

McGill University
Faculty Development Workshop

An Introduction to Participatory Research

Participatory Research at McGill (PRAM)

<http://pram.mcgill.ca>

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Introductions

Conflict of Interest

§ None of the presenters have any conflict of interest

Goal of workshop:

To build capacity to conduct Participatory Health Research

Workshop Objectives (after the workshop I will be able to):

- § Understand the principles of participatory research (PR)
- § Understand how PR promotes knowledge translation

- § Identify and recruit partners
- § Engage in collaborative research
- § Recognise challenges
- § Understand ethical issues

- § Identify funding opportunities/other resources

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
1995 Green LW, George MA, Daniel M, Frankish CJ, Herbert CP, Bowie WR, O'Neill M.

Definition also used by CDC and Institute of Medicine

Research with those affected, not 'on' or 'about' those affected

Different terminology

- § Action research
- § Participatory action research
- § Participative research
- § Collaborative inquiry
- § Participatory rural appraisal
- § Community-based participatory research
- § Dialectic research
- § Conscientising research
- § Emancipatory research
- § Social reconnaissance
- § Participatory learning empowerment
- § ...

History of Participatory Approach

Northern Tradition

Kurt Lewin's action research 1940's,
Emancipatory and feminist research in USA

Southern Tradition

Self-determination and empowerment research
the from 3rd world, 1970's (Paulo Freire and others)

Health Promotion

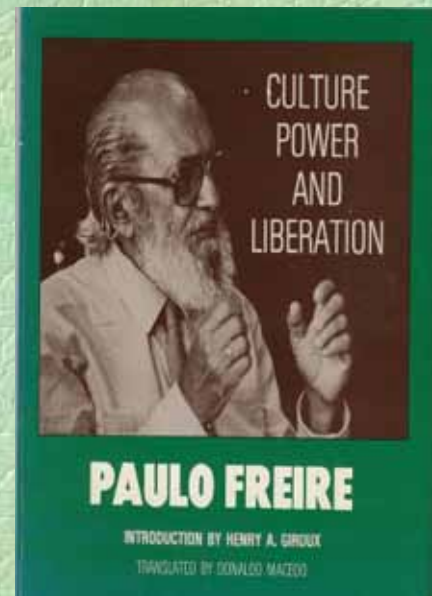
1980's - CDC funded PR centers:

B. Israel, L W Green, M. Minkler, N. Wallerstein.

Health Care; Practice-Based Research Networks

2000's -

Lewin K. Action Research and Minority Problems. J. of Social Issues 1946;2(4):34-46
Freire P. Pedagogy of the oppressed.



Participatory Research Principles

- § Participatory and cooperative
- § All partners are experts
- § Power differentials among partners are acknowledged and addressed (funding, political, gender, age, cultural)
- § Partners discuss potential harm as well as potential benefits of research

Participatory Research Goals

Equally important goals

- undertake quality research with high level of scientific rigour
- provide benefit and build capacity of all partners
- develop knowledge applicable to other settings

Scientific rigour should never be sacrificed!

- strongest PR projects are the most scientifically rigorous (systematic review Viswanathan 2004)

Participatory research is an *approach* to research – as opposed to a methodology

- can be RCT, quasi-experimental or observational; and qualitative, quantitative or mixed methods as appropriate

The Spectrum of Research



- Researchers select research topics, questions, methods, dissemination

- Power and decision making are in researchers' hands

- Researchers are the experts

- Knowledge production is primary

- Researchers and partners select topics, questions, methods, dissemination

- Power and decision making are shared

- Partners/ researchers are experts and co-learners

- Action, empowerment and capacity building are core

Thanks to K Culhane-Pera and Michelle Allan, North American Primary Care Research Group, 2008

Degrees of Stakeholder Engagement in Research



Thanks to K Culhane-Pera and Michelle Allan, North American Primary Care Research Group, 2008

Research for Knowledge Translation

Bill C-13 April 13 2000 “The objective of the CIHR is to excel, according to internationally accepted standards of scientific excellence, **in the creation of new knowledge and its translation into improved health** for Canadians, more effective health services and products and a strengthened Canadian health care system”

CIHR defines **knowledge translation** as "a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge **to improve the health of Canadians, provide more effective health services and products and strengthen the health care system**. This process takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user."

