Developing partnerships to Promote Engagement and Sensitivity in Aboriginal Health Research

Ann C Macaulay CM MD FCFP

Professor of Family Medicine
Participatory Research at McGill (PRAM)
http://pram.mcgill.ca

Kahnawake Schools Diabetes Prevention Project
www.ksdpp.org

October 4th 2013

I have no conflicts of interest to declare

Research “Subjects”

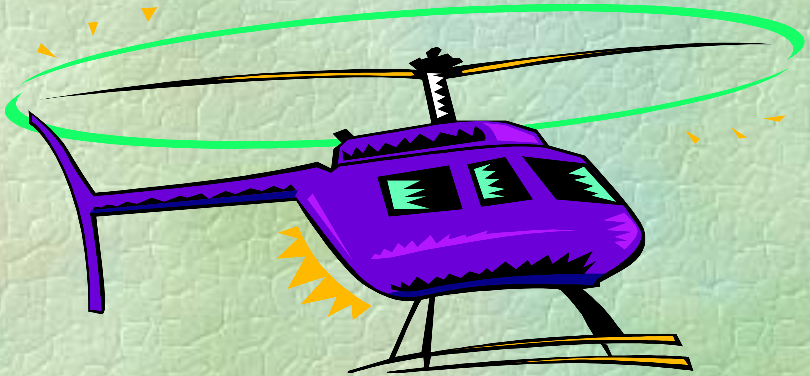
Researchers

↓

Communities

Conventional research is researcher directed

Nicknamed ‘helicopter research’



“Outside research teams swooped down from the skies, swarmed all over town, asked nosey questions that were none of their business and then disappeared - never to be heard of again.”

Montour LT, et al. ‘Diabetes Mellitus and Arteriosclerosis: Returning research results to the Mohawk Community’. Canadian Medical Association Journal 1988; 34: 1591-93

Research Participants

Researchers ↔ **Communities**

Being the subject of research is different from being a participant in research

Community engagement through Participatory Research

"Systematic enquiry

with the collaboration of those affected by the issue being studied, and/or those needing to use the results

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 et al

Definition used by CDC and Institute of Medicine

Participatory Research Principles

All partners have expertise

Recognise power differentials

Share the decision making

Build on strengths

Discuss potential harms in addition to potential benefits

Develop cultural humility

Participatory Research Goals

Equally important goals

- research is open and transparent
- undertake quality research with scientific rigour
- provide benefits, empower and build capacity of all partners
- develop knowledge applicable to other settings

Participatory research is a research *approach* –

not a methodology

- can be observational, RCT, or quasi-experimental

  using qualitative, quantitative or mixed methods

  as appropriate

Participatory Research supports integrated Knowledge Translation

Involves all stakeholders – those who be affected by, or will use, the results of the research – in the research process from formulation of the research question through interpretation, dissemination and application 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 relevance of the research to intended users
- Greatly increases the likelihood that results and recommendations will be acted upon: Knowledge-to-Action

Origin of the Research Question

- Did the question or concern come from the Aboriginal community?

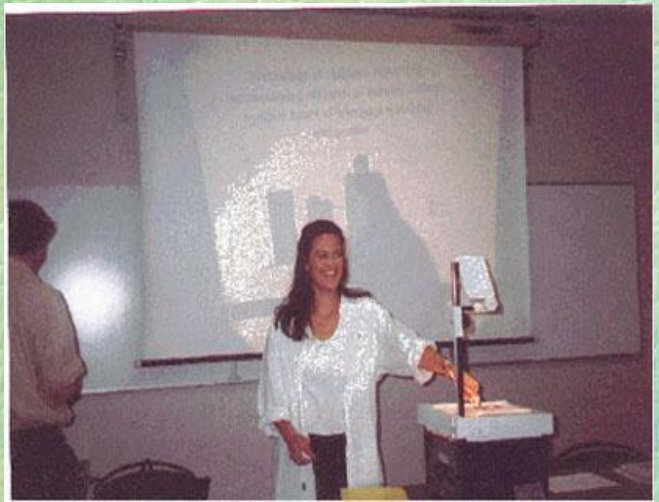
OR

- Did the question come from the researcher?
  - Clinical impressions, data from chart reviews, analysis of existing data, gap in the literature?

Is the research question or issue of interest supported by everyone?

What should the researcher and partners negotiate ? (1)

- Research goals and objectives
- Methods of data collection and duration of project
- Joint interpretation of data
- Degree and types of confidentiality- individuals and community
- Dissemination of results in plain language to communities, and scientific terms to clinicians, health organisations, scientists, funding agencies and policy makers



What should the researcher and partners negotiate ? (2)

- Where data are filed, future control and use of data and human biological material
- Methods of resolving disagreements
- 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

Challenges

- Time, time, time…
- Maintaining trust
- Power and control over resources
- Constraints
  - -changing personnel - partners and university
  - -balancing expectations
    - -university members – time, publications (promotion, tenure)
    - -partners – time, finances, work/family commitments
- Need for conflict resolution skills

Parker, EA et al. Community Action Against Asthma: Examining the Partnership Process of a Community-based Participatory Research Project J Gen Intern Med 2003;18:558-567

Evolving Ethics to Respect Communities and Individuals

- UNESCO, Universal Declaration on the Human Genome & Human Rights, 1997

  No research or research applications concerning the human genome, in particular in fields of biology, genetics and medicine, should prevail over respect for the human rights, fundamental freedoms and human dignity of individuals or, where applicable, of groups of people.

- WHO, Indigenous Peoples & Participatory Research, 2003

  Health research involving Indigenous Peoples, whether initiated by the community itself or by a research institute, needs to be organized, designed and carried out in a manner that takes account of cultural differences, is based on mutual respect, and is beneficial and acceptable to both parties.

- WHO, Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants, 2011

  Duties to respect and protect communities require examining ... and ... are aimed at minimizing... negative effects on communities such as stigma or draining of local capacity, and promoting positive effects.

Web-based Resources

- **Guidelines for Developing Partnerships**

  CIHR A Guide to Researcher and Knowledge-User Collaboration in Health Research. Parry D, Salsberg J, Macaulay AC
  http://www.cihr-irsc.gc.ca/e/44954.htmlH
  T

  Community Campus Partnerships for Health http://www.ccph.info
  http://depts/washington.edu/ccph/commbashtml

  Guidelines for assessing PR partnerships

  http://lgreen.net/guidelines.html#Guidelines for Participatory Research in Health

- **Examples of written agreements**

  CIHR Guidelines for Research Involving Aboriginal People

  See Template http://www.cihr-irsc.gc.ca/e/29134.html

  Kahnawake Schools Diabetes Prevention Project. Code of Research Ethics
  http://www.ksdpp.org/elder/ethics/html

- **Benefits of PR**

  Jagosh J, Macaulay AC, Pluye P, Salsberg J, Bush PL, et al Uncovering the Benefits of Participatory Research: Implications of a Realist Review for Health Research and Practice. *Milbank Q*. 2012;90(2): 311-46

Participatory Research at McGill (PRAM)

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

PRAM resources

- Consultations
- Workshops
- Seminars
- Website with: literature/toolkit; archive of past seminars