Computing Care: Governing U.S. Healthcare Through Markets and Data

by

Linda Huber

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Doctoral Committee:

Associate Professor Silvia M. Lindtner, Chair
Professor Mark S. Ackerman
Associate Professor Roi Livne
Professor Janet Roitman, RMIT University

Linda Huber

ludens@umich.edu

ORCID iD: 0000-0003-3726-8433

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Dedication

To the graduate workers of the University of Michigan: solidarity forever.

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I have written these acknowledgements many times over in my head during the six years it took me to reach this point. In the end I find that these meager pages can't begin to do justice to everything that I have been given by my friends, family, mentors, comrades, and community. The *real* acknowledgement, of course, is in the hugs, the shared meals and drinks, and the precious hours of my life that I will spend paying it all forward: in the work of reviewing shitty drafts for my students; the hours spent talking my colleagues through messy and partial ideas; the hours in meetings sorting through feelings and partial plans to try to find a way to make the road forward. But anyway: here is some partial piecemeal acknowledgement as it is, written out "for posterity", as my mom would say.

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Abstract

The U.S. healthcare system is in crisis, marked by soaring costs, inefficiencies, and stark disparities in health outcomes. Or at least, this is how U.S. policy makers have predominantly narrated and justified healthcare policy interventions since the 1970s. This dissertation examines how, starting in the 2010s, U.S. policymakers and politicians have turned towards data infrastructures – including new protocols and standards for exchanging clinical, billing, and administrative health data – as the newest site for reforming healthcare markets.

Drawing on 24 months of multi-sited ethnographic research in the U.S. healthcare industry, I trace how federal regulations, particularly the 21st Century Cures Act (2016), position data interoperability, or standardized data sharing, as a means to realign a fragmented, profit-driven healthcare market with the efficient production of population health outcomes. I describe this mode of governance, which merges market-solutionism and techno-solutionism, as "computing care."

Through a close examination of "value-based care" policies, social determinants of health data, and the automation of prior authorization, I show how computing care helps to depoliticize the failures of for-profit healthcare markets to produce equitable, accessible, affordable care. The failures of healthcare markets are instead narrated by policymakers as technical problems - of insufficient information and sub-optimal market design. I argue that intensified computation and continually evolving capacities to collect, analyze, and store data help reproduce this depoliticized, market-solutionist mode of governance.

Through this project, I interrogate the banal violence of computing care as a mode of governance and point towards the possibility of alternative modes of governance beyond market- and techno-solutionism. I also reflect specifically on the potential role of data infrastructures in advancing alternative modes of care governance. This project contributes to the fields of critical data studies, science and technology studies, and feminist political economy, highlighting the reconfigurations of data and governance necessary to achieve an equitable and just future of healthcare.

Chapter 1 Computing Care

"We're Not Doing Well": U.S. Healthcare as a Problem - And Data as its Solution

In February 2023, in a large, windowless ballroom at the Arlington, Virginia Hyatt Regency hotel, FDA Commissioner Robert Califf, mustachioed older white man in a bowtie, gave his keynote to the thousand plus attendees of the annual "Health Datapalooza" conference. In a southern drawl, Commissioner Califf sets the stage for the multi-day conference: *"Despite all the bravado about the U.S., we're not doing well compared to other countries with less economic means."* Commissioner Califf shows a slide narrating the strengths and weaknesses of US healthcare: *"US leads the world in medical technology innovation: drugs, biologics, vaccines, devices, diagnostic tests, novel foods and food production."* On the other side of the same slide: *"US continues to lose ground to other high-income countries in life expectancy and measures of health status with enormous disparities related to race, sex, ethnicity, wealth, education, and geospatial location."*

Commissioner Califf narrates the problems of the U.S. healthcare industry from the perspective of many of its policymakers and politicians. This problematization reflects a sense that the U.S. should be able to convert its wealth and leadership in technological innovation to world-leading health outcomes. (Califf asks rhetorically, *"Why do I have to call Israel to figure out what to do with the covid19 vaccine?"*). This narrative reflects an idea that our[1] competitive markets and cutting-edge medical technology should mean that other countries come to *us* to solve their problems, and turn to *us* as a beacon of healthy, long-lived populations. It narrates states as responsible for ensuring an efficient conversion of economic inputs (investment in medical technology and care) to health outputs (population health outcomes like life expectancy), and the U.S. as failing in this efficient conversion.

[1] Note on the use of "our" and "us" here and elsewhere in the dissertation, in relation to the American healthcare system. I use this not as an assumption that my readership is included within the category of "American", but that as an American citizen, as a taxpayer, I am in some sense directly implicated within this system. Me and my loved ones will live and die by the construction of this healthcare market. This system is in some way "ours", and we are mutually implicated in each other's success and failures.

Commissioner Califf goes on to suggest a diagnosis for the factors causing us to fall behind in this imaginary race between nation-states: *"Technology isn't the limiting factor - it's our culture and the way we do things.*[2]*"* To illustrate what he means by "the way we do things", Califf shows a slide with a dozen differently colored circles: patients and families, professional societies, payers, government, health systems, medical product industry, advocacy groups. Califf narrates: *"Every element of this system is looking out for their own - even if it's to the detriment of the system."* Califf attributes the U.S.'s failure to efficiently and effectively produce a healthy population to the sense of zero-sum competition between these different institutions and constituencies.

Commissioner Califf explicitly does not consider whether "our culture and the way we do things" - including the sense of competition between different elements of the healthcare system - reflects the way that healthcare is paid for and provisioned in the U.S. Among the 38 non-U.S. OECD member countries, the U.S. is unique in its reliance on private, often for-profit insurance companies as the primary financier of healthcare costs: a little under half of the U.S. population receives insurance from publicly-funded insurance programs; the other half is covered under health insurance plans subsidized by employers (US Census Bureau et al., 2024).

Likewise, in the U.S. the majority of healthcare facilities are private, run as either for-profit or non-for-profit businesses, relative to higher proportions of public hospitals in the other OECD countries[3]. In the U.S., healthcare is not a public infrastructure provisioned by the state, but is a *market,* paid for largely by employers as a benefit to their employees. The state is purely the insurer of "last resort", for the elderly or disabled, or otherwise unable to access employment-based insurance markets.

When Califf alludes to "our culture and the way we do things" as the cause of lower life expectancy and extreme disparities in health outcomes, he is alluding to the culture of competition that exists within a fragmented, largely private market. Yet this zero sum competition is construed, not as an inherent or necessary aspect of for-profit healthcare markets: it is construed as a problem for policymakers to *overcome.*

---

[2] This truism is repeated often among the technologists attempting to fix the healthcare industry: it isn't a technology problem.

[3] In both Reibling et. al's (2019) and Böhm et. al's (2013) classification systems, the U.S. standards apart from the other OECD countries for its largely private regulation, financing, and provisioning of healthcare services. Böhm's classification describes the U.S. as a "private health system."

The buzzword that U.S. policymakers and politicians use to describe this dynamic, of "every element of the system is looking out for their own…to the detriment of the system" is *"misaligned incentives."* This short phrase succinctly and neatly renders the failure to produce population health outcomes efficiently and effectively as a *technical* problem, a problem to be solved by economists through a thoughtful and careful re-designing of the incentives driving insurers, healthcare providers, and patients. This phrase, "misaligned incentives," steers the diagnosis *away* from considering whether organizing healthcare as a for-profit market is part of the problem, and *towards* an evaluation which says that these "ends" - profit, reduced costs, minimization of risk - pursued fastidiously by individual actors, must be re-engineered.

We might understand this phrase as conveying a kind of "market-solutionism": a sense that markets can be used to achieve optimal outcomes to public problems, if only they are properly designed and engineered. Lurking within Commissioner Califf's keynote is the implicit idea that the best, and possibly only way to efficiently achieve population health outcomes on par with other wealthy nations is through carefully designing market incentives to optimally orchestrate the self-interested choices of patients, providers, insurers etc. towards the maximal public good.

Through the lens of market solutionism, the failures of markets to efficiently and effectively produce the public good - as we see in the case of U.S. healthcare markets - is rendered as a problem to be addressed through the re-engineering of those markets. This is done not only by re-designing market incentives, but also by updating and continually refining the computational and information infrastructures undergirding markets. It is through *information* that prices are constructed, and the speed, scale, and complexity of information – and its differential availability to different market actors – fundamentally shapes the functioning of markets. Within emerging health data interoperability policies, we see how data-solutionism becomes an increasingly central part of the narratives and practices of market solutionism. It is this merging of these two -isms that I examine within this dissertation.

Commissioner Califf's keynote goes on to specifically emphasize the *role of data* in this re-engineering of markets. On the slide depicting this fragmented, competitive healthcare landscape is a label, emphasizing the *technical* problem underlying this zero-sum competition: *"The reality is that we have a disaggregated, fragmented system with a lack of organization around common, transparent high-quality information."* The problems of the U.S. healthcare

system here are framed as a problem of competition and fragmentation which can be overcome through improved and updated information infrastructures. Concluding the talk, Commissioner Califf frames the problem: how do we overcome this environment of fragmented interests competing to the "detriment of the system" *through* the creation of a standardized data-sharing infrastructure? In this narration, fixing fragmented data infrastructures is a key mechanism to fixing the overall system.

Commissioner Califf's keynote reflects a highly ritualized, institutionalized narrativization of the problems and solutions of the U.S. healthcare system. In this narrative, data "interoperability", or standardized data sharing across organizational boundaries, is central to enabling the U.S. to compete more effectively in the great race among nation-states to produce a healthy and productive population - at a minimum of public expense. Data interoperability is situated as a key mechanism to advance a particular policymaking goal: to efficiently manage the health of the U.S. population as an economic resource.

This particular focus on data interoperability as a key part of the solution to the problems of U.S. healthcare began to coalesce in the early 2010s, around the time of the 2009 HITECH Act. Through this act, undertaken as part of a broader economic stimulus package in the wake of the 2008 financial crisis, the federal government invested +$25 billion dollars in the switch to digital health records. A year later, the Affordable Care Act instantiated a set of policies and procedures to redesign healthcare markets in the U.S. At this moment, technocratic experts within Health and Human Services, major research hospitals, and policy think tanks began to articulate the idea that *interoperable health information infrastructures* had a central role to play in enabling the conversion from a fragmented and inefficient healthcare market into a market which would efficiently and effectively produce a healthy U.S. population.

This approach to market-reform-via-data-reform was subsequently adopted by healthcare policymakers and instantiated via the 21st Century Cures Act in 2016, which set forth a mandate for nationwide health data interoperability. The Cures Act has motivated nearly a decade of reforms and interventions, with new rules, incentives, guidelines being published by the department of Health and Human Services (HHS) every few months. This dissertation focuses specifically on exploring how these policies reflect and reproduce market-solutionism as a particular mode of governing healthcare, and the way that data infrastructures help extend and intensify this market-based mode of governance.

Health data interoperability policies are articulated by politicians, policymakers, and industry experts as a "solution" to the failures of the U.S. healthcare industry. Yet in this project I demonstrate how positioning health data interoperability as a "solution" relies on a particular economized framing and understanding of the *problems* of U.S. healthcare. Following Foucault, the construction of this domain of problems and solutions reflects a particular mode of *governmentality* (Foucault, 2008; Rose et al., 2006). "Governmentality", a portmanteau of 'governance' and 'rationality', describes the modes of knowledge and power through which "government makes it possible to address a problem and offers certain strategies for managing or solving the problem." (Lemke, 2007, p. 44). Foucault used the term to describe what he saw as a shift in governmentality between a mid-20th century mode of Western, liberal governance focused on the exertion of power through state welfare policies, to a contemporary neoliberal mode of governance rooted in the rationality of *the market* and the economization of governance problems and solutions.

In this dissertation, I interrogate health data interoperability policies as a key site for understanding contemporary governmentality. I build upon previous STS and economic sociology scholars who have analyzed *markets* as a tool of contemporary governance (Berman, 2023; Fligstein, 1996; Fourcade & Healy, 2016; Pistor, 2020; van Dijck et al., 2018). Extending this work, I show how governance through markets - market solutionism - is enabled and reproduced through intensified computation and datafication. Specifically, I argue that datafication and computation plays a key role in enabling an endless project of technocratic tinkering, even in the face of persistent failures of markets to produce the public good - such as we see in the U.S. healthcare industry (Evans, 1997).

Through a close examination of health data interoperability policies and the discourses that accompany them, I show how the continual failures of healthcare markets to produce accessible, affordable healthcare is constructed as a problem of misaligned incentives and outdated information infrastructures. Alternative ways of diagnosing or treating the failure to produce health within the U.S. - for instance, by seeing privatized healthcare markets as *part of the problem* - are foreclosed. This mode of market- and data-solutionism is pervasive across many different domains of governance; this dissertation focuses specifically on understanding how it unfolds within the context of healthcare. I coin the phrase *"computing care"* to describe how intensified datafication and computation help enable and reproduce market-solutionism as a

mode of governance, even in the face of the consistent failures of healthcare markets to meet the biopolitical goals of the state, as outlined by Commissioner Califf.

This research draws from two years of fieldwork and interviews in the U.S. healthcare industry, as well as discourse analysis of policy documents and industry coverage primarily from 2014 - 2024. In the remainder of this chapter, I continue to explore the contours of this dream of "computing care" and to sketch a brief history of U.S. health data interoperability policies. Through a series of short vignettes, I introduce some of the key actors in this story: federal policymakers, health data professionals, the data standards and policies which enact and reflect a particular mode of intervention. I briefly introduce some of the frictions and counter-narratives to computing care that appeared in my research. In the subsequent chapters, I explore in more depth how, exactly, computing care is instantiated and enacted within specific policies and data infrastructures.

Data Liberation Day

October 6, 2022 was declared "data liberation day." On this day, the Cures Act Final Rule, mandating healthcare providers to share data directly with patients via standardized API access, went into effect. This day was an important landmark for the shift towards health data interoperability. Yet the origins of "data liberation day" can be traced back to over a decade prior, well before the Cures Act itself.

Just as our current discursive moment is awash in talk of "AI", in the early 2010s the buzzword of the day was "big data." At this moment, a wide variety of public and private actors increasingly saw data as a valuable resource that would lead to new innovations, new insights, new and improved consumer experiences. This period saw the growth of the so-called "sharing economy" and meteoric expansion of platform business models predicated on data-sharing via APIs. Likewise, some policymakers saw this moment of "big data" and standardized, API-based information sharing as an opportunity to create more innovative, efficient, and effective healthcare markets within the healthcare industry specifically.

In 2010, Health and Human Services (HHS) Chief Technology Officer Todd Park began to use the catchphrase *"data liberación"* to describe the "movement" that Park and others were

fomenting within the government. Park, with his "private sector energy,[4]" sought to solve the problems of the healthcare market through big, standardized, open data[5]. During the early days of interoperability discourse within HHS, policymakers like Park imagined that helping to cultivate large-scale data sharing across the industry would help trigger a kind of sea change towards platform-like business models. Platform companies like Amazon or the still-emerging social media platforms were seen as uniquely capable of collecting and using data to create innovative, seamless, cost-effective experiences for providers and patients.

For instance, policymakers imagined that by implementing standardized health data APIs, patients would be able to access their health records via Apple's consumer-facing health apps, becoming more active managers of their data and their health through more consumer-friendly and engaging applications. Likewise, if electronic health records (EHRs) shared their data via APIs, third-party developers could develop new apps and services, and providers could then pick and choose the apps that most efficiently and effectively supported their care-work - rather than being locked into the apps provided or built by the EHR itself. Policymakers saw standardized health data sharing, and the emergence of platform-like markets, as a pathway to address the pervasive challenges of the U.S. healthcare industry through innovative, efficient, data-driven user experiences.

Yet most health data is controlled by private corporations - electronic health record companies, hospital systems, insurance companies. Even as early health data interoperability policies came online, these companies were continuing to build market-share on the hoarding and siloing of data and weren't eager to jump on the "data liberation" bandwagon. Nor were these companies prepared to invest the millions required to re-vamp and update their legacy data infrastructures for interoperability. By 2017, health data interoperability expert Dr. Julia Adler Milstein declared "the end of the kumbaya era.[6]" By the time that the actual policies came online

[4] Source: https://www.youtube.com/watch?v=G09JnD7vg0k. Todd Park was a former Booz Allen Hamilton employee and founder of health technology companies Athenahealth and Castlight prior to his time as HHS CTO.

[5] In his pitch for health data liberación, Park would point to the precedent already set by the National Oceanic and Atmospheric Administration (NOAA), which was publishing its data online in machine-readable form, enabling companies to use this data to create their own apps and services. Park pitches these third-party products and services, built on public data, as a win for the federal government: "This is a huge host of innovations that NOAA hasn't had to pay for, NOAA hasn't had to manage."

[6] Source: https://www.youtube.com/watch?v=NrFV9LnV1Ic

instantiating “data liberation day” in 2022, health data interoperability had ceased to be understood as a “movement” - and had become more of a compliance exercise.

Over the preceding decade of health data interoperability policies within the U.S., there is wide variability in the way that these policies are articulated and justified – and the actual ends to which they are applied. Still today, much of the discourse around these policies emphasizes “liberating” health data to create new products and services and more competitive markets. Yet looking at how these data streams are being used, we see that much of this is geared towards facilitating the discipline and control of market actors. In this regard, health data interoperability policies reflect an admixture of understanding data and competitive markets as innate engines of public good, and of understanding markets as something to be controlled and engineered, particularly through *data.*

We see this contradiction reflected in data interoperability policies more broadly. Interoperability is sometimes presented as a means to make new, digital markets: the 2010 EU Commission Digital Agenda highlighted interoperability as one of the most important barriers to value creation via digitalization (Kerber & Schweitzer, 2017). At other times, interoperability is positioned as one of the few tools available to regulators to help exert some degree of control over emerging platform monopolies (Bietti, 2024; I. Brown, 2020; Huber, forthcoming 2025; Scott Morton et al., 2023).

The tensions and contradictions between interoperability as a tool for value-production and interoperability as a tool for market discipline reflect a pressing set of questions of contemporary governance: how, exactly, do markets create the public good? How does datafication enable or intensify extraction, or the production of the public good? And how, exactly, can states seek to wield digital infrastructures to exert some form of discipline or control over these markets? We can see these questions being worked out, on a smaller scale, within the shift between Todd Park’s era of “data liberacíon” to the more structured enforcement of market discipline through data explored in this dissertation.

Health Data Interoperability: the “Rising Tide Which Lifts All Boats”

The dream of an efficient, innovative, collaborative-yet-competitive “sharing economy” is central within the health data interoperability space. I was able to see this dream embodied during my fieldwork at the annual Healthcare Information and Management Systems Society (HIMSS) conference in April 2023. HIMSS is the largest conference of health informatics

professionals in the world, and in 2023 it was held at the McCormick Place convention center in Chicago. It is largely a tradeshow, often hosted in Las Vegas, and includes thousands of vendors, huge colorful, well-lit booths for technology companies, medical device companies - even entire countries - that wish to advertise to this wealthy and innovative slide of the healthcare market.

However, each year at HIMSS there is a space carved out not for individual vendor booths, but for vendors to demonstrate the seamless flow of information across the fragmented and competing sets of market actors. This space is called the "interoperability showcase."

Under the fluorescent lights and soft light blue carpeting of the interoperability showcase, I wandered from demo to demo, trying to gather a holistic sense of *what health data interoperability looks like.* Each booth of the showcase was focused on a particular information use-case: "chronic diabetic care management"; "pregnancy and surgical complications"; "behavioral health and addiction management". Each booth's signage also listed the different organizations - health systems, data brokers, and specialized IT vendors - demoing the use-case. (EPIC and Cerner, two of the largest EHR vendors in the country, recur repeatedly across booths).

I saw a demo focused on automatically integrating dental care data, often excluded from the world of clinical data exchange, into a patient's health record. Vendors narrated this as a benefit for both patients and providers, enabling better coordination of care around complex dental surgeries and improving the referral flow for dental providers. Another demo includes *seven distinct vendors*, showcasing the flow of information as a patient is seen by their primary care physician in their home state, shows up to an emergency room in another state with heart issues, and receives continued care again in their home state.

These demos, and the promised mutual benefits of data exchange for providers, patients, health insurers and health systems, exemplifies the dream of standardized data sharing as a kind of rising tide which lifts all boats. Through these demos we see the bubbles of competing actors, described by Commissioner Califf as "each looking out for their own," using data to increase profitability, improve patient experiences, and achieve better population health outcomes more efficiently. Rather than competing on the hoarding and siloing of data, these vendors are competing on their capacity to deliver useful information at the right time to improve care. In the space of the interoperability showcase, all interests are aligned: data sharing enables both improved care and improved bottom lines for everyone.

Yet if the HIMSS interoperability showcase demonstrates the policymaker's dream of interoperable data as enabling a market which optimally and efficiently produces the public good, many industry practitioners readily trouble this dream.

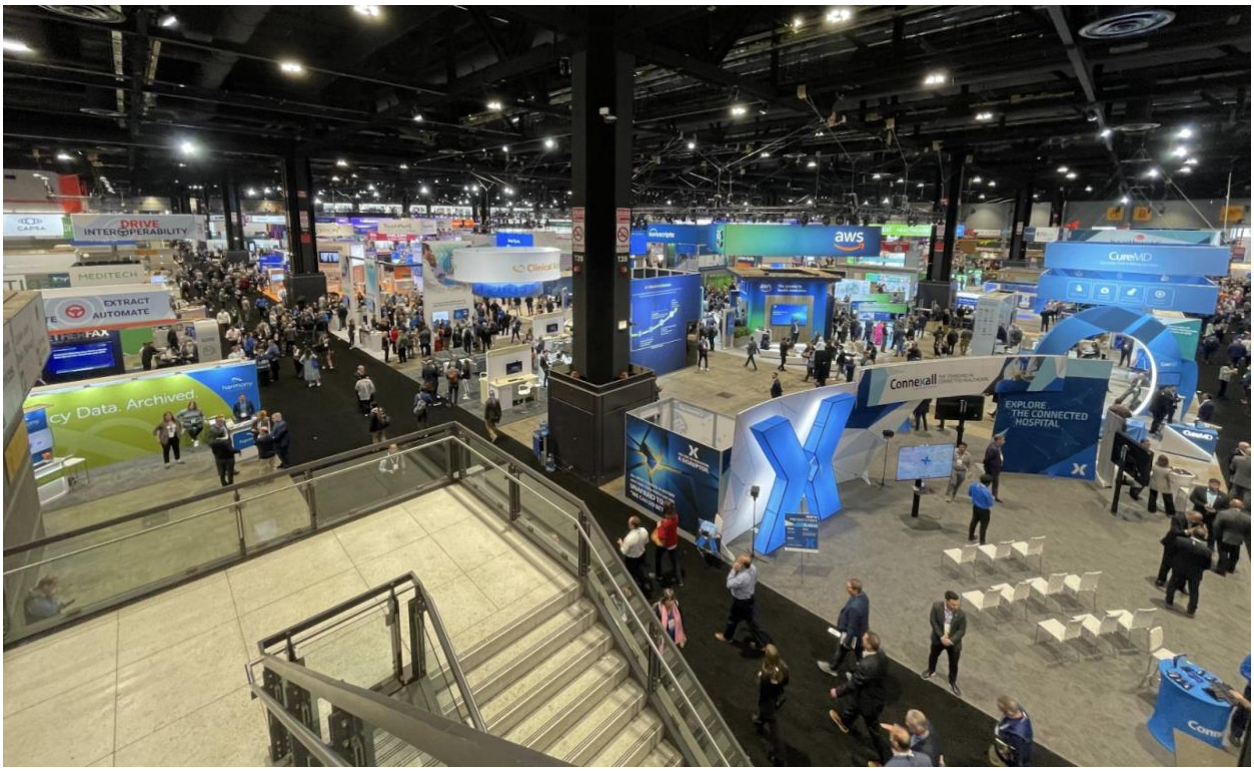


Figure 1.1 Vendor showfloor, HIMSS Annual Meeting. Chicago, IL, April 2023.



Figure 1.2 Interoperability showcase, HIMSS Annual Meeting. Chicago, IL, April 2023.



Figure 1.3 Interoperability showcase demo booth, HIMSS Annual Meeting. Chicago, IL, April 2023.

Counter-Narratives: The Role of Data in Care Markets

In May 2023, I have a zoom interview with Mark[7], an older white man and health IT vendor based in Michigan. Mark is one of the nearly thirty health IT professionals involved in the daily work of implementing interoperable data infrastructures that I interviewed as part of this study. Like so many conversations in this industry, what starts as a discussion about a technical infrastructure quickly spills over into something more personal. With audible frustration in his voice, Mark explains:

> *I'm 61. I can tell you, one of the biggest fears I have is that something will happen to me from a healthcare perspective and I will be bankrupt saving my sorry ass. Why is that even an option? Why would it cost me 10 thousand dollars, and doesn't even fix me but just prolongs things? I'm not gonna do it. I work 50 some years, why should I blow that in 18 months on healthcare?*

Like many of my other interviewees, Mark has a particular perspective, honed like a knife over many years, about the problems with the health system he fears will leave him broke at the end of his life. Mark is blunter in his evaluation than many of the healthcare policymakers and executives that I speak to: *"I don't know why healthcare in this country is a for-profit endeavor. That's starting off on the wrong premise. You're already a hypocrite before you ever start doing anything, because you tell me you care about my health, when in reality you just want my checking account."* Mark links his personal sense of precarity around the healthcare industry to the profits that healthcare companies seek to extract from him as a patient. He situates the troves of health data that he has spent decades safeguarding for insurance companies and providers as part of this system of profit-extraction:

> *Hospitals and providers are making money off your health record. Yours and 30 million others…They have all the advantages, in terms of economies of scale. They can run all these analytics…Just pick a prescription drug…If you have 150 million customers, and 25% of them are using this drug…if they can figure out a way to deny service to that drug, to reduce the use of that drug by 10%...That's gonna save them whatever that drug costs. Then, "how can we get that drug prescribed less?" How can we finally reduce the cost to us of that drug? … They don't give a rat's ass about you. They call the pharma*

[7] While I have retained the names of prominent policymakers and executives within this dissertation, the individual professionals quoted throughout are anonymized; alternate names are used in place of their real names.

companies, "can you charge X minus two cents?" 2 cents times 10 million. That adds up very quickly. Just one of thousands of scenarios they run constantly.

Having seen how the data he manages is used, Mark argues that changing ownership and control over health data would mitigate this extractive dynamic: *"If you own your data and they don't - that's a world of difference."* For Mark, health data should rightfully be owned and controlled by patients, instead of by insurers and providers, who use this data to extract value from patients.

Mark has one particular perspective on the problems of the U.S. healthcare industry and the role that data can play in mitigating those problems. As a manager at a relatively small security and IT vendor, Mark's narration reflects his positionality, outside of the heart of the institutional sensemaking machines. Mark is prepared to openly and bitterly critique the role of data in enabling insurance companies' extractivist practices, because he is not in the policymaker's position of "reforming" those companies. As a third-party vendor, he also has some degree of institutional separation from the practices of health insurance companies, even if he is "aiding and abetting" those clients by maintaining and safeguarding their data troves.

Mark, in this narration, is challenging the dominant narration of U.S. healthcare's problems as presented by Commissioner Califf and others. He narrates this as a problem of profit extraction by corporate actors, who he sees as actors which *categorically are not aligned with his own interests.* He sees data as a primary tool which these corporate actors wield to intensify this extraction of value. Through my conversations with policymakers and data professionals within this field, I encountered many individuals such as Mark: individuals with their own narration of the problems and solutions for the U.S. healthcare industry, articulated in terms other than "misaligned incentives" and the role of interoperable data in creating more rational and efficient healthcare markets. And yet, these doubts do not become central to the work. I feel that many of my interlocutors felt comfortable expressing these alternative problematizations and proposed solutions to me, as an outsider to the field, in ways that they would not express openly in a conference or a work setting.

This circumscription of the terms of debate - the foreclosure of a broader set of questions about the governance of care - is perhaps the direst and pressing of the issues that I raise in this dissertation. Rather than simply call out health data interoperability efforts as insufficient, or harmful, to remedying the crucial structural problems of U.S. healthcare, I seek to highlight the ways that the problem and solution frames about how best to govern care have been collapsed

down to a narrow set of technical concerns about market incentives and data infrastructures. How is it that one particular construction of the problems and solutions of governance have become so central, so stabilized? As I argue in this dissertation, the promise of ever-more-perfect datafication and computation is key to the ongoing reproduction and stabilization of market-solutionism as the primary mode of governing care.

As I explore in chapter five, sometimes these doubts and concerns about the actual material impacts of health data interoperability policies *are* discussed more openly. Nonetheless, these doubts and concerns about *how we govern care,* about the power and extractivism of for-profit healthcare corporations, are channeled into technocratic discussions about how best to implement a new data standard. As I argue in chapter two, this is not a matter of happenstance: contemporary modes of market-solutionist governance arise specifically from attempts by neoliberal thinkers like Fredrich Hayek to identify a mode of governance *devoid of politics.* Economists and policymakers of the time reconfigured governance as a technocratic act of designing infrastructures which enable decisions to be made in a decentralized way, through individual rational action within the marketplace.

We see the inheritance and continuation of this mode of governmentality within health data interoperability policies which convert complex political questions about how best to govern care into simple problems of engineering and market-design. Through this dissertation, I hope to create more visibility around the alternative possible ways of narrating the problems of the healthcare industry, and the alternative mechanisms or practices through which care can be governed.

In October 2024, I interviewed Melissa, a health data professional who has spent the last ten years working for a regional Michigan healthcare provider organization. And although passionate about the possibility of using health data to make claims about needed social infrastructure, she sees interoperability as a side-show, irrelevant and sometimes actively counter-productive to the changes needed to improve healthcare in the U.S.

"Food and housing are two of the most basic, stable, enduring human needs…they are consistently among the greatest barriers to clinical quality[8], to positive outcomes." Melissa argues that to increase healthcare outcomes, we need to address these structural issues: to build

[8] See Chapter 3 for a more extended discussion on quality metrics, and their role in new payment models intended to help incentivize improved healthcare outcomes.

more affordable and subsidized housing, more affordable grocery stories. But because these changes lie outside of healthcare business models, "*healthcare has no idea what to do with that."* Melissa's work helps to connect people in her community to local resources to meet these basic needs - and to generate data about that work to improve reimbursement rates for the healthcare provider system she works for.

While Melissa sees these referrals as a valuable and important stopgap, she argues that the data being collected and analyzed about these referrals often helps to reproduce the unaddressed structural problems. She describes the disjuncture between what she documents for her employer to justify higher reimbursement levels, and actually meeting people's needs:

> *It is so seductive to [tell] the lie that everybody wants to hear, which is we're meeting people's social needs. We're not meeting people's social needs. At best, we are connecting some people with very specific needs to the specific funding that is associated with the episodic support of that need…That's the best we can do, because we don't actually care whether or not people are housed as a society...We have decided that we can be the most resource rich history country in the history of civilization, and still, we're totally fine with people being homeless and kids sleeping in cars.*

Through this example, Melissa shows how data interoperability and data infrastructures - even those built to address and improve extractive healthcare markets - can help obscure and reproduce the structural violence of a system which turns the meeting of social needs into a business model, a site for the generation of profit. Nonetheless, Melissa sees a valuable role for data which can help honestly show these structural failures, and which can help create the "political will" to ensure that everyone's basic needs are met: *"I need to keep track of the needs that cannot meet, because I need that data so that I can demand something different from the people who have money and power and make decisions."*

These vignettes illustrate some of the many ways that problems of the healthcare industry are constructed, and the way that different actors (politicians, technocratic policymakers, health IT workers) understand data to be part of the solution to those problems. The purpose of this is to show the banal violence that lurks behind the state's construction of both problem and solution: the ways that the problems of the healthcare industry are positioned as problems of "waste, fraud, and abuse" by healthcare providers and patients; the way that health data infrastructures are designed to enable the exertion of ever-more exact forms of discipline over care; and the

ways that the production of improved population health metrics at the minimum of expense is situated as the ideal "end state" for the healthcare industry. But this story also shows that other constructions of both the problem and the solution are possible - not only speculatively, but concretely: in the everyday understandings and practices of healthcare workers, data professionals, and policymakers.

