermore, there are legal implications to asking about some of these activities (e.g., criminalization of non-disclosure). Researchers must familiarize themselves with relevant laws to ensure that they are not putting individuals at risk for legal sanctions. At the same time, the emphasis in CBR on involving multiple stakeholders in the research process and engaging whole communities may raise concerns from research ethics boards (REBs) tasked with protecting research participants (see also *Fact Sheets #3 Managing Multiple Roles & Boundaries* and *#6 Confidentiality in close-knit communities*). In this fact sheet, we identify various approaches to thinking about illegal, stigmatized and sensitive information and describe the strategies employed by Canadian HIV CBR teams to balance these competing issues.

Issue 1: Supporting participants following the disclosure of sensitive and illegal information

“The group told me that they shared information [about illegal activity] with me that they would not normally do...It was only because of the relationship that we built and their trust in me as to what I would do with that information that they treated me like a peer.”

CBR can be a powerful tool for collecting the stories of marginalized people. The researchers we heard from described the ways they were affected by hearing stories of violence, abuse, homophobia, racism, and exclusion. Many talked about having to comfort participants who had become upset during or after the data collection. Despite claims that social and behavioural research does not pose significant risks to participants, the researchers we heard from acknowledged the emotional impact participating in data collection can have on participants. Many of these researchers felt it was their responsibility to support participants, or refer them to someone else. Researchers should anticipate and consider these kinds of issues during the development phase of their project: What are known triggers for community members? How should these issues be approached, or not? Are some issues best left out of the questions unless participants bring them up? How will participants be supported during and after the research process? Here, we consider two related issues: a) Research vs. therapy and b) Professional and legal considerations (e.g., duty to report).

a) Research vs. Therapy:

Some methods may be more appropriate than others when dealing with potentially sensitive or stigmatized topics. For example, qualitative approaches can allow participants to frame issues in their own terms, but they can also parallel case management and counseling (Coy, 2006). Many of the researchers we heard from described balancing their dual roles as clinicians (physicians, social workers, nurses, etc.) and researchers. They drew on practice and methods training to inform how they engaged participants in discussions of sensitive topics. Researchers should always differentiate research from clinical practice and consider the research value of the data being collected (see also *Fact Sheet #3: Managing multiple roles and boundaries*). For instance, while clinically, it may be useful to revisit experiences of childhood abuse, reliving these experiences in the context of research may not be a nec-

essary objective of the research project. There may, of course, be arguments for encouraging these kinds of disclosures, particularly when little is known about the phenomenon. Researchers engaged in such research should always consider the potential risks to participants and what additional supports may be necessary for participants who are left in an emotionally vulnerable state after an interview.

Having a researcher with clinical training and experience on the team can be helpful to anticipate and respond to sensitive disclosures, as well as set up supports for participants outside the research project. Participants who disclose risk taking or harmful experiences may be disclosing for the purpose of getting help from researchers; not taking action may send a message that the problem is not significant enough to warrant action (Fisher, Higgins, D'Alessandro, Rau, Kuther, & Belanger, 1996). The process of disclosure of harm may be helpful to participants who have not had an opportunity to discuss these issues elsewhere (Bernard, 2013). However, disclosure can itself also be harmful and participants may leave the research experience feeling vulnerable and concerned about how their data will be used (Reeves, 2010).

In situations where a participant becomes emotionally distressed, the researcher may offer to contact their regular care provider, with the participant's express consent, and negotiate an appointment (e.g., I believe one of your patients is in distress, can you see them immediately?). For researchers working with a hosting social service organization, they may want to negotiate in advance with the clinicians on staff to meet with participants if they express suicidal or violent thoughts. Staff may already know the participant if they are a client of the organization and can sometimes “take over” for the researcher.

Researchers should facilitate self-referrals for situations when participants may require legal advice, or need to explore emotional issues that emerged during the data collection further, and are not in immediate distress. Teams should compile a list of appropriate referrals in case the information is needed (Fisher et al., 1996; Urquiza, 1991). Lists should be updated and checked to ensure that participants are able to reach any of the contacts or organizations, that they are accepting clients, and that their cost is not prohibitive. As issues often come up after a research project has ended, researchers should work with community partners to identify and implement ways of providing support beyond the term of the research project.

b) Professional and legal considerations – Duty to report

In some cases, participants will disclose information that requires researchers to breach their confidentiality and report what they have learned to appropriate authorities. This can be complicated when researchers hold dual roles (e.g., researcher and clinician), and clinician researchers are encouraged to seek guidance on any professional obligations and conflicts. Not all disclosures require immediate action, but if researchers feel unsure about their ongoing responsibilities, they should obtain legal advice on how to deal with information about illegal behaviour (Wiles, Crow, Heath, & Charles, 2008).

