

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

HIV CBR ETHICS

Engaging youth in CBR



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HIV CBR Ethics Fact Sheet Series:

- 1 Ethical issues related to compensation
- 2 Recruiting hard to reach individuals and communities in CBR
- 3 Managing multiple roles and boundaries
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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:

- working with marginalized youth and parental consent (balancing harms and benefits)
- addressing your *duty to report*
- implementing youth friendly protocols and methods
- collaborating with your REB.

Background

In this fact sheet, we discuss four key issues related to engaging youth in community-based research (CBR):

- working with marginalized youth and parental consent (balancing harms and benefits)
- addressing your *duty to report*
- implementing youth friendly protocols and methods
- collaborating with your REB.

Most of the social and behavioural health research on human sexuality and HIV is based on the perspectives of people over the age of 18. This is largely due to the perception that it is easier to do research with adults than with young people because of challenges associated with getting informed assent, consent and permission from REBs to engage youth. These hurdles are meant to protect vulnerable participants from potentially harmful research. From a research ethics standpoint, children and adolescents have been traditionally considered incapable of providing informed consent. The concern is that young people may not have the decision making abilities or autonomy of older people and may be more easily influenced into participating in research. As well, sexual health research is considered particularly sensitive and there are concerns that young people will be exposed to ideas through the research that they are not ready for. However, young people are becoming sexually active at young ages (Boyce et al., 2006) and attempts to shield them from sexual material through research may not reflect the realities of their lives. Despite concerns that young people will not be able to refuse participation, some studies show that youth age 14-15 have capacities similar to adults with respect to making informed decisions based on their own interests (Moolchan & Mermelstein, 2002; Mustanski, 2011). Researchers who want to include the perspectives of people younger than 18 in research are usually expected to obtain consent from the child's parent or guardian. Some research ethics guidelines make exceptions for emancipated minors whose personal circumstances make it impossible to obtain parental consent (e.g. they have been removed from the home because of abuse). These requirements differ between jurisdictions and research ethics boards (REBs), and researchers need to consult their own institutional guidelines, local

legislative context, professional regulatory frameworks, and community partner policies. Recently, there has been a shift towards lowering the age of consent to participate to 16 among more progressive REBs.

In community-based research (CBR), there is a strong emphasis on community development and capacity building. Youth are recognised as important stakeholders in communities and as important intermediaries between healthcare providers and other members of their families (e.g. when young people translate health information for non-English speaking members of their families). Globally, young people are themselves disproportionately affected by HIV and represent one of the fastest growing risk groups (UNAIDS, 2010; UNICEF, UNAIDS, & WHO, 2002). Here in Canada, some groups of youth (Aboriginal, young men who have sex with men, injection drug users, homeless youth and young women) are at higher risk for HIV (Public Health Agency of Canada, 2009). Involving young people in research and decision-making is necessary to develop programs and interventions to prevent the spread of HIV among them. CBR has proven effective at engaging groups of youth who would not otherwise participate in research or have been traditionally excluded (Flicker et al., 2010). However, the combination of sensitive research on youth with emerging methods has raised concerns among some REBs. In this fact sheet, we identify various approaches to thinking about engaging youth in research and describe the strategies employed by Canadian HIV CBR teams to balance these competing concerns.

Despite concerns that young people will not be able to refuse participation, some studies show that youth age 14-15 have capacities similar to adults with respect to making informed decisions based on their own interests.

Issue 1: Working with marginalized youth and parental consent (balancing harms and benefits)

“Pfft ! What do you mean that’s just not going to fly? It’s not like I told mom I’m gay necessarily or I told mom that I’m using [drugs].”

Current conceptions of youth promoted by research ethics guidelines often assume that young people live at home with parents or guardians who are actively engaged in their development and care. This does not reflect the realities of many young people who are street involved or live at home but experience abuse or neglect. Furthermore, even in relatively functional homes, very few youth openly discuss their sexual activity or substance use with their legal guardians. Many young people do not have anyone in their lives to consent on their behalf to participating in research. For youth who live at home, asking for parental consent to participate in research could mean disclosing information about their sexuality that could expose them to considerable risk (Flicker & Guta, 2008). For example, a young person asking to participate in a study about the experiences of LGBT youth would essentially be “coming-out” to their parents or guardians. This could put them at risk of violence or being expelled from the home, which exceeds any risks they would have been exposed to in the research itself. However, many REBs automatically label research with youth that includes sexual behaviour or gender identity as ‘high risk’ regardless of the project design and goals (Mustanski, 2011; Taylor, 2008). Unfortunately this may reflect individual REB members’ negative attitudes towards adolescent sexuality and sexual minority groups.

