



Framework for Research Engagement with First Nation, Metis, and Inuit Peoples



UNIVERSITY
OF MANITOBA

Faculty of
Health Sciences

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PREFACE

Traditional Knowledge

Research is not new to the First Nations, Metis or Inuit.

We created, anticipated, predicted change, tested new knowledge (hypotheses), synthesized experiences and conducted experiments since time immemorial. Drawing upon Indigenous sciences and applying methods and methodologies drawn from intergenerational transfer (oral tradition and writings) and integrating those adopted/modified from other knowledge origins across North America; Indigenous Peoples moved from survival to advanced creation like other traditions across the world. Indigenous Peoples share the same reverence and respect for epistemologies (knowledge) although its composition and space occupied unique language and cultural ecologies across Turtle Island (North America). “As Indigenous Peoples we have always done research, always searched for understanding, ways of being and knowing the world around us in order to survive, we just didn’t call it research” (former Chief Norman Bone, Keeseekoowenin First Nation).



**“As Indigenous Peoples
we have always done research,
always searched for understanding,
ways of being and knowing the world
around us in order to survive,
we just didn’t call it research”**

Former Chief Norman Bone,
Keeseekoowenin First Nation.

As Indigenous Peoples we studied the land and developed our own sciences, using astrology and physics following the moon cycles to tell us when to pick medicines, when to hunt, when to plant and when to share stories. “Indigenous knowledge is also inherently tied to land, not to land in general but to particular landscapes, landforms, and biomes where ceremonies are properly held, stories properly recited, medicines properly gathered, and transfers of knowledge properly authenticated”.¹

Today many Indigenous healers, scholars and scientists apply and test traditional knowledge, ceremony and medicines to those conditions acquired through socially constructed oppression like HIV, Diabetes, Suicide and other chronic diseases. Indigenous Peoples rely on ancient networks and protocols that employ healing, treatments and epistemologies (knowledge) to address the spectrum of challenges and celebrations they face on a daily basis. These traditions re-inscribe First Nation, Metis and Inuit humanity, ensure continuity and permit modification of a variety of current ecologies (urban, rural and remote, as examples) to the benefit of settler Canada and Indigenous Peoples. Many forget that North America’s first immigrants would not have survived without Indigenous science and generosity.

Dr Marie Battiste’s well-known inaugural essay on Indigenous knowledge² explores these themes further.

¹ Morphy, Howard. (1995) Landscape and the Reproduction of the Ancestral Past. In Eric Hirsch and Michael O’Hanlon, eds., The Anthropology of Landscape: Perspectives on Place and Space, Oxford: Clarendon Press.
Basso, Keith H. (1996) Wisdom Sits in Places: Landscape and Language Among the Western Apache. Albuquerque: University of New Mexico Press.

² Battiste, Marie (2005). Indigenous knowledge: Foundations for First Nations. World Indigenous Nations Higher Education Consortium (WINHEC) Journal, 2005 online at <http://www.win-hec.org/docs/pdfs/Journal/Marie%20Battiste%20copy.pdf>



INTRODUCTION

Addressing health inequities experienced by First Nations, Metis, and Inuit is the responsibility of all Canadians. This framework is intended to provide positive pathways to support all who want to contribute towards this objective.

Over the past decades, First Nation, Metis, and Inuit Peoples and organizations have advocated for the right to play a more active role in research. The 2007 Canadian Institutes of Health Research followed by the 2013 Tri-council Guidelines Chapter 9 Research Involving the First Nations, Inuit and Métis Peoples of Canada has defined the need for researchers to adopt a more collaborative approach in the conduct of First Nations, Metis, and Inuit research. In keeping with the development of the College of Medicine Strategy Map (Research), we recognize a need to clarify expectations and provide guidance to researchers and to First Nation, Metis, and Inuit Peoples (College of Medicine Research Strategic Plan (RSP) Project, 2012). The Vision, Mission, Stakeholder Outcomes, System Processes and Infrastructure and Capability and the Values identified in the Strategy Map are consistent with approaches for research engagement and outcomes in the Indigenous communities.

On March 8, 2013, the Office of the Associate Dean, First Nations, Metis, and Inuit Health, University of Manitoba, Faculty of Health Sciences, College of Medicine, hosted a planning session on research engagement with First Nation, Metis, and Inuit Peoples. Invitees to the session included representatives of First Nation, Metis, and Inuit governments and organizations, provincial and federal government departments, regional health authorities, and university and community-based researchers (Report: Towards a Framework for Research Engagement with First Nations, Metis, and Inuit Communities, 2013) http://umanitoba.ca/faculties/medicine/alumni/media/Final_Report_-_U_of_M_Frmwrk_Report_Research_Engagement_with_FNMI_Communities_July_2013.pdf

This framework was developed by Manitoba First Nation, Metis, and Inuit health researchers and for those involved in Manitoba First Nation, Metis, and Inuit health research. We recognize that University of Manitoba researchers also engage in health research with Indigenous Peoples across Canada and world-wide. Although this framework can provide some guidance, researchers are advised to consult with these Indigenous nations to clarify expectations, and to learn local protocols for developing meaningful partnerships.

Research Engagement with First Nation, Metis, and Inuit Peoples

Ongoing dialogue with our partners has highlighted the key components for inclusion in a Framework for Research Engagement with First Nations, Metis, and Inuit Communities. It was considered critical that the academic research community partner with First Nation, Metis, and Inuit Peoples to generate research outcomes that are of shared value, and to develop research relationships with communities and the University. A summary of the key components for a framework for research engagement is included in Figure 1. (Appendix 1)

Figure 1: Framework for Research Engagement between the University and First Nation, Metis, and Inuit Peoples

Purpose:

To partner with First Nation, Metis, and Inuit Peoples to develop and undertake world-class collaborative, respectful research.

Principles:

1. Commitment to authentic engagement with First Nation, Metis, and Inuit Peoples, and recognition that relationship is central to research.
2. Shared respect, trust, and commitment to mutually empowered long-term relationships.
3. Acknowledgement of:
 - i. the inherent rights of First Nation, Metis, and Inuit Peoples.
 - ii. the treaty rights of First Nation Peoples.
 - iii. the diversity and distinct identities within and among First Nation, Metis, and Inuit Peoples.
4. Shared authority, responsibility, and accountability.
5. Commitment to address the research-related priorities and needs of First Nation, Metis, and Inuit Peoples, and the University.

Goal:

To generate outcomes that are of value to First Nation, Metis, and Inuit research communities and the University.

Objectives:

To develop research relationships within First Nation, Metis, and Inuit Peoples and the University.

To develop and entrench research processes and practices within First Nation, Metis, and Inuit Peoples and the University.

Areas for Action:

Authentic Engagement and Relationship Building:

1. Provide appropriate resources, policies and procedures to support authentic engagement between University and First Nation, Metis, and Inuit Peoples.
2. Invest in relationship development, from conceptual stage of research project and throughout and beyond project term.
3. Collaborate with First Nation, Metis, and Inuit Peoples on the development of formal mechanisms and bodies to guide and oversee research activities.
4. Integrate two-way knowledge transfer (in which the university and community partners share knowledge with each other and with other stakeholders).

Research Practice:

1. Develop and entrench research processes, practices and research relationships with First Nation, Metis, and Inuit Peoples by providing financial resources to support opportunities for education, training, mentorship, and practical research experience to community members, with a focus on developing next generation of researchers.
2. Develop and entrench research capacity of University by:
 - actively recruiting First Nations, Metis, and Inuit students, researchers, and faculty members;
 - developing relationships with and learning from First Nation, Metis, and Inuit Peoples; and
 - in partnership with First Nation, Metis, and Inuit Peoples, reviewing and revising the Research Ethics process to make it more congruent with the needs and realities of First Nation, Metis, and Inuit Peoples.
3. Share resources, so that partners can draw on each other's expertise, skills, infrastructure, networks and other resources.

PURPOSE AND PROCESS

As a result of this planning day and the commitment of all participants to have a clear understanding of the need and the process for developing stronger research relationships; a Steering Committee was established. The Steering Committee included representatives of the University, the Assembly of Manitoba Chiefs, the Manitoba Metis Federation, the Manitoba Inuit Association and urban community members, for the purpose of further developing and finalizing a Framework for Research Engagement with First Nation, Metis, and Inuit Peoples.

Purpose

To partner with First Nation, Metis, and Inuit Peoples to develop and undertake world-class collaborative, respectful research.

This document will inform the academic research community and First Nation, Metis, and Inuit Peoples wishing to partner in research activities on key elements required for the development of an agreement that reflects authentic research engagement.

One of the identified commitments in the University of Manitoba's Strategic Plan is research excellence across our broad range of disciplines. Indigenous achievement is a fundamental priority in the strategic plan. From a more focused perspective, the College of Medicine's Research Strategic Plan recognizes First Nation, Metis, Inuit and Indigenous Peoples' health as an emerging area of research excellence within the Faculty. When this point is considered in light of the Faculty's research vision of "being a leading member of one of the top five integrated academic health sciences networks meeting the needs of Canadians", it becomes clear that the Faculty is committed to being a leader in Indigenous Health research – First Nations, Metis, and Inuit in Manitoba, across Canada and in Indigenous communities worldwide.


To meet this commitment and positively address this priority requires strong, supportive, and respectful relationships with First Nation, Metis, and Inuit Peoples, both within and outside of the University.

It is within this context that this framework seeks to advance and facilitate First Nation, Metis, Inuit and Indigenous research within the University of Manitoba and Manitoba at large.

The co-creation of knowledge with First Nation, Metis, and Inuit Peoples central to the research relationship is likened more to a journey, both personally and professionally. In some instances, the challenges to gain access to different and equally valid knowledge systems and sciences necessitates some Western based researchers to reflect on their own biases, stereotypes and knowledge deficits. Deconstructing these barriers may be a complex and challenging process for all involved; and yet successful relationships require this level of personal and professional literacy.³

The journey then requires resources, commitment and time to foster authentic relationships within which First Nation, Metis, and Inuit Peoples and western-based researchers work together. This framework outlines theoretical and practical components for successful working relationships in the co-creation of knowledge. (Kaupapa Māori research, National Aboriginal Health Organization (NAHO), Institute for Aboriginal Peoples Health (IAPH), Indigenous Physicians Association of Canada (IPAC), Royal Commission on Aboriginal Peoples (RCAP)) However, it is important to recognize that this document is only one step in this important journey to improving the health and well-being of Indigenous Peoples. Your journey will require more attention, dedication and effort over an extended period of time in order for you to positively contribute to the well-being of First Nation, Metis, Inuit and Indigenous Peoples.

³ Wilson, Shawn (1998) *Research is ceremony: Indigenous research methods*. Fernwood Publishing, 2008; Greenhalgh T, Hurwitz B, eds., *Narrative based medicine: dialogue and discourse in clinical practice*. London: BMJ Books.



This framework will guide members of the University of Manitoba in their research work with First Nation, Metis, and Inuit Peoples.

Specifically, it provides direction for developing meaningful and respectful partnerships that support and encourage shared excellence in collaborative, community-driven research. This framework provides guidance to ensure that the partnerships between First Nations, Metis, and Inuit people and researchers are characterized by ethical accountability and responsibility to First Nation, Metis, and Inuit Peoples, as well as the academic community.

Adopting, studying and embracing Indigenous worldviews, knowledge, cultural practices, aspirations and articulating First Nation, Metis and Inuit rights to their intellectual property are foundational challenges and commitments. Self-reflection and active exposure of the power differentials that act to diminish Indigenous peoples will support these efforts. Both researcher and supporting institution become positive agents of change for and with communities; scientific inquiry and integrity require employment of critical perspectives in this domain to ensure such an analysis. Inviting researchers to undertake anti-racist approaches in their work with Indigenous peoples unveils how racism and the resulting oppression operate. From personal to institutional self-reflection, researchers shed light on racism, challenge its presence and work with Indigenous communities to deconstruct such systems of oppression. By interrogating and interrupting both structural and personally mediated racism; the health and healing outcomes for First Nation, Metis and Inuit improve.

An anti-racist lens exposes how racism continues to operate to diminish the lives of Indigenous people. It permits exploration of the distal causes of socially constructed determinants of health, where negative outcomes for Indigenous peoples are disproportionately represented. The benefit of this critical work improves the lived experiences for all Canadians, through knowledge sharing of research conducted in this manner.

GOALS

To generate research outcomes that are of value to First Nation, Metis, and Inuit Peoples and the University in addressing health inequalities and reducing health disparities.

The goal of the Framework, as identified, clearly reflects the need to have academia and First Nation, Metis, and Inuit Peoples work closely together in the critical stages of relationship building in the development of the research project or program. There is a need for recognizing that respect for, and inclusion of, the perspectives and worldviews of all peoples will result in stronger and more meaningful research programs.

Objectives

- To support the development of research relationships with and between First Nation, Metis, and Inuit Peoples and the Peoples and the University.
- To raise awareness of and entrench research processes and practices.



