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### CHAPTER

## 26 Health and Digital Technology Partnerships: Too Close for Comfort?

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### Abstract

**Abstract:** Digital technology companies are seeking out partnerships with medical institutions at an astounding rate. Those involved tout these partnerships as empowering consumers, driving innovation, and increasing efficiency. At the same time, ethical red flags have gone up over potential violations of patient privacy and unsanctioned use of data for non-medical purposes. While contract transparency is a core ethical concern when personal health data is involved, a broader question is whether these contracts are different in kind than more established healthcare partnerships. Big data partnerships are relatively unique; these companies neither specialize in the healthcare industry nor provide healthcare institutions with an identifiable medical product. The ethical dimensions of these partnerships extend to broader questions about the appropriate role of digital technology corporations in an arena that, at least in theory, is oriented toward the physical, mental, and social well-being of everyone within our society.

**Keywords:** [big data](#), [conflicts of interest](#), [common good](#), [public interest](#), [institutional partnerships](#)

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## Introduction

In the past decade, digital technology companies have sought partnerships with academic medical institutions, governmental health agencies, and health-care companies at an astounding rate. Those involved tout these partnerships as empowering consumers, driving innovation, and increasing efficiency. At the same time, ethical red flags have been raised over potential violations of patient privacy and unsanctioned use of data for non-medical purposes (Mittelstadt and Floridi 2016; Vayena and Blasimme 2018). Most of these partnerships are designed to tackle the immense hurdle of making sense out of patients' medical data stored in electronic health records (EHRs), data which is protected by the Health Insurance Portability and Accountability Act (HIPAA) in the United States, the General Data Protection Regulation in the European Union (EU), and other privacy regulations elsewhere. While contract transparency is a core ethical concern when individuals' personal health data is involved, a broader question is whether these contracts are different from more established health-care partnerships.

Relationships between health-care providers and a range of companies, such as the pharmaceutical giant Pfizer, the medical technology creator Medtronic, and the electronic health-care software developer Athenahealth, are nothing new. Yet big data partnerships such as those entered into with Google, Amazon, Apple, and Microsoft are unique in that these companies neither specialize in the health-care industry nor provide health-care institutions with an identifiable medical product. In this chapter, I focus on the ethical issues that emerge when health-care institutions partner with digital technology companies to develop big data analytic tools for the health arena. The issues I address here are largely institutional, involving questions about the appropriate role of digital technology corporations in an arena that, at least in theory, is oriented towards the physical, mental, and social well-being of everyone within a society.

It is true that health care—digital technology partnerships come with undeniable, if at times overstated, benefits (Powles 2019). As marketing teams know all too well, these partnerships can generate new medical knowledge and can personalize clinical care. However, institutions have specific interests and missions. The health-care arena ostensibly targets health and well-being. Digital technology companies are not similarly oriented, even when they profess to aim at user wellness. This does not necessarily mean that they cannot improve the well-being of their users, just that they have private interests distinct from the common good, broadly conceived as the well-being of a community in terms of shared values and goals, a conception that includes health. These priorities can conflict with the goal of health-care institutions, which is—or ought to be—to improve the health of individual patients and the broader public. Other aims—financial solvency, technological progress, and so on—are means to that end. In short, there is a difference between the health-care industry using big data to improve medical practices and the digital technology industry using health data to improve algorithms. While the former tends to be oriented towards improving people's lives, the latter tends to be oriented towards improving proprietary tools.

This distinction between the goals of health care and the goal of digital technology are not insignificant. Yet while ethical analyses of big data often focus on the issues raised by the data science tools used to analyse and understand big data, such as machine learning algorithms, ethical issues are not limited to how technological tools are used but to who uses them and why. Different institutions in this landscape have different aims, and there may be good reasons for health-care institutions to avoid partnerships with digital technology corporations. Just as individuals have interests and allegiances due to their professions and their employers, so too do institutions. A corporation is answerable to shareholders in a way that a public health-care institution is not, and this difference is not inconsequential due to the way it shapes the institution's priorities. It is important to note that, due to differences in countries' approaches to public health-care systems, multinational digital technology companies' interactions with health-care institutions also varies, depending on the national context. This chapter focuses largely on Anglophone countries, within which the difference between the United States, where state and federal health care is relatively thin, and the United Kingdom, with a more substantial

social welfare programme, is stark. Due to this variation, some of the argumentation will be more relevant to the US context, while some will be a better fit for the United Kingdom.

In the second section, I describe how health-care institutions are partnering with digital technology companies to manage and utilize the big medical data in patients' EHRs. I observe in the third section that these partnerships do present opportunities, including—but not limited to—the production of new, knowledge-based analyses of EHR data and the capacity to use this new knowledge to better personalize patients' medical care. Yet they also pose ethical risks. In the fourth section, I explain that the nature of the institutions involved and their divergent missions—one set aimed at improving patients' health and well-being, another at perfecting and popularizing proprietary data analytic tools—lead to unique conflicts of interest. In the fifth section, I argue that these conflicts of interest can result in efficiency being prioritized over the common good, contributing to a feedback loop of injustice.

