

FOUR ARROWS REGIONAL HEALTH AUTHORITY INC.



prepared for FARHA Health Research and Policy unit

Guidelines for Ethical conduct of Health
Research in Island Lake Anisininew Nations,
Manitoba.

Anisininew Minoayawin Nanandowkendamowin



Recipient

Name: **Alex McDougall, Executive Director**
Organization: Four Arrows Regional Health Authority
Address: 500-338 Broadway, Winnipeg, R3C 0T2
Email: amcdougall@fourarrowsrha.org
Phone: 204-947-2397
Fax: 204-982-3359
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By Dr. Chukwudumebi Onyiuke

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Introduction

Dedicated health research has been mobilized worldwide for the benefit of global public health. This policy summarises the responsibilities, duties, and expectations for health research in the four Island Lake Anisiniw Nations of Manitoba. Health research in Island Lake Anisiniw Nations should align with the needs, values, principles and interests of the region, and must maintain mutual respect and promote cooperation between research teams, leadership and peoples in Island Lake Anisiniw Nations. It should be a partnership-based relationship, not singularly focused on research outcomes that are mainly beneficial to the research community and academia.

The history of research in Island Lake Anisiniw Nations, Manitoba has been fraught with assumed deficiencies, inequities and non-delivery of tangible benefits to the region. Research teams have become notorious for what the Indigenous Peoples describe as, ***“Researching the people to death”***. This guideline provides insight on the requirements for the ethical and responsible conduct of research in the Island Lake Anisiniw Nations region of Manitoba. The Anisiniw Nations have adopted research governance as one of the key nation-rebuilding strategies of the governing council, Anisiniw Okimawin. Four Arrows Regional Health Authority Inc. is the health arm of the governing council, with the responsibility of its program services and the mandate to serve the health research needs of the region.

The connection of past, present and future with the seven sacred teachings (love, respect, courage, honesty, wisdom, humility, and truth) provides a holistic view of how the responsibility to the wellbeing of future generations lies with the present, and directly connects with the legacies of the past. The sacred teachings of the Indigenous worldview also apply to health research in Island Lake Anisiniw Nations. The harmful acts and traumas of colonization, institutionalized racism, and cultural and human genocide were perpetuated by the colonial government and religious institutions. The pervasive colonial influences sabotaged Indigenous autonomy and self-determination. The government disenfranchised Indigenous Nations by the removal of their children to residential schools, forced relocations, resettlement and policy of assimilation, troubling and unethical conduct of research, the maleficent repercussions of the Indian Act of 1867, an unjust Indigenous healthcare structure, and inequitable interpretation of Treaty negotiations.

The malignant effects of this subjugation linger, and have been passed down through generations. The consequences of these colonial government policies, laws and regulations continue to cause untold hardship, untimely deaths and serious health concerns such as chronic illnesses, mental health barriers, infectious conditions, addictions, and food insecurity and lack of sovereignty in the region. Health research has long subscribed to this same path of hegemony.

Island Lake Anisiniw Nations has opened its arms to health research in the region, despite the seeming lack of tangible benefits of this warm welcome to the overall health and wellbeing of the people. This policy provides principles recommended for research conduct in the Anisiniw Nations region. For the intentions of health research to align with the goals and values of the Island Lake Anisiniw Nations, a three-pronged approach may be useful as listed:

- i. Researchers and their work will respect and honour the meritorious heritage of the past Indigenous health practices.
- ii. Research outcomes will safeguard, protect and preserve the present.



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- iii. Researchers' study outcomes should instruct policies and legislation that implement their findings in a way that provides for, and leaves a positively impactful legacy of health and wellness for the future.

The ethical conduct of research in the region will contribute to the body of evidence important for building culturally-appropriate health systems and structures. In Island Lake Anisininew Nations, health research must aim to influence positive policies and health laws that are of meaningful benefit to the research partnership. Such research should be useful and pertinent to the health needs of the region. Health researchers must deploy their study endeavours as a tool for the wellbeing of the Anisininewuk.

Health research in Island Lake Anisininew Nations must adhere to the universal medical credo; **FIRST DO NO HARM**. This guideline is a living document that provides useful recommendations for the ethical conduct of health research in Island Lake Anisininew Nations.

Nanandowkendamowin kawyapatak undowwaywin ekwa mina
kesi monyawach Anisininewuk.





Island Lake Anisiniw Nations

Demographics

Island Lake Anisiniw Nations is made up of four remote, isolated Indigenous Nations sited on Treaty 5 Adhesion territory in Northern Manitoba. There are more than 3000 islands of various sizes scattered all through the lake with a population of about 15,000. The four sub-regions, Garden Hill Anisiniw Nation ($\approx 3,054$), Red Sucker Lake Anisiniw Nation (≈ 872), St. Theresa Point Anisiniw Nation ($\approx 3,417$) and Wasagamack Anisiniw Nation ($\approx 2,088$) comprise the Island Lake Anisiniw Nations region. The Anisiniwuk are said to have migrated from Northern Ontario. The region has the only Anisiniw population in Manitoba and is gifted with artistic talent, eminent lawyers, pilots, teachers, scholars, healthcare providers, language specialists/experts, activists and leaders.

