

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

Today: Ethics of Human Subject  
Research

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### 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
  - fair selection of subjects

### 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

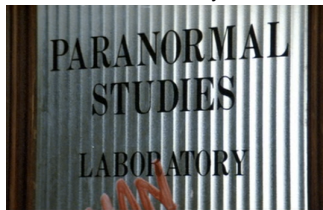
### Institutional Review Boards

- 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



### 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