

Ethics

University of Waterloo Ethics Requirements

- University has a formal process for ethics
 - Not something you need to deal with
 - I created letters, modified protocol, etc.
- Why would the university have ethics requirements for a course?

Principles

- Respect for human dignity
- Respect for free and informed consent
- Respect for vulnerable persons
- Respect for privacy and confidentiality
- Respect for justice and inclusiveness
- Balancing harms and benefits
- Minimizing harm
- Maximizing benefits

Ethics Review

- All research that involves living human participants requires review and approval before research is started
- When do projects require review?
 - Whether funded or not
 - Whether subjects are from university or not
 - Whether subjects are paid or not
 - Whether research is conducted inside university or not
 - Whether conducted by faculty or students
 - Whether information is collected from subjects or not
 - Whether published or not
 - Whether focused on the subject or not
 - Whether observation, experimental, or descriptive
 - Whether basic or applied
 - Whether for teaching or training or research
- Even naturalistic observation requires review
 - Especially when staged

Ethics Review (2)

- Research Ethics Board (REB) at Waterloo can:
 - Approve, reject, propose changes, or terminate any work with human subjects by members of the university
 - This includes you.
- REB consists of five members
 - Both men and women
 - One member knowledgeable in ethics
 - Two members have expertise in fields covered by REB
 - One member knowledgeable in biomedical law
 - One member from outside university
 - Goal is breadth – want a balanced perspective on projects being examined

Ethics Review (3)

- Course project is one of *Minimal risk*
 - Probability and magnitude of harm should be no greater than in everyday life
 - This can also be how you test new treatments on people (e.g. experimental surgeries or cancer treatments)
- Greater than minimal risk requires greater corresponding benefits
 - Benefit outweighs risk
 - May need peer review

Ethics Review (4)

- Canadian and UW guidelines
- They consider
 - Recruitment
 - Voluntary participation
 - Confidentiality and anonymity
 - Risks/benefits
 - Fully informed consent

Recruitment

- Use your classmates as pilot study participants
- Any time you want to use data, need consent form and consent.
- Also need gatekeepers permission if person is supervised: obtain manager's consent to use participants if in course of supervised duties in enterprise
 - I prefer you contact participants first
 - No on one = no on both
 - Examples: Principal if teacher, etc.

Consent forms

Informed Consent (1)

- Disclosure
- Comprehension
- Voluntariness
- Competence
- Agreement

Informed Consent (2)

- Should normally involve full and frank disclosure
 - Information that it is a research project, on the purpose of the project, on the procedures, and any perceived harms and benefits
 - Assurance subjects are free not to participate
 - Any possibility for commercialization and/or conflict of interest
 - May need to practice some deception, but if so must document that:
 - Minimal risk
 - Change won't affect rights/welfare
 - Research requires the deception
 - Subject informed after
- Must be voluntary
 - Subjects must be free to say yes or no, and can stop at any time
 - Military (for example), my own students
- Subjects must be competent
 - This is why no children
 - This is a risk for healthcare settings
- Typically by a signed statement
 - Can also be implied
 - Filling out a survey

Informed Consent (3)

- Participants can refuse to answer and can stop participating at any time
- If they say they don't want to participate, their involvement is done
- Never, ever push participants for information they cannot or do not want to disclose

Informed Consent (4)

- They can consent to all or part of process
 - Consider consent forms
 - Make them aware of selective exclusion
- As a minimum
 - Audio + photos + anonymous quotations are useful, but can say no.

Questions or Problems

- For questions, always give participants your email and supervisor's email
 - Also give to supervisors/managers if applicable
- If any problems occur, contact ORE immediately
 - Must be reported

Privacy and Confidentiality

- Any information disclosed must be held confidential
 - Legal and moral requirement
- Best protection is anonymity
 - All data will be anonymized for your studies
 - Use code names (e.g. P1) to refer to people
- Personal Information = need for REB approval
 - Name, age, occupation, etc.
- Secondary data, or re-contact with people who provided data by new researchers also requires approval

Privacy and Confidentiality (2)

- You will
 - Anonymize everything
 - Always refer to participants by code, even in your notes, labels for tapes, files, etc.
 - Anonymize pictures you plan to use
 - Extends to organizations
 - Do not say ‘the campus theatre group’
 - Say ‘a local theatre company’
 - Regardless, participant always has option to review data and relevant text of report

Take Aways

- You will be working with people in this course
- Must be mindful of their right to privacy and safeguard this
- Must study people in a way that ensures that they understand and agree to everything done