A Panacea or a Problem? Electronic Health Records and the Complicated Politics of Its Stakeholder Network

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TABLE OF CONTENTS

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INTRODUCTION:

In her book *Healthcare and Big Data: Digital Specters and Phantom Objects,* Mary Ebeling recounts an experience that launched her research into how personal health information is collected, repurposed, and sold to various markets in a data-centric world. Ebeling, who had just suffered a miscarriage, describes the proceedings of her phone conversation:

> "Hello?"
>
> "Congratulations on your pregnancy! I'm Marla from Allaboutthebaby.com and I want to talk to you today about some of the products and services that we can offer you as a…"
>
> "I'm not pregnant." I cut off Marla's chirpy little spiel mid-sentence. The tears began to well up in my eyes.
>
> "Uh, but the computer says you are."
>
> Caught off guard, Marla was momentarily less chirpy. She sounded perturbed, not with the fact that she had just caused a stranger anguish, but with the "they" that maintains the database… "They need to update this."[1]

In a few crucial ways, this small conversation illustrates the underbelly of data exchange within the American healthcare landscape. First, most of the data exchange occurred behind the scenes—unbeknownst to Mary. At some point, Mary's pregnancy was recorded. Then, whether that data was never de-identified or was made anonymous and then reidentified, Allaboutthebaby.com received this information. How did it get from A to B?

Next, Marla's comment: "Uh, but the computer says you are." Her statement reflects a trend in which decisions and processes are increasingly carried out based on the digitized version of a patient instead of the real-life experiences of the physical patient. Marla's initial reaction

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[1] Mary F. E. Ebeling, *Healthcare and Big Data: Digital Specters and Phantom Objects* (New York: Palgrave Macmillan, 2016), 4.

indicates surprise that Mary’s current condition does not match the display of her digital profile, not the opposite. While this may seem like a subtle distinction, it carries far-reaching effects.

Finally, upon realizing the glitch, Marla expresses frustration with the technology and exclaims, “They need to update this.” Her comment represents the typical response toward technical dysfunction throughout the greater healthcare landscape: improve the data; improve the technology. However, a deeper analysis of the political and social factors of health data exchange is necessary to investigate the more intrinsic issue lying below. In this case, the demands of the stakeholders involved in health information data and technology are often discordant. Applying various concepts and methodologies from the field of Science, Technology, and Society, my thesis aims to disentangle the complicated, vague, and often conflicting aspects of health data exchange in the United States (US). Through the lens of the electronic health record (EHR)—one of the most ubiquitous and controversial digital health technologies—I consider what purposes health information serve, for whom, and why problems with health data exchange are frequently translated from political into technological terms.

What is an Electronic Health Record?

According to the Office of the National Coordinator of Health Technology (ONC)—the top regulatory body of health information technology (HIT) in the US—an EHR is foremost “a digital version of a patient’s paper chart.”[2] The simplicity of this definition is surprising and, in many ways, contradictory, considering the primary intention behind the development and expansion of EHR was to provide a recordkeeping system that goes *beyond* the utility of a simple paper record.

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[2] “What Is an Electronic Health Record (EHR)?,” HealthIT.gov, accessed November 7, 2021, https://www.healthit.gov/faq/what-electronic-health-record-ehr.

The vision for EHR to expand past the traditional scope of written records that were historically completed and stored within one healthcare organization (HCO) is evident by comparing EHR to electronic medical records (EMR). In the literature, computerized patient records are often referred to as EHR and EMR interchangeably. However, ONC devotes an entire page of its website to qualifying the difference between the two. In many ways, the electronic *medical* record serves to digitally replicate the paper version of a patient's chart. Its primary function is to encode a patient's medical history, supplying providers with a longitudinal record of important notes and services, including visits, diagnoses, vaccinations, and so on. All the documented services occur and remain within the confines of the HCO responsible for the EMR. Thus, EMR intends to aid in the organization of local processes for stakeholders involved in the immediate realities of patient care—physicians, nurses, hospital administrators, and the payers of healthcare, such as insurance companies.

On the other hand, EHR is supposed to "do all these things—and more."[3] More specifically, the goal of EHR is to expand beyond the information-collecting HCO to create a comprehensive record of health services acquired by an individual, with data collected from, shared across, and consulted by all physicians, nurses, and providers responsible for that patient's care. According to this definition, EHR—as opposed to EMR or paper records—is bound to the concept of interoperability: the capacity of digital systems "to access, exchange, integrate and cooperatively use data in a coordinated manner, within and across organizational, regional, and national boundaries."[4] The shift to interoperable technology and data resulted in the expansion of EHR's utility to functions outside the immediate factors of managing a patient's health and

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[3] Peter Garrett and Joshua Seidman, "EMR vs EHR – What Is the Difference?," Health IT Buzz, January 4, 2011, https://www.healthit.gov/buzz-blog/electronic-health-and-medical-records/emr-vs-ehr-difference.
[4] "Interoperability in Healthcare," HIMSS, August 4, 2020, https://www.himss.org/resources/interoperability-healthcare.

medical care. The process of making EHR information shareable requires the contribution of data specialists and the collaboration of various HCOs, EHR product manufacturers, insurance companies, and so on.

Furthermore, the aggregation of patient data allows the US Government and other researchers to gather longitudinal and population-level information to instruct public health, clinical outcomes, and health equity policy. Pharmaceutical and biotechnology companies can also purchase this information to inform drug therapies and medical device development. Although EHR has made headway in many of these initiatives, its success has been limited, and many problems remain concerning the quality of the data. If EHR is meant to kill multiple birds with one stone, it has turned out to be a crude weapon.

The History of EHR:

EMR and its associated goal of digitizing paper records for increased optimization are older. The first electronic records in the 1960s and 1970s were independently developed in collaboration between specific academic medical institutions and industry partners to fit the needs of each independent organization. These early products—known at the time as "clinical information systems"—included the Lockheed Corporation's clinical information system, the University of Utah's Health Evaluation through Logical Processing, and the Computer Stored Ambulatory Records (COSTAR), a collaborative project between Massachusetts General Hospital and Harvard University.[5] These were recordkeeping systems meant to improve the institution's performance, not to share data across organizations. Thus, they lacked the comprehensive health and interoperability features associated with the modern EHR. Although more simplistic, these pioneering systems had notable accomplishments. For instance, Lockheed

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[5] Jim Atherton, "Development of the Electronic Health Record," *AMA Journal of Ethics* 13, no. 3 (2011): 187.

Corporation's clinical information system provided quick response times of less than a second and could flexibly support the needs of multiple users simultaneously.[6] Additionally, the design elements of COSTAR filtered out extraneous information to boost efficiency and incorporated a flexible vocabulary, which allowed the system to recognize various terminology applied by different users for the same condition or event.[7] These initiatives were primarily undertaken to reduce medical errors and increase organizational efficiency.

Still, the early clinical information systems from the 1960s and 1970s had significant shortcomings. Giebink and Hurst (1975) wrote, "Medical computer applications which meet the operational criteria are rare except for routine business applications…Other than in developmental projects, computerized medical records are abstracts of more complete records maintained in hard copy form."[8] That said, the original technology informs many of the EHR systems that dominate today's market.

Currently, hundreds of vendors offer EHR products, but only a fraction of these vendors control the majority of the market. According to a 2021 report by KLAS Research on the US EHR market, the top five vendors include Epic (31%), Cerner (25%), MEDITECH (16%), CPSI (9%), and Allscripts (5%).[9] In total, these five vendors account for 86% of the US market share.

Many of the most prominent vendors have a lineage to the earliest clinical information systems. Allscripts can be traced back to the Lockheed Corporation's clinical information system, and Epic is based on MUMPS (Massachusetts General Hospital Utility Multi-Programing System) software—the same programming language that was used to develop

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[6] Institute of Medicine (US) Committee on Improving the Patient Record, *The Computer-Based Patient Record: Revised Edition: An Essential Technology for Health Care*, ed. Richard S. Dick, Elaine B. Steen, and Don E. Detmer (Washington (DC): National Academies Press (US), 1997), 111.

[7] Atherton, "Development of the Electronic Health Record," 187.

[8] Institute of Medicine (US) Committee on Improving the Patient Record, *The Computer-Based Patient Record*, 112.

[9] "US Hospital Market Share 2021: EMR Purchasing Continued Despite Covid-19," Performance Report (KLAS Research, May 2021).

COSTAR.[10] The reach of these vendors, particularly Epic, is extraordinary: as of 2017, 94% of hospitals use EHR to manage clinical health data, and over half the US population has at least partial health information stored in an Epic EHR.[11]

However, the rise of EHR from a handful of individual projects to an industry-standard did not happen organically. It required the involvement of the US Government in the early 2000s. By this point, the technology had improved since the early clinical information systems from the 1960s and 1970s. In the 1980s, for instance, the Department of Veteran Affairs successfully implemented the Decentralized Hospital Computer Program—later known as VistA—which allowed data sharing across more than 170 medical centers.[12] By the late 1990s, prominent healthcare experts like the National Academy of Medicine released official policy suggestions which advocated for the use of "computer-based patient records" and outlined their value, current challenges, and possible paths forward for greater implementation.[13] These publications emphasized the potential of computerized health records to reduce medical errors and costs, improve clinical care, and allow data exchange across different institutions. In other words, the technology was adequate, and the cited benefits and challenges mirrored those currently reported. Still, until the late 2000s, the number of HCOs utilizing EHR remained under 10%.[14]

Everett Roger's theory on the diffusion of innovations—which attempts to explain the mechanisms behind adoption rates of new ideas and technologies—provides a framework for

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[10] Ross Koppel and Christoph U Lehmann, "Implications of an Emerging EHR Monoculture for Hospitals and Healthcare Systems," *Journal of the American Medical Informatics Association* 22, no. 2 (March 1, 2015): 465.

[11] Ibid.

[12] Institute of Medicine (US) Committee on Improving the Patient Record, *The Computer-Based Patient Record*, 120.

[13] Institute of Medicine (US) Committee on Quality of Health Care in America, *To Err Is Human: Building a Safer Health System*, ed. Linda T. Kohn, Janet M. Corrigan, and Molla S. Donaldson (Washington (DC): National Academies Press (US), 2000).

[14] JaWanna Henry et al., "Adoption of Electronic Health Record Systems among U.S. Non-Federal Acute Care Hospitals: 2008-2015," *ONC Data Brief No. 35,* May 2016.

describing the low utilization of EHR before government involvement. Roger's theory emphasizes five attributes of innovations that are critical to that innovation's rate of adoption:

1. *Relative Advantage* – The degree to which potential adopters perceive the benefits of the innovation as better than the status quo.
2. *Trialability* – the degree to which the innovation can be tested and implemented in increments.
3. *Complexity* – the degree to which the innovation is perceived as difficult to adopt and use.
4. *Compatibility* – the degree to which the innovation is perceived as consistent with the existing culture and values of potential adopters.
5. *Observability* – the degree to which the innovation is visible to others.[15]

Relative advantage, compatibility, trialability, and observability are positively related to quick adoption rates, while complexity is negatively correlated.

From Roger's diffusion of innovations perspective, EHR had few attributes conducive to quick adoption rates before government involvement. Notably, there was a low relative advantage for physicians and HCOs to adopt EHR. While most of the benefits of EHR implementation helped the buyers of healthcare, like insurance companies, it was the HCO and providers' responsibility to pay for the systems.[16] The start-up expenses for EHR typically cost $40,000 per physician and could total close to $10 million for an average-sized hospital.[17] In 2002, two-thirds of US hospitals were losing money, and implementing an EHR system required an astronomical investment in financial resources and organizational culture. HCOs not only had

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[15] Everett M. Rogers, *Diffusion of Innovations*, 4th edition (New York: Free Press, 1995), 25

[16] Donald W. Simborg, "Promoting Electronic Health Record Adoption. Is It the Correct Focus?," *Journal of the American Medical Informatics Association : JAMIA* 15, no. 2 (2008): 127.

[17] David Blumenthal, "The Federal Role in Promoting Health Information Technology," *The Commonwealth Fund,* January 1, 2009.

to purchase the initial technology, but they also needed to train and support their staff on how to adapt to it.[18]

Additionally, EHR implementation offered little trialability. Adopting a new EHR system typically requires a contractual commitment between the HCO and EHR vendor. With such steep costs, these commitments were often risky, and many providers worried about the ramifications of accidentally choosing an outdated or cumbersome system. For most HCOs, the overall risk was too high to surmount the potential benefits.

The complexity of EHR was also disadvantageous to its spread. It is extraordinarily challenging to inscribe clinically-relevant information into data structures within its physical technology. Furthermore, there is a steep learning curve for navigating the technology, and a lack of proper training can result in devastating errors. The complexity of EHR reduced its compatibility as well. The reluctance from providers to adopt EHR stemmed, in part, from concerns that the technology would upset workflow and limit time with patients—significantly disrupting the norms of their practice.[19]

Lastly, observability of the benefits of EHR implementation was complicated for most HCOs. As stated, the number of HCOs using EHR remained below 10% in the early 2000s, and one-third of these were either veterans or military hospitals.[20] While the Department of Veteran Affairs was lauded for its success in implementing productive, interoperable EHR systems, the resources and organizational structure of these institutions were incomparable to the majority of US HCOs.

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[18] Joan S. Ash and David W. Bates, “Factors and Forces Affecting EHR System Adoption: Report of a 2004 ACMI Discussion,” *Journal of the American Medical Informatics Association: JAMIA* 12, no. 1 (2005): 9.

[19] Simborg, “Promoting Electronic Health Record Adoption,” 127.

[20] Joan S. Ash and David W. Bates, “Factors and Forces Affecting EHR System Adoption: Report of a 2004 ACMI Discussion,” *Journal of the American Medical Informatics Association: JAMIA* 12, no. 1 (February 2005): 8.

Most providers in the 1990s and early 2000s agreed in principle with the potential utility of EHR. In a 2002 survey of US hospitals, for instance, 74% of respondents stated they were interested in implementing some form of EHR within the next five years.[21] However, the negative attributes intrinsic to EHR systems (expensive and highly complex) reduced their immediate feasibility and usefulness when most HCOs did not have the capital or resources to commit to investing in EHR. As a result, HCOs required the involvement of the US Government to overcome these constraints.

Facing pressure to improve healthcare in the US and compete with the HIT of other developed nations, President George W. Bush marked the turning point in government involvement in his 2004 State of the Union Address, during which he stated, "By computerizing health records, we can avoid dangerous medical mistakes, reduce costs and improve care."[22] However, it was not until the passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act, as part of the Recovery Act of 2009, that most HCOs adopted EHR. The Act aimed to boost the economy by investing in technology for health information use and exchange—mainly through EHR systems—while improving the nationwide HIT infrastructure. The ONC was charged with overseeing these aims. Since the passage of the HITECH Act, the US Government has spent over $30 billion to incentivize the implementation of EHR systems by elevating their relative advantage.[23] In terms of boosting adoption rates, this investment paid off: in less than ten years, the number of hospitals using EHR increased to 94%, cementing the dominance of a few well-positioned EHR vendors.[24]

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[21] Ash and Bates, "Factors and Forces Affecting EHR System Adoption," 8.

[22] George W. Bush, "Text of President Bush's 2004 State of the Union Address," (speech, Washington DC, January 20, 2004), *The Washington Post,* www.washingtonpost.com/wp-srv/politics/transcripts/bushtext_012004.html.

[23] Julia Adler-Milstein and Ashish K. Jha, "HITECH Act Drove Large Gains In Hospital Electronic Health Record Adoption," *Health Affairs* 36, no. 8 (August 2017): 1417.

[24] Sonal Parasrampuria and Jawanna Henry, "Hospitals' Use of Electronic Health Records Data, 2015-2017," ONC Data Brief (The Office of the National Coordinator for Health Information Technology, 2019).

Since its founding, initiatives at the ONC have mirrored trends in the greater medical and public health landscape—mainly regarding the prioritization of an individual's "whole health." Recognizing that patient care expands past the scope of one HCO, the aid provided to HCOs for adopting EHR systems required these organizations to also comply with the standards of "Meaningful Use." These standards include improving care cooperation and public health. Thus, by the late 2000s, interoperability became central to the policy of the ONC. A new emphasis focused on the entire network of stakeholders involved in EHR data use instead of the immediate patient/physician interaction and local interventions within one HCO. On their website, the ONC quotes the Healthcare Information and Management Systems Society, explaining, "the EHR represents the ability to easily share medical information among stakeholders and to have a patient's information follow him or her through various modalities of care engaged by that individual."[25] This statement contains two important caveats: in practice, the sharing of EHR data is not "easy," and the exchange of a patient's health information continues past the path of the patient. Nevertheless, understanding the full extent of this stakeholder network is crucial to unpacking the politics of EHR data exchange and the particular role the technology plays in negotiating stakeholder relationships.

Networks, Boundary Objects, and Sociotechnical Imaginaries:

The stakeholder network involved in collecting and using EHR data is extensive and diffuse, including—but not limited to—patients, physicians, EHR vendors, insurance companies, pharmaceutical companies, and researchers. Each party has varied and often conflicting interests, yet some level of cohesion is necessary to avoid complete system dysfunction. A common myth—particularly regarding science—emphasizes the notion of consensus-building to foster

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[25] Garrett and Seidman, "EMR vs EHR – What Is the Difference?"

cooperation, but this is rarely seen in practice. Theories emerging from Actor-Network Theory (ANT), such as translation, are helpful for understanding cohesion that does not arise from true consensus. ANT asserts that the social and natural world exists in a constantly shifting network of relationships in which all entities—including objects, ideas, and processes—are relevant to the construction of the network. Translation, developed by Michel Callon and Bruno Latour, refers to the process of actors negotiating their relationships with other social worlds by recruiting "allies" to establish authority for their own goals.[26]

Star and Griesemer (1989) push back against Callon and Latour's understanding of translation in that it "functionally presupposes the primacy of one viewpoint."[27] Instead, Star and Griesemer (1989) advocate for the application of an ecological approach in which "the unit of analysis is the whole enterprise."[28] Accordingly, "a many-to-many mapping, where several obligatory points of passage are negotiated with several kinds of allies" is necessary to completely and accurately account for the cohesion of a network.[29]

Within this ecological approach to networks, Star and Griesemer (1989) develop the concepts of methods standardization and boundary objects. Methods standardization "makes information compatible and allows for a longer 'reach' across divergent worlds."[30] Boundary objects are defined as "objects both plastic enough to adapt to local needs…yet robust enough to maintain a common identity across sites."[31] When multiple boundary objects "scale up," they form a "boundary infrastructure" that is maintained by standards.[32] In this context, a single EHR

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[26] Michel Callon, "Some Elements of a Sociology of Translation: Domestication of the Scallops and the Fishermen of St Brieuc Bay," *The Sociological Review* 32, no. S1 (1984).

