Whose Chart is it Anyway?: Autonomy, Bureaucracy, and the Infrastructure of Medical Recordkeeping

Katelyn Friedline

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Abstract: Electronic Medical Records (EMRs) serve as an infrastructural network that support and record some of the most intimate details of individuals' lives, while the companies that maintain this infrastructure remain relatively hidden from public scrutiny. These infrastructures are designed to support institutions and medical providers and rely on patients' sensitive data, while ignoring patients' perspectives themselves. In the last two decades, fed by government incentives to digitize recordkeeping, this infrastructure has ballooned in size and allowed the EMR market to be dominated by a few major players without significant oversight.

This thesis argues that the medical records application MyChart, which holds over 35% of the global medical records market share, should be considered a platform, as defined by Gillespie (2010), even though the actors involved may not exactly mirror those of large social media platforms. I argue that in viewing MyChart as a platform we can then consider it "gray media" (Fuller & Goffey 2012), meaning that it is media that is mundane and that mundanity serves a purpose towards furthering the aims of the platform. As Fuller and Goffey state, "Grayness is a quality that is easily overlooked, and that is what gives it its great attraction, an unremarkableness that can be of inestimable value in background operations", which in the case of MyChart has allowed it to amass a substantive amount of sensitive user data while going relatively understudied. Through using the methods of platform and infrastructure analysis (Gillespie 2010, van Dijck 2018) this paper will excavate these EMR and data infrastructures that have been intentionally grayed and explore the reasons why this has happened.

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Introduction

The first time I was aware that I had a medical record was when I was seven years old and had broken a bone for the third time. My orthopedic surgeon, who had pieced my hip and femur back together when I was four, was setting up my soft cast for my upper arm and remarked “you have a record thicker than most 16-18 year olds I see”. That was the first time I thought about my most painful moments being recorded, and I remember being both intrigued and freaked out with that thought. The idea that my experiences were being recorded by someone other than my parents, and that there were judgements, even lighthearted ones, being made about the number of medical encounters I had had surprised me. Though as I continued to interact with the medical system I grew more used to this reality.

In contrast to the rather lighthearted first encounter with my medical record, the first time I heard of MyChart was during one of the scariest medical moments of my life. The morning after my 20th birthday, I woke up with spreading numbness, tingling, and vision changes and was understandably terrified. When my friends drove me the hour to the UAB ER to get a barrage of tests run, I was told by the Emergency Room doctor to prepare myself for a multiple sclerosis (MS) diagnosis and left with a referral to a neurologist. Suddenly, I was twelve hours away from my family and trying to figure out how to research and find a trustworthy specialist when I had only made a handful of doctors appointments on my own beforet. After I was squeezed in to an earlier appointment by a sympathetic administrator, I remember arriving terrified for my appointment and then being given an iPad and prompted to sign-up for MyChart. I completed the necessary steps without asking any questions. While it was a few months later that we confirmed it was not MS and I left that neurology practice with no real explanation for my symptoms other than “maybe chronic Lyme disease,”

It was three years later that the MyChart account I made would reappear. I was seeing a neurologist about my continued numbness, tingling, and needle stabbing pain and we were discussing my medical history when he said “Oh your previous neurologist states in her notes that this could have been brought on by anxiety.” I had grown used to the manual process of transferring records at this point, and knew I had not yet done that for this office, so I was confused on how he could see that already. He explained that since their office also used MyChart, the records had moved with me, and which “makes things a breeze these days”. While this transfer certainly did save me some phone calls and paperwork, I remember being unsettled that this had all occurred without anyone speaking to me, and that note from my old neurologist about anxiety resulted in multiple follow up visits before my new neurologist even agreed to consider non-psychosomatic causes.

About MyChart

MyChart is an online patient portal, owned by Epic Systems, that stores patient medical records and offers a variety of health management tools that allow patients to interact with their providers without having to visit or call their offices. MyChart’s parent company, Epic, was founded as a medical software company in 1979, and the company summarizes their mission as “Epic develops software to help people **get well**, help people **stay well**, and help future generations **be healthier**” (Epic Systems). MyChart currently has over 305 million people within its system, and is the leading electronic medical record (EMR) software in the United States with a market share of 35.9% and 47.9% of US hospital beds (Becker’s Hospital Review, 2023).

Earlier this year, Epic Systems announced their new partnership with Open AI and Microsoft to bring the efficiency and time-saving benefits of generative AI into electronic medical record keeping. The company has announced a few different initiatives involving

generative AI, the first of them being a partnership between Nuance, a well-respected voice dictation software, ambient AI, and MyChart. This new tool would allow providers to switch on the voice dictation tool supported by ambient AI and transcribe full patient encounters. They would then have a draft write up of the encounter to approve following the patient visit. The involvement of AI in this case would be to constantly be listening and clarifying the voice transcription for tone and clarity. Additionally, Epic has announced other potential implementations of generative AI, such as generating responses to patients and filling out parts of the electronic medical record for providers. While these new announcements certainly promise increased efficiency for hospital systems and providers, and these softwares promise HIPAA compliance, there is room for apprehension around the security and privacy aspects that these new integrations could bring into the field. Since widespread AI adoption is still a relatively new phenomenon, it is important to look at these announcements critically and consider how the majority market share that MyChart has also may impact consumers' ability to opt out of these new implementations.

Background Information

Zooming out a bit, In order to understand the nuances of MyChart and Electronic Medical Record digitization it is first necessary to understand what is an electronic medical record. An electronic medical record is a digitized form of a patient's medical file. These digitized files can either be referred to as electronic medical records or electronic health records and while there are preferences for one term over the other for some providers and companies the field as a whole generally agrees that the two terms are interchangeable. EMR digitization has been a topic within the healthcare and Healthcare IT Industries over the last 25 years, but the massive push to digitize medical records happened with the passage of the Affordable Care Act

under the Obama Administration. The Affordable Care Act budgeted around thirty million dollars in incentives for healthcare providers and hospitals that met a meaningful use threshold of digitization, meaning that they had digitized their records and were using predominantly digitized records at the time of filing for a claim through Medicare or Medicaid. If they met this threshold they would then receive an increased Medicare or Medicaid payout as an incentive for their digitization. As of 2021, three out of four physicians and nearly 96% of hospitals had adopted electronic health records and nearly all of the promised incentives have been dispersed following the movement through the three different stages of increasing thresholds for meaningful use. These incentives to digitize directly created the increased demand for EMR software and storage solutions which has created the EMR Market that MyChart thrives in.

Critical Media Studies & STS

This work will be in conversation with and is built upon scholarly work in the area of platform studies, mainly the work of Tarleton Gillespie and his piece "The Politics of 'Platforms'" (2010), in which he argues that platforms are not neutral and, in fact, exert politics and privilege certain information for their users as well as create affordances that allow certain information to proliferate. This work will also be in conversation with the work of Josié Van Dijik, whose research about big platforms and their broader social, political, and legislative relationships to their surrounding societies analyzes the power relationships that are inherent in these systems. This project will also be in conversation with the field of Infrastructure Studies, which as a whole studies the fact that infrastructure and its artifacts have politics, absorb the politics that we build into them, and will continue to exert those politics upon users long after their creators have passed. Mainly, this project will focus on the work of Langdon Winner, who argues that artifacts have politics, and the work of scholars like Latour, Sandvig, and Parks, who

all analyze technology and technological infrastructure as places of political engagement and power negotiation. This research will build on and be based around Fuller and Goffey's framework of gray media, which is media that is mundane, bureaucratic, and wields its mundanus as a tool to maintain power or to obscure functions. More broadly, this work will also draw on other scholarship centering around bureaucracy and media studies, primarily that of Melissa Gregg, to better analyze how these bureaucratic artifacts function differently than their entertainment counterparts. Finally, this project will center the work of scholars that study media studies, medicine, and the body, which focuses on the media technologies that are used both within medicine and portrayals of medicine. Lisa Cartwright's work on screening the body analyzes medical imaging, medical imaging technology, its relationship to embodiment, while the work of Ostherr furthers Cartwright's work in her piece called Medical Visions. Finally, the works of Turow, Reagan, Tomes, and Treichler deal with the way the field of medicine is portrayed within media and how the image of medical providers is constructed in an entertainment context.

Disability & Critical Access Studies

In order to better contextualize and ground my work I will also be informed by texts from Disability Studies, Disability Studies on Surveillance, and Critical Access Studies. *Feminist, Crip, Queer* by Allison Kafer expands the social model of disability to better account for the politics of disability, as well as incorporate pain, and those disabled people that live with pain that may wish to be relieved of it, into discussions of disability. Additionally, Kafer explores the concept of "crip futures" and how current power structures envision progress as removing disability, and proposes a political/relational model of disability that is a useful foundational theory. *Discipline and punish: the birth of the prison* by Foucault explores the history and

development of the modern prison system, and is a helpful theoretical text when considering bodies, surveillance, and institutions. I feel that this text will be useful in supporting my discussion and analysis of the texts relating to privacy and surveillance, and it will hopefully aid the broader analysis of the central themes I am exploring historically and in the present. This discussion of Foucault and surveillance will also be supplemented by Tremain's book, *Foucault and the Government of Disability*, which expands on Foucault's discussions and places them directly into conversation with the work of disability studies theorists. While Saltes' article "'Abnormal' bodies on the borders of inclusion" focuses on disability surveillance in the context of Canadian immigration and biometric technologies, it does provide an incredibly useful framework for considering the surveillance of disabled bodies. I hope to use this in my research to further theoretically ground and situate the surveillance related pieces of my research into disability surveillance. Ellen Samuels' stellar article "Anomaly to Alarm" considers the surveillance of disabled bodies specifically within TSA airport security; however, it is foundational for considering how society and systems categorize non-normative bodies. This thesis will also be deploying work from the emerging field of Critical Access Studies, which draws on intersectional approaches to disability studies, crip theory, and disability justice to explore how users are conceptualized within the built environment. While Hamraie's book names and defines this growing field, they build of the work of a number of incredible disability and accessibility focused scholars like Elizabeth Ellcessor, whose book *Restricted Access* explores accessibility and universal design in online spaces, as well as the work on concepts of accessibility by a number of other scholars (Margaret Price, 2011; Jay Dolmage, 2017; Remi Yergeau, 2017; Mia Mingus, 2011).

History of Medicine

Additionally, I am informed by a number of foundational texts to the field of History of Medicine which explore the histories of how medicine developed into the industry that it is, and details the histories experimentation and disabled people with the field. Within the general field canon, this thesis is informed by Bynum and Duffy's overviews of the broader history of medicine. Beth Linker's essay, "On the Borderland of Medical and Disability History: A Survey of the Fields.", showcases to other medical historians where disability appears in medical history and demonstrates how medical historians can incorporate disability into their own work. Since I center disability in my thesis work this text provides an invaluable guide to how best to do that work, and allows me to better think through all the ways I may be missing disability in the medical history of it all. This text serves not only as a deeply essential background text for the history of medicine parts of my thesis, but also helps support and connect the various fields my work is grounded in. Other History of Medicine texts that explore the economic, educational, and technological histories of the medical field also serve to support this thesis. In the *Birth of the Clinic* Foucault dives into not only the history of medical clinics, but additionally how medicine assembled itself as an institution, both physically and ideologically, which further illuminates the relationships between the government and private healthcare companies that this thesis explores. Foucault's work is extended by Starr where he provides a broader history of the political, legislative, corporate, and social powers that shaped the practice of medicine into the medical industry that we know today. In order to accurately conceptualize how technology companies that serve the medical industry fit within the broader history of the medical field I need to grasp how these other histories played into constructing the institution that is medicine. The thesis will also be informed by histories of medical education (Ludmerer, 1985) and multiple texts on medical records role in medicine (Sandelowski, 2000; Risse & Harley Warner, 1992; Harley

Warner, 1999; Porter, 2018) Lastly, looking at the history of technology in the medical field I will be drawing from Greene's most recent book, *The Doctor Who Wasn't There*, which analyzes the relationship between doctors and technology through the lens of Tele-health, and explores the social and technical histories of medicine and electronic technologies and how they fed into and constructed our current medical moment involving Tele-health. Also, Howell's *Technology in the Hospital: Transforming Patient Care in the Early Twentieth Century* explores how the advent of new technologies in the 20th century changed and altered the medical field and medical care itself. Howell chronicles how these new medical technologies were used in practice, and uses this history to speculate how the current (at the time) technological medical moment would play out which provides a useful history that was more current to the initial rise of EMRs.

