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

HIV CBR ETHICS

Confidentiality in close-knit communities

6

Adrian Guta, Sarah Flicker, Robb Travers, Michael Wilson, Carol Strike, Sonia Gaudry, Louise Binder, Patricia O'Campo, Dario Kuzmanovic

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.

Please cite this document as:

For more information, please visit:
www.HIVethicsCBR.com

In this fact sheet, we discuss four key issues:

- Common challenges to maintaining confidentiality in communities

- Identifying the limits of confidentiality

- Data collection, analysis and dissemination

- When community members want to be named

Background

This fact sheet explores issues related to maintaining confidentiality in close-knit communities. Based on strategies employed by Canadian HIV community-based research (CBR) teams, the following four issues are addressed:

- Common challenges to maintaining confidentiality in communities
- Identifying the limits of confidentiality
- Data collection, analysis and dissemination
- When community members want to be named

According to the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans, privacy "is a fundamental right in a free and democratic society" and "individuals have privacy interests in relation to their bodies, personal information, expressed thoughts and opinions, personal communications with others, and spaces they occupy" (TCPS-2, 2010). Usually, researchers honour privacy obligations by collecting information that is either anonymous (identifying information is not collected) or the data is anonymized (direct identifiers are removed after the data is collected), and all of the data is kept confidential (protected from unauthorized access and misuse). In most social and behavioural health research, data are treated as confidential and identifiable information about individual participants is removed before it is analysed and shared through conferences, publications, reports, and via other outlets. However, confidentiality issues are often complicated in research involving close-knit communities because even when unique identifiers are concealed, some people might still be identifiable to their networks.

Most research ethics boards (REBs) will expect researchers to explain how the data will be treated once it has been collected (e.g., how will it be transferred and stored), how it will be kept confidential and anonymized (e.g., taking out names), who will have access to it (e.g., the entire research team or just some members), and any known limitations to maintaining the confidentiality of participants (e.g., limited confidentiality in group settings). Most researchers retain their data (e.g., interview recordings or completed surveys) until the information has been entered into a database and then originals are destroyed after a period (e.g., surveys are shredded after they have been entered into a statistical analysis software database). Some disciplines have requirements for how long data should be retained (e.g., the American Psychological Association requires researchers to retain original data for seven years), and some REBs may have their own specific requirements. Preserving data can allow for it to be re-analyzed at a later date and/or checked by others to minimize the potential for scientific misconduct. Whatever the length of time chosen or approach taken, researchers should justify their data collection and management plan to their REB.

In CBR, research is often conducted in small communities (defined by place or shared experience) and community members may interact on a daily basis and know a lot about one another. This close proximity may mean confidentiality will be more difficult to ensure than in traditional research projects where participants are more dispersed. Carleton University's REB recognizes that "the usual rules of anonymity and confidentiality may not apply in such a project" (2004). In HIV CBR, both individuals and organizations can become identifiable through a process of elimination (e.g., there is only one organization that fits the profile attended by a core group of service users). HIV CBR teams need to consider both individual and collective confidentiality. In this fact sheet, we identify various approaches to thinking about confidentiality and describe the strategies employed by Canadian HIV CBR teams to balance these competing issues.

> In most social and behavioural health research, data are treated as confidential and identifiable information about individual participants is removed before it is analysed and shared through conferences, publications, reports, and via other outlets.

Issue 1: Challenges to maintaining confidentiality in communities

"How, for example, can you as a researcher guarantee any kind of privacy in a community where you sneeze and somebody three doors down hands you a Kleenex?"

In small and close-knit communities, even minor and seemingly innocuous data excerpts might be recognizable to other members of the community, making protecting confidentiality a complex process (Damianakis & Woodford, 2012; Tolich, 2004). CBR promotes the involvement of numerous stakeholders, and often entails multiple, intersecting roles for both community-based researchers and participants (see also Fact Sheet # 5 on informed consent). However this might not be seen as a strength by some participants

who may understandably question whether their information will remain confidential (Woodman, Tully, & Barranti, 1995). When research teams (researchers, community members, service providers, etc.) have ongoing relationships with participants, there is an increased likelihood of confidentiality being breached (Marshall et al., 2012). When participants tell stories that describe community practices and norms, they are inevitably including other people's experiences, people who have likely not agreed to be part of the research and may not agree with its goals (Ellis, 2007; Ellis, Denzin, & Giardina, 2007). In small and close-knit communities, it may be useful to think about the confidentiality of entire communities and not just research participants (Woodman et al., 1995). Most REBs will not be familiar with the nuances of confidentiality in individual communities and research teams need to familiarize themselves with these issues during the design and consultation process.