Computing Care: Sustaining Market-Solutionism Through Datafication & Computation

This interrogation of health data interoperability policies and the mode of governance that they reflect and reproduce is critical for two reasons. First, because these data policies are in a moment of active construction - they are a site of "fresh power" (Bruno Latour, 1983) calling for attention and intervention to prevent the reproduction of structural violence. The restructuring of data infrastructures through interoperability policies enables techniques of advanced computation and datafication to be applied to patients and healthcare workers to surveil, categorize, and otherwise discipline the production of care.

Second, these policies also reflect a broader and reproduce a broader mode of governmentality, pervasive within the U.S. and beyond. This mode of governmentality is characterized by states' and policymakers' devotion to market engineering as an ideal mechanism of governance - despite the continuous failures of markets to efficiently and effectively produce "the public good" or meet the biopolitical goals of the state. Through a close reading of health data interoperability policies, we can better understand how this mode of market-solutionist governmentality is enabled and reproduced through intensified computation and datafication.

I coin the term "computing care" to describe this specific dynamic as I observed it within the domain of the U.S. healthcare industry. Through this phrase, I seek to convey the persistence and pervasiveness of the idea that *we can simply compute our way through* the failure of U.S. healthcare markets to achieve either the biopolitical goals of the state or accessible, sustainable, equitable forms of care. This market- and data-solutionism is reflected in the data policies and market reforms that I explore in the three empirical chapters of this dissertation, and in the ongoing production of policies devoted to data- and market-reform.

Through the phrase "computing care", I describe the convergence and mutual co-constitution of three key phenomena:

1. **First, computing care describes a market-solutionist mode of governance.**

My concept of computing care draws from and builds upon scholarship demonstrating how contemporary governance is organized around the design and maintenance of markets. In "The Birth of Biopolitics", Foucault describes a neoliberal mode of reason that sees human well-being as best supported through the creation of a strong economy which allows individuals to provide for themselves. Influential neoliberal thinkers of the early 20th century, like Friedrich Hayek and Adam Smith, articulated markets as an ideal mechanism of governance.

This idealization of markets rests partially upon the idea that markets allow for a *decentralization* of decision-making, and a de-politicization of governance itself. That is, the superiority of markets as a tool of governance relies on rendering markets as technological objects (Li, 2007a), and market-making as a fundamentally technical - rather than political – practice (Ferguson, 1994). Although neoliberal governance is often associated with practices of deregulation and privatization (Harvey, 2007; Vogl, 2014), economic sociologists have carefully traced the ways that states fundamentally enable and maintain markets (F. Block & Evans, 2005). Scholars like Philip Mirowski, have specifically focused on examining neoliberal governance not as a 'laissez faire' approach to free markets, but as a practice of *market design*, of economic engineering (Beverungen et al., 2019; Nik-Khah & Mirowski, 2019).

In my account of computing care, I emphasize the centrality of both market-solutionist ideologies and market engineering practices within emerging health data policies - and in contemporary governance more broadly.

2. **Second, computing care describes how market solutionism both foundationally relies upon and - crucially - is sustained by continually evolving processes of computation and datafication.**

Information infrastructures have always been central to the production and maintenance of markets - and states have always been centrally implicated in enabling the standardized information infrastructures which undergird markets (Mitchell, 2002; T. M. Porter, 2020). Yet computing care specifically seeks to characterize how intensified datafication and computation help entrench and reproduce market-solutionism as a viable pathway to producing "the public good." In the face of markets which fail to efficiently and effectively produce the public good, policymakers turn towards practices of market *re*-design, fine-tuning economic incentives, inventing new assets. Mirowski and Nik-Khah calls this practice of redesigning markets for the public interest, "going the market one-better" (Nik-Khah & Mirowski, 2019).

Intensified datafication and computation help reproduce the promise of achieving yet-more optimized, public-interest-aligned markets. Recent scholarship has explored how digital platforms represent the practice of market and mechanism design par excellence (Nik-Khah, 2023; Viljoen et al., 2021). Platforms are able to structure both the flows of information that are captured, and to use this information to continuously tinker with the design of the markets they intermediate in ways that are beneficial to them (Pistor, 2020; Srnicek, 2017; van Dijck et al., 2018; Zuboff, 2019). This scholarship demonstrates how intensified datafication and computation, enabled via platform architectures, helps to entrench *market design* as a key aspect of platform-based governance. I extend this work by exploring how, in the case of health data interoperability policies, the U.S. government adopts a platform-like mode of governance: by developing bigger, faster, more standardized data streams, the state seeks to enable new frontiers of market reform and re-design, exerting greater control over market actors in order to more efficiently and effectively produce the desired population health outcomes.

3. Third, computing care describes how this market-solutionist mode of governance, reproduced through data and computation, unfolds specifically within the governance of care.

A rich body of scholarship in STS and critical data studies has traced the way in which information is used to discipline, control, surveil, and construct identities, particularly within the healthcare domain (Ruckenstein & Schüll, 2017). Some scholars have specifically explored the role of health data in projects of austerity and organized abandonment by the state (Dencik & Kaun, 2020). Through the concept of computing care, I extend this previous, important work on the role of data in contemporary health governance by showing how these data infrastructures are designed, not only to enable intensified classification and control by the state, but to reform and discipline the behavior of patients and providers *as market actors.* Whereas previous scholarship helpfully outlines the role of data as a tool of discipline and subject-construction, I specifically show how these techniques of discipline and subject-construction are fundamentally *economic* in their character. I trace how data infrastructures thus materialize and embed a specific mode of governmentality organized around the production and discipline of economic actors.

In sum, **computing care describes how the market-solutionist governance of care is reproduced and sustained through datafication and computation.** This mode of governance, adopted and enacted by U.S. policymakers and politicians, construes poor health outcomes and

high costs as a matter of insufficient information and non-optimally designed markets. These policymakers seek to address these failures of the market through the re-design of financial incentives, updating data infrastructures to increase the speed and scale of measurement and control through these market mechanisms. The market is thereby "aligned" and optimized, made to be a more perfect device for formatting and organizing practices of care and health.

Although I focus specifically on analyzing the intersections of datafication and market solutionism within the context of U.S. healthcare, I draw parallels to other sites of governance as well. For instance, recent STS scholarship on climate governance has traced the role of information in constructing markets intended to increase corporate accountability for environmental impacts, and to create financial incentives for corporate actors to creatively, innovatively, reduce their environmental footprint in order to improve their bottom line (Callon, 2009; Liu, 2017; Lohmann, 2005; MacKenzie, 2009). In the face of markets which fail to efficiently and effectively produce the public good, policymakers turn towards new computational affordances - datafication, platformization, automation - to revitalize and reprogram these 'failing' markets.

Crucially, the primacy of market-solutionism as a mode of governance constrains our capacity to articulate the extractivism of for-profit markets as *part of the problem to be solved*. It deprioritizes other techniques of accountability beyond the financial, and sidelines non-market mechanisms for producing the public good and ensuring that all needs are met. Through understanding the project of computing care, we can better understand how this mode of governance is sustained through intensified datafication and start to imagine alternative modes of governance beyond markets. Likewise, we can begin to imagine how we might construct public data infrastructures to serve purposes beyond financialization, commodification, and the exertion of market-discipline.

Research Approach

To better understand this mode of governmentality, I followed the still-emerging federal interoperability regulations designed to create standardized, scalable health data sharing across the U.S. This project unfolded over 24 months of multi-sited ethnographic research (Marcus, 1995) from January 2023-January 2025. During this period, I conducted over 50 interviews with health informatics professionals, executives at health provider organizations, standards developers, and federal and state policy makers. In these interviews, I sought to understand how

these individuals and the organizations they work for understand the project of data interoperability: its goals, its histories, its successes and failures. I sought to understand how these differently positioned actors related to this project, personally and professionally.

In addition to these interviews, I conducted fieldwork at national and regional meetings for health informatics professionals and at state- and federal-level meetings for health IT regulations and policies (see: table below for a list of key events attended during this period). Through in-person participation at these events, I sought to understand how professionals narrate the work of interoperability *to each other,* and the technical, political, and organizational concerns motivating health data policy and practice. Following calls for "studying up" (Nader, 1972), these professional conferences, trade shows, and regional networking events provided a crucial site for understanding the professional and policymaking communities which are driving the shift towards interoperable data infrastructures (Nyqvist et al., 2017).

Table 1: Key In-Person Fieldwork Events

Date	**Location**	**Name of Event**
February 23-24, 2023	Hyatt Regency Crystal City | Arlington, VA	Health Datapalooza
April 17-21, 2023	Chicago, IL | McCormick Place Convention Center	Health Information and Management Systems Society (HIMSS) '23
June 14, 2023	Grand Rapids, Grand Rapids Brewing Co.	Michigan HIMSS Happy Hour
September 14-15, 2023	Soaring Eagle Casino & Resort, Mt. Pleasant MI	Michigan HIMSS Annual Conference
November 3, 2023	Altarum, Ann Arbor MI	Michigan HIMSS Board Retreat
Dec 14-15, 2023	Omni Shoreham Hotel, 2500 Calvert Street NW, Washington, DC	Office of the National Coordinator for Health IT (ONC) Annual meeting
February 13, 2024	Lansing, Michigan	Michigan HIT Commission
June 13, 2024	Lansing, Michigan	Michigan House Health Policy Committee on HDU
September 6, 2024	Lansing, Michigan	SDOH Hubs + CIE Workshop
October 15-17, 2024	Detroit, Michigan	Civitas Networks for Health



Figure 1.4 Key actors within the U.S. health data interoperability landscape

In addition to fieldwork and interviews, I conducted discourse analysis on a corpus of interoperability-related documents. It is largely during the period of 2009-2016 that interoperability came to be conceptualized and identified by the federal government as a problem to be addressed: from this period, I examined announcements and reports issued by federal policymakers (e.g., the HHS, ONC, and CMS), and contemporary industry coverage. Following the introduction of interoperability regulations within the 21st Century Cures Act, I analyzed both the texts of new interoperability policies and rules, and the archive of official reports, statements, blogs, news reports, webinars pertaining to these rules. My corpus of materials from

the period of 2016-present largely deals with the subsequent implementation of Cures Act regulations pertaining to health data interoperability.

Although my research is focused on understanding the contemporary moment (2020-2024), following interoperable data infrastructures has led me backwards in time, to major moments in healthcare regulation in the U.S. (see Fig 1.5). In particular, discourse dating back from the design and conceptualization of Health Information Technology for Economic and Clinical Health (HITECH) Act (2009) and the Affordable Care Act (2010) are important landmarks for understanding subsequent regulatory and infrastructural interventions following the 21st Century Cures Act (2016). It also extends back to connect the history of data interoperability to the history of value-based care, and managed-care before that, dating back to the 1970s.

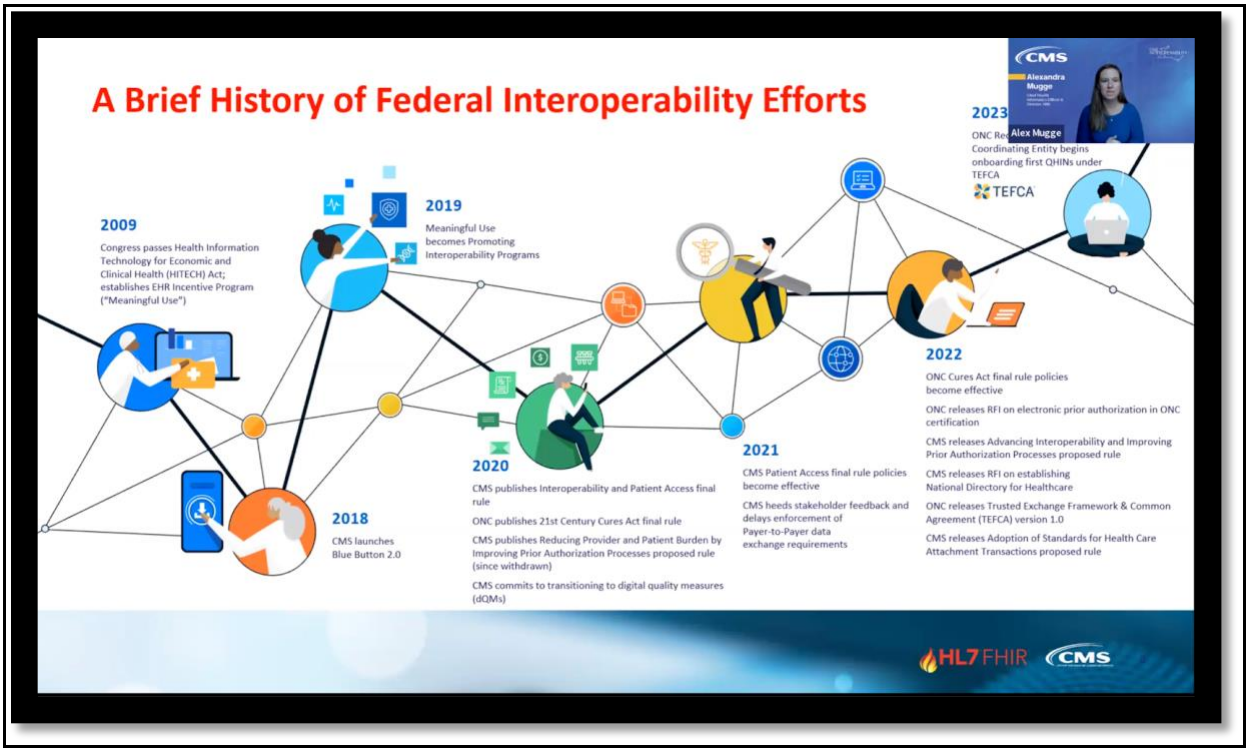


Figure 1.5 "A Brief History of Federal Interoperability Efforts." Screenshot from CMS HL7 FHIR Connectathon in July 2023.

My approach in examining health data interoperability policies draws from feminist HCI, science and technology studies, and economic anthropology. For instance, I do not take at face value the idea that data interoperability produces higher quality, more efficient care, but sought to understand "cost and quality" as a historically contingent and culturally constructed way of

framing the problem of the healthcare industry. Likewise, the positioning of standardized data sharing as a *fix* for this problem is a historical and cultural process that I have sought to interrogate.

I also draw from a tradition of STS-inflected economic sociology, which has sought to evaluate the sociotechnical construction of economic objects, in the same way that STS scholars have interrogated the sociotechnical construction of specific scientific facts and knowledge. This approach is informed by feminist HCI (Bardzell, 2010; Fiesler et al., 2016; Suchman, 2007), by STS approaches to the study of "market devices" (Garcia-Parpet, 2008; Holm & Nielsen, 2007; Muniesa et al., 2007), by Marxist analyses highlighting how technological infrastructures are produced *by* and *through* specific modes of value and specific kinds of social relations (Noble, 2017). To this end, I attend not only to the materiality of interoperable health data infrastructures, but also to the contracts, incentives, and institutional contexts that are part and parcel of the enactment of technological infrastructures.

Together, I contribute to our understanding of contemporary digital political economy - not in the register of sweeping claims about "platform capitalism" or "surveillance capitalism" - but by tracing a fractured and patchy enactment of a particular mode of governance and economic value production (Tsing, 2015). Following Collier & Ong's (2005) approach to understanding neoliberalism not as a "big leviathan", but through an approach which "remains close to practices, whether through ethnography or careful technical analysis" (p. 4), following the "little lines of mutation" (Deleuze & Foreword, 1979) in the neoliberal mode of governance.

Chapter Overview

In the following chapter, "Markets as Machines: Techno-Solutionism Meets Market-Solutionism", I further situate and unpack the idea of "computing care" in relation to previous Foucauldian and STS scholarship on contemporary modes of techno-economic governmentality[9].

[9] The ideas explored in this chapter build upon a body of scholarship in STS and economic anthropology theorizing the co-constitutive relationship between "the state" and "the market", and particularly on scholarship on economization within neoliberal governance. See, for instance: Barry, A., Osborne, T., & Rose, N. (Eds.). (1996). Foucault & political reason: Liberalism, neo-liberalism and rationalities of government. Routledge.; Collier, S. J. (2012). Neoliberalism as big Leviathan, or … ? A response to Wacquant and Hilgers. Social Anthropology, 20(2).; Collier, S. J. (2017). Neoliberalism and Rule by Experts. In V. Higgins & W. Larner (Eds.), Assembling Neoliberalism: Expertise, Practices, Subjects (pp. 23–43).; Ong, A. (2006). Neoliberalism as Exception: Mutations in Citizenship and Sovereignty. Duke University Press.; Ong, A. (2007). Neoliberalism as a Mobile Technology. Transactions of the Institute of British Geographers, 32(1), 3–8.

I specifically demonstrate how the concept of "computing care" extends this scholarship by emphasizing the role of datafication and computation in contemporary market-based governance. I draw from scholarship in economic sociology and STS to trace the convergence of practices of governance, economics, and engineering, and argue that intensified datafication and computation have transformed contemporary policy making to an infinite cycle of market "update" and optimization. In this process, values beyond efficiency and optimization are subjugated within technology design and governance, and critiques of markets as a mode of governance are pushed to the periphery. I propose the figure of the "biopolitical rodeo" to describe this uniquely American performance of market optimization through intensified datafication.

The subsequent three chapters focus on my empirical findings from my ethnographic research on emerging interoperable data policies and infrastructures. Chapter three, "Designing Markets, Governing Data: Engineering Value in the American Healthcare System," sets the stage for understanding the role of data infrastructures within practices of market re-design. Specifically, I situate emerging data interoperability regulations in relationship to "value-based care" policies, through which the state is attempting to move from *paying for care* (e.g., in the form of goods and services) to *paying for health*. I situate health data interoperability policies as part and parcel of this project of market re-design intended to incentivize healthcare market actors to more efficiently and effectively produce "the public good." This chapter extends the theoretical contributions introduced in chapter two by showing how value-based care and health data interoperability policies, together, reflect a *platform-like* mode of governance, predicated on optimized market design enabled by intensified datafication. I thus extend previous scholarship on contemporary governance by showing how practices of datafication and market design are intertwined. This chapter also demonstrates how both the public good and crucial data infrastructures are constrained through their enactment within a market-solutionist mode of governance.

Chapter four, "Social Determinants of Health Data: Between Actuarialism and Care", shows how payment and data infrastructures - built to enact market-based modes of discipline - push back against attempts to introduce a different politics of care. "Social determinants of health" is a framework, advanced by public health advocates and the World Health Organization in the early 2000s, which points towards the systemic inequities and unaddressed basic needs that shape health in fundamental ways. This framework was intended to redefine the work of

creating health as more than addressing individual health behaviors/practices, and more than what happens in a doctor's office. In an attempt to operationalize this more systemic or structural approach to creating health, policymakers and public health specialists have sought to collect social determinants of health *data* to help ensure that structural factors affecting patients' health are legible and accounted for within modes of healthcare governance and payment. Yet, this chapter examines how the values of the SDoH framework are over-written by the politics embedded within current payment and data infrastructures. Through this case study, I show how a framework intended to address structural inequities in health becomes subsumed by a different kind of politics as it becomes operationalized within a technical infrastructure governed by logics of market- and data-solutionism. This chapter contributes to existing critiques of SDoH frameworks within public health scholarship, specifically by drawing on the insights of STS scholarship and actor-network theory about the politics embedded within material, computational, bureaucratic infrastructures. It emphasizes that the politics of these infrastructures must also be accounted for and addressed if we hope to implement alternative modes of governance and accountability for care.

The final empirical chapter, "A Bridge to Nowhere": Prior Authorization and the Possibility of Non-Reformist Design," continues to develop a concrete set of ideas about how we might intervene within "computing care" as a mode of governance. This chapter describes how interoperable data infrastructures are being leveraged to re-design "prior authorization" - a process whereby insurance companies determine whether a treatment or service is "medically necessary" before agreeing to cover it. This widely unpopular process has been shown to delay vital treatments and create immense administrative burden for healthcare providers and patients. Federal regulators have thus turned towards interoperable data infrastructures to help automate the complex informational processes involved in prior auth, thereby reducing the burden while retaining the supposed benefit of prior auth in terms of reducing "low value care". This chapter draws from the fields of design justice and prison abolitionist scholarship to theorize the problem of conservativism and reformism inherent in market-solutionist modes of governance. Extending this scholarship, I propose four tenets for *non-reformist design* to help think through what it might look like to take an incremental step towards an alternative mode of governance of care.

The concluding chapter, "From "Computing Care" to Solidarity Infrastructures", reflects on the ways that computing care, as a mode of governance, helps to set the stage for the practices

of austerity and divestment from health infrastructures that we see unfolding currently within the second Trump administration. As throughout the dissertation, I draw connections between the current moment and previous scholarship[10] demonstrating how market-based modes of governance both rely on the production of social hierarchies of more- and less-valuable populations and reflect a fundamentally anti-democratic politics. I extend this scholarship on contemporary governmentality by showing how datafication and computation help to sustain and reproduce market-solutionism as a mode of governance. I argue that health data interoperability is a particularly fruitful site to explore the role of datafication in this mode of governance, because it shows how datafication is situated within a longer history of technocratic market reforms, and how the American state is now turning to intensified datafication to renew the promise that yet-more optimized markets will be able to efficiently produce the public good.

And yet, there is certainly an important role for data and computation in healthcare and governance – beyond market-based modes of governance. To help illuminate this potential, I close the dissertation by providing some concrete examples of potential ways that data and computation can contribute to a different politics of care: for instance, via enabling non-reformist political demands, and by supporting care infrastructures such as mutual aid "risk societies" and open source EHRs designed to meet the needs of patients and healthcare workers, rather than optimized production of profit. In this final section I hope to point towards paths for technologists and health data professionals interested in advancing modes of governing care beyond market- and techno-solutionism.

[10] E.g., these arguments appear in particular in Foucault's *Birth of Biopolitics* lectures (1978), in Michelle Murphy's *Economization of Life* (2017), and Wendy Brown's *Undoing the Demos* (2015)

Chapter 2 Markets as Machines: Techno-Solutionism Meets Market-Solutionism

In my research, I have sought to understand the goals and values of policymakers and industry leaders driving the enactment of new health data sharing policies and infrastructures. As outlined in the previous chapter, I have come to understand these data policies as rooted in a particular mode of governmentality (Dean, 2009; Foucault, 2008; Rose et al., 2006) characterized by market-solutionism. I introduce the term "computing care" to describe this market-solutionist mode of governmentality as applied to the domain of health specifically. In this chapter, I show how the concept of computing care extends our understanding of contemporary governmentality, particularly as articulated within the fields of STS and economic sociology. I argue that computing care helps us to better understand how market-solutionist modes of governance are reproduced and sustained through intensified datafication - even in the face of markets' consistent failure to achieve the biopolitical goals of the state.

This chapter begins with an overview of scholarship which helps to illustrate the origins and character of what I call a *market-solutionist mode of governance*. I draw from Foucauldian scholarship which has traced how modern, liberal, democratic states have come to be construed primarily as facilitators and maintainers of *markets.* I then further specify how and why markets came to be understood as a superior technology of governance, particularly among influential neoliberal thinkers like Friedrich Hayek (Halpern, 2022). I specifically argue that the *machinic* quality of markets is central to their entrenchment as a superior technology of governance.

I then explore how governance itself has been re-construed as a practice of economic engineering, or "market design" (Frankel et al., 2019; Mirowski, 2001; Nik-Khah & Mirowski, 2019). I argue that the move towards more technocratic modes of governance functions as a kind of "anti-politics" machine (Ferguson, 1994), a tool for the apparent "automation" of governance. Like all forms of automation, however, the construction of markets as machines for automating governance represents, rather than an elimination of this labor, a displacement and invisibilization of the work of governance. Policymakers are rendered as merely market technicians, while decentralized market actors become the true "decision makers."

To conclude the chapter, I connect this market-solutionist mode of governance back to the governance of health and care specifically. I return to Foucault's concept of biopolitics, which describes how people are rendered as populations, as an economic resource to be managed by the state. STS scholarship and accounts of colonial regimes of governance have traced the role of information and techniques of calculation in the biopolitical governance of care (Mitchell, 2002; Murphy, 2017; Ong, 2006). Computing care, likewise, is a fundamentally biopolitical project, organized around optimizing the management of the health of populations as an economic resource. I conclude by reflecting on the ways that intensified information and datafication help reproduce and extend this market-solutionist, biopolitical mode of governing care.

Finally, I introduce the image of the "biopolitical rodeo" to characterize the way that U.S. policymakers can continually articulate the failures of healthcare markets to achieve the biopolitical goals of the state as a problem of insufficient information. Intensified capacities for datafication and computation enable states to engage in a performance of continually pursuing *a more perfect market.* The state's performance of attempting to "corralling" the market through data ultimately helps to defer larger political questions, both about markets as the ideal technology of governance, and about the state's responsibility for producing equitable, accessible, quality healthcare.

A Genealogy of Market-Solutionism

"Techno-solutionism" describes "the idea that technology provides solutions to complex social problems" (S. Lindtner et al., 2016). Human-computer interaction, a field substantially organized around the design of digital and computational technologies to address complex social problems, has nonetheless generated robust scholarship around the *limitations* of technology when it comes to solving social problems (Ackerman, 2000). This scholarship emphasizes the *flattening* that happens as complex social, cultural, and political problems - for instance, anti-Blackness and structural racism (Cunningham et al., 2022; Ogbonnaya-Ogburu et al., 2020) - are narrowly construed in order to yield easy technological fixes. Scholarship in critical design and design justice has emphasized the vital necessity of modes of intervention and change *beyond the technical* (Costanza-Chock, 2018; D'Ignazio & Klein, 2023).

In this chapter, I explore the origins and reproduction of a particular type of techno-solutionism: market-solutionism. Specifically, I explore how it is that *markets* have come to be

construed as a kind of superior technology for solving complex social problems. **Market-solutionism can be understood as unfolding through two key processes:**

First, complex social problems are re-constructed as economic problems. Foucauldian scholarship traces how it is that modern, liberal, democratic states have narrowly constructed governance in economic terms: as a matter of optimizing for efficiency, costs, and risk. Furthermore, it is not just the state's mode of governance that is reconstructed in economic terms: complex human subjects are likewise enacted through a diffuse set of policies, institutions and cultures as "homo economicus": a flattened entity understood solely through its capacity to make rational, self-interested decisions (W. Brown, 2015). This "economization of the social field" (Foucault, 2008, p. 241) renders the state, its people, and complex social problems like the governance of care as economic entities and problems. Techniques and infrastructures of calculation, quantification, and datafication enable the economization of this reconstructed social field (Burrell & Fourcade, 2021; Murphy, 2017; T. M. Porter, 2020).

Second, markets are rendered as a *technological device* uniquely capable of solving these economic problems. As governance is rendered as a set of economic problems, the design of *markets* is constructed as an ideal technique for solving these problems. STS scholars have traced how economic problem solving was rendered as a *technical*, engineering practice of market design (Mirowski, 2001). Market design has become increasingly central to contemporary governance (Frankel et al., 2019), both by states and by powerful corporations. In particular, digital platforms have exemplified how the centralized control and design of information infrastructures enables intensified modes of market design (Sadowski, 2022; Viljoen et al., 2021). The design and control of data streams is increasingly central to market-solutionist modes of governance. In this dissertation, I situation emerging health data interoperability policies as part and parcel of a broader project of market re-design to "solve" problems in the governance of care.

By tracing the emergence and reproduction of market-solutionist modes of governance, I extend and further specify our understanding of techno-solutionism within contemporary governance and state-craft (Greene, 2021; S. M. Lindtner, 2020; Salman, 2024; Sims, 2017). This account specifically helps to situate the ways that engineering and control of data infrastructures is undertaken *as part of* the design and engineering of markets by states and platforms.

Additionally, this work contributes particularly to debates about the role of *technical expertise* within neoliberal governmentality (Collier, 2017; Foucault, 2008; Mitchell, 2002). This literature emphasizes how neoliberal governmentality is characterized by a division between a *political* domain of values, and a *technical* domain of governance. Collier summarizes this line of argumentation neatly: "by drawing a strict distinction between expert rule and politics—between facts and values—neoliberalism places its policy proposals beyond political dispute and thereby depoliticizes government administration and undermines democracy." (Collier, 2017, p. 26).[11] This dissertation extends our understanding of how technocratic governance is reproduced and extended, not only through the design and engineering of markets, but through intensified datafication and computation, promising yet-more precise forms of financial control over the behaviors of patients and providers, thereby finally eliminating from healthcare markets "waste, fraud, and abuse" resulting from "misaligned incentives."

Showing how techno-solutionism and economized political rationalities are intertwined also helps to illuminate how and why economized modes of governmentality infuse practices of technological innovation, design, and computation. In his book, "The Whale and the Reactor: A Search for Limits in an Age of High Technology" (2020), Langdon Winner critiques the economized frameworks which shape our collective evaluation and discussion around technologies:

> In debates about technology, society, and the environment, an extremely narrow range of concepts typically defines the realm of acceptable discussion. For most purposes, issues of efficiency and risk (or some variant of those) are the only ones to receive a thorough hearing. Any broader, deeper, or more perplexing questions are quickly pushed into the shadows and left to wither. How is it that we have gotten stuck packaging some of the important issues that face humanity in such conceptually impoverished terms? (p.xii)

[11] Following this summarization of contemporary debates, Collier in fact draws upon Foucault to trouble this neat line of argumentation among scholars of neoliberal governmentality. In a similar intervention into this discourse, Collier seeks to trouble the characterization of neoliberalism as "Big Leviathan" (Collier, 2012). In this dissertation, I do not engage with these debates on neoliberalism in depth - but rather stay close to an examination of the conjoined discourses and techniques of market-solutionism enacted via data-solutionism. In this sense, I hope to enact the underlying sentiment of Collier and Ong's work, which seeks to move away from grand theorizations of neoliberalism as a singular project of governance towards a closer, anthropological accounting of neoliberalism as a "mobile technology" (Collier Stephen & Ong, 2005; Ong, 2007): a set of strategies and techniques deployed differently in each local context and situation.

Winner highlights "efficiency and risk" as the central terms through which technologies are designed and evaluated, pointing towards the ways that we have become oriented towards thinking of technology as "inputs" to be maximized in order to grow the economy. Just as governance has been construed as an economic problem, *so too has technical work been construed in narrowly economic terms.* Meanwhile, other rationales which might motivate the design of new technologies - for instance, to "improve medicine, serve military needs, or address climate change" - are "displaced" (Berman, 2014, p. 401). In the following section, I situate the rise and persistence of economized modes of thinking about both technology and governance through key Foucauldian, STS and economic sociology texts.

Among the health data professionals and policymakers I spoke with there is a frequent refrain that the problems of healthcare are not primarily technological. And yet, the thrust of these professionals' daily work is towards constructing technical solutions to the problems of the healthcare industry. How is it that techno-solutionism has become so entrenched as a way of conceptualizing and addressing complex social problems, and how might we create space for alternative modes of governance within care?

The Economization of the State

This section traces how modern, liberal states have been constructed - by political theorists, by politicians and bureaucrats, and within broader civic imagination - as primarily responsible for solving economic problems, of efficiency, risk, and the construction and maintenance of markets.

In his lectures on "The Birth of Biopolitics" (1978-1979), Foucault argues that the legitimacy of the contemporary Western state was organized around the maintenance and growth of "the economy." He traces this idea back to the reconstruction of the German state 1948, which - for lack of a clear alternative political grounds for its legitimacy - was organized and conceptualized around maintaining the "freedom" of markets. Foucault argues that for this new state, its "function is not to constrain, but simply to create a space of freedom, to guarantee a freedom, and precisely to guarantee it in the economic domain." Foucault argues that this reconstructed German state, whose legitimate scope of action is constrained to cultivating and maintaining economic freedom, became a model for the governance of other modern, liberal states.

In these lectures, Foucault introduces and explores the idea of "governmentality", a portmanteau of governance and mentality. Through this phrase he seeks to convey a specific mode of reason or a kind of "logic" that grounds and motivates governance, and which is enacted not only by states but through a wide array of cultural and institutional apparatuses. He introduces the term to help describe what he sees as a *shift* in governmentality which occurred in Western, liberal, democratic states in the late 20th century.

