Planning a GREB Application

Jennifer Couture, Ethics Compliance Advisor
Dr. Joan Stevenson, Chair, GREB

Cultural Studies Feb 26, 2015
Agenda

✓ Why Research Ethics?
✓ Ethical Standards
✓ Course on Research Ethics (CORE)
✓ What is Research?
✓ When Ethics Clearance may not be Required
✓ Creative Practices and Visual Research Methods
✓ Ethics at Queen’s & GREB Application
✓ Body Worn Camera’s – Privacy Guidance
✓ Q&A - Your Research Studies
Why Research Ethics?

My friends, as a result of our experimentation, we have just lost a dear and valued colleague....

On the other hand, we have just gained a publication.
Why Research Ethics?

Images from the Stanford experiment
(with thanks to Philip Zimbardo)
Ethical Standards

The Nuremberg Code (1947):
• Voluntary consent of the human subject is essential

Declaration of Helsinki – WMA (1964):
• Health of patient is 1st consideration & to safeguard health, well-being & rights of patients

• Concerns broadened to social sciences and humanities because of impact of research on participants/communities
Minimum standards for ethics review involving human participants

1. Respect for Persons
2. Concern for Welfare
3. Justice
Human Research Ethics Education at Queen’s

- Human ethics training **required** for all students
- Online “CORE” (Course on Research Ethics)
- [http://www.queensu.ca/ors/researchethics.html](http://www.queensu.ca/ors/researchethics.html)
I WAS JUST RUBBING STICKS TOGETHER FOR FUN — I DIDN'T REALIZE I WAS DOING BASIC RESEARCH.
Research:

- “An undertaking intended to extend knowledge through a disciplined inquiry or systematic investigation”

- Disciplined Inquiry: “Conducted with the expectation that the method, results, and conclusions will be able to withstand the scrutiny of the relevant research community”
When Ethics Clearance may not be Required

Observation:

• It does not involve any intervention staged by the Researcher, or direct interaction with the individuals or groups
• Individuals or groups targeted for observation have no reasonable expectation of privacy
• Dissemination of research results does not allow for identification of specific individuals
When Ethics Clearance may not be Required

Publicly available information:
• Info is legally accessible to the public and appropriately protected by law
• Info is publicly accessible and there is no reasonable expectation of privacy

Secondary use of data:
• Use of information **anonymous information** originally collected for another purpose; however the process of data linkage/recording/dissemination **cannot** generate identifiable information
When Ethics Clearance may not be Required

- Quality assurance and quality improvement studies
- Program evaluation activities
- Performance reviews
- Testing within normal educational requirements when used exclusively for assessment, management or improvement purposes

Ethics clearance may be required if results are to be disseminated/published!
When Ethics Clearance may not be Required

• Creative practice activities, in and of themselves, do not require GREB review

Creative practice to obtain responses from participants that will be analyzed to answer a research question is subject to GREB review!

• Contact Office of Research Ethics if there is any doubt
1. Proportionate Approach to Research Ethics Review in the TCPS: Towards a Revised Definition of Research in the TCPS (Jan, 2008)

2. Guidelines for Ethical Visual Research Methods (Feb 2014, Australia)
Creative Practices

May involve research that:
1. Test hypotheses across many disciplines
2. Discovers new approaches for researchers inside & outside of art
3. Ask questions which challenge held beliefs
4. Provoke debate on/exploration of a critical social issue
5. Empower individuals who lack a voice in their community
Stages of Creative Practice Research

1. Reflection
2. Information gathering
3. Hypothesizing
4. Trial & error experimentation
5. Synthesis (creation/combination of ideas)
6. Dissemination of results (conferences, new media, live performances)
Creative Practice - Ethical Considerations

• Line of inquiry to extend knowledge?
• To what extent is the information, likeness or presence of the participants the immediate focus of the research?
• What kind of personal information will be obtained and how will it be used?
• What type of relationship will be established with the participants?
• What are the identifiable and significant harms/benefits to participants?
Two Main Boards at Queen’s:

1. Health Sciences Research Ethics Board (HSREB)
   - Chair – Dr. Albert Clark
   - Coordinator – Kathy Reed (ext 77000; reedk@queensu.ca)

