ETHICS OF BIG DATA & ARTIFICIAL INTELLIGENCE IN MEDICAL RESEARCH: CHALLENGES AND OPPORTUNITIES

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Research Integrity, McLaren Health Care – Brown Bag Session
June 04, 2024

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McLaren
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HOUSEKEEPING

Please feel free to raise hand or use the chat box to ask questions at the end of the presentation.

CME or CE certificate

- The link to CME Tracker is https://cmetracker.net/MCLAREN.
- **Activity code** will be sent to your email in 1-2 days

Presentation Slides – emailed out with CME code

Presentation recording – available on McLaren Research Integrity website

McLaren HEALTH CARE

OUR SPEAKER

Michael Zimmer, PhD

Experiences and Expertise:

- He the Director of Marquette's **Center for Data, Ethics, and Society** and Professor & Vice-Chair in the Department of Computer Science.
- Dr. Zimmer is a privacy and data ethics scholar whose work focuses on digital privacy & surveillance, the ethics of big data, internet research ethics, and the broader social & ethical dimensions of emerging digital technologies.
- Dr. Zimmer currently co-chairs the AoIR (Association of Internet Research) Ethics Working Group, serves on the SIGCHI Special Interest Group *on* Computer-Human Interaction Research Ethics Committee, and sits on numerous other advisory and editorial boards.
- He was recently named the ethics advisor for the European Commission-sponsored SPATIAL Project (Security and Privacy Accountable Technology Innovations, Algorithms, and Machine Learning).

McLaren HEALTH CARE

AGENDA

- How did we get here?
  - New epistemology of big data
  - AI/ML in research applications
- What makes big data ethics hard?
  - The data
  - Conceptual gaps
  - Understanding “harms”
- Where do we go from here?
  - Beyond IRBs?

CHRIS ANDERSON SCIENCE 06.23.08 12:00 PM

THE END OF THEORY: THE DATA DELUGE MAKES THE SCIENTIFIC METHOD OBSOLETE

* Illustration: Marian Bantjes * **"All models are wrong**, but some are useful."

THE NEW EPISTEMOLOGY OF BIG DATA

This is a world where massive amounts of data and applied mathematics replace every other tool that might be brought to bear. Out with every theory of human behavior, from linguistics to sociology. Forget taxonomy, ontology, and psychology. Who knows why people do what they do? The point is they do it, and we can track and measure it with unprecedented fidelity. With enough data, the numbers speak for themselves.

BIG DATA & COMPUTATIONAL SOCIAL SCIENCE

With an increasing amount of data on every aspect of our daily activities – from what we buy, to where we travel, to who we know, and beyond – we are able to measure human behavior with precision largely thought impossible just a decade ago, creating an unprecedented opportunity to address longstanding questions in the social sciences. Leveraging this sea of information requires both scalable computational tools, and understanding how the substantive scientific questions should drive the data analysis. Lying at the intersection of computer science, statistics and the social sciences, the emerging field of computational social science fills this role, using large-scale demographic, behavioral and network data to investigate human activity and relationships.

(Source: MSR NYC Computational Social Science Group)

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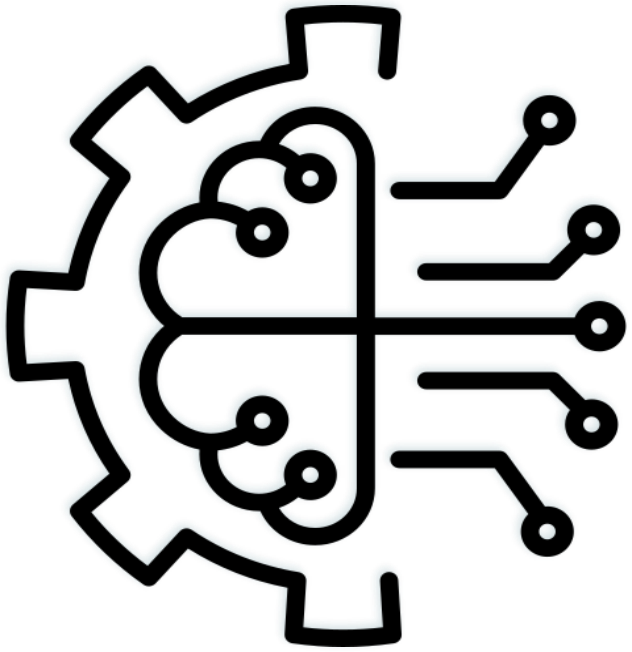
THE ERA OF BIG DATA

Big data analytics enables an entirely new approach for making sense of the world:

- Rather than testing a theory by analyzing relevant data, new data analytics seek to gain insights “born in the data”

This new epistemology drives much of our work in data science, analytics, machine learning, and artificial intelligence…

ARTIFICIAL INTELLIGENCE (MACHINE LEARNING)



- **Finds patterns, automates processes, generates outputs with human-like accuracy (most of the time)**
  - Data science & applied statistics
  - Extremely large datasets
- **Uses Algorithms**
  - Specified instructions to perform a concrete task
- **Uses Machine Learning**
  - Training a computer to discover patterns in data
- **Uses Natural Language Processing & Computer Vision**
  - Trained on Large Language Models & image datasets

BIG DATA AND AI/ML IN RESEARCH PROTOCOLS

Increased use of AI/ML models within social/behavioral & biomedical research that rely on the collection of (public) social data

- Growing use of digital data about people in computational social science research
- Text mining and natural language processing to help with public health surveillance
- Computer vision models to aid with detection of symptoms or risky behaviors

Data sources might include:

- Twitter feeds, Reddit forums, YouTube videos, Instagram images, pretty much anything with an API or scrapable…

BIG DATA AND AI/ML IN RESEARCH…

AOL search data release (2006)

- Poorly anonymized dataset of 20 million search queries from 658,000 users released; many users re-identified based on searches

