香港教育大學
The Education University of Hong Kong

HREC Research Ethics and Ethical Review Workshop

Presented by Dr. Emma E. Buchtel, October 2024
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Why research ethics? The researcher's dilemma:

- We are excited about our research goals
- But to do research, we may need help from other people, i.e. research participants
- Does research "use humans as a *means to an end?"* Are we "using" them to get to our goal?
  - *Unfortunately, yes. So:*
- How do we *respect and benefit our participants* instead?
  - This is the central concern of research ethics.

Today's main questions:

- **The Practical question: Before you do research with human participants,** the project must be ethically approved. How to get through it?
- **The Ethical question**: What kinds of things are "ethical problems" in research? How do we fix them?

- This workshop aims to help you be aware of and solve possible ethical issues in research, helping you:
  - Know the basic rights of participants
  - Know how to SOLVE ethical risks (= to minimize risks for participants)
  - Know about the Ethics Review process & how to facilitate it

1. The Practical question: Process of Applying for Ethics review

Who needs to apply for EdUHK HREC review?

- Staff or students of EdUHK who are doing *research* involving data (originally or newly) *from humans*

1(a) Research is any creative or systematic work or investigation, including research development, testing and evaluation, designed to develop or contribute to the human stock of knowledge – including knowledge of humankind, culture and society. A project is considered research if there will be public dissemination of findings for the purposes of advancing knowledge or solving problems…

1(b) "Human subjects" covers the subjects involved not only in research areas such as health or social studies or survey research but also other areas such as teaching (particularly teaching development) or other scholarly activities with elements of data collection or experimentation.

Source: EdUHK's Guidelines on Ethics in Research

Why do we need an ethics review process?

Which ones are correct?

Before you (university staff or students) do any research with human participants, your research needs to be approved by a university research ethics board. Why?

A. To check if you have good morals
B. To get an outside perspective on how your participants may be affected by the research
C. To improve the quality of your research proposal
D. To give you advice on how your research can treat participants more ethically
E. To protect you, and the university, from complaints
F. To allow you to publish your research findings

What is the purpose of human research ethical review?

Why does research need to undergo review by a Research Ethics Committee?

It is not to "ensure" that the research is ethical– this is ultimately the researcher's responsibility.

HREC provides *an outside, wider, experienced perspective* on:

- the potential negative implications/effects of the research for/on the participants,
- any unforeseen consequences of the research on participants or other associated parties, and
- Methods of reducing risk / increasing benefits to participants

Ethical review **helps protect** participants, but also the researchers / the Institute.

Also, if your data is collected without the approval of an Ethics Committee, *it cannot be used in a thesis or, generally, published in a reputable journal.*

The ethics application

- FORM: changes from time to time.
  - **Staff & Research Pg students (EdD / PhD / Mphil)**
    -> Online Application https://workflow.eduhk.hk/HREC/
  - Taught PG students (MA / MEd / PGDE etc.) & Undergraduate students (BEd, etc.)
    -> Currently: Printed Application Form
    - Download the most recent **forms** from the HREC
    -> Webpage: http://www.eduhk.hk/rdo/human.html
- To fill out the application, first READ the guidelines (BOTH):
  - "University's Guidelines on Ethics in Research" for general advice
  - "HREC Operational Guidelines and Procedures" (from *Procedures* page) for specific advice (e.g. types of consent required for different ages)

The application process: Flow

- Staff:
  - Submit your online application to the HREC
    - Can be drafted by another person first
  - RDO Staff will check for common problems (missing docs, etc.)
  - Application reviewed by a) an HREC member, and b) HREC chairperson
- Research Pg students (EdD / PhD / Mphil):
  - Seek endorsement from principal supervisor (PS) before online submission:

    1) draft an application at the Online System (save it but not submit), then send to Principal Supervisor (PS) for PS' comments or endorsement;

    2) then, Approval of the Principal Supervisor is recorded on the online application
  - Then, application reviewed by RDO staff & HREC as above
- Taught Pg students (MEd / PGDE etc.):
  - Forms submitted to thesis supervisor for his/her approval
  - Then, supervisor submits it to the HOD or HOD's delegate for ethical review & approval (FEHD: Faculty-level review board)
- Undergraduate students (BEd, etc.):
  - Submit to thesis supervisor for his/her approval
  - Then, supervisor submits it to the HOD / HOD's delegate for ethical review & approval

See "Flow of Application…" at https://www.eduhk.hk/human_hrec/view.php?secid=2551

Time: A major issue!

