

# Trust in Research Using Digital Devices

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Katie Shilton

Work done with the PERVADE Project

April 20, 2023

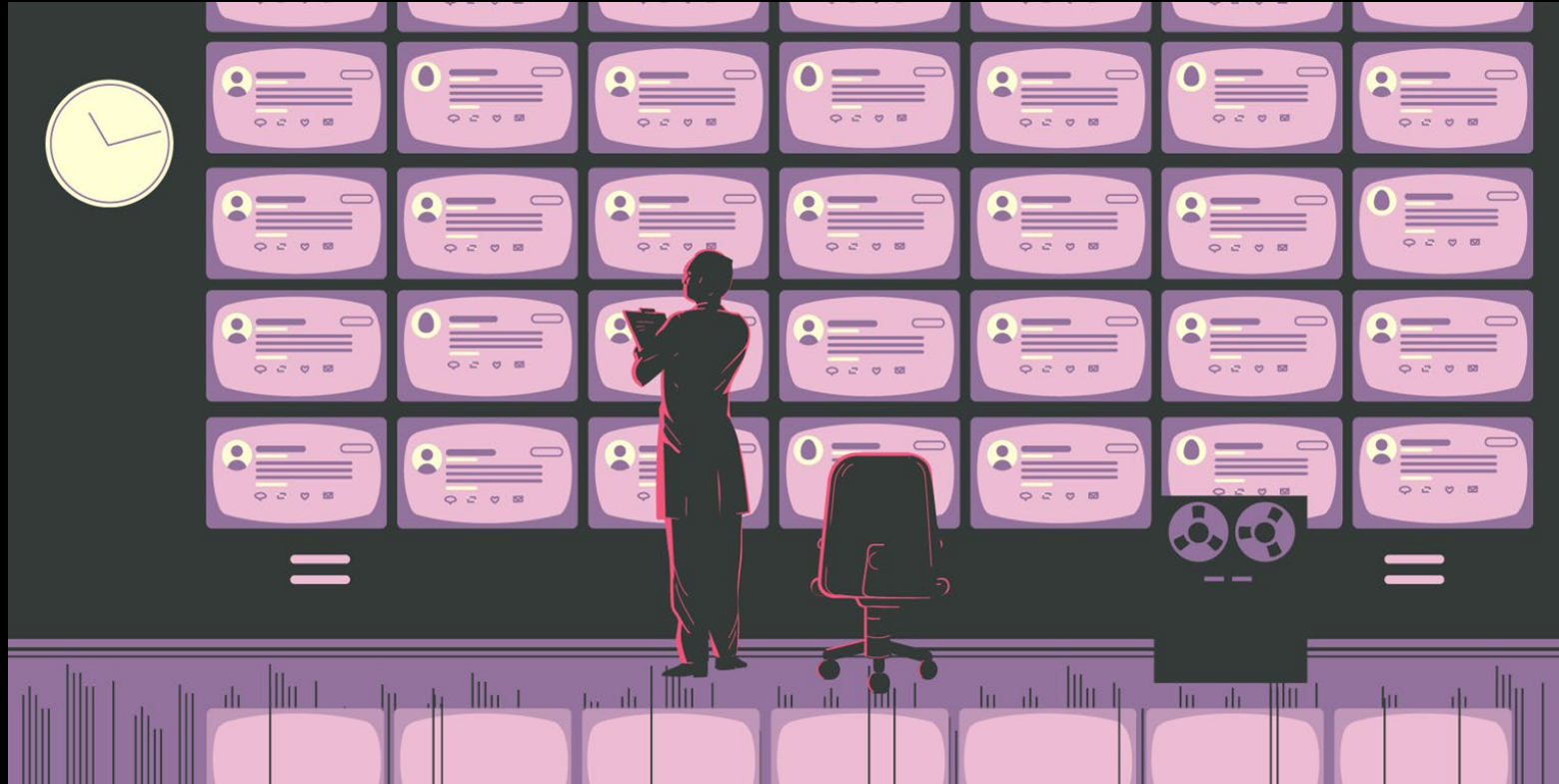


# Outline

1. Digital data research, data science, and research backlash
2. Why Belmont and IRBs aren't the whole answer
3. Parallels between ethnography and digital data research
4. Interventions for trustworthy digital data research



# A crisis of trust



Fiesler, C., & Proferes, N. (2018). "Participant" Perceptions of Twitter Research Ethics. *Social Media + Society*, 4(1). (Image credit: Darren Garrett for How We Get To Next).

Hemphill, Libby, Angela Schöpke-Gonzalez, and Anmol Panda. 2022. "Comparative Sensitivity of Social Media Data and Their Acceptable Use in Research." *Scientific Data* 9 (1): 643.

