Research Ethics in Social Research

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Session Outline

Part 1: What is research and why do we do it?
- People in research, what is ethics, why should we be concerned about ethics in research?
- Research Ethics Committees

Part 2: Incorporating Ethics Principles into your Research Project Before you Start
- Designing your study
- Recruitment & consent forms
- Applying for ethical approval & writing your ethics application
- REC response

- Part 3: Incorporating Ethics Principles into your Research Project During your Research
  - Children in the research process, debriefing participants, managing your data

- Part 4: Incorporating Ethics Principles After you have Completed your Research
  - Ethics in the write-up & publication

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Part 1

What is research and why do we do it?
What Is Research?

There are many definitions but one commonly accepted one is...

“Research is a formal, systematic application of the scientific approach to the study of a problem to discover new information or expand and verify existing knowledge”

[45 CFR 46.102(d)]
What is a human participant?

“A living individual about whom an investigator (professional or student) conducting research obtains;

1. Data or
2. Identifiable private information
Through intervention or interaction with the individual.”

[DHHS 45 CFR 46.102(f)]
What Do We Mean by Ethics?

• Morality or ethics represents a code of conduct that governs how people treat each other.

• In essence, it is concerned with the way people act or behave.

“The term ‘ethics’ usually refers to the moral principle and guiding conduct, which are held by a group or even a profession” (Wellington, 2015).
Ways of understanding and examining the moral life, or of right and wrong human conduct.
Why Be Concerned About Ethics In Research?

• If the objective of research is to “discover new information or expand and verify existing knowledge” it is important when conducting research involving people that this knowledge does not come at the expense of their welfare or rights.

• Research ethics provide a guideline or set of principles that support researchers in conducting research so that it is done justly and without harming anyone in the process.
It is the duty of the researcher to ensure they are carrying out their research project in line with established ethical standards.

Every step of the research project, from formulating your research question to publication, needs to be informed by ethics to ensure integrity of the project.
Ethical research ensures that the scales remain balanced.
Ethical guidelines were created in response to

1. Ethical lapses in research.
2. Provide answers to new problems and challenges in research.

Research history tragedies
   – Nazi experiments in WW2
   – Tuskegee Syphilis Study
Brief History of Research Without Ethics

Outcomes

• The Nuremberg Code
• The Declaration of Helsinki
• The Belmont Report

The establishment of early fundamental principles for ethical research:

• Respect for persons
• Beneficence
• Justice
Universal Guiding Ethical Principles Today

1. Autonomy
2. Free and informed consent;
   – Information,
   – Voluntariness and
   – Comprehension
3. Veracity
4. Respect for Vulnerable Persons
5. Privacy and Confidentiality
6. Justice and Inclusiveness
7. Harms and Benefits
   – Minimising Harm (Non-maleficence)
   – Maximising Benefit (Beneficence)
REC’s were established to

- Have formal procedures in place to monitor and assess the ethical standards of research within institutions
- Aid and support staff and student researchers in maintaining exemplary ethical standards in research within the school
- To foster a culture among staff and students that is sensitive to ethical considerations where research with people is concerned
The Role of REC’s

1. To receive research proposals involving human participants, human material, or human data from students and staff

2. Consider any ethical issue that might arise from carrying out this type of research

3. To decide whether
   - The research should proceed as planned
   - Or whether it needs to be modified in some way
     (more detail on this below)
Part 2

Incorporating Ethical Principles Into Your Research Project: Before The Research Process
There are a wide variety of research methods available to social researchers, and they each raise their own ethics questions.

