

Ethical Challenges in the Collection and Use of People- Provided Data

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2018 Chief Medical/Scientific Officers Conference
Sharing Patient-Centered Outcomes Data: Building a Better Mousetrap Based on Learnings from the Research Community
Washington, DC
October 17, 2018

Qualcomm Institute at UC San Diego

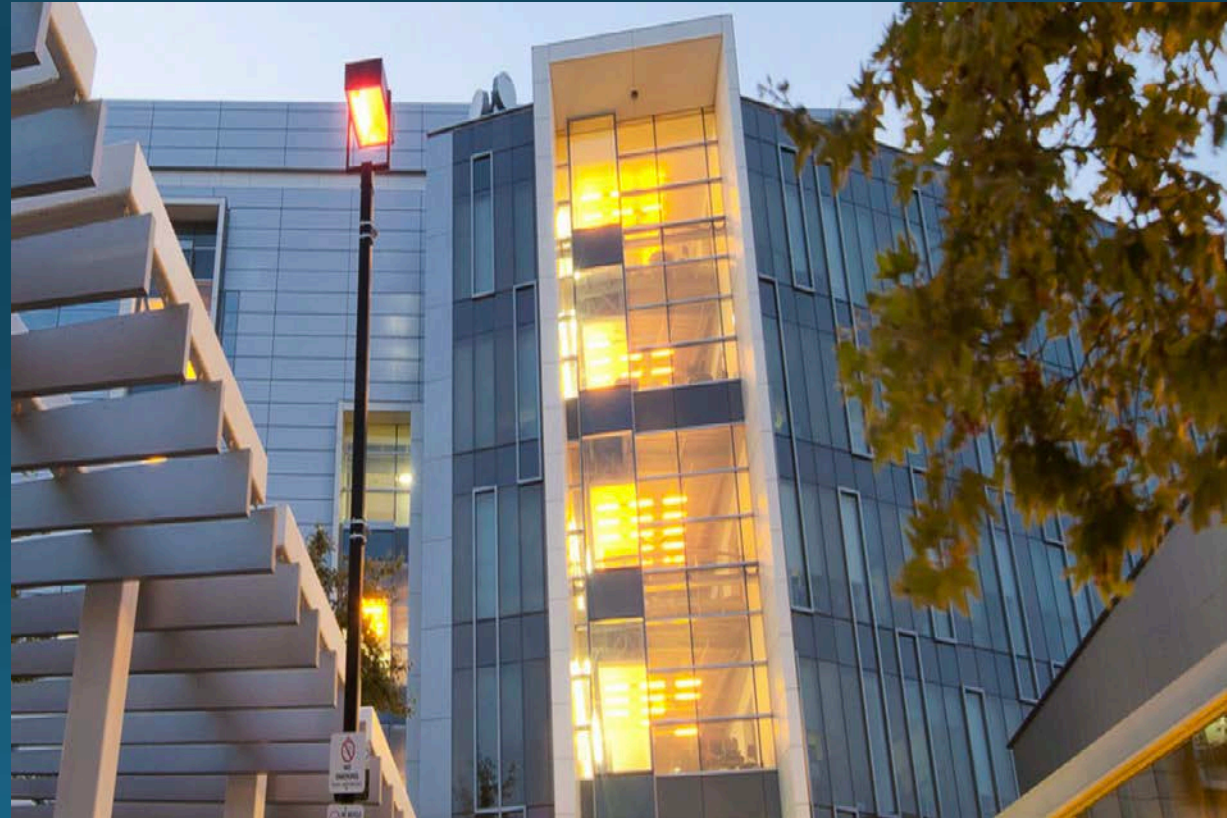
People

- 350 Faculty
- 120 Technical & Support Staffs
- 200 Industry Partners
- Students

Core Areas

- Culture
- Energy
- Environment
- Health
- Technology

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Center for Wireless and Population Health Systems



The Design Lab

A Center for Interdisciplinary Design

Focused on providing research, education, and community interaction to advance best practices in human-centered design and to address complex problems facing society.

