

# Kahnawake Schools Diabetes Prevention Project

## Code of Research Ethics Revised 2007



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## **Kahnawake Schools Diabetes Prevention Project (KSDPP) Code of Research Ethics (revised 2007)**

### **Introduction**

The Kahnawá:ke Schools Diabetes Prevention Project (KSDPP) Center for Research and Training in Diabetes Prevention is a community-based participatory research project.

KSDPP is a partnership between the Kanien'kehá:ka (Mohawk) community of Kahnawá:ke and researchers who are affiliated with KSDPP. Current researchers are from the community and the academic institutions of McGill University, Université de Montréal and Queen's University.

The partners will work cooperatively and collaboratively throughout the research process. The research process includes developing the research question, determining research methodology, the acquisition, analysis, and interpretation of data, and the dissemination of the experiences and results.

Each partner provides ideas and resources that come from their experience, knowledge, expertise and capabilities. Together, through respect for each other, consultation and collaboration, the partners significantly strengthen the project and its outcomes. The partners of the project share an understanding that community-based participatory research is a powerful tool for learning about health and wellness, which contributes to the health of the community in which it is being conducted.

Community-based participatory research assures that there is respect for the community's values and philosophy and the scientific integrity of the project. All partners have obligations towards the project and the community.

### **Purpose of the KSDPP Code of Research Ethics**

The purpose of the KSDPP Code of Research Ethics is to establish a set of principles and procedures that will guide the partners to achieve the goals and objectives of the KSDPP.

The KSDPP Code of Research Ethics outlines the obligations of the partners throughout all phases of the research process.

### **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.

**Indigenous Methodologies and Haudenosaunee Philosophy**

## Principles

- ?The Kanien'kehá:ka and the philosophy of the Kanien'kehá:ka must be respected.
- ?The academic researchers and the professional responsibilities of the academic researchers must be respected.
- ?The research must respect and include Indigenous methodologies, incorporating the strengths, knowledge, experiences, and culture of the community.
- ?The community is an equal partner in all aspects of the research. Continuous consultation and collaboration must characterize the partnership.
- ?The research must be relevant and beneficial to the community.
- ?The research must provide opportunities for the involvement of community researchers and utilize community resources.
- ?Meaningful community capacity-building must be incorporated into all aspects of the research process.
- ?All research must undergo the Review and Approval Process for Ethically Responsible Research.
- ?Ethical approval must be granted from all partners before research begins.
- ?Active, free and informed consent must be obtained from all participants.
- ?Research must ensure confidentiality and anonymity of individuals, organizations, and communities unless these parties choose to be named when the results are reported.
- ?Research analyses, interpretations and results must be presented to and discussed by all partners to ensure accuracy and avoid misunderstanding.
- ?Reports and summaries must be returned in a language and format that is comprehensible to the community.
- ?Research results must be presented to the community before being disseminated in the public domain.
- ?All partners must be involved in making decisions about the publication and dissemination of the research.
- ?A partner has the right to dissent concerning the interpretation of the research results. A

### **Obligations of the Partners**

- ?To ensure Kanien'kehá:ka culture and values are embodied in the research process, while maintaining the scientific integrity of the research.
- ?To represent the interests of the community and to be an ambassador of wellness by promoting the objectives of daily physical activity, healthy eating habits and positive attitudes to the community.
- ?To provide ongoing recommendations, to inform the planning, implementation, and evaluation of intervention activities.
- ?To collaborate with researchers to provide ongoing recommendations concerning the research.
- ?To be involved in knowledge translation with other communities and organizations at the local, national and international levels.
- ?To be in possession and to safeguard the data after the completion of the research components of the KSDPP.
- ?To be involved in the Review and Approval Process for Ethically Responsible Research

### ***Obligations of Community Researchers***

- ?To maintain the integrity of the partnership and a relationship of trust, the well-being of the community is always the first priority in any decision about research.
- ?To work with researchers to ensure mutual understanding of the strengths, knowledge, experiences and culture of the community.
- ?To facilitate exchanges between researchers and the community to ensure the integrity of the project.
- ?To promote the vision of KSDPP within the community, as well as nationally and internationally.

### ***Obligations of Academic Researchers***

- ?To develop cultural awareness of the community.
- ?To do no harm to the community.
- ?To collaborate with the community in the research design, implementation, data collection, data analysis, interpretation and the dissemination of results.

?To enhance community capacity by providing community members ongoing opportunities for active participation in the research.

?To train and mentor aboriginal and non-aboriginal students with preference to aboriginal students.

?To ensure that the research undergoes the Review and Approval Process for Ethically Responsible Research.

?To respond to community requests for information after the research project ends.

### **The Rights of the Community and Participants**

Research must respect the rights and dignity of the community and the people involved in the research.

#### ***The Collective Rights of the Community***

?To know why the research is being carried out.

?To know the objectives, methods and potential results of the research.

?To know how the research will benefit the community.

?To know if and how the research could potentially harm the community.

?To be involved in the Review and Approval Process for Ethically Responsible Research.

?To be given the opportunity to be involved in all aspects of the research process.

?To know that the research will respect the KSDPP Code of Research Ethics.

#### ***The Rights of Participants***

?? To ask the researcher questions about the research at any time.

?? To contact the selected KSDPP ombudsperson if they have any concerns about a research project.

?? To know that participation in the research is voluntary.

## **Review and Approval Process for Ethically Responsible Research**

(refer to Appendix B)

The Review and Approval Process for Ethically Responsible Research applies to any academic researcher who wants to conduct research with KSDPP.