Specifically, Foucault argues that a "grid of economics" came to be applied to the existence and operation of these states. Through this "grid of economics," governmental action is subject to public criticism and contention on the grounds of its "excesses, futility, and wasteful expenditure." This mode of criticism "is not just a political or juridical criticism; it is…the cynicism of a market criticism opposed to the action of public authorities." (p.246). In other words, the legitimacy of the state is collapsed to its ability to maintain and advance "the market." Any action by "public authorities" beyond this work of maintaining and advancing the market is subject to criticism as "excess" or "waste." (This description resonates particularly strongly with contemporary U.S. policies motivated and justified through addressing "waste", fraud, and "inefficiency".)

This "grid of economics", or economized governmentality, not only helped to justify and enable a program of privatization and divestment from public infrastructures. It also helped to motivate and justify states' active role in constructing and maintaining "free," competitive markets. Oftentimes, neoliberal governance is construed as the *absence* of state regulation over markets and the dismantling of state functions in favor of market functions. Yet, many sociologists (F. L. Block & Somers, 2014; Polanyi, 2002) and even influential neoliberal thinkers like Friedrich Hayek (Hayek, 2020) emphasize the active, interventionist role of the state in enabling and maintaining markets:

> The market, or rather pure competition, which is the essence of the market, can only appear if it is produced, and if it is produced by an active governmentality. There will thus be a sort of complete superimposition of market mechanisms, indexed to competition, and governmental policy. Government must accompany the market economy from start to finish. (Foucault, 2008, p. 121).

Foucault here suggests that in the shift to an economized mode of governance, policymaking becomes identical with the construction of *market mechanisms* for optimizing competition. In the

next section, I explore how the design and engineering of market mechanisms became a central practice within contemporary governance.

Markets as (Anti-Politics) Machine

Foucault describes the foundational shift through which the legitimacy of modern, liberal states became linked to their capacity to enable and advance competitive markets and economic productivity. In this section, I unpack further how *markets* became construed as an ideal technology of governance. In particular, I demonstrate how a specific imaginary of the *machine-like characteristic of markets* has contributed to the adoption and rise of market-solutionism.

The imaginary of the "invisible hand" looms large within collective imaginations of "the economy." First described by Adam Smith in the 18th century, the "invisible hand" describes the way that aggregated, individual decisions made by market actors result in an optimally efficient - and even socially beneficial - set of outcomes. Within this imaginary, the behavior of "the market" - or the aggregation of individual rational choices - is understood as an ideal way for organizing and coordinating modern society. Later neoliberal thinkers saw this *emergent, self-ordering* aspect of markets as evidence that markets are a superior technology of governance. When the state helps to enable and maintain markets, complex political problems can be solved through the aggregation of individual rational behaviors, rather than the centralized coordination or control of behaviors through bureaucratic states.

Orit Halpern's essay, "The Future Will Not Be Calculated: Neural Nets, Neoliberalism, and Reactionary Politics", provides a robust genealogy of the influential economist Friedrich Hayek's idea of the "self-regulating market" (Halpern, 2022). Halpern situates Hayek, whose writings and ideas provide the foundations for neoliberal modes of governance around the world, within the context of the Cold War. Within the context of a looming threat of "mutually assured destruction", the idea of automated governance through a "self regulating market" appears like a meaningful alternative to the chaotic and 'irrational' governance enacted by politicians and world leaders. Halpern also shows how Hayek's idea of the self-regulating market was influenced by emerging ideas about networked and cybernetic forms of intelligence. Hayek argued that markets, with the inherently self-correcting relationship between supply-and-demand, enabled a kind of coordination and emergent, distributed intelligence, superior to the intelligence and superior as a tool of governance to the centralized planning of the state.

In Hayek's writings, self-regulating markets can be understood as a way to automate and decentralize governance itself. Likewise, Block and Somers (2014) suggest that "The seductive persistence of free market ideology is rooted in its promise to reduce the role of politics in civic and social life." (p. 10). Elsewhere, Karl Polanyi (2002) describes the idea of the self-regulating market - of governance purely through the fluctuations of supply and demand - as a "stark utopia" (p.3). This political imaginary, critiqued by Polanyi, hinges upon imagining markets not as a messy social or cultural phenomenon, but as a *machine* or *technology.* Ferguson (1994) describes international economic development programs as an "anti-politics machine", a framework or mechanism skipping over sensitive local politics and rendering interventions as purely technical, purely economic. Likewise, I understand markets to function as a kind of anti-politics machine but argue that the literally *machinic* character of markets is key to their anti-political character.

Science and technology studies, of course, has explored extensively the ways in which politics are erased, obfuscated, or invisibilized through technoscientific interventions and practices (Haraway, 2006; Hecht, 2011; B. Latour, 2012; Winner, 2020). In "Political Machines" (2001), sociologist Andrew Barry explores the "tradition in social and political thought which sees technology as a way out of the apparent irresolvability of political controversies - as an anti-political instrument." Barry goes on to claim that we live in a "technological society", which "takes technical change to be the model for political invention." (p.2) Barry describes a fundamentally *techno-solutionist* mode of governance: markets, rendered as technical devices, become a central part of this techno-solutionism mode of governance.

In "Machine Dreams: Economics Becomes a Cyborg Science", Mirowski traces the processes through which markets became constructed not only as technical devices, but how the domain of economics became reconfigured as engineering and computation practices (Mirowski, 2001). Specifically, Mirowski argues that the field of "economics" became reconceptualized less as a matter of "the optimal allocation of scarce resources to given ends", and instead as a matter of creating the optimal processor of information. Cyborg (short for "cybernetic organism") economists were akin to designers of information processors, modelling the capacity of different market designs to achieve some computational optimum of "efficiency." Per Mirowski, economics as cyborg science is a practice of defining *economic problems* as *information-processing problems.* Mirowski shows how it was that economics, in part through contingent

histories of Cold War military funding for the field, became a practice of designing information-processors.

Turning markets into information processors and economics into a practice of engineering, as Mirowski describes it, represents a further shift towards depoliticization and the evacuation of political values beyond efficiency/optimization. Economists, rather than designing markets as a vehicle through which human needs are met and resources distributed, become engaged in a purely technocratic engineering project, oriented around optimizing the flow of information through self-organizing markets. This reconfiguration as markets-as-machines reflects a broader phenomenon of the substitution of science and technological expertise for other modes and ways of politics.

Through this shift away from economics as "the optimal allocation of scarce resources to given ends", what is lost is *the ends* toward which practices of market design and engineering are undertaken. These ends are rendered irrelevant, or self-explanatory, or outside the domain of expertise for economists whose job is to optimize for the efficient processing of information through markets. Of course, following the central thesis of much STS scholarship, this technical work of engineering markets is profoundly political - particularly when these markets are designed and implemented as techniques for governing key public goods, such as care and health.

Engineering Markets: Politics by Other Means

In contrast to the *dream* of markets as anti-politics machine, economic sociology and STS scholars have traced the ways that markets and economic value are actively constructed and maintained through particular organizational cultures, sets of practices, and material infrastructures (Fligstein, 1996; Garcia-Parpet, 2008; Holm & Nielsen, 2007; MacKenzie, 2009). For example, STS scholar Michell Callon outlined the intensive processes of material, discursive and social choreography necessary to render items as stable commodities, to disentangle social relations so that exchange becomes possible (Callon & Muniesa, 2005).

The basic work of exchange, of simplifying objects to apply a price, is intensely political. Callon emphasizes how, to buy a car as a commodity, the object must be "disentangled":

> To transform something into a commodity, and two agents into a seller and a consumer, it is necessary to cut the ties between the thing and the other objects or human beings one by one. It must be decontextualized, disassociated and detached…. It is on this condition

> that the calculation can be looped and the deal can be closed; that the buyer and seller, once the transaction has been concluded, can be quits. If the thing remains entangled, the one who receives it is never quit and cannot escape from the web of relations. The framing is never over. The debt cannot be settled. (Callon, 1998, p. 19).

Of course, this work of "disentanglement" is particularly fraught within the context of the commodification of care and health. Information infrastructures and practices of quantification play a key role in this work of alienation and disentanglement.

This scholarship, showing the intense socio-cultural and material work of constructing markets, runs counter to the narratives or imaginary of markets and economic value as somehow "emergent" from the aggregation of individual preferences and rational self-interested action. Callon describes the structuring of markets as "political engineering, that is, the way in which they organize the design of goods, profile innovations, shape identities, and format bilateral transactions. Politics plays out within markets and not outside of them, because markets produce the social rather than undoing it (Cochoy 2012; Geiger et al. 2015)." (Callon, 2016). Yet this centralized, active, political aspect of markets and economic value is consistently erased and invisibilized as part of the process of constructing markets as a superior technology of governance.

Frankel, Ossandón & Pallesen (2019) provide a close examination of an inconsistency that has emerged between the justifications of markets as a superior mechanism of governance based on their decentralized and emergent nature, and the immense level of intentional, technocratic work involved in designing and maintaining markets. They provide a comprehensive overview of the historical shift through which markets became "instruments of policy," a tool *par excellence* for managing and solving social problems (Frankel et al., 2019). They highlight that markets have come to be understood "as a type of distributed collective intelligence mechanism that outperforms planning or democratic decision-making in the task of searching for innovative solutions to uncertain problems." (p.159). However, they trace the shift from early neoliberal understanding of markets as mechanisms that should be created and left alone, to an understanding that the role of policy is *creating, managing, and repairing markets.* The irony, of course, being that this process of expert tinkering with markets starts to look more and more like the bureaucratic, top-down organizing processes that markets are meant to be opposed to.

Nik-Khah and Mirowski trace the emergence of a pervasive practice of "market design," in which economists design market configurations to optimize for a specific set of outcomes. They highlight the apparent contradiction between claims of markets as a neutral tool of governance and the ways in which markets are designed to achieve the outcomes preferred by their designers. Likewise, Viljoen et al. trace out a similar line of critique in relation to "mechanism design" via digital platforms. They highlight that these mechanisms are justified through a discourse of enabling and optimizing for individual "rational free choice", but in practice, looks like an engineering of individual behaviors to optimize for the outcomes that most benefit the platform (Viljoen et al., 2021). In the contexts of states, practices of market and mechanism design may be undertaken as a means to engineer the behavior of corporations and individuals to achieve the goals of the state: for instance, the biopolitical goals of reduced healthcare costs and improved healthcare outcomes.

If the market is a computational device, then like all other computational devices, it is designed, optimized, and maintained by human actors and institutions with specific sets of political values, goals, and interests. Practices of quantification and the design of information infrastructures have always been central to the work of economization and marketization, and a key site for interrogating the politics of markets. The next section highlights literature that specifically investigates the role of information within the construction and governance of markets.

The Role of Information and Datafication within Market-based Governance

In exploring the shift towards the economization of governance, I've already alluded to excellent work by scholars like Tim Mitchell and Michelle Murphy, which show the integral role of techniques and practices of quantification and informatization in rendering space, subjects, and their conduct as *economized*. This section explores in more depth the shifting role of information infrastructures within contemporary practices of governing-through-markets.

In "Seeing Like a State" (1998), Scott explores the ways that states seek to render the world simplified, legible, and therefore governable (Scott, 2020). Riffing on this idea, Fourcade and Healy's 2017 piece, "Seeing like a market", explores the way that markets render subjects legible through intensified processes of informatization and datafication (Fourcade & Healy, 2016). Fourcade and Healy specifically explore how the "digital economy" has created the potential for increasingly fine-grained quantification and classification of market actors: they

describe these as “classification situations.” Similarly, Wendy Chun’s 2021 book, “Discriminating Data”, explores how social media platforms construct and capture individual behavior via digital traces. Platforms then create feedback loops between an informationally stabilized “user” and content designed to appeal to this user-type, thus recursively constructing subjects that are maximally legible as consumers within digital markets (Chun, 2021).

This scholarship emphasizes the way that digital platform companies can engage in intensive processes of quantification and datafication, thereby constructing subjects and their behaviors in ways that contribute to platforms’ own market power. In this scholarship, we see how the construction of governable subjects through informational flows - traced in part in Foucault’s work on governmentality - is intensified and operationalized in the digital age.

In my own work on health data infrastructures, I have focused somewhat less on the way that these information flows have led to the construction of economized and governable subjects - and more on the ways that the state and corporations seek to wield and govern these information flows. This approach builds on scholarship which has explored how platform power hinges on companies’ capacity to control data flows (Birch, 2023; Pistor, 2020; Sadowski, 2019; Srnicek, 2017; Zuboff, 2019). Additionally, scholars have shown how control over these data flows enables platform companies to engage in a particular mode of governance: mechanism design (Viljoen et al., 2021).

Likewise, these informational flows, orchestrated and controlled primarily by corporate platforms, are an important site of state governance and intervention. States which seek to govern platform markets, to limit or direct platform power, may choose to do so through requiring increased data interoperability, or standardized data sharing, thereby loosening platforms’ control over data enclaves (Bietti, 2024; Huber, forthcoming 2025). On the other hand, states may seek to go beyond simply “reigning in” platforms’ control over these information flows to more actively engage in “political engineering”, themselves employing platform-like modes of control over both infrastructures of quantification and the design of digital markets (Bietti, 2024; Dencik et al., 2019; Sadowski, 2022; van Dijck, 2020).

In previous sections of this chapter, I have explored how contemporary neoliberal modes of governance are organized around an idea of *markets as information processors*, and of *policymaking as a practice of market design*. In a context of digital infrastructures which enable intensified processes of quantification and datafication, the neoliberal state may strive towards an

increasingly platform-like mode of governance. This platform-like mode of governance hinges on a practice of constructing a "more perfect market": a more comprehensive information processor, with datafied incentive structures subject to reprogramming and re-engineering by the state. When policymakers seek to exert more active control over the data that is collected and how it is used within the design of incentive infrastructures, we can understand this as striving towards a platform-like mode of governance (explored more in chapter three).

Computation & the Economization of Life

Thus far, this chapter has outlined the way that contemporary governance has been re-organized around a practice of *market engineering.* In this final section, I situate these ideas in relation to the governance of health and care specifically.

Notably, Foucault's lecture series which details the processes of economization of the state and of contemporary practices of governance is titled "The Birth of Biopolitics": in these lectures, Foucault shows how neoliberal governmentality reconstructs the governance of citizens or people as the management of *populations*. This biopolitical framework - of the governance of populations - aligns with the "economic grid" described earlier, in as much as states manage health and reproduction of populations as an economic resource. FDA Commissioner Califf's framing (chapter one) of a particular set of statistics about the health of the U.S. population relative to the *costs* of healthcare in the U.S. exemplifies this kind of biopolitical thinking, inasmuch as it imagines the health of the country's people as a kind of standardized economic indicator to be managed and compared to that of other states.

The biopolitical mode of governance incorporates an attitude of economization towards the social reproductive function of society. Within this frame, even the mother-child relationship can be understood in terms of an investment of time into the production of the human capital of the child. The practices of the state, in terms of welfare policies or social reproductive institutions such as health, education, childcare etc. revolve around an idea of "return on investment." The colonial governance of remote populations was a particularly important site for the development of this biopolitical mode of governance: both in terms of an extractive, economizing mindset, and the development of technoscientific techniques of quantification and management (Appadurai, 2016; Mitchell, 2002; Scott, 2020). This economized colonial governance is reproduced and reflected in contemporary management of populations, and particularly visible in the production of racialized and gendered populations construed either as

"surplus" populations (Ruth Wilson Gilmore, 2007), or targeted for "predatory inclusion" within extractive markets (K.-Y. Taylor, 2019).

STS scholarship has explored how techniques of quantification are central to the construction of "populations" as a site of governance. Michelle Murphy's "The Economization of Life" (2017), for instance, draws a linkage between the scientific modes of knowledge-production about populations of fruit flies and the ways that human populations are similarly measured and controlled. Murphy shows how metrics like "gross domestic product" (GDP) and population curves, populations become both visible and governable as economic objects. Murphy highlights as well the violence and racialization of these processes of economization and quantification, showing for instance how Bangladeshi NGOs differentially value racialized and gendered populations based on their expected contributions to globalized markets. As with Tim Mitchell, this work shows the intertwining of economized governance and techniques of quantification, and the latent colonial and extractivist politics beneath apparently "objective" practices of valuation.

This dissertation specifically contributes to a body of STS scholarship that examines the co-construction of devices of quantification and computation and the governance and management of populations. Information scholar Joanne Yates explores how the early histories of information technology were constructed through and within life insurance companies (Yates, 2005). STS scholars Bouk and Mills have shown how the category of "impairment" was constructed through and within specific computational techniques (Mills & Bouk, 2024). Dillard and Black provide a robust accounting of the role of IBM computing machinery within the genocidal project of Nazi Germany (Black, 2001; Dillard, 2003). Contemporary health data interoperability policies, likewise, are designed to enable a more precise visibility and control over patient and provider populations.

I seek to specifically extend this body of scholarship by tracing how these informational devices are specifically organized around a practice of *market engineering*, and the narrow construction of patients and providers *as economic subjects*. Here, I draw again upon Foucault's ideas about the biopolitical subject. Foucault theorized the way that neoliberal states reconstructed the subject as "homo economicus": the rational, self-interested, optimizing

subject[12]: "The surface of contact between the individual and the power exercised on him…will be only this kind of grid of homo œconomicus. **Homo œconomicus is the interface of government and the individual.**" (p. 253).

To amplify and extend the computational metaphor contained within Foucault's use of the term "interface", I argue that the economization of subjects as "homo economicus" also renders these subjects as tractable, as *computable.* The "problem" of governing people as complex human subjects becomes collapsed down to the simpler problem of designing an appropriate set of economic incentives to control and direct an individual's behavior towards optimal economic outcomes. This computable subject can be governed through practices of market design, through the design of incentives and the quantification of market-behaviors. "Homo economicus", in this sense, is what enables the state to imagine and undertake a project of *computing care.*

Furthermore, it is through the engineering and control of data infrastructures that the interface between the government and the individual is further refined. As scholarship examining contemporary platform governance has described, through intensified datafication the individual market actor becomes more visible, more manipulable - and the market-designer more able to implement fine-grained quantification and incentivization of their behaviors (Burrell & Fourcade, 2021; Chun, 2021; Srnicek, 2017). Through intensified datafication, the video streaming platform can quantify and measure audience behaviors, identifying those behaviors that maximize advertising revenue, and re-designing incentives around the design of video content in ways that maximize ad-revenue-producing viewer behaviors. Intensified computation and datafication promise a yet-more refined interface, a yet-more precise level of visibility and control between the state (or platform) and *homo economicus.* Through bigger, faster, more integrated data streams, the behaviors of each side of the market become more tractable, yielding more refined calculations about how to re-engineer those behaviors in ways that benefit the state (or platform).

Likewise, contemporary health data sharing policies can be understood as a move by the state to engage in a platform-like mode of re-designing and optimizing healthcare markets. Through the re-design of data infrastructures, the state seeks a more fine-grained quantification

[12] Recent critical computing scholarship has highlighted how this economized conception of the self plays out within the fields of computing specifically (Avle et al. 2019; Irani 2019; Lindtner 2020).

of provider behaviors and a more fine-grained set of incentive structures. As I explore in the next chapter on "value-based care", data is the mechanism through which the state seeks to quantify, not only the care practices and behaviors of healthcare providers, but to quantify and incentivize providers' successful production of healthcare *outcomes.*

Broadly, intensified datafication and computation are integral to the contemporary conduct of biopolitical governance. This is not only because these data streams make these populations more visible as an object of governance - but specifically because they enable the state to engage in the continual re-design and optimization of markets. Limitations and failures of the state to achieve its biopolitical goals, or to produce "the public good", can be recast as problems of insufficient information flows and sub-optimal market design. Yet more fine-grained processes of datafication enable states to continually undertake the project of designing a yet-more perfect interface for orchestrating the behavior of *homo economicus.*

In the next and final section, I stitch together the ideas explored so far in this chapter to propose a unified image of "computing care" as a project of market-solutionism and techno-solutionism rooted in the idea of markets as an ideal technology of governance. I further propose the figure of the "biopolitical rodeo" to characterize the performance of rational reformism and market-solutionism carried out through intensified datafication - particularly as applied to the governance of care and of populations.

The Biopolitical Rodeo

This chapter has explored existing scholarship which theorizes and critiques a neoliberal mode of governance which situates *markets* as a superior technology for solving complex social problems. I describe this as a kind of "market-solutionism," or a variation or kind of techno-solutionism. I trace how this mode of governance emerged from the economization of the state (Foucault, 2008) and the computationalization of economics (Mirowski, 2001), showing how governance became reoriented around efficiency and risk at the expense of other values like equity or care (Berman, 2023; Ong, 2006). The techno-economic management of care reflects colonial logics of biopolitical control, extraction and quantification (Mitchell, 2002; Murphy, 2017). I reveal how emerging data policies and data infrastructures are engineered to render populations governable through market logics, arguing that these technical reforms are not merely administrative but constitute a political project—one that obscures its normative commitments under the guise of optimization (Halpern, 2022; Winner, 2020).

I use the term "computing care" to describe the unified projects of market-solutionism and techno-solutionism as applied to the governance of care: the imaginary that we can compute our way through messy political problems of the governance of care, through the careful engineering and design of incentives, the quantification of care, etc. Following STS scholarship on governance and governmentality, this project seeks to examine not only the governmental imaginary but the *mechanisms* through which this economized mode of governance is enacted.

In my close reading of the data policies and infrastructures being developed under the banner of "interoperability", I came to see how this project is but the newest manifestation of decades of efforts directed towards using optimized informational flows to more rationally and efficiently govern care and care markets in the U.S. I came to think of what I was witnessing as a kind of "biopolitical rodeo." This term conveys several key aspects of the phenomenon of computing care.

First, the rodeo conveys the way that the U.S. state seeks to enact a particular political project of managing and controlling populations and the production of care - but at an appropriate remove. Rather than directly control the production of care or health, the state mediates its control through *the design of markets.* Market actors, like a bull in a rodeo, retain their apparent freedom to make individual, self-optimizing decisions. Rather than the centrally planned production of care by the state, private market actors retain their "freedom" to innovate and optimize towards more cost-effective care. The state's action appears to be constrained to an indirect "corralling" of the market through the design of incentive structures and new techniques of measurement and datafication.

The rodeo also conveys the *performative* aspect of this governance. First, there is the performance of control–without–control of market and mechanism design. This illusion is key within the U.S., which views with particular suspicion government-led control of care and other sectors. Second, there is the performance that the data-driven re-design of care markets will finally be able to solve or address the failure to produce equitable, accessible care - or that this is even the ultimate *goal* of these policies. Ultimately, the health data interoperability policies that I study in this dissertation are only the most recent instantiation of decades of attempted reforms and interventions through information and markets within the healthcare industry. Each of these waves of reform promise to finally address the everyday experiences of crises experienced by healthcare providers, by patients, by their families – without requiring a fundamental re-

evaluation of the source of these crises: unchecked extractivism of for-profit care markets, and systemic underinvestment and austerity by the state (Evans, 1997; Navarro, 2020; Scheffler et al., 2021; Waitzkin, 2015). Through the performance of data-driven market reform, these crises are instead attributed to the waste, fraud, and abuse of patients and providers - and their fix is just over the next techno-solutionist horizon.

Far from the orderly operation of the independent automaton evoked through the idea of the "invisible hand" or the "self-regulating market", the image of the rodeo evokes the chaos, the destructiveness, the painful comedy of errors of this performance of "corralling" the market through data and market reform. This chaos and banal violence is what patients across the U.S. experience as they navigate an ever-more datafied and bureaucratic infrastructure which ultimately serves to constrain their access to care. It is experienced by providers as more and more of their day is taken up by data work practices to comply with ever-more complex reimbursement regimes, while simultaneously navigating systemic shortages in staffing and patients with complex social problems which far exceed what can be represented neatly in the EHR.

The biopolitical rodeo also conveys the particular *Americanness* of this performance. Despite the continual encounter with a violent and extractive healthcare system, the rodeo persists, reflecting a deep political commitment to limit and constrain public investment in public infrastructures; a culture which identifies and locates systemic, social problems as individual problems; and an imagination that all problems can be resolved through sufficient innovation, competitive markets, and advanced technological engineering and design.

In the age of ever-increasing information/computation, this rodeo can be continually renewed: the promise of optimized governance via technocratic tinkering is refreshed every decade, as new techniques of datafication and computation make the previous techniques seem obsolete. Failure to produce the public good is continually ascribed to a failure to produce and utilize information appropriately within the market, and governance thus becomes a Sisyphean project of improving informational infrastructures. This ongoing renewal of market-solutionist modes of governing care through data is the *biopolitical rodeo*. Over time, this cycle leads to an accumulation of invisibilized data labor and data infrastructures, which themselves must be reformed and re-engineered. The prior auth case study explored in chapter five exemplifies the

ways that this intensified data work is itself subject to reform through automation and new informational processes.

In tracing these intensified processes of datafication and the recurrence and renewal of the biopolitical rodeo, I seek to challenge the idea of the market as a means of mechanizing governance. As always, "automation" is a process of the displacement and invisibilization of labor. In this case, the "automatic information processor" of markets - the promise of "computing care" - is sustained and made possible through intensive political engineering by the state, by the redirection of resources away from care and towards information infrastructures and data labor.

Through this accounting of market solutionism, I hope to also open up space for the reconsideration of alternative practices and techniques of governance beyond market design and intensified datafication. We must consider what governance looks like beyond the prescribed "interface" provided by rendering people as populations, and subjects as "homo economicus" - beyond the construction of financial incentives and the reliance on incentive infrastructures as the best mechanism through which to govern care.

Chapter 3 Engineering Value: Interoperability Policies and "Value-Based Care"

This chapter situates emerging interoperability regulations within broader federal efforts to redesign healthcare markets. Rather than implement price controls or other direct forms of control over private health insurance and healthcare providers, the U.S. federal government has preferred to re-design markets, implementing new payment models and privatizing administration of public insurance programs. This project of healthcare market reform has spanned federal administrations going back to President Nixon. Depending on the administration, the exact goals of these market reforms have shifted—from outright cost-cutting to the "triple aim" of improved population health, improved patient experience, and reduced costs—but the basic premise of market re-design has remained constant. Since the 2010s, this project has been renewed through intensified datafication, which promises a more precise quantification and incentivization of the public good.

This data-solutionism is not unique to the U.S. healthcare market. In a wide variety of industries and sectors, policymakers are turning to intensified datafication to grapple with the failure of markets to efficiently and effectively produce the public good. Most prominently, contemporary environmental governance attempts to calculate the production of "negative externalities"—that is, the environmental harms produced by a company but not accounted for on its ledger sheets—and to "internalize" these harms within the market. For example, cap-and-trade markets and carbon taxes rely on complex quantification processes (Liu, 2017; MacKenzie, 2009), instantiated to incentivize corporate behaviors aligned with the public good. The impacts of this mode of governance, characterized by *datafied market design*, warrant further scrutiny. This chapter seeks to highlight how the public good is enacted and constrained within datafied market design.

In what follows, I provide a detailed case study of state-led datafication and market design as a mode of producing the public good. First, I explore literature that situates the historical project of governing the public good through market design and its intersections with the broader phenomenon of datafied governance. I then present an empirical case study showing

how emerging federal health data policies are designed to support the shift towards "value-based care," a multi-decade project of reforming healthcare markets towards paying for health *outcomes* rather than care *inputs.* Finally, I draw out the social implications of this specific mode of data-driven, market-solutionist governance – in healthcare and beyond.

The Age of Datafied Governance

States have always relied heavily on information and quantification as a central aspect of governance. Indeed, information is central to the construction of the state as a stable entity—its people, its borders (Espejo, 2014; Mitchell, 2002; Scott, 2020; TallBear, 2015; Tooze, 2001). Recent scholarship has explored the ways that intensified processes of datafication, enabled by new forms of computation, are reshaping governance itself (Braman, 2009; Burrell et al., 2024; Cohen, 2016; Dencik & Kaun, 2020; Dencik et al., 2019; Johns, 2021; Purtova & van Maanen, 2024; Singh, 2019). This scholarship addresses the shifting relationships between states and big tech companies, which often control the means of datafication; the increasing opacity of algorithmic and data-driven modes of governance; the performance of increased rationality or efficiency enabled through computation/datafication; and the ways that publics are constructed and self-construct through data.

Previous Foucauldian scholarship on techniques of governmentality (Barry, 2001; Dean, 2009; Foucault, 2008; Li, 2007b; Rose et al., 2006), as well as postcolonial and STS scholarship on the role of information in constructing and extracting value from racialized populations (Murphy, 2017; Sunder Rajan, 2006; TallBear, 2015), has emphasized these techniques and information infrastructures as foundationally *political technologies*. By scrutinizing processes of datafication, we may excavate unexamined assumptions about the role of the state, its modes of action, and its relationship and accountability to its publics (Costhek Abílio & Cruz, 2024; Dencik & Kaun, 2020). For instance, the Data & Society anthology "Keywords of the Datafied State" (Burrell et al., 2024) explores how our core understandings of phenomena like "bureaucracy" or the "public interest" are reconfigured via practices of state governance organized around the capture, analysis, and utilization of digital data. In this chapter, I demonstrate how market design, a key aspect of contemporary market-based governance – is both enabled and reproduced via intensified processes of datafication.

Specifically, the case study I present in this chapter examines the politics of datafication as it relates to a specific type or mode of governance: market design.

Market Design in the Platform Economy

"Market design" describes the process of carefully constructing the rules surrounding markets to optimize their efficiency and effectiveness as markets. This practice is often deployed as a public policy intervention to "fix" markets that do not sufficiently increase social welfare or the public good. For example, market design is a central policy tool currently used to address the negative impacts of corporations on the environment. Instead of directly controlling carbon emissions, states use carbon taxes or credits to internalize negative externalities. In a wide variety of public policy domains, economists are called upon to design incentives and market mechanisms as a central tool for advancing the public good (Collier, 2017).

Market design is a crucial technique within neoliberal modes of governance, which situate the market as the ideal mechanism for efficiently and effectively producing the public good. Rather than rely on centralized, bureaucratic decision-making, subject to corruption or hierarchical favoritism, the "invisible hand" of the market in neoliberal accounts enables an apolitical, rationalized, decentralized mode of distributing goods and resources (Davies, 2014).

Crucially, scholars have pointed out that this narration of the market as an apolitical, decentralized tool of governance has remained in place despite the growth since the 1970s of market design practices, through which economists and policymakers design and curate markets towards particular ends (Birch, 2023; Lepage-Richer & McKelvey, 2022; Nik-Khah & Mirowski, 2019; Viljoen et al., 2021).

Nik-Khah and Mirowski argue that the ascendancy of market design as a practice coincided with the changing understanding of markets from being a kind of natural force to being like information processors or computing devices, which benefit from intentional design or engineering (MacKenzie, 2008; Nik-Khah & Mirowski, 2019). They argue that economists realized they could leverage market design and the information-processing capacities of markets to "go the market one better": to design *outcomes* that are favorable—for the public, for policymakers, or otherwise.

Viljoen et al. (2021) trace how this practice has become central within the platform economy, particularly via automated or algorithmic market design. Digital platforms are market designers *par excellence*. Uber uses information about rider behavior to design real-time pricing algorithms (Chen et al., 2015); Google collates multiple streams of information about users to automate real-time digital advertising auctions (Srinivasan, 2019); and social media platforms

continuously re-design the newsfeed and content recommendation algorithms to optimize for increased user engagement, thereby increasing advertising revenue (Ruckenstein & Granroth, 2020). Platforms can both structure the flows of information they capture and use this information to continuously tinker with the design of the markets they mediate in advantageous ways (Pistor, 2020; Srnicek, 2017; van Dijck et al., 2018; Zuboff, 2019).