Researchers need to familiarise themselves with the issues that must be reported or disclosed even without the consent of participants (Bernard, 2013; Wiles et al., 2008). Many researchers are unfamiliar with their legal duty to report (where it starts and where it ends, what to report, and who to report to). Usually, researchers are obliged to breach confidentiality, and report the following three disclosures:

1. Current and ongoing child abuse
2. Risk to self (e.g., suicidal ideation)
3. Risk to others (e.g., intent to harm someone else)

Who to warn (e.g., police, public health or child protection services) will depend on the specific issue being reported. However, reporting may not always be possible for a researcher when they do not know a participant (e.g., anonymous survey results that indicate high levels of depression and suicidal ideation for some participants) or be necessary (e.g., reporting past child abuse in a study of parents who have had their children taken away). Clinicians who regularly deal with the duty to report often establish certain criteria before reporting (e.g., has the individual experienced suicidal thoughts, have they been depressed over an extended period, is there a plan, and does the individual have the means to carry out the plan?) and consider whether they have reasonable grounds to believe disclosure is necessary to eliminate or reduce significant risk of serious bodily harm (e.g., clear risk of serious harm to identifiable persons).

“I mean, I’m not a gay man and I’m not HIV positive. I didn’t realize that there’s so much division and resentment. That kind of came up [in a] focus group [where] some people expressed judgment that people got HIV through ‘promiscuous behaviour,’ and then some people who were positive were extremely mad about that...”

Issue 2: Protecting participants and whole communities

“There was concern for us in terms of the population given [the] legal cases going on around sex work as well as a lot of the criminalization of HIV cases...When it comes to marginalized populations there needs to be a certain level of protection that you can be sure you’re ensuring so you don’t have someone show up on your door and subpoena you and take all the information.”

Once the data is collected, there may be ongoing considerations for protecting the confidentiality of individuals and the well-being of communities. The researchers we heard from were sensitive to the possibility that their research could be subpoenaed and some had interactions with police during and after their data collection. They took precautions in terms of what questions they asked, how they asked them, and how they stored and coded their data. Many of the researchers we heard from used strategies described in the literature: stopping participants if they sensed an illegal activity was about to be reported, stopping participants from continuing when they had started to disclose, reiterating what can/cannot be kept confidential, asking participants specifically to refrain from giving researchers their name; and ensuring that participants were aware of the possible consequences of disclosures (Wiles et al., 2008).

Experienced researchers can often anticipate the kinds of information participants will disclose and can redirect them in supportive ways (e.g., “Why don’t you tell me more about the experiences of other youth in your community?”). Of course, this raises the methodological concern that forewarning may change the information shared or result in potential participants self-selecting not to participate (McLaren, 2007; Urquiza, 1991). However, being upfront with participants and maintaining boundaries may actually increase trust (such as clearly stating that child abuse will be reported) (McLaren, 2007). There are often ways of collecting similar data without requiring detailed personal information that could be incriminating (e.g., researchers do not need to ask “Can you tell me where you buy and sell drugs and how often?”). Information that links participants to specific places and events can be used in court. Research records may be subpoenaed in some circumstances. Thus, what is documented and how must be carefully considered as well as how action or non-action on the part of the researcher might be later interpreted (Fisher et al., 1996). Unfortunately many universities are unwilling to support researchers to protect their data and they may have to incur personal legal costs and even risk incarceration. Many REBs require the disclaimer: “Data will be protected to the extent of the law” to reflect the reality that researchers may not be able to ensure confidentiality when faced with legal action. Researchers should consider whether their duty to report should preclude certain types of research, or parts of the research, from taking place (Fitzgerald & Hamilton, 1996; Wiles et al., 2008), as well how they frame their research and recruitment protocols.

“So the street outreach workers interviewing street youth about a range of really sensitive topics including whether they’d been asked to ever exchange sex for food or you know other items, so we were really careful again in the way, and [name] knew you can’t ask if they have done it, you can ask if they have ever been asked to do it in order to not to run afoul of some of the laws.”

Issue 3: Working with REBs to develop strategies to protect sensitive data

“You know we had a very difficult time with an REB of one of the institutions involved, related to moral beliefs... Part of it was about sex. We asked people about their sexual behaviours, we also asked people about issues related to condoms... That particular experience raised some questions about what it is that REBs are supposed to do, and is there any oversight of REBs.”