Harvard "Tastes, Ties and Time" dataset (2008)

- Facebook profile pages of an entire cohort of college students harvested over 4 years without consent; data released with poor de-identification

The Blackberry Project (2003-2012)

- Longitudinal study at UT-Dallas examining teen behavior and sociability; 4th graders begin with diaries and were later given free unlimited-plan Blackberries; all text & email traffic captured by researchers

Facebook emotional contagion experiment (2014)

- Altering of emotional content of news feeds of nearly 700,000 Facebook users; lack of specific, informed consent

BIG DATA AND AI/ML IN RESEARCH…

OKCupid Data Release (2016)

- Danish researches created OKCupid account to collect profile data from 70,000 users; all data later released without any de-identification

Stanford artificial intelligence infers sexuality (2017)

- Trained AI to guess sexuality based on 300,000 images from 75,000 users of a dating website

Arizona researcher captures students' digital traces (2018)

- Captured and analyzed all card swipes for entire University of Arizona student body, showing exactly where they were and when (and with whom).

Cambridge Analytica (2018)

- 87 million Facebook user profiles were harvested to build psychographic profiles for targeted political advertising

BIG DATA AND AI/ML IN RESEARCH…

HRT faces database (2012)

- Researchers at the University of North Carolina Wilmington amassed over one million images scraped from the YouTube videos of 38 people undergoing hormone replacement therapy to improve face recognition tech

Predicting “criminality” based on faces

- In 2016 researchers from Shanghai Jiao Tong University claimed their algorithm could predict criminality using facial analysis
- In 2020 researchers at Harrisburg University claimed the same with “80 percent accuracy and with no racial bias”

MegaFace database (2016)

- Researchers at the University of Washington posted a database of 3.3 million photos from nearly 700,000 individuals on the image-sharing site Flickr. The database was used to train dozens of facial recognition algorithms

Scraping autistic YouTube channels (2019)

- UK researchers scraped family videos from YouTube labeled with autism-related hashtags to train a diagnostic model on the kinesiological traits of the children in the video

BIG DATA AND AI/ML IN RESEARCH PROTOCOLS…

70,000 OkCupid Users Just Had Their Data Published

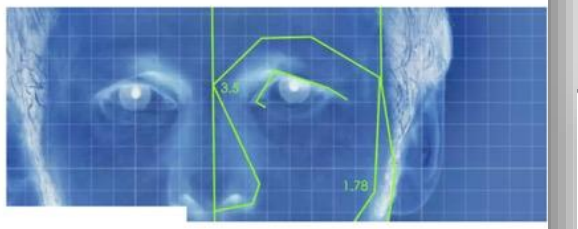
New AI can guess whether you're gay or straight from a photograph

An algorithm deduced the sexuality of people on a dating site with up to 91% accuracy, raising tricky ethical questions

TECHNOLOGY

YouTube Videos Are a Gold Mine for Health Researchers

"Digital exhaust" from online life could be transformed into health insights. Should it be?



REPORT | TECH | ARTIFICIAL INTELLIGENCE

Transgender YouTubers had their videos grabbed to train facial recognition software

future tense

Should Researchers Be Allowed to Use YouTube Videos and Tweets?

TECHNOLOGY

You No Longer Own Your Face

Students were recorded for research—and then became part of a data set that lives forever online, potentially accessible to anyone.

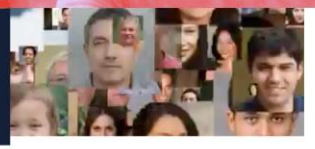
SIDNEY FUSSELL JUNE 27, 2019

The Secretive Company That Might End Privacy as We Know It

CULTURE

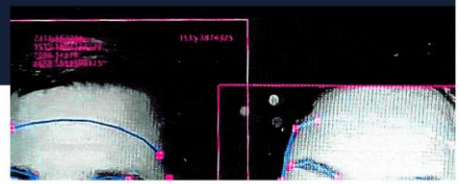
Facial recognition AI probably used your selfies for training

If you have a Flickr account, your selfies might have helped enable our surveillance state.



Facial recognition's 'dirty little secret': Millions of online photos scraped without consent

People's faces are being used without their permission, in eventually be used to surveil them, legal experts say.



How Photos of Your Kids Are Powering Surveillance Technology

Millions of Flickr images were sucked into a database called MegaFace. Now some of those faces may have the ability to sue.

By Kashmir Hill and Aaron Krolik

ETHICS OF BIG DATA RESEARCH

Each of these cases present novel approaches to understanding important social/medical phenomena through big data

But each also generated ethical controversy about their collection and use of social data / predictive models

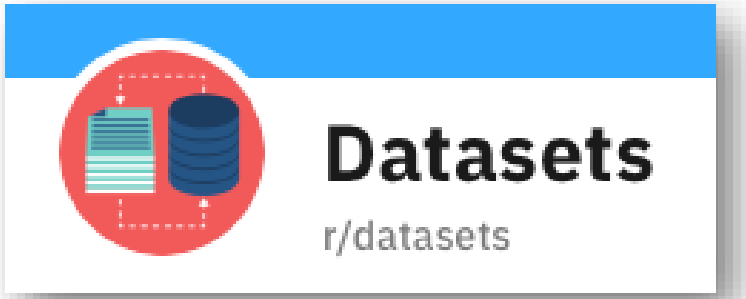
What makes ethics of big data research hard?