The 3,500 person off-reserve population is expanding even more rapidly. Anisiniwuk can be found in large numbers in Winnipeg. Thompson, Churchill, Selkirk, Steinbach and Brandon also have a number of Anisiniw who are found in institutions of learning. Research teams must be mindful of the urban Anisiniwuk's unique challenges. They face significant levels of inequitable access to health and social services including supportive health care, housing, mental health services and official identity documentation. Four Arrows Regional Health Authority has a dedicated patient navigation team for this purpose.

Elders and family values

The Anisiniwuk are family-oriented and pride themselves on their values and principles. They honour and respect the Elders and defer to the wisdom, experience, guidance and teachings of the Elders and Knowledge-Sharers. More than 70% of the population is younger than 40 years. Often, multiple generations cohabit in the same dwelling. Significant barriers to affordable, safe housing are faced by the Anisiniwuk. Extended waiting times for housing, and mould growth cause unsafe housing conditions. This predisposes them to dermatological and respiratory conditions leading to unnecessary exposure to antibiotics.

Anisiniwuk are very friendly and personable. They are curious about the constant cycle of research endeavours in the region though apprehensive of the value of this research to their health and wellbeing; due to historically traumatic antecedents. They are known for providing assistance and cooperation to researchers and make their stay as smooth as the elements allow. Health researchers can attest to their hospitality and generous spirit and there is always a warm, welcoming smile to visitors, and an invitation to share their meals with them and partake in feasts and other cultural events. While payment is not demanded of researchers, it is fair to compensate research partners for the time and labour of research in a substantively equitable manner. Prices of commodities and utilities tend to be way higher due to limited access which includes factors like isolation and remoteness.

Transportation

The region is accessible during the long winter months by a winter road. In warmer weather, there are scheduled flights. There is currently no designated water transport system from Winnipeg due to the geographical lack of access. Causeways and portage transport are laborious and cumbersome to maintain. Anisiniwuk who are ill or pregnant are flown to Winnipeg to access health services and to



give birth. This frequently creates prolonged separation from their homes, loved ones and familiar surroundings. This is very difficult when the primary caregiver or provider must be away from home. Language barriers and culture shock may further compound the loneliness and confusion that complicate poor health and systemically racist health care services. They are domiciled in unsavoury accommodations and exposed to pests like rodents, cockroaches and bed bugs, crime, and illegal access to alcohol and recreational drugs. They are at high risk of being targeted for abductions and kidnappings, hence, the high numbers of missing and murdered Indigenous persons, especially women and girls. The pests can also be transported back to their homes in their luggage, worsening the housing crisis.

Land-based living

Garden Hill Anisiniw Nations is known for its flourishing gardens. The other three sub-regions are more engaged in fishing, hunting for food, and trapping fur-bearing animals. All four Island Lake Anisiniw Nations sub-regions collectively operate a poultry facility in collaboration with the Kimeechiminan Food Security program initiative by Four Arrows Regional Health Authority Inc. The program introduced family plots for communal gardening and fish-farming.

Researchers should be well-acquainted with the importance of these land-based activities to the health and wellbeing of the people. They must acknowledge the role of the colonial governments' forceful removal of access to these activities in the epidemiology of disease and ill health in the region. There is a Northern store retail franchise in each sub-region with smaller outlets for confectionaries and such, run by families and individuals in the community. Researchers should be aware of the pricing inconsistencies and likelihood of extended shelf presence of the commodities. Potable water supplies may sometimes be contaminated by sewage and groundwater. Researchers should adequately prepare their own food and drink supplies. Health researchers must note these lapses while documenting the epidemiology of ill health in the region. Study recommendations must drive policy that improves the provision of basic amenities and infrastructural development in the region.

The seven sacred teachings are the guiding principles of the four Anisiniw Nations.

Love | Respect | Courage | Honesty | Wisdom | Humility | Truth

Festivals and Religious events

Researchers may find information about festivals and events useful for the purposes of planning. In general, the winter road is not accessible in early and late winter as the ice may not support the weight of automobile traffic. Anisiniwuk may not be available in sufficient numbers to participate in research during the September hunting and trapping season.

Garden Hill Anisiniw Nation has summer and winter activities. During the winter Ministic Carnival, events like skidoo races, cowboy singing contests, beauty pageants and other races are held. **Red Sucker Lake Anisiniw Nation** commemorates the annual period when they historically waited by the Wapisii river as it thawed to allow them passage across it, following the hunting and trapping season. While they waited to go back to their homes in the Island Lake Anisiniw Nations territory, they engaged in teaching camps. During Wapisii, they are engaged in teaching and learning activities. It is an opportunity to reflect on the sub-region's programs and activities and incorporate useful strategies from the invited



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speakers and guests at the event. There is a predominance of elder teachings and religious activities over the traditional ceremony, and the opportunity to fraternize with the rest of the community is celebrated.

St. Theresa Point Anisininew Nation's Bannock Festival occurs annually, in combination with the Treaty days, at the end of June to the beginning of July. It is 5 days of games, traditional events, boat races, and the Ironman/maiden competition. This competition is a composite of several tests of athletic prowess including running, swimming, biking, and jumping. **Wasagamack Anisininew Nations** holds the Metaway event that takes place in early August alongside its Treaty days. Notable activities include slingshot contests, archery and traditional drumming and singing. Researchers can experience the vibrant culture and energetic bustle while sharing in traditional food like moose, berries, and duck soup if they visit at these times.

