



PEER RESEARCH IN ACTION III: ETHICAL ISSUES

Flicker, S., Roche, B., Guta, A.

Community Based Research Working Paper Series

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- conduct research on the social determinants of health and health disparities, focusing on the relationships between health and housing, income distribution, immigrant health, social exclusion and other social and economic inequalities;
- identify and advance practical and achievable policy alternatives and solutions to pressing issues of population health;
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Executive Summary

ETHICAL ISSUES

This report is Part III of a series of working papers that provides an overview of research findings from our study related to the practice of peer research as a strategy in community-based research (CBR) in Toronto, Canada. In this section, we illuminate the particular ways in which participants discussed ethical challenges in their work when adopting a peer researcher approach.

Many participants articulated that the very decision to engage in more participatory processes was an ethical one. Nevertheless, new practices lay the foundation for different ethical dilemmas. When probed, many of our participants highlighted challenging ethical moments which emerged from their CBR practices. These included issues related to:

Formal ethics review: Those engaged in community based research sometimes have difficulty navigating the process. One strategy for dealing with this challenge is to start thinking about ethical review early in the proposal development process and as a group to identify potential red flags throughout the design.

Communication and power sharing: Many of the peer researchers we talked to felt like they had limited power and decision-making ability over the design or execution of project activities. Care should be taken to avoid research practices that benefit extensively from the labour and expertise of peer researchers, but offers little in return in the way of recognition, remuneration or a sense of ownership of the work.

Conflicts of interest: Many participants suggested that community members may be more inclined to participate in a study if approached by a known peer; however care needs to be taken to ensure that the likelihood of coercion is limited. It may be appropriate to have someone who is more at “arms length” walk through consent procedures and data collection.

Confidentiality: Confidentiality is always an issue in research. Peer researchers, like all staff with access to private information, need support and training to adopt careful protocols around privacy and confidentiality.

Emotional triggering and the need to provide special support: This phenomenon was experienced most acutely by peer researchers who had past experience with the topic under study (i.e. homelessness or drug use) rather than those currently being impacted by the issues. In these cases, peer researchers were sometimes asked to return to environments where they encountered peers, settings, and dynamics that were at times

traumatic. The level of on-going support and supervision necessary to ensure that project needs are met should not be underestimated.

Considerations beyond the life of the project: Peer researchers may find it difficult to transition out of the project.

Conclusion: Ethical issues are by their very nature complex. There are rarely easy right and wrong answers to challenging ethical issues. Careful ethical reflection throughout the life of a research project can provide a team with the opportunity to come up with creative, attentive and just responses to these challenges.

WE ENCOURAGE COMMUNITY-BASED RESEARCH TEAMS TO:

- Use the formal ethics review process as an opportunity to reflect on broader ethical issues with the entire research team.
- Align their rhetoric of participation with commensurate power-sharing schemas and create transparent decision-making structures.
- Explore issues relating to conflicts of interest and confidentiality broadly and extensively in their training, and ongoing support work, with peer researchers.
- Consider the emotional impact of the work that they are asking of peer researchers and provide appropriate mechanisms for ongoing support and supervision.
- Think about how to develop appropriate wrap-up activities and a sense of closure.

Introduction

Community-based participatory research “emphasize[s] the participation, influence and control by non-academic researchers in the process of creating knowledge and change” (Israel, Schulz, Parker, & Becker, 1998, p. 184). The participation of community members in research is believed to enhance the validity of research findings and assist in ensuring that research results are used to inform and foster social change at the local level. The benefits of community involvement in research are well recognized; they include improved access to and greater representation of marginalized groups in research; data that are richer in quality and more authentic in their representation; and the creation of opportunities for local capacity building and empowerment (Minkler and Wallerstein 2008; Israel et al 1998; 2005). These benefits are often (although not always) realized through authentic partnership approaches that leverage the skills and assets of all team members.

Community members are thought to bring expertise that is informed by life experience to research projects, including perspectives on the issues at hand and insights about solutions. Actively engaging and involving members of the community in research has, however, not been without its challenges. Community-based research initiatives are often better at establishing partnerships among community representatives (i.e., agency staff) than among community members themselves (Flicker, Guta & Roche 2009). This finding raises critical questions about the assumptions that underscore community involvement in research (Dewar, 2005).