2. General Research Ethics Board (GREB)
   - Chair – Dr. Joan Stevenson
   - Coordinator – Gail Irving (ext 78281; irvingg@queensu.ca)

http://www.queensu.ca/ors/researchethics.html
Unit REBs - GREB

Unit REB:
• Approve course-based & independent studies = low risk to participants
• Medium or high risk course-based research reviewed & approved by Unit REB & sent to GREB
• All thesis research must go to GREB for review

GREB Chair - evaluates risk/ethics concerns and recommends delegated or full review
• Delegated: 1 or 2 reviewers
“There now. We get our wish of continuing our work unimpeded, and they get their wish of being in a position of direct oversight at all times.”
Tools for Research at Queens (TRAQ)

• Complete Self Registration form – 1st time users
• [http://www.queensu.ca/traq/signon.html](http://www.queensu.ca/traq/signon.html)
Sign On

NetID: 
Password: 
Log In

Don't have a NetID?  
Forgotten Your NetID Password?
<table>
<thead>
<tr>
<th>Role: Principal Investigator</th>
<th>Role: Project Team Member</th>
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<tbody>
<tr>
<td>Applications (Saved - Not Submitted)</td>
<td>Applications (Saved - Not Submitted)</td>
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<td>Applications (Submitted - Requiring My Attention)</td>
<td>Applications (Submitted - Requiring My Attention)</td>
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<td>Applications (Submitted - Under Review)</td>
<td>Applications (Submitted - Under Review)</td>
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<td>Applications (Submitted - Post Review)</td>
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<td>Applications (Withdrawn)</td>
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Choose GREB or HSREB Application

New Application Forms

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<th>Application Name</th>
<th>Description</th>
<th>Status</th>
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<tbody>
<tr>
<td>GREB Application</td>
<td>GENERAL RESEARCH ETHICS BOARD APPLICATION FORM for ETHICS CLEARANCE (Social Sciences and Humanities)</td>
<td>Open</td>
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<tr>
<td>HSREB Application</td>
<td>HEALTH SCIENCES RESEARCH ETHICS BOARD APPLICATION FORM for ETHICS CLEARANCE</td>
<td>Open</td>
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<td></td>
<td>HSREB form - updated January 2013</td>
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<tr>
<td></td>
<td>Health Sciences Research Ethics Board Short Form for Critical Enquiry, Chart reviews, Questionnaires, Surveys</td>
<td>Open</td>
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<td>To be used for: chart review, critical enquiry etc.</td>
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<td>Biohazard</td>
<td>Biohazard Permit Application Form</td>
<td>Open</td>
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<td></td>
<td>New Electronic Form - updated September 2013 You will need to complete and attach a Biohazard Inventory and Risk Group Table and lab-specific SOPs to submit this form.</td>
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<td>TRAQ RSS Form</td>
<td>Submit this form if you are seeking approval for research funding. Only the Principal Investigator (a Faculty member) can submit TRAQ</td>
<td>Open</td>
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Project Team Information

Principal Investigator

Instructions: Do not hand type data for this section. The Principal Investigator (PI) section default populates with the researcher profile data for the project team member who creates the file. If you are not the PI, click the Change PI button to search for and select an alternate researcher profile. If you load an alternate researcher profile to the PI section, be sure to reload your researcher profile to the Other Project Team Info section below.

Prefix: Mrs.  Last Name: Couture  First Name: Jennifer

Affiliation: VR Research/University Research Services

Rank: Research Administrator  Gender: Female  Institution: Queen's University

Phone: 78233  Email: jennifer.couture@queensu.ca  Phone2:  Fax:  Alternate Address:

Preferred Address: Primary Address  Alternate Address: Country: Canada

Comments:

Other Project Member Info:

Instructions: Do not hand type data for this section. To add more project team members to this application file, click the Add New button to search for and select from other researcher profiles.

Add New
Section 1 - CORE Completion

1.1) Applicant CORE Completion: Students and staff submitting ethics applications must also attach their CORE certificate. To complete CORE go to http://pro.ethics.gc.ca/eng/education/tutorial-didactic/. If desired, CORE can appear on your transcript as S00004. (Click info tab for further details.)

