CS 3001-C: Computing, Society, and Professionalism

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Week 15: Research Ethics

April 18, 2022

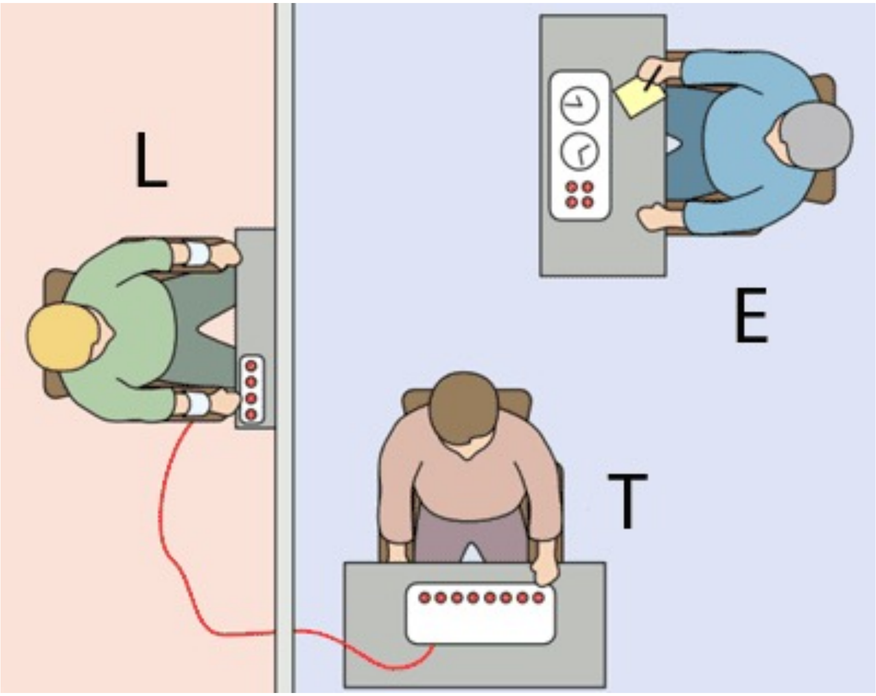
Research Ethics

Tuskegee Syphilis Experiment

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

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.

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

Adapting IRB review to Internet era and big data research

Experimental evidence of massive-scale emotional contagion through social networks

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 massivescale 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.

Example concerns

- Violation of the rights of research subjects

Article

new media & society
1–19

DOI: 10.1177/1461444819876944
journals.sagepub.com/home/nms
SAGE

Unexpected expectations: Public reaction to the Facebook emotional contagion study

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Abstract

How to ethically conduct online platform-based research remains an unsettled issue and the source of continued controversy. The Facebook emotional contagion study, in which researchers altered Facebook News Feeds to determine whether

Highlights of some findings…

- **Living in a lab**
  - *Dear Mr. Zuckerburg, Last I checked, we did not decide to jump in a petri dish to be utilized at your disposal . . . We connect with our loved ones.*
- ***Manipulation anxieties***
  - *Don't be fooled, manipulating a mood is the ability to manipulate a mind. Political outcomes, commerce, and civil unrest are just a short list of things that can be controlled.*
- **Wake up, sheeple**
  - *Anyone who doesn't realise that anything you put "out there" on Facebook (or any other social media site) is like shouting it through a bullhorn should have their internet competency licence revoked. We can't blame all stupidity on some or other conspiracy...*
- **No big deal**
  - *A/B testing (i.e. basically what happened here) when software companies change content or algorithms for a subset of users happens *all the time*. It's standard industry practice.*

A key takeaway – consent is important!

