

Educational Conference Call Series on Ethical Issues in Research



**Co-sponsored by Community-Campus
Partnerships for Health & Tuskegee University
Center for Bioethics in Research and Health
Care**

The Kahnawake Schools Diabetes Prevention Project: Community Advisory Board & Code of Research Ethics

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Kahnawake Mohawk Territory
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Staff: Cara Deer, Tracee Diabo, Amy Ing, Laura Jacobs, Rhonda Kirby, Ida Labillois-Montour, Dr Ann C Macaulay, Lois Montour, Geraldine Sky

Community Advisory Board: Alanna Atwin, Tom Dearhouse, David Diabo, Nancy Goodleaf, Vera Goodleaf, Kaherawaks Jacobs, Kanatakta, Sylvia Mayo, Eva Johnson, Rita McComber, Amelia McGregor, Kateri Oesterreich

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Dr. Louis T. Montour

Iroquoian World view

- ❖ Kaianereko:wa (The Great Law of Peace)

- ❖ People participate in decision-making

- ❖ The Iroquois Creation Story, The Great Law and its particulars, and The Condolence Ceremony:

- ❖ living in balance

- ❖ responsibilities as well as rights

- ❖ decision making for the Seventh Generation

Kahnawake Mohawk Territory

- Population 7000
- 13,000 square acres
- South shore of St. Lawrence River
- 15 miles from Montreal, Canada
- Decentralized operations
 - Government
 - Education
 - Health
 - Recreation
 - Community & social services

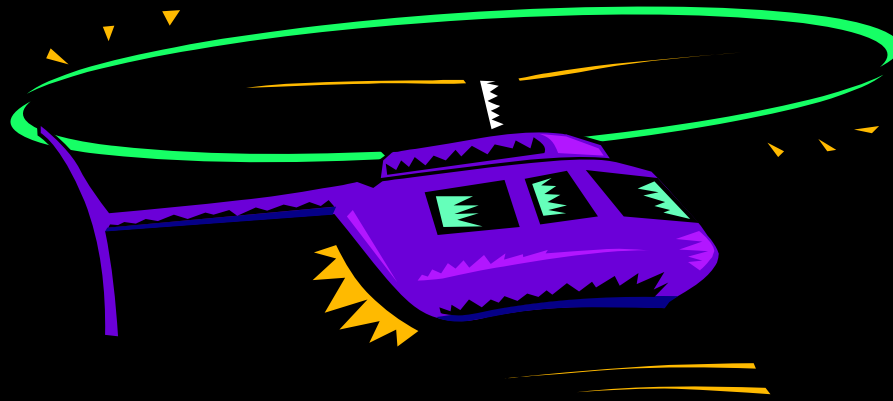


KSDPP Components

- ★ Creating Vision
- ★ Active Community Support
- ★ Diabetes Prevention Curriculum for Children
- ★ Nutrition and Physical Activities Programs
- ★ Dissemination Programs
- ★ Building Supportive School Environment
- ★ Building Supportive Community Environment
- ★ Building Capacity Among Community Members
- ★ Sustaining the efforts within the community



What type of
research project
was KSDPP
going to be?



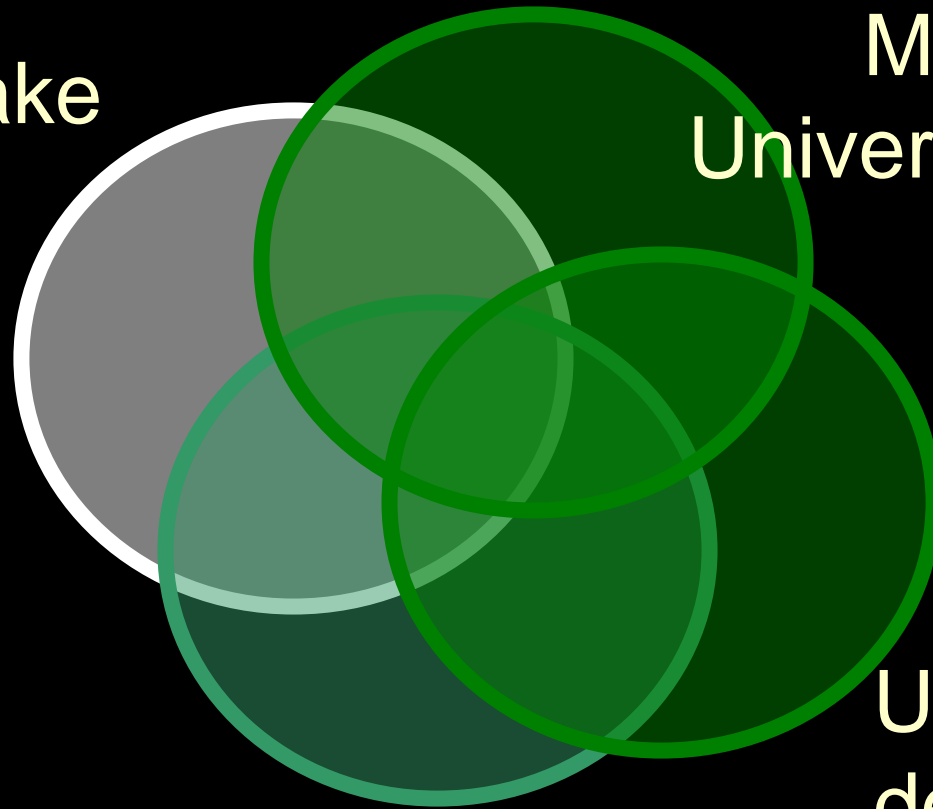
“Outside research teams swooped down from the skies, swarmed all over town, asked nosy questions that were none of their business and then disappeared never to be heard of again”