- **The data**
- **Conceptual gaps**
- **Understanding harms**

WHY IS IT HARD? THE DATA (IS EASY)

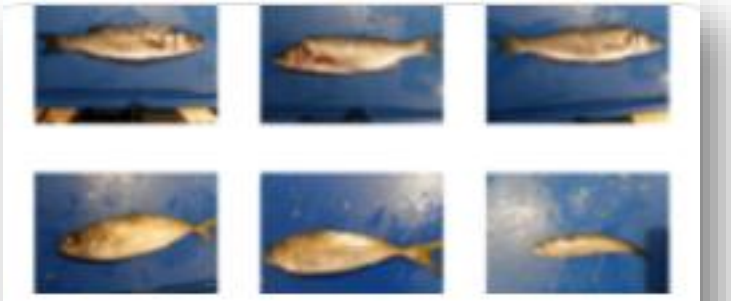
Gone are the times when big data needed a major lab and thousands and thousands of dollars, run by tenured professors with plenty of ethical training (and plenty at stake)…

WHY IS IT HARD? THE DATA (IS EASY)



kaggle

All COVID-19 Vaccines Tweets



A Large Scale Fish Dataset

NIH Chest X-rays TFRecords

Flickr-Faces-HQ Dataset

WHY IS IT HARD? THE DATA (IS PERVASIVE)

More than just “big data”

Rich, deep, often identifiable data about people available for computational research

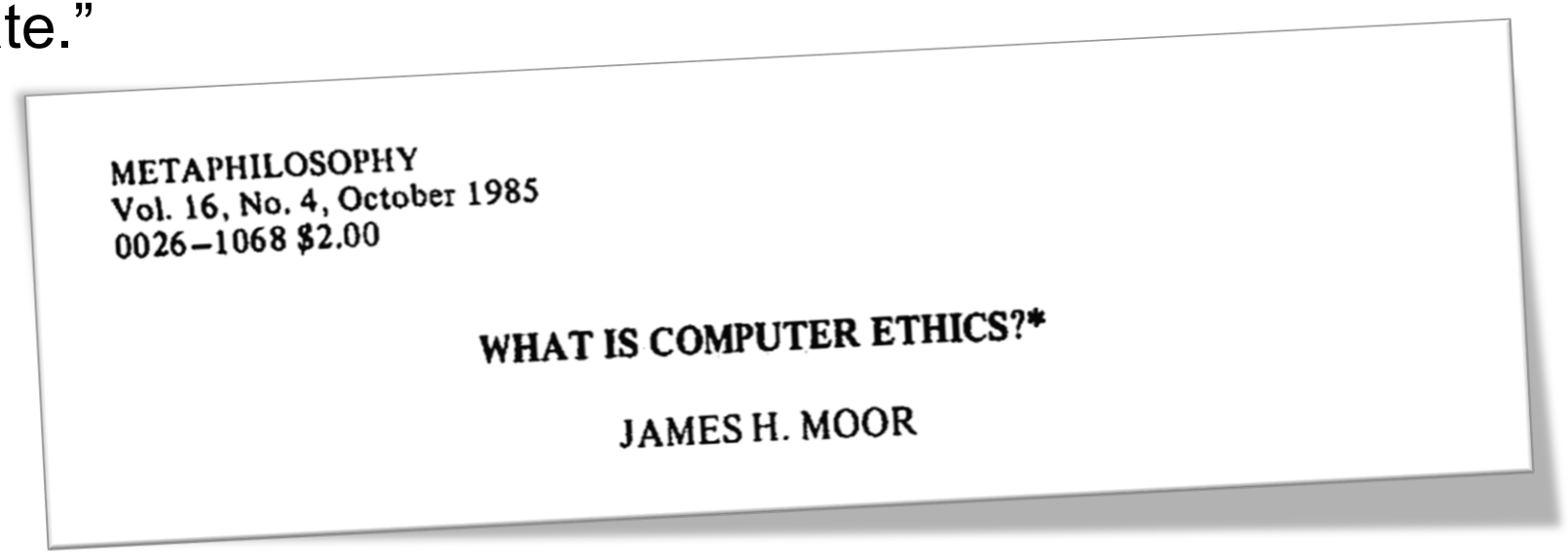
Data about people’s lives and activities, often collected, aggregated, exchanged, and mined without them knowing

Data that bridges multiple dimensions of a person’s life and mixes various contexts

CONCEPTUAL GAPS

Emergence of new technologies often lead to conceptual gaps in how we think about ethical problems, and how we address them

- Computer technology transforms “many of our human activities and social institutions,” and will **“leave us with policy and conceptual vacuums about how to use computer technology”**
- “Often, either no policies for conduct in these situations exist or existing policies seem inadequate.”


METAPHILOSOPHY
Vol. 16, No. 4, October 1985
0026–1068 $2.00

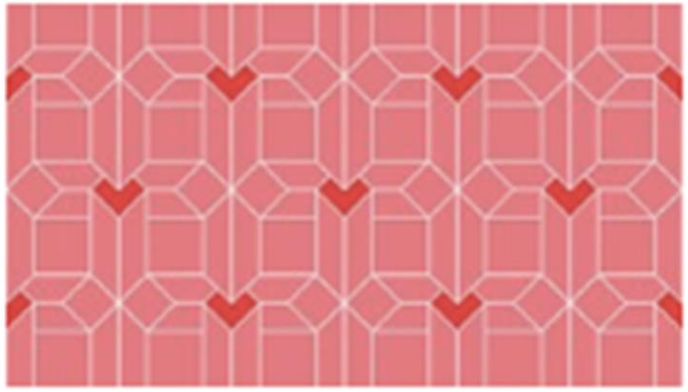
WHAT IS COMPUTER ETHICS?*

JAMES H. MOOR

CONCEPTUAL GAPS IN BIG DATA ETHICS

Growing use of big data in research creating new conceptual gaps in our ethical understanding of:

- Privacy and anonymity
- Informed consent
- Human subjects & harm



MAY 14, 2016 | MICHAEL ZIMMER

OkCupid Study Reveals the Perils of Big-Data Science

The data of 70,000 OKCupid users is now searchable in a database. Ethicist Michael T Zimmer explains why it doesn't matter that it was "already...

