#### DS-GA 3001.009: Responsible Data Science

#### **Ethical Frameworks**

Prof. Julia Stoyanovich Center for Data Science Computer Science and Engineering at Tandon

@stoyanoj

http://stoyanovich.org/ https://dataresponsibly.github.io/

## Al ethics from our finest news source!



4/22/19 7:02am • SEE MORE: SCIENCE ~

NEWS IN BRIEF

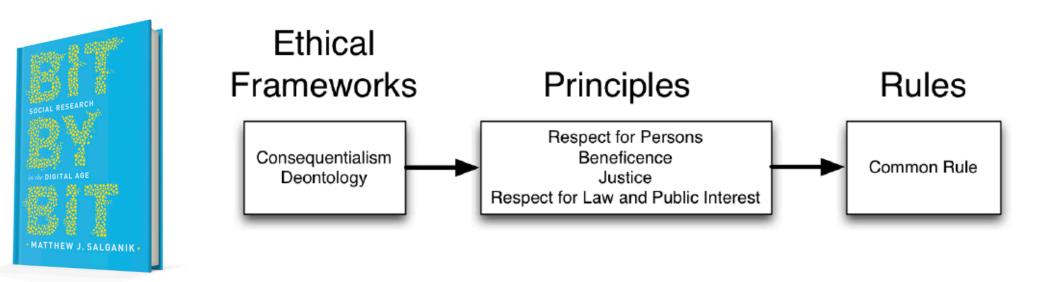
#### Computer Scientists Say AI's Underdeveloped Ethics Have Yet To Move Beyond Libertarian Phase

"While companies like Facebook and Google have allocated millions to making sure machine learning is guided by basic moral and ethical values, early prototypes, which achieved self-awareness, have yet to move beyond self-importance," said MIT robotics research engineer Dr. Alvin Dubicki, who hypothesized that **even the most advanced labs are decades away from developing neural networks sophisticated enough to analyze large quantities of data and output much else besides paraphrased Ayn Rand quotes**.



# principles-based approach to ethics

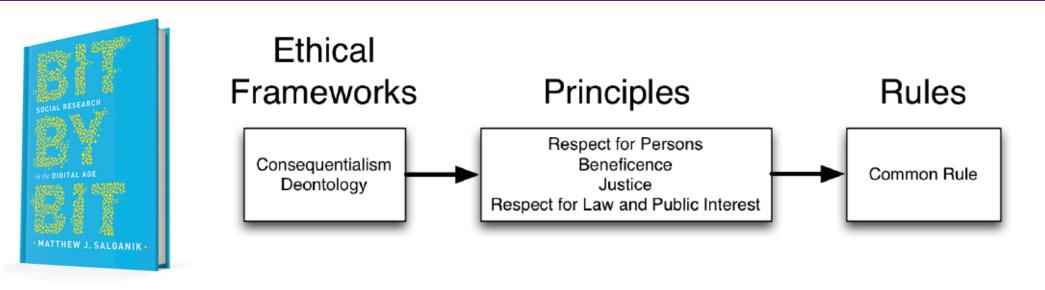
## Bit by Bit, Chapter 6: Ethics



The **rules** governing research are derived from **principles** that in turn are derived from **ethical frameworks**. A main argument of this chapter is that researchers should evaluate their research through existing rules—which I will take as given and assume should be followed—and through more general ethical principles.



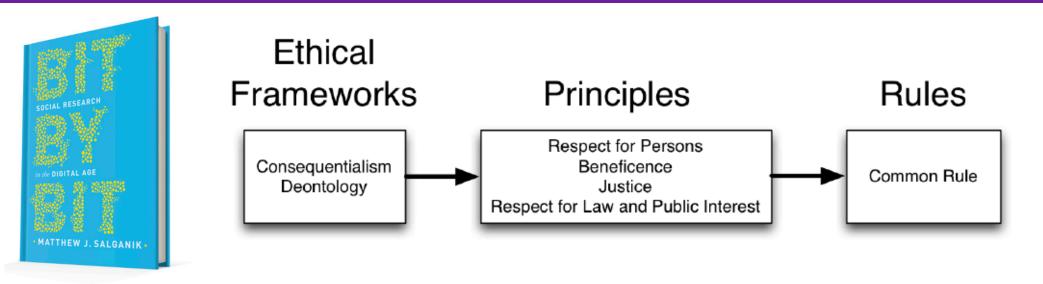
## Bit by Bit, Chapter 6: Ethics



The **Common Rule** is the set of regulations currently governing most federally funded research in the United States... The four **principles** come from two blueribbon panels that were created to provide ethical guidance to researchers: the **Belmont Report** and the **Menlo Report**.



## Bit by Bit, Chapter 6: Ethics



Finally, **consequentialism** and **deontology** are ethical frameworks that have been developed by philosophers for hundreds of years. A quick and crude way to distinguish the two frameworks is that deontologists focus on means and consequentialists focus on ends.