PRINCIPLES OF COLLABORATION

The principles for collaboration are consistent with the principles of engagement for any collaborative or participatory research project, and articulate the relevance of relationships, respect, trust and joint priority setting.

Principles

1. Authentic engagement with First Nation, Metis, and Inuit Peoples, and recognition that relationship is central to research.
2. Shared respect, trust, and commitment to mutually empowered long-term relationships.
3. Acknowledgement of the:
 - a. Inherent rights of First Nation, Metis, and Inuit Peoples.
 - b. Treaty rights of First Nation Peoples.
 - c. Diversity and distinct identities, histories, cultures, languages, geographies between First Nation, Metis, and Inuit Peoples.
4. Shared authority, responsibility, and accountability within the research relationships and engagements.
5. Address the research-related priorities and needs of First Nation, Metis, and Inuit Peoples, and the University.

Collaborative working relationships are strengthened when the principles under which the participants are engaging are viewed in a consistent manner. The above principles are considered vital for relationship building and successful research partnerships between First Nation, Metis, and Inuit Peoples and university based researchers.



**‘Research is a relationship based on respect,
and it takes time to build trust.’**
AMC Elder
(Assembly of Manitoba Chiefs Elders Workshop on Research Ethics, 2005)

AREAS FOR ACTION

The themes for action include those of relationship building and authentic engagement, and those of research practice.

Historically, research in First Nation, Metis, and Inuit health has largely focused on biomedical studies, social science studies or studies of a socio-political focus. Researchers did not always engage First Nations, Metis, and Inuit in identifying the goals of the research project. Researchers traditionally have not engaged the community in the analysis or returned to the community with a summary of the findings written in language accessible to the community. The community was not supported in distilling the findings into information that could be used by the community for their own purposes. Too often, the community’s critical role in the research process was not acknowledged.

The last two decades have seen a shift to a community-based and participatory action approach in research, with First Nations Metis and Inuit communities increasingly playing a greater role in the process of research. While initially these relationships were fragile, and community engagement somewhat marginalized, there is now greater clarity on the expectations of community in being recognized as an equal partner in an authentic research engagement process.

‘Research is a relationship based on respect, and it takes time to build trust.’ AMC Elder (Assembly of Manitoba Chiefs Elders Workshop on Research Ethics, 2005)

A. Relationship Building / Authentic Engagement:

The key to authentic engagement for research relies on mutual recognition and respect, with:

- Collaborators recognizing the importance of Indigenous and academic knowledges and expertise, and
- Translation of Indigenous and academic knowledges into action that results in health improvements.

This engagement is strengthened through a partnership that recognizes and respects the value of the skills that each partner brings. To assure that the relationship is successful, partners agree that deficits must be addressed through commitment to resource and knowledge sharing – this will include not only the need for infrastructure resourcing, but will include a respectful two – way sharing of knowledge throughout the project.

Criteria for Authentic Research Engagement:

The following criteria are considered critical to an authentic research engagement process with community. The research project agreement will:

1. Provide appropriate resources, policies and procedures to support authentic engagement between University and First Nations, Metis, and Inuit

1a. There will be active and shared participation at the outset of the research project development, during the life of the project, and a commitment to shared knowledge translation and knowledge mobilization efforts.

This commitment requires:

- Sufficient time dedicated to relationship building and an authentic research engagement process, Eg. Ensuring Elders engaged in helping to guide projects. Adaptation may be required to mitigate time and financial limitations of the project, or of the call for proposal. Human and financial resources must be made available to First Nation, Metis, and Inuit partners to support their contribution in the project.
- Initial discussions must focus on the difference in approaches and priorities and acknowledge the need to blend and /or accommodate various approaches in the project.

1b. Take the time to build the relationships required to build consensus.

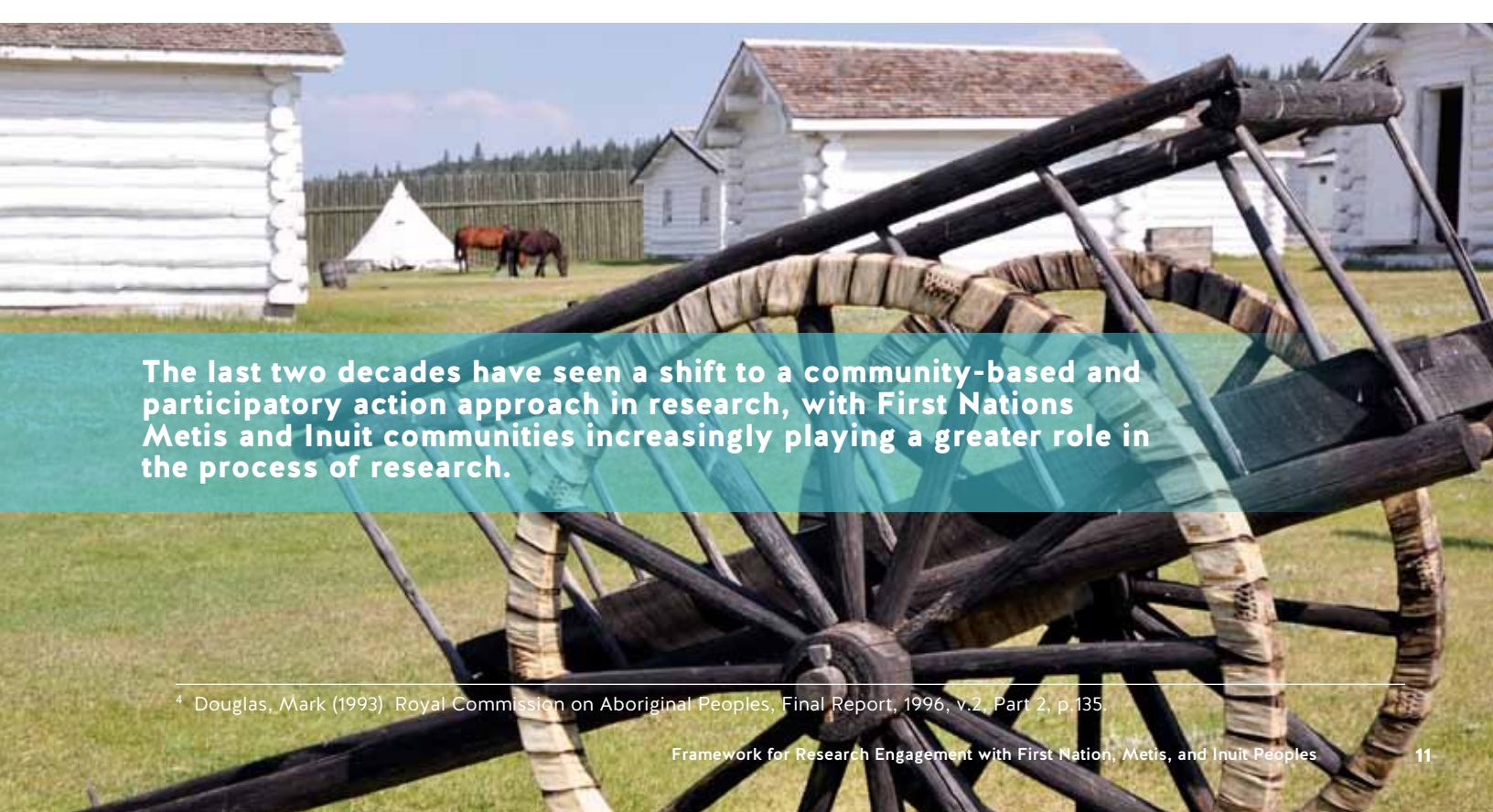
Anishinaabe Elder Peter O'Chiese explained reaching consensus as "seven twice is eight", whereby "seven perspectives are blended, seven perspectives working in harmony together to truly define the problem, truly define the action that is needed makes for an eighth understanding."⁴

Consensus then, will lead to the terms of a formal written partnership agreement that defines mutual expectations; including the ownership and stewardship of data, the role of community members in the research, and resources committed in order to ensure meaningful participation.

Many First Nation, Metis, and Inuit communities and organizations have developed their own research agreement templates. The First Nations, Metis, and Inuit organizations in Manitoba are represented by regional organizations. The Assembly of Manitoba Chiefs (AMC), the Manitoba Metis Federation (MMF) and the Manitoba Inuit Association (MIA) are organizations that strive for a reduction in health disparities and enhanced health equity for their members. The organizations fully recognize that relevant research is critical to achieving these goals. As such, each organization has established a process to guide the research engagement process and key points for an authentic research relationship.

See Appendices 3, 4 and 5 – Research Protocols and Engagement:

Appendix 3 - Research Protocols with First Nations,
Appendix 4 - Research Protocols with Metis, and
Appendix 5 - Research Protocols with Inuit



The last two decades have seen a shift to a community-based and participatory action approach in research, with First Nations Metis and Inuit communities increasingly playing a greater role in the process of research.

⁴ Douglas, Mark (1993) Royal Commission on Aboriginal Peoples, Final Report, 1996, v.2, Part 2, p.135.

2. Take the time to invest in relationship development, from conceptual stage of research project, throughout and beyond the project's term.

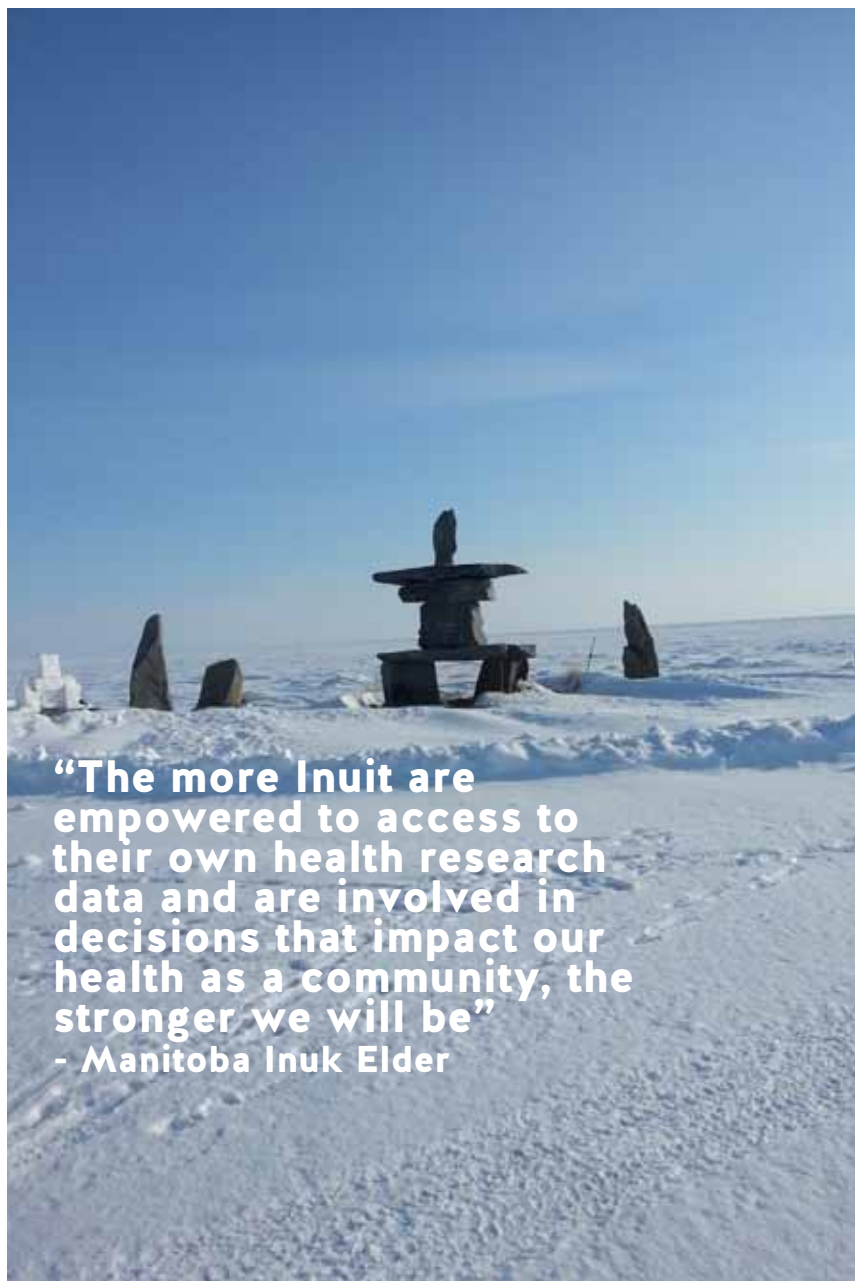
Relationship building is a critical component in establishing a research team that works well together. An “investment” in the relationship shall be a commitment from the community-based and university-based researchers and:

- Will begin early in the process of developing the research project proposal.
- Will build, maintain, and sustain a respectful relationship between First Nation, Metis, and Inuit Peoples and the University researchers.
- Will aim to create long term, innovative university and community-based research teams that create collaborative processes and deliver research outputs that meet the needs of First Nation, Métis, and Inuit Peoples in a timely manner.
- Will be devoted to advance a ‘supportive environment’ in which research can be accessed for effective uptake and deployment by First Nation, Métis, and Inuit Peoples may identify and guide future research endeavors.
- May inform community project development or implementation.