St. Theresa Point and Wasagamack are predominantly Catholic with a combination of Christian fundamentalists and traditionalists. Red Sucker Lake and Garden Hill are dominated by the United Church, Pentecostal and fundamentalist religious beliefs, with a sprinkling of traditionalists gaining more acceptance, post-colonization. Researchers must be mindful of these variations and respect the values, beliefs and ways of living unique, to each sub-region.

In the last two weeks of September, and sometimes into early October, there are cultural events taking place in all four sub-regions. Researchers should clarify scheduling conflicts, the availability of research partners, and their commitment to participation, to avoid disruptions to their research schedule. Bingo and draws are popular community activities that foster camaraderie and research relationships.

Governance

The governing body in Island Lake Anisininew Nations is the **Anisininew Okimawin**. It is led by the elected Grand Chief with a Grand Council comprised of each of the Chiefs and their Councils, from the four sub-regions. Four Arrows Regional Health Authority Inc. is the health arm of this body. Each of the four sub-regions has its own band council and leadership structure. Leadership oversees governance, child and family care, education, health and social services, land and water resources. The leadership councils are guided with the overarching objective of providing progress, development, wellness and prosperity for all. Each sub-region has its individual school and nursing station, education and health authority, child and family services, tv station, housing, water, and sewage facility, and a northern store for retail services.

The Grand Chief election is after three years and every four years thereafter. Elections in Red Sucker Lake and Garden Hill are biennial, but every four years in Wasagamack and St. Theresa Point Anisininew Nations. Researchers must establish a partnership with Island Lake Anisininew Nations leadership prior to initiating research. They must seek the permission and commitment of the people to visit and carry out studies.

Health

There is a nursing station in each of the four sub-regions and a dialysis facility in Garden Hill. Health researchers may benefit from collaborating with the services provided in the nursing stations. They will have a baseline idea of what health services are supported by the infrastructure in the region. Health



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research must support the longstanding call-to-action to federal and provincial governments by Leadership in the region. Proposals to provide healthcare infrastructure and develop commensurate manpower for an Indigenous health force to serve the health needs of the growing population in Island Lake Anishinew Nations have met with limited success. Researchers are urged to use their influence to advocate for enhanced healthcare delivery, Indigenous capacity development and infrastructural expansion in the region.

Four Arrows Regional Health Authority Inc. (FARHA)

The organization was incorporated in December 2001 under *The Public Health Act* of 1994 and *Provincial Health Authority Act* of 2017 by which health authorities can reach agreements with a Band council. Since 2003, FARHA, an Indigenous health organization, has served as the health arm of the Island Lake Anishinew Nations, under the governance structure of Anishinew Okimawin. It was selected by the Assembly of First Nations as one of the three sites for public health services in Manitoba First Nations in 2006. FARHA works in cooperation with community health services to improve health outcomes for the Island Lake Anishinew Nations region.

Mamow Anishinew Minoyawin

FARHA's activities are overseen by a board comprising distinguished members of the region with guidance from the Elders' Advisory Council. Under the dynamic leadership of its Executive Director, an enterprising senior management team of directors supervises its diverse, talented, creative, industrious and hardworking staff. Board members include Anishinew Nations Health Authority directors and Chiefs, and health portfolio Councillors.

FARHA supports home and community care services in Anishinew Nations with the following programs and services.

- Community Health
 - Aboriginal Diabetes Initiative
 - Canada Prenatal Nutrition Program
 - Children's Oral Health Initiative
 - Food Security
 - Foot care
 - Harm reduction
 - Home and community care
 - Jordan's Principle
 - Public health
- The Tribal Nursing Officer is responsible for:
 - Maternal care
 - Communicable disease control
 - Prevention and awareness
 - Healthy lifestyle
 - Injury prevention
 - Community support
- Regional programs
 - Wellness and health program including a clinical mobile crisis unit
 - Kimeechiminan food security
 - Renal program – dialysis



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- Manitoba Mobile Addictions Team to Increase Community Capacity and Access (MMATICCA)
- Opioid Agonist Therapy Program (OAT): Red Sucker Lake
- Health innovations
- Emergency medical response regional training
- Medical transport and communication
- Health research and data-sharing

Four Arrows Health Research and data-sharing unit provides direction on the ethical conduct of research in the region. The mandate to guide acceptable conduct of research was endorsed by leadership following recommendations from Anisininewuk perspectives in research partnerships. FARHA will provide templates for signing the research partnership agreement, data-sharing agreement, study summary, and a research policy. Where access to personal information, health and administrative data is required from the Manitoba Centre for Health and Policy, Indigenous and Northern Affairs, Manitoba Health, Shared Health and other Indigenous data, FARHA will invite researchers to submit an ethics application, in consultation with the Health Information Research Governance Committee (HIRGC) of the First Nations Health and Social Services Secretariat of Manitoba (FNHSSM) for approval.

Anisininewuk Elders and Knowledge-Sharers in research

Anisininew Nations Elders and Knowledge-Sharers are the custodians of the region's knowledge, wisdom, teachings, values, principles, language, customs and tradition. They have come into positions of honour and reverence due to their years of deep learning and immersion in the Anisininew ways of knowing and being, and their years of lived experience and connection to the land.