This chapter argues that, through intensified processes of datafication and market design, the state strives for a "platform-like" mode of governance: a capacity to use insights from comprehensive, centralized, and standardized data to re-program markets in ways beneficial to the state (Sadowski, 2022; van Dijck, 2020; Yuan & Zhao, 2025). Although scholars have explored the impacts of increasingly datafied, platformized governance (Kitchin, 2023), this chapter specifically theorizes market design as central to the function of the state-as-platform. Crucially, this mode of platform-like governance relies on constructing "the public good" in ways that can be quantified and enacted within the framework of market re-design. In the next section, I explore how other scholars have critically evaluated the project of computing the public good.

Governing Value

In contrast to the practice of market design through platforms, which are organized around the production of value for investors, market design in the context of public policy is in theory organized around the production of "the public good." Following Foucault, the construction of the public good, visible within the construction of particular policies, technical infrastructures (Gross & Geiger, 2023; Metcalf & Sadowski, 2024), and market designs, is an area for interrogation if we wish to understand contemporary politics and governance.

Following this line of inquiry, Sharon (2018) draws from Boltanski and Thevenot's (Boltanski & Thévenot, 2021) theorization of "orders of worth" to analyze the many ways that the common good is articulated in discourses surrounding the integration of Big Tech within digital health research practices. Specifically, she argues that a dichotomization of "public"/ "private" or "civic"/ "market" values is overly simplistic and does not enable a precise critique of Big Tech involvement that goes beyond privacy concerns (Sharon, 2018). Sharon instead articulates the "plurality" of ideas of "the public good" latent within these discourses, including not only doing good for society or enhancing wealth creation, but also increasing efficiency, increasing innovation and experimentation, and "proliferating life." Through this multiplicity,

Sharon complicates the equation of "private profit" and "public good" as self-explanatory frameworks for the morality of a given set of policies: as Sharon notes, a more nuanced approach is key for evaluating the growing "public-private partnership" nexus through which public goods and services are delivered.

The case studies below illustrate the idea that the "public good" as instantiated within emerging health data-sharing policies in the U.S. is substantively constrained by its enactment within a market-based mode of governance. This line of argumentation extends from Foucauldian examination of modes of rationality (or "governmentalities") that are implicitly embedded within and enacted through practices, language, and technical instruments (Barry, 2001; Rose et al., 2006). Constructions of the public good are enacted within and through data infrastructure policies, in the practices of patients, providers, and other actors engaged in the everyday production of care.

Mennicken and Muniesa (2017), for instance, highlight how governance of healthcare, higher education, and correctional services within France and the U.K. has moved away from an approach rooted in public investment towards an "asset rationale," focused on the optimization of return on investment. They stress how this mode of "governing through value" influences the "role and subjectivity…of public service users and providers." The authors describe how, in the 1980s, the U.K.'s National Health Service responded to a perceived funding crisis by redefining the role of clinicians as managers, responsible for optimizing their unit's performance on costs:

> These reforms transformed clinical managers into 'asset managers' who are responsible for the provision of good care, efficient working capital management, and for the management of the resources/assets entrusted to them, including patients. Patients are no longer merely recipients of care, but also sources for economic 'value creation' as their treatment has come to be linked to specific, variable financial returns. (Mennicken & Muniesa, 2017, p. 9).

Through treating the hospital as a business and the clinician as a manager, the "monetary imagination" becomes institutionalized within care providers and begins to shape "the mundane practice of performing (or not-performing) a medical act" (ibid., p.10).

This shift towards governing health through the lens of the asset rationale is pervasive, particularly within the U.S (E. C. Brown, 2024; McKinlay & Stoeckle, 1988; Salmon, 1985). Yet intensified datafication is also transforming the way that the public value of care is

conceptualized and managed by the state. Despite robust scholarship on the impact of datafication on the imaginaries and enactment of the welfare state (Dencik & Kaun, 2020), this literature has not closely attended to the intersection of datafication and practices of market design. In this piece, I explore how the public value of care is specifically constrained by and enacted through *datafied market design:* through the increased speed and scale of health data flows, the state seeks to re-design healthcare markets to more precisely optimize for the production of care as a public good.

From Managed Care to Value-Based Care: A History of Healthcare Market Governance

The U.S. is unique in the degree to which healthcare goods and services are provisioned through markets rather than direct investment by the state. A little over half of the U.S. population is covered under health insurance plans subsidized by employers (US Census Bureau et al., 2024). In contrast, among the 38 OECD member countries, almost *all* health insurance is directly paid for by the state.[13] This is not to say that in the U.S. context the state is absent from healthcare markets: since the 1940s, the U.S. federal government has maintained a regulatory infrastructure to support and manage this market-led provisioning of care—for instance, by exempting employer-sponsored health insurance from wage controls and taxes. Additionally, federal and state governments directly fund Medicare and Medicaid, public insurance programs that cover children, the elderly, and the disabled, individuals outside typical employer-based insurance markets. These programs cover approximately 40% of the U.S. population. Even these public health insurance funds are increasingly routed through private insurance companies: roughly 70% of Medicaid and 50% of Medicare enrollees are covered by a private insurance company contracted by the state (Freed et al., 2024; *Medicaid and Children's Health Insurance Program Managed Care Access, Finance, and Quality Final Rule (CMS-2439-F)*, 2024).

Despite the extent to which private insurance companies dominate the U.S. healthcare market, this industry has been the site of extensive regulatory tinkering to manage costs and improve health outcomes. One major benchmark in the history of healthcare market governance is the shift towards "managed care" models. In the 1970s, shortly after the implementation of public insurance programs via Medicare/Medicaid, the Nixon administration sought to address

[13] Source: https://data-explorer.oecd.org/vis?df[ds]=DisseminateFinalDMZ&df[id]=DSD_HEALTH_PROT%40DF_HEALTH_PROT&df[ag]=OECD.ELS.HD&df[vs]=1.0&dq=.A...&pd=2010%2C&to[TIME_PERIOD]=false

rapidly rising healthcare costs (Mechanic, 2004). During this period, there were growing calls for a national health insurance plan that would centrally address issues of both cost and coverage in healthcare (Starr, 2017). Ultimately, these calls were abandoned in favor of "market-based reforms" (Agrawal & Veit, 2002). The Nixon administration supported a shift towards managed care models, which sought to control costs through market re-design. This included moving away from fee-for-service models, which pay providers directly for services rendered, towards prepaid plans, which (in theory) incentivize providers to manage the costs of care.

Although the term "managed care" is no longer making headlines, the basic problematization—insufficiently disciplined care markets—and the proposed solution—"market-based reforms"— have remained consistent. As evidenced by the FDA Commissioner's keynote speech at the 2023 Health Datapalooza, regulators still agree that healthcare costs are too high, while health outcomes and access to care are too low. The contemporary framework for solving this problem is called "value-based care." Value-based care describes attempts to redesign healthcare payment models to more directly incentivize providers to improve "value": that is, to reduce healthcare costs and improve healthcare outcomes. The 2010 Affordable Care Act was the biggest stride towards implementing these alternative payment models. A wide variety of actors—including not only policymakers and pundits but also many of the healthcare practitioners and technologists I encountered in my research—see these payment model reforms as the best chance for achieving a healthcare market aligned with the public good.

After nearly 50 years of attempting to re-design healthcare markets to produce quality care that is accessible and affordable, the federal government has turned towards intensified datafication to revitalize the promise of designing markets aligned with the public good. In the next section, I describe the way that policymakers in the U.S. have problematized healthcare markets, and the role of intensified datafication in addressing this problem. I explore how the state has sought to fix healthcare markets through two intersecting regulatory projects: market re-design, in the form of "value-based" payment models that use data to quantify and incentivize the public good; and intensified datafication, through regulations to advance standardized, scalable data-sharing infrastructures.

Problematization: Misaligned Incentives, Inaccessible Information

Policymakers and pundits cite multiple reasons for the U.S. healthcare industry's high costs and poor outcomes, including an aging population, structural racism and other "social

determinants of health," and inconsistent access to care due to an employer-based healthcare system. Nonetheless, there is near consensus around "misaligned incentives" as a major problem within the industry. Since the managed care era of the 1970s, policymakers have pointed to the harms of fee-for-service payment models, which incentivize providers to offer more treatment or services regardless of their utility for patients. This incentive structure has consistently been faulted for driving up the costs of care, through to the present day.

In this problematization, providers are imagined as providing care that either directly advances their own financial interests—while neglecting larger concerns about efficient resource utilization—or is simply "undisciplined," not aligned with best practices for providing rational or efficient forms of care. To address this problem, federal regulators have spent the past few decades attempting to shift away from fee-for-service payment models towards payment models that incentivize improving healthcare outcomes while reducing costs.

In addition to these "misaligned" incentive structures, the problem of high costs and poor health outcomes is also attributed to insufficient access to and use of information. In this account, due to fragmented, siloed, and non-standardized data infrastructures, providers and patients do not have access to the information they need as rational actors to manage care effectively. This leads to duplicative treatments and "uninformed purchasing behavior," since providers are not aware of the costs of any given treatment. Likewise, neither health insurers nor federal or state policymakers feel that they have optimal access to information with which to govern the provisioning of care.

The Solution: Re-Designing Incentives, Re-Designing Information Infrastructures

Throughout the 2010s and until today, the federal government has sought to more efficiently and effectively produce the public good—conceived of as reduced costs and improved quality of care—through two intertwined regulatory projects: revised healthcare payment models and scalable, standardized data-sharing infrastructures. This section demonstrates how these projects are intertwined, highlighting the centrality of state-led datafication to the project of calculating "value" and "fixing" healthcare markets.

In 2006, Michael Porter and Elizabeth Teisberg coined the term "value-based care" in their book, "Redefining Health Care: Creating Value-based Competition on Results." They characterize the healthcare system as in "crisis," reflected via "high costs, unsatisfactory quality, and limited access to healthcare" (M. E. Porter & Teisberg, 2006). They conclude that previous

decades of reforms have done nothing to address the underlying issue, and that the market should be re-designed around competition on the production of tangible healthcare *outcomes*: "Competition on value must revolve around results. The results that matter are patient outcomes per unit of cost at the medical condition level. Competition on results means that those providers, health plans, and suppliers that achieve excellence are rewarded with more business, while those that fail to demonstrate good results decline or cease to provide that service" (M. E. Porter & Teisberg, 2006).

This book came during a period of increased attention to measuring and rewarding "quality" in the healthcare industry, or the *outcomes* of care based on adherence to best practices. The Center for Medicare and Medicaid Services (CMS) began to experiment with "pay-for-performance" schemes (Jha, 2017), measuring and financially rewarding healthcare providers for meeting established "quality metrics." By 2010, the Affordable Care Act (ACA) formally instantiated value-based care policies at the federal level. These policies included setting up the regulatory framework for "accountable care organizations" (ACOs), groups of provider organizations that can coordinate care, and the "Medicare shared savings program," through which ACOs are able to keep any financial savings that result from more efficient and effective care. The ACA also launched the Center for Medicare and Medicaid Innovation (CMMI), which is responsible for designing, piloting, and evaluating new value-based payment models.

In their book, Porter & Teisberg also emphasized that competition on value is impossible without broad access to information about patient results and prices. They urge the federal government to develop policies enabling more universal access to information about "results," including by "defining outcome measures," enacting "mandatory results reporting," and "establish[ing] information collection and dissemination infrastructure" (p.342).

Shortly before President Obama signed the ACA into law, the administration approved the HITECH Act, which allocated more than 20 billion dollars to incentivizing hospital and provider systems to digitize their paper records and adopt electronic health record systems (Blumenthal, 2009). Over the course of 2010–2018, the Department of Health and Human Services (HHS) set specific definitions for multiple phases of adoption and "meaningful use" of electronic health records (EHRs). As part of phase 1, providers only had to meet basic adoption criteria—but by the end of phase 3, they were required to demonstrate the use of electronic health information to meet improved quality measures. Representative Pete Stark (CA),

summarizing the intent of these phases, suggested that "simply handing out money to help providers pay for a health IT system was not good enough. Incentives should be provided only to those who use health IT in ways that markedly improve patient care" (Stark, 2010).

In the years after HITECH's enactment, policymakers became increasingly interested in advancing not only digitization of health records but also health data "interoperability," or standardized data sharing. In 2013, the federal government commissioned a report from a set of independent experts ("the JASON report") about the state of health data in the United States. The JASON report argued that *merely digitizing health data* would not be sufficient to address the inefficiencies in the healthcare market: "The twin goals of improved health care and lowered health care costs will be realized only if health-related data can be explored and exploited in the public interest" (The MITRE Corporation, 2013, p. 13). They argued that to design a more efficient health market, health data would need to be broken out of siloed electronic health records and not simply digitized. Taking cues from the JASON report, in 2016 President Obama signed into law the 21st Century Cures Act, which set forth the initial parameters and requirements for interoperability in U.S. health data infrastructures.

Through this history, we can see how state regulatory interventions into health data digitization and interoperability are situated within a broader project of quantifying and incentivizing "quality" and enabling competition around "results," as in Porter and Teisberg's (2006) definition of value-based care. These projects of state-led datafication were understood not only to help move data from one doctor's office to another, but also as a new approach to the problem of reducing costs and increasing quality in healthcare. The next section demonstrates in greater detail how these new data infrastructures are implicated in quantifying and paying for "value" in healthcare.

Datafication & the Quantification of "Value"

Datafication plays a key role in the shift from paying for "care"— in the form of treatments or services—towards paying for "health," including individual or population outcomes resulting from those treatments or services. Decades of organizational and technical infrastructure have been built around quantifying and paying for care inputs: this largely relies on tagging treatments or services with structured billing codes to comprehensively document the services rendered. Documenting, quantifying, and paying for *health* outcomes rather than care inputs requires a fundamentally different, and arguably much more complex, informational

infrastructure. The next two sections outline two key examples of these changing modes of valuing and paying for health outcomes via data: the encapsulation of value via quality measures, and the role of interoperable data in practices of risk adjustment.

Quality Measurement

Most of the early "pay-for-performance" models advanced through CMS relied on "quality measures," or standardized performance metrics for care delivery and outcomes. Quality measures play an increasingly important role in value-based payment models and involve several different subtypes: Process measures, for instance, track whether providers are adhering to recommended best practices for certain individuals and conditions—for example, whether patients undergo recommended preventative screenings. They also include "outcomes" measures, which measure things like the total rate of surgical complications, or "intermediate" outcomes, like the number of patients diagnosed with hypertension but whose blood pressure remained controlled over the course of a year following treatment. Value-based payment models offer financial incentives for provider organizations able to demonstrate certain thresholds of performance on these quality metrics.

There are numerous ways that quality measures are incorporated into different value-based care schemes. For instance, many "Accountable Care Organizations" (ACOs) participate in "shared savings programs," where the provider organization is given a benchmark for expected total cost for the year. If the ACO spends less than that financial benchmark, they can keep all or a percentage of that savings. To avoid cost-cutting at the expense of patients, however, ACOs must also demonstrate that they adhered to a broad range of quality measures over the same period. These quality measures include process and outcomes measures, as well as "structure" measures (whether a hospital has adequate beds or hospital staff, for instance) and more.

Importantly, this requires healthcare organizations to have robust data collection infrastructures to be able to capture and report on these broad and complex sets of measures. It may even require the provider organization to be able to capture data for patients that happens *outside* of their healthcare system. For instance, if patients receive their vaccinations at a retail location, the provider organization may seek a way to receive and incorporate that vaccination information to improve their performance on a particular vaccination-related quality metric. Likewise, the provider organization needs a mechanism to not only report this data at the end of

the year but also regularly track their performance in order to intervene or make improvements in real time. Making these improvements *scalable* may look like developing technical infrastructure to enable text-based notifications reminding patients about preventative care practices, or integrating prompts for providers within the EHR workflow about steps required to meet certain quality measures.

Broadly, policymakers imagine that the shift to value-based payment models will create a demand for more rationalized, information-driven forms of care. The 2015 "Interoperability Roadmap," developed by the Office of the National Coordinator for Health IT (ONC), envisioned a growing need for provider access to more and more complete patient records:

> When providers are rewarded for value, interoperability can be a significant tool to help them**…** Providers that are increasingly accountable for patient outcomes and total cost of care, regardless of where else that individual has received care, will increasingly demand access to an individual's complete clinical record, laboratory results, broader health-related information (human service and other community-based information) and total cost of care required to effectively manage the person's health. As models that reward quality over quantity continue to expand, providers are more likely to see a business case for making the time and cost investments to incorporate use of interoperable health information into how they deliver care. (Office of the National Coordinator for Health Information Technology, 2015, p. 1).

Although these quality metrics have been subject to financial incentives for many years, the efficacy of metrics as a tool of "accountability" is constrained by their enactment within legacy data infrastructures. Under the legacy quality reporting system, CMS requests quality measures for a random sample of a provider's Medicare patients. Provider organizations then manually go through their EHR system to report quality data on that subset of patients. This time-intensive process is called "chart abstraction." ONC and CMS are currently re-designing this system to move away from manual chart abstraction towards real-time reporting directly from EHRs via API. During a Health Datapalooza session on digital quality metrics, one healthcare executive described the shift to digital quality metrics as shifting from a "rear-view mirror" of care practices to a real-time, "dashboard" view of provider performance. This real-time view of quality metrics creates a tighter relationship of accountability between the provider, their

manager, and the payer. Don Rucker, former head of the ONC, described this as "computational accountability" (Mace, 2022).

Through intensified datafication, federal policymakers hope that quality metrics can become a more and more robust tool for exerting "market discipline" on healthcare providers. At a major health IT conference in 2022, Rucker spoke about the limitations of legacy quality measures as a tool for calculating value in healthcare, and the impact of API-based exchange on advancing the project of calculating and incentivizing value:

> We came up with what was, at the time, a state-of-the-art pastiche of *quality measurement as a proxy for consumer value*, which I think is a pretty slim proxy… We've had these things that are half-solutions, because we don't actually have the data. We don't actually know everything… so we'll say, 'Let's measure these things.' They're really narrow… Now with big data we have the opportunity that retail has had—*big data, volume, variety, velocity.* That is what makes FHIR [APIs] powerful. We finally have a way to answer the value question in a totally different way. - Don Rucker, HIMSS 2022, quoted in a piece by Jeff Lagasse in Healthcare Finance, March 17 2022.

Ultimately, this quote conveys an imagined future in which quality measures are not just cumbersome, partial "proxies" for value, but where increased speed and scale of data exchange—including via APIs—will enable healthcare to look more like retail markets, with each decision informed centrally by *return on investment*. In short, the underlying premise of datafied quality measures is to turn healthcare providers into "mini insurers"[14]: the provider adopts the investment rationale and re-aligns their behavior to the goal of maximizing population health outcomes while minimizing costs.

Risk Adjustment

Along with quality measures, "risk adjustment" is a central part of many value-based payment models. Shifting from paying for individual services to paying for efficient and effective production of health outcomes requires accounting for aspects of health outcomes that are not directly within providers' control. Risk adjustment describes the practice of documenting and offsetting the financial accountability for health risks. For instance, within the Medicare

[14] "Mini-insurer" is a framework that sometimes appears in descriptions of the impacts of the transition to value-based care, for instance: https://www.healthaffairs.org/content/forefront/expanding-vbp-overcoming-implementation-barriers; https://thetakeoff.substack.com/p/the-case-for-value-based-care

shared savings program described earlier, CMS collects data about key variables of the patient population to adjust the expected costs / financial performance for a provider organization based on the expected health risks of the population being served. Providers report on key variables within a patient population, including age, sex, disability, and chronic health conditions. Populations that are "riskier," or higher needs, may justify a higher rate of healthcare expenditure.

Using data to justify higher expenditures on higher-needs populations, on its face, seems like a socially good practice. However, the realities of risk adjustment highlight the difficulties of using data and market design to perfectly align market incentives with the production of the public good. Under risk adjustment regimes, healthcare provider organizations are incentivized to document a patient's risk factors—their chronic illnesses, their previous substance abuse issues—in comprehensive detail. This is known as increased "coding intensity." To mitigate the incentives towards maximizing patients' apparent risk scores, CMS has taken steps to constrain the allowable rate of increased "risk score" for providers participating in value-based care payment models. Arguably, however, no amount of technocratic tinkering can minimize the violence of a market framework that seeks to circumscribe social health needs as a financial risk to be moved from ledger to ledger.[15]

Through risk adjustment, certain aspects of health outcomes are circumscribed and deemed outside of the provider's direct control. To maximize the accounting of this risk, some insurers are increasingly interested in collecting "social needs" data, including through the integration of mental health records and data from community-based organizations. Sometimes the provider or insurer may implement programs to address these datafied health needs, such as referrals to social care to address housing or food instability. Other times, this data is collected purely as a financial accounting exercise, documenting health needs and then setting them aside as someone else's problem. And certainly, the hospital cannot be accountable for provisioning for all possible social care needs. Yet there is a violence in a practice of datafication undertaken - not to address needs - but to render these needs as an "externality", outside of what either the healthcare provider or payer can be held accountable for.

[15] Additionally, these "risks" are often documented within the patient's EHR—including risks that reflect structural inequities, such as living in a "socioeconomically stressed neighborhood" (Alcusky et al. 2023). Represented this way within the database, these structural inequities become reified as a characteristic of the individual.

The State-as-Platform

Through the story of the shift to value-based care, we can see how contemporary governance is rooted in intertwined processes of datafication and market re-design. This approach to governance draws explicit inspiration from the modes of control that platform companies exert as market- and data-intermediaries. As Viljoen et al. (2021) explain, "mechanism design"—the theoretical underpinnings for the practical art of *market* design—has come to be "regarded as an authoritative and generalizable science for engineering choice and distributing value in society", undergirding and justifying policymaking in a wide variety of domains. Viljoen et al. explore how the ethical narratives of mechanism design, as a tool to achieve the optimal distribution of resources, are "dispensed with" in the context of platform design. They trace how platforms, in particular online advertising auctions and gig work platforms, use computational techniques to engineer markets "to achieve information asymmetry, to distribute social costs in ways that benefit designers, and to orchestrate behaviors and choices in their systems" (ibid., p.2).

The state turns to intensified datafication, instantiated through regulatory interventions like HITECH and Cures Act, not only to improve provider and patient access to care, but also to enable insurers, including CMS, to exert a more platform-like mode of control over healthcare providers. Policymakers like former ONC head Don Rucker see APIs and other modern health data infrastructures as enabling a more direct insinuation of market discipline into providers' daily care practices, thereby aligning their behaviors with public value, in the sense of improved "return on investment": lower costs, higher quality of care. This is precisely the mode of intensified, algorithmic management that impacts platform-based workers, and an increasing number of professionals are "indirectly" managed through platform mechanisms.

Petre describes, for instance, the way that journalistic practices are re-engineered to better align with management goals through platforms that quantify journalists' performance on a wide variety of audience metrics (Petre, 2020). Introducing the idea of "engineering consent," a play on Burawoy's classic notion of "manufacturing consent," Petre argues that journalists do not necessarily experience this process as "algorithmic control." Rather, the incentives and choices of the professional are re-engineered through algorithmic feedback mechanisms. Likewise, media and platform studies scholars have explored the ways that social media platforms re-engineer the behavior and subjectivity of their users to increase their legibility to advertisers.

Wendy Chun's "Discriminating data: Correlation, neighborhoods, and the new politics of recognition" highlights how platform interfaces and recommendation algorithms are constructed to reproduce stable, machine-legible subjectivities and communities (Chun, 2021). In the shift from Nielsen audience scores to platform-based audience calculation, both the platform user and the content produced are re-programmed. Through a recursive interaction with algorithmic interfaces, both user behaviors and the content they are exposed to is nudged towards that which is most valuable for the platform itself.

Likewise, the shift in healthcare systems from quality metrics reported via chart abstraction to quality metrics reported real-time via APIs enables a recursive re-programming of behavior. As calculations about the value of a provider's behavior shift from the "rearview mirror" to a real-time dashboard, the healthcare provider begins to reconfigure their behavior in real time as well. In their critique of the practice of "governing through value," Mennicken and Muniesa (2017) highlight how accountability shifts as the clinician becomes the "asset manager." Through changing modes of management, they describe the clinician as adopting a "financial imaginary" that shapes their everyday care practices. Likewise, via datafied value-based care, the healthcare provider is re-programmed as a mini-insurer, internalizing the logics of population-level cost/benefit analyses.

This is the dream of "aligned incentives": re-programming care practices and care choices according to the reduced costs and improved population health outcomes in which the state is interested. This dream is what motivated the shift to managed care policies and what motivates the shift towards standardized, scalable health data–sharing infrastructures, enabling an intensified, platform-like mode of visibility and control over market actors. Just as platforms have adopted mechanism design techniques from economists seeking to design policy interventions (Viljoen et al., 2021), states seek to achieve the levels of datafication necessary to enact platform-like modes of market design. While other scholarship has examined the characteristics of "the platform state" in a wide variety of contexts (Kitchin, 2023; Sadowski, 2022; Singh, 2019; Törnberg, 2023), this chapter specifically argues that datafied market design is central to this emerging mode of platform-like governance.

Just as policy-makers, as well as everyday platform workers and users have sought to grapple with the implications and impacts of platform control across many industries, we must grapple with the political implications of state governance that increasingly adopts techniques of

platform control. For instance, platforms make decisions about optimizing for value in a very centralized way. They also exert total control over the data that is collected to calculate this value, and over the algorithms and interfaces that are constructed to shape user behavior: this operationalization of "value" and engineering of behavior towards it also tends to be opaque. Platform governance can be understood as a practice of centralizing and de-politicizing decisions about the definition of value, while intensifying the mechanisms of discipline and control in constructing user behaviors according to those definitions. Ultimately, this platform-like mode of governance exacerbates tensions and problems inherent in market design as a mode of governance.

Governing the Public Good Beyond Market Design

Intensified datafication revitalizes the promise of market design to help states efficiently and effectively produce the public good. However, market design requires the public good to be operationalized in a very narrow, economized sense. When public data infrastructures are designed to enable market design practices, these infrastructures likewise reflect this narrow definition. To more clearly draw out the harms and limitations of datafied market design, this section compares value-based care policies with carbon markets designed to incentivize more socially responsible climate practices.

Problematization—Through the Lens of Market Design

Seeing the world through the market design mode of governance constrains our understanding of the failure to produce the public good efficiently and effectively as a problem contained *within the market itself.* Questions about whether markets are the best tool to address a problem, or are in fact the source of the problem, are not included in this problem frame. In the case of the U.S. healthcare industry, for instance, the high costs and low outcomes of care are problematized as a problem of "misaligned incentives" for healthcare providers. Likewise, a market-design lens on the problem of climate change points us towards poor market design, which does not account for the negative externalities of climate impact. In both instances, it is assumed that markets can be optimized by the incorporation of additional variables as a set of financial incentives: e.g., the quantification of health outcomes, or the quantification of carbon emissions. In this account, the failure of markets to produce the public good is a problem of

misaligned incentives that can be remedied through a set of financial incentives, motivating corporate actors to innovatively pursue the efficient production of the public good.

Yet there are many other ways to problematize the high costs and low outcomes of care beyond the misaligned incentives of providers, and many other ways to understand climate change beyond the failure to sufficiently capture "negative externalities" within the market itself.

Within the healthcare industry, one might argue that making healthcare a matter of profit means that the production of health can only ever be a secondary concern relative to the production of profit. Likewise, in the climate change domain, one might argue that the very production of profit *always* hinges on the appropriation of "cheap natures" (Moore, 2016), and that no complete accounting or accountability of the environmental impact of markets is possible. Market design requires states to precisely calculate and quantify the public good and to make market actors financially accountable for its production: to make "the public good" and "profit" as close to synonymous as possible. This framework requires increasingly intensified datafication to capture the public good in an increasingly precise way.

In their paper, "The organization of markets for collective concerns and their failures," Frankel et al. (2019) note that instances of markets failing to produce the public good "does not pave the way for the introduction of non-market forms of solving collective problems" (p.155). Market design relies on an inherently conservative problematization: rather than consider non-market modes of governance, it assumes that the market can stay in place but must be re-organized, re-designed. Datafication opens up a new set of techniques for market designers to "assess, identify and repair market failures" (ibid., p.155), thereby extending and expanding the practice of technocratic tinkering instead of imagining other modes of governance beyond markets.

The "Public Good" as a Market Incentive

In this new direction towards which the market is driven, the public good is also constrained to a matter of technocratic engineering. In the market design mode of governance, the market designer is the ultimate arbiter of the public good. For instance, within value-based care payment models, valuable care is defined as the production of maximum health outcomes at a minimum of cost. Although patient experience is one dimension of CMS quality measures, quality metrics and the payment models and data infrastructures that support them undergird a

definition of health that privileges population health outcomes and the efficiency of care. This definition of health de-prioritizes the needs of the individual patient and the judgment of the individual provider in favor of a population-level calculus.

This is not to say that the state's definition of valuable care should be simply substituted with the definitions of patients or providers; there are likely significant disjunctures and fractures across the ways that "valuable care" would be defined by these groups. *Any* definition of "valuable care," or the ideal outcomes produced through healthcare markets, is intensely political. Yet rather than seek to address these fractures and disagreements through a political process, market design substitutes political decision-making with decentralized decision-making by self-interested rational actors. The market designer defines an ideal end state, designs financial instruments intended to make that end state more profitable, and leaves the rest of the decision-making to rational actors pursuing those financial incentives creatively and competitively.

For instance, in the case of cap-and-trade markets, the state defines a specific benchmark of acceptable emissions but also lets corporations buy and sell "allowances" for excess emissions. This theoretically creates a financial incentive for corporations to creatively and competitively reduce their emissions. Decision-making about what level of emissions to adhere to, and how best to adhere to those emission standards is devolved to individual corporate actors. Achieving the public good is operationalized not as a matter of collective concern, but as a matter of optimizing individual corporate finances. Likewise, under value-based care, the public good is centrally defined by states as a set of specific quality metrics and target acceptable costs, and provider organizations are individually responsibilized for finding creative ways to increase their performance on these metrics. In both instances, the public good is de-politicized, financialized—rendered as a technocratic benchmark rather than a matter of collective concern or debate.

The Economization of Public Data Infrastructures

Although datafication always entails some degree of abstraction, categorization, and imperfect representation, it can nonetheless be an important tool to advance the governance of the public good. But when these data infrastructures are built to enable market design and a financialized accounting of the public good, the data and its utility for actual care practices is likewise constrained. For instance, the electronic health records that were widely adopted as a

result of HITECH are criticized as being cumbersome for healthcare providers, a "billing machine" (Paull, 2022) more aligned with producing documentation necessary for reimbursement from insurers than with the needs of clinical care. Likewise, designing data infrastructures around the capture of quality metrics—or carbon emissions for the purposes of cap-and-trade—means that the possibility of re-using this data for alternative modes of accountability or governance beyond market design is limited.

Broadly, data that quantifies health outcomes, disparities, and the inequitable distribution of resources has immense potential social use. What might it look like to design health data infrastructures for purposes other than building efficient, optimized markets? Ottinger et al. (2023) argue that while "patterns of alienation characterize big data," there are also opportunities for data to be collected and used in ways that go beyond specific "regimes of value" like surveillance capitalism or data colonialism: "The questions for analysts and activists, then, are how particular practices of data collection and use may be weighted toward attunement or toward alienation; to what phenomena they attune or alienate us; and who is helped or harmed by these tendencies" (p.3).

Beyond "Computational Accountability"

Market design, in both the health and environmental domains, attempts to make market actors accountable for the production of the public good. Yet this is a highly constrained form of accountability, rooted only in what can be calculated and accounted for via predetermined metrics and market devices. This "thin," market-based accountability is readily subject to gamification and the "production of ignorance" (Kleinman & Suryanarayanan, 2013). Lippert (2022), for instance, describes how this gamification unfolds in the context of carbon markets:

> Once a carbon footprint is established, the organisation can 'outsource' the emissions it has calculated as having emitted (Ninan 2011): it can buy negative emissions via the carbon market and add these to its footprint, calculatively reducing its footprint by e.g. 20%, even by 100% to be carbon 'neutral' or by even more to be carbon 'negative'." This financial gamification of the "carbon footprint" implies "the risk of misjudging emissions at a global scale: subprime carbon (Chan 2009). – (p.7)

Rather than achieving the intended goal of reducing carbon emissions, the creation of carbon markets helps datafy, financialize, and ultimately erase actual material emissions impacts

in favor of abstract performances of carbon neutrality. Likewise, the practice of risk adjustment in value-based care markets entails the calculation of health risks, of "social determinants of health," specifically to place these outside the market, removing them from the ledger of accountability. Market actors may choose to address these as part of their business strategy, or they may not.