Research Focus and Methods

This thesis offers a modern history of medical record keeping, with attention paid particularly to the social and economic histories that have shaped this process, and how these factors gave rise to MyChart and its status as a platform. I will be using a variety of methods to approach this question, specifically archival, walk-through, close-read, and platform analysis methodologies.

Looking Ahead

As we move beyond this introduction, I will briefly map where this thesis is headed. In Chapter 1, I will first explore the history of Electronic Medical Records and how we arrived at the current EMR infrastructural moment, and use textual analysis to greakdown new patient intake form templates for their infrastructural similarities. In Chapter 2, I will use the walkthrough method to analyze MyChart's current affordances and barriers as I create a new account. Moving into Chapter 3, I will then draw on theoretical work of platform and

infrastructure studies, sociotechnical systems, and media studies scholarship on gray and bureaucratic media to argue that MyChart is both a platform and a bureaucratic media that has been intentionally grayed in order to maintain increased power. This will all be wrapped up by the Conclusion, which will summarize the findings of this work, discuss limitations, and forecast future work that needs to be conducted on the topic.

Chapter 1

Introduction

In order to effectively understand MyChart and the current cultural context in which it sits, it is important to look backward to see how MyChart fits within a history of medical industrialization that started long before the MyChart portal we know today. In order to understand this moment with MyChart, it's important to understand how the industrialization of medicine and the rise of third payer insurance systems created a demand for technological innovation in order to create market competition when price competition was ineffective. This built a narrative of automation and efficiency into medical care that then contextualized a lot of the same narratives that we currently see present in the discussion surrounding MyChart and the legislation that allowed it to rise to market dominance.

First, we will look at how the medical system as we know it today came to be structured around the hospital, which as Guian McKee argues, is the least efficient and most expensive form of specialized medical care. We will then look at the rise of patient care standards that defined how doctors were specifically meant to practice and their standards of procedures, the creation of medical boards and associations, and the standardization of medical education. Moving beyond these three building blocks that established the medical industrial complex, it is important to look at the rise of insurance and the movement of third party payment and capital within the medical system, as well as how creators of the third party payer system envisioned a consumerist American patient to be a check and balance on the rising cost of the healthcare system. Along with what this third party payment meant for rising market prices within healthcare and how the market competed when competition based on price was unavailable. Finally looking within this, we can begin to see threads of demands for automation and

technological improvement as means of competition within these burgeoning major medical centers that establish a thread of the need to make care more efficient and more technologized.

Moving beyond this broader history of the medical industry, we can then look specifically at medical record keeping using pre-electronic medical records. So by initially looking at the history of medical forms and new patient intake forms, as well as some of the technological origins of healthcare technologies outside of specified treatment machines, we can then begin to see some of the contours of technology's relationship with the more modern medical system within the US take shape. Finally, we will then look at how the rise of digitization and the creation of an electronic health record, as well as attempts at how interoperability shaped the current infrastructural moment with health records, through looking at the history of Epic Systems, the parent company of MyChart. This will trace the relationship between the Affordable Care Act and Electronic Health Records, movements to create interoperability between EHR systems, the years post this move to digitization and the rise of market leaders within the EMR market, the effect of COVID on the prevalence of an electronic medical record keeping system and the expansion of offerings within these EMR systems such as telehealth or expansions into medical research. Then finally this will showcase how that has set the stage for current developments within the implementation of generative AI within medical record keeping. Lastly, to better contextualize the broader contours of medical forms and the electronic medical record infrastructure, we will analyze and scrutinize the common infrastructural shapings of new patient intake forms across a few different medical centers.

Hospitals as Centers of Healthcare

The move from medical practice as a largely decentralized practice into the modern healthcare system that we know today can best be explained around the rise of hospitals as

Charles Rosenberg and Gillian McKee detail in their respective books, *Care of Strangers* and *Hospital City, Healthcare Nation*. They each trace complex social, economic and political histories that structured hospitals at the center of the US healthcare system, as a spoke and wheel model that was built centering around the hospital. The interesting thing about this model of care is, McKee argues, that when considering different kinds of medical institutions in which to center the US healthcare system around, hospitals are the most expensive and most highly specialized form of care (McKee, 24). Hospitals require significant amounts of land to build, capital to construct, people to employ, and they employ greater degrees of specialization within doctors as well as require increased technology. Therefore choosing to center the medical system around hospitals was a complex process that involved a large number of stakeholders, including different lobbying groups, political entities, policy decisions, and funding choices.

McKee argues that the rise of the hospital as the center of the US healthcare model rose to prominence at the same time that third party insurance was becoming a factor within the United States Medical System. The unique market forces that are at play with hospitals allowed the introduction of third party insurance to allow them to grow to the scale that they exist at today. A distinguishing factor about the rise of hospitals at the center of the US healthcare system is the lack of traditional market forces that govern healthcare within the US as compared to other sectors. As McKee details, the healthcare market cannot compete in terms of price for specific procedures for screening because of regulations around price based competition between healthcare systems. Therefore hospitals had to develop an alternative means of competition and distinction from their competitors. This created a technological arms race of both increased adoption of new medical technologies as well as specialization within employment of their doctors to differentiate different hospital systems from one another for competition sake (McKee,

69). It was because of the cost of specialization and adoption of new technology that hospitals needed to gain access to alternative sources of revenue outside of just that generated from treating patients. Hospitals investing in capital meant taking on bonds and debt, and it fundamentally altered the way in which hospital systems behave. Yet this also gave hospitals the means to continually acquire more and more specialized technology and to implement newer technological protocols so that they may have a means to compete with their peers.

Health records, EHR history

Patient management at these major medical centers had to involve some kind of standardized process and information gathering. This birthed the intake process–and the forms associated with it–as a patient's first exposure to a new medical office. How that process is designed and conducted can have large effects on patient comfort and security. NexHealth defines the patient intake process as "the method by which healthcare practices collect patient information, including demographic, medical, and social data; insurance and payment details; and consent forms that are essential to the onboarding process" (Nexhealth). In order to properly understand modern medical intake forms, and the medical history they collect, it is essential to understand the history of collecting medical histories and how they became integral to the practice of medicine. Julie Epstein defines the patient's medical history as having a distinct structure that involves elements from ethnography, biography, and chronicle. Epstein details this history by beginning with the Hippocratic cases in *Epidemics* as the first instance of "formal case recording in the West" (Epstein, 24). Moving forward in this history of medicine, Epstein states that:

> "The general historical assumption has been that medicine remained a bedside or protoclinical practice until the French

> Revolution, at which time the *clinic* — or modern hospital medicine — was born… … The hospital could become a new site for clinical experience and for the production, accumulation, and reproduction of medical knowledge only insofar as institutional records could be kept and conventional expectations and formal requirements for these records could be established." (Epstein, 26).

This emphasis on formal requirements for these patient records and histories in order to legitimize medical knowledge is the major point of interest for this chapter as we explore how these documents can function as infrastructure and what politics they may imbue into their users.

That is a broad history of forms prior to the conception of digitizing health records, but as Jeremy Greene and Joel Howell detail, electronic health records are not a new technology without a historical lineage. This history begins with both the conception of technology within healthcare, which we've traced through, but also the fear and promise of computers taking over certain parts of providers' jobs. Jeremy Greene begins this technological history with the telephone and then moves forward all the way to the electronic health record. Greene discusses the origins of phoned visits between providers and patients, as well as computer-assisted one stop shop patient evaluation centers all the way to the creation of the electronic health record as a means of greater efficiency, reducing bureaucratic workload and standardizing patient experience even further (Greene, 243). It is this technological history that takes us to the more modern history of the market factors that allowed for the rise of the electronic health record. So when considering the history of electronic health records, looking at the history of Epic Systems, MyChart's parent company, can illustrate their broader growth. Judith Faulkner, the founder of Epic, began as a student at the University of Wisconsin, Madison, in 1965. She happened to

arrive on campus at the same time as Warner Slack was building one of the first computer terminal interfaces for the direct entry of patient records. Faulkner enrolled in Slack's graduate class and became deeply engaged with this idea of computers and information technology and its relationship with medicine. Moving beyond her education at the University of Wisconsin, Madison Faulkner then became engaged with researchers with the Harvard Medical School. She was introduced to the MGH User Multi Programming System (MUMPS). She then used MUMPS to found her own firm in medicine and the first application that she created was a way to arrange physician call schedules. This application came out of her work with a medical resident at the University hospital, who had received complaints about existing call schedules showing signs of favoritism. Faulkner created algorithms that promised equity with a code to allocate call schedules by computer.

In 1979, Faulkner and the medical resident she'd been working with founded Human Services computing, which was then later renamed Epic in 1983, and they began to track patient data instead of provider schedules. Over the course of the 1980s and 1990s, their company grew, especially as this coincided with the shrinking of mainframe computers down to smaller computer sizes. They then grew and added new layers of functionality, such as reimbursement, software staffing, lab reports, pharmacy, and ER scheduling. Then in 2009, when the United States government, through the Affordable Care Act, allocated $30 billion for hospitals and clinics to switch to electronic medical record keeping through the Health Information Technology for Economic and Clinical Health (HITECH), Epic was one of a small handful of companies that had all of the technological infrastructure available to be perfectly poised to take advantage of this new legislative moment. As Jeremy Green details, this was not by accident as Faulkner had helped shape the contours of this new policy as a member of President Obama's

Health Information Technology Policy Committee (Greene, 245). It was the HITECH Act that accelerated the adoption of electronic medical records because it provided both additional stimulus money to hospital systems that chose to digitize and also created a standard that if providers that did not digitize their records they would receive less of a payout from Medicare and Medicaid until they digitized. Following the passage of the HITECH Act, the use of electronic medical records between 2008 and 2014 grew from fewer than 10% to more than 75% (Greene, 245), and with that Epic and its product, MyChart, gained significant market share.

Beyond the rise of Epic as an individual company, when electronic health records became more widely adopted, it also brought up questions of interoperability between these major electronic medical record systems. While within the Department of Health and Human Services, the Office of Federal Healthcare IT has worked with stakeholders to try and establish an interoperability framework between these major companies that provide electronic medical record services, interoperability between company systems has not yet been achieved. This means that currently each of these systems operates with a different coded format for their electronic medical record, and while these records may be moved and transferred between systems there is still not a standardized process that allows for patients to move these records completely freely. One of the major attempts at this interoperability was the FHIR framework which attempted to establish a set means of structuring the electronic medical record file so that patients could move their information more freely between these systems. The framework is in its infancy of implementation, and while there has already been mass adoption of the FHIR Standards, time is needed to see how effective this solution will be. Additionally, this lack of interoperability between systems is not to be mistaken with the interoperability that exists between hospital systems that use the same electronic health record provider. For example with

MyChart, hospital systems across the country that use MyChart have complete interoperability between their systems, even if they may have certain individual settings toggled on or off, dependent on the healthcare system itself.

Looking at the more current moment following this incentivization to digitize and attempts at interoperability, currently MyChart occupies about 35% of the US market share for electronic medical records and that market share represents 47% of hospital beds. When combined with the market share of their next closest competitor, Oracle and Oracle's product Cerner, these two companies occupy 65% of the US market share and represent 75% of hospital beds (Becker's Hospital Review, 2023). This becomes significant, particularly following the demand for digital means of medical care, following the lockdown proceedings of the COVID-19 pandemic and the greater reliance on telehealth as well as general accessibility of electronic apps within user cell phones. Now looking at where MyChart has expanded beyond offering storage of medical records, they position themselves as a central platform for care, providing end of life service care, end of life advice, holding of test results, advanced directives, visit scheduling, virtual care appointments, immunizations, and have aimed to centrally situate themselves within the patient experience within medical care. In addition they are beginning to provide greater offerings to medical systems and providers to help with increasing efficiency by lowering bureaucratic demands on providers and aiding medical research through the Cosmos data set, which boasts 224 million unique patients and over a billion patient encounters of the participating hospital systems that can be used for medical research. Additionally, they've now made announcements in Summer 2023, that they plan to implement generative AI within the electronic medical record as a means of creating even greater efficiency and automation. Their reasoning for doing so is these same threads that we've seen traced through to these much older

histories, as it is meant “To help aid providers and reduce burnout and allow them to see more patients.”