Key Question:

How well do your chosen methods fit the aims of your research and what, if any, ethical challenges do they pose?
• What are the ethical strengths and limits of the methods?
• Have they been used ethically in a similar context before?
• Are they respectful of your respondents’ capacity and willingness to participate? Some methods will work better with some groups than with others.
• Are there any potential unintended consequences of your research, e.g. disclosures of sensitive information, that may arise through those methods, potentially causing stress or embarrassment?
• Do the methods proposed fit with the ethics principles mentioned earlier in the webinar? If not, can the exception be justified? Is what you are proposing to do justifiable in terms of the benefits, risks and harms of your research?
Sampling

• Selecting samples or groups of people to study is one of the first tasks in designing your study, and the first ethics question you face in sampling is who you include, or exclude.

• You should be clear about why the people you want to study need to be involved.

• You should also reflect on who is left out of your study, and why.
Sampling

• Your sample will often determine which ethics committee you need to go to, and who you need to seek permission from, so it is critically important to think through the ethical implications of the sampling strategy you develop.

• If your sample includes particular groups in the population, such as children and young people, or vulnerable adults (a person aged 18 years or over who may require assistance to care for themselves, or protect themselves from harm or from being exploited) you will have additional requirements and considerations to address; for example getting consent from guardians, as well as the participants.

(more detail on this below)
To recruit potential participants, you need to provide them with information about your project, in order for them to be able to give you their fully informed consent.

Informed consent comprises three major elements:

– Information
– Voluntariness
– Comprehension
**Information & Consent**

- **Information** - When providing information researchers must ensure that participants are given sufficient detail about the nature of the research and the procedures involved; the information should highlight the objectives of the study, and any potential risks and benefits.

- **Voluntariness** - Consent must be freely given and may be withdrawn at any time. Undue influence may take the form of inducement or authority over prospective participants.

- **Comprehension** - Voluntary participation implies that participants make an informed choice while informed consent assumes that the information given is accurate. Both principles are underpinned by the principle that participant understands what it is they are being asked to participate in.
The way in which you provide information depends on who will take part in your research. You can provide information about your research in a number of ways such as with a DVD or in writing (whether on paper or in a webpage).
Recruitment of Research Participants

• The usual approach is to provide an information leaflet, and ethics committees will often expect you to do this (and want to know why you are not, if you don’t).

• Ethics committees sometimes prefer information leaflets (or require them) because they can check that a leaflet includes all the information that a potential participant might need to ensure valid.
Information Sheets – What to Include (1)

• Who you are (the members of the research team and their contact details)
• The aims of the research
• What the research involves:
  o how participants have been identified and approached
  o what participation involves, e.g. will the research participant be asked to take part in a 1:1 interview, in a focus group or to complete a survey
  o Identify any risks, inconvenience or discomfort, if appropriate, or any benefits...but be careful not to promise benefits if there are none
• If the research is linked to a service that participants are receiving, e.g. like teaching or social work, you need to reassure the participants that the service they receive will not be affected, whether or not they decide to take part in your research study.

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What happens to the data they provide as part of your study, including issues of confidentiality and anonymity in terms of how:

- Will the participant have access to their data; how will you manage this if data is collected via a focus group or other group-based data collection method
- Findings will be reported
- Who will have access to the data once collected
- How it will be securely stored
- How long it will be kept for

Are you or other researchers likely to use your study’s data for other research projects? If so, you will need to include a general statement seeking consent for their data to be archived and to made available for future research.

What will be done with the research, e.g. will there be a report, a briefing paper, a multi-media product etc.?
Confidentiality

• As part of the ethical guidelines; confidentiality of information supplied by research participants and the anonymity of respondents must be respected.

• In practise, this means that you must inform potential participants what is going to happen to the data they provide so they can make an informed decision about whether they want to participate in the study or not; and then follow through on whatever assurances you have given them both during and after your project.
Anonymisation & Confidentiality

Anonymisation
• How you ensure that the participants in the research and evaluation process cannot be identified

Confidentiality
• How you protect the identity of your participants during the collection, storage and analysis of your data and in the reporting of your findings
Limitations of Confidentiality (1)

While it is important that you both assure participants that their data will be kept confidential and ensure that it is, there are limits to this confidentiality:

• One reason for breaching confidentiality relates to a duty of care if you are concerned that someone could be at risk of harm.