Despite concerns raised that researchers are no longer able to conduct ‘risky’ research in the social and behavioural sciences (Haggerty, 2004), the researchers we heard from were able to obtain ethics approval for very sensitive research. Their approach was to demonstrate to their REBs why the research was necessary (including why this data was needed and relevant), the process of consulting with the broader community to establish the most appropriate design, why the research team was qualified to conduct the research, what ethical issues they anticipated, and how they would respond to mitigate any research-related risks to the extent possible. All protocols should detail the circumstances un-

der which the option to self-refer will be encouraged and include details about procedures to follow regarding the legal duty to report (including legal obligations to report child abuse, etc.) in the informed consent materials (Fisher et al., 1996; Wiles et al., 2008). When researchers were met with additional questions from their REBs, they answered them in a timely fashion and often received approval on the second iteration. While some researchers may feel that “less is more” when it comes to REBs, experienced researchers on the REB may see this as a lack of understanding and request additional information. Many REBs are trying to work with researchers to ensure CBR is done well and in a way that protects participants, researchers, and academic and healthcare institutions (Guta, Nixon, Gahagan, & Fielden, 2012). The combination of innovative methods, emergent risk practices and shifting legal and public health responses means that neither researchers nor REBs can ever fully anticipate the kinds of issues that may occur in the field. Researchers are advised to err on the side of caution and treat all data as potentially sensitive and at risk of being subpoenaed. In CBR with socially identifiable populations, the benefits should be high to offset any risks associated with visibility (American Academy of Pediatrics Committee on Native American Child Health, & American Academy of Pediatrics Committee on Community Health Services, 2004).

“Ethics review boards ... can only do so much. You know? Like they highlight some issues and they ensure that we adhere to some of those basics protective mechanisms... But all of the nuances, it’s very hard for a research board to know anything about all of the [details] unless you have somebody on that panel who’s been immersed in it...”

Issue 4: Framing sensitive research findings

“I think another issue [is] how do you speak about community in a way that doesn’t simply disparage people...how do you talk about your research results in a way which doesn’t simply scandalize the communities you’re supposed to be working with? I think that’s a real ethical issue for me. You know you want to remain true to the research results but you also want to remain true to the community, and the only way I think we could really address that issue is by, you know, having those initial discussions in a community context, not that you want to sort of white-wash or hide anything, but having those initial discussions in a community context so that people understand where this is coming from.”

CBR is committed to turning research into action by using research findings to change policies and practices within organizations and improve access to healthcare and services. HIV CBR strives to redress past research that stigmatized people living with, and at risk of, HIV by sensationalizing their lives. However, once data is shared at academic and community forums and in print, research teams lose control over how the data is ‘spun’ by media outlets and politicians. The research can be taken up in ways that

are exactly opposite to what was intended by the research team and their community partners. Published and publicized data may harm communities or groups in addition to individual participants (Bostock, 2002; Seal, Bloom, & Somlai, 2000). Collectively developing media/public messages about the research prevents some voices from being privileged over others (Walsh, Hewson, Shier, & Morales, 2008) and may help messaging remain consistent. It is especially important when researching illegal behaviour to ensure findings are presented in such a way as to keep participant identities anonymous. Options may be discussed with participants in deciding what data to publish or otherwise share (Wiles et al., 2008).

The researchers we heard from were committed to ensuring that their data were reported in such a way as to protect the communities they worked with from further stigma. In some cases, this meant undertaking additional consultation processes with community-based organizations, community leaders, and participants to establish what to share, where, and when. Researchers should not make assumptions about what communities want shared, and a number of participants described scenarios where they wanted to withhold some of the data but the community felt the data needed to be disseminated. Additionally, researchers should have conversations with their teams about what they are willing to share, and what they are not; just because the media requests certain kinds of information, does not mean there is a need to disclose it. There is no standard approach and decisions will need to be made on a case by case, project by project, basis.

Questions for consideration:

The following questions may be useful for HIV CBR teams to reflect on when researching illegal, stigmatized and sensitive topics. Thinking about these issues in advance may help facilitate the research process and maintain positive relations with individual participants and the community.

1. Are the issues you are researching considered sensitive topics?
 - a) What are the potential risks to participants?
 - b) What are the potential consequences of this research?
 - c) Do the benefits outweigh the risks?
2. What are creative ways of capturing data that would protect individuals in the case of subpoena, involvement of the police, or other legal challenges?
3. What are your team's policies and procedures regarding supporting participants when disclosing potentially sensitive or illegal behaviour?
4. What are the professional and ethical obligations of team members when conducting research?
 - a) Do any team members have dual roles (e.g., clinician and researcher)?
 - b) How will this affect their duty to report?
5. How will your team make decisions about sharing potentially stigmatizing research results?

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