## A principles-based approach to ethics

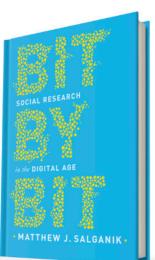


"... Neither of these approaches—the *rules-based approach* of social scientists or the *ad hoc approach* of data scientists—is well suited for social research in the digital age. Instead, I believe that we, as a community, will make progress if we adopt a *principles-based approach*.

That is, researchers should evaluate their research through existing rules—which I will take as given and assume should be followed—and through more general ethical principles. This principles-based approach helps researchers make reasonable decisions for cases where rules have not yet been written, and it helps researchers communicate their reasoning to each other and the public. "



## A principles-based approach to ethics



"The principles-based approach that I am advocating is not new. It draws on decades of previous thinking, much of which was crystallized in two landmark reports: the Belmont Report and the Menlo Report. As you will see, in some cases the principlesbased approach leads to clear, actionable solutions. And, when it does not lead to such solutions, it clarifies the tradeoffs involved, which is critical for striking an appropriate balance. Further, the principles-based approach is sufficiently general that it will be helpful no matter where you work (e.g., university, government, NGO, or company). "



# consequentialism & deontology

#### Two ethical frameworks

**Consequentialism** (Jeremy Bentham, John Stuart Mill): Take actions that lead to better states in the world

**Deontology** (Immanuel Kant): Focus on ethical duties, independent of their consequences

Deontologists focus on *means*, consequentialists focus on ends

"Arguments between consequentialists and deontologists are like two ships passing in the night."



## **Application: Informed Consent**

Deontologists focus on *means*, consequentialists focus on *ends* 

Individuals, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them. This opportunity is provided when adequate standards for informed consent are satisfied.

Both consequentialism and deontology support informed consent, but for different reasons.

## **Application: Informed Consent**

Deontologists focus on *means*, consequentialists focus on *ends* 

A **consequentialist** argument: Informed consent helps prevent harm to participants by prohibiting research that does not properly balance risk and anticipated benefit. In other words, consequentialist thinking would support informed consent because it helps **prevent bad outcomes** for participants.

A **deontological** argument for informed consent focuses on a researcher's duty to respect the **autonomy** of participants.

Given these arguments, a pure consequentialist might be willing to waive the requirement for informed consent in a setting where there was no risk, whereas a pure deontologist would not.

## Ad absurdum

Deontologists focus on *means*, consequentialists focus on *ends* 

**Transplant**: A doctor has five patients dying of organ failure and one healthy patient whose organs can save all five. A **consequentialist doctor is required to kill** the healthy patient to obtain his organs. This complete focus on ends, without regard to means, is flawed.

#### NB: putting a price on human life

#### **NB: reasoning under uncertainty**

**Time bomb**: A police office captured a terrorist who knows the location of a ticking time bomb that will kill millions of individuals if it detonates. A **deontological police officer would not lie** to trick a terrorist into revealing the location of the bomb. This complete focus on means, without regards to ends, also is flawed.



## The sad reality of today

#### IDEAS

#### The Atlantic

## The Extraordinary Decisions Facing Italian Doctors

There are now simply too many patients for each one of them to receive adequate care.

Now the Italian College of Anesthesia, Analgesia, Resuscitation and Intensive Care (SIAARTI) has **published guidelines for the criteria that doctors and nurses should follow** as these already extraordinary circumstances worsen. The document begins by likening **the moral choices Italian doctors may face to the forms of wartime triage that are required in the field of "catastrophe medicine."** Instead of providing intensive care to all patients who need it, the authors suggest, it may become necessary to **follow "the most widely shared criteria regarding distributive justice and the appropriate allocation of limited health resources.** 

https://www.theatlantic.com/ideas/archive/2020/03/who-gets-hospital-bed/607807/



## The sad reality of today

#### IDEAS

## The Extraordinary Decisions Facing Italian Doctors

There are now simply too many patients for each one of them to receive adequate care. MARCH 11, 2020

The principle they settle upon is utilitarian. **"Informed by the principle of maximizing benefits for the largest number,"** they suggest that "the allocation criteria need to guarantee that those patients with the highest chance of therapeutic success will retain access to intensive care."

"...I must admit that I have no moral judgment to make about the extraordinary document published by those brave Italian doctors. I have not the first clue whether they are recommending the right or the wrong thing. ... But if Italy is in an impossible position, **the obligation facing the United States is very clear: To arrest the crisis before the impossible becomes necessary.**"

https://www.theatlantic.com/ideas/archive/2020/03/who-gets-hospital-bed/607807/

The Atlantic

#### The sad reality of today

#### The New York Times

# *'Chilling' Plans: Who Gets Care as Washington State Hospitals Fill Up?*

#### By Karen Weise and Mike Baker

Published March 20, 2020 Updated March 22, 2020, 10:26 a.m. ET

"SEATTLE — Medical leaders in Washington State, which has the highest number of coronavirus deaths in the country, have quietly begun **preparing a bleak triage strategy to determine which patients may have to be denied complete medical care** in the event that the health system becomes overwhelmed by the coronavirus in the coming weeks.

