REGULATING DATA PRIVACY IN THE AMERICAN POLITICAL ECONOMY:

THE CASE OF HEALTH INFORMATION TECHNOLOGY AND HEALTH INSURANCE

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For my friends and family,

whose contributions to my health and well-being

cannot be quantified.

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ABSTRACT

REGULATING DATA PRIVACY IN THE AMERICAN POLITICAL ECONOMY:

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The modern data economy has reignited concerns about the privacy of consumer data and revitalized calls for more robust federal protections against data misuse. Yet, both data privacy and consumer advocates have struggled for decades to pass legislation to protect consumers. When and why does the federal government intervene to protect consumers from data-driven discrimination? I use three historical cases of federal consumer protection in health data technological change – the emergence of experience rating in health insurance in the 1940s, the development of electronic health records systems in the 1980s and 1990s, and the revolutionary discovery of the links between genetics and human health at the turn of the century – to understand federal responses to protect consumers from discrimination on the basis of their health status. Drawing from Congressional records, secondary policy analyses and reports, historiographies, archival records, news reporting, and trade organization documents, I argue that the federal government's increased role in governing consumer health data was shaped by the increased delegation of rationalization to private actors in health care. Specifically, as market reforms delegated responsibility for cutting costs and increasing the efficiency of healthcare delivery to private actors and individuals, a diverse set of interests became politically invested in a national system of data governance. These rationalization policies encouraged interest groups and federal policymakers to converge over support for greater federal intervention in consumer health data protections to protect the viability of interconnected health information systems.

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CHAPTER 1: REGULATING DATA PRIVACY IN THE AMERICAN POLITICAL ECONOMY

Introduction

New information technologies present a double-edged sword. In the context of health, innovations that increase the flow and volume of health and medical information hold great promise for improving the human condition. Drug development, personalized medical care, healthcare coverage, and public health surveillance rely on the vast collection and sharing of health data among government officials, medical providers, scientific researchers, and health insurers. From the creation of personal medical records to the minute, detailed tracking of individual behaviors and biometrics, health data about individuals form the foundation of the modern healthcare system.

As the data economy grows, however, there are also potential harms to healthcare consumers from the misuse of their data. Data breaches can reveal sensitive personal information, leaving individuals vulnerable to public embarrassment, fraud, and identity theft. Privacy intrusions diminish individuals' sense of control over the details of their personal lives, while threatening the established trust between providers and patients. Meanwhile, innovations in algorithmic decision-making systems can rely on flawed assumptions about the relationship between certain characteristics and behaviors in ways that perpetuate economic and social inequalities (O'Neil 2017; Eubanks 2017; Stone 2020).

Among the ways in which consumer data can be misused, data-driven discrimination is a policy problem about the boundaries of acceptable use of personal information. While civil rights statutes protect individuals against discrimination on the basis of protected categories such as race, sex, and gender, contemporary data-driven discrimination is harder to categorize as patently

unfair and the social categories for these data-driven categories may be less obvious. Anti-discrimination statutes of the civil rights era incentivized the adoption of "de-personalized" and automated decision-making systems; as a result, discrimination arguably became "data-driven" and justified as objective, impersonal, and depoliticized (Hyman 2011; Lauer 2017). Although explicit discrimination on the basis of "race, color, national origin, sex, age, or disability" is now widely understood to be unacceptable in a democratic society, discrimination on the basis of related factors such as one's health status, earnings potential, creditworthiness, criminal record, and health behaviors is less clear. As legal scholars have noted, "what makes one kind of differentiation acceptable and another morally reprehensible – and perhaps legally actionable – is a complicated question and one that relies heavily on historical and cultural context" (Roberts 2012: 11).[1]

Over the last three decades, the U.S. federal government has passed and enacted several key consumer protections against health status discrimination, especially in the areas of personal health information. These protections are puzzling given the U.S. tendency to prefer minimal data regulation when compared to other jurisdictions such the European Union. Unlike the E.U.'s comprehensive data protections that prioritize individual rights, the U.S. is considered an international data protection laggard with its fragmented regulatory regime and reliance on contested ideas of individual privacy (Bennett 1992; Regan 1995; Newman 2008; Schwartz 2009; Farrell and Newman 2019). While useful in identifying differences in national institutions, historical trajectories, and political culture that contribute to a relatively weak data protection regime in the U.S, the existing comparative research that emphasize the shortcomings of the U.S.

[1] Historically, discrimination has been justified as "data-driven" and deemed unacceptable only after political challenges by organized groups. Civil rights groups, for instance, mobilized against "red-lining" in home loans and the use of property values to discriminate by race (Thurston 2018).

overlook when and why U.S. data protections have succeeded, albeit in a limited fashion, and the domestic politics shaping this approach.

When and why does the federal government protect consumers from data-driven discrimination in new information technologies? This question strikes at the heart of political conflicts about fairness and distribution, as well as the acceptable criteria upon which decisions are made about access to services and opportunities. Existing literature on data regulation locates the development of the U.S. regulatory approach data in the nation's comparatively fragmented regulatory institutions and many veto points that create status quo bias in the policy-making process (Newman 2008). Other explanations rely on "punctuated equilibrium" as the government responds to data privacy scandals, power resources in social movement activism by advocacy groups, and a functionalist argument that regulations protect inherently "sensitive" data as technical innovations make privacy feasible (Regan 1995; Bennett 2008; Farrell and Newman 2019). These explanations, however, leave largely unexplained the variations in data governance over time, as well as why reforms happen absent a scandal, or how data "sensitivity" and the urgency of state intervention are constructed.

As new health information technologies have emerged, scholars have turned to study questions of data privacy regulation in the context of health. In studying the conflicts over health data, scholars have focused on the "balancing act" between individual privacy and broader transparency (Rosenbaum 2010). This attention to the "balancing act" between privacy and transparency in data regulation has limited the debate about data regulations, both in health care and in general information technologies, to studies of data management – who has authority, ownership, and control; the technical capabilities of data management; and the consequences of regulations for system operations (Regan 1995; Cohen 2013; Park 2019; Regan 2020; Burdon

2020; Gellman and Dixon 2020; Gellman 2022). These approaches, however, fail to thoroughly consider why data privacy matters. By focusing primarily on questions of data management, the current literature has overlooked how data privacy regulation has distributive consequences for groups and individuals.

Data privacy regulations encompass several related but distinct policy approaches to protect individuals against the potential harms of data misuse. Most broadly, data privacy regulations include rules about *data handling* and *data use*.[2] Rules about data handling address questions of data management. They include regulations about the extent of data collection, the conditions under which it can occur, and procedures for storing, linking, matching, and sharing information. These rules, which provide the legal infrastructure for data management, may manifest as information disclosures about how data will be used, consent agreements, limitations on the kinds of information that can be collected, and storage limitations for previously-collected data. Yet data handling requirements are constrained in their ability to protect consumers for several reasons. Consent agreements are generally passive protections that rely on individual consumer initiative, and consumers rarely read consent agreements before acquiescing to their legalese (Gellman 2017; Turow et al 2023). In health contexts, consent agreements and storage requirements serve namely as information disclosures given the infeasibility or undesirability of limiting health data collection (Rosenbaum 2010). Given these limitations, data privacy regulations that rely on rules about data handling are unable to protect consumers from data-driven discrimination.

[2] In the health information literature, data handling is sometimes referred to as "data stewardship." For a discussion about data governance as data stewardship, see Rosenbaum (2010).

Data privacy rules about data use, however, involve formal specifications about the permissible uses of personal data. These rules offer implicit agreements about the acceptable purpose of collecting personal data. For instance, can information about one's driving behavior be used to assess one's eligibility for a loan? Can individual health status be used to determine the quality of coverage offered by an insurer? Answering these types of questions involves determining the boundaries of data-driven discrimination, or the use of personal information such as individual records about one's health status and behavior to differentiate between groups and individuals. Such differentiation can be part of established, legal practices of information use and is often justified as necessary for program efficiency, financial responsibility, and risk management. However, in the American welfare state where universal social programs are rare and risk management has arguably become the paramount goal of social policy, data-driven discrimination fuels an engine of stratification, protecting or excluding different groups of people in ways that divide them by race, ethnicity, occupation, and gender (Lieberman 1998; Mettler 1998; Hacker 2004; Fox 2012).

The distributive consequences of data-driven discrimination are particularly pronounced in privatized health insurance, where goals for comprehensive coverage are often in tension with financial considerations. In insurance, actuarial methods create risk pools in which "risk is (approximately) equally shared" and there is minimal vertical redistribution or subsidization across risk groups. These actuarial methods were standardized and professionalized in the U.S. in 1919, when the founding document of the numerical rating system used in medical underwriting was published in the *Transactions of the Society of American Actuaries*. Included in the list of relevant information to calculate risk were entries for childbirth experience, reproductive health, age and menopausal status, and marital status for women (Stone 1993: 297). Occupation, however, was one of the most important variables for calculating life and health insurance ratings,

and the industry's dependence on occupation as a signifier of risk led to "occupational redlining" in the insurance industry (Gottschalk 2000; Kaiser Family Foundation 2012).

Political challenges to insurance underwriting practices have occurred periodically since the introduction of actuarial methods. In life insurance during the 1880s, several states attempted to address racial discrimination in life insurance pricing.[3] Insurers have also engaged in fights with states and interest groups over "redlining" along racial lines, gender disparities in insurance access and pricing, and insurers' use of disease information such as Tay-Sachs, sickle-cell anemia, DES syndrome, and HIV to limit coverage and benefits. In the context of privatized health insurance, data privacy requirements that limit data collection may not be feasible even when data-driven discrimination has real material consequences. Protections against data-driven discrimination, especially in the context of health insurance and required data collection, thus have distributive effects that consent agreements and data handling requirements cannot achieve.

Beyond the comparatively laggard status of the U.S. data regulatory regime, the success of government protections against data-driven discrimination in health insurance is puzzling for several additional reasons. Nondiscrimination in health insurance tends to benefit those who are considered "high risk" while "constrain[ing] those at low risk, and risks are correlated with politically salient socioeconomic divisions" where low risk groups tend to have more political and economic resources in policymaking (Iversen and Rehm 2022: 25). Consumer protections that

[3] Although life and health insurance similarly rely on actuarial methods, they have different priorities in calculating risk. In the nineteenth century, life insurance companies only sold to people who were considered "insurable" and refused to sell to those who had histories of disease or worked in occupations considered to be hazardous. The "substandard" insurance market emerged in the early twentieth century as life insurance companies began to consider higher risks as potentially more profitable since selling more expensive life insurance plans to individuals who were less healthy than the "standard" applicant but were still at a "very low risk of early death" became a profitable segment of the insurance market (Stone 1993: 295).

block data users from using information also prevent perfect information flows that are ideal for peak efficiency. Additionally, the American public policy process is famously riddled with veto points and a plethora of competing interest groups jockeying for influence. This minefield means that the American policymaking system displays a strong historical penchant for the status quo, even in the event of technological change. The issue of data-driven discrimination has also arguably become more subtle and complicated over time as civil rights laws carved out and protected specific categories, creating a policy context that makes it difficult for consumers to mobilize or even to detect discrimination.

When and why, then, have anti-discrimination laws protecting the health information of those deemed "high risk" managed to pass? My main argument centers on the idea that changes to the welfare state over time have affected when and why the federal government steps in to protect consumers against data-driven discrimination. In contrast to expectations that consumer protections result from consumer-driven activism, self-interested politicians, or weakened industry interests, I argue that policies that delegated healthcare rationalization to individuals and private actors shaped the preferences of interest groups and federal policymakers towards support for government regulation. Specifically, various interest groups converged to support federal consumer regulations in order to protect a system of privatized health insurance.

To build my argument, I compare federal responses to data-driven discrimination in three cases of health information technologies: 1) experience rating in health insurance, 2) electronic health records, and 3) genetic information. These case studies about health information technologies, which focus on Congressional debates and decisions to address data-driven discrimination in health insurance, are selected from different periods in the history of U.S. health policy to provide a combined most-similar and most-different case design. This case design allows

me to contrast federal responses to data-driven discrimination before and after the onset of delegated rationalization policy. I also address competing alternative explanations for when and why the government intervenes in consumer protection and discuss their limitations in explaining cases of consumer protection in health data technology.

I draw on both primary and secondary sources, given the significant existing scholarly work on health insurance and the much smaller body of literature on data regulation. Using process tracing to examine change in consumer protection legislation across several decades within each case, I show how federal approaches to consumer protection developed as health policy changed over time. While limited in their generalizability, case study designs are particularly useful for understanding rare events. Cases of disruptive technological change are rare by definition, as are events of successful federal consumer protection in an information regulatory regime otherwise characterized as lagging. As with any small-n research design, case studies are limited in their generalizability but can provide rich detail to aid in theory-building, especially for questions and topics that are comparatively understudied in existing scholarship (Gerring 2007). The method of process tracing, which is particularly useful in small-n analysis, is a primary way to identify and establish causal mechanisms in qualitative research while eliminating rival explanations. In the following chapter, I provide a more in-depth justification for the research design, methods, and case selection used in the project.

Data-driven discrimination can happen in many different domains, but I focus on consumer data protections in health information and health insurance for several reasons. First, there are serious material consequences of data-driven discrimination in health. Individuals can face higher prices or are even denied health insurance as a result of data-driven discrimination, making the governance of health data usage particularly controversial. Second, federal

protections against health status discrimination have been relatively delayed compared to other forms of discrimination, data-driven and otherwise. In other types of data-driven discrimination, namely determinations of creditworthiness, consumer protections quickly followed the passage of civil rights statutes in the late 1960s and 1970s.[4] Health status protections, on the other hand, are much more recent and have come on the heels of immense changes due to advances in information technology.

Despite the intimate relationship between the information economy and the welfare state, the connection between social policy and data governance remains largely underdeveloped. This project uncovers how the delegated welfare state has affected regulatory politics over time. More specifically, this study shows how the federal government has addressed data-driven discrimination in health insurance as a problem of data governance. Some argue that the "prohibition [against race for risk classification] appears to arise from the fact that a democratic society simply does not allow racial and ethnic minority individuals to be classified as poor risks and denied the benefits of insurance based on their immutable characteristics" (Rosenbaum 2009: 108). In this view, anti-discrimination regulations that prohibit exclusion on the basis of race and ethnicity are not surprising if the U.S. adheres to values of a democratic society. Yet state-sanctioned discrimination continues to persist in democratic societies.

This project is an intervention in the welfare state, health policy, and consumer protection literatures. By focusing on variations within the history of the U.S. fragmented data governance regime and on the history of health insurance, I argue that the politics of the changing welfare state is an underappreciated factor shaping the federal approach to consumer data regulation.

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[4] E.g., the Fair Housing Act (FHA) passed in 1968 while the Equal Credit Opportunity Act (ECOA) became law in 1974.

Regulations against data-driven discrimination are efforts to address whether and how organizations are allowed to use individual data in making decisions about the distribution of goods and services. By bringing in relatively-understudied examples from health policy, I also show why data regulation matters in material terms.

The Politics of Health Data Governance

Since the late 1970s, many advanced democracies have shifted from industrial to service-oriented economies. As part of this economic transformation to services, data became one of the key inputs and assets of the economy (Iversen and Wren 1998; Newman 2008; Zysman and Breznitz 2012). This transition has been aided by significant public investment in information technologies. For instance, the electronics industry became the third largest industry in revenue behind auto and steel in 1955 and became "an information business in the 1960s" with the development of the minicomputer and the move from hardware to software, operating platforms, and communication networks and devices (O'Mara 2019: 24, 53).

Health care has been no exception in this turn to data-driven services. Although personal information such as medical records have always held a central place in health care, technological developments such as risk calculation methods, digitalization and computerization, and genomics revolutionized health care from the patient-provider relationship into an interconnected network capable of cost control, preventative diagnostics, evidence-based and precision medicine, and streamlined services. At the same time, health policy moved towards cost-efficiency and individual consumer choice. Individuals and private actors – employers, insurers, and providers – became more responsible for controlling the rising costs of healthcare. I call this family of policies "delegated rationalization" because they made private actors rather than the public sector responsible for cost efficiency. Rationalization in health care is the "application of managerial and

organizational principles characteristic of large-scale business and industry, i.e., quantification of decision-making, consolidation of production, money rewards for cost savings, and economies of scale" (Battistella 1972: 331). I argue that policies of delegated rationalization played a major role in changing interest group behaviors towards regulation and the federal government's approach towards consumer data protections.

The government's regulation of data is a political minefield of competing interests. Although there is broad agreement on preventing data misuse, the definitions of misuse vary dramatically. Researchers, firms, and law enforcement generally want broad autonomy over their data use while supporting strong data protections to prevent third-party access. Consumers and their advocates, public interest groups, privacy advocates, and individuals concerned about discrimination are more supportive of rules that limit the autonomy of entities that use personal data. In a health system reliant on personal information to target treatments and individualize care and costs, healthcare researchers and insurers are particularly interested in accessing health data and find themselves at odds with disease advocacy groups, patient representatives, and providers who worry about discrimination, legal liability, and a loss of patient-provider confidentiality (Rosenbaum 2010: 1443). Who wins in these debates about regulating personal health data has important consequences for the metrics of inclusion.