[27] Susan Leigh Star and James R. Griesemer, "Institutional Ecology, `Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39," *Social Studies of Science* 19, no. 3 (1989): 389.

[28] Ibid.

[29] Star and Griesemer, "Institutional Ecology, 'Translations' and Boundary Objects," 390.

[30] Star and Griesemer, "Institutional Ecology, 'Translations' and Boundary Objects," 407.

[31] Star and Griesemer, "Institutional Ecology, 'Translations' and Boundary Objects," 393.

[32] Ibid.

can be considered a boundary object, while the system of EHR exchange is a boundary infrastructure.

The idealized view of EHR paints the technology as the perfect boundary infrastructure. By standardizing and aggregating patient information through clinical codes and regulated processes—and rendering the data interoperable—various stakeholders can apply the information to fit their particular needs. The optimistic conception of EHR as a perfect boundary infrastructure serves as a compelling *boundary concept*. This term, developed by Löwy (1992), refers to "the existence of loose, 'boundary' concepts" that make "the development of common 'federative' research strategies" possible.[33] In an analysis of patient care pathways, Allen (2009) suggests:

> The popularity of pathway methodology can be explained by its effectiveness in aligning a range of interests in offering a single solution to shared health service problems. However, this breadth of appeal disguises tensions between clinical, management and service user agenda which presents challenges for those charged with inscribing this multiplicity of interests in the actual technology.[34]

The relationship between boundary concepts and objects exemplifies the existence of a difference between an ideal and reality—an important distinction for this thesis. The role of EHR as a boundary concept that offers a "single solution" to health problems contributes to its image as a panacea for all healthcare woes.

Sheila Jasanoff and Sang-Hyun Kim (2009) developed the concept of sociotechnical imaginaries to fill the gap in theories relating to the relationship of "science and technology to political power."[35] Their original definition describes sociotechnical imaginaries as "collectively

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[33] Ilana Löwy, "The Strength of Loose Concepts — Boundary Concepts, Federative Experimental Strategies and Disciplinary Growth: The Case of Immunology," *History of Science* 30, no. 4 (1992): 371.

[34] Davina Allen, "Care Pathways: An Ethnographic Description of the Field," *International Journal of Care Pathways* 14, no. 1 (2010): 4.

[35] Sheila Jasanoff and Sang-Hyun Kim, "Containing the Atom: Sociotechnical Imaginaries and Nuclear Power in the United States and South Korea," *Minerva* 47, no. 2 (2009): 119.

imagined forms of social life and social order reflected in the design and fulfillment of nation-specific scientific and/or technological projects."[36] To account for the occurrence of multiple, coexisting imaginaries within a nation, Jasanoff and Kim (2015) refine their definition as "collectively held, institutionally stabilized, and publicly performed visions of desirable futures, animated by shared understandings of forms of social life and social order attainable through, and supportive of, advances in science and technology."[37] Thus, sociotechnical imaginaries are future-oriented and focus on social progress attained via science and technology initiatives. A nationwide exchange of interoperable patient data carries the sociotechnical imaginary of EHR as an optimal boundary infrastructure for solving many healthcare problems by providing flexibility for the local needs of the many stakeholders within the network.

The EHR Network:

In keeping with the ecological approach Star and Griesemer (1989) proposed, the first step to unpacking the politics of EHR and its network of interested parties is to identify the stakeholders involved. In the healthcare context, Concanon et al. (2012) propose a taxonomy called the 7Ps Framework for stakeholder engagement in patient-centered outcomes research, but this taxonomy can also be applied to the study of EHR networks to parse out the roles of various interested parties. The 7Ps include (1) patients and the public, (2) providers, (3) purchasers, (4) payers, (5) policymakers, (6) product makers, and (7) principal investigators.[38] Concanon et al. (2012) advocate for the flexible application of this taxonomy depending on the context.[39]

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[36] Sheila Jasanoff and Sang-Hyun Kim, *Dreamscapes of Modernity: Sociotechnical Imaginaries and the Fabrication of Power*, 1st edition (Chicago: University of Chicago Press, 2015).

[37] Ibid.

[38] Thomas W. Concannon et al., "A New Taxonomy for Stakeholder Engagement in Patient-Centered Outcomes Research," *Journal of General Internal Medicine* 27, no. 8 (August 2012): 986.

[39] Ibid.

Applying the 7Ps Framework for EHR stakeholders, my thesis will define each of the 7Ps as follows:

1. *Patients* - the subjects from which EHR data are collected.
2. *Providers* – individuals and groups who provide care and collect/record EHR data (physicians, nurses, pharmacists, etc.)
3. *Purchasers* - companies that buy EHR data and information (typically in aggregate.)
4. *Payers* - individuals and groups responsible for paying for care (insurers, individuals with deductibles, etc.)
5. *Policymakers* - governing and policymaking entities (ONC, Congress, healthcare administrators, etc.)
6. *Product makers* – technological innovators; this can refer to EHR developers and vendors (Epic, Cerner, etc.) or data software companies that repurpose EHR data for new applications.
7. *Principal investigators* - individuals and groups using EHR data for clinical and other research purposes; this can refer to both academic and industry entities.

While this framework is neither exhaustive nor reflects the extensive variation within each group, it provides an ecological starting point for unpacking the complicated relationships concerning EHR data exchange. It is important to note that healthcare providers—such as doctors and nurses—and healthcare administrators (listed as policymakers) have many different interests. While providers are concerned with providing medical care to their patients, healthcare administrators are engaged in figuring out the best way to manage large swaths of patients while allocating resources effectively. Additionally, the boundary between purchasers and primary investigators is often blurred. For example, many pharmaceutical companies purchase EHR data to research and implement new drug development.

Although this framework offers only a basic conception of the EHR stakeholder network, it provides scaffolding for considering the specific role of EHR in negotiating the relationships between disparate interests. Furthermore, it allows for the examination of the tension between the sociotechnical imaginary of EHR as an optimal boundary infrastructure and the less-than-ideal reality that results from attempting to inscribe the “multiplicity of interests” into an actual technology.[40]

The Role of EHR—Ideals and Realities:

The emphasis on the intrinsic tie between EHR and interoperability as outlined by ONC leads to the appearance of EHR as a perfect example of an effective boundary infrastructure. By incorporating standard codes for diagnoses, vaccinations, lab results, medication prescriptions, and so on, EHR can be shared across many providers within the healthcare network and adapted to local responsibilities. A lab technician, for example, can utilize the same EHR for largely different purposes than a primary-care physician. Other stakeholders in the network can benefit as well. For instance, the same codes can be used to provide billing information for insurance agencies (payers). Using portals, patients can also become more engaged with their health information. The construction of an extensive EHR infrastructure makes it easier for policymakers such as the US Government to oversee the use, exchange, and security of its constituent's health data. Lastly, if the data is de-identified according to national disclosure standards, it can be sent in aggregate to third parties for repurposed use (product makers). Other

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[40] Allen, “Care Pathways,” 4.

companies and individuals can then buy that data for marketing (purchasers) and research (primary investigators). In its idealized form, all stakeholders can benefit from EHR.

In practice, however, EHR data collection and exchange are fraught with challenges. Much of the burden of recording EHR data falls on physicians, nurses, and other caregivers. According to a survey conducted by Stanford Medicine and The Harris Poll that examined perceptions of EHR systems among primary care physicians (PCPs), 69% of PCPs expressed that EHR was disruptive to patient relationships, and over half of PCPs reported that they detracted from their professional satisfaction.[41] From a regulatory perspective, the high segmentation of healthcare in the US results in significant difficulties in attaining adequate interoperability standards between various HCOs. As of 2015, only 6% of providers could share data with clinicians using a different EHR system than their own.[42] Furthermore, digitized health records pose significant security and privacy risks, considering the sensitivity of health data. Although the Health Insurance Portability and Accountability Act (HIPAA) is designed to protect patient privacy through de-identification, it is also written to allow for the marketization of patient data. Most healthcare workers make a concerted effort to protect PHI, but often only a few data points are needed to re-identify a patient.

The unsatisfactory rollout of EHR and interoperability standards is due to technical and political reasons. There are hundreds of different EHR systems in use throughout the country, which involve different terminologies and capabilities. Additionally, it is highly challenging to distill clinically-relevant information into standardized codes. Many standards are in circulation depending on the type of clinical information (diagnoses, lab results, medication prescriptions,

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[41] The Harris Poll, "How Doctors Feel About Electronic Health Records: National Physician Poll" (Stanford Medicine, May 31, 2018).

[42] Miriam Reisman, "EHRs: The Challenge of Making Electronic Data Usable and Interoperable," *Pharmacy and Therapeutics* 42, no. 9 (2017): 572.

and so on). Each classification system contains thousands of terms. For instance, the World Health Organization's ICD-10 classification system for diseases, clinical signs, and symptoms includes over 14,000 terms, and the classifications are constantly evolving. Furthermore, these codes are primarily used for providing billing information, not for encoding health data in a clinically-relevant way. Finally, interoperability is disrupted by a healthcare culture "defined by silos, fragmented processes, and disparate stakeholders, and where data have become more of a commodity and competitive advantage than a basis for coordinated care."[43] Information blocking—where HCOs or EHR vendors intentionally interfere in the flow of health data exchange—continues to be a problem.

With so many challenges, why does EHR technology continue to dominate within the HIT industry? I argue that the current EHR landscape reflects the tension between the sociotechnical imaginary/boundary concept of EHR as a panacea for healthcare problems and the dysfunctional reality of inscribing entangled and conflicting interests within a physical technology. The appeal of interoperability and its local benefits are compelling to most stakeholders in a broad sense, but the political complexities and contentions intrinsic to an expansive stakeholder network prevent EHR from becoming an equally successful technology compared to its ideal. What results is a technology and network of exchange that fails to meet its lofty expectations. On the surface, technical solutions can seem like the path of least resistance to solve noticeable shortcomings, but they do not address the sociopolitical problem—that the local needs of various stakeholders are incompatible with one another. Thus, the crux of my argument identifies EHR as a currently flawed technology and failed boundary infrastructure due to the social and political tensions of the stakeholder network.

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[43] Reisman, "EHRs," 573.

Methodology:

In the following chapters, I analyze the discordance between the ideals and realities of EHR by examining the positions of three important stakeholders: the US Government, providers (physicians and nurses, in particular), and data brokers that repurpose and sell aggregate EHR data. While this approach is not entirely ecological in that it does not evaluate all stakeholders, the three chosen for analysis represent a range of roles and perspectives. The US Government reflects the overarching regulatory forces influencing the politics of health data exchange. Physicians and nurses offer insight into the immediate realities of EHR in clinical care. Finally, EHR data software companies encapsulate the marketization of EHR data and function as a broker between the primary healthcare coordination between patients, providers, and payers and the auxiliary EHR data applications of purchasers and primary investigators.

Chapter 1 examines the role of the US Government in the implementation of EHR, beginning with the Bush Administration in the early 2000s. Throughout the chapter, I analyze the creation and consequences of critical HIT policies, including the HITECH Act, “Meaningful Use” standards, and HIPAA. Overall, the chapter intends to demonstrate how the US Government crafted many of its HIT policies primarily to achieve economic goals over health initiatives and how this misalignment in intentions contributed to the dysfunctional rollout and exchange processes of EHR technologies and data.

Chapter 2 focuses on providers' experiences with implementing and adapting to EHR. For this chapter, I draw on research articles, surveys, and anecdotal evidence from secondary sources, as well as my own interviews with four physicians and nurses.[44] Chapter 2 intends to

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[44] See Appendix A for information on provider interviews.

illustrate how the current EHR landscape often transforms the responsibilities of physicians from providing care to compiling data and the ramifications of this process.

Finally, Chapter 3 analyzes data capitalism and the marketization of patient EHR information from the perspective of third-party data brokers that buy and sell EHR data in aggregate form. This chapter also contains interviews with two employees working at an EHR-based software company that advertises itself as a service connecting HCOs, clinical researchers, and pharmaceutical companies.[45]

Notably, my thesis does not include patients as a prominent position for examining the EHR stakeholder network. On the surface, this decision may seem surprising, considering EHR consists of patient health information. However, as my thesis will demonstrate, the HIT system was never designed to be patient-centered. In fact, it is very difficult for patients to get access to their own records.

The limited involvement of patients in the creation and exchange of their health information reflects larger trends within the US healthcare landscape where the patient is commonly rendered into a passive subject of care passed across various professional boundaries.[46] Through the process of encoding the patient's body and health status into standardized codes and clinical entries within the EHR, the physical patient is "de-activated," resulting in the "transformation of people into organisationally recognized patients."[47] Mary Ebeling, the woman whose experience is described at the beginning of this chapter, refers to this process as the conversion of "'dead' matter into 'lively' data."[48] Throughout my thesis, I will regularly refer to the digital data-patient as an entity constructed and molded by the politics of

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[45] See Appendix B for information on data company employee interviews.

[46] Simon Bishop and Justin Waring, "From Boundary Object to Boundary Subject; the Role of the Patient in Coordination across Complex Systems of Care during Hospital Discharge," *Social Science & Medicine* 235 (2019).

[47] Bishop and Waring, "From Boundary Object to Boundary Subject; the Role of the Patient in Coordination across Complex Systems of Care during Hospital Discharge," 2.

[48] Ebeling, *Healthcare and Big Data,* 7.

the EHR stakeholder network. That said, the typically passive role of physical patients reduces their impact as stakeholders in negotiating the politics of EHR.

CHAPTER 1: Regulating Health Information—The Role of the US Government in the Adoption, Use, and Exchange of EHR

Setting the Scene—A Tale of Two Speeches:

On the evening of January 20, 2004, former President George W. Bush stepped up to the Congressional podium in a black suit, red tie, and American flag lapel pin to kickstart his re-election campaign with the State of the Union address. According to an analysis by the *New York Times,* President Bush's speech began by "recounting his record on national security, ground where polls show he is politically strongest" before turning to domestic issues like education and healthcare, "where polls show voters far less sure about his leadership."[49] Although most national news focused on his remarks on the wars in the Middle East and taxes, his statement "by computerizing health records, we can avoid dangerous medical mistakes, reduce costs and improve care" piqued the attention of the HIT field.[50] The comment was met with tepid applause by Congress, but one healthcare magazine described it as the "Bush sentence heard round the health IT world."[51]

Following his speech, Bush created the ONC and set a goal for all Americans to have a personal health record by 2014. Regardless of these actions, the adoption rate of EHR remained below 10% at the end of his term (Appendix C).[52] Accordingly, Dr. Donald W. Simborg invoked

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[49] Todd S. Purdum, "STATE OF THE UNION: NEWS ANALYSIS; In Position for the '04 Race," *The New York Times*, January 21, 2004.

[50] George W. Bush, "Text of President Bush's 2004 State of the Union Address," (speech, Washington DC, January 20, 2004), *The Washington Post,* www.washingtonpost.com/wp-srv/politics/transcripts/bushtext_012004.html.

[51] Joseph Conn, "10 Years after the Revolution," *Modern Healthcare*, April 5, 2014, https://www.modernhealthcare.com/article/20140405/MAGAZINE/304059980/10-years-after-the-revolution.

[52] JaWanna Henry et al., "Adoption of Electronic Health Record Systems among U.S. Non-Federal Acute Care Hospitals: 2008-2015," *ONC Data Brief No. 35,* May 2016.

the same expression in a 2008 examination of the national EHR landscape that he used in 2005: EHR adoption is “the wave that never breaks.”[53]

On the evening of February 24, 2009, former President Barack Obama stepped up to the Congressional podium in a black suit, red tie, and American flag lapel pin to begin his first public address before a joint session of Congress. A *New York Times* analysis of the speech opened with the blunt statement: “It had all the trappings of a State of the Union address but since technically it was not, President Obama did not have to utter those traditional words: ‘The state of our union is strong.’ Because, frankly, it isn’t.”[54] Inheriting a government with an economy facing its largest recession since the Great Depression, Obama’s joint address focused primarily on stimulating the economy and providing jobs while seizing “opportunity from ordeal.”[55] The focal point of the speech was the American Recovery and Reinvestment Act of 2009, the enormous stimulus package signed by Obama one week prior that provided $831 billion for projects concerning infrastructure, education, energy, and healthcare.[56] He referred directly to EHR regarding the stimulus package, stating, “Our recovery plan will invest in electronic health records and new technology that will reduce errors, bring down costs, ensure privacy, and save lives.” Emphasizing many of the same selling points as Bush, his comment received a healthy round of applause.

In particular, Obama’s statement concerning EHR investment refers to the HITECH Act, which was passed as part of the recovery plan and provided $30 billion to establish a national EHR infrastructure. The HITECH Act outlined the same objective of creating a personal health

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[53] Simborg, “Promoting Electronic Health Record Adoption. Is It the Correct Focus?,” 127.

[54] Peter Baker, “In Time of Crisis, Urging Bold Action and Big Ideas,” *The New York Times*, February 25, 2009.

[55] Barack Obama, “Remarks of President Barack Obama—Address to Joint Session of Congress,” (speech, Washington DC, February 24, 2009) whitehouse.gov, https://obamawhitehouse.archives.gov/.

[56] Congressional Budget Office (CBO), “Estimated Impact of the American Recovery and Reinvestment Act on Employment and Economic Output from October 2011 Through December 2011,” *The Congress of the United States,* February 2012.

record for all Americans by 2014. However, in contrast to the Bush Administration, this particular goal resulted in success. In 2014, the ONC reported that 97% of all hospitals possessed a certified EHR system (Appendix C).[57] Yet the rollout resulted in countless problems, disruptions, and inefficiencies. Dr. David Brailer, the first National Coordinator of the ONC under Bush, commented, “We’ve built the Frankenstein I was most afraid of.[58]

With surprisingly similar rhetoric and policy initiatives, why were the trajectories of national EHR utilization under the two administrations different to the point that one was coined a crestless wave while the other was called a Frankenstein monster? In this chapter, I unpack the puzzle of the US Government’s impact on EHR by analyzing the contexts and effects of four notable policies: Executive Order 13335, the HITECH Act, “Meaningful Use” standards, and HIPAA. Through this, I consider policymakers’ interest in EHR and its ramifications for the EHR stakeholder network and the viability of the technology.

