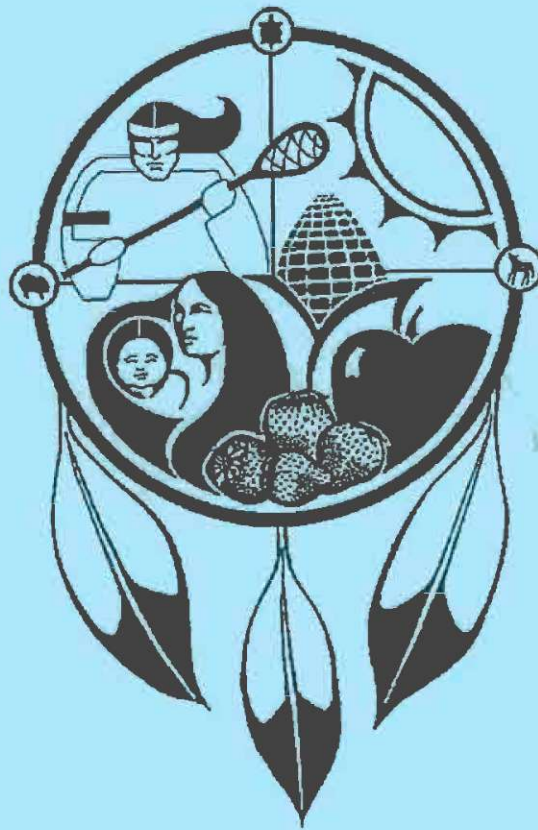


# Kahnawake Schools Diabetes Prevention Project

## Code of Research Ethics



The Kahnawake Schools Diabetes Prevention Project (KSDPP) is funded by the National Health Research & Development Program, Intervention Section #6605-4188-ND and Evaluation Section #6605-4187-ND.

The Code of Research Ethics was developed by KSDPP personnel (Edward J. Cross Ed, Treena Delormier P.Dt, M.Sc, Serge Desrosiers M.Sc, Chantal Haddad P.Dt, B.Sc, Rhonda Kirby, Ann C. Macaulay MD, Alex M. McComber, Gilles Paradis MD, Louise Stovin PhD, Mary Trifonopoulos P.Dt, M.Sc) and the members of the KSDPP Community Advisory Board.

WK  
810  
K346  
1996

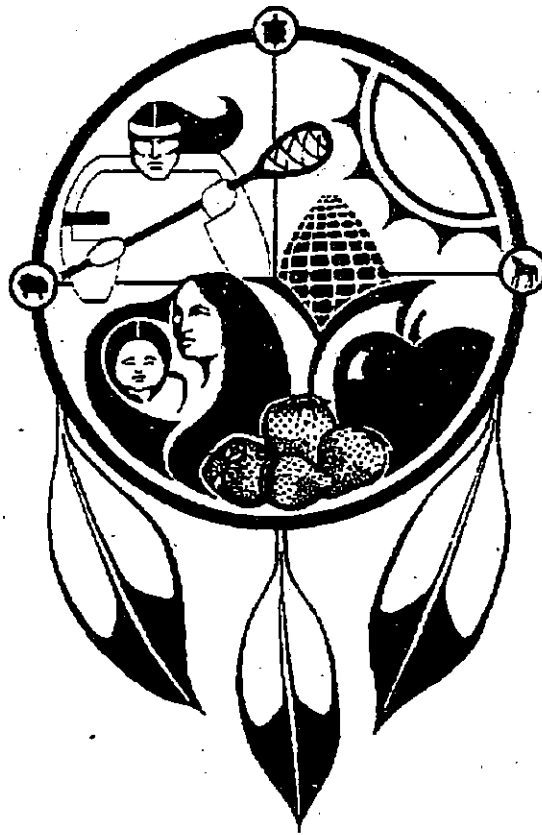


INSTITUT NATIONAL DE SANTÉ PUBLIQUE DU QUÉBEC  
CENTRE DE DOCUMENTATION  
MONTREAL

Copyright pending Spring, 1996  
by the Kateri Memorial Hospital Center  
P.O. Box 10, Kahnawake Territory, Mohawk Nation, via Quebec, Canada J0L 1B0  
on behalf of the Kateri Memorial Hospital Center Board of Directors,  
the Kahnawake Combined Schools Committee and  
the Kahnawake Schools Diabetes Prevention Project Community Advisory Board.  
To purchase (\$5.00) a copy of this Code of Research Ethics or for further information,  
you may write to:  
Mr. Edward J. Cross, Director of Educational Services  
Kahnawake Education Center  
P.O. Box 1000  
Kahnawake Territory, Mohawk Nation  
via Quebec, Canada J0L 1B0

# Kahnawake Schools Diabetes Prevention Project

## Code of Research Ethics



The Kahnawake Schools Diabetes Prevention Project (KSDPP) is funded by the National Health Research & Development Program, Intervention Section #6605-4188-ND and Evaluation Section #6605-4187-ND.

