# Ethics and the IRB

## Upcoming schedule

- **Today**: Lecture (Ethics and IRB)
- **Tues 10/15**: Group meetings
- **Thurs 10/17**: HW 3 due, Lecture (Analysis)
- **Tues 10/22**: Group meetings
- **Thurs 10/24**: Group meetings
- **Fri 10/25**: Midterm report draft due to mentors
- **Tues 10/29**: Midterm presentations, Final draft of midterm report due
- **Tues 10/31**: Midterm presentations

## Announcements

- **Website**
  - Please keep your website up-to-date, with your current research plan and timeline, and updates on project status
  - Website should always show the current plan for completing the project; i.e. timeline of who will do what and when
  - Please update at least weekly
  - We will publish the website URLs on OnCourse soon, so that anyone can see the current state of the projects
- **Peer feedback**

## Basic guidelines

- Be Honest
- Be Fair
- Do no harm
- Know and follow the rules
  - Bad rules should be changed, not broken
  - When in doubt, ask questions
- Be a good citizen
- Listen to your conscience
  - especially in times of stress

## Avoiding plagiarism

- When you write (or present) something, you are implying that you personally created all of it, including:
  - The ideas
  - The data, analysis, source code, etc.
  - The report (including all text, figures, tables, etc.)
  - The slides (including all text, figures, etc.)
- For ideas (or text, figures, slides, code, etc.) that came from someone else, you must give credit
  - A citation that identifies the source, and explicitly states which ideas you

## Research misconduct

- **Plagiarism**: Using the words, ideas, results, etc. of others without giving credit
  - Other variants: self-plagiarism, ghostwriting, ...
- **Fabrication**: Making up results
- **Falsification**: Manipulating materials or procedures, or changing or omitting data
- **Ethical violations**: Causing harm to research participants or the public

Adapted from Research Ethics Workshop, Missouri State
Example

• You need a description of Android in your paper. You find a sentence in a paper (or Wikipedia) that explains Android really well.
  – Bad: Copy the sentence word-for-word into your paper, without quotes or a citation.
  – Bad: Copy the sentence, rephrasing it a bit to match your style, without quotes or a citation.
  – Better: Put the sentence inside quotation marks, and give a citation. Or describe Markov Nets in your own words, based on your own understanding, and give a citation.

Acceptable options

“Android was built from the ground-up to enable developers to create compelling mobile applications that take full advantage of all a handset has to offer.” [5]

A main advantage of Android is that it is highly customized for mobile devices and applications. [5]


Example #2

• You need a survey to study topic X. You’d like to use the survey created or inspired by Y.
  – Bad: Present the idea in your paper (or presentation, etc.) as if it were your own.
  – Bad: Present the idea in your paper (or presentation, etc.), never mention where it came from.
  – Better: Cite the source of the idea, even if you modified it or developed it substantially. Do this even if Y never published the idea.

Better example: We used a survey to measure people’s attitudes towards politics. The survey was inspired by [4] and [5], and was originally suggested by George W. Bush.

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Case of Diederik Stapel

• Professor of Social Psychology
  – Tilburg University (Netherlands)
  – PhD 1997, Professor 2000-2011
  – Won international award for outstanding research (2009)
  – Many papers in prominent journals, including Science
Stapel research papers

• Prominent results: (highly simplified explanations)
  – Meat eaters are less social and more selfish than vegetarians
  – Trash-filled environments bring out racist tendencies (Science, 2010)
  – People consume more after seeing the word “capitalism”
  – People think of themselves as less attractive when around very attractive people
  – And many others...

Outcome

• Some warning signs
  – Always ran experiments by himself, never let people on his team see the raw data, ...
• University investigation concludes massive fraud
  – At least 55 papers contained falsified or fabricated data
• Striped of job and PhD
• Criminal charges

Hwang Woo-suk

• Professor of biotechnology
  – Seoul National University (S Korea)
  – Prominent stem cell researcher
  – First successful cloning of embryonic stem cells (2004)
  – Reported in two papers in Science

Outcome

• Fired from university (2006)
• Charged with fraud, embezzlement
  – Convicted, 2 year jail sentence
MMR vaccine paper

- Andrew Wakefield
  - Doctor at Royal Free Hospital (UK)
  - Published paper claiming Measles, Mumps, and Rubella vaccine causes autism (1998)
  - Received much public attention

- Problems with paper
  - General Medical Council concluded data was fabricated (2010)
  - Ethical violations in treatment of children
  - Wakefield did not disclose $100,000's in payments from lawyers trying to sue vaccine manufacturers

Lies by omission

- Scientists sometimes ignore or do not report results that contradict their desired findings
  - Sometimes intentionally, sometimes subconsciously due to confirmation bias
  - This is very hard to protect against
    - One step: researchers are typically now required to disclose any conflicts of interest

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Tuskegee syphilis experiments (1932-1972)

- Syphilis: STD was not understood in early 20th century
  - Researchers wanted to study its long-term effects on people
  - Study on 600 poor African American men in Macon County, Alabama, by U.S. Public Health Service, 400 with syphilis

- Were not told they had syphilis
  - Were told they were being treated for “bad blood”
  - Were told they were receiving free health care from U.S. government, also received free meals
  - Initially received some treatment, but no effective treatments were known anyway

Tuskegee experiments
Penicillin-based treatment (1947)

- Penicillin was found to treat Syphilis in 1940’s, but the U.S. government withheld it from Tuskegee subjects
  - Continued to tell subjects they were being treated
  - Withheld information about effective treatments
  - Prevented them from accessing nearby clinics
  - Prevented them from joining army (where they would receive treatment)
  - Some told they were given Penicillin but actually given placebo

Legacy

- Finally revealed to public in 1972 by a whistleblower
  - Study ended, congressional hearings investigate
- New ethical laws in U.S. introduced to protect human subjects
  - Require permission of subjects before they participate
  - Special protections for vulnerable groups who may be unduly influenced by offers of money, free care, etc.