# Data science and the “techlash”



# Empirical questions in data ethics

PERVADE is an interdisciplinary collaboration between seven researchers at six institutions to answer empirical questions in data ethics.

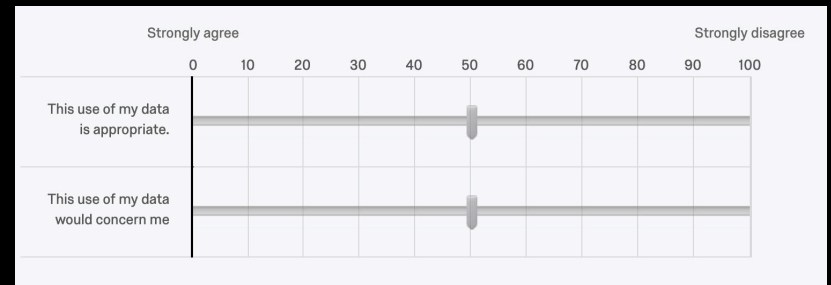




# Studies of American data subjects = it depends

- Factorial vignette surveys on contrasting platforms (Facebook, dating apps, Instagram, Reddit)
- Acceptability depended on the research domain, purpose of research, and content collected
- **But: consent and awareness of data collection mattered across scenarios and platforms**

**Tech company** researchers are collecting **posts about sexual habits, preferences or behaviors** that you've shared on Facebook with the goal of **personalizing advertising**. **Posts you've deleted from Facebook** will be analyzed by **humans**. **You will never be notified your data was used in a study.**



Sarah Gilbert, Jessica Vitak, and Katie Shilton. 2021. Measuring Americans' Comfort With Research Uses of Their Social Media Data. *Social Media + Society* 7, 3: 1–13. <https://doi.org/10.1177/20563051211033824>

Sarah Gilbert, Jessica Vitak & Katie Shilton. (In press). When Research Is the Context: Cross-Platform User Expectations for Social Media Data Reuse. *Big Data & Society*.



# Ethnography and Data Science: More Similar Than You'd Think

No matter how unobtrusive, ethnographic research always pries into the lives of informants. Participant-observation represents a powerful tool for invading other people's way of life. It reveals information that can be used to *affirm* their rights, interests, and sensitivities or to *violate* them (Spradley, 1980: 22).



