

Community-Based Research Ethics Review: Reflections on Experience and Recommendations for Action

Jocelyn Downie and Barbara Cottrell

I. Introduction

Research participants, researchers, and organizations that fund research share an interest in ensuring that the research meets high ethical standards. When community-based research (CBR) projects are developed, a number of significant questions emerge for all of those involved in the research about how to achieve such standards. Some of these questions are: how do community groups deal with the issue of confidentiality? How do they deal with the issue of liability? Is there any type of system in place which protects the participants? Do community groups feel that a formal ethics review process is an important component of research? Are existing review processes available to, and appropriate for, ethics review of this type of research? The absence of clear answers to such questions suggests a need to further explore the area of CBR ethics review. In response to a recognition of this need, the Canadian Research Institute for the Advancement of Women (CRIA), the Dalhousie University Health Law Institute and the Maritime Centre of Excellence for Women's Health (MCEWH) sponsored a three-part knowledge-generating initiative on CBR ethics review.¹ The initiative was also motivated by the fact that some community-based researchers had expressed concerns about the ethics review process required by the MCEWH for research it funds. We wanted to find out what their concerns were and whether there were alternative approaches the MCEWH could take.

The purpose of this paper is to provide a description of this initiative and a summary of its findings. First, we provide a description of CBR as well as our project and its goals. Then we describe the methodology and provide an overview of

the results. Finally, we offer some reflections on the study findings and recommendations for future action.²

II. Community-Based Research

For the purposes of this paper, community-based research is defined as research where there is no formal link with an institution such as a hospital or university. Although there are many exceptions to the rule, it is generally fair to assume that CBR differs from institutional research in a number of ways. Perhaps the most important difference is that it is rarely an individual

venture. CBR stems from a need identified by a group of people living and working at the community level, and is conducted with the guidance of an advisory group who are people close to the research problem.³ It is practical in nature: community-based research is not conducted for the sake of knowledge, but rather for the purposes of finding a practical solution to the identified need. A qualitative methodology is most frequently used, and, because the grants they are working on are likely to be under \$50,000, the research often includes small samples. The groups involved are usually small non-profit organizations with annual budgets under a million dollars, so the research is conducted with fewer resources available to the researchers than to institutional researchers. They do not have available to them the support staff, office equipment, or expertise that academics take for granted.⁴

III. Project Description

In the first phase of the research project, we interviewed a group of female community-based researchers in Atlantic

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Canada in an attempt to determine the prevailing attitudes and practices with respect to research ethics review. In the second phase, we surveyed the Chairs of all of the research ethics boards (REBs) in the local Halifax Regional Municipality to determine current practices respecting review of CBR and to solicit ideas about whether and how such practices could be improved. In the third phase, we brought together a group of experienced community-based researchers to explore the need for, and best means to facilitate, ethical CBR.

IV. Methodology

Phase one involved conducting telephone interviews with community-based researchers from the provinces of Nova Scotia, New Brunswick, Prince Edward Island, and Newfoundland. Twenty-four interviews were conducted, with participants selected from a network of personal contacts through CRIAW and the MCEWH. Participation was voluntary and the respondents were not remunerated. Following a standardized script, the interviewer asked each researcher whether her past CBR projects had involved any type of formal or informal ethical review. Where the community-based researcher had experience with ethics review, she was asked to expand on the nature of the review processes utilized.

Phase two involved surveying Chairs of the local REBs. Copies of an introductory letter and the survey were sent to the Chairs of each of the nine major research ethics review committees in Halifax. As in phase one, participation was voluntary and without remuneration. Six completed surveys were subsequently returned.

Phase three involved bringing together twenty women from the Atlantic provinces who had had experience in community-based research. The Round Table discussion took place at the IWK Grace Health Centre in Halifax on March 29, 1999 and opened with participant introductions and an overview of the project's history and rationale. Four questions then guided the proceedings. First, what do we mean by ethics? Second, are there problems with the current ethics review models? Third, what values and objectives should be expressed by an ethics process? Fourth, where do we go from here? Detailed notes were taken to document the Round Table process. These notes have been summarized into a report which is available from the MCEWH.

