

## Community-Engaged Research (CER) Ethics

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Pre-Conference Workshop  
Community-Campus Partnerships  
for Health  
11<sup>th</sup> Conference  
Portland, Oregon  
May 12, 2010



### Shape of our workshop

1:00 pm	Welcome and Introductions
1:20	Overview of community-engaged research (CER)
1:30	Case studies
2:30	<i>Break</i>
2:45	Discussing the potential for 'growing' the existing research-ethics review system to support CER
3:00	Small-group brainstorming
3:20	Large-group discussion
4:00	Wrap-up

## Introductions

Please introduce:

- Yourself
- Your organization (if applicable), and
- Why you have chosen this pre-conference workshop

## What is ‘ethics’ in research? In CER?

“Ethics is about how we must act to get along with each other, how we want to be treated and to treat others.”

(patterson, 2008, p. 24)

Procedural ethics

Situational ethics (Ellis, 2007)

As CER develops, how might the conventional ethics-review system evolve...?

## Conventional Practices

- Ethics Review has become a conventional practice in research
  - Institutional Review Boards in the US
  - Research Ethics Boards in Canada
  - Few community situated, non-institutional alternatives – but some exist:
    - CREBA (Alberta, Canada)
    - CBRC Research Ethics Board (Vancouver, BC)
    - Community Coalition Board (Atlanta, GA)
    - Special Services for Groups (Los Angeles, CA)

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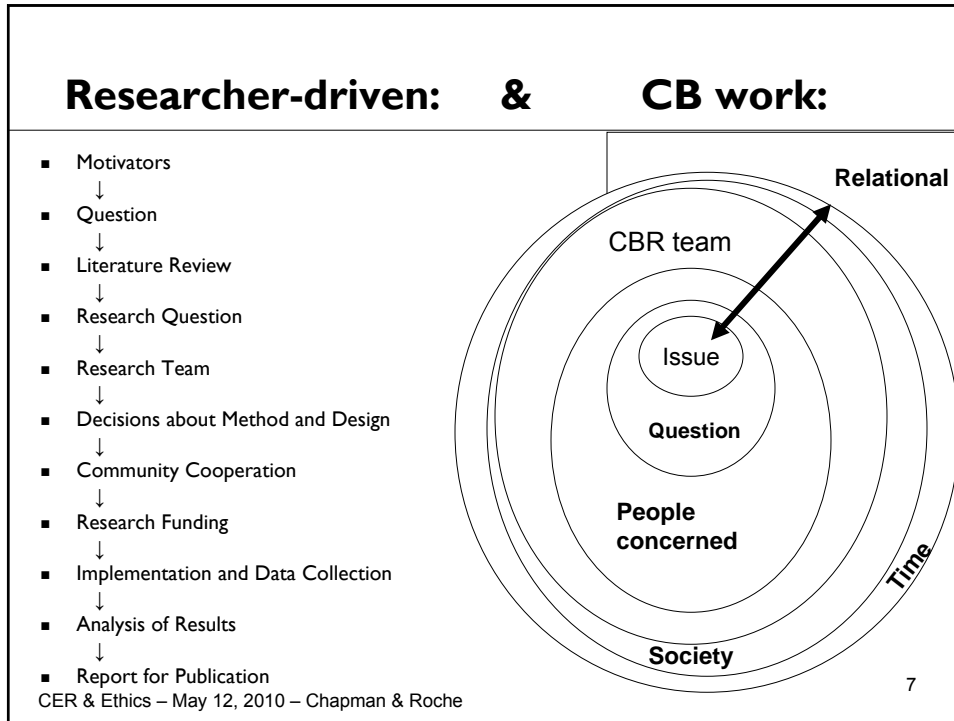
## Guiding Principles

(Belmont, 1979; Tri-Council Policy Statement, 1998...2005)

- Respect
  - Respect for human dignity
  - Respect for free and informed consent
  - Respect for vulnerable persons
  - Respect for privacy and confidentiality
- Justice
  - Respect for justice and inclusiveness
  - Balancing harms and benefits
- Beneficence (responsibility for participants' well-being relative to the research project)
  - Minimizing harm
  - Maximizing benefit

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**Community-Engaged Research (CER) is:**

“ . . . the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.

It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members.

It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices.”

(Fawcett, 1995)

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**Break (10-ish min.)**

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**How might an ethics-review process look today, if it were based on:**

- **Relationship as a way of knowing**
  - Not just based on principles, dominance, or conflict
  - Also on relationship, respect, negotiation, dialogue
  - Relational justice (Shore, 2006)
- **Grounded in an immediate time, place, culture, language, etc.**
- **Based on *interdependence* and engagement**
  - As compared with: independence and distance from
- **Living, ongoing process**

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## Relational ethics ...