# Colonial Legacy

WRITING PAST COLONIALISM

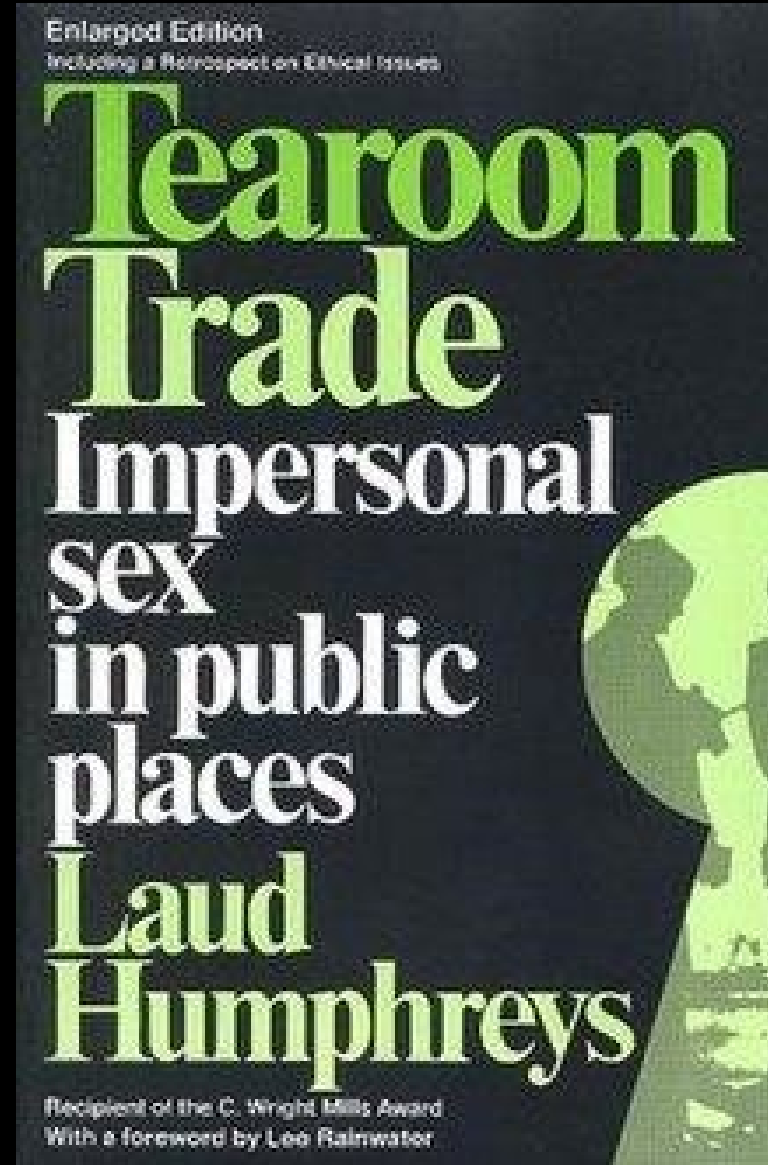
## SETTLER COLONIALISM AND THE TRANSFORMATION OF ANTHROPOLOGY

The Politics and Poetics  
of an Ethnographic Event

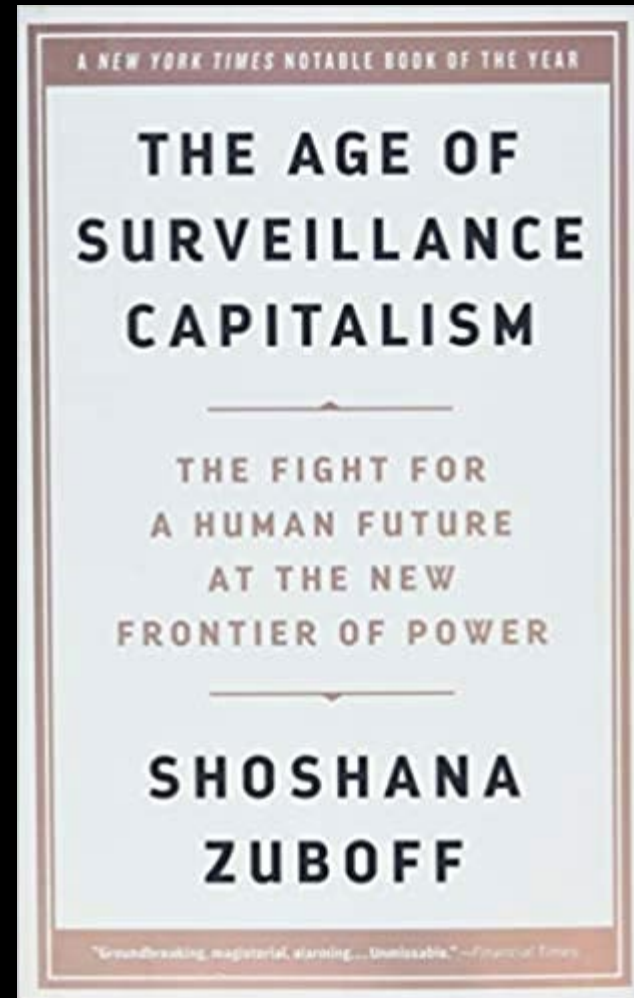


PATRICK WOLFE

# Tea Room Trade



Data science  
analogies:  
surveillance  
capitalism;  
data justice



# Excavating Trustworthy Digital Data Research

## Participant Awareness

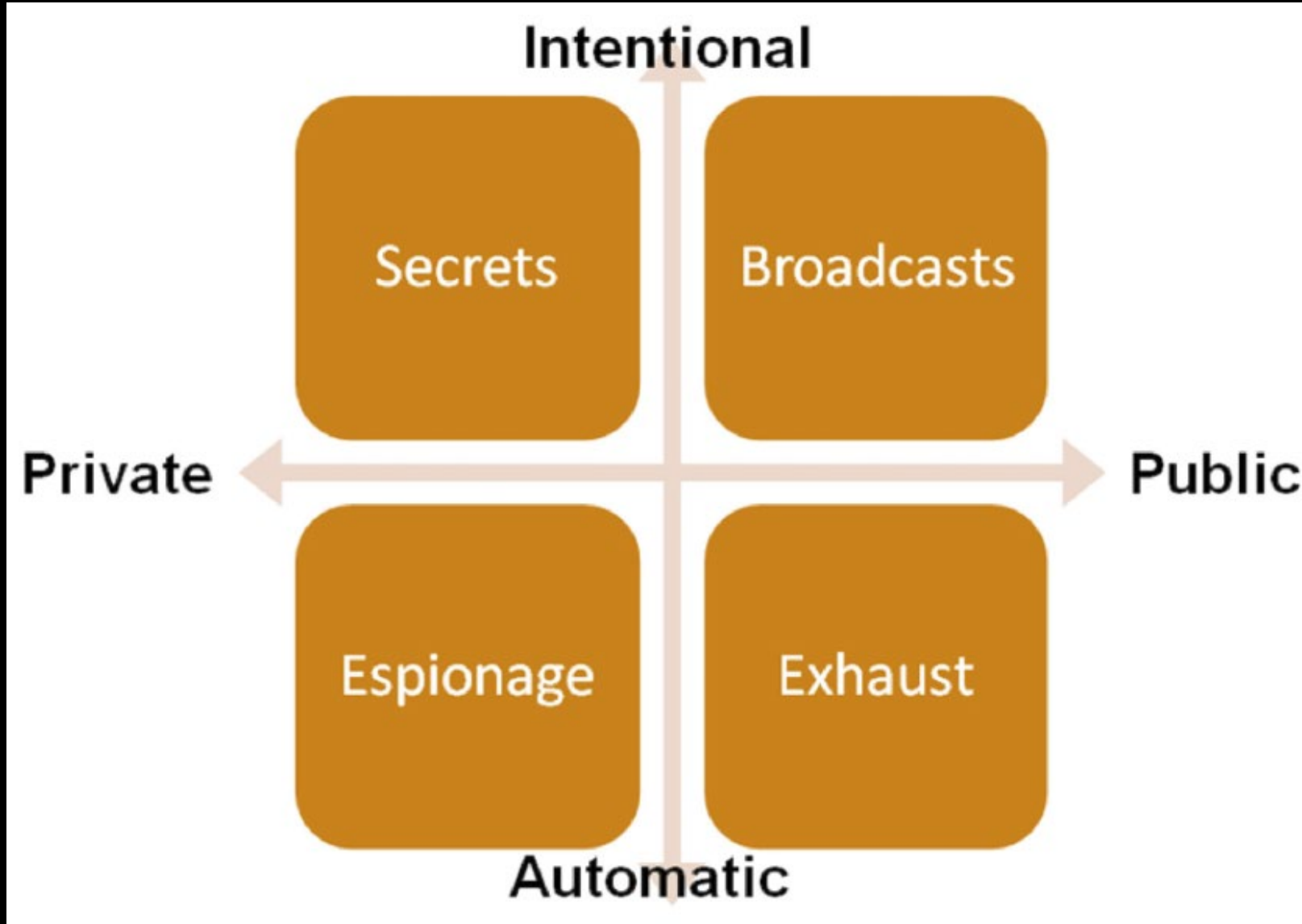
- Entrée
- Participant checking
- Collaborative ethnography

## Reflections on power

- Unpacking the history of the method
- Diversifying the profession
- Studying up



# Participant Awareness



Shilton, K., Moss, E., Gilbert, S. A., Bietz, M. J., Fiesler, C., Metcalf, J., Vitak, J., & Zimmer, M. (2021). Excavating awareness and power in data science: A manifesto for trustworthy pervasive data research. *Big Data & Society*. <https://doi.org/10.1177/20539517211040759>.

# Participant Awareness

Broadcasts (Public / Intentional)	Secrets (Private / Intentional)	Exhaust (Public / Automatic)	Espionage (Private / Automatic)

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Broadcasts (Public / Intentional)	Secrets (Private / Intentional)	Exhaust (Public / Automatic)	Espionage (Private / Automatic)
<ul style="list-style-type: none"><li>• Tweets</li><li>• YouTube likes</li><li>• Reddit posts</li></ul>			

