

Understanding Human Subjects Research Part 1

Agenda

- Icebreaker
- Research Ethics
- Risk and Consent
- Privacy, Confidentiality, and Data Security
- Closing Ritual

Icebreaker

Thorns and Roses

Research Ethics



Ethical Principles of the Belmont Report



Respect for Persons

- **Autonomy:** giving individuals the choice to participate
- **Voluntariness:** freedom to opt in and out of participation
- **Informed consent:** providing essential, understandable information about participation

Beneficence

- Designing research to minimize the risks of harm, stress or discomfort to participants, and maximizing any benefits.
- Ensuring the safety and confidentiality of participants.
- Benefits may be experienced by participants and the wider community.

Justice

- Fairness should be considered in all aspects of the research design including:
 - Recruitment of participants
 - Burdens on participants
 - Accurate reporting of results
 - Accessible reporting
- Benefits and burdens should be equitably distributed

Equity in Participant Selection

How do we inform individuals about the study?



Who did we recruit and who has participated?



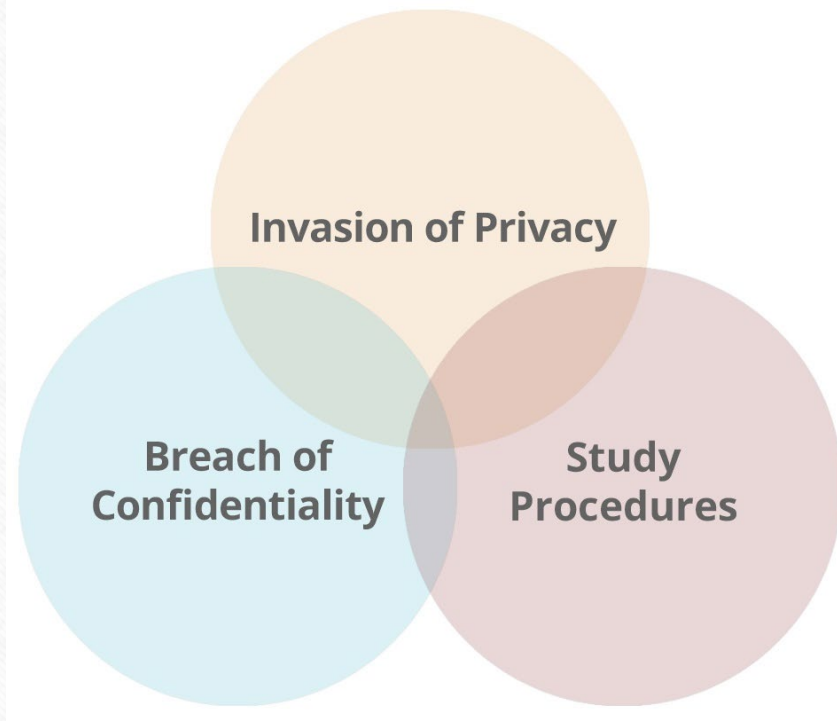
Where did the research study take place?



Risk and Consent



Assessing Risk



Invasion of Privacy

- Invasion of privacy can occur if personal information is accessed or collected without the subjects' knowledge or consent.
- It can also occur if a subject's participation in a study is revealed despite assurances that this would not happen.

Breach of Confidentiality

- Information obtained by researchers could adversely affect participants if shared.
- Confidentiality can be compromised through unauthorized release of data.

Study Procedures

- Taking part in study may put participants at risk
- Nature of research inquiry impacts risk
- Risks with confidentiality are higher in group settings

Informed Consent

Informed consent is a process that begins with the recruitment and screening of a participant and continues throughout the involvement in the research. It includes:

1. Providing specific information about the study to participants in a way that is understandable to them.
2. Answering questions to ensure that participants understand the research and their role in it.
3. Giving participants sufficient time to consider their decisions.
4. Obtaining the voluntary agreement of participants to take part in the study. The agreement is only to enter the study, as participants may at any time withdraw, decline to answer specific questions, or complete specific tasks during the research.

Privacy and Confidentiality

What to share
How much to share
When to share it
With whom to share it
How to share it

Privacy

Information

Confidentiality

Keep secrets
Do not share it

Privacy and Confidentiality

- Researchers can encourage participants to be as honest and open as they can, but when the topic warrants, also should encourage them to remain mindful of their privacy.
- Invasions of privacy can occur if questions are perceived invasive or if the questions unintentionally cause discomfort/harm.
 - Include disclosure about the possible sensitive nature of questions
 - Allow participants to skip questions
- Our role is to ensure confidentiality and data security.

Data Security

Data Security Procedures

- Researchers use several methods to keep participant's identity confidential when storing data online (e.g., use of password protected files and encryption) .
- Names and other personal, identifying information should be de-identified or removed for analysis and publication in reports or papers.
- Only the research team should have access to the data.

Closing Ritual



Go Forth and Be Great!

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