

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

HIV CBR ETHICS

Ethical issues related to compensation



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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 five key issues:

- Why do we compensate?
- How much should we compensate?
- When do we compensate?
- When compensating individuals in our research, how do we best support “vulnerable” communities?
- Whom do we compensate?

Background

This fact sheet explores the issue of compensation in community-based research (CBR), and the various approaches to thinking about, and compensating participants for their time.¹ Based on strategies employed by Canadian HIV CBR teams, the following issues are addressed:

- Why do we compensate?
- How much should we compensate?
- When do we compensate?
- When compensating individuals in our research, how do we best support “vulnerable” communities?
- Whom do we compensate?

In social and behavioural health research it is standard practice to pay participants as a way of showing appreciation for their contribution (Permuth-Wey & Borenstein, 2009). Researchers and REBs recognize that payment incentivizes participation and provides compensation (Ripley, Macrina, Markowitz, & Gennings, 2010). The ethical concern related to providing compensation is that participants may feel compelled to expose themselves to high-risk research out of economic need. As a result, the informed consent process may become compromised (Beauchamp & Childress, 2009; Grady, 2001). Concerns about compromised consent have led some researchers and REBs to conclude that offering little or no compensation is preferable. However, this solution may be paternalistic and serves to exclude some groups from participating in research who may benefit (Permuth-Wey & Borenstein, 2009).

In CBR there is a strong emphasis on reciprocity and a tradition of honouring the contributions of community members by offering compensation. Communities understand that universities and medical centres are paid to do research, and know that participants are valuable and necessary to the process (Permuth-Wey & Borenstein, 2009). Some researchers argue that participants’ efforts ought to be viewed as a form of labour and compensated as such. People living with, or at risk for HIV, are often considered “vulnerable” for reasons related to their illness (e.g., reduced functioning) and/or to various forms of discrimination (e.g., stigma directed at injection drug users). These vulnerabilities are often associated with social exclusion such as economic marginalization. Some REBs and researchers are concerned that people living with HIV will be unduly influenced to participate because of economic need. The debate surrounding compensation is often polarized between those who argue that cash incentives are potentially coercive and those who argue that not providing compensation is a form of exploitation. In this fact sheet, we identify various approaches to thinking about compensation and describe the strategies employed by Canadian HIV CBR teams.

The ethical concern related to providing compensation is that participants may feel compelled to expose themselves to high-risk research out of economic need (or desperation).

¹ While we acknowledge that the compensation of research team members (e.g., those employed by community-based organizations) is an important issue, in this fact sheet, we focus primarily on participant compensation.

Issue 1: Why do we compensate?

“If they were working in the informal economy, they could, you know, [be] making as much as \$30 that hour, so that’s how much we like to pay.”

We heard a range of reasons for compensating participants in HIV CBR projects. All of the researchers we interviewed offered some form of compensation to their participants. A majority stressed the importance of providing at least a token of appreciation to participants as a means of acknowledging their contribution to the research process. HIV CBR is not possible without community members giving their time and sharing their experiences. Compensation can mean different things to different people, based on their social and cultural location, their current economic circumstances, and the context of the project in their lives. Researchers tend to use one or more of the following justifications for providing compensation:

- a) **Incentives:** Providing incentives is used to motivate everyone from children to professionals and whole organizations to perform a variety of tasks. The average person is offered a range of incentives on a daily basis, whether at work in the form of bonuses or the chance to win a prize by filling out a consumer survey. Incentives have become an expectation and are regularly used to encourage desired behaviours, including participation in programs and research (Grant & Sugarman, 2004). In HIV research, incentives can take the form of giveaways (e.g., fill out a survey and receive a package of condoms), or a chance to win a bigger prize (e.g., a tablet device). Depending on the community, incentives can be adjusted to appeal to different groups. For example, providing movie tickets for youth or providing a meal to attract community members to a consultation session are both potential incentives that can be construed as compensation.
- b) **Reimbursement:** Providing compensation can reimburse participants for direct expenses they incur as a result of participating in research, as well as for lost wages. When participants have to travel to participate in research, they may incur various costs associated with transportation (gas, public transit, taxi, etc.), purchasing meals, and paying for childcare. Some may have to take time from work to participate, and may lose wages. Together, this can represent a considerable economic burden for participating in research. Reimbursing participants for individual costs or providing a flat rate that covers expected costs helps to ensure that participants are not worse off than before the research.
- c) **Research as work:** Some HIV CBR teams framed participating in research as a form of skilled labour. Participants bring specialized knowledge and years of experience that are comparable to the expertise offered by professionals with specialized training and advanced credentials. To support using a “research as work” approach, compensation was set by one research team using labour standards as a guide. For example, if the minimum wage in Ontario is \$10.25 per hour, then offering \$25 in compensation for a two hour focus group would reflect labour standards in the province. However, many teams offered more than the minimum in an attempt to offset additional barriers to participation. Researchers should consider whether the compensation they offer participants is commensurate with other potential sources of income (Bell & Salmon, 2011).

