# HEALTH AND DIGITAL TECHNOLOGY PARTNERSHIPS: TOO CLOSE FOR COMFORT?

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### Overview

- I. Health and Digital Technology Partnerships
- II. Opportunities for Benefit
- III. When Interests Diverge
- IV. Pursuing Efficiency and Amplifying Injustice
- V. Managing Interests in Big Medical Data

# I. Health and Digital Technology Partnerships

### • WSJ NEWS EXCLUSIVE | TECH Google's 'Project Nightingale' Gathers Personal Health Data on Millions of Americans

Search giant is amassing health records from Ascension facilities in 21 states; patients not yet informed

Pharmacy Owners Express Concern Over Amazon's PillPack Prescription Transfer Requests

Verana Health aims to organize and analyze doctors' clinical data sets, whether patients like it or not

Apple Health Records now available to all US providers with compatible EHRs

# Medical-Digital Partnerships

#### Google

- 2016: DeepMind & Britain's NHS, ended ethics panel 2019
- 2017: UCMC shares de-identified patient data with Google, and Google identifies patterns to enable predictive analysis in medicine (lawsuit dismissed 2020)
- 2019: Ascension Health, "Project Nightingale"
- Amazon
  - 2018: Purchased PillPack, an online pharmacy start-up
- Apple
  - 2018: Health App enabled HER
- Microsoft
  - 2019: Partnership between Azure (cloud computing) & UCLA

### The Purpose of Partnerships

- Verana Health: aims to "empower physicians and life science companies with deeper data insights to accelerate medical research and change lives" (their homepage, Shieber 2020).
- "These emerging partnerships enable providers to secure the capabilities that will be necessary to ensure their sustained growth and viability in this era of healthcare digital industrialization" (Chartis Group 2019).
- Health Care is 20% of the U.S. GDP one of the last frontiers of digital tech growth.

# A Range of Ethical Issues

- From implications to motivations:
  - What will happen when we use these tools (issues of privacy, safety, autonomy, etc.)?
  - Who is using this tools and why?
- What is the purpose of partnerships between healthcare and digital technology companies?

# II. Opportunities for Benefit

# Generation of New Knowledge

- Big Data in medicine: The three "Vs": high volume (lots of data), high velocity (data acquired and analyzed quickly), and high variability (data from different types of sources).
- Machine learning algorithms: analyze big data sets and predict how a new data point will fit into the set (too messy for statistical methods).
  - Healthcare administrators: identify trends in patient needs to better allocate funds and resources.
  - Individual clinicians: identify appropriate treatment for patients based on realtime analysis of symptoms and side effects of patients with similar profiles.

# Personalization of Clinical Care

- More precise predictions and recommendations, based on locating a patient's "data point" in the context of others.
- "Geomarkers" or "Community Vital Signs": data points about the communities in which patients live that can be used to predict factors that would help clinicians to personalize patient care.
  - Requires links between population-level data and patient's charts.
  - Also trades on markers of "social capital" such as credit score.
  - Insurance companies and those with a financial interest in healthcare also want this information.

### III. When Interests Diverge

# **Conflicts of Interest**

- Individual conflicts of interest in medicine:
  - Financial incentive to use a product clinically or to identify favorable results in research.
  - "Whenever a professional's judgment with respect to a primary interest is influenced by a secondary interest."
  - More powerful without \$\$: It is more likely for individuals to rationalize acting in their own financial interest at the expense of their professional integrity when the material they are dealing with is not cash and when their actions only indirectly provide financial benefit (Ariely, *Predictably Irrational*).

#### NEW YORK TIMES BESTSELLER

REVISED AND EXPANDED EDITION



# PREDICTABLY IVNOILVABLY

'Sly and lucid. . . . Revolutionary." — New York Times Book Review

The Hidden Forces That Shape Our Decisions



### New Partnerships, New Conflicts

- No clear product: the relationship with the digital technology company is institutional, not individual.
- Institutional conflict of interest: "a situation in which the institution or its leaders (such as presidents, chancellors, vice presidents, deans, or department heads) have interests that may compromise judgment or decision-making concerning its primary professional, ethical, or legal obligations or academic aims" (Resnik 2019: 1661).
  - "Institutional COIs can create ethical problems by threatening the objectivity and integrity of research and public trust in the institution, investigators, or the research enterprise" (Resnik 2019: 1661).

### Digital-Medical Partnerships: Whose Interests Count?

- Healthcare institutions are oriented around patient & community health.
- Digital technology companies are not, even when they profess to be.

"There are fundamental differences between the mission, purpose, and function of public sector bodies on the one hand, and corporations and trade associations on the other hand... Public officials and administrators frequently emphasize a convergence of interests with industry and downplay or ignore the divergence, in order to foster collaboration and 'getting things done.' This approach comes at a price. Not least, it provides industry actors with additional opportunities to influence public health policy and research in ways that are most consonant with their commercial interests" (Marks 2019: 4).