In the sixth section, I propose that mitigating these risks requires, as a first step, asking what these partnerships are for and whether they are truly necessary to meet health-care institutions' aims. If these partnerships are deemed necessary, then the second step is to be transparent with the public about the risks that these conflicts of interest pose. This includes creating a pathway for community interests to affect institutional decision-making, such as through a community advisory board. 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 health care–digital technology partnerships will not only fail to meet the goals of their contract but they will also erode the public value of, and the public trust in, institutions that are meant to facilitate health as part of the common good. The seventh section concludes.

## Health and digital technology partnerships

In 2017, the University of Chicago Medical Center (UCMC) and Google announced a new partnership. UCMC would share de-identified patient data with Google, and Google would investigate ways to put the data to use, identifying patterns to enable predictive analysis in medicine. By 2019, UCMC and Google were sued in a class-action lawsuit (later dismissed) alleging that the data had not been properly de-identified (Wakabayashi 2019; Landi 2020).

This is not a new position for Google. In 2016, a similar partnership between DeepMind Health and Britain's National Health Service (NHS) was alleged to compromise patient privacy. In autumn 2019, Google Health fully absorbed DeepMind Health and took over responsibility for all its contracts with the NHS, ending DeepMind's independent ethics panel and ceasing the policy of publishing its NHS contracts openly, raising concerns about legitimate oversight and transparency (Vaughn 2019).<sup>1</sup> In late 2019, Google announced a partnership with Ascension Health in the United States that would share patient data across twenty-one states (Davis 2019). They also acquired Fitbit, one of the most popular makers of fitness-tracking wearable devices (Wakabayashi and Satariano 2019).

Google is not alone in seeking such partnerships with medical institutions. In 2018, Amazon purchased the online pharmacy start-up PillPack, with plans to ship prescriptions to customers throughout the continental United States (Farr 2019). That same year, Apple enabled its health app to download patients' EHRs to view on an iPhone, described as a move that would 'empower consumers with convenient access to health information' (Muoio 2019). In 2019, the University of California, Los Angeles (UCLA) announced a partnership with Microsoft's cloud computing service, Azure, 'to synthesize vast amounts of clinical and research data to speed medical discoveries and improve patient care' (Microsoft News Center 2019). With the COVID-19 pandemic in 2020, companies like Google and Apple have partnered with governmental health agencies to track the spread between individuals.<sup>2</sup>

Digital technology companies such as Google, Amazon, Apple, and Microsoft are rapidly pursuing partnerships with academic medical institutions such as UCLA, governmental health agencies such as the NHS, and health-care companies such as Ascension Health. A 2019 report by the Chartis Group, an advisory firm based in the United States focused on the health-care industry, stated that by 2018, 84 per cent of Fortune 500 companies ‘play in healthcare’, an increase from 76 per cent in 2013. They also reported that in the first half of 2018, funding for health-care start-ups topped \$15 billion USD.

One of these start-ups is two-year-old Verana Health, which aims to ‘empower physicians and life science companies with deeper data insights to accelerate medical research and change lives’ (their homepage, Shieber 2020). The Chartis Group’s appraisal of these health-care industry developments is similarly rosy, suggesting that ‘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’ (The Chartis Group 2019). Indeed, a common refrain in announcements about partnerships between digital technology companies and medical institutions is that the partnership will develop better ways of managing and analysing patient information that lead to improvements in patient care. These developments will ‘empower’ both patients and providers. Less frequently stated is how these partnerships will benefit digital technology companies, as they surely will. In the United States, health care accounts for nearly 20 per cent of the gross domestic product (GDP).<sup>3</sup> For digital technology companies that have grown so big that antitrust efforts are frequently directed against them, health care remains one of the last areas in which these companies can target growth for their shareholders and expand their influence (Kang and McCabe 2020).

In these partnerships, the ethical issues include but also transcend privacy and the need to de-identify data; accordingly, this chapter focuses on the features of institutional partnerships that ground the use of big data tools in health care.<sup>4</sup> As digital technology companies continue to aggressively pursue novel relationships with the health sector, the different values of these two industries are salient, despite their emphasis on a shared dedication to health system improvement. While health care–digital technology partnerships may identify methods of generating meaningful outcomes from mountains of EHR data, for whom are they meaningful and for what purpose? Pursuing this question need not entail being a luddite about the possibilities of pairing medicine with technology. There are many ways in which these partnerships could be immensely helpful to patients and providers alike, as I explain in the next section. However, there will also be divergences of interests such that these partnerships pull health-care institutions, which should aim at the common good, in the direction of private interests. Given that neither health-care institutions nor the digital technology companies with which they partner have transparently acknowledged these divergences thus far, it is essential that those working in digital ethics do not lose sight of them.