3. Collaborate with First Nation, Metis, and Inuit Peoples on the development of formal mechanisms and bodies to guide and oversee research activities.

When considering entering into research with First Nations, Metis, or Inuit populations, there are several areas that must be considered. Researchers will understand that:

- First Nation, Metis, and Inuit Peoples have jurisdiction over their culture, heritage, knowledge, political and intellectual domains that must be explicitly recognized
- Prior to beginning research within a community, a research agreement must be negotiated and formalized with the authority of First Nations, Metis, or Inuit jurisdictions.



“The more Inuit are empowered to access to their own health research data and are involved in decisions that impact our health as a community, the stronger we will be”
- Manitoba Inuk Elder

3a. When in doubt, seek advice from the Manitoba First Nations – Centre for Aboriginal Health Research, at the University of Manitoba.

MFN-CAHR (since 2001) and its predecessor institute have been in existence for nearly 20 years. MFN-CAHR is skilled at navigating the interface between First Nation, Metis, and Inuit processes and protocols, funders’ requirements, the University of Manitoba’s administrative requirements, time and financial constraints. MFN-CAHR has developed a reputation for assisting university and community-based researchers in finding pragmatic solutions to produce in high quality research that meets the expectations of communities and of the academy.

A Research Agreement will include:

1. Clear articulation of researcher and community roles and responsibilities;
2. Demonstration of consent from recognized authority;
3. Clear articulation of individual and collective consent processes;
4. Demonstration of ongoing renegotiation of consent;
5. Inclusion of community members as members of research team not solely as research participants:
 - i. commitment to skill building and an understanding that this is bi-directional; and
 - ii. recognition and honoring of First Nations, Metis and Inuit Knowledges – inter-connection of all;
6. Appropriate resourcing of the partnership;
7. Recognition of power differentials specific to the research process between academic researchers and community;
8. Clear demonstration of unique challenges and processes of research with First Nation, Metis and Inuit Peoples and measures to mitigate these to maintain privacy and confidentiality of participants, and of the community(ies) as appropriate;
9. Seeking consensus on respecting intellectual property;
10. Commitment to a balanced representation (as opposed to sensationalization) of issues identified in the findings;
11. Demonstration of understanding of public vs. private (sacred) knowledge;
12. 'Completing the circle'⁵ – providing the information back to the community; including community members in Knowledge Translation

3b. Overarching principles of respect, responsibility, relevance, reciprocity, and relationships must be recognized

Specific principles of ethical research which have been established must be observed.

- Manitoba First Nations have adopted the OCAP principles⁶. OCAP refers to Ownership, Control, Access and Possession.
 - o **Ownership:** Refers to the relationship of a First Nations community to its cultural knowledge/ data/information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship [or possession].
 - o **Control:** The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions include research, information and data. The principle of control asserts that First Nations Peoples, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them. First Nations control of research can include all stages of a particular research project – from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management and so on.
 - o **Access:** First Nations people must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.
 - o **Possession:** While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between the owner and possessor.

⁵ Piquemal, N. (2001). Free and informed consent in research involving Native American communities. *American Indian Culture and Research Journal*, 25(1), 65-79.

⁶ Assembly of Manitoba Chiefs OCAP – Ownership, Control, Access and Possession, Sanctioned by the First Nations Information Governance Committee. <http://amc.manitobachiefs.com/images/pdf/ocap.pdf>

- The Manitoba Metis Federation subscribes to the OCAS principles: Ownership, Control, Access and Stewardship;
 - **Ownership:** Ownership refers to the legal possession of something. In this case we are referring to the Metis Population Data-Base (MPDB). The Metis Population Data-Base was developed for the Metis Health Status and Health Services Utilization study (Martens, Bartlett et al., 2010) and consists of over 90,000 anonymized individuals.
 - **Control:** Control refers to the power to make decisions about something and decide what should happen.
 - **Access:** Access refers to the right or opportunity to use something that will bring benefits.
 - **Stewardship:** Stewardship speaks to issues of responsible planning and management of resources. We have a responsibility to Metis to ensure that research that is completed is in their best interests, will result in positive changes in Metis health and health service delivery, and is done in as rigorous and ethical manner as possible.
- The Manitoba Inuit Association is committed to Inuit Qaujimajatuqangit (IQ)
 - **Inuit Qaujimajatuqangit** is an Inuktitut phrase that is often translated as “Inuit traditional knowledge”, “Inuit traditional institutions” or even “Inuit traditional technology”. It is often abbreviated as “IQ”. It comes from the verb root “qaujima-” meaning “to know” and could be literally translated as “that which has long been known by Inuit”, and used to mean the integration of traditional culture of the Inuit more into their modern governance structure in order to combat disempowerment.

Researchers and research teams should take it upon themselves to become familiar with and work within these principles. A detailed summary for each of First Nations, Metis and Inuit protocols follows. Accountability structures differ, and responsibilities for accountability will be understood by partners. The researcher is “accountable for the effects of the research project on the lives of the participants”⁷; the community members on the research team and oversight committee are accountable to ‘all their relations’

The Four R’s – Verna Kirkness Developed for issues related to First Nations and Higher Education but applicable to Research:

1. Respect – who you are as individuals, families, communities & nations
2. Relevance – research and education must be in accordance with a First Nation world-view, respecting community diversity
3. Reciprocity – exchange or interchange of knowledge or bi-directional storytelling
4. Responsibility – an exercise of sovereignty and responsibility over one’s own life

When strengthened, everyone benefits.⁸ Some First Nations, especially in British Columbia, have endorsed these principles, instead of OCAP.

The researcher is “accountable for the effects of the research project on the lives of the participants”; the community members on the research team and oversight committee are accountable to ‘all their relations’

University - Research Ethics boards will recognize and respect the First Nations, Metis, and Inuit ethics processes. We acknowledge the Tri-Council Guidelines as a set of guiding ethical principles.⁹ However, we consider that the Canadian Institutes of Health Research Guidelines for Health Research Involving Aboriginal People which were in force from 2007 to 2010 were more explicit on key issues of concern to First Nations, Metis, and Inuit, and encourage researchers to consult these guidelines as well.¹⁰

⁷ Weber-Pillwax, C. et al. (2004). Indigenous Researchers and Indigenous Research Methods: Cultural Influences or Cultural Determinants of Research Methods. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 2(1), 77–90.

⁸ Kirkness, V. J. and R. Barnhardt (2001). First Nations and Higher Education: The Four R’s - Respect, Relevance, Reciprocity, Responsibility. *Knowledge Across Cultures: A Contribution to Dialogue Among Civilizations*. R. Hayoe and J. Pan. Hong Kong, Comparative Education Research Centre, The University of Hong Kong. <http://www.afn.ca/uploads/files/education2/the4rs.pdf>

⁹ Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2010). *Tri-Council Guidelines for conducting research with Aboriginal Peoples* (pp. 1-93). Ottawa.

¹⁰ Canadian Institutes of Health Research. (2007). *CIHR Guidelines for Health Research Involving Aboriginal People* (pp. 1-44). Ottawa.

4. Integrate two-way knowledge transfer throughout project (in which the university and community partners share knowledge with each other and with other stakeholders).

First Nation, Metis, and Inuit recognize physical, mental, emotional, and spiritual elements and their articulation in the context of health and wellbeing as extensions to their traditional and current ecologies and beliefs systems. While settler and European science and tradition occupy some two thousand years of maturity, Indigenous science and tradition stem back to many thousands of years on Turtle Island (the name Indigenous People called what is also referred to as North America). Both forms of knowledge, called the Two Great Healing Traditions by the Royal Commission on Aboriginal Peoples (1996), bring immense knowledge and possibility to advance the health of Indigenous Peoples. The researcher and Indigenous community act interchangeably in one domain as teacher and the other as learner.

This two-way knowledge transfer employs dialogue as a means to advancing the relationship. Further, an “ethical space”¹¹ where different perspectives are shared in safe and respectful ways is paramount to success.

Indigenous ways of knowing and being remain free of settler or European interrogation in such ethical spaces. Expectations, outcomes and partnerships need to be defined and shared in discussions and dialogue leading to consensus.

Successful research partnerships entail learning from each other.

Indigenous ways of knowing and being remain free of settler or European interrogation in such ethical spaces. Expectations, outcomes and partnerships need to be defined and shared in discussions and dialogue leading to consensus.



¹¹ Ermine, W., Sinclair, R., Jeffery, B. (2004). The Ethics of Research involving Indigenous Peoples. Report of the Indigenous Peoples Health Research Centre to the Interagency Advisory Panel on Research Ethics. Saskatoon, SK: Indigenous Peoples Health Research Centre.



B. Research Practice

1. Develop research relationships with First Nations, Metis, and Inuit communities by:

- Building research relationships within a framework that embraces the strength and recognizes the challenges for university research environments and First Nation, Metis, and Inuit communities requires space for reflection.
- Providing opportunities for education, training, mentorship, and practical research experience to community members, with a focus on developing next generation of researchers.
- Recognizing and seeking to address how power and privilege differentials must be mitigated to ensure successful collaborations to advance the health and healing of Indigenous communities.

2. Develop research relationships within the University by:

- Actively recruiting First Nations, Metis, and Inuit students, researchers, and faculty members;
- Developing relationships with and learning from First Nation, Metis, and Inuit Peoples; and,
- Partnering with First Nation, Metis, and Inuit Peoples, review and revise the Research Ethics process to make it more congruent with the needs and realities of First Nations, Metis, and Inuit communities.

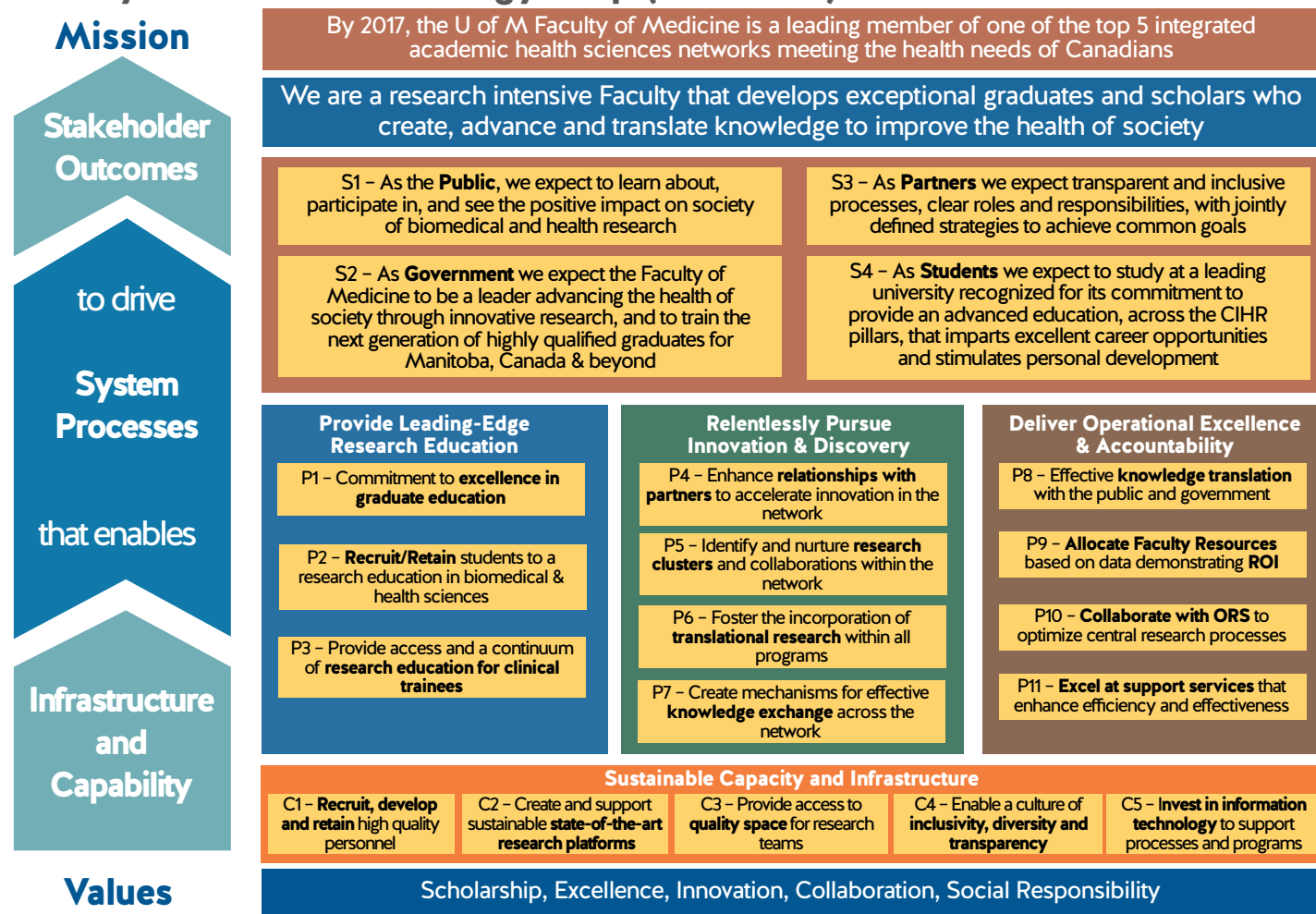
The College of Medicine Strategy Map for Research identifies stakeholder outcomes, system processes and infrastructure and capability requirements that will aid in achieving the vision and mission for research for the College of Medicine. (Figure 2, Appendix 2)

In this context of providing leading edge research education, the pursuit of innovation and discovery, and the delivery of operational excellence and accountability, the University of Manitoba, College of Medicine will identify and support those specific processes that will be enhanced through clear pathways of communication and engagement with First Nations, Metis, and Inuit for collaborative research relationships.

