Developing and Maintaining Partnerships with Aboriginal Peoples, Organisations and Communities

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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.”

The issues from the community perspective

- Need research to answer practical questions
- Need input in research priorities
- Need research to build on the positive (and not always focus on the negative)
- Need control over allocation of research resources
- Need consent for use of personal data
- Need understanding of research results
- Need control over dissemination of results
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.”

- Develop the question
- 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 used by Centers of Disease Control and Institute of Medicine, USA
Research with those affected, not ‘on’ or ‘about’ those affected

Is the purpose of the project to facilitate the empowerment of individuals, groups and community?

Will the project help participants and other stakeholders to deal with factors that influence their health and their community?

PR is an approach to research - not a method
Community is a group of people sharing a common interest. Cultural, social, political, health, and/or economic interests link the individuals, who may or may not share a particular geographic association.

Community has collective identity.
PRINCIPLES OF PARTICIPATORY RESEARCH
Participatory Research Principles

- All partners are experts
- Power differentials among partners are acknowledged and sensitively addressed (political, gender, age, cultural, formal education)
- Communities discuss potential harm as well as potential benefits of research

North American Primary Care Research Group www.napcrg.org
What should the researcher and participating community negotiate? (1)

- Research goals and objectives
- Methods and duration of project
- Terms of community-research 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

Participatory Research Maximizes Community and Lay Involvement Macaulay AC, Commanda LE, Freeman WL, Gibson N, McCabe ML, Robbins CM, Twohig PL, for the Northern American Primary Care Research Group BMJ 1999; 319;774-8
What should the researcher and participating community negotiate? (2)

- Methods of resolving disagreements with the collaborators
- Incorporation of new collaborators into the research team
- Joint dissemination of results in community language and scientific terms to communities, clinicians, administrators, scientists, and funding agencies
Principles for Community Research

- Recognizes community as unit of identity
- Builds on existing strengths
- Facilitates collaborative partnerships
- Integrates knowledge and action
- Involves iterative process

Partnership where researcher knowledge, drawing and abstracting from multiple contexts, is combined with insider knowledge rich in experience and detailed understanding of a specific setting

Potential Pitfalls

- Time...
- Changing community/academic personnel
- Conflicting expectations
- Miscommunication
ETHICS OF 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.

Rationale for respecting communities


1. Community interests are separate from individual interests, and may conflict
   - cancer genetic research on Ashkenazi Jewish population uncovered genetic predisposition to colon cancer; mutation present in 6.1% of sample (removal of individual identifiers does not protect the collective)
   - aggregating individual responses to personal characteristics to the community level -- » dissemination -- » potential stigmatization

2. Assigns the same moral status to communities by recognising the importance of community desires and interests.
Evolving health research ethics

- Ethics developed to ‘protect’ the individual

- Participatory research requires additional respect/protection of community or collectivity in addition to respect/protection of individuals

CIHR Guidelines for Research Involving Aboriginal Peoples 2007

http://www.cihr-irsc.gc.ca/e/29339.html

- Developed in consultation with Aboriginal peoples – incorporates Aboriginal values and beliefs
- Includes principles of participatory research and OCAP (ownership, access, possession and control)
- Includes template for communities and researchers – questions how will research benefit the community and support capacity building, address individual and collective interests
- Protocol for how research question developed and accepted by community
- Concept of ‘ethical space’
KSDPP Code of Research Ethics

http://www.ksdpp.org/elder/code_ethics.html

Developed in 1994 - 1996 to guide the research project
Developed collaboratively through a community process

“To establish a set of principles and procedures to guide
the partners to achieve the goals and objectives of the
KSDPP. It outlines the obligations of each partner through
all of the phases of the project from the design of the
research through to the publication and communication of
the experiences of the project.”

Extensive revision 2003 – 2007 Adds processes to
operationalise the principles
Policy Statement 2007

The self determination of the Kanien’kehá:ka of Kahnawake to make decisions about research is recognized and respected.

The academic researchers’ obligation to knowledge creation in their discipline is recognized and respected.

Research should support the empowerment of Kahnawake to promote healthy lifestyles, wellness, self-esteem, and the Kanien’kehá:ka’s responsibility of caring for the Seventh Generation.
KSDPP Code of Ethics 2007

- Principles
- Obligations of Community & Academic Researchers
- Rights of the Community and Participants
- Review and Approval Process for Ethically Responsible Research
- The Consent Process
- Ombudsperson
- Data Collection and Data Management, Access to Data
- Dissemination and Publication of Research Results
- Knowledge Translation
- KSDPP Authorship Guidelines
- Multi-site Research and Multi-site Research Agreement
- Researcher Check- list Principles
Kahnawake Schools Diabetes Prevention Project (KSDPP) 1994 – present

www.ksdpp.org

Funded by: CIHR, NHRDP, CDA, SSHRC, Aboriginal Diabetes Initiative (Health Canada), Kateri Memorial Hospital Centre Kahnawake, Kahnawake community, and Private Foundations
Kahnawake is a Kanien’kehá:ka (Mohawk) community