In an effort to achieve greater and more meaningful community participation in research, a rise has taken place in the number of projects that engage “peer researchers.” Peer researchers (sometimes referred to as PRs) are members of a research project’s target population who are trained to participate as co-researchers. In some cases, peer researchers partner in all facets of a research project. In others, they are instrumental in one or more aspects of a research project (e.g., participant recruitment and/or data collection). To date, there has been little critical discussion about the nature of peer researcher participation in community-based research.

The dearth of data on peer research in practice has meant that questions remain regarding the authenticity of community participation, how power differentials are addressed (if at all), and how participation may impact the lives of community members in social

or economic ways that have not been fully appreciated (Roche 2008; Greene et al., 2009).

The Wellesley Institute has created a three-part series of papers examining the use of peer research as a model of Community-Based research in practice. In this series we consider Models of Practice; Management, Support and Supervision, and Ethical Issues as they surface in the context of Peer Research in Action.

Research Design and Methods

In 2007, we began to examine community-based research projects that adopted a peer research approach to better understand (1) the processes (recruiting, hiring, training, and managing) used with peer researchers in various aspects of community-based research; (2) the dynamics among peer researchers, their respective communities, and other members of the research team/hosting organization; and (3) the ethical, social, and practical issues that are particular to peer research models.

Our study began with a working definition of peer researchers as members of the target population who are trained to participate as co-researchers. This definition functioned as an important starting point and reflects our observations as researchers engaging in and supporting community-based research. In the course of our study, however, we learned that the definition of peer research and the role of peer researchers shift according to context, community, the nature of the project, the understanding of community-based research, and time.

Academic leads and community partners who had used peer research models in their community-based research in Toronto were invited to attend two focus groups to identify and discuss ethical, social, and practical issues related to using a peer research model.¹ Most of those who participated worked as research managers or staff at non-profit agencies in Toronto that were broadly engaged in addressing the social determinants of health.

Peer researchers were recruited for individual semi-structured interviews to discuss their experiences. The peer researchers who participated reflect a diverse group in terms of age, gender, sexual orientation, socio-economic status, culture, and ethno-racial identity. Sixteen individual interviews were conducted with peer researchers.

¹ Projects were identified from among those that had been funded in full or in part by the Wellesley Institute.

Interviews and focus groups were audio-recorded and transcribed verbatim for coding and analysis. We conducted a thematic analysis using a coding scheme drawn from respondents' verbatim accounts of their experience. Coded data were analyzed and compared by theme, range, and type of peer research involvement, as well as the nature of the experience with peer research for both service providers and peer researchers.

Ethical Issues

In Part III of our three-part series on peer research, we provide an overview of the ethical challenges study participants noted in their work when adopting a peer research approach.

As described in Part I of this series, those engaged in community-based research often describe the approach in ideological terms. They are interested in democratizing the research process and finding mechanisms for those most affected by a problem to become part of imagining new solutions. Many study participants articulated that the very decision to engage in more participatory processes was an ethical one. They argued that conventional practices were often exclusionary and served to disenfranchise the very communities that health and social researchers were trying to reach. Moreover, historical abuses of power conducted in the name of research had left many communities angry and uninterested in research engagement (see Schnarch, 2004). By changing the rules of the game, and including peers in research planning and implementation, the practitioners in our study felt that they were challenging the status quo because it was “the right thing to do.” Many invoked a moral argument, suggesting that community-based research was an inherently more ethical approach. This line of argument is echoed in the literature. Other researchers have also written about how adopting a community-based research approach may be one strategy to redress historical inequities (Malone et al., 2003).

Nevertheless, new practices lay the foundation for different ethical dilemmas (Flicker et al., 2007). When probed, many of our study participants highlighted challenging ethical issues that emerged in their community-based research when they adopted a peer research approach. These issues related to:

- formal ethics review
- communication and power sharing
- conflicts of interest
- confidentiality
- emotional triggering and the need to provide spe-

cial support

- considerations beyond the life of the project

In addition, concerns around developing appropriate models of inclusion, hiring and compensation, covered in parts I and II of this series, were also seen as ethical issues.

