

SUPPORTING FIRST NATION-CENTRED RESEARCH & MEANINGFUL COLLABORATION

CHILD-BRIGHT 2019 SUMMER LEARNING SERIES – WEBINAR

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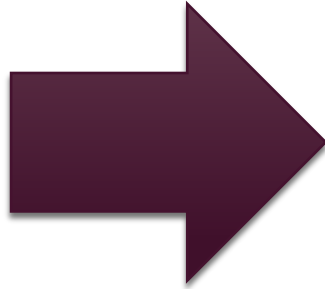


CONTEXT OF COLONIZATION

- Substantial negative impacts of colonization
- Multigenerational impacts of residential schools
- Ongoing experiences of systemic racism
- History of unethical and/or racially stereotyped research

5DS OF COLONIZING INDIGENOUS DATA

- Disparity
- Deprivation
- Disadvantage
- Dysfunction
- Difference



- Classifies us as “problematic”
- Data used to rationalize dispossession & marginalization, and to perpetuate narratives of dependency

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

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Published on September 21, 2000



For the hundreds of Nuu-chah-nulth people suffering the debilitating effects of arthritis, Dr. Richard Ward's groundbreaking study in the early 1980s was like a beacon of hope. But in the following years of no communication between medical researchers and their Nuu-chah-nulth subjects, that light has dimmed, flickered out, and has almost been forgotten.

Yet, after 15 years of waiting, many Nuu-chah-nulth people are now discovering that the blood they volunteered to help find a cure for rheumatic diseases has traveled the world, and has been used in a variety of genetic anthropology studies; outside the boundaries

of the consent forms they signed.



After months of trying to contact Dr. Richard Ward, the Oxford professor has finally responded, saying he is willing to do whatever Nuu-chah-nulth want done with their blood.

Question:You've seen the story in *Ha-Shilth-Sa* on the blood samples you took in the 1980's. What is your response to that story?

Answer:"It's always been my policy that any individual who participates in a study, who wants to withdraw from the study and have material destroyed, or who wants to have their samples placed in a repository, that those requests are always honoured. That's actually written

in the original consent form."

Question:But how could people do this when they had no idea where you, or their blood samples were?

Answer:"That's my fault and I accept the responsibility for that. It was not intended to be a bad thing, but that's one of the things I want to apologize for. I still accept the responsibility for not letting people know that [other studies] could be happening."

Question:So what do you see happening now?

Answer:"As I see it we can do one of three things: we can destroy the data so it's as if they never participated, and if we have any biological material we would destroy those too. If they want biological

FINDING ETHICAL PATHS FORWARD....

- TCPS2: Chapter 9: “Research Involving the First Nations, Inuit and Métis Peoples of Canada”.
 - <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9>
- Describes the terms and additional obligations for engagement with Indigenous communities and protection of Indigenous knowledge and rights that researchers must adhere to.

Article 3 – right to **self determination**

Article 4 – right to **autonomy** and **self-government**

Article 5 – right to maintain and strengthen **distinct** political, legal, economic, social and cultural **institutions**

Article 15 (i) – right to dignity and **diversity** of cultures traditions, histories and aspirations which shall be appropriately reflected in education and **public information**

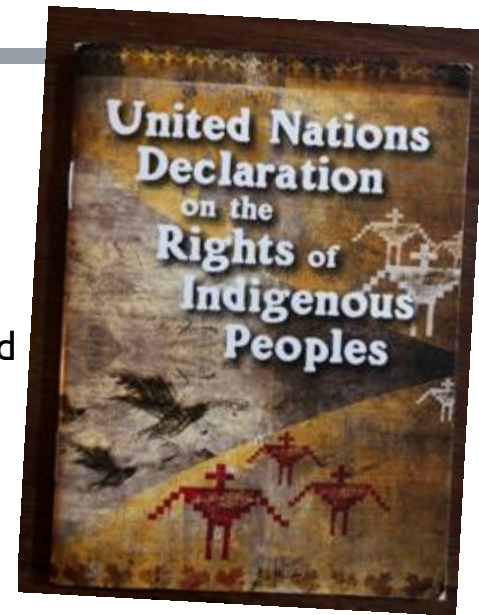
Article 18 – right to participate in decision-making in matters that would affect rights...and to develop indigenous **decision-making institutions**

Article 19 – States shall...obtain **free, prior and informed consent** before adopting and implementing legislative or administrative measures that may affect them

Article 23 – right to determine and develop **priorities and strategies**...and to administer **programs** through their own institutions if possible

Article 31 – right to maintain, control, protect and develop **intellectual property**

Article 33 – right to **determine their own identity or membership**. Right to determine structures and select membership of their institutions



2007



- developed through the First Nations Information Governance Centre.
- refers to the rights of First Nations communities to own, protect and control how their information is used for research and other purposes.

OWNERSHIP

CONTROL

ACCESS

POSSESSION

INDIGENOUS RESEARCH ETHICS

- Rights
- Responsibility
- Reciprocity
- Relationships
- Collective Decision-Making
- Community-centred

PROJECT: PRENATAL OPIOID EXPOSURE IN ONTARIO FIRST NATIONS COMMUNITIES

- Came from community concerns about opioid exposure – Funded by CHILD-BRIGHT
- 13 First Nation communities across southern Ontario participating – Research Agreement
- 2 arms to the project:
 - Quantitative
 - To determine the incidence rates and trends over time of prenatal opioid exposure and neonatal abstinence syndrome in First Nation communities in Ontario, at a community level and aggregated for all participating communities.
 - To identify and examine associated demographic and clinical characteristics of mothers and babies born with prenatal opioid exposure and neonatal abstinence syndrome such as mother's age at delivery, and health conditions during pregnancy and birth.
 - Qualitative (19 focus groups and 31 individual interviews to date)
 - To gather the perspectives of First Nation communities (e.g., parents, grandparents, teachers, leaders, health care providers, and Elders) in Ontario pertaining to prenatal opioid exposure, neonatal abstinence syndrome, and associated longer term neurodevelopmental impairments.



THE ANSWERS ARE IN THE COMMUNITY

Katsi:tsyawaks Christi Poulette, BScN

WHY IS COMMUNITY IMPORTANT?

Community is important because our people, families, and communities are connected.



Standing Stone School

WHY COMMUNITY FIRST?

Because community is who we are.





PEOPLE KNOW WHAT IS NEEDED

The community knows what they need. Ask!
It takes a community to raise a child.

IDENTITY

Community is the core of identity development.



CONVERSATION

Involve
community
and foster
participation.



ENGAGEMENT

- Every voice matters.



YAW^ KO (THANK YOU)



Christi Poulette, RN



Jennifer Walker, PhD