

Participatory Research in Health Promotion

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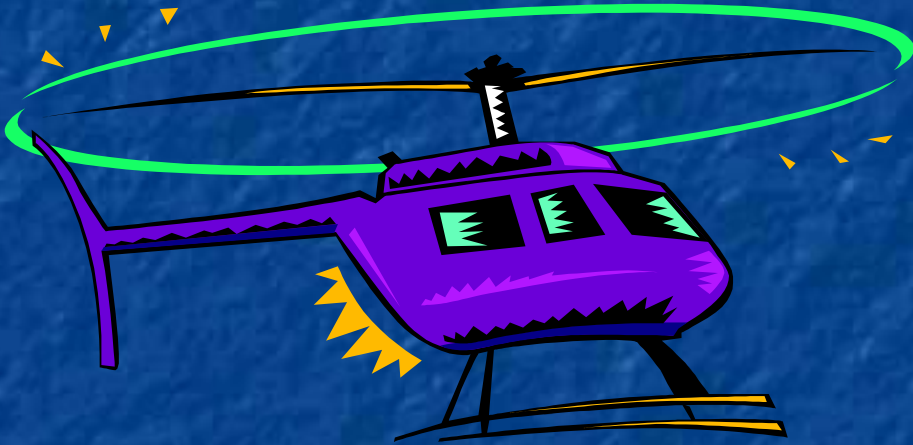
Population Health Promotion
Edmonton
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Outline of presentation

- 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>

More....

- 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.

The Royal Society of Canada - Study of Participatory Research in Health Promotion. Green LW, George MA, Daniel M, Frankish CJ, Herbert CP, Bowie WR, O'Neill M. 1995.

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”

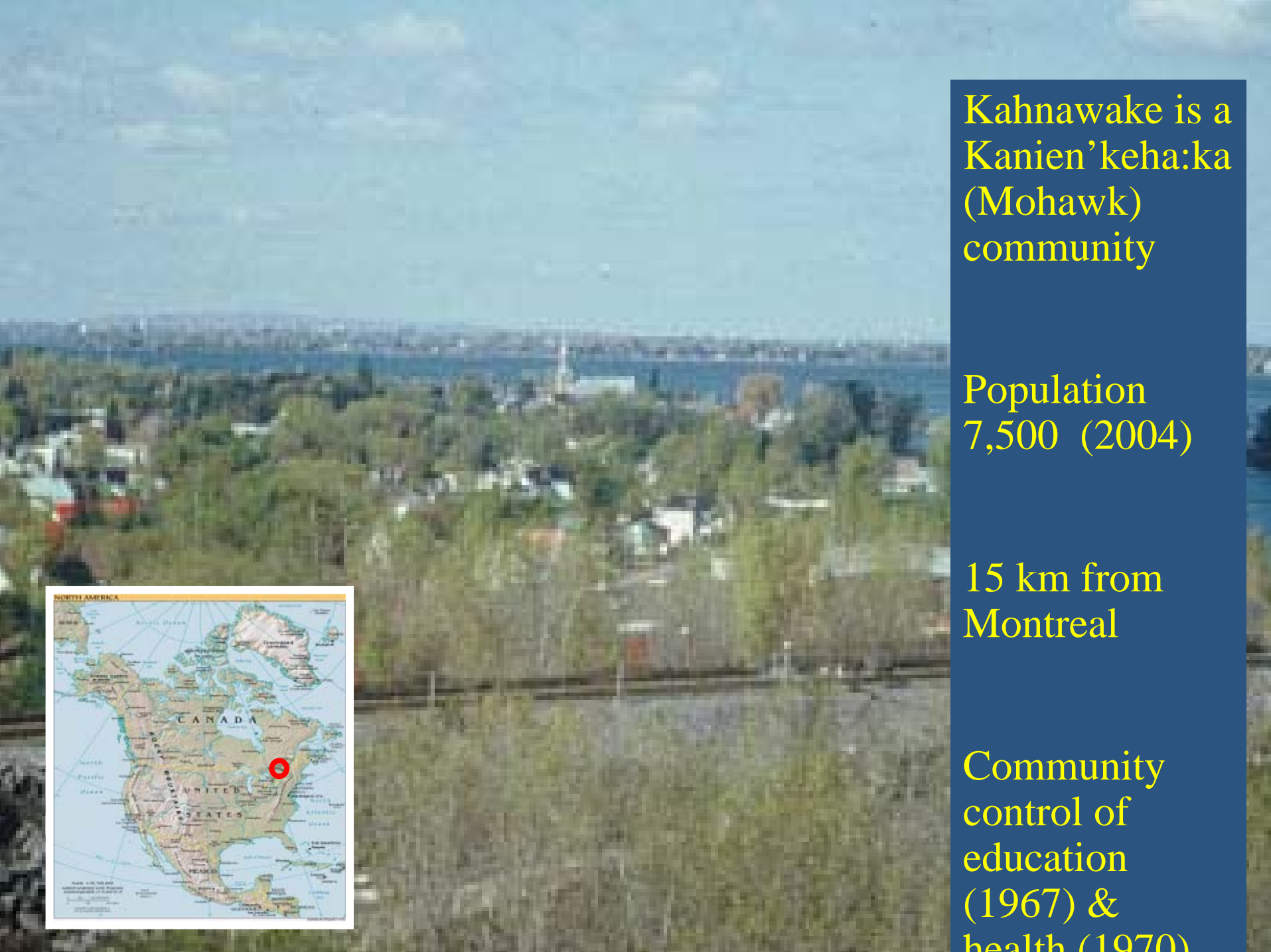
Minkler M. Using Participatory Action research to Build Healthy Communities. Public Health Reports 2000;115:191-197