V. Results

A. Phase One (Survey of Community-based Researchers)

The first phase of the initiative involved interviewing twenty-four women with experience in conducting community-based research. All of the women interviewed described having incorporated some form of ethical review processes into their research work. Each participant was asked to identify the review processes with which she had the most experience. Ten of the women identified conventional institutional ethics review processes at hospitals and universities, four identified other formal ethics

review processes external to their organizations, five identified formal ethics review processes internal to their organizations, and five identified informal ethics review processes. Each participant was then asked to describe what she perceived to be the benefits and

drawbacks of the review processes with which she had the most experience. The general picture that emerged from the interviews was a relatively high level of dissatisfaction with conventional institutional processes compared with the other processes.

Conventional institutional review was described as submission of an application and accompanying supporting documentation to a multi-disciplinary committee of, for example, a university or a hospital, followed by revisions and finally approval to proceed with the research. Only one of the ten participants in this category identified any advantages of the institutional process, saying that it required her "to be clear, to slow down and be mindful and sensitive." Nine others found no advantages associated with this type of process. The following major inadequacies were cited:

- the institutional REBs are not equipped to deal with various types of non-traditional research methodologies (e.g. standard forms are often inappropriate, language used is often too scientific, questions tend to relate exclusively to biomedical issues and not social issues);⁵
- the institutional process contributes little in terms of ethical guidance and there is no exchange of information or ideas;
- the process is frustrating and sometimes demoralizing;
- the process is needlessly time-consuming; and

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- taking place before the research starts, the institutional review system contains no mechanism for revisiting the issues as the research progresses despite the fact that anticipated ethical issues can evolve and unanticipated ethical issues can arise during the course of a research project.

Four of the women interviewed had primary experience dealing with other formal ethics review processes external to their organizations. Three characterized the processes as having no disadvantages while one said that the amount of time required was a drawback. Three of the four women cited advantages related to inclusiveness. These advantages included emphases on participant input and on ensuring diversity of backgrounds among the reviewers. One participant observed that the attention to inclusiveness had the positive effect of helping to generate more (and better) ideas on how to deal with issues of intersectional identities than was the norm. All four women chronicled experiences with formal external but not institutional ethics review processes that they felt ensured community voice, sensitivity and perspective, and “helped to validate recommendations” by adding soundness to the findings.

Five participants made primary use of formal ethics review processes internal to their organizations. The formal internal processes took several different forms including peer review, adherence to existing organizational policy, and review by representatives of diverse community groups. The following is an example of a formal internal ethics review process:

First, identify the target area, then find people who are experienced in that area. We always have a three-member committee – members are chosen because they are suitable. In addition, we include a student studying in that area, and a community member – a teacher or social worker, or sexual assault counsellor. Then they rate the project and ensure that...counsellors are available who can donate their time for follow-up.

Of the five women with experience of formal internal processes, two indicated “time consuming” as the only negative attribute while the other three cited no drawbacks to this method of ethics review.

The range of advantages associated with formal internal processes was broader than those mentioned concerning either of the external processes. In addition to contributing “voice,” “validity,” “inclusiveness,” and “on-going capability” to research projects, internal processes appeared to instill a level of confidence in the researchers that was not provided through the external processes.

In answer to the question “does your process strengthen the design or management of your projects?”, one of the women responded: “yes, that is why we...created our own ethics process. We found that [the university] review was not well equipped to deal with [social] issues.” Internal processes were also seen by some participants to contribute to ensuring a higher level of participant protection because, by virtue of the fact that they are ongoing processes, mechanisms exist to address ethical issues that shift and change during the course of the research. The capacity for ongoing discussion between the researcher and the review body was cited by some participants as a distinct advantage afforded by formal internal ethics review processes.