The Code of Research Ethics was developed by KSDPP personnel (Edward J. Cross M.Ed, Treena Delormier P.Dt, M.Sc, Serge Desrosiers M.Sc, Chantal Haddad P.Dt, B.Sc, Rhonda Kirby, Ann C. Macaulay MD, Alex M. McComber, Gilles Paradis MD, Louise Potvin PhD, Mary Trifonopoulos P.Dt, M.Sc) and the members of the KSDPP Community Advisory Board.

**KAHNAWAKE SCHOOLS DIABETES PREVENTION PROJECT  
CODE OF RESEARCH ETHICS  
MARCH 1996**

***INTRODUCTION***

The Kahnawake Schools Diabetes Prevention Project (KSDPP) is a partnership of the people of the Kanien'keha:ka (Mohawk) community of Kahnawa:ke, community based researchers of the Kateri Memorial Hospital Center and the Kahnawa:ke Education System, and academic researchers of McGill University and the Université de Montréal. In this document these three groups are referred to as the three partners.

The Kanien'keha:ka community is represented by the Community Advisory Board, the Kateri Memorial Hospital Center by its' Board of Directors, and the Kahnawake Education System by the Kahnawa:ke Combined Schools Committee.

The three partners will work cooperatively and collaboratively in the design, implementation, analysis, interpretation, conclusion, reporting and publication of the experiences of the project. Each partner provides ideas and resources that come from the experience, knowledge and capability of all its members. Together, through respect for each other, consultation, and collaboration, they significantly strengthen the project and its outcomes. All three partners of the project share an understanding that community based research is a powerful tool for learning about health and wellness, while contributing to the health of the community in which it is being conducted.

Collaborative research acknowledges that there must be respect for the scientific and social integrity of the project. Each group has obligations towards the other partners. The Kanien'keha:ka territory of Tyendinaga (Ontario) is also participating as the comparison community. The people of this community are represented by the elected Chief and Council and the Parents School Committee.

***PURPOSE OF THE CODE OF ETHICS:***

The purpose of this code of ethics is to establish a set of principles and procedures to guide the three partners to achieve the goals and objectives of the KSDPP. The code outlines the obligations of each of the three partners 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.

***POLICY STATEMENT:***

The sovereignty of the Kanien'keha:ka of Kahnawa:ke to make decisions about research in Kahnawake 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 lifestyles, improve its self-esteem and to fulfill its traditional responsibility of caring for the Seventh Generation.

### **PRINCIPLES:**

1. The community must be involved as a full partner in all aspects of the research. Continuous consultation and collaboration should characterize the partnership.
2. The strengths and culture of the community, including community researchers and staff as well as material resources must be respected and utilized whenever possible.
3. Written permission must be obtained from the three partners before beginning the research project.
4. Permission from individual students and their parents must be obtained prior to collecting personal information.
5. The confidentiality of students, parents and teachers and other individuals must be respected. If necessary, Kahnawake and any other community involved may choose to remain anonymous when reporting the results.
6. All research results, analyses and interpretations must first be reported to the three partners to ensure accuracy and avoid misunderstanding.
7. All data collected belongs to the community and must be returned as grouped results.
8. The three partners must all be involved in making decisions about the publication and the distribution of all or parts of the research results.
9. No partner can veto a communication. In the case of disagreement the partner who disagrees must be invited to communicate their own interpretation of the same data in an addition to the main communication, be it oral or written. All partners agree to withhold any information if the alternative interpretation cannot be added and distributed at the same time, provided that the disagreeing partner(s) do not unduly delay the distribution process.

### **OBLIGATIONS OF THE PARTNERS**

#### **OBLIGATIONS OF ACADEMIC RESEARCHERS**

1. To do no harm to the community.
2. To involve the community in active participation rather than passive acceptance.
3. To ensure the design, implementation, analysis, interpretation, reporting, publication and distribution of the research are culturally relevant to the community and in agreement with the standards of competent research.
4. To undertake research that will contribute something of value to the community in which the research is being conducted.
5. To impart new skills to community members i.e. data collection
6. To help to address any health or social issues that are raised as a result of research.
7. To provide expertise to scientifically answer questions that emerge from the community.

