

ETHICAL GUIDELINES FOR ABORIGINAL WOMEN'S HEALTH RESEARCH

Saskatoon Aboriginal Women's Health
Research Committee

Prairie Women's Health Centre of Excellence

Project #89



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Saskatoon Aboriginal Women's Health Research Committee Prairie Women's Health Centre of Excellence

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ETHICAL GUIDELINES FOR ABORIGINAL WOMEN'S HEALTH RESEARCH

The ethical guidelines for Aboriginal women's health research were developed by the Saskatoon Aboriginal Women's Health Research Committee with support from Prairie Women's Health Centre of Excellence.

These guidelines uphold the standard of best practice adopted by the Saskatoon Aboriginal Women's Health Research Committee. The guidelines were developed for use in two projects, *Naspici Miyomahcihowin: Continuous Good Health* by the Saskatoon Aboriginal Women's Health Research Committee and *Living Well: Aboriginal Women, Cultural Identity and Wellness* by Alex Wilson. The guidelines have been adapted from the *Royal Commission on Aboriginal Peoples – Ethical Guidelines for Research* (1993)¹ and *Ethical Guidelines for WUNSKA Research*. WUNSKA is a Cree word meaning, "To wake up". These guidelines were developed by a group of social workers, based upon the Royal Commission on Aboriginal Peoples' ethics in the early 1990s. The guidelines were developed to help facilitate research by and for Aboriginal people.

The need for these guidelines comes out of recognition of the historically detrimental relationship between Aboriginal peoples and researchers and the research process. The development of ethical guidelines by Aboriginal women will help toward creating relevant and accurate research. The committee developed these guidelines for their own work and also to be used by other researchers.

1 http://www.pre.ethics.gc.ca/english/pdf/RCAP_Guidelines_1993.pdf

Two documents were adapted by the committee, the *Royal Commission on Aboriginal Peoples' Ethical Guidelines for Research*, and the *Ethical Guidelines for WUNSKA Research* which include the principles of the research learning circle. Full citations are provided.

Adapted from the **Royal Commission on Aboriginal Peoples' Ethical Guidelines for Research:**

PURPOSE

These guidelines have been developed to help ensure that, in all research sponsored by the Aboriginal Women's Health Research Program, appropriate respect is given to the cultures, languages, knowledge and values of Aboriginal peoples' legitimate knowledge.

These guidelines represent the standard of best practice adopted by the Saskatoon Aboriginal Women's Health Research Advisory Committee.

PRINCIPLES

Aboriginal peoples have distinctive perspectives and understandings, deriving from their cultures and histories and embodied in Aboriginal languages. Research that has Aboriginal experience as its subject matter must reflect these perspectives and understandings.

In the past, research concerning Aboriginal peoples has usually been initiated outside the Aboriginal community and carried out by non Aboriginal people. Aboriginal people have had almost no opportunity to correct misinformation or to challenge ethnocentric and racist interpretations. Consequently, the existing body of research, which normally provides a reference point for new research, must be open to reassessment.

Knowledge that is transmitted orally in the cultures of Aboriginal peoples must be acknowledged as a valuable research resource along with documentary and other sources. The

means of validating knowledge in the particular traditions under study should normally be applied to establish authenticity of orally transmitted knowledge.

In research portraying community life, the multiplicity of viewpoints present within Aboriginal communities should be represented fairly, including viewpoints specific to age and gender groups.

Researchers have an obligation to understand and observe the protocols concerning communications within any Aboriginal community.

Researchers have an obligation to observe ethical and professional practices relevant to their respective disciplines.

Researchers have an obligation to observe and respect a holistic philosophy in practice. This includes the mental, physical, emotional and social well being of each person or groups involved in research.

There shall be fair treatment of all persons participating in Aboriginal women's health research.

GUIDELINES

- Researchers shall conscientiously address themselves to the following questions:
- Are there perspectives on the subject of inquiry that are distinctively Aboriginal?
- What Aboriginal sources are appropriate to shed light on those perspectives?
- Is proficiency in an Aboriginal language required to explore these perspectives and sources?
- Are there particular protocols or approaches required to access the relevant knowledge?

- Does Aboriginal knowledge challenge in any way assumptions brought to the subject from previous research?
- How will Aboriginal knowledge or perspectives portrayed in research produced be validated?
- How will all comments of participants be validated?
- How will comments be recorded to ensure the context of the participant is portrayed?

Consent

Informed consent shall be obtained from all persons and groups participating in research. Such consent may be given by individuals whose personal experience is being portrayed, by groups in assembly, or by authorized representatives of communities or organizations.

Consent should ordinarily be obtained in writing.

Individuals or groups participating in research shall be provided with information about the purpose and nature of the research activities, including expected benefits and risks.

No pressure or coercion shall be applied to induce participation in research.

Participants should be informed that they are free to withdraw from the research at any time.

Participants should be informed of the degree of confidentiality that will be maintained in the study.

Informed consent of parents or guardians and, where practical, of children should be obtained in research involving children.