Five participants said they made primary use of informal processes for addressing ethical concerns in their research and identified the main review mechanism as consensus-building discussion. One participant characterized informal processes as “organic” rather than “systematic.” Discussions about ethics generally took place in the early stages of research and arose again as new issues emerged. Consensus-building discussion was found to add a dimension of richness and insight not found through the other review processes. One respondent suggested that other processes are less effective because “sometimes ethics [review] is more of a rational/political process rather than an ethical/moral one, and in those cases, no ethical/moral questions tend to be resolved.”

Towards the end of the interview, participants were asked to make suggestions about what should be considered when developing an ethics review process for community-based research. Their responses fell into six broad categories, irrespective of which type of review process the participants had experienced.

1. The resources of community-based researchers

Researchers who are not formally affiliated with an organization do not generally have access to pre-established ethics policies and procedures. Additionally, they are often unfamiliar with some of the requirements of formal external ethics review and have limited resources to devote to fulfilling these requirements. One suggestion made for dealing with these problems was the development of an affordable information resource modeled upon non-hierarchical, consensus-oriented discussion.⁶

2. Membership of the ethics review committee

Closed-door institutional processes were seen to discount the wisdom and experiences of community-based researchers and research participants. Many women argued



that participants and researchers should be involved in defining ethics and in deciding what is needed by, and relevant to, their communities. Respondents also wanted to see greater diversity in ethics committee membership through the involvement of community members, the general public, people who have participated in many research projects, and other relevant experts.⁷

3. Awareness of variety of methodological approaches

Five of the interview participants felt there was too little awareness among members of ethics committees about the different methodologies that are used in CBR. Each method, they argued, requires specialized review procedures and raises specific types of ethical concerns. Several women suggested that educational measures are needed to raise awareness and understanding about CBR methodologies. It should be noted that this critique could also be applied to institution-based research using untraditional methodologies. Thus, while not unique to CBR, it is a common problem for CBR.

4. Necessity for process to be dynamic and ongoing

Some participants highlighted the fact that, in some instances, unforeseen ethical issues arise during the course of the research, yet current review processes are not set up to identify such issues and are ill-equipped to deal with them. Suggestions for reform included: the development of mechanisms to ensure the identification of ethical issues while the research is being carried out, the development of the capacity for ongoing ethics review and the retrospective evaluation of the effectiveness of ethics reviews (i.e., evaluation after research projects draw to a close).

5. Accountability

Many researchers felt that accountability to research participants and their communities should play a more central role in the ethics review process. Potential benefit to participants must be a more important consideration than it currently appears to be. Furthermore, the way in which research projects will benefit the participants' communities should be examined and evaluated by members of the communities rather than exclusively by the researcher. Recognizing that research participation involves risks, particularly when participants are from populations-at-risk or survivor groups, many of the community-based researchers spoke in favour of developing ethics processes which would foster greater trust and minimization of risk. It was also recommended that researchers and interviewers undergo crisis training in order to better deal with any crises

that might arise. Finally, participants were unanimous in citing post-research follow-up as a critical accountability measure.⁸

6. Consent and confidentiality

Many participants suggested that a CBR ethics review mechanism should contribute to heightened awareness of the problems, questions, and procedures associated with consent and confidentiality. Numerous problems and questions were raised. For instance, how can questions of confidentiality be reconciled with the wishes of some participants to have their voices heard? How long should information gathered in the research process be kept?

B. Phase Two (Survey of Chairs of Local REBs)

Phase two, the survey of the Chairs of local REBs, revealed that three of the six local REB chairs who responded to the survey currently do review, or in the past have reviewed, community-based projects. Two other respondents said that although their boards had never been asked to review community-based research projects in the past, they would review or consider reviewing such projects if a request was made. One respondent indicated that his/her REB would not review CBR projects (the REB had either been asked to review such projects in the past and declined or had never been asked but would be unable or unwilling to do so if asked in the future).