.... It's protecting the clinicians so you don't have one person who's kind of playing God," she said, adding, "It is chilling, and it should not happen in America."

https://www.nytimes.com/2020/03/20/us/coronavirus-in-seattle-washington-state.html



# human subjects research

## Tuskegee Syphilis Study

In 1932, researchers from the US Public Health Service (PHS) enrolled 400 black men from Tukegee, Alabama, infected with syphilis in a study to study the effects of the disease. The study was **non-therapeutic**: designed to document, not treat!

Date	Event
1932	Approximately 400 men with syphilis are enrolled in the study; they are not informed of the nature of the research
1937-38	The PHS sends mobile treatment units to the area, but treatment is withheld for the men in the study
1942-43	In order to prevent the men in the study from receiving treatment, PHS intervenes to prevent them from being drafted for WWII
1950s	Penicillin becomes a widely available and effective treatment for syphilis; the men in the study are still not treated (Brandt 1978) https://www.bitbybitbook.com/en/1st-ed/ethics/

## Tuskegee Syphilis Study

In 1932, researchers from the US Public Health Service (PHS) enrolled 400 black men from Tukegee, Alabama, infected with syphilis in a study to study the effects of the disease. The study was **non-therapeutic**: designed to document, not treat!

Date	Event
1969	The PHS convenes an ethical review of the study; the panel recommends that the study continue
1972	Peter Buxtun, a former PHS employee, tells a reporter about the study, and the press breaks the story
1972	The US Senate holds hearings on human experimentation, including Tuskegee Study
1973	The government officially ends the study and authorizes treatment for survivors
	https://www.bitbybitbook.com/en/1st-ed/ethics/

# The Belmont Report

## The need for ethical principles

#### THE BELMONT REPORT

Office of the Secretary

Ethical Principles and Guidelines for the Protection of Human Subjects of Research

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research

April 18, 1979

- Boundaries between practice and research
- Basic ethical principles
- Applications



## The Belmont Report: boundaries

#### **Boundaries between practice and research**

• Research seeks generalizable knowledge, practice includes everyday treatment and activities

"For the most part, the term "practice" refers to interventions that are designed solely to enhance the wellbeing of an individual patient or client and that have a reasonable expectation of success. The purpose of medical or behavioral practice is to provide diagnosis, preventive treatment or therapy to particular individuals ... By contrast, the **term "research' designates an activity designed to test an hypothesis**, permit conclusions to be drawn, and thereby to develop or contribute to generalizable knowledge (expressed, for example, in theories, principles, and statements of relationships). Research is usually described in a formal protocol that sets forth an objective and a set of procedures designed to reach that objective."

• Argues that ethical principles of Belmont Report apply only to research



# The Belmont Report: principles

#### **Respect for persons**

#### Individuals should be treated as autonomous agents

"To **respect autonomy** is to give weight to autonomous persons' considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others. To show lack of respect for an autonomous agent is to repudiate that person's considered judgments, to deny an individual the freedom to act on those considered judgments, or to **withhold information necessary to make a considered judgment**, when there are no compelling reasons to do so. "

#### **Respect for persons**

## Persons with diminished autonomy are entitled to protection

"In some situations, however, application of the principle is not obvious. The involvement of prisoners as subjects of research provides an instructive example. On the one hand, it would seem that the principle of respect for persons requires that prisoners not be deprived of the opportunity to volunteer for research. On the other hand, under prison conditions they may be subtly coerced or unduly influenced to engage in research activities for which they would not otherwise volunteer. Respect for persons would then dictate that prisoners be protected. Whether to allow prisoners to "volunteer" or to "protect" them presents a dilemma. Respecting persons, in most hard cases, is often a matter of balancing competing claims urged by the principle of respect itself. "



#### Beneficence

#### Do not harm

#### Maximize possible benefits and minimize possible harm

"The Hippocratic maxim "do no harm" has long been a fundamental principle of medical ethics. **Claude Bernard extended it to the realm of research, saying that one should not injure one person regardless of the benefits that might come to others.** However, even avoiding harm requires learning what is harmful; and, in the process of obtaining this information, persons may be exposed to risk of harm. Further, the Hippocratic Oath requires physicians to benefit their patients "according to their best judgment." **Learning what will in fact benefit may require exposing persons to risk.** The problem posed by these imperatives is to decide when it is justifiable to seek certain benefits despite the risks involved, and when the benefits should be foregone because of the risks."

