

# **Community-Based Research Ethics Roundtable Report \***

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by

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## Executive Summary

A Community Research Ethics Roundtable discussion, sponsored by the Canadian Research Institute for the Advancement of Women (CRIAOW), the Dalhousie Health Law Institute, and the Maritime Centre of Excellence for Women's Health (MCEWH), was held in Halifax, Nova Scotia on March 29, 1999. Financial support was provided by the Population Health Fund, Health Canada Atlantic Region.

The Community Research Ethics Roundtable was the third phase in the Community Research Ethics Project, which was conducted in three phases. In Phase 1 telephone interviews were conducted with community-based researchers in the four Atlantic Provinces about their experiences with research ethics review processes. Phase 2 was a survey of the Chairs of formal institutional Research Ethics Boards (REB) in Halifax to determine their experience with, and views on, reviewing community-based research projects. Phase 3 included the dissemination of the first phase report and the Roundtable discussion. This report is a summary of the Roundtable discussion. A description of the results of the entire project is available from the investigators.

The goal of the Roundtable was to explore community-based researchers':

- 1) definitions of ethics;
- 2) problems with current ethics review models;
- 3) values and objectives for an ethics review process; and
- 4) recommendations for future directions.

In brief, the results of the Roundtable were as follows:

1) Definitions of ethics. Roundtable participants agreed that ethics considerations centre on issues of consent, confidentiality, and accountability.

2) Problems with existing ethics review models. Community-based researchers report that they are excluded from the institutional review process, and are not offered any guidance, nor given the opportunity to change their research design during their projects. Lack of funding and time restraints are major barriers for a community-based ethics review process. Community-based researchers felt strongly that unless funding is made available for them to participate in ethics review procedures, ethics review processes that ignore community-based research methodologies and principles will remain yet another barrier to community-based work.

3) Values and objectives for an ethics review process. Community-based researchers stated that: the process of ethics review must maximize the potential benefits to the community and give voice to community members; funders must be willing to commit the necessary resources for community-based researchers to develop and deliver ethics reviews; advisory resources must be available throughout the research process so that additional ethical concerns can be addressed should they arise; any ethics review of community-based research should be linked with community-based experts and institutions that can provide issue-specific advice, objectivity, and lend formal legitimacy; and any process that aims to identify and addresses ethical concerns of community-based researchers must be affordable and accessible.

#### 4) Recommendations for Future Directions.

- \* The creation of links between community-based researchers and existing institutional processes with the goal of modifying current processes making them more consistent with community-based research. This would include having members with expertise in community-based research on the REBs.
- \* The creation of an Ethics Guide for community-based researchers that would include: a mission/values statement; a set of principles for researchers, participants, and funders; and an outline of methodological approaches to community-based research.
- \* The creation of a community-based research ethics review process or service.
- \* The creation of a pool of research ethics expertise available for consultation with researchers.
- \* Increased funding from donors to enable ethics review preparation and processes.
- \* Education in the form of affordable roundtables and fora for community-based researchers to shape the details of a community-based ethics review process.

## **Introduction**

Most community-based researchers are eager to ensure that their research meets high ethical standards. However, they are seldom required by funders to go through an ethics review, and resources for ethics review are rarely provided. Furthermore, community-based researchers often find that the established ethics review processes are not suited to their needs. Therefore, when the Maritime Centre of Excellence for Women's Health (MCEWH) required ethics review prior to release of research funds, concerns were raised by some community-based researchers. In response to these concerns, this project was initiated by the Canadian Research Institute for the Advancement of Women (CRIA W), the Dalhousie Health Law Institute, and the Maritime Centre of Excellence for Women's Health (MCEWH).

As part of this study on community-based research ethics, a Roundtable discussion of ethics reviews of community-based research took place at the IWK Grace Health Centre on Monday, March 29, 1999. Twenty women community-based researchers from the four Atlantic Provinces participated. Financial support was provided by the Population Health Fund, Health Canada Atlantic Region.