Issue 2: Identifying the limits of confidentiality

In response to concerns about confidentiality in CBR, many of the researchers we heard from were very upfront about identifying and discussing with participants limits to confidentiality. While participants who fill out web surveys in the privacy of their own homes can be guaranteed a relatively high level of anonymity and confidentiality, when participants are recruited through peer researchers and community-based organizations, their participation will likely be known to others (Simon & Mosavel, 2010; Woodman et al., 1995). It is important to be honest and upfront about there being no absolute guarantee of confidentiality when participants know one another intimately (Tolich, 2004; Woodman et al., 1995).

Many research methods that are popular in CBR, such as focus groups, community consultations, and arts-based approaches, are done in groups and involve openly sharing information with other participants who may know each other. Some projects developed ground rules with participants at the beginning of group data collection sessions to establish expectations and to encourage participants to share their information judiciously. Researchers should be careful about how they probe for information and be sensitive to when participants are reluctant to discuss certain issues. When researchers continue to push a line of questioning, they may risk causing conflict between participants. This should not be taken to mean that community members and service providers in CBR projects are unable to maintain confidentiality; on the contrary, they may be more likely to appreciate the importance of confidentiality over an average participant who is not living with HIV or engaged in stigmatized practices. However, the lines between research and other aspects of their lives and work may become unintentionally blurred (e.g., not remembering whether you heard

a piece of information at a social event or in a focus group, or whether a client shared a piece of information during a therapy session or you read it in a transcript).

Finally, it is important to note that there are some instances where researchers are legally bound to break confidentiality (e.g. when a participant poses a risk to themselves or others). Usually, consent forms include a clause to this effect (e.g., I can protect your confidentiality to the extent it is protected by law). For a fuller discussion of these instances and the legal "duty to report," please see *Fact Sheet #10: Learning about illegal, sensitive and stigmatized topics.*

Despite their efforts to maintain confidentiality, research teams may also want to develop a contingency plan for breaches of confidentiality. It may be wise to consult with REBs in advance to develop a protocol for responding to breaches in confidentiality.

"If you have a focus group, you can't as a researcher guarantee the confidentiality and privacy of your identity...I also added that I would introduce a confidentiality agreement...so what I do at the beginning of the focus group is generate, it's almost a social contract..."

Issue 3: Data collection, analysis and dissemination

"...how to involve community in analysis probably is [the one] we've sort of wrestled to the ground on a couple of occasions. You know, sort of access to raw data, access to transcripts, just to provide snippets of the transcript. How do you do that in a way that sort of respects the confidentiality that's been promised?"

In many of the projects we heard from, the academic researchers took the lead on data collection, management and coding, with the goal of ensuring that data were anonymized prior to sharing it with their community partners. This strategy was widely adopted in order to minimize opportunities for service providers on the team to be faced with ethical dilemmas. This approach has also been described in the literature and often involves bringing other project members back into the analysis process once qualitative data are coded (Marshall et al., 2012). In other projects that adopted a peer research approach, different dilemmas arose (see *Fact Sheet #8: Supporting Peer Research Assistants* for a fuller discus-

sion of these issues). Sometimes it can be helpful to offer participants a choice about who they would like to be interviewed by.

Despite their best efforts, researchers may not always understand close-knit communities (or relationships among participants) well enough to strategically disguise data. It is important that community partners be consulted before research reports are drafted and presented in order to prevent distributing identifiable information (Tolich, 2004). Even routine demographic information (e.g., race) that researchers consider important for analysis may compromise participant anonymity or confidentiality (Damianakis & Woodford, 2012). Protecting participant identities in close-knit communities involves more than disguising names; it involves ensuring that quotes and details of unique stories are not recognizable. Maintaining confidentiality may involve omitting relevant data to protect participants (e.g., hiding the gender of a participant may mean not using stories they tell about gender discrimination if there are very few persons of that gender in a close-knit community) (Damianakis & Woodford, 2012). To protect members of close-knit communities, researchers should be creative in the process of disguising data that might be identifiable (Woodman et al., 1995).