- An HREC review for staff research can take 4-6 weeks or more, depending on the "season," reviewers' availability, your availability etc.
- To apply for research ethics approval , you need to submit:
  - Application Form for Ethical Review, including open-ended sections describing research, protection of participants & data, etc.
  - Research proposal
  - Questionnaires, interview scripts
  - Consent forms to be given to participants / parents / school (organization)
- After ethics approval given: School/organization approval and parental consent may be required.
  - Signatures from school principal, parents, as well as participants…?

Time: Solutions

- Please submit the Ethics application **more than a month** before you wish to begin the research
  - Students need to plan even more time, as both the supervisor and approving committees need to find time to review the application
- **Questionnaires / Interview scripts: submit the "best draft"**
  - Minor changes after the ethical approval *may be* OK (don't need separate approval) as long as experimental procedures will not change in *ethically important ways.*
  - For example:
    - do not **newly** ask any potentially sensitive information of the participants (e.g. drug use; sexual activity; etc.),
    - do not **newly** recruit children as participants,
    - do not introduce **new** recruitment procedures that could pressure potential participants to participate
    - do not **change** anonymity or confidentiality of data (e.g. newly deciding to take videotapes or other recordings)
- When planning your project, you may need to plan time to get organizational & parental consent

Some mistakes to avoid:

- Thought it wasn't research & didn't apply for ethical review before collecting data
  - When in doubt, apply!
- Did not attach (draft) questionnaire and/or interview questions
- Did not include consent forms for **parents** or school when needed
- Information sheet and application form don't match
- On information sheet, describing the purpose of the study, but not giving information about the procedures
  - Should have basic information for informed consent, e.g. "The participant will fill out a **10-minute survey** about his/her **opinions about Active Learning Activities**"
- "Project from" date: This should be the date when you wish to start **data** collection (ideally 4+ weeks after your submission date)
- Before submitting your ethics application, please check it yourself using the "Reviewer Checklist" handout to avoid common oversights.

2. Knowing and Fixing Ethical Issues
about doing Research with Human Participants

A question for you:

Which ONE is correct?

- **The Human Research Ethics Committee (HREC) has reviewed a study and determined that participating in the study will likely make the participants feel uncomfortable and embarrassed. Could the HREC allow the researchers to begin this study?**

a. No; if any aspects of research studies are harmful in any way, HRECs cannot allow them.
b. Yes; the HREC examines only whether participants will be in physical pain.
c. Yes; as long as participants are not overly harmed and the research has significant value.

Ethical Research will *Balance* Risks and Benefits

All research should be designed:

- With a positive purpose in mind and be of benefit to individuals and society
- To avoid harm or risks to participants

- *But sometimes some risks are unavoidable!*
- Risks should be reduced as much as possible (try to make your research "Minimal Risk") and if risks are unavoidable, risks and benefits should be in balance.
  - E.g. if deception is necessary, are the benefits great enough to outweigh the deception?
- Benefits to participants can be increased, too

Risk : **Benefit** ratio
What are the benefits of your research?

- Doing your research WELL can benefit everyone
- **Research Merit:**
  - Important research questions, excellent methods
- **Research Integrity:**
  - Honesty, Accuracy, and Objectivity in evaluating and reporting evidence
  - https://grants.nih.gov/policy/research_integrity/what-is.htm
  - For example: If your results do NOT support your hypothesis, you report that, honestly, strictly, and with thoughtful analysis! (Students: It's TOTALLY FINE and YOU CAN STILL GET AN A.)

Risk : Benefit ratio
What are the risks of your research?

Aiming for minimal-risk means trying to NOT VIOLATE these basic research participant rights:

1	Right to refuse to participate	=	fully free to choose to NOT participate, without fear of consequences
2	Right to know what your research is about before consenting	=	Adequate information about research given to people who are competent to make decisions (leads to "informed consent")
3	Right to avoid negative outcomes and have positive outcomes	=	• to not feel social, mental, or physical discomfort, etc. • to benefit from the research as much as possible
4	Right to confidentiality of their data	=	participant data is anonymous, or individuating information hidden safely (confidential)

Minimal risk research means:

1	No excessive **inducements** to participate *(right to refuse)*	• E.g. personal pressure, or even too much $$$$.... • If student-teacher relationship exists, teachers should emphasize to their own students that they are free to NOT participate in the research, with no bad consequences
2	No **deception** (*right to know*)	• E.g. Purpose of study should be fully disclosed at beginning of the study
3	No "**undue psych. stress**" or "**discomfort** higher than a reasonable level" *(right to avoid negative outcomes)*	• Questions / methods will avoid embarrassment or discomfort for participants • No questions asked about "**sensitive** aspects of the participant's own behaviour such as **illegal conduct, drug or alcohol use, and sexual conduct**"
4	**Anonymous / Confidential** *(right to confidentiality of data)*	• Data should be fully anonymous (no names, student IDs etc.) whenever possible; or if not, then only "identifiable by codes known only to the researcher" (as stated in model consent form)

After submitting your ethics application, what changes can you make?