As part of these debates, there is fierce disagreement over when and whether data-driven discrimination is fair. In some cases, the federal government has moved to expand consumer data protections by banning the use of certain types of individual-level data. Government policies to address the use, collection, and exchange of personal information in the U.S. emerged in the late 1960s as information privacy first entered the national policy agenda. During this time, privacy over one's personal information was largely seen as an issue of correcting inaccuracies and anti-

statist tendencies against surveillance, though efforts were also motivated by an undercurrent of concern about discrimination in employment and insurance (Regan 1995).

During more recent years, the issue of consumer protection in data governance has risen to the top of the policy agenda as new information technologies exponentially increase the availability of data about individuals. As the result of policy decisions made during the 1970s, the U.S. does not have a general "comprehensive" law to govern the use of consumer data by private market actors (Newman 2008). Rather, a series of separate but often interconnected laws provide protections for consumers depending on the type of information involved. This has meant that, as new information technologies emerge and new forms of data are created, the U.S. has approached each of these developments as unique policy problems. In the domain of health, the U.S. has been unusually protective of consumers in their experiences with health insurance.

The use of "consumers" in reference to health care is controversial, given the debates over the privatization of health care and the commercialization of health insurance. Nonetheless, I use this terminology deliberately to bring attention to several features of the American healthcare system and the political economy of health data. First, consumer protections are government regulations that apply to markets. Federal protections against health data-driven discrimination are consumer-oriented regulations of the health insurance market; by outlining the acceptable uses of health data for insurers and other healthcare entities that interact with insurers, federal protections against data-driven discrimination affect consumer access to private health insurance and their experiences with the insurance market. Second, health-related data can be gathered and shared from consumers of health insurance in ways that mirror the market for consumer data in other industries but differ from patient data collection. Individual data can be gathered from health insurance consumers even when they are not actively patients. For instance, consumer

groups have expressed concerns about the collection and use of everyday health tracking devices by healthcare-adjacent entities such as information technology companies. Patients, on the other hand, include individuals who are not covered by private insurance and instead are members of public insurance plans such as Medicaid and Medicare. These public programs rely on public-private data systems that are governed by a different set of rules and regulations.

The Argument

My main argument centers on the idea that changes to the welfare state affect when and why the federal government steps in to protect consumers against data-driven discrimination. I argue that the delegated nature of the welfare state shapes the regulatory politics of health information. Specifically, the delegated rationalization of health care to private actors and individuals led diverse groups to support federal protections against data-driven discrimination in order to protect a system of privatized health insurance.

I develop a theory that the delegated welfare state affects the behavior of interest groups towards data governance through the following mechanisms. First, delegated rationalization pushes responsibility for cost containment to private actors and individuals, and by doing so requires the participation of individuals and private actors to provide accurate information. As a result, a wide variety of interest groups became incentivized to prioritize their involvement in policymaking about data governance. By marshalling individuals and private actors to pursue a shared goal of cost containment in health care, rationalization requires the participation of individual consumers and private actors in improving the data quality of information systems. Despite their varying initial positions over regulation, diverse interest groups converged over support for federal intervention that could maintain broad participation among individuals and private actors. Lastly, federal policymakers were receptive to interest group demands because

they also relied on this participation to implement delegated rationalization. In cases or times in which interest groups failed to converge over health policy, policymakers were hesitant to intervene for fear of derailing technological advancements and creating unintentional consequences. When interest groups did converge, however, federal policymakers became more involved in setting standards and rules for consumer protection to preserve delegated arrangements. In short, delegated rationalization in healthcare created interest convergence and federal policymaker action in favor of federal consumer protections against data-driven discrimination.

The remaining chapters in the dissertation explore the role of interest groups in addressing data-driven discrimination in a health system increasingly reliant on information technologies. In chapter two, I elaborate on my theory, the argument about federal intervention in consumer data protections, and the rationale for the case-based research design of the project. The theory argues that changes to welfare state institutions in health care over time have shaped interest group strategies and convergence over federal regulation of consumer health data. More specifically, a policy of "delegated rationalization" in health care pushed the responsibility of cutting costs and streamlining services to private actors and individuals, bringing these disparate groups together to support federal data governance.

Chapters three through five provide the empirical core of the project. Each focus on a case of the government's response to emergent health information technology and the problem of data-driven discrimination in health insurance. I argue that these regulations and protections were the result of conflicts and eventual convergence between organized interest groups and federal policymaker priorities about public investments in technology. Consumers, meanwhile, were largely absent from the debates, though their behaviors in their interactions with the health

system provided important information to set the policy agenda. In these three empirical chapters, I show that changes in the welfare state affects the way in which the federal government approaches the governance of health information.

In chapter three, I investigate the initial delay of the federal government in intervening in health insurance regulation as the insurance market adopted experience rating to manage risks. Experience rating is the use of historical health-related records such as medical claims to predict future health care utilization and costs. Insurers use experience rating to match the risk of insuring plan members with their likely cost, so they can price their products accordingly and avoid financial problems. The development of experience rating in health insurance represented a significant technological change in health information. Commercial insurance carriers and the adoption of experience rating in the 1940s and 1950s transformed the health insurance market and created an emerging problem of greater competition but rising costs for the most medically-needy. Even as public interest advocates made significant inroads for protection in various consumer markets, civil rights activists successfully argued for anti-discrimination protections for race and gender, and the inflationary consequences of health insurance discrimination for high-risk groups became increasingly clear, there was minimal federal intervention to protect consumers. I show that despite the growing use of experience rating for data-driven discrimination in private health insurance, the federal government was slow to respond. It was only until the context for health reform changed that the ACA passed rate restrictions in 2010 to ban experience rating.

Why did federal policymakers delay in intervening in private health insurance markets? The chapter on experience rating examines the lack of a federal legislative or regulatory response to the widespread adoption of experience rating and argues that the establishment of the private

benefits system in health insurance through ERISA in 1974 and the residual public programs Medicaid and Medicare in 1965 contributed to the fragmentation of interest groups. Public interest groups and the civil rights movement that had once fought strenuously to counter explicit racial and gender discrimination in private markets became largely quiet on the more subtle issue of health status discrimination amidst technological change and categorical anti-discrimination laws. This lack of interest convergence led to the decades-long delay in consumer protections; while the welfare state changed dramatically during this time, federal consumer protections did emerge before delegated rationalization became standard health policy.

Chapters four and five each dive into the political history of why the federal government intervened to protect consumers in two different, but related innovations in health information technologies. Chapter four examines the development of electronic health records (EHR) and the growing role of federal consumer protection for data privacy and anti-discrimination in the lead up and passage of the Health Insurance Portability and Accountability Act (HIPAA). Specifically, this chapter investigates why the federal government gradually assumed a stronger role in consumer protection against health status discrimination and why different interest groups of private data users eventually agreed to it. Using the case of EHR during the late 1980s and 1990s, I trace the factors leading to federal protections against data-driven discrimination in these nascent digitized information systems. The combination of longitudinal personal health data into a digital record made data privacy a major concern in health policy.

I argue that as rationalization in healthcare became delegated to private actors starting in the 1970s, the behavior of key interest groups towards federal consumer protections changed. In analyzing the history of federal consumer protections against data-driven discrimination in the Americans with Disabilities Act (ADA), the Health Insurance Portability and Accountability Act

(HIPAA), and HIPAA's Privacy Rule, I find that policy development of federal health data protections is more reflective of the early political engagement of industry interests and interest convergence among providers, employers, and insurers over shaping "fair health systems" than of any grassroots mobilization by consumers or their organized public interest advocates. These kinds of protections were politically popular and more feasible than expanding public health insurance or banning underwriting; thus, HIPAA was passed with overwhelming bipartisan support. The law restricted the use of pre-existing condition exclusions in health insurance and created standards for data privacy and patient consent in EHRs. This chapter shows that the federal government intervened to protect consumers as diverse interest groups converged to ensure that patients and providers provided the data needed for healthcare rationalization.

Chapter five examines the federally-funded Human Genome Project (HGP) during the late 1980s to the early 2000s, a revolutionary endeavor that offered new ways of understanding and predicting health risks, and why the federal government expanded anti-discrimination protections to prevent genetic discrimination by insurers and employers. Genetic information involves data about individual genes, while genomics examines genes collectively and how they interact in their environment. In this last empirical chapter, I trace the factors leading to federal regulation of genetic information with the passage of the Genetic Information Non-discrimination Act (GINA) in 2008. Nicknamed the "first civil rights act of the twenty-first century" by its sponsors, GINA addressed growing concerns among the public, providers, and researchers about the potential for misuse of genetic information by insurers and employers.

Ethical questions about genetics made regulation a major policy concern for the public, but consumer protections resulted from converging interest group concerns about waning participation in new data technologies rather than broad agreement on ethical issues. By tracing

the political history GINA, I argue that the federal government's response was motivated by concerns that public distrust of genetics fundamentally threatened private insurance and the information systems upon which delegated rationalization relied. Although insurers and employers were initially resistant to federal genetic anti-discrimination law, over more than a decade a gradual agreement emerged among diverse interests that government consumer protections were necessary to safeguard technological progress and delegated arrangements in rationalization. Researchers and ethicists were important in setting out the stakes of legislation, but they played an arguably limited role in the eventual success of GINA. Consumer and patient groups, on the other hand, were important in communicating to legislators about the need for government regulation in countering the threat of declining consumer confidence and the danger of privacy protective consumer behaviors on health information systems. Insurers and employers shifted from their initial stance of opposition to support GINA as the law's scope shifted away from comprehensive protections and narrowed to focus on bolstering public support for genetic research, private insurance, and the growth of health information systems. Although consumers and their representatives were more involved in genetic regulation, this chapter shows a similar pathway of interest group convergence over consumer protections as in the case of HIPAA.

Contributions

This project makes two major contributions to the literatures on welfare states and consumer protection in health policy. First, I argue that the delegated welfare state is an underappreciated factor that shapes federal consumer regulations over time. I provide in-depth case studies on relatively understudied health policies to show how interest groups interact in institutional contexts to shape the process by which data-driven discrimination becomes illegal. Second, I bring in historical examples from the long-existing health sector into contemporary discussions

about data privacy and data governance. In doing so, I show why data regulation matters in material terms by affecting who gets what and why.

By providing in-depth case studies of federal consumer protections against data-driven discrimination in health insurance, this project uncovers how the delegated welfare state has shaped the politics of regulation over time. The American welfare state is comparatively reliant on private actors to implement social policies and deliver benefits (Hacker 2002; Campbell and Morgan 2011). The delegation of responsibilities in the American welfare state also places significant blame on individuals for incurring social risks and attributes rising costs in social services to individual choices (Lynch 2014). At the same time, these delegated arrangements have downstream effects on interest groups and their policy preferences. By tracing the process by which data-driven discrimination in health insurance becomes legally unacceptable, I show how the delegation of healthcare rationalization to individuals and private actors changed the behavior of interest groups towards consumer protections. As the role and responsibility of distributing health care has fallen increasingly on private sector actors, government decisions about regulating consumer data have focused on bolstering and preserving this "delegated" arrangement.

By bringing historical examples from the health sector into contemporary discussions about data privacy and regulation, I show why data regulation has important distributive consequences. Despite the rich interdisciplinary literature on the causes and consequences of the information environment, scholars of privacy, data governance, and the politics of the welfare state have rarely been in conversation, though there is recent increased interest in the social and political consequences of "algorithmic governance" (Srivastava 2021; Iversen and Rehm 2022; Krippner and Hirschman 2022). The scholarly and popular attention given to general information technologies has downplayed how other quotidian stakeholders, namely private health insurers

and providers, play an especially important role in shaping the trajectory of data governance. In contrast to the existing literature on data regulation, I argue that consumer protections against "data-driven discrimination" are a central but overlooked part of the U.S. welfare state. The focus in this project on data governance in health policy and health insurance is partially a response to scholars who have called attention to the "'interestingly uninteresting' character of insurance" and who have noted that "insurance is hugely under-researched for an industry of its size and governmental importance" especially in the context of data regulation (McFall et al 2020: 2).

As data about individuals becomes more available and abundant, it has also increased the visibility – and thus the possibility of accurate assessment and sorting – of individual and group risks. Because such personal information can reveal health and income risks, the availability and accessibility of data can create conditions for risk segmentation, leading to the decline of social solidarity (Iversen and Rehm 2022; Newman 2008). Protections against data-driven discrimination in health insurance have distributive consequences because they limit or block the use of personal data for risk sorting among high- and low-risk groups. These potential effects demonstrate why consumer data privacy regulations matter in ways beyond data ownership, technical management, and system operations. In comparing federal responses to experience rating, EHR, and genetics, I show how federal policymakers in Congress and regulatory agencies changed how health status information could be used for data-driven discrimination and the role that diverse interest groups played in data regulation. While government regulations against data-driven discrimination were ultimately in service of maintaining a privatized health insurance system, they protected consumers in their interactions with healthcare entities and have implications for equity in the delegated welfare state.

CHAPTER 2: DELEGATED RATIONALIZATION AND CONSUMER PROTECTIONS IN THE INFORMATION AGE

Introduction

During the 1960s, the public and public officials uncovered a vast and growing system of computerized "hidden" information systems that governed access to services and markets. These data systems, however, were not so much "hidden" as they were previously perceived as normal, fair, and justified. Since the early days of information systems, the demand for privacy protections has been driven by public and policymaker concerns that the unregulated use of personal information could unfairly deny individuals from jobs, insurance, credit, and other opportunities (Igo 2018).

In response to the discovery of these eligibility and credentialing systems, the federal government created principles for "fairness" in the use of personal information. The Fair Information Practices Principles (FIPPs) originated in the U.S. with the U.S. Department of Health, Education, and Welfare (HEW) report on *Records, Computers, and the Rights of Citizens* (HEW 1973). Since then, FIPPs have been used internationally to formulate data privacy policies as new technologies create more ways to encode information. Nonetheless, FIPPs are guides, not formally binding laws. Most importantly, they do not include requirements for non-discrimination.

When and why does the government intervene to protect consumers against data-driven discrimination? To identify the factors influencing federal intervention, I draw on the literature about the sources and mechanisms of policy change, especially in the domain of consumer protection. Specifically, I argue that rationalization policies passed in the 1970s pushed interest

groups and federal policymakers to converge in favor of pro-intervention on data-driven discrimination in new health data technologies. In other words, welfare state institutions about the private responsibilities for cost containment created the context in which interest groups, consumers, and federal policymakers formed preferences towards a more active federal role in consumer data governance.

Alternative Explanations for Policy Change

The process of policy change is complicated, yet many competing theories aim to explain when and why policies change over time. These theories include demand from consumer constituencies that result in policy change, business capture, partisan legislative control, policymaker entrepreneurship, and changes in regulatory capacity. A closer look at these alternative theories reveals their limitations in explaining the federal government's varying responses to data-driven discrimination in new health information technologies.

Consumer Constituencies

For decades, scholars have debated the extent to which citizens or special interest groups dominate policy change about state intervention in the economy. On one end, consumers have much at stake in obtaining legal protections of their health and safety, as well as assurances of fairness and integrity in their experiences in economic exchange. As voters who can threaten or reward legislators' electoral prospects, consumers can influence legislation that affects them through the "electoral connection" linking them to their representatives. In issues of data-driven discrimination in the welfare state, voters as beneficiaries may be mobilized to push for government intervention to protect them even when these services are provided by private actors.

Nonetheless, the connection between consumer mobilization and federal intervention in data-driven discrimination is tenuous. In the area of data governance specifically, surveys show that although information privacy has been a consistent concern for American voters since the 1970s, this concern has rarely translated into public engagement for policy reforms. Even when there are public outcries about consumer protection issues, these events do not necessarily lead to federal intervention. For instance, public complaints and industry warnings about the effect of experience rating on insurance markets during the 1950s did not incentivize federal policymakers to intervene until many decades after insurers had widely adopted experience rating. Likewise, although the public was largely disengaged on the issue of privacy and discrimination during the advent of electronic health records, Congress introduced arguably the most stringent consumer data protection laws with the Health Insurance Portability and Accountability Act (HIPAA) in 1996. Federal consumer protections in genomics also occurred in the 2000s despite the general loss of public interest in the issue after the attacks of September 11, 2001 turned national attention towards national security policy.

Partisan Control

A vast literature in political science focuses on public opinion on various policy issues, but voters may not form coherent opinions about policy issues. Despite the public's abstract concerns about their personal information, data governance is a comparatively low salience policy issue and the electoral payoffs to politicians of responding to data-related concerns, even privacy and discrimination issues, is generally weak. Likewise, excluded groups such as those claiming discrimination often have difficulty making collective political claims and instead turn to individualized processes for redress. Consumer protections, especially those involving newly emergent technologies and complicated health systems, involve technical and complicated

interventions that can privilege well-resourced industry or insider groups. As a relatively unpolarized issue, the domain of consumer protections also complicates the picture of policy change as driven by partisan voters. Parties have largely been unwilling to distinguish their agendas on consumer protections, especially in regard to claims about unfair treatment, personal privacy, and discrimination.

