

Tâpwêwin “great and careful consideration”:
National Indigenous Diabetes Association Research Protocol



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1. Introduction

This document was designed for the purpose of clarity of priorities that the National Indigenous Diabetes Association (NIDA) has in potential research partnerships. This document includes an overview of NIDA's history and current priorities when working with Indigenous communities. It will outline the *Tâpwêwin* Research Partnership Framework including the Decision-Making Wheel teachings that are the guiding values, and the appendices - Pre-Screen (Appendix A), Application Review (Appendix B), and the Partnership Agreement (Appendix C) that the applicants must complete and send to NIDA for them make a careful consideration.

The Pre-Screen application's primary objective is to streamline the application process for NIDA's selection team and potential partners to identify if the proposed research or project aligns with NIDA's values and priorities. The Pre-Screen allows NIDA to screen out projects that do not fulfill their three major priorities and allows for a full review of the projects that do meet the priorities.

The Application Review is structured based on four components: values, partnerships, decision-making wheel, and Indigenous knowledge. The Application Review is designed for NIDA to make an informed decision on the project and partnership details and acts as a reflective practice for the applicants regarding their own organizational and project objectives.

Finally, the Partnership Agreement outlines the summary of NIDA's priorities and partnership framework that applicants must agree to and uphold. The Partnership Agreement gives full details of what is expected of the applicant after they have read



through the pre-screen and filled in the application. This is a legally binding document that states the consequences and steps taken when the potential partner or NIDA decides not to follow what is expected of them. The agreement is rooted in the values of NIDA and Indigenous Peoples. It includes the following:

- Termination of partnerships when not aligning with NIDA’s values and priorities;
- Termination can be done at any time to protect Indigenous communities and the dignity of the organization;
- Withdrawal of support from NIDA; and that
- NIDA will also adhere to these terms and the potential partner can withdraw from the research if NIDA does not uphold these priorities as well.

The conclusion summarizes that the utilization of a research partnership framework is essential for NIDA and Indigenous communities to prioritize communities, continue reconciliation work, and further self-determination in diabetes research.

a. Tâpwêwin

The title of this framework, Tâpwêwin, was chosen for two reasons. The first reason was based in its translation. The name of this framework is a Cree word meaning “speaking the truth” or “speaking with precision and accuracy”. The tangible part of this framework is its application process (see Appendices A-C). This application was designed to help NIDA determine whether a partnership with interested researchers would be of benefit to Indigenous Peoples and themselves. This application process requires researchers to be as transparent and honest as possible – speaking the truth. They are held accountable to their word as put out in the application through the Partnership Agreement (see Appendix C). The second reason Tâpwêwin was chosen was in its context. The word is often spoken in relation to treaties or



partnerships. When treaties are signed, signatories are obligated to speak with Tâpwêwin. This allows them to discuss the treaties with great and careful consideration. The use of Tâpwêwin implies that the partnership between NIDA and researchers are ones that are made with great and careful consideration.

2. National Indigenous Diabetes Association

NIDA works to “address diabetes and promote healthy lifestyles among Indigenous Peoples, gives information and resources for Indigenous Peoples with diabetes and their families, communities and health care providers, programs and services for Indigenous Peoples affected by diabetes”¹. For the past 24 years, NIDA has been the only organization providing resources and fighting injustices of Indigenous Peoples in relation to diabetes.

NIDA aims to protect the dignity of communities, by providing resources to help people be more informed and aware of diabetes. NIDA expressed concerns of having researchers who want to partner with them to research in Indigenous communities, but they often exclude them in findings and publishing of the findings. This contributes to publications that exploit Indigenous communities. There is a need for researchers to have relational accountability with communities and participants as this will help in what should be disclosed and what not to be disclosed to the public². Researching in Indigenous communities means interfering with peoples’ day-to-day activities to get the information they are looking for. While researchers may not be aware of valuable and

¹ National Indigenous Diabetes Association (NIDA). (2018). History. National Indigenous Diabetes Association. Retrieved from http://nada.ca/?page_id=287.