<http://www.cihr-irsc.gc.ca/e/29418.html>

Participatory Research Promotes Integrated Knowledge Translation (iKT)

<http://www.cihr-irsc.gc.ca/e/29418.html>

CIHR defines Knowledge Translation (KT) as

- n End of grant Knowledge Translation (KT)
- n Integrated KT (iKT)

Requires partnership of researchers and stakeholders

KT built into research as end-users involved throughout

Graham ID et al. Lost in knowledge translation: Time for a Map? *The Journal of Continuing Education in the Health Professions* 2006;26:13-24 Glasgow RE, Emmons KM. How Can We Increase Translation of Research into Practice? Types of Evidence Needed. *Annual Reviews Public Health* 2007;28:413-433

Benefits of Participatory Research and iKT

Involves all stakeholders – those who will use, or be affected by, the results of the research – in the research process from formulation of the research question through interpretation and dissemination of results.

And thus...

- By including all stakeholders, KT is built into the research process because the **intended users of the results** are involved in creating the knowledge
- Greatly increases the likelihood that results and recommendations will be acted upon: **Knowledge-to-Action**
- Greatly **increases the relevance** of the research to intended users
- Lessens end-of-grant ‘surprises’. All stakeholders are aware of ongoing developments.

Stages in Participatory Research and iKT

- § Getting Started
- § Generating action
- § Interpreting results & reality
- § Disseminating results, leaving a legacy

Origin of the Research Question

- § Did the original idea for the research project come from one of the partners?

- § Did the question come from the academic researcher?
 - | Clinical impressions, baseline data from chart review, analysis of existing data set(s)
 - | Is the research question or issue of interest supported by partners?

Getting Started

Who are the key stakeholders ?

- | how do you decide on key stakeholders?
- | how many are appropriate?

How can you contact them?

- | Do you have pre-existing partnerships from clinical work, administrative work or research?
- | Who are the natural leaders, who represents a group or organisation?

Guidelines for Assessing PR Projects

Has the proposed research project applied the knowledge and experience of intended users in conceptualizing and/or designing the research?

- o Knowledge and experience of intended users has not been applied or has been minimally applied.
- o Knowledge and experience of intended users has been partially but not sufficiently applied.
- o Knowledge and experience of intended users has been sufficiently applied.

Minkler M and Wallerstein N (Eds). *Community-Based Participatory Research for Health*. 2nd edition *Jossey Bass 2008* Reliability –Tested Guidelines for assessing PR Projects *Appendix C. pp 407- 418*

These have evolved from guidelines developed in 1995 - see <http://lgreen.guidelines.html>

Researchers...

“Researchers are co-learners rather than teachers, grappling as equal partners with ethical challenges and the need for research approaches that reflect both scientific and popular perspectives”

Minkler M. Using Participatory Action research to Build Healthy Communities. Public Health Reports 2000;115:191-197

Generating Action

What should the researcher and partners negotiate ? (1)

- § Research goals and objectives
- § Methods and duration of project
- § Terms of the partnership
- § Degree and types of confidentiality
- § Strategy and content of evaluation
- § Where data are filed, current interpretation of data, future control and use of data and human biological material

What should the researcher and partners negotiate ? (2)

- § Methods of resolving disagreements
- § Incorporation of new team members
- § Dissemination of results in plain language and scientific terms to communities, clinicians, health organisations, administrators, scientists, funding agencies and policy makers
- § Written agreement

Macaulay AC, Commanda LE, Freeman WL, Gibson N, McCabe ML, Robbins CM, Twohig PL, Participatory Research Maximizes Community and Lay Involvement. BMJ 1999; 319:774-8

Partnership in Tool Development

In the past week have you felt.....

Researcher's questions (deficit model)

- | | |
|--|-----|
| § Depressed or very unhappy | 78% |
| § Exhausted even though early in the day | 72% |
| § Lonely | 40% |

Partner's questions (asset model)

- | | |
|---------------------------------|-----|
| § Appreciated | 89% |
| § Meeting your responsibilities | 96% |

Joint Interpretation of Results

- § Allow for joint interpretation of preliminary analysis
- § Partners may have very different lenses and different interpretations

Joint Dissemination of Results

<http://www.cihr-irsc.gc.ca/e/29492.html>

- § Identify the appropriate audiences
- § Decide on credit and authorship
- § Disseminate in appropriate language and format
 - Diffusion (passive)
 - Dissemination (somewhat active)
 - Implementation (most engaged)
- § Who will be the ‘messenger’?
- § Use results to change practice and policies

Challenges

- § Time, time, time...
- § Need steering committee with wide representation
- § Ensure partners involved in research and governance
- § Maintaining trust
- § Power and control over resources
- § Constraints
 - changing personnel - partners and university
 - balancing partner and university expectations
 - university members – time, publications (tenure, promotion)
 - partners – time, finances, job commitment
- § Need for conflict resolution skills



Advantages of PR

For researchers

- § Data better reflects reality of study population
- § Incorporation of local knowledge
- § More accurate interpretation
- § Responsibility for outcomes shared by all
- § ñ Research-to-action

Advantages of PR and iKT....