Population 8,000

15 km from Montreal

Community control of services includes education (1967) & health (1970)
Six Nations Iroquois Confederacy (Haudenosaunee/People of the Longhouse) Territory

Iroquoia: Land Base - 1650

Iroquoia: Land Base - 1720

- Wikipedia
Hiawatha Belt: Symbolizes the agreement amongst 5 original Nations of the Iroquois Confederacy

Six Nations Iroquois Confederacy/Haudenosaunee (People of the Longhouse) Territory
Kahnawake Mohawk Territory

- Population: approx. 8,000; originally 40,000 acres - today 12,000 acres
- Originally governed by The Great Law of Peace/Kaianere'ko:wa
- People of the Longhouse
- The Indian Act of 1876 changed
- Governance: The Mohawk Council of Kahnawake (11 elected Band Councilors, 1 Grand Chief)
- Mohawk Council of Kahnawake works in conjunction with 8 other major organizations
Research questions came from taking care of patients

**Type 2 Diabetes**
Hospital chart reviews for people aged 45 to 64 years

**1981**
12% Type 2 diabetes (2x national average) – combination of genetic predisposition and lifestyle

**1985**
Heart Attacks, strokes and amputations 6x higher for those with diabetes (when compared to people of the same age and gender but without diabetes)

*Montour LT, Macaulay AC. High prevalence rates of diabetes mellitus and hypertension on a North American Indian reservation. CMAJ 1985;132:1110-12*

*Macaulay AC, Montour LT, Adelson N. Prevalence of diabetic and athero-sclerotic complications among Mohawk Indians of Kahnawake. CMAJ 1988;139:221-224*
Change of perceptions

Diabetes formerly a disease of individuals and families, was now a disease of the community.

Elders requested family MDs to “do something” to prevent diabetes, with focus on the children.

KSDPP Objectives from 1994 - present

- Short term goals: increase physical activity, healthy eating habits and a positive attitude
- Long term goal: to reduce Type 2 diabetes
- Capacity building and sustainability

KSDPP Partnership

COMMUNITY
- Community Advisory Board
- Intervention staff
- Research staff

UNIVERSITIES
- Researchers & students

CREATING KNOWLEDGE
KSDPP Community Advisory Board

Since 1994, 40 + volunteers

- Protect community values
- Guide research and training
- Role-model healthy lifestyles
- Develop Code of Research Ethics
- Disseminate results locally nationally and internationally
Outcomes

**Community** is perceived owner of KSDPP

– new recreation path, health curriculum, healthy foods in schools, youth centre and arena

Improved lifestyles - decreased junk food, decreased fats and sugars

**Capacity Building** for individuals, families, community

- Teachers, Community Advisory Board
- Summer students & post graduates from community (2 Masters and 2 PhDs)
- KSDPP Training Program in Diabetes Prevention

**Impacting National & International Policy**

- 2010 CIHR Partnership Award
- Codes of research ethics and ethics boards
- Funding agencies
- Research projects inside and outside community
Participatory Research at McGill (PRAM)

- Needs Assessment
- Seed Grants
- Training Grants
- Archive of past guest presentations
- Upcoming Seminars
- RSS Feed of Latest PR Lit in PubMed
- Other Web Resources
- Other Scholarships
- Members (find a PR expert)
- Resource Literature
- Scholarships

http://pram.mcgill.ca
- **PRAM – Participatory Research at McGill** ([http://pram.mcgill.ca](http://pram.mcgill.ca))


- **CIHR Guidelines For Health Research Involving Aboriginal People** ([http://www.cihr.ca/e/documents/ethics_aboriginal_guidelines_e.pdf](http://www.cihr.ca/e/documents/ethics_aboriginal_guidelines_e.pdf))

- **Guidelines for Participatory Research** ([http://lgreen.net/guidelines.html](http://lgreen.net/guidelines.html)) and Minkler M and Wallerstien N (eds) CBPR for Health second edition Appendix C

- **Community Campus Partnerships for Health** ([http://www.ccph.info](http://www.ccph.info))
  Includes examples of research agreements ([http://depts.washington.edu/ccph/commbas.html#Principles](http://depts.washington.edu/ccph/commbas.html#Principles))

- **NAPCRG Policy Statement on Participatory Research** ([http://www.napcrg.org/exec.html](http://www.napcrg.org/exec.html))
  Short version of this document published as
  Participatory Research Maximizes Community and Lay Involvement Macaulay AC et al, BMJ 1999; 319;774-8

- **KSDPP – The Kahnawake Schools Diabetes Prevention Project** ([http://www.ksdpp.org](http://www.ksdpp.org))

- **Agency Health Quality Research Community Based Participatory Research** ([http://www.ahrq.gov/clinic/epcsums/cbprsum.htm](http://www.ahrq.gov/clinic/epcsums/cbprsum.htm))
For consideration in your own projects.....

1. How can a research question be developed collaboratively?
2. What factors might influence the level of community involvement?
3. How is or should your academic institution prepare you for participatory research?
4. Other questions from your own experience?
Discussion......