• That could arise because a participant tells the researcher something that causes significant concern, or it could be something that is observed during fieldwork, such as an illegal activity.
• Alternatively, confidentiality may be limited because the nature of the research means that interviewees are potentially identifiable:
  o you are doing small a number of interviews
  o you have a public interest duty because of something that a participant reveals
• You should make sure that participants are clear of the limits of confidentiality in your project, and plan for the unexpected, in as much as you can.
• Once a potential participant has been given clear information about your study, and some time to reflect on what is being asked of them, they will then be able to decide whether they wish to participate in it or not.

• If they do agree to take part, you will need to give them a consent form which is a sheet that asks them to sign their name if they wish to participate in your study.
The consent sheet should include statements that:

- They have read and understood the participant information sheet
- They have had the opportunity to ask questions and had them answered
- Taking part in the study is voluntary, and there will be no penalty or loss of benefits if they do not want to participate.
- If they do to agree to participate in your research they are still allowed to change their mind and stop at any time, without having to face any penalties or loss of benefits as a consequence.
- If you wish to audio-record their contribution, then you should ask their permission to do so.
The ethics of research with children is a balance:

- Preventing and reducing potential harms of participating in research and ensuring adequate protections of children and young people.
- Avoiding the exclusion of children from research silencing their views and experiences.
The same ethical principles that apply to research with adults apply equally to children, however, there are also four additional considerations that are specific to research involving children:

i. Children’s competencies, perceptions and frameworks of reference, which may differ according to factors including, but not only, their age and developmental stage, and may differ from those of adults;

ii. Children’s potential vulnerability to exploitation in their interactions with adults, and adults’ specific responsibilities towards children;

iii. The differential power relationships between adult researcher and child participant; and

iv. The role of adult gatekeepers in mediating access to children, with related ethical implications in relation to informed consent.
The key points are as follows:

• You **must** get initial consent from gatekeepers, usually a parent

• In the absence of a parent, then you must get initial consent from the child’s guardian or other responsible adult with a duty of care for the child – and you need to consider who you have to get permission from.
This permission does not mean the child has consented to participate, but it allows you to seek consent from the child.

- You should get active consent from each individual child
- It is not sufficient to seek consent from children as a group, as children may feel pressurised into agreeing, against their wishes

If you are not going to get consent from each individual child, your approach is very likely to be questioned by an ethics committee, and so you need really clear justification.
Remember:

• The child is the participant, not the gatekeeper.
• Ethics principles about consent should always apply to the child – whatever the child’s age.
• Start from a position of assuming competence, do not assume children are incompetent, but recognise the need to adapt your methods for seeking consent to their level of understanding.

In practise this means:

• You will either have to create a consent form for both the adult gatekeeper, as well as an additional child-friendly information and consent form for the child to sign if they wish to participate in the study.
• You will need to consider what you will do if an adult gatekeeper consents to the child participating but the child does not consent.
You have designed your study and now need to gain ethical approval to carry it out.

- You can do this by downloading and filling out the application form particular to your institution, and submitting it your Research Ethics Committee.
Use the application form as a prompt for discussion and reflection on your study design:

- How would different team members or colleagues answer questions on the ethics application form?
- Do you all share common understandings of the ethical requirements and how they relate to your study?
- Does anyone have any worries about the ethical issues involved in your study?
- Have you considered and prepared for unlikely but possible outcomes relating to your study that may present ethical concerns?
Even if you are familiar with writing ethics applications, they can serve as useful exercises when conducting research by using them as:

- a mechanism for discussing ethics within your team, or with your supervisor or mentor;

- a way of preparing you, and less experienced researchers, where appropriate, for fieldwork.
The REC will write to you with their response to your application; they will either accept your application, ask you to modify it and re-submit, or reject it outright.

