#### INITIATIVE

# Health and Data

The Health and Data research initiative examines emerging opportunities and risks presented by innovations in health-related technologies and data practices.

The sheer volume of digital medical data—and associated methods of analysis—is outpacing both public understanding and the ability to assess the social impact of these new healthcare practices. At the same time, human health continues to be both positively and adversely affected by our increasing reliance on internet and information technologies that proliferate beyond the medical sphere.

While the increasing ubiquity of data and automation in health care enables novel approaches to a wide range of diseases and health concerns, Health and Data initiative projects underscore that these technologies may also exacerbate certain health disparities. "The excitement for these technological innovations must be matched with cleareyed examinations of the possibility for emerging fields to exacerbate existing risks or create new points of vulnerability."

> KADIJA FERRYMAN AND MIKAELA PITCAN FAIRNESS IN PRECISION MEDICINE

Health and Data projects examine the extent to which new technologies can address historical disparities in **data collection** and **access** to healthcare—and, in turn, introduce new forms of **inequity**.

Through empirical investigation, the Health and Data team seeks to understand the evolving and complex interdependence of our health and technology practices, including **precision medicine**, **algorithmic decision-making** in clinical care, **bias in genome databases**, **ethical collection of data**, **healthy interactions** with tech platforms and mobile devices, and the spread of **health misinformation** online.

#### **RESEARCH TRACKS**

#### 01 FAIRNESS IN PRECISION MEDICINE

Precision medicine is a growing field that aims to use multiple data sources to tailor medical care to individuals. The Fairness in Precision Medicine project aims to critically assess the **potential for bias and discrimination in health data collection, sharing, and interpretation**.

Explore this research track here (https://datasociety.net/research /fairness-precision-medicine/).

### <sup>03</sup> HEALTH EQUITY IN THE INFORMATION AGE

Digital information technologiesincluding electronic medical records, health risk detection and prediction algorithms, and other computational analytics-are increasingly becoming a part of data-informed, innovative biomedical research and care. At the same time, stark health disparities exist within populations. This set of projects investigates how and whether information technologies impact health equity.

#### 02 HEALTHY BEHAVIOR WITH TECH

Internet companies have prioritized engagement as the best metric to measure success, creating an economy where attention becomes the most important currency, even at the cost of users' mental health. This work analyzes the **mental health and behavioral impact of an increasingly technology-centric life** and explores potential design interventions and solutions.



RESEARCHERS ALEX ROSENBLAT, KADIJA FERRYMAN, AND MARY MADDEN

#### 01 FAIRNESS IN PRECISION MEDICINE

#### **02 HEALTHY BEHAVIOR WITH TECH**

RELATED OUTPUTS Internet companies have prioritized engagement as the best metric to measure success, creating an economy where attention becomes the most important currency, even at the cost of users' mental health. This work analyzes the mental health and behavioral impact of an increasingly technology-centric life and explores potential/design interventions and relutions-inprecision-medicine/)

#### 03 HEALTH EQUITY IN THE INFORMATION AGE

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#### PRIMER | 10.30.14

# Data & Civil Rights: Health Primer (https://datasociety.net /output/data-civil-rights-health-primer/)

ALEX ROSENBLAT, KATE WIKELIUS, DANAH BOYD, SEETA PEÑA GANGADHARAN, CORRINE YU

Data plays a central role in both medicine and insurance, enabling advances and creating new challenges. Although legislative efforts have attempted to protect the privacy of people's health data,... read more (https://datasociety.net/output/data-civil-rights-healthprimer/)

#### MIT TECHNOLOGY REVIEW | 10.23.18

Need medical help? Sorry, not until you sign away your privacy. (https://datasociety.net/output/need-medical-help-sorry-not-until-you-sign-away-your-privacy/)

#### MARY MADDEN

Data & Society Health + Data Lead Mary Madden considers what patient privacy means in the current age of technology. "In the era of data-driven medicine, systems for handling...

read more (https://datasociety.net/output/need-medical-help-sorrynot-until-you-sign-away-your-privacy/)

#### POINTS | 09.10.18

Technology's Impact on Infrastructure is a Health Concern (https://datasociety.net/output/technologys-impact-on-Infrastructure-is-a-health-concern/)

MIKAELA PITCAN, ALEX ROSENBLAT, MARY MADDEN, KADIJA FERRYMAN

Increasingly, technology's impact on infrastructure is becoming a health concern. In this Points piece, Data & Society Researchers Mikaela Pitcan, Alex Rosenblat, Mary Madden, and Kadija Ferryman tease out...

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Read on Points (https://points.datasociety.ne /technologys-impact-oninfrastructure-is-a-healthconcern-6f1ffdf46016)

### infrastructure-is-a-health-concern/)

POINTS | 04.25.18

### Proceed With Caution (https://datasociety.net/output/proceedwith-caution/)

KADIJA FERRYMAN, ELAINE O. NSOESIE

After the Cambridge Analytica scandal, can internet data be used ethically for research? Data & Society Postdoctoral Scholar Kadija Ferryman and Elaine O. Nsoesie, PhD from the Institute for... read more (https://datasociety.net/output/proceed-with-caution/)



Read on Points (https://points.datasociety.ne /proceed-with-caution-852d64faaed5)

#### POINTS | 02.27.18

# When verification is also surveillance (https://datasociety.net /output/when-verification-is-also-surveillance/)

JACOB METCALF

The rollout of Electronic Visit Verification (EVV) for Medicaid recipients has serious privacy implications, argues Data & Society Researcher Jacob Metcalf. "So why should we be worried about rules...

read more (https://datasociety.net/output/when-verification-is-alsosurveillance/)



## Health Data Rush (https://datasociety.net/output/health-datarush/)

KADIJA FERRYMAN

As data becomes more prevalent in the health world, Data & Society Postdoctoral Scholar Kadija Ferryman urges us to consider how we will regulate its collection and usage. "As... read more (https://datasociety.net/output/health-data-rush/)



Read on Points (https://points.datasociety.ne /when-verification-isalso-surveillance-21edb6c12cc9)



Read on Points (https://points.datasociety.ne /health-data-rusha1448129693a) BLOG POST | 10.17.16

Student Data & Mental Health: What the Blank Spots Say (https://datasociety.net/output/student-data-mental-health-what-the-blank-spots-say/)

MIKAELA PITCAN

D&S research analyst Mikaela Pitcan discusses how missing data can impact how students with mental health conditions. The areas in which data are lacking communicate priorities. However, without concrete... read more (https://datasociety.net/output/student-data-mental-

health-what-the-blank-spots-say/)



Read on Points... (https://medium.com /enabling-connectedlearning/student-datamental-health-what-theblank-spotssay-5fd6ea9c6bec)

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