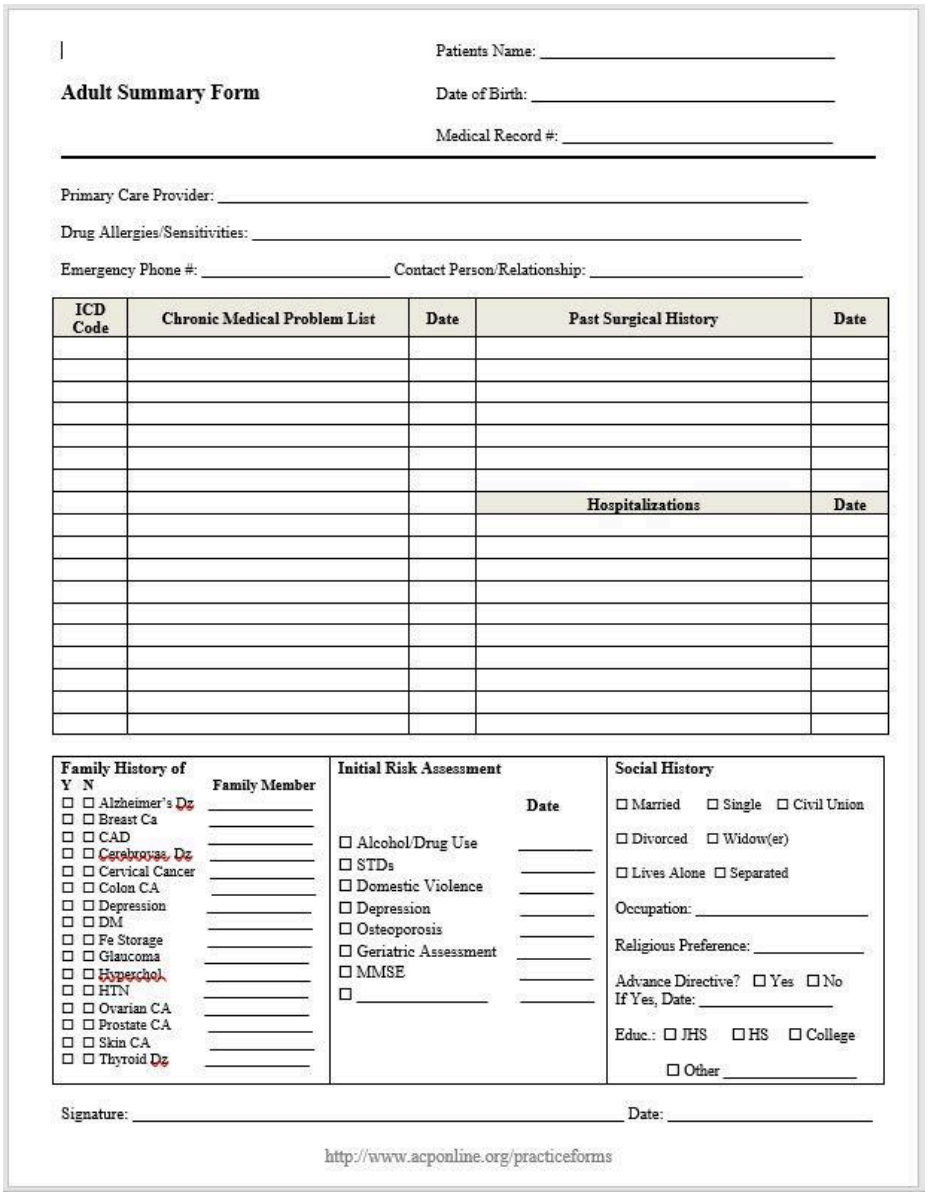
Form Analysis

Moving beyond medical forms, electronic or otherwise, as a broader history, looking more granularly now at individual medical forms can be useful for more considered analysis for how the infrastructure within these systems began and endures. While individual documents may not seem on the surface to be particularly enduring, the underlying standardized structure of patient intake forms that serves to facilitate the transfer of patient medical information falls within the definition of infrastructure. A simple definition of infrastructure is “infrastructures are systems composed of social and technical elements that transport material and information. They are standardized and repeatable” (Carter, 71). Within the field of Science and Technology Studies, many scholars have looked at infrastructure and its ability to transfer information, but also politics as a point of interest. Scholars such as Bruno Latour and Langdon Winner, as well as many others, have worked to demonstrate how these large scale systems exert agency over people and other objects. In Langdon Winner’s classic example, the Long Island overpasses in New York were designed by Robert Moses to be a low enough height so as to prevent buses from being able to drive under them, thus preventing low income and non-white citizens from being able to access those areas (Winner, 123). Due to their nature as a means of transferring object or information, medical intake forms as a system and the impacts of their structure may not have been investigated before. Which is why STS’s study of these objects and systems, that may not initially be regarded closely, is useful when scrutinizing them.

In addition to looking at the system of standardized medical intake forms as infrastructure, it is useful to analyze the documents themselves. Media studies scholar Lisa

Gitelman defines documents by stating “any object can be a thing, but once it is framed as or entered into evidence – once it is mobilized – it becomes a document, an instance proper to that genre” (Gitelman, 3). This definition points to a clear requirement of medical intake forms, that while any medical history can be a thing, it has to be recorded in the genre of intake forms to be a document. This formating can have further reaching impacts than one would naively expect, as explained by psychologist Patricia Wright when she said “The critical features of layout lie in the relationships (spatial and typographic) among elements. The crucial part of this relationship is the way they can change a variety of reading activities. Sometimes even having consequences for meaning” (Wright, 8). Wright explains that certain decisions we make in headings, font, character weight, etc. may lead readers to skip over necessary information entirely or interpret different meanings than the author intended. In addition to the format of the document giving the information weight, Gitelman argues that “documents are integral to the ways people think as well as to the social order they inhabit. … In the modern era, documents have cultural weight mostly according to their institutional frames – the university, the corporation, and the state, for example – however remote the contextual framework can seem” (Gitelman, 5). The medical system, particularly in the United States, wields tremendous social power, and thus the medical intake form and its layout bear a similar weight by the nature of its framing.

In order to illustrate this point, I will dissect and analyze three different new patient intake forms from three different prominent medical institutions: the American College of Physicians (Figures 1.1 & 1.2), Johns Hopkins Medical System (Figures 2.1 & 2.1), and the University of Washington Medical System (Figures 3.1, 3.2, & 3.3).



Patients Name: _____

Adult Summary Form

Date of Birth: _____

Medical Record #: _____

Primary Care Provider: _____

Drug Allergies/Sensitivities: _____

Emergency Phone #: _____ Contact Person/Relationship: _____

ICD Code	Chronic Medical Problem List	Date	Past Surgical History	Date
			Hospitalizations	**Date**

Family History of

Y	N		Family Member
☐	☐	Alzheimer's Dz	
☐	☐	Breast Ca	
☐	☐	CAD	
☐	☐	Cerebrovas. Dz	
☐	☐	Cervical Cancer	
☐	☐	Colon CA	
☐	☐	Depression	
☐	☐	DM	
☐	☐	Fe Storage	
☐	☐	Glaucoma	
☐	☐	Hypercho\	
☐	☐	HTN	
☐	☐	Ovarian CA	
☐	☐	Prostate CA	
☐	☐	Skin CA	
☐	☐	Thyroid Dz	

Initial Risk Assessment

	Date
☐ Alcohol/Drug Use	
☐ STDs	
☐ Domestic Violence	
☐ Depression	
☐ Osteoporosis	
☐ Geriatric Assessment	
☐ MMSE	
☐ _____	

Social History

☐ Married ☐ Single ☐ Civil Union

☐ Divorced ☐ Widow(er)

☐ Lives Alone ☐ Separated

Occupation: _____

Religious Preference: _____

Advance Directive? ☐ Yes ☐ No
If Yes, Date: _____

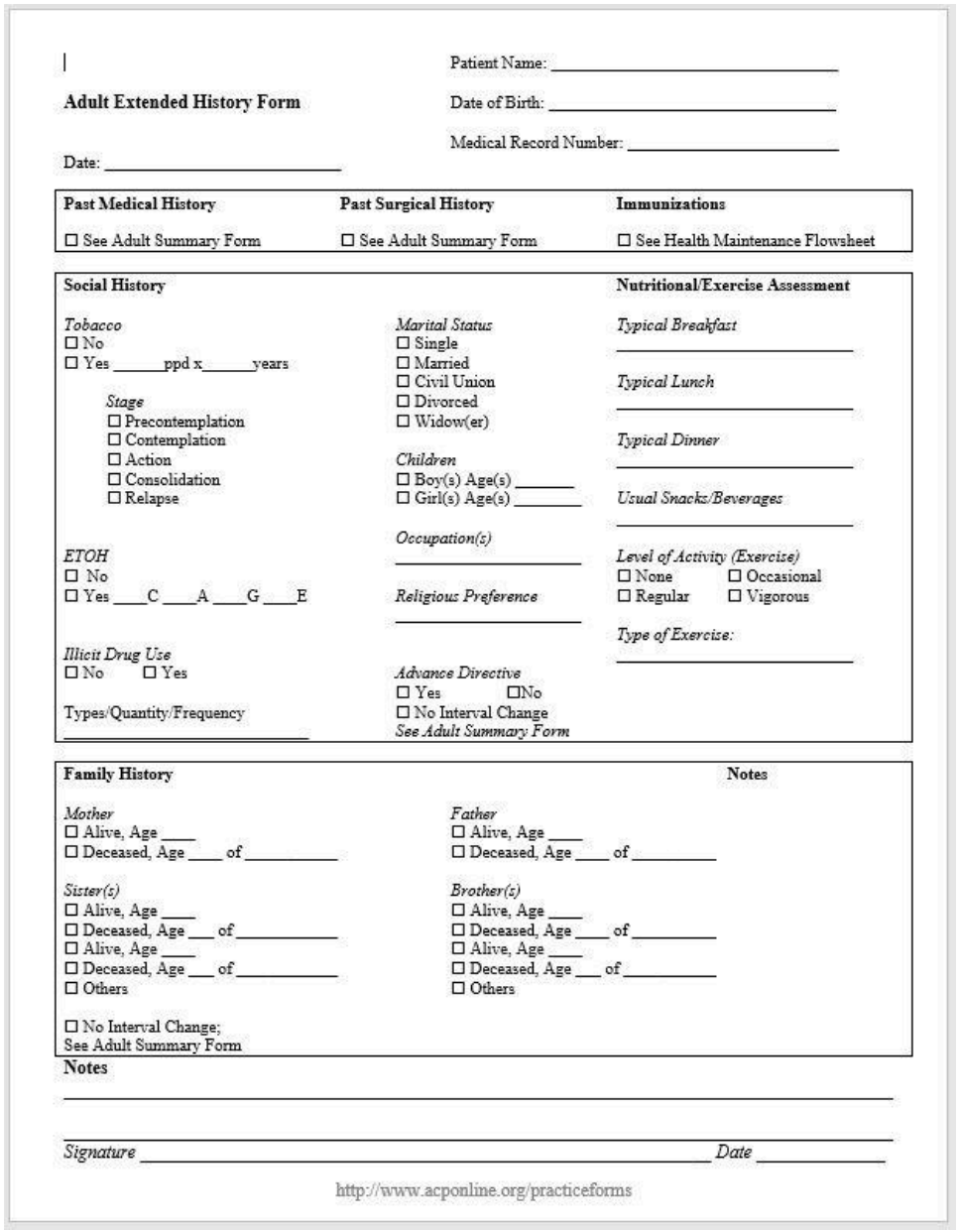
Educ.: ☐ JHS ☐ HS ☐ College

☐ Other _____

Signature: _____ Date: _____

http://www.acponline.org/practiceforms

(Figure 1.1)



Patient Name: _____

Adult Extended History Form

Date of Birth: _____

Medical Record Number: _____

Date: _____

Past Medical History	**Past Surgical History**	**Immunizations**
☐ See Adult Summary Form	☐ See Adult Summary Form	☐ See Health Maintenance Flowsheet

