Kahnawà:ke Schools
Diabetes Prevention Program

Code of Research Ethics

Revised 2023

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Contact the Kahnawà:ke Schools Diabetes Prevention Program:

E-mail: info@ksdpp.org
Phone: (450) 635-4374

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Kahnawà:ke Schools Diabetes Prevention Program (KSDPP)
Code of Research Ethics (revised 2021)

Introduction

The Kahnawà:ke Schools Diabetes Prevention Program (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 Kahnawà: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.

Throughout any research related process, the partners work cooperatively and collaboratively within a community-based participatory research approach. The research process includes developing the research question(s), determining research methodology and methods, 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 Kahnawà: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 Kahnawà: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

(Refer to appendix A)

The KSDPP Code of Research Ethics incorporates Haudenosaunee *("People of the Longhouse*") knowledge, ways of teaching and decision-making. Solving issues of ethically responsible research requires an understanding of what it means to be Onkwehón:we *("real human beings who exist in spirit"*). The development of distinctly Onkwehón:we research practices facilitates culturally relevant solutions to various research concerns. In this way, not only are Onkwehón:we contributing to developing respectful research protocols in their own communities, they are also using the knowledge they have inherited to understand themselves better. This can be referred to as decolonizing methodologies.

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 Onkwehón:we methodologies, incorporating the strengths, knowledge, experiences, and culture of the community.
- The KSDPP recognizes that research includes ceremony. Ceremony and ceremonial practices may be used during the research project, when deemed appropriate, to ensure that everyone joins the team with a clear mind, to ensure the minds of everyone come together, and to ensure we bring spirit into the process that will help to guide the research in a good way.
- The community, community researchers and academic researchers are equal partners in all aspects of the research. Continuous consultation and collaboration must characterize the partnership.
- The research must be relevant, useful, sustainable and beneficial to the community.
- The research must provide opportunities for the involvement of community researchers and use 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 differing interpretation of the results must be fully explained and agreed upon through the consensual decision-making process.
- The community retains data governance: ownership, control, access and possession of all data collected (First Nations Information Governance Centre, 2015). As guardian of the data, the community must continue to ensure confidentiality and anonymity of individuals, organizations and communities.

- 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.

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 a supporter of wellness by promoting the objectives of wholistic healthy lifestyles and positive attitudes to the community.
- To provide ongoing recommendations, to inform the planning, implementation, and evaluation of intervention activities.
- To collaborate on providing ongoing recommendations concerning the research.
- To be involved in knowledge translation with other communities and organizations at the local, national and international levels.
- 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 academic researchers to ensure mutual understanding of the strengths, knowledge, experiences and culture of the community.
- To facilitate exchanges between academic 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

Academic researchers must develop cultural awareness of the community, which entails the following obligations:

- 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 ensure that the research is relevant and beneficial to the community and in agreement with the standards of competent research.
- To promote creation and dissemination of knowledge through written publications, and oral presentations. This includes the documentation of the undertaking of the project, and of the results.

- To ensure that the community has opportunities to participate in all aspects of the research.
- To enhance community capacity by providing community members ongoing opportunities for active participation in the research.
- To provide training and mentor Onkwehón:we and non-Indigenous academic trainees, with preference to Onkwehón:we academic trainees.
- 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.
- "To educate oneself and others on the realities and histories of Indigenous people and other marginalized groups. To demonstrate understanding and support through actions, relations" (Montreal Urban Aboriginal Community Strategy NETWORK, 2019).
- "To engage in projects with open minds and hearts" (UBC Indigenous Research Support Initiative, 2019).
- "To take the time to learn appropriate cultural protocols and language to use (or to avoid). To truly hear the concerns and needs of the community, as well as the considerable wisdom that community members have to share. To listen first, for every step of the research project being undertaken" (UBC Indigenous Research Support Initiative, 2019).

Obligations of Academic Trainees

- "To educate oneself and others on the realities and histories of Indigenous people and other marginalized groups. To demonstrate understanding and support through actions, relations" (Montreal Urban Aboriginal Community Strategy NETWORK, 2019).
- "To engage in projects with open minds and hearts" (UBC Indigenous Research Support Initiative, 2019).
- "To take the time to learn appropriate cultural protocols and language to use (or to avoid). To truly hear the concerns and needs of the community, as well as the considerable wisdom that community members have to share. To listen first, for every step of the research project being undertaken" (UBC Indigenous Research Support Initiative, 2019).

The Rights of the Kahnawà:ke Community and Research 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 understand why the research is being carried out.
- To understand the objectives, methods and potential results of the research.
- To understand how the research will benefit the community.
- To understand 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 understand that the research will respect the KSDPP Code of Research Ethics.