The researchers we heard from recognized that young people are heterogeneous and diverse, with varying levels of experience and interest with being involved in research. Some of the youth they work with are living with HIV and others could be described as being at ‘high risk’ of infection. Some of these youth experience high degrees of social exclusion that leave them isolated from schools, family, and healthcare providers. Some are very vulnerable. Others are highly creative in adapting and building alternative support networks. REBs need to differentiate between vulnerability in terms of health status (e.g. living with HIV) and vulnerability in terms of being susceptible to coercion to participate in research (Mustanski, 2011). Many youth living with, and at risk for, HIV demonstrate a high degree of personal agency and self-determination, in some cases hiding their sexuality or HIV status from their family while being actively engaged in community services, programing, and research. In effect, some young people are living two separate lives and it does not make sense for researchers and REBs to insist the two be brought together.

However, this should not be taken to mean that researchers know best. Rather, the principles of community consultation in CBR should be applied to establish parameters for ethical engagement when researching with youth (Flicker & Guta, 2008). Community consultation can be an important part of research planning, implementation and overall process when researching sensitive issues with youth (Rew, Taylor, Seehafer, & Thomas, 2000).

Some strategies in use by researchers are:

- a) **No parental consent:** Many researchers we heard from tended to not require parental consent because it would exclude youth who were reticent about approaching their guardians and those who had none. (Sometimes these were precisely the youth they wanted to hear from most). Youth who consented for themselves were understood to be mature minors who were capable of providing informed consent (King & Kramer, 2008).
- b) **Passive consent (or, “opt-out”):** For low risk research in community settings (like schools), some researchers use a passive consent process which requires parents to sign if they do not want their children to participate in research (Jason, Pokorny, & Katz, 2001).
- c) **Sharing responsibility:** Some CBR studies are partnering with community-based host organizations with relevant expertise to provide organizational consent (a kind of community consent) when the research reflects the values of the organization (Flicker & Guta, 2008). This does not replace individual consent, but shows that the research team has consulted with service providers to develop appropriate research designs that reflect community norms and needs.
- d) **Obtaining parental consent:** Some researchers obtained parental consent, recognizing that some communities want this and are committed to improving the sexual health of their youth. For example, some Aboriginal communities may require parental consent because of historical legacies of the residential school system and exploitive research. The process of obtaining consent from parents and guardians may actually improve researcher-community relationships by showing respect for the community (Moolchan & Mermelstein, 2002). Two-spirit youth (and other youth) may be cared for by family members other than parents. In these instances, broader consent processes may be appropriate (Taylor, 2008).

Whether an express parental consent, passive consent, or community consent approach is taken, a separate assent process for youth should still be included to allow youth to decline participation (Moolchan & Mermelstein, 2002).

Issue 2: Duty to report

“I’ve interviewed a kid who tells me that the only person they share needles with is their mother. At the end, I say, “Listen you shouldn’t be sharing needles with anybody.” And they say, “Well it’s my mother, she’s not going to hurt me. She would never hurt me.” You are in really dangerous water there...I mean I don’t want to damage that relationship, that’s a really important relationship...”

Confidentiality is an important feature of social and behavioural health research, and is especially important when working with vulnerable youth who are at risk of increased social exclusion if their sexual or drug use practices become public. However, there are situations in which confidentiality may have to be breached as part of the legal duty to report possible harm to self and others (e.g. suicidal ideation and threats of violence) (Fisher, Higgins, D’Alessandro, Rau, Kuther, & Belanger, 1996). Research with youth requires anticipating the possibility of child abuse disclosure (e.g. sexual abuse and exploitation) (King & Kramer, 2008; Moolchan & Mermelstein, 2002). In Ontario, for youth under the age of 16, researchers have a duty to report sexual abuse they hear about, and for youth over the age of 16, to report sexual abuse when

there is suspicion of ongoing abuse (e.g., when the participant has a young sibling in the home). There may be regional variation to these regulations, so it is very important to consult with local authorities and/or partnering youth serving organizations to ensure that research protocols adhere to local legislative requirements. The researchers we heard from were sensitive to these issues but were not always able to act because the young people they were hearing from did not live at home or have any connections to facilitate disclosure. Youth who are street-involved and substance-using are often very guarded about their personal information and may move from place to place. This makes it challenging, if not impossible, for researchers to always fulfil their duty to report. If possible, researchers should ask youth for the necessary information to follow up, or provide them with other resources to disclose the information themselves (e.g., ask them to contact the Kids Help Phone or the Children’s Aid Society to anonymously report abuse) if they do not want to give the researcher all of the relevant information.

Researchers working in international settings may need to be more creative in planning how they will handle disclosures in contexts where different legal and social structures are in place.

“We were trying to get everybody - from kids who were, you know, just hanging out on the street or engaged in street culture all the way through to those kids who had been on the street multiple times...”

Issue 3: Youth friendly protocols and methods

“[We are] interested in what kinds of methodologies are appropriate for engaging young people and for engaging teachers in thinking about sexuality...”