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

Population
7,500 (2004)

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)

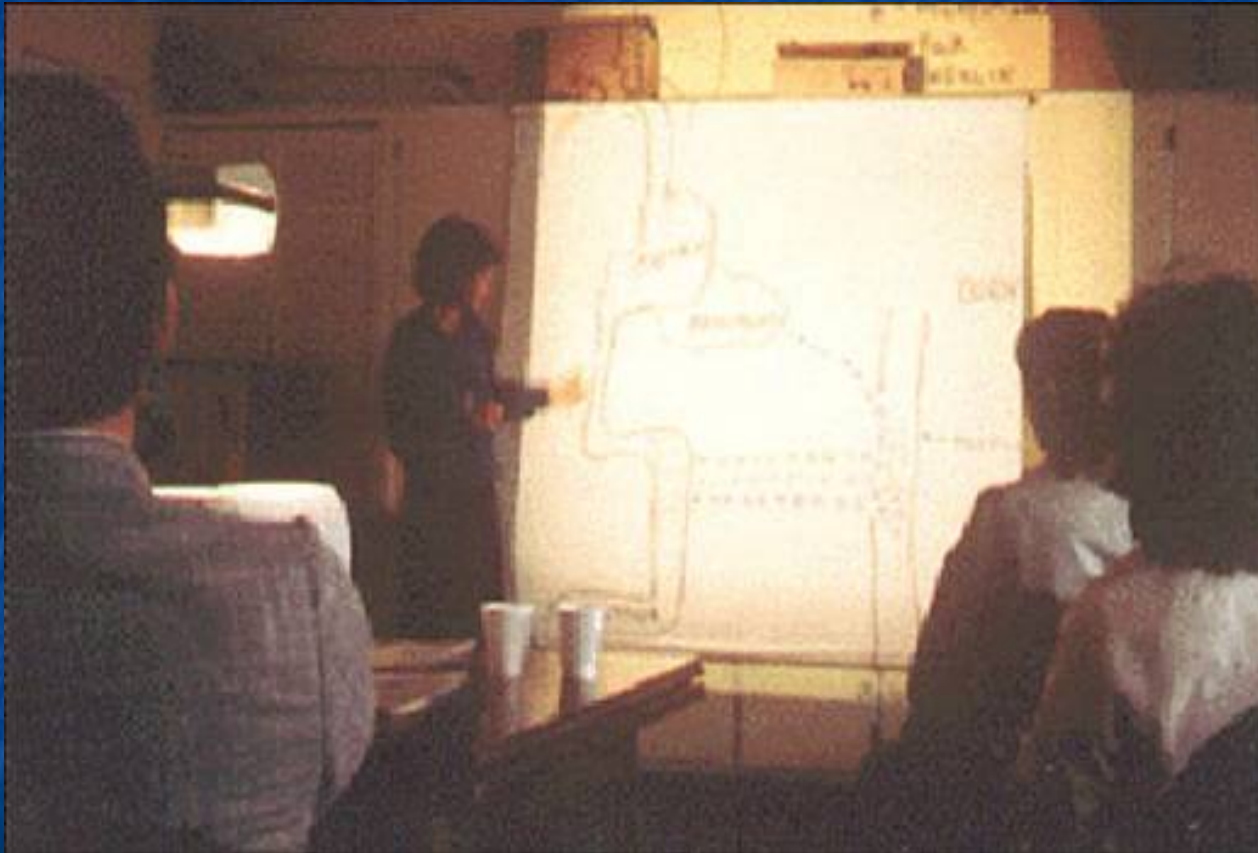


Montour LT, Macaulay AC. High prevalence rates of diabetes mellitus and hypertension on a North American Indian reservation. CMAJ 1985;132:1110-12

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



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

KSDPP Partnership

COMMUNITY

UNIVERSITIES

Community Advisory Board

Intervention staff

Research staff

Researchers & students



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

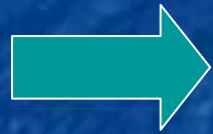
More explicitly, CAB



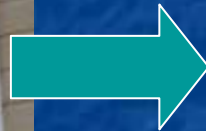
Helps formulate the Research Question



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



Macaulay AC, Delormier T, Cross EJ, et al Participatory Research with Mohawk Community Creates Innovative Code of Research Ethics: The Kahnawake Schools Diabetes Prevention Project. *Canadian Journal of Public Health* 1998;89(2):105-8

