

# CS 4001: Computing, Society & Professionalism

Munmun De Choudhury | Assistant Professor | School of Interactive Computing

## Week 14: Research Ethics

April 11, 2019



# Term Paper Presentation Schedule

# Format


- What was the issue?
- What are the different perspectives on the issue?  
Presentation of your analysis.
- What did you learn?
- What is your final stance on the issue?

# Final Exam

- Final exam – take home
- **Apr 29, 2019**
- Exam released by 12am on Canvas
- Answers to be submitted by 11:59pm on Canvas



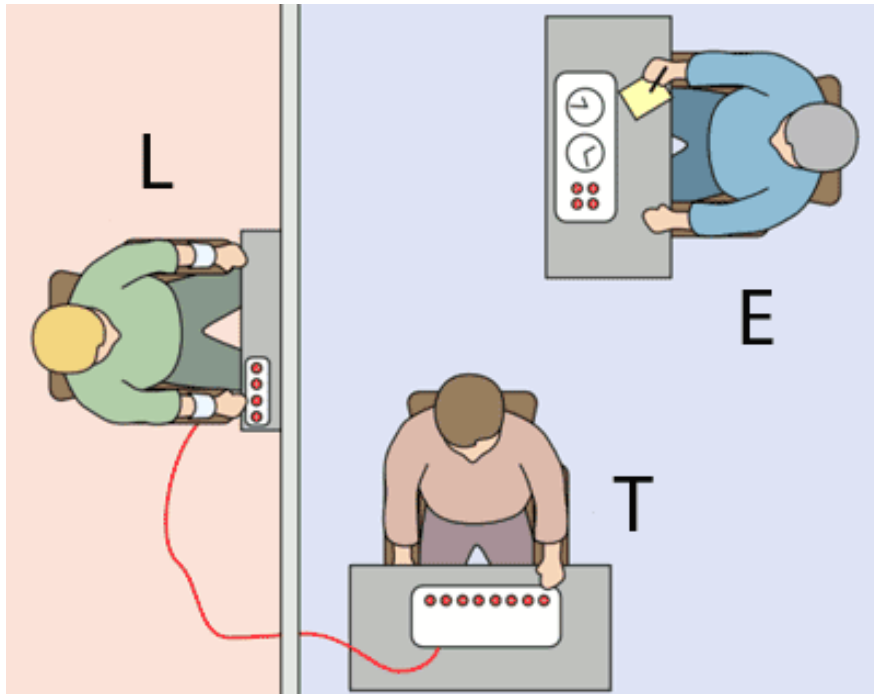
# Research Ethics



*For the most part, doctors and civil servants simply did their jobs. Some merely followed orders, others worked for the glory of science.*

— John R. Heller Jr., Director of the Public Health Service's Division of Venereal Diseases

# Milgram's Obedience Study



- Experiment on obedience to authority figures
- Study measured the willingness of study participants, men from a diverse range of occupations with varying levels of education, to obey an authority figure who instructed them to perform acts conflicting with their personal conscience
- 65% (two-thirds) of participants (i.e., teachers) continued to the highest level of 450 volts. All the participants continued to 300 volts

<https://www.youtube.com/watch?v=yr5cjoyokVUs>

# Ethical Issues

- Deception
- Protection of participants
- Right to withdrawal



# Institutional Review Boards

- Formal review procedures for institutional human subject studies were originally developed in direct response to research abuses in the 20th century.
- Among the most notorious of these abuses were
  - the experiments of Nazi physicians, which became a focus of the post-World War II Doctors' Trial,
  - the Tuskegee Syphilis Study, a long-term project conducted between 1932 and 1972 by the U.S. Public Health Service,
  - numerous human radiation experiments conducted during the Cold War,
  - Controversial projects such as the Milgram obedience experiment, the Stanford prison experiment

# Institutional Review Boards

- Congress passed the National Research Act in 1974.
  - Established the “National Commission for Protection of Human Subjects of Biomedical and Behavioral Research.”
  - The Belmont Report was released in 1979 as a result of the Commission’s meeting.
- Overseen by the Office of Human Research Protections (OHRP), which is under the Department of Health and Human Services (DHHS).

# Institutional Review Boards

- Development of the **Belmont Report**, which outlined the primary ethical principles in human subjects review; these include "respect for persons", "beneficence", and "justice".
- An IRB may only approve research for which the risks to subjects are balanced by potential benefits to society, and for which the selection of subjects presents a fair or just distribution of risks and benefits to eligible participants.
- A bona fide process for obtaining informed consent from participants is also generally needed.



About OHRP



Regulations & Policy



Education & Outreach



Compliance & Reporting



News



Register IRBs & Obtain FWAs



SACHRP Committee



International

[HHS Home](#) > [OHRP](#) > [Regulations & Policy](#) > [Regulations](#) > Federal Policy for the Protection of Human Subjects ('Common Rule')

Statutes

Belmont Report

Regulations -

45 CFR 46

Common Rule

FDA

Final Rule

Guidance +

Requests for Comments

Text Resize **A A A**

Print

Share

## Federal Policy for the Protection of Human Subjects ('Common Rule')

The current U.S. system of protection for human research subjects is heavily influenced by the [Belmont Report](#), written in 1979 by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Belmont Report outlines the basic ethical principles in research involving human subjects. In 1981, with this report as foundational background, HHS and the Food and Drug Administration revised, and made as compatible as possible under their respective statutory authorities, their existing human subjects regulations.