It is this aspect of carbon markets that leads Lohmann (2005) to characterize them as successful—not in terms of reducing carbon emissions or environmental impact, but of "diverting financial and intellectual resources away from political actions and technological innovations that could stem the flow of fossil carbon from below- to above-ground" (p.230). In short, Lohmann argues that governance of climate change through carbon markets enables a *diversion of accountability.*

The same critique might be applied to the practice of value-based care: to what extent does datafication enable the continued displacement of forms of accountability for care *beyond* financialization or market discipline? How do datafied quality metrics substitute increasingly complex, non-transparent forms of computation for collective accountability that would ensure all health needs are met? And what might data infrastructures look like that would support alternative modes of accountability or relationality?

To date, scholars have critiqued both the politics of market design (Frankel et al., 2019; Nik-Khah & Mirowski, 2019; Viljoen et al., 2021) and datafied and platformized modes of control (Chun, 2021; van Dijck, 2020). Through the case study of value-based care, this chapter explores the convergence of these phenomena via *datafied market design.* Specifically, this chapter demonstrates how the U.S. federal government has sought to implement standardized data-sharing infrastructures to enable a platform-like re-programming of healthcare markets. In the face of pervasive market failures, datafication enables the eternal project of technocratic tinkering, designing markets that internalize "negative externalities" and make the production of profit synonymous with the production of the public good.

Parallels between the project of value-based care and climate change governance demonstrate the limits of how public value is conceptualized when decided by centralized market-makers and operationalized as a set of financial incentives or other market devices—and the limits on vital public data infrastructures when they are designed and instantiated with this kind of governance-through-market-design in mind. This analysis also suggests that the

"computational accountability" that these policies seek to enact is necessarily thin, subject to gamification, and ultimately, a diversion from alternative forms of governance or accountability.

Chapter 4 Social Determinants of Health Data: Between Actuarialism and Care

On a sunny day in early September 2024, I drove an hour north to a golf club banquet venue in East Lansing for a day-long workshop hosted by the Michigan Department of Health and Human Services (MDHHS). The workshop was developed as part of a recent state initiative to address "social determinants of health" (SDoH), a term used to describe the non-medical factors which shape[16] health outcomes, such as access to food, clean water, or housing. I am invited to this workshop by one of the MDHHS employees helping to facilitate and organize the event.

The term "social determinants of health" first gained prominence via a 2008 report from the World Health Organization (2008), "Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health."[17] The WHO suggests that these non-medical, largely socio-economic factors may determine more than 30-40% of health outcomes.[18] Since 2008, the social determinants of health framework has been increasingly taken up in the U.S. by state and federal policymakers, public health researchers and practitioners, and healthcare organizations looking to address health inequities and the persistence of poor health outcomes, despite rising costs of care.

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[16] SDoH are sometimes instead called social "drivers" of health, to avoid the implication that an individual's health outcomes are inescapably predetermined by systemic factors. See: https://www.nachc.org/social-drivers-vs-social-determinants-using-clear-terms/

[17] This report argues that inequities in health outcomes, both within and across countries, is heavily shaped by socioeconomic inequities: "The poor health of the poor, the social gradient in health within countries, and the marked health inequities between countries are caused by the unequal distribution of power, income, goods, and services, globally and nationally, the consequent unfairness in the immediate, visible circumstances of people's lives – their access to health care, schools, and education, their conditions of work and leisure, their homes, communities, towns, or cities – and their chances of leading a flourishing life. This unequal distribution of health-damaging experiences is not in any sense a 'natural' phenomenon but is the result of a toxic combination of poor social policies and programmes, unfair economic arrangements, and bad politics. Together, the structural determinants and conditions of daily life constitute the social determinants of health and are responsible for a major part of health inequities between and within countries."

[18] https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1

The workshop I attended in East Lansing was focused on showcasing the work of Michigan's new "SDoH hubs" initiative, launched in 2024. These hubs, often pre-existing organizations like county-level health departments and large NGOs, received grants from the state to develop improved infrastructures and services for addressing social determinants of health. The exact nature of these SDoH efforts varied widely, from directly investing in social services programs to building out apps or websites to help coordinate services across a fragmented network of large and small non-profit, NGO, and state-run organizations. These SDoH hubs are also responsible for improving *SDoH data collection* and reporting infrastructures: the key currency through which the impact of these state-level interventions are measured.

The day-long workshop was attended by hundreds of practitioners and policymakers from across the state working at the intersection of medical care and "social care". Social care is the industry term for the world of care services and organizations beyond doctor's offices and hospitals, including long-term residential care facilities; community organizations addressing housing, food assistance; and social workers addressing mental and behavioral health needs in prisons, schools. After hours of presentations, breakout group discussions with sticky notes and sharpies, and a speed dating session - a final panel of speakers summarizes and reflects on the work of the SDoH hubs.

Receiving the mic, a middle-aged Black woman in a white pantsuit raises a pointed critique: "*As community mental health workers, we always feel like we are responding to problems that shouldn't exist. We are always looking for upstream solutions. I didn't hear a lot of upstream solutions today."* Although charged with helping to address the big structural barriers to health, this panelist suggested that the services and solutions being offered by SDoH hubs are still better characterized as *responding* to human crises, rather than preventing them in the first place.

This panelist's comments struck me as bold - a direct critique of other attendees' efforts to address the effects of structural racism, poverty, and organized abandonment[19] with the

[19] Ruth Wilson Gilmore uses the phrase "organized abandonment" to describe the intentional erosion of the social safety net so that these social needs can be commodified and turned into new markets (R. W. Gilmore, 2022).

meager tools available to them as under-funded social care organizations.[20] Yet I would come to realize that this panelist's comment reflects a much larger history of contestation around the boundaries between health and social care, and about our collective responsibility to address the structural causes of health inequity within society. The "social determinants of health" framework represents an attempt to intervene and reconfigure these boundaries. Likewise, new SDoH initiatives like the Michigan SDoH Hubs program are where new practices and infrastructures are being developed that intentionally seek to shift or re-construct these boundaries.

In this chapter, I explore how the social determinants of health framework is operationalized within a specific set of practices around the collection, storage, and use of SDoH data. The collection of this data is motivated, in part, by an attempt to make the structural inequities in access to housing, food, shelter and other fundamental human rights more visible, and to hold insurance companies, healthcare providers, and the state itself more accountable for addressing these needs. However, I show how *social determinants of health data* are enacted within a sociotechnical infrastructure organized around individual responsibilization and actuarial practices of shifting risk and accountability in ways that benefit powerful corporate actors. By examining the collection and use of SDoH data within the health economy, I reveal the fundamental contradiction between the goal of addressing the "upstream" problems of maldistributed resources - and a set of technical, financial, and bureaucratic infrastructures designed to produce commodifiable "downstream" solutions to structural problems.

The Rise of the SDoH Industry

Several factors are driving the collection and use of SDoH data in the U.S. healthcare industry. These drivers themselves reflect an important set of political contradictions.

On the one hand, SDoH gained additional traction during a particular political moment in the U.S., in the wake of #blacklivesmatter movement - including the summer of 2020 uprisings in the wake of George Floyd's murder, and the CoVID-19 pandemic, which brought racial and class disparities to the forefront. During the pandemic, some workers were able to stay home -

[20] The kinds of social care services represented at this workshop are typically non-profits, reliant on meager state funding and philanthropic donations to continue their work. These social care organizations are fantastically underfunded relative to the medical care sector yet are vital stopgap infrastructure in the context of the U.S.'s wildly underfunded social safety net.

while others remained on the front lines as "essential workers", subject to increased risk of severe illness and death. The health disparities faced by racialized and impoverished communities meant that these populations faced increased risks of poor outcomes from infection by covid19. These interlinked phenomena pushed concerns about health equity to the forefront of collective consciousness in the U.S. Addressing health inequity became an increasingly central goal and benchmark of health policies and initiatives in the period of this study (2020-2024), and collecting "social determinants of health data" - typically, data about an individual's lack of access to food, housing, water, or other basic infrastructures - provided a way to make these disparities visible. This data enabled increased advocacy for policies to address these structural failures.

On the other hand, social determinants of health have also been identified as a means to *manage the costs of care*. As policymakers and healthcare executives grapple with the recalcitrant problem of "high costs and poor outcomes", SDoH are construed as one explanatory factory: when patients lack access to necessities like housing or clean water, no amount of high-tech treatments or intensive medical care can make people "healthy." And so, SDoH data are increasingly collected by some healthcare provider systems to identify targeted areas for "quality improvement", to attempt to mitigate or address the extra-clinical factors which determine the success or failure of clinical interventions. These programs may look like identifying which patients have issues with transportation which make it difficult for them to make it to crucial appointments: the hospital may provide free or low-cost transportation services for these specific patients. Or patients without stable housing may be referred to a caseworker to help them find a placement.

Finally, SDoH data have also become implicated within the shift towards value-based care. Value-based care, as I explore in chapter three, describes an effort by U.S. policymakers and regulators to improve the "return on investment" from public expenditures on Medicare and Medicaid by making healthcare providers financially accountable for the costs and outcomes of care. Yet these new payment models open a "pandora's box" in terms of specifically identifying and locating accountability for the costs and outcomes of care. To what extent can the provider be held accountable for health outcomes, especially when we consider that a large part of health is shaped by non-clinical factors?

For example: if a hospital serves a poor community in a food desert with unsafe housing and water infrastructure, should the hospital be held financially accountable for their patients' high costs and poor outcomes of care? If not, who is accountable for addressing these structural factors which increase healthcare costs? Is it the city, or the state, or the federal government? What role can or should the hospital or the insurer or federal government play in addressing these structural factors of care, for instance by getting new affordable housing built in the neighborhood? Value-based care opens this space of contestation about *who should be accountable for health inequities,* and the mechanisms through which these structural factors should be addressed. SDoH data, likewise, plays a key role in this shifting landscape of accountability for healthcare's costs and structural factors which shape health outcomes.

As a result of this changing culture around health equity concerns and changing payment models, public and private payers have introduced new requirements for healthcare providers around the collection and reporting of SDoH data. The below graph, from a 2023 KFF survey (Hinton & Diana, 2024), provides an overview of the different contract requirements related to SDoH for healthcare providers contracted under state Medicaid agreements. These requirements range from collecting data about "social needs", to referring patients to external social care organizations, to more directly partnering with or investing in social care. This graph reflects state efforts to enroll healthcare provider organizations in addressing health inequities and structural barriers to health.

In what follows, I explore in more depth how different types of SDoH initiatives - reflected to some extent in this graph - represent different configurations of financial and moral accountability for the systemic factors which shape care. Broadly, the SDoH framework as introduced by the WHO represents a shift towards examining the state's moral accountability for the lack of housing, food, clean water - particularly among poor and racialized communities - that produces health disparities in those communities. Yet, I argue that the technical and financial infrastructures that surround SDoH data collection and use represent a subsumption of this broad moral accountability towards interventions that seek to address structural problems at the individual level to mitigate costs, and as an actuarial tool for displacing financial responsibility for the costs of structural failures away from insurers or providers. Moral and financial accountability for addressing social determinants of health remains in flux, dislocated, - and this is reflected in the collection and use of SDoH data itself.

In the next section, I provide a brief overview of the boundaries which are re-negotiated through the SDoH framework, including the historic and contingent processes through which the state's accountability for addressing health inequities have been constructed.

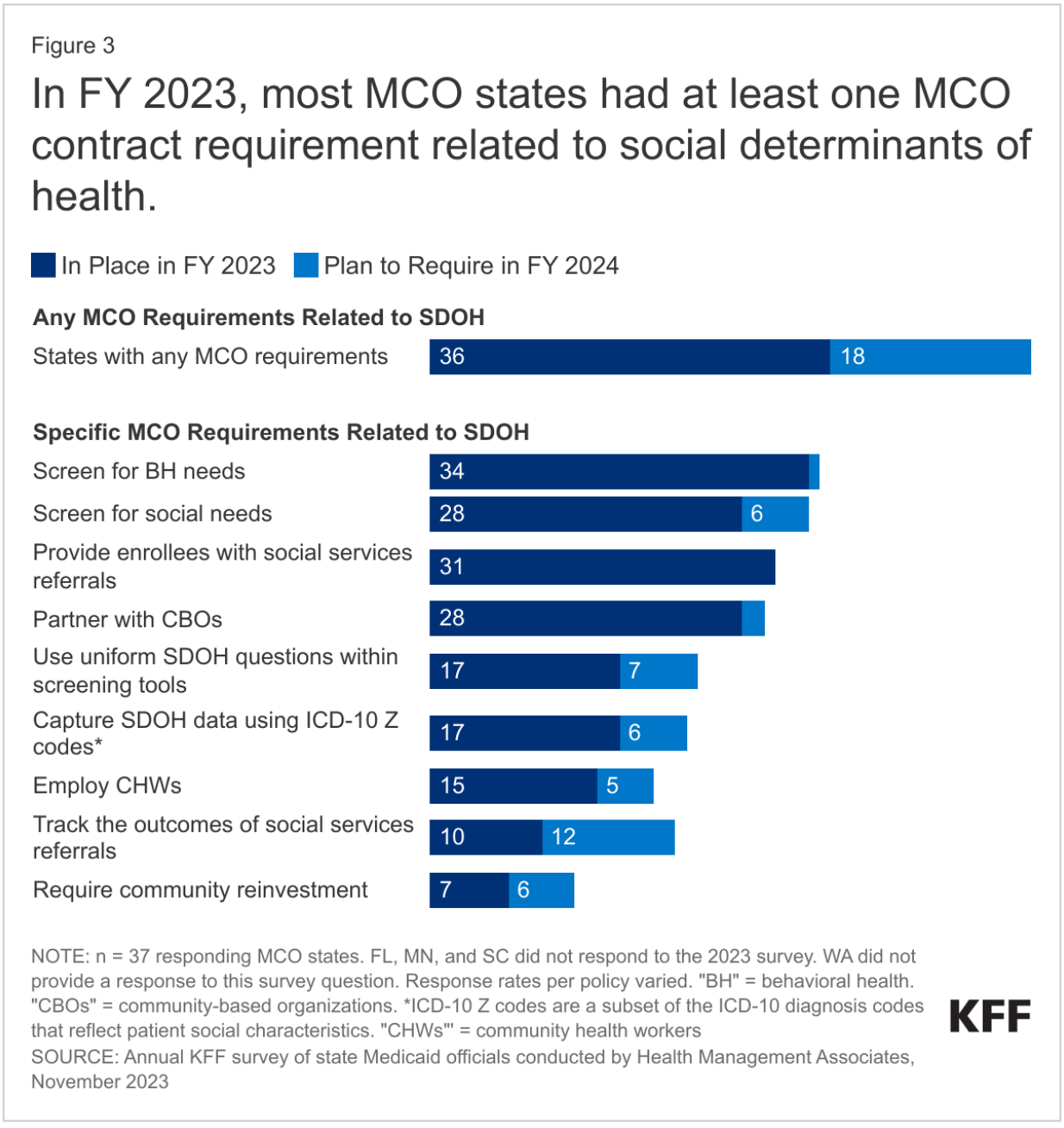


Figure 4.1 "MCO" or "managed care organization" refers to health insurers contracted to provide Medicaid services. With the shift to value-based care, MCOs are increasingly required to address SDoH. (Hinton & Diana, 2024).

Constructing Accountability for Care: A Brief History

"Social determinants of health" interventions can be situated within a much larger world-historical contestation about how best to govern care in industrialized, contemporary societies. In brief, we might summarize this as a contestation over *what kinds of need* should be addressed, and *who* is responsible for addressing those needs. The rise and evolution of the "welfare state" reflects, for instance, a shifting set of political understandings about what kinds of need should be addressed by the state. In parallel, the boundaries between "social care" and "medical care" reflect a boundary constructed around discrete kinds of needs, warranting discrete kinds of intervention, and differential levels of investment/accountability by the state. Social determinants of health policies and interventions reflect a relatively recent site of the renegotiation of the boundaries, both between "medical care" and "social care", and a renegotiation of the accountability of state and of non-state institutions for each domain of care.

The Welfare State

Over the course of the last century, political consensus about the responsibilities of the state in addressing illness, poverty, and in meeting basic social needs for housing and food has been reshaped by shifting geopolitical, economic, and ideological conditions. "The welfare state" is the term typically used to describe modern constructions of state accountability for meeting basic social needs - though the definition of these "needs" and the state's role in addressing them has of course varied widely. Some historical narrativizations position the welfare state as a necessary epiphenomenon of urbanized, industrial capitalism: as workers moved into the city and away from community networks of mutual aid, the nuclear family became less capable of addressing social needs independently. Illness and disability, to the extent that they represented disruptions to a workers' capacity to generate a wage, became reallocated as a problem for the state (Polanyi, 2002).

In this sense, welfare state policies can be understood as a means to address the social dysfunction that arises from industrial capitalism - without fundamentally restructuring society. UK Labour Party founder Keir Hardie, for instance, noted that the 1911 National Insurance Act did "not uproot the cause of poverty but...[provided] a porous plaster to cover the disease that poverty causes." (D. Porter, 1998, p. 26). Welfare policies, according to this line of argumentation, exist only and up to the extent that they help maintain a productive labor force for capitalist exploitation.

Welfare state policies also reflect complex and shifting attitudes about the origins of inequity, and the extent to which these inequities are understood as "natural", a result of individual social choice, or positioned as a social flaw to be eliminated. For instance, eugenics ideologies of the early 19th century articulated social inequity as a "natural" phenomenon, arising from innate genetic differences between individuals and populations (D. Porter, 1998). These ideologies suggest that "social Darwinism" is a self-regulating force which serves to civilize society - and that the role of the state is to enhance this self-regulation process through the management of reproduction, rather than through the redress of social inequity. The height of eugenicist ideology in the West came along with state policies of forced and voluntary sterilization.

Eugenicist ideologies reached an apotheosis within Nazi Germany mass extermination campaigns and were largely discredited in the West in the post- World War two era. Subsequently, many European countries shifted towards supporting universal state welfare policies and social security, including universal health insurance. These welfare policies were designed *not just* in service of the most destitute, but benefitted middle-class workers as well, enabling strong cross-class solidarity around these welfare programs (Esping-Andersen, 1990).

The U.S., however, could not achieve the same level of broad political support for universal health coverage (Weir et al., 1988). Prior to the Great Depression, in the U.S. most social needs and redress for the conditions of poverty were provisioned through philanthropic, voluntary organizations. Yet as the Great Depression threatened to push even middle class workers into the almshouses, welfare state policies became more popular, enabling the establishment of social security and other New Deal policies (Rothman, 1997). And yet, the provisioning of medical care via socialized health insurance was not included as part of these policies. During this post-Depression period in the U.S., Blue Cross and Blue Shield voluntary, and later employer-based, health insurance schemes arose to redistribute the financial risks of medical care. Even as the federal government instituted and funded public health institutions, and sought to manage hygienic conditions within cities through the management of streets, water, and housing, the management of medical risk remained largely a voluntary, decentralized concern (D. Porter, 1998).

In 1965, long after health insurance policies had been well-established in many Western European states, the U.S. moved to take up a small portion of accountability for unaddressed

care. That year, Lyndon B. Johnson signed into law Medicare and Medicaid policies to help address and socialize medical expenses for the aged and disabled. These state-funded health insurance programs, which remain in place today, are constructed largely as a matter of last resort, rather than universal programs which benefit working class populations.[21] Whereas most Western European countries came to construct healthcare coverage as a universal right, in the U.S., state-provisioned health coverage remains a privilege reserved only for those whose healthcare needs *cannot be served by the market*.

Paul Starr argues that this lack of cross-class solidarity around the provisioning of public services has left these programs open to attack by political forces - including conservative Republican politicians which narrativize social inequity as "natural" and necessary - which do not support the state in provisioning "charity" (Starr, 2017). At the time of this writing, the proposed introduction of new "work requirements" for those receiving Medicaid within Trump's "big, beautiful bill" reflect the ongoing boundaries being drawn around which kind of needs the state is responsible for addressing, and which it is not.[22]

The Boundaries Between Social and Medical Care

In parallel with this ongoing construction of state accountability for addressing social need, the boundaries between "medical care" and "social care" have likewise been made and re-made. "Medical care" often involves intervention in illness and health at the individual level, often through sets of pharmaceutical treatments, while "social care" involves approaches that address health on a more structural level, through the creation of infrastructures and social structures which support health, such as clean water or clean streets. These two domains have been marked by different sets of professional practices, different models of public and private financing.

One of the major reactionary political forces which helped to demobilize demands for socialized health insurance was the American Medical Association, the professional association of doctors, which saw it as a threat to their autonomy and their livelihood to have their work centrally managed by the state. In this regard, the boundaries between medical care and social

[21] See also: Stevens, R. A. (2017). Welfare medicine in America: A case study of Medicaid. Routledge.; Engel, J. (2006). Poor people's medicine: Medicaid and American charity care since 1965. Duke University Press.

[22] See: https://www.nytimes.com/2025/06/08/opinion/medicaid-work-requirements-arkansas.html; https://soundcloud.com/deathpanel/waste-fraud-and-abuse

care have been entrenched in the U.S., not only through particular constructions of spheres of governance and financing - but also through staunchly defended professional boundaries. In the U.S. in particular, medicine has become an increasingly science- and technology-driven profession, concerned with advancing cutting-edge solutions to complex biomedical problems (Rothman, 1997). Social needs, including mental and behavioral health needs, housing, income, food, water, have been situated outside the professional boundaries of medical care – often the responsibility of feminized and devalued "social workers."

The "social determinants of health" framework, however, challenges the understanding of "health" as a product of individual, technological intervention by a medical expert. SDoH research suggests that *health* is not primarily created through advanced forms of specialized, technology-driven care, but through preventative care and by ensuring that basic needs are met (Braveman & Gottlieb, 2014; *Closing the gap in a generation: Health equity through action on the social determinants of health*, 2008). The concept of "social determinants of health," at least as articulated within the World Health Organization and by the public health advocates who laid the foundations for this framework, contains a very explicit political message: that health inequities are not inevitable, and that it is the duty of states and the world to address the structural causes of these inequities.

Broadly, different configurations of the welfare state reflect different allocations of accountability for addressing social need: what kinds of need and inequities should be addressed, and by whom? What should be addressed by the state, and what should be left to the market - or to "natural" processes of social death? Social determinants of health initiatives reflect an ongoing reconfiguration of these boundaries and allocations of accountability. Yet, as I explore in the following sections, the enactment of SDoH initiatives within data and payment systems nonetheless tends to reproduce a highly technologized and individualized approach to addressing health inequity. SDoH data also become mobilized within actuarial practices which help reproduce the boundaries between medical and social care, and to invisibilize unmet social needs.

The Datafication of SDoH

In this section, I explore specific examples of SDoH interventions that are playing out in the U.S., in order to more closely examine how these interventions are renegotiating accountabilities for addressing the causes of health inequity. I specifically focus here on the role

of *SDoH data* as a boundary object (Leigh Star, 2010) through which these renegotiations are mediated. These examples include: screening and referral, through which providers screen patients for unaddressed social needs and refer them to social care services; risk adjustment practices, through which payments to healthcare providers are adjusted based on patients' levels of social need/risk; and "community information exchange" infrastructures, through which SDoH data are exchanged between healthcare and social care sectors.

Screening & Referral

You find yourself in a doctor's office, or the ER, for your annual check-up or for a new malady. Among the plethora of paperwork you fill out, you may find yourself answering some questions like: "In the past year, was there a time when you needed to see a doctor but could not because it cost too much?" or, "Do you have a dependable way to get to work or school and your appointments?", or, "Does getting child care make it hard for you to work, go to school or study?" You may also be asked, "Would you like to receive assistance with any of these needs?" Your answers to these questions may be recorded within your electronic health record, and a social worker may connect with you after your appointment to help refer you to community resources for food, housing, or transportation needs.

These questions come from a template SDoH screener developed for healthcare organizations in Michigan[23]. Across the country, a growing number of healthcare providers conduct this kind of SDoH screening and referral - either because they are required to do so by health insurers, or because healthcare providers can bill the insurer for conducting this referral and screening. This practice institutes a formal bridge between the domain of medical care and social care, one small way in which unmet social needs are incorporated within the scope of clinical care practices. Yet some healthcare practitioners and public health scholars are skeptical about the impact of these screening and referral practices - both on the social care providers that receive these referrals, and the benefits to patients themselves.

A 2023 opinion piece from public health scholars Fichtenberg and Fraze (2023), titled "Two Questions Before Health Care Organizations Plunge into Addressing Social Risk Factors," includes a scathing critique of the practice of screening and referrals:

[23] https://www.michigan.gov/-/media/Project/Websites/mdhhs/Folder2/Folder24/Folder1/Folder124/SIM_Brief_Screening_Questions.pdf?rev=6d4c7462a632469499a354050e9d132d

> The idea that patients are food insecure because they have not figured out where the local food bank is, or the idea that they are homeless because they do not know how to contact a homelessness services agency, both underestimates patients' knowledge and ignores the elephant in the room[24]: specifically, that the U.S. social safety net is woefully underfunded...The idea that health care organizations can help patients by focusing on screening and referrals feels misguided at best and willfully ignorant at worst.

The authors argue that healthcare organizations should "right size" their investment of time and energy into screening and referrals, and instead consider directly funding social services provisions, e.g. by co-hosting a foodbank, and using their political power to advocate for policies which directly address social needs.

At the SDoH workshop in Lansing with which I opened this chapter, I met Melissa, the health data professional quoted in the introduction chapter. Among other duties, Melissa is responsible for managing the data infrastructures behind her employer's referral and screening and care navigation programs. In our conversation, Melissa highlighted the role that *SDoH data* plays in enabling the perpetuation of "willful ignorance" around the underfunded social safety net. Melissa describes how the documentation of "closed loop referrals" helps to obscure and distract from the real social needs. Data professionals like Melissa are encouraged to capture data about "closed loop referrals", which refers to the process of documenting not only that a referral has been made, but receiving data *back* from a social care organization documenting the outcome of that referral. With frustration in her voice, Melissa walks me through what she sees as the harms of "closed loop referral" data:

> *So I [the healthcare system] have a referral system. I do not provide services. My community health workers provide a navigation service, but they're not putting people in houses, right? They're referring them to the agencies that do that. I need to have a good referral system, right? And for that I want to make sure that when I refer somebody… to one of my partners, I want to make sure that a person just doesn't go into a queue and get forgotten. That is closing the loop on a referral. It means that … If I referred you to someone, did you call them?*

[24] As one patient with experience getting handed a referral list or advised to call 211 shared: "They might as well spit in your face."

Melissa continues, describing, in technical terms, exactly what the "closed loop referral" metric means:

> *You [the agency] have up to three contact attempts. We're really specific. You have three contact attempts, and you have to make them within five days, five business days, and if they don't answer the phone or they don't call you back, that's fine, but you've logged three contact attempts. We can tell the amount of time in between when you get the referral and when you call them for the first time. We look at these things. These are quality metrics.*

Here, Melissa is specifying that closed loop referral data is included as part of quality metrics: measurements which can improve or reduce healthcare reimbursements under value-based payment models. Melissa then contrasts this specific, constrained, technical definition of a "closed loop referral" as documented within quality metrics, and the overall goal of *meeting people's social needs:*

> *However, that is different than saying I am dispositioning the need…It is so seductive…the lie that everybody wants to hear, which is we're meeting people's social needs. We're not meeting people's social needs. At best, we are connecting people to episodic support for systemic problems. That's the best we can do, because we don't actually care whether or not people are housed as a society…I can tell you that an agency talked to them. But you know what they did? They put them on a section eight waiting list that will take four months. So is their housing need met? No, I don't think so.*

Melissa describes the way that "closed loop referral" can create the appearance, "the lie that everybody wants to hear", that healthcare providers are meeting unmet social needs through SDoH screening and referrals. In this regard, the production of data about closed loop referrals comes to substitute for the actual meeting of social needs. In contexts wherein insurance companies reimburse for these screenings and referrals, the production of these metrics becomes reified as an end-goal in and of itself. The "closed loop" reflects the *closure* of the provider's accountability for addressing their patient's unmet social needs - and by proxy, the closure of the insurance company, and even the state's accountability for the lack of actual social care resources, such as affordable housing.

Melissa's critique of the closed loop referral is not that these screenings are conducted, or that this data is collected, but the mis-use and mis-representation of this data. The problem that

Melissa identifies is of the "seduction" or temptation to have this data - which represents something very limited and constrained, an attempt to contact a social care provider – to come to stand for something MORE than that, to stand for the healthcare provider meeting a structural need. When construed to mean this, this data help reproduce the invisibilization of unmet social need.

In October 2024, I attended a conference in Detroit by Civitas, a national coalition of health and social care organizations building and advocating for funding of "health data utilities." Many of the panels focused specifically on the infrastructures and practices being built to integrate the domains of medical and social care. In these sessions, healthcare provider organizations would often proudly report the number of successful SDoH screenings they had completed in the past year, or the number of closed loop referrals. In one panel, I witnessed a woman from a social care organization raise her hand during the question-and-answer session and talk about how their organization had been inundated with new referrals since these screenings had become incentivized by one of the state's Medicaid/Medicare plans. Yet, she emphasized, they had no new resources with which to actually meet this influx of new referrals. In her comment, it became apparent that this same metric which signals success for a provider organization signals the scale of still-unmet need for social care organizations.

This example highlights the recalcitrance of the boundary between health and social care when it comes to accountability for addressing unmet social needs – and the role that SDoH data can play in reproducing the boundary that it is meant to challenge. While social care providers seek to broaden the scope of healthcare and the state's accountability - and financial investment in - unmet social needs, healthcare provider organizations have a vested interest in producing data which shows that they *have* met a social need, thereby contributing to the reduction of structural health inequities which drive up the costs of care. Likewise, the state has a vested interest in interpreting data, such as closed loop referrals, in ways that abrogate their responsibility for more substantive investment in social care and unmet social needs.

Risk Adjustment

Let's return to our imaginary doctor's appointment. Imagine that you have completed screener questions about your financial situation, your mental health, your access transportation, etc. This data about your potentially unmet social needs is not only used to directly inform patient care - for instance, via screening and referrals - but is also used in determining the

appropriate *payment* for your care. That is, SDoH data plays a role in establishing who is accountable for the increased financial risk of your unmet social needs.

As explored in chapter three, healthcare policymakers are moving towards value-based care models which make healthcare provider organizations financially accountable for overall patient costs and health outcomes. The goal of these policies is to incentivize healthcare provider organizations to innovate in their treatment of patients in ways that reduce costs and increase health outcomes. However, this requires the construction of payment models which carefully draw the boundaries of *which costs and outcomes* the healthcare provider can be reasonably held accountable for.

Recognizing that outcomes and costs of care are, to some extent, outside of a healthcare provider's direct control, "risk adjustment" describes a process whereby a healthcare provider is subject to reduced financial accountability for the costs and outcomes of patients' care, depending on the overall "risk" of the population they care for. To date, the "risk" of a given population is calculated primarily based on demographic and medical diagnosis data. For example, a 60-year-old woman with no chronic conditions is likely to have a lower risk score than an 84-year-old man with diabetes. If a provider is paid by an insurer under a "value-based" contract, that provider may be paid *more* for treating patients with higher risk score - or subject to reduced financial penalties for the high costs/poor outcomes of patients categorized as higher risk.

Of course, the fundamental concept of "social determinants of health" is based on the identification and recognition of factors that shape health outcomes which are outside of the traditional medical care system. As a result, *SDoH data* can be mobilized not only as a tool for targeting treatment or care - but as an actuarial tool to characterize patients with risk factors for which a healthcare provider perhaps should not be held financially accountable for. While SDoH data are not currently a part of CMS's risk adjustment models, these risk scores are already being reflected in payment models in some states. For instance, Massachusetts' Medicaid program uses a risk adjustment model which adjusts payments to providers based on patients' risk factors, including homelessness, substance use, and a "composite neighborhood stress score" which includes "economic stress, income, employment, education, and transportation" (Alcusky et al., 2023). In other words, a patient's address is used to associate them to a neighborhood, which in turn is associated with a particular risk-score for that neighborhood.

