

Developing and Maintaining Partnerships with Aboriginal Peoples, Organisations and Communities

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Content

- Introduction
- Using a participatory research approach
- Ethics
- Kahnawake Schools Diabetes Prevention Project as case study
- Discussion

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

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

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

*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*

Principles for Community Research

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

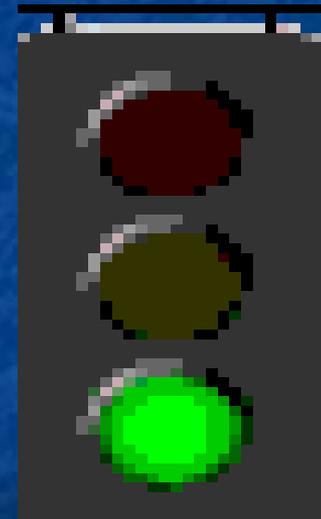
Review of community based research: assessing partnership approaches to improve public health. Israel BA et al. Annu Rev. Public Health 1998;19;173-202

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

Gaventa J. In Park P, Brydon-Miller M, Hall B & Jackson T (Eds) 1993

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.

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

Rationale for respecting communities

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

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
- Currently being addressed in new draft of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS)* <http://pre.ethics.gc.ca/eng/policy-politique/tcps-eptc/readtcps-lireeptc/>

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'keha:ka
(Mohawk)
community**

Population 8,000

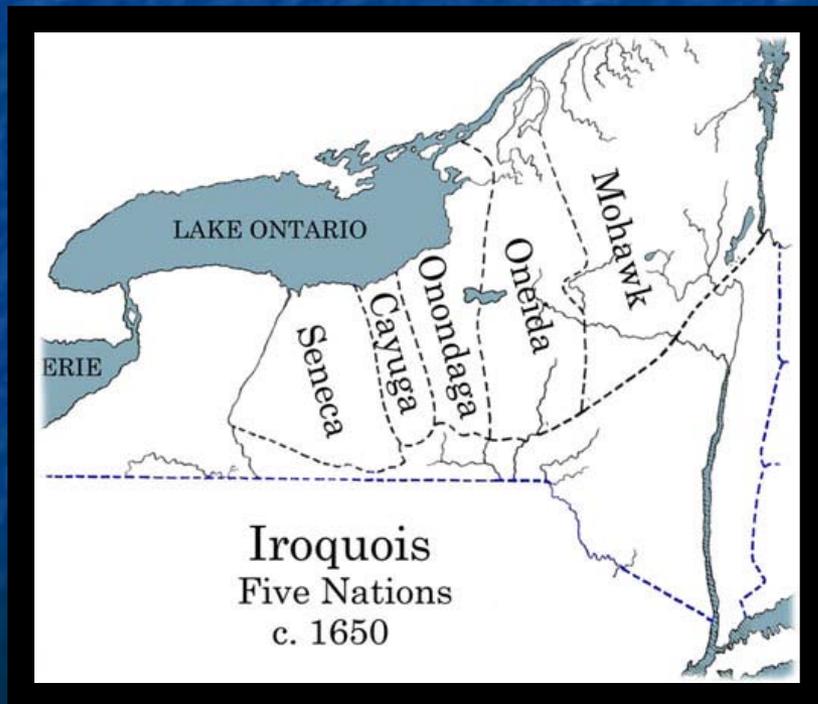
**15 km from
Montreal**

**Community
control of services
includes
education (1967) &
health (1970)**

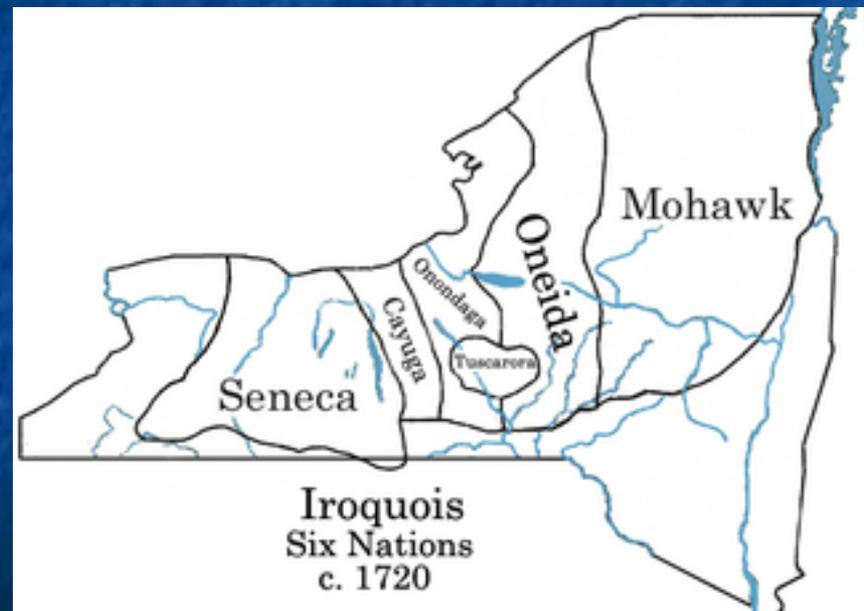


Six Nations Iroquois Confederacy (Haudenosaunee/People of the Longhouse) Territory