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## Opportunities for benefit

Partnerships between health-care providers and digital technology companies are not necessarily opportunistic, solely for the sake of profit. Rather, these contracts reflect health-care institutions’ need for data analytic tools that can manage and make use of the medical data they collect. Given the vast amount of data that is locked away in EHRs, it would be irresponsible *not* to identify patterns in this data that enable health-care systems to run more smoothly in ways that lead to improvements in patient care.<sup>5</sup> The question is how to do so.<sup>6</sup>

Identifying patterns across innumerable patient charts is a herculean effort. The information in EHRs qualify as what is known as ‘Big Data’: data sets that meet the ‘three Vs’ of high volume (large amounts of data), high velocity (data acquired and analysed quickly), and high variability (data from different types of sources). The statistical methods common in clinical research are not suitable for such data sets because these methods are theory-driven and confirmatory. In the absence of any theories that can be tested with such large and ‘messy’

data sets, data-driven and exploratory methods using machine learning are more appropriate (Cobb et al. 2018). Machine learning algorithms can then be used as tools for the analysis of big data sets and the prediction of how a new data point will fit into the set. Health-care administrators may be able to more accurately and quickly identify trends in patient needs, allowing them to better allocate funds and resources in their institutions. Individual clinicians may be able to identify appropriate treatment for patients based on real-time analysis of symptoms and side effects of patients with similar profiles.

The first major opportunity in bringing digital technology companies' tools to bear on big medical data is the generation of new knowledge. Currently, we do not know the full range of patterns that might be identified by allowing machine learning to work through the data in patients' EHRs. Much of this information is unstructured. By using natural language processing, it may be possible to identify trends in the chaotic content of patients' charts that improve their care (Murdoch and Detsky 2013). There have already been some breakthroughs. Big data analytics have been used to analyse radiation images and to interpret genetic data (Ienca et al. 2018). For example, it may be possible to more accurately predict breast cancer survival based on genetic and molecular markers that are analysed via machine learning (Cobb et al. 2018). These are possibilities, not certainties, and scepticism about whether digital technology companies will actually be able to deliver on their promises is warranted (Emanuel and Wachter 2019).<sup>7</sup>

p. 513 The second major opportunity represented by health care–digital technology partnerships is the personalization of clinical care. The more clinicians can use individual patient data to locate a patient within a broader pattern of effective care, the better they can offer precise predictions and recommendations. Essentially, the more clinicians can relate patients' individual information to broader data sets, the better they can identify unique features of patients' situations that make a difference for their health. This second opportunity with health care–digital technology partnerships builds on the first—the more patterns that are identified within big medical data, the more individual patients can be located within those patterns.

One of the major proposals for personalizing care is also the most controversial. Researchers have suggested linking patients' medical data with their socio-demographic data—information about where they live, where they shop, their credit score, and so on. Just as biomarkers can be used to predict disease, so is there increasing interest in what are known as '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 (Bazemore et al. 2016; Hughes et al. 2016; Beck et al. 2017). Recent years have seen increasing interest in how patients' home location can affect their health, with studies linking US zip codes to life expectancies, not just extrapolating from the particular environment of that zip code but also based on information about who tends to live there.

Such research seeks to identify and, ideally, rectify health disparities based on social determinants of health by accounting for the effect of social, economic, occupational, and environmental factors (Bazemore et al. 2016, DeVoe 2016, Cantor 2018). Yet, this research is controversial because such linkages can also serve to reinforce disparities by contributing to explicit and implicit biases about patients based on where they live and other elements of their socio-demographic background. Further, the more information that is collected about individuals, the more that re-identification from large data sets becomes possible (Rocher et al. 2019). In other words, as with many aspects of big data research, the analytical tools developed can be used to help or to harm, and the boundary between the two is not always clear.

Nevertheless, for those whose glass is half full, big data analytics does offer one means of identifying health disparities. While some information about social determinants of health can be individually collected, not all health-care institutions have the capacity to manage it. Further, population-level data must be connected with individual charts to generate meaningful recommendations. Some have proposed linking community-level geocoded data with EHRs such that providers can identify whether a particular patient 'lives in the presence of poverty, healthy food and water sources, walkable streets and parks, and has social capital—or how these add



up to predict increased risk of morbidity, early mortality, or other adverse health outcomes' (Bazemore et al. 2016: 408). Setting aside the ethical concerns about privacy and the unintentional amplification of disparities noted above, such linkages could improve patient care by accounting for the effects of social determinants of health. As Kristin Voigt has argued, there may be costs to particular patients in not making some of this information available (Voigt 2019).

p. 514 Patients and providers are not the only ones who would be interested in this information; insurance companies and other gatekeepers have an interest in it as well. For example, Lysaght et al. describe how predictions of disease course and likelihood of re-hospitalization are simultaneously useful in the clinic and helpful for insurers. The more insurers know about the likelihood of particular patient's re-hospitalization, the more precisely they can calculate their risk profiles and adjust their premiums (Lysaght et al. 2019: 304). Thus, personalization of care is not always intended to benefit the patient—it can also be used to mitigate risk for insurance companies and others with financial interests in health-care systems. This is clearly a benefit for the insurance industry; whether it benefits the patient is another matter, which I will address in more detail below.

This section has shown that there are opportunities in partnerships between health-care institutions and digital technology companies to analyse and utilize the big data currently captured in the chaos of patients' EHRs. However, opportunities rarely come without costs. In the following sections, I detail two major, linked ethical concerns: (a) the influence of divergent institutional interests on decision-making; and (b) the prioritization of economic efficiency over other aims, such as health-care equity or justice.