Social History

Tobacco
☐ No
☐ Yes _____ppd x_____years

Stage
☐ Precontemplation
☐ Contemplation
☐ Action
☐ Consolidation
☐ Relapse

ETOH
☐ No
☐ Yes ____C ____A ____G ____E

Illicit Drug Use
☐ No ☐ Yes

Types/Quantity/Frequency
_____

Marital Status
☐ Single
☐ Married
☐ Civil Union
☐ Divorced
☐ Widow(er)

Children
☐ Boy(s) Age(s) _____
☐ Girl(s) Age(s) _____

Occupation(s)
_____

Religious Preference
_____

Advance Directive
☐ Yes ☐No
☐ No Interval Change
See Adult Summary Form

Nutritional/Exercise Assessment

Typical Breakfast
_____

Typical Lunch
_____

Typical Dinner
_____

Usual Snacks/Beverages
_____

Level of Activity (Exercise)
☐ None ☐ Occasional
☐ Regular ☐ Vigorous

Type of Exercise:
_____

Family History

Mother
☐ Alive, Age ____
☐ Deceased, Age ____ of _____

Father
☐ Alive, Age ____
☐ Deceased, Age ____ of _____

Sister(s)
☐ Alive, Age ____
☐ Deceased, Age ___ of _____
☐ Alive, Age ____
☐ Deceased, Age ___ of _____
☐ Others

Brother(s)
☐ Alive, Age ____
☐ Deceased, Age ____ of _____
☐ Alive, Age ____
☐ Deceased, Age ___ of _____
☐ Others

☐ No Interval Change;
See Adult Summary Form

Notes

Notes

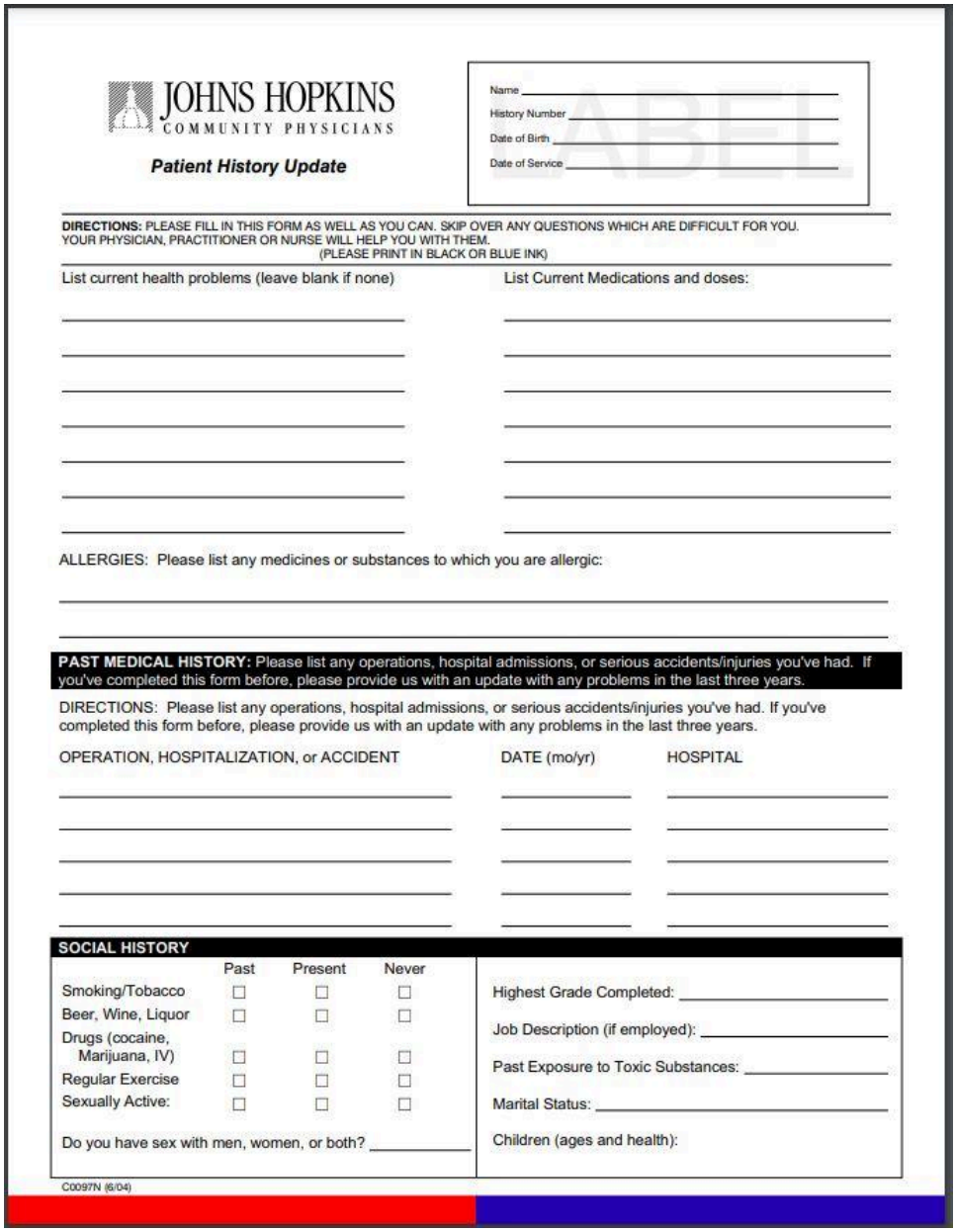
_____

_____

Signature _____ *Date* _____

http://www.acponline.org/practiceforms

(Figure 1.2)



JOHNS HOPKINS
COMMUNITY PHYSICIANS

Patient History Update

Name _____
History Number _____
Date of Birth _____
Date of Service _____

DIRECTIONS: PLEASE FILL IN THIS FORM AS WELL AS YOU CAN. SKIP OVER ANY QUESTIONS WHICH ARE DIFFICULT FOR YOU. YOUR PHYSICIAN, PRACTITIONER OR NURSE WILL HELP YOU WITH THEM.
(PLEASE PRINT IN BLACK OR BLUE INK)

List current health problems (leave blank if none)

List Current Medications and doses:

ALLERGIES: Please list any medicines or substances to which you are allergic:

PAST MEDICAL HISTORY: Please list any operations, hospital admissions, or serious accidents/injuries you've had. If you've completed this form before, please provide us with an update with any problems in the last three years.

DIRECTIONS: Please list any operations, hospital admissions, or serious accidents/injuries you've had. If you've completed this form before, please provide us with an update with any problems in the last three years.

OPERATION, HOSPITALIZATION, or ACCIDENT	DATE (mo/yr)	HOSPITAL

SOCIAL HISTORY

	Past	Present	Never
Smoking/Tobacco	☐	☐	☐
Beer, Wine, Liquor	☐	☐	☐
Drugs (cocaine, Marijuana, IV)	☐	☐	☐
Regular Exercise	☐	☐	☐
Sexually Active:	☐	☐	☐

Do you have sex with men, women, or both? _____

Highest Grade Completed: _____

Job Description (if employed): _____

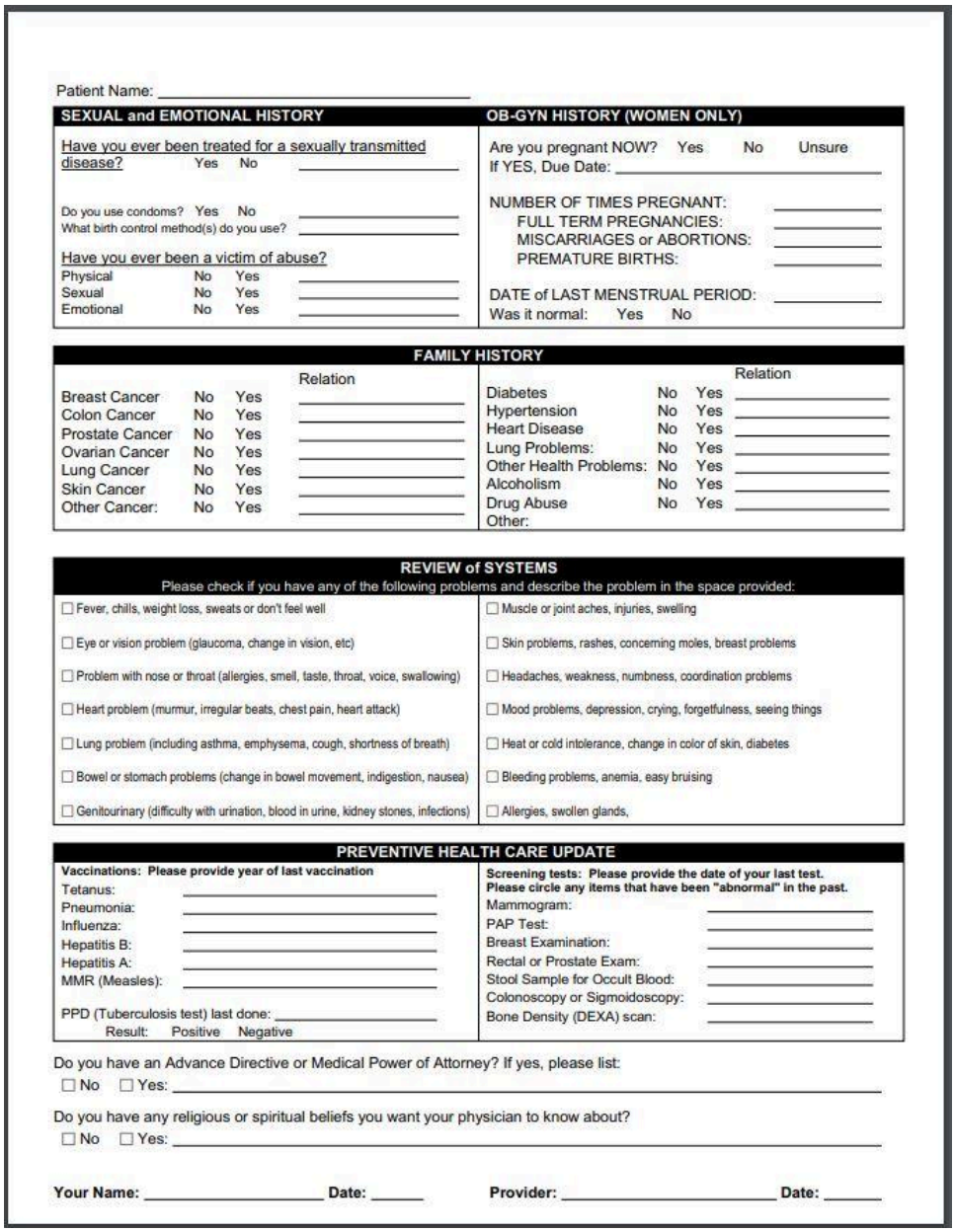
Past Exposure to Toxic Substances: _____

Marital Status: _____

Children (ages and health):

C0097N (6/04)

(Figure 2.1)



Patient Name: _____

SEXUAL and EMOTIONAL HISTORY

Have you ever been treated for a sexually transmitted disease? Yes No _____

Do you use condoms? Yes No _____
What birth control method(s) do you use? _____

Have you ever been a victim of abuse?