The environment of mutual respect, the recruitment, development and retention of high quality research personnel, the creation and support of sustainable research platforms, the provision of access to quality space for research tables, the establishment of a culture of inclusivity, diversity and transparency; and the investment in information technology to support processes and programs will support a focus in Indigenous Health research and enrich current and future research project relationships.

Dialogue, rather than discussion, remains a foundational underpinning of successful research. Removing the tension between knowledge systems ensures congruency with First Nation, Metis, or Inuit values and ways of knowing, and provides rich opportunities for university-based researchers.

Figure 2:
Faculty of Medicine Strategy Map (Research)



The Faculty of Health Sciences will continue to proactively work with funding agencies to promote the development of funding pathways aligned with the principles embedded in this document, thereby promoting the development of research platforms in First Nation, Metis, and Inuit and Indigenous Health Research. These platforms shall:

- Be designed to strengthen the institutional capacity, human and other resources of First Nation, Metis, Inuit, and Indigenous research and development systems.
- Focus on research management, quality and continuing education inclusive of First Nation, Metis, Inuit and community members, all students, and all Faculty members.

3. Share resources, so that partners can draw on each others expertise, skills, infrastructure, networks and other resources.

To date, funders and as a result, research grant applications and budgets have not always recognized the wealth of information that can be gained by partnering with Indigenous communities and as a result, grant funded resources have not included community resources. On a go forward basis, it is considered vital to engage in a research partnerships that will acknowledge the need for shared resources. Each partner brings to the relationship a wealth of expertise, skills, infrastructure, networks and other resources, and the partnership development should include discussion on all issues that will result in agreement for authentic research engagement in the relationship.



CONCLUSION:

This Framework has identified the systemic processes for engagement with First Nation, Metis, and Inuit scholars and communities to ensure that research platforms in Indigenous health are developed in a robust and collaborative manner and to ensure that Indigenous Knowledges are incorporated in to and valued by the researchers.



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GLOSSARY OF TERMS

For the purpose of this document:

Aboriginal: Aboriginal is a legal term from Canadian Constitution Act 1982 s.35 which includes First Nations (Indians), Inuit and Metis.¹² However that term “hides the reality of the unique peoples” First Nations, Metis, Inuit, and their cultures, languages, geographies, histories and other distinct ways of knowing. (Wilf Falk, Head of Demographics Province of Manitoba, in his urging of analysts to go deeper into Census Canada’s release of 2006 data on ‘Aboriginal Peoples’ and to avoid that term). Aboriginal refers to the residents of Canada who are biologically related to a group through bloodlines either maternally or paternally. Thus, “aboriginal” encompasses those Peoples who may be Native, First Nation, Indian, Status, Non-status, Metis and Inuit.¹³

All My Relations: Mitakuye Oyasin is a Lakota Dakota Nakota term meaning “All My Relations.” or ‘all my relatives’, referring to the ones who have been before us, who are present with us, and who are yet unborn, including all that the Great Mystery has created. “Mitakuye oyasin is said at the end of every prayer, when entering and leaving a sweat lodge, after smoking a sacred pipe. It is intended to remind the one speaking that all in the universe is related”.¹⁴

Authentic Research: Authentic research occurs when the quality and authenticity of research is guaranteed by the involvement of community members and their representatives throughout the research process. This may involve the inclusion of First Nations, Metis and Inuit scholars in the conducting research on their respective Peoples and issues, attributing to them the benefits of an insider’s view and experiences, enhanced passion and commitment, and the “authority to ask new and different questions”.¹⁵

Collaboration: In the context of research studies with First Nation, Metis and Inuit, research collaboration is an approach that involves community members/partners in all phases of the project. It seeks a collaborative approach that is equitable for stakeholders involved in the research process, from the inception of the research idea to the dissemination and publication of research findings. Collaborative research partnerships should embody a committed vision to working together through any challenges or problems that may arise. Such principles provide a solid foundation for partners to develop their relationship.¹⁶

Collaborations are established by virtue of procedures that enable community participation in the research planning and design, implementation and evaluation of results. In collaborative research, researchers shall ensure that a representative cross-section of community perspectives and experiences are included in formulating solutions that incorporate advice and recommendations into decisions to the maximum extent possible.

Colonialism: refers to a form of imperialism that is based on maintaining a sharp distinction between the ruling power and the colonial (exploited) populations. Unequal rights are a fundamental feature of colonialism, as it is the imposition of a dominant culture’s values and practices on that of a subordinate group.¹⁷

Colonization: a process, that, outlined by James Frideres, includes geographical incursion, sociocultural displacement, the establishment of external political control and economic dispossession, the provision of low-level social services, and finally, the creation of ideological formulations around race and skin colour, which position the colonizers at the higher evolutionary level than the colonized.¹⁸

¹² Government of Canada. (1982). Constitution Act: Section 35. Retrieved April 17, 2014 from <http://laws.justice.gc.ca/eng/Const/page-12.html#anchors:7-bo-ga:LI>

¹³ Dumbrill, G.C., Lee, B., & Sammon, S. (2005). Glossary of terms for antioppressive policy & practice. Common Act Press: Mississauga. (pp 1-2).

¹⁴ Wm S Lyon, Encyclopedia of Native American Healing, Santa Barbara, CA: ABC-CILO Inc 1996 Archie Fire Lame Deer & Richard Erdoes, Gift of Power: The Life and Teachings of a Lakota Medicine Man. Rochester: Bear & Co. 2001

¹⁵ Lomawaima, K. T. & McCarty, T. L. (2002). Reliability, validity, and authenticity in American Indian and Alaska native research. Charleston, WV: Retrieved from ERIC database: (ERIC EDO-RC-02-4). Swisher, K. G. (1996). Why Indian people should be the ones to write about Indian education. American Indian Quarterly, 20(1), 83-90.

¹⁶ Shiu-Thorton, S. (2003) Addressing cultural competency in research: integrating a community based participatory research approach, Alcoholism – Clinical and Experimental Research 27(8): 1361-1364.

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¹⁷ Dumbrill, G.C., Lee, B., & Sammon, S. (2005). Glossary of terms for antioppressive policy & practice. Common Act Press: Mississauga. (p.6).

¹⁸ Frideres, J. (1983). Native people in Canada: Contemporary conflicts. (2nd Ed.) Scarborough: Prentice-Hall Canada. (p. 295-95) In Keirn, M.E. (1998). Colonizing Bodies: Aboriginal Health and Healing in British Columbia 1900-50. UBC Press: Vancouver. (p. xviii)

Culture: The commonalities around which a group of Peoples have developed values, norms, family styles, social roles, and behaviours, in response to the political, economic, and social realities they face. It is a pattern of beliefs, symbols and values that develop over time among groups of Peoples. It is the symbolic order through which Peoples communicate and organize their social life. Culture helps Peoples adapt to their environment and it usually facilitates group survival. It provides both a glue that binds us together, and a boundary that identifies our differences from others.

Culture is a much broader term than ethnicity. It revolves around the fact that groups differ in their worldview, their perspectives on patterns of life, their concept of the essential nature of the human condition, and the way they structure behaviour. It is influenced by many factors including one's social location, language, family and social relationships. Culture often runs so deep that one may be unconscious of its influence, and hence misinterpret it as an objective reality.¹⁹

Cultural Competence: This refers to a specific set of values, attitudes, knowledge and skills that sensitize and improve sharing of information and assistance between Peoples of different cultural orientations. Cultural competence is defined as a set of congruent behaviours, attitudes, and policies that come together in a system, agency or among professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations.²⁰

Cultural Safety: Cultural safety refers to what is felt or experienced by a patient when a health care provider communicates with the patient in a respectful, inclusive way, empowers the patient in decision-making and builds a health care relationship where the patient and provider work together as a team to ensure maximum effectiveness of care. Culturally safe encounters require that health care providers treat patients with the understanding that not all individuals in a group act the same way or have the same beliefs. Includes cultural awareness, cultural sensitivity and cultural competence and involves the recognition of unequal power relations to address inequities in health care.²¹

Discourses: A set of topics for discussion and a way of talking about those topics that is continued over time by a number of participants. Discourse includes not only language, but also the rules governing the choice and use of language and how the ideas and language will be framed. A discourse is a framework of thought, meaning and actions, which does not reflect knowledge, reality, or truth, but creates and maintains them. Knowledge is produced by discourse - it is the way in which power, language and institutional practices combine to produce particular ways of thinking. Although there is always more than one discourse at any point in time, there is usually one dominant discourse. The current dominant discourse consists of a set of assumptions about the social world that largely reflects the interests of capitalism, patriarchy, and people of European descent. The concept of discourse is an important tool for understanding oppression and for developing anti-oppressive practices.²²

Elder: Generally means someone who is considered exceptionally wise in the ways of their culture and spiritual teachings. They are recognized for their wisdom, their stability, their humour and their ability to know what is appropriate in a particular situation. The community looks to them for guidance and sound judgment.²³ Some First Nations people who are recognized as Elders prefer the term, "Knowledge Keepers".²⁴

Everyday Racism: Daily experiences which are characterized by routine encounters with another's and discriminatory behavior that pervade people's daily social interactions. Everyday racism can include mundane hassles as well as overt, severe racist experiences.

First Nations: First Nations are the original Peoples of Canada. They are tribally and linguistically diverse Peoples who live throughout all geographic regions of Canada and are the majority of the Indigenous Peoples who have lived on the lands the country. Often, the term "First Nations Peoples" is an updated version of the term "Indian" used in the Constitution Acts and successive Indian Acts. First Nations Peoples were divided by the Indian Act, which determined who would be considered "registered" or "status" Indian or non-Indian.²⁵

¹⁹ Christensen, C. (1995). Cross-cultural awareness development: An aid to the creation of anti-racist feminist therapy. In J. Adelman & G. Enguidanos (Eds.), *Racism in the lives of women: Testimony, theory and guides to anti-racist practice* (pp. 209-227). New York: Harrington Park Press. (p. 212)

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²⁰ Mussel, B., Cardiff, K., & White, J. (2004). "Glossary." In *The mental health and well-being of Aboriginal children and youth: Guidance for new approaches and services*. Chilliwack, BC: Salishan Institute. (p. 6).
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²¹ National Aboriginal Health Organization (2008). *Cultural competence and safety: A guide for health care administrators, providers and educators*. Health Canada: Ottawa. (p. 19)

²² Dumbrill, G.C., Lee, B., & Sammon, S. (2005). *Glossary of terms for antioppressive policy & practice*. Common Act Press: Mississauga. (p. 11).

²³ Legacy of Hope Foundation. (2008). *Where are the Children? Healing the Legacy of Residential Schools*. Retrieved January 5, 2008, from <http://www.wherearethekids.ca> Fondahl, G. et al. (2009). *Co-Managing Research: Building and Sustaining a First Nation – University Partnership*. Community Development Institute, UNBC: Prince George.