Executive Order 13335 and the Creation of the ONC:

Before 2004, the US Government displayed limited interest in implementing EHR technology beyond running the veteran’s healthcare system under the Department of Veterans Affairs. Bush’s State of Union comment surprised many, but the administration collaborated with Dr. Brailer about HIT policy for almost a year behind the scenes. According to Brailer, “By November (2003), it was nonstop. I spent a month alone on the draft in the State of the Union address.”[59] A month of work for a single sentence.

Nevertheless, that sentence translated into concrete action. On April 16, 2004, Dr. Brailer provided the Bush Administration with a 54-page document of policy options that informed the

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[57] Henry, et al., “Adoption of Electronic Health Record Systems.”
[58] Robert Wachter, *The Digital Doctor: Hope, Hype, and Harm at the Dawn of Medicine’s Computer Age*, 1st edition (New York: McGraw Hill, 2017), 19.
[59] Conn, “10 Years after the Revolution.”

development of the ONC.[60] Bush signed Executive Order 13335 eleven days later, which officially created the ONC under the Department of Health and Human Services (HHS). The Executive Order tasked Dr. Brailer—who was selected as the first National Coordinator— with developing and implementing the national strategy to achieve the goal of creating an EHR for all Americans by 2014. In particular, the directive outlined the responsibilities of the ONC to include developing HIT standards, evaluating the costs and benefits of sharing interoperable data, and considering potential privacy and security concerns.

The commentary from the Bush administration in 2004 invokes the sociotechnical imaginary of HIT as the key to attaining a modernized healthcare landscape freed from its woes of high costs, unnecessary mistakes, and siloed processes as a rhetorical tool. Frequently, the Administration applied discursive strategies to describe the paper-based record system as obsolete. In an October presidential debate with Senator John Kerry, for example, Bush emphasized the importance of his commitment to HIT, stating that technology within the US healthcare system was "equivalent of buggy-and-horse days, compared with other industries here in America."[61] This rhetoric was even more explicit in official policy publications released by the Bush White House. For instance, one April publication stated:

> All these problems – high costs, uncertain value, medical errors, variable quality, administrative inefficiencies, and poor coordination – are closely connected to our failure to use health information technology as an integral part of medical care. The innovation that has made our medical care the world's best has not been applied to our health information systems. Other American industries have harnessed advanced information technologies, to the benefit of American consumers. Our air travel is safer than ever, and consumers now have ready and safe access to their financial information. Unlike these other industries, medicine still operates primarily with paper-based records. Our doctors and nurses have to manage 21st century medical technology and complex medical information with 19th century tools. America's medical professionals are the best and

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[60] Conn, "10 Years after the Revolution."

[61] Steve Lohr, "Health Care Technology Is a Promise Unfinanced," *The New York Times*, December 3, 2004.

> brightest in the world, and set the standard for the world. It is a testament to their skill that they are able to achieve high-quality care in this antiquated system.[62]

This passage contains a few crucial messages. First, it acknowledges the frustrations of many Americans about the healthcare industry, including high prices, poor communication, and disjointed services. Second, it places the blame for these problems solely on "antiquated technology and "19th-century tools."[63] This rhetoric effectively diverts attention away from the political, cultural, and structural challenges contributing to the healthcare system's dysfunction. More importantly, it positions the Bush Administration as a presidency willing to do something about it. Third, the publication makes repeated references to the US compared to the rest of the world. In effect, the statement argues that the US healthcare system and its providers are the best globally, and it is only the technology holding it back. The US placed 37th for overall health system performance according to the World Health Organization's 2000 report that ranked the health systems of its member states.[64] Accordingly, the US was facing significant pressure to improve the image of its healthcare industry. Dr. Paul Tang, who served on several advisory panels for the ONC, explained that the role of National Coordinator was created "because America was clearly behind a lot of other developed countries with a health information infrastructure."[65]

Bush also had a problem with domestic support on his healthcare policy. A Gallup Group survey taken at the time of the 2004 State of the Union address indicated that his approval rating for his handling of healthcare fell to 35%—an 11% drop from the previous year.[66] Therefore, as

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[62] The White House—President George W. Bush, "Promoting Innovation and Competitiveness: President Bush's Technology Agenda,"(Accessed December 19, 2021) https://georgewbush-whitehouse.archives.gov/infocus/technology/economic_policy200404/chap3.html

[63] Ibid.

[64] World Health Organization, *The World Health Report : 2000 : Health Systems : Improving Performance* (World Health Organization, 2000), https://apps.who.int/iris/handle/10665/42281.

[65] Conn, "10 Years after the Revolution."

[66] Tony Fong, "Bush's Approval Rating Falls on Healthcare Issues," *Modern Healthcare*, February 18, 2004.

Bush began his re-election campaign, he needed a way to pledge "to confront the domestic issues that his Democratic rivals hope[d] may keep him from winning a second term."[67] Having previously signed a Medicare reform law that failed to boost constituents' approval of his handling of healthcare, the techno-optimist rhetoric recognized common complaints but painted these problems as rectifiable with a simple technological fix. In effect, Bush could publicly advocate for a new policy plan to sway voters to keep faith in him for the upcoming election.

However, while the Bush Administration cited HIT as a priority to convince voters of his competence in improving healthcare, his rhetoric did not align with his actions on the logistical side of pushing for HIT reform. For instance, one of the provisions in Executive Order 13335 stated that the National Coordinator should "not assume or rely upon additional Federal resources or spending to accomplish adoption of interoperable health technology."[68] A few months after the creation of ONC, Congress eliminated the National Coordinator's request of $50 million while determining the annual budget. Newt Gingrich—who supported the budgetary proposal—complained, "no one at the White House or in the senior staff of the Department of Health and Human Services fought for this," which suggests a disconnect between Bush's rhetoric and actions.[69]

While the real intentions for HIT reform under the Bush Administration can not be known definitively, it is notable that the Administration spent considerable time working with Dr. Brailer on one line in the State of the Union address but left the ONC largely on its own to fight for funding in Congress. Considering the costs of EHR, the lack of funds prevented Dr. Brailer from making much of an impact in swaying HCOs to adopt the technology. As one healthcare magazine reported, "His HIT funding plan was fiscally and philosophically dead on

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[67] Baker, "In Time of Crisis, Urging Bold Action and Big Ideas."
[68] Exec. Order. No. 13335, Code of Federal Regulations, title 3 (2005).
[69] Lohr, "Health Care Technology Is a Promise Unfinanced."

arrival, so Brailer soldiered ahead, deflecting numerous calls for federal IT support in favor of market-based initiatives, even though multiple surveys of providers in those days found that the high cost of EHR systems was the biggest deterrent to their adoption."[70] The idea of technology as a solution for healthcare problems served mainly as a rhetorical selling point for Bush's re-election campaign than a legitimate policy goal worth fighting for.

The early governmental involvement from 2004 to 2008 marked a turning point in the trajectory of EHR implementation and set the tone for major ONC initiatives. However, without the funds to tackle the financial burdens preventing HCOs from adopting EHR, the Bush-era ONC struggled to incite tangible results such as improved adoption rates. By 2008, only 9.4% of non-federal acute-care hospitals had implemented EHR—still under the 10% threshold that existed before government involvement (Appendix C).[71] The wave refused to break.

The HITECH Act, "Meaningful Use" Standards, and Expanded Government Involvement:

The tide for EHR implementation changed with the passage of the HITECH Act in 2009. Entering office during a time of devastating financial crisis, the incoming Obama Administration sought projects they could include in their recovery efforts to stimulate the economy. The Administration quickly landed on enhancing the national HIT infrastructure—mainly by investing in EHR—because improving HIT had relatively broad support from Congress and the public. Furthermore, while Dr. Brailer's ONC did not have the funds to produce tangible results concerning EHR adoption rates, it had crafted extensive policy recommendations. These suggestions could be used by the Obama-era ONC—with Dr. David Blumenthal serving as

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[70] Joseph Conn, "Brailer's Untold ONC Story: He Wanted $17 Billion for HIT," *Modern Healthcare*, April 9, 2014.
[71] Henry et al., "Adoption of Electronic Health Record Systems."

National Coordinator—as a blueprint for quick action. In effect, HIT reform policy was "shovel-ready;" it just needed the funding.[72]

The Obama Administration determined that by investing approximately $30 billion in EHR infrastructure, it could create up to 50,000 new jobs while also providing HIT to reduce medical errors and improve care.[73] The policy could create "opportunity from ordeal" by investing in a technological cure-all. Thus, on February 17, 2009, the HITECH Act passed with the rest of the Recovery Act, rectifying the funding issue plaguing the efforts of the Bush-era ONC to boost EHR adoption rates. While Congress had scrapped the budget for ONC under the Bush Administration, the national context was vastly different. Financing two wars and lowering the federal deficit were primary concerns in 2004. In 2009, the focal point was almost exclusively on stimulating the economy. Congress and the Obama Administration needed to offer actionable solutions that translated to real jobs to convince voters that they were qualified to pull the country out of recession. While EHR served as a persuasive talking point for Bush in 2004, the Obama Administration had to back its rhetoric with action.

Thus, while the ONC under both administrations shared similar initiatives, the responsibilities and resources were significantly more robust after the HITECH Act. The Act explicitly called for the ONC to ensure "the utilization of an electronic health record for each person in the United States by 2004."[74] It was also tasked with designing strategies to improve interoperability, maintain privacy and security of personal health information, reduce health disparities, and apply EHR data to improve medical care, public health initiatives, and the coordination of resources. Again, the language of policymakers invokes the imaginary of EHR

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[72] Jeff Hecht, "The Future of Electronic Health Records," *Nature* 573, no. 7775 (2019): S115.

[73] Paul Christopher Webster, "Electronic Health Records a 'Strong Priority' for US Government," *CMAJ* 182, no. 8 (2010): E315.

[74] Health Information Technology for Economic and Clinical Health (HITECH) Act**,** Pub. L. No. 111-5, 123 Stat. 231, U.S.C. (2009).

and HIT as the panacea of healthcare problems, with the implementation of an EHR infrastructure meant to solve a host of structural and cultural challenges embedded in the American healthcare system while also creating jobs.

Additionally, the HITECH Act called for creating a HIT Policy Committee (HITPC) tasked with developing policy recommendations and a HIT Standards Committee (HITSC) responsible for recommending implementation standards and certification criteria to the National Coordinator. Here, the US Government directly defines the top priorities for a national EHR infrastructure and describes who it believes are the most critical stakeholders by outlining the membership criteria for the HITPC. The Act specifies that the HITPC should include three members appointed by the HHS Secretary (including one member to represent public health officials), four members of Congress, three patient advocates, two healthcare providers, one member of a labor organization representing healthcare workers, one HIT privacy expert, one expert on the health of "vulnerable populations," one third-party payer representative, one HIT vendor representative, and one expert on healthcare quality evaluation.[75] Invoking the image of HIT as an ideal boundary infrastructure, the membership diversity established by the "HITECH Act" was the mechanism by which the US Government intended to balance the multiplicity of interests. For instance, the "Participation" clause for the HITPC states that "The members of the HIT Policy Committee shall represent a balance among various sectors of the health care system so that no single sector unduly influences the recommendations of the Policy Committee."[76] However, a seat at the table does not always translate to a balance of power; membership alone does not always reflect the economic and political influence some members have over others. Most notably, the membership clauses of the HITECH Act concretely demonstrate the

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[75] Health Information Technology for Economic and Clinical Health (HITECH) Act**,** Pub. L. No. 111-5, 123 Stat. 236-237, U.S.C. (2009).

[76] Ibid.

positioning of the US Government as the agent responsible for defining and overseeing the negotiation of competing stakeholder interests. Since the US Government was primarily focused on stimulating the economy, stakeholders more directly involved with financial aspects of EHR implementation—like EHR vendors—had an advantage.

Under the HITECH Act, providers that chose to opt into the program could receive between $44,000 and $63,750 per physician over five to six years by adopting “certified EHR.”[77] The HITSC determined the certification criteria, known as the “Meaningful Use” standards. From a diffusion of innovations perspective, the incentives program was crucial. In 2014, 97% of all hospitals possessed a certified EHR system demonstrating the effectiveness of financial compensation for boosting adoption rates (Appendix C).[78] Although incentives are an efficient strategy for increasing the rate of adoption by heightening the innovation’s relative advantage, the motivation for the adoption is typically to receive the incentive and not for the intrinsic value of the invention. As a result, the quality of the adoption, in this case, the *adaption* and *integration* of EHR in a meaningful way, was relatively low even when the adoption rate was high. While benchmarks—like the number of EHR installed by 2014—are visible indications of progress, they correspond more with economic-based goals than organizational goals. Access to a record system does not necessarily mean access to a useful record system.

Since the primary goal was to stimulate the economy instead of establishing a HIT infrastructure in a clinically-valuable way, the HITECH Act prioritized speed over deliberation. The HITSC had only 90 days to specify the criteria. The “frenetic pace” of the EHR rollout was worrisome to many healthcare experts during the initial implementation, who expressed concerns that the EHR systems were “not mature,” the policies were not fully established, and many

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[77] Stephen T. Mennemeyer et al., “Impact of the HITECH Act on Physicians’ Adoption of Electronic Health Records,” *Journal of the American Medical Informatics Association: JAMIA* 23, no. 2 (March 2016): 375.

[78] Henry, et al., “Adoption of Electronic Health Record Systems.”

HCOs did not possess the skilled labor required to train staff and operate the technology successfully.[79] Although the economically-minded US Government needed to act quickly to respond to the recession, the haphazard rollout policies resulted in a flawed boundary infrastructure that struggled to correct itself logistically.

Regardless of their readiness, most HCOs were required to adhere to the "Meaningful Use" standards set forth by the ONC and HITSC since the US Government was providing the funds for the adoption. HCOs that opted in to the program but did not comply with the standards could be financially penalized. Thus, the "Meaningful Use" standards were highly influential in shaping the realities of EHR implementation since they determined an HCO's eligibility for incentives. The policy's timeline was divided into three stages with progressively more demanding criteria. According to the ONC, Stage 1 criteria focuses on "Data Capture and Sharing," Stage 2 looks to "Advance Clinical Processes," and Stage 3 works to "Improve Outcomes," both on the individual patient and population health levels.[80] Stage 1 began in 2011, Stage 2 started in 2014, and Stage 3 opened in 2016 (Appendix D).[81]

While the staged integration design of "Meaningful Use" standards appears to allow for systematic implementation of a cohesive EHR infrastructure, the actual rollout did not match the ONC's vision. Critics pointed out that the policy's structure was fit to boost the adoption rates of EHR more than to provoke meaningful health information exchange (HIE).[82] Although Stage 1 was intended to focus on data capture and sharing, it primarily centered on installing EHR because this directly corresponded with job creation. Reisman (2017) explained that Stage 1 "includes neither any requirements nor vision for interoperability, allowing EHR systems to be

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[79] Webster, "Electronic Health Records a 'Strong Priority' for US Government," E316.

[80] "What Is Meaningful Use?," HealthIT.gov, June 1, 2013, https://www.healthit.gov/faq/what-meaningful-use.

[81] See Appendix D for more information on the "Meaningful Use" stages.

[82] Miriam Reisman, "EHRs: The Challenge of Making Electronic Data Usable and Interoperable," *Pharmacy and Therapeutics* 42, no. 9 (2017): 572.

designed and adopted in ways that did not take HIE into account."[83] Interfacing EHR to exchange health information is highly expensive, and sharing data is not always advantageous for an HCO because it provides free resources to competitive organizations.[84] The incentive payments also declined throughout Stage 2, with some physicians receiving half the money they received from Stage 1.[85] Furthermore, the logistics of the "Meaningful Use" program allowed a handful of vendors—including Epic, and Cerner—to dominate the EHR market by providing "certified EHR" technology compliant with Stage 1 to a rapidly expanding pool of customers. The condensed timeline for EHR rollout following the HITECH Act resulted in a drastic increase in the profit and influence of these vendors. By the start of Stage 2, EHR vendors had little incentive to make interoperability easy and often charged between $5,000 and $50,000 per physician to provide the software that allowed for the exchange of EHR data.[86] According to the ONC, providers that were in the "Meaningful Use" program for at least two years had to begin complying with Stage 2 interoperability standards by 2014. Due to the challenges impeding interoperability—such as high costs and the unwillingness to share information—only 12% of providers were able to successfully complete Stage 2 by 2015.[87]

Ensuring EHR interoperability continued to pose a significant challenge for the ONC under the Obama and Trump administrations (which worked to advance many of the same initiatives). Besides the structural and financial difficulties involved with interfacing EHR systems, information blocking—which refers to the deliberate and unreasonable interference of HIE—significantly detracts from interoperability initiatives. For instance, in a 2015 survey of

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[83] Reisman, "EHRs," 572.

[84] Reisman, "EHRs," 573.

[85] Jason Mitchell and Steven Waldren, "Making Sense of Meaningful Use Stage 2: Second Wave or Tsunami?," *Family Practice Management* 21 (January 21, 2014): 20.

[86] Arthur Allen, "Doctors Say Data Fees Are Blocking Health Reform," *POLITICO*, February 23, 2015.

[87] "EHR Meaningful Use Doomed Unless Congress Steps In," American Medical Association, November 3, 2015, https://www.ama-assn.org/practice-management/medicare-medicaid/ehr-meaningful-use-doomed-unless-congress-steps.

141 leaders in HIE, 50% of respondents reported that EHR vendors engage in information blocking, and 25% of respondents said providers engage in the practice.[88] Accordingly, the ONC released its Information Blocking Final Rule in May 2020 under the provisions established in the 21st Century Cures Act of 2015. The policy prohibited providers and HIT/HIE developers (including EHR vendors) from undertaking "any practice likely to interfere with, prevent, or materially discourage access to, exchange of, or use" of EHR information.[89] HIT/HIE developers engaged in information blocking face a penalty of $1 million per violation, while providers may be subject to "appropriate disincentives" that have yet to be established by the HHS Secretary.[90] Enforcement of the policy began in April 2021, so it is too early to tell whether the new policy is effective for improving EHR interoperability. However, the policy reflects the catch-up work by the US Government to make the network of EHR exchange functional.