Physical	No	Yes	_____
Sexual	No	Yes	_____
Emotional	No	Yes	_____

OB-GYN HISTORY (WOMEN ONLY)

Are you pregnant NOW? Yes No Unsure
If YES, Due Date: _____

NUMBER OF TIMES PREGNANT: _____
FULL TERM PREGNANCIES: _____
MISCARRIAGES or ABORTIONS: _____
PREMATURE BIRTHS: _____

DATE of LAST MENSTRUAL PERIOD: _____
Was it normal: Yes No

FAMILY HISTORY

			Relation
Breast Cancer	No	Yes	_____
Colon Cancer	No	Yes	_____
Prostate Cancer	No	Yes	_____
Ovarian Cancer	No	Yes	_____
Lung Cancer	No	Yes	_____
Skin Cancer	No	Yes	_____
Other Cancer:	No	Yes	_____

			Relation
Diabetes	No	Yes	_____
Hypertension	No	Yes	_____
Heart Disease	No	Yes	_____
Lung Problems:	No	Yes	_____
Other Health Problems:	No	Yes	_____
Alcoholism	No	Yes	_____
Drug Abuse	No	Yes	_____
Other:			

REVIEW of SYSTEMS

Please check if you have any of the following problems and describe the problem in the space provided:

- ☐ Fever, chills, weight loss, sweats or don't feel well
- ☐ Eye or vision problem (glaucoma, change in vision, etc)
- ☐ Problem with nose or throat (allergies, smell, taste, throat, voice, swallowing)
- ☐ Heart problem (murmur, irregular beats, chest pain, heart attack)
- ☐ Lung problem (including asthma, emphysema, cough, shortness of breath)
- ☐ Bowel or stomach problems (change in bowel movement, indigestion, nausea)
- ☐ Genitourinary (difficulty with urination, blood in urine, kidney stones, infections)
- ☐ Muscle or joint aches, injuries, swelling
- ☐ Skin problems, rashes, concerning moles, breast problems
- ☐ Headaches, weakness, numbness, coordination problems
- ☐ Mood problems, depression, crying, forgetfulness, seeing things
- ☐ Heat or cold intolerance, change in color of skin, diabetes
- ☐ Bleeding problems, anemia, easy bruising
- ☐ Allergies, swollen glands,

PREVENTIVE HEALTH CARE UPDATE

Vaccinations: Please provide year of last vaccination

Tetanus: _____
Pneumonia: _____
Influenza: _____
Hepatitis B: _____
Hepatitis A: _____
MMR (Measles): _____

PPD (Tuberculosis test) last done: _____
Result: Positive Negative

Screening tests: Please provide the date of your last test.
Please circle any items that have been "abnormal" in the past.

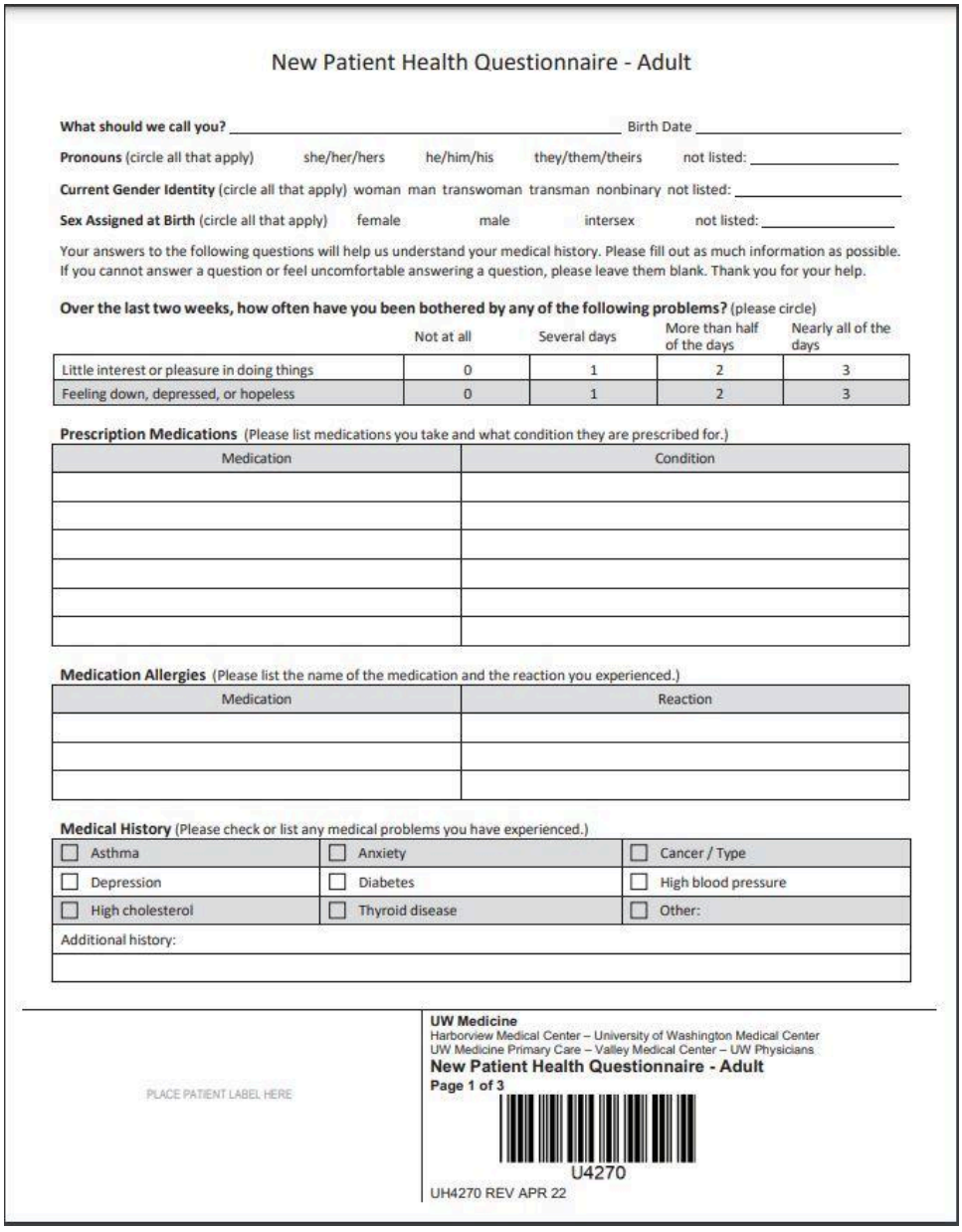
Mammogram: _____
PAP Test: _____
Breast Examination: _____
Rectal or Prostate Exam: _____
Stool Sample for Occult Blood: _____
Colonoscopy or Sigmoidoscopy: _____
Bone Density (DEXA) scan: _____

Do you have an Advance Directive or Medical Power of Attorney? If yes, please list:
☐ No ☐ Yes: _____

Do you have any religious or spiritual beliefs you want your physician to know about?
☐ No ☐ Yes: _____

Your Name: _____ **Date:** _____ **Provider:** _____ **Date:** _____

(Figure 2.2)



New Patient Health Questionnaire - Adult

What should we call you? _____ Birth Date _____

Pronouns (circle all that apply) she/her/hers he/him/his they/them/theirs not listed: _____

Current Gender Identity (circle all that apply) woman man transwoman transman nonbinary not listed: _____

Sex Assigned at Birth (circle all that apply) female male intersex not listed: _____

Your answers to the following questions will help us understand your medical history. Please fill out as much information as possible. If you cannot answer a question or feel uncomfortable answering a question, please leave them blank. Thank you for your help.

Over the last two weeks, how often have you been bothered by any of the following problems? (please circle)

	Not at all	Several days	More than half of the days	Nearly all of the days
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed, or hopeless	0	1	2	3

Prescription Medications (Please list medications you take and what condition they are prescribed for.)

Medication	Condition

Medication Allergies (Please list the name of the medication and the reaction you experienced.)

Medication	Reaction

Medical History (Please check or list any medical problems you have experienced.)

☐ Asthma	☐ Anxiety	☐ Cancer / Type
☐ Depression	☐ Diabetes	☐ High blood pressure
☐ High cholesterol	☐ Thyroid disease	☐ Other:
Additional history:		

PLACE PATIENT LABEL HERE

UW Medicine
Harborview Medical Center – University of Washington Medical Center
UW Medicine Primary Care – Valley Medical Center – UW Physicians
New Patient Health Questionnaire - Adult
Page 1 of 3

U4270

UH4270 REV APR 22

(Figure 3.1)

Surgical History (Please list all previous surgeries and the year they occurred.)

Surgery	Year

Family History (Please place a check mark in the box if any of these diseases run in your immediate family.)

	Mother	Father	Brother	Sister
Cancer	☐	☐	☐	☐
Diabetes	☐	☐	☐	☐
Heart disease	☐	☐	☐	☐
Additional family history:				

Health Habits (Please circle or note the appropriate answer.)

Tobacco Use:						
Smoking status/history	I smoke everyday		I smoke some days		I am a former smoker	
	I am a passive smoker (live with others who smoke)				I have never smoked	
How many years total have you smoked?	<5	5-10	11-15	16-20	21-25	>25
On average, how many packs per day have you smoked during your lifetime?	¼	½	1	1.5	2	3
Smokeless tobacco status/history	Current user		Former user		Never used	
If you use any tobacco, are you ready to quit?	No / Yes					
Physical Activity:						
On average, how many days per week do you engage in moderate to strenuous exercise (like walking fast, running, jogging, dancing, swimming, biking, weightlifting or other activities that cause a light or heavy sweat)?	0 1 2 3 4 5 6 7					
On average, how many minutes do you engage in exercise at this level?	0 10 20 30 40 50 60 70 80 90 >90					
Alcohol Use:						
How often do you have a drink containing alcohol?	Never	Monthly or less	2-4 times per month	2-3 times per week	4 or more times per week	
How many drinks containing alcohol do you have on a typical day when you are drinking?	1 or 2	3 or 4	5 or 6	7 to 9	10 or more	
How often do you have six or more drinks on one occasion?	Never	Less than monthly	Monthly	2-3 times per week	4 or more times per week	
Note the number of each item you drink per week	Glasses of wine ___		Cans/bottles of beer___		Shots of liquor ___	
Recreational Drug Use:						
Do you use recreational drugs?	No / Yes					

PLACE PATIENT LABEL HERE

UW Medicine
Harborview Medical Center – University of Washington Medical Center
UW Medicine Primary Care – Valley Medical Center – UW Physicians
New Patient Health Questionnaire - Adult
Page 2 of 3

U4270

UH4270 REV APR 22

(Figure 3.2)

Sexual History (Please circle all that apply or leave blank if you prefer not to disclose.)

How do you describe your sexual orientation?	Lesbian/Gay	Straight	Bisexual	Asexual	Queer			Not Listed: ____
What genders are your sexual or romantic partners, if any?	Men	Women	Transmen	Transwomen	Nonbinary	None	All	Not listed: _____
Do you use anything to prevent pregnancy in yourself or your partners?	No		Yes		If yes, what type? _____			

Pregnancy (Please circle or note the appropriate answer or leave blank if not applicable.)

Have you ever been pregnant?	No	Yes	If yes, how many times?
Number of:	Miscarriages ___	Abortions ___	Living children ___

If there is anything else you think is important for your provider to know, please share it in the space below:

Thank you very much for your time, your medical history is very important to us!

PLACE PATIENT LABEL HERE

(Figure 3.3)

Each of these three examples share a similar format, even though they come from entirely separate medical institutions across the United States. All of these cases are drawn from internal medicine, both for ease of comparison and because this subfield is essential to medical systems while adopting a general approach.

All of these forms ask similar questions, although only one form attends to different gender and sexual identities. All three forms ask patients to describe the "problems" they are having as an essential part of the information needed for their visit. Additionally, the smaller provided spaces on these forms for questions such as "How many surgeries have you had?" assumes that patients have not had many major health issues before.

The commonalities between the forms are prime examples of the politics that these forms, as infrastructure, imbue. The lack of alternative gender and sexuality identity options on two of the three forms speaks to an observed problem within clinic form research. Multiple researchers have published on the social and emotional impacts non-inclusive medical forms can have on trans patients (Racila, 2020, Sheedy, 2016 & McPhail, et al., 2022). This exclusion of bodies that do not fit into heteronormative binaries on medical intake forms imbues two forms of politics onto users: queer users are reminded again of their otherness within "traditional"society, and providers may fail to realize the true diversity of their patients as their identities are erased by a lack of space for them in the form.

Additionally, this assumption of medical "problems," when discussing current and past medical history serves to other disabled bodies and imply they are "broken" or "bad", and furthers the common able-bodied assumption that disabled individuals are inherently "worse-off" because of their disabled existence. Additionally, the space provided for short answer style

questions, such as surgical history, communicates an assumed amount of surgeries that fit within the “normal amount”, and further others and stigmatizes disabled individuals with complex medical histories. These instances only serve to further establish and entrench the societal concept of the “normate”, as coined by disability studies scholar Rosemarie Garland Thomson, which is used to define the societally assumed definition of what a normal (and able) body is.

Moving beyond the more glaring commonalities between these examples, it was also striking to see how each of the forms contended with the social/lifestyle history and family history. While two of the forms specifically name the familial relationships that the doctor's office is seeking histories for, it was striking that the final form left that relationship section as a fill in the blank which seemingly left it up to the patient's discretion to decide how significant different familial relations were. This presents an interesting place for analysis because it not only structures how providers view genetic inheritance and the nuclear family, but it also may shape patients’ views on what information is deemed as significant to their provider. This could possibly cause them to overlook genetic conditions that are present in more distant relations in favor of only discussing health conditions that affect their immediate family.