Collaborative Research

In studies that are carried out in the general community and that are likely to affect particular Aboriginal communities, consultation on planning, execution and evaluation of results shall be sought through appropriate Aboriginal bodies.

In community-based studies, researchers shall ensure that a representative cross-section of community experiences and perceptions is included.

The convening of the Aboriginal Women's Health Research advisory group to provide guidance on the conduct of research shall not pre-empt the procedures laid down in this part but shall supplement them.

Review Procedures

Review of research results shall be solicited both in the Aboriginal community prior to publication.

A cross-section of the participants of the study will be brought together to review the document before publication.

Access to Research Results

Aboriginal Women's Health Research shall maintain open public access to final reports of research activities. Reports may be circulated in draft form, Aboriginal community response at this stage is deemed useful for purposes of revision.

Results of community research shall be distributed as widely as possible within participating communities, and reasonable efforts shall be made to present results in non technical language and Aboriginal languages where appropriate.

Community Benefit

In setting research priorities and objectives for community-based research, the Aboriginal Women's Health Research Advisory Council and the researchers shall give serious and due consideration to the benefit of the community concerned.

In assessing community benefit, regard shall be given to the widest possible range of community interests, whether the groups in question be Aboriginal or non Aboriginal, and also to the impact of research at the local, regional or national level. Wherever possible, conflicts between interests within the community should be identified and resolved in advance of commencing the project. Researchers should be equipped to draw on a range of problem-solving strategies to resolve such conflicts as may arise in the course of research.

Whenever possible research should support the transfer of skills to individuals and increase the capacity of the community to manage its own research.

Implementation

These guidelines shall be included in all research that Aboriginal Women's Health Research initiates.

It shall be the responsibility, in the first instance, of all researchers to observe these guidelines to monitor the implementation of the guidelines and to make decisions regarding their interpretation and application.

Where, in the opinion of the Aboriginal Women's Health Research or the research team, the nature of the research or local circumstances make these guidelines or any part of them inapplicable, such exception shall be reported to the Research Coordinator, and the exception shall be noted in the research contract or contract amendments as well as in any publication resulting from the research.

Adapted from the **Ethical Guidelines for WUNSKA Research**

PRINCIPLES OF THE RESEARCH LEARNING CIRCLE

We strive to live in harmony with one another and with all creation around us in this circle of life. In a circle no one is above another. There is a sense of belonging to a family and to a community.

These are the principles that the researchers will follow in terms of how they conduct themselves.

The Fifteen Poles represent the Following Values:

1. Obedience

We learn by listening to traditional stories; by listening to our parents or guardians, our fellow students and our teachers. We learn by their behaviours and their reminders, so that we know what is right and what is wrong.

2. Respect

We must give honour to our Elders and fellow students, and the strangers who come to visit our community. We must honour other peoples' basic rights.

3. Humility

We are not above or below others in the circle of life. We feel humbled when we understand our relationship with Creation. We are so small compared to the majestic expanse of Creation. "*We are just a strand in a web of life*" and we respect and value life.

4. **Happiness**

We must show some enthusiasm to encourage others at social functions. Our actions will make our ancestors happy in the next world.

5. **Love**

If we are to live in harmony we must accept one another as we are and to accept others who are not in our circle. Love means to be kind and good to one another.

6. **Faith**

We must learn to believe and trust others, to believe in a power greater than ourselves whom we worship and who gives us strength to be a worthy member of the human race.

7. **Kinship**

Our family is important to us. This includes our parents, our brothers and sisters who love us and gives us roots, the roots that tie us to the lifeblood of the earth. It also includes extended family; grandparents, aunts, uncles, and cousins and their in-laws and children. These are also our brothers and sisters and they give us a sense of belonging to a community.

8. **Cleanliness**

We must learn not to inflict ills on others, for we do it to ourselves. Clean thoughts come from a clean mind and this comes from Indian spirituality. Good habits also reflect a clean mind.

9. **Thankfulness**

We learn to give thanks for all the kind things others do for us and for the Creator's bounty, that we are privileged to share with others in the spirit of love.

10. **Sharing**

We learn to be part of the family by helping in providing food or other basic needs. This is sharing responsibilities in order to enjoy them.

11. **Strength**

We must learn to be patient in times of trouble and not to complain but endure and show understanding. We must accept difficulties and tragedies so that we may give others strength to accept their own difficulties and tragedies.

12. **Good Child Rearing**

Children are unique and blessed with the gift of life. We are responsible for their well-being, spirituality, emotional, physical, and intellectual development. They represent the continuity of our circle of life which we perceive to be the creator's will.

13. **Hope**

We must hope for better things to make life easier for us, our family and the community, both materially and spiritually.

14. **Ultimate Protection**

The ultimate responsibility to achieve is *“health for a balanced caring for the body, mind, emotions, and the spirit of the individual, the family, the community and the nation.”*

15. **Control Flaps**

We are connected by relationships and we depend on each other. This controls and creates harmony in the circle of life.