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My Work

NIH

NSF

ORI

RWJF

UC San Diego

ACTRI

CA-DOR

IBM

Research Literacy: BRIC is education designed for novice-research team members to increase research literacy and awareness of ethical practices. The BRIC programs have received support from the NIH, NSF, ORI and local sources.



[@UCSD_BRIC](#) | bric.ucsd.edu

Tech-Ethics: CORE is a learning “ethics” community developed to facilitate the sharing of resources and access to digital health research experts to foster ethical and responsible research and innovation. The CORE is supported by the Robert Wood Johnson Foundation.



[@COREethics](#) | thecore.ucsd.edu

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Citizen Science via Participant-Led Research: People and groups motivated to conduct self-study (e.g., QS, DIY), yet they lack the infrastructure needed. We are working with **Project Apollo** patients to reflect upon and apply ethical principles, design self-studies, analyze data and share what they learn.

AI to Support Healthy Aging : We are working with residents of a retirement community to identify barriers to tech adoption and learn whether they want to be involved in co-design of tech to support their aging independently.

All of Us Research Program infrastructure development and bioethics research. We conducted qualitative research to learn about informed consent via “broad” consent and return of information to achieve return of value.

Determinants of Health



Current estimates indicate genetics explain an important but modest portion (e.g., ~30%) of an individual's variability in health. Health behaviors (e.g., physical inactivity, diet, tobacco use) explain an additional 40% of variance, with the remaining variance attributed to environment factors, social circumstances, and healthcare utilization and delivery.

Image courtesy of Dr. Kevin Patrick, Principal Investigator of the Health Data Exploration Project

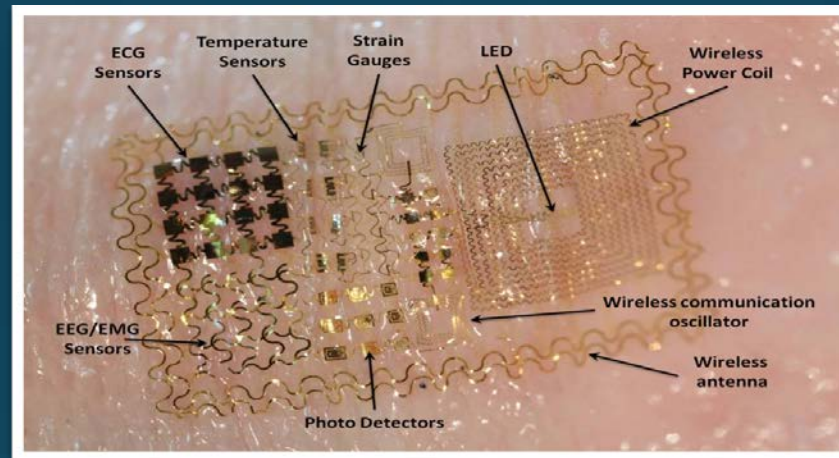


Visual Methods

Increasing interest in studying “free-living” behavior “in the wild” prompts increased use of visual methods.



Sensing Methods









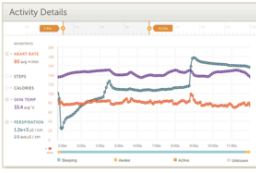
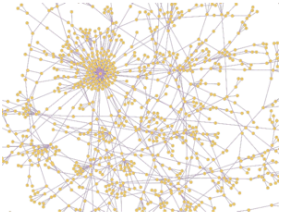
Passive, Pervasive, Ubiquitous

With permission of Dr. Todd Coleman, UC San Diego Professor of Electrical & Computer Engineering and CORE Advisor