## The perils of partnership: when interests diverge

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While the use of big data analytic tools in health care could generate new knowledge and personalize care, as well as potentially improve other dimensions of health-care systems, there is also a wide variety of ethical questions about these tools. Ethical concerns include privacy violations, explainability of AI algorithms and machine learning tools (see also Mittelstadt, this volume), incorporation of bias into supposedly objective algorithms, and so on (see Mishra et al., this volume). While these are all valid concerns, here, I do not consider ethical issues with big data tools themselves; rather, I address the kinds of institutional partnerships that are pursued to make them possible. Specifically, as I explain in this section, health care—digital technology partnerships open the door for conflicts of interest that diverge from those traditionally seen in medicine.

The traditional worry with conflicts of interest in medicine is that, if a provider is being paid by a pharmaceutical company, it incentivizes them to prescribe that company's product, even if it is not the best prescription for a given patient. These same conflicts are also a risk in industry-sponsored research, where a researcher may feel pressure to produce a result favourable to the sponsoring company's product. In one influential definition, a conflict of interest occurs whenever a professional's judgement with respect to a primary interest is influenced by a secondary interest, such as personal financial benefit (Marks 2019: 113). In the clinical case, the conflicting interests are the providers' self-interest due to their financial benefit from the pharmaceutical company and the patient's interest, the latter of which ought to be prioritized in fiduciary relationships in which a beneficiary entrusts something of value, such as their health, to a trustee who is thereby obligated to act in the beneficiary's interest with respect to the object of trust. In the case of the researcher, the conflict is between the researcher's self-interest and objective science; results are supposed to flow from the data and not from the researchers' allegiances or financial interests.

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Even well-intentioned clinicians are liable to lapses of judgement when financial conflicts exist. For instance, psychologist Dan Ariely has shown how 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 2008). In other words, the less

directly an action is tied to actually taking money for it, the more likely it is that an individual will justify doing something they ought not to do.

In the case of health care–digital technology partnerships, the conflicts are even less direct than in these traditional types of conflicts of interest—there is not any one product that a provider is being paid to peddle, and the relationship with the digital technology company is institutional, not individual. One way of thinking about these conflicts is as institutional conflicts of interest. David Resnik defines an institutional conflict of interest as ‘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). As with individual conflicts of interest, institutional conflicts of interest skew decision-making in the direction of an institution’s financial relationship with another organization, potentially leading it to compromise its mission.

The ethical worry with institutional conflicts of interests is not just the harm that biased decision-making may visit on patients and other fiduciary clients of the institution. There is also the risk that once mistakes are made public, trust in the institution will degrade, just as it would with an individual whose decision-making has been compromised (Resnik 2019: 1661). Institutional trust is key because of the mission of health-care institutions, providers, and researchers to pursue patient and public well-being—a mission that arguably exists whether that health-care institution exists in the capitalistic US context or in the social welfare context of the United Kingdom. An institution’s financial self-interest, or that of any one of the providers within it, can threaten that mandate. As with an individual conflict of interest, the core of an institutional conflict of interest is the introduction of an interest or a goal that competes with what ought to be the primary goal of the institution. Both individual patients and broader public groups trust health-care institutions to have their best interests in mind. Health-care institutions must be exceedingly careful that they do not betray the public trust by making decisions in pursuit of other interests.

p. 516 Partnerships with digital technology companies may introduce competing interests. In *The Perils of Partnership*, Jonathan Marks argues that public and private institutions have fundamentally different missions, purposes, and functions. While advocates of ↴ partnerships tend to emphasize the convergences between public and private interests, Marks highlights their divergences (Marks 2019: 4). He distinguishes between three concepts that can aid in thinking about the goals of institutions and how financial interests might distort them: the common good, the public good, and the public interest. The common good is the well-being of the community in terms of its shared values and goals. The public good is the good of the public understood as the space where individuals interact in social life, while not necessarily being members of a shared community. Finally, the public interest is the collection of private interests of individuals within a society.

Marks proposes that while corporations (such as Google or Apple) may contribute to the common good, they are not guardians of the common good and they do not aim at the common good. Rather, in pursuing their private commercial interests, they may incidentally also help the community due to intersections between their private interests and the common good (Marks 2019: 35). Yet, it does not follow that the company has the same interests as the community merely because it contributes to the common good. Private corporations, especially digital technology companies without local footprints, tend to not be members of local communities and thus do not participate in the common good. There are real divergences between the benefit they receive from the sale of private goods and the good of the communities to whom they sell those goods.