- The first step in dealing with the REC’s response is to make sure that you understand the reasons for the Committee’s decision, and you know what you are being asked to do.
- Read the Committee’s response carefully and:
  - discuss it with colleagues on the research team
  - it can also be useful to get a fresh perspective, from someone who is not involved in the study
• If you have applied to an external ethics committee, it can sometimes be helpful to seek advice from someone involved in your institution’s ethics committee – especially if you have significant concerns about what you are being asked to change.

• If the rejection has come from your institution’s ethics committee, you can usually approach the committee chair for a more detailed explanation of the decision.
Ethics committee requirements often fall into one of three categories:

1. **Asking for more information**, e.g. to clarify something in your application, or to address something the committee feels you have missed out.

2. **Minor changes**, e.g. changes to the wording of a consent form, information sheet, or even an interview schedule or questionnaire.

3. **Significant changes** to your research design, e.g. a change in your sampling strategy or research method.
Go through the comments/recommendations you receive and see which of these categories different elements of the responses fall into. Work through each of the points in turn, and ask yourself:

• Do they have a point?
• Have they picked up on something you had not thought of?
• Is it simply that something needs more explanation?
• Are they asking you to change the way you do something? What would that mean?

Use the answers to those questions to help you to plan your response.
Part 3

Incorporating Ethical Principles Into Your Research Project: During The Research Process
General Points To Consider...

- As mentioned earlier participants should be recruited ethically by providing them with the appropriate information about your research so that they can make an informed decision.
- Extra time should be taken when recruiting participants so that they have a chance to voice any questions or concerns about your study. This is not only vital to the informed consent process but is also valuable for the researcher as it ensures participants fully understand the research, builds trust and can help to maintain participation in the study.
When conducting your research, participants should be reminded that they:

- Do not have to do or answer anything they do not feel comfortable with
- That they can leave at any time without penalty or loss
- That they can take breaks whenever they wish
Power Relationships

As a researcher you should be mindful of the disparities in power between adults and children (Morrow & Richards, 1996). For example, but not limited to, teacher-led studies:

- Where children are used to engaging with their teachers in a different way
- The teacher has a personal or professional stake in achieving student participation
- The teacher has a personal or professional stake in the research findings e.g. assessing class scores, assessing child behaviour, etc.

You should ask yourself: Is there a possibility of appointing an individual from outside the organisation to act as an intermediary?
Sensitivity to specific needs

• Research should not unjustly single out or overburden any group of children

• Researchers should be sensitive to the diversity and individuality of children, and be scrupulously non-judgmental with regard to the children’s care experience or family circumstances

To ensure an ethical approach, you should discuss the specific ethical issues with people who work with the children on a daily basis and, if possible, with representative groups of the children to be studied.
• Research involving the use of standardised measures will require researchers to pay particular attention to potential risks or discomfort for the children in relation to:
  o the duration of the testing period;
  o whether the research procedures or interventions are reasonably comparable to past tests or treatments undergone by the children and their knowledge and understanding of the treatments that they might undergo in the future;
Ethical issues of using group-based methods:

Researchers need to be aware of the risks associated with research methods that allow for unpredictable interaction between participants or when potentially sensitive topics are being investigated. For example,

• There is a risk of limited confidentiality when children participate in the research process as they might accidently repeat sensitive information they learn about other participants to those not involved in the project.

• There is also a risk that children may overshare or contribute sensitive information during the data collection process that may put them in danger of being ridiculed by their peers later on.
Debriefing Your Participants (1)

What is debriefing and why should you do it?

• “The purpose of debriefing is to remove any misconceptions and anxieties that the participants have about the research and to leave them with a sense of dignity, knowledge, and a perception of time not wasted” (Harris, 1998).