Anisininew Elders are characterized by their core values of truth, honesty, humility, respect, understanding, love, flexibility, patience, tolerance and acceptance. They share this knowledge freely, providing guidance and direction with no expectations of recompense. They provide leadership during times of crisis, conflict, and uncertainty. While they do not self-proclaim as Elders, Anisininew Nations Elders are prominently recognized and held in highly esteemed positions of authority. Health researchers in the Anisininew Nations region should make no assumptions and must always ask to be referred to Elders. Each sub-region is unique. Health researchers should endeavour to get acquainted with the different cultural characteristics, well before the need to invite the Elder arises.

The participation of Anisininew Elders in research should be greeted with gratitude, respect and honour. Researchers must avoid tokenism and extending symbolic gestures without the proper context. They should apply the proper cultural etiquette relevant to each Anisininew Nations sub-region in all dealings with Anisininew Nations Elders. Researchers must have Anisininew Nations Elders and Knowledge-Sharers participating in the Elder Advisory group, and patient advisory group to ensure a balanced perspective, and optimized research outcomes for the region. FARHA will provide a template for providing honoraria that factors in the time, expertise and inconvenience to the Anisininew Elder and Knowledge-Sharer. Researchers should ensure that information about research activities is provided to the Elders in a clear, concise and easily understood manner, avoiding technical jargon and obfuscations.



Purposive Indigenous research in Island Lake Anisininew Nations

Strengths-based approach to research

Health researchers must adopt a strengths-based narrative that is respectful of the ways Anisininewuk have dealt with longstanding health inequities. Health research must take into account and be cognizant of the harms and traumas of the past. The social determinants that evidently shape structural health inequities in the region compared to non-Indigenous health services must be factored into the research narrative. Researchers must acknowledge and affirm the true nature of the epidemiological basis of the health status of the Anisininewuk. Research should acknowledge the role of colonialism, forced relocation and displacement, forceful removal of children to the residential school system, and the policy of forceful assimilation, on the overall health status of those in the Anisininew Nations region. Research instruments should be culturally-relevant to inform high quality outcomes. Researchers must be careful to avoid the biases of a Eurocentric worldview, and make reasonable effort to do research that is culturally relevant to the Anisininewuk.

Truth and reconciliation

Health research has a powerful role to play in truth and reconciliation. Research in Island Lake Anisininew Nations should aim towards lending its voice to Indigenous narratives that have long been silenced. It has the responsibility to address the question, “**WHOSE TRUTH**”. Here the truth stands for research that is safe, useful, relevant, culturally appropriate and designed to meet the health and wellbeing needs of the Anisininewuk. The research premise should be designed, developed, investigated and concluded in ways that truly validate Indigenous health concerns.

- i. Where social determinants of Indigenous health are demonstrably associated with inequitable health indices, research studies must emphasize this.
- ii. Research studies should not imply genetic causation and correlation to the Anisininewuk due to the historical potential to perpetuate racist and discriminatory stereotypes. Such findings may bear negative connotations to the heritage and identity of Anisininewuk with unpleasant and/or harmful consequences to them. According to The Universal Declaration on the Human Genome and Human Rights, ratified in 1997, prior, free and informed consent for research participants (Article 5b) is important. “No research or research applications concerning the human genome, in particular in the fields of biology, genetics and medicine, should prevail over respect for the human rights, fundamental freedoms and human dignity of individuals or, where applicable, of groups of people” (Article 10). Genomic research must respect and acknowledge the rights to participation. Such research must be executed with integrity and respect for social, cultural, religious and spiritual values.
- iii. Health research must be tailored towards policy that provides high-quality, accessible, available and affordable health care that is substantively equitable to the care available to other non-Indigenous Canadians in the spirit of truth and reconciliation.



Beneficence

Health research in Island Lake Anisininew Nations should demonstrate a clear pathway for ways it can provide tangible and impactful benefits to the region. These benefits include but are not limited to:

- i. Measurably improving the health and wellbeing of individuals and families in the region, generally, and more specifically, the public health concern the research wishes to address.
- ii. Building the capacity, knowledge-base and technical know-how of the people in ways that enhances the holistic use of research in wellness.
- iii. Instructing Indigenous policy initiatives that are instrumental to the health, wellbeing, success and prosperity of the region. Health research in the region should be directed towards a felt need, as established by the region. The research should therefore demonstrate how it will champion policy that will address the need for the wellness benefits of the region. Where the research has uncovered traumas, harms and injustices, it should take the necessary steps to publicize these and initiate a conversation to address reconciliation. Research findings that can assist efforts by the region to lobby the federal and provincial governments, raise funds and attract impactful stakeholder engagement in the region should be deployed in this way.
- iv. Providing fair, just, and substantively equitable compensation for participation and assistance in health research in Island Lake Anisininew Nations. This compensation is presented in a form that honours the time, labour and effort of the research participants.
- v. Recognizing and acknowledging the role of Indigenous wisdom, experience, knowledge, perspectives, ways of knowing and being in the health research. For example, stating the contributions of Knowledge-Sharers in academic citations included in the research publications, inclusivity and participation in research conferences and plenary discourse.

