Participatory Research in Health Promotion

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Population Health Promotion
Edmonton
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Outline of presentation

- Introduction to Participatory Research (PR)
- Case study: Kahnawake Schools Diabetes Prevention Project (KSDPP)
- Opportunities and challenges for communities, universities and ethics boards
In Conventional Research…

researchers make all the decisions

“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”

Aboriginal physician

Dr Louis T. Montour 1987

Montour LT, Macaulay AC. Diabetes Mellitus and Arteriosclerosis: Returning research results to the Mohawk Community. CMAJ 1988;34:1591-93
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 et al.

PR guidelines available at http://lgreen.net/guidelines.html
Research *with* community, not ‘in’ or ‘about’ community

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

Will the project help community participants (and others) to deal with factors that influence their health and that of their community?
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.

Researchers and communities

“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
Case study

Kahnawake Schools Diabetes Prevention Project (KSDPP)

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


15 km from Montreal

Community control of education (1967) & health (1970)
Kahnawake Prevalence of Disease

Aged 45 to 64 years

1981
• 12% Type 2 diabetes
(2x national average, reconfirmed in 2007)

1985
• Macro-vascular complications
  6x higher for those with diabetes
  (matched for age and sex)

Montour LT, Macaulay AC. High prevalence rates of diabetes mellitus and hypertension on a North American Indian reservation. CMAJ 1985;132:1110-112
Macaulay AC, Montour LT, Adelson N. Prevalence of diabetic and athero-sclerotic complications among Mohawk Indians of Kahnawake. CMAJ 1988;139:221-224
Elders requested family MDs to “do something” to prevent diabetes, with focus on the children.
Guiding Principles of KSDPP 1994 - present

“Health promotion is the process of enabling people and communities to take control over their health and its’ determinants” WHO 1984

Use participatory research
• Community and researchers as equal partners
• Promote local traditions and values

Use health promotion models
• Promote community changes for diabetes prevention

Potvin LP, Cargo M, McComber AM, Delormier T, Macaulay AC. Implementing Participatory Intervention and Research in Communities:Lessons from the Kahnawake Schools Diabetes Prevention Project. Social Science and Medicine 2003;56(6):1295-1305
KSDPP Partnership

COMMUNITY
- Community Advisory Board
- Intervention staff
- Research staff

UNIVERSITIES
- Researchers & students

NEW KNOWLEDGE
KSDPP Community Advisory Board

Since 1994, 40+ volunteers aged 26 – 82 years

- Role-model healthy lifestyles
- Represent the community
- Protect community values
- Guide intervention, research and training
More explicitly, CAB ....

- Helps formulate the Research Question
- Advises on Data Collection
- Helps with Results Interpretation
- Reviews and Disseminates Results at the community, regional, and national level at conferences and through publications
KSDPP Code of Research Ethics
www.ksdpp.org

In 1994, joint development to outline obligations of all partners, for protection of individuals and the community

Development of a written agreement - process as important as product

2007 revised version coming soon

www.ksdpp.org

KSDPP Objectives from 1994 to the present

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

STRENGTHENING COMMUNITY ACTION

Community takes action:
- setting priorities
- making decisions
- program planning, implementation and evaluation

Community empowerment is central to community ownership and control.

(World Health Organization, 1986)
School Interventions

Health Education Program
- Grades 1-6
- developed by community
- delivered by teachers
- Mohawk and English

Teachers extra activities

Schools Nutrition Policy
- bans ‘junk food’


Community Interventions

Community events

- Partner with other organisations (builds on strengths and resources, builds capacity, supports sustainability)
- Same messages as in the schools
- Physical activities and healthy meals - offer opportunities to ‘walk the talk’

Evaluation and Results
**Outcome Evaluation Grades 1-6**

**Anthropometric Measurements**
- Weight & height
- Skinfold thickness (subscapular, triceps)

**Fitness Test**
- 1994 - 1999
  - 1 mile Run / Walk
  - 1/2 mile Run / Walk
- 2002 - 2004
  - Shuttle run test

**Student Questionnaires**
- 7 day recall
  - Food frequency
  - Activity frequency
  - Television watching
  - Video game playing
  - Organized sports

**24-Hour Food Recall**
- Grades 4-6
Baseline results 1994
Grades 1-6

- Weight similar to N. American counterparts, but heavier children are heavier and carry their weight centrally

- Girls watching excess TV are heavier (not true for boys)
  Horn O. et al. Preventive Medicine 2001;33:274-281
24-Hour Nutrition Recalls Grades 4-6