² Wilson, S. (2008). Research is ceremony: Indigenous research methods. Black Point, NS: Fernwood Publishing.



sacred knowledges in the community, much about Indigenous Peoples has been exploited, breaking the trust of the researcher to participant or community.

Thus, this protocol serves to protect Indigenous Peoples and their knowledge and stories. This protocol will help NIDA and research participants to agree on what is expected from them.

a. The National Indigenous Diabetes Association's Priorities

Understanding NIDA's concerns, researchers wishing to partner with them should align with NIDA's priorities. The following section further discusses these priorities and how they align with NIDA.

i. Self-Determination

NIDA encourages self-determination for all communities to have the right to accept the research they want to be done and how they want it to be carried out, this includes:

- Research that will consult and be given consent by individuals, communities, and leadership where appropriate before being.
- Research that will respect leadership, that exist beyond a political level, found in Indigenous communities.
- Research that will be community driven (TRC Call to Action 19)³.

ii. Prioritize Indigenous Peoples

Acknowledging Indigenous Peoples as the original inhabitants and caretakers of this land which is now called Canada⁴. Realizing that Canadian policies have continuously oppressed Indigenous Peoples, leading to social problems, the move

³ Truth and Reconciliation Canada. (2015). Honouring the truth, reconciling for the future: Summary of the final report of the Truth and Reconciliation Commission of Canada. Winnipeg: Truth and Reconciliation Commission of Canada.

⁴ Restoule, J.P. (2019). Understanding Indigenous perspectives. University of Toronto. Retrieved from <https://www.oise.utoronto.ca/abed101/what-is-reconciliation/>.



towards reconciliation and self-determination is navigating the priorities of Indigenous Peoples, their wellbeing, communities and relations.

- Researchers need consent from Elders and the community at large to carry out their research stating clearly what they would be doing.
- The researcher should truthfully, and be held accountable, disclose only what the community has agreed to be published.
- Researchers need to see the importance of Indigenous knowledge and should be willing to have the community and Elders as co-authors.
- The researcher should be aware of Indigenous values and respect them throughout the research.

iii. Reconciliation

What is reconciliation? It means the bringing together of Indigenous Peoples and Canadian settlers to repair relationships and come to shared understandings about the history and self-determined future of Indigenous Peoples. Reconciliation aims at building relationships and trust between Indigenous and non-Indigenous people. NIDA, the only organization raising awareness about diabetes for Indigenous Peoples, aims at reconciling people with the information and findings collected in Indigenous communities to aim at reconciliation and improvement rather than exploitation and discrimination.

- Research that will realize that the roots of diabetes are not self-inflicted but colonially inflicted on Indigenous Peoples (Call to Action 18)³.
- Research that aims at advocating the government to improve Indigenous Peoples' wellbeing (Call to Action 19)³.
- Research that will follow the four R's – respect, responsibility, reciprocity, and relationality. All these, act towards reconciliation and progress.
- Research that will respect the values of Indigenous Peoples and make them their



guidelines during research.

First Nations, Inuit and Métis are diverse populations whose health is affected by the myriad social determinants of health, as well as a complex history of colonialism, racism, oppression, and starvation. Social determinants have a significant impact on disease and recovery experiences within these communities.

3. Purpose of Indigenous Focused Research Guidelines

NIDA envisions diabetes-free communities that promote healthy environments and prevent and manage diabetes through partnerships with communities and organizations. NIDA has been approached by numerous research projects interested in their support investing in diabetes research among Indigenous communities. The primary issue evident among the proposals asking for NIDA support is that the organizations are not using an Indigenous research framework to approach working with Indigenous communities about diabetes. By not abiding by an Indigenous research framework, organizations are undermining the value of Indigenous knowledge in diabetes research and thus not aligning with NIDA's values of reconciliation between Indigenous and non-Indigenous people, self-determination of research and programming involving their communities, and Indigenous communities being involved in research and programming processes that directly and indirectly affect their communities. NIDA has developed a research protocol that is inspired by the decision-making wheel teachings and allows for NIDA to address the importance of utilizing Indigenous research methodologies as a tool for challenging organizations to position their research interests in Indigenous knowledge. NIDA has named the research



protocol *Tâpwêwin* to explain First Nations laws that require striving to discuss such subject matters with great and careful considerations of potential partnerships between NIDA, communities, and other organizations.