Nonetheless, the inclusion of SDoH data within risk adjustment models is an active site of contestation among policymakers, healthcare providers, and insurers. For instance, the National Quality Forum, the organization responsible for developing and validating quality metrics used across the country in value-based payment programs, prohibited the use of socio-economic status or other "social risk factors" within payment programs prior to 2014 (*Risk Adjustment for Socioeconomic Status or Other Sociodemographic Factors*, 2014; *Social Risk Trial Final Report*, 2017). This prohibition was based on the grounds that the production of high social risk scores would be used to, in a sense, justify poor health outcomes among populations with unmet social needs, thus potentially masking or perpetuating those health disparities.

Likewise, a 2016 report from the Office of the Assistant Secretary for Planning and Education on "Social Risk Factors and Performance Under Medicare's Value-Based Purchasing Programs" grapples with the complex trade-offs between making providers financially accountable for the health outcomes of at-risk patients:

> If beneficiaries with social risk factors have worse health outcomes **because the providers they see provide low-quality care**, value-based purchasing could be a powerful tool to drive improvements in care and reduce health disparities. However, if beneficiaries with social risk factors have worse health outcomes **because of elements beyond the quality of care provided, such as the social risk factors themselves**, value-based payment models could do just the opposite. If providers have limited ability to influence health outcomes for beneficiaries with social risk factors, they may become reluctant to care for beneficiaries with social risk factors, out of fear of incurring penalties due to factors they have limited ability to influence. (*Report to Congress: Social Risk Factors and Performance Under Medicare's Value-Based Purchasing Programs*, 2014, p. 7)

In this quote, we see practice of mechanism design at work: value-based care policies are intended to use financial incentives for providers to drive increased efficiency and effectiveness of care practices. Yet if providers are made financially accountable for things that they cannot change - say, the healthcare outcomes for patients with unmet social needs - they are likely to simply turn those patients away, as representing an increased financial risk with little to no opportunity for increased financial reward. Mechanism designer-policymakers remain at odds as

to whether, and to what extent, medical care providers can be pushed to improve care outcomes for "high risk" patients with unmet social needs.

One justification for social-needs-based risk adjustment is that this practice enables a redistribution of funds towards hospitals and providers that treat populations disproportionately facing structural barriers to health. Functionally, this may be the outcome of these policies, but policymakers debate whether this increased funding actually goes towards increased investment in care. Does this mechanism for redistributing money towards higher-risk patient populations actually reach those in need, or is it absorbed by for-profit insurers and healthcare providers?

Additionally, some policymakers argue that risk adjustment is subject to being gamed: that healthcare providers are incentivized to maximize the documentation of risk - and thus maximize the reimbursement for covering high-risk patients - via a practice called "upcoding." This also incentivizes payers to have a "complete" medical record, integrating data from as many sources as possible to most comprehensively document chronic conditions, thus increasing the risk scores. As with closed-loop referrals, the construction of financial incentives attached to high-risk scores instantiates the production of this documentation of risk as an end-in-itself.

In this regard, the practice of risk adjustment threatens to make the production of SDoH data into a primarily actuarial practice: rather than collecting data about unmet social needs to address those needs through revised care practices, SDoH data are collected to displace financial accountability away from the provider or insurer. In this regard, the collection of SDoH data for risk adjustment purposes may serve as a driver for "predatory inclusion" (McMillan Cottom, 2020; Seamster & Charron-Chénier, 2017), through which marginalized populations are subject to intensified datafication for the financial benefits - increased reimbursements from insurers, or decreased accountability for costs - that can be derived from this construction of difference. Rather than expanding the number of actors accountable for unmet social needs or expanding the domain of investment or practices devoted to meeting unmet social needs, through risk adjustment practices, SDoH data may help stabilize and reproduce these unmet social needs as beyond the domain of accountability for healthcare providers and insurers.

Community Information Exchange (CIE)

As the previous two examples illustrate, the incorporation of SDoH data into healthcare payment models is a major driver for data sharing between the worlds of "medical care" and "social care." Specifically, insurers and healthcare providers have a financial interest in the

production of metrics and measurements - such as documentation of closed loop referrals, or information about social needs which can be integrated into risk-adjustment formulas - that social care organizations can provide.

In my fieldwork at health data conferences and in policymaking and health IT spaces, there was often intense discussion about how to build out the data infrastructure to enable interoperable data exchange between the worlds of medical and social care providers. Technical and governance efforts to improve interoperability, both between medical and social care and between the sprawling, fragmented world of social care organizations are typically called "community information exchange", or CIE. Many of these conversations revolved around addressing two key barriers: first, social care organizations' lack of trust in medical care organizations, and the dire lack of resources - including staffing and technical skills - within social care organizations to support data collection and exchange.

In this way, the boundaries between the domains of medical and social care, constructed and maintained over centuries, manifests as a set of socio-technical barriers in the exchange of information between these two domains. Building bridges between these two domains is, in fact, perhaps the core impetus for the "social determinants of health" framework. Dating back to the 1960s, healthcare practitioners and public health advocates sought to grapple with the limited impact of merely providing biomedicalized forms of treatment to patients and populations grappling with larger structural conditions like the lack of food, water, or housing (Irwin & Scali, 2007; Lucyk, 2018). These advocates worked under various terminologies and banners before the language of SDoH took hold in the early 2000s, but consistent throughout this work is an effort to increase "intersectoral collaboration" between the fields of medical and social care.

Yet within contemporary efforts to enact this kind of "intersectoral collaboration" through SDoH data exchange, we can see the persistent structural barriers between these two domains. **Techno-solutionist models which seek to address these barriers *through data exchange alone* do nothing to address the problems of unequal power, differential missions and values, and unequal resources between these two sectors.**

Reflecting on this dynamic, a 2021 report by the advocacy organization *Health Leads* explores the flow of power, money, and data resulting from SDoH interventions (Faustino et al., 2022). The brief report draws on a workshop conducted with stakeholders including health systems, government, community-based organizations, and technology vendors. The report,

"Who Has the Power? An Analysis of Where Power Lies Within SDOH Interventions," emphasizes that healthcare systems, technology vendors, and government agencies have far more power and financial resources than community-based organizations. As a result, the partnerships formed between health organizations and social care organizations are inequitable, largely shaped by the needs and requirements of healthcare systems, insurers, and the state, rather than the needs of the community-based organizations and the communities they serve.

Other research points to the rise of a *for-profit SDoH industry,* centered around organizations which are better positioned to meet the data demands of healthcare systems and insurers. This SDoH market has been valued at $18.5 billion in 2021, roughly the same size as the U.S. telehealth market (Bettencourt et al., 2023; Goldberg et al., 2024). Some social care leaders have expressed frustration that these for-profit organizations, better equipped to meet the datafied business demands of Medicare/Medicaid, are able to absorb capital flows and partnerships over systematically under-funded CBOs (Thomas, 2022). Yet the alternative is problematic as well: some community-based organizations find themselves reconfiguring their practices and organization structures to better meet the demands for SDoH data and payments from Medicare and Medicaid. One 2018 study demonstrated how Massachusetts CBOs adopted increasingly medicalized practices in order to attract new streams of Medicaid funding for addressing SDoH, including hiring clinical staff and adopting clinical language for non-medical work (L. A. Taylor & Byhoff, 2021).

In my fieldwork, I saw how CIE advocates have sought to grapple with the imbalanced resources and power between medical and social care domains. I closely followed the Michigan Community Information Exchange advisory committee, which has sought to develop governance supporting SDoH data exchange between healthcare and social care. This group, led by employees within the Michigan department of Health and Human Services, is well aware of the unequal power-dynamics around SDoH data exchange.[25] In an August 2024 conversation with several members of the advisory committee, they shared their struggle to concretely overcome the power and interests of the healthcare industry:

[25] The 2023 "Michigan Community Information Exchange (CIE) Task Force Final Report" quotes the organization ReCODE, about community data sharing in other states: *"Until data systems are overseen and owned by community, the systems who have power over these data ecosystems must begin to share and cede power back to that community."*

> *Healthcare tends to take up too much space, and tends to kinda push people around with their money…and yet, they do have money? There isn't an obvious social care counterpart that's gonna have those dollars…But our workgroup just wanted to make sure we aren't starting with healthcare, but are starting with the community based organization experience.*

For this workgroup within the Michigan CIE advisory committee, they sought to explicitly focus on the needs and goals of CBOs - including "sustainable funding", increased financial resources. Yet this leads back to the contradiction, reflected in this interviewee's quote above; the primary source of funding to advance information exchange among social care providers is from healthcare… *"and yet, they do have the money?"* Trying to achieve data exchange on equitable terms seems like a circular path, leading these policymakers back to the fundamental problem of unequal power and resource allocation between the two industries.

Rather than presenting a partial *solution* to the problem of increasing coordination and collaboration between social and medical care, interoperable data exchange is a site where the fundamental inequities between these two domains are resurfaced and re-produced. This raises important questions for those attempting to build and develop CIE infrastructures: to what extent can SDoH data exchange enable or extend investment, funding in, and support for social care - versus redirecting or reshaping social care to look more like medical care? Focusing on data exchange without addressing the differences in power, resources, and values between health and social care threatens to reproduce the divisions between these domains, rather than to resolve them.

(Re)locating Accountability for Care through SDoH Data

The panelist mentioned at the beginning of the chapter described feeling like SDoH hubs continue to solve "problems that shouldn't exist," and the need for solutions targeted further "upstream." As it turns out, the upstream/downstream metaphor is central within discussions about SDoH initiatives. In their widely cited 2019 article, 'Meeting Individual Social Needs Falls Short of Addressing Social Determinants of Health", Castrucci and Auerbach included a diagram to illustrate this "stream" of social intervention.[26] The authors specifically argue against

[26] This subsequent publication from the CDC includes a modified version of this same stream graphic. https://jphmpdirect.com/cdcs-approach-to-social-determinants-of-health/ mom

pretending that new initiatives by hospitals and insurers to meet individual unmet social needs - for instance, to pay for food, or offer transportation - meaningfully address "upstream" causes of ill-health. They argue that "words matter":

> If we, even inadvertently, imply that social determinants of health can be solved by offering Uber rides to individual patients or by deploying community health navigators, it will be challenging, if not impossible, for public health advocates to make the case for proven policies like alcohol sales control, complete streets, and healthy food procurement.

This quote emphasizes that interventions introduced in medical contexts to address immediate social needs should not be conflated with addressing larger structural unmet social needs. As Castrucci & Auerbach emphasize, the issue is not necessarily that social care issues are being taken up within medical domains: the threat is of rendering these medicalized, individualized interventions as *sufficient* to address the problems of SDoH. This argument echoes Melissa's frustration with the interpretation of "closed loop referral" metrics: that a closed loop referral should not be mistaken for evidence that social needs are being met.

Throughout the implementation and enactment of SDoH data infrastructures, we see a consistent threat: that of invisibilizing "upstream", structural problems of unmet social need. Through the techno-solutionist and market-solutionist practices, upstream problems are rendered tractable within healthcare payment models and data collection practices. Structural failures to fund housing, food, and social care are rendered as an *individual problem* recorded within an individual patient's EHR record. While the "social determinants of health" framework is motivated by a need to highlight and address structural inequities that exist beyond the domain of healthcare, particular implementations *SDoH data* threaten to re-convert these structural factors into individual, medical concerns.

To that end: what role *can* SDoH data play in addressing "upstream" issues of resource allocation? Melissa hints at this role, as quoted in chapter 1: *"I need to keep track of the needs that cannot meet, because I need that data so that I can demand something different from the people who have money and power and make decisions."* For Melissa, the role of data is to document *unmet need,* and to use this data to help address the lack of "political will" to ensure that basic needs for food and housing are met.



Figure 4.2 "Social Determinants of Health and Social Needs: Moving Beyond Midstream" (Castrucci & Auerbach, 2019).

In 1985, at a conference convened by the Rockefeller Foundation, "Good health at low cost", the public health scholars and activists which helped to set the state for the social determinants of health framework assessed how China, Costa Rica, Sri Lanka, and the Indian state of Kerala had been able to achieve improved health outcomes and improved health equity, with relatively minor investment of resources. One analyst pointed specifically to 'five shared social and political factors' which were shared among these sites: *"Historical commitment to health as a social goal; Social welfare orientation to development; Community participation in*

decision-making processes relative to health; Universal coverage of health services for all social groups (equity); Intersectoral linkages for health." (Irwin & Scali, 2007).

In short, these sites were characterized by a shared political will - to use Melissa's own terminology - to social welfare, and to universal coverage and addressing health inequities. The uptake of the social determinants of health framework - particularly in the period of 2020-2024, in conjunction with broader efforts across the country to grapple with structural and racialized health inequities - seems to reflect a movement towards building this political will. The continued insistence on focusing on "upstream" solutions, reflected in the panelist's comments at the start of this chapter, likewise points towards a robust political commitment to addressing the causes of health inequity. Yet as this chapter explores, the datafication of SDoH often runs counter to this political movement to expand accountability for persistent health inequities. Rather, SDoH data is subsumed within structures of market- and data-solutionism, and actuarial practices which displace accountability for social inequity.

In the final chapter, I will reflect more on the role of health data infrastructures in enabling demands for health equity and justice.

Chapter 5 "A Bridge to Nowhere": Prior Authorization and the Possibility of Non-Reformist Design

While the previous chapters have sought to uncover the techno-solutionist and market-solutionist politics of "computing care" operationalized within emerging interoperable data policies, this chapter specifically explores what it might look like to challenge the politics of computing care and instead advance or propose interventions rooted in values of data- and design-justice. As automated decision-making and data-driven business models become increasingly prevalent within public sectors like healthcare, transportation, housing and agriculture, frameworks which help identify and mitigate the structural harms and inequities of technological systems are increasingly crucial. Within HCI scholarship, a growing body of work points to the importance not only of "data ethics," or mitigating bias and harm within specific datasets or algorithms, but of "data justice," which calls us to challenge the power inequities and structural harms within broader sociotechnical systems (Costanza-Chock, 2018; D'Ignazio & Klein, 2023). Related scholarship explores how the feminist practice of "refusal" can inform designers and technologists, including via the generative, creative aspects of refusal (Garcia et al., 2020). This chapter seeks to contribute to this growing practice of data justice, specifically as it relates to health data infrastructures in the U.S.

Through a case study of policies focused on automating the information flows behind prior authorization, this chapter explores what it looks like to move towards more systemic or structural forms of data justice - including the very real difficulty of balancing immediate harm reduction with long-term systemic change. This chapter specifically explores the framework of "non-reformist reform," initially outlined by social theorist Andre Gorz (Gorz et al., 1967) and developed and advanced primarily by prison abolitionists. The framework of non-reformist reform help describe the creative challenge of identifying small, actionable steps towards systemic change (Akbar, 2022-2023; Ruth Wilson Gilmore, 2007) or at least, to identify ways to reduce immediate social harms without perpetuating inequities and injustice.

As a case study in non-reformist reforms, this chapter critically examines emerging efforts to automate prior authorization, a process whereby insurance companies determine whether a treatment or service is "medically necessary" before agreeing to cover it. Prior authorizations are intended to mitigate rising healthcare costs - but mounting evidence of the harm caused to both patients and providers has made it the subject of reformist interventions by state and federal regulators. This chapter argues that the automation of prior authorization may have a short-term harm reduction impact - but nonetheless extends and reproduces larger systemic harms and inequities. Specifically, I argue that the automation of prior authorization helps to extend insurance companies' power to control care in ways that are fundamentally extractive. I apply the framework of non-reformist reforms to help imagine alternative, incremental changes that would help reduce the immediate harms of prior authorization without extending the power of insurance companies over care.

The reformist reform framework can also help us to think critically about how techno-solutions, such as value-based care or SDoH data collection, can in fact, contribute to some immediate reduction in immediate harm, while also expanding a larger system of extraction, austerity, and structural violence. I find this framework useful both for analyzing the specific phenomenon of "computing care", and - more broadly - a useful framework for designers and technologists looking for ways to advance design justice, particularly in the face of intensified datafication and automation in public sectors and industries. I point towards theories and practices of abolitionist activists and scholars as a powerful resource for thinking about creative ways to seed alternative futures within our work today.

This chapter proceeds as follows. I first review frameworks proposed in HCI and critical data studies literature that highlight the limits of proceduralist approaches to "ethics," and point towards the necessity of both technical- and non-technical practices that grapple with the structural violence of overall systems. I then provide a brief overview of the 24+ months of qualitative fieldwork on the datafication of the U.S. healthcare industry from which the current case study is drawn. I then move into the case study itself, providing a detailed overview of the intent and impact of prior authorization as a mechanism of rationing care - and the intent and likely impact of technological reforms to this system. This overview lays the groundwork for my evaluation of prior authorization as part of a fundamentally unjust, extractive system - and its proposed automation as a kind of reformist-reform. I then provide four proposed tenets of non-

reformist design to help think through how else the immediate harms of prior authorization might be addressed without reproducing the injustice of the current system for adjudicating "medically necessary care." I conclude by exploring how non-reformist reforms can help inform the work of design, particularly given the inherent conservatism of fixes rooted in improved "user experience" and technological efficiency.

From Data Ethics to Data Justice: Frameworks for Systemic Change Through Design

Within critical data studies and feminist HCI scholarship there have been multiple frameworks introduced to distinguish between design practices that are largely conservative - in the sense that they are averse to change or preserve traditional institutions - and those that more fundamentally challenge an overall system. D'Ignacio and Klein, for instance, contrast *data ethics* as a framework that "secures power" by "locat[ing] the source of the problem in individuals or technical systems" with *data justice* as a concept that challenges power differentials and "work[s] towards dismantling them" (D'Ignazio & Klein, 2023). Green and Viljoen (2020) point to a similar distinction in Dunne and Raby's foundational framework of "critical design":

> Design can be described as falling into two very broad categories: affirmative design and critical design. The former reinforces how things are now, it conforms to cultural, social, technical and economic expectation. Most design falls into this category. The latter rejects how things are now as being the only possibility, it provides a critique of the prevailing situation through designs that embody alternative social, cultural, technical or economic values. (Dunne & Raby, 2001, p. 58)

In a poignant caricature of this distinction between the type of framework that 'reinforces how things are now' and one that 'provides a critique of the prevailing system," Keyes, Hutson and Durbin (2019)outline a proposal for a "fair," "ethical" algorithmic system for targeting elderly individuals for processing into a "high-nutrient slurry". After walking through a detailed and thorough procedure for ensuring a more ethical algorithmic system - including input from salient stakeholders - the authors suggest that "sometimes the problem is not how the sausage gets made, but that they're making people into sausage" (Keyes et al., 2019, p. 7).

Green and Viljoen suggest that Andre Gorz's schema of "reformist" versus "non-reformist reforms" likewise helps to describe this split between affirmative and critical design, or between data ethics and data justice:

> While a reformist reform "subordinates its objectives to the criteria of rationality and practicability of a given system and policy," a non-reformist reform "is conceived not in terms of what is possible within the framework of a given system and administration, but in view of what should be made possible in terms of human needs and demands. (Green & Viljoen, 2020, p. 26)

Refusal & Abolition as Generative

A related thread of literature explores how designers and data professionals might respond when called to build systems that, metaphorically, are making people into sausage. These scholars point towards the feminist, abolitionist practice of "refusal" (Garcia et al., 2022). Broadly, "refusal" looks like the individual and collective tactics that users and designers employ to step outside of the prescribed "problem frame" of fundamentally extractive and unjust systems. As Barabas summarizes, "In its most potent form, refusal operates as a framework for renegotiating the terms of engagement"(Barabas, 2022). For data professionals and designers immersed in discourses of responding to these injustices through increased access, inclusion, or transparency (James et al., 2023), "refusal" looks like side-stepping the imperative to improve these existing technical infrastructures and systems (Hoffmann, 2021). Users and those directly impacted by harmful data systems can also practice refusal; Zong and Matias powerfully argue that users' practices of refusal should also be understood as a kind of design-practice (Zong & Matias, 2023).

The framework of refusal as articulated within critical data studies and feminist HCI literature explicitly draws from abolitionist scholarship, including Ruha Benjamin's "Race After Technology: Abolitionist Tools for the New Jim Code" (2019), and from abolitionist geographer Ruth Wilson Gilmore. Central to abolitionism is the idea that abolishing prisons and policing is not simply about destroying current carceral systems, but an imaginative and generative practice of building alternative forms of safety and care. Refusal, likewise, is understood as a "strategic and generative act" (Barabas, 2022).

Non-Reformist Reforms as a Practical Framework for Data Justice

Seeking to expand our theoretical and practical capacities for "doing" refusal - doing data justice - this chapter takes up the framework of "non-reformist reforms," specifically as developed by abolitionist scholars and activists. Every day, prison and police abolitionists

struggle to identify paths forward for addressing the immediate harms of mass incarceration - over 1.9 million people being held in cages in the United States alone (Sawyer & Wagner, 2024) - and racist and violent policing. Especially when it comes to collaborating with lawmakers or the non-profit industrial complex, it can be particularly difficult to do this harm reduction work in ways that are not reformist: "Unfortunately, many remedies proposed for the all-purpose use of prisons to solve social, political, and economic problems get caught in the logic of the system itself, such that a reform strengthens, rather than loosens, prison's hold" (Ruth Wilson Gilmore, 2007, p. 242). For instance, immense efforts are being made by organizers in the New York City area to close the Rikers Island jail, which has been the site of sensational abuse, scandal, and violence. Yet the state's proposed path for closing Rikers involves opening four new jails across the City (Rubinstein, 2024): a troubling but extremely common example of the ways that efforts to reduce the harms of prisons and policing often reproduce prisons and policing in new ways.

This problem is likely familiar to anyone who has ever attempted to make change within any kind of institutional system or structure: what incremental changes are possible today that do not reproduce the very same problem we are trying to solve? How do we differentiate between reformist reforms and non-reformist reforms? In what follows, I analyze proposed efforts to automate prior authorization through the lens of non-reformist reforms, providing a concrete example of what it looks like to apply this framework to emerging data- and technology-driven reforms of harmful and extractive systems.

Method

The findings presented in this chapter emerge primarily from three different sources. First, I draw from fieldwork at a two-day workshop, hosted in summer 2024 by a national health informatics professionals association following the release of the final prior authorization regulations earlier in the year. This workshop explicitly focused on exploring the impact and implications of these new prior authorization regulations and included around 200 attendees and presenters from federal regulatory bodies, health insurance organizations, healthcare provider organizations, national advocacy organizations (such as the American Medical Association), and a wide variety of technical and administrative vendors implicated in the prior authorization process. I also did follow-up interviews with several event attendees in the weeks following the event.

Additionally, the findings outlined here draw from a close analysis of the Center for Medicaid & Medicare Services (CMS) Interoperability and Prior Authorization Final Rule (CMS-0057-F), released in January 2024, as well as the public comments and industry coverage about this regulation and previous proposed rules (released in December 2022 and December 2020). I also draw from technical documentation for updated data exchange standards that are referenced in these regulations. This approach draws from a Critical Technical Discourse Analysis (CTDA) method (Brock, 2018), and brings together a close analysis of the regulatory and technical artifacts in and of themselves with an articulation of the meaning and intent as understood by their designers and implementers.

These fieldnotes, interview transcripts, and discourse analysis of regulatory, technical, and industry coverage documents were collectively annotated and coded to explore the following research questions:

- What do different actors within the field understand to be the goal or purpose of prior authorization?
- What do different actors within the field (e.g., policymakers, health IT professionals from insurance and healthcare provider organizations) understand to be the goal or purpose of emerging prior authorization reforms, particularly the reforms focused on modernized data exchange via APIs?
- What are the likely impacts of these prior authorization reforms, particularly the forms focused on modernized data exchange via APIs, according to experts within the field?

This analysis surfaced the idea of the "bridge to nowhere" as an analytic that helped to describe both the likely limited impact of these prior authorization reforms, as understood by participants themselves, and what I understood as the gap between the stated purpose or intent of prior authorization (e.g., to avoid extractive, harmful, or exploitative forms of care by providers) and its operationalization (e.g., a demonstrably harmful and extractive gatekeeping of care by insurance providers).

Harm Reduction Through Datafication? A Case Study of Prior Authorization Reforms

This case study explores emerging federal regulations pertaining to prior authorization: a bureaucratic process whereby insurance companies require review and approval for coverage of certain procedures or treatments. This bureaucratic gatekeeping is intended to mitigate the use of unnecessary, unsafe, and/or unnecessarily costly medical interventions. Yet this process has been

demonstrated to cause harm to patients via delayed care, or coverage rejections for needed care - and to create additional administrative hurdles for already overstretched healthcare providers. As a result, prior authorization has been the target of widespread criticism from groups like the American Medical Association, and legislators have called for federal reforms to prior authorization to reduce the burdens of this process for both providers and patients.

The typical prior authorization workflow involves a doctor recommending a treatment to a patient; the provider organization will then check to make sure that this treatment will actually be covered by the patient's insurance. Some treatments are not covered at all, while others require the provider to first provide documentation to the insurance company about the “medical necessity” of this specific treatment. This documentation is reviewed, variously, by medical practitioners employed by the insurance company - sometimes from the same field of medicine, sometimes not - or by a third-party firm. Medical necessity is often determined by pre-written policies following industry “best practices” - though a common complaint among providers and patients is that these standardized policies do not account for the wide variation in human lives and illnesses, and the medical discretion a provider uses when attempting to treat a real patient, not a “standard” patient.

Even if coverage is approved, this process requires significant documentation labor by the provider organization and often introduces weeks-long delays in receiving medical treatment. Sometimes, a claim is outright denied, and a provider and patient must either choose an alternate course of treatment or begin the appeals process, introducing further delays to treatment. Sometimes, the insurer may request additional documentation before they make a decision. Other times, an insurer may require the patient to first try a less costly or more "traditional" form of treatment and demonstrate that this treatment is unsuccessful, before they can be approved for the treatment suggested by the provider originally.

Prior authorizations essentially function by introducing "friction" into the utilization of higher-cost forms of care: it is a soft barrier rather than a hard wall. But these frictions can be life-threatening. One recent study of 178 patients with cancer found that 73% reported a delay of 2 or more weeks, and 22% did not receive the treatment recommended by their doctor due to prior authorization denials/delays (Chino et al., 2023). An interview with radiation oncologists about the impacts of prior authorization highlights the impacts of these delays for cancer patients (Marshall, 2024): a 21-year old patient with a rare tumor was recommended for surgery paired

with a new form of "proton therapy." During the year-long delay waiting for the new form of treatment to be approved, the tumor came back, and the patient ultimately needed a tracheostomy and a feeding tube. This patient's doctor is quoted as saying, "Unfortunately for this patient, it went from a potentially curable situation to a likely not curable situation… I wanted to cry every day that she waited" (Marshall, 2024).

Rapidly growing cancer is one of the more dramatic examples of the impacts of prior authorization on patients - but the slow train-wreck that many chronically ill patients experience is just as troubling. Often, patients report needing to go through the same battle over treatments multiple times per year, such as when a prescription gets refilled or when they change providers, or when insurance companies tweak their plans. Prior authorization also impacts healthcare providers; a recent survey by the American Medical Association found that physicians and their staff spend an average of 12 hours each week completing prior authorization documentation, and 95% of physicians responded that prior authorization "somewhat" or "significantly" increases physician burnout (*2023 AMA prior authorization physician survey*, 2024).

Responding to concerns about the harms of prior authorization, the federal government has recently taken steps to reduce the burden of prior authorizations on patients and providers. In March 2024 the Center for Medicare and Medicaid (CMS) released new regulations requiring insurance companies who manage federal plans such as Medicare Advantage to modernize the data infrastructure behind their approval processes and provide greater transparency about their decisions to patients, providers, and the federal government, and reducing the time that insurance companies have to make a decision (e.g., from 14 to 7 days, depending on the type of decision).

These interventions are described under the banner of "burden reduction": that is, reducing the burden of prior authorization processes for healthcare providers and patients through transparency and improved efficiency in the review process. Importantly, the provisions updating the data infrastructure behind approval processes are explicitly meant to be a step towards enabling the automation of these decision-making processes. Currently, the prior authorization workflow is largely carried out via the exchange of faxes or digital documents between providers and insurers. These new regulations require insurance companies to develop APIs through which the necessary information can be exchanged in a more granular way, and in real-time. Automated information exchange and decision-making via APIs is understood as the "north star" in terms of reducing the burden of prior authorization.

These changes will not fully go into effect until 2027. As of 2025, health IT professionals and executives within both payer and provider organizations are assessing how these regulations will impact their workflows and data infrastructures. As I explore further in the following sections, many health IT professionals and health executives charged with implementing these changes are skeptical that these data modernization requirements will have the intended effect of harm reduction and burden reduction for patients and providers, with several describing their work as building a bridge to nowhere. The following case study outlines in more detail the overall design problem that the federal government is intending to solve through datafication and automation and sets the stage for evaluating how a non-reformist reforms framework might help us to avoid building a "bridge to nowhere."

This case study is broken into three sections, outlining:

- How prior authorization works currently, and its intended purpose in managing "low value care";
- How regulators imagine datafication and automation as a tool to reduce the harm/burden of prior authorization processes; and
- Why these automation/datafication efforts are understood as a "bridge to nowhere" by some health IT professionals.

The Goals of Prior Authorization: Insurance Companies as Managers of "Low Value Care"

Regulators' and insurance companies' stated rationale for prior authorization is to reduce "unnecessary" or "wasteful care." Under a typical fee-for-service model, the more treatments and interventions a doctor provides, the more money a healthcare organization makes. To mitigate unnecessary treatments and interventions that benefit healthcare providers financially but do not have a big impact on patients' health outcomes, insurance companies identify certain procedures and treatments that require a doctor to demonstrate "medical necessity" before they agree to cover the treatment. A typical insurance policy outlines which kinds of services or treatments are covered or not, and which require prior authorization and/or a "co-pay" by the patient - another mechanism intended to mitigate "unnecessary" and costly forms of care. Some services or treatments are conditionally covered, if the provider can provide a proof or rationale that it is needed. Prior authorization may be required, for instance, in cases of expensive surgical procedures or for the use of non-generic medications when a generic is available. Additionally, prior authorization requests submitted by a provider do not just yield a yes/no response: often the

insurer requires the provider to first try less costly interventions, called "step therapy," and then demonstrate the failure of those interventions before they can get approved for the more costly intervention.

Prior authorization is intended to reduce what insurers describe as "low value care": that is, costly or unnecessary care with a relatively low "return on investment" in terms of improved patient health. Broadly, prior authorization reduces costly care in a few different ways. First, through outright rejections, insurance companies effectively require patients to pay for treatments themselves, or to seek other, less costly forms of treatment. Second, by introducing time-consuming prior authorization requirements, insurers are able to deter providers from using more costly interventions, even if those interventions are likely to be approved given proper documentation from the provider. This is known as the "sentinel" effect (Gupta et al., 2024). Finally, by introducing friction into the process, there is a significant amount of attrition around more costly forms of treatment. For instance, patients may not be willing to pursue time-consuming step therapy treatments. Additionally, there is evidence that while only a small fraction of denied prior authorization requests are appealed, a high number of those appeals are ultimately approved (Biniek et al., 2024). This suggests that the cause of these denials is simply to deter the use of costly care interventions, regardless of their "medical necessity."

The use of prior authorization by both private insurance companies and public programs such as Medicare and Medicaid has expanded significantly since its introduction in the 1980s (Institute of Medicine (US) Committee on Utilization Management by Third Parties et al., 1989), and has recently become a site of increased political contestation and scrutiny. Organized medicine, including the American Hospitals Association and the American Medical Association, has pushed back about the time-consuming paperwork and delays to care that current prior authorization workflows entail, with negative impacts on both patients and care providers. In a 2023 survey of 1,000 practicing physicians, the AMA found that 56% reported that issues in the prior authorization process sometimes led to patients abandoning a recommended course of treatment, while 19% of physicians reported that prior authorization had led to a patient's rehospitalization (*2023 AMA prior authorization physician survey*, 2024). Responding to these concerns about the impact on patients and providers, states and the federal government have sought to reform prior authorization. The next section outlines the goals and values articulated through these specific reforms.