1994 Baseline:
• fat intake good (30%), high sucrose (16%), low fruits and vegetables

1998 and 2002:
• decreased sodas, french fries, chips and candy. Stable fat, decreased
  fruits and vegetables, switch from whole milk to lower fat milks,
  increased whole wheat bread
  Salmon L. Master’s Thesis. McGill University 2004

1994, ’98, 02:
• overweight (>95%ile) children consume more French fries. At risk of
  overweight (85-95%ile) consume more chips than normal weight
  children (5-85% tile)
## Nutrition 7 day food frequency

<table>
<thead>
<tr>
<th></th>
<th>1994</th>
<th>1999</th>
<th>2002</th>
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</thead>
<tbody>
<tr>
<td><strong>Age and sex-adjusted means (std err)</strong></td>
<td></td>
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<tr>
<td>Sugar consumption index</td>
<td>2.22 (0.07)</td>
<td>1.39* (0.08)</td>
<td>1.29* (0.07)</td>
</tr>
<tr>
<td>Fat consumption index</td>
<td>1.28 (0.05)</td>
<td>1.14 (0.05)</td>
<td>0.84* (0.05)</td>
</tr>
<tr>
<td>Fruit and vegetable consumption index</td>
<td>2.91 (0.07)</td>
<td>1.96 (0.08)</td>
<td>1.87 (0.07)</td>
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*p<0.05

### Physical Activity and Fitness

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<tbody>
<tr>
<td><strong>Physical activity frequency</strong></td>
<td>22.53 (0.93)</td>
<td>27.76* (0.99)</td>
<td>22.27 (0.96)</td>
</tr>
<tr>
<td>(# 15-min bouts last7 days)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Run/walk time: best of 2</strong></td>
<td>540.5 (8.7)</td>
<td>496.4* (9.8)</td>
<td>-</td>
</tr>
<tr>
<td><strong>times (in seconds)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TV watching on school days</strong></td>
<td>2.62 (0.06)</td>
<td>2.95* (0.06)</td>
<td>2.67 (0.06)</td>
</tr>
<tr>
<td>(higher #=less TV)</td>
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<tr>
<td><strong>TV/ video watching on Sat</strong></td>
<td>2.81 (0.04)</td>
<td>2.95* (0.04)</td>
<td>2.74 (0.04)</td>
</tr>
<tr>
<td>(higher #=less TV)</td>
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* p<0.05

## Anthropometric Measures

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<tr>
<td><strong>Age and sex-adjusted means  (std err) Grades 1 - 6</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>BMI (kg/m²)</strong></td>
<td>18.86 (0.20)</td>
<td>19.08* (0.23)</td>
<td>19.46* (0.23)</td>
</tr>
<tr>
<td><strong>Mean of 3 subscapular skinfold thicknesses (mm)</strong></td>
<td>10.04 (0.37)</td>
<td>10.74 (0.42)</td>
<td>12.50 (0.43)</td>
</tr>
<tr>
<td><strong>Mean of 3 triceps skinfold thicknesses (mm)</strong></td>
<td>13.58 (0.34)</td>
<td>10.22* (0.39)</td>
<td>15.19 (0.40)</td>
</tr>
</tbody>
</table>

* p<0.05 Paradis, Macaulay, Lévesque, Cargo et al. Pediatrics 2005;115(2):333-339
Kids are packing on the belly fat, U.S. study shows

SHARON KIRKEY
CANWEST NEWS SERVICE

OTTAWA – Five-year-olds are developing middle-age paunches – a bleak sign that children are not only getting heavier, they’re packing on the worst kind of fat. Abdominal obesity increased more than 35 percent among children and scores, a worrying trend because of emerging evidence that belly fat is riskier than overall obesity. Studies have shown the increased risk of heart disease and type 2 diabetes due to excess body fat is mainly because of abdominal fat.

The percentage of 6- to 11-year-olds with high BMI scores in

Cochrane data base review 2005

- 22 RCT/QEx studies
- Only 4 reduced obesity or body fat index
Community presentations
(Knowledge translation)

1994
- Normal weight < 85th %ile: 14%
- At risk of overweight 85-94th %ile: 17%
- Overweight ≥ 95th %ile: 69%

2002
- Normal weight < 85th %ile: 17%
- At risk of overweight 85-94th %ile: 17%
- Overweight ≥ 95th %ile: 55%
Community Reactions Spring 2004

Presentations to 16 community organisations to discuss findings and to get community interpretation of results

“Message for parents to be a role model. Pay attention to your children - get involved!”