Consent at Scale – why it is hard

SM+S
social media + society

Article

Social Media + Society
January-March 2018: 1–14

DOI: 10.1177/2056305118763366
journals.sagepub.com/home/sms
SAGE

“Participant” Perceptions of Twitter Research Ethics

Casey Fiesler[1] **and Nicholas Proferes**[2]

Abstract
Social computing systems such as Twitter present new research sites that have provided billions of data points to researchers. However, the availability of public social media data has also presented ethical challenges. As the research community works to create ethical norms, we should be considering users’ concerns as well. With this in mind, we report on an exploratory survey of Twitter users’ perceptions of the use of tweets in research. Within our survey sample, few users were previously aware that their public tweets could be used by researchers, and the majority felt that researchers should not be able to use tweets without consent. However, we find that these attitudes are highly contextual, depending on factors such as how the research is conducted or disseminated, who is conducting it, and what the study is about. The findings of this study point to potential best practices for researchers conducting observation and analysis of public data.

Keywords
Twitter, Internet research ethics, social media, user studies

“Participant” Perceptions of Twitter Research Ethics

Social Media + Society
January-March 2018: 1–14

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DOI: 10.1177/2056305118763366
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Casey Fiesler[1] and Nicholas Proferes[2]

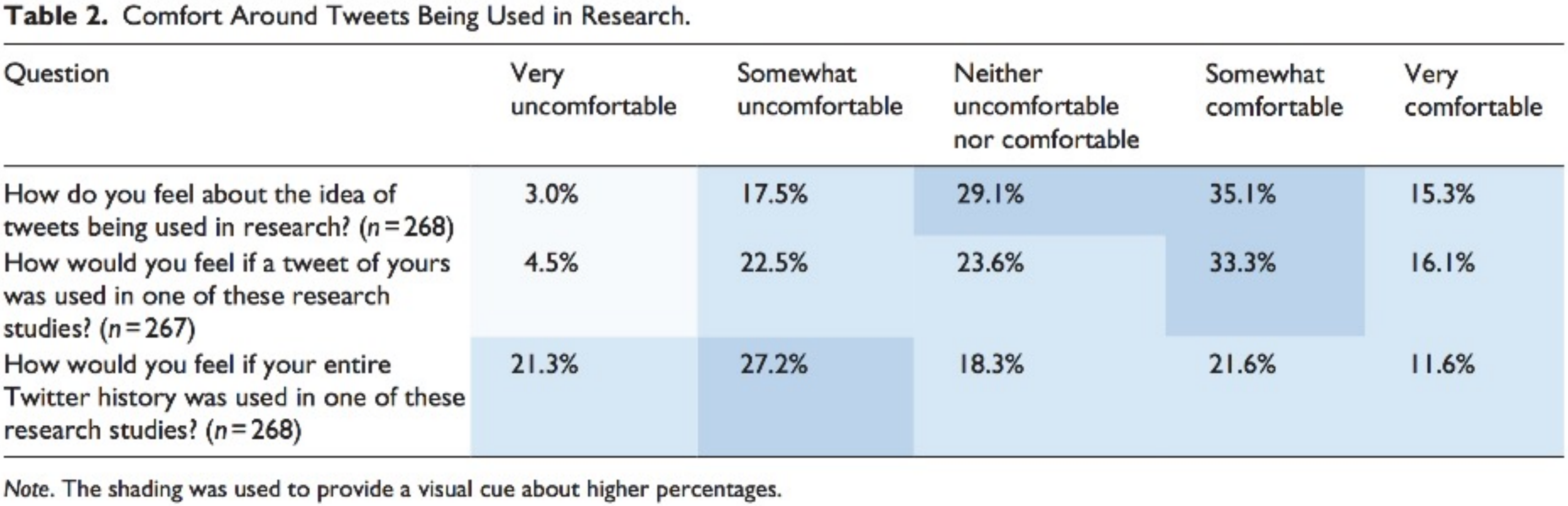
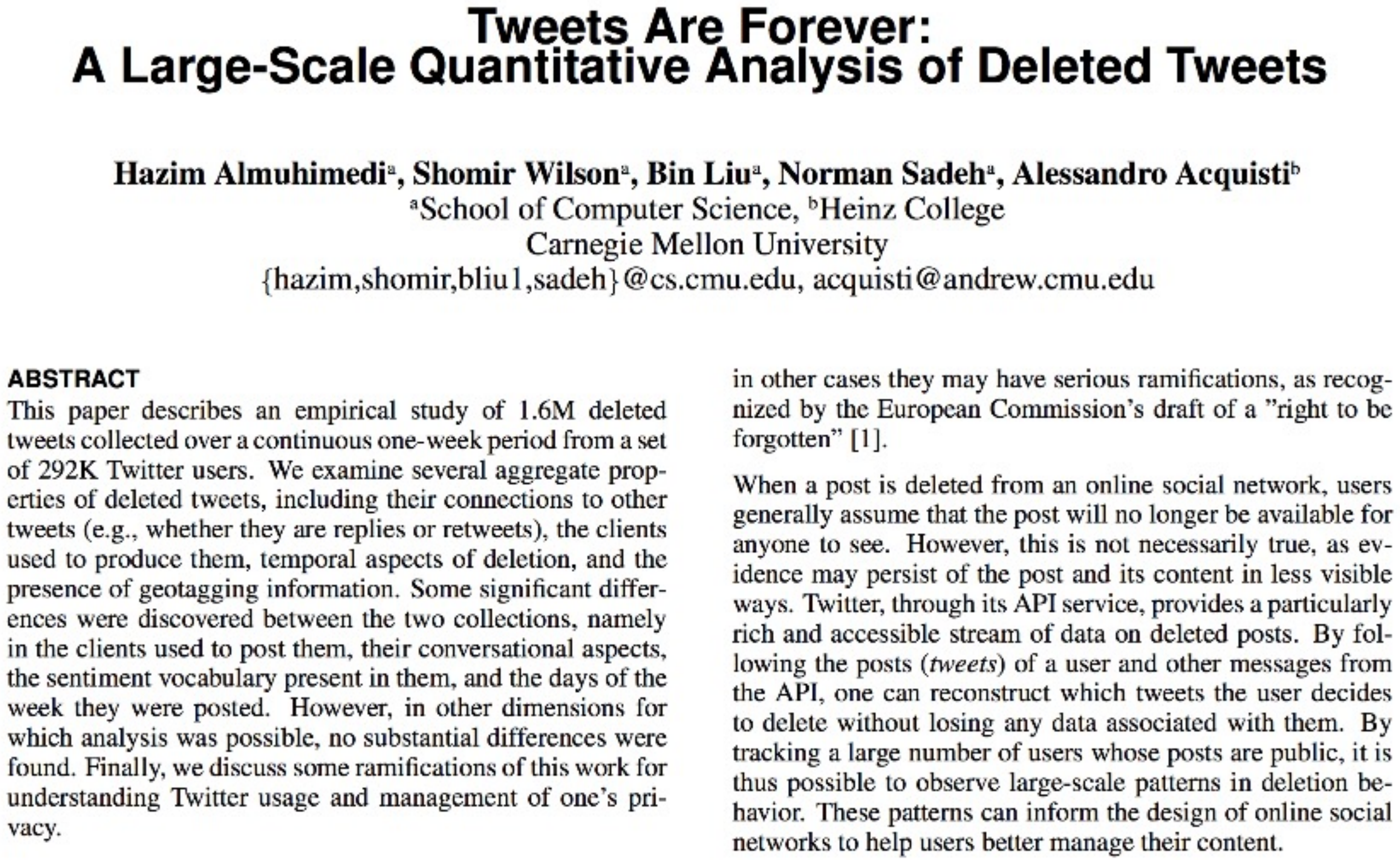


Table 2. Comfort Around Tweets Being Used in Research.

Question	Very uncomfortable	Somewhat uncomfortable	Neither uncomfortable nor comfortable	Somewhat comfortable	Very comfortable
How do you feel about the idea of tweets being used in research? ($n = 268$)	3.0%	17.5%	29.1%	35.1%	15.3%
How would you feel if a tweet of yours was used in one of these research studies? ($n = 267$)	4.5%	22.5%	23.6%	33.3%	16.1%
How would you feel if your entire Twitter history was used in one of these research studies? ($n = 268$)	21.3%	27.2%	18.3%	21.6%	11.6%

Note. The shading was used to provide a visual cue about higher percentages.