### **Goods and Interests**

- Common Good
  - The well-being of the community in terms of its shared values and goals.
- Public Good
  - The good of the public understood as the space where individuals interact in social life, while not necessarily being members of a shared community.
- Public Interest
  - The public interest is the collection of private interests of individuals within a society.

# Corporations, Goods, Interests

- Corporations may contribute to the common good but are not guardians of it: it is not their aim or end.
- In pursuing their private commercial interests, they may "improve the economic and social well-being of the community" (Marks 2019: 35): there are intersections between private interests and the common good.
  - "Corporations may contribute to the good of the community...However, policymakers should not conflate the promotion of the public good with the sale of private goods, and they should be attentive to actual and potential inconsistencies, divergences, and tensions between the public good and the commercial interests of proposed collaborators" (Marks 2019: 49).
  - Marks warns, "the emphasis on convergences of interest between industry and the academy is a Panglossian view that can lead administrators to downplay or ignore the ethical perils arising from fundamental divergences in interests" (Marks 2019: 71).

### Better Care/Better Algorithms?

Chen and Asch, "Machine Learning and Inflated Expectations":

- Perfecting the tool can quickly become the goal of big data partnerships in medicine: "The apparent solution is to pile on greater varieties of data, including anything from sociodemographics to personal genomics to mobilesensor readouts to a patient's credit history and Web-browsing logs... Research continues to improve the accuracy of clinical predictions, but even a perfectly calibrated prediction model may not translate into better clinical care" (Chen and Asch 2017: 2507).
- Marks suggests that "institutions should look for and take steps to address any inconsistencies, divergences, or tensions in what they do (practices), what they say they do (mission), and what they are obligated to do (purpose)... partnerships and close relations with other institutions whose mission, purpose, or practices are at odds with one's own are ethically problematic" (Marks 2019: 22).

# IV. Pursuing Efficiency and Amplifying Injustice

# Inefficient Medicine

- Big data analytics can increase healthcare system efficiency by extracting more benefit from EHRs, by identifying areas of waste that may only be visible using big data analytic tools.
  - Efficiency can come at the expense of other goods, especially those that operate in the background of our human systems rather than ones we must intentionally incorporate. (e.g., *paperclip maximizer*)
- Artificially intelligent systems only prioritize what they are told to prioritize – human values that are not built into the system are excluded, and so background conditions that we may take for granted could be unintentionally left out.



# Algorithms and Red Flags

 Virginia Eubanks: Algorithmic systems aimed at efficiency intensify surveillance of poor and otherwise marginalized communities.

"Marginalized groups face higher levels of data collection when they access public benefits, walk through highly policed neighborhoods, enter the health-care system, or cross national borders. That data acts to reinforce their marginality when it is used to target them for suspicion and extra scrutiny. Those groups seen as undeserving are singled out for punitive public policy and more intense surveillance. It is a kind of collective red-flagging, a feedback loop of injustice" (Eubanks 2018: 7).



### AUTOMATING INEQUALITY

HOW HIGH-TECH TOOLS PROFILE, POLICE, AND PUNISH THE POOR



# **Structural Injustice**

- Justice is defined by the "degree to which a society contains and supports the institutional conditions necessary for the realization of [the values that constitute the good life]..." These values are, "Developing and exercising one's capacities and expressing one's experience and participating in determining one's action and the conditions of one's action" (Young 1990: 37).
- Injustice, in a structural view, is not any one unjust decision one person may make or any single material good being unfairly distributed but patterns of decision-making, labor distribution, and cultural practices that further entrench domination (the institutional constraint on selfdetermination) and oppression (the institutional constraint on self-development).



# **Injustice and Intentions**

- Structural injustice is produced and reproduced by thousands or millions of persons usually acting within institutional rules and according to practices that most people regard as morally acceptable." (Young 2011: 95).
  - Injustice refers to positions in society: "persons in this position differ from persons differently situated in the range of options available to them and in the nature of the constraints on their action... the issue of social justice raised... is whether it is right that anyone should be in a position of housing insecurity, especially in an affluent society" (Young 2011: 45).
- "Automated decision-making technologies used in public services cannot escape the history that spawned them...This doesn't require bad intentions on the part of designers, data scientists, or program administrators. It only requires designing "in neutral," ignoring the entirely predictable consequences of super-charging already unequal and discriminatory systems" (Eubanks 2018: 223).

#### Responsibility for Justice



# Privatization and Racial Injustice

The New Jim Code is "part of a broader push toward privatization where efforts to cut costs and maximize profits, often at the expense of other human needs, is a guiding rationale for public and private sectors alike" (Benjamin 2019: 30).

"Race as technology: this is an invitation to consider racism in relation to other forms of domination as not just an ideology or history, but as **a set of technologies that generate patterns of social relations**, and these become Black-boxed as natural, inevitable, automatic" (Benjamin 2019: 44-45).