Special Interests

On the other end of voter-driven theories of policy change are arguments that public policy is largely determined by special interests. Public choice theory is perhaps the most famous of these formulations, in which special interest groups and policymakers make decisions about state intervention in the economy based on their own self-interest. Industry groups, in particular, possess specialized knowledge and expertise that give them significant leverage over the policies that affect them. Business interests thus engage in a form of "quiet politics" to shape corporate governance policies while the public is largely sidelined (Culpepper 2010). More generally, interest groups can promise or threaten electoral support in exchange for votes on policy proposals. As "intense policy demanders" that lobby and pressure legislators to take their preferred positions on policy issues, interest groups dominate the strategy of political parties and the agendas that parties adopt (Bawn et al 2012; Stokes 2020). In other cases, however, interest groups do not align with partisan priorities and parties have not distinguished their agendas. This is especially true in areas of emergent and rapidly-changing technology, in which the consequences of technological change are not yet clear to legislators, regulators, or interest groups.

Public choice theories of policy change are influential in explaining regulations that concentrate benefits to existing players but may be less capable of explaining consumer

protections. Important exceptions to the view of politics as dominated by interest groups occur when an otherwise arcane issue rises in public salience. When organized as public interest groups, consumer advocates can marshal public opinion or reveal to the public the importance of state intervention in protecting their interests (Thurston 2018). Even when disorganized, public interest concerns can prevail over business interests when issues have high public salience, such as in the case of executive compensation limits and high regulatory burdens for food and drug safety (Smith 2000; Culpepper 2010; Trumbull 2012).

Policy Entrepreneurship

Policymakers may be motivated by reelection and thus particularly sensitive to interest groups or voters in their constituency. Yet others argue that policymakers independently promote their own preferences and their visions of the public interest. These theories stem from observations that lobbying can be ineffective even when groups have significant resources, leading an understanding of legislators as strongly biased in favor of the status quo (Baumgartner et al 2009). A related body of literature argues that policymakers hold their own pre-existing policy preferences and act as their own agents of policy change. In this view, interest groups regardless of their campaign contributions have limited ability to influence elected representatives because politicians enter policymaking institutions with existing policy commitments (Ansolabehere et al 2003). As agents with their own motivations, legislators and bureaucrats can push for state intervention into private industry (Carpenter 2001, 2010). In several cases of privacy and anti-discrimination legislation, for instance, policy entrepreneurs with personal experience in these issues were at the forefront of introducing proposals and advocating for protections. For example, both landmark legislation such as Americans with Disabilities Act (1990) and idiosyncratic protections in the Video Privacy Protection Act (1988) were motivated in part by the personal

experiences of legislative sponsors (Regan 1995; Young 1997). Although the support of sponsors with pre-existing policy convictions can help explain agenda-setting, it is not enough to explain why some consumer protections pass after years of disagreement and stalemate. Additionally, in cases of emergent technologies, the policymaking environment is highly uncertain. Representatives are unlikely to hold pre-existing preferences about the nature of government intervention in these contexts.

Regulatory Capacity

Lastly, policy change in consumer protection can be highly dependent on the capacity of regulatory institutions. Policymakers may be unwilling to introduce legislation for which there are limited avenues for successful implementation. Existing comparative literature on regulatory institutions argues that the U.S. compared to Europe has become less willing over time to institute precautionary consumer regulations since the 1990s as polarization weakened public pressure on political leaders for consumer protection (Vogel 2015). Comparative work on data governance locates the U.S. approach to consumer information to the comparatively fragmented national and subnational regulatory institutions and veto points that create status quo bias in the policy-making process (Newman 2008). As a result, the U.S. federal government's approach to governing personal data is considered generally weak when compared to other countries. Data governance in the U.S. is characterized by a reliance on voluntary self-enforcement by industry players and a reluctance of policymakers to disrupt established business practices. Weak regulatory institutions and partisan polarization, however, still do not fully explain when policy change in consumer protection *does* happen or the within-country variation in federal responses to data-driven discrimination in emergent health technologies.

A Welfare State View of Data Governance: A New Theory

Drawing on the literature on interest group coalitions and the political consequences of the information economy, I propose a theory takes into consideration the pivotal role of interest groups, the context of emergent technologies, and the receptivity of policymakers to policy change in consumer protections. In the rest of this chapter, I build my theory that rationalization policies in health care push interest groups and federal policymakers to converge over government intervention to protect consumers against data-driven discrimination.

The theory argues that delegated rationalization creates interest convergence on the issue of consumer anti-discrimination protection in health data. Specifically, interests and federal policymakers converged in favor of pro-intervention against data-driven discrimination as their policy goals about information aligned towards maintaining rationalization policies. This mechanism of interest convergence happens in the following ways. Rationalization delegates the responsibility for cost containment in health insurance to individuals and private actors in ways that creates interest group stakeholders in data governance. As a result, interest groups prioritize their political involvement in shaping federal responses to new information technologies. Interest group preferences converge over their shared interest in maintaining or improving their relationship to health information. This convergence means that interest groups form diverse pro-intervention coalitions to maintain their capacities for cost containment when interpreting the threat of data-driven discrimination to legislators. Lastly, rationalization incentivizes federal policymakers to protect emergent information technologies that facilitate private responsibility for cost containment and thus makes policymakers particularly receptive to demands for state intervention. In the following sections, I discuss each of these arguments in turn.

I examine the theory in the context of emergent health information technologies, and in the last part of this chapter, I provide an overview of the three substantive cases used to support the argument. I discuss how the federal government's varying policy responses to three cases of modern health information technological innovations – the emergence of experience rating in health insurance, the development of electronic health and medical records (EHR), and the revolution of human genomics as health information – demonstrate the argument that rationalization policies in health care affected federal policy change in consumer protections. In the first case of health insurance experience rating, the federal government refrained or delayed in intervening to protect consumers when interest groups had not yet converged on an institutional arrangement about the value of personal health information. On the other hand, federal consumer protection intervention occurred when diverse interest groups converged in favor of consumer protections in the latter cases of EHRs and genomics.

I end with an explanation of how and why I use a comparative case study design, process tracing, and qualitative data sources to make my argument. Lastly, while I am interested in understanding why consumer protection policies changes, I do not address whether government intervention in health data technologies is necessary to protect consumers against data-driven discrimination nor do I assess the effectiveness of policy implementation. These other questions have motivated a heated debate over the effectiveness of consumer data regulations, as well as a huge literature in regulation and policy evaluation, but they are beyond the scope of this inquiry.

How Social Policy Shapes Data Governance

Existing institutions create the contexts that affect the preferences and behavior of political actors towards policy change. In other words, institutions create the "incentive structure of an economy" from which policy preferences on new and emergent issues flow (North 1990; Barma and Vogel

2022). In pushing the responsibility for cost containment to individuals and private actors, the policy of delegated rationalization in health care made consumers and industry groups more sensitive to policies about health information. As I argue in further detail, delegated rationalization created information environments in which access, privacy, and trust in information systems became paramount to achieving effective cost strategies in health care. Rationalization thus created the conditions for a diverse coalition of interest groups to form shared preferences about information policy and for federal policymakers to become receptive to their policy demands. As a result, interest groups and federal policymakers converged in support of government intervention against data-driven discrimination.

Delegated Rationalization

With the passage of national anti-discrimination statutes in the 1960s, the federal government became more involved in regulating discrimination in the market economy. At the same time, the individual characteristics against which individuals could be discriminated became arguably more subtle as data proxies took the place of protected categories (Hyman 2011; Lauer 2017). In addition to these changes in the legal environment, advances in computer technology from the mid-1960s to the late 1980s ushered in an "information age" that fundamentally altered the way in which individuals could be catalogued and assessed. The widespread adoption of computerized information technology and rapid advances in techniques for managing, collecting, and sharing personal data in the late 1980s and early 1990s coincided with political pressures to control rising health costs in the welfare state.

Harnessing inflation in health care has been one of the most challenging policy problems of the 20th century. The turn to market-based rationalization policy in health care during the 1970s and 1980s steered health policy towards goals of streamlining services, private provision,

and individual responsibility for cost control. Since the 1970s, the policy to tackle rising costs in health care can be described as "delegated rationalization" since instead of using government price controls, regulations, subsidies, and central planning to rationalize medical care, delegated rationalization relied on consumer choice, market transactions, and competitive pressures to address healthcare costs and service delivery in both public and privately-funded health care. Although proponents of market-based rationalization argued against government intervention, in reality the turn towards delegated rationalization was a deliberate policy pursued by both centrist Democrats and establishment Republicans in Congress to encourage and maintain private sector responsibility for healthcare costs (Campbell and Morgan 2011: 87-89). The guiding principle in rationalization focused bipartisan energy in health policy towards achieving cost-efficiency and optimizing resource distribution to save money and reduce redundancies.

The policy of delegated rationalization consisted of two overarching approaches that pushed the responsibility for costs to individuals and private actors. First, individual patients were recast as "consumers" with responsibility for their healthcare expenses through increased cost-sharing and personal health savings accounts. As a result, some scholars have argued that delegated rationalization and its reliance on consumer choice created "highly diversified insurance market [that] will stratify itself according to income" in ways that perpetuate racial disparities in the distribution of medical care (Stone 2005). Second, the task for managing risks and costs was delegated to private actors, namely insurers and managed care, to discipline providers and contain costs. Providers and employers were incentivized to pursue cost efficiency through capitation payments and the loss of fee-for-service arrangements and tax subsidies that had previously benefited them. As insurers became more aggressive in cost control and the burden of cost containment fell more heavily on individual consumers, providers, and employers, the issue of data governance rose in prominence for these groups.

Interest Group Prioritization of Data Governance

Faced with limited resources, interest groups must decide where to spend their time and resources. When and why do interest groups expend their resources and energies on lobbying the issue of data-driven discrimination? I argue that delegated rationalization motivates certain interest groups to prioritize their involvement in health data governance when rationalization elevates information as paramount in managing risks. Thus, threats to information become central to the survival of these interest groups.

Interest groups do not have unlimited resources; as a result, interest groups need to select which issues to prioritize in their political activities. They become involved in issues that they consider particularly central to their survival. Given the concentrated benefits and costs of policy change, interest groups are often the main actors in policy debates. Policy decisions about the responsibility of individuals and private actors to manage costs in health care elevated the importance of policymaking about new information technologies for these groups. In the context of health costs, information about health status is the main ingredient in assessing and managing risks. Thus, delegated rationalization made policymaking about information and threats to information central to many interest groups' survival.

Convergence in Interest Group Preferences

Interest groups prioritize their involvement in policymaking about data, but how do they form preferences about the policies governing emergent data technologies? Policymaking environments can be highly uncertain during emergent technologies, as the nature of technology and its consequences are not yet clear. In taking consideration of the endogenous quality of policy decisions and policy preferences, I argue that policy decisions about rationalization shaped the preferences of interest groups on data governance in ways that converge on state intervention

against data-driven discrimination. Specifically, rationalization made consumers more sensitive to health-related discrimination while private sector actors ranging from insurers to providers to employers became more politically active on issues that affected their ability to control costs.

There are few goods or services that are as essential as those that affect public health. In his examination of the design of U.S. public health insurance programs, Kelly (2023) argues that private health insurers, through their role in managed care, have become increasingly influential in shaping Medicaid and Medicare while simultaneously becoming dependent on federal revenue. Due to policies that encouraged the use of managed care to control public health insurance costs, the responsibility for service delivery in these public programs is delegated to private market actors. More generally, businesses can exercise power across different national institutional contexts because the goods and services they provide are considered crucial public services, and policymakers are interested in maintaining functional essential services for their electoral constituencies (Busemeyer and Thelen 2020).

Insurers and businesses, however, do not have wholesale control over the issue of health data technologies. Instead, the reliance on consumer participation in health information systems gives consumers leverage in policies about health data. I argue that welfare state institutions create interest convergence among data subjects and data users in favor of state intervention because maintaining these existing institutions requires public trust in information systems. A core component of rationalization policy targeted consumers by making them "face the true costs of care, by removing the shield provided by employer-sponsored coverage, insurance plans, and physician claims to professional expertise and authority" (Morgan and Campbell 2011: 88). While this focus on individual responsibility for healthcare costs aimed to discipline consumer utilization of healthcare services, this policy heightened consumer perceptions of their

vulnerability to discrimination, especially from their employers and insurers involved in healthcare decisions.

Although specific segments of consumers such as those with disabilities and hereditary diseases organized to lobby for protections against discrimination, consumers are a large and diffuse group that struggles to mobilize for policy change. Instead, the main channel of consumer political influence works through the ability of consumers to question the viability of institutions directly or indirectly. Consumers, while diffuse and unorganized, can shape data policy because their behavior – specifically, their lack of confidence in information systems – can imperil delegated rationalization. Tasked with managing risks and containing costs, industry groups such as insurers, employers, and providers are similarly concerned about public trust and converge on the need to allay consumer fears in order to continue collecting and using accurate information. Interest groups thus form diverse coalitions to support consumer protections, even in the absence of consumer mobilization. Meanwhile, federal intervention in consumer protections is often motivated by issues of public confidence, such as health and safety regulations. Delegated rationalization thus incentivizes policymakers to protect consumer confidence in technologies that facilitate cost containment activities by private actors and individuals.

Policymaker Receptivity to State Intervention

During emergent technological change, the contexts for policymaking can be highly uncertain. Voters may not be able to form coherent opinions or determine their preferred course of policy action, while policymakers face competing interpretations about the direction and implications of the technology. The existing literature presents several approaches to explain how interest groups influence policymaking. Interest groups set party agendas by lobbying to prioritize certain issues and keeping other issues off the policy agenda (Bawn et al 2012; Hertel-Fernandez 2019; Stokes

2020). Interest groups also work to control the scope of conflict, "the most important strategy of politics" (Schattschneider 1960). In contexts of high uncertainty, interest groups influence policymaking through their ability to communicate and interpret technological change for policymakers in ways that set the policy agenda and determine the scope of conflict.

Even so, interest groups are only as influential as the extent to which political decision-makers are receptive to them. Data governance is not a polarized issue since discrimination on the basis of health status cuts across the constituencies of both parties. Even in areas of polarized health policy, privacy and anti-discrimination are difficult issues to characterize along partisan lines. I argue that in this policymaking context, federal policymakers rely on interest groups to provide valuable information and perspectives from their constituencies. In policy questions about how the state can or should protect consumers during emergent technologies, interest groups provide critical information to policymakers about the status of consumer confidence and thus the viability of technological innovations.

In sum, delegated rationalization leads interest groups and policymakers to converge in their preferences about governing emergent information technologies. Specifically, social policies to delegate healthcare rationalization to private actors and individuals shaped their relationships with consumer data and incentivized interest groups to support protecting consumer trust in information systems. Voters, meanwhile, do not mobilize as consumers but indirectly motivate the policymaking process through their behavior in healthcare interactions. Federal policymakers rely on interest groups to provide information interpreting the status of consumer confidence and thus the viability of emergent technologies, while the non-partisan distribution of health status issues among voter constituencies leads to the emergence of bipartisan support for formal consumer protections against data-driven discrimination.

Research Design

This theory implies that when healthcare rationalization is delegated to private actors and individuals, the federal government is more likely to intervene to protect consumers against data-driven discrimination. In order to test this hypothesis about federal government intervention in consumer protections against data-driven discrimination, I conduct in-depth case studies on three cases of health data technological change and examine the federal policy responses towards regulating their use in health insurance. As a relatively unpolarized policy domain, health information technology regulation allows me to understand how interest groups influence policy change beyond partisan politics in an environment of high uncertainty. To identify the most relevant cases for the study and to build policy histories for my selected cases, I relied on policy summaries produced by the Congressional Research Service (CRS) and drew on the historical scholarship about federal data governance and consumer protection in U.S. health insurance. I also used the Congressional Record, Congressional Quarterly Almanac, and the Congressional Quarterly Researcher to build an original dataset of federal policy decisions related to the three health technological innovations that I selected for my cases.

Case Selection

The first case focuses on experience rating and federal responses prior to 1980. In the first case, I describe the emergence of experience rating in health insurance and the delay in federal intervention decades after its widespread adoption in the private insurance market. Experience rating is an actuarial method that relies on historical health-related records, such as medical claims and filed expenses, to predict future healthcare costs and determine premium rates for groups or individuals. Insurers argued that such strategies were consistent with actuarial practices in matching risks with costs, but opponents charged that the transition from community

rating to experience rating introduced data-driven discrimination into health insurance and reallocated the burden of healthcare costs to those in poor health. In this case, the federal government remained unwilling to directly address data-driven discrimination for decades until the passage of the Affordable Care Act in 2010 altered the market for private health insurance. This chapter shows that the regulation of data-driven discrimination does not necessarily follow the introduction and adoption of a new health data technology. Instead, the establishment of the private benefits system in health insurance and residual public programs fragmented interest groups. The lack of convergence among interest groups over data-driven discrimination and federal policymakers' reliance on new expansions in the public-private welfare state contributed to the decades-long delay in consumer protections.

