

# BIG DATA

Privacy, Implications for Medical  
Care, Public Health, and  
Cybersecurity



# Reframing Use Authorization: Upstream & Macro, Prevention of Harm, Inability to Equalize Power

Antitrust issues—who uses and how in the economic marketplace

Corporate welfare; Marketing is generally not an ethics-centric use

Government responsibility to prevent hacking (pipeline example)

Public and individual health benefits might provide possible ethical justification, but are they enough to compensate for the power asymmetry?

People have no ability to be compensated for the data

No practical ability to opt out of sharing data (unrealistic)

Privacy protections



# Data Abuse

Marketing without permission

Discrimination

Use of non-health data to predict health

Disease creep and upselling



# A Full Profile: Public Records and Cookies

Biometrics

Facial recognition

Where you shop

Credit rating



# A Full Profile—Slide 2

- Qualities collected
- Way of thinking
- Habits and associations
- Vaccination records
- Health and medication data
- Online shopping



# Combining Health Data and Consumer Data



How the systems work



They mix habits with other data



Public records



Prescriber habits



Uses become consumer, marketing, but health is not governed by data laws



CCPA, CDPA, WaPA (pending) and GDPR



HIPAA does not cover it all



# Clinical Care

Black box  
data

Know how it  
is used

Absence of  
known cause

Many  
correlations

Diagnose and  
treat

Supplant  
expertise and  
experience



# Criminal Activity

FBI and warnings about data, hacking, ransomware attacks, financial motivation

Wrongdoers, extortion, and political motivation

Regime change and criminalization of some activities, genetics as crimes and genocide



# Data- Generating Patents

Trade secret law has no expiration

Patent law protects the data generated

An antitrust approach should end data-generating patents

Competition suffers



Used to mean  
both confidential  
and freedom of  
choice

Right to control  
data is complex

Sign off without  
full information

Knowing the  
scope of the use  
of data

Right to be free  
from government  
intrusion still  
exists

Treat as though  
everything is  
hackable once  
collected

Modern  
Privacy: Is it  
still two-  
pronged?



Modern Privacy Framework

Harms and Benefits of Big Data

A company stores children's health records for many schools called Magnus Health. Parents prefer records in paper form stored only at the school.

Stakeholders

The public and all individuals (privacy as well as suffering when infrastructure is hacked like pipeline, shipping, state department, large Target credit card breach), corporations (reputation), government entities (role of hackers; national security)

The child, the child as a future adult, potential for extortion and discrimination.

Ethical Issues

Navigating the weighing process of benefits to individual and public health against possibly privacy violation, is privacy sacrificed once data is entered,

Is there a narrow solution—some parents submit paper documents. Are parents aware that Magnus aggregates and shares? Is the school obligated to tell the parents? Is the deidentification enough. Why are the families not paid if the data can be used commercially?

Macro to micro issues

Policies like California Consumer Privacy Act, role of HIPAA, European Union General Data Protection Regulation (GDPR) Individual's ability to keep things private.

From the Magnus website: "Magnus may aggregate your information with information from other users and share aggregated information with interested third parties." <https://magnushealth.com/18-2-28-privacy-policy/>

Considerations

Deidentification, Discrimination, Privacy, Black-Box method of clinical care, Cloud computing, edge computing, hackability, bad actors, future extortion, political manipulation, vulnerability of children

Is there a data-generating patent allowing one company to use the data. Children are vulnerable and not decision makers with any control over their data.

Think Critically

Can convenience be put in ethical terms? What are the benefits beyond convenience? Are other substantive benefits ethically necessary? Is public health a government stake? Could antitrust enforcement offer personal protection?

Is there really a public or private health benefit to outsourcing data storage for children. (There is still a school nurse...)



# An Idea

- What if everyone affiliated themselves with one big data collector and had an ID or bar code so that everywhere they entered collectible data (shopping, health care, public records, speeding tickets, liens, smart TV exposures, and any website where they accept cookies) would know which company they chose for data, what uses they agree to, and what compensation they get for each use? A new system could put the control in the consumer's hands, reimburse them, and still lead to the benefits of big data in public health. Then, those data agencies could abide by the agreed upon terms of each person who provided data. Antitrust enforcement should stop data collection from being linked to retail, health care, etc. For example, people using a pharmacy could give their bar code and deidentified prescription data could go to the chosen organization and not be available for use by the pharmacy, which should not be in the data collection business. The chosen organization could compensate the person. The organization could aggregate the deidentified data and sell according to stipulated conditions, making the health benefits possible.