## Objective

The objective of the Roundtable was to discuss with community-based researchers from the Atlantic Region the development of a research ethics review process responsive to the needs of community-based researchers (CBRs), which could be used by:

- \* the MCEWH, CRIAW and other granting organizations; and
- \* community-based researchers

## Process

As the focus of the Roundtable was on the specific needs of community-based researchers, researchers who were based exclusively in universities, government and other large institutions were excluded. However, it was noted that exclusivity is impossible with such a wide range of women. As one participant said, "All categories are false. We all have feet in different camps."

The Roundtable began with an introduction of the project. The history and rationale for the project and the Roundtable were laid-out by Barbara Cottrell and Jocelyn Downie, Project Co-Investigators. Both women outlined their experiences with community-based research and/or the research ethics review process, and described how they had learned that community-based researchers were dissatisfied with conventional institutional research ethics review processes. Barbara Cottrell explained:

*I have worked with communities for over 15 years, and people kept telling me that the university ethics review is inappropriate to their research. So the members of the Steering committee of the Maritime Centre of Excellence in Women's Health decided to explore our ethics process options.*

The dissatisfaction with the institutional process was mirrored in many of the initial comments made by participants. For example, one woman said, "In my experience, there has been very little of value to be gained from the university process. Last time, I began to even wonder if they had even read my proposal." And another woman offered, "With the closed committee format that the university uses, nobody really knows whose power interests are being served. We need to be able to name the power. There is always power, it is just being able to recognize it."

The participants then introduced themselves and explained why they thought the goal of the project was important, and what they hoped to achieve at the Roundtable. All of the participants expressed a desire for a process that spoke to the unique needs of community-based researchers, ensured the highest ethical standards, and protected participants from any harm. One woman noted:

*Because of economic rationalization and bureaucratization, community organizations are finding that they have to comply with many external norms and values to attract*

*scarce funding resources. Increasingly, we have to collect more and more depersonalized data. And often that data must be passed on to government - which has its own agenda. How we, as intermediaries or as women, deal with that information and our responsibilities, is critical right now.*

Several women also expressed concern about the potential dangers and pitfalls inherent in creating an ethics process. Specifically, they felt that a poorly designed process could be onerous, expensive and frustrating. One woman commented, "The question that concerns me is: Will this new process discourage people from doing research? My fear is that the result will be punitive. Will we create a process ultimately controlled by government and one with which community-based researchers will be forced to comply?" Another woman recounted her negative experiences with a recently developed ethics process for community-based researchers:

*I worked on a project for the [a women's network]. This organization has done a lot of work creating standardized ethics tools. Last year when I worked for them their review process became a nightmare. I had to work with another consultant, who was in Ontario. Then, the organization gave her more autonomy than me, so a lot of power issues emerged. And then we had to send our stuff to a coordinator. And after that it went to another committee. It was very onerous and time consuming. So, I think we do not want to attach too much complication to situations that are already under-staffed and under-funded.*

After these concerns were heard, the agenda for discussion was divided into four main questions:

1. What do we mean by ethics?
2. Are there problems with current ethics review models?
3. What values and objectives should be expressed by an ethics review process?
4. Where do we go from here?

The findings of the report from the first phase of the research project formed the basis for discussion of the first two questions.

## **Part I - What do we mean by ethics?**

Most of the participants agreed with the findings of the Phase 1 study report<sup>1</sup> that ethics considerations centre on issues of consent, confidentiality, and accountability. It was felt that: participants should be clear about the intent of the research and how the information will be used; issues of literacy and language are important concerns; and confidentiality connotes joint rights and responsibilities, which should be agreed upon, by both the researchers and participants. One woman reported:

*For work that was done in small communities, I had to take out every single piece of information that could possibly identify anyone, and as a result, the research was dead.*

*And even then, people were easily identifiable anyway. Everyone knows which people went to the hospital. In a small community, anonymity is a joke.*

In response, one woman recounted how she resolved the confidentiality issue in her work with First Nations women:

*The open talking circle is a contentious issue because as a method of data collection it can be considered a violation of confidentiality - because everyone in the circle knows everyone else. But the participants have their own rules of confidentiality that work. People do not talk about the issues raised in a talking circle outside of it. So, before we begin, we distribute pamphlets with all the information about the project, and we warn participants about the process. Then, we allow them to censor whatever information they would like to after the research stage. And, we make sure that there is no way the government can identify anyone. We used this strategy on a project on Fetal Alcohol Syndrome, which is a very touchy subject, and it worked very well. We achieved a lot of important resources...Confidentiality is assured outside of the community, and the talking circle format assured that questions of confidentiality are dealt with at the community level as well.*

Many of the participants felt that confidentiality at the community level is an issue that requires more in-depth study and analysis.

Participants agreed that accountability means that a key goal of research must be to give back something to the community. This could be giving some control of the research process and findings to the community. The control could be reflected in the research process by participant input into research design, the provision of counselling, if necessary, and mechanisms through which participants can amend findings and have input into recommendations. One woman noted, "We went quite far to give participants a voice in the process, and it was very time consuming, but in the end we felt a lot more confident about the project, and so did the participants."

## **Part II - Are there problems with the current models?**

The four types of ethics review processes identified in the Phase 1 report were discussed:

1. Institutional- researchers go through formal university and hospital ethics review processes.
2. External- researchers are contracted by an external organization with its own pre-existing ethics review process
3. Internal - researchers are part of an organization with its own ethics review process,
4. Informal - research teams deal with ethical issues informally.

The participants agreed with the Phase 1 report that they experienced a high level of dissatisfaction with the institutional process. Dissatisfaction was due mainly to the fact that it

precludes researcher and participant input into the process, provides little in the way of guidance in the research design phase, and has no mechanism to revisit ethical concerns after the project has been approved. The remaining three processes were problematic almost exclusively because they were time consuming and typically demanded more resources than funding provided.

The discussion highlighted that funding and time constraints were a main concern. Many women noted that irrespective of the type of ethics process used, most funding agencies do not pay for the preparation for the ethics review. This was a particularly frustrating point for one woman who said, "I have a big problem with funding agencies that require review before the project is approved. I just don't have the time anymore!" Some women argued that at least the university process is straightforward and affordable. As one woman noted, "The university process is being framed negatively, but it may be the least intrusive and most efficient process available." Another woman responded, "Is it that institutional bodies are the right bodies to do the review? Or, are they just ending up with these reviews by default? I find it disturbing that Status of Women Canada supports projects but has no ethics review [process] or guidelines."

While the institutional process scored high on issues of affordability and simplicity, many women still felt that there were too many ethical issues that it did not and could not address. For example, the institutional process is not well equipped to assess the various methodologies that community-based researchers may use (i.e. participatory action research and feminist research). This often leads to institutional REBs assessing community-based research as problematic, and then attempting to force community-based researchers to comply with methodologies with which the institutional REB is more familiar, despite that fact that these approaches are inappropriate for community circumstances and needs. Further, the institutional process does not allow for dialogue or exchange of ideas between the researcher and the REB through which these and other issues can be resolved. One woman pointed out the dangers of this:

*There needs to be more dialogue between the ethics committee and the researchers. A lot of new researchers don't know all the rules. For example, my friend didn't know that she couldn't change her research process after the review. A rubber stamp was not enough. There needed to be some interaction between researcher and ethics process.*

Finally, the institutional process was seen to have no capacity to revisit issues. As one woman noted, "What if it becomes clear during your first interview that participants don't understand the project, and the researchers cannot change the questionnaire because it has already passed ethics? That is unethical." Many women felt that ethics review processes must also have participant involvement. For example, it was suggested that "the research participants should be included in creating consent forms. They should be asked, 'What type of information should be on the consent form that will make your participation possible?'"

Specific concerns identified included the tensions inherent in the institutional REBs' insistence on complete confidentiality. Most women felt that the institutional stance on confidentiality displayed a fundamental lack of understanding about both the nature of confidentiality in small communities and the value of community-based research. For example, one woman said, "The Dalhousie ethics review insists on anonymity, but lots of people don't want anonymity. It should be about what people want." In community-based researchers' experience, what is defined as

confidential in community-based research is quite different from what they have experienced undergoing an institutional ethics review process.