Inclusivity: Nothing about Anisininewuk without Anisininewuk

Health research should integrate meaningful teachings and knowledge intersecting Indigenous and non-Indigenous principles. Research teams should create opportunities and spaces where these different knowledges coexist and aid easy collaboration of Indigenous Knowledge-Sharers within their academic and institutional settings. Health researchers should create spaces where Indigenous feedback is prioritized for Indigenous policy and legislation to create a strengthened, more robust Indigenous health system. This collaboration will contribute in great measure to undoing the harms of paternalistic and colonial approaches to health research and service delivery.

Sovereignty, nationhood and self-determination

Health research in the Island Lake Anisininew Nations should not serve to further amplify European sovereignty over Anisininew Nations lands and peoples. Its focus must always be directed towards advancing respectful nation-to-nation relationships and conciliation over past harms and traumas to Indigenous Peoples. Research must always acknowledge, affirm and implement the unique rights, interests and circumstances of the past. Anisininewuk will exercise



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ownership, control, access, and possession of their health research data as right to self-determination, autonomy and sovereignty.





Impacts and benefits agreements for Research in Island Lake Anisininew Nations

Fiduciary duties for researchers

1. Research study groups will meet with Island Lake Anisininew Nations leadership and stakeholders in the region and elsewhere, including urban centers. At the initial meeting where a fresh research study, sub-study or additional study is being deliberated upon, the research team should present and justify their research intention. The research team is obligated to determine, recognize, acknowledge and network with stakeholders to form relationships that will be mutually beneficial for optimal research outcomes.
2. The details of the research will be clearly spelt out from the beginning of the research.
3. Researchers must demonstrate ways their study will provide tangible benefits to the Anisininew Nations.
4. Researchers must complete and sign any partnership agreement, data-sharing agreement, research ethics guidelines, and privacy policy, provided by the Four Arrows Regional Health Authority Inc., prior to commencing research that involves the Anisininewuk in the region or off-reserve.
5. Researchers must get ethical approval prior to accessing Anisininew Nations personal information, personal health information or administrative data.
6. Researchers are obligated to undertake cultural training to acclimatize themselves with the Anisininew Nations values, beliefs, culture, tradition, and way of life. This is necessary to ensure that the research is carried out in a culturally-safe, secure and relevant manner.
7. Researchers must use the opportunity of their partnership to train and build local capacity in the Anisininew Nations population.
8. Research informed consent process is iterative and takes place in every instance where consent is imperative in research activities. Researchers must demonstrate a clear, informed consent process.
9. Researchers should identify, recognize, and acknowledge Indigenous ways of knowing and being, oral histories, and wisdom and contribution of Elder and Knowledge-Sharers.
10. Researchers' activities should not impact the resources, environment and wildlife in a negative or harmful manner.
11. Researchers must consult with the region's research partners during all stages and at all levels of health research conducted in the region. For example, research instruments should be discussed extensively to ensure that the research drives a narrative that is strengths-based, without a deficit or weakness-based slant. The narrative should be relevant to the Indigenous culture, language, tradition, lifestyle, ways of being and knowing in the region. Extensive consultation to incorporate the wisdom, knowledge, experience and Indigenous worldviews of Elders and Knowledge-Sharers from the region is recommended.
12. The research team has the responsibility to communicate periodically with the leadership, stakeholders, individuals and families in the Anisininew region about the progress, development and findings of their health research. Access to published versions of the research will be made available to the Four Arrows Regional Health Authority senior management team and ILAN leadership in the spirit of OCAP™. Island Lake Anisininew Nations ownership and control of



dissemination of research data and publications is foundational to ethical and equitable Indigenous research.

13. Research teams will make project updates available as follows, or on demand:
 - i. The Board, Four Arrows Regional Health Authority, Winnipeg – Biannually
 - ii. Anisininew Okimawin Governing Council – Annually
 - iii. Leadership in all four Anisininew Nation sub-regions – Annually
 - iv. Periodic updates to Anisininewuk research participants, stakeholders and partners - Quarterly
14. The Anisininew Nations region reserves the right to decide how research materials, data, records and specimens collected from the research participants will be used, stored or destroyed at the stipulated end of the research. The decisions on the fate of the research materials, data, records and specimens collected from the research participants must be clearly stated and agreed upon by the Island Lake Anisininew Nations.
15. Researchers should provide honoraria of \$25 to each participant at each contact of research activity. For example, the stipend should be provided prior to interviews, focus groups, filling of research surveys and questionnaires, etc. This is a token of appreciation to each participant for their time investment. It is presented as cash, or gift cards redeemable in the Island Lake Anisininew Nations region for local participants. It is a polite gesture, in lieu of coffee, that could have been provided during this encounter regardless of the person, status or position. For off-reserve participants, this is provided as cash or gift cards that are redeemable at available retail outlets.
16. Researchers are encouraged to sponsor, host and participate in cultural events to nurture the research partnership and enhance cultural understanding. These include regional festivals, bingo, draws, feasts, sporting events and activities, annual festivities, sharing circles, etc.
17. Research teams must constitute an Elder Advisory Group (Elders and Knowledge-Share partners in research), and Patient Advisory Group (patient-partners in research). They should make every effort to include Anisininew Nations Elders, Knowledge-Sharers and patient advocates in these advisory groups.