Formal Ethics Review

Study participants identified a number of reasons for undertaking a formal ethics review of their research. A formal ethics review is often a requirement of funders. In addition, having arms-length reviewers examine policies and procedures from an ethical perspective can be very useful in illuminating unintentional potential harms. Finally, gaining ethics approval by a large institution can offer an air of legitimacy:

[T]here was something about the University of Toronto's stamp on it, that I think actually had a fair amount of weight ... it made a difference in terms of how we internally understood ... how much we were bound to do certain kinds of things, or not. (Service Provider)²

Nevertheless, those engaged in community-based research sometimes have difficulty navigating the ethics review process (Flicker et al., 2006). One strategy for dealing with this challenge is to start thinking about the ethics review early in the proposal development process and to identify red flags throughout the design. Discussing these potential issues with the entire research team (including peer researchers) may help researchers see problems in new ways and develop creative solutions. The more documentation provided to review boards about how you came to your well-reasoned and thought-through approach, the less likely it is that you will be turned down. Another strategy might be to work with your university partners and contact the staff at the ethics review board to help you think through difficult issues prior to submitting your research protocol for review.

Very few of the peer researchers in our study were involved in the upfront work of thinking through the requirements of ethics review. Moreover, few of the service providers played a role in this process. Most told us

² Many of our participants were affiliated with academic and community based organizations. We have chosen to use the label “service provider” as a way to differentiate these researchers from “peer researchers.”

Table 1

**REFLECTION QUESTIONS THAT MAY NOT BE RAISED IN A
TRADITIONAL ETHICS REVIEW**

Background, purpose, objectives	<ul style="list-style-type: none"> • How was the community involved or consulted in defining the need for the study? • Who benefits from this research?
Decision making	<ul style="list-style-type: none"> • How will decisions be made? What role will community members or peer researchers have?
Research methodology	<ul style="list-style-type: none"> • How will the community be involved? At what levels? • What training or capacity-building opportunities will be built in?
Hiring staff	<ul style="list-style-type: none"> • What skills do the different staff members need to have? • What ongoing training and support do different team members need?
Participants	<ul style="list-style-type: none"> • Will the research process include or engage marginalized or disenfranchised community members? How? What kinds of support will be put in place?
Recruitment	<ul style="list-style-type: none"> • Who will approach people about the study and how? Who will seek consent? How can coercion (or the perception of it) be minimized? • How will (real or perceived) conflicts of interest be resolved?
Risks and benefits	<ul style="list-style-type: none"> • What are the potential risks associated with involvement for communities? For individuals? • Are there built-in mechanisms for how unflattering results will be dealt with?
Privacy and confidentiality	<ul style="list-style-type: none"> • How will the boundaries between multiple roles (e.g., researcher, counsellor, and peer) be maintained or broken-down? • What processes will be put in place to be inclusive about data analysis and yet maintain privacy of participants? • Where will data be stored? Who will have access to the data? How? • What rules will be put in place for working with transcripts or surveys that contain identifying information?
Compensation	<ul style="list-style-type: none"> • Who will be compensated for what? Who will be considered a volunteer? How will those decisions be made? • Who will have control over the budget?
Informed consent process	<ul style="list-style-type: none"> • What could “communal consent” look like? • Whose permission will be needed to talk to whom? • What mechanisms will be set up to ensure that everyone involved really understands all the risks and benefits?
Outcomes and results	<ul style="list-style-type: none"> • How will the research be disseminated? • What are the new ways that this research will be acted upon?

Expanded and adapted from Flicker, S., Travers, R., Guta, A., McDonald, S., & Meagher, A. (2007). Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health, 84*(4), 478-493.

that their academic partners had largely handled this “hurdle.” Despite being uninvolved with the administration associated with an ethics review, several participants talked about how they had made important contributions to improving recruitment, data collection, analysis, and dissemination (many of which are arguably decisions about ethics).

All of the projects in our study underwent a formal ethics review, but there were some questions regarding the degree to which university review boards are equipped to deal with emerging new dilemmas in community-based research (Guta et al., 2010). Most conventional ethics reviews continue to focus their efforts on risks and benefits to individuals and do not take a community-level perspective. Review boards often see research as a short-term relationship that begins and ends after signing a consent form and filling out a survey. Community-based researchers may want to take a broader perspective when thinking about risks and benefits to the community as a whole. This is especially true for those that see research as a communal intervention that is part of a larger emancipatory agenda of community building and social development. Some questions that teams may want to consider that may not necessarily be covered in a traditional ethics review are outlined in Table 1.