The second and third case studies form the core empirics for testing how rationalization shapes data governance in health data systems. In these two cases, I explore contemporary health data technologies that resulted in new federal legislation to protect consumers. The second empirical case examines federal legislation passed to protect patient data privacy in electronic health records (EHR) during the 1990s. EHR encompasses the digitalization of patients' paper charts, including their comprehensive medical history, diagnoses, medications, allergies, treatment plans, dates of immunization, radiology images, and laboratory test results. The introduction of EHR allowed healthcare providers to access and share patient information across many different healthcare settings and improved efforts to coordinate care across healthcare entities. Digitalization and greater data-sharing of patient health information spurred fears of privacy violations and misuse of sensitive health-related information by parties other than patients and providers, namely insurers access to EHR for underwriting. As the first federal law to address discrimination on the basis of health status, the Health Information Portability and Accountability Act (HIPAA) established privacy rules and expectations in the use of medical

information across healthcare entities. The case of HIPAA and regulation of EHRs shows that the federal government intervened to protect consumers against data-driven discrimination as diverse interest groups converged over bolstering both patient and provider participation in EHRs as the technology became integral to healthcare rationalization.

The third and final case concerns the development of human genomics and the federal government's expansion of anti-discrimination law to include genetics in health insurance and employment during the 2000s. Genomics, the study of an organism's complete set of DNA, aims to understand all of an organism's genes and their functions. The successful sequencing of the human genome in the 1990s and early 2000s created a new form of health status data that revealed hereditary links to diseases, providing unprecedented, individualized information about health risks. In its ability to predict disease, genomics engendered a lively debate about the potential for data-driven discrimination based on results from genetic tests. In the face of consumer apprehension, federal policymakers moved to protect the cost-saving benefits of genetic technology through expansions of anti-discrimination law. The case of federal intervention in genetic information with GINA shows that federal action against data-driven discrimination followed growing reliance of the government on genetic data technologies and their associated interest groups to reform health care.

To improve the internal validity of my cases about federal data governance, I limit my cases to events of U.S. federal consumer protection in areas concerning health information technology.[5] In each of these cases, an emergent technological innovation disrupted current

[5] To select my three cases of health data technologies, I define information technological change as an innovation that causes a disruption to the format of individual-level information. This definition of information technology is necessarily subjective, as is the criteria upon which cases are deemed comparable in a research design (Gerring 2007: 53).

health data practices in ways that prompted concerns about the potential or actual practice of data-driven discrimination by health insurers. Although in each case policymakers considered the potential for data-driven discrimination to affect consumers, the federal response to formalize consumer protections varied.

Selecting cases that share characteristics across all cases, despite varying policy outcomes, allows me to rule out alternative explanations. By limiting my cases to the contemporary U.S. and to policymaking at the national level, I eliminate explanations for policy variation across the cases such as electoral and regulatory institutions, legal culture, and international standing since these have remained relatively stable over the time period of the cases (Lynch 2005). To further improve internal validity, my policy case studies are drawn from the post-war period and examine federal policymaking after the passage of the Civil Rights Act of 1964, when the U.S. first introduced national-level anti-discrimination legislation. I select cases that take place after the Civil Rights Act because I am interested in how the state addresses "data-driven discrimination" in health status that may not constitute unfair treatment on the basis of protected categories established by civil rights law but nevertheless mirror systematic social inequities.

In choosing these three cases, I use a combined most-different and most-similar case design to first identify the variable of interest – in this case delegated rationalization – before conducting in-depth process tracing. In most-different cases, the pair of cases are different in all dimensions that typically matter for consumer protection policy outcomes except for the context of emergent health information technology, the variable of interest, and the outcome of federal intervention. The cases of genomics and EHR are different in their level of public salience of the discrimination problem, public political engagement, and party control of Congress during the main legislative effort. These are all dimensions that could be reasonably expected to affect the

outcome, yet they do not explain the way in which the theorized mechanism plays out. Both cases involved a successful federal policy response against data-driven discrimination, and both unfolded in the shadow of rationalization policy in health care. By tracing the hypothesized causal mechanism in both of these cases, I test whether the mechanism works in a similar fashion in both cases despite their differences.

In most-similar cases, the pair of cases are similar along key dimensions except for the variables of interest and the outcomes. The cases of experience rating and EHR are both cases of health data interventions in health insurance that involved similar levels of low public salience of data-driven discrimination and public engagement, yet the time period of each case means that the rationalization policy had not yet taken shape during the advent of experience rating.[6] The federal government intervened against data-driven discrimination in the case of EHR while such a response was delayed for experience rating until the passage of the Affordable Care Act (ACA) in 2010.

Methods and Sources

In order to test my hypothesis that delegated rationalization in health care affects federal health data governance by shaping interest convergence among diverse groups and policymakers, I employ the method of process tracing in each of my cases. Process tracing is an in-depth case study method in which the observable implications of several promising, competing hypotheses about causal mechanisms are tested against the historical record to identify the most plausible explanation for within-case variation (Beach 2019, 2020; Bennett 2010). In other words, cases

[6] The cases do differ in terms of party control of Congress during key legislative moments, as experience rating took place during a Democrat-controlled Congress while the federal response to EHR happened during the Republican takeover of Congress, but this is arguably in ways that challenge assumptions about the likelihood of consumer protection in a Democrat-controlled Congress.

are studied in-depth to understand the links that connect the hypothesized causes with the observed outcomes.

The method of process tracing can be used alongside a comparative case design to improve the generalizability of theorized causal mechanisms. Combining process tracing with comparative cases is key to making more generalizable claims about the mechanisms identified in a single case, since different contexts may change the way in which causal mechanisms work from case to case (Falleti and Lynch 2009). I thus trace the theorized process in two cases and include a contrasting case in which neither the causal mechanism nor the outcome is present. By asking the same questions of the historical data in a structured comparison of these three cases, I show how the theory operates in more than one case. Process tracing methods allow me to identify and evaluate the hypothesized mechanism of interest convergence linking together my theorized explanatory variable of rationalization with the policy outcome of consumer protection. However, although I can reject alternative hypotheses logically or empirically, I cannot definitively rule out all other possible explanations using these methods (Beach and Pedersen 2013; Galvin 2015).

In each of the selected cases, I test my theory against alternatives to determine how well my hypotheses can explain the policy trajectories of data-driven discrimination in health information technology. Although the cases were selected to provide a comparison between cases with varying outcomes in federal intervention, the primary benefit of process tracing is the ability to study change over time within each case. Process tracing of policy development involves examining a sequence of events – multiple instances of problem creation, policy enactment, and implementation – in the policy process (Howard 2017). These repeated occurrences allow me to observe variation in key dimensions *over time*, such as the extent of the federal government's role in regulating consumer data, the types of protections that are proposed or passed, and the

behaviors and relative influence of different interest groups at multiple points in time. This is done to pinpoint which changes over time contributed to the historical outcome while eliminating constants as alternative explanations. The attention to temporal change allows me to examine policy change that occurs *within* each historical case and to examine how rationalization as a welfare state institution affects interest group and policymakers' behavior in this policy change.[7]

In the empirical chapters, I draw on a variety of primary and secondary sources. These sources include historiographical and journalistic accounts of health policy, as well as policy analysis from the Congressional Research Service (CRS), the Kaiser Family Foundation (KFF), and The Commonwealth Fund. I also rely on the text of statutes, regulations, Congressional hearings and floor debates, and summary reports of the relevant laws and policies to understand the context and substance of the laws. To understand the behavior of interest groups, I draw on archival sources from industry associations. Since many archival materials are held by private companies or by trade associations and they are not available to the public, I relied on documentation about the political activity of industry organizations from the federal government and public interest groups including the American Civil Liberties Union (ACLU) and the National Consumer Law Center (NCLC). Secondary sources that previously gained access to similar archival materials were also a helpful resource.

The unusual arrangements in American health insurance and the status of the U.S. as an international outlier in health outcomes has generated an immense amount of scholarly and critical work. As a result, there exists a remarkably rich and varied literature about the history of

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[7] There are always trade-offs in research design. Although in-depth case studies can help to elucidate the mechanisms by which organized interests affect policy change, case studies can also "overestimate the extent to which organized interests affect policy" given case selection biases since "it is difficult to specify the class of political controversies to which they can be generalized" (Schlozman et al 2012: 310).

health policy and the reasons for Americans' experience with coverage and cost problems. I use this abundance of existing analysis of health policy reform to my advantage. Although the existing research provides ample analyses of the successes and failures of American health reform and the historical contingencies leading to the U.S. public-private welfare state, few if any examine this history from the lens of consumer regulation or data protection. In this chapter, I draw extensively on the interdisciplinary secondary literature, but I bring this existing work on health policy into conversation with the concurrent historical and legal scholarship on data privacy. By reinterpreting the secondary literature and combining it with a different set of primary sources than what is typically referenced in histories of health policy, I build my argument about the relationship between welfare state institutions and the development of federal protections for consumer information.

Conclusion

As data about individual health become cheaper and abundant, insurers, providers, and employers have improved their ability to assess health and income risks more accurately. The extent to which these users of information are able to use information in this way, however, depends on the data governance environment in which new technologies emerge. This project is driven by the question why the federal government sometimes limits the use of data-driven discrimination in emergent health technologies. The cases of technological change and policy responses to data-driven discrimination in experience rating, digitalization of health records to EHR, and genomics provide insights into the mechanisms of policy change in governing data.

Government regulation is a flashpoint in the debate over the role of the state in emergent technologies and in protecting consumers against discriminatory uses of their information. In the case of data-driven discrimination, the intervention of the federal government has consequences

for how private market actors do business and the extent to which technological advancements can be used. Should private market actors be concerned about anything other than maintaining their profits and managing their financial risks? Or should they be subject to rules and regulations that advance political or social goals even if they are at the expense of economic efficiency and sound risk management? The political debate over federal regulation of data-driven discrimination engages with these questions.

This project presents a theory about the process by which discrimination on the basis of health data becomes legally unacceptable. The argument implies that the welfare state's institutional arrangements can affect how the state regulates the use of health data in information technologies. By focusing on the pivotal role of interest groups in interpreting the problems of technological change during highly uncertain contexts, I aim to understand how existing welfare state institutions affected the policy preferences and motivations of key stakeholders in emergent problems of data governance. I draw from theories about policy feedback and policy change and apply them to interest group behavior to understand how and why interests converge over government intervention. In doing so, I argue that prior policies can affect subsequent rounds of policymaking in *different* domains in ways that reinforce earlier policies.

CHAPTER 3: EXPERIENCE RATING AND THE DELAYED DEVELOPMENT OF FEDERAL PROTECTIONS AGAINST HEALTH STATUS DISCRIMINATION (1945-1980)

Introduction

For decades, insurers and policymakers have grappled with how to determine coverage and pricing in the business of private insurance. On the one hand, data about individual health status can help insurers assess the future healthcare needs of their enrollees and help insurers manage healthcare costs. On the other, this logic of managing risk through "health status discrimination" plays out in a commercialized healthcare system by distributing affordable health care away from the people who need it most (Stone 1993; Roberts 2012: 1203-1204). The spread of experience rating in private insurance plans in the 1950s and the adoption of health status discrimination across the insurance market segmented the patient population into low-risk, low-need individuals able to access affordable health insurance and high-risk, high-need individuals that struggled to do so. Key stakeholders in insurance at the time recognized that trouble was brewing with the turn to experience rating. As early as 1952, plan directors at an annual Blue Cross conference "condemn[ed] the practice [of experience rating] as 'contrary to the community service ideal' and likely to 'destroy the voluntary, non-profit prepayment plans throughout the United States'" (Starr 1982: 330). Federal policymakers sensed that a healthcare system based on private insurance and tied to employers could leave out vulnerable groups but supported its growth, nonetheless.

These dire warnings would give way to the transformation of Blue Cross as the non-profit carriers adopted experience rating under intense competitive pressure from commercial insurers. Meanwhile, federal policymakers turned towards expanding categorical social safety net programs to address the consequences of health status discrimination. The establishment of Medicare and Medicaid to cover the aged and poor was a landmark achievement in the expansion

of public insurance, yet it left gaps in coverage that would trap individuals ineligible for both private and public insurance between the "Medicaid-private insurance corridor" (Starr 1982: 374). Despite arguments that the logic of experience rating would eventually destabilize private health insurance and evidence that health status discrimination was invasive of personal privacy and abusive at worst, federal consumer protections against health status discrimination in private insurance were delayed until the 1990s.

This chapter considers the history of consumer regulations in health insurance from the early dominance of experience rating in the 1950s to the end of the consumer movement in the late 1970s. As health economists have shown, experience rating "rearranges the cost burden of health care but has little or no effect on overall costs" (Austin and Hungerford 2010: 48). In this chapter, I ask specifically why – even as consumer advocates made significant inroads for protection in various markets, civil rights activists successfully argued for anti-discrimination protections for race and gender, and the inflationary consequences of health insurance discrimination for high-risk groups became increasingly clear – federal policymakers delayed in intervening in private insurance markets.

The political development of consumer protection is a relatively understudied aspect of health policy compared to issues of financing arrangements and cost control. However, consumer protection against health status discrimination is intimately related to these central issues, and additionally it is a good window through which to examine how the government's approach to regulating consumer personal information has evolved over time. Industry groups have deep stakes in the way in which the government regulates personal health data and the ways in which it can be used. Information about individual health status is uniquely sensitive, and the vast increase in genomic information over the last thirty years has further heightened the stakes. One's

health status can be extremely valuable to both the physicians tasked with providing care and to insurers responsible for paying for it.

Consumer protection in health insurance poses a complicated regulatory problem for state and federal regulators.[8] Like product markets, consumer protection regulations can increase costs to producers that are passed on to consumers. Unlike in other markets, however, consumer protections in health insurance redistribute costs so that the most desirable consumers leave the market. In health care spending, about 20% of a large insured population is responsible for 80% of that population's health care spending (Reinhardt 2016: 1347). With protections against health status discrimination, the costs of covering this minority of sick individuals are redistributed among a large number of healthy individuals. In other words, because the need for insurance varies greatly among the population, protective regulations result in low-risk individuals or groups facing higher costs. In this scenario, the low-risk groups will forgo coverage, leading to the problem of adverse selection in insurance. These dynamics incentivize a turn to smaller risk pools of insurance, the forgoing of coverage by individuals and employers, and coverage shortfalls among high-risk groups. Without a large risk pool created by mandated insurance, consumer protections against health status discrimination instead contribute to rising costs and worsening coverage for those who do enroll (Rosenbaum 2009: 113).

The technical difficulties of consumer regulation in health insurance notwithstanding, existing explanations attribute the delay of federal policymakers to address health status

[8] While I discuss protections for patients and health plan consumers as a consumer protection issue, I do not mean to imply that patients or health plan consumers behave as traditional market consumers. For a more detailed critique of the "patient-as-consumer" framing in health policy's market reforms, see Gusmano et al (2019) and Goldstein and Bowers (2015). For a historical view about how the language of the "patient-as-consumer" has changed between the 1930s-1940s and the 1970s-1980s, see Lee (2015).

discrimination to two different political problems: a collective action problem and a problem of unequal power resources. These alternative explanations, while they uncover some of the obstacles that faced federal policymakers in the early years of consumer protection in health insurance, are limited in several ways.

The collective action problem facing consumers is an oft-cited explanation for the obstacles facing consumer protection, but it is inadequate in explaining the early failure and later progress of consumer protections. Most famously associated with Olson (1965), collective action theory explains the failure of diffuse groups to mobilize to promote their interests and the difficulty of sustaining political action when incentives to free-ride outweigh the benefits of active participation. Consumer protection appears to be a classic example of a collection action problem in which the costs are concentrated, and the benefits are diffuse, and a small number of affected consumers are activated by consumer protection issues, but the vast majority remain politically quiescent. Furthermore, health status may be less resonant as a collective organizing identity for consumers than other categories such as gender or race.

While it is true that consumers faced many difficulties in collective action to organize, the delay in federal protections against health status discrimination cannot be fully attributed to collective action problems. Consumer groups, which were largely elite-driven rather than grassroots movements and led by lawyers, academics, and political entrepreneurs, were able to mobilize and lobby successfully for protections in markets in which the population was segmented by risk groups. These included federal rules against racial discrimination in mortgages and gender discrimination in credit and auto insurance during the 1960s and 1970s (Thurston 2018; Krippner & Hirschman 2022). Health status also manifested in the form of disability advocacy groups, demonstrating that it had resonance as an organizing dimension for consumer political action.

