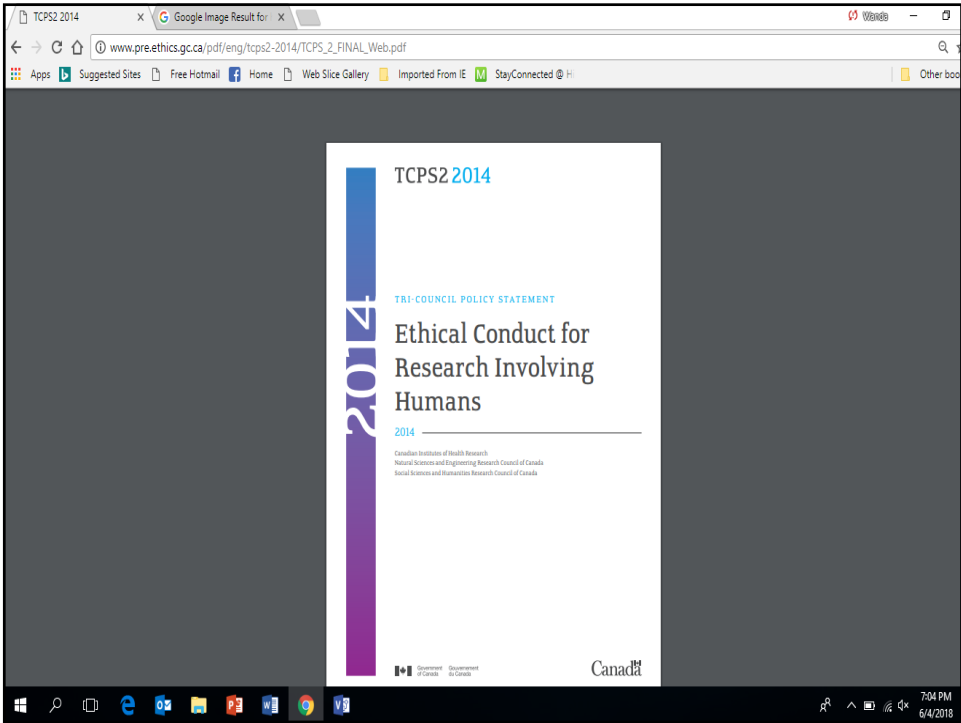


**“Exploring the Ethical Landscape
of Research involving First
Nations People in Manitoba”**

June 5, 2018

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Nanaandawewigamig (FNHSSM)



TCPs2 2014

Google Image Result for

www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPs_2_FINAL_Web.pdf

Apps Suggested Sites Free Hotmail Home Web Slice Gallery Imported From IE StayConnected Other books

TCPs2 2014

TRI-COUNCIL POLICY STATEMENT

**Ethical Conduct for
Research Involving
Humans**

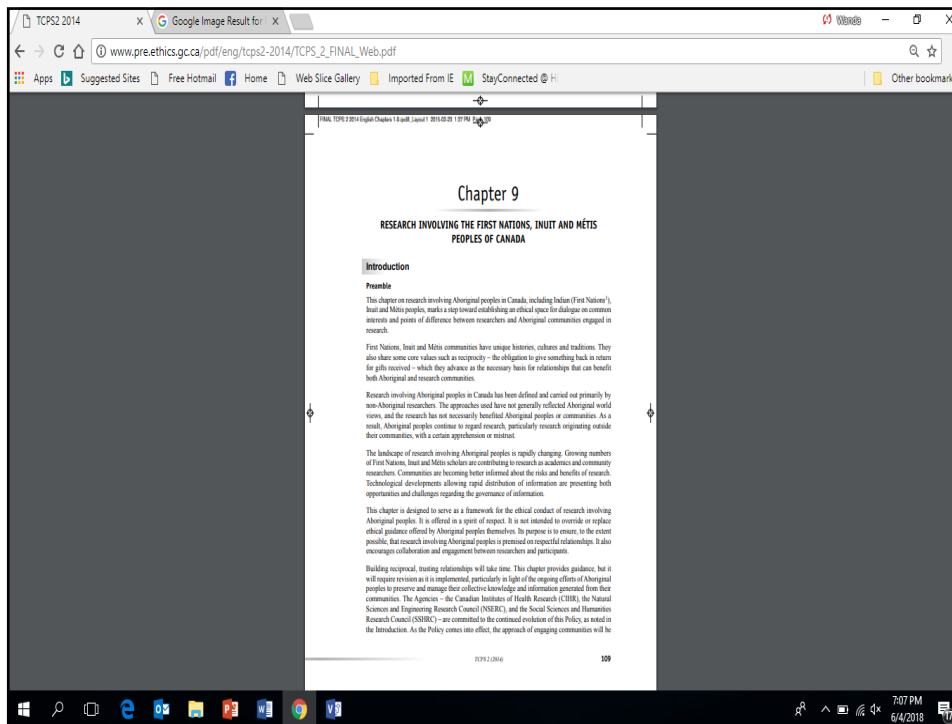
2014

Canadian Institutes of Health Research
Natural Sciences and Engineering Research Council of Canada
Social Sciences and Humanities Research Council of Canada

Government of Canada

Canada

7:04 PM
6/4/2018



AMC Chiefs in Assembly

1996 - Mandated AMC-Health Information Research Governance Committee (AMC-HIRGC) as the First Nations research ethics board to:

- Oversee Regional Health Survey (RHS, 2001-2002)
- Review research proposals

2007 - Amended the AMC constitution to support research for self-determination. Research must be done with First Nations and follow:


- Free Prior Informed Consent;
- First Nations OCAP Principles First Nations have Ownership, Control, Access and Possession of their own data and;
- First Nations Ethical standards.