- Calls for a shift in focus away from the procedural tasks associated with rights and responsibilities towards a recognition of *relationships* as critical
- A framework of ethics that is more:
  - Engaged with and grounded in everyday practice
    - “the ordinariness of everyday ethical issues” (Austin, 2007)
  - Person-centered, and context is given precedence
    - ‘fostering autonomy’ through mutual respect (Lambert et al., 2003)

## Relational ethics

### May Inform our Understandings of Ethically Sound Research in CBR

- Ethically sound research as being understood as related to the ideas and values of working with community
- understandings of community, and of community engagement
  - the role of communication and practices around decision-making
  - related to ideas of ‘community accountabilities’
  - and to enacting social action through research

Community Based Research Ethics Needs Assessment Study  
The Wellesley Institute and The Centre for CBR (2010)

## Discourse ethics...

- Recognizes the conventional ethics-review system's power structure:
  - Based not only on a power differential between researchers and participants but also between review boards and researchers in determining what is ethical (Boser, 2007).
- Supports a balancing of power across partnerships
  - Involving all partners/participants in the discussion of respect, beneficence, and justice as research is designed.
  - Facilitating ongoing dialogue between CER partners and members of their REBs/IRBs.

(Halse & Honey, 2005)

So...Ethical according to whom?

- Ethical according to the diverse perspectives involved...

## Key questions – Small Groups

Group A:

- What are the ethical issues/implications of research that involves community members as active partners?

Group B:

- What strategies help to maximize community benefits and minimize community risks in CER?

Group C:

- What policies/systems can partnerships put in place to ensure that their research attends to community-level ethical considerations?

Group D:

- What policies/systems can IRBs/REBs put in place to ensure that CER attends to community-level ethical issues?

## Given the nature of CER...

- Blurred participant/researcher roles
  - Protecting whom from whom?
- Iterative and emergent research designs
  - When will you start?
  - When will you be finished?
- Representation in the partnership
  - Who represents each of the partners?
    - For example, who represents 'community'?
      - Substantively?
      - Demographically?
- Community-level informed consent
  - Relative to individual-level informed consent
    - How?
  - Community-level risks and benefits? Privacy? Confidentiality? Anonymity?
- Unconventional informed consent processes
  - For example: Permitting youth under the age of 18 to provide their own consent

(Shore, 2007; Flicker, Travers, Guta, McDonald, & Meagher, 2007; Jacklin & Kinoshameg, 2008; patterson, 2008)

## Next Steps

Identify possible next steps for thinking about and acting on our pooled understanding of ethics in CER.

## What could 'ethics' look like... into the future?

- Dialogical and Relational
  - Multi-vocal and multi-faceted
- Structure and processes, too
  - CIHR Guidelines for Health Research Involving Aboriginal People (May 2007)
    - <http://www.cihr-irsc.gc.ca/e/29134.html>
    - "a collaborative tool" <http://www.cihr-irsc.gc.ca/e/29339.html>
  - TCPS Revised Draft 2<sup>nd</sup> Edition (Dec. 2009)
    - <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/revisee-revisee/chapter1-chapitre1/#toc01-1a>
    - Chapter 9 – "Research involving Aboriginal Peoples in Canada (Dec. 2009)
      - <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/revisee-revisee/chapter9-chapitre9/>

### Connecting with Colleagues with Interest in the Ethics of CER

- We invite you to stay connected with us and with colleagues who share your interest in the ethics of CER by joining CCPH's listserv on the topic at <http://mailman1.u.washington.edu/mailman/listinfo/ccph-ethics>

### Watch for the online curriculum:

IRB-REB Workgroup on Community-Engaged Research. *The IRB/REB Curriculum on Ethical Considerations in Community-Engaged Research* (Working Draft). (2010). Co-sponsored by Community-Campus Partnerships for Health and Tuskegee Bioethics Center.

- Who for?
  - Administrators and members of IRBs and REBs
  - United States and Canada

## Additional resources

- CBPR Curriculum [www.cbprcurriculum.info](http://www.cbprcurriculum.info)
- Community-Campus Partnerships for Health (CCPH) [www.ccpb.info](http://www.ccpb.info)
- Community Tool Box: <http://ctb.ku.edu/en/tablecontents/>
- Family Health International – basic ethics training
  - <http://www.fhi.org/training/en/RETC>
- Flicker, S. & Savan, B. (2006). *A snapshot of CBR in Canada*. Toronto: Wellesley Institute. Available: [http://wellesleyinstitute.com/files/CBR\\_snapshot.pdf](http://wellesleyinstitute.com/files/CBR_snapshot.pdf)
- CBR&E Workshops' Reference List at: <http://www.cup.ualberta.ca/>
  - After *Welcome* page, go to the *Documents* tab (left of screen), then *CBR Workshops* option, and scroll down to the end of the page.

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## Additional reference

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## Thank you!

Citation for the Pre-Conference Workshop:

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