Structural injustice thus yields biased data through a variety of mechanisms—prominently including under- and overrepresentation—and worrisome feedback loops result. Even if the quality control problems associated with an algorithm's decision rules were resolved, we would be left with a more fundamental problem: these systems would still be learning from and relying on data born out of conditions of pervasive and long-standing injustice" (Zimmerman 2020).



### Health and Automated Decision-Making

Benjamin describes practices of "hotspotting," in which location is used to identify populations that are "medically vulnerable" (i.e., so-called 'super-utilizers' of healthcare systems) in order to target resources in a way that "lowers the monetary debt incurred by hospitals" (Benjamin 2019: 156).

"Automated eligibility systems and predictive analytics are best understood as political decisionmaking machines. They do not remove bias, they launder it, performing a high-tech sleight of hand that encourages us to perceive deeply political decisions as natural and inevitable. **They reinforce some values: efficiency, cost savings, adherence to the rules. They obscure or displace some others: self-determination, dignity, autonomy, mutual obligation, trust, due process, equity**. They embody very particular ways of understanding the world and foreclose more promising visions" (Eubanks 2018: 224).

Benjamin agrees, "'Health,' 'safety,' 'efficiency,' and even 'diversity' mask newfangled forms of classification and control, which often take shape under the rubric of customization and individualization" (Benjamin 2019: 151).

### Transformation for whom?

- "This is the allure of tech fixes. They offer pragmatic inclusion in place of political and social transformation. The medical means justify the social ends, we are led to believe. But too often the means are the end. New Jim Code fixes are a permanent placeholder for bolder change.... Medical inclusion, in short, can be a lucrative stand-in for social and political justice" (Benjamin 2019: 156-157, emphasis in original).
- "For any given issue of justice there may be agents in addition to victims whose perceived self-interest may coincide with promoting justice... Aligning interest with responsibility is not a problem; indeed, one way of looking at what taking political responsibility means is to figure out how to align one's interests with those of agents that suffer injustice" (Young 2011: 146).

# V. Managing Interests in Big Medical Data

### **Closing thoughts from Marks**

- Marks writes in the context of public health agencies, "Public health agencies should begin by asking themselves three questions. First, what important public health challenges are not being addressed sufficiently or at all? Second, which challenges – and which methods of addressing them – might other entities have no (or insufficient) interest in pursuing?... Third, how can we address these challenges without entering close relationships with industry actors?" (Marks 2019: 125).
- Marks also offers a set of norms for public-private interactions, including independence (from the influence of private interests), integrity (avoiding relationships with institutions that do not share the same mission), credibility (transparency about relationships), stewardship (protecting vulnerable parties), public good (promoting the good of everyone in a society, not just private interests), and anti-promotion (of private interests that counter the public interest) (Marks 2019: 113).

# **Closing thoughts from Benjamin**

Benjamin describes forms of resistance that she conceives of as abolitionist tools for the New Jim Code. These tools aim to resist coded inequity, build solidarity, and engender liberation (Benjamin 2019: 168). They including asking who benefits from a new technology, whose interests are subverted by it, whether market imperatives are prioritized over social goods, whether an algorithm would pass an "accountability audit," and what stories are told about the success or failure of the technology.

### Closing thoughts from Eubanks

Eubanks offers what she calls an "Oath of Non-Harm for an Age of Big Data," which includes that one will:

Understand that people are experts in their own lives, create tools that remove obstacles between resources and the people who need them, not use technical knowledge to compound disadvantage and oppression, design with history in mind, integrate systems for the needs of people, not data, not collect data for data's sake, nor keep it just because one can, prioritize informed consent over design convenience, not design a data-based system that overturns an established legal right of the poor, remember that technologies are designed for human beings, not data points, probabilities, or patterns (Eubanks 2018: 212).

### Taking a pause

"Rather than rushing to quick, top-down solutions aimed at quality control, optimization, and neutrality, we must first clarify what particular kind of problem we are trying to solve in the first place. Until we do so, algorithmic decision making will continue to entrench social injustice, even as tech optimists herald it as the cure for the very ills it exacerbates" (Zimmerman et al. 2020).

# In Conclusion

- Medical-Digital partnerships are tempting: they produce new knowledge from data analytics and improve the capacity to use this new knowledge to personalize patients' medical care.
  - Yet the institutions involved have disparate missions: improving patients' health and wellbeing versus perfecting and popularizing proprietary data analytic tools.
  - These conflicts of interest run the risk of prioritizing efficiency over the common good, contributing to a feedback loop of structural injustice.
- Evading these risks requires, as a first step, asking what these partnerships are for and if they are truly necessary to meet healthcare institutions' aims.
  - If these partnerships are deemed necessary, then the second step is to be transparent with the public about the real risks that these conflicts of interest pose. Finally, the third step is to identify both a set of shared norms to regulate the relationship and a set of bright lines that will not be crossed.
- Without these steps, then healthcare-digital technology partnerships will not only fail to meet the goals of their contract – they will also erode the public value of, and the public trust in, institutions that are meant to serve the public good.

# Thank you!

Please contact me for references.

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