(Louis T. Montour MD , 1987)

Community-University Partnership

Kahnawake

McGill
University 1994

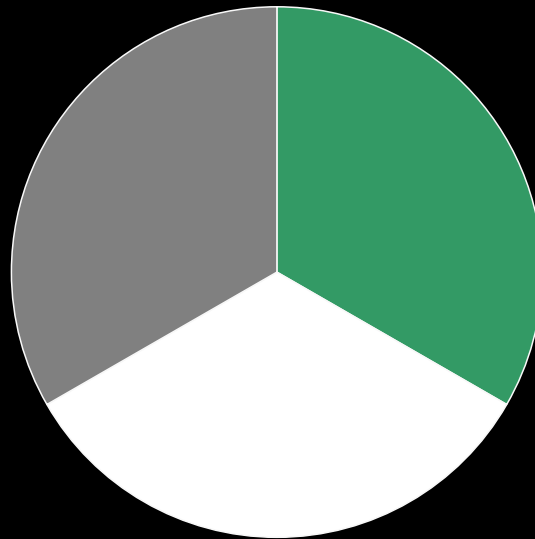


Queens University - 2002

Université
de Montréal
1994

Kahnawake Partnership

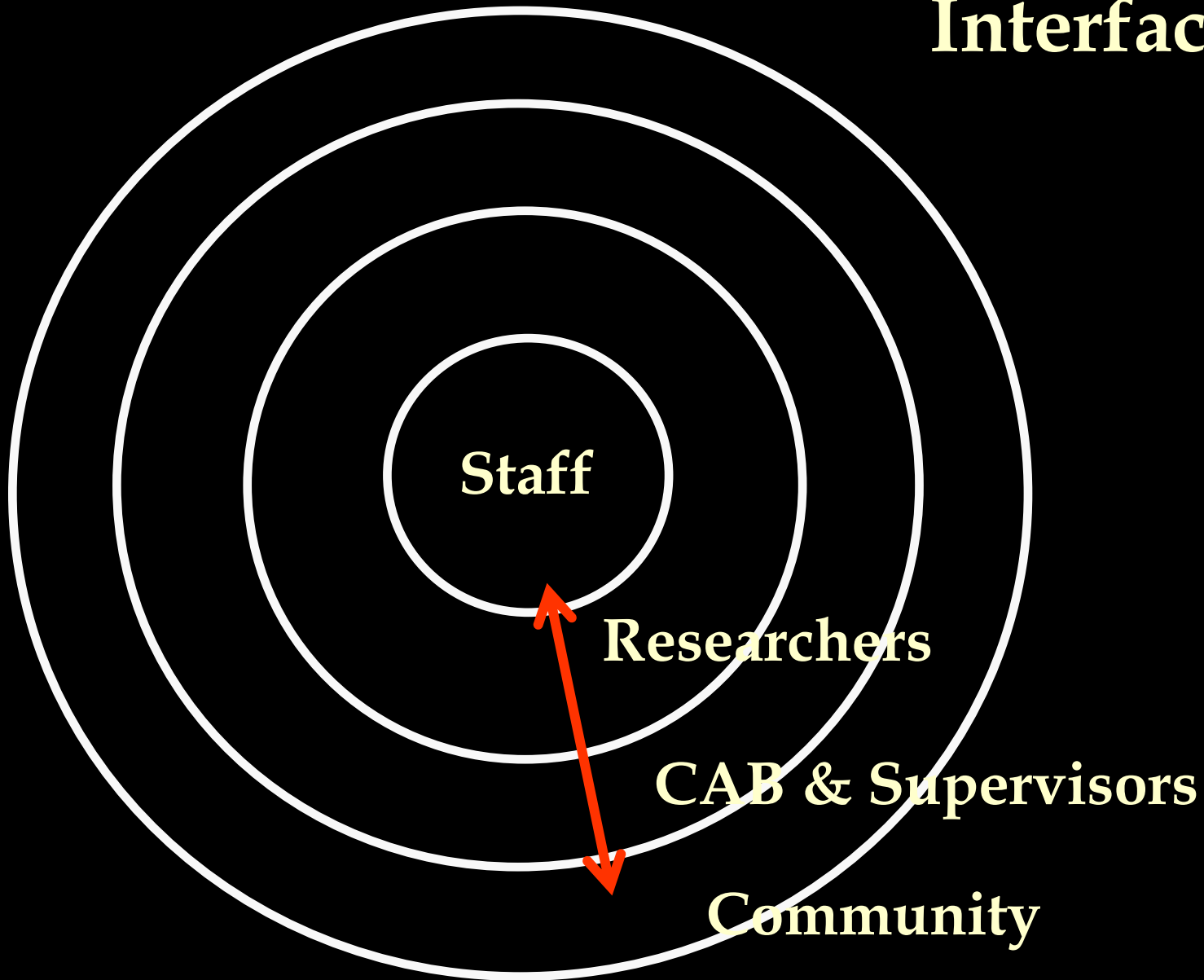
KSDPP



Kahnawake
Education
Center

Onkwata'karitáhtshera
(Kahnawake One Health Agency)

Interface



Community Advisory Board



- Education
- Health & Social Service
- Recreation
- Political
- Social
- Economic
- Spiritual
- Culture and Environment

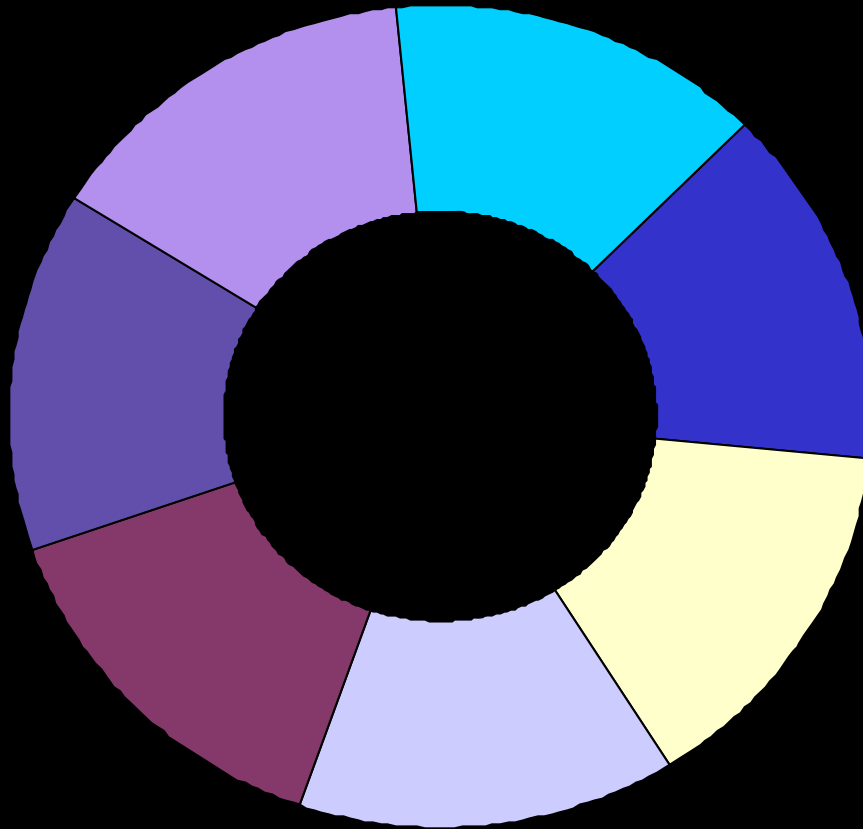
Community Advisory Board

- ❖ Grass roots representatives of community & organizations
- ❖ Over 40 volunteers during the past 10 years
- ❖ Members ages range from 26 – 80 years
- ❖ Monthly meetings since 1994
- ❖ Facilitate communication among organizations

Community Advisory Board

- ❖ Monitor and review project activities
- ❖ Participate in intervention activities
- ❖ Participate in the evaluation process – data collection process, analysis, interpretation
- ❖ Review and approve abstracts, papers & presentations, research proposals
- ❖ Co-author project writings
- ❖ Represent project at meetings and conferences
- ❖ Participation in creation of Code of Research Ethics