HIPAA, Privacy, and Disclosure Regulation:

Health information privacy regulations are also highly influential to the effectiveness of the EHR network. As digital technology and the influence of data rapidly expanded at the end of the 20th century, the US Government grappled with balancing the vast utility of data with its potential for damaging security breaches. While this tension was critical to many types of data management, it was particularly salient for health data, considering the sensitivity of the information. At the time, privacy breeches were primarily handled reactively through legal torts. A victim of a privacy breach that resulted in harm or embarrassment could directly sue the responsible party. However, with computerized data and the network of individuals who handle it

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[88] Julia Adler-Milstein and Eric Pfeifer, "Information Blocking: Is It Occurring and What Policy Strategies Can Address It?," *The Milbank Quarterly* 95, no. 1 (March 2017): 118.

[89] Iliana Peters and Adrienne Testa, "21st Century Cures Act Information Blocking Rule: Innovative and In Effect," *The National Law Review* 12, no. 106 (August 10, 2021).

[90] Ibid.

expanding at an accelerating pace, the US Government pivoted to proactive legislation to attempt to secure data while still enjoying the utility and profit emerging from the data market—a major pillar of its economy.

In the healthcare sphere, the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and its subsequent amendments embody this critical juncture in data privacy and security regulation. Yet, the primary concern for these policies was not to protect the confidentiality, privacy, and security of an individual's data or to ensure patients with the right to control how their health information is used and shared. Instead, the policies were designed to serve as a business driver by standardizing HIE between stakeholders for greater efficiency while avoiding the most nefarious privacy offenses like fraud and defamation. As a result, many privacy and security experts conclude that HIPAA serves more as a disclosure regulation than a privacy rule.[91]

Under HIPAA, there are three subject classes: the patient (or "consumer," as it is stated in the law), covered entities, and business associates. Covered entities include health insurers, healthcare clearinghouses, and providers that exchange, handle, or utilize protected health information (PHI). When HIPAA went into effect in 2003, the government recognized over 600,000 covered entities with "regulatory permission to use or disclose protected health information for treatment, payment, and health care operations" without the patient's knowledge or consent.[92] Business associates refer to ancillary healthcare service providers who receive identifiable patient health data through disclosures made by covered entities. HHS estimates that more than half a million business associates handle PHI.[93] Under the Enforcement Final Rule of

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[91] Richard Sobel, "The HIPAA Paradox: The Privacy Rule That's Not," *The Hastings Center Report* 37, no. 4 (2007): 40.

[92] Sobel, "The HIPAA Paradox," 40-41.

[93] Ebeling, *Healthcare and Big Data*, 75.

2006 and the revised penalties updated by the HITECH Act, the HHS Office of Civil Rights can fine non-compliant covered entities and business associates from $100 to $1.5 million per violation, depending on the severity of the breach and the willfulness of the violator.[94] Overall, HIPAA policymakers sought to balance the streamlining of a disclosure system with data security by keeping patient PHI private and protected within a vast but "closed" system. As a result, HIPAA's structure resulted in the shift of data privacy rights "from the body of the patient upward to the covered entities."[95]

However, HIPAA regulations only apply to covered entities and business associates handling PHI, which refers to eighteen "identifiers." According to Ohm (2010), the shift to proactive data security legislation resulted in a "Linnaean" risk assessment strategy in which lawmakers "try to enumerate and categorize types of information that contribute to risk."[96] By scrubbing the data of these eighteen identifiers, health data is considered "de-identified" or "anonymized" and can be exchanged with and sold to third parties outside the jurisdiction of HIPAA. Ohm describes the appeal of this anonymization policy:

> What will remain is a best-of-both-worlds compromise: Analysts will still find the data useful, but unscrupulous marketers and malevolent identity thieves will find it impossible to identify the people tracked. Anonymization will calm regulators and keep critics at bay. Society will be able to turn its collective attention to other problems because technology will have solved this one. Anonymization ensures privacy.[97]

Again, the imaginary of technology as a panacea to problems is used to legitimize a business model. The government could use HIPAA policy to drive business and research while also protecting private information by applying anonymization principles.

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[94] Steve Alder, "What Are the Penalties for HIPAA Violations?," *HIPAA Journal* (blog), January 23, 2022, https://www.hipaajournal.com/what-are-the-penalties-for-hipaa-violations-7096/.

[95] Ebeling, *Healthcare and Big Data*, 75.

[96] Paul Ohm, "Broken Promises of Privacy: Responding to the Surprising Failure of Anonymization," *UCLA Law Review* 57, University of Colorado Law Legal Studies Research Paper No. 9-12 (2010): 1734.

[97] Ohm, "Broken Promises of Privacy," 1732.

However, the perfect effectiveness of anonymization is an illusion. By combining a few data points from other public sources, most “anonymized” patient data can be re-identified. In an influential re-identification experiment in 1997, researcher Latanya Sweeney demonstrated that it was possible to re-identify the health records of virtually all Americans—including the Governor of Massachusetts—with only three data points.[98] In contradiction with the imaginary, anonymization does not ensure privacy; it provides a regulatory loophole for businesses to circumvent privacy restrictions without penalty. According to Ohm, it is impossible to guarantee complete confidentiality and utility simultaneously, “Because the utility and privacy of data are intrinsically connected, no regulation can increase data privacy without also decreasing data utility. No useful database can ever be perfectly anonymous, and as the utility of data increases, the privacy decreases.”[99] The central tension between privacy and utility leaves policymakers with two options: re-evaluate the entire system of data capitalism or invoke the imagery of a perfect solution through the advancement of technology and data regulation. The second option is more lucrative. Following Sweeney’s publication, the government tightened security regulations with the 2003 HIPAA Privacy Rule to reduce the risk of reidentification. However, Sweeney could still re-identify 43% of patients from a publicly available hospital admission dataset and news articles over a decade later.[100] No amount of advanced encryption techniques or regulatory updates has allowed technology to solve the complexity of competing interests.

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[98] Ohm, “Broken Promises of Privacy,” 1719-1720.

[99] Ohm, “Broken Promises of Privacy,” 1705-1706.

[100] Latanya Sweeney, “Patient Identifiability in Pharmaceutical Marketing Data,” Data Privacy Lab Working Paper 1015 (2011), https://dataprivacylab.org/projects/identifiability/pharma1.pdf.

CHAPTER 2: Transforming Clinical Practice into Data Entry—The Effect of EHR on the Provider Experience

Setting the Scene—Working in the Impact Zone:

On a rainy morning in March, I called Dr. Nicholas Brown, who worked as a cardiologist for thirty-two years before signing on to work at an insurance company in upstate New York. Throughout our hour-long conversation, he was matter-of-fact: calmly explaining what he saw as the biggest challenges facing providers as they adapt to an EHR world. Having gone through all of my prepared questions, I asked him if there was anything else that he felt was important to touch on before we ended the call. This answer felt more personal. He stuttered a little as he gathered his thoughts:

> I think…I just…I think people just need to realize…I don't think the public realizes how awful it is to bill on an EMR for a visit. Like the last medical record I went on was Athena, and for about 18 months, I spent every Saturday and Sunday—eight hours each day, eight to ten hours for a year and a half—bringing everything from the old record to the new record to populate my patients' charts coming in that week so that I had what was in the prior chart, and so that I had a good note. I mean that actually—it actually scars you; it's such a traumatic experience. And I was on four EMRs in ten years. And the systems will decide we're going on this one; now we're going on this one. For the administrator, it doesn't matter; it's no skin off their nose. For the doctor, though, it's awful. And the doctors often have very little say, believe it or not, in what EMR a system goes on. There is often no input at all.[101]

Dr. Brown's experience mirrors countless others expressed by providers across the country. In many ways, the rapid adoption of EHR in the wake of the HITECH Act and "Meaningful Use" standards caught providers between a rock and a hard place. On the one hand, providers need twenty-first-century technology to keep up with rapid advances in medicine and healthcare. On the other, the vast complexity of the technology proved to be a significant burden when implemented without the social and technical infrastructure to support it. Regarding this

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[101] Interview 3, 3/17/2022.

challenge, a 2013 RAND study on physician opinions of EHR concluded, “No other industry, to our knowledge, has been under a universal mandate to adopt a new technology before its effects are fully understood, and before the technology has reached a level of usability that is acceptable to its core users.”[102]

Thus, as the US turned to EHR to manage its constituents' health information, most of the burden to adapt to EHR fell on providers. Yet, providers continue to be consulted the least about EHR policies and the most liable when things go wrong. Due to the rollout of EHR and their position within the stakeholder network, providers work at the volatile collision site between the imaginary of EHR and its reality.

Throughout this chapter, I draw on information obtained from interviews with four providers. Dr. Thomas Miller is a vitreoretinal surgeon based in New York City. Nurse Laura Anderson is a Maine-based behavioral health nurse who now works as a nursing informaticist. Dr. Nicholas Brown is a former cardiologist and currently works at an insurance company in upstate New York. Nurse Sarah Martin is a Maine-based nurse and the Chief Nursing Informatics Officer for a multi-hospital integrated healthcare system.[103] I also utilize secondary information from books, articles, and surveys to examine providers’ experiences adapting to EHR in clinical practice. In doing so, I aim to demonstrate how the appetite for EHR data from various stakeholders frequently transforms the responsibilities of providers as entities offering care to entities collecting data. Structurally, this is accomplished by analyzing multiple issues that emerge from the politics of using EHR in clinical practice.

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[102] Mark W. Friedberg, Francis J. Crosson, and Michael Tutty, “Physicians’ Concerns About Electronic Health Records: Implications And Steps Towards Solutions,” Health Affairs, March 11, 2014.

[103] See Appendix A for the interview questions and more information. In this chapter, the citation “Interview 1” refers to the interview with Dr. Miller, “Interview 2” refers to Nurse Anderson, “Interview 3” refers to Dr. Brown, and “Interview 4” refers to Nurse Martin.

A Satisfaction Conundrum:

Since the rollout of EHR, numerous polls have investigated physicians' opinions on the technology. Results from a 2013 RAND study—which surveyed and interviewed physicians and clinical staff from thirty practices across the country—led to the conclusion that "physicians approved of EHRs in concept" due to their capacity to access patient health information remotely and improve patient quality of care through the integration of records.[104] All four of my interview participants independently described the potential for seeing a comprehensive picture of a patient's medical history as a valuable concept regarding the technology. Both nurses, Laura Anderson and Sarah Martin, explicitly cited the "one shared record" or "one patient, one record" imaginary—a common phrase indicative of the interoperable EHR ideal.

Yet, most respondents from the RAND study reported that EHR detracted from professional satisfaction due to poor user experience, lengthy data entry, the reduction of "face-to-face" patient care, insufficient interoperability capacities, and the "degradation of clinical documentation."[105] Dr. Brown contrasted the promise and shortcomings of EHR, stating that while data-driven solutions are necessary to keep pace with modern medical advancement, the mystery is that "so far, there's been almost no studies showing that anything in healthcare has improved…Nobody's doing better with EMRs. Hospitals are not doing as well. Doctors aren't doing as well. Insurance companies aren't doing as well."[106] Thus, there is a disconnect between the appealing concept of EHR and its reality. As the authors of the RAND study explained, physicians "believe in the 'promise of EHRs,'" but "cannot buy, install, and use a promise to help them deliver patient care."[107] Still, many providers in the study were optimistic, stating that

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[104] Mark W. Friedberg et al., "Factors Affecting Physician Professional Satisfaction and Their Implications for Patient Care, Health Systems, and Health Policy" (RAND Corporation, October 9, 2013), xvi.
[105] Ibid.
[106] Interview 3, 3/17/2022.
[107] Friedberg et al., "Factors Affecting Physician Professional Satisfaction," xx.

they believe EHR would improve professional satisfaction and patient care in the future as the technology and interoperability standards improved.

Yet, five years later, a survey of primary care physicians conducted by Stanford Medicine and The Harris Poll found that physicians' views on EHR had mainly stayed the same. While approximately two-thirds of respondents reported that EHR "generally led to improved care," half of the physicians noted that it reduced professional satisfaction.[108] Additionally, 74% stated EHR increased workload, 69% expressed they take valuable time away from the patient, and 49% reported that they detract from clinical effectiveness.[109] Again, the authors of this survey came to an almost identical conclusion to the one for the RAND study: "Doctors see value in EHRs, but want substantial improvements."[110] Epic—the most pervasive EHR vendor in the US—updates its software four times a year. With physician opinions remaining essentially unchanged across these five years, the hopes that improvements within the technology would eventually meet the lofty expectations for EHR remain unfulfilled.

The Interoperable Patient Record:

Many providers view the potential of seeing a patient's comprehensive record—a prospect based on interoperability—as the most promising feature of EHR. For instance, when I asked Nurse Anderson what she believed was EHR's most valuable functionality, she responded, "the fact that I could have a patient theoretically who comes from Florida, because we have snowbirds, and I could get their medical records delivered electronically into their current record if they sign a release of information."[111] Dr. Miller stated something similar, describing an

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[108] The Harris Poll, "How Doctors Feel About Electronic Health Records: National Physician Poll" (Stanford Medicine, May 31, 2018).
[109] Ibid.
[110] Ibid.
[111] Interview 2, 3/10/2022.

example case where he determined that an antiretroviral medication that a patient received six years earlier from a different HCO out of state could be a contributory cause of the patient's retinal toxicity.

Yet the ability to see notes gathered at an HCO across state lines—or even in the same city—is far from straightforward and relies on agreements between different provider sites, vendors, and patients. For example, Dr. Miller works at a medical school and a major hospital that, until recently, did not have the same EHR systems or policies that allowed for easy access to records across institutional boundaries. It was only after the main hospital decided to switch to Epic and struck an agreement with the medical school that the systems were able "to speak with" each other.[112] Dr. Miller described how the consolidation of disparate records had a substantial impact on improving the efficiency of his workflow but made an important caveat: "I will say it's all relative, right, because the degree of discordance two years ago was extraordinary. I've been at a lot of different hospital systems in the past, and having really three different EMRs across the street from each other that didn't speak to each other was just dumbfounding."[113] While providers appreciate improvements, the excitement is muted. In his book *The Digital Doctor: Hope, Hype, and Harm at the Dawn of Medicine's Computer Age,* Dr. Robert Wachter summarizes the relationship many providers have with their EHR systems as a "cranky truce."[114]

The inability to consolidate records from systems across the street from one another is undoubtedly frustrating, but the process of integrating EHR systems between newly associated HCOs is not easy. Many institutions, and even specialties within those institutions, will outfit their EHR according to a design that makes sense to their workflow. Unfortunately, this customization makes it more difficult to populate a note from an EHR that does not have the

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[112] Interview 1, 12/15/2021.

[113] Ibid.

[114] Robert Wachter, *The Digital Doctor*, 72.

same layout. When a healthcare system in Maine decided to merge its EHRs, the most contentious challenge was getting the various institutions within the healthcare system to agree on the EHR buildout. This challenge continues to plague the nursing informatics team. Nurse Martin invoked Henry Ford's famous quote—"If I had asked people what they wanted, they would have said a faster horse"—while describing the challenge of balancing the unique desires of different institutions and specialties with the need to make notes compatible within the system.[115] Thus, the diverging interests of various stakeholders become contentious in the arena of the physical technology.

Interestingly, Nurse Anderson and Dr. Miller—who both mentioned recent improvements in accessing records from outside their HCO systems—work at HCOs that are a part of Epic's Care Everywhere Network. The Care Everywhere Network is a federated HIE platform that allows providers to share patient information with other organizations associated with the Network. As of October 2017, 100% of Epic's US customers involved in clinical applications were part of the Network—consisting of 1,700 hospitals and 34,000 clinics.[116] 99% of these customers are also connected to more than 70,000 non-Epic provider sites.[117] Data exchange across the Care Everywhere Network got a significant boost during the COVID-19 pandemic, with Epic releasing statistics in December 2020 that showed the exchange of 221 million patient records in one month [118] While the Care Everywhere Network indicates hopeful progress in achieving improved interoperability capabilities nationwide, it also marks a turning point in which HIE is increasingly carried out in the private sector opposed to the public sector.

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[115] Interview 4, 3/17/2022.

[116] "Care Everywhere," HIMSS, February 7, 2020, https://www.himss.org/resource-environmental-scan/care-everywhere.

[117] Ibid.

[118] Kat Jerich, "Epic's Care Everywhere Interoperability Platform Shows Big Jump in Data Exchange," *Healthcare IT News*, December 14, 2020.

Importantly, provider sites that do not use Epic can be part of the Care Everywhere Network. According to an interview in *Healthcare Innovation,* Dr. Alison Weathers stated that “we’ve made such strides” in integrating non-Epic data into the Network. However, she clarified that “the experience is still a little bit different for data that’s pulled in from non-Epic clients. It doesn’t come across in quite the same way. It’s not quite as integrated.”[119] At one point or another, all of my interview participants used “Epic” as a synonym for EHR and, like the conflation of “Kleenex” and “tissue,” it demonstrates the dominance of Epic in the EHR market and in the eyes of providers. When comparing Epic to other EHR models, Dr. Miller told me, “it's hard to say that it's, you know, more functional, but because it's so dominant and it's just kind of what people are used to using…[that] increases the functionality of it.”[120] An article examining the “implications of an emerging EHR monoculture” describes the possibility of a future “Pax Epic,” where the vendor shapes the norms of practice for EHR use and exchange.[121] The authors conclude that Epic’s “emerging monopoly” has advantages (including the creation of common data and interfacing standards) and disadvantages (increased costs and lower competition-driven innovation) for providers.[122] Regardless of its specific pros and cons, the ascendence of Epic exemplifies the reach of data capitalism and shows how one stakeholder group can have profound effects on the others.