4. The Decision-Making Wheel as an Indigenous Research Partnership Framework

The decision-making wheel is based on the concept of Indigenous research frameworks, and it is a model for inclusion in research when working with Indigenous communities. Indigenous research frameworks describe research methodologies that encompass tribal or Indigenous epistemologies⁵. This is the basis of why the decision-making wheel was chosen as the foundation for our Indigenous research framework. In relation to Indigenous epistemologies, the focus is bringing culture, Indigenous way of knowing and overall 'self - in-relation'⁵. The decision-making wheel was adopted from *Full Circle: First Nations, Métis, Inuit Ways of Knowing* created by the Ontario Secondary School Teachers' Federation (OSSTF)⁶ (See Figure 1).

⁵ Kovach, M. (2010). Conversational method in Indigenous research. *First Peoples Child & Family Review*, 5(1), 40-48.

⁶ Ontario Secondary School Teachers' Federation (2012). *Full circle: First Nation, Métis, Inuit ways of knowing*. Common Thread Resource.





Figure 1 - Full Circle: First Nations, Métis, Inuit Ways of Knowing (Ontario Secondary School Teachers' Federation, 2012)

The project was aimed at addressing the current shortage of curricular materials that focus on First Nations, Métis and Inuit history and culture. Furthermore, this model was adopted from the symbol of the circle or medicine wheel which was used throughout. It is important to note that not all First Nations, Métis or Inuit peoples use the medicine wheel, but it is useful as an organizational tool and provides a holistic and balanced approach and a model that can embrace researching with partners. The concept of the decision-making wheel refers to the unending journey that many Indigenous Peoples continue to find themselves on as they claim and reclaim their culture, their land, and their identity⁶.

The medicine wheel can be used for reflecting on one's life and striving for a balance that the wheel presents through four equal parts⁷. It's an imaginary circle upon which everything can be plotted. The concept is one which one can see themselves positionally rather than occupying a specific moment in linear time. As a result, space

⁷ Ross, R. (2014). Indigenous healing: exploring traditional paths. Toronto: Penguin Canada Books.



may replace time in self-determination, and used holistically the medicine wheel is supposed to be a teaching tool.

This model encompasses Indigenous beliefs, values, and customs as part of the research process and thus the research becomes inherently Indigenous. An important aspect of the emerging styles of research is that Indigenous Peoples themselves decide when and where they are studied². Furthermore, as an Indigenous research paradigm grows and evolves, there is need to go beyond the tendency to compare it with mainstream research, and the need to develop theory, practice and methods that are uniquely Indigenous, this is what the NIDA model is working to achieve in totality.

This model of research allows encompassing of Indigenous worldviews and 'being.' The concept chosen does not only allow Indigenous worldviews, but incorporates cosmology, worldview, epistemology and ethical beliefs². In this methodology, the circle is often seen and never ending, this is further supported by other scholars who have referred to the circle as a form of teaching or a healing circle⁷. NIDA adopted the circle to acknowledge that Indigenous epistemologies are ongoing processes of research, learning, and re-learning.

In choosing the decision-making wheel as a conceptual framework, NIDA acknowledges that conceptual frameworks make visible the way the world is seen. Within this research framework NIDA aims to provide insight into the researcher's belief about knowledge production, and how these beliefs will impact the research project.

