

# Research Ethics as Praxis

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# CBRC Webinar Presentation

- ▶ Special thanks to Daniela and Leah for their contributions to this webinar.
- ▶ For information about CREO and our Board, please see <http://www.communityresearchethics.com/>



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# CBRC Webinar Presentation

- ▶ For a PDF of this slide deck:  
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# Agenda

- ▶ What is “Research Ethics?”
- ▶ Guiding Principles
- ▶ Five Common Stumbling Blocks
- ▶ Question Period

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# Show of Digital Hands...

Who in the audience:

- ▶ Has their TCPS Certification?
- ▶ Has filled out an (any) ethics application?
- ▶ Has never run a study before?

Photo by [naaman frenkel](#) on [Unsplash](#)





What is “Research Ethics?”

# What is “Research Ethics?”

- ▶ Research and History
- ▶ Research, Humans, and Justice
- ▶ REBs and Proportional Response
- ▶ Balance of Risk and Benefit

# Guiding Principles

## Respect For Persons

- Free and Informed Consent
- Autonomy and Voluntariness
- Vulnerability

## Concern for Welfare

- Balance of Risks and Benefits
- Participant Perspective
- Confidentiality and Anonymity

## Concern for Justice

- Equitable Treatment
- Appropriate Inclusion
- Power

## Respect for Community

- Understanding the Community
- Respect for Community
- Community Inclusion



# Five Common Stumbling Blocks



# Stumbling Block #1

DOWNSTREAM INCLUSION

Photo by [Jeniffer Araújo](#) on [Unsplash](#)



# Stumbling Block #2

DATA VERSUS STORIES

Photo by [Adrian Swancar](#) on [Unsplash](#)

## Blood taken for research destroyed

Like 0

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Ha-Shilth-Sa, July 17, 2008



Larry Baird holds a box of blood samples, taken from Nuu-chah-nulth-ahnt under the guise of a study on rheumatoid arthritis, but used for a variety of other experiments without the study subjects' permission, was taken to the West Coast General Hospital to be destroyed on July 17, 2008

**Port Alberni** — When Larry Baird gets up in the morning and feels the twinges and pain of the arthritis in his hands he thinks of Dr. Ryk Ward and the relief his research on rheumatic diseases promised to Nuu-chah-nulth peoples.

In the early 1980s, Ward took 883 vials of blood from Nuu-chah-nulth subjects to study the high incidence of such ailments as rheumatoid arthritis, episodic inflammatory arthritis and lupus in the Nuu-chah-nulth population.

Baird runs his hands across the smooth surface of a cardboard box on July 17. It is filled with what is left of the blood from that study. That day it is scheduled to be destroyed, ending an unpleasant chapter in the Nuu-chah-nulth people's experience with Ward, who

MENU ▾

**nature**  
International journal of science

News | Published: 14 November 2002

## Tribe blasts 'exploitation' of blood samples

Rex Dalton

*Nature* **420**, 111 (2002) | [Download Citation](#) ↓

# Stumbling Block #3

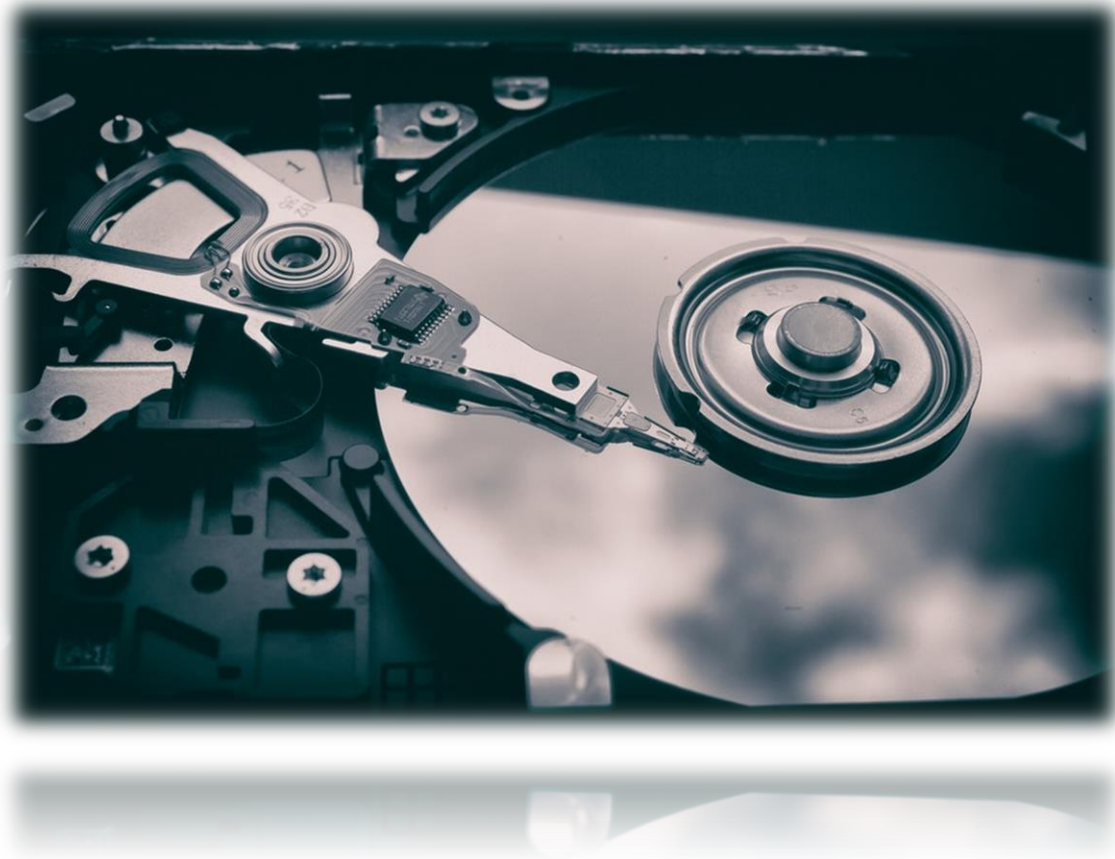
DATA OWNERSHIP



# Stumbling Block #4

(ONGOING) INFORMED  
CONSENT

Photo by [Eepeng Cheong](#) on [Unsplash](#)



# Stumbling Block #5

DATA STEWARDSHIP

Photo by [Patrick Lindenberg](#) on [Unsplash](#)

# In Summary

- ▶ The best practice is to build ethics into the foundation of your study
- ▶ Consider the downstream effects of your project
- ▶ Remember that you are dealing with people, not data points
- ▶ Reflect on ownership over the lifetime of the project
- ▶ Consent must be ongoing and (re)affirmed
- ▶ Protect your participants through good data stewardship



Question Period

# Thank You!



► Website:

<http://www.communityresearchethics.com/>

► Email:

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► Panel on Research Ethics:

<http://www.pre.ethics.gc.ca/eng/index/>