Attending to the Ethics of Community-Based Research

Presented by the Community Research Ethics Office
Who We Are

The development of the Community Research Ethics Office was based on a need for ethics review and protocols in CBR, as identified by over 45 representatives within the Waterloo Region.

Implemented in 2011 and funded by the Ontario Trillium Foundation, CREO has been in service for 2 years, responding to the needs of community researchers to easily access an ethical support and review process.
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What We Do

PURPOSE:
To offer a supportive environment that encourages community researchers to participate and collaborate in a process of reflection that promotes awareness of ethical issues and maximizes the ethical conduct of research.

PRINCIPLES:
Respect for Persons
Respect for Community
Concern for Welfare
Concern for Justice
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**Community Research Ethics Board (CREB)**

- Board positions
  - Chair (in kind)
  - Board members (in kind)
- Staff
  - Part-time Coordinator (paid)
  - Administrative support (in kind)
- Community governance
  - Annual community review

**Consultation and Education**

- One-on-one consultation about research ideas and ethical conduct of research
- Reciprocal education through training and workshops

**Review of Research Proposals and Ethical Conduct of Research**

- Ethical review of a proposed research project to determine if the project is ethically sound

**Community Research Ethics Network**

- Creates and maintains:
  - Resources related to CBR projects
- Forum for: Questions and answers relating to CBR and ethics: sharing and discussion
Workshops:
- Am I Being Ethical In My Treatment of Participants and Communities?
- What Are the Ethical Considerations in PAR?
**COMMUNITY**

**Consultation and Education**
Facilitates:
* One-on-one consultation about research ideas and ethical conduct of research
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Examples:
- Ontario Health Family Transplant
- University of I
- WoodGreen C
Examples:
Ontario Health & Phys Ed Association
Family Transitions Place
University of Liverpool
WoodGreen Community Services
Issues & Concerns
About Research

Four themes identified:
1. Dissemination of information
2. Confidentiality procedures
3. Data collection, input, analysis
4. Consent from participants
Issues & Concerns

- Dissemination of Information: 46%
- Confidentiality Procedures: 35%
- Data related Issues: 8%
- Consent from Participants: 11%
General Observations

High quality
High awareness
CREO is appreciated
Requests from outside the Region of Waterloo

However,
1. Demand
2. Membership
3. Sustainability
Questions? Comments?
Stories about successes and struggles?