Issue 4: When communities and participants want to be named and recognized

Typically, it is assumed that participants in a study should not be identified unless they make it clear that they wish to waive their right to anonymity. Many of the researchers we heard from had experiences in which individual participants and whole communities wanted to be identified in research reports. This was often understood as part of wanting to de-stigmatize HIV and create more of a sense of community in some organizations. Identifying participants, if they choose, can be an excellent way to honour their contribution, as in arts-based projects where community members present and discuss their artistic contributions. In research with some Aboriginal peoples, it might be disrespectful not to acknowledge the source of the knowledge that a researcher has gathered (Davison, Brown, & Moffitt, 2008). The requirement to destroy data may be waived in cases where the data has archival value (e.g. recording of life histories). In these cases, participants should be told in advance, and a separate consent procedure may be required to allow their identifiable information to be shared back with the community or publically archived. Research teams, however, should not assume participants want to be iden-

tified. Participants need to be made aware that information that is shared may end up leaving their organization or small community, and become accessible to the wider public who may not always be sympathetic or supportive. Research teams need to balance an individual's desire to be named with the impact it could have on them, an organization, or an entire community (Giordano, O'Reilly, Taylor, & Dogra, 2007). When one individual wants to be named, they inevitably involve others in their families and networks.

"'Of course we're going to consent because we want it to be known.' And many of them said 'Yeah, I'm happy to be recognized.' That's the irony of it, some people would like to be acknowledged by name."

Questions for consideration:

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

1. What strategies will your team adopt to maintain individual privacy concerns?

2. What strategies will your team adopt to maintain communal privacy concerns?

3. What challenges to maintaining confidentiality might you anticipate? How might you mitigate these?

4. Who will have access to raw data? What training will be provided to this group? Is everyone on the team (staff, students, volunteers) familiar with privacy, confidentiality and duty to report protocols?

5. What are the pros and cons (with regard to privacy concerns) for having different team members (e.g., peers, graduate students, service providers, staff, academics) engaged in data collection and analysis?

6. How might you handle a breach in confidentiality?

7. Are there any participants or groups who may not want to remain anonymous in your study? Do you have mechanisms in place to handle these "special cases"?

Works cited:

Damianakis, T., & Woodford, M.R. (2012). Qualitative Research With Small Connected Communities: Generating New Knowledge While Upholding Research Ethics. *Qualitative Health Research,* 22(5), 708-718.

Davison, C.M., Brown, M., & Moffitt, P. (2008). Student researchers negotiating consent in northern Aboriginal communities. *International Journal of Qualitative Methods,* 5(2), 28-39.

Ellis, C. (2007). Telling Secrets, Revealing Lives: Relational Ethics in Research with Intimate Others. *Qualitative Inquiry,* 13(1), 3-29.

Ellis, C. (2007). "I just want to tell my story": Mentoring students about relational ethics in writing about intimate others.". In N.K. Denzin, & M.D. Giardina (Eds.), *Ethical futures in qualitative research: Decolonizing the politics of knowledge* pp. 209-227): Left Coast Press.

Giordano, J., O'Reilly, M., Taylor, H., & Dogra, N. (2007). Confidentiality and autonomy: the challenge(s) of offering research participants a choice of disclosing their identity. *Qualitative Health Research,* 17(2), 264-275.

Marshall, Z., Nixon, S., Nepveux, D., Vo, T., Wilson, C., Flicker, S., . . . Proudfoot, D. (2012). Navigating Risks and Professional Roles: Research with Lesbian, Gay, Bisexual, Trans, and Queer Young People with Intellectual Disabilities. *Journal of Empirical Research on Human Research Ethics,* 7(4), 20-33.

Simon, C., & Mosavel, M. (2010). Community Members as Recruiters of Human Subjects: Ethical Considerations. *The American Journal of Bioethics,* 10(3), 3 - 11.

The Carleton University Research Ethics Committee. (2004). General Application to the Carleton University Research Ethics Committee. Otttawa: Carleton University.

Tolich, M. (2004). Internal confidentiality: When confidentiality assurances fail relational informants. *Qualitative Sociology,* 27(1), 101-106.

Tri-Council of Canada. (2010). Tri-Council policy statement 2: Ethical conduct for research involving humans. Retrieved 21/02/2103 from: http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf. Ottawa: Interagency Secretariat on Research Ethics on behalf of The Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada and the Social Science and Humanities Research Council of Canada.

Woodman, N.J., Tully, C.T., & Barranti, C.C. (1995). Research in lesbian communities: Ethical dilemmas. *Journal of Gay & Lesbian Social Services,* 3(1), 57-66.