

## Community-Based Research Ethics\*

*We find our [ethics] design very useful [for working with First Nations communities]. It was constructed by ourselves with input from the people in many communities ... research is for the community and we are committed to that standard.*

Project Participant

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 a community-based ethics review are seldom provided. Community-based researchers often find that the established ethics review processes are not suited to their needs. They often find that ethical problems shift as their project progresses and thus they require a flexible ethic process that is fully integrated into all stages of their projects to deal with unexpected issues as they arise.

The long-term goal of this project is to develop a mechanism for ethics review of community-based research where existing ethics review processes are either not available or are not considered appropriate.

**\* This community research ethics project was conducted jointly by the Health Law Institute, Dalhousie University, MCEWH, and the Canadian Research Institute for the Advancement of Women (CRIAW). Funding was provided by the Population Health Fund, Health Canada Atlantic Region. The project leaders were Barbara Cottrell, CRIAW, and Jocelyn Downie, Health Law Institute. Telephone interviews were conducted with 25 community-based feminist researchers in Atlantic Canada. A background paper was prepared based on these interviews, and at least two women from each province were invited to a Community-Based Research Ethics Roundtable in March 1999. Chairs of local research ethics boards were also surveyed.**

### Key Issues

Community-based research ethics considerations centre on issues of consent, confidentiality and accountability.

**Consent** means participants should be clear about the intent of the research and how the information will be used. To that end, issues of literacy and language are a primary consideration. It may be necessary to read consent forms out-loud in case participants have difficulty reading for themselves. Obtaining consent may be more appropriate at the end, when the participant is clear to what they are consenting to.

**Confidentiality** is best expressed as an agreement between the researchers and participants. 'Agreement' connotes joint rights and responsibilities. Community-based researchers face ethical issues around the disclosure of information by the people participating in studies whom often live in small communities. Often the information used in quotes can be identifying. The issue of confidentiality must be reconciled with those participants who want to have their voice heard.

**Accountability** means that a key goal of research must be to give back to the community. Research subjects need to be clear about the reasons why they are participating and the overall benefits that might accrue if the criteria of informed consent are to be satisfied. When researchers enter a community there is an expectation, on the part of community members, that some tangible benefit will result. When benefits are not forthcoming, communities are often disillusioned and possibly worse off than before. The way in which research projects benefit the community has to be decided by the community rather than the researcher.

This must be reflected in the research process through participant input into research design, the provision of counselling, if necessary, and mechanisms through which participants can amend findings and have input into recommendations.

## Why Are Community-Based Research Ethics Important?

Research dealing with populations at risk is fraught with potential risks to participants. Community-based researchers face issues of politeness and common courtesy, as well as moral issues such as the capacity of the research to ‘hurt’ participants. Researchers studying participants at risk (e.g., survivors) or stigmatized issues face unique challenges. Such research must build risk-minimizing processes into the project design (e.g., talking to councillors in advance about what might happen during interviews with groups at risk and using this information to develop procedures to deal with any crisis that might arise, and training interviewers who might be bringing difficult issues to the attention of participants and ensuring that someone is available to handle the situation appropriately). Accountability to the research subjects or the community being studied must form a central part of the ethics process.

The various methodologies that community-based researchers may use (i.e., participatory action research, feminist research) require specialized procedures and, consequently, involve specific types of ethical concerns. These methodologies require that the researcher and participants have input into the ethics review process, provide guidance in the research design phase, and have mechanisms to revisit ethical concerns after the project has been approved.

Community-based research ethics reflects the special needs of community-based researchers and their research approach. Most importantly, community-based research ethics recognizes the need for inclusiveness to ensure that participants are being protected while the research objectives are being met.

## Recommendations By Community-Based Researchers

1. **Create links** between community-based researchers and existing institutional ethics processes to ensure the institutional ethics review process is consistent with community-based research.
2. **Create an ethics guide** for community-based researchers that includes a mission/value statement, a set of principles, and an outline of community-based research methodological approaches.
3. **Create a process** for community-based research ethics review.
4. **Create a pool of ethics experts** available for consultation with researchers.
5. **Increase funding** from donors to enable ethics review preparation and support community-based researchers throughout the ethics process.
6. **Provide education** sessions and roundtable with community-based researchers to develop the details for a community-based ethics review process.

### Maritime Centre of Excellence for Women's Health

PO Box 3071 Telephone: 902-420-6725 [info@mccewh.ca](mailto:info@mccewh.ca)  
Halifax, Nova Scotia Toll-free: 1-888-858-1112 [www.medicine.dal.ca/mcewh](http://www.medicine.dal.ca/mcewh)  
B3J 3B9 Canada Fax: 902-420-6752

The Maritime Centre of Excellence for Women's Health is supported by Dalhousie University, the ANK Health Centre, the Women's Health Bureau of Health Canada, and through generous anonymous contributions.