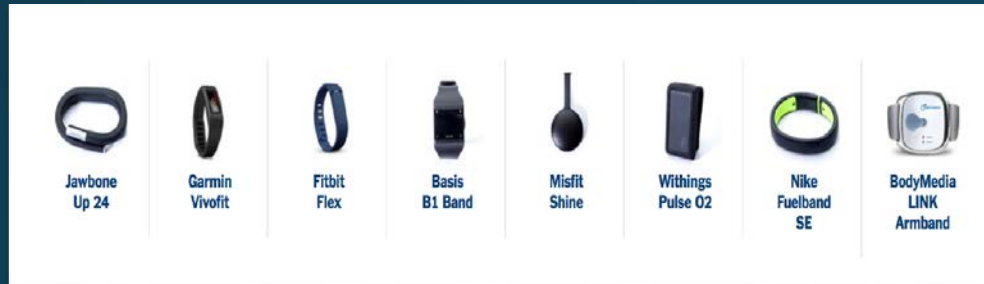
Social Media Methods



New Methods = New Data

Wearable Cameras	GPS Tracking	Smart Phones	Social Media
			 <p data-bbox="1574 725 1885 762">The CORE UCSD @UCSDHxCORE - Apr 5 Rashed Al Kotob proudly represents our #COREHxics team @UCSDH #PublicHealthWeek #mHealth #DigitalHealth #research_ethics @APHU</p>
			

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Characteristics of Digital Research

We live in an increasingly smart and connected environment and research methods and tools are changing.

Now people can monitor or be monitored and/or intervened with 24/7, on the fly and in real time.

Research isn't exclusively an academic venture – industry, non profits and citizens are in the game.

We can now know 'everything' at a granular level using new digital technologies.

Promising data anonymity is not realistic.

Not all in this emerging digital research ecosystem are regulated and not all are socialized in ethical practices.

Key Ethical Legal and Social Areas

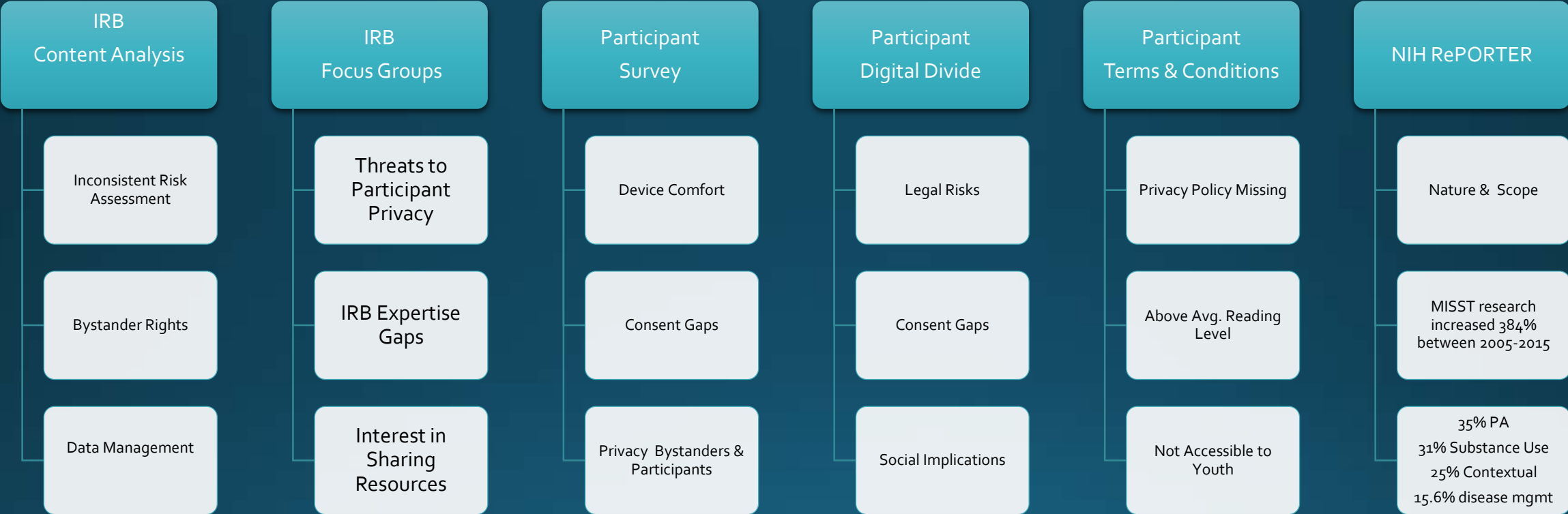


- Research Literacy
- Cultural Literacy
- Data Literacy
- Bystander Rights
- Risk / Benefits