Communication and Power Sharing

Invoking democratic ideals, many researchers write about the importance of sharing power and ownership with community members (Ross et al., 2010). Implementing this ideal, however, is persistently challenging (Flicker et al., 2008). Several participants in our study highlighted the importance of transparent decision-making and open communication regarding roles and responsibilities:

People need to know where they stand and people also need to know that we all understand each other’s roles in the same way. They are important conversations to have ... just to feel out how people understood the roles in terms of hierarchy and power ... I mean it’s not power over in terms of you’re a lesser of a person because you don’t have letters behind your name or anything like that. (Service Provider)

Nevertheless, many of the peer researchers we talked to felt like they had limited power and decision-making ability over the design or execution of project activities.

When peer researchers were asked whether they felt ownership or had an opportunity to participate in larger project decisions, one responded:

I think I got a “don’t worry about it” ... I feel a little bit of a disconnect between what the coordinators know and what’s filtered down to me. So, I feel a little bit of, like, they’re withholding knowledge somehow ... I feel a little bit on the outside. Like, that I’m part of the experiment, and that doesn’t sit that well with me. Cause I want to be included in it ... part of me thinks that ... [at investigator meetings] there should be at least ... a representative of the peer researchers. (Peer Researcher)

In some projects, peer researchers felt totally included in project decision-making, while in others, they felt excluded. In instances of the latter sort, peer researchers articulated that it did not feel right to hear project spokespeople using the rhetoric of participation when they felt like that was not the case.

The effective inclusion of peers relies on attention to power differentials and a commitment to shared, transparent decision-making processes. Failure to adopt these inclusionary practices runs the risk of making peer involvement instrumentalist rather than empowering. As Simon and Mosavel (2010) argue, used in isolation from many more comprehensive community-engagement approaches, peer research involvement can easily become tokenistic or exploitative. Care should be taken to avoid research practices that benefit extensively from the labour and expertise of peer researchers but offer little in return in the way of recognition, remuneration, or a sense of ownership of the work (Elliot, Watson, & Harries, 2002; Simon & Mosavel, 2010).

Nevertheless, these dynamics are complex. One service provider noted:

Can we comment on the decision-making process, and what peers are involved in? I mean, in some ways we try to involve the peers themselves in terms of what they’d like to ... but that brings this very interesting ethical dilemma, conflict of interest kind of complexity as well, because we have peers involved in the advisory committee having shaped the research, right, and its these peers themselves, they often then get hired if there’s actually data collection they can help with, whatever tasks, but in some ways we’re sort of strug-

gling about the conflict of interest, where we're in these decision making meetings, where we're saying, ok, we need to decide how many peers will be involved in data, ok, what peers will be involved in data collection, and analysis? ... So, we're struggling with, maybe it's a better system that people on the advisory committee are notified beforehand that they can't be hired as actual research ... surveys. (Service Provider)

Although community members did not always use philosophical language to talk about ethics, they were more than able to describe when something simply did not “feel right.” As well, community members often spoke from a lived experience of having been “researched” in the past, and could identify aspects of the research process that made them uncomfortable or that they would like to see used again:

[A]ctually, every member around the table ... has been part of a study ... and they actually have some fairly strong ideas, that's one of the places we started, was actually to talk about what it was like to be interviewed, you know, what their experience was like with research ... we had done some of that conversation about “how do you want,” “how do you like to be treated?” (Service Provider)

Drawing on this rich experience can be beneficial in the planning stages. In one research project, peer researchers argued that it was wrong to survey youth about gaps and barriers to sexual health resources (including basic information about STIs and HIV) and leave without providing the needed information. In response, the research team decided to follow survey administration sessions with a sexual health education workshop. The youth advisory committee members also asked that the survey be administered in community rather than school settings, as they were worried about how other youth would feel filling out the survey sitting near their peers and teachers (for a full discussion of the ethical aspects of this study, see Flicker and Guta, 2008).

Conflicts of Interest

In research ethics, conflicts of interest are commonly understood to arise when a researcher has more than one role (e.g., a physician conducting research on his or her patients). The concern is that participants may become confused about the difference between

these roles, and feel undue pressure to participate. For instance, patients may participate in a study out of a fear that their future care may be compromised.