The Goals of Prior Authorization Reform: "Burden Reduction" Through Datafication, Automation

Over the past few years, prior authorization has been a target of significant reform at both the federal and state levels. Many of these interventions are focused on modernizing the prior authorization workflow in order to increase its efficiency and reduce the administrative burden on patients and providers. In June 2023, 233 representatives and 61 senators signed a letter advocating for CMS to finalize prior authorization reforms that include "a mechanism for real-time decisions" (United States Senators (undersigned), 2023). The Senate letter notes that "the health insurance industry has been actively working towards real-time decisions through automation and artificial intelligence from end-to-end" (p.2) - emphasizing that "end-to-end" automation would be central to providing relief for the harms of prior authorization.

In December 2022, the Center for Medicare and Medicaid Services (CMS) released a proposed rule, "Advancing Interoperability and Improving Prior Authorization Processes," for public comment and feedback. This proposed rule outlined potential requirements for payers to build APIs enabling the more seamless exchange of information between providers and payers about prior authorization requirements, requests, and documentation. As of 2023, 37% of the information sent by medical plans for the purposes of prior authorization was relayed manually, via phone, fax, email, or mail (*The 2023 CAQH Index Report*, 2024). Fig. 5.1 provides a basic overview of the discrete information transactions involved in the prior authorization workflow.)

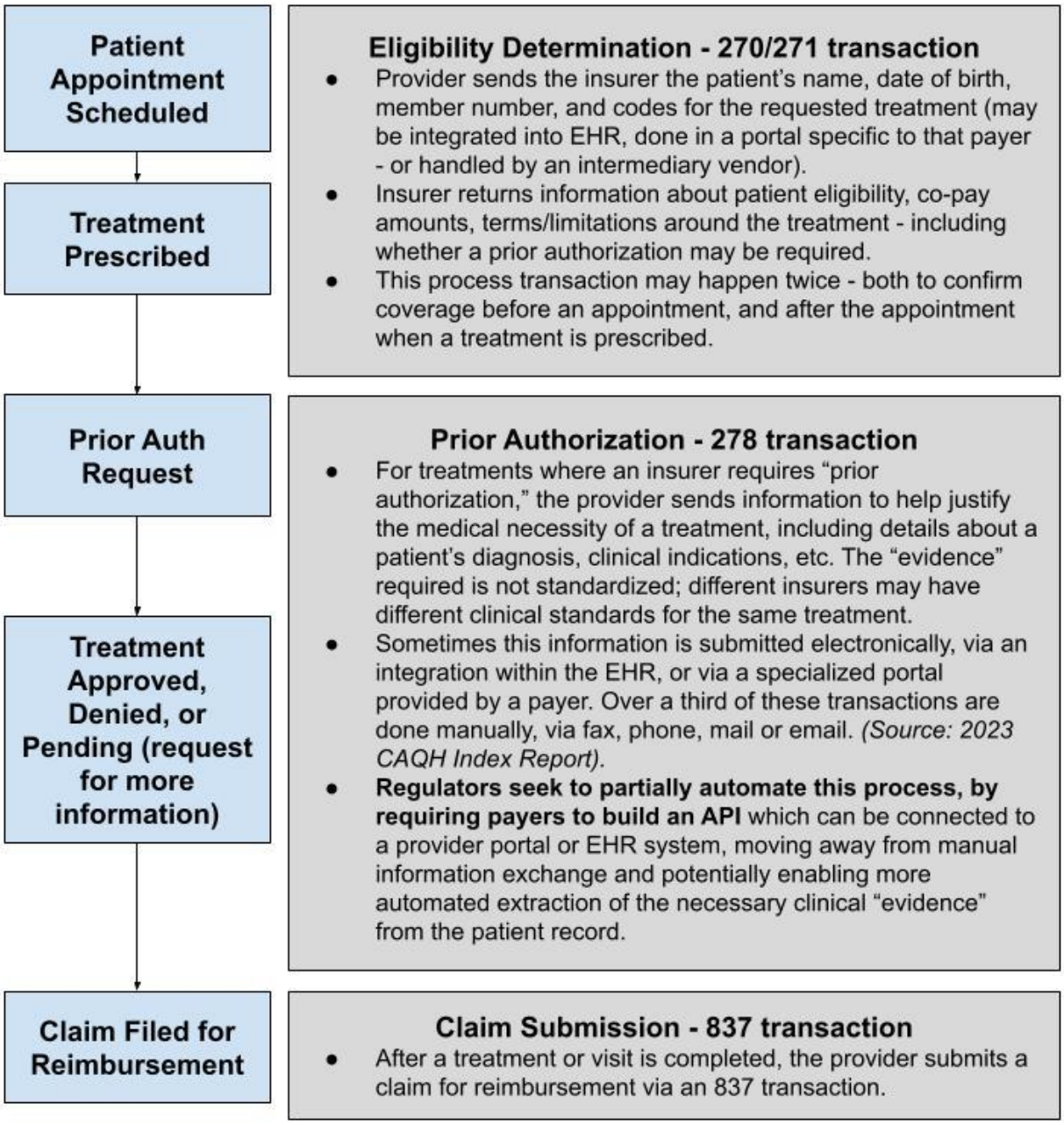


Figure 5.1 Overview of the discrete information transactions involved in the prior authorization workflow.

CMS' final rule, released in January 2024, also includes new requirements for insurance companies beyond data modernization that are intended to reduce the harm of prior authorization (Advancing Interoperability and Improving Prior Authorization Processes, 2024). The final rule also attempts to increase the transparency and accountability for prior authorization practices by requiring insurers to provide providers and patients with a reason for prior authorization denials, and to publicly post summary metrics about their use of prior authorization. These regulations

also reduce the time frame allowed for insurers to respond to prior authorization requests, e.g., from 14 to 7 days for non-expedited requests. Overall, these regulations do not challenge insurance companies' right to determine what is or is not "low value" or "medically necessary" care. CMS sees the prior authorization "problem" as a user experience issue: a matter of "burden reduction." Through data modernization requirements, they seek to improve the user experience and mitigate the harms of prior authorization to patients and providers through faster, more scalable forms of data exchange and automation.

In summer 2024, a national health IT professionals organization held a two-day workshop dedicated to exploring the impact of emerging prior authorization regulations. Speakers included federal regulators and standards-makers responsible for developing these regulations - as well as executives and data professionals from insurance companies, healthcare provider organizations, and a wide range of intermediary vendors involved in the prior authorization workflow.

At this workshop, attendees were presented with a success story about the potential impact of improved data infrastructures for prior authorization. A technology executive from a provider organization shared a story about their close collaboration with an insurer to implement automatic, API-based prior authorization requests. The health provider executive described how doctors in her organization reacted to the faster, more automated prior authorization process, which allowed them to get nearly real-time responses to their prior authorization requests. She cited statistics about the reduced hours of labor required, described how providers in her organization called this the "easy button" - and cited requests from doctors and nurses to route more of their workflow through this new "easy button."

This user experience success story was intended as a motivational example for the other healthcare data executives and professionals in the room about the potential positive impacts of increased automation and real-time data exchange around prior authorization. Yet following this demo, much of the subsequent panel discussion revolved around whether this success story was realistic for other organizations with fewer resources or different business models. Many in the room were skeptical that they could ever replicate the experience of the "easy button." The next section explores the many critiques and concerns that health data professionals raised about the kind of impact that these data-modernization efforts would have in terms of reducing provider burden.

“A Bridge to Nowhere”: Health Data Professionals' Perspectives on Prior Authorization Burden Reduction

During this two-day workshop for health industry executives and data professionals, many described how complying with these regulations felt like building a “bridge to nowhere.” They cited numerous organizational and technical barriers that would reduce the likely positive impact of these regulations. One major common concern pertained to the limited scope of these regulations, which only apply to a few specific types of federally funded insurance plans, and which only apply to decision-making around medical services, whereas the overwhelming majority of prior authorization requirements pertain to pharmaceuticals.

Professionals also highlighted the large number of different actors that would have to collaboratively move in sync to achieve an improved user experience, many of whom are outside of the direct purview of these regulations. These intermediaries include the vendors that support prior authorization on both the provider and insurer sides, and the electronic health record companies that would be the primary interface for providers seeking to find information about prior authorization requirements or submit a prior authorization request. Significantly, provider organizations are not required to adopt API-based information and PA requests, and providers said that they were reticent to build out new information infrastructures until they saw clear return-on-investment in terms of significantly reducing the burden of prior authorizations. This, they pointed out, would largely rely on the benevolence of insurance companies in going above and beyond simple compliance to try to more intentionally reduce the burden of prior authorization by responding in real-time, or enabling the use of API interfaces across all their lines of business, not just the federally funded programs. In this regard, both ends of the intended information “bridge” were skeptical about the other side.

A button (Fig. 5.2) distributed at this workshop emphasizes the idea that improved data exchange via APIs can help rectify the tensions and conflicts around prior authorization. The button says, "PRIOR AUTH PEACEMAKER," and depicts a cat in a white coat and boxing gloves - presumably a healthcare provider - swinging at a dog in a suit - perhaps representing the insurance company or other intermediary vendor. The dog, smiling, absorbs the cat's blows. This obviously silly button nonetheless gives insight into the mental model of some in the room: that the conflict over prior authorization can be defused through new information infrastructures that

make the process more seamless for providers. Regulators construe modernized data exchange via APIs as the technical fix for the conflict over who gets to make decisions about care.



Figure 5.2 A "Prior Auth Peacemaker" pin distributed at a workshop on emerging prior authorization reforms attended by health data professionals.

Yet many of the health data professionals within this workshop, from both payer and provider organizations, expressed deep reservations about the ability of these reforms to the data infrastructures underlying prior authorization to make a meaningful impact on the lives of patients or overstretched healthcare providers. These concerns were largely about the organizational and technical complexity the reforms required, and the likelihood of failure in a context where change is both immensely expensive and against the immediate financial interests of the companies implementing the changes.

Even if we imagine these complex reforms being implemented seamlessly and with full-throated enthusiasm from the necessary players, through the lens of "non-reformist reforms" we might understand these proposed changes as a “bridge to nowhere” in another sense entirely.

These reforms ultimately reaffirm insurance companies as an appropriate adjudicator of "medically necessary care." Rather than directly addressing the underlying conflict around whether insurance companies' own profitability is the best proxy for ensuring the equitable and responsible distribution of limited healthcare resources, federal regulators seek to act as a "peacemaker" by making insurance companies' control over care decisions less visible and less disruptive through increased automation of the prior authorization workflow. In the next section, I explore how the framework of non-reformist reforms can help us to imagine alternative pathways for reducing the harm of prior authorization, without extending and reproducing the power of insurance companies over care.

Prior Authorization Automation as a Reformist Reform

If we set aside the many operational concerns raised by the health technologists in the room that day, we can speculate that perhaps a widespread "easy button" for prior authorization would help achieve the intended goals of harm reduction: reducing the workload for over-worked healthcare providers and reducing harmful delays in care for patients. However, this easy button solution would also secure, rather than challenge, insurance companies' power to make unilateral decisions about "low value" or "medically necessary" care. Additionally, by reducing the administrative friction of prior authorization, insurers may be enabled to require prior authorization for a broader set of treatments and services. In this regard, prior authorization policies that seek to improve the user experience represent a retrenchment and potential expansion of insurance companies' unilateral power to define "low value care."

Intervening to improve the user experience of prior authorization takes a fundamentally conservative approach to existing power relations. In their messaging about these regulations, policymakers reaffirm that "there is a place for prior authorization" in terms of governing care. The problem-frame, and its solution, is specifically focused on the last mile: fixing the user experience of an existing decision-making system. Important questions remain unasked: is prior authorization an effective design mechanism for reducing "low value" care? By what definition of low-value care? For-profit insurance companies may well have a different definition of "low value care" relative to the patients and taxpayers who both pay for and receive that care, yet the state treats insurers' definitions of low value care as an appropriate proxy for the nation's.

This mechanism for utilization management is not applied to the other major public insurance programs Medicare and Medicaid. Likewise, there is no consistency in the treatments

that require prior authorization across different insurers (Gupta et al., 2024). This suggests that there is not strong consensus or evidence about the effectiveness of this mechanism for managing exploitative or costly forms of care, even across different insurance companies. It makes little sense to build data infrastructures to automate decisions about what kind of care is valuable, given this lack of consensus even among the insurance companies - let alone between the state, patients, providers, etc. I argue that these data governance interventions represent a "bridge to nowhere," not only in terms of technical and organizational barriers described by professionals in the field - but in terms of developing an infrastructure that enables the redistribution of power over decisions about the best way to allocate healthcare resources to patients, rather than to insurance companies interested in maximizing shareholder value.

In the next section, I reflect on the broader implications of this case study for policymakers and designers interested in advancing data justice. I analyze the focus on prior authorization user experience as an example of a "reformist reform," and reflect on the possibility of interventions that would represent "non-reformist reforms," drawing here from terminology advanced by abolitionist and legal scholars. This framework points towards the possibility of designing interventions that both alleviate immediate harms while also building a bridge towards the dismantling of unjust systems.

Having provided an overview of prior authorization, its goals and proposed reforms, the following section explores how we might view these reforms differently through the lens of non-reformist reforms. I then propose four tenets of non-reformist design more broadly.

How Not to Build a Bridge to Nowhere: Refusing Prior Authorization

Ultimately, the introduction of APIs and modernized data infrastructure to move towards automated prior authorization is a push that increases, rather than decreases, the power and control that insurance companies wield over healthcare decisions. While it would potentially improve some patients' and providers' experience with the prior authorization workflow, if successful it may in fact enable insurance companies to further expand the domain of treatments that require prior authorization, further extending insurance companies' domain of authority to determine "low value" or "medically necessary" care.

Abolitionist organization "Critical Resistance" has a rubric to help activists evaluate the difference between reformist and non-reformist reforms (Critical Resistance, 2020). This rubric asks questions like: "Does this reduce the number of people imprisoned?", "Does this reduce the

reach of jails, prisons, and surveillance in our everyday lives?", "Does this create resources and infrastructures that are…accessible without police and prison guard contact?" In the domain of prior authorization, a similar set of questions might look like: "Does this reduce the control that for-profit entities have over the care that a patient receives?" - or, "Does this help ensure that health resources are distributed equitably, and in a way that is collectively decided by people and communities, not corporations?"

Using data infrastructures to improve the efficiency of prior authorization does not meet any of these criteria. However, it is important to highlight that data modernization interventions are only one piece of the prior authorization reforms that have recently been introduced. Other aspects of recent regulations - including limiting the scope of treatments that can be subject to prior authorization - look more like a non-reformist reform, to the extent that they reduce the power and control of for-profit entities and corporations over the distribution of care. Other dimensions of these regulations exist in a kind of gray area, mitigating the harms of prior authorization in ways that do not obviously expand the power or control of insurance companies over care decisions - for instance, by reducing the amount of time that an insurance company has to respond to a prior authorization claim. We might understand these interventions as aligning with Creary's definition of "bounded justice" (Creary, 2021; El-Azab & Nong, 2023): interventions that seek to advance health justice in a context fundamentally structured around social inequity.

Regulators' attempts to mitigate the harms of prior authorization through improved data infrastructures do not call into question the basic premise that insurance companies have a role to play in determining whether proposed treatments are "low value" or "medically necessary." Within the U.S. healthcare system, health insurance companies have been designated as the "check and balance" on overtly extractive or exploitative tendencies of healthcare provider organizations. Yet there is relatively little by way of checks and balances on the extractive or exploitative tendencies of the insurance companies themselves. A more radical kind of "non-reformist reform" would look like abolishing prior authorization entirely, based on the understanding that insurance companies' own bottom line is not a sufficient proxy for determining the most equitable distribution of healthcare resources.

In my fieldwork and interviews, even the most vocal critics of prior authorization were reluctant to suggest that there is no place for prior authorization within our healthcare system.

And yet - the widespread push for prior authorization reforms, including among powerful actors like the American Medical Association, suggests that there is momentum that could be channeled into non-reformist avenues of change. The recent outpouring of public rage in the wake of the targeted assassination of UnitedHealthCare's CEO highlights that there may yet be more broad political support for measures that reduce insurance companies' scope of control over care. Regulations that focus on improving the "user experience" of prior authorization seek to quell, rather than channel, this broad discontent among patients and healthcare workers.

In the remaining sections of this chapter, I move beyond this specific case study to explore how the framework of "non-reformist reforms" helps us to imagine alternative ways to mitigate harm and redistribute power.

Designing Data Justice: Four Tenets for Designing Non-Reformist Reforms

Inspired by abolitionist advocacy organization Critical Resistance's rubric for reformist versus non-reformist reforms, I have outlined below four tenets for non-reformist design, broadly speaking. In the following sections, I briefly reflect on the ways that these tenets echo and amplify themes from existing literature on design justice, abolition, and refusal in the context of critical data studies and feminist HCI.

- Expanding the problem frame
    - Is the problem being located within individuals or technical systems - or within structural power differentials or inequities?
    - Follow the problem "upstream": are we solving a problem that shouldn't exist?
- Expanding the methods or strategies for intervention:
    - Is the proposed intervention working narrowly within the confines of interventions or methods that are currently trendy or fund-able? Or are a broader set of tools and techniques considered?
- Expanding the power of users, marginalized groups
    - Does this intervention increase the involvement of those who are most impacted or marginalized in defining the social good to be achieved and the best mechanism for achieving it?
- Reducing the power of already-powerful actors
    - Does this reduce or lessen the role of already-powerful organizations in defining the social good to be achieved and the best mechanism for achieving it?

- Does this reduce the scope for already-powerful actors to structure, extract, and control data flows?

Expanding the Problem-Frame

Most of the regulators and health IT professionals working on implementing these changes were prepared to evaluate emerging prior authorization reforms within the problem-frame of "improving the user experience." Relatively few questioned the larger goals or values of prior authorization itself, or even whether there was clear evidence of the necessity of prior authorization as a tool for achieving those goals (e.g., reducing "low value care").

Passi and Barocas, in their ethnographic research with a corporate data science team, highlight problem-formulation as a site of extensive normative decision making, often unexamined by data scientists themselves (Passi & Barocas, 2019). Similarly, within the site of prior authorization reform, the problem-formulation stayed within the scope of "user experience" around prior authorization. Designing non-reformist reforms, in contrast, requires a careful investigation of the terms of the "design challenge" itself. Just as focusing on "how can we reduce racial biases in policing?" is a problem-frame that takes as a given that police are a good way to ensure safety in our communities, focusing on improving the user experience of prior authorization is a problem frame that takes as a given that limited care resources are being unnecessarily wasted by providers and patients, and that for-profit insurance companies are a good arbiter of that "waste."

Within HCI scholarship, Dencik, Hintz and Cable (2016) likewise highlight the central importance of redefining the problem frame to the work of data justice. Speaking with social justice activists in the wake of the Snowden leaks, the authors show how privacy and surveillance concerns among the activist community are treated as a discrete techno-legal problem, to be addressed by a subset of experts within the group - rather than considering the implications of data-driven governance more broadly for the possibility of social justice work and activism. They propose the term "data justice" to describe this broader conceptualization of the structural and systemic concerns of data-driven governance.

In a related vein, some of the HCI and critical data studies scholarship introduced earlier highlights the issues that arise when a problem is framed specifically as a *technical* or computational problem. D'Ignacio and Klein (2023), for instance, point toward an inherent conservatism in data ethics approaches that narrowly locate "the source of the problem in

individuals or technical systems." Keyes et. al's article (2019) similarly highlights how simple checklists for fair, ethical, and transparent algorithms are perfectly designed to produce an apparently "ethical" technical process that in no way addresses the fundamentally violent purpose of the underlying system or infrastructure. This brings us to the second tenet of non-reformist design.

Expanding the Methods or Strategies for Intervention

In addition to expanding the problem frame, designing for data justice requires broadening the scope of methods, strategies, and tactics for intervention and problem solving. Legal scholar Amna Akbar, in exploring the possibility for legal professionals to contribute to the development of non-reformist reforms, examines how her own discipline, law, has historically contributed to processes that concentrate power and allocate decision-making to experts - even in cases where they are pursuing a social good (Akbar, 2022-2023). Akbar highlights the critical importance of "horizons beyond legalism." Green and Viljoen (2020) draw a parallel between the limits of legalism for achieving non-reformist reforms and the limits of computational approaches, which tend to re-frame the fluid, complex social problems of the world to make them amenable towards universal, "objective," scalable solutions.

In a similar vein, Ruth Wilson Gilmore explicitly points towards the role of professionalization and funding streams in perpetuating the production of reformist-reforms that adhere to an overly narrow set of interventions which are not fit to make systemic or structural change. She argues that professionalization "has made many committed people so specialized and entrapped by funding streams that they have become effectively deskilled when it comes to thinking and doing what matters most" (Ruth Wilson Gilmore, 2007, p. 242). What might it look like for HCI scholars to move beyond the constraints of professionalization - to put down the hammer for a moment to engage social problems more fully, rather than remaking them into nails?

In "HCI Tactics for Policy from Below," Whitney et. al provide concrete examples of what this might look like. The authors use as a case study their involvement with community-based organizing and advocacy around smart city interventions, and specifically highlight strategies they employed to "attune HCI to the needs and practices of those excluded from power over widespread technology infrastructures" (Whitney et al., 2021, p. 1). They highlight their work interpreting legal and technical blackboxes, in reading documents and in translating

information learned from a hackathon into a policy report. They argue that “solidarity means going beyond the questions that we, our field, or our employers find interesting. It means taking an interest in what others want or need to know” (ibid, p.12), and point towards the necessity of engaging in “forms of political struggle that exceed the limits of project duration, grant funding, and other bureaucratic hurdles common in both industry and academia” (ibid, p.13).

Ruha Benjamin argues that the term "design justice" re-defines justice in terms of that which is institutionally recognizable or rewarded: "by adding "design" to our vision of social change we rebrand it, upgrading the social change from 'mere' liberation to something out of the box, disrupting the status quo" (Benjamin, 2019, p. 179). She suggests that "maybe what we must demand is not liberatory designs but just plain old liberation" (ibid, p.179). Likewise, perhaps a practice of "non-reformist design" should take us beyond what is recognizable as "design."

In the case of prior authorization automation, we see a complex social problem - how do we make decisions about how to allocate care resources? - flattened and constrained, boiled down into a problem that can be solved through the mechanisms of law and computation. Addressing this complex social problem starts with forming alliances with others who seek to solve this problem and finding ways to support their work. For example, it might look like partnering with patient advocacy organizations proposing legislation to eliminate the use of prior authorization. It might look like interviewing patients and providers about the impacts of prior auth workflows - including the impact of "faster" workflows that still end up restricting access to care. It might look like sharing these testimonials with legislators and on social media to catalyze a broader recognition of prior authorization as a fundamentally harmful practice that should be abolished rather than reformed. Of course, this is just an example: the most important "method" of non-reformist design is to become an accomplice to the users and groups harmed by the current system.

Expanding the Power of Users, Marginalized Groups

Whitney et. al’s piece also points towards another crucial aspect of data justice practice: to support, through their methods, the community members who are typically excluded, whether structurally or due to the opacity of technical and legal structures, from decision-making about the data infrastructures that shape their lives. Their interventions as HCI scholars are oriented not

towards fixing a problem for others, but towards providing tools and information that support their more direct involvement and power over those structures (Whitney et al., 2021).

Often, in HCI, we identify user discontent as a problem to be solved through a user experience intervention. But user discontent is also an important signal that perhaps a systemic change is needed, and that there are users, patients, and community members prepared to take action for that change, if they are given the tools and structural power to do so. In this sense, to seek data justice may not be a matter of solving the problem at hand, but of enabling users to have the power to solve the problem themselves.

Akbar suggests that "non-reformist reforms…embrace antagonism and conflict rather than depoliticization and neutrality" (Akbar, 2022-2023). In the case of prior authorization regulations, we see widespread discontent among providers and patients about the harms of insurance companies' intervention into decision-making about "medically necessary care." This seems to present a valuable entry point for dialogue and organizing around the structural power that insurance companies wield in determining the optimal distribution of care resources, and for examining how patients can have more power over these decisions.

Expanding the power of users to make their own decisions is an approach that takes seriously the maxim, "nothing about us without us" (Harbord et al., 2021; Spiel et al., 2020) - not in the sense of "inclusion" or "participation," which may often involve marginal or performative roles for users - but in terms of changing the structures of power. In the case of prior authorization governance, for instance, perhaps the important design challenge is to ask how people could be more involved in defining the social good and the best mechanisms for achieving it - that is, how do we ensure that there are enough care resources, equitably distributed? How do we minimize treatments given for the sake of profit rather than care?

Reducing the Power of Already-Powerful Actors

Hand-in-hand with the need to expand the power of marginalized users, data justice requires actively curtailing the power of already-powerful actors. In particular, although data can be useful in projects of counter-power and resource allocation, data is an important form of market and social power (Pistor, 2020), and it is difficult to avoid creating data infrastructures that do not in some way rely on the expansion of the data-power of already-powerful actors.

For instance, the prior authorization interventions examined here are intended to reduce harm and burden through automated data transfer between electronic health records and the

payer. Ultimately, this is a governance strategy that re-affirms insurance companies' power to make decisions about care, and furthermore potentially expands the speed and scale at which clinical health record data is shared with insurers. Looking more broadly within the healthcare industry, we already see that health data is significantly structured and controlled by insurance company payment regimes, which dictate the input of diagnostic and treatment codes that will yield the highest rate of reimbursement. This highlights the critical importance of identifying interventions that shift away from, rather than reproduce, insurance companies' power to structure what data is collected, how, and what it is ultimately used for.

As explored in the previous section, these regulations are designed to enable automated decision making around prior authorization, re-inscribing a system in which decision-making is deferred to "the market" (e.g., insurance companies are able to define "low value care"), to medical experts hired by insurance companies to write clinical policies, and to computational/algorithmic enactments of those expert decision-making structures. What interventions would instead curtail or limit the decision-making by these already-powerful actors, and redistribute this power to patients and their healthcare providers?

Overall, these four techniques (expand the problem frame, expand the methods or strategies, expand the power of marginalized users, reduce the power of already powerful actors) - which build and draw upon the insights of abolitionist organizing, as well as from the insights of feminist HCI, critical data studies, and critical design - may be helpful as we seek to develop interventions advancing data justice. By applying this framework to the domain of prior authorization regulations design to reduce provider and patient burden, we can see how this intervention at the level of user experience represents a "bridge to nowhere," working with a constrained set of tools/strategies within a constrained problem-space, seeking to build solutions for users rather than to build user power. This framework helps to counteract the inherent conservatism of interventions at the level of "user experience," particularly within data infrastructures in domains like healthcare, housing, education, or safety - critical sites for ensuring that our data infrastructure designs do not reproduce a politics of extraction and injustice.

Conclusion

This chapter explores a particular case study of health data reform, analyzing federal interventions to automate prior authorization decisions by health insurers as a "bridge to

nowhere." These regulations are described by health IT professionals in this field as a bridge to nowhere inasmuch as these interventions are partial, fragmented, and rely on the benevolence and goodwill of insurers in their approach to compliance. Applying the framework of "non-reformist reforms" developed by prison abolition scholars and activists, I analyze these interventions as a "bridge to nowhere" inasmuch as they reflect an intervention at the level of "user experience": a reformist reform that seeks to mitigate the burden of prior authorization for patients and providers while reproducing and potentially expanding insurance companies' unilateral control over the definition of "medically necessary care."

Hoping to identify a horizon "beyond user experience" (as abolitionist scholars have sought a horizon "beyond legalism"), I outline four tenets for non-reformist design and data justice: expand the problem frame, expand the methods or strategies, expand the power of marginalized users, and reduce the power of already powerful actors. I weave together insights from this case study, from abolitionist thinking, and from previous scholarship in the domain of feminist HCI, critical data studies, and critical design scholarship to demonstrate the importance and practical usefulness of these four tenets as part of a design and data justice approach. These tenets are crucial for moving beyond the inherent conservatism of data justice interventions that operate purely at the level of "user experience," and are particularly key for ensuring that our data infrastructures in domains like healthcare, public safety, or education are aligned with the pursuit of data justice.

Chapter 6 From "Computing Care" to Solidarity Infrastructures

Through the preceding chapters, I've sought to give a sense of computing care as a mode of governance characterized by engineering markets and information infrastructures to optimize the efficient production of population health outcomes. Through this concept, I seek to highlight the role of datafication and computation in reproducing *market-solutionism* in contemporary governance. Through the concept of the "biopolitical rodeo" (chapter two), I extend previous scholarship critically examining neoliberal, market-based modes of governance by emphasizing the role of datafication in enabling an ongoing performance of market reform and the promise of "harnessing" extractive markets for the public good.

Through the three preceding empirical chapters, I have explored three concrete domains where this project of computing care is unfolding within the design and implementation of health data interoperability policies. In chapter three, I showed how intensified datafication is renewing the promises of value-based care policies, a decades-long project to reform healthcare markets by redefining care as a commodity. Data is a key mechanism through which inefficient, wasteful care providers are to be disciplined, and markets re-made into efficient and effective producers of care outcomes. Chapter four outlines the ways that the "social determinants of health" framework, which advocates for addressing structural inequities which fundamentally condition health costs and outcomes, is subsumed within SDoH data and payment models. These bureaucratic and technical infrastructures reproduce a politics of individual responsibility and financial accountability that runs directly counter to the notion of building political will to address unmet structural conditions of unmet social need. Finally, in the preceding chapter I highlight how policymakers have sought to solve the harms of prior authorization, through which insurers make decisions about medically necessary care, through processes of automation. I argue that this techno-solutionist approach seeks to reform the market without addressing the fundamental political conflict over who has the power to define "medically necessary care."

This final chapter seeks to do two things: first, I show how the concept of "computing care" is salient for advancing our understanding the contemporary moment of care governance

within the U.S., six months into the second Trump presidency. In doing so, I extend previous scholarship which has demonstrated the harms of market-solutionist modes of governance. Second, I introduce three small examples of openings towards non-market and techno-solutionist modes of governing care, and the role of data and computation in these projects: open source EHRs, health insurance via mutual aid societies, and practices of data-driven refusal. Through these examples, I seek to emphasize opportunities for health informaticists and health data professionals who wish to contribute to contribute to care infrastructures rooted in collective, democratic governance, and ensuring that all needs are met.

In the overall dissertation, I have sought to show how health data interoperability policies reflect a market- and techno-solutionist mode of governance. The main contribution of this work is to extend our understanding of contemporary governmentality (Foucault): what goals, values, and techniques are driving the way that we govern care in the U.S.? In this final chapter, I hope to both make this theoretical intervention more immediately salient to our current political situation, and to highlight pathways towards alternative modes of governing care.

Computing Care: Reflections on the Current Moment

My research on health data interoperability began during the covid19 lockdowns of 2021 and ended during the first six months of Project 2025, the conservative policy agenda advanced during the second Trump presidency to centralize power and dismantle government-funded public infrastructures. Although these both mark two particular moments of crisis for the U.S. healthcare industry, I have sought to emphasize the fundamental *continuity* of values of economization, efficiency, and reduced investment in public infrastructure throughout and beyond this period. The project of computing care, of designing markets and information flows to efficiently achieve the biopolitical goals of the state has been a future-in-the-making for over 50 years. Datafication and automation are only the latest mechanisms through which this promise is renewed.

Many of the data policies and protocols traced in my research originate during the two terms of the Obama administration (2009-2016), but their origins date back to the second Bush presidency and the Iraq war and continued through the first Trump presidency. Within these policies we can see particular cultural moments reflected: the early 2010's hype and promise of "Big Data", the late 2010's discourse of "the sharing economy" and API-based data exchange as defining characteristics of modern, innovative markets. We can also see the push to redesign the

market and its information infrastructures to achieve *health equity*, an echo of the Black Lives Matter movement of the ascendancy of DEI policies following the summer 2020 uprisings. What further remaking of healthcare data and healthcare markets can we see on the horizon?