Outside of family history, the section for lifestyle or social history is worthy of scrutiny because of its focus on recreational drug use, alcohol use, physical activity, sexual behavior, and diet/nutrition. While all of these categories were not present in all of the forms, each form did ask questions relating to recreational drug use, alcohol, and sexual activity and two of the three forms addressed physical activity. It was also striking that one form included questions of occupation and education of the patient, and while this definitely can help to provide a clearer picture of the lifestyle factors that may be present in a patient's life it is interesting that this was not deemed significant enough to be present on the other two forms. The construction of this

category seems to speak to the necessity to gather information on patients' riskier behaviors that could have significant impacts on their overall health, but also its prominence on the form when compared to the size of sections for medical history or past surgical experiences seems to show a increased focus on these lifestyle factors impacting health rather than patients being given the autonomy to explain other factors more thoroughly that they know could be impacting their overall health.

Finally, the choice of language is fascinating. While there seems to have been an effort made to ensure that the terminology that the forms use is legible to the average patient there are a number of more technical words phrases and diagnoses on each of these forms that could prove challenging for a number of patients, specifically if they have a lack of experience navigating the medical system. Of course, if patients are experiencing a lack of understanding of a certain part of the form they can speak to office administrative staff, but this presence of technical language points to these forms' intended audience being medical staff and not patients. Considering that these forms are meant to be the first impression that a new patient has with their provider, the document being geared towards providers' as an audience, rather than patients', indicates how patients' fit within the broader medical system.

Conclusion

Overall, medical forms and EMRs exist in a broader history of the US medical system that began with the rise of the hospital as the center of our medical model, and created a demand for technological excellence and bureaucratic efficiency that fundamentally shape our medical system today. It is these throughlines that laid the foundation for the rise of MyChart and Epic Systems, and shaped the infrastructure of the forms and patient encounters that this platform hosts. Therefore, as we move forward and scrutinize the MyChart user experience directly,

considering the platform within its broader context of historical influences,q allows for a greater depth of consideration.

Chapter 2

Introduction

Beyond the history of the US medical system, medical records, and Epic Systems, evaluating the user experience within the MyChart portal is useful for considering how MyChart positions itself and views its users. In order to effectively evaluate the MyChart platform, this chapter will utilize the walkthrough method, which was introduced in 2016 by Light, Burgess, and Duguay, in order to critically analyze the MyChart portal, and the broader societal and cultural connotations of the choices within the design and navigation of the application. The walkthrough method serves to allow for the evaluation of an application's "environment of expected use" (Light, Burgess, & Duguay, 2018), meaning how the app provider expects the application to be received by users. The walkthrough evaluation of MyChart will begin linearly with the account creation page, then move on to the Frequently Asked Questions, then the identity verification process, then the new account homepage, the patient education library, and finally the sharing hub, while scrutinizing each of these sections for data use/privacy, intended user, platform branding, and other significant imagery.

Creating an Account

Walking through the MyChart account setup process for the UVA health system, the first page that you're met with when you access the page to create a MyChart account is a page that says *sign up for MyChart* with a logo that says *UVA Health*. The information that's underneath the sign up for MyChart header says *we need some information in order to grant you a MyChart account. Enter your demographics here and in the next step we will verify your identity using questions from a third party verification system. If you have any questions, please contact your clinic*. The required fields on this page are rather standard of a majority forms, them being first,

middle, last name, Address, Date of birth, Legal sex (the categories for legal sex that they list are female, male, unknown and non binary), the last four digits of your Social Security number, mobile phone, home phone and then email address. Finally, you are asked to complete a CAPTCHA box to certify that you are not a robot, as well as a checkbox notice that states:

"*By checking this box I agree that I have read this notice and I am providing written instructions to UVA health under the Fair Credit Reporting Act, authorizing UVA health to obtain information from my personal credit profile or other information from Experian, which is an identity verification software. I authorize UVA health to obtain information solely to confirm my identity prior to activation of a MyChart account in my name. The questions in the following page are from a third party system. Questions from your credit profile will be used to confirm your identity. This process will not affect your credit rating."*

On the lower part of the page before you submit your information to create an account, there are six menu items that are listed: an option to download the MyChart app on your iPhone, an option to download the MyChart app for Android, an interoperability guide, FAQs, privacy policy terms and conditions, and then an option to select on a high contrast theme. When clicked into, the interoperability guide starts with the header *Patient Authentication: How to allow a third party app to access your health records*. This page then lists off that patients of providers that use Epic software are able to connect third party applications to retrieve parts of their health record for their own personal use, and examples of data that can be pulled into an app include lab results, allergies, medications, and immunization history. The page then walks through the process of authenticating an app to retrieve your health data, and it states that to follow the steps of making sure that you have a MyChart account created for your healthcare provider organization and you will need your login credentials. The page then makes sure to state that

MyChart is an Epic branded name, and that *your organization may use a different name for their patient portal*. Then it directs that you would access the application on your personal device, and should carefully review the terms and conditions, and explains the app may ask you to select your healthcare provider from the list and you would select your healthcare provider and you would be redirected to your provider's MyChart login screen. The user would enter their credentials to continue, and there is a note stating that you should not share your password directly with another person or application and the *MyChart login page is designed to let you securely share your health record without disclosing your password. The logo and background image on this page might look different for your healthcare provider, but the general layout of the page should be similar with the Epic Systems Corporation copyright in the bottom right of the screen*. The page then details a walkthrough of how to execute this process step by step.

The initial account creation process feels rather standard in the information it asks the new user for, although it is interesting that users with questions are encouraged to reach back out to their clinic rather than contacting Epic or an IT department within UVA Health. The more notable pieces of this process involve the consent for your credit profile to be used to validate your identity, and the information regarding integrating your MyChart account with third party applications. It makes sense for an application dealing with sensitive medical information to have measures in place to ensure that the account they are creating is for the correct person, and that this person is not attempting to act as a proxy for any other individual without going through the proper channels. Finally, the most interesting piece of this initial set up process is the interoperability guide, and how it walks users through the process of sharing some of their medical information with third party applications. The piece that stands out the most is how Epic ensures to state that patients may only pull out some of their medical record to share, which

seems a bit odd that users may not have full ability to share as much of their own records as they please, but also seems to speak to Epic's assumption about the knowledge base of its user surrounding data privacy and safety. The step by step guide, mention of branding to look for, and the limiting what may be shared really showcases that MyChart does not have enough faith in its average user to be able to make decisions about how to steward their own data well.

FAQ

Returning to the create an account page you can then navigate to the FAQs page and major headings include enrollment and accounting assistance, your UVA Health patient health record, using MyChart, and privacy confidentiality and security. Diving into the frequently asked questions, the first question is *What is MyChart?* The portal itself describes that *MyChart is a secure online portal that provides information about your medical care and connects you to your UVA healthcare team. With MyChart, you can:* followed by a bulleted list that says medical appointments, view your electronic health information, including test results, healthcare documentation after visit, summaries, etc. request prescription renewals, pay your medical bill, access trusted health information, resources, communicate electronically and securely with your medical care team, and request a copy of your historical non-electronic electronic patient health record.

The next section is titled *UVA health patient health record*. The first question of this section asks *When will my test result and other information be posted in MyChart?* And the answer is listed as *The 21st Century Cures Act requires healthcare providers to give patients access to all health information without delay. In most cases, which means that MyChart users may see their results etc. as soon as or shortly after they become available many times before the healthcare provider has had the chance to review them and contact the patient. While some*

patients are happy to see results immediately, others may be uncomfortable or anxious. Seeing results before a provider can interpret and explain them. Please discuss these concerns with your UVA health provider. The rest of the questions are as follows:

What is Lucy? Lucy is a personal health record where you can permanently organize all of your medical information into a single document. You can also add personal information about your health and choose to share it with UVA Health.

Why are certain test results not showing up in MyChart? Tests of an extremely sensitive nature such as HIV or genetic testing are not released to MyChart, according to Virginia law.

If my information is not correct in MyChart, what should I do? UVA Health offers three options to request an amendment to your patient health information, which are to ask your UVA health provider to correct any inaccurate information at your next appointment, send your UVA health provider a message through MyChart, or complete a UVA health request for amendment of health information form at the provided a link.

What is your privacy policy? MyChart is owned and operated by UVA Health and is fully compliant with federal and state laws pertaining to your privacy. Your name and e-mail address will be treated with the same care and privacy given you, your patient health records, and will never be sold or leased by UVA Health. The UVA Health MyChart terms and conditions state that UVA MyChart is a personalized, secure way to access portions of your medical information MyChart is not your official UVA patient health record and may not contain all of the information that is in that record. You may obtain a copy of your official patient health record from health information management via MyChart or the authorization to release patient health information form.

The frequently asked questions are the first place that MyChart is allowed to tell us in their own words who they perceive them to be, and what it is about their offerings that deserve highlighting. The framing of MyChart as a "portal" that provides access to medical information evokes a neutral hosting connotation that seems to suggest they have very little interaction with or impact on the data that is on their platform. Additionally, the choice to highlight "Lucy" as a customizable medical record within the platform that allows for personal information seems to imply utter control in the hands of the user, when just a few questions down the privacy policy states that MyChart is a way to access portions of your medical record. Finally, you have this interesting humanization element of the platform where they seem to acknowledge and attempt to mitigate an emotional reaction within a user through the discussion of the immediate release of test results causing anxiety to some users, and that while this is a legal standard they may prefer to just speak to their provider instead. Overall, the tone of these FAQs is informative, but a bit light-hearted, and continues to position MyChart as a neutral host.

Identity Verification

Then, I began the account creation process, and I was responsible for answering questions that were generated by a third party system to verify my identity and it was titled with the header *Precise ID powered by Experian*. The first question said *using your date of birth, please select your astrological sun sign from the Zodiac from the following choices*. When I answered that question, the next one that came up said *you may have opened a student loan in or around a certain date, please select the lender that you have previously or you are currently making payments to*. The question after that one *was which of the following is a previous phone number of yours? If there's not a matching phone number, please select none of the above*. The

final question was *which of the following represents the last four digits of your primary checking account number?*

Then, after I had answered all of those questions, it said *Hello Katelyn, choose a username and password. All fields are required. You'll have to contact your MyChart help desk at 434-243-2500 if you ever need to change it, so think of one that is secure and memorable. Then create a password. Your password must be different from your username. For increased security use a combination of numbers and letters, lowercase and uppercase*. The next screen that came up asked if I wanted to enable email notifications when new information is available, such as test results or messages will send a notification or e-mail address. Then there was a space to enter my email address and it said *your email address will be used only for notifications and we will not share your email address with anyone*. I was then asked to enable text message notifications for when new information is available, such as test results or messages. There was a box asking for your mobile phone and then it listed my mobile phone number. The page stated that *your mobile phone number will be used for notifications only*. *We will not share your mobile phone number with anyone* and my number had come prefilled in and I was unable to edit that box. To proceed, you must agree to the following conditions governing the use of MyChart, and these terms were the same terms and conditions seen previously..

Navigating a New MyChart Account

Once completing that, the first screen that greets me says *Welcome Katelyn, let us show you some features that will help you find what's most important to you*. The first option on the home screen has a yellow yield sign icon. It says *you currently do not have verified contact information on file, and prompts to update your e-mail address or phone number* with a green button that says update contact information info. Below that section is a little letter icon and it

says *Welcome to your UVA MyChart Account, University of Virginia Health System and Affiliates* with a faceless person icon in a message bubble that begins to say *we are so pleased you have joined and that you have selected us as…* and then there's a green button to view message. The next section has a bell with a heart on it and it shows vaccinations it believes I may be overdue for and when and where I last received them. Below that has like a swooped letter "i" icon and it asks if I received care at different medical offices I have been to and prompts me to *link your medical records to view them here* and then the options or the button options are *learn more* or *dismiss*. The next section below has a globe with dashed arrows moving around and says *share everywhere give one time access to your medical record to any clinician in the world with Internet access*. It says *learn more* or *dismiss* the learning library with a little movie film icon with a play button in it and it says *Learning Library, learn how you can get the most out of your. MyChart experience by watching videos*. Under that is a light bulb icon that says *explore more*, and the first card says *Talk face to face. Find care fast with on demand video visits* with a green talk bubble with a video camera icon in it with a green button that says *talk to urgent care*. The next card says *patient education video library* and above it is a blue circle icon with an eye in it and it says *Find videos to learn more about you or your loved ones health* with a button that reads *Learn*. The card after says *Invite friends and family, invite a family member or close friend to have access to your medical record* with a green button that says *Manage Access* and a file folder icon with a heart in it. The next card says *price transparency* with a calculator icon above it with light blue and orange buttons and it says *wondering how much the procedure is going to cost. Get an estimate from one of our locations* with a green button that says *Get Enough Plan Ahead*. The final card says *Your Health Record Everywhere* with a purple film strip icon with a

play button in the middle of it and says *Watch the video to learn how we can securely share your health data to provide you with the best possible care* with a green button that says *Watch Video*.