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



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

OTTAWA CHARTER FOR HEALTH PROMOTION



Health Canada, Health Promotion and Programs Branch AB/NWT/Nunavut

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'



Macaulay AC, Paradis G, Potvin L, et al. The Kahnawake Schools Diabetes Prevention Project: A Diabetes Primary Prevention Program in a Native Community in Canada. *Intervention and Preventive Medicine* 1997; 26: 779-790.

Cargo M, Salsberg J, Delormier T, Desrosiers S, Macaulay AC. Understanding the social context of school health promotion program implementation. *Health Education* 2006;106(2):85-97

Community Interventions

Community events

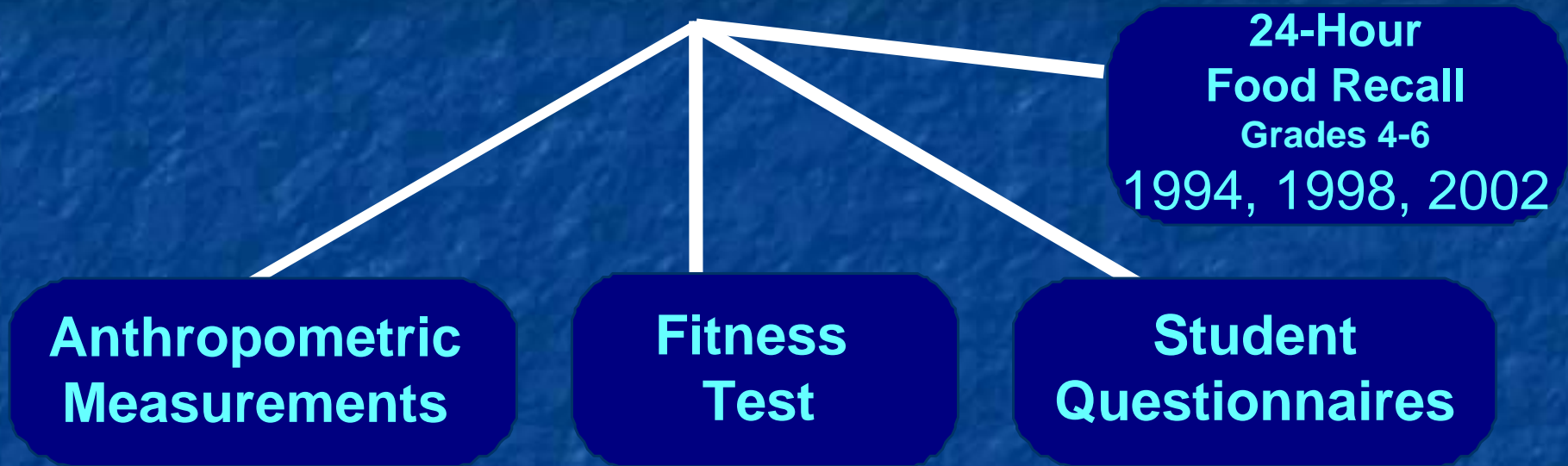
- Partner with other organisations (builds on strengths and resources, builds capacity, supports sustainability)
- Same messages as in the schools
- Physical activities and healthy meals - offer opportunities to 'walk the talk'

