Presenter

Ryan Huckle
Research Ethics as Praxis

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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/
For a PDF of this slide deck:
http://www.communityresearchethics.com/resources/presentations/
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?
What is “Research Ethics?”
What is “Research Ethics?”

- Research and History
- Research, Humans, and Justice
- REBs and Proportional Response
- Balance of Risk and Benefit
<table>
<thead>
<tr>
<th>Guiding Principles</th>
<th>Respect For Persons</th>
<th>Concern for Welfare</th>
<th>Concern for Justice</th>
<th>Respect for Community</th>
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<td>Free and Informed Consent</td>
<td>Balance of Risks and Benefits</td>
<td>Equitable Treatment</td>
<td>Understanding the Community</td>
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<td>Autonomy and Voluntariness</td>
<td>Participant Perspective</td>
<td>Appropriate Inclusion</td>
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<td>Vulnerability</td>
<td>Confidentiality and Anonymity</td>
<td>Power</td>
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Five Common Stumbling Blocks
Stumbling Block #1
DOWNSTREAM INCLUSION
Stumbling Block #2
DATA VERSUS STORIES

Photo by Adrian Swancar on Unsplash
Tribe blasts 'exploitation' of blood samples

Rex Dalton

Nature 420, 111 (2002) | Download Citation

Port Alberni — When Larry Baird gets up in the morning and feels the tingles and pain of the arthritis in his hands he thinks of Dr. Ryp 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
Stumbling Block #4

(ONGOING) INFORMED CONSENT

Photo by Eepeng Cheong on Unsplash
Stumbling Block #5

DATA STEWARDSHIP
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: 
  creo@communitybasedresearch.ca

- Panel on Research Ethics: 
  http://www.pre.ethics.gc.ca/eng/index/
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“Tell us what you think!”

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How CBR theory is put into practice: Research Ethics and Praxis

Start  press ENTER
Thank You!

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