The Rights of Participants

- To ask the researcher(s) questions about the research at any time.
- To contact the selected KSDPP ratiriwahseron:nis (a group of persons or a person who fixes matters or issues) if they have any concerns about a research project.
- To understand that participation in the research is voluntary.
- To understand that they can refuse to participate in the research and still be entitled to benefit from KSDPP and KSDPP related activities.
- To understand that they can withdraw from participating in the research at any time and still be entitled to benefit from KSDPP and KSDPP related activities.

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 or trainee 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 (for scientific rigour), the KSDPP Community Advisory Board (for cultural relevance and to assess benefit to the community) 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, unless approval is delegated to another institution.

7. Issuance of approval in principle through CAB decision before applying to the Kahnawake Education Center Research Advisory Committee or other community organisation.

8. Issuance of KSDPP Certificate of Approval from the Community Advisory Board if other community organisation is agreement

9. Submission of application to the appropriate University Institutional Review Board.

10. Parallel Review and Approval Process.

11. Continuous consultation, collaboration and reporting.

The Consent Process

(refer to Appendices A and C)

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

Before any data are 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 or other acceptable form from individual participants before data are collected. Individual participants will be asked to review and sign or orally consent to a KSDPP consent form. The consent form will include the KSDPP ratiriwahseron:nis' name and contact number.

KSDPP Ratiriwahseron:nis

Each KSDPP research project will have an ratiriwahseron:nis; someone who can be contacted regarding the participants' rights, ethical questions or any concerns that may arise in relation to the research. The ratiriwahseron:nis 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 ratiriwahseron:nis will be included on the consent form. Study participants (or their guardians) may contact the ratiriwahseron:nis 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 will ensure that research methods and methodologies are as culturally appropriate as possible.
- KSDPP, on behalf of the community, will ensure ownership, control, access and possession of the data.
- The coding, management and safeguarding 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 safeguard and ensure the privacy and confidentiality of the data.

Access to Data

Evolving research questions within the objectives of the original grant. Within the overall objectives of the grant and individual research projects – which have already been granted ethical approval by CAB and the relevant university Institutional Review Board (IRB) – new research questions may arise which could be investigated using existing data.

- 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) The 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 unless they choose to be.
- 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.
- Respect: The cultural and intellectual integrity of the Kanien'kehá:ka must be respected in all KSDPP disseminations.

Knowledge Translation

(refer to Appendix E)

KSDPP knowledge translation is an interactive process that integrates new knowledge gained from research into practical solutions, tools and/or information that will improve the overall health and well-being of people.

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
- Eligibility criteria for invitation for authorship
- Criteria for authorship
- Authorship responsibilities
- Academic trainee authorship
- Acknowledgment section of KSDPP authorship guidelines

Multi-site Research and Multi-site Research Agreement

Multi-site research involves research conducted collaboratively by KSDPP and other communities, research teams, academic institutions, or organizations.

Multi-site research that is conducted collaboratively with KSDPP will be guided by the KSDPP Code of Research Ethics or an adaptation of the KSDPP Code of Research Ethics (e.g., the Community Mobilization

Training Code of Research Ethics (KSDPP CMT Pathways Team, 2020)). The KSDPP Review and Approval for Ethically Responsible Research or an adaptation of the procedure will be applied.

A research agreement, signed by all parties, 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 by all relevant community(ies) (and organizations - in the case where universities or regional organizations are involved). The research agreement should specify ownership and control of the data and the fundamental principles and obligations that the research partners must follow when collecting, using, storing, and disclosing individual and aggregated data. The agreement(s) should include the values and traditions, rights and responsibilities of each community.

Researcher Checklist

(refer to Appendix E)

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

Each new research project and researcher is responsible for ensuring that they understand the requirements for the process of timely sharing and development of research ideas, proposals and publications at Research Team meetings and CAB meetings.

Appendices

Appendix A. Indigenous Methodologies and Haudenosaunee Philosophy

Decolonizing methodologies incorporate methods and theories rooted in Indigenous knowledge. This involves reclamation of Indigenous history and culture and its dissemination in our own voices and ways. Māori scholar Linda Tuhiwai Smith explains that Onkwehón:we methodologies *are 'factors' to be built into research explicitly, to be thought about reflexively, to be declared openly as part of the research design, to be discussed as part of the final results of the study, and to be disseminated back to the people in culturally appropriate ways and in a language that can be understood* (1999). In this regard, Haudenosaunee knowledge and ways of teaching provides a distinctly Onkwehón:we way of doing research in Kahnawà:ke. The underlying philosophy serves as a basis for a culturally relevant way of doing research and incorporates the Haudenosaunee principles of skén:nen (peace), ka'shatsténhsera (power), and karíwi:io (righteousness).