1. REBs that do review or have reviewed CBR

Of those who currently review community-based research projects, or have reviewed such projects in the past, all three stated that they adhered to their usual review process for these projects. One described this process as follows: "the researchers were asked to submit a completed REB package which was reviewed in the standard manner. If the proposal meets the ethical standards of the REB it is certified. The institutional research officer and the REB do not accept any responsibility for further surveillance or quality assurance."

In response to the question, "did any issues arise that seemed peculiar to CBR and/or CBR ethics review?", one respondent said that the REB specifically identified the issues of "liability, responsibility, [and] audit potential." Another stated that while no particular issues had emerged thus far, too few CBR projects had come through the REB to draw conclusions on the matter of whether CBR raises unique issues.

Two of the three respondents indicated a belief that CBR should go through an ethics review process of some kind. One stated that “research conducted on human subjects in any venue should be subject to the same scrutiny and expected to meet the same standards as research conducted in a health care centre. Subjects have the same right to protection from unethical practice of research regardless of the location of the research.” Another commented that review was necessary as per the Tri-Council Policy Statement (i.e., the guidelines that govern research involving humans in Canada).⁹ The question “do you believe that your REB should be reviewing such research projects?” generated a varied response, with two respondents saying “Yes” and one saying “No.” Of the respondents who said “Yes,” one noted that “REBs in academic institutions are properly constituted and equipped to conduct a proper review. An REB constituted by a community organization is unlikely to have either appropriate expertise among its membership or the ongoing experience necessary to ensure comprehensive, high quality review.” The other affirmative respondent added the cautionary note, “if resources are adequate.” This concern about resources was echoed in the one negative response: “No, because we do not have the resources to do so. The Tri-Council imposition of much more rigorous review inside the university is already taxing our resources.”

All three respondents indicated that they believe that the current methods used by their REBs for ethics review are adequate for reviewing CBR projects. Two indicated that they had no suggestions as to how to improve the process and one commented only that “we are working with the Tri-Council agency to improve and expedite procedures.” At the end of the questionnaire, one respondent observed that “if the amount of community-based research increases over time, some means of monitoring the conduct of researchers is necessary to ensure that ethical standards are maintained.”

2. REBs that might review CBR

The second category of responses came from those Chairs who indicated that their REBs might review community-based research but had not yet been asked to do so. Of the two respondents in this category, both agreed that CBR should go through an ethics review process of some kind and gave examples of CBR projects that raised ethical questions in their minds. One respondent commented at length, discussing Tri-Council imperatives and specific questions relating to release of community agency membership information and the use of harm-benefit analysis in reviewing CBR projects. Demonstrating in-depth knowledge of both the issues surrounding CBR and the pertinent Tri-Council guidelines, the respondent made it clear that the

guidelines are imprecise and do not provide adequate guidance to researchers and REBs involved with community-based initiatives. The two respondents differed in regards to the question “Do you believe committee members would be willing to do ethics review of community-based research projects?” One respondent checked “Yes”. The other checked “No” and commented that while some members of the REB might be interested and willing, the general workload of REB members was already so heavy that demands for reviews of projects not directly linked to the institution were unlikely to be well-received. This respondent noted that “[t]here has been considerable discussion about the review process and when a research [project] may or may not have a direct link to the institution. There have been discussions around fee for service and whether or not a research project is bringing in research dollars such as overhead.”

The two respondents also differed in their answers to the question “Do you believe that your REB is an appropriate body to review community-based research?” One said “Yes” and the other said “No,” explaining that his/her REB lacked expertise in the area. “I do not feel that my Ethics Research Board would be appropriate as the knowledge from a methodological perspective and a content perspective would be missing. It would require external reviewers. However...there may be a willingness to attract and include this expertise if required or to facilitate a review process from the agency perspective.” The respondents had a number of suggestions as to how ethics review of CBR should be conducted. One idea was to involve Community Health Boards at some level. Another suggestion was to educate REB members on CBR methodologies.