The second leading explanation pins the delay of consumer protections on unequal power resources of competing organized interest groups. In power resources theory, political power is derived from control over various resources, such as economic wealth, social connections, or knowledge, and those with more resources have greater influence and authority in shaping political outcomes through the legislative, regulatory, and judicial process. In the "organized combat" of politics, better resourced business groups often outcompete consumer groups. Industry actors, such as the powerful medical establishment and commercial insurers, have significantly more lobbying power than consumers or patients to argue for private insurance and oppose reform for more inclusive plans. Meanwhile, the public interest movement led by Ralph Nader distrusted the state to have consumers' best interests in mind, instead pursuing a reform strategy that put faith in pluralistic politics and made bureaucratic agencies more permeable to outside pressures including from organized business (Vogel 1980).

Nonetheless, taking a longer view of the development of consumer protections suggests that the initial failure of federal policymakers to address health status discrimination in private health insurance was not a matter of lopsided power resources between industry and consumer advocates. Anti-discrimination protections for racial discrimination were introduced in insurance regulation and insurers were subject to stringent regulations even if these were not explicitly about health status discrimination. In addition, states were more active in passing consumer protections about insurance, even though organized industry interests might be expected to have more power at the state level given lower barriers to coordination. In 1970, as the consumer protection movement revved up, organized business interests in medicine, hospitals, and the insurance industry were comparably "frail" and uncoordinated (Starr 1982: 382; Vogel 1989). The power resources theory thus fails to explain why consumer protections against health status discrimination did not occur during the height of the consumer movement. Rather, federal

protections progressed in the decades when the consumer movement had declined, and businesses had organized and mobilized in national politics.

The overall argument about regulatory policy development in health insurance is that the delayed start and later halting progress in consumer protection against health status discrimination over the last fifty years is the result of the development of welfare state institutions that shaped which interest groups emerged around the issue of consumer protections and their behaviors towards addressing health status discrimination. Specifically, the evolution of two institutions in American health care – the private benefits system and the residual role of the federal government in providing public insurance through the 1960s, and the delegation of health care rationalization to private insurers during the cost crisis in the 1980s – contributed to the emergence of interest groups that sparred over the content of consumer protections but shared enough in common to slowly promote limited consumer protections against health status discrimination over time.

In this chapter, I discuss the first of these two developments in the welfare state and how it contributed to the failure of federal policymakers to address protections against health status discrimination in health insurance throughout the rise and fall of the public interest movement. Consumer and patient interests first materialized in the 1960s and 1970s, respectively, alongside the politicization of "public-interest" consumer groups. Yet momentum for consumer protections rarely initiated protections in health insurance and patients never became a prominent political force in consumer anti-discrimination protections.

Certain institutional features in health insurance contributed to the early failure of federal consumer protections to address health status discrimination, specifically the entrenchment of a private benefits system by the mid-1940s, the changes to health insurance wrought by the

entrance of commercial carriers in the 1950s, and establishment of categorical social programs in public health insurance in the 1960s. I argue that these existing and newly established welfare state institutions from the 1940s to the 1960s shaped the behavior of federal policymakers and public interest groups away from protections against health status discrimination. The creation of Medicaid and Medicare addressed public concerns about issues of inequalities in health care but fragmented consumer and patient groups away from generalized claims against health status discrimination. Furthermore, the delay in regulating health status discrimination and health insurance information practices provided insurers with the ability to further develop and deploy "experience-rating" in plans, which widened the differences in pricing and coverage based on health status and further intensified insurer demand for consumer health data. These developments in the welfare state shaped the limited extent to which interest groups representing consumers and patients promoted federal protections against health status discrimination.

Experience Rating and the Problem of Health Status Discrimination

Through insurance, "humans have attempted to outcalculate fate, reapportioning misfortune so that no policyholder need face its effects alone" (Baldwin 1990: 5). Early efforts to hedge against new social risks among workers emerged during industrialization in the nineteenth century. In the United States, at least a third of adult males joined these "mutual aid societies" to pool their risks. These early risk pools were often built on trust and reputation, established as ethnically homogenous immigrant groups with shared languages, cultures, and ethnic identities. Although these organizations reflected concepts of solidarity, the motivations for solidarity were not necessarily the result of ideological principles; groups that faced similar risks and those that feared the future possibility of those risks could come together in support of risk-pooling, even if they did not come from the same social classes (Baldwin 1990: 20-29, 64). These associations

were relatively limited in their coverage and offered some forms of life insurance, payments for lost wages due to sickness, and financial support for burial costs.

Generally small and with strict membership requirements, these early risk pools tried to avoid problems of moral hazard and free riding, sometimes using intrusive and abusive community surveillance to keep its members in check (Iversen and Rehm 2022: 44-48). Breaches of personal privacy thus were part of early risk-pooling to address the challenge of collective action. In order to make insurance more feasible and scalable, predictions of risk were formalized in late eighteenth-century England and Scotland when mathematicians, along with clergymen concerned about the church's ability to support ministers' widows, developed the early actuarial logic undergirding contributory amounts for life insurance funds.[9] These actuarial methods formed the basis of insurance underwriting. In health insurance, underwriting meant the use of health status discrimination to determine risk and manage the solvency of insurance funds.

Before the Affordable Care Act (ACA) banned its use in 2010, health status discrimination was considered a necessary part of risk management in private health insurance. In health insurance, consumers have more information about their own health status than insurers. For insurers, any information that provides hints about the future health care costs of current and prospective members can help them avoid covering those who are expensively sick or to raise prices for those they anticipate will become sick. Data on individual health status, and on existing

[9] In Scotland in 1744, clergymen Robert Wallace and Alexander Webster collaborated with mathematician Colin Maclaurin to create "life tables" to calculate life expectancy and insurance rates. Meanwhile, the Englishman James Dodson developed the foundations of actuarial science beginning with his "First Lecture on Insurances" in 1756 in England (see Iversen and Rehm 2022: 45).

or potential health conditions in personal medical records in particular, were especially valuable to commercial insurers in assessing and managing potential healthcare costs.

The use of health status discrimination in private health insurance included ratings practices to determine the cost of premiums as well as rules about the content of coverage. As the primary source of insurance for working age Americans, private health insurance includes large and small group plans purchased by employers or unions from commercial insurers that are licensed by the state; individual insurance plans purchased directly by individual consumers; non-profit Blue Cross plans; and self-insured plans funded and provided directly by employers.

In determining costs, health insurers use "community rating" in which all members regardless of their health make the same contributions to the plan, or "experience rating" in which members are charged different premiums depending on their health "experience" i.e., their use of health services. Before the ACA explicitly banned experience rating in 2010 and implemented modified community rating in 2014, consumers in small group and individual health insurance markets were particularly susceptible to health status discrimination in insurers' determination of premium costs. For individual plans prior to the ACA, individual purchasers faced a poorly regulated market rife with low-quality and discriminatory plans. These individual plans were also more expensive and riskier than large group plans which benefit from economies of scale, reduced adverse selection from risk-pooling, and exemptions from income taxation (NBER 2009).

In terms of coverage, prior to the ACA insurers could include "pre-existing conditions" exclusion clauses to preemptively reject claims for treating certain conditions. Pre-existing condition exclusion clauses in plan contracts discouraged people with certain conditions from signing up, quickly becoming a tool for limiting coverage in individual, small group, and large group plans without the need for medical underwriting (Stone 1993: 304-305, 314). Additionally,

the clauses also did not just exclude patients – they also excluded providers from networks. Without the need to threaten exit from the market themselves, insurers could essentially block providers from accessing the healthcare market by refusing to pay for their services.

Although experience rating was limited in large group employer-sponsored plans and self-insured plans, health status discrimination in coverage also touched the group insurance market. Both large and mid-sized employer group plans used pre-existing condition exclusion clauses in their policies to limit the content of coverage prior to the ACA (Gottschalk 1986; Stone 1993: 305). These exclusions were difficult for state regulators to control after the passage of the Employee Retirement Income Security Act (ERISA) in 1974 exempted employers' self-insured plans from state regulations about costs, coverage requirements, and legal remedies.[10] Known as "ERISA plans," employer self-insured plans are funded by employers who also bear the risk of their employees' medical expenses. Today, most Americans have health insurance through employer-sponsored large group plans that are tax-subsidized, self-insured, and voluntary.[11]

Consumer protection laws against health status discrimination create guardrails against the misuse of patient information and define the conditions under which discrimination is considered illegitimate. Consumer protections against health status discrimination in health insurance have taken two main forms at the state and federal levels: protections against discrimination in underwriting, namely in the form of rating restrictions or modifications that limit the criteria and types of patient information that can be used to calculate premiums and the

[10] Employee Retirement Income Security Act, P.L. No. 93-406 (1974). For employer-sponsored health insurance, plans are community-rated so that all employees contribute the same amount from their paychecks to the plan.
[11] When I discuss "private insurers" throughout this chapter, I mean the insurance carriers of large group, small group, and individual insurance rather than employers that self-insure their employees.

allowable spread in pricing differences; and prohibitions or limits on coverage exclusions, through the use of coverage mandates, guaranteed issue requirements, guaranteed referrals, or bans against pre-existing condition exclusions. In the private health insurance market "the heart of actuarial fairness is distinction based on health status" (Rosenbaum 2009: 113). Nonetheless, what *kind* of health status discrimination is allowed has changed over time as a matter of law and regulation.

The ACA's new federal regulations against health status discrimination were possible only under a very specific set of conditions that coalesced after decades of development and change in the institutional and interest group environment for health insurance. With the assurance of a universal mandate for private insurance, private insurers were finally convinced that they could manage risks adequately without health status discrimination. The government's willingness to subsidize low-income and high-risk members while instituting new risk management mechanisms in the individual marketplace further allowed consumer protections to become feasible in private health insurance. Until these multiple conditions coalesced in the 2000s, however, the problem of health status discrimination in private health insurance posed a complicated regulatory problem for decades. In this chapter, I examine the delayed development of consumer protections against health status discrimination in health insurance, beginning with the 1950s when commercial insurers transformed the health insurance market, through the rise and fall of the public interest movement and the dramatic expansion of the regulatory state in the mid-1960s to the late 1970s.

The Delayed Development of Consumer Protections

The contours of health status discrimination as potential policy problem first emerged in the 1950s, when experience-rated plans began to dominate the health insurance market. From the

1950s to the rise of the consumer movement in the mid-1960s and its fall in 1978, federal consumer protections against health status discrimination in health insurance failed to materialize. As private health insurers competed to manage their risk pools by identifying and weeding out the sick and those more likely to be sick, federal and state governments faced an emergent policy problem of how to address rising health care costs while simultaneously protecting individuals and from health status discrimination and preventing commercial insurers from off-loading high-risk groups onto the public sector. In commercial insurance, high-risk groups of the aged and disabled would be priced out and virtually excluded from the market without government intervention. Instead of intervening in the private market, however, federal policymakers allowed commercial health insurance plans to flood the market and did little to staunch the adoption of experience rating even as raised costs for high-risk groups and threatened their coverage. Expansions in coverage during the 1940s and 1950s masked the negative effects of commercial insurance on who received coverage (Starr 1982: 327-328).

Although insurers have a long history of using individual health status information, experience rating set in motion the wholesale transformation of group health insurance and the perceived value of medical records for private insurers. The insurance industry has long demanded access to personal information, including sensitive records about health status. Early risk assessments in insurance had relied on "prejudicial social sorting" outlined in guides and manuals that categorized some racial and ethnic groups as uninsurable. Presented as objective, these guides such as the *Transactions of the Society of American Actuaries* in 1919, the founding document of the numerical rating system in risk assessment, reflected societal biases and understandings of social groups at the time (Stone 1993: 296). While life insurers relied on information provided directly by the applicant – including personal records about finances, medical experiences, and personal habits – health insurers were more interested in information

that could reveal a "person's character and propensity to make claims or likelihood of suffering a disabling illness" (Collins 1979: 37-38). This included occupational information, which became an important signifier of health risks for the life and later health insurance industry, as well as financial reports and medical records that revealed intimate personal details.

States had actively encouraged the growth of Blue Cross in the mid-1940s, granting legal charters that recognized Blue Cross plans as nonprofits and exempted them from general insurance laws and state taxes (Hacker 2002: 215). Commercial insurers, however, gained an edge by marketing towards employers' expanding benefit plans at competitive, experience-rated prices (Starr 1982: 329-330). With the entrance of commercial insurance carriers into health insurance, medical records and their usefulness in health status discrimination became vital to the business of insurance. Since its founding in 1902 in Braintree, Massachusetts, the Medical Information Bureau (MIB) has functioned as the life and health insurance industry's "central data bank" (Collins 1979: 40; Iversen and Rehm 2022: 49). A private trade association for the medical records industry, the MIB collects and catalogues medical information on insurance applicants and policyholders to protect insurers from inaccurate or fraudulent insurance applications.[12] Largely unknown outside of the insurance industry, the MIB was a critical source of relevant consumer information for commercial insurers throughout the evolution of health insurance in the 1950s and 1960s, as commercial carriers upended the community-oriented and provider-controlled Blue Cross insurance plans. By the 1950s, commercial insurance had taken over the private health insurance market, challenging existing Blue Cross non-profit insurers by offering "experience-

[12] Although the MIB began as a centralized medical records database, it no longer holds medical records or test results. Instead, the organization holds individual files with codes that signify medical conditions or other risk factors, such as information about adverse driving records (Garfinkel 2000: 180).

rated" plans that promised to better rates and significant savings for purchasers with "lower-risk" groups (Stone 1993: 301; Gottschalk 2000: 58).

Without the ability to exclude members based on religion, ethnicity, residency, or occupation as mutual associations had up to their demise in the 1950s, commercial insurers relied on the use of financial and medical records – or "experience" with medical care – to underwrite their plans. The life insurance companies Metropolitan and Prudential, which offered experience-rated group insurance plans, came to dominate the health insurance market by packaging together life insurance with pensions and health benefits, thereby providing a "one-stop service" for employer purchasers (Starr 1982: 329; Klein 2003: 10-11). As the market for health insurance became increasingly competitive, health insurers across the market adopted medical underwriting in order to provide more competitively priced but increasingly limited coverage. Blue Cross, the non-profit insurer once committed to community ratings, abandoned its former social insurance approach to avoid becoming "dumping grounds" for high-risk groups and subsequently lost its federal designation as a tax-exempt non-profit in the Tax Reform Act of 1986 (Starr 1982: 330; Hacker 2002: 201-204; Quadagno 2006). Health insurers turned more heavily to medical records, data about the utilization of health care, and demographic correlates of health including income, geography, gender, race, and age to determine the likelihood of making claims and falling ill.

Although managing risk is integral to insurance, the use of health status discrimination for cost and coverage decisions in insurance was a tool developed to commercialize health insurance and was subject to competitive pressures. Experience rating "changed the nature of competition in the health insurance market" as commercial insurers shifted risk to others "rather than finding more efficient was of managing risks for a given pool of subscribers" (Austin and

Hungerford 2010: 6). Some insurance carriers engaged in questionable ratings practices to gain an edge in the market (Stone 1993). Insurers also engaged in illegal means to gather individuals' information beyond what was available through the MIB. In a House committee report in 1980, for example, committee members claimed that "surreptitious trafficking in medical information was widespread." A particularly egregious example cited was a 1975 grand jury investigation from Colorado that "uncovered a 25-year history of medical records theft by a private firm whose investigators posed as doctors to solicit information by telephone or paid hospital employees to smuggle out medical records" to more than one hundred prominent insurance companies (CQ Almanac 1980). Highly subjective in practice, experience rating transformed the market for medical records and established health status discrimination as a virtual requirement for insurer competitiveness in the private health insurance market.

The movement for consumer protections came on the heels of the transformation of the health insurance market. During the mid-1960s and early 1970s witnessed a surge of interest in consumer protections. Public confidence in the leaders of major firms declined more than 50% in the mid-1960s to 15% by the mid-1970s, just as businesses were reaping record post-war profits (Vogel 1989: 42; Waterhouse 2017: 187-189). During this time, consumer legislation was the product of policy entrepreneurship by northern Democratic senators who began placing issues of automobile and consumer product safety onto the policy agenda (Vogel 1989: 38). In response to legislative efforts by political entrepreneurs, the public skepticism towards business translated into the emergence of public interest lobbies and a burst of policymaking to contain the worst tendencies of the private market. Between 1969 and 1976, legislators passed more than a hundred legislative initiatives to address consumer concerns about product safety in the retail, automobile, food, and financial industries (Trumbull 2012: 64). Efforts to regulate the pharmaceutical industry's collusion on drug pricing were less successful, but an "extremely high burden" for drug

safety passed with the Kefauver-Harris amendment to the Food, Drug, and Cosmetic Act of 1962 (Trumbull 2012: 175). Consumer protections represented a form of government intervention that could improve the welfare and wellbeing of Americans with minimal redistributive spending, and many a liberal politician jostled to take credit for consumer legislation.