A tangible manifestation of this philosophy can be found in the Haudenosaunee Consensual Decision-Making Process. The foundational principles of this process provide a basis for understanding the collective thinking and conduct that should be transmitted to the research process. The Enhse'nikonhraketskon carried out at the beginning of this process is used before any public gathering as well as social and political meetings, where deliberation on an issue takes place. The term Enhse'nikonhraketskon means "the words that are used to lift up the minds of those whose minds are on the ground" or, in the case of newcomers to the village or new researchers, "the words that we use at the wood's edge to greet newcomers who have journeyed a long distance to be here". The Enhse'nikonhraketskon has an important part to play in this as it sets the mind for what follows. Essentially, the ceremony is a figurative wiping of the eyes, clearing of the ears, and cleansing of the throat, which represents the need for clarity, fairness, and objectivity, that is essential to any decision-making process or research partnership. The Process requires individuals to participate fully, to listen, and to contribute to the discussion. In this way, fairness, accountability, and equality become the foundational principles of research as a process of knowledge translation. The final decision, outcome, or even research report has to consider the future generations (those to come).

Appendix B. Review and Approval Process for Ethically Responsible Research

1. Submission of a letter of interest from the researcher to the KSDPP Scientific Director or their KSDPP supervisor

An academic researcher should be affiliated with a university. A community-based researcher should be affiliated with KSDPP.

The Scientific Director will distribute the researcher's letter of interest to the KSDPP Research Team.

It is expected, in the meantime, that the researcher (if new) will visit the community and become familiar with KSDPP and Kahnawà:ke culture.

2. Introduction and consultation meeting(s) with the KSDPP Research Team

At a KSDPP Research Team meeting, the researcher will have the opportunity to discuss his/her letter of interest and research possibilities.

3. Submission of a detailed research proposal after consultation meeting(s) with the KSDPP Research Team

After appropriate consultation, and with continued guidance and support, the researcher will submit the proposal to the Scientific Director, or in the case of an academic trainee, to their research supervisor.

The research supervisor will ensure that the proposal supports the principles of community-based participatory research and respects the KSDPP Code of Research Ethics.

The research supervisor will ensure that the proposal is distributed to the Research Team one week prior to a Research Team meeting.

The proposal will include a summary description of the proposed research, including question(s) and/or hypothesis, methods, its relevance to KSDPP's priorities, potential risks and benefits to the participants, both as individuals and as the collective community, potential for community capacity building, a time frame, how research progress will be reported, how the research and the knowledge generated will be disseminated, and a knowledge translation plan for how the research findings will benefit community and others outside of the community.

The researcher, accompanied by his/her KSDPP research supervisor, (if applicable) will attend a meeting to consult with the KSDPP Research Team about the proposed research.

4. KSDPP Research Team's review and approval in principle of the research proposal

The researcher will incorporate the KSDPP Research Team's feedback and recommendations into the proposal, which may require further review and approval by appropriate Research Team members. This stage is to ensure appropriate choice of methodology, data collection, and analysis and scientific rigour.

The KSDPP Research Team will decide, through consensus, to grant approval in principle or to reject the proposal, providing reason.

5. The researcher's presentation of the research proposal to, and consultation with, the Community Advisory Board

After receiving approval in principle from the KSDPP Research Team, the researcher will present the proposal to the Community Advisory Board for review and approval.

The researcher will send their proposal to the Research Team coordinator or KSDDP General Manager or other designated person, and a copy to the Community Advisory Board coordinator or KSDDP General Manager or other designated person one week prior to the researcher's presentation to the Community Advisory Board.

The Community Advisory Board coordinator will distribute the proposal to the Community Advisory Board.

The researcher, accompanied by their KSDPP Research supervisor (if applicable), will present their proposal to the Community Advisory Board.

The researcher will address the Community Advisory Board's questions or concerns and incorporate their feedback and recommendations.

The Community Advisory Board will decide, through consensus, to approve or disapprove the proposal. A second or more Community Advisory Board meeting(s) may be necessary**.** This stage is to ensure that the proposed research is culturally appropriate and will benefit the community.

6. Issuance of a KSDPP Certificate of Approval from the Community Advisory Board

When review and approval is not required from any other community organization, a member of the Executive Committee of the Community Advisory Board will issue a "KSDPP Certificate of Approval" to the researcher within 7 to 10 days of the decision.

When the proposal includes the participation of children and/or staff attending school under the mandate of the Kahnawà:ke Education Center, approval in principle must first be obtained from the Research Team, then approval in principle or a certificate of approval must be obtained from the Community Advisory Board. The researcher then presents the proposal to the Kahnawà:ke Education Center Research Advisory Committee for review and approval. A Certificate of Approval will be issued after review and approval by the Kahnawà:ke Education Center Research Advisory Committee. Further, researchers will be responsible for following and respecting the protocols and procedures outlined by the Kahnawake Education Center Research Advisory Committee.

When the proposal includes the participation of other community schools or organizations, approval in principle must first be obtained from the Community Advisory Board. The researcher will be advised by the Research Team and/or the Community Advisory Board to seek the appropriate community school or organization approval. A Certificate of Approval will be issued after review and approval by the relevant community school or organization.

7. Submission of application to the appropriate university Institutional Review Board

The researcher will submit a completed ethical review and approval application to the Community Advisory Board before submitting the application to the appropriate Institutional Review Board.