In the space provided for additional comments at the end of the questionnaire, one respondent offered the following valuable insight:

What is interesting, although not explicitly asked in this questionnaire, is [that] the calls for proposals from various granting agencies do lend themselves to community-based research. For example, the Social Science and Humanities Research Council (SSHRC) has announced a Community-University Research Alliance (CURA) granting opportunity between universities and communities. If granting agencies are going to focus on this type of collaborative research initiatives, then there will be a demand within the research community to provide for reviews if applicable. The tension comes between what is or is not applicable, and the general public’s understanding of informed

consent in terms of participating in research. So it is a complex issue, but I think one question that really is not raised is the need and whether or not the need and the traditional research approach is being challenged by the grant opportunity requests.

3. REBs that will not review CBR

The last category of questions was directed toward REBs that will not review community-based initiatives. One respondent fit this criteria. In response to the question of why the REB would choose not to review such projects, the following comment was made: “we no longer satisfy the Tri-Council directives for an REB. Furthermore, our mandate is to evaluate...research in our department not covered by other REBs. It isn’t clear what our responsibilities would be in evaluating community-based research – both legal and ethical.” This respondent did, however, indicate a belief that CBR should go through a process of ethics review, “mainly because active researchers are not always fully attuned to the ethical issues involved in their research.” However, the respondent answered “No” to the question “Can you suggest an appropriate body to do community-based research ethics review?” This respondent also had no suggestions as to how such review should be conducted.

C. Phase Three (Round Table with Community-based Researchers)

As with those interviewed in phase one, all Round Table participants noted significant dissatisfaction with the existing processes for ethics review of community-based research. It was agreed that there is a definite need for a process that speaks to the unique needs of these researchers, ensures the highest ethical standards, and protects research participants from any harm.

Six questions guided the discussions. What do we mean by “ethics”? Are there problems with the current models? What values and objectives should an ethics process express? What can we learn from past experiences? What are appropriate future directions for work on this issue? What are your final reflections at the end of the roundtable?

1. What do we mean by “ethics”?

In conceptualizing what is meant by the term “ethics,” discussion centred on considerations relating to consent, confidentiality, and accountability. Issues of literacy and language were raised as important concerns with regard to ensuring genuine consent. Several participants stressed that research accountability should include involvement of research volunteers in the design of a study and a commitment to give something back to the participants’ community. Confidentiality issues were of particular interest, with many participants saying that the institutional ethics processes on these issues reflect a fundamental lack of understanding about the nature and value of CBR.

2. Are there problems with the current models?

Numerous problems with current ethics review models were identified. Institutional review processes were reported to be very unsatisfactory. The main problems identified with this model were that researchers and participants are precluded from having input

into the process, little guidance is provided during research design, and current processes do not allow for ethical concerns to be revisited once approval is granted. With alternative review processes, the major concerns identified were the considerable time demands and lack of funding to complete the ethics review phase of research projects.

3. What values and objectives should be expressed by an ethics process?

Discussion of appropriate values and objectives focussed on how the credibility and legitimacy of community-based research could be increased. The following practical objectives emerged:

- creating an affordable and accessible process primarily devoted to the identification and resolution of ethical concerns;
- maximizing potential benefits to the community and giving voice to the community members through the process;
- making advisory resources available throughout the research process so that if additional ethical concerns arise they can be addressed effectively;
- linking the process with experts (community-based, where possible) and institutions that can provide objective advice and lend formal legitimacy; and

It was agreed that there is a definite need for a process that speaks to the unique needs of these researchers, ensures the highest ethical standards, and protects research participants from any harm.

- convincing funders to commit the financial resources needed for CBRs to develop and carry-out ethics review processes.

