Today: Ethics of Human Subject Research
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- 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

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