[ODP] The OKCupid dataset: A very large public dataset of dating site users

2016-May-08, 21:22:30, (This post was last modified: 2016-Aug-04, 06:20:58 by Emil.)

Emil ●
Admin, reviewer (ODP, OBG, OQSPS)

[ODP] The OKCupid dataset: A very large public dataset of dating site users

Journal:
Open Differential Psychology.

Authors:
Emil O. W. Kirkegaard
Julius D. Bjerrekær

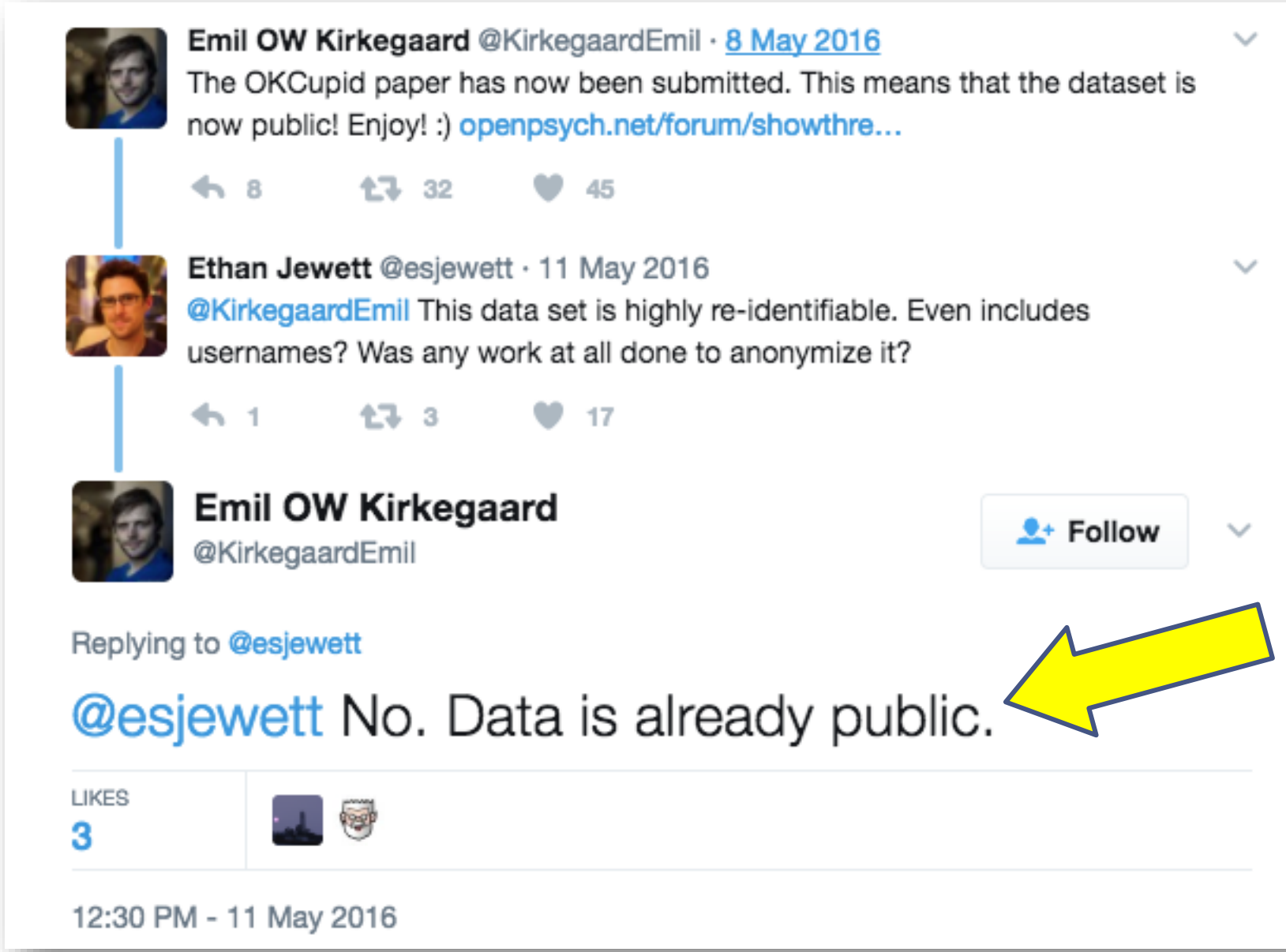
Title:
The OKCupid dataset: A very large public dataset of dating site users

Abstract:
A very large dataset (N=68,371, 2,620 variables) from the dating site OKCupid is pr
As an example of the analyses one can do with the dataset, a cognitive ability test i

Emil OW Kirkegaard
@KirkegaardEmil

Follow

The OKCupid paper has now been submitted. This means that the dataset is now public! Enjoy! :) openpsych.net/forum/showthre …