As with more traditional conflicts of interest, digital technology companies—especially Google, Apple, Amazon, and Microsoft, the first three of which are the subject of antitrust investigations in the United States and the EU—have private financial interests that can sway decision-making away from the well-being of their customers and thus away from both the common good and the public interest (Kang and McCabe 2020). These companies have no broader mandate to improve public health, even though they may profess to aim at it. The same cannot be said of health-care institutions, which do take the well-being of their patients and broader

communities—and thus the common good and the public interest—as their mission and mandate. This discrepancy between institutional goals can lead to potential conflicts in discrete decision-making, such as when it may be economically profitable to monetize patients' data or to use it to create more precise marketing profiles based on patients' health-care system usage. It can also slightly alter the priorities of institutions in non-discrete ways, such as when a health-care institution favours technologically advanced approaches to patient care that privilege some patient groups over others, reducing communities' equity of access.

p. 517 As Marks warns, emphasizing convergences of interests downplays the risks of divergences of interests and is a 'Panglossian' view such that these partnerships take place in the best of all possible worlds (Marks 2019: 71). This emphasis is readily apparent in the descriptions of health care—digital technology partnerships above, where there is an optimistic celebration of harnessing the computing power of technology to make new discoveries in health data in line with the long-standing tradition of Silicon Valley's techno-optimism, an outlook that is not universally shared in other cultural contexts. Marks's concern is that the more institutional leaders focus on the favourable side of ↴ partnerships between organizations with different mandates, the less they will be able to identify and manage the influence of the more powerful organization on the mandate of the weaker one. In health care—digital technology partnerships, it is not difficult to pick out the more powerful entity.

Due to the imbalance in power and resources between health-care institutions and digital technology companies, the core mission of the latter—developing better digital technology tools—can usurp the former's mission to serve their populations. This can be seen in digital technology companies' attempts to solve clinical problems by, in essence, throwing more data at the problem. Yet, as Chen and Asch observe, 'even a perfectly calibrated prediction model may not translate into better clinical care' (Chen and Asch 2017: 2507). In their estimation, there is immense predictive power in health care—digital technology partnerships—as long as these partnerships are pursued in the right way. The key is recognizing that big data analytic tools are useless without clinician insight (Chen and Asch 2017: 2508).

The skewed perspective of digital technology companies is not just apparent in the search for nails to fit their hammer; it can also be seen in the optimistic faith that digital technology will inevitably improve health care. In a popular *New Yorker* article entitled, 'Why Doctors Hate Their Computers', Atul Gawande explains how, as technology is integrated with medicine, individual clinicians form closer connections with their computers to navigate increasingly complex EHRs, leading to more distant connections with their patients (Gawande 2018). In Gawande's estimation, the human core of the physician–patient relationship was neglected in the move to EHRs. While many clinicians have now returned to taking notes by paper and pen during the clinical encounter to enable eye contact and other methods of interpersonal connection, doing so adds an additional step to each patient encounter, creating more work, not less. Had medical technologists recognized that the goal is the care and not the tool, such a predicament might have been avoided.

A central concern of health care—digital technology partnerships ought to be the management of conflicting missions and aims between these two very different types of institutions. Divergent interests ought to be monitored and tracked, especially when those divergences can decrease the health-care institution's ability to contribute to the common good or the public interest or can lead it to violate its obligations to fiduciaries. While institutional conflict-of-interest policies and disclosure of financial relationships may help by repairing trust through transparency (such as through the Physician Payments Sunshine Act in the United States, part of the Affordable Care Act), few health-care institutions publicly acknowledge—or describe attempts to mitigate—conflicts of interest in digital technology partnerships, and transparency itself is a complex notion in this context (see Mittelstadt, this volume). Marks's concern of a 'Panglossian' perspective seems apt. While a critical question for these partnerships moving forward is how institutions will manage their conflicts, a first step is acknowledging that such conflicts exist—something that so far, few health-care institutions partnering with major digital corporations have voluntarily done.



## Pursuing efficiency and amplifying injustice

A common refrain in the discussion on big data in health care is that current methods of recording data, such as in EHRs, are inefficient—clinicians spend immense amounts of time keeping them up to date without comparable benefit. Big data analytics are advocated as a means of increasing health-care system efficiency by extracting more benefit from EHRs, a benefit that, in an optimistic estimation, contributes not just to the bottom line but to patient care as well, although the two can come apart.

Efficiency is certainly a value for health-care systems facing excessive demand for their resources, but it need not be the only one or the most pressing. Currently, many health-care systems are inefficient—especially in the United States, more is spent per patient than necessary and significant resources are utilized on diagnosis and treatment rather than on preventive care (not to mention the use of excessive and unnecessary tests that drive profit but have no real effect on patient care) (Berwick and Hackbarth 2012; Fuchs 2018). Data technology partnerships may seem like an attractive way to pursue efficiency, identifying areas of waste that may only be visible using big data analytic tools. By isolating where resources are used unnecessarily, data analytics can help to trim budgets and allocate expenditures in ways that are responsive, in real time, to changes in patient and provider needs.

The concern with this focus on efficiency is not just that it reflects a private interest but that its pursuit can be at the expense of other goods, especially those that operate in the background of our human systems rather than ones we must intentionally incorporate. In Nick Bostrom's well-known example of the paper clip maximizer (Bostrom 2014), prioritizing the efficient production of paper clips leads the maximization machine to create paper clips out of everything, including human beings and, eventually, the whole world. This example is meant to show, among other things, that artificially intelligent systems only prioritize what they are designed to prioritize—human values that are not built into the system are excluded, and background conditions that we may take for granted could be unintentionally left out (e.g. we know that human beings ought not to be used as material for paper clips, but our technology does not know this unless we tell it so). In the context of health care—digital technology partnerships, while big data analytics can be a useful tool for streamlining and operationalizing patient health data, caution must be taken not to exclude values that humans know to consider but digital tools do not.