• The aim of the debriefing is not just to provide information, but to help the participant leave their engagement in the research process in a similar frame of mind as when he/she entered it (Aronson, 1988).
Once a participant has completed their participation in your study, you should:

• Thank them for agreeing to take part.
• If relevant, remind them if they will be given an opportunity to review their transcript.
• Explain the purpose of the study again, the logic of it, what you predict and possible applications of this work, if relevant.
• If the study involves any kind of possible stress, however mild it might seem, e.g. in answering a depression or anxiety questionnaire, the participant must be told to whom and where they can access support after their participation.
Debriefing Your Participants (3)

• Inform participants that if they would like any information about the results of the study once it is completed, they should feel free to contact you. Provide a name, your own or that of your supervisor, along with up-to-date contact information that they can take with them.

• You should provide one or two complete and easily accessible general references for those respondents interested in learning more about your topic. The articles should be obtainable from a website if possible. Conference proceedings, book chapters and technical reports are all harder to access and therefore should not be included unless available in PDF form from the author or supervisor.
• Should you need to ask participants to refrain from talking about the experiment while you are still running it, you should explain why.

• If time is a factor in your research you should make a debriefing sheet with some or all of this information so that the participant can peruse it later at their leisure. Sometimes a REC will require you to do this as part of your application.
Dealing with data is a key element of research ethics, regardless of whether you are collecting new data, or if you are using existing data for secondary analysis or review.

Data management is also increasingly highlighted by funders and research ethics committees as an explicit priority for researchers.

In part this reflects the legal requirements of the Data Protection Act, but this concern is fundamentally rooted in key ethics principles, about the anonymity and confidentiality that participants are promised when they give their informed consent.
Tips For Anonymising Your Quantitative Data

Quantitative data

• Remove direct identifiers, e.g. personal information such as names and addresses

• Aggregate or reduce the precision of variables that might be identifiable, e.g. recode postcode or neighbourhood data to Dublin North, Dublin South; Galway urban, Galway rural.

• Generalise text variables to reduce identifiability

• Restrict continuous variables to reduce outliers

• Pay particular attention to anonymising relational data, for example, some anonymised variables may become identifiable when considered in combination, combining location with special educational needs.
Qualitative data

- Anonymisation of qualitative data can be particularly complex, and is not simply a matter of removing personal information such as names or addresses, or of using pseudonyms.
- You do not need much of somebody’s life history to work out who they are, if you know them, or if they are distinctive in some way.
- A distinctive event or combination of descriptions in a qualitative account could make somebody recognisable.
These concerns can mean that qualitative data may need some editing to ensure their anonymity. When the data editing is complete, researchers should take care that:

• The editing has not distorted their data or changes what the data is telling you, for example, deleting all possible identifiers from text or sound recordings is a simple but blunt tool that creates data that are confidential but may be unusable.
Whether you are collecting new data or accessing existing data, you need to consider:

• How your data will be stored
• Who will have access to the data
• If, and how the participants will be able to access data

• Your planning should take account of what you need to do with hard copies, such as, paper notes of interviews; computer files with anonymised data that are not identifiable; and computer files with personal or identifiable data.
Research ethics is all about unanticipated events. You need to plan for unexpected and undesirable events, like leaving a bag on a train, or losing a USB stick.

What systems can you put in place to protect your participants, yourself and your institution if something like that happens?
Hard copies such as interview notes, prints of photographs, or video or audio tapes need to be kept securely locked away - for example in a locked filing cabinet that can only be accessed by agreed members of the research team. Ask yourself:

• Who needs to have access to hard data?
• Will these data be anonymised before they are stored? If not, why not?
• Will these data be stored separately from personally identifying data?
• Where will the key be stored?
• Could someone who should not have access to it, find your data and access it?
• How will you deal with hard copies in the period between data collection and data storage?
• Files - including computer files - that contain personal or identifiable data (such as names) come under the terms of the Data Protection Act.

• These files need to be encrypted or password protected, and only accessed by agreed members of the team.

