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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**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

Université de Montréal 1994

Queens University - 2002
Kahnawake Partnership

KSDPP

Kahnawake Education Center

Onkwata'karitáhtshera
(Kahnawake One Health Agency)
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
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

1. Well keepers
   (Global input develops agenda)
   
2. People Across the Fire
   (Consensus through discussion)
   Researchers

3. Fire Keepers
   (Confirm the decision of the two sides)

Community Advisory Board, Governing Bodies
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