#### Justice

## Who ought to receive the benefits of research and bear its burdens?

"Questions of justice have long been associated with social practices such as punishment, taxation and political representation. Until recently these questions have not generally been associated with scientific research. However, they are foreshadowed even in the earliest reflections on the ethics of research involving human subjects. For example, during the 19th and early 20th centuries the **burdens of serving as research subjects** fell largely upon poor ward patients, while the benefits of improved medical care flowed primarily to private patients. ... "



## Justice

## Who ought to receive the benefits of research and bear its burdens?

".... Subsequently, the **exploitation of unwilling prisoners as research subjects in Nazi concentration camps** was condemned as a particularly flagrant injustice. In this country, in the 1940's, **the Tuskegee syphilis study** used disadvantaged, rural black men to study the untreated course of a disease that is by no means confined to that population. **These subjects were deprived of demonstrably effective treatment in order not to interrupt the project, long after such treatment became generally available.** "



# The Belmont Report: applications

## Informed consent

"Respect for persons requires that subjects, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them. This opportunity is provided when adequate standards for informed consent are satisfied.

While the importance of informed consent is unquestioned, **controversy prevails over the nature and possibility** of an informed consent. Nonetheless, there is widespread agreement that **the consent process can be analyzed as containing three elements: information, comprehension and voluntariness.** ..."



#### Informed consent

#### Information, Comprehension, Voluntariness

"Most codes of research establish specific items for disclosure intended to assure that subjects are given sufficient information. These items generally include: the research procedure, their purposes, risks and anticipated benefits, alternative procedures (where therapy is involved), and a statement offering the subject the opportunity to ask questions and to withdraw at any time from the research.

## ... A special problem of consent arises where informing subjects of some pertinent aspect of the research is likely to impair the validity of the research.

... In all cases of research involving incomplete disclosure, such research is justified only if it is clear that (1) incomplete disclosure is truly necessary to accomplish the goals of the research, (2) there are no undisclosed risks to subjects that are more than minimal, and (3) there is an adequate plan for debriefing subjects, when appropriate, and for dissemination of research results to them. "

## Informed consent

#### Information, Comprehension, Voluntariness

"The manner and context in which information is conveyed is as important as the information itself. For example, **presenting information in a disorganized and rapid fashion, allowing too little time for consideration or curtailing opportunities for questioning, all may adversely affect a subject's ability to make an informed choice.** 

Because the subject's ability to understand is a function of intelligence, rationality, maturity and language, it is **necessary to adapt the presentation of the information to the subject's capacities**. Investigators are responsible for ascertaining that the subject has comprehended the information. "

#### Recall: racial bias in resume screening

#### Are Emily and Greg More Employable Than Lakisha and Jamal? A Field Experiment on Labor Market Discrimination

#### September 2004

**Marianne Bertrand** 

Sendhil Mullainathan

AMERICAN ECONOMIC REVIEW VOL. 94, NO. 4, SEPTEMBER 2004 (pp. 991-1013)

We study race in the labor market by sending fictitious resumes to help-wanted ads in Boston and Chicago newspapers. To manipulate perceived race, resumes are randomly assigned African-American- or White-sounding names. White names receive 50 percent more callbacks for interviews. Callbacks are also more responsive to resume quality for White names than for African-American ones. The racial gap is uniform across occupation, industry, and employer size. We also find little evidence that employers are inferring social class from the names. Differential treatment by race still appears to still be prominent in the U. S. labor market.



@stoyanoj



## More on informed consent

**Research question**: Does an employer unlawfully discriminate against applicants based on membership in protected groups?

#### **Employers don't provide consent, in fact, they are actively deceived!**

Field experiments to study discrimination are legally permissible if:

- 1. the harm to employers is limited, and
- 2. there is great social benefit to having a reliable measure of discrimination, **and**
- 3.other methods of measuring discrimination are weak; **and**
- 4. deception does not strongly violate the norms of that setting.

#### Assessment of risks and benefits

"Risks and benefits of research may affect the **individual subjects**, the **families** of the individual subjects, and **society** at large (or special groups of subjects in society). ....

In balancing these different elements, the **risks and benefits affecting the immediate research subject** will normally carry special weight. ....

Beneficence thus requires that we protect against risk of harm to subjects and also that we be concerned about the loss of the substantial benefits that might be gained from research. "



## Selection of subjects

Just as the principle of **respect for persons** finds expression in the requirements for consent, and the principle of **beneficence** in risk/benefit assessment, the principle of **justice** gives rise to moral requirements that there be fair procedures and outcomes in the selection of research subjects.

- Individual justice in the selection of subjects would require that researchers exhibit fairness: thus, they should not offer potentially beneficial research only to some patients who are in their favor or select only "undesirable" persons for risky research.
- Social justice requires that distinction be drawn between classes of subjects that ought, and ought not, to participate in any particular kind of research, based on the ability of members of that class to bear burdens and on the appropriateness of placing further burdens on already burdened persons.