The Review and Approval Process for Ethically Responsible Research is a multistage process that requires community consultation and community involvement. Ongoing consultation ensures that the research supports the principles of community - based participatory research and respects the KSDPP Code of Research Ethics.

All proposed research must be reviewed and approved by the KSDPP Research Team the KSDPP Community Advisory Board and the appropriate university Institutional Review Board.

The Review and Approval Process for Ethically Responsible Research involves:

1. Submission of a letter of interest from the researcher to the KSDPP Scientific Director or their KSDPP supervisor.
2. Introduction and consultation meeting(s) with the KSDPP research team.
3. Submission of a detailed research proposal after consultation meeting(s) with the KSDPP research team.
4. KSDPP Research Team's review and approval in principle of the research proposal.
5. The researcher's presentation of the research proposal to, and consultation with, the Community Advisory Board.
6. Issuance of a KSDPP Certificate of Approval from the Community Advisory Board.
7. Submission of application to the appropriate university Institutional Review Board.
8. Parallel Review and Approval Process.
9. Continuous consultation, collaboration and reporting.

## **The Consent Process**

(refer to Appendix C)

Research must respect the rights and dignity of the community and the people involved in the research.

Before any data is collected, consent must be obtained from the community and individual participants. Community consent means that the community, through CAB via the Review and Approval Process for Ethically Responsible Research has agreed to participate in the research.

?Active, free and informed consent must be obtained in writing from individual participants before data is collected. Individual participants will be asked to sign a KSDPP consent form. The consent form will include the KSDPP ombudsperson's name and contact number.

## **KSDPP Ombudsperson**

Each KSDPP research project will have an ombudsperson, someone who can be contacted regarding their rights, ethical questions or any concerns that may arise in relation to the research. The ombudsperson is a KSDPP team member who has volunteered for the position, is knowledgeable about the research project, but not directly involved in research activities. The name of the ombudsperson will be included on the consent form. Study participants (or their guardians) may contact the ombudsperson if they have concerns or complaints or feel they (or their children) have been treated unfairly during the project. Any complaints will be discussed immediately with the researcher in charge. (The name of the KSDPP research assistant will also be included on the consent form and will be available for general questions pertaining to the details of the project).

## **Data Collection and Data Management**

### ***Data collection***

?KSDPP will ensure that the collection of individual and community data respects the community's intellectual and cultural integrity, as well as ensure competent scientific research practice.

?KSDPP, on behalf of the community, will ensure ownership, control, access and possession of the data.

?The coding, management and safeguard of the data will be specified in the research proposal before the start of any research.

?All data collected will be documented by the KSDPP Scientific Director or delegate to

?The researchers will always apply for review and approval for the new research questions from CAB.

?University IRB review is not required if the data are not linked to individuals and are completely anonymous and /or anonymised.

?University IRB review is required if the original ethical application and/or consent forms were very specific and did not include the new question. IRB ethical approval is not required if the IRB application and/or consent forms are very general and cover future research.

?University IRB approval is always required if the question involves high risk to the community and/or individuals.

**Secondary data analysis.** Secondary data analysis is (a) reanalysis of existing research project data to answer a research question not included in the objectives of the original research grant or original ethical application and (b) the analysis of data collected by another organization for a purpose other than research i.e. hospital records. Both of these situations require the researchers to apply for ethical approval from CAB and the relevant university IRB.

### **Dissemination and Publication of Research Results**

(refer to Appendix D)

Dissemination, or knowledge dissemination, is the process of presenting the research results back to the community as well as within the public domain.

All research results and knowledge generated by the KSDPP will be considered worthy of dissemination.

All research results and knowledge generated by KSDPP will be presented, discussed and approved by the Community Advisory Board, relevant organizations and/or communities participating in the research, before the results are disseminated externally to the general public, including scientific publications and conferences.

?The publication and dissemination of the research results will follow generally accepted ethical principles. These principles include:

?Anonymity: The research results will be presented in an aggregate or grouped manner. That is, individual participants will not be identified.

?Anonymity of community: The community has the right to decide if they want to be identified or not identified in the dissemination of the research results.

?Privacy and Confidentiality: All information collected from individual participants and the community will remain private and confidential.

## KSDPP Authorship Guidelines (refer to Appendix F)

The dissemination of research results and knowledge generated will respect the KSDPP Authorship Guidelines that include:

- ?? Planning and development of a manuscript
- ?? Lead author responsibilities and protocol for invitation to authorship
- ?? Eligibility criteria for invitation for authorship
- ?? Criteria for authorship
- ?? Authorship responsibilities
- ?? Student authorship
- ?? Acknowledgment section of KSDPP authorship guidelines

## **Multi-site Research and Multi-site Research Agreement**

Multi-site research involves research conducted collaboratively by research teams that are affiliated with different communities, academic institutions or organizations.

Multi-site research that is conducted collaboratively with KSDPP will be guided by the KSDPP Code of Research Ethics and the KSDPP Review and Approval for Ethically Responsible Research.

A multi-site research agreement is required to be in writing before the research begins. It must be reviewed and approved by the KSDPP Research Team, KSDPP Community Advisory Board and with the other community(ies) specifically for the ownership and control of the data. The agreement(s) should include the values and traditions, rights and responsibilities of the other community(ies).

## **Researcher Check- list** (refer to Appendix E)

**This outlines the specific items that each new researcher must fulfill in order to do research in the community. These include the review and approval process, dissemination process and return of data to KSDPP.**

**THE CONFERENCE WAS ONLY ABLE TO ACCEPT THE FIRST 10 PAGES OF THIS DOCUMENT.**

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