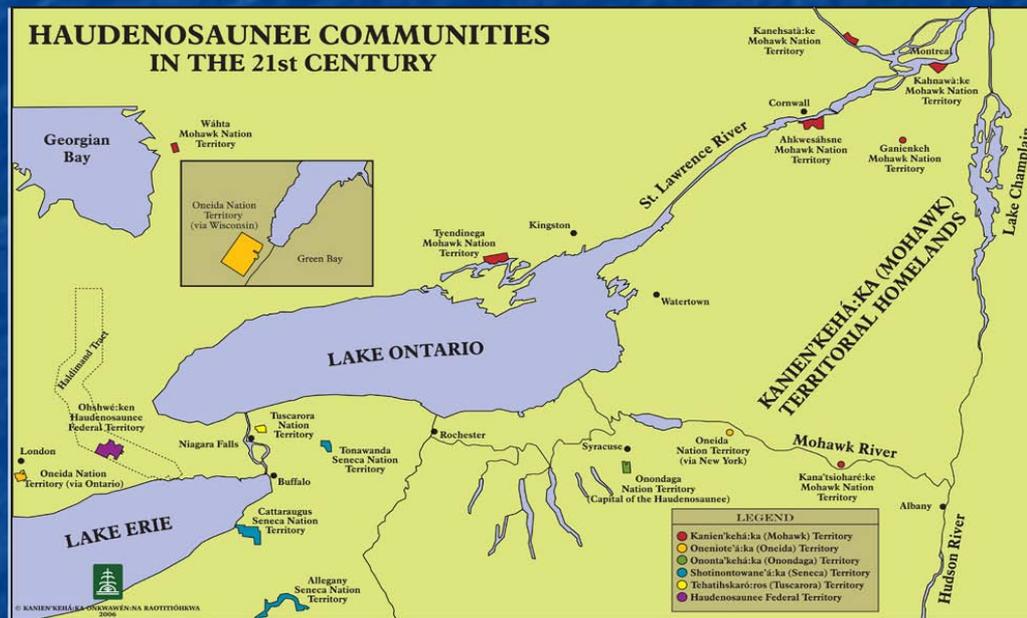
Iroquoia: Land Base - 1650



Iroquoia: Land Base - 1720



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



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

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

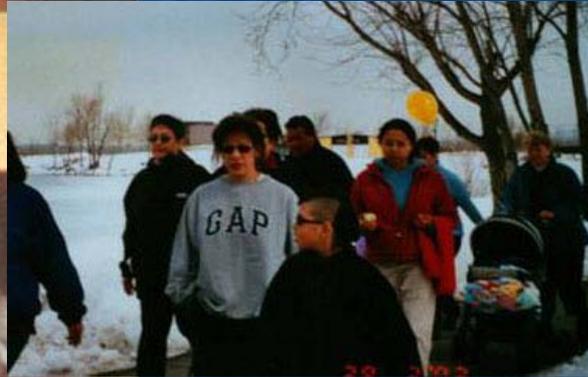
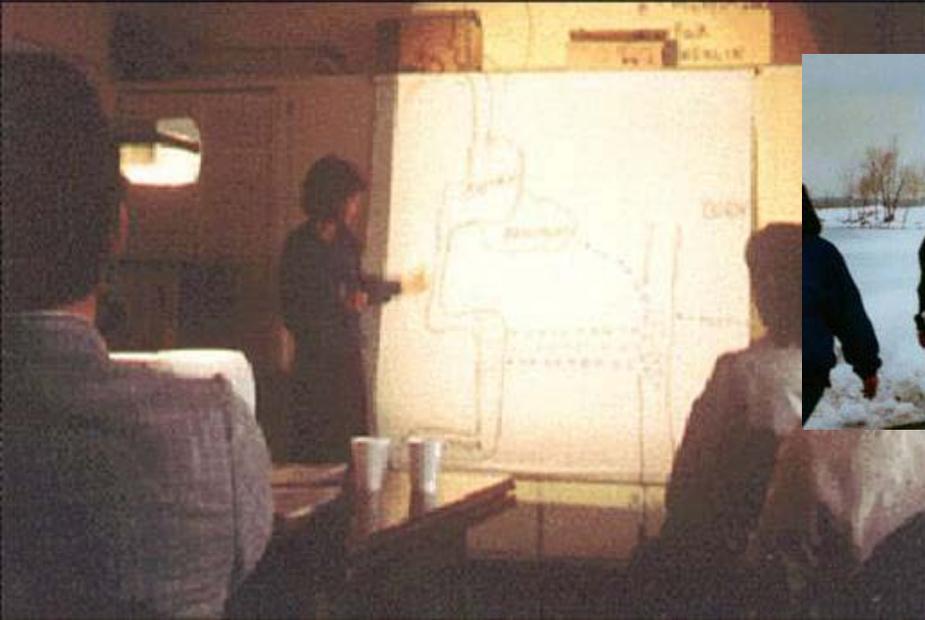
Sharing Results with Community (1987)