The researcher is expected to adhere to the requirements and processes of the appropriate university Institutional Review Board. The submission should include the KSDPP certificate of approval, or notification of approval in principle (see #8).

When applying for ethical review and approval from the appropriate university Institutional Review Board the ethical review and approval application should contain the cover letter, the research proposal including methods of assessment, the assessment tools and the consent forms.

The application must be reviewed by relevant members of the Research Team, members of the Community Advisory Board and if necessary, other relevant community organizations.

8. Parallel Review and Approval Process

A parallel review process, whereby ethical review and approval is sought concurrently with either the university Institutional Review Board or a community organization may occur after the Community Advisory Board has granted approval in principle of the proposal.

Before the research begins, certificates of approval must be obtained from both the Community Advisory Board and the university Institutional Review Board.

9. Continuous Consultation, Collaboration and Reporting

In the spirit of continuous consultation and collaboration, the researcher has the responsibility to attend Research Team and Community Advisory Board meetings to respect the partnership.

The Scientific Director will submit annual reports on the progress of the research to the KSDPP Supervisory Board, the Chairperson of the Executive Committee of the Community Advisory Board, and the Chairperson of the Onkwata'karitáhtshera Health and Social Services Research Council.

Appendix C. The Consent Process

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

Active, free and informed consent must be obtained in writing or other form from individual participants before data are collected. Individual participants will be asked to sign or give oral consent to a KSDPP consent form. The consent form will include the KSDPP ratiriwahseron:nis' name and contact number.

The KSDPP consent form / letter of information will:

- Explain why the research is being done.
- List the objectives, methods and potential results of the research.
- List what the research requires of the participant.
- Explain that participation in the research is voluntary and that the participant can withdraw from the research at any time, for any reason, without any negative impacts to the individual.
- Describe the benefits of the research results to the individual and the community.
- Explain any potential risks that may be incurred during or following participation in the research.
- Describe any incentive that the participant may receive for their participation in the research.
- Explain the protection of the individual's privacy through the confidentiality of data.
- Inform the participant that the research results will be published in relevant journals.
- Inform the participant that that the research results will be presented to the community before the results are published locally, nationally or internationally.
- Inform the participant that the participant's signature on the consent form does not waive any legal rights.

Appendix D. KSDPP Submission Process for Abstracts, Posters, Articles and Academic Trainees Theses and Dissertations

Submission process for abstracts

The decision to submit an abstract to a conference will be approved by the KSDPP Research Team.

This decision will be brought to CAB as an FYI (for your information) at least one month, when possible, before the abstract is submitted.

Information on the conference will be made available at the CAB meeting and the FYI will include the rationale for the choice of conference.

CAB will have the opportunity to ask for clarity on the fit of the abstract with the conference venue and any other dissemination plans.

The CAB abstract review committee must review the abstract before the abstract is submitted.

Two versions of the abstract must be submitted to the Scientific Director or delegate for distribution to the reviewers one week prior to review. The scientific version will be the draft planned for conference submission written within the word limit requested by the conference. The community version will include the same contents as the scientific version but written using non-academic language and community concepts. There is no word limitation on the community version.

Results that are to be presented at the conference must first be presented to community members (including CAB, community at large, or KSDPP staff who are community members), in some format, before the conference.

Submission process for posters and articles

All articles (scientific or for local media), posters and presentations must be reviewed and approved by at least two (2) CAB reviewers before they are submitted, in the case of articles, or presented, in the case of posters and presentations.

A copy of the article or the contents of the posters and presentations must be submitted to the Scientific Director or delegate for distribution to the CAB reviewers one week prior to review.

Submission process for academic trainees' theses or dissertations

All academic trainee theses or dissertations must be reviewed by at least two (2) CAB reviewers in a timely manner for academic trainees to consider incorporation of feedback before final submission of their theses to the university.

Appendix E. Knowledge Translation

There are many different and complex descriptions of knowledge translation (KT). The Canadian Institutes of Health Research (CIHR) defines KT as**: "**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 further explains: "this process takes place within a complex system of interactions between researchers and knowledge users (those using the knowledge or results) which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user" (Canadian Institutes of Health Research, 2016). CIHR Institute of Indigenous Peoples' Health also includes a section on knowledge translation from 2009 (Estey, Smylie & Macaulay, 2009).

In practice knowledge translation is the way of making sure that research results, which are knowledge, are made easily available so that everyone can understand the meaning and relevance of the findings. The goals are that research results can be used to improve health of individuals and communities, to improve health services (e.g., how health organisations and individuals provide care to patients and clients) and to improve policies that promote good health (e.g., no smoking inside buildings). Translation is the description of how the results are disseminated and discussed with anyone who can benefit. This includes both research papers in academic language and using non-academic language to share and discuss the results with anyone else who can benefit. This includes those who participated in the research, community members and organisations, and those in positions to use results to develop and/or improve programs and policies. This dissemination can be local, regional, national, and international.

