Research Ethics: A Brief Introduction

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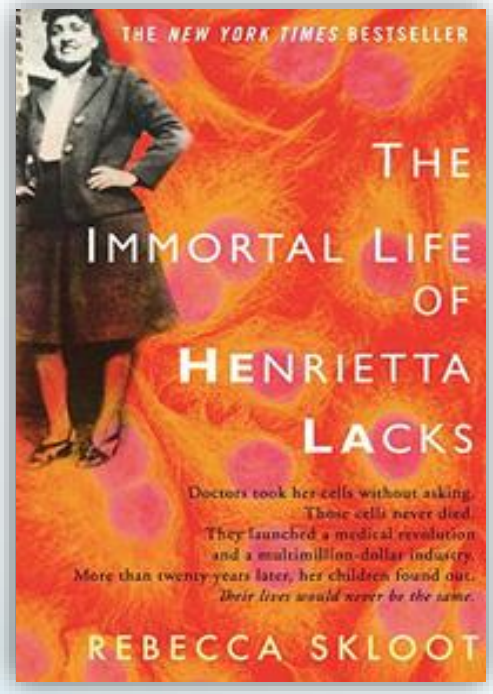
Why Does Research Ethics Matter?



Biological Samples 1951

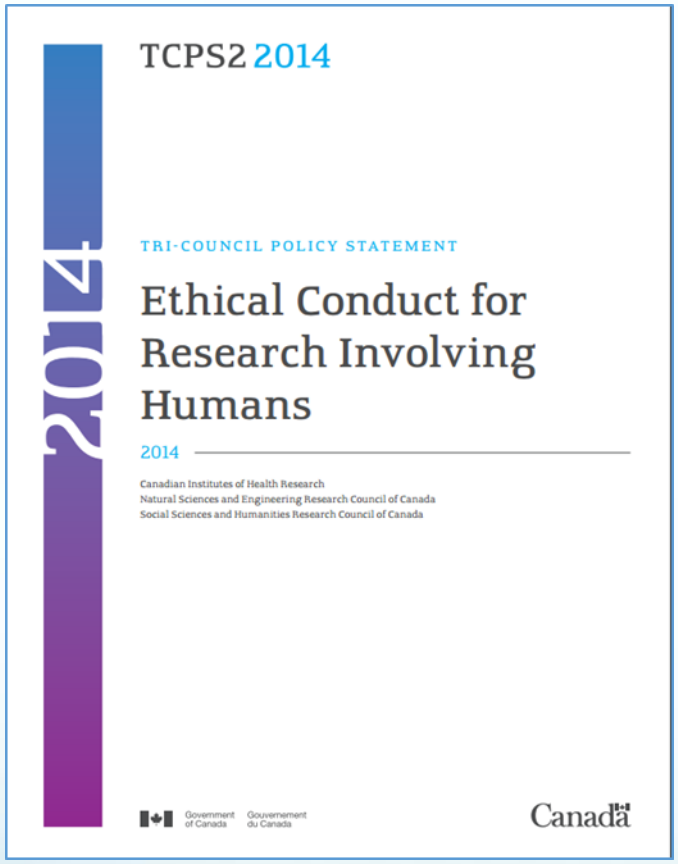
Tuskegee syphilis experiment
1932-1972

DTES Current

Stanford Prison experiment 1971

Objectives

- Apply the three core ethics principles to your own research studies
- Anticipate ethical issues in research
- Identify the risks of participating in research
- Identify the components of informed consent



- Tri Council Policy Statement: *Ethical Conduct for Research Involving Humans* (TCPS 2)
- Overarching Canadian policy framework for research involving human participants
- TCPS published in 1998
- Revised in 2010 and 2014 after extended periods of consultation with relevant stakeholders
- Clear efforts to make TCPS more relevant/applicable to social scientists

TCPS2- Key Principles

Respect for Persons

Centering on the Human Participant

- Who's Participating?
- Recruitment process
- The consent or assent relationship
- Methods employed
- Risk/benefit assessment
- Confidentiality and privacy protections

TCPS2- Key Principles

Respect for Persons

Principles of Consent

- Free
- Informed
- Ongoing

The Consent Process

- Consent is not a single act of someone agreeing to participate in a study. It is a process that begins with the recruitment and screening of participants and continues throughout their involvement in the research.
- Components of the Consent Process are:
  - Recruitment
  - Information
  - Documenting Consent
  - Debriefing (when required)

Keeping Consent Free

- When someone consents to be a participant in a study it is important that they have done so entirely of their own free will.
- Are there ways in which voluntariness can be compromised?
  - Incentives
  - Authority/Power Relationships
  - Undue Influence