4. What can we learn from past experiences?

Reflection on past experiences dealing with ethics review processes as community-based researchers revealed several key themes. First, a lack of meaningful dialogue between institutional ethics committees and community-based researchers was an oft-cited issue. Furthermore, REB members were seen to be unfamiliar with the methodologies used by community researchers. Consequently, designs for community-based research were often viewed by REB members as problematic and community-based researchers were instructed to utilize methodologies that were more familiar to the committee but were inappropriate for the purposes of the research. Second, particular concerns arose with regard to the strict confidentiality demanded by institutional processes. Those with experience doing research in small communities, where confidentiality was seen as nearly impossible, felt that insistence on complete confidentiality could have the effect of distilling findings to the point where the study had no value. Third, participants were emphatic that the design of any new ethics review processes should attend to the fact that CBR projects are generally short-staffed and under-funded. Making the process too complicated and/or expensive could have the effect of discouraging researchers from taking on important projects. Finally, participants also urged that new processes should avoid overtones of forced compliance and must be free from government control. On the other hand, it was recognized that any new processes must be seen as legitimate by the wider research community in order to contribute to greater acceptance of community-based research.¹⁰

5. What are appropriate future directions for work on this issue?

Three distinct future directions were identified through the Round Table discussions, with all participants noting that each would require further consideration prior to adoption.

With the goal of modifying current processes, the first strategy would involve establishing linkages between

community-based researchers and currently existing institutional processes. In order to make the review process more closely resemble genuine peer review, reconstituted REBs would have some members with expertise in methods commonly used in CBR. A second strategy would be to create entirely new REB entities with the mandate to provide ethics review for CBR. The third strategy that emerged from the Round Table is an option that could be pursued either alongside or independent of the other possible strategies and would entail developing an ethics package for CBR. This would include: a mission/values statement; a set of guiding principles for researchers, participants and funders; an explanation of CBR methodological approaches; a list of experts with whom community-based researchers could consult in preparing submissions for ethics review; a mandate for an increase in the funding levels allowed by funders for ethics processes; and a commitment to providing affordable education about research ethics.

Community-based researchers frequently do not have the human or financial resources required to prepare the documents required by conventional institutional ethics review. Institutional REBs frequently do not have the human resources required to provide ethics review for community-based researchers.

6. What are your final reflections at the end of the round table?

Participants in the Round Table noted that partnerships between institutional and community-based researchers and independent CBR initiatives are increasingly common in research. The challenges that these partnerships and independent CBR pose to conventional ethics review processes are a significant, but understudied, element of the promotion and pursuit of these partnerships.

Participants felt that attempting to evaluate CBR protocols through a lens created primarily for the review of biomedical research is not an effective way to ensure that ethical standards are met. While there is some overlap in the general principles (e.g. consent and confidentiality apply to all types of research), there are considerable differences in the ways that problems related to the principles manifest themselves in CBR and institutional research.¹¹ Existing guidelines such as those prescribed by the Tri-Council are inadequate in this arena.

There are both theoretical and pragmatic arguments to be made for the development of tools appropriate for reviewing CBR. On the theoretical side, and from the feminist standpoint, more suitable review tools are needed in order to encourage the use of non-traditional research



methodologies; facilitating the growth of alternative approaches is an integral part of the feminist critique of and response to traditional methods of generating knowledge about women's issues. On the pragmatic side, the resources of time and money available to institutional REBs are already stretched thin in the course of routine work. REBs simply cannot conduct adequate reviews of CBR protocols by using the existing review tools and resources. At the same time, community-based researchers who want or need to engage in ethics review of their projects face serious financial and information constraints when preparing for and accessing review processes.