The Federal Policy for the Protection of Human Subjects or the “Common Rule” was published in 1991 and codified in separate regulations by 15 Federal departments and agencies, as listed below. The HHS regulations, [45 CFR part 46](#), include four subparts: subpart A, also known as the Federal Policy or the “Common Rule”; subpart B, additional protections for pregnant women, human fetuses, and neonates; subpart C, additional protections for prisoners; and subpart D, additional protections for children. Each agency includes in its chapter of the Code of Federal Regulations [CFR] section numbers and language that are identical to those of the HHS codification at 45 CFR part 46, subpart A.

# IRB Oversight

- Non-human Subject and Non-research
- Human Subjects Research
  - Clinical Investigations
  - Diagnostic or Therapeutic Procedures
  - New Interventions or Treatments
- Data and Specimen Repositories
- Humanitarian Use Devices
- Emergency Use of Investigational Drugs
- Case Studies
- Internet Research
- Pilot Studies

# Adapting IRB review to Internet era and big data research

- Data breaches
- Potentially dangerous predictive analytics with unintended consequences
- Compromised privacy



## NEW RESEARCH IN

Physical Sciences

Social Sciences

Biological Sciences

# Experimental evidence of massive-scale emotional contagion through social networks



Article Alerts

Email Article

Citation Tools

Request Permissions

Share

Tweet

Like 1.1K

Mendeley

Adam D. I. Kramer, Jamie E. Guillory and Jeffrey T. Hancock

PNAS June 17, 2014. 111 (24) 8788-8790; published ahead of print June 2, 2014.

<https://doi.org/10.1073/pnas.1320040111>

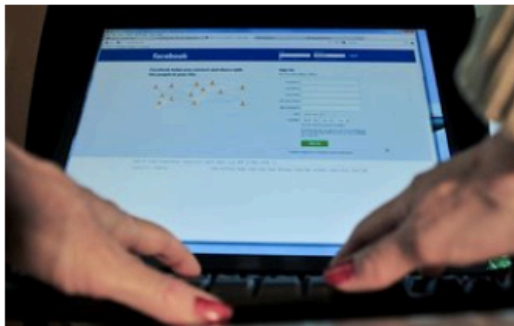
Edited by Susan T. Fiske, Princeton University, Princeton, NJ, and approved March 25, 2014 (received for review October 23, 2013)

**This article has corrections. Please see:**[Editorial Expression of Concern: Experimental evidence of massive-scale emotional contagion through social networks](#)[Correction for Kramer et al., Experimental evidence of massive-scale emotional contagion through social networks](#)**More Articles of This Classification****Social Sciences**[Identifying psychological responses of stigmatized groups to referendums](#)[Grassland biodiversity can pay](#)[Cracking the social code of speech prosody using reverse correlation](#)[Show more](#)**Psychological and Cognitive Sciences**

TECHNOLOGY

# Facebook Tinkers With Users' Emotions in News Feed Experiment, Stirring Outcry

By VINDU GOEL JUNE 29, 2014



Facebook revealed that it had altered the news feeds of over half a million users in its study.  
Karen Bleier/Agence France-Presse — Getty Images

To Facebook, we are all lab rats.

Facebook routinely adjusts its users' news feeds — testing out the number of ads they see or the size of photos that appear — often without their knowledge. It is all for the purpose, the company says, of creating a more alluring and useful product.

But last week, Facebook revealed that it had manipulated the news

## RECENT COMMENTS

**GSP13** July 1, 2014

Shocked that this study - at least from what I can tell - was not subjected to an IRB.

**Superpower** July 1, 2014

"...my co-authors and I are very sorry for the way the paper described the research and any anxiety it caused," -once again the progressive,...

**Faith** July 1, 2014

Just another vindication for dropping out of FB months ago. My emotion? Never been happier.



# Everything We Know About Facebook's Secret Mood Manipulation Experiment

It was probably legal. But was it ethical?



# Editorial Expression of Concern: Experimental evidence of massivecale emotional contagion through social networks



Article Alerts

Email Article

Citation Tools

Request Permissions

Share

Tweet

Like 7

Mendeley

PNAS July 22, 2014. 111 (29) 10779; published ahead of print July 3, 2014. <https://doi.org/10.1073/pnas.1412469111>

See original article:

[Experimental evidence of massive-scale emotional contagion through social networks](#)

Article

Authors & Info

PDF

**PSYCHOLOGICAL AND COGNITIVE SCIENCES** PNAS is publishing an Editorial Expression of Concern regarding the following article: “Experimental evidence of massive-scale emotional contagion through social networks,” by Adam D. I. Kramer, Jamie E. Guillory, and Jeffrey T. Hancock, which appeared in issue 24, June 17, 2014, of *Proc Natl Acad Sci USA* (111:8788–8790; first published June 2, 2014; 10.1073/pnas.1320040111). This paper represents an important and emerging area of social science research that needs to be approached with sensitivity and with vigilance regarding personal privacy issues.