Emil OW Kirkegaard @KirkegaardEmil · 8 May 2016
The OKCupid paper has now been submitted. This means that the dataset is now public! Enjoy! :) openpsych.net/forum/showthre…
8
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Ethan Jewett @esjewett · 11 May 2016
@KirkegaardEmil This data set is highly re-identifiable. Even includes usernames? Was any work at all done to anonymize it?
1
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Emil OW Kirkegaard
@KirkegaardEmil
Follow
Replying to @esjewett
@esjewett No. Data is already public.
LIKES
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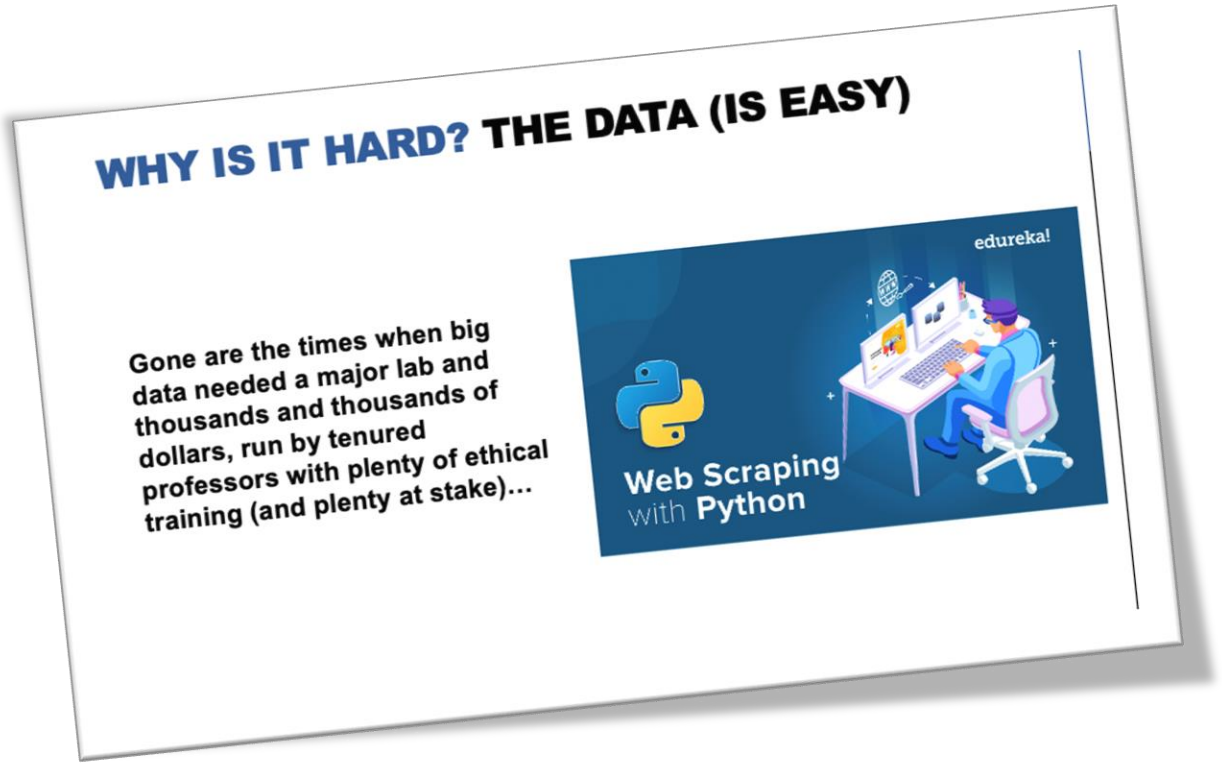
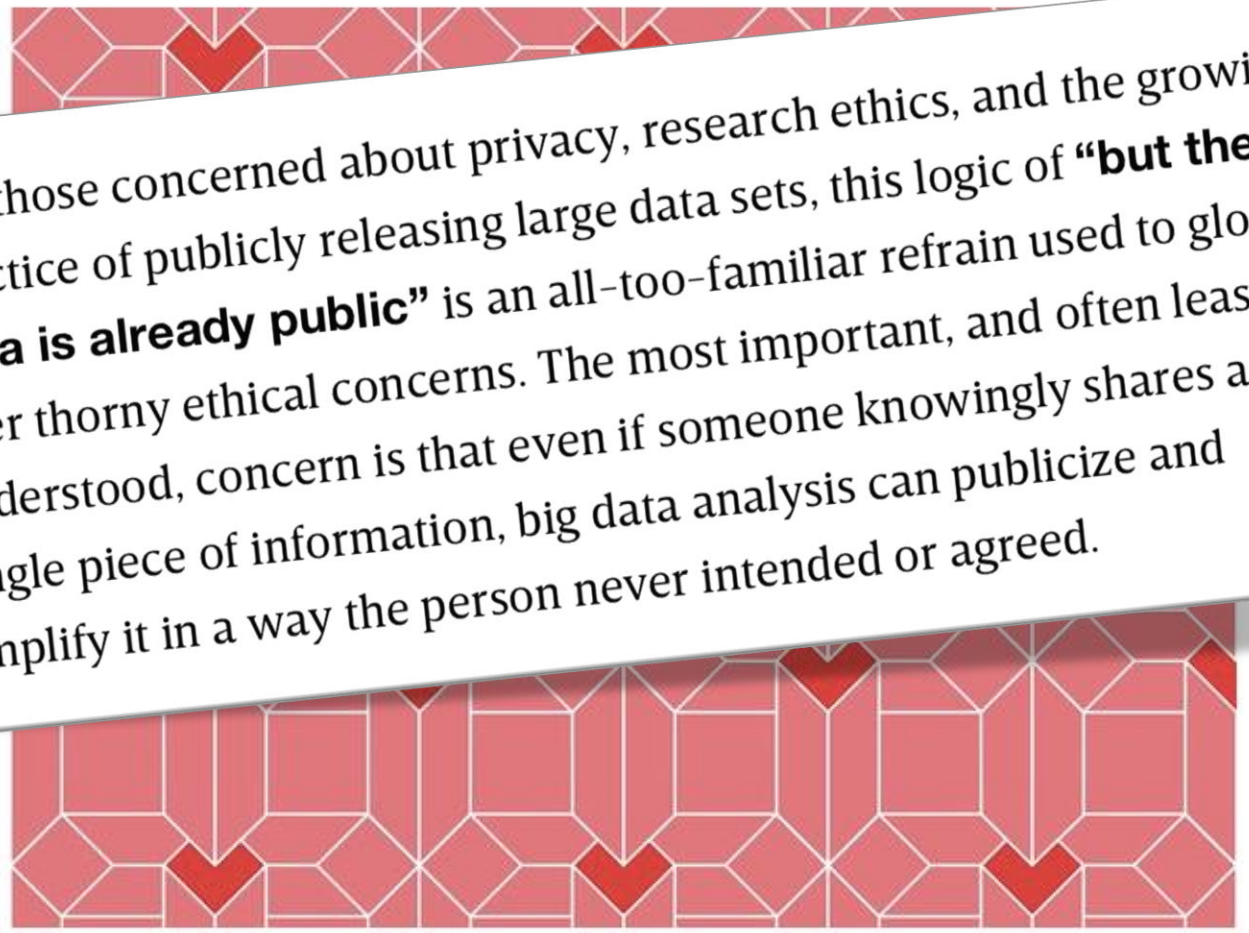
12:30 PM - 11 May 2016

Some may object to the ethics of gathering and releasing this data. However, all the data found in the dataset are or were already publicly available, so releasing this dataset merely presents it in a more useful form.