"Activity Implementation as a Reflection of Living in Balance: The Kahnawake Schools Diabetes Prevention Project." Delormier T, Cargo M, Kirby R., McComber A. Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health 2003;1(1): 45-163, www.pimatisiwin.com/Articles/1.1G_ActivityImplementation.pdf

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
1994, 1998, 2002**

Baseline results 1994

Grades 1-6

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

Potvin L. et al. J American Dietetic Association. 1999;99(8):955-961

- 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
Trifonopoulos M, et al. J Am Diet Assoc. 1998;98(7):814-816.

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

Jimenez M. et al. J Am Diet Assoc 2003;103(9):1191-4.

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)

Receveur O, et al. Under revision 2007

Nutrition 7 day food frequency

	1994	1999	2002
Age and sex-adjusted means (std err)			
Sugar consumption index	2.22 (0.07)	1.39* (0.08)	1.29* (0.07)
Fat consumption index	1.28 (0.05)	1.14 (0.05)	0.84* (0.05)
Fruit and vegetable consumption index	2.91 (0.07)	1.96 (0.08)	1.87 (0.07)

*p<0.05

Physical Activity and Fitness

	1994	1999	2002
Age and sex-adjusted means (std err) Grades 1 - 6			
Physical activity frequency (# 15-min bouts last 7 days)	22.53 (0.93)	27.76* (0.99)	22.27 (0.96)
Run/walk time: best of 2 times (in seconds)	540.5 (8.7)	496.4* (9.8)	-
TV watching on school days (higher # = less TV)	2.62 (0.06)	2.95* (0.06)	2.67 (0.06)
TV/ video watching on Sat (higher # = less TV)	2.81 (0.04)	2.95* (0.04)	2.74 (0.04)

* p<0.05

Paradis, Macaulay, Lévesque, Cargo et al. Pediatrics 2005;115(2):333-339

Anthropometric Measures

	1994	1999	2002
Age and sex-adjusted means (std err) Grades 1 - 6			
BMI (kg/m ²)	18.86 (0.20)	19.08* (0.23)	19.46* (0.23)
Mean of 3 subscapular skinfold thicknesses (mm)	10.04 (0.37)	10.74 (0.42)	12.50 (0.43)
Mean of 3 tricep skinfold thicknesses (mm)	13.58 (0.34)	10.22* (0.39)	15.19 (0.40)

* 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

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-

Cochrane data base review 2005

- 22 RCT/QEx studies
- Only 4 reduced obesity or body fat index

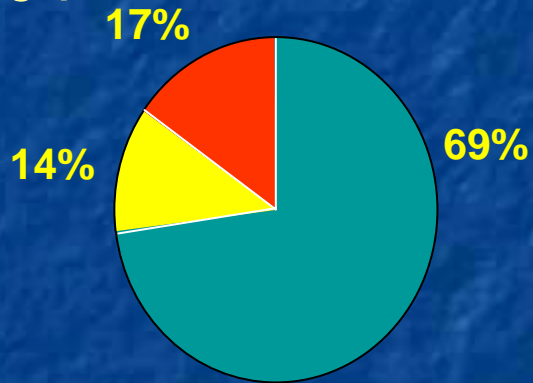
essor of pediatrics at the University of Rochester Medical School.