- When applying for ethics approval, you can submit a "rough draft" of your questionnaires / interview scripts etc. , as long as you don't make "ethically important" changes later:

- **Questionnaires / Interview scripts: You can submit your "best draft."**
  - Minor changes after the ethical approval are OK, don't need another approval, as long as experimental procedures will not change in *ethically important ways.* For example:
    - do not **newly** ask any potentially sensitive information of the participants (e.g. drug use; sexual activity; etc.),
    - do not **newly** recruit children as participants,
    - do not introduce **new** recruitment procedures that could pressure potential participants to participate
    - do not **change** anonymity or confidentiality of data (e.g. newly deciding to take videotapes or other recordings)

"Ethically important" = affects participant rights.

- **Which participant right(s) would the following changes affect?**

1. Right to refuse to participate
2. Right to know what your research is about
3. Right to avoid negative outcomes and have positive outcomes
4. Right to confidentiality of their data

Questionnaires / Interview scripts:
Minor changes after the ethical approval are OK, don't need another approval, as long as procedures will not change in *ethically important ways*. For example:

1. do not **newly** ask any potentially sensitive information of the participants (e.g. drug use; sexual activity; etc.),
2. do not **newly** recruit children as participants,
3. do not introduce **new** recruitment procedures that could pressure potential participants to participate
4. do not **make data less anonymous** or less confidential (e.g. newly deciding to take videotapes or other recordings)
5. do not make your consent process more **lenient** (e.g. originally say you will get parent approval, then later decide this is too much trouble)

Risk : **Benefit** ratio

Aiming for *ethical* research also means BALANCING these rights with the needs for **Research Merit** (more discoveries with excellent methods).

If your research is riskier on one, balance it with another, & vice versa.

1	Right to refuse to participate	=	fully free to choose to NOT participate, without fear of consequences
2	Right to know what your research is about before consenting	=	Adequate information about research given to people who are competent to make decisions (leads to "informed consent")
3	Right to avoid negative outcomes and have positive outcomes	=	• to not feel social, mental, or physical discomfort, etc. • to benefit from the research as much as possible
4	Right to confidentiality of their data	=	participant data is anonymous, or individuating information hidden safely (confidential)

Typical ethical issues at Different Stages of Research

What to watch out for, and how to address them!

How to solve potential ethical issues at all stages of research

1. Recruitment of participants
   - How will you find them without violating privacy? How will you ask them to participate without coercing them?
   - Compensation: How much will you be giving them? Is it too much?
2. Informed consent and Consent & Information Sheet
   - What do participants need to know so that they can give informed consent? Have you told them everything about compensation, method, risks & benefits, privacy?
   - Is parental/guardian consent needed? Etc.
3. Methodology: Care and protection of participants
   - Could the kinds of questions or activities cause discomfort, embarrassment, loss of reputation, etc? How can you minimize this?
4. Privacy and confidentiality of Data
   - How will you anonymize data? If your data will not be anonymous, what promises do you make about keeping it confidential?
   - How will you prevent data leakage, esp. individually identifying information? Or, will you publicly share data– if so, how to hide individually identifying information?

(Stage 1 / 4) Recruitment

Participants may worry:

How will you find me & persuade me to participate?

Examples of potential issues: Recruitment

- *Main concerns:* *Privacy / confidentiality (4), Right to refuse (1)*
- Does how you recruit particular populations make privacy an issue?
  - E.g. students with ADHD: Parents don't want you to know…
    - Possible solution: *Intermediary*. Ask those who know the diagnosis to privately pass consent / information sheets to potential participants
- Are power relations existent and an issue?
  - E.g. recruiting one's own students; difficult to refuse you
    - Possible solution: Verbal assurance / explanation to participants that this is not a school assignment; they have the right to refuse to participate & can do so without consequence
    - Possible solution: Make refusal of participation as anonymous / hidden as possible. E.g. : Intermediary, leaving the room, no names on survey
- Are you tempting participants too much?
  - E.g. Paying poor participants a lot of money; difficult to refuse
    - Possible solution: Find evidence of what an appropriate reimbursement is in that context

(Stage 2 / 4) Consent & Information sheets

Participants may worry:

Before I agree, tell me: what will I do, and why?