In community based research, the benefits associated with leveraging these complex relationships are often promoted. For instance, peer researchers are often encouraged to use their personal contacts and stature to recruit their sometimes hidden networks into a study. Participants highlighted the benefits of “peer-to-peer” interactions:

I think whenever you're doing a project that's looking at marginalized communities, you bring someone from that community into a leadership position, it really sends a strong message to the community you're actually interviewing, that you're important, you can play a bigger role. (Service Provider)

Indeed, peers highlighted the benefits of being a community member with a shared experience when doing outreach with participants:

I think the fact that we were peer researchers ... they were more comfortable ... I think it actually improved the quality, the fact that they were very comfortable. So they started talking, and they were open, and they felt free with us. (Peer Researcher)

Many study participants suggested that community members may be more inclined to participate in a study if approached by a known peer rather than a researcher that they did not know. Furthermore, it was acknowledged that peers are often able to navigate hidden networks better than outsiders, especially when the community of interest has been traditionally difficult to engage through research. Peer recruiters could be a practical and benign way to overcome language barriers and cultural differences when recruiting potential subjects (Phillips, 2010). As a result, most of the studies we examined used peer researchers in their recruitment efforts.

In contrast to a physician-patient relationship (where a clear power differential exists), many participants in our study felt that peers were better able to level the playing field and help participants make informed decisions about participation. Nevertheless, a variety of more subtle power differentials surfaced. Several peers reported recruiting their close friends, intimate partners, and/or family members into studies. They spoke with pride about their ability to tap into these personal

networks and how the inclusion of their contacts contributed to the success of the research:

It could not have been done without the peer researchers. Mainly, it could not have been done without the people we knew. (Peer Researcher)

Often, peer researchers not only recruited these participants but also were the ones to go through informed consent procedures and data collection with their close relations. This practice raises a number of ethical issues. First, it can sometimes be very difficult to say no to someone you know personally. Similar to the physician-patient example provided above, a close friend may agree to participate in a study to avoid jeopardizing a friendship (Bean & Silva, 2010; Phillips, 2010). On the other end of the equation, a peer researcher may feel uncomfortable about approaching those in his or her close circle. In one study, a peer researcher described how he stayed with an abusive partner in an effort to minimize study attrition because he had recruited his partner into the study. Another issue we heard about was how challenging it was for some peer researchers who felt confused by their dual role of researcher (who maintains confidentiality) and friend/family member who felt compelled to become an outspoken advocate. Others studies have also documented this challenge (Elliot et al., 2002; Simon & Mosavel, 2010).

While peer researchers are able to leverage their personal networks to recruit, it may be appropriate to have someone who is more at “arms length” walk through consent procedures and data collection (Bean & Silva, 2010). When that is not possible, it is doubly important for peer researchers to reiterate to study participants that they are participating in research (not just friendly conversations), and that they have the right to refuse to participate and not answer particular questions (Molyneux, Kamuya, & Marsh, 2010; Ross et al., 2010). In fact, “refusals by community members are not only acceptable, but potentially indicative of an ability to make a choice” and should be seen as a good sign (Molyneux, Kamuya, & Marsh, 2010).

Confidentiality

I don't think that ... somebody who's not skilled in research wouldn't have the capacity to pick up the importance of the logic of confidentiality. It's just getting that match in terms of maturity and work ethic. (Peer Researchers)

Confidentiality is always an issue in research. Peer researchers, like all staff with access to private information, need support and training to adopt careful protocols around privacy and confidentiality. However, their training needs may be slightly different. They have likely never had professional training on clinical ethics that other members of the team may have undergone; moreover, the concept of confidentiality may be newer for them. Furthermore, because of the close relationships that peer researchers often have with research participants, and the community at large, they may feel increased pressure to share things that participants have disclosed. However, we should not necessarily assume that peer researchers will not honour the commitment to confidentiality. Many peer-researcher participants in our study felt that they had been adequately trained in this regard and were able to explain the value of maintaining strict policies around confidentiality. Nevertheless, in some cases additional training may be required to explore the challenges (and legal limits) of discretion in close-knit communities. In response to peers recruiting from their personal networks, one researcher told us about how confidentiality was discussed as an ongoing issue in the team:

[P]art of the debriefing session was also to ... re-highlight the importance of confidentiality, we had done that before, but again, after learning all that ... and we wanted to double emphasize the importance of confidentiality. (Service Provider)

In this project, discussions of confidentiality were ongoing to make certain that all involved had a shared continuing understanding of their commitment. In another project, researchers only became aware of the complexities of confidentiality well into the project:

[S]o in this one we involved them in actually, they helped in recruitment, they did the actual focus groups, and then we realised, wait a minute, there's lots of complex ethical issues about actually involving peer researchers, peers interviewing or conducting focus groups within their, among their own peers. (Service Provider)

Confidentiality of data may be more difficult to ensure when socially proximate individuals collect data from each other (Bastida et al., 2010). It can be hard to know how or why a secret becomes more widely known. Issues of confidentiality are not limited to data collection; they also need to be considered when analyzing

the data. Questions to consider include: Who will have access to the data? In what form? For what purpose? To what extent can the data be anonymous? How will data be shared among team members?