Research Protocol recommended for Island Lake Anisininew Nations

Study justification

Researchers should justify their project. They should explain why it is useful to carry out the study in Island Lake Anisininew Nations territory. They should elaborate on antecedents of the study, related studies, their previous research involvement in the region, and any other concomitant studies.

Researchers should demonstrate the relevance of the study to the needs of the region, and how the study differs from other studies to avoid unnecessary repetitions of the same underlying concerns.

They should provide evidence of the ways the research will yield tangible benefits to the region.

These do not include any form of personal inducements to participate. They should provide reliable information on the risks and potential harms to research participants.

A Band Council Resolution (BCR), and/or letter of approval will be provided by Anisininew Leadership and Health Directorate. FARHA will provide partnership agreement, data-sharing agreement, study summary template, privacy policy and research guidelines. Ethics approval from HIRGC will be requested for access to personal information, personal health information and sensitive administrative data.

Study methods

Researchers should provide details about their study funding. They should explain how they will obtain approval from Anisininew leadership, research partners and stakeholders, and their ethics approval process.

Researchers should describe the methodology in clear, concise terms and simple language. The information should include the research sampling criteria with reasons, the duration of study and time commitment required from participants. They should define their expectations of research involvement, and receive feedback from the region. Every effort should be made to ensure that there is proper understanding of all the activities, including the use of clear, concise language, graphical representation and translators. Where the researcher provides clinical or other health services to the region, they will differentiate this from their research work in a just and equitable manner and avoid conflicts of interest or abuse of power and privilege. The research team should demonstrate justification for its study that aligns with Anisininewuk needs, not just the convenience of carrying out research in the region.

During recruitment, the researcher should make use of traditional media in the region to announce their research intention and advertise locally using the approved media stations, newsletters, digital media and bulletin boards. Adequate steps to maximize participation should be explored in an acceptable manner and in collaboration with Anisininew leadership and stakeholders. Researchers should provide adequate information to enable participants to make informed decisions during all stages of the research. This includes information about:

- The objectives of the research.
- Recruitment process.
- The time commitment involved in participation.
- Clinical treatment or research procedure.



- Clinical treatment and supportive management provided for adverse research outcomes.
- Benefits and risks of research involvement.
- How the benefits will be provided to the participant and the region.
- Steps taken to mitigate coercion, and the harms and risks of research.
- Alternatives to participating in research where clinical treatment is provided.
- Procedure to refuse or terminate participation and the consequences of such refusal.
- Provisions that will be made in the event of adverse outcomes to the participant during research.
- The use of biological and non-biological data, describing steps to protect and preserve biological privacy and confidentiality.
- The fate of this data after the study, including ownership, control, access and possession.
- The outcome of the data and any incidental findings.
- Persons to whom the data will be disclosed.
- Information about research products, publications and events.
- Information about sponsorship and hosting of cultural activities that improve research partnerships.
- Contact details of the research team.
- Financial considerations that will benefit the Anisininew participants and the region.
- Other inquiries that the regional participants are entitled to know.

Study Data

The researcher should explain what data is to be collected and how it will be used. The ownership, control, access and possession of the data should be clearly defined. The way the data will be stored, and the steps taken to protect it, as well as the ways any other data that is linked to this primary data is used, should be defined. The ways the data will be handled and analyzed, and interpretations of the data should be provided in simple, clear, concise language. Every effort must be made to avoid misunderstanding and misrepresentation. Anisininew Leadership and stakeholders must be involved in these discussions to ensure that the research narrative is found acceptable, and is accessible to the population it serves. The data is to be relayed in a form that is understood by all, employing translators and technical assistants where necessary.

Researchers should describe the data-reporting process, taking care to acknowledge the contribution of Indigenous experts, Elders and Knowledge-Sharers. The language of the data must be from a strengths-based narrative, avoiding deficit-dense depictions of Anisininewuk. Researchers should provide all data-publication and dissemination information.

End of Study

The research team must provide end-of-project updates. There must be no rolling over to another study, sub-study or additional study without the consent of Anisininewuk Leadership and stakeholders. The reports should be in oral and documented form with summaries made available in approved outlets like the local newsletters, bulletin boards, digital media and traditional media outlets.

At the end of the study, Anisininew Nations will inspect and examine the information gathered from the study, and presented to them. Their views and concerns are to be prioritized in a manner that ensures the research results will be relayed in a culturally safe and secure form. The research narrative must be



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acceptable to the Anisininew Nations leadership and maintain a high fidelity to accuracy and research facts.

Researchers must avoid commercial exploitation of research data without agreement and robust negotiations with the Anisininewuk Leadership, and research stakeholders. The end of the study provides an important opportunity to demonstrate and actualize the tangible benefits of the research to the Anisininew Nations. Researchers should explain how the study has provided measurable training and development of Anisininewuk capacity, improvement in healthcare infrastructure, and enhancement of service delivery to the region. Researchers should detail the advocacy benefits of their research and ways the research can instruct government policy or Indigenous health legislative options in a positive way, for the Anisininew region.





Conclusion

Health in Island Lake Anisiniw Nations should be a partnership between the researchers and the people for whom the research is meant to benefit. Researchers should acknowledge and recognize the ways Indigenous worldviews, principles and values can enrich and augment the researchers' expertise. Island Lake Anisiniw Nations Leadership, Elders, families, individuals and other stakeholders must be consulted by researchers prior to initiating research, and at all critical research decision levels, and informed consent obtained from them. Collaborating in this way ensures that the narrative and research outcomes will represent the health needs and priorities of Island Lake Anisiniw Nations.