Take, for example, the personal anecdote Virginia Eubanks uses to begin *Automating Inequality* (2018). When Eubanks's partner was attacked soon after she began a new job (and thus new health insurance, which is tied to employment in the United States), her access suddenly changed—one pharmacy's system showed that she had no coverage and the hospital showed no start date for coverage. She suspected that her family had been red-flagged by an algorithm, which had identified her partner's ↴ large hospital costs directly after gaining new insurance as possible evidence of fraud (Eubanks 2018: 3). While she was able to correct these errors eventually through her employer's human resources department and her own (fortunate) free time, Eubanks explains that algorithmic systems designed to improve efficiency often target poor and otherwise marginalized communities, whose environments necessitate behaviour that may be judged risky: accessing public benefits, walking through highly policed neighbourhoods, requiring emergency health care, and crossing national borders. This behaviour leads these groups to be targeted by punitive public policy and more intense surveillance, 'a kind of collective red-flagging, a feedback loop of injustice' (Eubanks 2018: 7).

Arguably, justice is one of the background conditions that is easy (especially for those who enjoy relative privilege) to unintentionally omit from automated systems. Perhaps most commonly understood as models for the fair distribution of goods, many theories of justice consider health care to be one of many social goods that ought to be evenly distributed among all members of society (or distributed such that there is equality of access, or equity of opportunity, or some other way of assessing fair distribution). Without examining the

details of theories of justice just yet, suffice to say that there is broad agreement that health-care justice, conceived as equal access, is important, even though there is specific disagreement about how to achieve it.

In describing injustice as a feedback loop of inequality of access to resources and care faced by individuals who are already marginalized in a given society, Eubanks's use of injustice trades on a conception of justice as structural. The concept of structural injustice is explicated by Iris Marion Young in *Justice and the Politics of Difference* and *Responsibility for Justice*. In the former, Young proposes that a just society is one which contains and supports the institutional conditions necessary for the realization of the general requirements for the good life, which are self-development and self-determination (Young 1990: 37). Injustice, in a structural view, refers not to any one unjust decision one person may make or any single material good being unfairly distributed but to patterns of decision-making, labour distribution, and cultural practices that further entrench domination, which is the institutional constraint on self-determination, and oppression, which is the institutional constraint on self-development (Young 1990: 37). Societies exhibit structures of domination when they limit individuals' abilities to develop their capacities (such as through education and training), and they exhibit structures of oppression when they limit individuals' abilities to make particular choices and to shape the environment in which their choices are made (such as through voting).

p. 520 As in Eubanks's 'feedback loop of injustice', no one person is responsible for structural injustice. The term refers to the way that we set up institutions. In her later book, Young proposes that structural injustice is perpetuated by individuals acting within institutional and social rules and practices that are superficially morally unproblematic but which, nevertheless, have problematic downstream effects for others, such as seeking affordable housing in ways that lead to gentrification or selecting private schools for one's children such that local public schools lose funding (Young 2011: 95).<sup>4</sup> Due to these structural social arrangements about who can make which choices and how they are made, some positions are more socially vulnerable than others in that their choices are constrained. Others who have maximal choice inadvertently reproduce this arrangement. Young posits that, especially in affluent societies, this leads to social injustice because affluent societies ought to have the resources to support just social arrangements (Young 2011: 45).

Young uses housing insecurity as an exemplar of structural injustice; her argument equally applies to health care. In the United States, an affluent society, many people experience health-care insecurity. Until the passage of the Affordable Care Act, health insurance was tied either to one's family or to one's employer. Losing a job also meant losing insurance coverage, and even with full employment, insurance companies often change each time one takes up a new position. This is not just an inefficient system but it is also arguably an unjust one, whether justice is understood as the distribution of goods within a society (of which health care is one) or the capacity of all within a society for self-determination and self-development.

Once automated systems get started, the logic of their design can seem inevitable (as with Bostrom's paperclip maximizer), even though careful design is capable of predicting and thus forestalling undesirable results. Arguments utilizing the concept of structural injustice highlight that injustice is not inevitable if the values built into systems are questioned early. If justice is not intentionally incorporated, then the system will continue to replicate inequitable outcomes for the marginalized.<sup>8</sup> As in her negative experience with her insurance company after switching employers, Eubanks argues that the use of automated systems for eligibility for benefits like health insurance and the use of predictive analytics to determine which patients will incur the highest costs do not 'remove bias, they launder it' in a 'high-tech sleight of hand' (Eubanks 2018: 224). They do this by prioritizing values of efficiency, cost-cutting, and rule-following, while downgrading others, such as dignity, trust, and equity for all within a society. While it is easy to see how this could occur in the US context, it is perhaps less likely in a nationalized health-care system, yet still possible. The motivation to decrease costs exists in both private and public systems, although it may be stronger in the former than the latter.