Examples of potential issues: Informed Consent

Main concern: *Right to know before consenting (2)*

Before starting a study, the participant should read an *Information Sheet* and sign a *Consent Form*.

The person signing should be giving *informed* consent: So that they understand **what** they will do and **why** the research is being done.

- Sample editable consent form templates, for participants, parents, and organizations, are available (see Moodle)
- But….

DO NOT BLINDLY USE THE TEMPLATE PROVIDED!!!

- …if it is not totally applicable…! (e.g. data anonymous, not confidential; addressed to children instead of parents; written in language participants wouldn't understand)
- Carefully consider if the template is accurate for your study, and please EDIT.

What should be included in information sheet?

- Participants need to know:
  1. What is the **purpose** of your research?
  2. What will they be asked to do as part of your research? (**Procedures**: What kinds of questions or activities? How long will it take?)
  3. **Where** will the findings and data **go/be reported** later? (Journal? Conference? Etc) Will identifying information be shown?
  4. How will their **data be stored**– will it be anonymous, etc.?
  5. What are the **potential risks** of participating in your research?
  6. What are the **potential benefits**? (e.g. is there payment? Or benefits to your academic field, in general?)
  7. They also need to be REMINDED that they have the right to halt participation (**choose not to participate**) at any time

Informed consent from whom?

Also: Carefully consider **who** should be informed of an individual's participation

- Who would expect to be informed that the research is happening?
- What if participants are not able to give consent?

- Unique consent/information sheets may be needed for:
  - Site/School consent
  - Parent/guardian consent
  - Child consent

Informed consent: from whom?

- Who should be asked for consent, additionally or instead of the participant?
  - *Consider: Who **can** or **should** give "informed" consent: the participant, a parent/guardian, an organization?*
- If your participants are:
  - 5-year-olds in a kindergarten
  - EdUHK Students, 18 years old
  - Some other school's students, 18 years old
  - Adult cancer patients currently in the hospital
  - 16-year-olds
  - Autistic 16-year-olds
  - 16-year-olds, and you'll ask them to do something potentially harmful to them

EdUHK rules about who must give consent:

If taking place in a non-EdUHK site, find out if you need approval & how to obtain it (e.g. generally required from school principals; other universities may have an ethics review system. Ask the site.)

Age-specific rules: from the "HREC Operational Guidelines and Procedures:"

(i) For children aged below 9, only signature of their parents/guardians on consent form is required; completion of the task, after verbal explanation of its nature by the researcher, provides implied consent by the child;

(ii) For children aged 9 to 15, signature of both the children and their parents/guardians on consent form is required; and

(iii) For adolescents aged 16 to 17, signature of the adolescents on consent form would be required, while consent from their parents/guardians is optional for studies involving [only] minimal risk.

*If it is **more than** minimal risk, parental/guardian approval is required.*

(Stage 3 / 4) Methodology

Participants may worry:

Will I suffer if I do in this study??

Examples of potential issues: Methodology: Surveys

- *Main concern: Avoiding negative outcomes (3)*
- Be careful of your wording.
  - Is there possibility of questions being intrusive, inappropriate, offensive?
  - Are demographic details appropriate/necessary?
  - Are the topics under investigation/measurement appropriate to the participants?
    - Are there religious, social, gender, economic, or cultural issues that might make particular questions and demographic details inappropriate?
    - Choose selectively & edit to make it more appropriate.

What topics are inappropriate?

- Pay attention to the local context & concerns particular to your participant groups
- e.g.: What kinds of questions would be inappropriate to ask:
  - Elementary school students?
  - LBGTQ+ students?
  - University students in Mainland China?
- For example, from wjx.cn:

Examples of potential issues: Methodology: Experiments

Is it ethical if you do not reveal the existence of two conditions (in the consent form)?

- *Main concern: Right to know about research before consenting (2)*
- Is the deception absolutely necessary (for "research merit")?
- What can you do to minimize the negative effect?
  - Debriefing; Minimize the deception (don't actively deceive)

Is it ethical if you provide a presumably beneficial treatment to the experimental group but not to the control group?

- *Main concern: Right to avoid negative & have positive outcomes (3)*
- If unequal benefits accrue (e.g. educational benefits), what can you do to reduce unfariness?
  - Control group = waitlist group?
  - Note: For very strong benefits (e.g. lifesaving medical interventions), experiment may be ended as soon as benefits are evident, & provided to control group.