Elements of Informed Consent

Consent form should be written in plain and simple language and provide an accurate description of:

- The research purpose and proposed use of data collected
- Foreseeable risks and potential benefits
- Extent of confidentiality promised
- Requirements of the study (e.g. duration, frequency, nature of tasks and/or measures)
- Withdrawal procedure
- Extent of incentives
- Data management (access and safeguards)
- Plans for provision of new information
- Plans for dissemination of results
- Contact information of the researcher in charge of the study
- Contact information of the REB

Capacity to Consent

- Some research requires participants who may lack the necessary cognitive capacity to decide whether or not to participate in research.
- In research, capacity refers to the ability of prospective participants to:
  - appreciate the possible impact of foreseeable risks and potential benefits on their own well-being
  - understand how the conditions of the research may affect them (e.g. time required, difficulty of tasks)
  - evaluate whether participation in a particular research project may or may not be in their own best interest
  - when research involves those who are not capable of giving consent on their own behalf, researchers must seek the consent of an authorized third party

What scenarios/participant populations can you think of where capacity to consent may be an issue?

- children whose capacity is still developing
- Adults whose capacity is diminishing or fluctuating due to illness or injury
- Those whose capacity remains only partially developed
- Participants who are under the influence of drugs and alcohol

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Types of Risk

- Physical
- Psychological
- Economic
- Social
- Legal

Probability & Magnitude of Risk

- **PROBABILITY:** How likely is it that any participant will suffer any harm as a result of the study?

- **MAGNITUDE:** How severe could the harm be?

Minimal Risk Research

“Research in which the probability and magnitude of possible harms implied by participation in the research is no greater than those encountered by participants in the aspects of their everyday life that relate to the research.”

How To Apply The Principle of Concern for Welfare

- Consider potential impacts on participants' physical and mental health, on their social or economic circumstances, and on their privacy
- Consult any groups that may be affected by the research to assess the risk of negative impacts such as stigmatization and discrimination
- Eliminate and/or minimize risks
- Maximize benefits
- Provide accurate and accessible information

ACTIVITY

A researcher wants to recruit transgender/gender non-conforming youth to examine their experience with cyber bullying.

Youth will be recruited through LGBTQQ services like QMUNITY. Youth will sign a consent form. Parents will not be asked to provide consent nor will they be notified of their child's participation in the study.

The youth be interviewed for 1 hour to discuss their experiences with cyber bullying and they will be asked about the help they may or may not have sought when the bullying started. Pseudonyms will be used in all publications; no identifying information will be released.

TCPS2- Key Principles

Respect for Persons

How To Apply The Principle of Justice

- In research design it is important to address the following issues:
  - Who are the participants? Why this group and not others?
  - Are any participant groups over- or under-represented because of their vulnerable circumstances?
  - Are there measures in place to treat people in vulnerable circumstances justly in the context of the research?
  - Is there an imbalance of power between participants and researchers?

Centering on the Human Participant

- Who's Participating?
- Recruitment process
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- Methods employed
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- Confidentiality and privacy protections

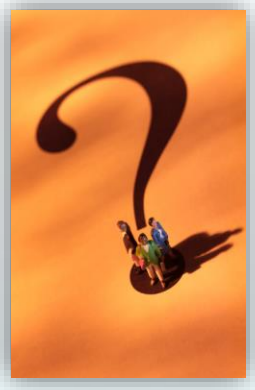
Confidentiality

Is the obligation of an individual or organization to

- safeguard entrusted information
- protect information from unauthorized access, use, disclosure, modification, loss or theft

Major Concepts: Confidentiality and Anonymity

- Directly Identifying Information
- Indirectly Identifying Information
- Coded Information
- Anonymized Information
- Anonymous Information



Research Integrity

- Adhere to relevant ethical principles and seeking approval from the appropriate institutional committee
- Carry out research in an honest and rigorous search for knowledge when obtaining, recording and analyzing data, and in reporting and publishing results; not fabricating or falsifying data or results
- Ensuring that authorship of published work includes all persons who have materially contributed to, and share responsibility for, the contents of the publication
- No plagiarism
- Revealing any perceived or potential Conflicts of Interests
- Make results of work accessible

R60.01 – Integrity in Research and Misconduct in Research - http://www.sfu.ca/policies/gazette/research/r60-01.html

Summary

- The 3 core ethics principles **(Respect for Persons, Welfare, & Justice)** are the foundation for the ethical reasoning that guides interactions with participants in all research involving human participants.
- Researchers are obligated to provide as much information as individuals need to make a **fully informed choice** to consent or refuse to participate.
- **Context matters** when determining risk to participants and their vulnerability

Need Help? Let us know!!!

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