MICHAEL ZIMMER SECURITY 05.14.16 7:00 AM

OKCUPID STUDY REVEALS THE PERILS OF BIG-DATA SCIENCE

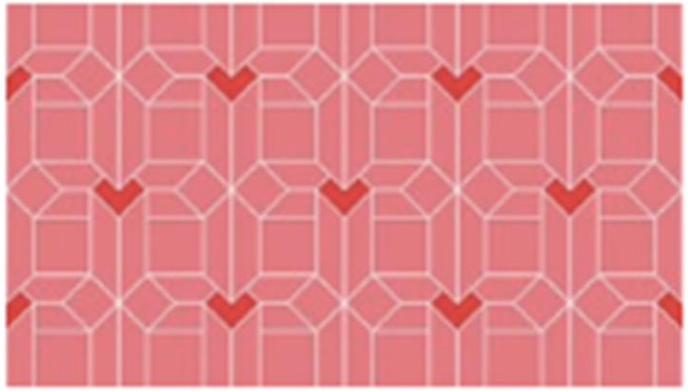


For those concerned about privacy, research ethics, and the growing practice of publicly releasing large data sets, this logic of **"but the data is already public"** is an all-too-familiar refrain used to gloss over thorny ethical concerns. The most important, and often least understood, concern is that even if someone knowingly shares a single piece of information, big data analysis can publicize and amplify it in a way the person never intended or agreed.

CONCEPTUAL GAPS IN BIG DATA ETHICS

Growing use of big data in research creating new conceptual gaps in our ethical understanding of:

- Privacy and anonymity
- Informed consent
- Human subjects & harm



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CONCEPTUAL GAP: PRIVACY

Presumption that because subjects make information available online, they don't have an expectation of privacy

- "There is no privacy online, get over it"
- Researchers/IRBs might assume if something is generally publicly available, then they can grab it and do what they want
- Assumes no harm could come to subjects if data is already "public"

New ethical considerations…

- Fails to recognize that the old dichotomy of public/private doesn't apply in today's networked-data society (see Nissenbaum, 2010, 2019)
- Ignores contextual nature of sharing (see Zimmer, 2018)

CONCEPTUAL GAP: CONSENT

Presumption that because something is shared online, the subject is consenting to it being harvested for research

- Assumes no more interest in controlling access to information shared
- Assumes no harm can come from use of data already shared with friends or other contextually-bound circles

New ethical considerations…

- Must recognize that a user making something public online comes with a set of assumptions/expectations about who can access and how – must respect "contextual integrity"
- Must recognize how research methods might allow un-anticipated access to presumed "restricted" data
    - Need to track if ToS/architecture have changed, or if users even understand what is available to researchers (see Fiesler & Proferes, 2018)

CONCEPTUAL GAP: HUMAN SUBJECTS

Big data researchers often interact only with datasets, objects, or avatars, thus feel a conceptual distance from an actual human

- Might not consider what they do as “human subject” research

New ethical considerations…

- Must bridge this (artificial) distance between researcher and the actual human subject (see Carpenter & Dittrich, 2011)
  - Avoid the *“I’m just an engineer”* excuse….
- Also consider other stakeholders within the complex arrangement of information flows (i.e., larger *communities*, not just research subjects)

CONCEPTUAL GAP: HARM

Presumption that "harm" means risk of physical or other tangible impact on subject

- Researchers often imply "data is already public, so what harm could possibly happen?"

New ethical considerations

- Must move beyond the concept of harm as requiring a tangible consequence
  - Protecting from harm is more than protecting from physical attack, hackers
- Consider dignity/autonomy theories of harm
  - Must a "harm" occur for there to be damage to the subject?
  - Do subjects deserve control over the use of their data streams?
- Think about **"wrongs"** – not harms

CONCEPTUAL GAPS IN BIG DATA ETHICS

Growing use of big data in research creating new conceptual gaps in our ethical understanding c

