data-ppf.github.io 2020-04-14

lecture 12 of 14: 'what we talk about when we talk about ethics'

chris wiggins + matt jones, Columbia

student observations: data

```
...
10 facebook
8 hipaa
7 panopticon
5 pandemic
5 organizational
5 $50
4 coronavirus
4 bluetooth
3 virus
...
```

student observations: power

the seemingly only consequence for these serious ethics breaches was public backlash

Salganik's piece and the three examples discussed reveal the power of public backlash in the face of lost privacy,

In this way, relying on researchers to integrate Salganik's "Common Rule" might relate back to Metcalf and Moss's analysis of the factors that oppose more ethical standards in corporations collecting data, such as money/corporate interest, or even the simplicity of not acting ethically when it is unclear if you will be caught

I'm skeptical about the survivability of this ethics trend - whether it can actually achieve the ideal in which ethical violations are a thing of the past

student observations: our valuable data

I started this week's readings with Sweeney's piece and I was honestly a little shocked I knew companies were involved in the selling of user data and such, but I never realized the government encouraged (and sometimes required it)

On the other hand, there are benefits of accessibility to medical history and data, including research in not only the medical field, but also about inequality in the US (who gets what treatment and where, etc)

Both the Salganik and Metcalf et al article brought up ideas I had not considered about ethics in data science, with the first, from the Sagalnik piece, being the idea that privacy concerns could be preempting valuable research from occurring

student observations: principles

The Salganik chapter argues for the use of principles-based approach to ethics that is transferable to all sectors, rather than just one,

Metcalf et al point out that the work of ethics consists of working through and not resolving these tensions of underlying logics and normative goals.

It's a little funny to me that the report includes Respect for Law and Public Interest, when sometimes laws (or lack thereof) are inherently biased themselves and don't protect all people equally

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- today: how researchers *design for* ethics
  - remaining 2 weeks: political dynamics of data ethics IRL

readings: Salganik, Sweeney, Metcalf

Salganik, esp. Belmont

- Belmont 1 of many ethics

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Salganik, esp. Belmont

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- has been *so stress-tested* (abundant literature)

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“the Road to Belmont”: Tuskegee as flash point

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Figure 1: your local paper

Tuskegee and race

ARCHIVES | Syphilis Victims in U.S. Study Went Untreated for 40 Years

The experiment, called the Tuskegee Study, began in 1932 with about 600 black men mostly poor and uneducated, from Tuskegee, Ala., an area that had the highest syphilis rate in the nation at the time.

Four hundred of the group had syphilis and never received deliberate treatment for the Venereal Infection. A control group of 200 had no syphilis and did not receive any specific therapy.

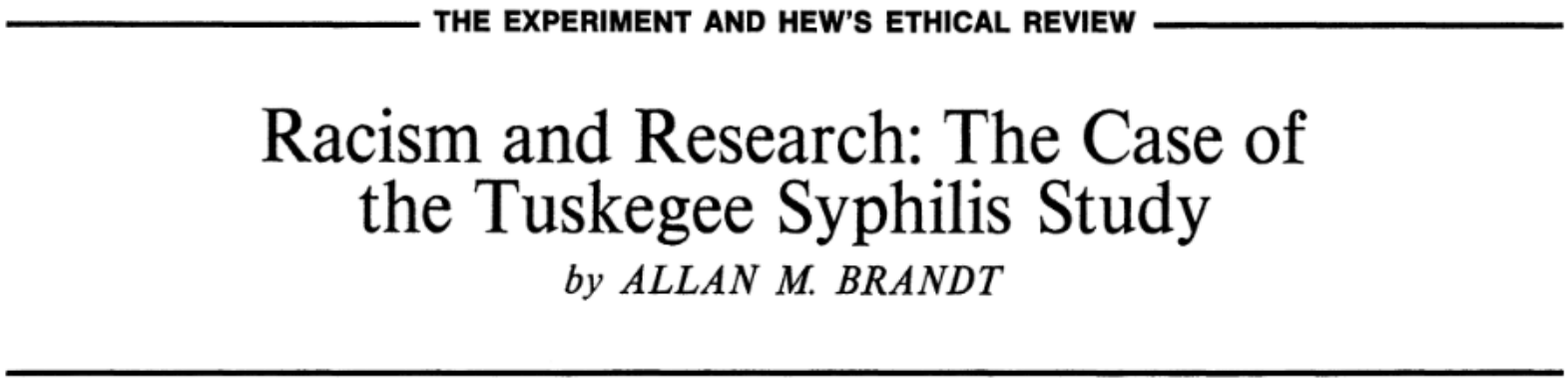
Some subjects were added to the study In its early years to replace men who had dropped out of the program, but the number added is not known. At the beginning of this year, 74 of those who received no treatment were still alive.