Among 18- to 19-year-old girls,

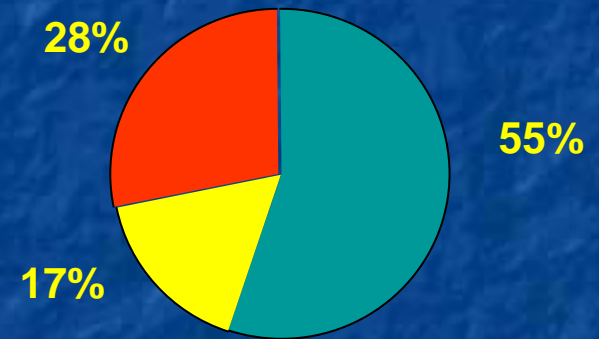
in 1966. Girls of the same ages saw their belly girth rise to 64.7 cm from 61.7 cm over the same period.

Community presentations (Knowledge translation)

1994



2002



Normal weight
<85th %ile



At risk of overweight
85-94th %ile



Overweight
≥ 95th %ile

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*

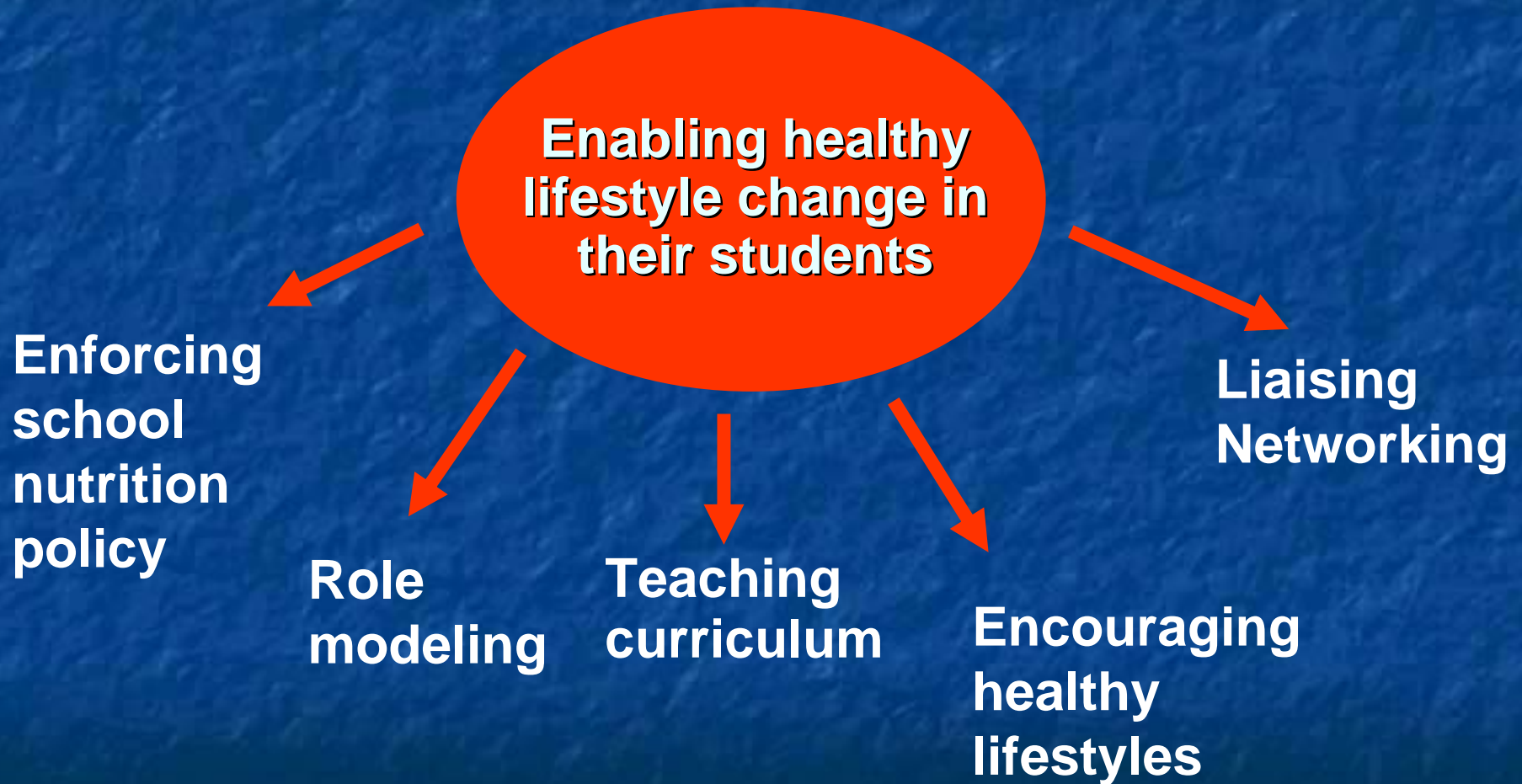
- 61% in 2003-2004**

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

** Building Community Capacity Through Physical Activity Interventions Implemented by the Kahnawake Schools Diabetes Prevention Project (KSDPP) Doxsee E, Lévesque L, Cargo M, Rice J, Kirby R, Macaulay AC. Canadian Diabetes Association Conference 2006

Multi-faceted Roles of Teachers in Diabetes Prevention



