

**Principles of Pilot Project Collaboration Agreement
Between the Assembly of Manitoba Chiefs and the
for the ...Research Project (or Study)
For the purpose of**

Parties

This document constitutes an agreement of collaboration between the Assembly of Manitoba Chiefs (AMC), as represented by Executive Director..., and the (university or company) as represented by ...(name of title and person).

Purpose

The purpose of this Agreement is to establish a set of principles that will guide the conduct of the research project entitled "...". These principles recognize and emphasize Manitoba First Nations cultural values and perspectives into the research process.

Relevant Documents

In March 2004, Elders who represented the five nations within Manito Ahbee/ Manitoba of Cree, Dakota, Dene, Ojibway/Anishinaabe, and OjiCree, agreed that "research is a relationship based on respect, and that it takes time to develop trust".

In January 2007, the AMC Chiefs in Assembly resolved that for research partnerships to be supported, research must be based on the following principles: free, prior informed consent (individually and collectively); First Nations OCAP principles, that First Nations have Ownership, Control, Access and Possession of their own data; and First Nations ethical standards; these now form part of the Constitution of the Assembly of Manitoba Chiefs.

In September 13, 2007, the United Nations General Assembly adopted the United Nations Declaration on the Rights of Indigenous Peoples, which the Chiefs immediately supported. On November 12, 2010, the Government of Canada advised the United Nations that it was now in formal support and recognition of this UNDRIP.

Process Records

(name or position/title) will coordinate all administrative matters relating to the above named research project, with recognition of the collaborative partnership with the AMC. The research team will be based at *(location in territory of research)* and *(maybe university or ...)*.

Ethical Considerations

The research collaboration partners to this agreement collectively share the responsibility for ethical standards throughout the project. Ethical codes of conduct for research in Aboriginal

communities have been articulated in the federal government's Tri-Council Policy Statement (1996), and in the Canadian Institutes for Health Research Guidelines for Research with Aboriginal Peoples (2008). In addition, each member of the pilot project team has responsibility for raising any ethical concerns and/or issues. Ethical dilemmas are to be resolved on the basis of the research team (or unit) striving for a significant degree of consensus. [*OR you state your own ethical standards*].

Duration and Amendments

This Agreement on Research Collaboration will be in effect throughout the entire research process, from the moment efforts are made to implement the proposal, through the development of the research methodology and questions, data collection, and analysis phases into the dissemination of and publication of the findings, and in the case of blood samples, until all blood is either returned to disposed of in a culturally appropriate manner, according to this agreement. This agreement can be amended upon mutual consent by the *partners to this agreement*.

Principles: Ownership, Control, Access, and Possession

It is recognized that while all members of the pilot project team have the obligation to recognize the cultural-based perspectives of First Nations, and particularly AMC has additional duties to ensure that this research project does not counter First Nations governance and self-government, which includes jurisdiction and control over a full range of processes and institutions, including research and information (Schnarch, 2004). The primary means of fulfilling this obligation is to follow the OCAP principles. This research team acknowledges, supports, and will follow the principles of ownership, control, access, and possession as defined by the *Manitoba First Nations as represented by the AMC Health & Information Committee (HIRC) (or your ethical and research review body)* who have agreed to appoint a member to the Research Advisory Committee and to review ongoing progress of this project at its quarterly meetings.

We agree to follow these principles in the manner outlined below:

- § **Research Advisory Committee:** Purpose of committee; name of members and organization representing; frequency of meetings; location.
- § **Special Responsibility of AMC HIRC** (*insert your ethical and research review body*) : The AMC HIRC will ensure benefits to Manitoba First Nations and adherence to the OCAP principles, and will provide advice and support to the *research team* throughout the project, including providing guidance if the team is having difficulty reaching consensus.
- § **Reporting:** The *research team* will report to HIRC at their quarterly meetings, and annually to the AMC Chiefs in Assembly through the AMC Chiefs Task Force on Health

during the course of the project.

§ Members of the *research team* acknowledge and respect the First Nations right to self-determination, including the jurisdiction to decide about research and projects in their communities. In doing so, the research process shall be built upon meaningful engagement and mutually respectful interactions between the research team and First Nations communities. In addition, in recognition of the obligatory role the AMC in serving the Manitoba First Nations, the research process shall be built upon meaningful engagement and mutually respectful interactions between the units. Further, the *research team* agrees they will respect the privacy, dignity, culture and rights of First Nations peoples.

In the case of research involving the obtaining of blood samples, special attention must be addressed to this matter, to ensure that (i) blood samples are only used for the express purpose of the stated research project that the individual and the First Nation (or First Nation representative organization, as it is defined) agrees to; (ii) that blood samples are handled in a respectful manner; (iii) that the blood samples are kept for a limited period of time, no longer than 5 years; (iv) that the blood samples are either returned or destroyed in a culturally appropriate manner, according to the advice provided by the Elders, to be identified by the First Nation(s) or First Nation organization involved in this research.