• Particular care needs to be taken if you are sharing files within the research team - e.g. on shared computer drives, or by email - or if you are transferring personal data beyond the research team (e.g. if a gatekeeper is giving you a list of contacts).
Data Storage and Security – Computer Files

• If your research involves data that comes under the remit of the Data Protection Act - and most research does - then it is a good idea to check with the Data Protection Officer in your organisation, to see if there are any standard protocols you should be following.

• Computer files including those that have been anonymised still need to be held securely, and can only be shared according to the terms of your consent from participants. Thus - for example - you need to get prior consent from participants if you plan to archive data for use by other researchers.
• However simple or complex your data set, think about what you might need to do to ensure that your management of the data respects the terms of your consent, and in particular, the confidentiality and anonymity that participants were promised.
Part 4

Incorporating Ethics Principals After You Have Completed Your Research
Ethically Analysing and Reporting your Data

Mistakes you should avoid!

• Failure to deal ethically with non-random error (bias)
• Developing a post-hoc hypothesis, when using a deductive research approach, that is:
  o Data mining or looking at previously collected data sets for patterns rather than stating a hypothesis and then collecting data to test it
• Inappropriate statistical tests or procedures, which produce unreliable and erroneous results

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• Low statistical power
• Cooking the data – the practise of producing a group of values where you know or expect them to occur
• Trimming – not reporting an outlier when they are not justifiably omitted
• Cutting corners/ fabricating data – sometimes done to meet a publication deadline or other obligation
• Selective reporting of findings – reporting only what supports your hypothesis
Set ground rules for collaborations, including authorship, before you begin a collaborative research project.

Think about sharing data before you begin and if there is a possibility that you will want to share the data, include that in the informed consent documents, so that you do not share what was not authorised. By the same token you have an obligation to make sure that data that is shared with you was authorised.

Data should be archived for at least five to seven years so that others can re-analyse the results, or if your findings are challenged, you can go back and look at it again.
Grant and/or journal reviewers hear about new ideas as part of that process; if you are in this position it is unethical for you to take those ideas without giving credit to the originator.

Ownership is the primary means of giving credit, but also designates responsibility for the study and the results of it.

The use of anyone else’s discovery, words, ideas, data or analysis must be cited in a way that others can find the references and see the contribution.
Ethics Related to Publication

- Publication helps to fulfil the responsibility to the funding agency, the public and our participants. It is the point at which our academic/research community can assess, validate and further develop the results of your work. Articles should contain all of the information necessary for others to repeat the work.

- Fragmentary publication of the results of findings or multiple publications of the same or similar data are not appropriate.
• Publication credit should accurately reflect relative contributions to the research. Institutional position does not justify authorship credit. Minor contributions should be acknowledged in the introductory statement or in footnotes.

• After publication, if you learn of errors that change the findings, you are obligated to correct the error(s) in a correction, retraction, erratum or other means.
Canterbury Christ Church University Research and Development Centre (2014) An introduction to ethics issues and principles in research involving human and animal participants.


https://www.childrensrights.ie/childrens-rights-ireland/childrens-rights-ireland

Department of Children and Youth Affairs (2012). Guidance for developing ethical research projects involving children


The Ethics Guidebook on-line resource

http://ethicsguidebook.ac.uk/


Kennan, D., Forkan, C., and Brady, B. (2017) Children and young people’s participation in decision making with Tusla: a baseline assessment prior to the implementation of the Programme for Prevention, Partnership and Family Support


Pobal, (2014) Safeguarding Children, Young People and Vulnerable Adults Policy

References & Further Reading

Psychological Society of Ireland code of ethics

https://www.psychologica lsociety.ie/footer/PSI-Code-of-Professional-Ethics-3

Social Research Association Ethical Guidelines

http://the-sra.org.uk/research-ethics/ethics-guidelines/

The Tusla Research Centre

http://www.tusla.ie/research/tusla-research-office/ethics-committee


Google Book Sample
Thank You

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