- Privacy and anonymity
- Informed consent
- Human subjects & harm

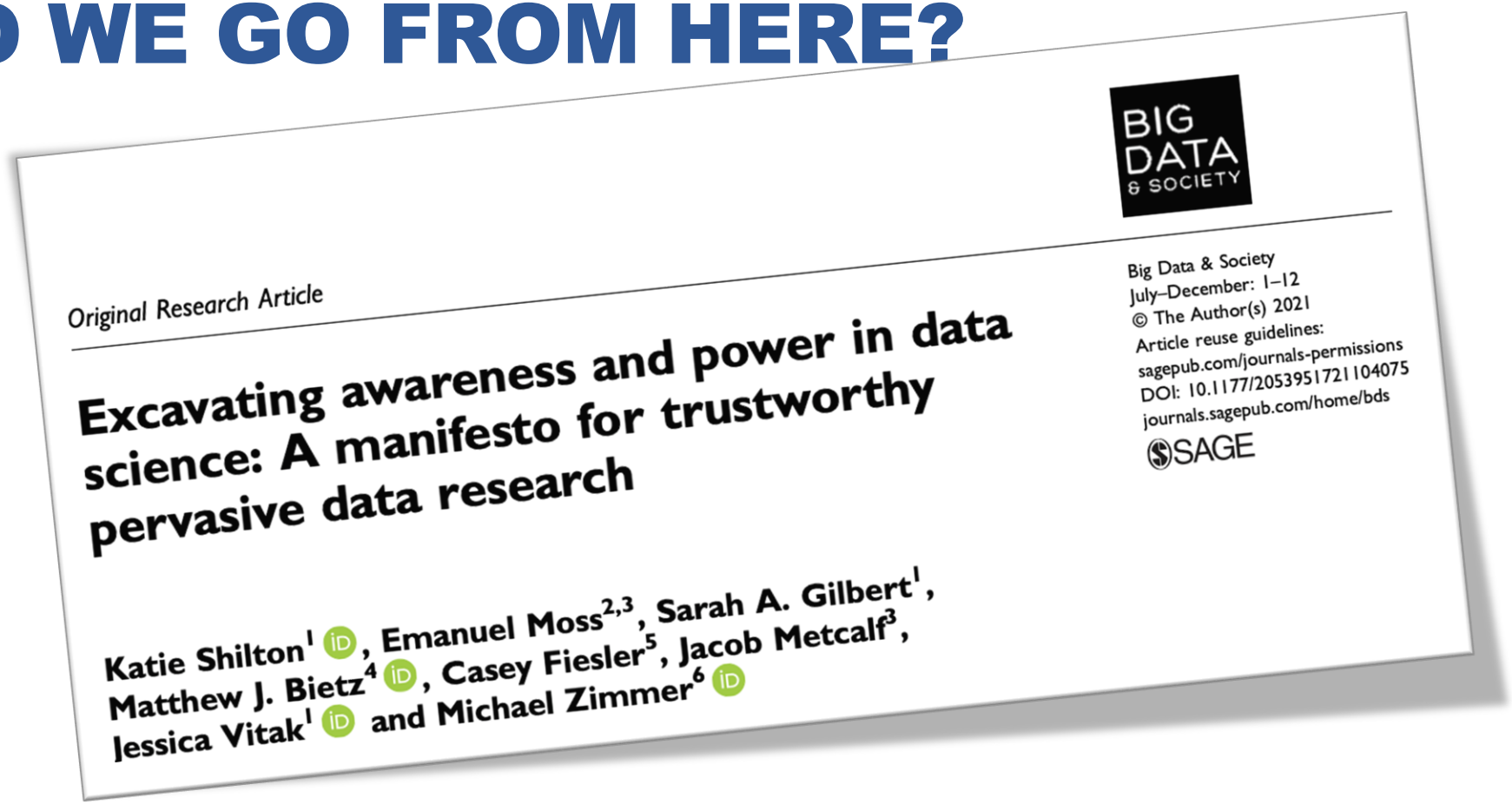
WHERE DO WE GO FROM HERE?

Provide <u>empirical measures</u> of ethical threats/concerns/approaches across stakeholder communities

- Ongoing empirical research of user communities, data platforms, IRB members, and researchers themselves
- Creating metrics for assessing and moderating risks to data subjects
- Adapting existing ethical codes for pervasive data
- Understanding the impact of academic and corporate regulators
- Disseminating evidence-based tools & best practices for research ethics

PERVADE
PERVASIVE DATA ETHICS
for computational research

WHERE DO WE GO FROM HERE?



Original Research Article

Excavating awareness and power in data science: A manifesto for trustworthy pervasive data research

Katie Shilton[1], Emanuel Moss[2,3], Sarah A. Gilbert[1], Matthew J. Bietz[4], Casey Fiesler[5], Jacob Metcalf[3], Jessica Vitak[1] and Michael Zimmer[6]

BIG DATA & SOCIETY

Big Data & Society
July–December: 1–12

DOI: 10.1177/20539517211040759
journals.sagepub.com/home/bds
SAGE

- We propose ways that social media data researchers can incorporate **reflection on awareness and power** within their research to support the development of trustworthy data science.

PERVADE
PERVASIVE DATA ETHICS
for computational research

WHERE DO WE GO FROM HERE?

- We propose ways that social media data researchers can incorporate **reflection on awareness and power** within their research to support the development of trustworthy data science.

Reddit research studies

- Review of over 700 studies using Reddit data didn't show much reflection on ethics
- But some researchers engaged in **critical reflection** beyond what their IRB required…

Suicide prediction algorithm

- Can we improve suicide prediction algos by incorporating public "derogatory" data?
- Research team **engaged with ethical assessment** and willing to exclude data, despite IRB waiver…

ZOOM IN ON A CASE…

Let's look at a case of researchers seeking to deploy ML/AI systems in public health contexts, and how they grapple with ethical issues around public data:

- Multifactorial Prediction of Suicidal Behavior through Integration of Multiple Datasets

MULTIFACTORIAL PREDICTION OF SUICIDAL BEHAVIOR THROUGH INTEGRATION OF MULTIPLE DATASETS

Suicide is the tenth leading cause of death in the United States, with more than 40,000 deaths and over one million attempts estimated annually

- Most attempts to predict suicidal behavior have relied on self-reporting of suicidal thoughts and intentions
- Yet, nearly half of all suicide decedents have contact with a healthcare professional in the month before their death

There's an opportunity to help at-risk individuals who interact with the healthcare system shortly before their suicide attempt

MULTIFACTORIAL PREDICTION OF SUICIDAL BEHAVIOR THROUGH INTEGRATION OF MULTIPLE DATASETS

Initial machine learning methods analyzed electronic health record (EHR) data and detected more than 1/3 of first-episode suicidal behavior cases, on average 3 years in advance, with at least 90% specificity.