²⁴ Assembly of Manitoba Chiefs

²⁵ Assembly of Manitoba Chiefs

Health Disparities: differences in health status that occur among population groups defined by specific characteristics. For policy purposes, the most useful characteristics are those consistently associated with the largest variations in health status. The most prominent factors in Canada are socio-economic status (SES), Aboriginal identity, gender, and geographic location.²⁶

Health Inequalities: "...is the generic term used to designate differences, variations, and disparities in the health achievements and risk factors of individuals and groups...that need not imply moral judgment...[and may result from] a personal choice that would not necessarily evoke moral concern". Some inequalities reflect random variations (i.e. unexplained causes), while others result from individual biological endowment, the consequences of personal choices, social organization, economic opportunity or access to health care. Public policy is concerned with health inequalities attributable to modifiable factors, especially those that are perceived as inequitable.²⁷

Health Inequities: "...refers to those inequalities in health that are deemed to be unfair or stemming from some form of injustice.... The crux of the distinction between equality and equity is that the identification of health inequities entails normative judgment premised upon (a) one's theories of justice; (b) one's theories of society; and (c) one's reasoning underlying the genesis of health inequalities. Because identifying health inequities involves normative judgment, science alone cannot determine which inequalities are also inequitable, nor what proportion of an observed inequality is unjust or unfair."²⁸

Note: "Health disparities are, first and foremost, those indicators of a relative disproportionate burden of disease on a particular population. Health inequities point to the underlying causes of the disparities, many if not most of which sit largely outside of the typically constituted domain of "health".²⁹

Historic Trauma: This is a term originally coined by Maria Yellow Horse Brave Heart-Jordan, Professor of Social Work, Columbia University. Brave Heart is internationally recognized for developing historical trauma and historical unresolved grief theory and interventions among American Indians (alanhealthcareers.org). Historic trauma the result of multiple and compounded layers of pain, grief and loss experienced over generations and contributing to underlying psychological wounding in individuals and groups. The wounding is understood as being passed on from one generation to the next without opportunity for processing and healing. Symptoms may include prolonged signs of acute grief, depression, substance abuse, etc. The concept was designed to apply to the situation of North American Aboriginal Peoples who shortly after contact and throughout the generations have experienced acts of forced removal, killings, attempted assimilation and apartheid through the Indian Act. These originated in history but their effects are maintained and the underlying issues have not been addressed or redressed. It has been applied also to individuals or groups of Peoples whose experience of loss has originated in prior generations, for example, the children of Jewish victims of Nazi genocide, Palestinian victims of forced removal from their homelands and where redress and/or healing is not complete.³⁰

Indian: refers to the past and current legal standing of Aboriginal Peoples under the Indian Act. This label was originally and inaccurately applied by a confused explorer upon his arrival in "the New World". It continues to be applied inaccurately as the defining legal term regarding roles and responsibilities between Canada and Native Peoples as determined by the Indian Act. Other terms used under the Indian Act are "Status" and "Non-status" meaning those individuals who are recognized as Indians and those who are not. A Status Indian has greater accessibility to the benefits of the Act than a Non-status Indian does. [historically individuals lost their status for various reasons including: marrying a White man; enfranchising to vote, own property off reserve lands, drink alcohol, fight in a war, go to University -although this is no longer the case, there are still strict rules regarding who is eligible to be a Status Indian].³¹

²⁶ Health Disparities Task Group. (2004). Reducing Health Disparities- Roles of the Health Sector: Discussion Paper. Federal/Provincial/Territorial Advisory Committee on Population Health and Health Security. Retrieved June 11, 2009 from http://www.phac-aspc.gc.ca/ph-sp/disparities/pdf06/disparities_discussion_paper_e.pdf

²⁷ Health Disparities Task Group. (2004). Reducing Health Disparities - Roles of the Health Sector: Discussion Paper. Federal/Provincial/Territorial Advisory Committee on Population Health and Health Security. Retrieved June 11, 2009 from http://www.phac-aspc.gc.ca/ph-sp/disparities/pdf06/disparities_discussion_paper_e.pdf

²⁸ Health Disparities Task Group. (2004). Reducing Health Disparities- Roles of the Health Sector: Discussion Paper. Federal/Provincial/Territorial Advisory Committee on Population Health and Health Security. Retrieved June 11, 2009 from http://www.phac-aspc.gc.ca/ph-sp/disparities/pdf06/disparities_discussion_paper_e.pdf

²⁹ Adelson, Naomi, The Embodiment of Inequity: Health Disparities in Aboriginal Canada, Canadian Journal of Public Health, Mar-April 2005, 46-61.

³⁰ Dumbrill, G.C., Lee, B., & Sammon, S. (2005). Glossary of terms for antioppressive policy & practice. Common Act Press: Mississauga. (p. 15).

³¹ Dumbrill, G.C., Lee, B., & Sammon, S. (2005). Glossary of terms for antioppressive policy & practice. Common Act Press: Mississauga. (pp 1-2).

Indigenous: Indigenous populations are communities that live within, or are attached to, geographically distinct traditional habitats or ancestral territories, and who identify themselves as being part of a distinct cultural group, descended from groups present in the area before modern states were created and current borders defined. They generally maintain cultural and social identities, and social, economic, cultural and political institutions, separate from the mainstream or dominant society or culture.³²

Indigenous: refers to those individuals and groups who share and maintain the traditional cultural and spiritual understandings and world views of their ancestors. That is, “Indigenous” depicts those Peoples who belong to the original understandings of the various groups. The term “Indigenous” typically relates to the mentality and spirituality of those determined to maintain their original ways; that is, their ways of thinking and being members of the specific Nations into which they were born and to which they belong.

In Canada, the Constitution terms Indigenous peoples as Aboriginal and includes First Nations, Metis, and Inuit peoples.³³

Indigenous communities, Peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing in those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as Peoples, in accordance with their own cultural patterns, social institutions and legal systems.”

Inuit: Inuit is the Inuktitut word used by the people themselves to describe who they are, “the people”. Inuit are the Indigenous peoples of the arctic and circumpolar regions of the earth. In Canada, there are four major traditional territories for the Inuit that include Western North West Territories (Inuvialuit), Nunavut, Northern Quebec (Nunavik) and Labrador (Nunatsiavut), however one quarter of the Inuit in Canada live outside of these traditional territories in southern locations, such as Winnipeg and Churchill. The Federal Government’s power under Section 91 (24) of the Constitution Act of 1867 to make laws in respect to “Indians and Lands reserved for Indians” was interpreted to extend to Inuit. However, Inuit are not covered by the Indian Act.³⁴

Inuit Ethics: Inuit Qaujimajatuqangit is an Inuktitut phrase that is often translated as “Inuit traditional knowledge”, “Inuit traditional institutions” or even “Inuit traditional technology”. It is often abbreviated as “IQ”. It comes from the verb root “qaujima-” meaning “to know” and could be literally translated as “that which has long been known by Inuit”. It has recently become something of a political slogan in Nunavut, as the government attempts to integrate the traditional culture of the Inuit more into their modern governance structure in order to combat disempowerment. Its critics, however, tend to view it as little more than window dressing for more conventional politics.³⁵

Inuit Qaujimajatuqangit is a body of knowledge and unique cultural insights of Inuit into the workings of nature, humans and animals. Inuit Qaujimajatuqangit, then, has both practical and epistemological aspects that branch out from a fundamental principle that human beings are learning, rational beings with an infinite potential for problem-solving within the dictates of nature and technology. The Igloodik Research Centre in Igloodik, Nunavut focuses on documenting Inuit Qaujimajatuqangit, as well as climatology and seismic data research.³⁶

³² World Health Organization Health Topics: Indigenous Populations. Retrieved April 17, 2014 from http://www.who.int/topics/health_services_indigenous/en/.

³³ Dumbrill, G.C., Lee, B., & Sammon, S. (2005). Glossary of terms for antioppressive policy & practice. Common Act Press: Mississauga. (pp 1-2).

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³⁴ Clark, W., V. Whetung, D. Kinnon and C. Graham. 2010. “Part IV. Canada.” In L.J. Pulver, M.R. Haswell, I. Ring, J. Waldon, W. Clark, V. Whetung et al., eds., World Health Report – Financing for Universal Health Coverage Background Paper, No 33. Indigenous Health – Australia, Canada, Aotearoa, New Zealand and the United States – Laying Claim to a Future That Embraces Health for Us All. Geneva, Switzerland: World Health Organization.

³⁵ Clark, Ibid

³⁶ Clark, Ibid

Inuvialuit: Inuvialuit means “the real people”. Believed to have descended from the Thule people who once lived in the Arctic, Inuvialuit also count Tan’ngit (foreign) whalers and Alaskan Inupiaut among their descendants. Today, many of the 5,000 Inuvialuit reside in the communities of Aklavik, Inuvik, Paulatuk, Sachs Harbour, Tuktoyaktuk and Ulukhaktok (Holman).³⁷

Metis: The Metis are descendants of early 17th-century relationships between North American Indian and Europeans.³⁸ The genealogy of the first Metis nation: The development and dispersal of the Red River Settlement, 1820-1900. Winnipeg, MB: Pemmican Publications.. The Metis coalesced into a distinct nation in Manitoba in the late 18th century. After the 1885 fall of Batoche “Metis were denied a separate identity and ignored for a century”³⁹ By the 1967, with formation of the Manitoba Metis Federation, the Metis in Manitoba were again asserting their capacity to advocate and function once more in a collective manner. In the 1982 amendment to the Canadian Constitution Metis were named as one of the three Aboriginal peoples of Canada.⁴⁰

Non-Status Indian: An Aboriginal person who is not recognized as “Indian” under The Indian Act. This term does not apply to Inuit or Metis persons. Many Non-status individuals were not enrolled on Treaty or Band lists at the time these systems were occurring; or were removed from the Band lists due to disenfranchisement based on discriminatory policies targeting Aboriginal women who married non-Status men or arbitrary actions by Indian agents.⁴¹

Oppression: a system that maintains advantage and disadvantage based on social group memberships and operates, intentionally and unintentionally, on individual, institutional, and cultural levels.⁴²

Partnership: A partnership is an alliance that promotes mutual trust and communication that is based on mutually identified research goals and benefits. A partnership will ensure that the conduct of research adheres to core guiding principles which include the welfare of the collective as understood by all parties involved. Partnerships involving research with First Nation, Metis and Inuit include mutually agreed upon goals and objectives for the research process that involved terms with community researchers and others in the community who play a part in supporting the research partnership. Confidentiality and privacy of collective and personal information are upheld as are control and access to data, including data stewardship and analysis. Partnerships also involve agreed upon methods for disseminating the resulting information to stakeholders including communities, healthcare professionals, the academic world and funding bodies.⁴³

Relationship: A research relationship is defined as how communities and researchers collaborate together in a co-learning environment whereby mutual interests and agendas are discussed and enacted in the entire research process. The history of First Nations, Metis and Inuit oppression in Canada, particularly by researchers, has shaped the concept of authenticity and the context in which trust becomes paramount.⁴⁴

Status Indians: An Aboriginal person who is designated an “Indian” by the Indian Act, determining who can or cannot receive various rights or benefits conferred by the Act.⁴⁵

³⁷ Inuvialuit Regional Corporation (2007). Modern Inuvialuit Culture. Retrieved July 23, 2009 from <http://www.irc.inuvialuit.com/culture/modern.html>

³⁸ Sprague, D. N., & Frye, R. P. (1983). The Genealogy of the First Métis Nation: The Development and Dispersal of the Red River Settlement, 1820-1900. Winnipeg, MB: Pemmican Publications.

³⁹ McMillan, A.D. (1995). Native peoples and cultures of Canada. Toronto, ON: Douglas & McIntyre. (pp312-313)

⁴⁰ Government of Canada. (1982). Constitution Act: Section 35. Retrieved April 17, 2014 from <http://laws.justice.gc.ca/eng/Const/page-12.html#anchors:7-bo-ga:LI>.

McMillan, A.D. (1995). Native peoples and cultures of Canada. Toronto, ON: Douglas & McIntyre.

⁴¹ Canada Race Relations Foundation (2005). Glossary of terms: Non-status Indian. Retrieved April 15, 2009 from <http://www.crr.ca/divers-files/englossary-feb2005.pdf> (p12)

⁴² Hardiman, R. and Jackson, B. (2007). conceptual foundations for social justice education. (pp. 35-66).

Adams, M, Bell, L.A. and Griffin, P. (Eds.). Teaching for diversity and social justice. (2nd Ed.) New York: Routledge. (p. 58).

⁴³ Boffa, J., King, M., McMullin, K., Long, R. (2011). Process for the inclusion of Aboriginal People in health research: Lessons from the Determinants of TB Transmission project. Social Science & Medicine, 72(5): 733-738.

⁴⁴ Bull, J. R. (2010) Research with Aboriginal Peoples: Authentic relationships as a precursor to ethical research. Journal of Empirical Research on Human Research Ethics: An International Journal 5(4), pp. 13-22. University of California Press.

⁴⁵ Canada Race Relations Foundation (2005). Glossary of terms: Status Indian. Retrieved April 15, 2009 from http://www.crr.ca/component?option=com_wrapper&Itemid,548/lang.english/C (p. 16).

Stereotype: A generalized conception of a group of people, which results in the unconscious or conscious categorization of each member of that group, without regard for individual differences.⁴⁶

Traditional Healing: has been defined as “practices designed to promote mental, physical and spiritual well-being that are based on beliefs which go back to the time before the spread of western ‘scientific’ bio-medicine. When Aboriginal Peoples in Canada talk about traditional healing, they include a wide range of activities, from physical cures using herbal medicines and other remedies, to the promotion of psychological and spiritual well-being using ceremony, counseling and the accumulated wisdom of elders.”⁴⁷

Traditional Medicine: refers to the knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, used in the maintenance of health and in the prevention, diagnosis, improvement or treatment of physical and mental illness. Traditional medicine covers a wide variety of therapies and practices which vary from country to country and region to region. In some countries, it is referred to as ‘alternative’ or ‘complementary’ medicine (CAM).