The efforts of consumer activists and entrepreneurial politicians created some of the major regulatory agencies that we have today. By the mid-1960s, mandates established thirty-five federal agencies to protect consumers (Trumbull 2012: 63). From 1969 to 1974, the Nixon Administration oversaw one of the largest expansions of the regulatory state in the post-war era. Led by a Democrat-controlled Congress from 1955 to 1981, the federal government funded or created new regulatory bodies: the Equal Employment Opportunity Commission (EEOC), which had been created in 1964 with the Civil Rights Act, saw its budget increase from $13.2 million to $43 million between 1969 and 1974; the Environmental Protection Agency (EPA) was created in 1970 through Nixon's executive reorganization; the Occupational Safety and Health Administration (OSHA), created in the Department of Labor in 1971 by Congress, had "economy-wide" jurisdiction; and the independent Consumer Product Safety Commission (CPSC) was created by legislation in 1972. The Federal Trade Commission (FTC), which oversaw financial privacy regulations and would later be tasked with policing information privacy across many industries including on the Internet, was reorganized and revitalized as the Nixon Administration responded to recommendations by the American Bar Association. As a result, between 1969 to 1978 the FTC transformed from an antitrust enforcer to an "activist consumer agency" (Vogel 1989: 91, 163; Harris and Milkis 1996: 141; Eisner 2014: 107-109).

The public revelation of centralized data banks in the mid-1960s struck at the heart of the consumer records industry. Physicians had played an early role in the creation of early risk

management in the 1800s, providing information about their patients on illness and mortality that was useful for calculating risk in life and, later, health insurance (Bouk 2015). These uses of medical records stayed relatively hidden from public scrutiny until the mid-1960s, when the advent of computerization and data centralization set off a public panic about general misuse of personal information by government and private actors. Both the mass public and public officials uncovered a vast system of information systems that governed their access to services and markets. In response to these fears, individuals, citizen groups, and public officials turned to federal and state legislation to regulate the use, collection, and exchange of personal data (Igo 2018). The federal government chose to create a statutory "right to privacy" of personal information in the Privacy Act of 1974 and formulated principles for "fairness" in the use and access of personal data in the 1973 HEW Report on *Records, Computers, and the Rights of Citizens*.[13] Nonetheless, these were limited to governing the interaction between individuals and federal agencies.

The successes of consumer advocates in the late 1960s to mid-1970s and a Democrat-controlled Congress seemed to portend a window of opportunity for ambitious consumer protections. Consumer protections have political appeal because they are a "vehicle by which liberal politicians could continue to increase the responsibilities of government without increasing federal spending." The costs of reform would be borne instead by the regulated industries and passed onto consumers, who were more willing to shoulder the additional costs in a healthy national economy (Vogel 1989: 40-41). The emergence of experience rating and public concerns about the privacy of consumer records seemed to suggest a potential for greater mobilization on the part of patients and consumers for protective regulation. Lastly, not only did

[13] The Privacy Act, P.L. No. 93-579 (1974).

the practice of health status discrimination increase costs for high-risk groups in private insurance, but it also pushed a greater burden of covering the cost of these groups to the public sector. Federal policymakers, however, did little to address the rise of experience rating or the adoption of health status discrimination across health insurance. Why were consumer protections in health insurance largely absent from the larger push for consumer regulation during the movement's heyday in the 1970s?

State-level efforts to address the problem would emerge only in the 1980s while federal consumer protections against health status discrimination in health insurance would be delayed until the 1990s, when Congressional efforts to salvage parts of the Clinton Administration's failed healthcare reform resulted in the Health Insurance Portability and Accountability Act (HIPAA), which included the first federal statutory protections for consumers from health status discrimination. Even as experience rating raised rates for those most in need of medical care and generated intense demand for third-party access to sensitive medical records, it failed to generate more protections for consumer or patient interests.

Welfare State Institutions, Interest Groups, and Policy Development in Consumer Protections

Despite the arguably unique challenges of consumer protection in insurance regulation and its potentially inflationary effects, there is nothing that suggests health insurance, or its practice of health status discrimination, was a uniquely untouchable corner of business. For one, the practice had only become recently widespread in the 1950s with the entrance of commercial insurers. For another, there were successful efforts to address discrimination in risk assessment in other industries with similar obstacles. Consumer regulations of the financial industry targeted fairness of risk assessment in the marketing and granting of loans, especially as consumer and mortgage

debt ballooned in the late 1950s and early 1960s. In addition to the Truth in Lending Act (1968), which required credit-granting institutions to disclose the annual interest rates of their loans, consumer activist groups protested the practice by private banks and government lenders of using race and gender as proxies for financial health (Thurston 2018; SoRelle 2020). These protests and their resulting statutes – in housing, credit reporting, and access to credit – helped to anti-discrimination in lending and establish consumer expectations of expanded and "fairer" access to goods and services.[14] Policymaker fears over the inflationary consequences of regulation are also not enough to explain the delay in protections against health status discrimination, at least until the mid-1970s. During the 1960s and 1970s, the dominant trend in government regulations changed from economic regulations, which had been primarily concerned with economic stability, to social regulations that expanded government's purview into health and safety aspects of business behavior (Waterhouse 2017: 187-188).[15] While economic realities in the mid-1970s eventually tempered ambitions for broad government regulation, the problems of health status discrimination had surfaced during an earlier period of strong business performance and had contributed to increasing rates for high-risk groups.

What cannot be overlooked in the delayed development of federal consumer protections against health status discrimination is the institutional and interest group context in which the health status discrimination issue emerged. Existing and newly established welfare state institutions shaped the behavior of federal policymakers and public interest groups away from protections against health status discrimination. Specifically, I argue that three factors

[14] These statutes include the Fair Housing Act of 1968, Fair Credit Reporting Act of 1970, and Equal Credit Opportunity Act of 1974 that established the statutory basis for anti-discrimination law in banking, finance, housing, and personal financial information.
[15] For a different view, see SoRelle (2020) who argues that "social regulations" about consumer safety in the financial sector were ultimately driven by policymaker concerns about economic stability.

contributed to the trajectory of consumer protections from the 1950s to the late 1970s. First, the entrenchment of a private benefits system by the mid-1940s positioned the federal government not as a consumer advocate with regulatory authority but as the "residual provider" for those excluded from the private market. Second, the increased reliance on experience-rated plans in the 1950s intensified the individual stakes of consumers in protective regulations about their health insurance and personal information. The establishment of categorical but limited public insurance in the 1965 passage of Medicare and Medicaid, alongside the expansion of experience-rated private insurance, served to fragment the public interest movement into diametrically opposed groups. Lastly, the creation of categorical public insurance and laws against racial and gender discrimination in the 1960s successfully preempted the primary champions of antidiscrimination, the civil rights movement, even when the dimensions of discrimination by private market actors had become increasingly complex and hidden by the end of the 1970s.

The Federal Role as Social Safety Net

The development of the post-war American health insurance system set federal policymakers on a path towards providing categorical and residual social services instead of playing an explicit consumer protection role. In the 1930s, reformers shifted their priorities from sickness benefits, which aimed to replace lost wages in the event of illness, to better access to services and insurance against growing medical costs. The success of early Blue Cross plans, which relied on pooling risks by employer groups to provide insurance, during this time was further encouraged by federal policymakers who permitted companies to offer health insurance benefits despite wage-and-price controls. During the Second World War, employment-based health insurance expanded and cemented in place the system of private health insurance benefits. Commercial insurers, convinced by the Blue Cross experience of the viability of selling health insurance, targeted

employers with healthier workers and sold them cheaper "experience-rated" plans (Starr 2013: 36-43). By the 1950s, a voluntary system of private health insurance had become the primary social insurance mechanism for covering the costs of health care.

In the context of private insurance entrenchment and the growing market share for commercial insurers, federal policymakers grew concerned about those excluded from the private market even as they encouraged its expansion. As early as the 1930s, themes of the federal government's support of a "right" to medical care had appeared. President Roosevelt included a "'right to adequate protection from the economic fears [of illness]" in his 1944 State of the Union address. Expanding access to medical care through taxes was generally supported by the public, as evidenced by opinion polls in the 1940s showing that almost three-quarters of Americans approved of this approach (Schlesinger 2005: 96-97). While the policy issue of health status discrimination would not be fully articulated until the 1980s and 1990s, when reformers adopted this framing of consumer protections to promote regulatory interventions, it became increasingly clear during the 1950s that the growing private health insurance system did not favor those of poor health status. Although the growth of commercial insurance plans provided a greater variety of insurance options and lowered costs for some groups, providing competitive rates for lower-risk groups, however, pushed high-risk individuals out of coverage. Federal policymakers knew that private insurance, especially a system tied to the employment relationship, could pose problems; Social Security administrators "were very well aware of what difficulties [federal policymakers] were creating for the future" by relying on voluntary private insurance through employment (Hacker 2002: 226). The bulk of federal policymaker concern focused on the elderly and the disabled, two groups clearly excluded from employment, since the architects of Social Security remained in the federal government and colored the goals for social policy reform (Starr 2013: 43). Rather than challenge the system of private, employer-based health insurance and its

tendency to discriminate against poor health risks, federal policymakers supported its expansion even historical precedent and industry opposition stymied the government's regulatory abilities.

Federal policymakers recognized the early drawbacks of commercialization in health insurance, but the established consumer protection role of the states and the opposition to federal regulation from insurers prevented the federal government from addressing health status discrimination. In some ways, it is unusual that federal policymakers chose to expand the government's provision of health insurance to address health status discrimination rather than to rely on greater government regulation of private insurers. However, after years of facing virulent resistance against federal intervention through compulsory insurance, federal policymakers were less than willing to intervene directly in the business practices of commercial insurers. Insurers, historically regulated by the states since 1868, had also been largely protected from federal regulation and were extremely wary of any increased federal scrutiny of their practices. States' primary regulatory role in insurance was codified in the McCarran-Ferguson Act of 1945, which gave state regulators the power to license insurers to operate in the state (Mach and Fernandez 2014; Webel 2018).[16] The Eisenhower administration's reinsurance proposal in 1954, which aimed to encourage private insurers to extend coverage to high-risk groups by providing a one-time indemnity of $25 million, failed when insurers and the AMA lobbied against it. The proposal would have required insurers to provide evidence of their losses to federal authorities, a step that insurers warned would set a "dangerous precedent" of federal regulation in the industry (Hacker 2002: 238). In another effort to forestall federal intervention, insurance companies of all sizes "liberalized their underwriting rules" starting in the mid-1950s and extended coverage to groups that had been "previously classed as uninsurable" (Decormis 1961). These gestures may have

[16] McCarran-Ferguson Act, P.L. No. 15 (1945).

convinced federal policymakers to step away from regulating private insurance practices, but it did not erase the problem of unaffordable coverage for the poor or unemployed.

In the 1960s, the landscape of American health insurance reform was defined by inadequate coverage for the aged as hospital costs grew and a concern that there were not enough doctors and nurses to provide services to everyone who needed them. Just as the U.S. consumer movement had used research and public exposés to stoke public indignation over product safety, documented disparities in healthcare coverage showed that families without full-time, able-bodied workers and individuals most likely to need medical care, namely the elderly and chronically-ill, were disproportionately uninsured. Although the majority of American workers were covered by private insurance by the 1960s, the introduction of the National Health Interview Survey in 1958 revealed stark racial and income disparities in health care. Spurred in part by from the evidence from this survey, political pressure built up for a major federal intervention in health insurance (Smith 2003: 43).

The establishment of Medicare and Medicaid in 1965 set an important, if flawed, precedent for a more inclusive but costly form of health insurance.[17] The Democratic majority in Congress, bolstered by Lyndon B. Johnson's presidential victory in 1964, provided the opportunity for reform. The result was the creation of the landmark public health insurance programs Medicare and Medicaid. Since their formation in 1965, the public programs Medicare and Medicaid have covered the elderly, disabled, and poor – groups that may struggle to secure employment with health benefits and that private insurers on the individual market do not want to cover. As a contributory entitlement program, Medicare uses eligibility rules that require only

[17] Medicare and Medicaid Act, P.L. No. 89-97 (1965).

that recipients have contributed through payroll taxes. Medicaid, on the other hand, specifically targets those who are likely to be excluded from the private insurance market because of their lack of funds.[18] By creating a program for the elderly with Medicare, the constituency most in need of coverage, health reformers had closed a major gap in the employer-based health insurance system. By targeting specific groups, however, the design of these health insurance programs and their passage set U.S. health reformers on a path towards categorical rather than universal coverage expansion (Hacker 2002: 248-250). The aged and the poor were covered through Medicare and Medicaid, respectively, while later additions to Medicare and the creation of the Supplemental Security Income (SSI) program in 1974 included the disabled and those with end-stage renal disease. The Children's Health Insurance Program (CHIP) created in 1997 helped to cover low-income families with children. Thus, expansions in health insurance in the U.S. have been achieved through the piecemeal creation of categorical programs and the subsequent protection or reform of these programs.

While providing an avenue to tackle health status discrimination head-on, the successful passage of Medicare and Medicaid effectively removed the pressures to challenge the dominance of private insurance during the "window of opportunity" afforded to Congressional Democrats in the 1960s. The creation of public insurance for the aged and poor also served as a safety valve for commercial insurers, who could continue to shed higher-risk groups and push the cost of providing their coverage onto the public. Blue Cross, private insurers, and the American Hospital Association had all come to realize that these high-risk groups were challenging to cover without public help. Private insurers did not object to later proposals to expand Medicare to cover

[18] Eligibility for Medicaid varies greatly across states, and rules omit many different households (e.g., two-parent families, childless couples, widows, single people under 65, families with low-wage working father, medically needy families).

catastrophic care because insurers "had no desire to pay for lengthy hospital stays beyond the Medicare limit," though healthcare providers later came to reject Medicare expansion as a threat to their price-setting power (Quadagno 2006: 148-155). With the state footing the bill, these relatively generous programs paid for whatever providers charged and subsequently ballooned in cost.[19]

Federal policymakers also opted to step away from a stronger consumer protection role in private health insurance, leaving state regulators to keep watch instead. Even as the national health insurance landscape changed in the 1950s and 1960s, state regulators retained their role as the primary advocate for consumers. Until 1944, the U.S. Supreme Court had supported the view that insurance is "an activity other than commerce and, as such, not the subject of federal regulation. The Supreme Court's ruling in *U.S. v. Southeastern Underwriters Association* (1944) recharacterized insurance as "commerce" and motivated Congress to clarify in the McCarran-Ferguson Act (1945) that states held the primary responsibility in regulating insurance (Markus and Hauch 1972: 4-5). The National Association of Insurance Commissioners (NAIC), the leading representative organization for state insurance regulatory officials, drafted model laws that allocated significant power to state insurance commissioners during the mid-1940s to early 1960s while Congress largely "ceded authority to regulate insurance" to the states (Webel and Cobb 2005: 8-12). State insurance regulators, however, largely viewed the direct regulation of commercial health insurance rates as beyond their responsibility even as they aimed to preempt federal law. In Congressional testimony by the NAIC, state insurance regulators argued that

[19] In fiscal year 2022, the federal government spent $1.5 trillion on Medicare, the single most expensive budget function of the federal government (USASpending.gov).

"health insurance, especially that written on a group basis, has a history of being quite competitive" (Markus and Hauch 1972: 11).

As I elaborate in the following chapter, the federal position on insurance regulation vis à vis the states would gradually shift after the passage of ERISA's preemption clause. ERISA incentivized the creation of loosely-regulated self-insured plans beyond states' regulatory jurisdiction but also paved the way for a greater federal role in consumer protection.

The Fragmentation of the Public Interest

The reticence of the federal government in addressing health status discrimination was exacerbated by the failure of patient-related interests to form a coherent political coalition around health status discrimination. The public-private system of health insurance split Americans split between the employed and unemployed, the young and the aged, and the healthy and the sick. What has been discussed to a lesser degree but had significant implications for the development of consumer protections is how these divides weakened the public interest movement that had emerged during the 1960s and its push for stronger consumer regulations.

Consumer groups were not so much absent from the health status discrimination issue as they were increasingly fragmented over their concerns about the health sector. Early progressive consumer groups like the Consumers Union in the 1930s and 1940s had advocated for patients by arguing for universal health insurance. In an analysis by Lee (2015) of *Consumer Reports* articles from 1936 to 1949, the lack of affordable health insurance took center stage as the Consumers Union criticized the AMA's opposition to national health policy reform. By the 1960s, however, consumer groups had backed away from the insurance issue; their concerns had effectively been addressed with the growth of employer-sponsored coverage and the establishment of Medicaid

and Medicare (Lee 2015). Consumer groups returned in the mid-1970s to the health policy debate with the urging of organized labor, but by then the representatives of the "public interest" – many of them led by activist lawyers and academics rather than grassroots consumers – had fragmented into several opposing groups.

