

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

HIV CBR ETHICS

Ethical issues in visual
image-based research



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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
- 4 Ethical issues in visual image-based research
- 5 Informed consent
- 6 Confidentiality in close-knit communities
- 7 Community consent in Aboriginal communities
- 8 Supporting Peer Research Assistants (PRAs)
- 9 Engaging youth in CBR
- 10 Learning about illegal, sensitive and stigmatized topics

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:

- Who needs to provide consent in visual image-based research methods?
- How to obtain consent when using visual image-based research methods?
- What to do when consent is not obtained?
- When to anonymize visual data?
- How to present arts-based methods?

Background

In this fact sheet, we discuss five key issues related to ethics and visual image-based research¹:

- Who needs to provide consent in arts-based methods?
- How to obtain consent for arts-based methods?
- What to do when consent is not obtained?
- When to anonymize visual data?
- How to present arts-based methods?

Social and behavioural health researchers are always looking for effective ways to engage research participants and to represent complex social phenomena. Arts-based and visual methods provide a means to include research participants who might not otherwise participate (e.g., children with low verbal skills) and to examine sensitive topics that are difficult to discuss (e.g., homophobia). Arts-based methods include a range of approaches: photography, collage, sculpture, poetry, dance, performance, and cultural practices that are unique to particular cultures (e.g., Aboriginal carvings). Many of these approaches are relatively new as research methods and research ethics boards (REBs) may not be familiar with them (Prosser, Clark, & Wiles, 2008). From a research ethics perspective, the concern is that arts-based approaches often include a lot of identifiable information (e.g., photographs of people and places) (Wang & Redwood-Jones, 2001). Part of what makes arts-based products so compelling is their personal, situated nature. Often researchers and participants want to use products to mobilize and share knowledge. However, researchers

and participants may not be aware of the long-term implications of producing and sharing these materials in the public domain. In addition, REBs are often concerned with issues of consent, confidentiality, and management of arts-based data.

In community-based research (CBR), there is a strong emphasis on community engagement through accessible methods. Arts-based methods provide a way to involve a range of community members, with different experiences, and with different levels of ability. As well, arts-based methods may be a more culturally appropriate method for working with some communities (see Lavalley, 2009 for a discussion of visual methods and Aboriginal world views). However, arts-based methods may make some community practices visible in unexpected and unwelcome ways. Researchers collecting visual data should take the time to understand the context of any situation in which images are being collected and produced to ensure that community norms are not violated (Clark, Prosser, & Wiles, 2010). In this document, we identify various approaches to thinking about managing and protecting visual data and the strategies employed by Canadian HIV CBR teams to balance competing interests.

From a research ethics perspective, the concern is that arts-based approaches often include a lot of identifiable information.

¹ It is beyond the scope of our project to consider fully all the ethical issues related to arts-based work. This document highlights salient issues associated primarily with participatory visual research (e.g., photovoice, photo-elicitation, digital storytelling).

Issue 1: Who needs to provide consent in visual image-based research methods?

“I mean we bought 20 disposable cameras. The instructions were to take pictures of preferably places and things, but if you have to take pictures of people or want to, that’s fine too, but the ethics process helped me understand that then there’s big issues around that. So we would have to get release forms signed by the people whose pictures were taken to use the photos.”

Obtaining consent in arts-based research may require both additional steps and defining “participants” more broadly. CBR teams will need to think about who should be part of the consent process. Researchers may be responsible for obtaining consent from individuals, groups, and organizations. For example, when conducting research in an organization, should every person involved, or potentially involved, in the research be part of the consent process, and in what ways (Prosser et al., 2008)?

- a) Research participants: Consent will be required from participants who are creating visual works (e.g., video or photos). They will need to be told how their works may be used and for what purposes. Often, participants are given the choice to pick which works they want to share and the ability to set limits (e.g., “yes” to reports; “no” to websites).
- b) People and organizations represented in the data: If people and places are captured in visual data, additional consent may be required (e.g., from a person who is in a photo or a unique and identifiable place, such as a store).

We heard from some CBR researchers that they use the same formal consent process for both research participants and people who might be included in the data (e.g., traditional consent forms), while others used oral consent approaches for people who might be included in images. Other CBR teams used additional consent forms and media releases that delineate the ways images or film may be used. Researchers should advise participants as to how data will be used and where it will be shared (e.g., research conferences, online, via social media, and publications). Once materials are available on the internet, including in journal articles, they can be used by third parties for other purposes without permission and research teams can lose control over them (Clark et al., 2010). Participants need to be advised of these issues when consenting and reminded that this kind of data is not as manageable as other forms (Gubrium & Harper, 2013; Mitchell, 2011).

