

# Data collection ethics

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# Why collect data

- Sometimes Census data and existing surveys aren't enough, and you need to collect your own data
- A survey is one of the most common ways to do this

# Human subjects research ethics

- Surveys are answered by humans
- In many case this means they are considered human subjects research
- Academia has a bad history with human subjects research
  - Medical experimentation, Stanford Prison Experiment, etc.



# Human subjects research ethics

- Since the goal of research is not to benefit participants directly, incentives to protect respondents may not be aligned with research goals
- If you're at a university, anything considered human subjects research *must* be reviewed by the Institutional Review Board
- In professional practice, there may or may not be ethical review committees



# Risks to survey respondents

- Most often: breach of confidentiality
  - Severity depends on the content of the survey
  - Be careful where you keep your survey data
  - In some cases, you may make de-identified data publicly available, or occasionally even identified data - this is okay as long as respondents provide *informed consent*
- Mental discomfort
- Legal action



# The informed consent process

- Subjects have a right to know how their data will be used, distributed, and stored
- Surveys generally start with an informed consent document—clear language explaining the study, its purpose, what will be done with the data, and who to contact with concerns
  - Often also includes time estimates and information about incentives



# IRB approval process

- Submit online through the IRBIS system
- Fill out a form specific to the type of research you're doing
- Wait (generally 1-2 weeks)
- Generally, respond to comments from IRB and resubmit



# What are human subjects?

- A living individual about whom an investigator conducting research obtains
  - data through intervention or interaction with the individual, or
  - identifiable private information.

source



# What is research?

- Research contributes to generalizable knowledge.
- Research is designed in advance.
- Research utilizes a systematic approach.

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# I am not the IRB

- If you're doing anything that's remotely unclear whether it's human subjects research, it's a good idea to be in touch with the IRB
- The UNC IRB has a specific approval type "Not Human Subjects Research" where you describe a research project that you don't believe will be human subjects, and they approve it
  - This gives you a paper trail if anyone ever asks
  - Often used when conducting a survey that does not ask personal questions (e.g. a survey of planners)



# Exempt reviews

- Most planning human subjects research projects are reviewed by the IRB, then “exempt from continuing review”
- There are several other IRB levels, based on the risk the subjects are exposed to and who the subjects are, but these are rare in planning



# CITI training

- Everyone needs to take the CITI training
- Link on Canvas
- No credit, but required to pass this class

