



CENTRE FOR
COMMUNITY
BASED RESEARCH

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Development of the Community Research Ethics Office

Supporting Community Based Research in
Waterloo Region

By

The Centre for Community Based Research

communitybasedresearch.ca

Stages of Developing the Proposed Community Research Ethics Office in Waterloo Region

The purpose of this document is to describe the process of developing the CBR Ethics Support Office and to describe the future functions of the Office in Waterloo Region.

Rationale

In Canada, all research conducted through academic institutions that receive funding from Tri-Council agencies (SSHRC, CIHR, NSERC) require an ethics review through an established Research Ethics Board. Increasingly, research in Canada is being conducted outside of academia (e.g., NGO's, government, independent consultants) and more and more knowledge is being produced through these community-based research (CBR) initiatives. Even though much of this research follows some established professional ethical standards, no ethical review procedures are required for most CBR projects, as well as ethical support and review of CBR is difficult to access. There is a need to respond to the immediate urgency of community-based researchers to easily access an ethical support and review process.

Initial Community Meeting

In January 2008, CCBR hosted an open community meeting to discuss the need and vision for ethical reviews of CBR in Waterloo Region. The meeting was attended by over 45 representatives from local community organizations, social institutions, government, non-governmental funders, and academics. The purpose of this meeting was to determine if there is a local need for ethics review and protocols in CBR and if so, how this can be accomplished in Waterloo Region. A main finding from the meeting was a strong need for a collective response in the near term. The meeting ended with a call for a working group to implement the ideas generated by meeting participants. Twelve people volunteered to join this working group.