In a changing health insurance system organized along risk groups and tied to private sector employment, there was no single political constituency promoting protections in private health insurance even as the consumer protection movement reached its height in promoting environmental and social regulation in other product markets. Instead of organizing to promote protections for the larger patient population, consumer interests quickly fragmented into different segments with diametrically opposing goals. Patient groups and specific disease-oriented groups emerged to promote individual rights and a targeted form of anti-discrimination by categorically banning discrimination by disease status. For instance, interest groups representing people with Tay Sachs, sickle-cell anemia, and diethylstilbestrol (DES) syndrome lobbied against underwriting on the basis of their disease during the 1970s (Stone 1993: 310). On the more radical end of patient advocacy, the Oregon Insane Liberation Front emerged sometime between 1969 and 1970 to promote consumer rights for mental patients (Tomes 2006: 722). Labor unions, arguably the largest and most well-organized proponents of the public interest, retained some interest in expanding public health insurance but were internally riven by commitments to protect the terms of the private, employer-sponsored insurance plans that they had negotiated (Stevens 1990; Gottschalk 2000; Klein 2003). Lastly, consumers concerned about discrimination on the basis of personal health information did mobilize, but in the form of privacy advocacy groups that promoted federal protections against third-party access to personal medical information. This particular approach, which aimed to limit information access by both private actors and government agencies, would later stymie the efforts of insurance regulators to monitor

for health status discrimination. Distrustful of both government and business, privacy advocates have tried to prevent government regulators from accessing personal health information without individual consent. Civil rights groups, meanwhile, had targeted racial and gender discrimination in health insurance but failed to recognize how health status provided a useful proxy for the very categories that they had worked so hard to protect.

Although early consumer interests about patients had engaged in health insurance reform, patient interests in the 1960s and 1970s focused almost entirely asserting individual rights in the patient-provider relationship. Some of the earliest efforts by patients to assert their rights occurred in the 1950s, when a series of cases brought by patients to the courts formed the law of informed consent, or the right of patients to be informed of treatment plans (Rodwin 2003). As healthcare costs grew in the 1970s, segments of the consumer movement became increasingly critical of the medical profession. The Health Research Group, the first branch of Nader's Public Citizen consumer advocacy organization, took aim at physician expertise and "tried to provide consumers with a directory of doctors as well as their fees, hours, and other items, in an effort to provide patients with the information they needed to make informed decisions about their care" (Gusmano et al 2019: 370). Advocacy groups and a new social movement for mental health patients also asserted a patient-centered approach to health care. Led first by psychiatrists, lawyers, and academics and later by "ex-patients" with mental illness experience, groups like the National Mental Health Association (NMHA) and the Oregon Insane Liberation Front focused on questioning medical authority through the lens of health care as a right (Tomes 2006: 722).

The focus of patient groups on individual rights in the patient-provider relationship and their pursuit of a strategy through the courts served to divert the patient-centered arm of the consumer movement away from regulating health status discrimination in insurance. The

women's movement in reproductive rights encapsulated these goals and their unintended consequences. *Roe v. Wade* (1973), which established a constitutional right to privacy as the basis for women's reproductive autonomy in abortion decisions, patient privacy rights aimed to limit the ability of the state to interfere in the patient-provider relationship. This emphasis on privacy protections from the state, however, split consumer groups and would later motivate some branches to oppose regulatory oversight of insurer information practices.

Although patient rights groups remained largely removed from issues about health insurance coverage during the 1960s and 1970s, the emergence of disease-oriented consumer groups did frame health status discrimination a consumer protection issue albeit for specific groups. In a health insurance market dominated by experience-rated plans, consumer protections against health status discrimination became most valuable to individuals with the most expensive medical conditions. In the 1960s, as the burden of health costs fell disproportionately on high-risk groups such as the poor and retirees, addressing health status discrimination became a question of government intervention. The establishment of Medicare and Medicaid provided a safety net for these groups, yet it did not address the problem of health status discrimination in private insurance for other high-risk groups. In response to revelations about medical records databases and evidence that insurers were using personal health status to deny or price insurance, disease-specific interest groups during the 1970s challenged the practice of insurance companies over the "redlining" of certain conditions. Several groups emerged to fight discriminatory practices in health insurance, and while some were successful in pushing forward consumer protections, they were organized by specific medical conditions and focused their attention on

winning coverage for defined diseases rather than challenging the practice of health status discrimination in private insurance more generally.[20]

Public interest groups became interested in the health insurance reform issue on the urging of labor unions in the 1973 health policy debates, but their coalition faced daunting obstacles. Although labor unions could have been a potent political force against health status discrimination, they became riven internally by incentives to protect their own members over pursuing anti-discrimination measures. As Gottschalk (2000) shows, although labor unions and public interest groups shared an interest in national health insurance in the early 1970s, this changed with ERISA's creation of a regulatory pre-emption for union-negotiated employer-provided plans that set labor unions on a path of interest convergence with employers and private insurers on the issue of health status discrimination. The proliferation of experience-rated plans was supported by unions and large employers, both of which benefited financially from the segmentation of risks in the private market. Experience rating meant better rates and significant savings for many unions and employers with lower-risk members, and they became unwilling to challenge these practices of private health insurers at the expense of broader risk-pooling (Gottschalk 2000: 59-63). ERISA also cleaved apart the "patient rights" branch of the public interest movement, which lost their rights to sue their plans under state laws as a result of preemption, and labor unions that were protective of their negotiated Taft-Hartley plans and

[20] As I discuss in the next chapter, high-profile cases of coverage problems for individuals with AIDS in the 1980s would convince the AARP and other "categorical" groups to challenge health status discrimination more broadly. These efforts suggest that the issue had potential to bring public interest groups together, but the social stigma of AIDS prevented the cause from taking greater hold more broadly and among the general public (see Gottschalk 2000).

lobbied to preserve preemption from state regulation (Gottschalk 2000; Patel and Rushefsky 2002: 270-271;).

Privacy advocates represented an unusual arm of the consumer movement. They became diametrically opposed to other groups jockeying to represent the public interest. By the late 1960s, the biggest problems in health insurance appeared to have been put to rest with the creation of Medicare for elderly retirees and Medicaid for the poor. These developments in public health insurance meant that, even as insurers came under renewed scrutiny for their access and use of patient information in the late 1960s and early 1970s, there was no major push or successful legislation to address the discriminatory consequences of health insurer data practices. By the time the federal government had completed its preliminary inquiries into private sector data practices in the mid-1970s, enthusiasm for new, extensive consumer regulations had all but faded.

The revelation of automated data systems put systems of consumer records into the public spotlight. Although medical records and insurance practices were scrutinized, they were rarely examined together. In 1973, the HEW Report on *Records, Computers, and the Rights of Citizens* catalogued what the federal government perceived as the most pressing problems emerging from automated personal data systems. The Report, which outlined guidelines for data governance that would become the basis for internationally-recognized Fair Information Practice Principles (FIPPs), gave ample treatment to financial information in insurance and medical records in health providers' systems but barely mentioned health insurers (HEW 1973).

The distrust of the consumer movement towards both government and corporations created an irreconcilable problem within the public interest movement on the problem of medical records and hampered its ability to tackle problem related to their use. Convinced that corporations and government agencies were equally corrupt, the consumer movement became

caught between diametrically opposed interpretations of the public interest. Privacy advocates in the early 1970s were led primarily by the ACLU and focused on constraining both government and business in their efforts to protect the sensitive records of the public. Consumer protection advocates such as Nader's Public Interest Research Group and John W. Gardner's Common Cause, on the other hand, feared that the privacy claims of advocates like the ACLU would hamper corporate transparency and accountability. They refrained from throwing their weight behind privacy protections, preferring instead to promote consumer protections via disclosure requirements (Newman 2008: 173, fn 68).

In the wake of scandals involving government surveillance, Congress was quick to pass legislation regulating the government's access and use of personal information. A leak in 1969 of the U.S. Army's monitoring of civil rights activists and some Democratic lawmakers, the June 17th break-in of the Democratic National Committee headquarters in 1972, and the subsequent attempts by the Nixon Administration to conceal its involvement did the federal government no favors in the eyes of citizens. The Privacy Act of 1974 established rules about the collection, use, and disclosure of personal information by federal agencies and granted individuals the right to access, correction, and consent about their records held by the federal government.[21] The private sector's data practices, meanwhile, were taken out of the final legislation. The Privacy Protection Study Commission' (PPSC) Report in 1977, *Personal Privacy in an Information Society*, one of the few tangible yet fleeting products from the Privacy Act, was tasked to study the feasibility of data legislation for the private sector. The PPSC identified personal health information as uniquely sensitive and subject to potential abuse, and unlike the HEW Report several years prior,

[21] See *Federal Data banks, Computers and the Bill of Rights: Hearings before the Subcommittee on Constitutional Rights, Committee on Judiciary*, 92nd Congress 1 (1971).

the PPSC recognized that “health insurers generally seek less financial data…but are concerned with the person's character and propensity to make claims or likelihood of suffering a disabling illness” (Collins 1979: 38).

The commission struggled, however, to determine how to “balance” the “legitimate business needs” of the insurance industry with demands for consumer privacy protections of sensitive medical records. Recognizing that its recommendations would require extensive amendments to the federal Social Security Act, its regulations, and states’ health statutes, the Commission encouraged “a medical record or medical information record keeper voluntarily follow the Commission's recommendations in order to give all medical information equal confidentiality protections” where legislation was “not appropriate” (Collins 1979: 49). Policymaker concerns about third-party access to medical records, even in the context of health insurance, did not translate into explicit protections for consumers or into any formal rules for private medical and health entities. The privacy of patients, meanwhile, was asserted in terms of greater patient autonomy in medical treatments while the practices of insurers to determine coverage and costs remained relatively hidden from view.

The failed effort of the Federal Privacy of Medical Information Act (H.R. 5935) in 1980 demonstrates the difficulty of pursuing consumer protections in an environment in which patient information had become valuable to a wide range of organizations. Introduced in November 1979, the bill tried to formalize the patients’ rights agenda by giving patients the right to access and correct their medical records. The bill failed as legislators could not reconcile conflicting demands from law enforcement, the American Psychiatric Association, the ACLU, the American Medical Records Association, the American Medical Association (AMA), and the American Hospital Association (AHA) (CQ Almanac 1980). The PPSC had previously “identified insurance carriers

and governmental agencies, both federal and state, as the most frequent requestors of patient-identifiable medical record information." [22] In hearings over medical information privacy, insurers warned that restrictions on data-sharing could "inadvertently hamper both the issuance of insurance policies and the prompt payment of claims." The HIAA considered the priority of health insurers to retain broad information access to be largely self-evident, stating that "we are certain that [Congress] appreciate[s] the need for certain medical information by life and health insurance companies, with proper authorization, for both underwriting and claims purposes. And, if such access, with appropriate authorization, is impeded, risk classification and claims administration will be unduly restricted to the detriment of insurance applicants and policyholders alike."[23]

The Decline of the Civil Rights Movement

The civil rights coalition, meanwhile, supported federal intervention to desegregate and expand access to health care, but their focus on addressing overt racial discrimination overlooked how health status discrimination continued to perpetuate racial inequalities in healthcare access. Regulatory challenges to discriminatory insurance underwriting practices had occurred periodically since the 1880s, when several states first attempted to address explicit racial discrimination in life insurance pricing (Stone 1993). Although pricing regulations banning racial discrimination passed in the states for property and casualty insurance in the early 20th century, pricing regulations against discrimination in health insurance were much more difficult. Anti-

[22] *The Federal Privacy of Medical Information Act: Hearings* , 96th Congress 2 (1980) (statement of the American Hospital Association).
[23] *Privacy of Medical Records: Hearings before the Subcom. on Government Information and Individual Rights, Committee on Government Operations*. 96th Congress 1 (1979) (letter from R. Otto Meletzke, American Council of Life Insurance, and David J. Pattison, HIAA).

discrimination in health insurance would only take off after the federal government intervened through the Civil Rights Act in 1964.

In the 1950s and 1960s, reducing discrimination in consumers' interactions with market actors was clearly a priority for social reformers. While consumer protection advocates did not necessarily use the language of anti-discrimination, civil rights advocates in a simultaneous push for social regulations directed their concerns about consumer experiences in the market economy towards anti-discrimination statutes. Their success led to far-reaching federal regulations in the private sector. By regulating private employment, the Civil Rights Act through Title VII outlawed intentional and unintentional discrimination on the basis of race, sex, or national origin in employee benefits, including employer-provided health insurance benefits, while "legislation implementing the Civil War Amendments has been interpreted as prohibiting the use of race as a classifier in private insurance contracts" (Rosenbaum, 2009: 108). These statutes directed any public and private entities benefiting from public funding to accommodate or serve an increasingly diverse consumer population.

By addressing race and gender in federally-funded entities and employment benefits, the passage of the Civil Rights Act in 1964 provided the early basis for federal regulation of health status discrimination in health insurance. Title VI of the Civil Rights Act banned discrimination by federally-funded entities including public insurance, while Title VII prohibited both intentional and disparate impact discrimination on the basis of race, sex, or national origin in employment and the conditions of employment, including employee fringe benefits (Crossley 2005: 86). These anti-discrimination protections in the Civil Rights Act removed race and gender, risk classifiers that are correlated with health status, from what was considered allowable in health insurance enrollment and coverage. The introduction of Medicare and Medicaid further changed

health care financing so that hospitals received significant funds from public sources; in doing so, these entities also became subject to the anti-discrimination requirements of the Civil Rights Act.[24] These limitations on health status discrimination in health insurance were the byproduct of anti-discrimination in employment rather than a direct effort to regulate discrimination in health insurance, but civil rights law served to create the statutory basis for contestations against risk classification practices of health insurers.[25]

Despite the role of the civil rights movement in laying foundations for anti-discrimination, civil rights advocates were wary of expanding the Civil Rights Act's protections to poor health status. Efforts by Senator Hubert H. Humphrey (D-MN) to amend the Civil Rights Act to include disability as a "protected class" failed in 1972, as there was no organized support for such a measure. Civil rights advocates also "feared that the addition of 'disability' as a 'protected class,' similar to ethnic minorities, might dilute the Civil Rights Act" and that amending the Act would open up the legislation to rollback efforts if the definition of "protected classes" came under renewed fire (Young 1997: 10). Other efforts to expand anti-discrimination on the basis of health status proved limited, with unintended consequences for record-keeping practices. The Pregnancy Discrimination Act (PDA) in 1978 extended Title VII's anti-discrimination protections in employer-sponsored health insurance to medical conditions related to pregnancy (Crossley 2005: 88). Age remained a too-valuable proxy for insurers and employers to impute health status, however. Despite its name, the Age Discrimination in Employment Act (ADEA) passed in 1967

[24] Civil Rights Act, P.L. No. 88-352 (1964). Physicians' services, meanwhile, were deemed exempt by Title VI of the Civil Rights Act.

[25] The racial impact of classifications in individual insurance, however, remained legal. As in other areas of anti-discrimination law, laws against race discrimination in health insurance are limited by differential treatment, not disparate impact. Title VII of the Civil Rights Act, however, regulates employment benefits and has been interpreted by the courts to prohibit disparate impact in racial and gender discrimination in employee-sponsored health benefits (Crossley 2005: 86; Rosenbaum 2009; 102).

explicitly permitted employers to provide lesser benefits to older workers (Rosenbaum 2009: 108). Policymakers in the states outlawed the use of race criteria in health and life insurance, either by banning race-based classifications explicitly or by defining the use of race in insurance as an "unfair trade practice" (Crossley 2005: 85-86). By banning certain criteria from use in insurance decision-making, however, anti-discrimination protections created incentives for risk assessors to hide discriminatory treatment of consumers through the creation of other, apparently neutral proxies.

Discrimination became much more subtle than in previous iterations. Instead of data on an individual's gender or race, which strongly predicts healthcare costs, commercial insurers could access more and more granular patient records about past, current, and future health conditions and treatment as technological changes transformed consumer medical and transaction records. Records turned to codes and files into scores for individuals, and a range of data on consumer behavior became proxies for insurance-relevant risks (Hyman 2011: 228; Krippner and Hirschman 2022).

The Cost Crisis and the Federal Regulatory Role

As issues of rising health costs and inadequate coverage became most prevalent in the 1970s, concerns about discrimination in health insurance that had surfaced in the 1950s faded into the background. By the 1970s, containing the "cost crisis" had become the primary policy goal, at direct odds with anti-discrimination on health status. The growth in health costs, driven in part by Medicare's passage and design, fell increasingly on the government. With the resignation of Nixon in August of 1974 and stagflation, President Ford declined to re-submit to Congress Nixon's plan for health insurance reform "on the grounds that it would exacerbate inflation" (Starr 2013: 58). By this time, health insurance was primarily provided by employers, and policymakers came

to believe consumers were shielded from the direct costs of care. As a result, consumers themselves would need to be forced to become more selective and efficient in their utilization of health care (Campbell and Morgan 2011).