- OHRP
- FDA
- Liability
- Legitimacy
- Intellectual Property

- Downstream impact
- Unknown Unknowns
- Obligations to share
- Sociotechnical

EMPIRICAL RESEARCH ON RESEARCH ETHICS



Precision Health/Medicine Considerations

Capacity Building	<ul style="list-style-type: none">• Accessible Education• Authentic Engagement
Informed Consent	<ul style="list-style-type: none">• Research Literacy• Data Literacy
Bystander Rights	<ul style="list-style-type: none">• Right to Consent• Governance
Risk Assessment	<ul style="list-style-type: none">• Subjective• Evidence-based
Data Management	<ul style="list-style-type: none">• Security• Sharing - Return of Information
Team Science	<ul style="list-style-type: none">• Common Language• Involvement of Behavioral and Social Sciences
Participants as Partners	<ul style="list-style-type: none">• Authentic Engagement• Capacity Development

Nebeker, C., Harlow, J., Giacinto-Espinoza, R., Linares-Orozco, R., Bloss, C., Weibel, N. (2017) Ethical and regulatory challenges of research using pervasive sensing and other emerging technologies: IRB perspectives, *American Journal of Bioethics: Empirical Bioethics* 8:4, 266-276, DOI: 10.1080/23294515.2017.1403980

We asked: How Might People Shape Ethical Practices?





Connected
& Open
Research Ethics

The CORE is a “research ethics” learning community where people share their expertise to shape ethical practices in the digital age.