The KSDPP research approach of using community-based participatory research, which is based on a partnership of community members, community researchers and university-based researchers, also supports Integrated Knowledge Translation (IKT) (Canadian Institutes of Health Research, 2016). IKT occurs through the discussions and knowledge sharing during the entire research process with the partners continuously learning from each other.

Knowledge translation can occur through storytelling, ongoing discussions and active participation in diabetes prevention. Indigenous story telling involves the sharing of knowledge – the living and lived experiences of peoples and communities. The process of storytelling, in itself, expresses the interrelatedness and interactions of people and their environment. Story telling provides the forum for knowledge to be thought provoking and provides an opportunity to incorporate the knowledge into practical solutions. As in storytelling, with knowledge flowing in both directions between community members and researchers, knowledge translation can be used to accelerate the understanding and benefits of research results for community members in Kahnawà:ke, other Indigenous communities, scientists, health professionals and policy makers. Furthermore, within a cross-cultural research environment, the "ethical space" between the community and the researchers allows knowledge translation to take place (Ermine, 2006).

Appendix F. KSDPP Authorship Guidelines

Introduction
All knowledge generated by KSDPP can be considered as worthy of dissemination. All dissemination pertaining to KSDPP will follow generally accepted ethical standards.

The principles guiding dissemination include:

- Anonymity: The research results will be presented in an aggregate or grouped manner. Individual participants will not be identified unless they so choose.
- 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. This will be a Community Advisory Board decision.
- Privacy and Confidentiality: All information collected from individual participants and the community will remain private and confidential.
- Respect: The cultural and intellectual integrity of the Kanien'kehá:ka must be respected in all KSDPP disseminations.
- Results will be presented in a manner that is relevant and meaningful to the community.
- Dissemination must follow the KSDPP abstract and manuscript review process.

Dissemination of knowledge can be presented in the following format(s):

- Manuscript in a scientific or peer reviewed journal
- Oral presentation of a manuscript at a scientific conference or meeting
- Poster presentation at a scientific conference
- Oral presentation to the community
- Written document to the community
- Monograph or monograph chapter
- KSDPP as an example for a case study
- KSDPP Diabetes Prevention Training Program
- Videos/digital stories
- Art displays and other creative ways of disseminating knowledge

Planning and Development of a Manuscript

When planning and developing a manuscript for publication, all potential authors should acknowledge the KSDPP authorship guidelines as the protocol for determining authorship. Consensus among lead author and co-authors pertaining to roles and responsibilities should be agreed upon at the earliest planning stages of the manuscript.

Lead Author: Person who takes primary responsibility for the manuscript as a whole even if he or she does not have an in-depth understanding of every part of the work. The lead author must adhere to the Lead Author responsibilities.

Co-author: Any person who accepts the responsibilities of co-authorship once their eligibility for authorship has been confirmed.

Lead Author Responsibilities

- Coordinates the planning and development of the manuscript in collaboration with KSDPP Research Team members.
- Determines who has satisfied eligibility criteria for invitation for authorship.
- Sends out invitation and a developed plan/outline of the manuscript to invited co-authors, along with the KSDPP authorship guidelines.
- Ensures invited co-authors discuss the plan/outline of the manuscript (via e-mail, telephone conference, meeting, etc.).
- Ensures that co-authors outline their contributions and agree on their contribution before the writing process begins.
- Establishes that criteria for authorship and responsibilities are respected.
- Maintains contact with the Research Coordinator, to ensure that the community manuscript review process is followed.
- Submits manuscript to scientific journal, obtaining signatures for disclosure, etc.
- Coordinates multi-site manuscripts and acts as a liaison with the other multi-site team members.

Eligibility Criteria for Invitation for Authorship

Lead author and co-authors must satisfy at least one of the following criteria to be invited for authorship:

- Have contributed substantially to the implementation of a specific intervention (relevant to the manuscript).
- Have contributed substantially to the concept and design of the research.
- Have contributed substantially to a synthesis of the literature review.
- Have contributed substantially to acquisition of the data.
- Have contributed substantially to the analysis of the data.
- Have contributed substantially to the interpretation of the findings.
- Can provide essential expertise (e.g., academic, Indigenous knowledge, historical clarification, cultural relevancy, etc.).

Criteria for Authorship

- Have satisfied at least one criterion for invitation to authorship, and
- Have contributed substantially specific and relevant ideas to the overall manuscript or to a section of the manuscript, and
- Accept the responsibilities of an author.

Authorship Responsibilities

The following responsibilities are required for KSDPP authorship. All authors must respect each of the four authorship responsibilities:

1. Read and understand the overall manuscript.
2. Provide a written outline of his /her contribution to the manuscript to be approved by all of the co-authors before writing begins.
3. Work within the set timeline.
4. Approve the final draft of the manuscript.

Academic Trainee Authorship
If an academic trainee is writing an article based on his/her thesis then s/he will be the first author.