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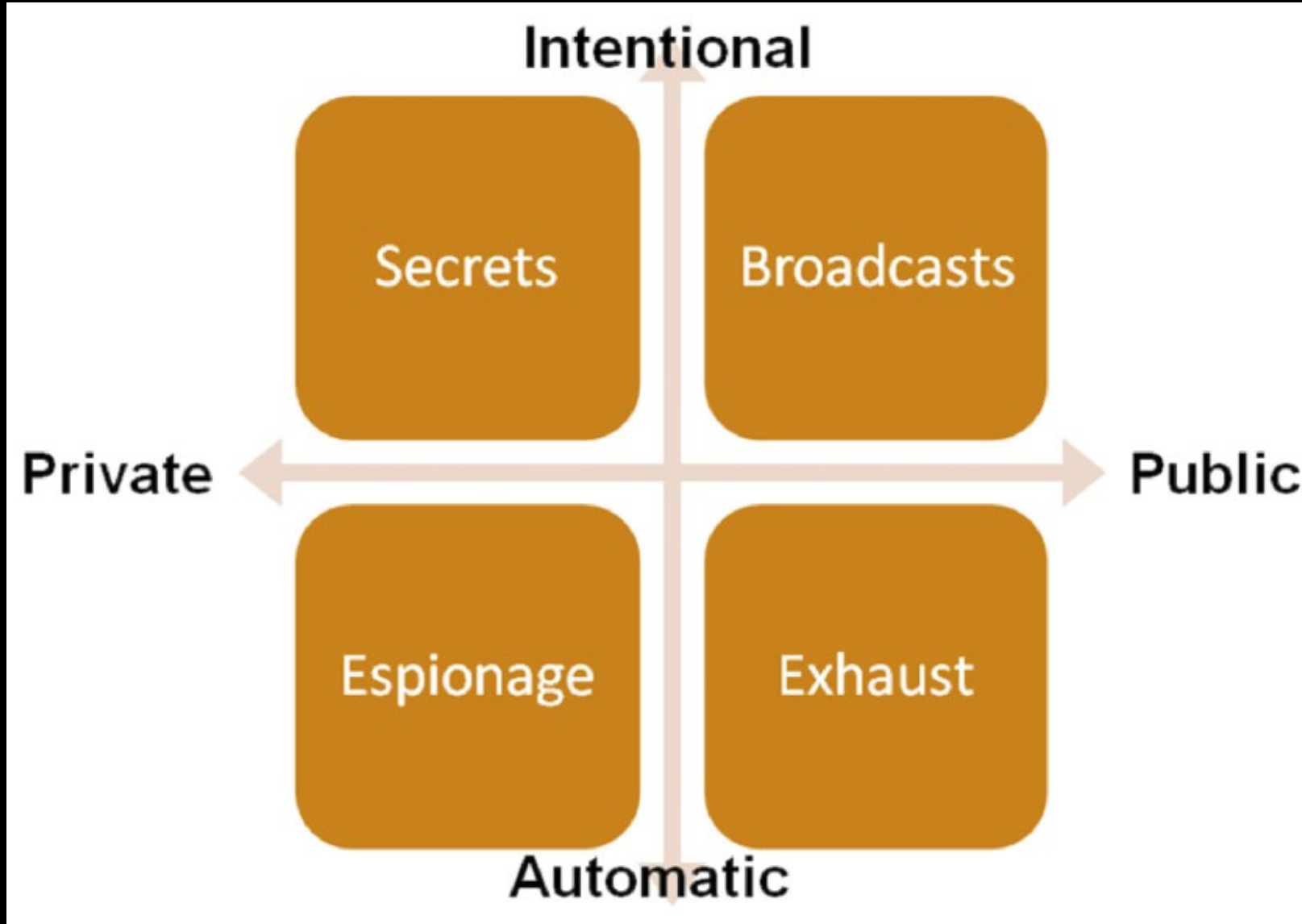
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# Participant Awareness

Broadcasts (Public / Intentional)	Secrets (Private / Intentional)	Exhaust (Public / Automatic)	Espionage (Private / Automatic)
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# Participant Awareness



Shilton, K., Moss, E., Gilbert, S. A., Bietz, M. J., Fiesler, C., Metcalf, J., Vitak, J., & Zimmer, M. (2021). Excavating awareness and power in data science: A manifesto for trustworthy pervasive data research. *Big Data & Society*. <https://doi.org/10.1177/20539517211040759>.

# Participant Awareness



Depression got hands not gonna lie



Ima beat depressions ass today! Wish me luck

2:11 PM · Sep 19, 2020 

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 232.8K    308    Share this Tweet

[Tweet your reply](#)



# Participant Awareness

Connecting those pings reveals a diary of the person's life.

Opinion | [THE PRIVACY PROJECT](#)

## Twelve Million Phones, One Dataset, Zero Privacy

By Stuart A. Thompson and Charlie Warzel

DEC. 19, 2019



**E**VERY MINUTE OF EVERY DAY, everywhere on the planet, dozens of companies — largely unregulated, little scrutinized — are logging the movements of tens of millions of people with mobile phones and storing the information in gigantic data files. The Times [Privacy Project](#) obtained one such file, by far the largest

# Robust De-anonymization of Large Datasets

## (How to Break Anonymity of the Netflix Prize Dataset)

Arvind Narayanan and Vitaly Shmatikov

The University of Texas at Austin

February 5, 2008

### **Abstract**

We present a new class of statistical de-anonymization attacks against high-dimensional micro-data, such as individual preferences, recommendations, transaction records and so on. Our techniques are robust to perturbation in the data and tolerate some mistakes in the adversary's background knowledge.