(Stage 4 / 4)
Data Confidentiality

Participants may worry:

Where will my personal data go-- who will know my answers?

Examples of potential issues: Confidentiality/Data management

- *Main concern: Right to confidentiality of data (4)*
- Information about data storage should be *given* to participants, in their Information Sheet.
  - Participants should be told how long you will keep their data, and in what format (identifiable or not, etc.)
  - Personally identifiable data should be kept confidential, and ideally anonymous (= identifiable information destroyed)
  - Security issues related to data must be addressed:
    - How will you anonymize stored data?
      - Do you even NEED to collect non-anonymous data…?
    - Where will you store the data: office, password protected computer? Who can get access to the data? How long the data will be kept for?
  - More sensitive data = more sensitive data storage

Examples of potential issues: Confidentiality/Data management

- If data is not anonymous (names/IDs on a survey; photos; recordings; etc.), how should you hand it to prevent that identifiable data from being "leaked"?
  - (Think about both *on-paper* and *on-computer* data)
  - Survey with ID: Have identifiable data on a *separate page* from the rest of the survey; *tear that page off* and make the connection with codes only
  - Computer data files: Have *two separate data files* on the computer. One has name/ID and a Code; other has Code and the rest of the data.
  - Computers (and, ideally, files) should be password-protected; only certain people should be able to see identifiable data

Benefits: How to increase them?

- *Main concern: Benefit vs. risks*
- You may think about, and tell REC about, the specific benefits that will come about from your research; either for participants directly, or for the world at large
  - Address the benefits in your research proposal (why this study is important to the field, why it is high-quality research, etc…)
  - Remember that publishing your research can be a benefit… (to whom or what…?)
- If possible, report your findings to your participants, so that they may personally benefit from the new knowledge
  - E.g. give participants a link to a webpage where you will eventually post the findings… Collect email addresses to which you will eventually send a soft copy of the final report…

Final words

Importance of Ethical Clearance

Ethical clearance will help to **PROTECT** the following parties:

- The participants
- The researcher himself/ herself
- The University

Declaration of Ethical Clearance

For any **research with human participants** *(i.e. is not merely a class project or exercise, but collecting data for the potential purpose of expanding human knowledge & public dissemination):*

- Make sure that ethical approval has been obtained **BEFORE** contacting any participants!
- You **MUST NOT** proceed with any data collection until ethical clearance has been obtained. **This is both an international and UGC requirement.**

UGC 大學教育資助委員會 University Grants Committee

Research Ethics is all of these:

Increasing benefits

- **Research Merit:**
  - Important research questions, excellent methods
- **Research Integrity:**
  - Honesty, Accuracy, and Objectivity in evaluating and reporting evidence

Reducing risks

- **Protection of Human Participants:**
  - Prioritizing rights of participants over your own self-interest
    - Right to informed consent; Right to refuse; Right to avoid harm; Right to know what will happen to their data.

Thank you!

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(Beyond the basics: Discussion slides for Staff Briefing)

What needs HREC review?
(research ethics vs. ethics)

- You are applying for a TDG. You will:
  - A) start a website that showcases some past student work.
    - Depends: Do you want to use anything here as research data?
  - B) interview your own students about their experience in your class.
  - C) introduce e-learning in one class, but not in another.
  - D) ask students to take exams on their content knowledge.
    - Depends: Do you want to use the exam scores as research data?
  - E) ask students to fill out a survey about their class experience.
- **Which need to be described in your HREC ethics application?**
  - Answer: If an activity may be used for "research purposes," describe it.
    - Research: will contribute to generalizable knowledge, may be disseminated in public
- What if you're not sure? Talk it out with someone; err on the side of caution; and / or ask HREC secretary for advice
- Note that there are certainly ethical issues with (A) that should be addressed (e.g. consent from students, anonymity, etc.)– but HREC can't review ALL of your ethics… only how you are doing research. ☺

What could you do to ethically handle these problems?

- You will do a survey in school during school hours
  - Problem: Will students who don't consent feel uncomfortable? What will they do at that time?
- You will do interviews and want to tape-record them for later coding
  - Problem: What can you do to protect confidentiality and / or to make them anonymous?
- Your friend would like to collect data at EdUHK
  - Problem: Should you apply for ethics approval here? [yes]
- You would like to collect data at CUHK / etc.
  - Problem: Should you apply for ethics approval here or there or both…? ASK your friend at CUHK.