Traditional medicine has been used for thousands of years with great contributions made by practitioners to human health, particularly as primary health care providers at the community level. TM/CAM has maintained its popularity worldwide.⁴⁸

Trust: Trust occurs within the interplay of culture, influence, and relationships of integrity. A meaningful process is based in cultural protocol and is confirmed by a commitment and continued involvement in a research project.⁴⁹

⁴⁶ <http://dictionary.reference.com/browse/stereotype?s=t>

⁴⁷ Royal Commission on Aboriginal Peoples. (1996). Bridging the cultural divide: A report on Aboriginal people and criminal justice in Canada. Ottawa: Royal Commission on Aboriginal Peoples. (Vol. 3:348).

AFRO Technical Report Series 1976, cited in B. Velimirovic, “Is Integration of Traditional and Western Medicine Really Possible?” in J. Coreil and J.D. Mull, eds., *Anthropology and Primary Health Care*, (Boulder, Colorado: Westview Press, 1990)

Martinez Coho, J. (1986/7). Study of the problem of discrimination against Indigenous populations. UN Doc E/CN.4/Sub.2/1986/7. In United Nations (2008). Resource kit on Indigenous peoples’ issues. New York. Retrieved March 31, 2009 from http://www.un.org/esa/socdev/unpfii/documents/resource_kit_indigenous_2008.pdf (p. 7)

⁴⁸ World Health Organization (2009). Health topics: Traditional Medicine. Retrieved March 27, 2009 from http://www.who.int/topics/traditional_medicine/en

⁴⁹ Baydala, L. T. et al (2013). “Making a Place of Respect”: Lessons Learned in Carrying Out Consent Protocol With First Nations Elders. *Progress in Community Health Partnerships: Research, Education, and Action*, 7(2): 135-143.





APPENDICES

- Appendix 1. Figure 1: Components of a Potential Framework for Research Engagement between the University and First Nations, Metis, and Inuit Communities
- Appendix 2. Figure 2. Faculty of Medicine Strategy Map (Research)
- Appendix 3. First Nations Research Protocols
- Appendix 4. Metis Research Protocols
- Appendix 5. Inuit Research Protocols

Appendix 1

Framework for Research Engagement between the University and First Nations, Metis, and Inuit Communities

Purpose:

To partner with First Nation, Metis, and Inuit Peoples to develop and undertake world-class collaborative, respectful research.

Principles:

1. Commitment to authentic engagement with First Nation, Metis, and Inuit Peoples, and recognition that relationship is central to research.
2. Shared respect, trust, and commitment to mutually empowered long-term relationships.
3. Acknowledgement of:
 - i. the inherent rights of First Nation, Metis, and Inuit Peoples.
 - ii. the treaty rights of First Nation Peoples.
 - iii. the diversity and distinct identities within and among First Nation, Metis, and Inuit Peoples.
4. Shared authority, responsibility, and accountability.
5. Commitment to address the research-related priorities and needs of First Nation, Metis, and Inuit Peoples, and the University.

Goal:

To generate outcomes that are of value to First Nation, Metis, and Inuit research communities and the University.

Objectives:

To develop research relationships within First Nation, Metis, and Inuit Peoples and the University.

To develop and entrench research processes and practices within First Nation, Metis, and Inuit Peoples and the University.

Areas for Action:

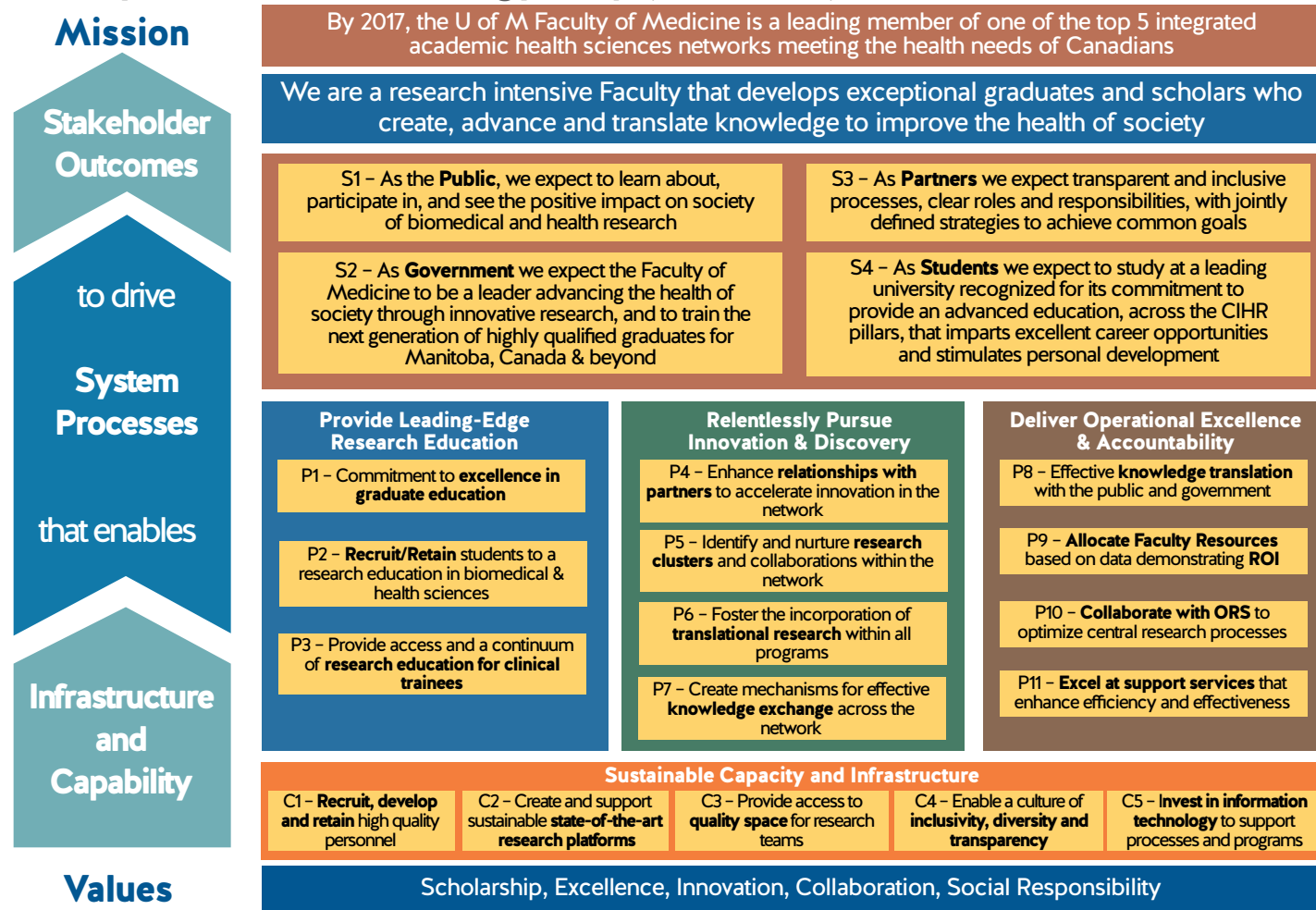
Authentic Engagement and Relationship Building:

1. Provide appropriate resources, policies and procedures to support authentic engagement between University and First Nation, Metis, and Inuit Peoples.
2. Invest in relationship development, from conceptual stage of research project and throughout and beyond project term.
3. Collaborate with First Nation, Metis, and Inuit Peoples on the development of formal mechanisms and bodies to guide and oversee research activities.
4. Integrate two-way knowledge transfer (in which the university and community partners share knowledge with each other and with other stakeholders).

Research Practice:

1. Develop and entrench research processes, practices and research relationships with First Nation, Metis, and Inuit Peoples by providing financial resources to support opportunities for education, training, mentorship, and practical research experience to community members, with a focus on developing next generation of researchers.
2. Develop and entrench research capacity of University by:
 - actively recruiting First Nations, Metis, and Inuit students, researchers, and faculty members;
 - developing relationships with and learning from First Nation, Metis, and Inuit Peoples; and
 - in partnership with First Nation, Metis, and Inuit Peoples, reviewing and revising the Research Ethics process to make it more congruent with the needs and realities of First Nation, Metis, and Inuit Peoples.
3. Share resources, so that partners can draw on each other's expertise, skills, infrastructure, networks and other resources.

Faculty of Medicine Strategy Map (Research)



Contact Information:

Assembly of Manitoba Chiefs Sub Office:

Suite 200-275 Portage Avenue, Winnipeg, Manitoba R3B 2B3 Canada

Phone: (204)956-0610

Toll Free Number: 1(888) 324-5483

Fax: (204)956-2109

<http://www.manitobachiefs.com>

Email: Istar@manitobachiefs.com

The AMC is a Provincial/Territorial Organization comprised of the elected Chiefs of the majority of First Nations of Manitoba. Our Elders from the five language and cultural territories of Cree, Dene, Dakota, Ojibway (Anishinaabe) and OjiCree have guided us: "Research is a relationship based on respect, and it takes time to build trust" (March 2006 AMC Elders meeting on Research Ethics).

The document located at www.manitobachiefs.com under 'Policy Areas/Research/Research Documents/Other' provides information on the three basic conditions for Respectful Research Relationships and includes a draft template agreement suggested for research projects involving First Nations people in Manitoba. In brief, the process for approaching and obtaining organizational support for proceeding with a joint research project is outlined below or you may contact the Assembly of Manitoba Chiefs (AMC) office directly for assistance.

In 2014, the AMC established the First Nations Health and Social Secretariat of Manitoba (FNHSSM), which will include Research Initiatives outlined in this booklet. Further information will be updated through the website: www.fnhssm.com. There will be a Research Orientation requirement for all researchers online through this website in coming months.

RESEARCH PROTOCOL FOR FIRST NATIONS

The Manitoba First Nations Health Information Research Governance Committee (HIRGC) has been an established Research Ethics Committee since 1996, providing oversight to the First Nations Regional Health Survey, and providing ethics review and advice to outside researchers with First Nations. HIRGC reviews research applications and RHS data access requests that involve First Nations at a regional level; the committee does not grant approvals that involve specific individual First Nations or Tribal Councils. Such research partnerships belong to the First Nations or Tribal Councils wishing to be involved. HIRGC is available to recommend presenting a research project idea to individual communities or to one of the seven Tribal Councils, to seek partnership and pursue a research collaboration agreement, which could lead to a letter of support for the research.

Researchers may SEEK ADVICE from AMC HIRGC for any of the following:

1. Advice on undertaking research with First Nations in Manitoba;
2. Advice on how to contact or who to contact about research with First Nations, which may include individual First Nations, Tribal Councils, or Urban First Nation organizations.
3. An application to AMC HIRGC is required if a researcher wishes to access Provincial or Federal databases regarding First Nation regional data. (Note: This is a regulation in the Manitoba Health Information Privacy Act.) Notification to HIRGC is required by UM Ethics Boards when First Nations are a targeted part of a research study (see UM Health Research Ethics Board Guidelines). Application to AMC HIRGC is not required if a researcher has a genuine research partnership and agreement with a First Nation or Tribal Council or other First Nation representative organization.
4. There may be 2 different categories that your research may fall into:
 - A. Research Application that seeks First Nations as partners, or identifies research requesting First Nations data at a regional level.
 - B. Research Application to access Regional Health Survey (RHS) or First Nations Regional Early Childhood Development, Education and Employment Survey (FNREEES) regional data.

Category Application Processes:

A. Application that seeks First Nations as partners, or identifies research requesting First Nations data at a regional level.

PROCESS:

- 1) Researchers complete and submit a formal application to HIRGC (applications found on AMC or FNHSSM Website) along with supporting any documentation (concept paper, grant application, ethics status, etc.)
- 2) Researchers complete online ethics training seminar.
- 3) AMC HIRGC reviews research application based on 3 criteria: a. Free Prior Informed Consent on a collective and individual basis; b. First Nations OCAP principles whereby First Nations have Ownership, Control, Access and Possession of their own data; c. First Nations Ethical Standards. As well, HIRGC assesses relevance to First Nation research priorities, and benefits to the First Nation(s).
- 4) If HIRGC supports the research, a letter of support will be provided, noting the requirements that:
 - (i) The Researcher will report back to AMC HIRGC on an annual basis until research is complete.
 - (ii) Prior to publication or presentation of findings, the Researcher will present a draft to AMC HIRGC for review and approval. The Researcher will invite First Nation partners and/or member of advisory board to co-present at any conferences or workshops
- 5) If HIRGC does not support the research, a notification letter will be provided. The letter may outline why the research is not supported and provide recommendations on how to improve application.

B. Research Application that seeks to access Manitoba First Nations Regional Health Survey (RHS) data at a regional level (E.g.. Diabetes, Smoking, traditional activities, etc. amongst First Nations living in Manitoba).