As Incentives to enter the Program, the men were promised free transportation to and from hospitals, free hot lunches, free medicine for any disease other than syphilis and free burial after autopsies were performed.

Could Have Been Helped

The Tuskegee Study began 10 years before penicillin was found to be a cure for syphilis and 15 years before the drug became widely available.

Tuskegee and race, 2



THE EXPERIMENT AND HEW'S ETHICAL REVIEW

Racism and Research: The Case of the Tuskegee Syphilis Study

by ALLAN M. BRANDT

Figure 3: power, examined

Tuskegee and race, 3

ALLAN M. BRANDT *is a doctoral candidate in the Department of History, Columbia University. He is presently writing a social history of venereal disease in the United States. Mr. Brandt was a student intern at The Hastings Center in 1977.*

Figure 4: power, examined – grad student

Amalie Kass Professor of History of Medicine and Professor of . . . The Cigarette Century: The Rise, Fall, and Deadly Persistence of the Product that Defined America

Tuskegee: 'never clandestine'

ARCHIVES | Syphilis Victims in U.S. Study Went Untreated for 40 Years

'Never Clandestine'

The syphilis study "was never clandestine" and 15 scientific reports were published in the medical literature, Dr. Millar said in a telephone interview yesterday from Atlanta.

Officials who initiated the study in 1932 had informed the syphilis victims that they could get treatment for the infection at any time, Dr. Millar said.

"Patients were not denied drugs," Dr. Millar stressed. Rather, they were not offered drugs.

When the study began, doctors could offer only what is now regarded as poor therapy —injections of metals like bismuth, arsenic and mercury. Such treatments were known to be toxic.

Many doctors, Dr. Miller said, then thought "it better not to treat syphilis cases because of the mortality from" the metal therapies.

The critical period in ethics was in the late nineteen lforties and early nineteen–fifties when antibiotics could have been but were not prescribed for the syphilis patients

Tuskegee: in full view

The American Medical Association meeting May 1936 a lecture on untreated syphilis in black American men.

> *A population of untreated individuals from the Tuskegee Alabama area "seemed to offer an unusual opportunity to study the untreated syphilitic patient from the beginning of the disease to the death of the infected person."*

(our italics)

> *"An opportunity was also offered to compare this process, uninfluenced by modern treatment, with the results" obtained from people who had been treated.*

The results were clear: treatment has dramatically positive effects. AND YET ....

- R. A. Vonderlehr et al., "Untreated Syphilis in the Male Negro: A Comparative Study of Treated and Untreated Cases," Journal of the American Medical Association 107, no. 11 (September 12, 1936): 856.

