

**6.S196 / PPAT:
Principles and Practice
of Assistive Technology**

Today: Ethics of Human Subject
Research

Ethics of Human Subject Research

- Human subjects have been seriously abused in the past
 - Nazi concentration camps
 - Tuskegee Institute study
 - MIT Fernald School study
 - Yale electric shock study
 - Stanford prison experiment

Nazi Concentration Camps (1940s)

- Prisoners were used for horrific medical experiments
 - extreme cold
 - extreme low pressure
 - typhus, tuberculosis, malaria, hepatitis, ...
 - chemical weapons
- Thousands of people were killed

Tuskegee Institute Syphilis Study (1930s-72)

- US Government (Dept of Public Health) + Tuskegee Institute researchers
 - recruited black males with syphilis, without telling them, and studied the progress of the untreated disease

Fernald School & MIT Study (1940s-50s)

- MIT researchers studying calcium/iron absorption from breakfast cereal
 - enrolled children at Fernald School for mentally-disabled
 - got parental permission, but omitted to mention the radioactive tracer isotopes

Yale Shock Study (1950s)

- Yale psychologists studying power of authority to overcome personal morals
 - participants told to give electric shocks to another person (a confederate simulating real pain)

Stanford Prison Experiment (1971)

- Stanford psychologists studying people's responses to captivity
 - recruited Stanford undergrads to live in a mock prison, randomly assigned as either “guards” or “prisoners”
 - guards rapidly became abusive, and prisoners became traumatized

Basic Principles (Belmont Report)

- Respect for persons
- Beneficence
- Justice

Respect for Persons

- Voluntary participation
- Informed consent
 - not only say yes, but *understand* what saying yes means
 - studies that require initial deception must meet a higher bar, and must eventually debrief
- Protection of vulnerable populations
 - children
 - prisoners
 - people with disabilities (esp. cognitive)

Beneficence

- Do no harm
 - not just physical well-being, but also privacy
- Must weigh the risks vs. benefits
 - risks to participants should be commensurate with benefits of the work to the participants or to society as a whole

Justice

- Fair selection of participants
 - opportunity to be in clinical trials of new treatments must be available to all (scientifically-appropriate) participants

Institutional Review Boards

- Research with people is subject to scrutiny
 - All federally-funded institutions have an *institutional review board* (IRB) that approves human subjects research
 - MIT's IRB is called the Committee on Use of Humans as Experimental Subjects (COUHES)

What is Research?

- IRB oversight is confined to research
 - “Research” is work leading to generalizable knowledge
 - “Practice” (clinical medicine, product development, class projects) does not require IRB approval
 - But all work with human beings should follow the IRB ethical guidelines, even if it doesn’t need to do IRB paperwork

Case Study

- Venkman, P. “The Effect of Negative Reinforcement on ESP Ability.”
Unpublished monograph, 1984.

Treat the Client with Respect

- Time
 - Don't waste it
- Comfort
 - Accessible & convenient meeting location
 - Energy & fatigue
- Informed consent
 - Inform the client fully
- Privacy
 - Preserve the client's privacy
- Control
 - The client can stop at any time

Summary

- Know about the history of human subjects abuse
- Treat people with respect, beneficence, justice
- Respect your client's time, comfort, informed consent, privacy, and control

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