When developing research or programming aimed at youth, it is important that project materials be youth-friendly and accessible. Many researchers have developed approaches to working with youth to develop accessible and engaging recruitment and informed consent materials and processes (Chabot, Shoveller, Spencer, & Johnson, 2012; Flicker & Guta, 2008; King & Kramer, 2008). Flicker and Guta (2008) recommend piloting project materials with youth and youth servicing organizations to ensure they are accessible and respectful. When conducting CBR with youth, research teams need to remain sensitive to the needs of the larger community and not just the youth involved (see Flicker et al., 2010 for a discussion of resolving the tensions between sensitive and accessible language in a survey developed by youth). Project materials need to balance being youth friendly with providing the necessary information that young people need to understand the research and its goals, weigh risks and benefits, and make decisions as to whether to participate (Mustanski, 2011). Chabot, et al. (2012) have developed a “Know Your Rights with Research” checklist for youth to review which research teams may want to consult or adopt.

The researchers we heard from used a range of community engagement and methodological approaches to attract youth. There was no assumed “right way” to make research accessible, but a number of researchers integrated some form of arts-based methods or multi-media dissemination strategies. Researchers need to balance project goals with young people’s interests, capacities, and needs (e.g., keeping research activities short and working around school hours or employment). Youth may need additional reminders about confidentiality and project ground rules throughout data collection activities. Some of the projects we heard from involved youth as more than participants and included youth perspectives in advisory positions and as peer researchers. This offered additional opportunities for some youth to be involved in their community, to earn extra money or volunteer hours required to graduate from high school, or obtain reference letters for future employment. There are inevitably challenges to fully collaborating with youth researchers and sharing decision-making power, including building trust, and avoiding tokenism (Chabot et al., 2012). However, some researchers were able to make it work and described projects that were much more youth-driven: where young people took on significant leadership positions (including acting as co-leads) and set the agenda.

“I think a lot of people who are afraid to work with youth, are afraid of using media as a tool with youth because it’s so unpredictable. The photographs, videos, those kinds of storytelling venues....”

Issue 4: Working with the REB (making your case)

Despite the challenges that many researchers have reported when negotiating ethics review for sexual health research with youth, the researchers we heard from had all ultimately been successful. The challenges of obtaining ethics approval for research with some populations reflects a lack of institutional knowledge about these populations, such as LGBT youth (Mustanski, 2011; Taylor, 2008). The researchers we heard from used the ethics review process as an opportunity to educate their REBs about CBR, the realities of young people's lives when they are living with, or affected by HIV, and the role of community partners in brokering re-

search partnerships while remaining committed to their mandate to provide services for youth. Most importantly the researchers we heard from demonstrated an understanding of young peoples' vulnerability and their "duty to report," and how risks and benefits would be handled. Many researchers said they had to go above and beyond what is expected in most research protocols but that they were ultimately able to conduct research that balanced their research interests, youth engagement, and REB standards.

“...[The Researcher] wrote a lot about why it might be that somebody who is queer couldn't be out to their parents [and] trying to get their consent would be more harmful than giving them the, you know, agency allowing them to just consent themselves to a survey that they were really interested in participating and talking about their experiences. And they did accept it, but you know, she had to write an awful lot to explain that whole context.”

Questions for consideration:

The following questions may be useful for HIV CBR teams to reflect on when involving youth in their research. Thinking about these issues in advance may help facilitate the research process and maintain positive relations with individual participants and the community.

Getting Ready

1. What are the age parameters of the youth population you want to include in your study?
 - a. Have you familiarized yourself with local legislation, policies and regulations around key considerations for including this group?
2. How will you handle issues of assent and consent?
 - a. Is parental consent appropriate in this context? Why or why not?
 - b. What are some additional/alternative safeguards that can be put in place?
3. How accessible, inclusive and engaging are your recruitment, consent and research materials?
 - a. Do your inclusion processes inadvertently put youth at risk (e.g., needing to “come out” to participate in your research)?
 - b. Do they unwittingly exclude populations of interest (e.g. young men who have sex with men who might not consider themselves gay)?

4. What supports are in place to ensure that youth (advisors, peers and participants) are adequately supported during the entire research process?
5. What level of power sharing and engagement will youth have in your research?

Communicating with your REB

1. Have you considered the make-up of your REB? Are there individuals on your REB who have sufficient expertise in youth-driven, youth-focused CBR? Have you considered serving on your REB?
2. Do you have a plan in place to work with your REB to ensure they understand the choices you have made with input from youth advisors and community partners in terms of the study questions, methods, language, etc.?
3. Have you fully considered the implications for the youth involved in your research in reporting to your REB and/or authorities something that may have occurred in the conduct of the research?

Further reading:

United States government regulations: 45 CFR 46.116d and CFR 46.408c (exemptions from parental consent for youth participation in health research)

National Statement on Ethical Conduct in Human Research in the Australian National Health and Medical Research Council

United Nations Convention on the Rights of the Child (right to participate in research, right to protection from exploitation)

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