For more information on RHS or FNREEES, please visit www.fnhssm.com or manitobachiefs.com - see research - and the First Nations Information Governance Centre, of which AMC is a founding member (fnigc.ca).

PROCESS:

- 1) Researchers complete a formal HIRGC application and Manitoba First Nations RHS or FNREEES Data Access Request Form detailing variables of interest (applications found on AMC Website) along with any supporting documentation (concept paper, grant application, ethics status, etc.)
- 2) Researchers complete First Nations online Research Ethics training seminar, outlining the purpose of the project and an identified partnership with First Nations.
- 3) Research Unit reviews and approve the request to ensure availability and feasibility of data analysis. If RHS regional data is available, HIRGC then reviews the Manitoba First Nation RHS or FNREEES Data Access Request form and the process outlined in A is followed.

The rules and guidelines for access to regional RHS or FNREEES data are:

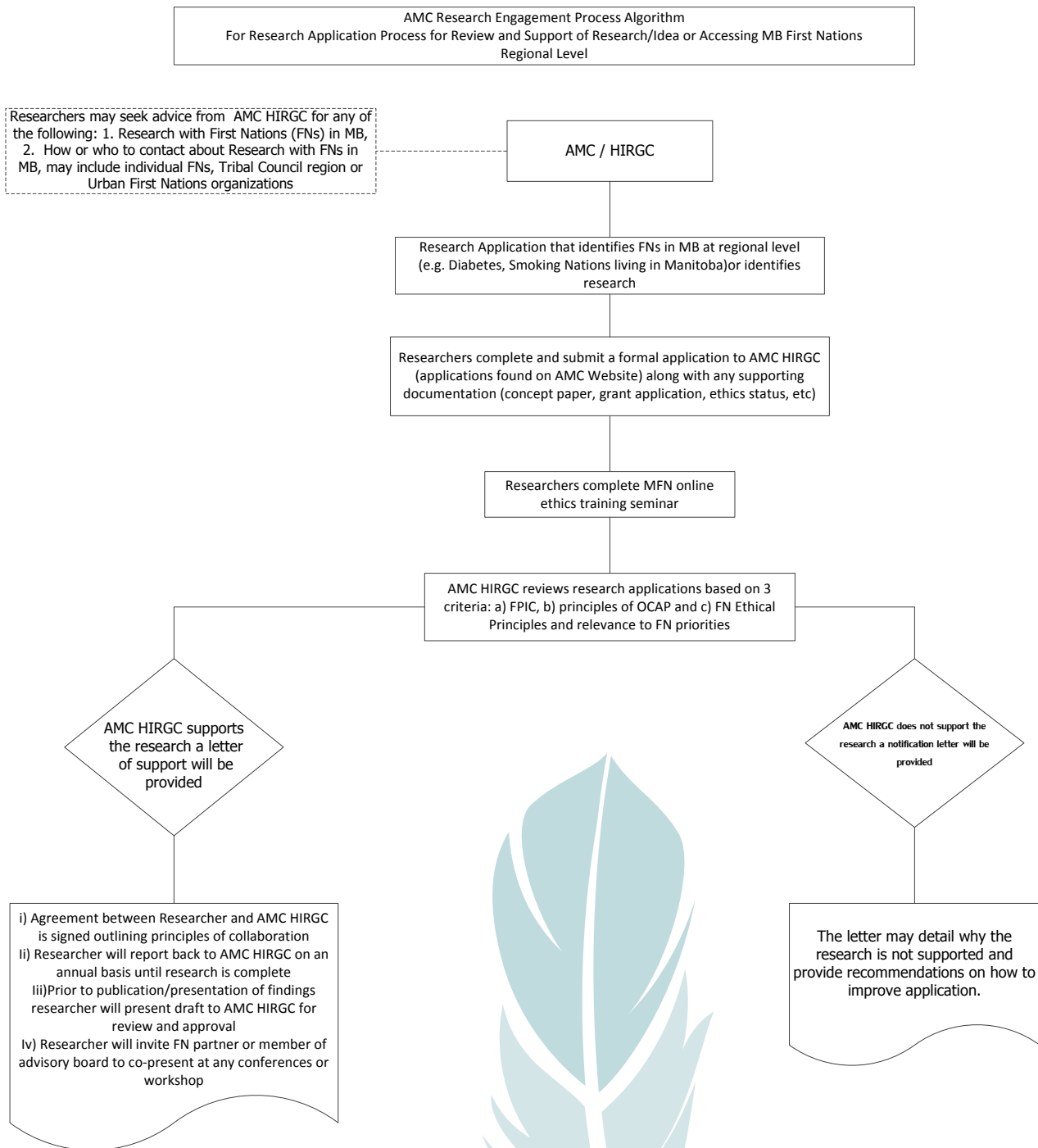
- i) Researchers will work onsite at the MFN Research Centre (locked down computer under the supervision of AMC Research team); researchers leave with aggregated results only in the format of statistical tables. No raw data leaves the MFN Research Centre;
- ii) Researcher will report back to HIRGC on an annual basis until research is complete;
- iii) Prior to publication/presentation of findings, the Researcher will present a draft to AMC HIRGC for review and approval
- iv) Researcher will invite the First Nation partner or member of advisory board to co-present at any conferences or workshops.

Note: If RHS data is not available, feasible or HIRGC does not support the research, a notification letter will be provided. Such letter may outline why the research is not supported and provide recommendations on how to improve the application.

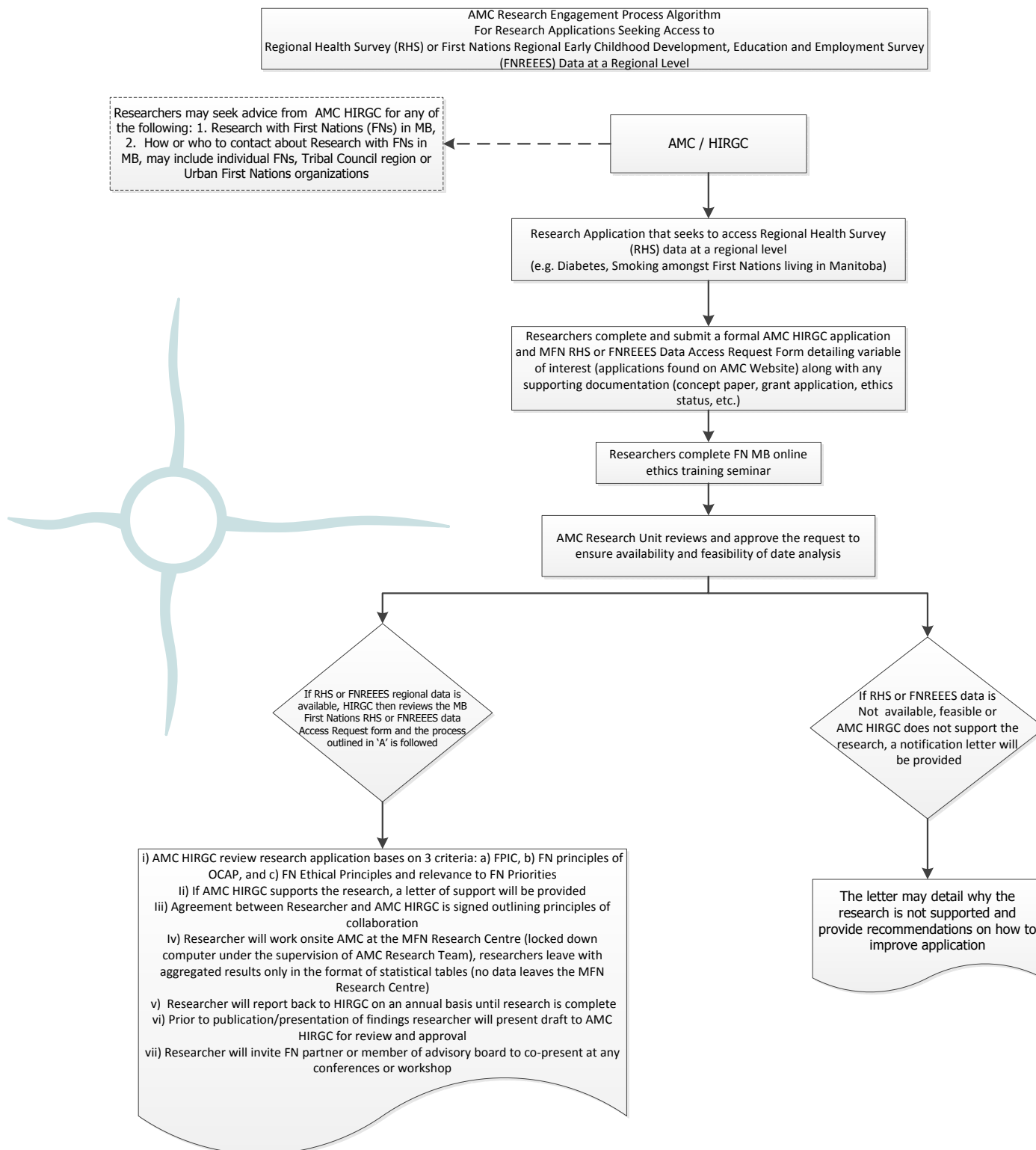
Note: The Researcher and the FNHSSM may sign a collaboration agreement for partnership research. Or HIRGC will outline principles of collaboration this committee may require. However, any such agreement does not replace the need for a research collaboration agreement which may be required by a First Nation or Tribal Council, depending on the focus of the research project.

First Nations Algorithms

A. Research Application that identifies MFNs at a Regional Level



B. Research Application that seeks to access Regional Health Survey (RHS) or First Nations Regional Early Childhood Development, Education and Employment Survey (FNREEES) data at a Regional Level (Eg. Diabetes, Smoking amongst First Nations living in Manitoba)



Appendix 4

Metis Research Protocols

Contact Information:

Manitoba Metis Federation – Health & Wellness Department (MMF – HWD)
300-150 Henry Avenue, Winnipeg, Manitoba, R3B 0J7
Telephone: 204-586-8474
Fax: 204-947-1816
<http://www.mmf.mb.ca>
E-Mail: info@mmf.mb.ca

RESEARCH PROTOCOL FOR MMF - HWD

In order to have successful outcomes for research the Manitoba Metis Federation–Health & Wellness Department (MMF–HWD) believe it is essential to build respectful relationships between researchers and participants. The model used in Knowledge Networks can provide a framework for engagement. For more information on this approach please see Bartlett, J.G., Carter, S., Sanguins, J., & Garner, B. (2012). Manitoba Metis Federation Health & Wellness Department. Use of a Holistic Wellness Framework & Knowledge Networks in Metis Health Planning. CIHR Casebook on Community Engagement. Ottawa ON: Canadian Institutes for Health Research: <http://www.cihr-irsc.gc.ca/e/45358.html>

Ethical Principles for Metis Research:

Ownership – Ownership refers to the legal possession of something. In this case we are referring to the Metis Population Data-Base (MPDB). The Metis Population Data-Base was developed for the Metis Health Status and Health Services Utilization study (Martens, Bartlett et al., 2010) and consists of over 90,000 anonymized individuals.

Control – Control refers to the power to make decisions about something and decide what should happen.

Access – Access refers to the right or opportunity to use something that will bring benefits.