Issue 2: How much should we compensate?

“So we gave 50 dollars but it was a two-hour focus group and we didn’t give child care, we didn’t give transportation money.”

Regardless of the approach taken, neither the type nor amount of compensation offered should unduly influence people to participate in research (Fry, Hall, Ritter, & Jenkinson, 2006). Researchers should effectively communicate how and why payments are calculated and be transparent with funders, REBs, and participants (Fry et al., 2006; Seddon, 2005). In determining the level of compensation to offer participants, researchers considered:

a) **Research Design:** It is important to consider and calculate all anticipated participant costs and be clear about the purpose of the payment and/or reimbursement (see also Ripley et al., 2010). In determining how much to compensate participants, many HIV CBR teams factored in the demands of the research design to make the compensation commensurate with the requirements of the chosen methods (see also Permuth-Wey & Borenstein, 2009). For a brief survey (e.g., to determine whether someone qualified for inclusion into a larger study) they might pay smaller amounts. Longer and more involved procedures (e.g., a photo voice project that required several meetings) warranted greater compensation (and/or multiple payments) and often included other incentives such as meals, transit tickets, etc.

b) **Reimbursement (itemized vs. flat rate):** When reimbursing participants, researchers had to decide between requiring receipts for individual costs or providing a flat rate. Providing a flat rate had a number of advantages because it was quicker and some participants either forgot or misplaced receipts. However, a flat rate may poorly reflect the actual costs incurred by participants (e.g., child care costs can be more than expected).

c) **Culture and context:** Culture and context should be considered when determining appropriate compensation. Culture can refer to a community’s formal practices, customs, and traditions (e.g., gifting tobacco when researching with some First Nations communities may be appropriate). However, culture can also include informal organizational and community practices. For example, the host community-based organization (CBO) holds regular drop-ins where food, transit tickets, and \$20 are provided to improve access. Researchers working with this CBO may want to replicate this familiar model and advise their REB that their decision is based on organizational practices effective at engaging people. Context can further influence expectations for compensation; researchers will benefit from consulting with potential participants and CBOs in the planning phase to determine what is appropriate (Fisher, 2004).

“Promoting that they’d earn credit towards their volunteer hours, they’d make some money on the side, they’d learn some stuff about sex. I’d be flexible for them, it’d be fun, and it’d be a group.”

Issue 3: When do we compensate?

“You will get your honourarium no matter what. So I would appreciate it if you talked to me a little bit, but ultimately it’s completely up to you.”

We heard about the importance of appropriately scheduling research (time of day, month, and year), as well as the timing of financial compensation (before, during, or after participation). Some researchers described having to find a balance between wanting to use their limited resources to economically support research participants and the expectations to collect data held by various project stakeholders (the broader community, partners, and funders). The timing of compensation should be determined in a way that reduces the risk of harm to participants (Fry et al., 2006). Researchers are also encouraged to think through who provides compensation (e.g., person doing the interview or another team member).

- a) **Beginning:** Some researchers provided compensation at the beginning of the research procedure to show that any level of participation would be compensated.
- b) **Pro-rated:** Other researchers used a system where compensation was pro-rated based on how long participants stayed. For example, if a participant wanted to leave halfway through a focus group, they only received half of the established compensation.
- c) **End:** Some researchers provided compensation at the end of the data collection session. This was a common approach as it ensured that project resources were paid only to those who actually participated in data provision.

We also heard about the importance of timing research events to reflect community norms, to align with other services, and to account for cultural considerations.

- a) **Time of day:** Researchers also considered community norms when scheduling research activities (e.g., not scheduling research events in the morning for sex workers who work at night). This helped to avoid situations in which participants have conflicting obligations.
- b) **Time of month:** Researchers familiarized themselves with key community events likely to bring participants into community based organizations (e.g., a weekly community drop-in event at which food is provided). The first of the month – when many people receive social assistance and disability cheques – was considered an inappropriate time to schedule research activities as participants are attending to other priorities (e.g., paying bills).
- c) **Cultural considerations:** Researchers should consult their community partners about cultural considerations that may dictate when it is appropriate to give/receive money, participate in group events, and eat certain foods. For example, many faith groups have customs that discourage eating certain foods at specific times. Organizing a focus group and serving lunch during Ramadan may create an uncomfortable situation for Muslim participants. Researchers are advised to avoid assumptions and to consult their community partners about these kinds of considerations.

“Don’t do it the day before a welfare cheque...people have run out of money about mid-month.”

Issue 4: When compensating individuals in our research, how do we best support “vulnerable” communities?

We heard that justifying the provision of compensation to REBs can sometimes be challenging. While most REBs do not take issue with professionals such as HIV physicians and nurses being compensated for their time, they may take issue with compensating people who use drugs, sell sex, or are street involved. While these groups are considered especially vulnerable to coercion from financial incentives, we heard that such generalizations do not always reflect the reality of doing research with these communities.