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- 1979-04-18: federal register, i.e., law

Belmont report

- Beauchamp: “consultant philosopher”

  “the project of creating a framework of basic principles for all federally funded research had been mandated by a public law enacted by the us congress”

  “the national commission viewed these principles as embedded in preexisting pubic morality”

Belmont: outputs

- report, 1979-04-10, 10pp

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- appendix v1 “78-0013”: 611pp
- appendix v2 “78-0014”: 705pp

Principlism: granularity

- “frameworks->principles->rules” (Salg)

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- tensions will be negotiated and interpreted into rules and process

Principlism: tension

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Belmont: beneficence vs. personhood

- inadequacy of utilitarian calculations of public good

Certain groups, such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized may continually be sought as research subjects, owing to their ready availability in settings where research is conducted. Given their dependent status and their frequently compromised capacity for free consent, they should be protected against the danger of being involved in research solely for administrative convenience, or because they are easy to manipulate as a result of their illness or socioeconomic condition.

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- https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html

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Principles other than Belmont

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Alternative Ethical Philosophies

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- Van den Hoven, et al. "The design turn in applied ethics." Designing in ethics (2017)

Ethics: define vs design (intra mūrōs)

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- 'accountability'
- IRB "most [scientists] experience ethical debate. . . through the bureaucratic process of IRB"
  - why limit researchers? "IRBs in the United States are required to include at least one non-researcher."

researchers Q:

> *so long as most of these principles rely on the interpretation of researchers, making them prone to biases, we have a long way to go*

–Bennett Brown

Belmont A:

> *The Commission's deliberations on Institutional Review Boards began with the premise that investigators should not have sole responsibility for determining whether research involving human subjects fulfills ethical standards. Others who are independent of the research must share this responsibility, because investigators have a potential conflict by virtue of their concern with the pursuit of knowledge as well as the welfare of the human subjects of their research.*

1978-09-01 IRB recommendation

Ethics: define vs design (extra mūrōs)

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  - agile software as ethics

Ethics: define vs design, and principles

INTERVIEWER: You have to feel good about it today.

DR. BEAUCHAMP: Well, yeah, it worked out well, exactly.

INTERVIEWER: Did you expect that the report would be translated as the basis for regulations to the extent that it was?

DR. BEAUCHAMP: No, it is a surprise to me, today, that that happened and that it continues to sustain the kind of interest that it sustained.