# The Menlo Report

Ethical Principles Guiding Information and Communication Technology Research

August 2012

http://www.caida.org/publications/papers/2012/menIo\_report\_actual\_formatted/ menIo\_report\_actual\_formatted.pdf

... the Menlo Report calls on researchers to **move beyond the narrow definition of "research involving human subjects" from the Belmont Report** to a more general notion of "research with human-harming potential."

A principles-based approach means that **researchers should not hide behind a narrow, legal definition of "research involving human subjects,"** even if IRBs allow it. Rather, they should adopt a more general notion of "research with humanharming potential" and they should subject all of their own research with human-harming potential to ethical consideration.

https://www.bitbybitbook.com/en/1st-ed/ethics/ethics-appendix/



Principle	Application					
Respect for Persons	Participation as a research subject is voluntary, and follows from informed consent; Treat individuals as autonomous agents and respect their right to determine their own best interests; Respect individuals who are not targets of research yet are impacted; Individuals with diminished autonomy, who are incapable of deciding for themselves, are entitled to protection.					
Beneficence	Do not harm; Maximize probable benefits and minimize probable harms; Systematically assess both risk of harm and benefit.					
Justice	Each person deserves equal consideration in how to be treated, and the benefits of research should be fairly distributed according to individual need, effort, societal contribution, and merit; Selection of subjects should be fair, and burdens should be allocated equitably across impacted subjects.					
Respect for Law and Public Interest	Engage in legal due diligence; Be transparent in methods and results; Be accountable for actions.					

http://www.caida.org/publications/papers/2012/menlo\_report\_actual\_formatted/ menlo\_report\_actual\_formatted.pdf

#### **Respect for Law and Public Interest**

- Implicit in the Belmont Reports' application of Beneficence
- In Information and Communication Technology Research (ICTR), included as a separate principle with two applications - *Compliance* and *Transparency and Accountability*

"The second application refers to **transparency of methodologies and results**, and accountability for actions. Transparency and accountability serve vital roles in many ICTR contexts where it is challenging or impossible to identify stakeholders (e.g., attribution of sources and intermediaries of information), to understand interactions between highly dynamic and globally distributed systems and technologies, and consequently to **balance associated harms and benefits**. A lack of transparency and accountability risks undermining the credibility of, trust and confidence in, and ultimately support for, ICT research."

http://www.caida.org/publications/papers/2012/menIo\_report\_actual\_formatted/ menIo\_report\_actual\_formatted.pdf

#### **Respect for Law and Public Interest**

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"Accountability demands that research methodology, ethical evaluations, data collected, and results generated should be documented and made available responsibly in accordance with balancing risks and benefits. Data should be available for legitimate research, policy-making, or public knowledge, subject to appropriate collection, use, and disclosure controls informed by the Beneficence principle. The appropriate format, scope and modality of the data exposure will vary with the circumstances, as informed by Beneficence determinations."

http://www.caida.org/publications/papers/2012/menIo\_report\_actual\_formatted/ menIo\_report\_actual\_formatted.pdf

## case studies

## Case study: Barrow, Alaska, 1979

Native leaders and city officials, worried about drinking and associated violence in their community, **invited a group of sociology researchers** to assess the problem and work with them to devise solutions.

#### Methodology

- 10% representative sample (N=88) of everyone over the age of 15 using a 1972 demographic survey
- Interviewed on attitudes and values about use of alcohol
- Obtained psychological histories & drinking behavior
- Given the Michigan Alcoholism Screening Test
- Asked to draw a picture of a person (used to determine cultural identity)



## Study "results"

#### Alcohol Plagues Eskimos; Alcoholism Plagues Eskimo Village

DAVA SOBEL (); January 22, 1980, , Section Science Times, Page C1, Column , words

PERMISSIONS

[ DISPLAYING ABSTRACT ]

THE Inupiat Eskimos of Alaska's North Slope, whose culture has been overwhelmed by energy development activities, are "practically committing suicide" by mass alcoholism, University of Pennsylvania researchers said here yesterday. The alcoholism rate is 72 percent among the 2,000 Eskimo men and women in the village of Barrow, where violence is becoming the ...

At the conclusion of the study researchers formulated a report entitled **"The Inupiat, Economics and Alcohol on the Alaskan North Slope"**, released **simultaneously** at a press release and to the Barrow community.

The press release was picked up by the New York Times, who ran a front page story entitled "Alcohol Plagues Eskimos"



## Harms and backlash

Study **results were revealed** in the context of a press conference that was held far from the Native village, and **without the presence, much less the knowledge or consent**, of any community member who might have been able to present any context concerning the socioeconomic conditions of the village.