Alienation from conventional REBs is a particular challenge that community-based researchers noted in relation to attempting to increase the legitimacy of CBR within the broader research community and to meet the requirements of some funding agencies. While apprehension about the review process is experienced among community-based researchers, persons serving on REBs demonstrate some misunderstanding of the nature of CBR. When it comes to ethics review of this type of research, REB members and community-based researchers appear as two solitudes. They have different perceptions of how research should be reviewed, how successfully it is being reviewed at present, and what ethical standards apply. Bridging the two solitudes is a desirable objective that requires substantially increased mutual understanding. As a first step, improved information exchange and communication are needed. Ethics review processes developed within the community context in which research is being done, and by those most affected by this research, seems to be one way to make ethics review relevant, valid and empowering. The question, of course, is how to produce such ethics review processes within current constraints.

VI. Final Reflections of the Authors

It is clear that everyone is committed to the goal of ensuring that research is conducted in an ethical manner. However, CBR currently gets very different levels of ethics review ranging from none to extensive. The quality of the review is also varied and ranges from poor to excellent. There appear to be a number of significant barriers to ensuring that CBR gets adequate and appropriate ethics review.

A. Lack of Human Resources

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documents required by conventional institutional ethics review.

Institutional REBs frequently do not have the human resources required to provide ethics review for community-based researchers. REB members are fully occupied with reviewing protocols emanating from within the institution the REB serves. REBs generally already have a workload that exceeds their human resource capacity.

B. Lack of Capacity

Institutional REBs frequently do not have the appropriate expertise for reviewing community-based research. They often lack an understanding of methodologies employed in CBR (e.g. qualitative research and participatory action research) and of the contexts within which CBR takes place. Community-based researchers in turn have expertise in CBR methodologies but do not always have access to individuals with expertise in research ethics.

C. Concerns About Liability

Institutional REBs may be concerned about assuming liability for harms arising out of the research if they undertake to provide ethics review for community-based researchers.

D. Conclusions

There appears to be a serious gap between the commitment to ethical research and the reality of ethics review for CBR. In order to bridge that gap, the following possibilities should be considered.

First, community-based researchers could seek to develop guidelines for the conduct of ethical research to serve as the voluntary standard to which CBR could be held by formal ethics review processes. Community-based researchers could seek to have these guidelines reflected in the evolving national guidelines governing research involving humans in Canada.

Second, institutional REBs could strive to include members with expertise in CBR or to develop a list of local resource people with such expertise who could be consulted when CBR projects come before the REB. Careful attention would have to be paid to the fact that involvement in institutional ethics review could prove difficult for many community-based researchers as it would take time and resources away from providing much needed services in the communities. Institutional REBs should also seek to provide continuing

education opportunities for their members to learn more about CBR and the particular challenges it poses for and faces in institutional ethics review.

Third, in consultation with experienced community-based researchers, the National Council for Ethics in Human Research could offer educational programs for community-based researchers (along the model of those offered to institutional REB members) and develop a position paper on CBR ethics review.

Fourth, the Working Group for the evolution of the Tri-Council Policy Statement for Research Involving Humans could attend to issues relating to CBR in the revisions to the Policy Statement.

Finally, research funders (including, for example, Status of Women Canada and Health Canada) could require that all research that they fund has been through an appropriate process of ethics review and should provide funds to facilitate the meeting of this requirement.

If all of those involved bring their expertise, experience and resources to bear on the problems currently facing community-based research ethics review, then the shared objective of ethically sound community-based research is more likely to be realized.

Jocelyn Downie is Executive Director of the Health Law Institute at Dalhousie University, Halifax, Nova Scotia. Barbara Cottrell is a freelance researcher, writer and educator, and has designed and conducted many community-based research projects..

