Chapter 8: Analyzing Research Ethics

A. Introduction
B. The Rules of Research
C. Institutional Review Boards
D. Researcher and Participant Relationships
E. Analyzing Ethical Ambiguity

Introduction:

- The application of ethics in research field started in the mid and late 1970s, following the atrocities committed by the Nazi regime in the name of research, and the unethical medical practice committed by the U.S. Public health service such as "Tuskegee Study of Untreated Syphilis in the Negro Male".
- In that study doctors deliberately withheld medical information and treatment from African American males.
- As a result, the Department of Health, Education, and Welfare (DHEW) in the U.S. published the **Belmont Report, in 1979**.
- It included three ethical rules:

1. **Respect for person**: all people should be treated as autonomous agents, people with special autonomy such as children should be entitled to protection, research subject participate voluntarily and they should be given the adequate information about the study to decide.
2. **Beneficence**: "maximize possible benefits and minimize possible harms", "do no harm".
3. **Justice**: this regards people who benefit or who are burdened by the research findings and its educational innovations. "Whenever research supported by public funds leads to the development of therapeutic devices and procedures, justice demands both that these not provide advantages only to those who can afford them and that such research should not unduly involve persons from groups unlikely to be among the beneficiaries"(DHEW,179).

The Rules of Research:

There are 5 C's that each qualitative and quantitative researcher should be familiar with:

1. Consent: researchers have to clearly explain to the participants the exact nature of the study, what they hope to learn, what the participants will do, what information the researchers will obtain about the participants, and what will they do with those information. Thereafter, researchers have to ensure that the participants

understand what has been explained to them (ex: participants who are not English fluent can ask questions in other languages).
Finally, participants willingly consent to participate and they can revoke their consent at any time during the study without any repercussion.
NOTE: Researches on minors (<18 years old) generally need the minor's assent "nonlegally binding agreement" to participate and their parent's/guardian's consent. Either the minor or the guardian can terminate the participant's involvement at any time.

2. Confidentiality: **Anonymity** specifically means not sharing (or in some cases, never initially collecting) the identity of participants; **confidentiality** means protecting the data that participants share.

   In some cases, when disclosing the participants' identities would be a key feature of a project, a lack of anonymity is permissible. An example is a hypothetical study asking U.S. senators for their views on government efficiency.

   In some cases, such as studies on prisoners, researchers draft informed consent documents that clearly outline what the researcher will do to protect the participants' identities. Such documents will usually indicate that it is always possible that a participant would be identified. For example, if a participant shares a very specific story, it is possible that someone who is familiar with the story could determine the identity of the participant.

   Furthermore, there is always the small chance that security measures could be compromised. Even if all data are stored in password-protected files on a computer in a locked room, as most institutional regulations require, there is always a chance that someone will steal the computer and find a way to access the file.

   One way researchers can provide participants an additional degree of anonymity is by reporting the data they share in **aggregate form** rather than through direct quotes, by using statements that reveal that many of the participants share a certain theme of data, it is not possible to identify which specific participant shared this with the researchers.
   If researchers do want to share quotes, they can create **composite narratives** that bring together elements of interviews from different participants and stating that the quotes do not represent the views of one particular person, but rather have been constructed from a much larger corpus of data.

3. Comprehensive information: Participants are entitled to know as much about the study as possible in advance. this means participants should know upfront exactly what they will be asked to do or share, when and where the research will take place, for what duration, how many other participants will be involved, what benefits and risks they might face, and what will be done with the information they provide or that is collected from them.

4. Communication: It might be necessary to translate materials into other languages to ensure all targeted participants are able to enrol in a study. If a study includes children, their parents/guardians must also be able to fully understand all study materials in order to consent. Researchers should be prepared to translate consent forms into multiple languages.

5. Conflict-free research: Researchers working for universities and other public-sector research institutions must generally always avoid conflicts of interest in their research. This means that a researcher should not conduct research when some factors could prevent him from reasonable and objectively fulfilling his duties to the research project.

   In qualitative research, **conflict of interest** is stronger than a lack of objectivity. Conflicts of interest most often occur when a researcher serves as an officer or director with any organization that could be involved in his study, or if he holds a significant financial interest in such an organization. If a researcher or member of his family has any potential financial or other gain because of a study, he should recuse himself from it and not participate in any way.

   Conflicts of interest can also involve receiving gifts from organizations related to the study, or having relationships (familial, business, academic) with individuals or organizations who have a stake in the study.

   It is important to note that there might be instances when a university or other organization approves a researcher working on a study despite a conflict of interest, but the researcher should always disclose potential conflicts to avoid behaving (or appearing to behave) unethically.

Institutional review boards:

- Most rules have agencies or individuals who enforce them. ln the university context, this is most often the Institutional Review Board (IRB) (also sometimes referred to as a Human Subjects Review Board or an Ethics Committee).
- IRB's ultimate purpose is always to ensure the safety and well-being of human participants.
- IRB's aim to protect both researchers and their institutions from liability by ensuring that all research is conducted in a legal and ethical manner.