Completeness versus Bulkiness:

In April 2009—two months after the passage of the HITECH Act—a statement made by cardiologist Dr. Paul Yock appeared in an *Economist* article about the promise of digital

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[119] David Raths, “Care Everywhere Adding Use Cases for Epic Users,” *Healthcare Innovation*, May 19, 2021.
[120] Interview 1, 12/15/2021.
[121] Ross Koppel and Christoph U Lehmann, “Implications of an Emerging EHR Monoculture for Hospitals and Healthcare Systems,” *Journal of the American Medical Informatics Association* 22, no. 2 (March 1, 2015): 465.
[122] Koppel and Lehmann, “Implications of an EHR Monoculture,” 469.

technology: “The dirty little secret about medicine…is that we physicians make decisions all the time based on woefully incomplete information.”[123] Many providers and policy experts hoped that investing in EHR for all individuals would provide the “critical scaffolding” required to reduce this weakness.[124]

In theory, EHR technology offered by the top vendors appears to provide the software necessary to quickly input comprehensive patient information through “checkboxes, templates, and copy and paste” features, where a provider can use a past note as the template for the current one.[125] In practice, however, the constant additions of information with very few deletions create records so overwhelmed with data that they resemble a Christmas tree “sagging under the weight of many ornaments.”[126] In my interview with Dr. Brown, he explained that the provider site he worked at had developed its own EMR before switching to commercial EHR. He compared the two models, stating:

> They [the independently-designed EMRs] were really great notes. I mean, from a clinical point of view, in two pages, you would have everything you need to know about that patient. You had their complete past medical history, every test done, the results of every test, what was pending, what the plan was, and you outlined the plan so that any doctor [that picked it up] actually knew what you were thinking. I get a 13-page note now from Epic that says absolutely nothing.[127]

Dr. Miller elaborated that it takes about 50 to 60 clicks for each patient to enter all of the required fields, significantly adding to the volume of information in the record and the time it takes for the provider to complete it.[128]

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[123] “Flying Blind: Digital Medicine Will Improve Medical Care—and Possibly Revive Drug Discovery Too,” *The Economist*, April 18, 2009, https://www.economist.com/special-report/2009/04/18/flying-blind.

[124] Ibid.

[125] Wachter, *The Digital Doctor*, 72.

[126] Wachter, *The Digital Doctor*, 41.

[127] Interview 3, 3/17/2022.

[128] Interview 1, 12/15/2021.

The build-up of redundant information with little clinical utility is, in many ways, a product of the billing policies for healthcare services in the US and the role EHR serves in mediating this process. Since the creation of Medicare in the 1960s, provider reimbursement depends on the complexity of services given to the patient. More complex medical services correspond to higher-level visits, which lead to increased reimbursement by healthcare payers. While this policy may seem logical, it becomes less straightforward when inscribed in the technology. How does one efficiently and consistently measure medical complexity? The current system seems arbitrary at best. For example, entering the diagnosis of *pneumonia with major complications* into an EHR can increase the reimbursement by as much as $5,000 compared to simply recording *pneumonia*; examining nine body parts instead of eight can elevate a patient visit to a "high-level" distinction.[129] It pays more for providers to saturate records with often clinically-meaningless facts to reach the threshold of a higher reimbursement. As a result, the current EHR is designed primarily to generate a bill, not to provide clear and meaningful clinical information.

One of the main intentions for investing in a national infrastructure of electronic records was to decrease the cost of healthcare. A 2005 RAND study suggested the US would save $81 billion on healthcare expenditures.[130] Instead, due to the oversaturation of billable codes within medical records, many HCOs that transitioned to EHR increased their billing. While most of the superfluous information entered by providers is legitimate, some whistleblowers, including a premedical emergency room scribe, note the transition to EHR increased fraud. The whistleblower explained that some physicians told him to click a button denoting the counseling

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[129] Wachter, *The Digital Doctor*, 38.

[130] Richard Hillestad et al., "Can Electronic Medical Record Systems Transform Health Care?: Potential Health Benefits, Savings, and Costs," *Health Affairs* 24, no. 4 (2005).

for cigarette use when they did not actually provide this service.[131] While this is undeniably illegal and improper, Dr. Richard Wachter notes that it is part of the "ludicrous but high-stakes cat-and-mouse game" between providers and payers.[132] The reimbursement-maximizing activity reflects the breakdown of EHR as a panacea for healthcare management once inscribed into the existing technology. A theoretical win-win situation for providers and payers regarding simplified data entry processes and cost reduction becomes a lose-lose situation for both stakeholders. Providers get bogged down with clinically-irrelevant information, and billing agencies and patients often pay the price.

Billing policies are not the only contributor to the volume of redundant data in EHR. The "Meaningful Use" policies stipulate the collection and review of regulatory-mandated information. For instance, Nurse Anderson explained that a patient's medications and medical history must be "marked as reviewed." She emphasized that this is important considering that the accuracy of this information is crucial to safe and effective care. However, Nurse Anderson wonders how meaningful these policies truly are when there seems to be little oversight. She told me, "if no one's monitoring it, how meaningful is it. Like, if no one's regulating that; no one's looking that they're marking it as 'marked as reviewed,' then it seems irrelevant."[133] Dr. Miller expressed a similar sentiment, explaining that many federal requirements—such as checking each patient's smoking status—are not "necessarily metrics or parameters that are particularly applicable" to proper medical care.[134] The abundance of clicks and entries that providers must perform, and the time it takes, are direct evidence of the burden that corresponds with the multiplicity of interests inscribed in the technology. As Dr. Miller elaborated,

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[131] Wachter, *The Digital Doctor,* 81.
[132] Ibid.
[133] Interview 2, 3/10/2022.
[134] Interview 1, 12/15/2021.

> There are 50 clicks, right? How many of each of those clicks are from, you know, regulatory burdens? Some of them, right? How many of them are on data collection from the EMR specifically wanting it? And then how many of them are, you know, from like the hospital administrators, right? Those are all different interested parties that have competing interests.[135]

The effort to collect health data for many parties with varied interests translates to increased workloads for providers as the collectors of this data. Unfortunately, this arrangement has a worrisome side effect: records are often so bogged down with information that they are not compatible for efficient clinical use.

The 'Whole Patient' or an Aggregate of Parts:

The physical design of most EHR interfaces not only increases the entry times for providers but also detracts from the creation of a clear, holistic view of a patient. In a 2010 critique of electronic records, Dr. Danielle Ofri writes, "The system encourages fragmented documentation, with different aspects of a patient's condition secreted in unconnected fields, so it's much harder to keep a global synthesis of the patient in mind."[136] Some EHR systems cap certain fields to specific character counts. Dr. Ofri notes that the patient assessment field of her EHR—a vital entry, in her case, for indicating whether a patient is a good candidate for surgery—caps entries at 1,000 characters.[137] So, while the system prioritizes clicks that are often unrelated to the clinical issue at hand to fulfill billing, regulatory, and administrative purposes (for instance, Lungs are clear without crackles or wheezes), it limits fields that are critically relevant to the overall care of the patient.

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[135] Interview 1, 12/15/2021.

[136] Danielle Ofri, "The Doctor vs. the Computer," *Well* | *The New York Times* (blog), December 30, 2010, https://well.blogs.nytimes.com/2010/12/30/the-doctor-vs-the-computer/.

[137] Ibid.

Frustration with this aspect of EHR led Dr. Robert Wachter to express in a healthcare blog post that, if he were in charge of improving EHR records, it would include an "Uber Assessment" field with the following instructions:

> In this field, please tell the many people who are coming to see your patient – nurses, nutritionists, social workers, consultants, your attending – what the hell is going on. What are the major issues you're trying to address and the questions you're struggling to answer? Describe the patient's trajectory – is he or she getting better or worse? If worse (or not better), what are you doing to figure things out, and when might you rethink the diagnosis or your therapeutic approach and try something new? Please **do not** use this space to restate the narrow, one-problem-at-a-time-oriented approach you have so competently articulated in other parts of this record. We know that the patient has hypokalemia and that your plan is to replace the potassium. Use this section to be more synthetic, more novelistic, more imaginative, more expansive. Tell a story.[138]

In many ways, Wachter's "Uber Assessment" critique reflects two commonly cited and interrelated issues among providers: the deterioration of clinical information and the degradation of meaningful interactions with patients. While the relationship between patients, doctors, and nurses historically has been marked by a tremendous degree of vulnerability and trust considering the sensitivity of health matters, the transition to EHR contributed to a more interpersonal culture of clinical care.

In an influential 2008 article in the *New England Journal of Medicine,* Dr. Abraham Verghese described this digitally-induced shift in patient-physician relationships as the care and treatment of the "iPatient." Dr. Verghese explains the detached style of care resulting from digitization: "While the real patient keeps the bed warm and ensures that his folder remains alive on the computer, the iPatient's blood counts and emanations are tracked and trended like a Dow Jones Index, and pop-up flags remind caregivers to feed or bleed."[139] Verghese's account is clearly exaggerated, but it exemplifies the commonly-felt frustration among providers

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[138] Wachter, *The Digital Doctor,* 79.

[139] Abraham Verghese, "Culture Shock — Patient as Icon, Icon as Patient," *New England Journal of Medicine* 359, no. 26 (December 25, 2008).

concerning the metamorphosis of their patients from people into data points and their own professional transfiguration from care providers to clinical robots.

Furthermore, the enormous amount of information providers must enter chips away at the quality of face-to-face interactions. The 2018 Harris Poll survey found that for every half hour a physician spent on behalf of a patient, two-thirds of that time was spent on the EHR.[140] In our call, Dr. Brown came up with a similar estimation, explaining, "let's say you've got 20 minutes with a patient…whether you are a nurse or a physician. In the old days, that was fifteen minutes with the patient and five minutes charting. Now it's five minutes with the patient and fifteen minutes charting. It's totally flipped around."[141] As a result, many providers face the difficult choice of entering data during patient encounters or adding additional work hours to the end of their day, which often significantly reduces professional satisfaction. In sum, Dr. Eric Topel explains the mirrored challenges faced by both the physician and patient during these exchanges: "in the mind of the physician, a lot of insight is missing as a result of less direct communication with the patient and less ability to freely express one's thoughts. Symmetrically, the patient feels less direct contact and is often disturbed by the doctor's pecking on the keyboard and looking at the screen."[142] Thus, the complexity inscribed in EHR to fulfill various interests has downstream effects that result in the overburdening of providers and the distortion of traditional patient-physician norms.

Useability and Expertise:

Providers consistently cite poor useability and user interfaces as the most pressing technical issue facing the utility of EHR. In the Harris Poll survey, nine out of ten physicians

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[140] The Harris Poll, "How Doctors Feel About Electronic Health Records: National Physician Poll."

[141] Interview 3, 3/17/2022.

[142] Wachter, *The Digital Doctor,* 150.

stated EHR should be more “intuitive” concerning user experience, and 71% of respondents said the top short-term improvement should be to enhance interface design.[143] All of my interview participants explained that problems with the useability of EHR detracted from their satisfaction. Issues with user experience were a significant reason Nurse Anderson and Nurse Martin got involved with nursing informatics. For Nurse Martin, it started in 2012 when the HCO she works at planned to adopt Epic EHR with funds from the HITECH Act. She explained,

> In preparation for that, I could see…we were the first hospital; it wasn’t well managed, and I could see it was going to not go well. And for nothing else, I wanted to at least get myself embedded in the change because if I could make it easier for my own staff, I was going to do that. So I got myself involved, and to the point where the CINO [at the time of the adoption] asked me to manage the stabilization after the go-live because, as I predicted, it did not go well.[144]

When I asked why it did not go well, she explained it was mainly due to mismanagement and inexperience, as well as making “decisions in the dark and in a silo.”[145] Although these reasons are unrelated to usability, the concern for her colleagues' experience with using the technology prompted Nurse Martin to get and stay involved in informatics. Due to persistent problems with aligning the technology to meet the needs of each site, what was supposed to be a six-month job turned into a full-fledged informatics team. The construction of this team was largely unplanned and erratic on behalf of the HCO administrators. According to Nurse Martin, she “finally convinced leadership” that “there is no going back” and created job descriptions and a business case for her position and other specialists on her team.[146]

In this regard, many providers sense the political influences preventing intuitive user experiences. When asked which obstacles impede technological improvements, approximately one-third of providers answered, “EHR vendors aren’t concerned about improving user

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[143] The Harris Poll, “How Doctors Feel About Electronic Health Records: National Physician Poll.”
[144] Interview 4, 3/17/2022.
[145] Ibid.
[146] Ibid.

experience for physicians" and "financial interests within the healthcare industry are too entrenched to change the status quo."[147] Due to the hasty nature of EHR rollout in the US, most HCOs were more focused on implementing the technology as quickly as possible to secure the monetary incentives than ensuring that the rollout was seamless and user-friendly for staff.

Additionally, the rollout left many of the most prominent vendors free from worrying about the need to improve user design to increase sales. Strict contracts and costly ramifications for switching vendors reduce the incentive for EHR vendors to consider or address users' frustrations. Dr. Roni Zeigler places part of the blame on assumptions concerning expertise, stating: "When you're building for experts, you don't think too much about user interface."[148] He adds, "the mom using a photo-sharing program—it's going to be easy and intuitive. When health IT started, there was no consumer market. And medicine is an unusually expert-centric and somewhat arrogant field, so we were slow to embrace user-centered design."[149]

Asking for customer assistance from the vendor is no easy feat either. Dr. Brown explained that Epic is so inundated with onboarding new sites and rolling out updates that "if they respond in six months or a year, that's pretty good…. As far as customer support, especially at an individual level and at a physician level, forget it."[150] Besides staffing shortages, there is also a technical aspect that impedes quick fixes. According to Dr. Miller,

> [Epic is] not very good at adapting when there's a problem to how things are being captured because it's such a large infrastructure. So that's actually been one of the bigger issues we've had with Epic, is that they updated our system, and yet here we are a year later. And many of the things that were highlighted…that weren't nimble, or were causing problems, or inefficient, are still the same.[151]

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[147] The Harris Poll, "How Doctors Feel About Electronic Health Records: National Physician Poll."
[148] Wachter, *The Digital Doctor,* 76.
[149] Ibid.
[150] Interview 3, 3/17/2022.
[151] Interview 1, 12/15/2021.

In terms of both human and technological resources, EHR platforms are so expansive that it is challenging to troubleshoot the local problems experienced by providers. While this does not currently seem to hurt vendors like Epic—which, on average, acquires ninety new hospital additions each year—it certainly hurts providers, who must take more time away from their day to adjust to poor usability.[152]

Without customer support from vendors, many HCOs and providers have resorted to taking matters of improved useability into their own hands. Nurse Anderson stated that a large part of her informatics job revolves around making "the workflow more user-friendly for the staffers" and helping with any new problems.[153] Similarly, Nurse Martin explained that the "bilingualism" of the nursing informatics team—in that they can understand both the IT and clinical workflow components—is helpful because "when an analyst just says 'the system is just not built to accommodate that' and then closes the ticket, that's not helpful to a nurse."[154] According to Nurse Martin, the informatics team does not "shut the door and say 'you're out of luck'…they're on the ground."[155]

Furthermore, providers are often deemed "technophobic, resistant, and uncooperative" when they publicly express their frustrations with the technology.[156] For example, in a 2011 *Economist* article, the former CEO and co-founder of Athenahealth—the EHR vendor Dr. Brown described switching to at the start of this chapter—called the medical industry "anti-innovation."[157] This political back-and-forth between providers, payers, and product makers

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[152] "US Hospital Market Share 2021: EMR Purchasing Continued Despite Covid-19," Performance Report (KLAS Research, May 2021).
[153] Interview 2, 3/10/2022.
[154] Interview 4, 3/17/2022.
[155] Ibid.
[156] Ross Koppel, "Patient Safety and Health Information Technology: Learning from Our Mistakes," *PSNet Collection*, July 1, 2012, https://psnet.ahrq.gov/perspective/patient-safety-and-health-information-technology-learning-our-mistakes.
[157] "Heads in the Cloud: Digitising America's Health Records Could Be a Huge Business. Will It?," *The Economist*, March 31, 2011, https://www.economist.com/business/2011/03/31/heads-in-the-cloud.

often ends in a stalemate resulting in little technical improvement. The onslaught of name-calling has led many physicians to internalize their qualms with their computers, believing that its challenges and inefficiencies are a product of their own shortcomings. This feeling is particularly pervasive among older providers. Dr. Friedberg—one of the authors of the 2013 RAND study—explained that many interviewees began with statements such as "It must just be me, I'm a bad typist" or "I know the younger people don't have this problem, but I do."[158]

Additionally, many contracts between EHR vendors and HCOs contain nondisclosure agreements that prevent providers from speaking badly about the software in public forums. The legal principle behind these agreements is called "learned intermediaries," which asserts that physicians—and not the technology—are culpable for any harm because they are in the best position to make medical judgments.[159] This "guns don't kill people, people kill people" argument further cements the status quo by shielding vendors from liability.[160] Instead, providers are forced into the unfavorable position where they are legally liable for any damages resulting from the technology but legally silenced from demanding any changes that could prevent the problems from occurring in the first place. Dr. Koppel argues that this presents a significant "seldom voiced barrier," where "researchers and data that do not support the syllogism of *health IT equals patient safety* and *more health IT equals more patient safety* are ruthlessly attacked."[161] Thus, the invisible politics between stakeholders in the HIT network results in a toxic and—in some cases—coercive imaginary of EHR as a panacea. Yet, this imaginary prevents improvements in the existing technology and places the burden of making EHR user-friendly onto the users themselves.

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[158] Wachter, *The Digital Doctor,* 74.

[159] Ross Koppel and David Kreda, "Health Care Information Technology Vendors' 'Hold Harmless' Clause Implications for Patients and Clinicians," *JAMA The Journal of the American Medical Association* 301, no. 12 (March 25, 2009): 1276.

[160] Wachter, *The Digital Doctor,* 89.

[161] Koppel, "Patient Safety and Health Information Technology."

Disclosure and Liability:

Providers also face liability concerning HIPAA policies. As mentioned in the previous chapters, providers are "covered entities" and bear the responsibility of obtaining and disclosing protected patient information. With this responsibility comes liability: should a provider intentionally or accidentally breach HIPAA protocols, they face debilitating financial ramifications, job loss, and potentially jail time. While it is essential to hold providers accountable given the sensitivity of health information, HIPAA privacy laws lopsidedly affect providers—with many nurses and physicians considering the legislation like the "Sword of Damocles" hanging over their clinical and research practice.[162]

Furthermore, most providers feel a moral and ethical obligation to protect the privacy and dignity of their patients. However, since the design of HIPAA is primarily to *disclose* patient data securely, many providers feel frustrated by their inability to protect patient information once it leaves their hands. As Mary Ebeling describes in her book, "All the care a surgeon may take to ensuring patient privacy, by not talking about her patients in an elevator or by locking her computer with extra passwords, is rendered essentially meaningless with every bit of data that she enters into an electronic record."[163] While expressing doubt about the HIPAA Privacy Rule's ability to improve patient protections, many practitioners believe that it is their own "ethical and professional obligations, not regulatory mandates" that ensure patient confidentiality. Yet, providers must disclose patient information due to the nature of the stakeholder network and the complicated policies that oversee and cement them. Patient data is too powerful and lucrative as a commodity.