8. To promote academic diffusion of knowledge through written publications and oral presentations. This includes the documentation of the undertaking of the project and of the results.
9. To be guardians of the data until the end of the project and to return that data to the community at the end of the project.
10. To be involved in any future analysis of the data after the data has been returned to the community.

#### **OBLIGATIONS OF COMMUNITY RESEARCHER:**

Community researchers are regarded as the KSDPP Staff and those Co-investigators who are employed within the community. In addition to the obligations listed for academic researchers, the community researcher is obligated:

1. To maintain a long term relationship of trust in the dual role of caregiver/educator and researcher: this will only be possible if the needs of the community are always considered as the first priority in any decision.
2. To communicate with academic researchers during all phases of the research.
3. To arrange for academic researchers to meet with the Combined Schools Committee and the Kateri Memorial Hospital Board of Directors and any other local organizations to implement and promote the project.
4. To promote the intervention objectives of the project by working closely with the staffs of the schools, the community advisory board, community recreation, sports organizations and all food service outlets.
5. To facilitate supervisory meetings of the Intervention and Evaluation teams.

#### **OBLIGATIONS OF THE COMMUNITY PARTNER:**

1. To represent Kahnawakero:non through their respective organizations. To promote the objectives of daily physical activity, healthy eating habits and positive attitudes to the community.
2. To be updated by the KSDPP Staff on a determined basis to support the development and offer analysis of the school and community activities to ensure compatibility with the Project goal and objectives.
3. To meet with the KSDPP Co-investigators to maintain an awareness and to offer recommendations concerning the research aspect of the project.
4. To communicate with representatives of other communities to share ideas and program development for benefit and involvement.
5. To serve as the guardian of all evaluation data after the completion of the KSDPP.
6. To receive all requests for the use of the data by other researchers after the completion of the KSDPP.
7. To approve or write a disagreement to the interpretation of the data analysis.

## **KSDPP AUTHORSHIP GUIDELINES**

### **INTRODUCTION**

The purpose of KSDPP is to investigate the research questions described in the protocol. This community based program has been developed to promote a positive attitude towards health and community support regarding healthy eating and daily physical activity. In the short term it aims to improve the lifestyles of the elementary school children of Kahnawake. In the long term it aims to prevent the development of diabetes. Since this project is unique, the results will be of interest to those who wish to prevent diabetes in their communities. For this reason it is necessary to share the experience of KSDPP with the largest audience who might benefit from it. Part of the research process includes the communication of research results to other people and organizations in similar areas of research.

### **AUDIENCE**

Communications will be directed at four general audiences:

1. Health and Education officials
2. Scientists and Researchers
3. The Mohawk Council of Kahnawake
4. The Kahnawake community at large

Health and education officials are those people working on programming and planning. They will be interested in how KSDPP was developed and implemented as well as the outcome of KSDPP efforts. Scientists and researchers will be interested in the methods used, the process of the program, the impacts measured, and the answers provided to the research questions. The Kahnawake community at large is everyone who participated in the project as well as those who are generally interested in preventing diabetes in future generations of Kahnawake. Kahnawake:non will want to know how well they are doing with respect to preventing diabetes and what they can continue to do to keep on a wellness path.

### **PRINCIPLES**

All aspects of KSDPP can be considered as worthy of communication. All communication pertaining to KSDPP will follow generally accepted ethical standards. The principles include:

1. **Anonymity:** Results to be presented in a grouped, not individual manner.
2. **Confidentiality:** All personal information provided by individuals will be made anonymous whenever possible and remain confidential.
3. **Priority of Communities Involved:** The communities participating will be the first to receive results and the first invited to provide input and feedback on the results.
4. **Respect:** Consideration for the Mohawk communities and all Kanien'keha:ha must be observed in all communications.

## **PROCESS**

Results from research projects usually are presented in the following ways:

1. Articles in scientific journals, referred to as "a paper".
2. Oral presentation of "a paper" at a scientific conference or meeting.
3. Oral presentation to the community at large.
4. Written document to the community at large.
5. Teaching examples.

For scientific journals and oral presentations at scientific conferences and meetings there is a standard process involved. It is therefore possible to outline the steps from idea to final communication and outline the responsibilities for those involved with the authorship. However, these points should also apply to communications to the community. From here on the word communication will be used to describe both oral presentations and written papers.