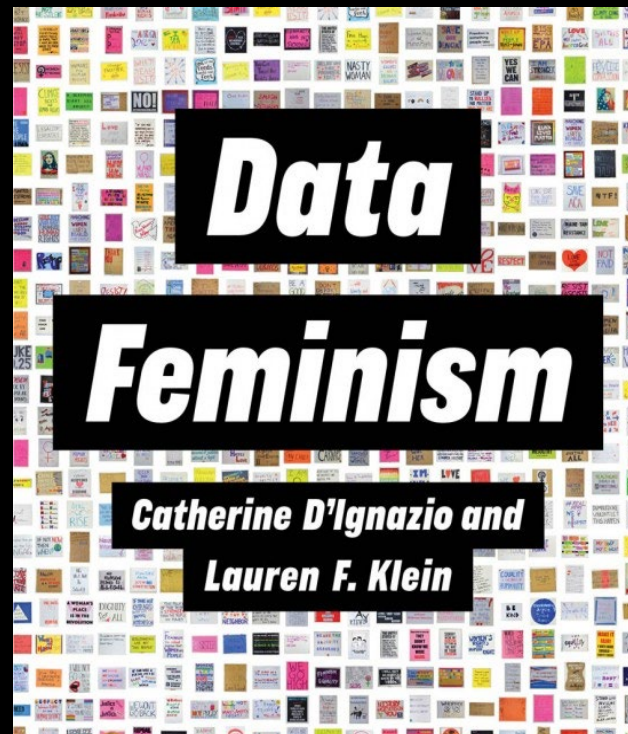
We apply our de-anonymization methodology to the Netflix Prize dataset, which contains anonymous movie ratings of 500,000 subscribers of Netflix, the world's largest online movie rental service. We demonstrate that an adversary who knows only a little bit about an individual subscriber can easily identify this subscriber's record in the dataset. Using the Internet Movie Database as the source of background knowledge, we successfully identified the Netflix records of known users, uncovering their apparent political preferences and other potentially sensitive information.

# Reflecting on Power

- What consent was given for data?
- Is personal information being revealed out of context?
- Can individuals or vulnerable groups be identified from your data, analysis, or product?
- Can anonymized datasets be de-anonymized?
- Does your data come from a particularly vulnerable population?
- Is it more likely to produce errors when it is applied to a population that has historically been harmed by such errors?
- Does it help a less vulnerable population at the expense of a more-vulnerable population?
- Does the research design include members of the population group it is targeted at helping?



# Reflecting on Power



## From Treatment to Healing: Envisioning a Decolonial Digital Mental Health

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### ABSTRACT

The field of digital mental health is making strides in the application of technology to broaden access to care. We critically examine how these technology-mediated forms of care might amplify historical injustices, and erase minoritized experiences and expressions of mental distress and illness. We draw on decolonial thought and critiques of identity-based algorithmic bias to analyze the underlying power relations impacting digital mental health technologies today, and envision new pathways towards a decolonial digital mental health. We argue that a decolonial digital mental health is one that centers lived experience over rigid classification, is conscious of structural factors that influence mental wellbeing, and is fundamentally designed to deter the creation of power differentials that prevent people from having agency over their care. Stemming from this vision, we make recommendations for how researchers and designers can support more equitable futures for people experiencing mental distress and illness.

### ACM Reference Format:

Sachin R. Pendse, Daniel Nkemelu, Nicola J. Bidwell, Sushrut Jadhav, Soumitra Pathare, Munmun De Choudhury, and Neha Kumar. 2022. From Treatment to Healing: Envisioning a Decolonial Digital Mental Health. In *CHI Conference on Human Factors in Computing Systems (CHI '22)*, April 29–May 5, 2022, New Orleans, LA, USA. ACM, New York, NY, USA, 23 pages. <https://doi.org/10.1145/3491102.3501982>

**Content Warning:** This work includes descriptions of mental illness, involuntary hospitalization, and suicide. This work also includes descriptions of colonialism, racism, slavery, and police brutality in the context of mental health. Additionally, Aboriginal and Torres Strait Islander readers are advised that the following article may contain the words of people who may have died.<sup>1</sup>