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[162] Ebeling, *Healthcare and Big Data,* 84.

[163] Ebeling, *Healthcare and Big Data,* 84.

CHAPTER 3: Finding Markets in Medical Data—How Companies Make Profits by Selling Patient EHR Information

Setting the Scene—The Ascension of Data

In the 1950s, pharmacy student Raymond Gosselin conducted research for his thesis where he analyzed trends in the sales and costs of drugs across select pharmacies in Massachusetts.[164] Gosselin hand-recorded the transactions of each medication and published the results of his compilation in an audit. His report was well-received by pharmacists, who could use the data to analyze their sales practices. Sensing a market for this information, Gosselin established the National Prescription Audit, which paid pharmacists a small sum to access their drug sale records and then published the data reports for a profit.

The agreement worked well for the pharmacists. Adam Turner, the author of *Our Bodies, Our Data: How Companies Make Billions Selling Our Medical Records*, explained, "like lumber mills selling wood chips to particle-board manufacturers, pharmacies and various healthcare middlemen could now profit from data they were producing anyways.[165] The agreement worked even better for the data companies. In the 1970s, Gosselin sold his profitable company to the healthcare research and marketing goliath IMS Health (now called IQVIA). In 2000, IMS Health reported annual revenue of more than $1 billion, derived from an expansive market research portfolio of health databases—including EHR— that provide patient health information on a global scale.[166]

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[164] Raymond Gosselin, "Massachusetts Prescription Survey [Master's Thesis]," (Boston: Massachusetts College of Pharmacy, 1950).

[165] Adam Tanner, *Our Bodies, Our Data: How Companies Make Billions Selling Our Medical Records*, 1st edition (Boston: Beacon Press, 2017), 11.

[166] Jeremy A. Greene, "Pharmaceutical Marketing Research and the Prescribing Physician," *Annals of Internal Medicine* 146, no. 10 (2007).

Although healthcare stakeholders have noted the value of data for decades, its impact was limited until the emergence of new technological advancements and the "big data" movement in the late 1990s. Currently, the term "big data" is ubiquitous in popular media, but its definition and theorization are nascent. The Three Vs proposed by Laney (2001) is a popular framework for demarcating what qualifies as big data and uses the dimensions of volume, velocity, and variety.[167] Volume denotes the magnitude of data involved. While Gosselin's National Perscription Audit used the data it received directly from a sample of retail pharmacies across the country, its successor IQVIA creates its reports from 30 petabytes (equal to 1 million gigabytes) of proprietary data collected from over 120,000 data suppliers.[168] Variety refers to the data's structure, which can fall into structured, semi-structured, and unstructured categories. 95% of big data is semi-structured or unstructured, which can be immensely challenging to render useable, but provides significant value to those who can harness it.[169] Lastly, velocity indicates the rate at which data are generated. The rise of the Internet, smartphones, and other digital technology drastically increased the volume, variety, and velocity of data.

In a 1996 essay, Microsft's founder, Bill Gates, proclaimed that "Content is King," expressing that content is where "most of the real money will be made."[170] During the dot-com bubble of the late 1990s, "Big Tech" companies primarily considered the Internet as an online marketplace for exchanging goods. After the dot-com crash in the early 2000s, however, the underlying business logic of Internet companies transitioned from "an e-commerce model

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[167] Doug Laney, "3D Data Management: Controlling Data Volume, Velocity, and Variety," *Gartner,* file no. 949. (February 6, 2001).

[168] Jonathan Foster, "Business Intelligence & Big Data: Are You Drowning or Surfing?," *IQVIA* (blog), September 27, 2018, https://www.iqvia.com/blogs/2018/09/business-intelligence-and-big-data.

[169] Amir Gandomi and Murtaza Haider, "Beyond the Hype: Big Data Concepts, Methods, and Analytics," *International Journal of Information Management* 35, no. 2 (2015): 137.

[170] Bill Gates, "Content is King," (essay, Microsft website, January 3, 1996), *Medium,* https://medium.com/@HeathEvans/content-is-king-essay-by-bill-gates-1996-df74552f80d9.

premised on the sale of goods online to an advertising model premised on the sale of audiences—or, more accurately, on the sale of individual behavioral profiles tied to user data."[171] By gathering and optimizing the massive amounts of data generated by customers using digital technologies, tech companies could gain insight into people's behaviors and work with marketers to promote customized advertisements. This new model proved to be highly lucrative, with the top six American Big Tech companies holding a collective market value of $11 trillion in 2021; accounting for more than a quarter of the S&P 500's entire value.[172] Thus, throughout the twenty-first century, data underwent the process of *assetization*—the "transformation of a resource (e.g., data) into capitalized property."[173] For digital technology companies, it became increasingly clear that while content may be the figurehead, data is the real power behind it.

It is noteworthy that a quarter of the S&P 500's value is tied to only six companies because it exemplifies that—while big data is incredibly lucrative—it is also highly complex and difficult to optimize. According to Gandomi and Haider (2015), "Big data are worthless in a vacuum. Its potential value is unlocked only when leveraged to drive decision making."[174] The capacity for opportunity derived from big data's volume, variety, and velocity requires highly advanced analytic capabilities to reap the rewards. The related factors of value and complexity create a peculiar dynamic concerning data and the actors involved in its assetization. West (2019) describes this emerging political-economic system as data capitalism, an arrangement "where the commoditization of our data enables an asymmetric redistribution of power that is weighted toward the actors who have access and the capability to make sense of information."[175] Due to its

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[171] Sarah Myers West, "Data Capitalism: Redefining the Logics of Surveillance and Privacy," *Business & Society* 58, no. 1 (January 1, 2019): 23.

[172] Sara Fischer, "The Year Big Tech Leapfrogged the Stock Market," *Axios*, November 9, 2021, https://www.axios.com/big-tech-leapfrog-stock-market-valuations-a5bfff95-85ee-43f8-841c-bf8b0ed2d33d.html.

[173] Kean Birch, DT Cochrane, and Callum Ward, "Data as Asset? The Measurement, Governance, and Valuation of Digital Personal Data by Big Tech," *Big Data & Society* 8, no. 1 (January 1, 2021): 20539517211017308.

[174] Gandomi and Haider, "Beyond the Hype," 140.

[175] Birch, Cochrane, and Ward, "Data as Asset?"

complexity, only a small subset of companies have the technical, social, political, and economic resources to leverage data and, through its leveraging, amass more political and economic power.

While data capitalism is most visible among the Big Tech giants like Google and Amazon, its reach also extends to the healthcare industry. For instance, a 2009 article—invoking the phrase "Data is King" in its title—outlined why healthcare stakeholders who embrace and invest in data management will thrive compared to those who do not.[176] The article includes a statement from Matthew Josefowicz, the founder of the insurance advisory firm Novarica: "An insurer's number one asset is the knowledge they have about their customers...It's most important to think of data as a strategic asset."[177] The US Government created HIPAA regulations in the late 1990s and early 2000s in response to the changing culture surrounding patient data. At the time, however, most data brokers were involved in prescription and insurance claims data since EHR was not widely implemented throughout the US until after the HITECH Act in 2009. Thus, most EHR-based data brokers have only been operating for a decade or less.

In the following chapter, I consider the rise of EHR data brokers within the context of data capitalism. I draw from secondary sources and an interview with two employees, Maya Light and Olivia Peterson, who work at an EHR-based software company (Appendix C)[178] Through these sources, I examine the interests of healthcare-related data brokers and their impact on EHR technology and its stakeholder network.

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[176] Pat Speer, "Diagnosis: Data Is King: The Health Care Industry Is Entering a World Where Insurers and Other Stakeholders That View Patient Data as an Asset Will Thrive," *Information Management* 19, no. 5 (2009): 20.

[177] Ibid.

[178] See Appendix C for the interview questions and more information. In this chapter, citations from the interview will be cited as "Interview 5, 4/6/2022."

Aggregating EHR Data—Possibilities and Challenges

Data brokers and other companies selling aggregate EHR data are quick to invoke the imaginary of EHR as an optimal boundary infrastructure for marketing purposes. For instance, a 2014 advertisement for IMS Health stated in a voice-over:

> Physicians need to know what medicines are effective for their patients. Researchers need to identify treatment gaps to develop more targeted novel medicines. Biopharmaceutical companies want to better pinpoint the patient groups that will benefit most from specific therapies. And hospitals must understand the total patient experience to improve efficacy and quality of care.[179]

Unsurprisingly, these advertisements argue that purchasing the company's databases and analytics platforms to evaluate patient data is the answer to attaining a desirable future where all stakeholders benefit through data-driven solutions. Furthermore, the goals described in these advertisements echo much of what was outlined in the HITECH Act and other government policies: EHR and HIT can boost clinical research, improve patient outcomes, and increase healthcare efficiency while promoting business. The sociotechnical imaginary of HIT as a healthcare panacea is on full display to help sell a product.

The value of EHR data for healthcare purposes stems from its potential for advanced analytics. Advanced analytics—or big data analytics—refers to electronic health data sets that are so expansive and complex that they are difficult to manage with traditional software and data management methods.[180] However, the successful application of advanced analytics can help determine patterns at a scale that is not feasible with traditional approaches. Analytics fall into several categories, including descriptive (what happened?), diagnostic (why did it happen?), predictive (what will happen in the future?), and prescriptive (what actions should be taken?).[181]

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[179] Tanner, *Our Bodies, Our Data,* 21.

[180] Wullianallur Raghupathi and Viju Raghupathi, "Big Data Analytics in Healthcare: Promise and Potential," *Health Information Science and Systems* 2 (2014): 3.

[181] Iqbal H. Sarker, "Data Science and Analytics: An Overview from Data-Driven Smart Computing, Decision-Making and Applications Perspective," *SN Computer Science* 2, no. 5 (2021): 377.

Each type can provide immense value to the healthcare industry if successfully applied. For instance, researchers have noted its potential for analyzing patient characteristics, outcomes, and care costs to provide the most clinically and cost-effective treatments, improving decision-support functionalities for providers, predicting which patients could benefit from preventative care, enhancing infectious disease and public health surveillance, and assisting pharmaceutical companies in identifying patients for inclusion in clinical trials.[182]

Applying advanced analytics approaches to EHR data is particularly appealing in the realm of clinical trials. Traditionally, most drug development follows a randomized control trial (RCT) design where participants are randomly allocated to either a group receiving the treatment or a control group that does not receive the treatment. Patients with particular traits are often balanced among the two groups to reduce bias and potentially confounding variables. RCTs have many strengths and are the standard practice. However, they also have shortcomings, including high costs, long timelines, comparison to only placebo or few alternative treatments, impractical eligibility criteria, underrepresentation of some groups of people, and trial effect.[183] The average trial takes over eight years between the application and approval of a new therapy, and the average cost is over $2.5 billion.[184] Additionally, it is often challenging to find a sufficient number of eligible patients for a trial, and protocol amendments can cost up to $8 million for every day of delay.[185] TriNetX—one of the fastest-growing technology companies in North America—advertises that it can reduce the number of protocol amendments by up to 50%.[186] Within the TriNetX business model, clinical researchers and pharmaceutical companies looking

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[182] Raghupathi and Raghupathi, “Big Data Analytics in Healthcare.”

[183] David C. Klonoff, “The Expanding Role of Real-World Evidence Trials in Health Care Decision Making,” *Journal of Diabetes Science and Technology* 14, no. 1 (2020): 175.

[184] Jennifer Stacey and Maulik D. Mehta. "Using EHR data extraction to streamline the clinical trial process." *Clinical Researcher* 4 (2017).

[185] John Harvey, “Why Using Real-World Data Internally During Clinical Trial Design Is a Must for Every Sponsor,” *TriNetX* (blog), August 4, 2021, https://trinetx.com/using-real-world-data-internally/.

[186] Ibid.

to acquire data or use its analytics platform must pay for a subscription to these services. Still, its data and software applications can be highly lucrative and typically offset the costs.

In response to the logistical challenges of RCTs, real-world evidence (RWE) studies are increasing in popularity and rely on big data and advanced analytics. In an RWE study, data are pulled from "real-world" clinical and healthcare settings from sources including EHR and insurance claims. The appeal of RWE is that the information stems from data that are already in existence and a close approximation of what is occurring in reality. Ms. Peterson explained that "it's not necessarily the perfect trial setting, but it's a nice way to show what's actually happening at the institution level, and how providers are treating, how they're diagnosing, and how patients are progressing in an actual healthcare setting."[187]

Furthermore, since most Americans have their information stored in EHR, access to its data can allow for high generalizability in RWE studies and trials.[188] The approach also lends itself to longitudinal research by providing the capabilities to track patients over time. Ms. Light identified both these qualities as some of the most valuable features that EHR analytics platforms can offer in terms of RWE:

> I think one of the most exciting things about the datasets we work with is just the sheer volume of patients…we get access to data to create large, physically significant cohorts that we can then analyze. And that, I think, is a differentiating factor compared to some other datasets. The other thing is that we have a pretty long length of data that we are able to look at. So, a lot of times, we'll have at least ten years of data on a particular patient. And that allows us to do really robust longitudinal analyses. So, like, we're not really limited in scope there, and I think that means that we are able to do a lot of research that you wouldn't be able to do if you didn't have that kind of large, longitudinal dataset.[189]

Ms. Peterson agreed and added that RWE is also beneficial in terms of efficiency, explaining:

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[187] Interview 5, 4/6/2022.

[188] Kimberly McCord and Lars Hemkens, "Using Electronic Health Records for Clinical Trials: Where Do We Stand and Where Can We Go?," *Canadian Medical Association Journal* 191 (2019): E128.

[189] Interview 5, 4/6/2022.

> Once we set up our processes of uploading the information or gaining it on our platform and the downloads, they're already there for us; we're not having to go out and find additional variables on a kind of ad hoc basis. It's already there. And so as long as we can answer a question within the scope of what data we have, then they can be answered relatively quickly, and it can be a nice option for all kinds of reasons…for budget; for personnel constraints.[190]

Due to the financial burdens of finding trial participants, many pharmaceutical companies and contract research organizations are willing to pay data brokers for real-world data to speed up the trial process.

That said, success in these initiatives requires rendering the data meaningful, which is an extraordinarily complicated task. Part of the challenge is structural. For one, the volume and complexity of the data contained within each EHR system are astronomical. EHR systems from the vendor Epic, for example, have a base structure containing approximately 95,000 data elements.[191] Its data warehouse, or central repository that stores the information collected from disparate sources, has over 12,000 tables, each consisting of approximately 125,000 columns.[192] Thus, only an exceptionally skilled informaticist who understands the design of each system can extract useable data elements for productive and valuable clinical research.

Additionally, clinically-relevant information is scattered in different fields, clicks, and checkboxes throughout the EHR. To make the data meaningful, informaticists and data scientists must create "computable phenotypes" through Boolean definitions consisting of thousands of diagnostic codes, prescriptions, lab values, symptoms, and clinical presentations.[193] Furthermore, many EHR fields are designed for open entries. While this format is beneficial to the provider for recording specific and relevant information about the patient, it is much more challenging to map

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[190] Interview 5, 4/6/2022.

[191] Benjamin A Goldstein, "Five Analytic Challenges in Working with Electronic Health Records Data to Support Clinical Trials with Some Solutions," *Clinical Trials* 17, no. 4 (2020): 371.

[192] Ibid.

[193] Goldstein, "Five Analytic Challenges," 372.

onto standardized terminology. Addressing this complication is an important frontier for data scientists and engineers. Ms. Light noted that one improvement with her company's analytics platform concerned "using natural language processing to extract data from unstructured fields like a doctor's note" to add data elements that are normally difficult to extract.[194] However, this initiative is still a work in progress. Regardless, the tension between the needs of providers and data brokers concerning the physical structure of EHR technology provides another example of how challenges within the EHR network are commonly treated with technological solutions.

Finally, the data must also be anonymized and aggregated to comply with HIPAA regulations. For this, data-mining companies can use software that strips PHI from EHR before it passes through the HCO's firewall. Some companies implement additional measures to de-identify patient health information. Ms. Light explained that her company goes to "pretty great lengths to make sure that we are anonymizing the data appropriately."[195] Some of these measures include rounding the number of patients from each HCO, only showing broad geographical locations, excluding easily-identifiable terms such as "car accident," and censoring information from patients who are over 90 years old or have a BMI over 40 because those criteria leave "a limited pool of patients."[196] In this way, many data brokers utilize the risk-based rationale described in Ohm (2010) to balance the utility and security of the data by making the re-identification process more challenging.[197]

Behind all these technical challenges lies a political one: EHR was not initially designed for research objectives.[198] Its primary purpose is to compile, store, and record a patient's information to coordinate healthcare services between payers, providers, and patients. Therefore,

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[194] Interview 5, 4/6/2022
[195] Ibid.
[196] Ibid.
[197] Ohm, "Broken Promises of Privacy."
[198] Goldstein, "Five Analytic Challenges," 372.

there are issues with data quality for RWE and other research applications. For instance, Ms. Light and Ms. Peterson both identified "missingness" as the most significant problem facing the accuracy of their company's data sets.[199] Data brokers and researchers can only see data entered into the record. Since the information is anonymized and artificially extracted, it's difficult to verify whether that information is a complete picture of a patient's health profile. Furthermore, while RCTs are designed to address confounding variables, it is more challenging to accomplish this process for RWE studies using aggregated and anonymous EHR data. For instance, Ms. Peterson explained:

> With EHR and really any real-world evidence data stores, we're seeing patients who are being treated in real-time, so that same randomization [in comparison to RCTs] is not going to be present naturally in patients. There's going to be a reason why one patient got one treatment, and another patient got another [treatment]. Typically providers are not just going to say, "you get this one, and you get this one." So, the flip side of the data being already accessible, quick, and easy is that there's much more work that needs to be done to address that kind of level of confounding.[200]

Selection bias can occur in instances where physicians prescribe more effective treatments to patients they deem more likely to benefit from them.[201] Meanwhile, adherence bias is possible in cases where a patient who adheres to treatment also engages in other healthy practices.[202] There can also be an imbalance of risk or protective factors among patients in the data set.[203] Each of these biases can lead to incorrect conclusions about the efficacy and safety of a treatment. According to Ms. Peterson, there are some steps data analysts can apply to correct for these confounding factors, including appropriate inclusion and exclusion criteria, stratifying by patient demographics like age and sex, and applying matching techniques based on potential confounders.[204] However, all of these methods are only partially effective.