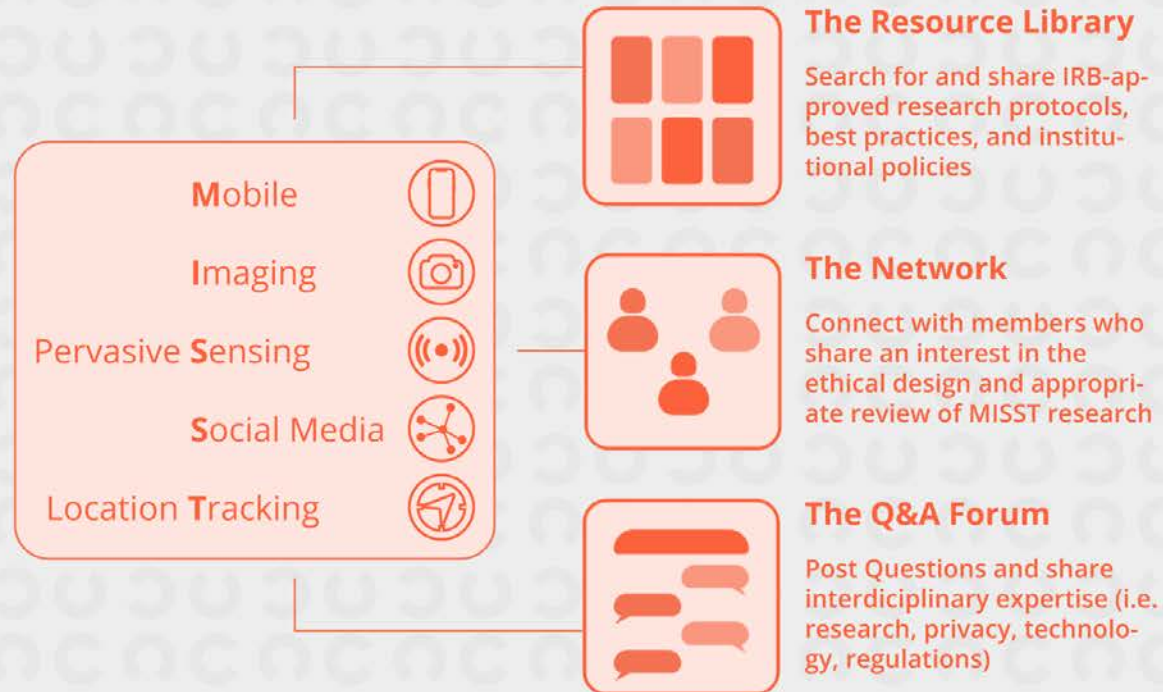
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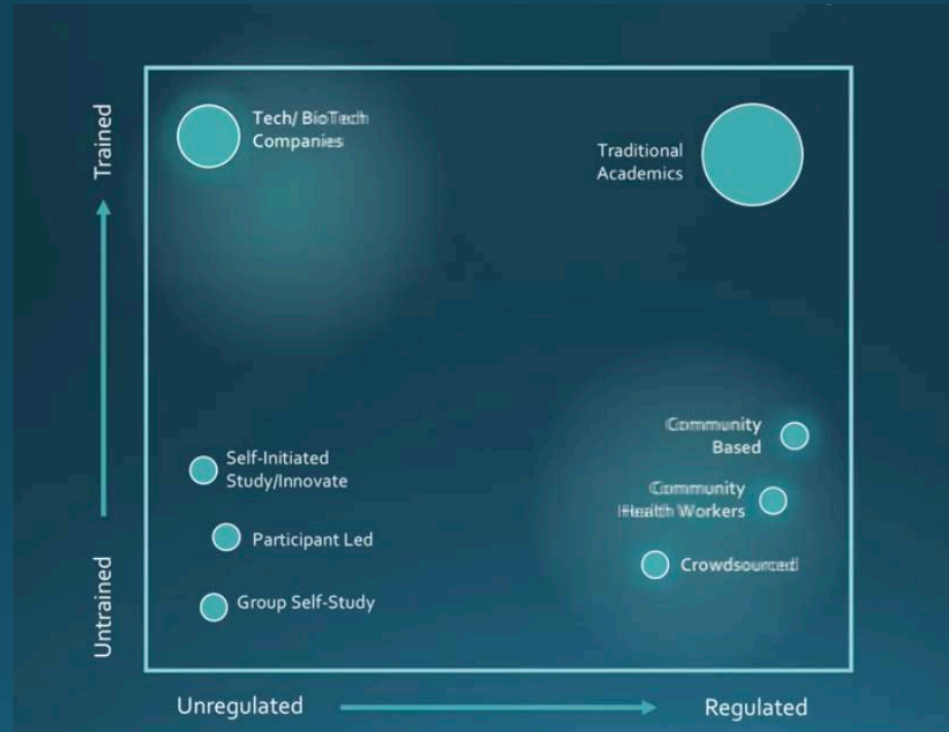


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Precision Medicine/Health Ecosystem



Digital Research Making Headlines

Facebook Manipulated User News Feeds To Create Emotional Responses

Gregory S. McNeal Contributor
Washington

TWEET THIS

- Facebook conducted a massive psychological experiment on 689,003 users, manipulating their news feeds to assess the effects on their emotions.
- The short version is, Facebook has the ability to make you feel good or bad, just by tweaking what shows up in your news feed.

1,021 views | Aug 13, 2018, 1:49 pm

Social Science One And How Top Journals View The Ethics Of Facebook Data Research

Kalev Leetaru Contributor
AI & Big Data
I write about the broad intersection of data and society.



Facebook and Cambridge Analytica: What You Need to Know as Fallout Widens

By KEVIN GRANVILLE MARCH 19, 2018



Our report that a political firm hired by the Trump campaign acquired access to private data on millions of Facebook users has sparked new questions about how the social media giant protects user information.

Who collected all that data?

Cambridge Analytica, a political data firm

TECH • OKCUPID

Researchers Caused an Uproar By Publishing Data From 70,000 OkCupid Users

Brief Communication | OPEN | Published: 02 August 2018

Don't quote me: reverse identification of research participants in social media studies

John W. Ayers, Theodore L. Caputi, Camille Nebeker & Mark Dredze

npj Digital Medicine 1, Article number: 30 (2018) | Download Citation ±

What Might be Unknown Unknowns?