This model allows both reflective and reflexive practices and offers an opportunity to decolonize the western components of partnerships. The introduction of Indigenous knowledge in any form of academic discourse (research or otherwise) must ethically



include the influence of colonial relationships and thereby introducing a decolonizing perspective⁵. This model aims to improve the way research is done with and for Indigenous Peoples, by not assuming to come to study Indigenous problems but instead to come and work and research with Indigenous communities and in that process create partnerships⁸. It is imperative that in this framework NIDA acknowledges that the illustration is based on a practical way of creating partnerships with and for Indigenous communities that allows the ‘thinking’ and the ‘doing’ to take place.

5. Research Guidelines – Tâpwêwin

a. *The Framework Wheel*

The framework was created in the image of a circle for many reasons. The circle signifies a continuum and holism. In many Indigenous cultures, a circle is a sacred concept, for example the medicine wheel. It represents balance, reciprocity, cohesion, and renewal. Central to this framework is values. When values are centered, everyone understands where each are coming from and are able to be accountable to and respectful of each other’s, and their own, values. The next layer of the framework is relationships. These relationships are built based on mutual respect and accountability. They are also equal in their power. No one partner is above the other. Once relationships are formed, the process moves to the decision-making wheel. This wheel represents the research process. All of these parts are then embedded in Indigenous knowledge. They should not exist outside of them or it can create imbalance. Then finally, throughout the entire wheel, there is ongoing consideration of respect for others,

⁸ Smith, L.T. (1999). Decolonizing methodologies: Research and Indigenous peoples. London: Zed Books Ltd.



research that is relevant and relational, being reciprocal in our relationships, and exercising responsibility over our own lives⁹.



Figure 2 - Tâpwêwin Research Protocol Wheel

b. Values

To establish if a relationship with you as a researcher is an appropriate partnership, NIDA would like you to share the values that influence your research. Some research methodologies regard values as barriers to research, but in Indigenous research methodologies, these values are integral to their success. Research that does not reinforce, or at the very least, respect, both NIDA’s and Indigenous Peoples’ values can be dangerous in that it does not support self-determination, reconciliation, and it denies Indigenous existence. By acknowledging your values, you are showing personal integrity and collective responsibility to this relationship.

⁹ Kirkness, V.J., Barnhardt, R. (2001). First nations and higher education: The four r’s – respect, relevance, reciprocity, responsibility. Knowledge Across Cultures: A Contribution to Dialogue Among Civilizations. Ed. Hayoe, R., Pan, J. The University of Hong Kong, Comparative Education Research Centre.



c. Relationships

Relationships are an integral part of doing research, especially with Indigenous populations. The history of relations with Indigenous and non-Indigenous peoples in Canada has been tumultuous, and in an era of reconciliation and decolonization, it is essential these relationships are equal, accountable, collaborative, and reciprocal^{5,10}. Communities, partners, and researchers are equal partners, and the whole purpose is to create equality within the research paradigm. This is to reduce the problem of a dominant scientific approach to Indigenous research. The relationship you enter into with NIDA is very much akin to a treaty. In First Nations traditions, these treaty relationships are governed by laws, values, and principles between the Creator and us⁹. Establishing a relationship based on these protocols builds trust between all parties. Through sharing all partnerships and each partners' roles and responsibilities in your project, NIDA is better able to understand the organization's role and responsibilities to you as a partner and see how we are all connected and accountable to one another.

d. The Decision-Making Wheel

There are four quadrants in the decision-making wheel. Each quadrant represents a different process that occurs during the timeline of a research project.

Idea: This quadrant represents the inception of a research project. The idea quadrant is situated in the Eastern doorway. This doorway represents the spring, the beginning of a journey. Research ideas can stem from previous research, grow out of interest, or more importantly, be brought to the attention of a researcher by a community. It is important that NIDA understands where your research idea comes from

¹⁰ Carlson, E. (2017). Anti-colonial methodologies and practices for settler colonial studies. *Settler Colonial Studies*, 7, 496-517.



to determine if it is community-based (involving a community but brought in from the outside) or community-driven (self-determined by the community).