The longstanding health inequities and harms from unjust, racist health systems experienced by Indigenous Peoples in Island Lake Anisiniw Nations can be halted and reversed. The time is long overdue to disengage health research from the antecedents of health/medical racism. This is possible where health researchers partner with the people and agree on respectful and ethical ways to conduct research that is mutually beneficial. Understanding the Indigenous worldview provides researchers important insight into the ways of being and knowing from the past (that mould the present), and can transform the health outcomes of the future generations of Island Lake Anisiniw Nations Peoples. Research should be meaningful, ethical and instructive to health programs, methods and goals.

**By Anisiniwuk
For Anisiniwuk
With Anisiniwuk**





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APPENDIX A

STATEMENT OF INTEGRITY AND COMMITMENT TO ETHICAL CONDUCT OF RESEARCH IN ISLAND LAKE ANISININEW NATIONS, MANITOBA

I hereby certify that the information presented in my research intention and documentation is accurate, complete, and honestly presented. I certify my commitment to the highest standard of ethical conduct while carrying out research activities in Island Lake Anisininew Nations, Manitoba, and with the Anisininewuk in on-reserve and off-reserve populations.

I authorize Four Arrows Regional Health Authority Inc., Winnipeg to verify any aspect of my documentation. I understand and agree that any inaccurate information, misleading information, or omission will be cause for the rescission of any offer to partner in research, or legal proceedings, if discovered at a later date.

This application is my own honest statement to Four Arrows Regional Health Authority Inc., Winnipeg, Manitoba.