While some women felt the institutional process was preferable to community-based researchers having to conduct ethics reviews themselves without the necessary time and funds, all agreed that the current ethics review processes were deficient. A number of women expressed the fear that if community-based researchers don't devise their own ethics procedure, they are at risk of having one created for them.

To resolve these conflicts, two possible future strategies were suggested:

1) The identification of strategic issues (i.e. joint university/community research grants) that could provide leverage for the creation of a partnership between community-based researchers and institutions. Through this partnership, institutional ethics processes could be transformed to be more responsive to the needs of community-based researchers. One woman suggested that, "We could start that partnership process by looking at funding like the CURA (Community-University Research Alliance). No university can get [a CURA grant] unless the university gets community signatures."

2) The creation of a community-based ethics association with ethics guidelines and certification process. Based on the experiences of several women present, it was thought that while the initial start up costs will be higher than proposal #1, operation costs would be reasonable and satisfaction levels high. For example, one participant noted:

*There are so many ethics processes, standards and disciplinary codes, but some central board with some legitimacy, like a community-based research professional organization stamp, could provide ethics approval and show that the project complies with some principles. It may be something that is community generated. We must respect differences, but I think that we can find some common principles.*

And another participant offered:

*We find our design very useful [for working with First Nations communities]. It was constructed by ourselves with input from the people in many communities. And we did this because we are committed to doing what we say we are going to do. Research is for the community and we are committed to that standard. It cost a lot up front, but we are learning about a lot of ways to cut costs now that the groundwork is laid.*



## **Part III - What values and objectives should be expressed by an ethics process?**

With the goal of either transforming existing institutional processes or creating a new community-based process, the participants were asked to identify the objectives and values they felt were important in an ethics review process. Some women were reluctant to participate in this stage of the Roundtable stating that it is dangerous to think of objectives outside of the context of what is possible. The fear was that smaller community organizations with less funding and fewer resources would fall short of idealized objectives, and, therefore, be the least likely to attract funding. As one woman noted, "We need to be careful that we are not creating guidelines that move more and more funding to bigger organizations that can achieve closer to the ideal." Other participants felt that it was important that community-based researchers identify their ethics review objectives, however ideal, and one woman added, "If you lose sight of your objectives, how can one push forward?"

Another concern centred on how objectives for an ethics review process would be tailored to the practical and ultimately subjective needs of community members. For example, one woman asked, "Who decides what is going to benefit the community?" But many of the participants felt that at the objectives and values level, the question was more about providing community-based researchers with the opportunity to gain more credibility and legitimacy for their methods. For example, one woman pointed out, "We have to start recognizing that we know our stuff and we have valuable skills to contribute." Another suggested that one way community-based researchers could have their research and methodologies recognized as valuable and legitimate was for a community-based ethics review board to be set up. This board would review research based on a broad set of ethics guidelines and its stamp of approval would show that "the project complies with some principles." She added, "Maybe they could be something that is community generated - we have to respect differences...but I think we can find some common principles. The problem might be more the need to be seen as legitimate by universities and other formal ethics processes."

The question of legitimacy was another central concern. One of the difficulties with creating review boards for community-based researchers was that they would be of little use if they lacked formal legitimacy. If established ethics review bodies refused to acknowledge the review as valid, would the community-based review increase the burden on community-based researchers who would still be required to go through the institutional review? As one woman asked, "Is it possible for the Maritime Centre to have its own process and ethics committee? I suppose the answer is yes, but will it be seen as being credible? Or, will the university still insist that we go through their process as well?" The issue emerged as one that will require consultation with existing organizations and institutions to resolve. One woman suggested, "This process [objective creation] is a key component to formulating a new process for the Maritime Centre. At that point we have something to go to [the university] with." To that end, one woman stated:

*We need some values guidelines and some directed points. I think that the values and guidelines may be the same for all types of processes. We need to create guidelines that are broad enough to be interpreted in a useful way for a wide variety of processes.*

Participants agreed that, at the very least, institutional REBs should make efforts to expand their membership and outreach to include experienced community-based researchers. A far superior process would be the creation of an affordable and accessible process that identifies and addresses ethical concerns of community-based researchers. The participants stipulated that:

Advisory resources must be available throughout the research process so that additional ethical concerns can be addressed should they arise.