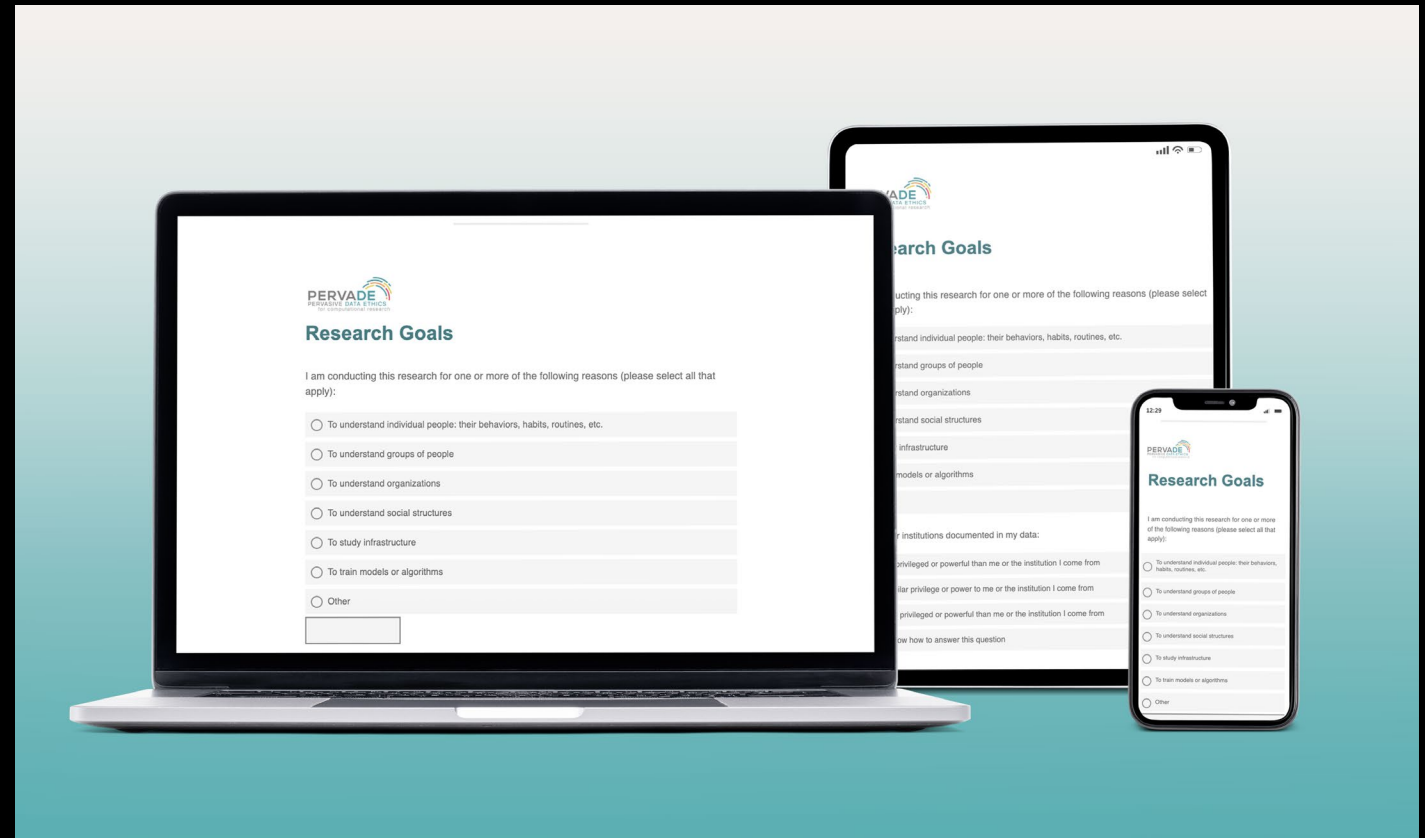
### 1 INTRODUCTION

<sup>1</sup>So [I'm] being assessed for my behaviour, not for what I'm feeling. Not for my story. They're not in-



# Design Intervention: The PERVADE Decision Support Tool

How can we help data  
science researchers  
reflect on *awareness*  
and *power*?



# Research Design for Trust

- Research goals
  - Whose interests are represented?
  - Are there clear REB or disciplinary guidelines?
- Power and data extraction
  - Studying up and down
  - Representation
- Data sources and contextual expectations
  - Data quadrants
  - Acquisition methods (scraping, APIs, hacks)
  - Norms of the collection context



## Collection

The data that I'm working with for this project (please select all that apply):

- ☐ was collected with the informed consent of participants
- ☐ was collected without explicit informed consent of participants (e.g. is a reuse of publicly-available data)
- ☒ was produced knowingly and intentionally (e.g. Tweets)
- ☐ was collected without subjects' knowledge (e.g. location traces)
- ☒ is public-facing (e.g. Tweets)
- ☐ has an expectation of privacy (e.g. text messages)
- ☐ has unclear privacy expectations
- ☐ was collected under a terms of service agreement that permits research

### "was produced knowingly and intentionally (e.g. Tweets)"


We call such data broadcast: it was created in public, on purpose. Though this data is generally understood as public, people may still be quite surprised about this use of their data. We recommend you try to increase data subject awareness of your work. Consider using informed consent, or if not possible, other tools of awareness such as sharing results with participants ([link to awareness best practices/resources](#)). For a discussion of challenges using broadcast data, we recommend the video of the PERVADE Conversation with [Dr. Stevie Chancellor](#).