- YES
- NO
- N/A

1.2) Co-Applicant I - CORE Completion

- YES
- NO
- N/A

1.3) Co-Applicant II - CORE Completion

- YES
- NO
- N/A

1.4) Co-Applicant III - CORE Completion

- YES
- NO
- N/A

1.5) Co-Applicant IV - CORE Completion

- YES
- NO
- N/A

1.6) Co-Applicant V - CORE Completion

- YES
- NO
- N/A

1.7) Co-Applicant VI - CORE Completion

- YES
- NO
- N/A
Section 2 - Project Details

- Student research – Must add supervisor’s name to application & attach proof of approval
- **Abstract** - Concise description of project rationale, objective and methods
- **Methods** – Summary of how you will conduct research
- Conflict of Interest Disclosure/Funding
- Location - *Does off Campus Activity Policy apply (OCASP)*?
- Archived data/Source/Custodian
Section 3 - Recruitment

• Number & description of participants
• Vulnerable populations/Aboriginal populations
• How will participants be recruited - attach all samples
• How can participants withdraw?
• Participants compensated?
Section 4 - Risk Assessment & Benefits

Will study involve?:
✓ Questions about sensitive or personal issues?
✓ Psychological/Economic risk/Social risk?
✓ Dangerous locations?
✓ Risk of power imbalance situations?
✓ Language & cultural sensitivities?

• Any additional risk?
• Plan to minimize risks/provide support?
• Benefits to participants, research community, society at large?
How do you intend to protect participant privacy?
✓ Content (types of info)
✓ Paper/electronic records
✓ Mobility
✓ Vulnerability to unauthorized access (password/encryption)
✓ Recording of observations
✓ Limits on the use, disclosure and retention of data
Section 7 - Informed Consent

- Written/verbal Letter of Information/Consent form?
- Does project involve deception?
- Debriefing procedures?
- Process for withdrawal?

GREB checks the reading level of documents!
Should use lay language!
Alterations to Consent: TCPS2 3.7A&B

- No more than minimal risk to the participants
- Unlikely to adversely affect the rights and welfare of the participants
- Research could not practicably be carried out without the waiver or alteration
- The precise nature and extent of the alteration is defined
- The information is used in a matter that will ensure its confidentiality
- Debriefing must be provided whenever possible, practical & appropriate

Responsibility of the researcher to justify the need for any alteration to consent!!!
Supreme Court of Canada
- “An individual does not automatically forfeit privacy interests when in public, especially given technological developments that make it possible for personal information to be recorded with ease, distributed to an almost infinite audience, and stored indefinitely”
- “The right to informational privacy includes anonymity which permits individuals to act in public places but to preserve freedom from identification and surveillance”

• https://www.priv.gc.ca/information/pub/gd_bwc_201502_e.pdf
Privacy Impact Assessment (PIA):

• **Necessity**: Demonstrable operational need

• **Effectiveness**: Effective solution to the needs that have been identified

• **Proportionality**: Any privacy intrusion must be minimized to the extent possible and offset by significant and articulable benefits

• **Alternatives**: Would less privacy-invasive measure achieve the same objectives?
Notifying the Public/Bystanders

• Transparency is integral to the public’s ability to exercise their rights under privacy laws
• Make a short statement that meets notice requirements
• A prominent pin or sticker on researcher
• Minimize the recording of innocent bystanders/images of bystanders should be anonymized through face blurring, and the distortion of sound
Documents required:

✓ CORE certificate
✓ CF/LOI
✓ Questionnaires, interview guides, verbal scripts, etc.
✓ Recruitment tools (emails, posters, advertisement scripts, etc.)
✓ Confidentiality letters (transcription)
✓ Debriefing letter
✓ Other supporting info (i.e. sponsor or supportive organization)
✓ Email from supervisor
RUN THIS BY THE LEGAL DEPARTMENT, BUT RUN SUPER FAST SO THE ETHICS DEPARTMENT DOESN'T SEE IT.
Thanks for your time!