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1. Others are also aware of this need and are responding in a variety of ways. For example, the National Health Research and Development Program (NHRDP) has recently built *Procedures for Assessment of Community-based Research Projects* into its program to design Canadian strategies on HIV/AIDS-extramural research. For more on this see online: <<http://www.hc-sc.gc.ca/iacb-dgiac/nhrdp/resources/hiv-aids.htm>> (last modified: 15 February 1999). The Canadian Strategy on AIDS has also conducted studies concerning CBR. See for example R. Ogden, "Report on Research Ethics Review in Community-based HIV/AIDS Research" (For the Canadian HIV/AIDS Legal Network under contract with AIDS Vancouver, July 1999) [unpublished].
3. For further reflection on the issues discussed in this paper, see Ogden, *ibid.* and R.E. Sclove, M.L. Scammell & B. Holland, *Community-based Research in the United States:*

An Introductory Reconnaissance (Amherst, MA: The Loka Institute, 1998).

3. B. Cottrell, "Working With Research Ethics: The Role of Advisory Committees in Community-based Research" (2001) 25.2 *Atlantis* 22.
4. The following examples of CBR that one of the authors of this paper has been involved with, fitting all the above criteria, illustrate the nature of CBR. In the *Liberty Project*, a manual was produced for group leaders and survivors of woman abuse. Participants in a series of facilitated workshops for women who had left abusive partners were interviewed to find out what should be included in the manual. In the *Parent Abuse Project*, parents, teenagers, service providers and academics were interviewed about the abuse of parents by their adolescent children. A pamphlet, short guide, and report for parents and service providers, detailing the findings about why the abuse occurs, who the perpetrators and victims are, and how parents and service providers deal with the issue, were produced. In the *Women Down Prospect Health Project*, a group of women from a small Nova Scotia coastal community learned the basics of social research and interviewed each other about their health needs. The women, most with less than Grade 7 education, organized a series of workshops on various health topics in response to their findings. In a project called the *Youth Health Centre Project*, youth and service providers discussed the meaning of the term 'youth driven,' and whether the involvement of youth in youth health centres is essential at all levels, and a discussion paper for youth health centre workers was produced. The budgets for these projects ranged from \$5,000 to \$50,000.
5. For more information on the perpetuation of the scientific model in research, see for example L. Code *et al.*, *Is Feminist Ethics Possible?* (Ottawa: CRIAW, 1991) and S. Harding, ed., *Feminism and Methodology: Social Science Issues* (Bloomington: Indiana University Press, 1987).
6. For more discussion on dismantling hierarchical processes surrounding research and methodology, see for example E. Browning Cole & S.M. Coultrap-McQuin, *Exploration in Feminist Ethics: Theory and Practice* (Minnesota: Midland Book, 1988); Code *et al.*, *supra* note 5; M. Eichler, *Sexism in Research and its Policy Implications* (Ottawa: CRIAW, 1983); R. Klein, *The Dynamics of Women's Studies: Its International Ideas and Practices in Higher Education* (Doctoral Thesis, Institute of Education, University of London 1986) [unpublished].
7. This position is consistent with experiences in participatory research in HIV. For more on this see T. Trussler & R. Marchand, *Knowledge from Action: Community-based research in Canada's HIV strategy* (Ottawa: AIDS Vancouver and Health Canada, 1998) and Ogden, *supra* note 1.
8. See in particular J.L. Ristock & J. Pennell, *Community Research as Empowerment: Feminist Links, Postmodern Interruptions* (Toronto: Oxford University Press, 1996) at 66 (on reflexivity in research).
9. Medical Research Council of Canada (MRC), National Sciences and Engineering Research Council of Canada (NSERC) & Social Sciences and Humanities Research



Council of Canada (SSHRC), *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Ottawa: Medical Research Council of Canada, 1998).

10. For further discussion on the objectives, interests and values of academic discourse and the universities' role in promoting diversity and autonomy in research see M. Jackson & M. MacCrimmon, "Research Confidentiality and

Academic Privilege: A Legal Opinion" (Commissioned by the Simon Fraser University (SFU) Research Ethics Policy Revision Task Force, July 1999) [unpublished].

11. See for example CRIAW/ICREF, *Feminist Research Ethics: A Process*, 2d ed. (Ottawa: CRIAW/ICREF, 1996).