'knowledge translation'

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



Bisset S, Cargo M, Delormier T et al. Legitimizing Diabetes as a Community Health Issue: a Case Analysis of an Aboriginal Community in Canada. Health Promotion International 2004;19(3):317-326

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



*Macaulay AC,
Paradis G, Cross
EJ et al. KSDPP
Intervention,
Evaluation and
Baseline Results.
Prev Med
1997;29:779-790*

KSDPP Partnership

COMMUNITY

Community
Advisory Board
Intervention
staff
Research staff

UNIVERSITIES

Researchers &
students



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)

The image shows a screenshot of the PRAM website with several arrows pointing to specific sections and external resources. The website content includes:

- Navigation:** Home, NEAHR, Scholarships, Events, Seminars, Resources, Members, Archives, [Français]
- News:** Assessing your Needs: Take the Survey; NEW PR Toolkit: References & Resources; NEAHR Network: Environment for Aboriginal Health Research; PRAM in the McGill Reporter: May 3, 2007 - Jan 10, 2008; Fellowships & Scholarships; What's new in PubMed: RSS feed of last 31 days of Participatory Research items indexed in NCBI PubMed; Past Presentations available! Ian Graham; Lawrence W. Green; See Archives.
- Participatory Research @ Lunch:** Second Friday of each month, guest speakers will discuss topics of interest to Participatory Research. See Seminars. Next one will be on Friday, February 8 @ 12:00PM. Speaker: Dr. Christophe Bedos, McGill Faculty of Dentistry. Topic: « À l'écoute les uns des autres » : a PRA project to improve communication between the poor and oral health professionals.
- Goals:**
 - Further critical scholarship in participatory research
 - Develop a network of multi-disciplinary researchers in the medical and allied faculties.
 - Offer monthly seminars
 - Assess the needs of faculty and researchers for participatory research
 - Offer expertise to other faculty members e.g. for grant submissions
 - Supervise undergraduate and postgraduate students and post-doctoral fellows
 - Develop and deliver faculty development workshops
 - Consultation with community organisations
 - Resources for communities engaged in research
 - Work with university ethics boards to develop guidelines for participatory research
- Postgraduate scholarships available 2006-2008:**
 - Graduate student spend to undertake a systematic review on the benefits of participatory research. Competition CLOSED
 - In partnership with the Anisawbe Kekandazone NEAHR (CIHR Network Environment for Aboriginal Health Research - <http://www.ciel.org/>), Scholarships to Masters students, PhD candidates and postdoctoral fellows to undertake research in Aboriginal health care (Aboriginal and non Aboriginal students). Current Post-doc competition closed. Doctoral and Masters opportunities ongoing.
- Search:** McGill Google Search

External resources and website sections are indicated by arrows:

- Needs Assessment:** Points to the "Assessing your Needs: Take the Survey" link.
- Seed Grants:** Points to the "NEW PR Toolkit: References & Resources" link.
- RSS Feed of Latest PR Lit in PubMed:** Points to the "What's new in PubMed: RSS feed of last 31 days of Participatory Research items indexed in NCBI PubMed" link.
- Training Grants:** Points to the "Fellowships & Scholarships" link.
- Archive of past guest presentations:** Points to the "Past Presentations available!" link.
- Upcoming Seminars:** Points to the "Participatory Research @ Lunch" section.
- Resource Literature:** Points to the "Resources" navigation link.
- Other Web Resources:** Points to the "Resources" navigation link.
- Members (find a PR expert):** Points to the "Members" navigation link.
- Other Scholarships:** Points to the "Postgraduate scholarships available 2006-2008" section.

<http://pram.mcgill.ca>

- PRAM – Participatory Research at McGill (<http://pram.mcgill.ca>)

[A Guide to Researcher and Knowledge-User Collaboration in Health Research](http://www.cihr-irsc.gc.ca/e/39128.html). Parry D, Salsberg J, Macaulay AC <http://www.cihr-irsc.gc.ca/e/39128.html>

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

- Guidelines for Participatory Research (<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>)
Includes examples of research agreements
(<http://depts.washington.edu/ccph/commbas.html#Principles>)

- NAPCRG Policy Statement on Participatory Research
(<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>)

Agency Health Quality Research Community Based Participatory Research
(<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.....