Sweeney

Bio on Sweeney

- PhD in CS, MIT w/Hal Abelson

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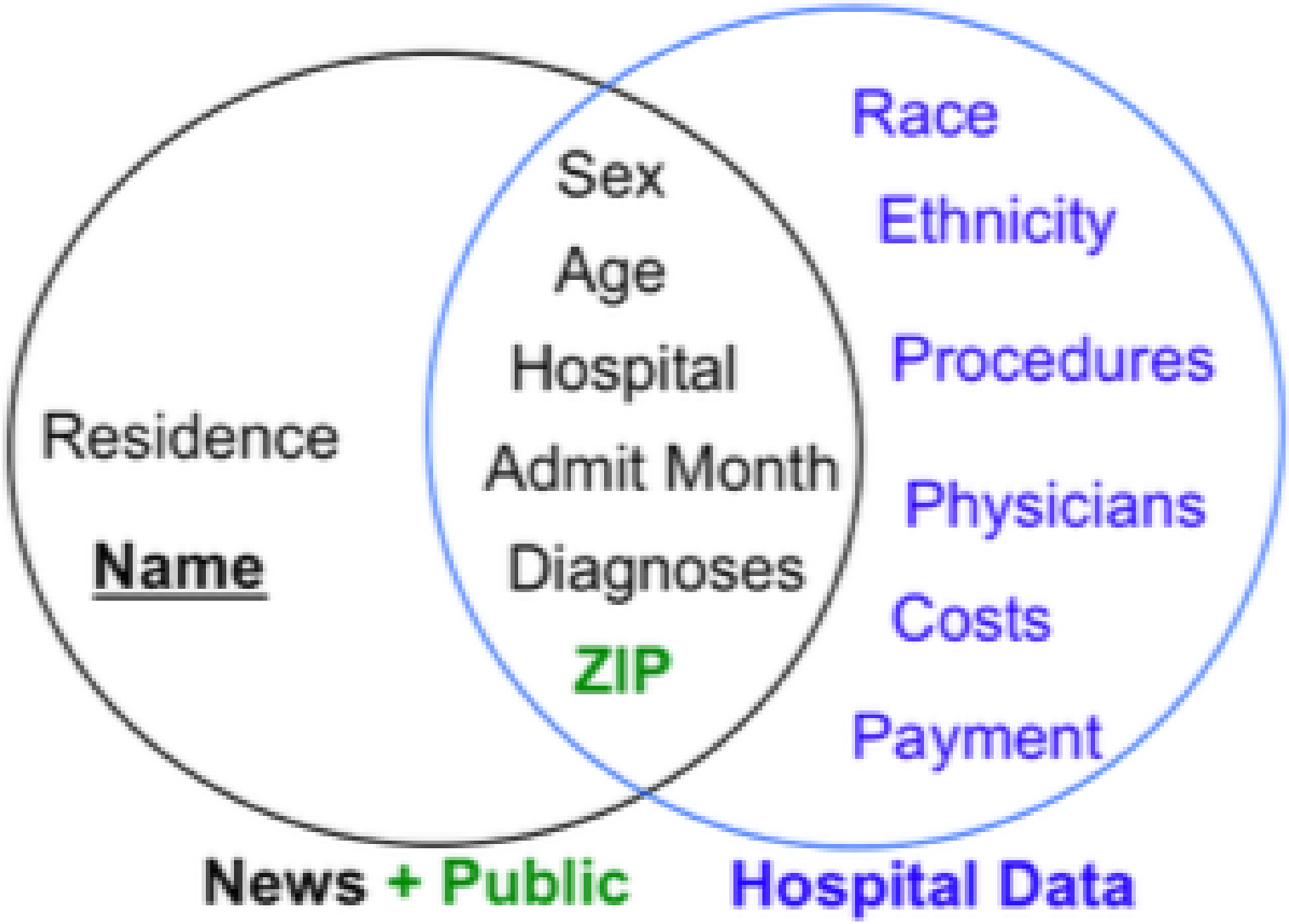
  - more than I can list. . . .

Sweeney insight on code and law

"The design of the technology, and how it works is really the new policy. And the thing about these designs as policymakers is that we didn't vote for them, we didn't elect them, and we didn't have any say in the things that they believed in. And yet, the decisions that they make turn out to be the rules that we have to live by."

- FAT-star conference 2018, NYU

Sweeney method



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Key technical idea:

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- related: what even is privacy?

What even is privacy?

In *Privacy in Context: Technology, Policy, and the Integrity of Social Life,*[7] I give an account of privacy in terms of expected flows of personal information, modeled with the construct of *context-relative informational norms.* The key parameters of informational norms are actors (subject, sender, recipient), attributes (types of information), and transmission principles (constraints under which information flows). Generally, when the flow of information adheres to entrenched norms, all is well; violations of these norms, however, often result in protest and complaint. In a health care context, for example, patients expect their physicians to keep personal medical information confidential, yet they accept that it might be shared with specialists as needed. Patients' expectations would be breached and they would likely be shocked and dismayed if they learned that their physicians had sold the information to a marketing company. In this event, we would say that informational norms for the health care context had been violated.

Figure 6: Helen Nissenbaum

reference: Helen Nissenbaum, Privacy in Context: Technology, Policy, and the Integrity of Social Life (2010).

from "Nissenbaum, Helen."A contextual approach to privacy online." Daedalus 140, no. 4 (2011): 32-48."

Beneficence & disclosure, 1/3

While the court praised my skill and advocates dubbed me "the goddess of re-identification," the court ordered knowledge of my method sealed, barring me from publication. Similar fates awaited my other early re-identifications of survey and pharmaceutical data.