1. **Drug users:** There has been much debate in the research ethics literature about compensating people who use drugs owing to the perception that using prevents people from making rational choices. However, drug users have a right to participate in and benefit from, research that addresses their issues (Bell & Salmon, 2011). Attitudes towards drug use may affect the review process because of further assumptions that participants will spend their compensation on drugs. The researchers we heard from provided different justifications for compensating drug users:

- a) Some researchers felt it was inappropriate to question the way in which compensation is spent by participants. This is a question that is not asked of other groups who participate in research and, as such, is regarded as discriminatory.
- b) Some researchers questioned whether there is any evidence to show that drug use patterns are affected by research participation (see also Festinger et al., 2005). Rather, receiving compensation may offset the need to engage in other illegal income-generating activities and reduce participants' risk taking practices (e.g., petty crime).

2. **People who are street involved:** People who are street involved (homeless and under-housed) are also understood as susceptible to coercion owing to their economic marginalization. However, researchers working with street-involved communities (especially homeless youth), described compensation as a necessity and not an option. They regarded it as unethical to not compensate street-involved research participants. They cited the normative practice in many CBOs of providing compensation and meals and snacks to this population; they regarded compensation for their participation in research as in line with these service provision practices. As well, researchers described compensation as a symbolic attempt to redress some of the power differentials between researchers and street-involved participants. As such, they saw it as their duty to 'give back' to participants through compensation.

3. **Sex workers:** People who sell sex are also considered a vulnerable group because of assumptions about sex work. Generalizations are made that ignore diversity in terms of the kinds of services provided and working conditions (e.g., equating sex trafficking with escorting). The assumption is that individuals involved in sex work are coerced into doing so and may also be coerced by research compensation. Researchers told us that for many sex workers, participating in research took them away from more lucrative options (e.g., dancers in some venues can make hundreds of dollars per hour). For sex workers in different working conditions, participating in research may provide an alternative to higher risk activities (e.g., engaging in unprotected sex for higher amounts).

“We provide honourariums for other populations when we interview, so why wouldn't we also provide it for marginalized populations that would be doing something else at this time?”

Issue 5: Whom do we compensate?

“So we were able to give \$800 in compensation to seven [community] groups that was donated by participants in our survey... It was a labour of love all around and I think you have to respect that.”

We heard that compensation in HIV CBR is not just about individual participants but includes the broader community. While the standard approach to compensation requires compensating individual participants, some researchers reported that participants wanted funds directed to the community. In these cases, participants wanted the money offered to them to be given to someone in greater need or donated to a community-based organization (CBO). Research teams may want to explore this option in advance, as some funders and REBs have stipulations on how money can be used. Some researchers reported providing credit for volunteer requirements (e.g., towards the minimum hours students need to graduate from high school in some provinces) or reference letters for education or employment opportunities. Participants may also appreciate receiving project or institutionally branded items (e.g., t-shirts, pens, buttons) when appropriate. What is important is that research teams establish in advance if these are appropriate options and budget accordingly. Lacking funds to support purchasing food, and providing compensation or expense reimbursement can be very difficult to rectify once funding has been received.

In addition to compensating participants in the research process, research teams are advised to think through providing compensation for community partners. Community partners' time and access to their space can be very valuable resources, making the research possible. For example, community-based research members who are on staff at CBOs may not have protected research time, meaning that research tasks are often done in addition to regular work or overtime. Research can also have indirect costs for organizations through accessing the space. Teams should identify those costs and write budget items into their grants to reciprocate and/or reduce the burden on the organization (e.g., seconding staff time, purchasing project equipment or software that remains with the CBO after the research). Last, research teams may need to compensate other community members for their involvement in a research project (e.g., having an Aboriginal Elder present to open and close a focus group). HIV CBR research teams should not make assumptions about what has a value and what is “free”.

“I think from a funding perspective what's really useful is... the Canadian Institutes of Health Research allowing compensation for knowledge users and community based organizations who ... dedicate time and space to these projects.”

Questions for consideration:

The following questions may be useful for HIV CBR teams to consider when making decisions about compensation. Thinking about these issues in advance may help facilitate the research process and maintain positive relations with individual participants and the community.

1. What is your process for deciding on appropriate compensation? Who will be involved in the decision making?
2. What is your rationale for compensation?
3. What are the compensation norms in the community you are working with? How will cultural, geographic, socio-economic or organizational contexts impact your decisions?
4. Have you considered flexible approaches to compensation format and delivery?
 - a. Who will be compensated for what?
 - b. When during the research process will you compensate participants (before, during, after data collection)?
 - c. Who will provide compensation during the research process?
 - d. In addition to money, what other incentives might you provide or account for?
5. How will you explain the context and your process for deciding on your compensation approach to your Research Ethics Board?

Further reading:

The University of Toronto's Office of Research Ethics (ORE) has developed a useful bulletin: *Guidelines for Compensation and Reimbursement of Research Participants*. <http://www.research.utoronto.ca/wp-content/uploads/2010/01/Guidelines-for-Compensation-and-Reimbursement-of-Research-Participants-Approved-Feb-16-11.pdf>

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