The Case of Deleted Tweets/Social media posts



Tweets Are Forever:
A Large-Scale Quantitative Analysis of Deleted Tweets

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ABSTRACT

This paper describes an empirical study of 1.6M deleted tweets collected over a continuous one-week period from a set of 292K Twitter users. We examine several aggregate properties of deleted tweets, including their connections to other tweets (e.g., whether they are replies or retweets), the clients used to produce them, temporal aspects of deletion, and the presence of geotagging information. Some significant differences were discovered between the two collections, namely in the clients used to post them, their conversational aspects, the sentiment vocabulary present in them, and the days of the week they were posted. However, in other dimensions for which analysis was possible, no substantial differences were found. Finally, we discuss some ramifications of this work for understanding Twitter usage and management of one's privacy.

in other cases they may have serious ramifications, as recognized by the European Commission's draft of a "right to be forgotten" [1].

When a post is deleted from an online social network, users generally assume that the post will no longer be available for anyone to see. However, this is not necessarily true, as evidence may persist of the post and its content in less visible ways. Twitter, through its API service, provides a particularly rich and accessible stream of data on deleted posts. By following the posts (*tweets*) of a user and other messages from the API, one can reconstruct which tweets the user decides to delete without losing any data associated with them. By tracking a large number of users whose posts are public, it is thus possible to observe large-scale patterns in deletion behavior. These patterns can inform the design of online social networks to help users better manage their content.

Also what about those who can‘t give consent any more? *The case of dead people*

- Warning: I am not a historian ;-)
- Today‘s view
- Medieval view

- Things are muddled when it comes to dead people‘s digital lives – legislation has not kept up with technological change

Digital Wills and Beneficiaries (Forbes)

… still particularly nascent when it comes
to data stored by a third-party company

https://www.forbes.com/sites/bernardmarr/2017/02/01/what-really-happens-to-your-big-data-after-you-die/

When there is no consent, researchers have poor understanding of what can go wrong, and “participants” or research subjects have limited understanding of risk.

What's at Stake: Characterizing Risk Perceptions of Emerging Technologies

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ABSTRACT

One contributing factor to how people choose to use technology is their perceptions of associated risk. In order to explore this influence, we adapted a survey instrument from risk perception literature to assess mental models of users and technologists around risks of emerging, data-driven technologies (e.g., identity theft, personalized filter bubbles). We surveyed 175 individuals for comparative and individual assessments of risk, including characterizations using psychological factors. We report our observations around group differences (e.g., expert versus non-expert) in how people assess risk, and what factors may structure their conceptions of technological harm. Our findings suggest that technologists see these risks as posing a bigger threat to society than do non-experts. Moreover, across groups, participants did not see technological risks as voluntarily assumed. Differences in how people characterize risk have implications for the future of design, decision-making, and public communications, which we discuss through a lens we call risk-sensitive design.

ACM Classification Keywords

H.1.2 User/Machine Systems: Human Factors; H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous

and behavior-driven design. These users must rely on the companies and parties to whom they have given their data (knowingly or not) to be ethical.

Yet, we already know that many impacts (e.g., privacy, ethical, legal) and constraints (e.g., protocols, technological capabilities) of online technologies are poorly understood by users [24, 8, 36, 15]. We also know that, when asked, users are often uncomfortable or find undesirable the practices of online behavioral advertising (OBA) and personalization [37, 34]. This misalignment is often framed as a consumer tradeoff between privacy and personal benefit [13, 40]. Framing it this way leads to an assumption that the benefit of web services must outweigh consumer's privacy concerns since users are not opting out of services.