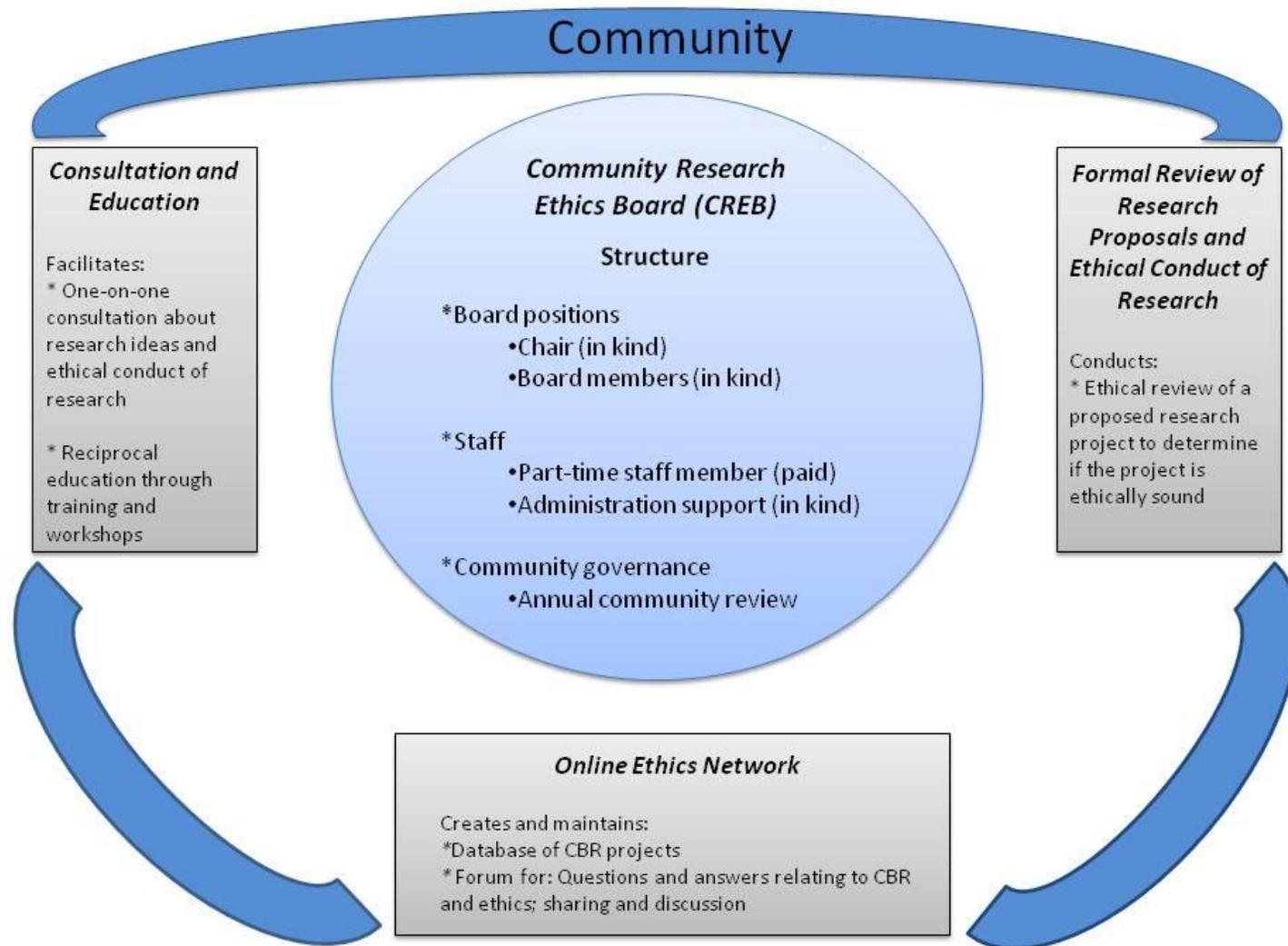
Needs Assessment and Feasibility Study

In the fall of 2008, a steering committee was struck from the larger working group. The steering committee decided to develop a needs assessment and feasibility study to better understand the challenges associated with CBR and possible future actions that could be taken. Also at this time, the Wellesley Institute located in Toronto, Ontario joined the team as a funder and as a research partner in the project. In January, 2009 the CCBR team began conducting the needs assessment and feasibility study. By September, 2009 the Waterloo site had completed data collection. Ten key informant interviews were conducted and 15 people participated in focus groups. In addition, at this time the Toronto site had conducted 18 key informant interviews and had 31 people participate in focus groups. In total, knowledge and ideas were shared by 74 people including academics, members of community organizations and peer researchers. Between September, 2009 and January, 2010 the information was analyzed and summarized with the purpose to share the findings and explore action strategies at another community forum.

Community Forum and the Development of the Proposed Community Research Ethics Office

On Feb. 5, 2010 a community forum was held to share the findings from the needs assessment and feasibility study. Once again, multiple stakeholder groups participated in the forum. The overarching purpose of the community forum was to use what we have learned so far to develop a feasible approach for improving ethical review of/support for CBR that can be implemented in Waterloo Region. Since the 2010 community forum, the steering committee has grown in size and been working hard to combine the feedback from the community forum into one actionable approach to providing ethical support for CBR in Waterloo Region. This process is complete and the steering committee is now turning to you for feedback and suggestions related to the work-to-date, prior to implementing the Community Research Ethics Office into Waterloo Region.

Proposed Community Research Ethics Office in Waterloo Region



Proposed Community Research Ethics Office in Waterloo Region

Purpose and Procedure

The Community Research Ethics Office strives to offer a supportive environment that encourages community researchers to participate and collaborate in a process of ethical reflection that promotes awareness of ethical issues and maximizes ethical conduct of research.

Community researchers (community members, service providers, members of organizations, and other individuals) may contact the Office for two different forms of support: For Consultation and Education; or to access the Research Ethics Board. In addition, the Online Ethics Network may be accessed at any time without prior consultation with the Office. When seeking support, community researchers are to submit a short application (provided to the researcher and available online) to the part-time staff member. The application includes what form of support the community researcher is seeking and brief information about the applicant and the applicant's research. The part-time staff member will review the application and direct it to the appropriate positions within the Board.