- Some IRBs might approve a generally solid proposal quickly, while others might require several rounds of revisions until all of their concerns are addressed.
- In general, researchers must have full IRB approval before beginning any work with human participants.
- Virtually, any study with minors as participants requires !RB application and review.

What Is **Human Subjects Research**?

Before submitting an IRB form, a researcher must know if his research is a human subjects research or not. Surprisingly, not all research with humans is considered human subjects research, and some work that might not at first seem to be human subjects research might be, under the guidelines of an IRB. For this reason, it is generally wise for new researchers to apply to their IRB for a research determination. Answering a few brief questions will generally allow the IRB to inform a researcher whether a study is considered human subjects research and if a full application must be submitted.

Example: Omasta, 2011 has conducted a study exploring if and how middle school students'' values, attitudes, and beliefs were affected by viewing a single theatre performance. In this case, because the purpose of the focus groups was specifically to learn about the participants themselves,, his IRB determined that the study was human subjects research, and an IRB-designed template was used.

However, in 2017, he has conducted another project when he has interviewed professional playwrights, directors, and other theatre professionals regarding their perspectives on writing plays for young people. In this case, because the participants being interviewed were offering their expert opinions about the topic rather than sharing information about their lives, Omasta's university's lRB determined that as long as participants were told the purpose of the project, their agreement to participate was sufficient and no formal written consent was required.

In other cases, a book or journal publisher might require a participant to sign a release that is similar to an informed consent document, even if an lRB does not require that step.

another factor an IRB considers in its determination of research of human subjects is the study's public **dissemination of results**.

Example: In a project conducted in a university department, If the findings are intended solely for departmental purposes and will not be published, an lRB might waive the need for the study's approval. On the other hand, if the findings are intended for a written report to be published in an academic journal on higher education, the IRB will most likely require a formal application from the principal investigator and all participants' consent to proceed with the evaluation study.

Review Types and Timelines:

Type 1: An **Exempt** study: معفى

- This includes studies involving the collection and analysis of public data, studies overseen by certain government agencies such as the Department of Health and Human Services, and studies involving taste and food quality. These studies do not require the completion of consent forms, but rather the distribution of letters of information for the participants.

Type 2: An **expedited** study: مسرَّع

- This is the next type of review in which only selected members of an IRB review the study instead of the entire board. Studies in this category might be those that would have been exempt but did not meet all requirements, studies on human characteristics and behaviour, collection of data from recordings, and a variety of medical studies subject to certain conditions. These studies will normally require informed consent paperwork and all standard requirements, but might be approved more quickly than those undergoing full review.

Type 3: studies that require **full review**:

- These studies are generally reviewed by every member of the IRB and therefore usually require several meetings of the IRB before the IRB grants approval. These are studies that do not meet the criteria for exemption or expedited review due to their complexity, multi-method research design, or sensitive research topics.

- Timelines:
  - One to two months for exempt
  - Two to four months for expedited
  - Four to nine months for full review studies

- Any of these timelines could be faster or slower depending on any given IRB, application, and factors such as the number of other applications under review.

- The review timeline varies by institution, but is rarely fast, so the earlier the application the better it would be.

IRB Applications:

The actual IRB application a researcher must complete will differ by the institution.

- **Project title:** insert the full working title of a project at the time of submission; the title itself should give reviewers a clear description of the nature of the study. For example, "An Ethnographic Case Study of a Sheltered Homeless Family in the Phoenix Metropolitan Area."

- **Principal and other investigators:** The principal investigator is the lead researcher on a study. It is important to note that at most universities, students (including graduate students) cannot serve as principal investigators; faculty mentors must serve as the principal investigator for IRB purpose, while students are listed as either coinvestigators or student investigators, depending on a particular university's policies.

- **Timeline**: List the full range of dates you expect the study to take, from the day it is approved until all data analysis and write-ups are complete. A study does not end the last day researchers work with human participants, it ends when the analysis is complete and, in most cases, when identifiable data are deleted or destroyed (a requirement of many IRBs).

- **Proposal and scientific validity**: Most IRBs will request a complete copy of the research proposal. Some will ask if it has been reviewed by an internal or external source for scientific validity and for documentation of that review.

- **Participants**: Describe the participant population in detail. This requires knowing the approximate ***number*** of participants broken down by ***gender*** and ***age*** range. It might be necessary to anticipate what percentage of recruited participants are expected to complete the study, depend on the literature in this. ***Inclusion and exclusion criteria*** should be mentioned, In general, avoiding any exclusion criteria is recommended unless they are necessary and justifiable for a particular project. Moreover, If using ***recruitment materials*** (such as flyers or posters seeking volunteers, or texts the researcher will ask teachers to read aloud to their classes), you will likely need to compose those materials beforehand and submit them at the time of IRB application submission.