What if we could enhance our predictive models by **linking structured EHR data to public record databases containing financial, legal, life event and sociodemographic data?**

Smoller & Reis, NIH RO1 Project 1R01MH117599-01

MULTIFACTORIAL PREDICTION OF SUICIDAL BEHAVIOR THROUGH INTEGRATION OF MULTIPLE DATASETS

Personal Finances

Fluctuations in an individual's financial circumstances are often linked to health for a variety of reasons.

Education

Lower levels of education may be linked to lower health literacy, which may determine higher levels of risk.

Voter Registration

Individuals showing engagement in their community may be more likely to engage in their own health.

Law Enforcement

Records pertaining to accident investigations may indicate future medical issues.

Derogatory Records

Liens, evictions and felonies indicate that individual health may not be a priority.

Smoller & Reis, NIH RO1 Project 1R01MH117599-01

MULTIFACTORIAL PREDICTION OF SUICIDAL BEHAVIOR THROUGH INTEGRATION OF MULTIPLE DATASETS

Research team's IRB approved the use of the LexisNexis derogatory data

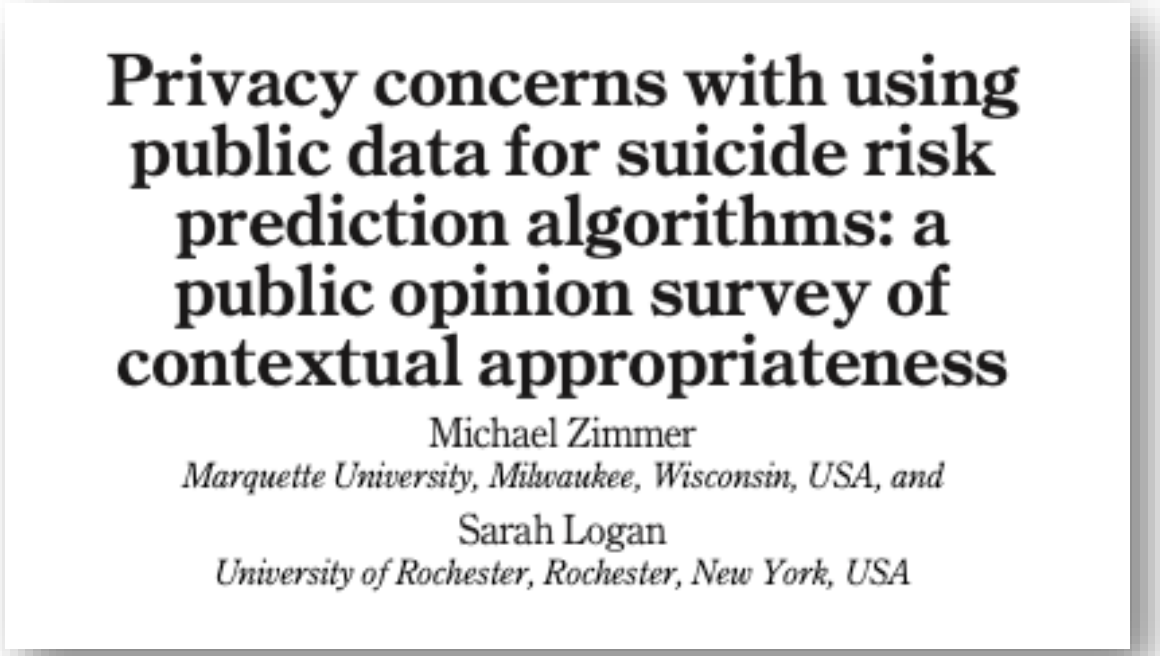
- Data was publicly available

But the research team was hesitant…

- Do patients expect their social, legal, financial data to be co-mingled with their EHR data?
- Even if publicly available, could some data be particularly sensitive when considered in this context?

Smoller & Reis, NIH RO1 Project 1R01MH117599-01

MULTIFACTORIAL PREDICTION OF SUICIDAL BEHAVIOR THROUGH INTEGRATION OF MULTIPLE DATASETS



Privacy concerns with using public data for suicide risk prediction algorithms: a public opinion survey of contextual appropriateness

Michael Zimmer
Marquette University, Milwaukee, Wisconsin, USA, and
Sarah Logan
University of Rochester, Rochester, New York, USA

- Respondents did not realize all data elements were publicly-available
- Data related to income, assets and criminal records were particularly sensitive
- Using data from household members was considered problematic
- Overall, appropriateness of using derogatory data was contextually-bound
  - And mixed as to whether ok for suicide-prediction tools

Zimmer, M. and Logan, S. (2022), "Privacy concerns with using public data for suicide risk prediction algorithms: a public opinion survey of contextual appropriateness", *Journal of Information, Communication and Ethics in Society*, Vol. 20 No. 2, pp. 257-272

MULTIFACTORIAL PREDICTION OF SUICIDAL BEHAVIOR THROUGH INTEGRATION OF MULTIPLE DATASETS

Research team has acknowledged and embraced these results

Will consider removing certain variables from model even if they have high predictive value

Also now concerned about how to ethically deploy such a tool into clinical settings

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BEYOND IRBS?

How should we address possible limitations of relying solely on IRB review?

- Thinking about broader downstream & community impacts?
- Thinking about ethical implications beyond regulatory compliance?

Burden on research communities?

- NeurIPS requires “broader impact statements” and review process can flag ethical concerns…
- Challenges of self-regulation, plus geographic, regulatory, and disciplinary diversity….

AGENDA

- How did we get here?
  - Rise of big data
  - AI/ML in research applications
- What makes big data ethics hard?
  - The data
  - Conceptual gaps
  - Understanding “harms”
- Where do we go from here?
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ETHICS OF BIG DATA & ARTIFICIAL INTELLIGENCE IN MEDICAL RESEARCH: CHALLENGES AND OPPORTUNITIES

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MARQUETTE UNIVERSITY

Center for Data, Ethics, and Society

Research Integrity, McLaren Health Care – Brown Bag Session
June 04, 2024