Research Team

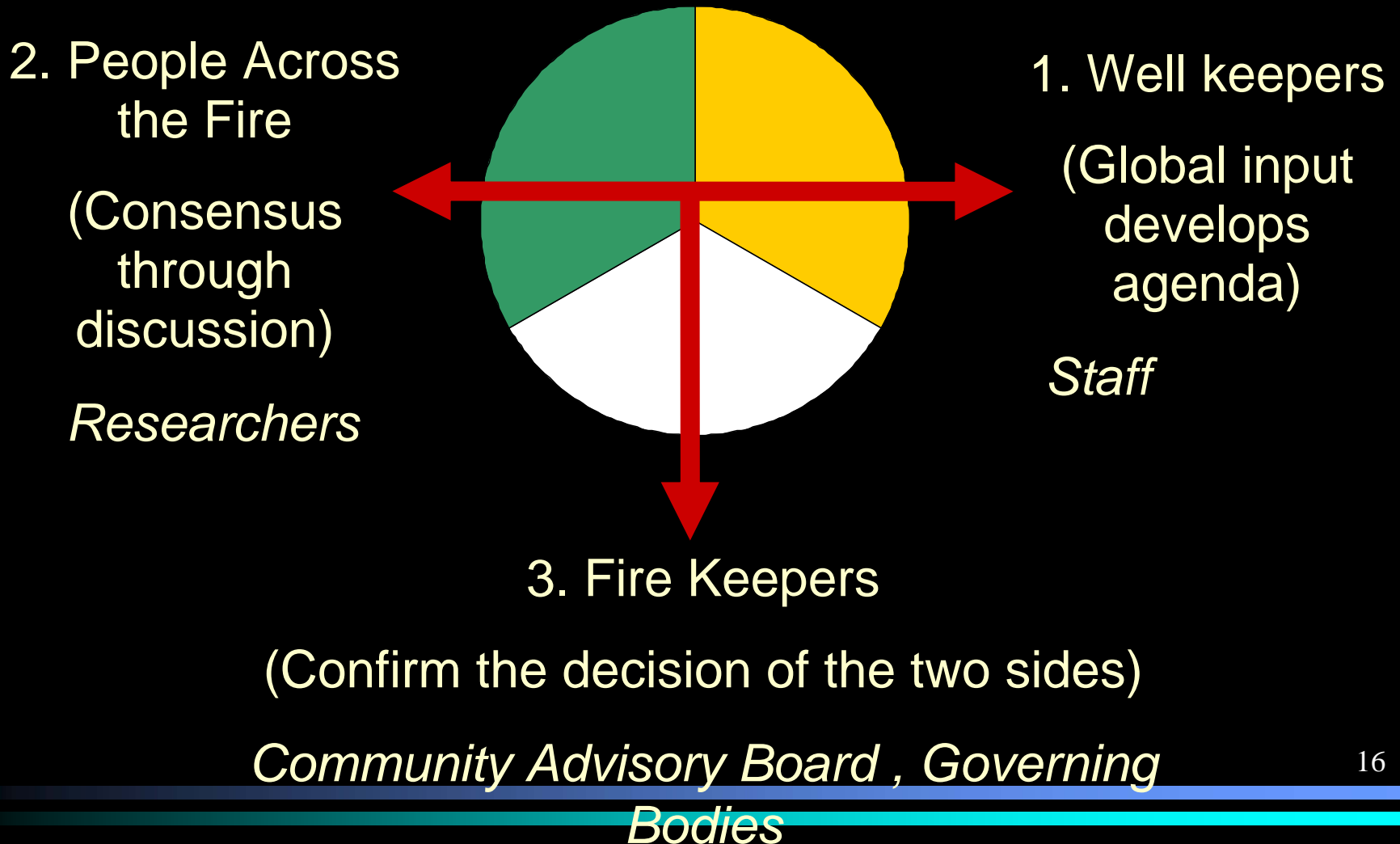


- McGill
- U de M
- Queen's
- Students
- Staff
- Onkwata'karit ahshera
- Education

University - Researchers

- ❖ Scientific Director
- ❖ Research Team members
 - ❖ Co-investigators
 - ❖ Community researchers (staff): coordinator, assistant, intervention staff
- ❖ Students
 - ❖ Post-doctoral
 - ❖ Doctoral & Masters
 - ❖ Bachelors & college
 - ❖ High school
- ❖ Supervisory Committee

Using Traditional Mohawk Decision Making Process



KSDPP Code of Research Ethics

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 - 2006

Statement

The sovereignty of the Kanienkehá:ka of Kahnawa:ke to make decisions about research in Kahnawa:ke is recognized and respected. The benefits to the community as a whole and to individual community volunteers should be maximized by the researchers.

Research should empower the community to support community goals of health and wellness, to promote healthy lifestyle, improve its self-esteem and to fulfill its traditional responsibility of caring for the Seventh Generation.

Code of Ethics Content 2006

- 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