For partners

- § Power to determine research priorities, allocation of resources, outcomes
- § Control of local data
- § Increased knowledge, capacity and skills
- § Action on priority issues being addressed by the research
- § Job creation
- § Sustainability of outcomes, influencing policy

Ethics

Ethical Considerations in Participatory Research

Code of Ethics

A collection of aspirations, regulations, and or guidelines that represent *values* of the group or profession to which it applies.

Jane Pritchard (1998). Codes of Ethics. *Encyclopaedia of Applied Ethics*, Volume 1 (pp.527-533). Academic Press.

Rationale for respecting communities in addition to respecting individuals

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

CIHR Guidelines for Health Research Involving Aboriginal People

2007 (Institute of Aboriginal Peoples' Health with CIHR Ethics Office)

http://www.cihrirsc.gc.ca/e/documents/ethics_aboriginal_guidelines_e.pdf

**Includes a research agreement template very relevant
to many other groups**

Tri-council Policy Statement: Ethical Conduct for Research

Involving Humans. Draft 2nd edition. 2008 <http://www.pre.ethics.gc.ca>

Chapter 5. Privacy and Confidentiality..... ‘despite removal of personal identifiers, a small or unique group (such as a group with a rare condition or Aboriginal community) may be identified. Individuals within that group may experience stigma, embarrassment or other harm.....’

Chapter 9 Research Involving Aboriginal People - Article 9.9 addresses PR

Ethical challenges (1)

For University

- § Does ethical review board have knowledge and respect of PR ?
- § 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 ?
- § How to use amendment forms ?

Ethical challenges (2)

For Partner

- § Do partners have a review and approval process?
- § If yes, what power does it carry ?
- § University consent forms often not appropriate for PR
i.e. to date communal protection not addressed

For Both

- § Who gets the final say? Partner or University?
- § Where, if anywhere, do interests conflict?



Knowledge Translation Funding Opportunities

KT Focus	Funding mechanisms
Synthesis	CIHR funds the Canadian Cochrane Network and Centre KT Synthesis Operating grants competition - reviewed by a panel of KT experts
Integrated KT	Partnerships in Health System Improvement (PHSI) KT Synthesis Knowledge to Action (end of grant KT) Strategic research funded through institutes Proof of Principal (POP) Meeting, Planning and Dissemination grants to develop collaborative relationships and grant proposals
End of Grant KT	Allowable expense as part of a grant application Knowledge to Action (integrated KT) KT Supplement Grants Proof of Principal (POP) Meeting, Planning and Dissemination grants to disseminate results
Science of KT	Operating grants competition- KT Panel, Strategic calls from the KSE Branch on theories and methods of KT

Participatory Research at McGill (PRAM)



<http://pram.mcgill.ca>
email: pram.med@mcgill.ca

PRAM resources

- Website with: literature/toolkit;
archive of past seminars
- Consultations
- Workshops
- Monthly Seminars
- Postgraduate scholarships
- Seed grants in Aboriginal Health



Web-based Resources

- § **Reliability –Tested Guidelines for assessing PR Projects**
Minkler M and Wallerstein N (Eds) *Community-Based Participatory Research for Health* 2nd edition *Appendix C. pp 407-418 Jossey Bass 2008*
(these have evolved from Guidelines to Assess a PR Project 1995:
<http://lgreen.net/guidelines.html>)
- § **Community Campus Partnerships for Health** <http://www.ccph.info>
<http://depts.washington.edu/ccph/commbas.html>
<http://www.cbprcurriculum.info/>
- § **Agency for Healthcare Research and Quality**
Creating Partnerships, Improving Health. The Role of Community-Based Participatory Research. *Community-Based Participatory Research: Assessing the Evidence* (Publication No. 04-E022-1, 2004)
<http://www.ahrq.gov/downloads/pub/evidence/pdf/cbpr/summary.pdf>
- § **North American Primary Care Research Group (NAPCRG) Policy Statement on Participatory Research** www.napcrg.org/exec.html
- § **CIHR Knowledge Translation Portfolio – Integrated KT:**
<http://www.cihr-irsc.gc.ca/e/29418.html>
- § **Kahnawake Schools Diabetes Prevention Project. Code of Research Ethics**
http://www.ksdpp.org/elder/code_ethics.html