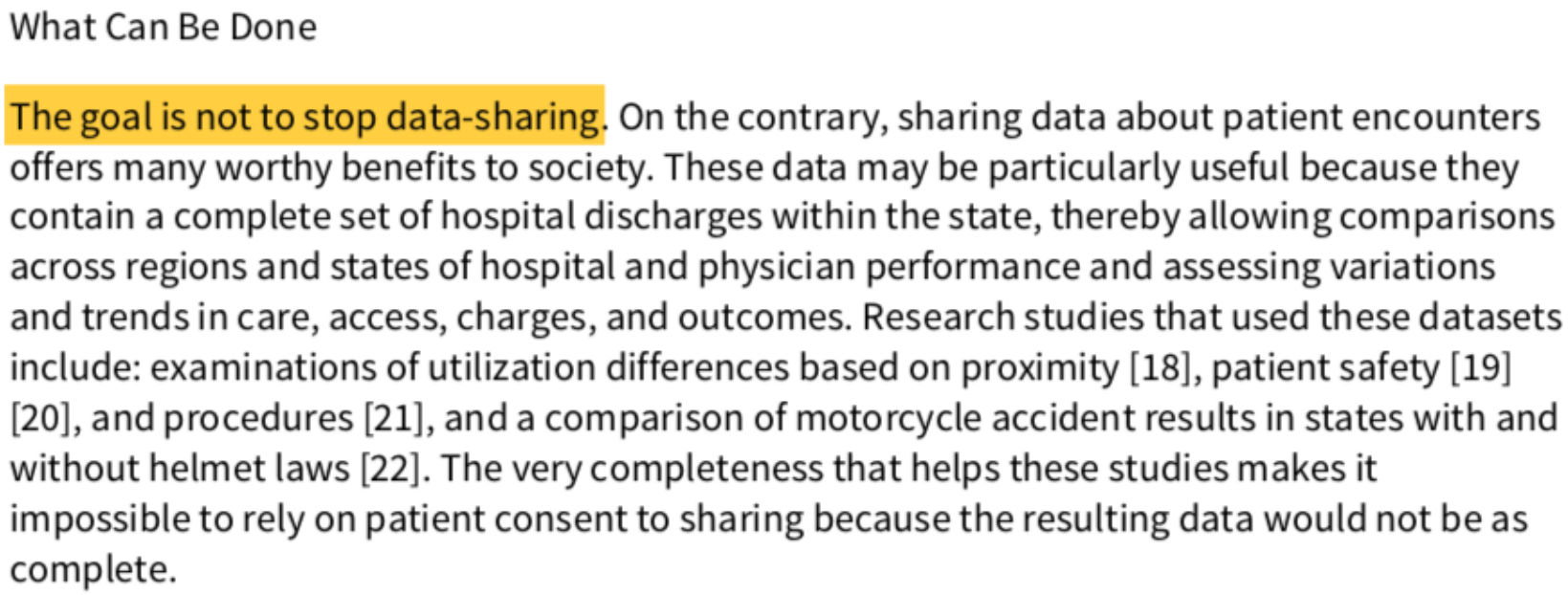
Beneficence & disclosure, 2/3

Computer-science publications refused to publish re-identification experiments unless the paper also included a technological solution, notwithstanding assertions that publishing these experiments would inspire technological innovation to address the real-world problem.

Beneficence & disclosure, 3/3

funding sources refused to fund re-identification experiments unless there was a promise that results would likely show that no risk existed or that all problems could be solved by some promising new theoretical technology under development. Financial resources were unavailable to support rigorous scientific studies otherwise.

Sweeney: response 1/2



What Can Be Done

The goal is not to stop data-sharing. On the contrary, sharing data about patient encounters offers many worthy benefits to society. These data may be particularly useful because they contain a complete set of hospital discharges within the state, thereby allowing comparisons across regions and states of hospital and physician performance and assessing variations and trends in care, access, charges, and outcomes. Research studies that used these datasets include: examinations of utilization differences based on proximity [18], patient safety [19] [20], and procedures [21], and a comparison of motorcycle accident results in states with and without helmet laws [22]. The very completeness that helps these studies makes it impossible to rely on patient consent to sharing because the resulting data would not be as complete.