If a manuscript is not initiated within six months and submitted within 12 months of obtaining a degree, the supervisor or other delegate may take over preparation and submission of the manuscript(s). In such a case, the order of authorship may be changed to allow the supervisor, or delegate, to become the first author.

Acknowledgment Section of KSDPP Authorship Guidelines
All those who contributed to the research project, but do not meet the KSDPP authorship criteria, may be offered inclusion in the acknowledgment section of the manuscript.

The lead author of the manuscript must acquire written permission from those who are acknowledged.

Funding
The funding source for the research being disseminated must be included.

Appendix G. Researcher Checklist

Review and Approval Process	Date completed
1. Submission of letter of interest to KSDPP Scientific Director	
2. Submission of detailed research proposal and presentation to KSDPP Research Team	
3. Approval in principle received from KSDPP Research Team	
4. Presentation of research proposal to KSDPP Community Advisory Board	
5. Presentation to Kahnawake Education Center Research Advisory Committee or other community organisation (if applicable)	
6. Certificate of Approval obtained from the KSDPP Community Advisory Board	
7. Submission of ethics application to the appropriate university Institutional Review Board	
8. Certificate of Approval received from the appropriate university Institutional Review Board (IRB)	
9. Summary of research proposal and copy of CAB Certificate of Approval and IRB approval to OHSSRC	
10. Completion of ethics tutorial or course	

Dissemination process	Date completed
1. Presentation of final results to KSDPP Research Team	
2. Presentation of final results to KSDPP Community Advisory Board and any other community organisation who gave ethical approval	
3. Submission of summary article written for Kahnawà:ke community	
4. Summary of research findings given to OHSSRC	
5. Submission of draft of scientific article to Supervisor	
6. Submission of thesis draft for community and academic review	

Upon completion of requirements for degree	Date completed
1. Return of data to KSDPP (check where applicable) a) consent forms b) completed questionnaires c) focus group audio tapes d) focus group transcripts e) other, please specify	
2. Provide permanent address, phone number and email address to Research Secretary or designated other KSDPP member	
3. Complete summary form (see next page)	

APPENDIX G (continued)

Researcher Check List

Summary of Research:

1. Title of research project:

2. Author (principal investigator) and collaborators (include Master's/summer students):

3. Funding agency:

4. Year(s):

5. Summary (one paragraph including research objective and methods, sample size, and description of participants)

6. Results (main findings)

7. Dissemination (where results were presented e.g., poster presentation at a conference-give name and year of conference, name of published article and journal citation, etc)

8. Recommendations from results (for intervention team)

Appendix H. Community Reviewer Checklist

Respect for Indigenous Ways of Knowing

Some things to look for…	Y/N	Comments
Included Indigenous methodologies, knowledge(s), and experience		
Complied with the local community's code of ethics		
Researcher developed cultural awareness of the community		
Community agreed with the interpretation of results		

Relevance to the Community

Some things to look for…	Y/N	Comments
Community history and/or description (if named)		
Community members involved in the decision-making/research design process		
Decisions were non-hierarchical/consensus-driven		
Community understood the purpose of the research		
Research project improved/will improve community well-being		

Reciprocity between Research Partners

Some things to look for…	Y/N	Comments
No harm caused to the community		
Benefits of the research to the community were clear		
Community members had opportunity to build capacity		
A plan for the community to become data stewards is in place		

Responsibility through Community Participation

Some things to look for…	Y/N	Comments
Community members were able to participate in the entire research process		
Community members were consulted on participation, data collection, and data analysis		
Community members had control over, and ability to access, data at all times		
Researcher acknowledged community ownership		
Results presented to the communities		
Results interpreted and agreed to by community		

Acknowledgement: The development of this checklist was led by Colin Baillie, in consultation with CAB members Amelia Tekwatónti McGregor and Morgan Kahentonni Phillips.

Glossary of Terms

Academic researcher: within the framework of community-based participatory research, an academic researcher is a researcher with a university appointment and is autonomous regarding their research activities. The academic researcher works collaboratively with community members and community-based researchers. The academic researcher holds responsibilities towards projects' funding institutions, their academic institution and the community.

Academic trainee: an individual who is enhancing their research skills through actual involvement in research and who works under the formal supervision of an academic researcher. Examples of academic trainee include: an undergraduate student engaged in research at an academic institution; a graduate student enrolled in a graduate course of study at an academic institution; a postdoctoral fellow (post-PhD) at an academic or research institution. (CIHR, 2020)

Active, free, and informed consent: refers to the consent process, the consent form and the rights of participants and the community. The researcher must explain thoroughly and clearly what the research is about and what participating in the research entails to the prospective participant. The rights of the participant must be explained to allow the participant to make an informed decision to choose to participate in the research i.e. participants cannot be coerced, forced or fooled into taking part in the research.

Aggregate data: data that are presented in a grouped or summarized format. For example, with the elementary school data collection, the results are presented as aggregate data. Student's individual data are not presented.