- **Participant incentives**: Be prepared to describe and justify any participant incentives offered. These incentives include anything that researchers might offer to participants as compensation for their time (e.g., money, gift cards…). Note that participant incentives are often useful but sometimes prohibited as New York City Department of Education has done. A researcher should check with participants and partner organizations in advance about their own ethical guidelines related to participant incentives.

- **Vulnerable participants:** Federal law and local guidelines identify a number of populations as protected or vulnerable. These generally include minors, prisoners, senior citizens, pregnant women, people with physical or mental impairments, non-English speakers, and anyone else at risk for coercion. Certain settings such as schools, nursing homes, and hospitals might be flagged by an IRB, which will require justification for why the study takes place there.

- **Informed consent**: It will be necessary to describe in detail how researchers will gain informed consent from the participants and parents/guardians if necessary. This includes providing a copy of the consent document indicating who will get the consent and when, and how consent documents will be made accessible to non-English speakers.

- **Deception**: In rare cases where researchers must deceive participants to some degree in order to carry our a study, a request for deception must be made to the IRB. In mot cases, the IRB will grant the request only when the use of deception is absolutely necessary, when it will not have any negative impact on the participants, and when participants likely would have agreed to participate in the study even if they knew there was deception involved. When deception is used, participants must typically be debriefed (told of the deception) and given the opportunity to withdraw from the research and have any data collected from them while they were being deceived deleted.

- **Procedures**: Explain in detail exactly what the participants will do as part of the study (e.g., be interviewed, be observed as they go about their daily lives), including details as to how long and how often these procedures will take place. copies of all surveys, interview questions, and other data collection instruments must be included.

  The procedures section sometimes cause problems for qualitative researchers, especially those working with community-based or action research projects. These approaches often necessitate developing research questions once the researcher is already in the field working with participants to discover their needs, as opposed to

prior to beginning the study: Researchers engaging in these types of research should consult this problem with their IRB administrators.

- **Risks:** Explain the risks to participants, recognizing that there are always risks of one kind or another involved in social research. At minimum, it is important to acknowledge that, despite the researchers' best efforts, there is always the possibility that confidentiality will be breached. Explain how the risks will be mitigated, e.g., paper documents will be stored in a locked filing cabinet in a locked room, or electronic information will he stored in a password-protected file on a password-protected computer.

- **Benefits:** The benefits of a study should be described in detail and in such a manner that it is clear that they outweigh any potential risks. Research with no educational or scientific value is inherently unethical in light of its guaranteed risks.

- **Privacy**: Include a detailed plan for how confidentiality will be maintained, including a discussion of how nonparticipants will be prevented from identifying actual participants, to how files will be maintained, to how data will be reported in a way that maintains anonymity. Describe any recordings (audio, video, photographs) and discuss when they will be destroyed.

- **Mandatory reporting:** Your IRB might ask if a study has the potential to discover illegal activities, reveal that participants or others are victims of abuse, or other conditions such as suicidal thoughts. In these cases, explain how researchers might respond to these revelations. Be sure to follow both institutional policies as well as local, state, and federal laws. This might require some researchers to determine if they are a mandated reporter (university employees, including student employees, often are mandated reporters under various state laws), so it is imperative to be in line with legal and ethical requirements in these areas.

- **Conflicts of interest:** Most IRB applications will ask about conflicts of interest, so review each question and disclose any possible conflict, keeping in mind that such conflict might not interfere with your ability to conduct the study but you must report it nevertheless.

- **Informed consent documents:** Most institutions have template letters for researchers to work from, in which all basic information about what the study hopes to learn, what the participant will do, and the potential risks and benefits should be described.

CHECK FIGURE 8.4 IN THE BOOK AS AN EXAMPLE.

Researcher and participant relationships:

The relationships between researchers and their participants are professional, and ethical boundaries should. be maintained throughout any study. In most cases, researchers will not know their participants before a study begins, which makes it easier to establish neutral yet cordial relationships from the beginning. In rare cases, researchers will study participants they already know and have relationships with (e.g., a classroom teacher conducting a study with her students), but in most cases it is best if there is a degree of professional distance.

An ethical stance considers an equitable relationship that does not exploit participants for information but genuinely cares about and learns from them. Participants are more likely to share openly and honestly about their lives with someone they believe they can trust, and trust develops not from a written informed consent letter but from mutual respect.

The researchers' positionality with their participants varies from project to project.

Analyzing ethical ambiguity: this includes scenarios in which neither the law, an IRB, nor another agency can guide how researcher might respond to them.

At the end of this chapter, there are three different examples on this, please CHECK them in the book. (It's really hard to mention them here).

Nothing is clear about ethically ambiguous conundrums. In cases where laws or regulations require certain actions, researchers have guidance, but in many other cases they do not. Ethics are not universal, and researchers must carefully contemplate the consequences of their actions. We offer a classic adage for consideration: Not everything that is legal is ethical, and not everything that is ethical is legal.

The End