

Ethics for Research with Community Groups

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Protecting communities as well as individuals

As history demonstrates in Indigenous communities: “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.



Defining community

 “individuals who share characteristics”
very well defined to very broad



IRBs, designed to protect the rights and welfare of individual study participants, are neither expected nor equipped to protect the rights and welfare of communities involved in research.



IRB and assessment of risks for communities?

- Protection of individuals
- Protection of communities... add to stigmatization.



Community Based Participatory Research (CBPR)

A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR also begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change.



So....

- Research subjects vs. research participants
- Community members make many decisions
- Capacity building is enhanced



How to insure community protection

- Role of community members (non-scientific members) on the IRB...
- training, mentoring,
- respect, feedback, and a sense of community
- insurance etc

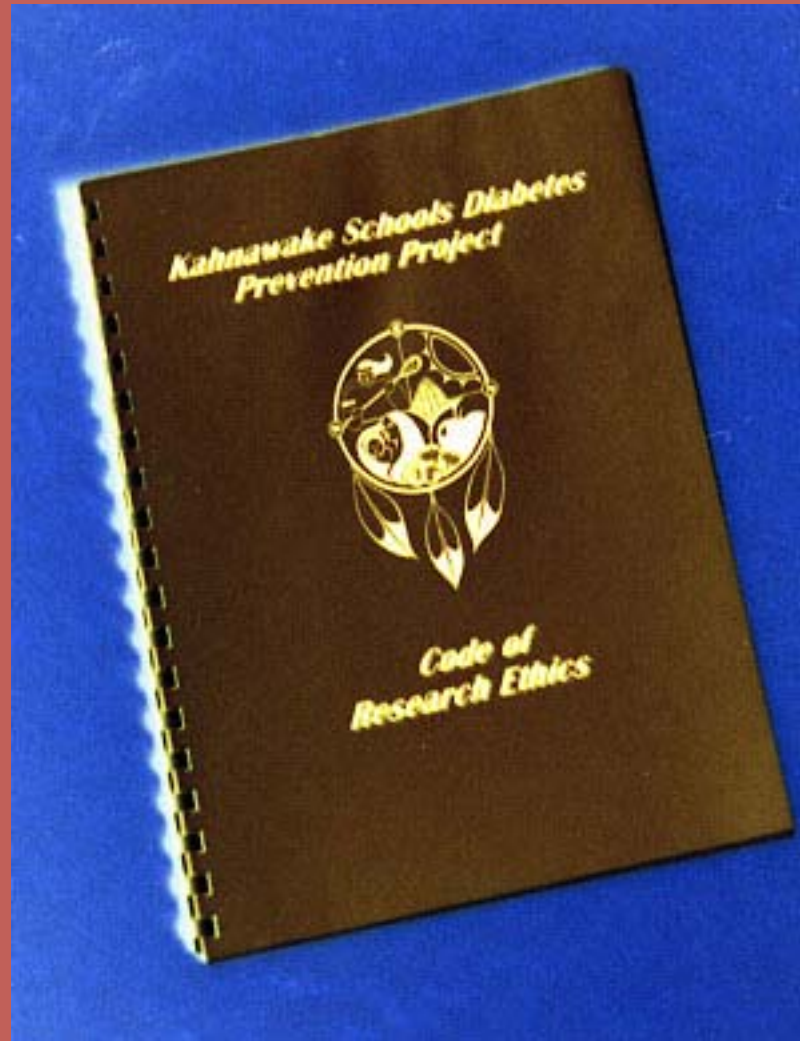


Working with communities

 Approval process within communities



KSDPP Code of Research Ethics



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

Policy statement

- The self-determination of the Kanien'kehá:ka of Kahnawá:ke to make decisions about research is recognized and respected.
- The academic researchers' obligation to contribute to knowledge creation in their discipline is recognized and respected.
- Research should support the empowerment of Kahnawá:ke to promote healthy lifestyles, wellness, self-esteem, and the Kanien'kehá:ka's responsibility of caring for the Seven Generations.



Responsibilities

- Research results must be presented to the community before being disseminated in the public domain.



Responsibilities

- All partners must be involved in making decisions about the publication and dissemination of the research.



Responsibilities

- A partner has the right to dissent concerning the interpretation of the research results.
- A differing interpretation of the results must be fully explained and agreed upon through the consensual decision making process.



Responsibilities

- The community retains ownership, control, access and possession of all data collected. (As guardian of the data, the community must continue to ensure confidentiality and anonymity of individuals, organizations, and communities).



Responsibilities

- Academic researchers must keep a copy of data to meet their institutional responsibilities. (All future use of this data must comply with all the above-mentioned principles).



Knowledge translation

- Get the results back to the participants and communities
- Individuals must know their risks
 - Medical testing (NuAge, anemia)
- Communities must know the results and have help with implementation
 - KSDPP, northern Communities,
 - NuAge (results)



Knowledge Translation

“a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system.”

CIHR



Websites

 <http://www.ccph.info>

 [**http://www. KSDPP.ORG**](http://www.KSDPP.ORG)