HEAL THYSELF, ALGORITHM

If AI is going to be the world's doctor, it needs better textbooks

By [Dave Gershgorn](#) • September 6, 2018

Fitbit leans hard into healthcare with a new enterprise offering

Fitbit Care can help businesses and organizations keep employees healthy.

What Can You Do to Change the Culture?



Courtesy of DJ Patil

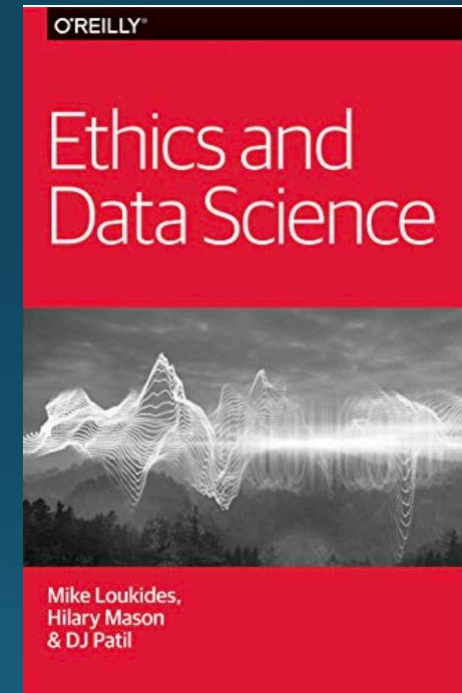
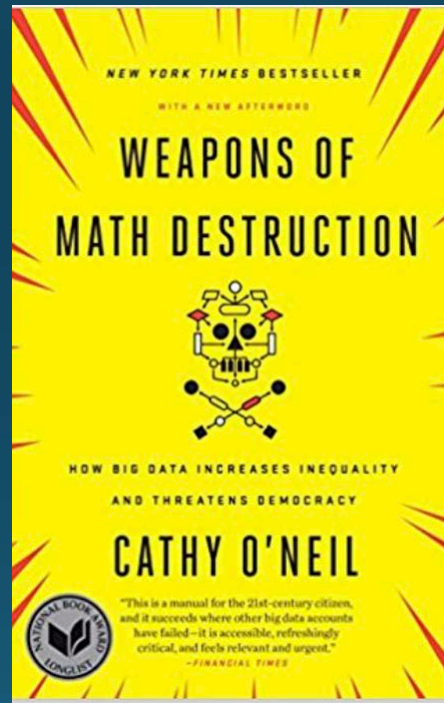
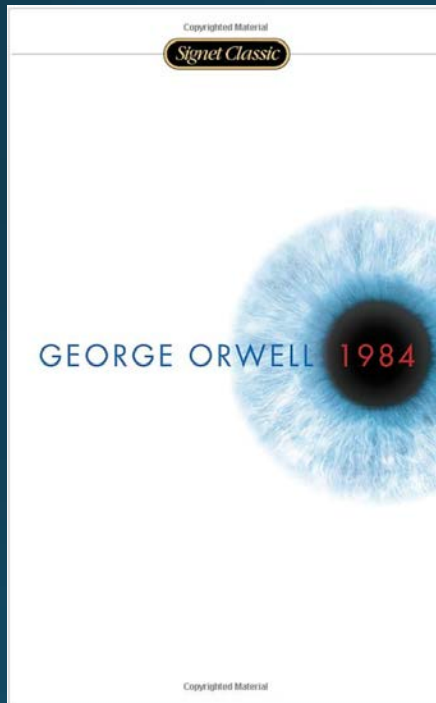
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What Can Employees Do?

what if every technologist
asked during their interview
how the org deals with
ethical issues?

<https://www.linkedin.com/pulse/ethics-data-science-dj-patil/>

What Can You Read?



https://www.amazon.com/dp/Bo7GTC8ZN7/ref=cm_sw_r_cp_ep_dp_fKyLBboYVWHg4

What Can Organizations Do?