Community is perceived primary owner of KSDPP

75% response rate (51/68 surveys)

Perceived Primary Owner	%	n
KSDPP Community Advisory Board	52.9	27
KSDPP Staff	39.2	20
Academic Partners	0	0
Community Affiliates	0	0
Supervisory Board	5.9	3

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

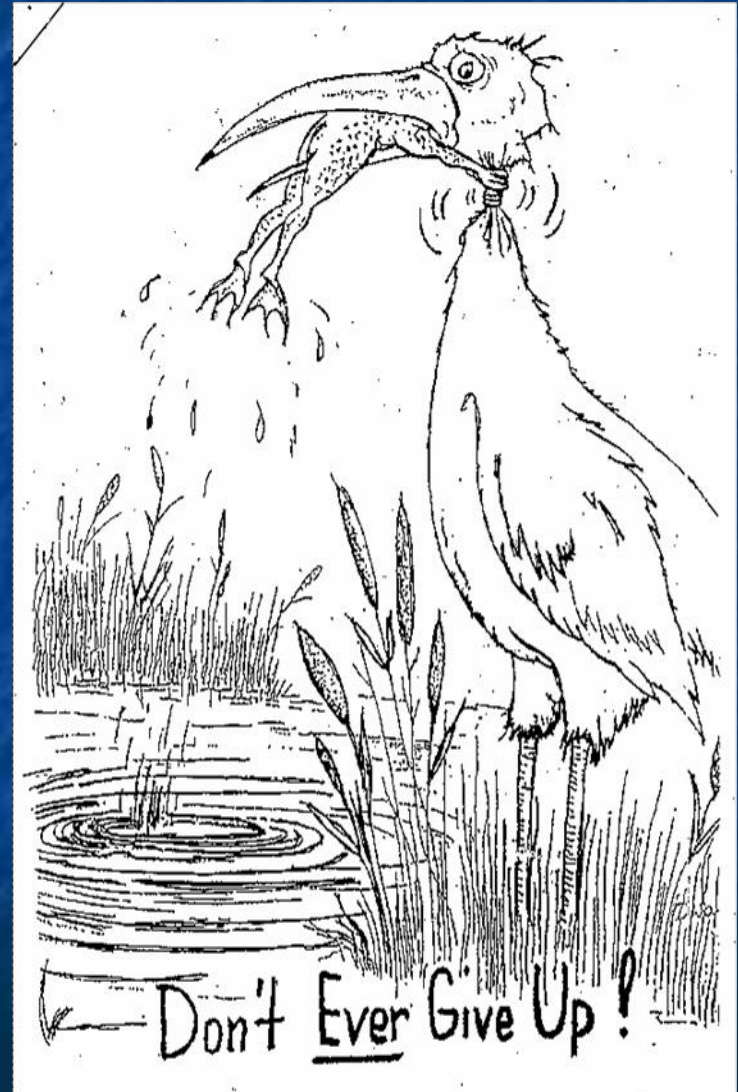


Our Blood is Sweet: The Wampum Belt Journey.
Joe Jacobs with N. Gibson Pimatisiwin 2003;1(2):59-72
<http://www.pimatisiwin.com/Issues/AllIssues.html>

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)

<http://www.ahrq.gov/downloads/pub/evidence/pdf/cbpr/summary.pdf>

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