Anonymity: an ethical principle that applies to the dissemination and publication of research results**.** Any data collected from an individual or the community must never be identified. Data are never linked to a single individual or a community.

Anonymous data: are data that have no identifying connection to an individual whatsoever. For example, asking a person on the street to fill out a survey but not recording their name.

Anonymised data: are data that was once linked to a person but has been permanently stripped of identifiers. The data are coded (no names) and there is no master list.

Approval in principle: refers to the conditional approval of a research proposal. Approval in principle means that the KSDPP Research Team has reviewed the research proposal, and therefore, supports the researcher's proposal in principle. Following the Review and Approval Process for Ethically Responsible Research, the research proposal must be reviewed and approved by the Community Advisory Board, the appropriate community organizations and the university Institutional Review Board before the research begins.

Capacity building: is a process that develops and strengthens a community's capacities to effect change by providing individuals with the opportunity to have a direct role in the economic and social regeneration of their communities. Capacity building is a process that empowers people to manage their own affairs by promoting community ownership and self-determination.

Certificate of Approval (COA): the COA is issued by both the CAB executive committee and the appropriate university Institutional Review Board (IRB) after the research has undergone the Review and Approval Process for Ethically Responsible Research.

Coded data: when data are collected from participants, their names are initially recorded. When the data are entered into a database, the participant's names are removed and are replaced with a unique pseudonym or identification number.

Community Advisory Board (CAB): is made up of community members and community-based researchers. The work and dedication of CAB in the research and intervention activities of KSDPP is evidenced in the sense of ownership CAB has for KSDPP. CAB's commitment is rooted in a strong belief of the importance of the inclusion of community traditions, values and culture in all aspects of KSDPP involvement in the prevention of diabetes and ensuring a well future for Seven Generations.

Community-based participatory research: is a research partnership that equitably involves the community and researchers in all aspects of the research process. The partners contribute unique strengths and shared obligations to enhance the understanding of an issue and the social and cultural dynamics of a community, integrating the knowledge generated with action to improve the health and well-being of communities and to create new knowledge for the benefit of society. There are many other terms for community-university partnership research: these include - but are not limited to - community engagement, participatory research, participatory action research, action research, collaborative research, patient and public involvement, co-production, and integrated knowledge translation.

Community-based researcher: within the framework of community-based participatory research, a community-based researcher is a person based in the community (by either coming from, living or working in the community) who contributes to the research process of generating knowledge that is relevant and beneficial to both the community and the research process. The community-based researcher has the opportunity to learn about the theories and practices of research, and the development of interventions and evaluations. A community-based researcher also has the opportunity to contribute their community expertise and perspective to the research process, in a co-learning process that values both academic and community ways of knowing. In this way, a community-based researcher is well placed to combine the knowledge of science and community ways, which brings about a collaborative and cohesive community-based research project.

Confidential data: is data that is coded (no names) and could be linked or traced back to the specific individual participant through a master list. However, the researcher has no access to the master list.

Consensual decision-making process: is a decision-making process that not only seeks the agreement of most participants, but also to resolve or mitigate the objections of those not in general agreement. It is a process that attempts to achieve the most agreeable decision by providing a voice to all those effected or concerned. Consensus is usually defined as both a) general agreement, and b) the process of getting to such agreement.

Confidentiality: refers to the legal and ethical obligation that arises from a relationship in which a person receives information from or about another person. The recipient has an obligation not to use that information for any purpose other than that for which it was given and not disclose it.

Consent: refers to the consent process. When consent is obtained a person agrees to participate and gives their written permission.

Consultation: consultation is an open communication process for presenting and receiving information before final decisions are made. Consultation involves an honest exchange of information about aims, methods, and potential outcomes of the research for all partners. Consulting with a community includes incorporating feedback and concerns.

Data: facts, observations, information or measures that have been collected and recorded. This also includes, but is not limited to, verbal quotations, photographs, pictures, and artwork.

Database: a collection of data that is organized for easy access and analysis. Databases are usually computerized.

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

Ethics: refers to the rules of conduct that express and reinforce important social and cultural values of a society. The rules may be formal and written, spoken or simply understood by groups who agree to the rules. Ethics are the rules governing a partnership/relationship (Brant-Castellano, 2004).

Ethical Space: Willie Ermine (2000) in his M.Ed. thesis, *A critical examination of the ethics in research involving Indigenous peoples,* developed the concept of *"ethical space"* as the space between the Indigenous and Western spheres of culture and knowledge relative to research issues. Within research involving Indigenous peoples, the abstract space, is the space between Indigenous and Western worlds, the separation between cultures and worldviews, the division. However, the division or space can be perceived as the bridge between community and researchers that provides for an understanding that is substantial and ethical. The ethical space provides a framework for how people from different cultures, worldviews and knowledge systems can engage and work in an ethical/moral manner.