Upon clicking into the message that I had from the University of Virginia Health system and affiliates, the message says *we are so pleased you have joined and that you have selected us as your trusted care provider. MyChart helps you access care even after your appointment. Did you know you can access test results? Send us a message or request a refill while you're on the go by downloading the MyChart app from your favorite App Store. Just log in with your UVA health user name and password and you're all set to get started, choose the profile option in the menu to customize your communication preferences and update your information. We'll take care of the rest. This account is a care companion to the services provided by you via healthcare provider. As always, our patient services are also available by phone to support you at every step of the way. Kind regards your partners in care at UVA health.* And then it details UVA health system, 1215 Lee St. Charlottesville, VA 22903 uvahealth.com. And it says showing message one of one and then there's a button to hit reply

Next, upon clicking into the *Link My Account* section there are two tabs, one says *discover* and says *you can now use MyChart to view your health information from organizer or other organizations where you and your family have records* with a blue linked and underlined word saying details with an upward facing arrow. If you click *Details* it would release detailed information on *when you connect to your accounts from the participating organizations you may be able to see the following types of information alright here in your account with MyChart*. The options that are listed are allergies, health issues, messages, visits, care team medications and test results. Below that is a film icon with the play button that says *watch to learn* and then learning topics are listed. Then the visited organizations that it gives options to link to are different doctor

offices I had been seen at in the last 3 years. Then it gives me organizations in my area and lists out other available clinics that are within a pre designated radius. Looking at the learning topics section it lists *for access linking your accounts, learn how to see your health information together in one unified view*, and there's a video to click. Then if you click into *Share Everywhere* you see a much larger version of the Globe icon with the dashed arrows around it that says Share Everywhere and the text says *share your health record, grant one time limited access to health information. You can see metrics including medications, allergies, health issues, and immunizations, and the person accessing your record will also be able to write a clinical note to your care team if you request to share code, it will expire after 60 minutes.* You can then elect to share your record and provide the name of the physician and request a share code. Otherwise there's an option to return to the home page.

The initial new patient homepage is busy, both in design and information, and the sheer amount of existing medical information that they list for the user to verify off the bat is incredibly overwhelming. To be confronted with information dating back three years, that includes medical encounters as small as needing to get a single vaccination at a CVS, as soon as you login for the first time comes across as an overload of the senses. While the convenience of these features is nice, it is hard to shake the questions surrounding how this information is sourced, stored, and managed, and the added additional prompts to further connect your account feels excessive. These moments in particular break the facade of neutral hosting of information precisely because they host your medical data and insistently push for you to provide more, even while not detailing how they gained their data in the first place.

Patient Education Library

If you click into the *Patient Education Library*, as opposed to the *MyChart Learning Library*, it opens to a UVA health title page, not a MyChart page that says patient education library. *Welcome to your health and Wellness Resource Center here at UVA Health, we want you to have the information you need to manage your health and live your healthiest life. We invite you to explore our recommended learning playlist library for easy to understand health and Wellness education*. There is then a search bar and then below that in a blue section says *What you need to know. Sometimes finding and understanding health information can feel daunting, but it doesn't have to. Learn some tips and tricks for using this resource to get the information you want.* with a button that says learn more and then recommended learning. It says *We've compiled the playlists of our top health education video recommendations. Click below to browse and view the topics of interest to you from our recommended learning playlist.* The first one has an image of an infant in a crib that says *infant safety*. The next one is two older white women sitting at a table in what appears to be a clinic office, one holding orange prescription bottles and one with her hands on top of paperwork. It says *medication safety*. The next one has an image of a younger brunette woman in dark blue scrubs standing next to the bedside of an older woman patient lying in a hospital bed that says *infection prevention* and then the last one shows a person's hands holding on to a remote and with one finger pressing an alarm button that says *fall prevention at home*. Finally, clicking into the friends and family access, the section is titled *who can see my record* and right now mine says no one can see your information within the option to Click to invite someone. It then says *whose records can I see* and it lists myself and then below to watch a video on providing family access or head back to the sharing hub or watch more videos. Clicking into the estimate section it says. *Are you wondering what a procedure will cost?* And then you can create a new estimate. It says that I do not have any estimates right now and I

can go back to the home page below. *What is an estimate? An estimate is the predicted amount you will pay for medical service based on your insurance and what patients have been charged in the past says how accurate our estimates and estimate is not a guarantee. There are many factors that determine the final cost.*

Clicking into the *end of life planning* section opens to a section of the UVA health website that has the MyChart icons at the top, but then it has *end of life planning* and then it has a image of a person holding a coffee cup with a that is partially drank from with another coffee up in front of it and on it has the quote *to make your treatment choices known*. Then there's one section that says healthcare agent. It says *you currently have no healthcare agents* and then it says *add healthcare agent, designate one or more healthcare agents who can make healthcare decisions for you*. Then the other section on the page says *planning documents: if document should be removed, send us a message* and it says *documents on file*. My page says *there are no documents of this kind to display*. It then prompts to add a document, and states *You will use this feature to upload your advanced directive or living will. All of the documents, including, but not limited to, do not resuscitate DNR orders, Physician orders for life sustaining treatment, etcetera will not be added to your record below*. Then there is a button that says *back to the home pag*e and then on the side it says *related links* there is a icon with chat bubbles overlapping that says. *Ask a question* and it says *Helpful Resources: these resources will help you make care decisions and prepare for conversations with your family, friends and doctors*. And there's an information icon with a blue circle with a white eye that says *prepare for your care step by step program with video stories to help you have a voice in your medical care, helping with comforting care advice to call cultivate, comfort and happiness towards the end of life, and plan your lifespan, help plan for health events that may happen as you get older*.

This section stands out as it appears to contain more UVA Health specific resources than any other area of the portal, yet there is still an obvious Epic Systems footprint on many of the articles through branding specific choices. The choice to include a Patient Education Library when MyChart also has a learning library is intriguing, and the difference between the two areas mostly seems to center around the Learning Library being for learning about how to get the most out of MyChart, versus the Patient Education Library serving as a more health focused information hub. The end of life section within this library was the most striking, as not only does it provide resources about adding end of life documents to MyChart, but it also has informational videos about how to comfort your family through impending grief. This seems to very much play into the thread that MyChart is attempting to be a do it all platform, as it offers hosting of all your test results, end of life directives, and is there for you to comfort your family through loss.

Sharing Hub

Next section is the sharing hub which is headed by the text *There are many ways to share your health information. Let us help you find what you need. Who do you want to share your health information with?* The first option says *yourself*, and it has a blue singular person icon that says *you might be trying to get a copy for your personal reference*. The button below says a *family member, close friend or caretaker* and it has a purple dark purple singular person with two lighter purple people on either side that says *this person might be taking care of you or helping you track your health*. Healthcare provider and there is an icon of a Med bag in red with a white cross, says *a healthcare provider is a health professional, for example a doctor, dentist, nurse or social worker, or a healthcare organization*. Finally it says anyone else and that has a file folder icon with a heart in it that says *this might be someone in another organization, your insurance or*

workplace. Below that is a section that says *watch to learn* with a film strip icon with a play button image which says *learning topics, your health record on the go, learn how health data is securely shared between doctors and organizations, and sharing your record learn more about how you can share your record with a video*. It gives five buttons, one that says manage friend and family access, grant one time access with share everywhere, download health and visit summary, request formal copy of health record, request computer readable export, and then back to the homepage. If you click into the computer readable export request, it says *your health information and computer readable files are files that a computer or app can read, but the files in this export are not designed to be read by humans*. That section is bolded. *The files and this export could be very large and could take your organization a few days to process. You will need an application that can use computer readable data to understand these files. Click here to request your information in a human readable format such as a PDF*. Below that text is a submit a new request for computer readable report with a file folder icon with a coding symbol. *This is what will be included in your export computer readable to export all electronic health information. Do you have any comments or questions to add to this request* with an open box for typing and then a green button that says *continue request formal copy of health record. Request your medical record from your healthcare provider by answering a few questions. This request requires processing of your by your healthcare organization might take a few days, submit a new request for a formal copy of a health record*. The form indicates a required field with a red asterisk and then there's a required question that says *Where would you like to send this request form?* With a clickable menu with a green button that says *continue*. Next is v*iew download or send visit records*. *You can send a single visit in a date range or all of your visits. Any visit selected will include a copy of your health summary*, the drop down is automatically selected on

single visit. The document center says *please select the option that most closely matches the information you would like*. First options of view, download, or send visit records. These include details such as health issues, medications, allergies, immunization plan of care, requested records, download records specifically requested, such as legal information, coordination of care, government recording, reporting, workers comp information, accounting disclosure, visit in health summaries or my documents sign view, download and print documents you have on file.

While MyChart does share all these different user options for sharing user medical records, the tone around each different style clearly showcases preference. The phrasing that the computer readable file will be large and only readable by computers is the emphasis of this, plus the extensive additional steps required to complete the request that do the heavy lifting to convince users that this method is not worth it. On the other hand, when the pages have discussed the share anywhere link there is an unending focus on how convenient it is. This emphasis of the extreme lift and form required to even request one format, while their tool version is a breeze showcases the lack of neutrality in MyChart's hosting and demonstrates the clear ways the platform benignly attempts to influence users into believing they aren't knowledgeable enough to manage certain parts of their medical record.

Conclusion

Overall, this walkthrough of the creation of a MyChart account clearly displays the way the platform presents itself as neutral while attempting to parentally guide the user to the preferred usage of its tools. This account creation process raises questions of Epic's data use and governance, as well as how knowledgeable they perceive their user to be. The frame of convenience being employed to guide users down a suggested route through the platform that

seems to serve to provide Epic the most user data is a fascinating development, and once that calls into question how MyChart should be categorized as a whole.

Chapter 3

Introduction

Now that we have looked at the history of the medical system that both created this modern prevalence of electronic medical records, structured a prioritization of technological innovation and adoption, as well as this emphasis on efficiency within medical care. Along with looking closely at the MyChart portal as it is experienced by patients, we can then begin to consider how MyChart functions within a sociocultural sense. In order to make that analysis, I will be pulling in information from platform studies, which is informed by scholars such as Tarleton Gillespie and José Van Dijick, and posits that platforms posit themselves as neutral hosts of information. Platforms establish that they merely serve to prop up content that is populated by other people, and it is this positioned neutrality, openness and egalitarianism that allows them to avoid or obscure the amount of decisions and curation of content that exists on the platform, as well as the affordances that are structured within the platform to privilege certain kinds of content. When considering these platforms, it's important to engage with infrastructure studies which has a long lineage within the field of STS, and argues within the artifacts and infrastructures that we build, we imbue our politics into them, and those infrastructures will continue to exert those politics long after we are gone. Which means that those structures will maintain the initial biases and privileges and positionality built in long after their creators are gone. Expanded upon by Fuller and Goffey in their book *Evil Media*, which explains that grayness is a way that technologies and media that are considered more boring and mundane leverage that bureaucratic identity to avoid critical scrutiny, therefore making themselves less interesting to look at and so less likely to be analyzed critically.