Figure 7: reacts, 1/2

Sweeney: response 2/2

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Another goal is to be smarter about how we perform data sharing. This is particularly important as the top buyers of statewide databases are not researchers but private companies, especially those constructing data profiles on individuals [23].

Figure 8: reacts, 2/2

Owning ethics: Logics

> *Ethics is arguably the hottest product in Silicon Valley's hype cycle today"*

1. Meritocracy: "post hoc justification for inequality in society"

Owning ethics: Logics

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1. Meritocracy: "post hoc justification for inequality in society"
2. Technological Solutionism

Owning ethics: Logics

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1. Meritocracy: "post hoc justification for inequality in society"
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3. Market Fundamentalism

Owning ethics: Pitfalls

1. Normalizing Ethical Mishaps

[Ethics owners are] enmeshed in organizational cultures that reward metric-oriented and fast-paced work with greater resources, thereby ratcheting up the ability to fit in and ratcheting down the capacity to object. In a situation like that — just as it is with current critical data studies scholarship — it is necessarily challenging to distinguish between success and failure. Thus, the work of ethics consists of working through, and not resolving, these tensions.

Owning ethics: Pitfalls

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- "ethics . . . as something to implement rather than something to design organizations around"

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- "ethics . . . as something to implement rather than something to design organizations around"

2. Blinkered Isomorphism

[Ethics owners are] enmeshed in organizational cultures that reward metric-oriented and fast-paced work with greater resources, thereby ratcheting up the ability to fit in and ratcheting down the capacity to object. In a situation like that — just as it is with current critical data studies scholarship — it is necessarily challenging to distinguish between success and failure. Thus, the work of ethics consists of working through, and not resolving, these tensions.

Owning ethics: Pitfalls

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- "perform ethics rather than make the structural changes"

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Related: Ethics Theater

> *I think, in the wake of these controversies, there has been kind of ethics theater, almost. We actually look at this in our 2018 report, where we looked into these a little bit. All of these questions around, "What do these boards actually do," right? Are product decisions run by them? Can they cancel a product decision? Do they have veto power otherwise? Is there any documentation on whether their advice was taken or whether it was not?"*

- from Meredith Whittaker, note: define vs design

see ethics washing

dataethics.eu

1. External Participation: early and regular engagement with all relevant stakeholders.

Wagner, Ben. "Ethics as an Escape from Regulation: From ethics-washing to ethics-shopping?." Being Profiling. Cogitas Ergo Sum (2018).

see ethics washing

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6. Provide a clear statement on the relationship between the commitments made and existing legal or regulatory frameworks, in particular on what happens when the two are in conflict.

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Apex Predator Problem

> *Currently the loudest voices debating the potential dangers of super-intelligence are affluent white men, and, perhaps for them, the biggest threat is the rise of an artificially intelligent apex predator.*

https://www.nytimes.com/2016/06/26/opinion/sunday/artificial-intelligences-white-guy-problem.html

power and principles

how did new capabilities rearrange power? who can now do what, from what, to whom?

- re-identification

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- re-identification
- privacy vs.:

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- re-identification
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  - predictive policing from police data...
  - hiring from hiring data...
  - contact tracing...

role of rights, harms, justice?

foreshadowing data for Thursday

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- privacy & FAT lab

reminder of themes/big main takeaways

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  - remaining 2 weeks: political dynamics of data ethics IRL

up next

- 4/23: the business of data

up next

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  - the attention economy, 1971->present

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  - the attention economy, 1971->present
  - venture: accelerant and destabilizer

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- 2020-01-28 : 2 of 14 setting the stakes

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