§ The *research team* will strive to include meaningful and equal participation from First Nations community members. Therefore, the parties will be jointly involved as partners from the development of pilot project operational plan, methodologies and questions, data collection, and analysis phases into the dissemination of and publication of the findings. The AMC and agree that a research office and staff operate from the (*name location in territory of the research*).

§ The *research team* will strive to demonstrate leadership support by obtaining and attaching resolutions or letters of support from First Nations leadership, when required. Primarily, the task of negotiating evidence of First Nations leadership support resides with the AMC unit.

§ The *research team* fully respects the rights of individuals to the confidentiality of their health data, the rights of First Nations to control over their community information and traditional knowledge; and the rights of contributors to their intellectual property rights, which shall not supersede the rights of First Nations.

§ The *research team* will collectively make decisions on research questions, in data collection, interpreting results, in drafting reports, and in dissemination of findings.

§ The research questions will seek to address the purposes of the research study and will

work to ensure that the pilot project is relevant and beneficial to First Nations communities.

- § In dissemination strategies to First Nations communities, the research team agrees that the language and manner of sharing will be appropriate to Manitoba First Nations. All material disseminated to the First Nations communities must be jointly developed by (*name of partner*) and AMC.
- § The purpose of the *research study* and its benefits and risks will be explained clearly in a language that is appropriate to the people receiving the information. Any time such explanations are to be undertaken, a member of the AMC unit or a delegate identified by the AMC unit is to be present.
- § The *Research team* agrees they will not sensationalize problems in First Nations communities, but will strive to present a balanced portrait that also focuses equal attention on the more positive aspects. As such, the *research team* understands that they will collaboratively prepare draft findings prior to submission for publication or presentation. Any draft findings for publication or presentation must receive commentary from the AMC unit, even if it is only a note that it has been reviewed. The draft findings will be reviewed in a timely manner and any questions regarding the draft findings from team members posed to other team members must be answered in a timely manner with due consideration for the tight time frame within this project is undertaken.
- § Given that all members of the *research team* will be provided the opportunity to review and comment on findings prior to publication or presentation, any one member of the research team may not, particularly once initial dissemination occurred, further analyze, publish or present findings resulting from the above mentioned research study unless the entire team reaches a consensus.
- § The *Research team* is responsible for maintaining the integrity of all data collected, such as storing participant consent forms, storing raw data, destroying data, and identifying who will destroy the data. Determination of how the integrity of the data will be maintained will be made by consensus. Any changes to how the data is maintained must be reached by consensus. If no consensus can be reached, then the data must be maintained at a site identified or acceptable to the AMC and (*name of partner*), upon recommendation by the Research Advisory Committee.
- § Once the privacy and confidentiality of participants has been demonstrated, data sets in the form of the appropriate computer files may be shared with all members of the research team. In cases of disagreement over transfer of data sets, the AMC and (*partner*) will strive to achieve a significant degree of consensus.
- § The *Research team* agrees to provide meaningful and appropriate capacity-building, as indicated by including First Nations project staff and the First Nations community

participation in an Advisory/Oversight Committee and throughout the project.

- § The *Research team* agrees that First Nations communities have the right to follow cultural codes of conduct and community protocols. In situations where First Nation community members are in disagreement, the pilot project team will strive to resolve conflict towards achieving a significant degree of consensus.
- § The *Research team* agrees that it may be necessary to seek advice and support from the AMC HIRC, or First Nation Elders and other leadership, including in situations where difficulties arise in obtaining consensus. Recognition of who is considered an Elder is to be made by the AMC, who are or would be informed by First Nations communities and citizens.

Authorship

Criteria outlined by Huth (1986) will be used as guidelines for authorship of publication based upon the findings of the research. The criteria recommend that all authors must (i) make a substantial contribution to the conception, design, analysis, and/or interpretation of data; (2) be involved in writing and revising the manuscript for intellectual content; and (3) approve the final draft and be able to defend the published work. Those who have made other contributions to the work (e.g. data collection without interpretation, etc.), or only parts of the above criteria should be credited in the acknowledgements, but not receive authorship. Further,

- § All members of the research team will be provided the opportunity to review and comment on findings prior to publication or presentation.
- § The explicit permission of an individual, unit, or organization must be sought prior to acknowledging their contribution in a paper or presentation.
- § A research team member or a partner may chose to include a disclaimer if they do not agree with the content or views presented in a publication or presentation. In the case of a presentation, the disclaimer must be incorporated in the presentations in a manner which gives it the possibility of noticeable attention by those attending the presentation. The manner which the disclaimer is to be included must be approved by those providing the disclaimer.

Signed this _____ day of _____, 200_:

Name of Head & PTO or FN

Name of Research Partner & Institution

Witness

Huth, E. J. (1986). Irresponsible authorship and wasteful publication. *Annals of Internal Medicine*, 104(2), 257-259.

Schnarch, B. (2004). Ownership, control, access, and possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health*, 1(1), 80-95.