#### Study results suggested that nearly all adults in the community were

**alcoholics.** In addition to the shame felt by community members, the town's Standard and Poor bond rating suffered as a result, which in turn decreased the tribe's ability to secure funding for much needed projects.

Article Preview Eskimos Irate Over Alcoholism Study [DISPLAYING ABSTRACT] BARROW, ALASKA HOT tempers and tension arising from a scientific report that found a high rate of alcoholism in this predominantly Eskimo community have abated somewhat after two days of meetings here at the northernmost point of Alaska.

## Problems

Edward F. Foulks, M.D., "Misalliances In The Barrow Alcohol Study"

#### Methodological

- "The authors once again met with the Barrow Technical Advisory Group, who stated their concern that only Natives were studied, and that outsiders in town had not been included."
   any chance of selection bias?
- "The estimates of the frequency of intoxication based on association with the probability of being detained were termed "ludicrous, both logically and statistically."

#### Ethical

- Participants not in control of how their data is used
- Significant harm: social (stigmatization) and financial (bond rating)
- No laws were broken, and harms are not about individual privacy!



## Case study: Emotional contagion

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



Proceedings of the National Academy of Sciences of the United States of America

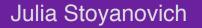
Adam D. I. Kramer, Jamie E. Guillory, and Jeffrey T. Hancock

PNAS June 17, 2014 111 (24) 8788-8790; first published 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)

#### Significance

We show, via a massive (N = 689,003) experiment on Facebook, that emotional states can be transferred to others via emotional contagion, leading people to experience the same emotions without their awareness. We provide experimental evidence that emotional contagion occurs without direct interaction between people (exposure to a friend expressing an emotion is sufficient), and in the complete absence of nonverbal cues.





## Case study: Emotional contagion

- **Criticism** in the research community, in the press
  - users were not consented to participate in the study
  - there was no third-party review of study design -Facebook did not even have an IRB at the time
- Result
  - PNAS placed a disclaimer on the article
  - Facebook instituted an internal ethics review board

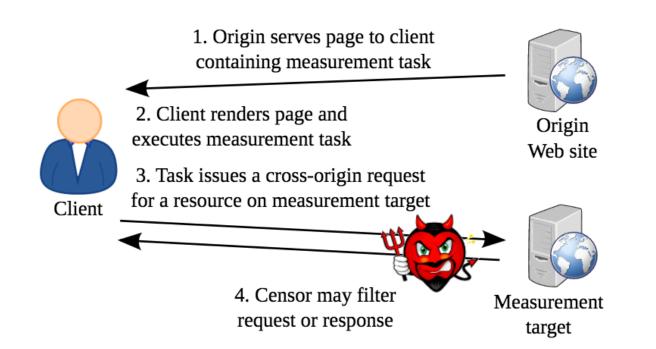
#### **Did Facebook stop running these types of experiments?**

## Case study: Encore

#### Encore: Lightweight Measurement of Web Censorship with Cross-Origin Requests

#### ACM SIGCOMM 2015

Sam Burnett School of Computer Science, Georgia Tech sam.burnett@gatech.edu Nick Feamster Department of Computer Science, Princeton feamster@cs.princeton.edu





## Case study: Encore

#### Encore: Lightweight Measurement of Web Censorship with Cross-Origin Requests

#### ACM SIGCOMM 2015

Sam Burnett School of Computer Science, Georgia Tech sam.burnett@gatech.edu Nick Feamster Department of Computer Science, Princeton feamster@cs.princeton.edu

"...We present Encore, a system that harnesses cross-origin requests to **measure Web filtering** from a diverse set of vantage points without requiring users to install custom software, enabling longitudinal measurements from many vantage points. We explain how Encore **induces Web clients to perform cross-origin requests** that measure Web filtering, design a distributed platform for scheduling and collecting these measurements, show the feasibility of a global-scale deployment with a pilot study and an **analysis of potentially censored Web content**, identify several cases of filtering in six months of measurements, and **discuss ethical concerns** that would arise with widespread deployment."



## Case study: Encore

#### Encore: Lightweight Measurement of Web Censorship with Cross-Origin Requests

#### ACM SIGCOMM 2015

Sam Burnett School of Computer Science, Georgia Tech sam.burnett@gatech.edu Nick Feamster Department of Computer Science, Princeton feamster@cs.princeton.edu

**Statement from the SIGCOMM 2015 Program Committee:** The SIGCOMM 2015 PC appreciated the technical contributions made in this paper, but found the paper controversial because some of the experiments the authors conducted raise ethical concerns. The controversy arose in large part because the networking research community does not yet have widely accepted guidelines or rules for the ethics of experiments that measure online censorship. In accordance with the published submission guidelines for SIGCOMM 2015, had the authors not engaged with their Institutional Review Boards (IRBs) or had their IRBs determined that their research was unethical, the PC would have rejected the paper without review. But the authors did engage with their IRBs, which did not flag the research as unethical. The PC hopes that discussion of the ethical concerns these experiments raise will advance the development of ethical guidelines in this area. It is the PC's view that future guidelines should include as a core principle that researchers should not engage in experiments that subject users to an appreciable risk of substantial harm absent informed consent. The PC endorses neither the use of the experimental techniques this paper describes nor the experiments the authors conducted.

