

Collective vs. Individual Rights: Protection of Collectivities in Participatory Research and Integrated Knowledge Translation

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CAREB Montréal
May 2010



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Outline of presentation

- Participatory Research (PR) and Integrated Knowledge Translation (iKT)
- Protecting the *Community*
- TCPS Draft 2nd Edition and CIHR Funding Guidelines
- Strategies for REBs / IRBs

Participatory Research (PR)

“Systematic enquiry,

with the collaboration of those affected by the
issue being studied,

for the purpose of education and taking
action or effecting social change.”

- Undertake the research
- Within the partnership
- To make a difference

*The Royal Society of Canada- Study
of Participatory Research in Health
Promotion: 1998 Green LW, George
MA, Daniel M, Frankish CJ,
Herbert CP, Bowie WR, O'Neill M.*

*Definition used by CDC and
Institute of Medicine*

Integrated Knowledge Translation

In integrated KT, **stakeholders or potential research knowledge users are engaged in the entire research process**. By doing integrated KT, researchers and research users work together to shape the research process by **collaborating to determine the research questions, deciding on the methodology, being involved in data collection and tools development, interpreting the findings, and helping disseminate the research results**. This approach, also known by such terms as collaborative research, action-oriented research, and co-production of knowledge, should produce research findings that are more likely be relevant to and used by the end users.

CIHR Knowledge Translation Portfolio: <http://www.cihr.ca/e/39033.html>

Rationale for respecting communities in addition to respecting individuals

1. Community interests are separate from individual interests, and may conflict

genetic research in Ashkenazi Jewish people uncovered genetic predisposition to colon cancer; mutation present in 6.1% of sample; removal of individual identifiers does not protect the collective – repercussions for access to insurance and services

2. PR requires ethics to assign the same moral status to communities by recognising the importance of community desires and interests.

Weijer, C (1999) Protecting communities in research: Philosophical and pragmatic challenges. *Cambridge Quarterly of Health Care Ethics*, 8, 501-513.

Protection of the Community

To be found in the TCPS and CIHR Guidelines...

CIHR Guidelines for Health Research Involving Aboriginal People 2007

(Institute of Aboriginal Peoples' Health with CIHR Ethics Office)
http://www.cihr-irsc.gc.ca/e/documents/ethics_aboriginal_guidelines_e.pdf

Includes a research agreement template very relevant to many other groups

Revised Draft 2nd Edition of the TCPS (Dec. 2009)
<http://www.pre.ethics.gc.ca>

Chapter 5 Privacy and Confidentiality

*"Group" is liberally strewn throughout the document.
(examples:)*

'Privacy risks in research relate to the identifiability of participants and the potential harms they, **or groups to which they belong**, may experience from collection, use and disclosure of personal information.'

'Breaches of confidentiality may harm the participant, the trust relationship between the researcher and the participant, other individuals **or groups**...'

Chapter 9 'Research Involving Aboriginal Peoples in Canada'

The guidance provided in this chapter is based on the premise that **engagement with community is an integral part of ethical research** involving Aboriginal peoples. While continuing to respect individual autonomy, this Policy acknowledges the **role of community in shaping the conduct of research**, in particular, research that affects First Nations, Inuit and Métis peoples.'

Ethical challenges (1)

For University

- Does ethical review board have knowledge and understanding of PR principles?
- Are appropriate end-users included in the review and what weight do they carry?
- How can review occur when researcher needs to co-develop proposal?
- How can review board evaluate an evolving project?

Ethical challenges (2)

For Partner ('community')

- Do partners have a review and approval process?
- If yes, what power does it carry?
- Who actually does represent the community?

For Both

- Who gets the final say? Partner or University?
- Where, if anywhere, do interests conflict?
- University forms often not appropriate for PR
i.e. to date communal protection not addressed

Strategies From the McGill Faculty of Medicine IRB:

- community certification first!
- community member on committee for that case
- Iterative approach to review and approval

Also to consider... CIHR allows knowledge user PI
(*'Principle Decision-Maker'*)

Resources:

CIHR Knowledge Translation Learning Modules:

A Guide to Researcher and Knowledge-User
Collaboration in Health Research

<http://www.learning.cihr-irsc.gc.ca/course/view.php?id=3>

CIHR IRSC **Chapter 6** PRAM
Participatory Research at McGill

Ethics and partnership agreements

Learning objectives:

- 1) Learn about the ethical considerations inherent in IKT projects, that necessitate a discussion that goes beyond the principles traditionally underlying research ethics.
- 2) Learn that IKT ethics endows both researchers and integrated knowledge users with clearly defined rights and responsibilities, and understand the value of jointly negotiating these with respect to trust and mutual respect.
- 3) Learn the advantage of written partnership agreements, and some models/examples for developing them.
- 4) Learn how Research Ethics Boards (REBs) may approach IKT projects, and strategies for working with REBs to ensure an adequate and timely ethics review.

McGill <http://pram.mcgill.ca> Canada

Resources:

Community-Campus Partnerships For Health:

IRB/REB Curriculum on Ethical Considerations in
Community-Engaged Research

In Preparation...

Examples of PR Communities in health care (our involvement...)

- **Geographical communities**
Aboriginal communities, urban neighbourhoods...
- **Other communities**
Ethnic communities
Women prisoners/prison alumni/prison staff
Patients during relocation of a FM teaching unit
Patients on renal dialysis
Homeless
- **Organisational communities**
Practice-based research networks, YMCA, Canadian Pharmacists Association, Pharmacogenomics, Patients/staff assessing patient satisfaction in FM teaching unit
- **Health service professionals**
Assessing impact of point of care information

Web based resources

- PRAM – Participatory Research at McGill (<http://pram.mcgill.ca>)
- CIHR Knowledge Translation Portfolio (<http://www.cihr-irsc.gc.ca/e/29418.html>)
- CIHR: A Guide to Research and Knowledge User Collaboration in Health Research (<http://www.learning.cihr-irsc.gc.ca/course/view.php?id=3>)
- CIHR Guidelines For Health Research Involving Aboriginal People (http://www.cihr.ca/e/documents/ethics_aboriginal_guidelines_e.pdf)
- Guidelines for Participatory Research (<http://green.net/guidelines.html>) and Minkler M and Wallerstein N (Eds) CBPR for Health second edition Appendix C
- Community Campus Partnerships for Health (<http://www.ccpf.info>)
Includes examples of research agreements (<http://depts.washington.edu/ccph/commbas.html#Principles>)
- NAPCRG Policy Statement on Participatory Research (<http://www.napcr.org/psac.html>)
Short version of this document published as Participatory Research Maximizes Community and Lay Involvement Macaulay AC et al, BMJ 1999; 319:774-5
- KSDPP – The Kahnawake Schools Diabetes Prevention Project (includes Code of Research Ethics) (<http://www.ksdpp.org>)