### "is public-facing (e.g. Tweets)"

We call this data exhaust: it was collected in public, but people didn't know they were creating it. We recommend you try to increase data subject awareness of your work, share data and results directly with data subjects, and/or use informed consent. We also recommend the video of the [PERVADE Conversation with Dr. Mark Dredze](#) for a discussion of using exhaust data.

# Research Design for Trust

- Storage and processing
  - Security
  - Retention
- Analysis
  - Binaries and categories
  - Linking datasets
  - Distressing inferences
  - Harms for participants and beyond
- Sharing
  - Deidentification challenges
  - Balancing open science and data protection



## Data Storage and Processing

I am storing my data (please select all that apply):

- ☐ In an institutional repository
- ☒ On local machines owned by my institution
- ☐ In cloud storage provided by my institution
- ☐ In cloud storage that I purchased

*"On local machines owned by my institution"*

This is a good start, but you might consider taking advantage of data stewardship offered by an institutional repository. For recommendations on data stewardship, a good place to start is with ICPSR's best practices: [here](#)

When my project is done, we will (please select all that apply):

- ☒ Archive the data in an institutional repository
- ☐ Share the data via an open repository (GitHub, a website)
- ☐ Destroy the data

*"Archive the data in an institutional repository"*

Good choice! For any data you decide not to keep, or that must be destroyed because of sensitivity, a good resource to start with is CDT's guide to data destruction: [click here](#)

[Previous](#)[Next](#)

# Research Prescriptions

## Recommended Resources

These are the data ethics resources that have been recommended to you based on your responses:

- Using pervasive data to train models or algorithms can raise ethical questions about data quality, appropriateness and bias. For discussion of factors to consider, we recommend the video of the PERVADE Conversation with Dr. Amandalynne Paullada. [click here](#)
- That's great. Users of even public platforms still express a preference for giving informed consent before participating in research. For a discussion of consent in data science research, we recommend the video of the PERVADE Conversation with Dr. Camille Nebeker.
- "Social context describes the values and norms of a social setting, and may be the single most important predictor of how people react to research uses of their data. A good resource to start your exploration of social context is Michael Zimmer. 2018. How Contextual Integrity can help us with Research Ethics in Pervasive Data. Medium. Retrieved July 27, 2018 from [here](#).

**Have additional questions or maybe have a resource you would like to share with us?**

Contact the PERVADE team at [pervadeischool@umd.edu](mailto:pervadeischool@umd.edu)

Visit the PERVADE Website

[View this email in your browser](#)



## Thank you for using the PERVADE Data Ethics Tool!

Below you can find your results from your most recent completion of the data ethics evaluation tool.

## Your Diagnostic Score

**50**

**Hard Mode: 39 - 60**

To do this project ethically will take considerable time and effort. The project studies individuals; it may use data we would label as "espionage"; the analysis involves tricky binaries and potentially invasive conclusions; you haven't yet explored contextual norms for analysis and sharing; you have plans to combine datasets or share your data; and you're not yet sure of your discipline or profession's ethical norms. These answers indicate that you have a very difficult task in front of you. We recommend some homework to help you get started on this work. 1) Follow up with the resources and guidelines provided throughout the quiz. 2) Try some design fiction. Create a dystopian or worst case scenario for your research. What could go wrong? Who could use your data or results for evil? Then work backwards to try to mitigate some of those potential hazards. 3) Run a contextual integrity audit for your project. [See here to get started.](#)

## Recommended Resources

These are the data ethics resources that have been recommended to you based on your responses:

# Researchers

- Lead reflection on awareness and power with students and collaborators
- What does this look like?
  - Getting to know communities through time spent
  - Participatory research
  - Ethics and positionality sections in papers
  - Studying up





# Professional organizations

- Establish norms and codes for trustworthy data science
- Publish methodological reflections
- Peer-checking
- Paper reviews
  - Expect reflections on awareness, power in the methods sections of papers



# Harnessing Existing Trust Infrastructures: IRBs

- Building and relying upon expertise, rather than compliance
- An advisory role even for data reuse?
- An educational role through certification requirements?





# Going Forward

- Digital device users are already quite vulnerable
- Data scientists, and the organizations that support them, can:
  - Embrace reflections on how to decrease this vulnerability
  - Hold each other to higher ethical standards.



Image by JasonGoto/ Flickr

# Thank you!

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PERVADE Project

<http://pervade.umd.edu>

Ethics & Values in Design (EViD) Lab

<http://evidlab.umd.edu/>



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