Emotional Triggering and the Need to Provide Special Support

Emotional triggering was another area of particular ethical concern that emerged in our interviews with study participants. This phenomenon was experienced most acutely by peer researchers who had past experience with the issue under study (such as homelessness or drug use) rather than those currently impacted by the issue. In these cases, peer researchers were sometimes asked to return to environments (e.g., shelters or needle exchanges) where they encountered peers, settings, and dynamics that were at times traumatizing. These difficult environments were often supportive of behaviours and lifestyles that peer researchers were struggling hard to “move on” from.

Service providers described how the strategy of hiring those with past experience of an issue was very useful because these peers were likely to be more stable and able to commit to project needs, and had an intimate cultural understanding of the community. Nevertheless, some projects underestimated the emotional toll that re-immersing peer researchers in spaces that they had worked hard to leave behind might take:

Well, for me personally, um, it was a bit of an issue because I ... wasn't really prepared for that aspect of it—for whatever reason ... It had more of an impact than I thought it would ... There [were] a couple people who got emotional and upset about certain issues. (Peer Researcher)

Some study participants described how they had tried to prepare peer researchers for this challenge during training. Others described how their teams instituted ongoing support meetings with peer researchers to debrief and assist peer researchers with the unanticipated emotional impact of the work. The level of ongoing support and supervision necessary to ensure that both project and peer researcher needs are met should not be underestimated (Elliot et al., 2002).

Considerations Beyond the Life of the Project

Whereas academics and service providers are often hurried along to the next project or pulled back to pre-

vious commitments following the completion of a project, peer researchers may find it difficult to transition out of the project. This may be especially true when a strong team has been developed, and peer researchers become accustomed to regular support. Coordinators should be wary of creating false expectations for individual peer researchers that exceed the limitations of any one community-based research project. As many peer researchers are drawn in from existing services and will continue to access those services, unmet expectations could create future problems in those relationships if the benefits of the project are not articulated clearly from the beginning.

Furthermore, it may be important to think through how to create closure and ensure that peer researchers find other mechanisms for support after the project ends. Many peer researchers talked about ongoing project meetings as a time when they could personally connect with others and get help with a variety of personal and work related matters. An abrupt end to these activities might leave many vulnerable peer researchers with a large void. Developing a thoughtful wind-down, with some additional follow-up mechanisms may be helpful for ensuring a smoother transition.

Conclusion

Ethical issues are by their very nature complex. There are rarely easy right and wrong answers to challenging ethical issues. While participants in our study were quick to argue that adopting a peer research approach was simply “the right thing to do,” when probed they identified a number of new and emerging ethical issues that resulted from this approach. Careful ethical reflection throughout the life of a research project can provide a team with the opportunity to come up with creative, attentive, and just responses to these challenges. Failure to take the time to think them through could have devastating consequences.

Recommendations

WE ENCOURAGE COMMUNITY-BASED RESEARCH TEAMS TO:

- Use the formal ethics review process as an opportunity to reflect on broader ethical issues with the entire research team.
- Align their rhetoric of participation with commensurate power-sharing schemas and create transpar-

ent decision-making structures.

- Explore issues relating to conflicts of interest and confidentiality broadly and extensively in their training, and ongoing support work, with peer researchers.
- Consider the emotional impact of the work that they are asking of peer researchers and provide appropriate mechanisms for ongoing support and supervision.
- Think about how to develop appropriate wrap-up activities and a sense of closure.