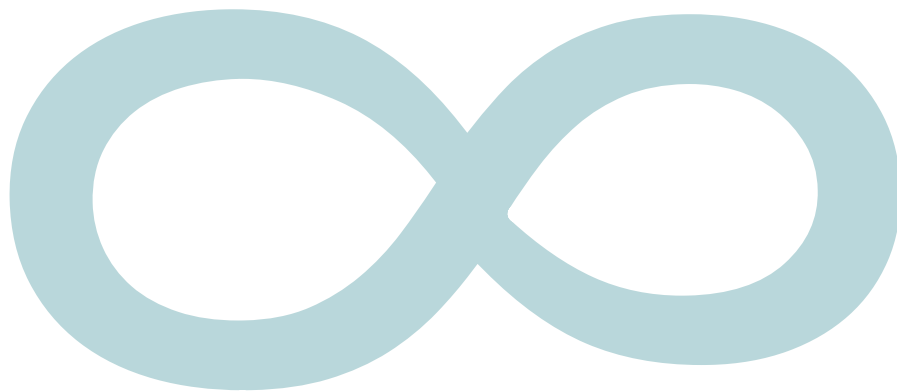
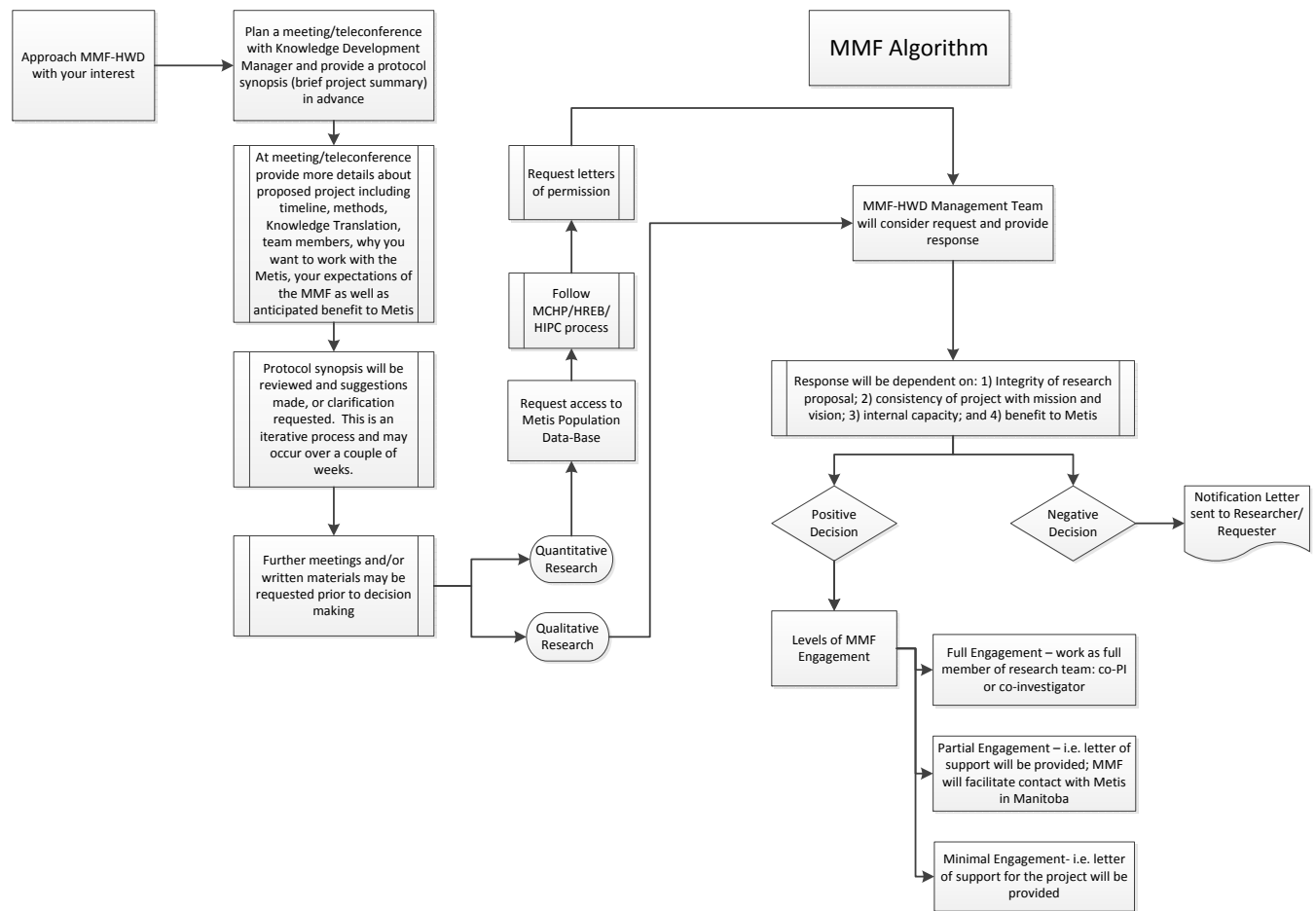
Stewardship – Stewardship speaks to issues of responsible planning and management of resources. We have a responsibility to Metis to ensure that research that is completed is in their best interests, will result in positive changes in Metis health and health service delivery, and is done in as rigorous and ethical manner as possible.

The MMF is a Provincial Organization representing Metis Peoples of Manitoba. Contact Knowledge Development Manager, MMF Health & Wellness Department by phone at 204-586-8474 or email at info@mmf.mb.ca to obtain direct advice and guidance on developing a joint research project with Metis Peoples.

For those wishing to work with MMF–HWD on research projects:

- Approach Knowledge Development Manager with your interest
- Plan a meeting or teleconference with Knowledge Development Manager and provide a protocol synopsis (brief project summary) in advance
- At the meeting or on phone call, provide more details about proposed project including timeline, methods, Knowledge Translation, team members, why you want to work with Metis, your expectations of the MMF as well as anticipated benefit to Metis
- Protocol synopsis will be reviewed and suggestions made, or clarification requested. This is an iterative process and may occur over a couple of weeks
- Further meetings and/or written material may be requested prior to decision being made
- If doing quantitative research and requesting access to Metis Population Data-Base, letters of permission need to be secured and MCHP/HREB/HIPC/researcher agreement processes need to be completed
- If doing qualitative research, letter of support and HREB approval need to be secured
- MMF-HWD Management team will consider request and provide response. The responses will be dependent on 1) integrity of research proposal; 2) consistency of project with mission and vision; 3) internal capacity; and 4) benefit to Metis
- Levels of MMF engagement:
 - Full Engagement – work as full member of research team: co – PI or co-investigator
 - Partial Engagement – i.e. letter of support will be provided; we will facilitate contact with Metis in Manitoba
 - Minimal engagement – i.e. letter of support for the project will be provided
 - No engagement – The project is not consistent with our departmental or organizational priorities at this time
- It is an expectation that researchers conducting research with Metis in Manitoba will acknowledge the support of the President and Board of Directors of the Manitoba Metis Federation, as well as acknowledge research participants in all Knowledge Translation

Metis Algorithm



Appendix 5

Inuit Research Protocols

Contact Information:

Manitoba Inuit Association Inc.
823 Ellice Avenue, Winnipeg, Manitoba, Canada R3G 0C3
Phone: 204-77-INUIT (774-6848)
<http://www.manitobainuit.ca>
Email: info@manitobainuit.ca

RESEARCH PROTOCOL FOR INUIT

Manitoba Inuit Association (MIA) is an organization that serves the Inuit community of Manitoba through social outreach that promotes and enhances the quality of life through programs and services to help orient Inuit to the southern culture and environment. MIA offers programs and support to Inuit who are receiving health care in Manitoba or are attending post-secondary institutions throughout the province. MIA can provide referral information to researchers who wish to conduct research outside of the Manitoba jurisdiction.

Inuit Qaujimajatuqangit (IQ) is a body of knowledge and unique cultural insights of Inuit into the workings of nature, humans and animals. Inuit Qaujimajatuqangit, then, has both practical and epistemological aspects that branch out from a fundamental principle that human beings are learning, rational beings with an infinite potential for problem-solving within the dictates of nature and technology.

The MIA is an organization with an elected board that represents Inuit Peoples of Manitoba. There is the template agreement available for research partnerships with Inuit who reside in Manitoba please contact MIA for more information. The projects that involve Inuit peoples outside of Manitoba please contact the MIA at 204-774-6848 or email info@manitobainuit.ca for assistance in linking you to the appropriate Inuit representative group.

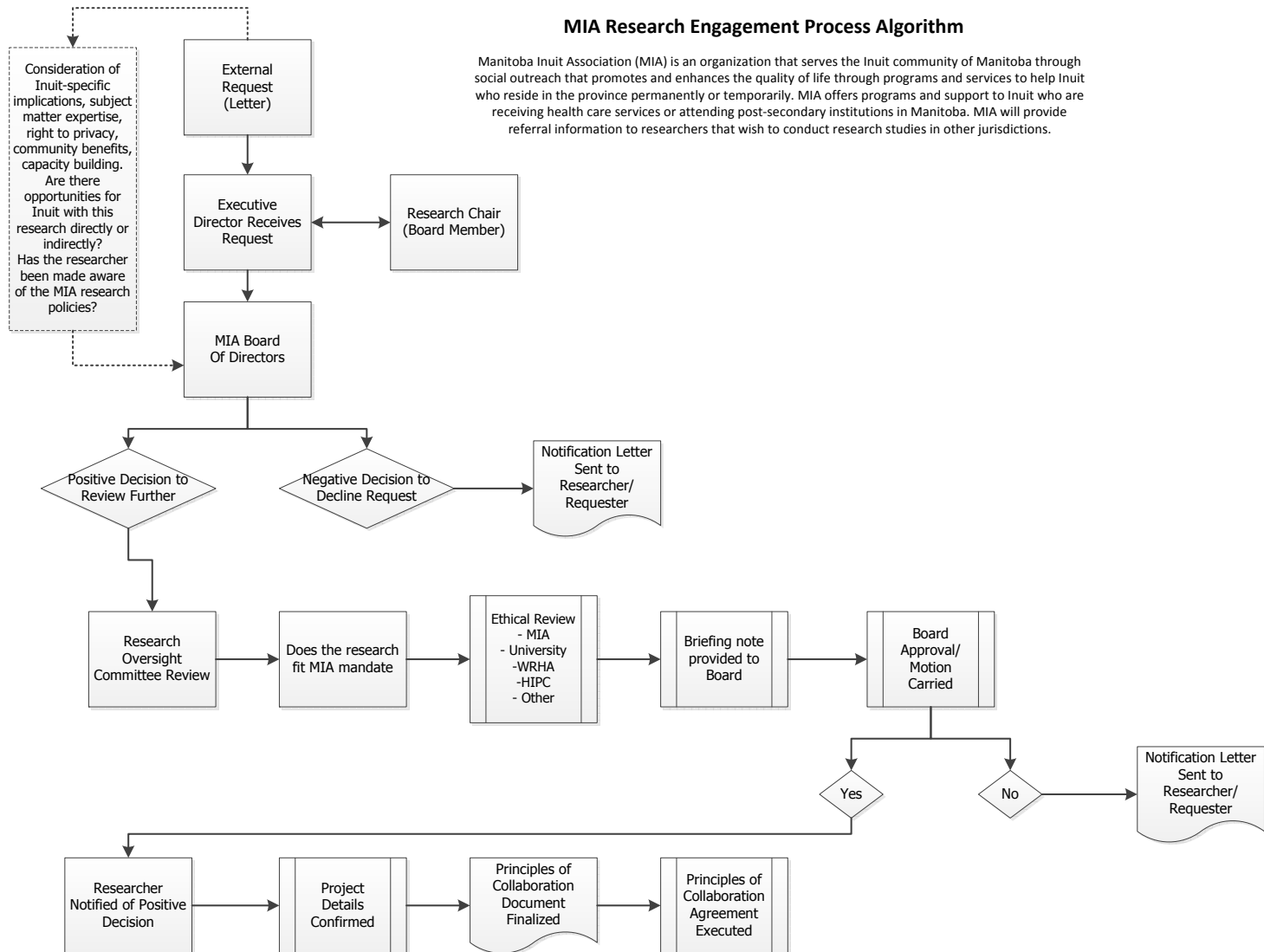
For those wishing to work with MIA on research projects:

- External letter of request providing a synopsis of intended research
- Request forwarded to both Executive Director and Research Chair (Board Member) for review/approval to proceed
- Request forwarded to MIA Board of Directors – the following criteria are reviewed during the above process:
 - Consideration of Inuit-specific implications, subject matter expertise, right to privacy, community benefits, capacity building.
 - Are there opportunities for Inuit with this research directly or indirectly?
 - Has the researcher been made aware of the MIA research policies?
- Following MIA Board of Directors deliberations a decision to approve request for further review or decline the research request will be forthcoming. Notification of negative decision will be sent to researcher/requester
- If the decision is positive the request will be forwarded to the Research Oversight Committee for review
- Does the research fit MIA mandate?
- Ethical review undertaken: MIA, University, WRHA, HIPC and other
- Briefing note to be provided to the Board
- Board approval/motion carried – decision to approve or decline research request made at this juncture –
 - If a negative decision is made a notification letter will be sent to the researcher/requester
 - If a positive decision is determined the following steps will be taken
 - Researcher is notified of decision
 - Project details are confirmed
 - Principles of collaboration document is finalized
 - Principles of collaboration agreement is executed

Inuit Algorithm

MIA Research Engagement Process Algorithm

Manitoba Inuit Association (MIA) is an organization that serves the Inuit community of Manitoba through social outreach that promotes and enhances the quality of life through programs and services to help Inuit who reside in the province permanently or temporarily. MIA offers programs and support to Inuit who are receiving health care services or attending post-secondary institutions in Manitoba. MIA will provide referral information to researchers that wish to conduct research studies in other jurisdictions.







The University of Manitoba is located in Treaty One territory and on the traditional territory of the Anishinaabe peoples and the homeland of the Metis Nation. Our campuses and the historic Forks of Winnipeg sit at the crossroads of the Anishinaabe, Metis, Cree, Dakota and Oji-Cree Nations.

First Nations, Metis and Inuit Health
Room P122 - Pathology Building
770 Bannatyne Avenue
Winnipeg, Manitoba
Canada, R3E 0W3

Phone: 204-272-3167

Email: FNMIH.community@umanitoba.ca

umanitoba.ca/faculties/medicine/fnmi_health/



**Framework for Research Engagement
with First Nation, Metis, and Inuit Peoples**



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