“We are fortunate to have 10 years of data, but they are discouraging results; don’t know how to reverse the trend.”

“What would be the results if the project didn’t exist?”
Process evaluation
Developing Physical Activity Interventions

Complex packages targeting multiple settings
Implemented in partnership with other organisations
(KSDPP - organisation or organisation - KSDPP)

- 47% in 1996-1997*
- 61% in 2003-2004**

Individual spin-offs (new recreation path, soccer and lacrosse teams, breast cancer walk, wampum belt walk, etc)

*Unpacking the Black Box: A Deconstruction of the Programming Approach and Physical Activity Interventions Implemented in the Kahnawake Schools Diabetes Prevention Project Lévesque L, Guilbault G, Delormier T, Potvin L. Health Promotion Practice 2005;6(1):64-71

Multi-faceted Roles of Teachers in Diabetes Prevention

Enabling healthy lifestyle change in their students

- Enforcing school nutrition policy
- Role modeling
- Teaching curriculum
- Liaising
- Networking
- Encouraging healthy lifestyles

### Community is perceived primary owner of KSDPP

75% response rate (51/68 surveys)

<table>
<thead>
<tr>
<th>Perceived Primary Owner</th>
<th>%</th>
<th>n</th>
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<tbody>
<tr>
<td>KSDPP Community Advisory Board</td>
<td>52.9</td>
<td>27</td>
</tr>
<tr>
<td>KSDPP Staff</td>
<td>39.2</td>
<td>20</td>
</tr>
<tr>
<td>Academic Partners</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Community Affiliates</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Supervisory Board</td>
<td>5.9</td>
<td>3</td>
</tr>
</tbody>
</table>

not statistically significant ($p > 0.05$)

More Positive Outcomes

Ecological changes – recreation path, health curriculum, nutrition policies

Capacity Building for individuals, families, community
- Teachers, Community Advisory Board
- Kahnawake community researchers, summer & graduate students (Masters and PhD)
- KSDPP Training Program in Diabetes Prevention

New computer based tool to assess physical activity

Incidence/prevalence rates Type 2 diabetes lower than other Aboriginal communities (CJPH in press)

Impacting National & International Policy
Wampum Belt Walk

Our Blood is Sweet: The Wampum Belt Journey.
Joe Jacobs with N. Gibson Pimatisiwin 2003;1(2):59-72
http://www.pimatisiwin.com/Issues/AllIssues.html
Current activities

- Co-presenting (CAB and researchers) to community leadership to promote building community wellness policy
- Using results to focus interventions
- Adding programs for high school & children 0-5 years

www.ksdpp.org
KEY POINTS for PARTNERSHIPS

Process

- Ottawa Charter of Health Promotion
- Respond to community priorities
- Build on community strengths
- Develop partnerships
- Requires community readiness

Sustainability

- Capacity building
- Knowledge translation
- ‘Kitchen table’ discussions

Opportunities & challenges

Communities

- internal readiness & external support
- time commitment
- research dollars for interventions
- does community review and approval process exist? If yes, what power does it carry?
- tensions between interventions and research
- who owns the data?
Opportunities & challenges

- **Universities**
  - increased grants for participatory research
  - challenges of time with impact on promotion and tenure in ‘community engaged scholarship’
  - balancing university and community interests and expectations
  - issues of power, trust, partnership

www.ccph.org
http://depts.washington.edu/ccph/index.html
http://depts.washington.edu/ccph/scholarship.html
Opportunities & challenges

- Ethics Boards
  - new guidelines* coming for reviewing PR proposals
  - university consent forms often not appropriate for PR
    i.e. use objectifying language (subjects of research)
  - PR requires protection of community in addition to protection of the individual

*Current guidelines at http://green.net/guidelines.html
Web-based resources

Community Campus Partnerships for Health

www.ccph.info
http://depts.washington.edu/ccph/commbas.html

Agency for Health Research Quality

Creating Partnerships, Improving Health. The Role of Community-Based Participatory Research *Community-Based Participatory Research: Assessing the Evidence* (Publication No. 04-E022-1, August 2004)

NAPCRG Policy Statement on Participatory Research

www.napcrg.org/exec.html

PR Guidelines to Assess a Project

http://green.net/guidelines.html
Participatory Research at McGill (PRAM)

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

PRAM resources

• Consultations
• Workshops
• Speakers
• Postgraduate scholarships