REFERENCES

- Bastida, E. M., Tseng, T.-S., McKeever, C., & Jack, L., Jr. (2010). Ethics and community-based participatory research: Perspectives from the field. *Health Promotion Practice*, 11(1), 16–20.
- Bean, S., & Silva, D. S. (2010). Betwixt & between: Peer recruiter proximity in community-based research. *The American Journal of Bioethics*, 10(3), 18–19.
- Brugge, D., & Cole, A. (2003). A case study of community-based participatory research ethics: The Healthy Public Housing Initiative. *Science & Engineering Ethics*, 9(4), 485–501.
- Elliot, E., Watson, A. J., Harries, U. (2002). Harnessing expertise: Involving peer interviewers in qualitative research with hard-to-reach populations. *Health Expectations*, 5(2), 172–178.
- Flicker, S., & Guta, A. (2008). Ethical approaches to adolescent participation in sexual health research. *Journal of Adolescent Health*, 42(1), 3–10.
- Flicker, S., Savan, B., McGrath, M., Kolenda, B., & Mildemberger, M. (2008). If you could change one thing...What community-based researchers wish they could have done differently. *Journal of Community Development*, 43(2), 239–253.
- Flicker, S., Savan, B., Mildemberger B., Kolenda, K., & McGrath, M. (2006). *A snapshot of community based research in Canada*. Toronto: Wellesley Institute.
- Flicker, S., Travers, R., Guta, A., Macdonald, S., & Meagher, A. (2007). Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health*, 84(4), 478–493.
- Greene, S., Ahluwalia, A., Watson, J., Tucker, R., Rourke, S. B., Koornstra J., et al. (2009). Between scepticism and empowerment: the experiences of peer research assistants in HIV/AIDS, housing and homelessness community-based research. *International Journal of Social Research Methodology*, 12(4), 361–373.
- Guta, A, Wilson, M. G., Flicker, S., Travers, R., Mason, C., Wenyeye, G., & O'Campo, P. (2010). Are we asking the right questions? A review of Canadian REB practices in relation to community-based participatory research. *Journal of Empirical Research on Human Research Ethics*, 5(2), 35–46.
- Israel, B. A., Eng, E., Schulz, A. J., & Parker, E. A. (Ed.). (2005). *Methods in community-based participatory research for health*. San Francisco: Jossey-Bass.
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173–202.
- Khanlou, N., & Peter, E. (2005). Participatory action research: Considerations for ethical review. *Social Science and Medicine*, 60(10), 2333–2340.
- Malone, R. E., Yerger, V. B., McGruder, C., & Froelicher, E. (2006). “It’s like Tuskegee in reverse”: A case study of ethical tensions in institutional review board review of community-based participatory research. *American Journal of Public Health*, 96(11), 1914–1919.
- Minkler, M. (2004). Ethical challenges for the “outside” researcher in community-based participatory research. *Health Education & Behavior*, 31(6), 684–697.
- Minkler, M., & Wallerstein, N. (2003). *Community-based participatory research for health*. San Francisco: Jossey-Bass.
- Minkler, M., & Wallerstein, N. (2008). Introduction to community based participatory research. In M. Minkler & N. Wallerstein (Eds.), *Community-based participatory research for health* (pp. 3–26). San Francisco: Jossey-Bass.
- Molyneux, S., Kamuya, D., & Marsh, V. (2010). Community members employed on research projects face crucial, often under-recognized, ethical dilemmas. *The American Journal of Bioethics*, 10(3), 24–26.
- Phillips, T. (2010). Protecting the subject: PDR and the potential for compromised consent. *The American Journal of Bioethics*, 10(3), 14–15.
- Roche, B. (2008). *New directions in community based research*. Toronto: The Wellesley Institute.
- Ross, L., Loup, A., Nelson, R., Botkin, J., Kost, R., Smith, G., & Gehlert, S. (2010). Challenges of collaboration for academic and community partners in a research partnership: Points to consider. *Journal of Empirical Research on Human Research Ethics*, 5(1), 19–31.
- Schnarch, B. (2004). Ownership, control, access, and possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations

communities. *Journal of Aboriginal Health*, 1(1), 80–95.

Shore, N. (2006). Re-conceptualizing the Belmont principles: A CBPR perspective. *Journal of Community Practice*, 14(4), 80–95.

Simon, C., & Mosavel, M. (2010). Community members as recruiters of human subjects: Ethical considerations. *The American Journal of Bioethics*, 10(3), 3–11.

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Peer Research in Action III: Ethical Issues

Peer research has emerged as a popular form of community-based research (CBR) where research projects include members of the target population who are trained to participate as co-researchers. The inclusion of community members in CBR through peer research initiatives is thought to enhance the quality of the data collected, allow for the expertise of lived experience to be incorporated over time, while promoting capacity building at the local level.

In Part III, we consider the particular ways in which ethical challenges surfaced and were addressed when using a peer researcher approach. We consider issues related to formal ethics reviews, communication and power sharing on projects, conflicts of interest, confidentiality, and the emotional challenges that can accompany community based research projects in action.