Develop a community culture where it is safe for people to question the questionable practices

Develop a code of ethics as a community

Get to know a tech ethicist

Know where to find resources

Contribute to shaping ethical practices in the digital age

Questions?

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Sources

- <https://www.linkedin.com/pulse/ethics-data-science-dj-patil/>
- <http://fortune.com/2016/05/18/okcupid-data-research/>
- <https://www.mobihealthnews.com/content/digital-health-technologies-come-responsibility-imagining-unintended-consequences>
- <https://docs.google.com/document/d/1SN6hYeKe3eRK6x9DoSr7GpCA4nirpy03u68xG1A6NDs/edit#>
- <https://qz.com/1367177/if-ai-is-going-to-be-the-worlds-doctor-it-needs-better-textbooks/>
- <https://www.engadget.com/2018/09/19/fitbit-care-health-wellness-coaching-humana/>

Related Publications

- Dunseath, S.E., Weibel, N., Bloss, C.S., Nebeker, C. (2018). NIH support of mobile, imaging, pervasive sensing, social media and location tracking (MISST) research: laying the foundation npj Digital Medicine (2018) 1:1 ; doi:10.1038/s41746-017-0001-5
- Das G, Cheung C, Nebeker C, Bietz M, Bloss C (2018). Privacy policies for apps targeted toward youth: Descriptive analysis of readability. *JMIR Mhealth Uhealth*;6(1):e3 URL: <http://mhealth.jmir.org/2018/1/e3> DOI: 10.2196/mhealth.7626 PMID: 29301737
- Nebeker, C., Harlow, J., Giacinto-Espinoza, R., Linares-Orozco, R., Bloss, C., Weibel, N. (2017) Ethical and regulatory challenges of research using pervasive sensing and other emerging technologies: IRB perspectives, *American Journal of Bioethics: Empirical Bioethics* 8:4, 266-276, DOI: 10.1080/23294515.2017.1403980
- Nebeker, C., Murray, K.E., Holub, C., Houghton, J., and Arredondo, E. (2017). Acceptance of mobile health in communities underrepresented in biomedical research: Barriers and ethical considerations for scientists. *JMIR Mhealth Uhealth* 2017;5(6):e87 URL: <http://mhealth.jmir.org/2017/6/e87> DOI: 10.2196/mhealth.6494 PMID: 28659258
- Torous J, Nebeker C. Navigating ethics in the digital age: Introducing Connected and Open Research Ethics (CORE), a tool for researchers and Institutional Review Boards. *J Med Internet Res* 2017;19(2):e38 URL: <https://www.jmir.org/2017/2/e38> DOI: 10.2196/jmir.6793 PMID: 28179216 PMCID: 5322198.
- Bloss C, Nebeker C, Bietz M, Bae D, Bigby B, Devereaux M, Fowler J., Waldo A, Weibel N, Patrick K, Klemmer S, & Melichar L. (2016) Re-Imagining Human Research Protections for 21st Century Science. *J Med Internet Res.* ; 18(12):e329. doi: 10.2196/jmir.6634.
- Nebeker, C., Lagare, T., Takemoto, M. et al. (2016) Engaging participants to inform the ethical conduct of mobile imaging, pervasive sensing and location tracking research, *Translational Behavioral Medicine: Practice, Policy and Research* doi:10.1007/s13142-016-0426-4. <https://www.ncbi.nlm.nih.gov/pubmed/27688250>
- Nebeker, C., Linares-Orozco, R., & Crist, K., (2015). A multi-case study of research using mobile imaging, sensing and tracking technologies to objectively measure behavior: Ethical issues and insights to guide responsible research practice. *Journal of Research Administration* 46(1):118-137
- Nebeker, C. and Lopez-Arenas, A. (2016). Building Research Integrity and Capacity (BRIC): An educational initiative to increase research literacy among community health workers and promoters. *Journal of Biology and Microbiology Education* (17): 41-45 DOI: <http://dx.doi.org/10.1128/jmbe.v17i1.1020>