## Case study: 2014 Ebola outbreak



- Public health officials wanted information about the mobility of people in the most heavily infected countries in order to help control the outbreak
- Mobile phone companies had detailed call records that could have provided some of this information
- Yet ethical and legal concerns bogged down researchers' attempts to analyze the data

If we, as a community, can develop ethical norms and standards that are shared by both researchers and the public—and I think we can do this—then we can harness the capabilities of the digital age in ways that are responsible and beneficial to society.

https://www.bitbybitbook.com/en/1st-ed/ethics/



professional responsibility

## The ACM Code of Ethics

Association for	Digital Library 🗗	CACM 🗗 🛛 Que	ue 🖸 🛛 TechNews 🖸	Learning Center	Career Center 🗗			
Computing Machinery Advancing	Computing as a Science & Profession		Join	Volunteer myACM	<b>Q</b> Search			
ABOUT ACM MEMBERSHIP PUBLICATIONS SPECIA	AL INTEREST GROUPS CONFERENCES CHAPTER	RS AWARDS ED	UCATION PUBLIC P	OLICY GOVERNANCE				
Home > Code Of Ethics								
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ACM Code of Ethics and Profe	ssional Conduct							
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Preamble								
Computing professionals' actions change the wo impacts of their work, consistently supporting th Conduct ("the Code") expresses the conscience	e public good. The ACM Code of Ethics and I							
			On This Pa	ige				
The Code is designed to inspire and guide the et current and aspiring practitioners, instructors, st		Preamble						
technology in an impactful way. Additionally, the occur. The Code includes principles formulated a			1. GENERA	L ETHICAL PRINCIP	LES.			
understanding that the public good is always the by guidelines, which provide explanations to ass the principle.	e primary consideration. Each principle is sup	pplemented	well-being	oute to society and t acknowledging that olders in computing.	all people			
			1.2 Avoid I					
Section 1 outlines fundamental ethical principles Section 2 addresses additional, more specific con			1.3 Be hor	est and trustworthy				
guides individuals who have a leadership role, w capacity. Commitment to ethical conduct is requ	ired of every ACM member, and principles ir		1.4 Be fair discriminat	and take action not e.	to			
compliance with the Code are given in Section 4 The Code as a whole is concerned with how func		ting	new ideas,	t the work required inventions, creative ting artifacts.				
professional's conduct. The Code is not an algori basis for ethical decision-making. When thinking			1.6 Respec	t privacy.				
find that multiple principles should be taken into	account, and that different principles will ha	ave different	1.7 Honor	confidentiality.				
relevance to the issue. Questions related to thes consideration of the fundamental ethical principl		5	2. PROFES	SIONAL RESPONSIB	ILITIES.			
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				in high standards of				

#### https://www.acm.org/binaries/content/assets/about/acm-code-of-ethics-booklet.pdf

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## The ACM Code of Ethics (2018)

#### **General ethical principles**

- Contribute to society and to human well-being, acknowledging that all people are stakeholders in computing
- Avoid harm
- Be honest and trustworthy
- Be fair and take action not to discriminate
- Respect the work required to produce new ideas, inventions, creative works, and computing artifacts
- Respect privacy
- Honor confidentiality

https://www.acm.org/binaries/content/assets/about/acm-code-of-ethics-booklet.pdf



## Personal responsibility?

#### NATURE | NEWS

#### Italian seismologists cleared of manslaughter

Appeals court says six scientists did not cause deaths in 2009 L'Aquila earthquake and cuts sentence of a government official.

Alison Abbott & Nicola Nosengo

10 November 2014

**Six seismologists accused of misleading the public about the risk of an earthquake in Italy were cleared of manslaughter** on 10 November. An appeals court overturned their six-year prison sentences and reduced to two years the sentence for a government official who had been convicted with them.

The magnitude-6.3 earthquake struck the historic town of L'Aquila in the early hours of 6 April 2009, killing more than 300 people.



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nature.

## Personal responsibility?

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Appeals court says six scientists did not cause deaths in 2009 L'Aquila earthquake and cuts sentence of a government official.

Alison Abbott & Nicola Nosengo

10 November 2014

The finding by a three-judge appeals court prompted many L'Aquila citizens who were waiting outside the courtroom to react with rage, shouting "shame" and saying that the Italian state had just acquitted itself, local media reported. But it **comes as a relief to scientists around the world who had been following the unprecedented case with alarm**.