“The ethics review was very straightforward, I think the biggest issue we had with our ethics review was, if we’re doing photovoice like photography, whether we could use oral consent or we had to get written consent from the people we were taking pictures of.”

Issue 2: How to obtain consent when using visual image-based methods research?

“We’ve trained the young photographers, for example to, you know, monitor informed consent... and who they are going to take pictures of and what their responsibility is. So, its’ been kind of almost like a pedagogical piece, I guess.”

Obtaining consent when using arts-based methods is a collaborative and iterative process that may require multiple steps: first negotiating participation; followed by discussions about the kinds of materials that will be produced and how they will be used and, finally, selecting individual pieces for inclusion in dissemination materials (Teti, Massie, Cheak-Zamora, & Binson, 2012). Often, researchers find it useful to think of consent as an ongoing process with multiple checkpoints. For instance, (a) in the beginning of a project, you will need consent to engage participants; (b) during the project, you may need consent to discuss and share some images with your research group (internal use); and (c) as the project wraps up, you may need consent to share the images more widely (external use), with clarification and limits about the scope of their use. Some researchers also build in a three-to-six month follow-up checkpoint just to ensure that participants have had enough time to fully digest the implications of sharing their work.

The consent process should be flexible and interactive to respect participant decision-making (Ponic & Jategaonkar, 2012; Prosser et al., 2008). During the consent process, participants, through conversations with researchers, decide how and if participation makes sense to ensure informed decision-making (Ponic & Jategaonkar, 2012). Negotiating consent in this way can be complex, requiring training for those involved; members can role play asking permission to take photos and completing the forms until they are comfortable (for a discussion see Teti et al., 2012). Finally, research teams should consider the broader impact they might have on a particular community context by representing it through arts-based methods (e.g., a needle exchange), even if consent is sought and obtained for each photograph taken (Barrett, 2004). Understandably, some community members might be reluctant to return to a place where photography or filming is happening, or if they know the space will be used as the basis for a dramatic production.

Often, in research, we give participants the opportunity to be able to withdraw from a study at any time. Care should be taken to explain to a participant that once a piece is shared (especially online), it is nearly impossible to be removed from the public domain.

“I have a PowerPoint presentation that I use when we are working with groups on photovoice on what you could take instead of faces, but even if you didn’t have a face, how could the person, like, still be recognized if they didn’t, so it’s not a this-is-a-how-to, but kind of like a discussion of kind of media ethics, and how that becomes sort of part of the process.”

Issue 3: What to do when consent is not obtained?

“We thought about different levels of use, so for some people they allowed us to take the pictures or they took the pictures, they allowed us to keep the pictures, they did an interview about the pictures but they said, Please don’t ever use the images, just describe them.”

In some cases, it will not be possible to obtain consent from everyone who participates in arts-based methods. The researchers we heard from said it was not uncommon for some participants to take photographs of other people despite being asked not to, or without being able to provide signed consent forms if this was the project protocol. In some cases, it may be possible to find the person in the photo and obtain consent. However, re-consenting may not always be an option or necessary. When using archived visual data (e.g., photos from an album), it may be adequate to obtain consent from the person in possession of the album rather than from every person in the images used (Clark et al., 2010; Prosser et al., 2008). However, care should be taken in reproducing any of the images. In cases where consent forms have been lost or were not obtained and there is a reasonable expectation that participants should have been consented, the data may not be usable in part or in full.

- a) In part: Some photos or videos can be edited to remove people and identifiable aspects of places. Teams may need to limit the use of some images to the analysis phase, but not share them with the public.
- b) In full: Unfortunately, some photos or videos may need to be destroyed if they were obtained without consent and if they cannot be edited. Data that shows illegal activity is especially sensitive and may be subject to subpoena.

Participants may be disappointed when their photos are not included in data analysis or exhibited to the public (Teti et al., 2012). This may create conflict within a CBR project and researchers may need to work with participants to find solutions (e.g., allowing participants other opportunities to take different photos).

“It ended up being unrealistic. Not everyone was able to get that. It was impractical for one: people will go out and take pictures and they couldn’t carry the consent forms with them, so we had all these layers of consent where we said ‘Okay, at least can you get consent for us to look at the pictures?’ You know, can we really look at those pictures? So there were a few scenarios we had to run through that will allow the project to move forward in a way that was ethically sound.”