Decision: This quadrant represents the second stage of a research project – where you are planning, applying for ethics and funding, and making big decisions around your project. This quadrant is situated in the Southern doorway. This doorway represents the summer, when everything is new and growing quickly. This is the stage of research where the most important decisions are made, you are consulting partners and community members. Here is where your project is set up for success or failure. It is important that NIDA understands your processes and plans so they can know whether or not they will play a role in guiding your project.

Action: This quadrant represents the hands-on part of your project. This is where you are implementing methods and collecting and analyzing your data. This quadrant is situated in the Western doorway. This doorway represents end of summer where you begin to harvest, enjoy the fruits of your labor, and prepare to finish. It is important that NIDA understands your methods for data collection and analysis and how you will deal with unexpected changes. By doing so, they can make sure to keep you accountable to all involved.

Result: This quadrant represents the final stage of your project. It is situated in the Northern doorway. This doorway represents end of the year, or a remembrance period where you contemplate what has happened. It is a time of reflection and also where you honor those who have been involved in your journey. This is where you report on your findings – back to the partners, community, and project participants. Reciprocity and accountability play a large role in this quadrant. It is important to explain to NIDA how





you will honor those who have played a role in your project.

Figure 3 - The Decision-Making Wheel

e. Indigenous Knowledge

The parts of this framework, as mentioned earlier, are embedded in Indigenous knowledge. Indigenous values, relationships, and decision-making cannot be discussed in isolation of Indigenous knowledge. Local and Indigenous knowledge refers to the understanding, skills, and philosophies developed by societies with long histories of interactions with their natural surroundings. For Indigenous Peoples, local knowledge informs decision-making about fundamental aspects of day-to-day life¹¹. sharing how your research is embedded in Indigenous knowledge – through epistemologies, ontologies, and methodologies – NIDA is better able to understand how your research centers Indigenous Peoples in a way that is respectful, reciprocal and shows how your research relates and is responsible to Indigenous Peoples.

¹¹ UNESCO. (2017). Local and Indigenous knowledge systems. United Nations Educational, Scientific, and Cultural Organizations. Retrieved from <http://www.unesco.org/new/en/natural-sciences/priority-areas/links/related-information/what-is-local-and-indigenous-knowledge>.



f. The Four R's – Respect, Reciprocity, Responsibility, and Relationality

An essential part of the framework to always consider are the four R's. These are represented in Figure 1 as arrows, as they are an ongoing practice when doing research. Doing research is a long-term commitment, and throughout the entire process, each of the four R's should be considered and reconsidered as processes, methods, and relationships grow and change.

Respect: Respect is an integral part of any relationship. Acknowledging differences and respecting them is key to building trusting and long-lasting relationships. NIDA needs to know that your research is going to respect the organization, its members, the participants, the values, and the land your research is held on.

Reciprocity: A key concept in Indigenous cultures is reciprocity. Often research practices have been one-sided, in that researchers usually take what is shared with them and give nothing in return. Respectfully sharing your results is a significant example of reciprocity, but how else will you be reciprocal? NIDA would like to know how you will give back to those who are sharing their experiences, knowledge, and lives with you.

Responsibility: In all research, there is a need to be responsible to your partners and participants, responsible for your methods and data, and responsible for your values and NIDA's.

Relationality: A vital part of research is relationality. There are two aspects to this concept. The first is considering how your research idea or topic relates to those involved in the project. Is your research project relevant to participants? The second is Indigenous axiology or relational accountability (Wilson, 2008). NIDA wants to know, are



you accountable to your relations?

6. Conclusion

This protocol was developed to ensure partnerships between Indigenous communities, the National Indigenous Diabetes Association, and the academy are reciprocal, respectful, and accountable. The protocol is embedded in reconciliation, self-determination, and hopes to ensure that Indigenous Peoples are at the forefront of the research process. The protocol and application were designed to reduce the workload for NIDA as they are often approached by researchers and organizations to partner in research projects. *Tâpwêwin* was created specifically for these kinds of processes to consider Indigenous epistemologies, ontologies, methodologies, and axiologies when it comes to research partnership involving Indigenous Peoples.



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