- \* The process should be linked with experts (particularly community-based experts) and institutions that can provide issue-specific advice, objectivity, and lend formal legitimacy.
- \* The process must stress the maximization of potential benefits to the community and give voice to community members.
- \* Funders must be willing to commit the necessary resources for community-based researchers to develop and deliver ethics review processes.

## **Part IV - Future Directions**

Combining the ideal with the practical led to three distinct future strategies:

1) The creation of links between community-based researchers and existing institutional processes with the goal of modifying current processes making them more consistent with the objectives outlined in Part III. This would include having members with expertise in community-based research on the REBs.

2) The creation of a community-based research ethics review process or service.

3) The creation of an Ethics Guide for community-based researchers. This would include:

- \* A mission/values statement
- \* A set of principles for researchers, participants, and funders
- \* An outline of methodological approaches
- \* The creation of a pool of expertise available for consultation with researchers
- \* A mandate to increase the level of funding donors are willing to allot to ethics preparation and processes.
- \* A commitment to providing education in the form of affordable roundtables

However, a number of concerns were raised and all of the participants felt that each strategy merited further consideration.

Many of the concerns about a community-based ethics review process centred on the lack of funding available for ethics processes. As one woman noted:

*It seems that what I am hearing is that ethics is essentially about caring about the participants. Yet, it is a research component that most funding agencies are expecting community-based researchers to do for free - this is the same dilemma that women's caring labour faces across the social spectrum. And it is a vicious cycle. When women perform this service for free, it becomes expected unpaid-for service. And that is where we are now. Yet, if women abdicate their responsibility to participants as a sign of protest - in order to impress how valuable ethics is to the research process - then how will participants be protected?*

And another woman noted: "I would like to see the amount of unpaid labour that goes into feminist research versus the amount that goes into research that follows the male model. Women can't just keep working for free. That just reinforces the status quo." Putting funding for ethics on the agenda of a future ethics process was a key goal for most women.

Some women were sceptical that community-based objectives could be combined with the institutional process in a satisfactory way. They stressed the fact that the institutional process has proven unsatisfactory. "If we keep thinking about how we can please (universities) or integrate them into community ethics, then we aren't going to get anywhere. Community-based researchers neither have the time or resources to educate the university." For these women, reforming existing processes seemed counter-productive, and working within them unsatisfactory. "I am against going through a review where my way of doing research is not respected. I will not put myself in a vulnerable and abusive position."

However, other participants felt that a university/community-based researchers partnership is an achievable and worthwhile endeavour. Further, they identified some places to begin. For example, some current sources of research funding for universities require community partnerships. To that extent, many women felt that this may encourage the university to meet with and understand the needs of community-based researchers, as one participant stressed, "We should not give in to the institutional model, if we see the leverage that we have, it can be of benefit to us all. Nothing really happens without resistance." Women felt that a university/community-based research partnership goal could also be served by reinforcing the values of community-based researchers through the provision of affordable roundtables and educational seminars that reflect the key values and key principles of community-based research. Further, they would like to see the creation of "documents that facilitate the translation of community-based research values and methods to funders and external ethics processes." This would entail the creation of standardized tools and forms that could be attached to grant applications and ethics submissions. The forms would outline methodologies, procedures, and objectives. The benefit would be that funders and external processes would become familiar with the procedures of community-based researchers. Ultimately this would facilitate greater understanding of, and legitimacy for, community-based research.

Discussion ended on an optimistic note: "When women enter a space, there is potential for women's vision to transform the process for the better." All but one of the participants expressed the desire to continue involvement in the exploration of community-based ethics review and to pursuing discussion of the future directions outlined at the roundtable.