In this moment in 2025, six months into the second Trump presidency, there does seem to be a move away from the *computing care* approach taken during the preceding decade. Rather than technocratic tinkering, the approach *du jour* is one of massive divestment from public healthcare. It feels like the scalpel has been replaced by the sledgehammer: precision austerity replaced with outright divestment. In this specific political moment, it feels somewhat counter-productive to criticize technocratic policies, such as SDoH screening or referral programs or prior auth automation. Even if these programs attempt to mitigate harm in the most conservative, reformist ways possible - they seem preferable to current policies which seem to dismantle the existence of public investment in health whatsoever.

Yet, computing care - the political rationalities that it reproduces and reflects - nonetheless helps set the stage for the more explicitly violent social policies we see unfolding today. First, the problematization which underlies computing care as a mode of governance helps to construct and maintain the problem of U.S. healthcare as one of "waste, fraud, and abuse" - a narrative which has become even more central within the current Trump administration. Second, through governance via the "anti-politics" machine of engineering markets and data infrastructures, spaces and modes for collective articulations of the benefits, and the problems, of public care infrastructures have been eliminated. By making the governance of care the domain exclusively of market engineers, we have severely impeded our collective capacity to articulate the social value of public care infrastructures.

"Waste, Fraud and Abuse": Problematizating the U.S. Healthcare Industry

A central idea explored in this dissertation revolves around the way that social problems - particularly of the distribution of care, of need, and of governance - are framed and constructed. Computing care, as a mode of governance, entails a particular way of narrating the problems of the U.S. healthcare industry, and the role of the state, of markets, and of information in solving those problems. Although the exact techniques for solving these problems have shifted over the preceding two decades - and are shifting again under the second Trump administration, the problematization has remained largely consistent.

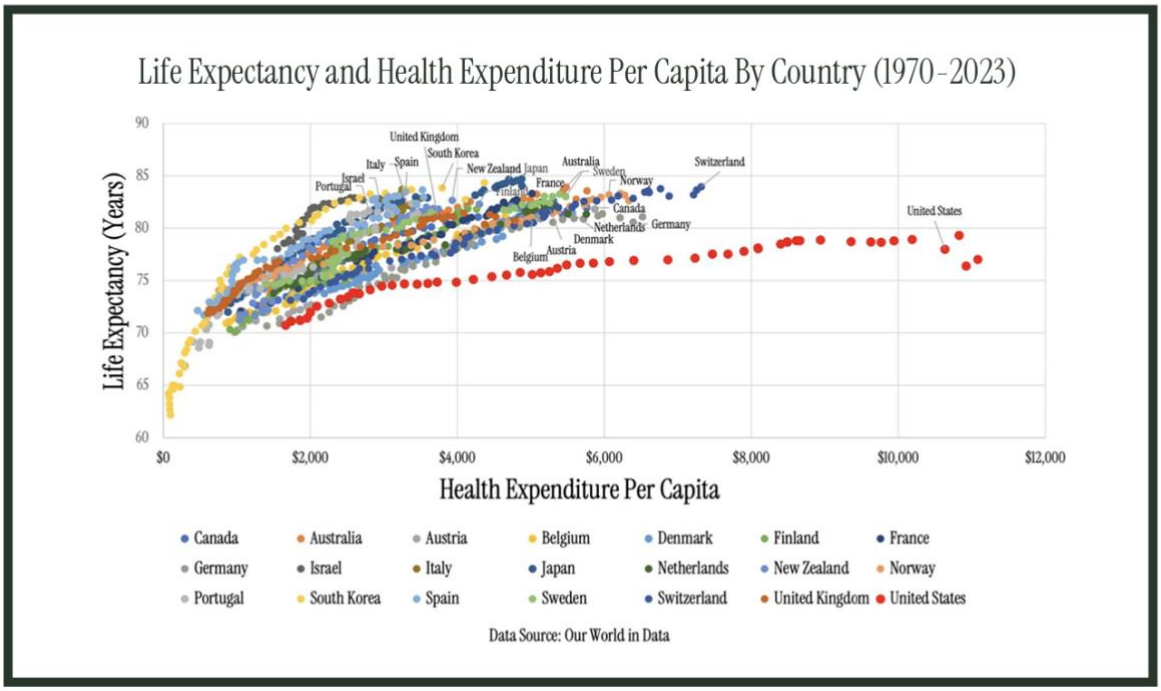
In Callon's "sociology of translation", he outlines four phases through which a knowledge claim is constructed (Callon, 1984). The first step in this framework is "problematization." Callon shows how, by a research team's specific framing of a research question about scallops, a network of actors is delimited, their identities stabilized, and the relations between those actors constructed to make this question legible. Through problematization, the researchers exert a kind of discursive power to shape our understanding of the world and begin to arrange and coordinate actors towards a particular *solution* - the construction of what Callon calls the "obligatory passage point."

Likewise, through the discourse of computing care, U.S. politicians over the preceding decades have constructed a very specific narrative about the problems of the U.S. healthcare industry. I gestured toward this problematization in the introductory chapter, showing the standardized narrative of the U.S.'s relatively high costs and poor outcomes of care articulated by politicians and policymakers like FDA Commissioner Robert Califf. This narrative is repeated at the beginning of a recent Trump administration report establishing the "Make America Healthy Again" commission (see Fig. 6.1 below). Although the takeaways - the proposed solutions - are different from those proposed in Commissioner Califf's keynote - the problematization remains consistent.

This problematization, ironically, focuses on the U.S.'s spectacularly high costs and relatively poor population health outcomes relative to other high-income countries. Yet, this problematization pointedly does *not* consider whether our unique mode of privatized, employer-based insurance and private provisioning of care services is perhaps part of the cause. Rather, this problematization focuses on "misaligned incentives", on the need to redesign financial incentives and penalties so that market actors - whether insurers, hospitals, doctors or patients - better adhere to the behaviors that most efficiently and effectively produce healthy populations.

Introduction

The health of American children is in crisis. Despite outspending peer nations by more than double per capita on healthcare, the United States ranks last in life expectancy among high-income countries – and suffers higher rates of obesity, heart disease, and diabetes.[1,2] Today's children are the sickest generation in American history in terms of chronic disease and these preventable trends continue to worsen each year,[3] posing a threat to our nation's health, economy, and military readiness.



In 2023 alone, national health expenditures were projected to grow by 4.4%,[4] outpacing real U.S. GDP growth of just 2.5%.[5] Yet despite the ever-growing financial investment in the U.S. healthcare system, American life expectancy lags other high-income countries.

Figure 6.1 Screenshot from page 7 of the "Make America Health Again" (MAHA) report, issued in early 2025 along with an executive order establishing the MAHA Commission, focusing particularly on the crisis of children's health.

The narrative of computing care promises that through increased information flows, more rationally designed markets, these inefficient markets *can be fixed*. We can engineer a perfect device through which insurance companies, hospital systems, potentially fraudulent patients can be datafied and their behaviors optimized in such a way that everything operates seamlessly; that only those who deserve care receive it, only those providers that provide "good" care are paid for it. These are not just narratives: this computing care approach motivates the policies outlined in

the preceding three chapters - value-based care, SDoH initiatives, prior auth automation - and many more besides.

Yet this problematization - of the wasteful, extractive, even fraudulent behaviors of market actors, particularly patients and providers - has also helped to motivate policies beyond the data-driven, market-engineering policies covered in this dissertation. This problematization has also helped to motivate more direct forms of austerity and divestment from public care infrastructures. For instance, during the Biden administration more than 25 million individuals were kicked off Medicaid for bureaucratic or procedural errors. Medicaid enrollees had grown significantly as a result of pandemic-era "continuous enrollment" policies, which made it easier for people to access and stay on Medicaid; Congress allowed these policies to end in 2023, enabling states to begin "re-determinations" processes to remove people from Medicaid roles with incomplete paperwork. Data suggests that many of those kicked off the roles as part of this process are children who should be otherwise eligible for Medicaid coverage - but with incomplete documentation (*As Medicaid Unwinding Concludes in Most States, KFF Finds 25 Million Lost Medicaid Coverage but Enrollment is 10 Million Higher Than Pre-Pandemic Levels*, 2024).

This process of terminating Medicaid coverage for those otherwise eligible, but with incomplete documentation, reflects a set of policies rooted in mitigating "waste, fraud, and abuse" among patients. These policies sometimes look like the technocratic tinkering of value-based care programs, and other times look like the application of blunt, bureaucratic instruments for cutting costs and reducing the scope of public investment in care. This problematization of waste, fraud and abuse also helps to justify the Trump administration proposal to impose work requirements - including annual or semi-annual documentation checks - for those enrolled on Medicaid. This proposal is projected to remove an additional 10 million individuals from Medicaid enrollment (Karpman et al., 2025).

Computing care perpetuates a particular problematization of healthcare markets as inefficient and overly expensive, specifically as a result of practices of waste, fraud, and abuse – primarily patients and care providers. Discipline is thus enacted on these populations, whether through the scalpel or sledgehammer, to manage the costs of care. Yet *there are alternative ways that we might construct the problem of governing care.* We might focus on the extraordinarily high costs and relatively poor outcomes of U.S. healthcare as a problem of extractive corporate

actors and regulate accordingly. To some extent, this is the part of the intent behind value-based care policies, although they construct providers as the primary site of market discipline. Or we might, like Mark from the introduction chapter, see for-profit healthcare markets themselves as the primary driver of costs in the U.S., and regulate accordingly. Yet these problematizations still construct the state as primarily responsible for *managing the costs of care.*

There are yet other problematizations, other ways of configuring the state's responsibilities with regards to the governance of care. Chapter four, on social determinants of health, introduced one such alternative problematization. SDoH frameworks, as advocated and advanced through the World Health Organization, suggest that the state is responsible for addressing structural inequities in access to basic resources like food, water, and housing that lead to poor health outcomes. Yet without careful attention to the politics that are embedded within our payment and data infrastructures, this problematization is overwritten by the logic of computing care.

In chapter three I outline how value-based care initiatives reflect a problematization of the costs of care because of inefficient and wasteful provider behaviors, and the solution as one of ever-more precisely tuned incentive and surveillance mechanisms to align provider behavior with the economic and biopolitical goals of the state. We might construct both the problem and the solution quite differently here. For instance, we might instead seek to create a system of governance that ensures that providers are accountable both to patients' goals and are responsible for helping to ensure that resources are distributed equitably, such that all needs are met. This problematization opens up the need for mechanisms of provider accountability that extend beyond what is possible through datafication and financial incentives.

More broadly, even the problem of data interoperability itself is constructed as a problem of inefficiency and insufficient market discipline. The 2013 JASON report constructs the problem of interoperability as one of EHRs and other health companies hoarding and siloing data in ways that limit the efficient production of public value (see chapter three). The solution proposed - and taken up in Cures Act regulations - is to build interoperability standards that enable new market entrants and enhance public value through competition. Rather than seeing new, competitive markets as the solution to creating public value from this data, what if we identified this as a problem of corporate control over health data? What alternative mechanisms

might we introduce to ensure that this vital public resource is utilized and managed in the public interest?

These alternative problematizations sound rather utopian, don't they? Winner (2020) reflects that this reaction, too, is characteristic of "modern political discourse":

> It is characteristic of societies based on large, complex technological systems, however, that moral reasons other than those of practical necessity appear increasingly obsolete, "idealistic," and irrelevant. Whatever claims one may wish to make on behalf of liberty, justice, or equality can be immediately neutralized when confronted with arguments to the effect: "Fine, but that's no way to run a railroad" (or steel mill, or airline, or communications system, and so on). *(p.36)*

In this dissertation, I hope to have provided some ground - some conceptual space - to challenge this "conceptual impoverishment" through which claims of "practical necessity" come to trump all other possible values.

In the preceding chapters, I have sought to make these familiar constructions of problems of care and their solutions *strange*, manifest within the discourse and practices of computing care. By making these problematizations and their solutions more visible, they become more amenable to dislocation and reconfiguration. This analytical strategy is central to disability studies scholars, who highlight the processes by which human difference becomes problematized as individual failure or illness. Rather than constructing autism as an illness which needs to be prevented or cured - as the current U.S. Secretary of Health and Human Services is seeking to do - disability scholars suggest an alternate problematization: of social institutions and a culture which marginalizes, stereotypes, and fears neurodivergence.

This interrogation of the problem/solution frames opens space for us to imagine a path forward - beyond reform, beyond the limitations of either Republican or Democratic constructions of the problems and solutions of U.S. healthcare. Particularly as designers and technologists, we would do well to interrogate problem/solution frames which limit us to the "conceptually impoverished" frames of managing efficiency and risk. Computing care exemplifies this conceptually impoverished mode of governance. In the next section, I further explore how computing care, as a particular mode of governmentality, has contributed to our inability to articulate alternative problematizations and solutions around the governance of care.

Markets-as-Machines: Automating Democracy?

The policies and interventions I trace in the preceding chapters are but the most recent instantiation of decades of previous market reforms by the state. Yet intensified datafication and automation renews the promise that it is possible to achieve a healthcare market that efficiently and effectively produces robust population health outcomes - *without* fundamentally restructuring society or markets. Through larger, faster, more standardized data streams, the state and the corporations responsibilized for achieving its biopolitical goals become more surveillable, more governable, more rationalized (see figure below). Policymakers and politicians reproduce the promise that, through computation, we will achieve a perfect *synecdoche* between healthcare corporations' economic self-interest and "public value."

This utopian promise of synecdoche through computation is fundamentally misguided. First, "public value" is itself intractable: there is no stable, universal "public good" which can be computed, in any domain, and particularly in the production of care and health. The ways that we distribute care resources, the ways that we coordinate and organize care practices, will always be a site of active contestation and harm. Care is fundamentally characterized by messy entanglements (Berlant, 2022) that resist easy commodification, and is often a fraught site of discipline and the reproduction of unequal social relations (Murphy, 2015). We cannot simply compute our way through this messiness.

As with any process of commodification, the commodification of care will always be a project of simplification, of disentanglement: "To construct a market transaction, that is to say, to transform something into a commodity...it is necessary to cut the tie between the thing and the other objects or human beings one by one. It must be decontextualized, dissociated, and detached." (Callon, 1998, p. 19). "Good care" cannot be completely represented as data in an EHR, captured via quality measurements, or reimbursed through specific billing codes. Certainly: there are better and worse computational operationalizations of care, with vitally important impacts on the everyday lives of millions of Americans, but there is no *way* to neatly and completely commodify care in such a way that no "negative externalities" remain.

Of course, this is not to say that any other system for the distribution and coordination of care can get around this messiness either. Rather, this is to say that the messiness and disagreement around what constitutes "good care" is not something to be flattened or erased through leaving these decisions up to "the market." As explored in chapter two, markets gained

traction as a governance mechanism because they seem to function as a collective calculative device, a space for the automation of collective political processes through rational individual choices. This mode of governance seeks to substitute the messy work of collectively defining shared values with decentralized decisions of economic actors. Yet in this process, we have dissolved necessary democratic and collective spaces for negotiating *how best to govern care.*

By pretending that care *can* be optimally "computed" through the market, we rob ourselves of the chance to actively and collectively construct what we mean by "good care". The social processes through which care is constructed as a shared set of values, practices, and priorities become collapsed and centralized as a technocratic process of quality metrics and incentive design. The current political moment, with its threats to the continued existence of the U.S. welfare state, reveals the secondary damage incurred when we try to find a computational shortcut for the messy political work of defining and operationalizing the public good. Even if some marginal improvements in patient experience or efficiency or health outcomes may be achievable through these technocratic methods, by embracing computing care as a mode of governance we are reproducing a system in which public value is imagined to be best produced through market actors' self-interested pursuit of profit.

This attempted automation of the governance of care, ironically, erodes our capacity for moral clarity around policies which advance social violence and death. It erodes our capacity to clearly name the contradiction in values in claiming to want to advance health equity through SDoH datafication, while simultaneously removing children from Medicaid roles for clerical errors. Frameworks like interoperability and value-based care, rooted in the language of "efficiency" and "return on investment", serve to advance a "compromise" between those who want to reduce harm and those who want to reduce costs. We need to clarify that these are fundamentally different projects, with different moral grounds. We need to ensure that those actors with a genuine commitment to care are not subject to capture by reformist, austerity-advancing policies in techno-solutionist clothing.

Through the regime of computing care, likewise, actual practices that produce care are obscured: the only relationships of accountability that are legible within this system are financial, the only drivers are economic. The "engine" of good care is not the rational, economizing choices made by market actors - it is the social and personal entanglements, the relations of *care* between providers and their patients. Even the policymakers and data professionals that I

encountered through this research help insert and reproduce care within the cracks of the market machine, driven by their own relationships of love and care for their families, for their patients, their concerns for their own futures. Yet by invisibilizing these non-market aspects of care, these social infrastructures are thereby made vulnerable to the axe of the private equity firm which buys the regional hospital, or state budget cuts, or the latest federal government "efficiency" efforts.

What Should Be Done? Computing Care - Beyond Techno-Solutionism

The values and goals of U.S. health data interoperability policies reflect a mode of governance oriented towards using the market as a lever for producing social good. But what other sets of values and goals might motivate or orient the design of new computing and data infrastructures? In this final section, I will briefly highlight a few "cracks in the edifice" - small efforts which run counter to the techno-solutionist, market-solutionist logic of "computing care."

Open Source EHRs

During this research, I came to learn about the history of electronic health records in the U.S. I was surprised to learn that the U.S. had funded and developed an electronic health record system to serve the needs of public VA hospitals. This system, called VistA, is open-source software developed in-house by VA developers starting in the 1970's. Versions of VistA have subsequently been adopted and adapted in several other health systems in the U.S. and internationally. In the past decade, there has been a significant push to switch the VA to commercial EHR software – in part to enable more interoperable data exchange between the VA and other parts of the federal government which already use commercial EHR software. However, many clinicians within the VA say that they find the VistA system equal to or better than commercial alternatives (Rodriguez, 2023). VistA is likely to remain in use for the foreseeable future, as efforts to adopt commercial EHR system Cerner have stalled due to safety concerns, including among provider-users.

I found this history exciting because it highlights the possibility for alternative EHR systems that are not unilaterally controlled by private, for-profit commercial players. VistA was designed and is maintained in-house within a healthcare provider system, reflecting a mode of governance and design more closely aligned with the goals and needs of clinicians than with the interests of a private EHR company. Across the U.S. - and even beyond - many health systems

use dominant commercial platforms for the same reason that we continue to use social media platforms like Facebook and Twitter: because these platforms have infrastructural power, garnering massive network effects over their decades of use and adoption. These are also extremely well-developed and maintained systems, reflective of their immense amount of financial resources and investment. Just as open-source, decentralized platforms like Mastodon are gaining traction in the social media space, open-source EHR systems like VistA suggest that alternatives to the dominant commercial EHR platforms *do exist.* Advocating for more federal funding for this kind of system may help chip away at the infrastructural power of private, corporate EHR systems.

The U.S.'s health data interoperability policies - like other interoperability policies introduced in other industries and national contexts - represent one tactic or effort to break up the infrastructural power of commercial EHRs, which have every incentive to maintain market control through the creation of data enclaves. But, at least in the context of U.S. EHR systems, these interoperability interventions should be understood as half-measures. The reality is that building interoperable APIs does little to mitigate the entrenched infrastructural power of these systems: rather, any new market entrants, like the third-party apps and services that surround the major social media platforms, are likely to be built *on top of* the existing EHR infrastructures. This produces new, private, for-profit data intermediaries layered on the old one. We must be honest that creating an opening for some degree of market competition through data interoperability does not resolve the lack of a publicly accountable, collectively governed EHR system. Market competition and customer choice alone may bring us new products and services but will not bring new modes of governance and public accountability of these vital data infrastructures.

Open source EHR systems like VistA may represent an incremental step towards this, and there are many ways that technologists can help contribute to this alternative. For instance, schools and researchers can contribute to the ongoing development of these open-source systems. It would be particularly interesting to see development projects that take a sociotechnical approach, for instance by thinking more broadly about the process for collective and democratic modes of feature development. It would also be interesting to explore the development of data ontologies and data sharing models for this system, oriented not primarily towards payment models, but rooted in practices of solidarity and care. For instance, would it

make more sense to capture data about a patient's "social determinants of health" - e.g., lack of housing or access to transportation - in a way that *does not get stored within an individual's EHR record*, reflecting an individual condition? Could this instead be collected and stored in the aggregate, as a means to report on the continued lack of investment in key public infrastructures that fundamentally shape health outcomes?

Health Insurance as a Project of Solidarity

Much of the history of health insurance in the U.S. is rooted in practices of actuarialism: of the construction of categories of risk and exclusion, upon which certain populations or certain conditions are deemed uninsurable, or otherwise unworthy. For instance, Mara Mills and Dan Bouk's history of "impairment" traces the way that this term emerged not only as a medical construct, but as an actuarial category for identifying specific types of people who should be removed from the insurance pool (Mills & Bouk, 2024). This history, likewise, highlights how computing itself evolved in tandem with the need to scale up actuarial practices.[27]

Yet the foundational premise of the redistribution of risks and costs of care can also be understood as a project of *solidarity.* Prior to the rise of the welfare state, voluntary fraternal orders and mutual aid societies helped to redistribute risk and responsibility among members through collective forms of social insurance. Historian David Beito estimates that, in 1920, one of three adult males was a member of a mutual aid society. Although the white, man, working class "lodge" looms large in this history, there were also societies specifically for women, racial and ethnic minorities and immigrants. Although these social infrastructures have largely fallen away, they point towards an alternative history of insurance rooted in solidarity, rather than charity or profit.

In the U.S. today, perhaps the most similar or parallel infrastructure takes the form of GoFundMe pages, through which we redistribute financial risks for medical bills, for funeral costs, via fundraising in our informal social networks. Similarly, during the covid19 pandemic we saw a surge of mutual aid organizing conducted online, via social media platforms. What might it look like to lean into these practices, moving them further from models of charity and towards solidarity, via more formalized regular contributions, or lasting reciprocal commitments

[27] See also: Yates, J. (2005). Structuring the information age: Life insurance and technology in the twentieth century. JHU Press.

beyond the one-time donation? This kind of model would also create space for collective governance and an explicit articulation of values and practices of solidarity which are largely absent, both in corporate models of insurance and relatively inaccessible within welfare state policies.

In a country where single-payer healthcare increasingly seems like a utopian fantasy, perhaps small-scale mutual aid societies can function as a "prefigurative practice" through which to begin developing a sense of what it looks like to provision insurance rooted in a culture and practice of solidarity. Per the definition provided by Prainsack and Buyx, "solidarity signifies shared practices reflecting a collective commitment to carry 'costs' (financial, social, emotional or otherwise) to assist others." (Prainsack & Buyx, 2011). What might it look like to build computational and data infrastructures that help advance and enable solidaristic sharing of health and financial risk, transparency, and practices of collective governance – rather than anti-solidaristic practices of risk stratification and the construction of categories of exclusion?

It is tempting here, to think of the potential value of blockchain or distributed autonomous organizations (DAOs) for the organization and management of contemporary mutual aid societies. Yet, as always, the key would be to lead with the construction, renegotiation, and maintenance of *social* infrastructures – the shared values, governance practices, and social relations – rather than to lead with the technology. (Many social solidarity projects like this are subject to capture by technologization, by the "innovative" technological dimension which makes this work appealing to grant issuers or researchers.) Though this would require careful and intentional work to avoid falling back into the trap of techno-solutionist approaches, small-scale mutual aid societies would be a compelling space to explore how computation might enable practices of solidarism and distributed governance, rather than centralization, opacity, and actuarialism.

Abolishing Prior Auth - And Data-Driven Refusal

Open source EHRs and mutual aid societies represent examples of "positive" alternatives to data- and market-solutions rooted in extractivism and austerity that we might begin building *today.* But this dissertation has also emphasized the importance of *refusing* policies and technical infrastructures which reproduce current, harmful systems. In chapter five, I draw upon abolitionist theories to reflect on the tricky, practical matter of reducing harm today, without perpetuating harmful systems.

Specifically, I explore emerging regulations specifically designed to reduce harm of current prior authorization processes through automation and faster data exchange. In that chapter, I suggest that - rather than improving the user experience of a fundamentally harmful process, wherein insurers exert patient-level control over decisions about medically necessary care, that this process should be *abolished.* I make this claim not only out of moral necessity, but also from a belief that there is already widespread political will behind a move in this direction.

Prior authorization is a highly contested process, disliked by patients and providers. The American Medical Association has mobilized immense political power behind writing and passing legislation to reform prior authorization. Over the past few years, dozens of states have recognized the importance of this issue to their constituents and have passed regulations seeking to mitigate the harms of prior authorization (Henry, 2024). It would be hard to say that these policies have been genuinely "abolitionist" in their tenor: most follow the path of reformism and harm-reduction over challenging the basic premise of prior authorization. Nonetheless, I think that these regulations speak to the existence of widespread political will and urgency around addressing the harms of prior authorization.

One long-standing leader in the health data interoperability space, Josh Mandel, current chief architect for Microsoft Health, reflected on the likely secondary-effects of regulations that introduce stringent controls on prior auth practices by insurers: "Mandating physician review for every routine approval would drastically increase costs, introduce potentially massive delays for necessary care (ironically contradicting the proposal's title), and could disincentivize the use of PA altogether, possibly leading to broader utilization controls elsewhere." (Mandel, 2025). Mandel sees this as an argument for improving the efficiency and reducing the burden of prior authorization through technology. While I agree with his diagnosis of the potential outcome of these regulations, I would argue that this indicates a need, not for technological and reformist interventions into prior auth, but to situate policy reforms within a broader contestation of utilization management techniques as undertaken by for-profit health insurance companies. Any approach to "fixing" prior authorization which does not address the broader issue of who gets to determine medically necessary care, is not a fix at all.

An abolitionist lens can also help us to think through strategies for refusal in relation to health data interoperability policies and infrastructures more broadly. In "Resisting AI", Dan McQuillan argues that "algorithmic power is applied to the unwanted to determine their

disposability. Such systems should be refused outright, not given oxygen by the idea that they can be reformed."(McQuillan, 2022). Refusal, of course, is more than a matter of making a statement in a dissertation or a CHI paper. It is a matter of constructing new shared narratives about what is normal, what is acceptable, and what must be done. It is a matter of building *political will* for radical change. Rather than design systems to enable reform, what role can data and data infrastructures play in building power and political will for refusal?

This is a line of inquiry explored in data feminist scholar Catherine D'Ignazio's most recent book, "Counting Feminicide" (D'Ignazio, 2024). In this book, D'Ignazio provides a detailed account of her work, alongside dozens of other collaborators and activists across Latin America, to count the uncounted gender-related killing of women and girls. She explores the potential of data and data science to envision and work towards the elimination of feminicide. D'Ignazio is careful to note that data-based interventions aren't a "techno-solution" for complex political problems: "On the contrary, the demand for more proof— more data collection, more analysis, more research— is often a terribly effective delay tactic employed by mainstream institutions to avoid taking meaningful action on social justice." (p.274). She argues that data is "not a "solution" and it is not saving anyone or anything anytime soon. Rather, it is something much humbler: "Restorative/transformative data science is a specific tactic of knowledge generation and consciousness building deployed amid deeply unjust information ecosystems." (P.274).

With this in mind: what particular, humble role might data play in, for instance, building consciousness about the harms of prior authorization - and in making claims for a different, or better system? Following the premise that "what isn't counted doesn't count", some of the regulations being introduced at the federal and state level focus on data transparency - requiring insurers to report the number and reasons for denials. This represents an important, small step towards making the harms and extent of prior authorization delays and denials more visible. Similarly, the American Medical Association has produced data about the impact of prior auth on providers through a nation-wide survey. What similar kinds of stories and data might be told about the impact on patients?

Data alone cannot make change. This data must be produced and mobilized within a broader social infrastructure. What social infrastructures - what coalition of patients - might be able to take up this data and use it to craft legislation, to make demands, in the same way that the

American Medical Association has? And if this effort is rooted in abolitionist politics – how might this coalition prepare to make a broader set of claims about the injustice of all forms of "utilization management" by for-profit insurance companies?

Towards Data Solidarity

"Computing care" constructs a story: that we can engineer a perfect market through which all actors within the healthcare market - insurance companies, hospital systems, providers and patients - can be incentivized to efficiently and effectively produce healthy populations. In this market, only those who deserve care receive it, and only those providers that provide "good" care are paid for it. Yet we are met with the persistent reality that the machine is broken: that our best policymakers and our best incentive designers cannot reduce healthcare costs, nor are we healthy, nor are our basic needs being met. There is a shared rage and frustration with the machine.

This failure, this injustice is intuitively felt even if it isn't articulated by either of the leading political parties. In December 2024, the CEO of UnitedHealth, one of the largest insurers in the country, was assassinated outside of a board meeting in New York City. This assassination was politically motivated: the bullets used to shoot the CEO were inscribed with the words, "Delay, Deny, Depose". The public response was one of overwhelming support and solidarity *for the assassin*, reflecting on their own rage and frustration at their experiences at the hands of U.S. insurers. To honor this rage, we must be more honest about the nature of the "crisis" or failures of U.S. healthcare: it is not contained within outdated data infrastructures, or insufficient incentive design, but within the organization of healthcare as a market for the production of economic value. The failure is contained within a state-run insurance program built not around values of universal access or care, but as a stopgap solution to address the "failures" of the private market.

It is also vitally important to be honest about the ways that datafication and computation have helped to **perpetuate the fantasy that the for-profit healthcare market can be made more rational, more efficient, more caring - with only a few more updates.** Chapter three has shown how value-based care policies are rooted in the idea that the high costs of U.S. healthcare are primarily the result of wasteful, fraudulent, and unaccountable practices by providers: and that this can be remedied through the design of new data and financial infrastructures to more precisely incentivize behaviors in line with the biopolitical goals of the state. Chapter four has

shown how the political demand to address structural inequities in access to housing and food which in turn, yield to inequities in health incomes, has been subverted through processes of datafication, rendering structural inequities as individual failures to be accounted for through minor modifications to clinical practice or through actuarial practices of risk adjustment. And finally, chapter five has shown how widespread outrage around harmful prior authorization processes has been subverted and captured through the promise of the techno-fix. Through automation and datafication, these harmful policies and the power of insurers over care is retrenched and reproduced.

Any system which is rooted in care decisions made by for-profit insurers or for-profit hospitals over doctors and patients – any system rooted in constructing categories to justify exclusion or denial of care – *should be refused.* Interoperability, at least as manifest within contemporary health data policies, might be understood as a project of engineering "interest convergence" across the biopolitical goals of the state and for-profit healthcare companies. Rather than utilize data interoperability to reform extractivist healthcare markets, how can we build towards data solidarity - towards data infrastructures which reflect a value or ethos, not of fragmentation, individualization, and control, but a path to more equitable distributions of wealth and risk? How might data serve as solidarity infrastructure, binding together fragmented communities?

These are problems to be collectively solved and answered, but they must begin with creating greater shared political clarity about the threats to life and wellbeing contained within the current organization of for-profit health insurance, for-profit pharmaceutical companies, and the vital need for public health insurance rooted in universal coverage. Building a data infrastructure rooted in solidarity and care starts with dismantling the "compromise" between those who are interested in using data to advance "cost cutting" and "efficiency" in healthcare, and those who wish to genuinely improve access, equity, and quality of care.

This moment shows us starkly the violence of the datafied, reformist state, and the necessity for those of us interested in preventing social death to make our own blunt and bold political claims: that healthcare should not be a market. That everyone deserves access to healthcare, that the problems of high costs and low-quality care are the result of healthcare's commodification, and profit being systematically extracted, by private equity firms, by insurance firms, by healthcare systems. The biggest structural problems are abundantly obvious, and no

further data, no AI, no technocratic tinkering is needed to directly and immediately invest in housing, food and universal healthcare. DOGE wields no scalpel in their defunding of vital public infrastructures. Likewise, those interested in a more just healthcare system need not wield a scalpel in identifying need and making claims for infrastructures and services that address that need.

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