


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

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**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

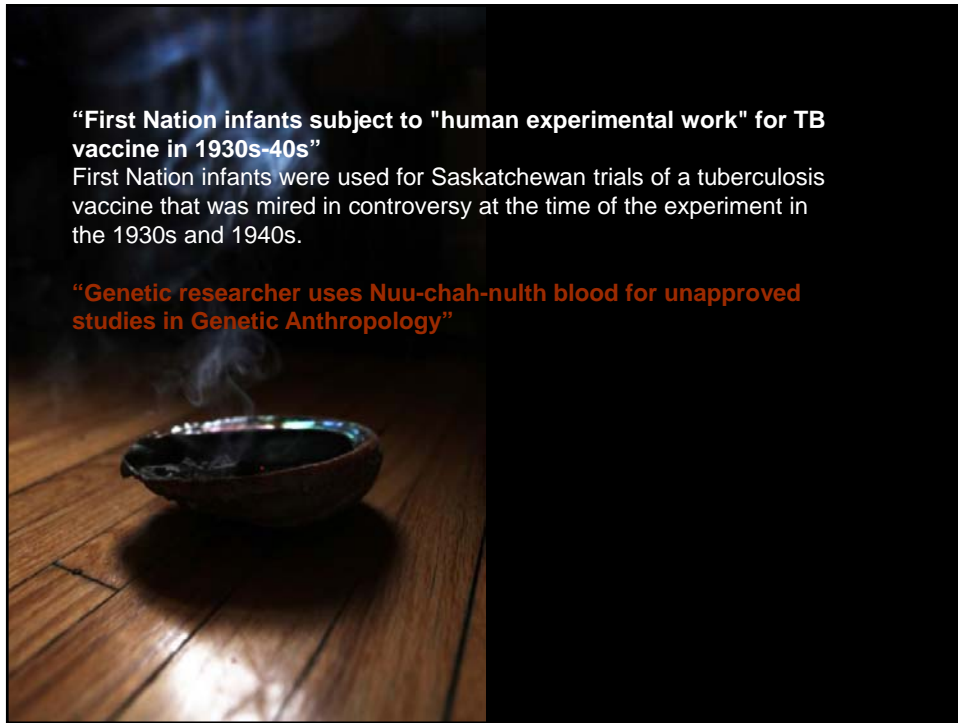
2007 - Amended the AMC constitution to support research for self-determination. Research must be done with First Nations and follow:

- 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.

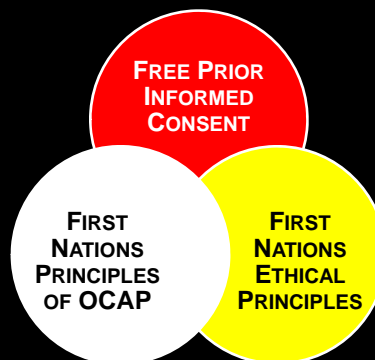
**"First Nation infants subject to "human experimental work" for TB vaccine in 1930s-40s"**

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"**



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





## 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/>



## 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.



## 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



iPHIT *Innovation Supporting Transformation in  
Community-based Primary Healthcare in First  
Nation and Rural/Remote Communities in  
Manitoba*

INSERT QUOTES FROM WORKSHOP  
ON HOW IPHIT HAS HELPED  
COMMUNITIES

## 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!  
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