In a helpful amplification of these points, Ruha Benjamin describes the replication of injustice in digital technology through her conception of the New Jim Code, which she describes as the inequitable results of a

focus on maximizing profits and cutting costs in an attempt to engineer the most economically efficient system (Benjamin 2019: 30). In effect, the removal of human discretion and contextual analysis from automated systems, even if based in a desire to reduce bias and discrimination, removes human values altogether in an attempt to make the most paperclips. Lost is careful consideration, in Eubanks's words, of 'who we are and who we want to be' (Eubanks 2018: 12). In the place of this critical reflection is an engineering value: efficiency.

p. 521 In her work, Benjamin explores how economic drivers in digital technology can have deleterious effects on social justice, exacerbating the patterns of domination and oppression theorized by Young. Benjamin conceives of injustice in digital technology as ↪ a result of design choices that come to seem natural, inevitable, and automatic; as with Young's definition of structural injustice, harm is systemic and does not result from any one agent's choices (Benjamin 2019: 44–45). Eubanks makes the same point, describing these design choices and decisions made 'in neutral' by ignoring perfectly predictable consequences of unequal systems (Eubanks 2018: 223). Benjamin is even more suspicious than Eubanks and justifiably so—she writes that even well-intentioned attempts to design automated systems with 'health' or 'safety' in mind may assume that these values are best pursued through customization and individualization, techniques that can negatively affect communities even as particular individuals flourish independently (Benjamin 2019: 151).

These harms include the difficulty of those in poverty navigating the health-care system (because it is even harder to access a human being to whom one can describe the situation, and when one does finally reach such an individual, they are unlikely to possess the expertise to determine where the algorithm went wrong), increased surveillance of those in poverty in contrast to those who have the financial stability to not interact with social welfare programmes, and increased targeting of individuals labelled 'super-utilizers' to decrease health-care systems' monetary debt (Benjamin 2019: 156). These systems do nothing to ameliorate the conditions leading to community-level poverty in the first place. While their targeting of individuals in poverty might seem to reflect values of 'inclusion' and 'diversity', they do so at the expense of these individuals' capacities for self-determination and self-development and thus would be classified by Young as conditions of domination and oppression. As Benjamin writes, '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'—they displace more foundational change (Benjamin 2019: 156–157).

The ideal of efficiency, when pursued in systems engineering, can have inequitable, deleterious effects in the real world. The resulting harms are not due to any one individual's transgression, nor do they map directly onto designers' nefarious intentions. Rather, they are the result of a contraction of designers' perspectives and values from social and community values to engineering and economic values. While health care—digital technology partnerships need not necessarily contribute to injustice by prioritizing efficiency and other economic ends, they are more likely to do so when their private interests coincide with these ends. As Young writes in *Responsibility for Injustice*, conditions of structural injustice can be tackled by realigning the interests of system designers with promoting justice (Young 2011: 146). In the next section, I consider how this realignment of interests in health care—digital partnerships might occur.

## Managing interests in big medical data

p. 522 In the preceding sections, I have described the kinds of opportunities that lead health-care institutions to enter into partnerships with digital technology companies. While ↪ these opportunities may benefit patients, in the fourth section I described how they also occasion unique conflicts of interest. In the fifth section, I expanded on these conflicts of interest, explaining how a focus on efficiency or profit could contribute, even if indirectly, to health-care injustice. In this section, I describe how health-care institutions and digital technology companies might work to manage these conflicts of interest with the goal of refraining from further contributing to health-care injustice.

As I argued in the fourth section, one of the main sources of conflicts of interest in these types of partnerships is different institutional missions. These conflicts are avoided if partnerships with institutions with different missions are never entered into at all. As Marks writes, improving health care involves identifying challenges to good health care and developing methods for addressing those challenges without entering into partnerships with industry (Marks 2019: 125). This is not to say that industry is categorically incapable of benefitting communities, just that it is wise to keep separate institutions whose missions are dictated by conflicting interests. The goal should be to ensure that the interests of the institution coincide with its mission, which for most health-care institutions is to ensure the well-being of the population it serves. It makes sense to keep the development of big data analytic tools that affect our health and well-being within the institutions dedicated to protecting these goods.

One of the first means of preventing conflicts of interest with health care—digital technology partnerships is to build capabilities within medical institutions to analyse their own data or to support non-corporate organizations in doing so. In fact, EHR data analysis can occur within health-care institutions and does not require partnership with digital technology corporations. In the United States, the Centers for Medicare and Medicaid Services Hospital Inpatient Quality Reporting Program uses big data analytics, as does the Patient Centered Outcome Research Institute and the Food and Drug Administration’s Sentinel System (Price and Cohen 2019). Likewise, in the United Kingdom, Health Data Research UK is a hub for big data analytics in health care. Machine learning algorithms can be used by academic medical centres to create new clinical tools, as with an AI algorithm developed by researchers at Mount Sinai in New York to detect age-related macular degeneration (Mount Sinai 2020).