“First Nation infants subject to “human experimental work” for TB vaccine in 1930s-40s”
First Nation infants were used for Saskatchewan trials of a tuberculosis vaccine that was mired in controversy at the time of the experiment in the 1930s and 1940s.

“Genetic researcher uses Nuu-chah-nulth blood for unapproved studies in Genetic Anthropology”

A photograph of a small, dark, shallow bowl containing incense, with wisps of smoke rising from it. The bowl sits on a light-colored wooden surface. The background is dark and out of focus.



Learn about MFN Chiefs 3 conditions for research with First Nations:

FREE PRIOR
INFORMED
CONSENT

FIRST
NATIONS
PRINCIPLES
OF OCAP

FIRST
NATIONS
ETHICAL
PRINCIPLES

Free Prior Informed Consent

Consent (agreement) to participate in research requires both community and individual consent

Key Questions to ask:

- Does the research involve a significant # of FN?
- Does the research involve 1 FN, or more? (If one or a group of communities in a Tribal Council area, individual community or TC Council protocols prevail.)
- Consent must be:
 - free (voluntary – no pressure);
 - prior (before any info collected), and
 - informed (FN and person needs to know what research purpose, methods, use would be ahead of participation).





FIRST NATIONS PRINCIPLES OF OCAP

O- OWNERSHIP
C- CONTROL
A- ACCESS
P- POSSESSION

Originally coined in 1998 as "OCA"

OCAP is fundamentally tied to:


- self-determination
- self-governance – First Nations governments, like other governments, need data on their people
- the preservation and development of First Nations cultures.

OCAP allows a community to make decisions regarding why, how and by whom information is collected, used and shared for research, evaluation and planning purposes.

OCAP : Ownership

- Relationship of First Nations to their cultural knowledge/ data/ information;
- Community/group owns information collectively just as individuals own their personal information;
- Distinct from possession (stewardship).


- First Nations Centre, National Aboriginal Health Organization
<http://www.naho.ca/firstnations/>

A small, dark bowl sits on a wooden floor, with wisps of white smoke rising from it. The background is dark, making the smoke and the floor's texture stand out.

OCAP: Control

- maintain, regain control in all areas of their lives includes research, information and data
- ***control*** over all aspects and stages of research and information management projects and processes that impact them. ***This includes generating or validating research questions that are meaningful and important to FN.***
- extends to resources, policy, review processes, formulation of conceptual frameworks, data management etc.

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A small, dark bowl sits on a wooden floor, with wisps of white smoke rising from it. The background is dark, making the smoke and the floor's texture stand out.

OCAP: Access

ACCESS – First Nations:

- must have access to information, data about themselves and their communities, wherever it is held.
- manage and make decisions regarding access to their collective information.

- First Nations Centre, National Aboriginal Health Organization
<http://www.naho.ca/firstnations/>

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OCAP: Possession

POSSESSION

- Possession (stewardship) is a mechanism to assert, protect ownership.
- When FN data is in the possession of others (e.g. government, universities), there is a risk of breach or misuse. Especially when trust is lacking between owner and possessor.

- First Nations Centre, National Aboriginal Health Organization
<http://www.naho.ca/firstnations/>

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First Nations Ethical Standards

- 63 First Nations in Manitoba are peoples of several indigenous nations – Cree, Dakota, Dene, Ojibway, OjiCree.
- We each have our own views and ideas within our own languages.
- In March 2005, Elders from our nations in MB met in workshop on research ethics and agreed:

“Research is a relationship based on respect and it takes time to build trust.”



Overall Protocol

- Contact and engage FNHSSM/AMC/Community/FN partner prior to/or at the idea or draft stage of research proposal
- Draft proposal, if possible involve partners in design, consider feedback
- Finalize proposal
- Submit proposal to FNHSSM HIRGC/Community/Tribal Council obtain letter of support
- University Research Ethics Board
- Maintain communication/consultation/engagement through entire research process



ACCOUNTABILITY TO MANITOBA FIRST NATIONS

- Researchers and research teams first and foremost consult, dialogue, report data/findings, and be accountable to their First Nation partners/leaders/community prior to **any publication**.
- First Nation partners/leaders/community have right to **dissent**
- First Nations partners/leaders/community have right to be **acknowledged or participate in authorship** depending on role in research.



How can I learn more about OCAP®?

FNIGC's website, includes links to videos which help explain the history and importance of the First Nations principles of OCAP® (["Understanding the First Nations Principles of OCAP™: Our Road Map to Information Governance"](#)).

We also suggest you read two papers FNIGC commissioned on OCAP® which track the development and implementation of OCAP® in detail: [Ownership, Control, Access and Possession: The Path to First Nations Information Governance](#) and [Barriers and Levers for the Implementation of OCAP®](#).

For a more in-depth understanding of OCAP®, FNIGC has launched [The Fundamentals of OCAP® course](#), an online course developed in conjunction with Algonquin College that provides a comprehensive overview of the history of OCAP® and its applications in research and information governance today.

Miigwech Mahsi Ekosani Wopida!
For more information contact FNHSSM:
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Development

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*Photo credit: Scott Benesiinaabandan