However, if consumers really are performing this cost-benefit analysis and making a conscious decision, then why we do we see such hype and panic around risks and harms caused by technology in the media? Daily news headlines relay injustice [19, 1, 4, 33], personal boundary violations [32], and gloom [26, 18, 14] over the impacts of technology on society. Some of these problems may indeed warrant concern from the public and social advocates; others might be overblown

What's at Stake: Characterizing Risk Perceptions of Emerging Technologies

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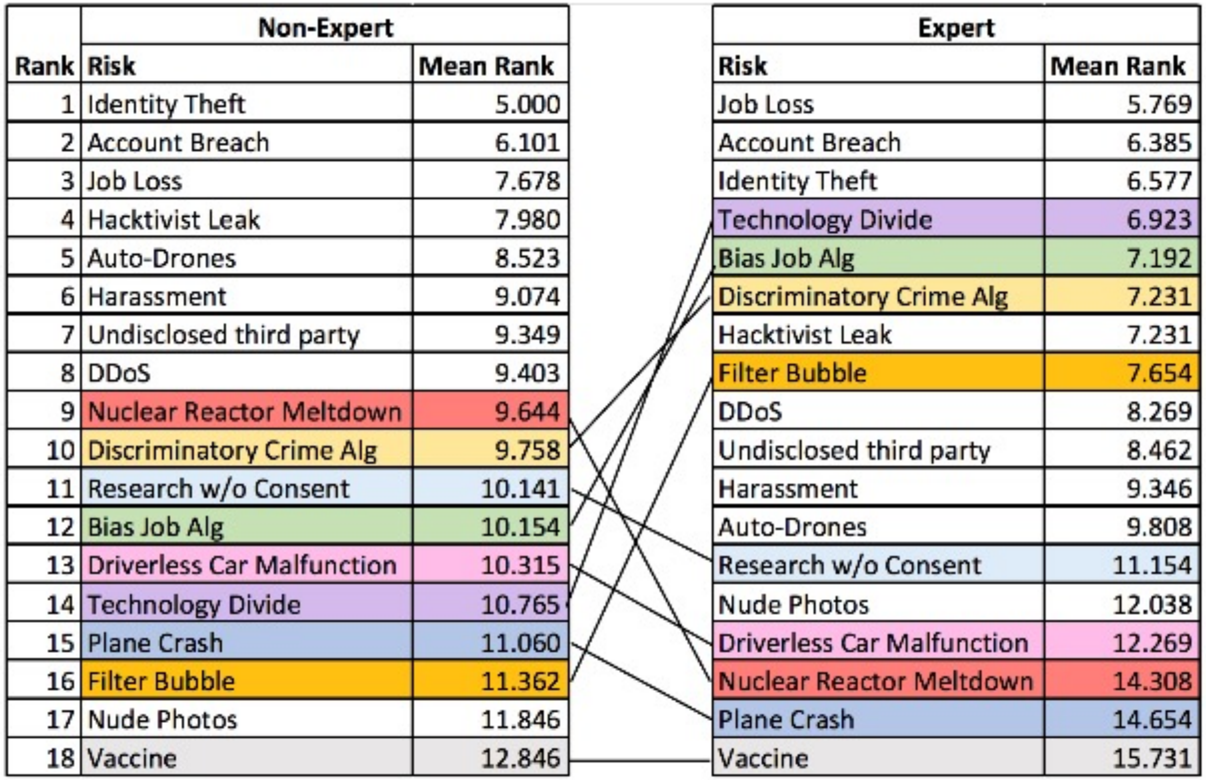

	Non-Expert	
Rank	Risk	Mean Rank
1	Identity Theft	5.000
2	Account Breach	6.101
3	Job Loss	7.678
4	Hacktivist Leak	7.980
5	Auto-Drones	8.523
6	Harassment	9.074
7	Undisclosed third party	9.349
8	DDoS	9.403
9	Nuclear Reactor Meltdown	9.644
10	Discriminatory Crime Alg	9.758
11	Research w/o Consent	10.141
12	Bias Job Alg	10.154
13	Driverless Car Malfunction	10.315
14	Technology Divide	10.765
15	Plane Crash	11.060
16	Filter Bubble	11.362
17	Nude Photos	11.846
18	Vaccine	12.846