Issue 4: How to anonymize visual data

“There are people who are downright upset when they don’t see their image being displayed somewhere.”

Anonymizing visual data is not as simple as working with textual data, where words can simply be deleted. Editing film and digital photos properly requires more skill and specialized equipment. While many programs can swirl a face in a picture or pixelate it, this may not always be adequate, as the process can be reversed. As well, pixelating alters data. It may be perceived as dehumanizing the individuals in the images, and can be associated with negative connotations and criminal acts (Clark et al., 2010). Researchers should consult with their teams and with participants to determine whether anonymizing images is useful and protects participants or whether the images lose their impact and research value (Gubrium, Hall, & Flicker, 2014; Prosser et al., 2008).

With some forms of arts-based methods, participants will want to forgo their right to confidentiality and be credited for their work (Daykin, 2008). In such cases, it is important to have participants sign consent forms indicating they want to be credited and to have an open discussion about the implications of being associated with images where certain practices may be depicted. As discussed previously, images are easily transferable and can take on a life of their own. Participants may not want to be associated with their photos for years to come, especially if they depict stigmatized practices (e.g., sex work or drug use). A technique that is growing in popularity, and that allows for greater anonymity with regards to sensitive data while still using the arts, is using drama (or staging) to recreate events on video, stage or photographs (Clark et al., 2010). This way data can be discussed by the team and blended to produce performances depicting original images or video.

Issue 5: How to present arts based methods

“We are going to exhibit all those photos for which we have release forms for, but then in any publications or anything that could potentially be sort of uploaded. There will be no pictures of people. It will be the pictures of the places and things.”

Many CBR projects that use arts-based methods share their products in multiple forums: research conferences, academic journals, professional training, online, and via community exhibitions. The latter provides an opportunity for researchers and community members who participated in the research to mingle with the larger community and discuss the issues represented in the created works. Teams need to consider who the audience is and what is appropriate to share (e.g., sharing photos in presentations for some audiences and not others) and restrictions they put on the event (e.g., not allowing anyone to take photos with their cell

phones of the exhibit), and restricting how images and video are shared on-line (e.g., labelling images in a way that will make them not appear in search engines and restricting certain functions on website to reduce downloading). Nevertheless, these approaches are not guaranteed to prevent misuse or unauthorized distribution of materials, and research teams need to consider whether some materials should not be shared at all (Switzer & Ibramovich, 2012).

Teams may also want to work with participant artists to prepare them for what it may feel like to have their work shared with wider audiences. Sometimes, working in intimate supportive research environments gives participant artists a false sense of security and they may not fully be prepared for a diverse spectrum of reactions from the general public (which can sometimes be quite negative). Ensuring that there is adequate preparation and support in place is key to minimizing the harm associated with such exposure.

Questions for consideration:

The following questions may be useful for HIV CBR teams to reflect on when deciding to use arts-based methods. Thinking about these issues in advance may help facilitate the research process and maintain positive relations with individual participants and the community.

General Questions

1. Are these the right methods for your research question?
 - a. Are you the right people (knowledge, skills, resources, experience)?
 - b. Is this the right time?
 - c. What will you learn?
2. What infrastructure do you need to put in place throughout to ensure that everyone (researchers, participants, audience members) is being adequately supported?
3. What will the process for discussions of ongoing consent look like? How many checkpoints will you incorporate? What is feasible and realistic?
4. Do you have an ethics training plan for your participants?
 - a. Do you have case studies or role playing activities developed for training?
 - b. Are there strategies you can use to leave people less vulnerable?
5. How will you handle anonymity vs. attribution in your project?
 - a. What are the pros/cons of your approach?
6. What will you do with images/products that reproduce dominant oppressive narratives (e.g., discriminatory, racist, homophobic or sexist images) or dangerous messages?
7. Who will own the products? What policies will you put in place for how they can be shared?
8. How can you ensure that your methods and approaches are adapted to be culturally and contextually appropriate (see: Castleden, Garvin, & Huu-ay-aht First Nation, 2008)

Working with your REB

9. What is your REB's familiarity and comfort level with visual methods?
 - a. Do you need to do some upfront consultation and discussion with them?
 - b. Can you provide them with examples from the literature demonstrating that your method is credible and your approach to ethics is reasonable and sensitive?

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