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[199] Interview 5, 4/6/2022.
[200] Ibid.
[201] McCord and Hemkens, "Using Electronic Health Records for Clinical Trials," 175.
[202] Ibid.
[203] McCord and Hemkens, "Using Electronic Health Records for Clinical Trials," 176.
[204] Interview 5, 4/6/2022.

Finding Markets in Dysfunction:

In the context of data capitalism, the volume of information contained within EHR corresponds with significant potential for research and profit. Current data extraction for business endeavors is not as simple as it was at the time of Raymond Gosselin's National Prescription Audit, but if data agreements were once lumber mills, they are now goldmines. The financial potential of patient health data is worth the technical hurdles for data brokers aiming to market the information. However, the complexity of the data prevents most entities from leveraging the information themselves. Even if HCOs and independent researchers had access to the raw data, the technical challenges, expenses, and time constraints associated with the data-mining process are often too prohibitive. This dynamic creates a niche market for data brokers ranging from industry giants like IQVIA to recent start-ups like TriNetX. By extracting and organizing EHR information from multiple data sources to provide RWE and data analytics services to third parties, data brokers convert patient data and their associated computable phenotypes into purchasable assets. The system of data capitalism "enables an asymmetric redistribution of power" away from the patients and providers creating the data to the actors who have the capabilities to "make sense" of the information and the financially-powerful actors who can buy it.[205]

Data brokers must make agreements with HCOs and provider sites to get access to their patient data in the first place. While the purchasers of aggregate EHR data are typically willing to pay for access to the information, it is different for the suppliers. Unlike the data exchange models used throughout most of the twentieth century—where data-mining companies paid small sums to providers for the information they received—many current business models do not

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[205] West, "Data Capitalism." 20.

offer payments to the patients and providers that produce and compile the data for sale. In the case of TriNetX, the company agrees to install the necessary software and allows the HCOs to use its services and join its research network to entice providers to supply their patient's anonymized data.[206] Provider sites can make $70 to $80 thousand for each clinical trial, so the possibility of additional trial opportunities can be financially advantageous to HCOs and providers.[207] Furthermore, many HCOs conduct their own research, and access to an intuitive platform with standardized data from their institutions and others within the network is appealing when the format of their EHR is cumbersome or insufficient. Notably, the failure of interoperability policies and the dysfunctional interfaces of EHR technology force many HCOs—and the providers within each organization—to accommodate new technology and supply additional free labor to enjoy the benefits of EHR. Data brokers are successfully able to hone the dysfunction of EHR to renegotiate the relationship within the stakeholder network to their benefit.

However, tensions emerging from the stakeholder network and problems with interoperability negatively impact data-mining companies in other ways. Regarding missingness, Ms. Light stated:

> It's hard to track patients when they visit additional health care providers. Like I said, if they're seeking care outside of their usual healthcare providers, then we're not going to see that data. So, sometimes you have a really complete picture of a patient if they've received all their care within the same organization, but if they're not, then we don't see that and, like, we don't know what we don't know. So, if a patient has some data available, I won't know how much of their additional healthcare-related data exists elsewhere because I just don't see that.[208]

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[206] Umit Topaloglu and Matvey B. Palchuk, "Using a Federated Network of Real-World Data to Optimize Clinical Trials Operations," *JCO Clinical Cancer Informatics* 2 (December 2018): 3.

[207] Leslie Kane, "Clinical Trials Can Boost Your Bottom Line—Are They Worth It?," *Medscape*, June 2, 2010, http://www.medscape.com/viewarticle/720914.

[208] Interview 5, 4/6/2022.

Thus, tensions emerging from the siloed nature of the US healthcare system and the lack of incentive for EHR vendors to address interoperability within their technologies have downstream effects for ancillary research purposes by introducing confounding variables. Ms. Light also explained that because the terminology of EHR is primarily structured to provide billable codes for insurance companies, some clinically-important fields—like disease scale—are not included in a structured EHR field.[209] Similar to the problems providers face, the misalignment of clinical and billing interests reduces the insightfulness of aggregate EHR data for research purposes.

A Privacy Conundrum:

The renegotiation of data disclosure pathways and the policies and norms that regulate them have resulted in new understandings of ownership and privacy rights. In *Healthcare and Big Data,* Mary Ebeling explains that "Protected health data, taken from the bodies of patients who are dispossessed of any ownership claims over their data and its financial value, is standardized and instrumentalized through innovations made upon data, through processes such as anonymization and big data analytics."[210] HIPAA and related court cases such as *Moore v. Regents of the University of California, et al. (1990)*—which found that therapeutic innovation emerging from a non-consenting patient's medical waste nullified any ownership right—created a legal underpinning that prioritizes the utility of data over the privacy and ownership rights of the person supplying it.[211]

Processes concerning de-identification and anonymization are crucial to the ability of data-mining companies to conduct their business. Many companies accomplish anonymization by scrubbing the data of the eighteen protected patient identifiers outlined by the HIPAA Privacy

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[209] Interview 5, 4/6/2022.
[210] Ebeling, *Healthcare and Big Data,* 98.
[211] Ebeling, *Healthcare and Big Data,* 103.

Rule and aggregating patient data to obscure information that may be easily traced back to an individual. As demonstrated by Latanya Sweeney's research, the current privacy and security precautions under HIPAA are often insufficient to protect anonymized patient data from re-identification.[212] Instead, this policy officially provides a regulatory rationale for data business models and serves to renegotiate who holds power over data. The anonymization and data analytics features are considered "innovations" that transfer data ownership rights from the patients and providers to the data brokers and purchasers.[213] In this way, innovation is the mechanism by which companies with the capability to make sense of big data legitimize their ownership in a system of data capitalism. Since HIPAA does not require consent from patients to disclose their information, and providers are explicitly and implicitly forced to share this data due to legal and logistical concerns, neither the producers nor the compilers of the data have a voice in the process. According to legal scholars, privacy refers to who has the right to *control* how personal information is used and shared.[214] Ironically, a regulation called the "Privacy Rule" legally strips the right to privacy away from patients.

While the exchange and sale of health data can happen with or without the patient's consent, misconceptions concerning HIPAA and a "hush-hush" approach by data brokers keep most patients unaware of their health information's exchange and sale. Although many might know or assume other healthcare providers and insurance representatives get access to their records, few understand the magnitude of the stakeholder network involved in their health information. Ebeling writes, "when I asked the health professionals I interviewed if they knew how large the network is or how many people will handle patient data once it leaves their hands,

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[212] Latanya Sweeney, "Patient Identifiability in Pharmaceutical Marketing Data." Data Privacy Lab Working Paper 1015 (2011), https://dataprivacylab.org/projects/identifiability/pharma1.pdf.

[213] Ebeling, *Healthcare and Big Data,* 98.

[214] Anita Allen, *Unpopular Privacy: What Must We Hide?*, 1st edition (New York, N.Y: Oxford University Press, 2011).

most responded that they imagined 'hundreds of people may see a record or at least part of a record.'"[215] While many providers struggle to secure health information from another institution due to poor interoperability standards, data can be sent, used, and sold by virtually anyone once an algorithm has pulled the data and stripped it of eighteen factors.

The guise of anonymization and de-identification allows many companies involved in EHR data to avoid transparency when it comes to their business. For instance, Per Lofberg, the Executive Vice President of CVS Health, explained that "The patient is not really a component of this [data-sharing activity] because their name and connection to the prescription have been stripped off."[216] Therefore, according to Lofberg, companies do not need to alert patients about their data-sharing practices. Latanya Sweeney identifies the lack of transparency as a significant reason "personal harms" emerging from health data networks are difficult to detect.[217] In response, she created an online portal called "theDataMap," which documents the flow of personal health information through the extensive network of stakeholders that get access to it (Appendix E). Efforts toward improving privacy protections tend to focus on transparency, but there are still shortcomings to privacy improvements built solely on this notion. According to West (2015), "While transparency regulations have the considerable benefit of making otherwise invisible tracking more visible, they place the onus on the users to make the unenviable choice between opting out of services entirely…or acquiescing to the collection of their data[218] Sharing data is crucial for improving care outcomes and its inclusion in research can help facilitate impactful therapy development. For now, the influence of data capitalism on the US healthcare

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[215] Ebeling, *Healthcare and Big Data,* 82.
[216] Tanner, *Our Bodies, Our Data.*
[217] Latanya Sweeney, "TheDataMap," The Data Privacy Lab at Harvard University, accessed April 18, 2022, https://thedatamap.org/index.php.
[218] West, "Data Capitalism," 29.

system results in patients (consumers) without a choice to participate in the arrangement that profits from their data (assets). However, is a choice between two flawed options much better?

CONCLUSION:

Recordkeeping—particularly regarding health and medical services—is crucial to maximizing the efficacy and safety of patient care. In the past century, medical knowledge has expanded exponentially, mainly due to technological breakthroughs and the speed of information exchange. In 1950, the doubling time of medical knowledge was estimated to be 50 years; by 2010, its doubling time had accelerated to 3.5 years.[219] Accordingly, it is crucial to apply advanced technological solutions to ensure that the logistical support—in this case, patient record keeping—mirrors the rampant expansion of innovations and knowledge. In this view, EHR is an essential technology for contemporary healthcare. Why, then, did its implementation result in so much tension and trouble? Throughout my thesis, I indicate that its multifaceted potential regarding various stakeholder interests corresponds with the propensity for problems within the technology. My goal is not to portray EHR as an inherently *bad* technology (in fact, I believe it is a vital one) but rather to characterize it as a *flawed* technology, hindered by the competing interests of the diffuse stakeholder network in which it is enmeshed. To explore this premise, I focus on three central research questions: what purposes do EHR serve, for whom, and why are political issues concerning EHR frequently translated into technological terms?

What purposes to EHR serve?

Compared to the early clinical information systems from the 1960s, which were solely intended to boost the administrative efficiency within individual organizations, contemporary EHR and its data are meant to accomplish a wide array of objectives. Policies like the HITECH Act and HIPAA, opinions from healthcare experts, and company advertisements frequently paint EHR as the key to improving patient quality of care, boosting efficiency, reducing costs,

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[219] Peter Densen, "Challenges and Opportunities Facing Medical Education," *Transactions of the American Clinical and Climatological Association* 122 (2011): 48.

avoiding medical mistakes, increasing access to health information, harmonizing national care standards, promoting research and drug development, providing jobs, and ensuring data security. Although EHR started as a logistical tool, its potential utility—and the interested parties involved—proliferated throughout the twenty-first century. The sociotechnical imaginary of EHR as a panacea to US healthcare challenges emerges from its many goals.

For whom?

In contrast to the idealistic view of EHR as a perfect boundary infrastructure that is adaptable to the local needs of its many interested parties, problems emerge within the existing EHR technology because the stakeholders involved are focused on achieving discrepant objectives. In Chapter 1, for instance, I demonstrate how the US Government's prioritization of stimulating the economy through incentives programs resulted in the mass implementation of EHR in a manner that often disregarded clinical utility. Additionally, the implementation program inadvertently put EHR vendors in a dominant financial position where they did not have a strong incentive to boost interoperability or usability for providers. In Chapter 2, I show how EHR's primary structure as a billing system results in the contentions between payers and providers that unintentionally increase cost and lower clinical efficiency. In Chapter 3, I explain how forces of data capitalism commodify data and redistribute power from patients and providers to data brokers and purchasers. In doing so, I demonstrate how a technology primarily described as benefitting patients further strips away their control over their information. These examples illustrate the challenges of inscribing a multiplicity of interests into a physical technology.

Notably, the outcomes of many of these tensions indicate a trend where economic and financial interests are prioritized. The rollout of EHR under the HITECH Act focused primarily on creating jobs, which gave economic power to EHR vendors to control the terms of interoperability standards. EHR terminology is based on billing, simplifying the process on behalf of the payers at the expense of the providers. Regulations like HIPAA and US business practices consistently favor protecting the financial utility of information at the risk of reduced privacy instead of protecting privacy at the risk of reduced profit. The system of data capitalism redistributes data ownership from the entities that produce the information to the entities that can buy it.

Although the trajectory of EHR has typically favored the stakeholders with greater financial interests and power, these parties are not immune to the dysfunction emerging from competing stakeholder interests. The hasty rollout of EHR was costly for the US in the long term, and problems with interoperability impede other national goals, such as improved public health monitoring. Reimbursement-maximizing practices by providers heighten the costs for payers and patients. Shortcomings concerning the clinical relevance of EHR terms and poor interoperability increase missingness and reduce research quality for data brokers, purchasers, and primary investigators. Thus, challenges with balancing the diversity of interests impact all stakeholders involved.

Why are political issues concerning EHR frequently translated into technological terms?

Technological shortcomings—like poorly designed interfaces and missing data—are typically the most apparent sign of tensions within the EHR stakeholder network, even when they stem from social and political factors. In response, most demands for EHR reform focus on improving user interfaces, standardizing codes, enhancing anonymization techniques, bettering analytic approaches, and so on.

Regarding many challenges and disputes facing EHR, technological solutions offer a path of least resistance for stakeholders attempting to advance their particular interests. In the case of policymakers, invoking techno-optimist imagery of improved healthcare capabilities and a revived economy through a simple technological fix is an effective rhetorical strategy, even when those two aims are not in perfect alignment. Stripping PHI from records and tweaking inclusion and exclusion criteria strengthens the argument of data brokers that patient data is secure and protected to avoid scrutiny for profiting from the data of unwitting patients. Yet, technological solutions alone do not sufficiently address the underlying social and political tensions within the stakeholder network. It is impossible to create a system that wholly prioritizes monetary profit and clinical value simultaneously, just as it is unattainable to get complete data utility without reducing privacy. While technological solutions are important tools for streamlining the use and exchange of EHR, consideration of the sociopolitical tensions within the stakeholder network is crucial for unpacking EHR's underlying challenges. This process starts with the question: what do we value?

Looking forward:

There will be no perfect EHR infrastructure, just as there will be no panacea for healthcare issues. The ability to correct a host of issues does not mean it can correct all of those problems at once. It is essential to consider how the techno-optimistic portrayal of EHR as a perfect healthcare solution is often used as a rhetorical strategy to boost a stakeholder's aims than an accurate reflection of the physical technology.

That said, there is cause for cautious optimism. While marginal, many providers have noted improvements in the useability of the technology. Furthermore, many doctors and nurses who recently entered the field have interacted with EHR during their medical education and training, easing the learning curve for working with the technology. One study found that medical students on rotation spent 37% of each day with an EHR, increasing exposure.[220]

Although it is too early to tell, regulations like the 2021 Information Blocking Rule may help to incentivize HCO administrators and EHR vendors to move away from information blocking practices and expand the exchange of patient health information, improving care quality and coordination. Better record integration can enhance the accuracy and utility of vital research objectives concerning public health, treatment development, and health equity.

Furthermore, the COVID-19 pandemic helped to boost attention toward improving data standardization and exchange principles.[221] For instance, Epic's interoperable Care Everywhere Network saw a 40% increase in data exchange after the pandemic.[222] These forces may help ease some of the burdens and contentions emerging from EHR.

While these are hopeful signs of improvement, they still do not fully address many of the sociopolitical problems facing EHR. For example, what will happen to the quality of patient-provider interactions with providers (and medical students) spending so much of their time on the computer? Although emerging vendor monopolies may streamline standards and improve interoperability, what could happen if one financially-focused stakeholder has complete control over the use and exchange standards? How can the privacy and security of patient data be balanced with the potential to further crucial research endeavors like new drug discovery and public health surveillance? Is it ethical to allow companies to own and profit off health data from patients who are largely in the dark and cannot consent?

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[220] Jeffrey Chi et al., "How Are Medical Students Using the Electronic Health Record (EHR)?: An Analysis of EHR Use on an Inpatient Medicine Rotation," *PLoS ONE* 14, no. 8 (2019): e0221300.

[221] Frank Gao et al., "Management and Data Sharing of COVID-19 Pandemic Information," *Biopreservation and Biobanking* 18, no. 6 (2020): 572.

[222] Kat Jerich, "Epic's Care Everywhere Interoperability Platform Shows Big Jump in Data Exchange," *Healthcare IT News*, December 14, 2020.

Although these questions are outside the scope of my paper, their answers are crucial to the quality of our collective care. It is easy—as the writer of this thesis and perhaps as the reader—to distance oneself from “the patient.” However, it's a role that the majority of us embody, even if we may have other stakes in the EHR network. EHR is not going away, nor should it. Yet its trajectory will impact the quality of our healthcare, interactions with our nurses and doctors, costs we pay for services, the access we have to our medical histories, the robustness of clinical and public health research capabilities, and the privacy, security, and ownership of our most sensitive information. The problems and possibilities of electronic health records are critical to us all.

APPENDIX A: Interviews with providers.

*The following four interviews took place separately with two physicians and two nurses. The research methods were exempt from Vassar IRB review. Interview participants' names are aliases to provide anonymity.

Interview 1 occurred on December 15, 2021, with Dr. Thomas Miller. Dr. Miller is a vitreoretinal surgeon based in New York City. He mainly splits his time between surgery, clinics, teaching, and clinical research.

Interview 2 occurred on March 10, 2022, with Nurse Laura Anderson. Nurse Anderson is a Maine-based behavioral health nurse who has been in practice for over twenty years. She began working as a nursing informaticist two years ago. In this role, she provides EHR training for nurses and works to make the EHR workflow more user-friendly.

Interview 3 occurred on March 10, 2022, with Dr. Nicholas Brown. Dr. Brown is a former cardiologist and currently works at an insurance company in upstate New York.

Interview 4 occurred on March 17, 2022, with Nurse Sarah Martin. Nurse Martin is a Maine-based nurse and currently serves as the Chief Nursing Informatics Officer for a multi-hospital, integrated healthcare system.