Haudenosaunee: People of the Longhouse, Iroquois people.

Institutional Review Board (IRB): a committee established by an institution/university that carries out the ethics review of research projects involving humans. All research that involves living human subjects requires review and approval by a research ethics board in accordance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.*

The Review and Approval for Ethically Responsible Research Process within KSDPP involves review and approval by the appropriate university Institutional Review Board.

Kanien'kehá:ka: People of the Flint, Mohawk people, which is not specific to Kahnawà:ke and includes Mohawks of Kanehsatà:ke, Ahkwesásne, Wáhta, Kenhtè:ke (Tyendinaga), Ohswken, Ganienkeh and Kana'tsioharè:ke.

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. […] This process takes place within a complex system of interactions between researchers and knowledge users (those using the knowledge or results) which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user" (Canadian Institutes of Health Research, 2016).

KSDPP Research Team: includes academic researchers, community researchers, academic trainees, and KSDPP intervention and administrative staff.

Letter of Interest: in relation to the Review and Approval of Ethically Responsible Research Process, the letter of interest outlines the general research interests and objectives of a potential researcher wanting to do collaborative and community-based participatory research with KSDPP.

Master list: a list of all the participants in a research project with unique identification numbers that is only accessible by the research assistant, to ensure confidentiality. The master list is locked in a safe.

Ownership, Control, Access and Possession (First Nations Information Governance Centre, 2015):

- **Ownership**: the notion of ownership refers to the relationship of a community to its cultural knowledge, data, and information. The principle states that a community or group owns information collectively in the same way that an individual owns his or her own personal information. It is distinct from guardianship/stewardship.

- **Control:** this asserts that Indigenous people, their communities, and representative bodies are within their rights in seeking to control all aspects of research and information-management processes that impact them.
- **Access:** Indigenous people must have access to information and data about themselves and their communities, regardless of where these are held. This includes their right to manage and make decisions regarding access to their collective information.
- **Possession**: a mechanism by which ownership can be asserted and protected.

Onkwehón:we: real, natural, or native person/people who live in spirit. This can also be understood as an Indigenous person/people.

Onkwata'karitáhtshera Health and Social Services Research Council (OHSSR): Kahnawà:ke's One Health and Social Services Agency.

Parallel / concurrent review and approval process: refers to the Review and Approval Process for Ethically Responsible Research Process. Review and approval are required from the CAB, and if necessary, also the Kahnawà:ke Schools Combined School Committee before the start of any research. However, if other community organizations are involved in the research, submission for review and approval can be made in parallel/concurrently to that organization and the Institutional Review Board.

Partner: the Kanien'kéha word for partner is *Teionkwarihwaienawá:kon.* This is defined as "more than three partners working together on matters that are important to us."

Primary data analysis: is the first analysis of the original data.

Ratiriwahseron:nis: a group of persons or a person who fixes matters or issues. The Kanien'keha word *ratiriwahseron:nis* is used to replace the word ombudsman that was used in the previous KSDPP Code of Research Ethics.

Research protocol: explains how the research is going to be carried out. The protocol includes the research rationale, design, methodology, and expected contribution to the advancement of knowledge.

Research process: aspects of the research process includes: development of the research question; determining the research design/methodology; the acquisition of data; the analysis of data; the interpretations of the results; and the dissemination and publication of the results.

Review and Approval Process for Ethically Responsible Research: the process that applies to any 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.

Please see Appendix A: Review and Approval Process for Ethically Responsible Research

Research: a systematic investigation to establish facts, principles or generalisable knowledge. Activity intended to investigate, document, bring to light, analyse, or interpret matters in any domain to create knowledge for the benefit of society.

Research ethics: a collection of aspirations, regulations, and/or guidelines that represent values of the group or profession to which it applies. A system of rules or standards that distinguishes between acceptable and unacceptable research practices.

Skén:nen, Ka'shatsténhsera, and Karihwí:io In relation to the Indigenous methodologies section of the Code's preamble, and Haudenosaunee (Iroquois) consensual decision-making: *Skén:nen*,

Ka'shatsténhsera and *Karihwí:io*, are the philosophical underpinnings of the Kaianere'kó:wa, or the Great Law of Peace. Literally translated *Skén:nen* is peace, *Ka'shatsténhsera* is power and *Karihwí:io* is righteousness.

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- Includes examples of many Indigenous research agreements, protocols, initiatives, and articles about research ethics, including the following article:

  Delormier, T, McComber, AM, Macaulay, AC. (2018). Kahnawà:ke Schools Diabetes Prevention Project Code of Research Ethics: Development and application, in: Toolbox of research principles in an aboriginal context: Ethics, respect, fairness, reciprocity, collaboration and culture. First Nations of Quebec & Labrador Health and Social Services Commission (FNQLHSSC), Université du Québec en Abitibi-Témiscamingue, Université du Québec en Outaouais. https://files.cssspnql.com/index.php/s/8aBAkl1pjHeOWd0

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