It will be the responsibility of the Supervisory Board to ensure that the staff and investigators who have made significant contribution to KSDPP can qualify for authorship. These are people who have worked on the design and method for collecting data and those who developed the health promotion programs. However, being involved only in data collection or delivery of a health promotion program will not be sufficient for authorship. Also, investigators on evaluation teams will not be excluded from communication on intervention issues and vice-versa.

### ***1. The Idea***

All ideas for communications must be presented to the Principal investigators before writing begins.

### ***2. Preparing the Communication***

The first author of an article i.e. the person whose name appears first on the article will assume the major responsibility for preparing the article. The first author will assume most of the writing responsibility. Other authors contributing to the communication will appear in descending order. This order will depend on the contribution made to the subject of the communication and the preparation and writing of the communication.

### ***3. Submitting a Communication***

All authors on the paper must approve of the final version before the paper is submitted to the journal, conference, etc. Furthermore final versions of all papers must be approved by the Principal Investigators before submission. Any disagreement about approval of a communication will be settled by a majority vote by the Principal Co-investigators. There are no veto rights.



#### **4. Peer Review**

Once a communication is submitted to a journal it will be reviewed by people considered experts in the subject of the communication. This peer review process results in suggested changes of the communication in order for publishing the article in the journal of interest. Any changes made in the review must be approved by all the authors of the communication. This will be done by a letter to the editor signed by all the authors.

*The next section deals with special communications*

#### **5. Abstracts**

An abstract is a short summary of the content of a communication. When someone wants to present a paper at a conference an abstract will be sent to the conference organizers. The abstract will then be used to decide if the communication will be accepted for presentation. In case of a late call for an abstract, the Principal Investigators should be contacted as soon as possible. If there are no objections the abstract should be sent immediately. The preparation of the communication will proceed following the steps outlined previously.

#### **6. Responsibility of Communication by the Principal Investigators**

It is part of the shared responsibility of the Principal Investigators to prepare communications for the Kahnawake community and the scientific community. Communications for Kahnawake would appropriately be prepared by those who have more of an interest in them; likewise for communication to the scientific community. This should not limit the authors to one or the other.

### **EVALUATION GUIDELINES:**

#### **CODIFICATION, DATA ENTRY AND DATA CLEANING**

1. The activities organized by the KSDPP should ensure that the data collection process is in accord with the host community values and norms and competent scientific practice.
2. Participation in the evaluation activities is voluntary for the people in both communities. The people who express the desire to withdraw will be able to do so at any time.
3. All information or data collected on individuals will be kept strictly confidential. An identification number will be given and the names of participants will be removed. A file containing names and identification numbers will be kept for future follow-up. Only the Evaluation Project Coordinator will have access to this file
4. For reasons of confidentiality, the person responsible for coding the collected information should not have access to the names of the participants. The names of the participants should be removed prior to data coding.
5. The coordinator is responsible for the quality control of the data coding and entry.

### **COMPARISON COMMUNITY:**

A copy of the data files from the comparison community with the unidentified participants will be returned to that community. Anyone requesting information from the comparison community of Tyendinaga must contact the representatives ie. the elected Chief and Council and the Parents School Committee.

### ***PROCESS FOR APPLICATION TO RESEARCH IN CONJUNCTION WITH KSDPP:***

The researcher and community need to meet for the purpose of discussion and approval of the research idea and the protocol involved. To meet this end, the following steps will be followed to make application:

- A letter is sent to one of the three partners to request a meeting to discuss the research proposal. This letter is to include a summary description of the proposed research, a time frame for research, reporting and the expected conclusion.
- The recipient of the request is responsible to: distribute the material to the other two partners within one working week of receipt of the letter, establish a meeting with the Three partners and the researcher, and send a copy of the Code of Research Ethics to the applicant to allow for preparation.
- If there are no objections from any of the members of the three partners to the research proposal, formal written consent is to be sent within thirty (30) days of the meeting.
- In the event of any objections, a second meeting with the proposed researcher is to be held within two working weeks for discussion on the objection.
- The researcher must agree to comply with all aspects of the KSDPP Code of Research Ethics. The proposal will be rejected if the researcher refuses to comply with any aspect.
- All partners will review and discuss the completed research document(s) before publication. This review is to take place thirty (30) days following receipt of the research document(s).
- If there is any dissent, the dissenter is responsible to write a present a written response at this meeting. The dissent is to be included with the submission of the research document(s).

M 13,294  
Ex. 2