*The guiding questions for the interviews are provided on the following two pages:

Providers Interview Questions:

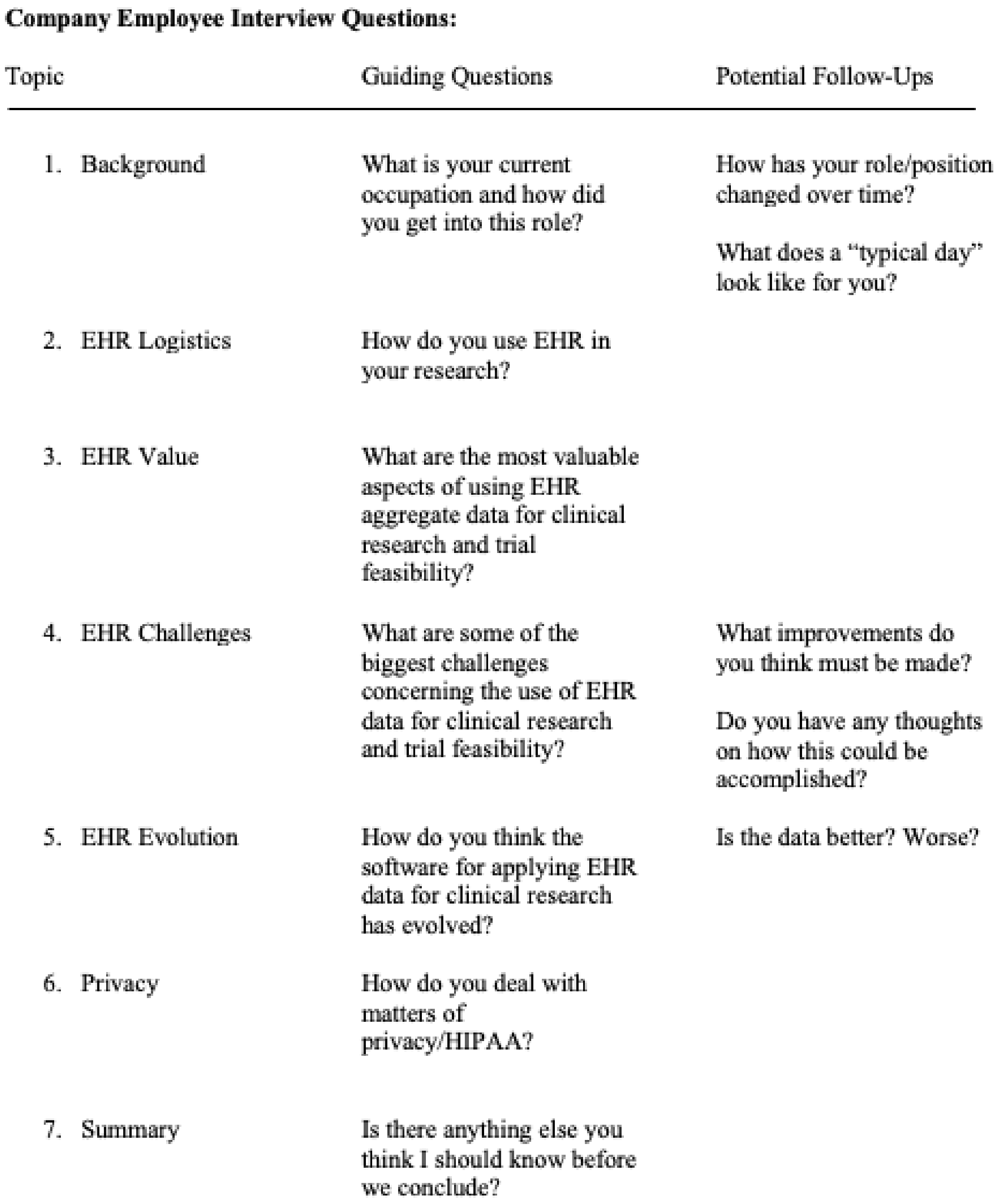
Topic	Guiding Questions	Potential Follow-Ups
1. Background	What is your current occupation and how did you get into this role?	How has your role/position changed over time? What does a "typical day" look like for you?
2. EHR Logistics	How big of a role does EHR play in your responsibilities as a physician/nurse and what applications do you use it for?	Which functionalities take up the most of your time? How do EHRs inform your field/specialty in particular?
3. EHR Evolution	When did EHRs start to become incorporated into your job? Have you always used them? How has the role of EHR in your practiced changed over time?	How many different EHR systems have you used over the course of your career? What were the reasons your HCO switched to new EHR systems?
4. EHR Value	Overall, how satisfied are you with your current EHR system and policies? Who do you think benefits most from EHRs?	Do you think EHRs are necessary/worthwhile? Which EHR functionalities do you think are the most/least valuable? Why?
5. EHR Challenges	In your eyes, what are the biggest challenges facing EHRs?	Of these which are the most pressing? Can you think of any solutions for these challenges?

6. EHR Regulation	Who do you think is most responsible for improving the functionality of EHRs (individual HCOs, EHR vendors, governments) and why?	Do you think technological improvements or policy changes would be more effective for improving EHR challenges? Why?
7. Interoperability	How satisfied are you with your EHR system's capacity to share information outside of your HCO? What are the biggest challenges impeding the exchange of EHR info?	How do you think sharing patient data affects quality of care? Have you experienced or heard about any information blocking? How big of a problem do you think this is?
8. Interpersonal Relationships	Do EHRs affect your relationship with your patients? If so, how? Do EHRs affect your relationships with other providers or healthcare administrators?	How much time of your patient interactions are spent with EHRs? In the context of the pandemic, what role do EHRs play in facilitating your relationship with patients?
9. Summary	Thank you for taking the time to speak with me about your experience with EHRs. Is there anything else you think I should know before we conclude?	

APPENDIX B: Interview with data company employees.

*This interview took place with two employees who work at a data software company that applies aggregate EHR patient data. The interview participants were Maya Light, a clinical analyst, and Olivia Peterson, a research scientist. Both employees have worked at the company for a few years. The interview took place over a video conference on April 6, 2022 (cited in the footnotes as **Interview 5**). The research methods were exempt from the Vassar IRB review and the participants' names are aliases to provide anonymity.

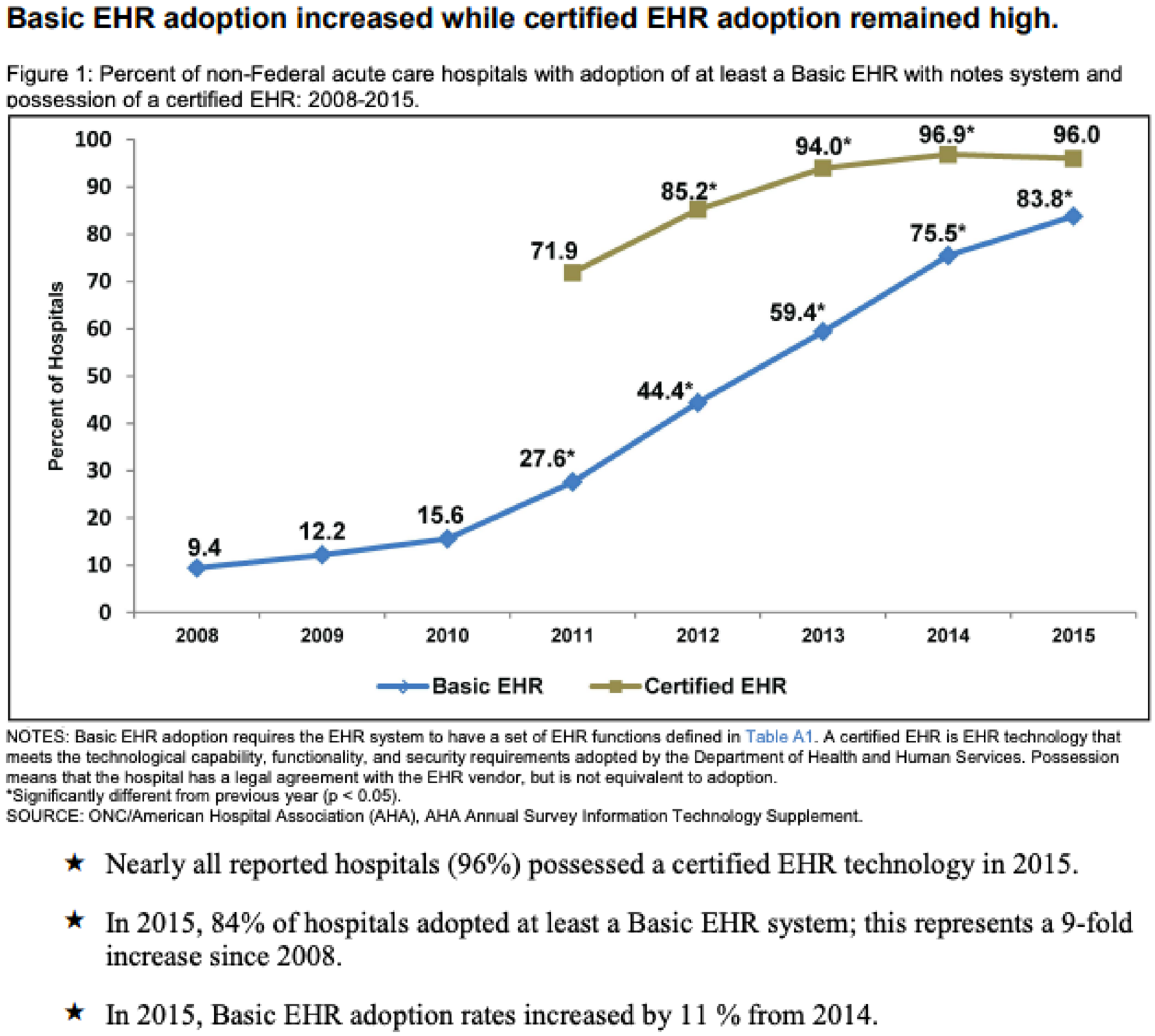
The guiding questions for the interview are provided below:



Company Employee Interview Questions:

Topic	Guiding Questions	Potential Follow-Ups
1. Background	What is your current occupation and how did you get into this role?	How has your role/position changed over time? What does a "typical day" look like for you?
2. EHR Logistics	How do you use EHR in your research?	
3. EHR Value	What are the most valuable aspects of using EHR aggregate data for clinical research and trial feasibility?	
4. EHR Challenges	What are some of the biggest challenges concerning the use of EHR data for clinical research and trial feasibility?	What improvements do you think must be made? Do you have any thoughts on how this could be accomplished?
5. EHR Evolution	How do you think the software for applying EHR data for clinical research has evolved?	Is the data better? Worse?
6. Privacy	How do you deal with matters of privacy/HIPAA?	
7. Summary	Is there anything else you think I should know before we conclude?	

APPENDIX C: EHR possession and adoption graph from a 2006 ONC data brief.[223]



Basic EHR adoption increased while certified EHR adoption remained high.

Figure 1: Percent of non-Federal acute care hospitals with adoption of at least a Basic EHR with notes system and possession of a certified EHR: 2008-2015.

NOTES: Basic EHR adoption requires the EHR system to have a set of EHR functions defined in Table A1. A certified EHR is EHR technology that meets the technological capability, functionality, and security requirements adopted by the Department of Health and Human Services. Possession means that the hospital has a legal agreement with the EHR vendor, but is not equivalent to adoption.
*Significantly different from previous year ($p < 0.05$).
SOURCE: ONC/American Hospital Association (AHA), AHA Annual Survey Information Technology Supplement.

- ★ Nearly all reported hospitals (96%) possessed a certified EHR technology in 2015.
- ★ In 2015, 84% of hospitals adopted at least a Basic EHR system; this represents a 9-fold increase since 2008.
- ★ In 2015, Basic EHR adoption rates increased by 11 % from 2014.

***For clarity, the small text below the graph reads:** Basic EHR adoption requires the EHR system to have a set of EHR functions defined in Table A1. A certified EHR is EHR technology that meets the technological capability, functionality, and security requirements adopted by the Department of Health and Human Services. Possession means that the hospital has a legal agreement with the EHR vendor, but is not equivalent to adoption.

*Significantly different from previous year ($p < 0.05$).

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[223] JaWanna Henry et al., “Adoption of Electronic Health Record Systems among U.S. Non-Federal Acute Care Hospitals: 2008-2015,” *ONC Data Brief no. 35,* May 2016.

APPENDIX D: "Meaningful Use" stage objectives outlined by the ONC.[224]

Stage 1
2011-2012
Data capture and sharing

Stage 2
2014
Advance clinical processes

Stage 3
2016
Improved outcomes

Stage 1: Meaningful use criteria focus on:	Stage 2: Meaningful use criteria focus on:	Stage 3: Meaningful use criteria focus on:
Electronically capturing health information in a standardized format	More rigorous health information exchange (HIE)	Improving quality, safety, and efficiency, leading to improved health outcomes
Using that information to track key clinical conditions	Increased requirements for e-prescribing and incorporating lab results	Decision support for national high-priority conditions
Communicating that information for care coordination processes	Electronic transmission of patient care summaries across multiple settings	Patient access to self-management tools
Initiating the reporting of clinical quality measures and public health information	More patient-controlled data	Access to comprehensive patient data through patient-centered HIE
Using information to engage patients and their families in their care		Improving population health

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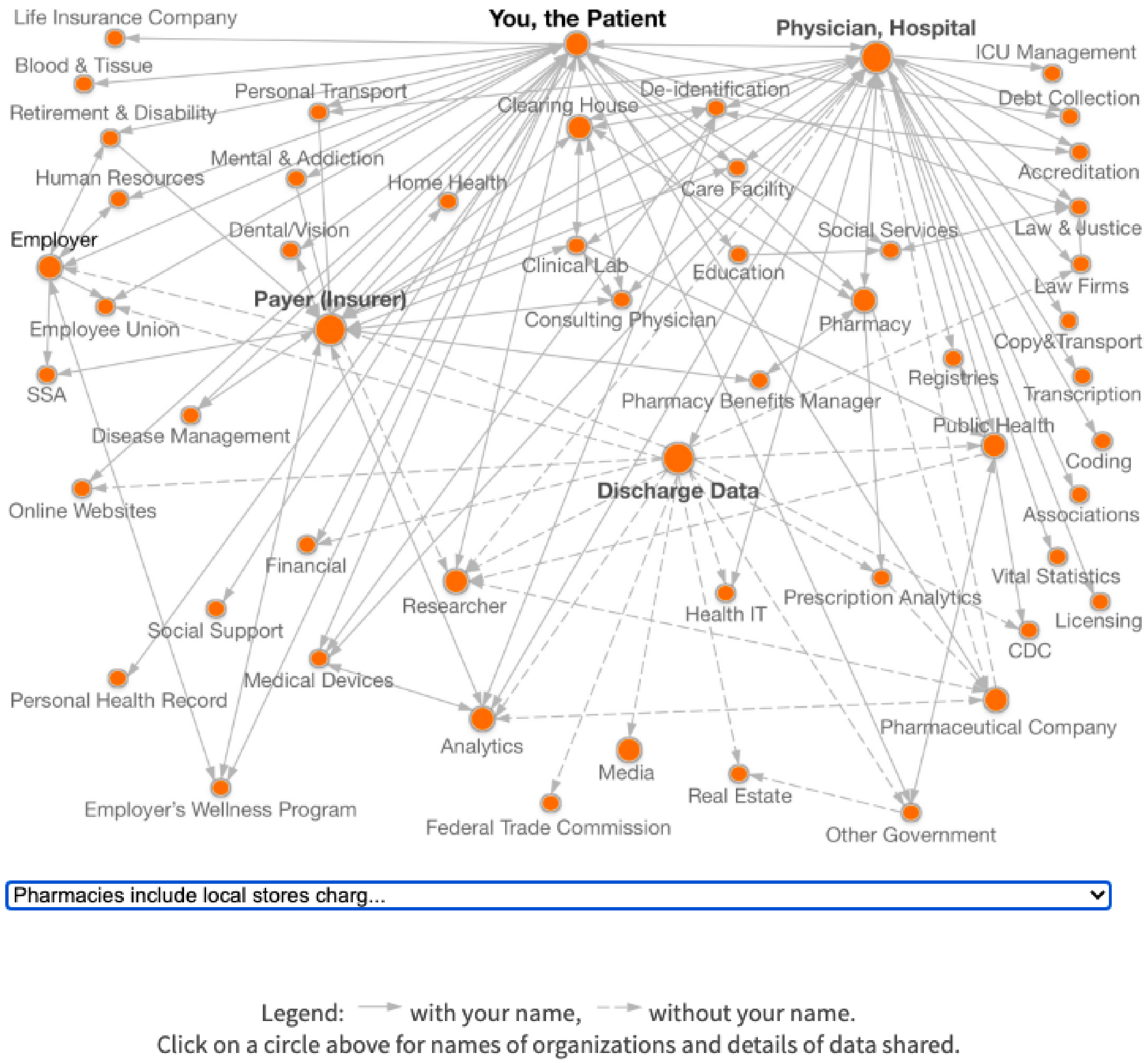
[224] Mary Butler, "Meaningful Use Opens Up Its Deep End: With Some Providers Still Dipping Toes, CMS Has Opened up Its Health IT Program's More Challenging Deep End with Stage 2," *Journal of AHIMA* 84, no. 10 (October 2013).

APPENDIX E: Network of personal health data flow.[225]



Pharmacies include local stores charg...

Legend: with your name, without your name.
Click on a circle above for names of organizations and details of data shared.

*The interactive data map can be found at https://thedatamap.org/map2013/p46.html.

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[225] Latanya Sweeney, "TheDataMap," The Data Privacy Lab at Harvard University, accessed April 18, 2022, https://thedatamap.org/index.php.

GLOSSARY OF ACRONYMS AND ABBREVIATIONS

ANT	Actor-Network Theory
COSTAR	Computer Stored Ambulatory Records
EHR	Electronic Health Record
EMR	Electronic Medical Record
HCO	Healthcare Organization
HHS	United States Department of Health and Human Services
HIE	Health Information Exchange
HIPAA	Health Insurance Portability and Accountability Act of 1996
HIT	Health Information Technology
HITECH	Health Information Technology for Economic and Clinical Health Act
HITPC	Health IT Policy Committee
HITSC	Health IT Standards Committee
ONC	Office of the National Coordinator of Health Information Technology
PCP	Primary Care Physician
PHI	Protected Health Information
RWE	Real World Evidence
US	United States of America

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