Milgram Experiment on Obedience to Authority (Yale, 1961)

- Recruited subjects to participate in a “study of memory”

Milgram study

- The participants thought they were helping to teach another person, but really the study was about them
  - Participant believed that learner was receiving shocks of increasing severity
  - Also heard screams, banging on wall, etc.
- When participants tried to leave, they were told:
  - Please continue.
  - The experiment requires that you continue.
  - It is absolutely essential that you continue.
  - You have no other choice, you must go on.
- Ended if participant refused after those 4, or after 3 450-volt shocks.

Results

- 65% of people continued through final shock
  - Even after learner had stopped responding
  - All people questioned study at some point; most showed signs of stress like sweating, groaning, laughing, or having seizures
  - Milgram argued this shows human tendency to follow orders; may explain human rights violations
- But also inflicted long term psychological damage on participants
  - Some claimed to be much less trusting afterwards
- Was this study ethical?

Risks to subjects, and Deception

- Milgram study created a lot of controversy
  - Many protections researchers use today were created because of Milgram
- Now, studies have to disclose potential risks to participants
  - And obtain “informed consent”
Deception

- Sometimes a study cannot reveal its true purpose ahead of time
  - E.g. in the Milgram experiment
- To use deception, a researcher must
  - Justify need for deception to a review board
  - Reveal as much as possible to subjects
  - Minimize risks to participants from the deception
  - De-brief subjects with truth after the study

Case study: Stanford Prison Experiment (1971)

- Designed to study psychological effects of prison life
  - Recruited college students to be in mock “prison”
  - Half were chosen as guards, half as prisoners
  - Realistic simulation: guards and inmates wore uniforms, inmates given ID numbers, limited food, strict rules, criminal backstories, realistic “booking” procedure, etc...

Day 2: Rebellion

- Inmates takes off ID numbers, barricade inside cells
  - Guards respond with fire extinguishers, strip searches

Day 2: First prisoner “released”

- One participant started suffering from acute psychological distress
  - Researchers eventually dismiss him from study
End of study

• Researchers finally end study after 5 days
  – Many prisoners behaving pathologically
  – Guards behaving sadistically abusive
  – Only ended after outside researcher visited and objected to what was going on

Legacy

• Revealed interesting (and disturbing) facts about prison and effects on human psyche
  – Cited to explain abuse like Abu Ghrab prison
• But inflicted lasting psychological harm on some participants
• Was this study ethical?

AOL Search terms

• In 2006, America Online released a dataset of users’ web search terms
  – Very useful to CS researchers trying to improve web search algorithms, and social scientists interested in peoples’ searches for information
  – Data was anonymized by assigning users random ID numbers, not real user IDs or IP addresses
  – E.g.: User_323456: iphone deals, movie listings, best sandwich shops, calories in BLT, ...

Another example

User_4417749: numb fingers, 60 single men, dog that urinates on everything, landscapers in lilburn, ga, homes sold in shadow lake subdivision gwinnett county georgia, school supplies for iraqi children, safest place to live, best season to visit italy, termines, tea for good health, mature living, hand tremors, nicotine effects on the body, dry mouth, bipolar, ...
Privacy concerns

• Many studies collect sensitive information
  – Date of birth, income, marital status, sexual orientation
  – Answers to (often) highly personal questions
• Studies need to guarantee privacy of this information
  – Either names are not collected at all, or IDs are assigned to each person and the mapping from ID to name is secret
  – In publications and talks, anonymize data; report only aggregate results (e.g. averages over many people)
  – Store data in locked facilities and on secure computers

Institutional Review Board

• All U.S. research universities must have an Institutional Review Board
  – Required by 1974 National Research Act
  – Reviews all studies that involve human subjects
  – Provides a "check" on researcher ethics
  – Purpose is "to protect the rights and welfare of human subjects (including patients) recruited to participate in research activities"
  – IRB does not help decide if research is important, useful, worthwhile, etc.

Institutional Review Board

• At least 5 people, at least one person outside of university, 1 scientist, and 1 nonscientist
  – makes sure subjects are informed about nature of study and any potential risks.
  – IRB monitors progress at least once a year
  – Studies with "minimal risk to subjects" will have a shorter review process (ex., sample surveys)

Informed Consent

• Subjects must be informed in advance about...
  – Nature and purpose of the study
  – Possible risks
  – If it’s a survey, what kinds of questions which will be asked
  – How much time will be required
• Then they must give their consent in writing
  – Some people cannot give informed consent: prisoners, children, mentally-challenged people
  – These cases are handled specially

Informed consent

• Name and purpose of study
• Procedures for study (what subjects will do)
• Potential risks of taking part in study
• Potential benefits of taking part in study
• Confidentiality policy
• Payment
• Voluntary nature of study
• Contacts for questions or emergencies
Research ethics in this course

• Obviously don’t plagiarize, falsify, fabricate
• For human subjects experiments:
  – Course projects are exempt from IRB review, so you do not need to have your project reviewed by them. You do not need to give informed consent in this class.
  – However, you won’t be able to publish your research in a scientific conference or journal unless you get IRB approval. (See me if you’re worried about this.)
  – Please use your best judgment and see me if you have questions.