Expert	
Risk	Mean Rank
Job Loss	5.769
Account Breach	6.385
Identity Theft	6.577
Technology Divide	6.923
Bias Job Alg	7.192
Discriminatory Crime Alg	7.231
Hacktivist Leak	7.231
Filter Bubble	7.654
DDoS	8.269
Undisclosed third party	8.462
Harassment	9.346
Auto-Drones	9.808
Research w/o Consent	11.154
Nude Photos	12.038
Driverless Car Malfunction	12.269
Nuclear Reactor Meltdown	14.308
Plane Crash	14.654
Vaccine	15.731

Figure 1. Average comparative risk ranking by non-experts vs experts where items with significant differences (p<.05 for two-tailed t-test) are highlighted.

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?

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

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?

Code	Definition	Example Statements
Public Data	Only using public data / public data being okay to collect and analyze	*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.*
Do No Harm	Comments related to Golden Rule	*Golden rule, do to others what you'd have them do to you.*
Informed Consent	Always get informed consent / stressing importance of informed consent	*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).*
Greater Good	Data collection should have a social benefit	*The work I do should address larger social challenges, and not just offer incremental improvements for companies to deploy.*
Established Guidelines	Including Belmont Report, IRBs Terms of Service, legal frameworks, community norms	*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.*
Risks vs. Benefits	Discussion of weighing potential harms and benefits or gains	*I think I focus on potential harm, and all the ethical procedures I put in place work towards minimizing potential harm.*
Protect Participants	data aggregation, deleting PII, anonymizing / obfuscating data	*I aggregate unique cases into larger categories rather than removing them from the data set.*
Data Judgments	Efforts to not make inferences or judge participants or data	*Do not expose users to the outside world by inferring features that they have not personally disclosed.*
Transparency	Contact with participants or methods of informing participants about research	*I prefer to engage individual participants in the data collection process, and to provide them with explicit information about data collection practices.*

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

[1] *Prompt: “I think researchers should....”*

[2] *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.

A Taxonomy of Ethical Tensions in Inferring Mental Health States from Social Media

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ABSTRACT

Powered by machine learning techniques, social media provides an unobtrusive lens into individual behaviors, emotions, and psychological states. Recent research has successfully employed social media data to predict mental health states of individuals, ranging from the presence and severity of mental disorders like depression to the risk of suicide. These algorithmic inferences hold great potential in supporting early detection and treatment of mental disorders and in the design of interventions. At the same time, the outcomes of this research can pose great risks to individuals, such as issues of incorrect, opaque algorithmic predictions, involvement of bad or unaccountable actors, and potential biases from intentional or inadvertent misuse of insights. Amplifying these tensions, there are also divergent and sometimes inconsistent methodological gaps and under-explored ethics and privacy dimensions. This paper presents a taxonomy of these concerns and ethical challenges, drawing from existing literature, and poses questions to be resolved as this research gains traction. We identify three areas of tension: ethics committees and the gap of social media research; questions of validity, data, and machine learning; and implications of this

Conference on Fairness, Accountability, and Transparency (FAT '19).* ACM, New York, NY, USA, 10 pages. https://doi.org/10.1145/3287560.3287587

1 INTRODUCTION

Last year, Facebook unveiled automated tools to identify individuals contemplating suicide or self-injury [75, 62]. The company claims that they "use pattern recognition technology to help identify posts and live streams as likely to be expressing thoughts of suicide," which then can deploy resources to assist the person in crisis [75]. Reactions to Facebook's suicide prevention artificial intelligence (AI) are mixed, with some concerned about the use of AI to detect suicidal ideation as well as potential privacy violations [86]. Other suicide prevention AIs, however, have been met with stronger public backlash. Samaritan's Radar, an app that scanned a person's friends for concerning Twitter posts, was pulled from production, citing concerns for data collection without user permission [54], as well as enabling harassers to intervene when someone was vulnerable [4].

Since 2013, a new area of research has incorporated techniques from machine learning, natural language processing, and clini-

Overview of Taxonomy

- Participant and research oversight
- Validity, interpretability, and methods
- Stakeholder implications

Possible Ethical Solutions