Components of the Community Research Ethics Office

Consultation and Education (CE)

Community researchers may contact the Community Research Ethics Office for one-on-one consultation about research ideas, methodology and ethical conduct of research. To facilitate this process, researchers are to submit an application to the part-time staff member working in the Community Research Ethics Office. This staff member will proceed to direct the application and community researcher to the appropriate board member/s who will consult with the community researcher and provide assistance in identifying ethical issues. The consultation process is intended to assist the community researcher in determining solutions for possible ethical dilemmas arising in the research. The Office will keep a record of the consultation meetings and the Chair of the Board will be kept informed about all decisions that are made.

Community researchers may also participate in training sessions and workshops intended to facilitate reciprocal education related to CBR and ethics. The training sessions and workshops will be designed based on community needs and interests and hosted by the CBR Ethics Support Office. To ensure that the training sessions and workshops reflect community needs and interests, community members and community researchers are encouraged to approach the Office with topic suggestions. Based on experience with a specified topic, community members and researchers may also have the opportunity to direct the training sessions or workshops.

Community Research Ethics Board (CREB)

Community researchers may contact the Community Research Ethics Office for review of a proposed research project. A request for ethical review of a research proposal should be submitted by way of application to the part-time staff member working in the Office. This staff member will proceed to direct the application to the Chair of the Board. Initially, the Chair will consult with the applicant to discuss the ethical aspects of the application. This process is intended to assist the community researcher in determining solutions for possible ethical dilemmas arising in the research and to help facilitate the review process. When the Chair and applicant have completed the initial process, the application will be submitted to the other Board members for consideration. The Chair and Board members will review the research proposal as quickly as possible and issue a statement regarding the ethical integrity of the proposed research project. It should be noted that there may be a series of communications between the CREB and the applicant before a statement is issued by the CREB that a project is ethically sound. Also,

Proposed Community Research Ethics Office in Waterloo Region

there is no obligation for researchers to follow the feedback provided by the Office; however, it is encouraged to maximize the standard of CBR in Waterloo Region. In addition, researchers are asked to consult with the CREB about new or emerging ethical issues that arise after a project has begun. These issues will be documented and relevant advice will be communicated to the researcher in charge of the project.

Online Ethics Network (OEN)

Community researchers may also contribute to and access an Online Ethics Network. This network is intended to keep community researchers informed and will consist of a database of CBR projects that are taking place in Waterloo Region. The network is also intended to provide a forum for questions and answers relating to CBR and ethics and to create the opportunity for community researchers to share and discuss issues relating to CBR.

Structure of the Community Research Ethics Office

Board and Staff Positions

The structure of the Community Research Ethics Office will include volunteer Board and paid Staff positions. The Board will consist of a Chair and a small number of board members. The Chair will be responsible for over-seeing the Board functions for both consulting with community researchers and reviewing research proposals. The Board will be multidisciplinary in nature and the main criteria in hiring Board positions will include:

- Gender and cultural diversity
- Expertise in the methodology and ethical considerations salient to CBR
- Expertise in ethics and law
- Community research experience (as either researcher or participant)

The Staff positions will include a part-time staff member and administration support. The part-time staff member will act as the liaison between the community and the Office and will be in on-going contact with the Chair and board members. The part-time staff member will link community researchers to appropriate forms of support, resources and to educational training sessions and workshops. The administration support will assist the part-time staff member and be responsible for managing Office resources and day to day operations.

Community Governance

The Community Research Ethics Office is intended to meet the needs of the community. Accordingly, the community is encouraged to provide on-going feedback to the Office. The Office welcomes diverse voices and opinions to be shared and hopes that the community will be actively involved in monitoring the processes, actions and decisions occurring within the Office. To create this opportunity, the Office will prepare at least one community forum per year intended to promote feedback related to the components of the Office. In keeping with its role in raising awareness of ethical issues in CBR, a periodic report will be prepared for the community and will summarize the nature of ethical issues arising from CBR and the techniques used to address them.