MyChart as a Platform

MyChart presents itself as open, and with its hosting within medical systems it is free for patients to access, and is meant to be a user friendly experience for navigation so that they may easily engage with their providers and contact them more readily to access health in ways that previously required in person visits. Patients can see all of their test results, and sometimes receive these prior to the physician being able to discuss them with them. These are all central pillars that MyChart highlights in its projection of its perceived openness. This openness is even taken further as it offers learning hubs and videos for users to engage with that educate them on the use of their record, how to share it with anyone, and bring this to their providers – including providers that may not even be using MyChart. In addition, that information can then move its way back into their MyChart record through the "share anywhere" link. Beyond this, MyChart additionally provides end of life planning, resources and support for patients to create living wills and do not resuscitate orders, as well as guides for discussing end of life feelings and emotions with family members, as well as learning hubs for infant safety, medication safety, and fall prevention. These all exude a positionality that MyChart itself is an open host of medical information for patients to take control of their medical experience in a way that was not possible prior to this digitization.

Moving onto why MyChart considers itself neutral or positions itself to appear neutral in the construction of the platform. The ability to interconnect a patient's MyChart accounts from different medical systems allows MyChart to position itself merely as a host of patients' longitudinal records. MyChart itself seems to portray that it is not providing any politics or thoughts on the records, it is just merely offering patients the means at which to manage their own care. Yet within that portrayed neutrality, there is no discussion of the benefits that MyChart itself receives from hosting this medical information on its system, be that its engagement and

payment that it receives from hospital systems for its use, the way that the MyChart environment can be customized by the hospital system, or its ability to load data into large and anonymized medical research data sets. Let alone its participation in selecting patients for clinical trials or its newer implementations of generative AI within the medical record to aid providers' ability to manage caseloads. It also doesn't disclose that all of the online messages that patients' exchange with their providers become a permanent part of their medical record, and therefore if a patient is ever experiencing distress and speaks with a providor in a less than professional way that can then be stored in their record forever and be used to prevent patients from accessing care in the future. As well, within the terms and conditions MyChart details that grounds for removal are if a patient "excessively messages their provider" with no elaboration on what this word "excessive" means in this context. Beyond this, if a patient becomes incarcerated or they pursue legal action against the hospital system that is hosting their MyChart account, those are also grounds for the patient's account to be canceled, and they will then lose access to their medical data that they may not have stored elsewhere.

This also connects in with the projected egalitarian positioning of MyChart. Egalitarian in the sense that MyChart attempts to communicate that MyChart is meant for everyone and it's meant to provide patients the means to access their care, even if their doctor doesn't use MyChart. MyChart provides videos with easy and simple to understand animations that are meant to help direct patients on how to move their records. These videos portray that MyChart reduces the delay of faxing so that you can access care more quickly and efficiently. MyChart posits itself as this equalizing factor that places patients on a more even level with their provider, and instead of waiting for them to process through your results and then pass that information, patients are getting information at the same time as their provider thus equalizing the field. Yet

MyChart doesn't make available outside the fine print that certain test results will not be released immediately or they will not be made available on a MyChart account at all, or that on the provider side, if a provider finds your responses to them to be hostile or aggressive they can then flag that within the system that will then pop up whenever your record is accessed. Beyond this patients also often lack the permissions to fix incorrect medical record information within their own record, and these are only able to be edited by providers and not patients, which presents a direct contrast to this egalitarian footing that MyChart seems to position itself to patients.
Even considering MyChart's original roots as a physician scheduling tool that was meant to connect patients to their providers, MyChart has now moved into a place of profiting off the forged connectivity of its users and that follows an incredibly similar trajectory as the social media platforms that Jose Van Dijick discusses, such as Facebook, Twitter, and Youtube. Van Dijick explains that while users initially joined platforms in search of "connectedness", meaning true social connections, soon enough platforms began to see "connectivity" as a valuable resource to mine for personal information and user data (Van Dijick, 4). This move to connectivity, Van Dijick, explains was categorized by a move from platforms providing a public utility to providing a customized service for each user. Similarly, MyChart moved from a public utility aimed at providers to providing a customized service to health systems in order to better access user data.

Overall, MyChart has presented itself as a platform by portraying itself merely as a portal of health information that serves just to host your information for free and for anyone, while obscuring its own benefits from hosting that information, the way that its true clients are health systems and not patients, and framing medical record information as too complicated for users to hand on their own so it is best left to MyChart.

Politics of MyChart's Platform

When considering electronic medical records and MyChart, more specifically, as a socio-technical system, the most significant factor that impacts the movement of information between different EMR platforms is the question of interoperability. While digitization of EMRs has been widely embraced since 2009, there continues to be a need for agreed-upon interoperability standards between medical providers, EMR companies, hospital institutions, and other actors. The most significant issues that stand in the way of true interoperability are a need for agreed-upon file formats, data standards, cultural terms, and mutual trust between EMR actors. When considering the interoperability of EMRs, this concept of control is particularly fruitful because individual actors seeking to maintain control have actually prevented them from agreeing upon an interoperability framework. Their interest in maintaining market dominance and their own API standards has directly flown in the face of the efficiency and cost-effectiveness that true interoperability would bring, which also gets into Raetzsch et al.'s discussion of the benefits and downsides of APIs, which ties into this conception as well because while the individual APIs of these EMR systems and hospitals do allow users to see their own Medical Data, there is not a shared API between systems that allow users to move information effectively. This privileges certain kinds of information moving through a system and puts moving information between systems at a disadvantage. With the discussions of interoperability and how this works as a sociotechnical system, we can see even more broadly that MyChart, while it aims to present itself as an open, neutral and egalitarian platform, is anything but, and it is mainly meant as a tool for providers and hospital systems. While aiming to position itself as a useful tool for patients, when in reality it is their data that is serving a much more broad array of offerings for its ideal client.

Finally, engaging with MyChart as a platform allows us to then see it as a platform that has grayed itself. MyChart has grayed itself through both its bureaucracy of the separation of its information for hospital systems and providers from its information for patients, and the lack of transparency, both in its corporate function and its corporate relationship with federal policies that aided its current ubiquity. So first this grayness through its overabundance of information, for example the menu has over 20 options for patients to select, and by seeming to conceptualize its users that is able to leverage all these offerings as highly technologically, bureaucratically, and medically literate user, MyChart truly does not seem to expect most people to dive into all of the details that their system has to offer. Even though MyChart offers a large amount to patients seemingly, and so this over offering of information makes it so that it seems to be too big of a hurdle for patients themselves to dive into and figure out how it's working so that they may identify things that they don't love or miswritings or things that need to be changed and then advocate for themselves. Thus MyChart obscures itself, and its ideal client, from excessive and inefficient scrutiny by over offering options and information so that scrutinizing MyChart from the patient side is far too large of a hurdle.

Beyond this within its website offerings and marketing materials, MyChart provides one page that provides very sanitized bullet point information for patients while offering a massive marketing hub to hospital systems with webinars, conversations about new offerings and developments, and press releases.What this means is this information about new systems that are only available to providers because of patient medical data is directly obscured from the patient themselves. One illustration of this is information about generative AI implementation within the MyChart EMR ecosystem, the Cosmos data set, or how to leverage this available data for patient insights and efficiency is all available only to its client, hospital systems and medical providers,

not its user. On top of this the visual design and layout of these two sites illustrates a clear divide between what patients are meant to see and what is for providers. The patient site is animated in the same way that the MyChart portal is, while the site for providers and health systems is much more typical of a regular business website, and that's significant in that it is not meant to even allow easy access to information that patients may want to scrutinize. So by serving itself as a neutral host of their information, by softening its edges and making everything animated, and by both presenting an overload of information within the system and then sanitizing itself in the materials it provides to patients about itself outside of the platform it makes it seem much more palatable, friendly and neutral, when in reality there is a larger business enterprise that is functioning that is obscured from the user itself.

Finally considering its corporate functioning within Madison, which is removed from typical technological hubs such as New York or Silicon Valley, Epic shields itself from scrutiny due to nearby corporate competitors, as well as reporters and other watchdogs that are based in the major epicenters of their industry. Additionally Judith Faulkner's involvement in the structuring of the HITECH Act that incentivized the digitization for EMR's was obscured, or at least in no way emphasized, so that both providers and users are prevented from seeing just how much the federal policy was shaped by Judith and positioned MyChart to be at the center of the EMR market. All of these factors come together to show that through making information boring and uninteresting,along with seemingly palatable and softened, it prevents users from engaging with MyChart as a money making apparatus. It is rather impossible to find as a patient or a user within the platform what it would cost for a hospital system to adopt MyChart, let alone what the offerings that it is providing to users may cost. It is this separation of how MyChart and Epic present themselves to hospital systems and providers versus patients posits a strong bureaucratic

knowledge that substantive information should only be offered to insiders that have a shared interest or a shared set of values to prevent its offerings from being misinterpreted. Which speaks to an intentional power dynamic that MyChart is both knowledgeable of and capitalizes on to avoid scrutiny as compared to companies that users may interact with more regularly and thoroughly.

Conclusion

Therefore, by considering MyChart a platform we can also see that it is a platform that acts to protect itself and its market power by graying itself and appearing boring and far too complicated for users to comprehend. This framing allows for MyChart to operate with very little scrutiny from the users whose data it profits off of, and prevents patients from understanding or advocating for alternate solutions that center their own autonomy over their records.

Conclusion

Truly the idea for this work came out of a morbid curiosity about the afterlives of my own personal moments of pain, fear, and injury. I was fascinated by how something both so personal to me as when I dislocated my jaw and frantically sought out help at an urgent care could also be so divorced from my influence of control that I would be unable to remove the meds I was prescribed at that visit until 3 years later. It is this tension between how, within these large bureaucratic systems, my data is not my own and may even outlive me, yet medical information is still regarded as some of our most personal information. In this push and pull over ownership of this data who wins and how many stakeholders are even involved?

This thesis begins to contextualize the EMR platform MyChart within a broader medical history of intake forms and technology as competition, explores how the platform presents itself to users, and investigates whether MyChart can be considered both a platform and a piece of bureaucratic media that has grayed itself to avoid critical scrutiny. This was done through consultation of healthcare IT Legislation and scholarly works from the field of the history of medicine, analysis of paper medical intake forms, a walkthrough of the account creation process, and placing these findings in conversation with the field of platform studies to evaluate MyChart under a set of platform criteria.

While scrutinizing medical recordkeeping may seem as though it is not a significant or pressing issue, this topic has become increasingly relevant following the rise of digitization of EMRs in the wake of the Affordable Care Act, as well as with major players in the EMR market announcing the implementation of generative AI within the forms themselves. These major sweeping changes have a fundamental healthcare experience for a significant number of Americans, and yet there is very little information made available to everyday users in order to

better understand the usage and management of their data. Additionally, within the fields that may be evaluating electronic medical record platforms there is a marked lack of literature that considers whether patients have a right to have autonomy over their own medical data, or what a patient led approach would look like.

This gap in the field is precisely where I believe that research on electronic medical records would benefit from better engagement with Disability Studies and Critical Access Studies, as it is disabled and other marginalized people that interact with and are affected by this infrastructure the most. To consider how this infrastructural built environment may be made more accessible and equitable, would be a huge step forward in ensuring that disabled people could lead the conversation in how to reform our system for better patient support and results.

Limitations and Areas of Future Work

While I initially had plans for this work to be a grand opus, it became clear that the best function for this thesis was to serve as a test balloon for future work on this topic, which means there were definitely limitations that changed the development of this project. Aside from the major unforeseen circumstance that altered the end of my spring semester, if I had had additional time for this thesis I would have dove further into archival work, both the Micheal M. Davis Archive and the informal Federal Healthcare IT Legislation I was loaned. These were great to have exposure to, as they confirmed that this work could benefit from a strong historical foundation, but I unfortunately ran out of time to include them in the major way I initially hoped. Additionally, because of how recent Epic's announcements surrounding AI were, I was unable to bring in more concrete information or impacts on their implementation in a way I would have liked. FInally, I think this thesis would have benefitted from further engagement with the fields

of Critical Access Studies and Disability Studies that I was trained in, and that is a direction I hope to pursue.

Looking forward I hope to expand this work and want to look more closely at how the social and economic histories of medicine impacted our current EMR infrastructure. Specifically, I think that looking at the rise of third party insurance could be incredibly fruitful, especially when looking at the introduction of billing codes and what they mean for the commodification of bodies. Beyond this, investigating how precisely we chose the structure of the first EMRs is an intriguing question to me, and I am curious to see if that research could be aided by FOIA-ing the Department of Health and Human Services meeting on the HITECH act. Lastly, looking more closely at the thread of technologization and efficiency as the metrics of competition in the medical market, and how this originated and what the impact of it was within MyChart's own language and selling points today.

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