"We don't want to have to be worried about the possibility of being prosecuted if we give advice on earthquakes," says seismologist Ian Main of the University of Edinburgh, UK. "That would discourage giving honest opinion."



# laws and regulation (another time)

#### GDPR

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#### https://gdpr-info.eu/

#### General Data Protection Regulation GDPR

Welcome to gdpr-info.eu. Here you can find the official PDF of the Regulation (EU) 2016/679 (General Data Protection Regulation) in the current version of the OJ L 119, 04.05.2016; cor. OJ L 127, 23.5.2018 as a neatly arranged website. All Articles of the GDPR are linked with suitable recitals. The European Data Protection Regulation is applicable as of May 25th, 2018 in all member states to harmonize data privacy laws across Europe. If you find the page useful, feel free to support us by sharing the project.

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## GDPR: scope and definitions

#### Article 2: Material Scope

• This Regulation applies to the processing of personal data wholly or partly by automated means and to the processing other than by automated means of personal data which form part of a filing system or are intended to form part of a filing system.

#### Article 4: Definitions

- 'personal data' means any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person;
- 'processing' means any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction;



## GDPR: scope and definitions

#### Article 4: Definitions

- 'controller' means the natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of personal data; where the purposes and means of such processing are determined by Union or Member State law, the controller or the specific criteria for its nomination may be provided for by Union or Member State law;
- **'processor'** means a natural or legal person, public authority, agency or other body which processes personal data on behalf of the controller;
- 'consent' of the data subject means any freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her;

#### Art. 7 GDPR Conditions for consent

- Where processing is based on consent, the controller shall be able to demonstrate that the data subject has consented to processing of his or her personal data.
- 2. <sup>1</sup> If the data subject's consent is given in the context of a written declaration which also concerns other matters, the request for consent shall be presented in a manner which is clearly distinguishable from the other matters, in an intelligible and easily accessible form, using clear and plain language. <sup>2</sup> Any part of such a declaration which constitutes an infringement of this Regulation shall not be binding.

#### Art. 7 GDPR Conditions for consent

- 3. <sup>1</sup> The data subject shall have the right to withdraw his or her consent at any time. <sup>2</sup> The withdrawal of consent shall not affect the lawfulness of processing based on consent before its withdrawal. <sup>3</sup> Prior to giving consent, the data subject shall be informed thereof. <sup>4</sup> It shall be as easy to withdraw as to give consent.
- 4. When assessing whether consent is freely given, utmost account shall be taken of whether, *inter alia*, the performance of a contract, including the provision of a service, is conditional on consent to the processing of personal data that is not necessary for the performance of that contract.



## Chapter 3 Rights of the data subject

Section 1	-	Transparency and modalities
Article 12	-	Transparent information, communication and modalities for the exercise of the rights of the data subject
Section 2	_	Information and access to personal data
Article 13	-	Information to be provided where personal data are collected from the data subject
Article 14	_	Information to be provided where personal data have not been obtained from the data subject
Article 15	_	Right of access by the data subject



## Chapter 3 Rights of the data subject

Section 3	-	Rectification and erasure
Article 16	-	Right to rectification
Article 17	_	Right to erasure ('right to be forgotten')
Article 18	_	Right to restriction of processing
Article 19	_	Notification obligation regarding rectification or erasure of personal data or restriction of processing
Article 20	_	Right to data portability



## Chapter 3 Rights of the data subject

Section 4	-	Right to object and automated individual decision-making
Article 21	_	Right to object
Article 22	_	Automated individual decision-making, including profiling

### Recital 58 The principle of transparency\*

<sup>1</sup> The principle of transparency requires that any information addressed to the public or to the data subject be concise, easily accessible and easy to understand, and that clear and plain language and, additionally, where appropriate, visualisation be used. <sup>2</sup> Such information could be provided in electronic form, for example, when addressed to the public, through a website. <sup>3</sup> This is of particular relevance in situations where the proliferation of actors and the technological complexity of practice make it difficult for the data subject to know and understand whether, by whom and for what purpose personal data relating to him or her are being collected, such as in the case of online advertising. <sup>4</sup> Given that children merit specific protection, any information and communication, where processing is addressed to a child, should be in such a clear and plain language that the child can easily understand.

https://gdpr-info.eu/recitals/no-58/



Transparency, Fairness, Data Protection, Neutrality: Data Management Challenges in the Face of New Regulation

SERGE ABITEBOUL, Inria & Ecole Normale Supérieure, France JULIA STOYANOVICH, New York University, USA

- Legal frameworks: the EU's General Data Protection Regulation (GDPR), the New York City Automated Decision Systems (ADS) law, the Indian Net Neutrality Regulatory Framework
- Common threads:
- data subject's **informed consent** to data collection and processing
- right to an **explanation** of decision-making processes and results
- data rights: correction, deletion, portability of personal data

https://arxiv.org/abs/1903.03683