Signature of Research Lead

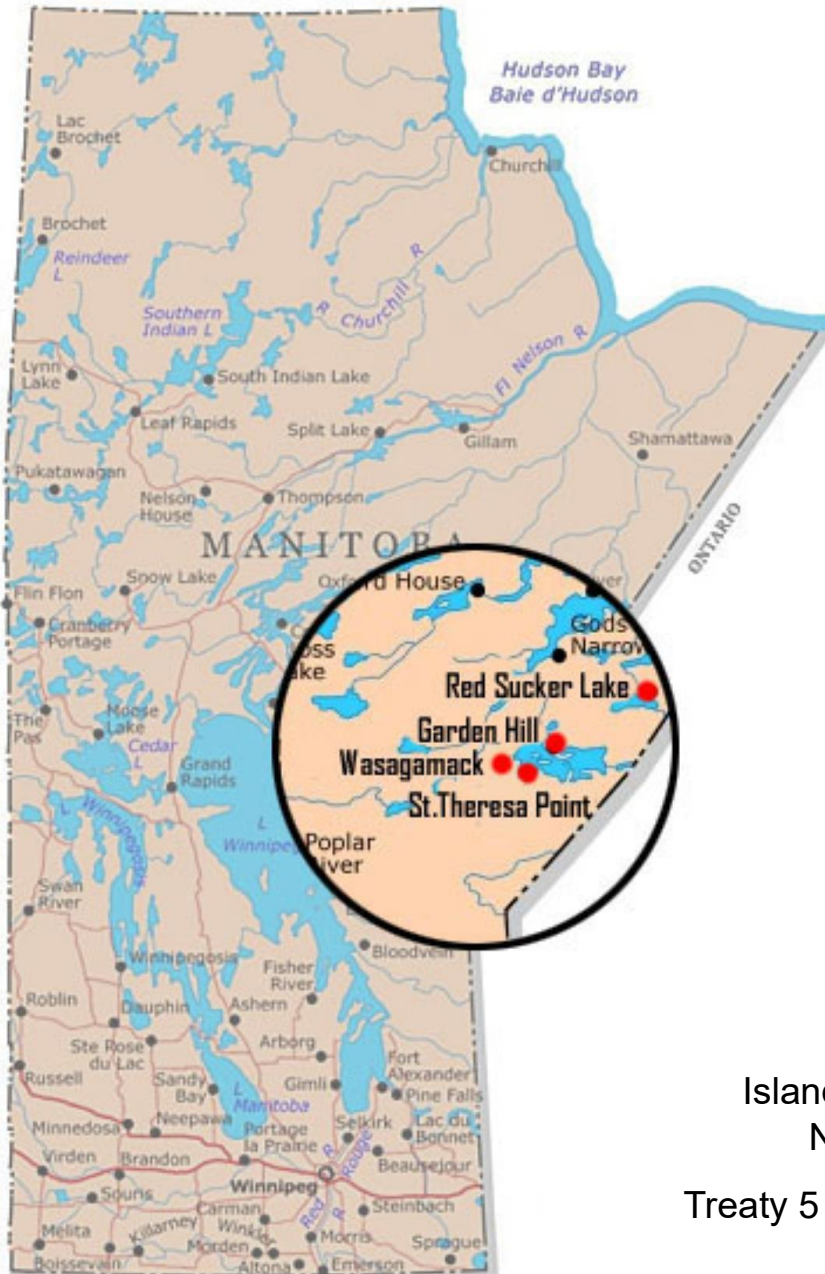
Date

Signature of Witness

Date



APPENDIX B



Island Lake Anisiniw Nations, Manitoba.
Treaty 5 Adhesion territory



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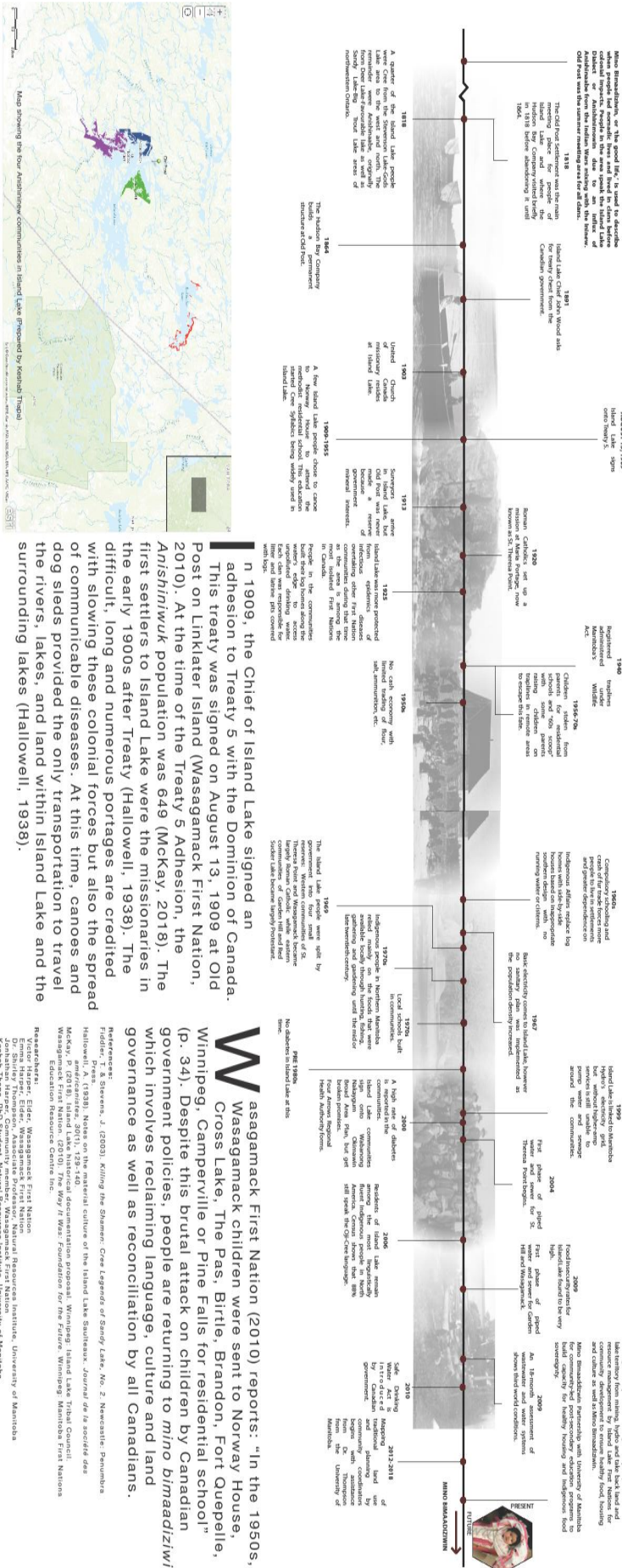
An Anishiniw Timeline of Island Lake, Manitoba, Canada

APPENDIX C Historical Timeline of Island Lake Anishiniw Nations, Manitoba, Canada Treaty 5 Adhesion territory

<https://docslib.org/doc/729226/an-anishiniw-timeline-of-island-lake-manitoba-canada>

This timeline displays the oral history of Island Lake, Manitoba, as well as other Elders from Island Lake region. The *Anishiniwuk* in Island Lake are united by language, culture, family relations, and geography. All the four *Anishiniwew* communities -- Garden Hill, Red Sucker Lake, St. Theresa Point, and Wasagamack First Nation -- were originally part of the Island Lake Band, sharing one Chief at the time of Treaty in 1909 until 1969 (Wasagamack First Nation, 2010).

Island Lake's history is unique. Being in a remote region of the boreal forest, the territory has old growth forests, pristine lakes and *Anishiniwew* who fluently speak their language and expertly participate in traditional land uses. Language, Elders, ceremonies, and *nopimink* (land-based education) continue to animate Indigenous knowledge systems, providing people with a strong cultural foundation in a territory having ecological integrity. Before planes, the location was described as being as remote as the North Pole (Fiddler & Stevens, 2002). From Norway House to Island Lake required portaging more than 30 times, and canoeing for more than a week (Hallowell, 1938).



Wasagamack First Nation (2010) reports: "In the 1950s, Wasagamack children were sent to Norway House, Cross Lake, The Pas, Birtle, Brandon, Fort Quappelle, Winnipeg, Camperville or Pine Falls for residential school" (p. 34). Despite this brutal attack on children by Canadian government policies, people are returning to *mino bimaadiziwin*, which involves reclaiming language, culture and land governance as well as reconciliation by all Canadians.

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Dr. Shirley Ferguson, Associate Professor, Natural Resources Institute, University of Manitoba.

Karen Hallowell, PhD, Professor, Department of Anthropology, University of Manitoba.

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