In addition, if partnerships are necessary to develop technological tools with good outcomes, then health-care institutions should be transparent with those they serve about the realities of the relationship. This means accurately portraying the risks of the relationship to the community, including the private interest that the digital technology company will inevitably retain in perfecting and promoting the proprietary data analytic tools it develops. The more these partnerships are described in prevalently positive terms, the more sceptical administrators and the public ought to be about the real aims of the contract. Transparency is arguably a key to trust; it is important for institutions to acknowledge that they are fallible and that they could become compromised by relationships they enter into with corporations whose mission is not health and well-being.

p. 523 A corollary to this is that health-care institutions that enter into partnerships with digital technology companies ought to develop methods of incorporating community interests into decision-making procedures so as to ensure that the common good is taken at least as seriously in these decisions as companies’ private interests. Community engagement takes many forms, but it can involve the creation of a community advisory board, recruitment of community members onto big data and digital technology task forces, canvassing of community opinions on the use of digital technologies in health care, and so on.

Further, health-care institutions ought to identify general norms they will follow in these partnerships, as well as bright lines they will not cross. Marks, Benjamin, and Eubanks all provide starting points that institutions can work from. Marks outlines a set of norms for public–private interactions, including independence (reducing the influence of private interests), integrity (avoiding relationships with institutions that do not share the same mission), credibility (being transparent about relationships), stewardship (protecting vulnerable parties), public good (promoting the good of everyone in a society, not just private interests), and anti-promotion (reducing private interests that counter the public interest) (Marks 2019: 113).

Moreover, 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 include 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.

Finally, 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; and remember that technologies are designed for human beings, not data points, probabilities, or patterns (Eubanks 2018: 212).

Marks, Benjamin, and Eubanks all express concern about the risks inherent in the kinds of public–private partnerships that are currently being pursued to manage big medical data. They do not think these partnerships are necessarily bad but that private interests in technological development have a tendency to usurp broader social goods. Preventing this usurpation requires being attendant to this risk but also taking proactive steps to curtail it. Of course, whether these steps will have any effect on the broader space of digital technology partnerships is an open question; following these steps alone cannot be the answer to ethical use of digital technology in health care.

## Conclusion

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Health-care institutions are increasingly partnering with digital technology companies to sort through patients’ medical data, with the goal of developing new knowledge and personalizing patients’ care. These are worthwhile aims, but it is important to ask whose values are guiding the design process of the automated and algorithmic systems that will monitor and analyse the data and how these values will impact the systems’ outcomes. While private companies are not incapable of improving the common good of communities, and indeed often must do so in order to remain solvent, the allegiance of private industry interests with efficiency, cost-cutting, and profit maximization can contrast with the allegiance of health-care institutions to advancing the health and well-being of the communities they serve.

Especially in the context of digital systems that shape health-care institutions’ decisions, caution about whose interests guide system development is essential. Even well-meaning attempts to use technology to improve community health can inadvertently contribute to structural injustice by dictating the options that are available to community members and how they must be selected, thus decreasing individuals’ capacities for self-development and self-determination. The first step in digital technology design for health care ought to be reflection on the following questions: what challenge should we prioritize, and who judges this to be the priority? What are their interests, and what is their role in the community and their relationship to the common good? Health-care institutions should align their design priorities with the interests of those in the community whose care they are responsible for and not with the interests of those developers of digital technologies whose priorities lie elsewhere.

## Notes

1. Google’s partnership with London’s Royal Free Hospital was found by the Information Commissioner’s Office to violate the UK’s Data Protection Act in 2017 (Hern 2017).
2. Google made the news in 2008 for tracking the spread of the flu based on online searches for flu symptoms and treatment on its platform. Named, ‘Google Flu Trends’, the tracker later failed in part due to Google’s unwillingness to work with public health agencies in perfecting their analysis (Lazer and Kennedy 2015). Most recently, Britain’s NHS has been criticized for partnering with Palantir (BBC News 2021).
3. It was 17.7 per cent in 2019; see <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsHistorical>, accessed 25 April 2022.



4. This is not to say that privacy is unimportant—it is. Rather, it is to say that the ethical issues with health care–digital technology partnerships are not limited to privacy concerns.
5. Of course, it is possible that big data will improve health-care operations' efficiency in ways that do not facilitate patient care but that do increase profit. In this section, I am focusing on the improvements that do in fact improve patient care, while recognizing that efficiency and patient care do not always cohere.
6. Murdoch and Detsky in 'The Inevitable Application of Big Data to Health Care' describe four ways that big data may advance the economic mission of health care delivery by improving quality and efficiency: (1) by greatly expanding the capacity to generate new knowledge; (2) by helping with knowledge dissemination; (3) by translating personalized medicine initiatives into clinical practice; (4) by delivering information directly to patients. ↪ In this summary, I abstract from their points 1 and 3. Point 2 refers to using natural language processing to analyse clinical trial reports and scientific papers to help individual physicians stay up to date on trends. Point 4 refers to developing apps to allow patients to download EHRs onto personal devices to make them more accessible. As these points do not relate directly to the focus of this chapter on big data partnerships in health care, I do not examine them in detail here (Murdoch and Detsky 2013).
7. For instance, a 2019 review of deep learning algorithms diagnostic performance compared with health-care professionals found no meaningful difference between the two (Liu et al. 2019).
8. This is not just a matter of algorithms relying on data sets reflecting unjust and unequal societies, although this is also a concern (Zimmerman et al. 2020).

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