## More Articles of This Classification

[Correction for Bernardo-Seisdedos et al., Structural basis and energy landscape for the Ca<sup>2+</sup> gating and calmodulation of the Kv7.2 K<sup>+</sup> channel](#)

[Correction for Bevan et al., Holocene fluctuations in human population demonstrate repeated links to food production and climate](#)

[Correction for Jiang et al., Proteins induced by telomere dysfunction and DNA damage represent biomarkers of human aging and disease](#)

Show more

# Example concerns

- Violation of the rights of research subjects
- Facebook co-opted users into a system that took information initially shared to meet socially laudable goals (e.g. stay in touch with loved ones) out of context, re-purposed it, and deployed it—by way of secondary use—in ways that potentially could harm those we care about and try to behave responsibly towards



# Class Discussion Point 1

Internet companies “manipulate” what we see and read all the time. Google was doing it for years without getting into trouble. Why did this Facebook study generate so much criticism?




## Class Discussion Point 2

Adopting the following ethical theories, discuss whether this Facebook study was ethical: a) Kantian perspective; b) social contract theory perspective; and c) rule utilitarian perspective



# Class Activity

Discuss a study design so that this research could have been done ethically. Assume you are internal to Facebook and have access to any data/experimental framework.



Beyond the Belmont Principles:  
Ethical Challenges, Practices,  
and Beliefs in the Online Data  
Research Community

# Online data create gray area

Is it feasible to collect informed consent?

Should you be more transparent about your research?

Who is being left out by your data collection strategies?

Isn't public data public?

Is it possible to truly anonymize a dataset?





# Research Questions

---

1. What are the research ethics practices of researchers using online datasets?
2. What do researchers using online datasets believe constitutes ethical research?
3. How do these practices and beliefs vary among social computing researchers?

Code	Definition	Example Statements
Public Data	Only using public data / public data being okay to collect and analyze	<i>In general, I feel that what is posted online is a matter of public record, though every case needs to be looked at individually in order to evaluate the ethical risks.</i>
Do No Harm	Comments related to Golden Rule	<i>Golden rule, do to others what you'd have them do to you.</i>
Informed Consent	Always get informed consent / stressing importance of informed consent	<i>I think at this point for any new study I started using online data, I would try to get informed consent when collecting identifiable information (e.g. usernames).</i>
Greater Good	Data collection should have a social benefit	<i>The work I do should address larger social challenges, and not just offer incremental improvements for companies to deploy.</i>
Established Guidelines	Including Belmont Report, IRBs Terms of Service, legal frameworks, community norms	<i>I generally follow the ethical guidelines for human subjects research as reflected in the Belmont Report and codified in 45.CFR.46 when collecting online data.</i>
Risks vs. Benefits	Discussion of weighing potential harms and benefits or gains	<i>I think I focus on potential harm, and all the ethical procedures I put in place work towards minimizing potential harm.</i>
Protect Participants	data aggregation, deleting PII, anonymizing / obfuscating data	<i>I aggregate unique cases into larger categories rather than removing them from the data set.</i>
Data Judgments	Efforts to not make inferences or judge participants or data	<i>Do not expose users to the outside world by inferring features that they have not personally disclosed.</i>
Transparency	Contact with participants or methods of informing participants about research	<i>I prefer to engage individual participants in the data collection process, and to provide them with explicit information about data collection practices.</i>

Item	M	SD
...notify participants about why they're collecting online data <sup>1</sup>	3.89	0.96
...share research results with research subjects <sup>1</sup>	3.90	0.80
...Ask colleagues about their research ethics practices <sup>1</sup>	4.27	0.74
...Ask their IRB/internal reviews for advice about research ethics <sup>1</sup>	4.03	0.90
...Think about possible edge cases/outliers when designing studies <sup>1</sup>	4.33	0.71
...Only collect online data when the benefits outweigh the potential harms <sup>1</sup>	3.62	1.10
...Remove individuals from datasets upon their request <sup>1</sup>	4.56	0.71
Researchers should be held to a higher ethical standard than others who use online data <sup>2</sup>	3.46	1.22
I think about ethics a lot when I'm designing a new research project <sup>2</sup>	3.96	0.93
	<b>Full Scale (<math>\alpha=.71</math>)</b>	<b>4.00</b>
		<b>0.49</b>

<sup>1</sup> Prompt: "I think researchers should...."

<sup>2</sup> Prompt: "To what extent do you agree with the following statements?"

Both sets of items were measured on five point, Likert-type scales (Strongly Agree-Strongly Disagree).

## Codification of Ethical Attitudes Measure

# Ethics Heuristics for Online Data Research: Beyond the Belmont Report

## 1. Focus on transparency

- Openness about data collection
- Sharing results with community leaders or research subjects

## 2. Data minimization

- Collecting only what you need to answer an RQ
- Letting individuals opt out
- Sharing data at aggregate levels

## 3. Increased caution in sharing results

## 4. Respect the norms of the contexts in which online data was generated.