No longer could consumers take coverage for granted, but no longer could providers take payments for granted either. Although market reforms were premised on the belief that patients could "vote with their feet" and push insurers to improve their products, consumers in health insurance are much less willing to forgo a service due to cost if the need is pressing enough. Even as private insurers offloaded high-risk groups onto the government and public insurance programs, the introduction of managed care organizations and their use of pre-paid plans rather than fee-for-service delegated much of the responsibility of reining in costs to private actors. Beginning with the Health Maintenance Organization Act in 1973 to encourage the growth of HMOs, the government's efforts to tackle rising health costs would reshuffle the interests in health insurance politics.[26]

Federal policymakers meanwhile had established the federal government's role as a social safety net for high-risk groups excluded from the market, not as a protector of health plan consumers overall. Reformers recognized that the development of private insurance, Social Security, and Medicaid and Medicare had resulted in a disjointed but acceptably adequate system for covering groups with the highest need. The creation of categorical programs thus put the federal government in the role of "propping up or patching up the leaky private welfare system" (Klein 2003: 260). The worsening economic climate perpetuated wariness over the inflationary potential of consumer protections. Although the public still distrusted businesses, the costs of

[26] Health Maintenance Organization Act, P.L. No. 93-222 (1973).

sweeping economy-wide regulations were quickly becoming unpalatable to both the business community and the new administration. When Ford assumed the presidency in August 1974, inflation was approaching 12% compared to 5% when Nixon had started a contractionary policy to address it. Declaring inflation "domestic enemy number one" in his address to Congress on August 6, 1974, Ford was wary of the potential inflationary impact of instituting more regulations on industry (Eisner 2014: 111). New regulation against the use of personal information in the private sector was out of the picture; concerned that a Federal Privacy Board would function as a "super-regulator" over the public and private sectors and "second-guess citizens and agencies," Ford indicated that he would veto any legislation that included the creation of an independent privacy regulatory body (Ford 1974: 7; Bennett 1992: 198; Flaherty 1992: 312; Newman 2008: 59). Ford expanded this promise to tackle inflation in his State of the Union address in January 1975, stating that he would veto any new spending legislation that crossed his desk.

By the late 1970s, the public interest movement had fragmented into diametrically opposed groups. After 1965, the approach of new social movements diverged from that of the consumer protection movement. As Graham (1990) has argued, consumer protection groups had advocated for statutory and administrative rules for all citizens in environmental protection and product safety, while new social movements targeted the courts using an approach of group rights that "drew them, unlike the other social regulators [in consumer protection]…into thorny controversies like the constitutional suits over reverse discrimination" (468). The rise of the patient-centered movement and disease-oriented groups turned questions about the problems of discrimination in health insurance into an issue of individual rights rather than universal coverage, while privacy advocates muddied the waters of the government's regulatory role by protesting government's general capacity to surveil and oversee both individuals and corporations. Labor unions and civil rights advocates retreated from the issue as their prior

categorical wins came under potential threat. The deteriorating economic environment dealt a severe blow with the failure of the proposed consumer regulatory agency in 1978, marking the unofficial end of the consumer movement.

While the consumer movement declined and the federal government turned against regulation, the success of ERISA and its preemption of state regulation also marked the beginning of a period of gradually increasing federal involvement in regulating private health insurance. In the 1960s and 1970s, a majority of Americans had access to adequate private insurance through their employers, but by 1980 coverage began to shrink (Klein 2003: 259). The trend brought new scrutiny to the business of health insurance. An increasing proportion of plans were out of state regulators' jurisdiction, but they were also subject to federal civil rights rules about discrimination. A revolutionary technology was also taking shape in the advancement of genetic sciences. A new era of political conflict over health status discrimination, consumer protection, and health insurance was about to begin.

Discussion

In many ways, the idea of health insurance as risk-spreading has been replaced by one of risk separation. As Edward Kane, the general counsel for Guardian Life Insurance Co. during the Clinton health reform summarized, "Risk selection has always been part of insurance…now they call it discrimination" (Steinmetz 1993). The trajectory of the federal government's efforts to tackle health status discrimination is a journey through the contemporary history of U.S. health policy reform. The transformation of health insurance by commercial insurance carriers and the adoption of experience rating created an emerging problem of greater competition but rising plan costs for the most medically needy. Even though community rating already existed as an alternative and the strategies of commercial insurance had inflationary effects, albeit for targeted

high-risk groups, federal policymakers encouraged their growth and took the position as a safety net for the elderly and the poor. States retained their role as the primary regulators of insurance, a consumer protection role that would gradually come under stress after the growth of self-insured ERISA plans that were exempt from state regulations.

While federal policymakers were limited by the existing regulatory institutions for insurance, the creation of categorical public insurance programs in 1965 to offset the exclusionary effects of commercial and experience-rated private insurance also neutralized general mobilization against health status discrimination. In the wake of the establishment of Medicare and Medicaid in 1965, the absence of a robust branch for patient protections in the consumer movement and the civil rights movement turned federal policymakers towards reforming categorical social programs rather than to federal regulation of private insurance to address the worst consequences of the private market's health status discrimination. Public interest groups like the civil rights movement that had once fought strenuously to counter explicit racial and gender discrimination in private markets became largely quiet on the more subtle issue of health status discrimination, and labor unions were uninterested in challenging private insurers.

Insurers have a strong interest in perfecting their ability to collect complete risk information, accurately classify them, and price insurance accordingly. The methods by which risk is determined all aim to predict an individual's likelihood of experiencing misfortune or illness. In life and health insurance markets, the practice of medical underwriting relies on insurance pricing tables to calculate the perceived insurability of consumers. This allows insurers to differentiate among consumers and decide whether to accept the risks of extending coverage. Using insurance pricing tables to assess the level of financial risk during underwriting helps

organizations segment people and employment groups into risk pools, locate the most profitable consumers, and price their products according to perceived risks.

While there has been a rich literature about how industry groups have shaped the development of the welfare state, the politics of consumer protection regulation and data-driven discrimination in the welfare state has been largely overlooked. In recognizing that discrimination on the basis of poor health has implications for health equity but is also integral to the business of private health insurance, this chapter examines the issue of conflicts over personal health information as a political issue in which multiple interests have a stake.

This chapter contributes to the theory that the historical development of welfare state institutions, through their rules about the eligibility of members, shapes the behavior of interest groups and federal policymakers towards consumer protections. The case of consumer protections against health status discrimination joins a growing literature on the politics of consumer regulations in health care, including an older literature on the political development of drug safety and a new literature on the origins and creation of price controls (Carpenter 2010; Garlick forthcoming). I further elaborate on this theory by examining another aspect of welfare state institutions, the proper scope of responsibilities delegated to market actors, that shaped the development of consumer protections in the late 20th and early 21st centuries.

Conclusion

Not only did the consumer movement fail to address health status discrimination during its height in the 1970s, but reforms of private employee benefits also exacerbated the regulatory problems in private health insurance. The passage of ERISA in 1974 introduced a giant loophole in the regulation of private health insurance, complicating efforts to reform the private insurance

market. The law, which included language meant to exempt a small handful of union-negotiated Taft-Hartley health plans from state regulation and to address concerns from large multistate employers about inconsistent laws across the states, created incentives for employers to move away from purchasing commercial or Blue Cross insurance plans and towards funding their own employees' medical costs. In the two decades after the passage of ERISA, employers increasingly opted for these self-insured plans so that by the mid-1990s almost half of the workforce with employer-sponsored plans – and almost two-thirds of all companies – were covered by self-insured and loosely-regulated ERISA plans (Quadagno 2006: 142; Webel 2018; Mach and Fernandez 2014).

The emergence of ERISA plans that were both exempt from state regulations and state taxes, including from state rules about the content of coverage and underwriting, strengthened the unusual coalition of employers, insurers, and unions that fended off regulatory challenges to insurers and efforts to reform ERISA (Hacker 2002: 257). In the wake of ERISA, efforts by Treasury officials to include federal non-discrimination requirements in fringe benefits in President Carter's 1978 tax plan failed (Hacker 2002: 259).

ERISA's preemption of state regulations for self-insured plans was a significant blow to state regulatory authority over insurance. While ERISA incentivized the creation of plans exempt from state jurisdiction, it also effectively moved the locus of regulatory authority for private insurance from the states to the federal level. ERISA's creation of a regulatory vacuum in private health insurance pushed the prerogative for consumer protection in the area of health insurance from the states to the federal government, paving the way for a more robust federal regulatory intervention on behalf of consumers. Likewise, insurers had been the financial intermediary between patients and providers, remaining comparably hidden from view until the introduction

of managed care and its rapid growth in the late 1970s and 1980s. The downturn in health insurance coverage and tactics of cost control by managed care organizations led to a shift in the development of health status anti-discrimination protections beginning in the 1980s.

In the following chapter, I examine this gradual movement of the federal government into the regulation of private health insurance in the context of electronic health records and the creation of more robust consumer protections against data-driven discrimination. In analyzing the historical development of consumer protections in response to growing digitalization of personal health data from the 1980s to the 1990s, I consider the changing institutional and interest group factors that contributed to and limited the federal government's growing role to protect consumers against health status discrimination in private health insurance.

CHAPTER 4: ELECTRONIC HEALTH RECORDS AND FEDERAL PROTECTIONS IN HIPAA (1980-2009)

Introduction

While the immediate purpose of the Health Information Portability and Accountability Act (HIPAA) in 1996 was to address the problem of "job lock" in employment-based health insurance, the statute and its privacy regulations created by the Department of Health and Human Services represented the first federal foray into regulating the information practices of health insurance companies. HIPAA introduced both federal-level standards for health data privacy in the private sector and the first federal consumer protections against health status discrimination into health insurance.

This chapter addresses the evolution of federal consumer protection against data-driven discrimination after 1980. Now synonymous with public expectations for medical and health data privacy, HIPAA established both restrictions to pre-existing condition exclusions and standards for data privacy and patient consent in the use and handling of electronic health records (EHRs). While a significant part of HIPAA's consumer protections aimed to improve patient access to their own health-related information, HIPAA also regulated the health data behaviors of various data users by imposing privacy restrictions on data-sharing across certain healthcare entities.

After decades of inaction, what explains the federal government's intervention in regulating EHRs to prevent data-driven discrimination? Data-driven discrimination is an integral part of the business of private health insurance, which oversees and provides a crucial service in the health sector, and the issue is as technical as it is virtually hidden from the vast majority of health insurance consumers. The combination of industry structural power, established business

practice, and the technicality of the issue would lead one to expect very little, if any, movement on federal protections against data-driven discrimination. Yet, while HIPAA was and remains arguably limited in its ability to protect patients from health status discrimination in the content of insurance, its passage and subsequent rules signaled an important change in the federal government's approach to insurance regulation. By focusing on the case of privacy and anti-discrimination protections in EHRs, this chapter explains why and how the federal government became increasingly motivated to protect consumers against the potential harms of such promising technology.

I argue that the movement of the federal government into regulating consumer health information can be explained not by policymaker learning, general voter demands for better consumer protections, Democratic control of Congress, or traditional business capture. Rather, the federal government moved to prevent data-driven discrimination in EHRs because the increased delegation of healthcare rationalization to private actors changed the behaviors of health sector interest groups towards health data and their perceived legitimacy in the eyes of federal policymakers.

As I argued in the previous chapter, the emergence of experience rating was a fundamentally disruptive technological change in health information that reallocated the burden of medical costs towards the unhealthy. Rather than intervene to limit the negative consequences of this technology on health status discrimination, the federal government refrained from regulation and instead continued its established role as a social safety net provider by creating comparably inclusive but categorical public insurance programs. In the case of experience rating, the federal government may have been receptive to demands to address health status discrimination, but there were few advocates for such regulatory intervention. The creation of

categorical public programs preempted the public interest movement, which failed to contest experience rating and its effects on health status discrimination. No robust public interest movement materialized around the issue of health data protections, and industry interests opposed federal intervention in private sector data practices.

On the other hand, the federal government set far-reaching standards to protect consumers against data-driven discrimination in EHR systems. Although a federal regulatory response to the technology lagged for almost two decades, Congress acted to address potential harms to consumers from the technology before explicit harms had materialized, in the hopes that doing so would ease the transition to more cost-effective information practices. As in the case of experience rating, consumers and their advocates played a marginal role in actively pressuring the federal government to address data-driven discrimination. The public interest movement was only abstractly interested in health privacy protections, while anti-discrimination laws in health insurance were deemed impractical by disability and civil rights advocates. Although divisions remained over the scale and scope of federal intervention, interest groups of private data users converged over their agreement for federal involvement. The increased private rationalization of health care during the 1970s and 1980s, which emphasized the need for private actors to cut costs to address coverage problems, redirected the health sector's main interest groups of insurers, providers, and employers towards supporting greater federal intervention in consumer protection.

The Development of Electronic Health Records (EHRs)

The digitalization of individual health data into EHRs at the end of the twentieth century revolutionized the data ecosystem in health care. EHRs consist of longitudinal records of patient medical encounters and include demographics codes, clinical notes, vital signs, diagnostic test

records from lab tests and radiology records, medical use and evaluation, and immunization records (Atherton 2011: 186-187; Yang et al 2020: 8).[27] EHRs promised to update paper patient records into a more streamlined, standardized, and networked data system for providers while improving the accuracy and completeness of the patient record for various data users. These benefits accrued to insurers as well, who would be able to process billing and claims as well as finetune their underwriting processes.

The growth of the commercial health insurance industry in the 1930s and 1940s ushered in the development of early health information practices. Health insurers created consumer-facing insurance application forms and physician-facing clinical forms to collect patient data that insurers could use to evaluate and process insurance claims. As health insurers formalized their record-keeping practices and directed physicians to follow protocols for their clinical records, the practice of medicine adapted to these billing requirements to provide the required patient data (Koopman et al 2022: 792-796). The informational requirements of the health insurance industry arguably shaped the eventual format of both paper and electronic patient record-keeping used by clinicians throughout the U.S. health system.

The modern health informatics system took shape after the introduction of computers in the late 1950s. Computers in the public and private sectors facilitated the automated collection and creation of centralized databanks of information. In the 1960s, multiple projects to develop EHR were underway in academic centers and in industry. Lockheed developed an early "clinical information system" in the 1960s, while separate efforts at the University of Utah and Harvard-

[27] While the term "electronic medical records" (EMRs) is sometimes used interchangeably with "electronic health records" (EHRs) to refer to documentation of a patient's medical history, health records include a patient's lifestyle and health information beyond medical encounters.

Massachusetts General Hospital created new health information systems using EHRs. These concurrent, yet separate, efforts to build EHRs in academic and private systems created frictions in integrating public, private, and academic information system. Nonetheless, across these different EHR systems, the informational needs of health insurers became paramount in their design. Lawrence Weed, a physician and researcher, proposed a "problem-oriented" approach to formatting computerized medical records in his 1968 essay "Medical Records that Guide and Teach" that demonstrated the influence of health insurance on the design of EHRs (Gillum 2013: 855). His recommendations for standardized data collection "took billing and insurance to be of [great] importance for a complete medical records system" and influenced emerging EHR technology (Koopman et al 2022: 800).

Critical technological advances in the 1960s and early 1970s created the conditions for EHR development. The U.S. Department of Defense began funding the Advanced Research Projects Agency Network (ARPANET) in 1996; in 1969, the project demonstrated the ability to link computers into a network, giving government and business organizations the capability to share information easily and efficiently. Applied to patient information, these technological advances of computerization and information transmission via online networks promised dramatic changes to the healthcare system. The federal government adopted EHRs in the 1970s, when the Department of Veteran Affairs implemented the Decentralized Hospital Computer Program (DHCP) (Atherton 2011). By the late 1970s, EHRs had become commercially promising, even if nascent. In 1979, Judith Faulkner and John Greist founded Human Services Computing, later known as Epic Systems, to commercialize EHRs.

EHR promised to create a more cost-efficient, integrated, and accurate information system for health care. Its development, on the other hand, fueled concerns about the security

and privacy of sensitive personal information and potential discriminatory treatment from improved but unregulated ease of access. Whereas the previous chapter investigated the reasons for why the federal government refrained from intervening in "experience rating" risk assessment techniques for decades, the government set far-reaching regulatory standards to protect consumers against potential discrimination in EHR. Using a dual approach of privacy and anti-discrimination protections, Congress and regulators in the mid-1990s and 2000s set in place restrictions on EHR that would have long-term consequences for the trajectory of health data technology.

Data Privacy and Data-Driven Discrimination: Origins of a Policy Problem

The link between information privacy protections and anti-discrimination was made clear during the privacy debates of the 1970s. The potential of EHR to improve the ease of data-sharing engendered concerns about health data privacy and discriminatory misuse, especially in areas beyond patient care.[28] Breaches of health data privacy could lead to unauthorized third-party access to sensitive personal information and discriminatory treatment by credit bureaus, insurance firms, and employers.

Public distrust of businesses during the height of the consumer movement and an emergent movement for privacy posed a potential regulatory threat to information-reliant organizations. The initial scope of the proposed Privacy Act of 1974, the first major federal legislation about data privacy, included both private and public sector information practices as

[28] The concept of privacy can refer to the desire of individuals to preserve personal dignity and perception of control over one's personal facts. In the context of medical records privacy, privacy advocates have articulated the material consequences of personal privacy in terms of potential discriminatory treatment. For a similar discussion of the usefulness of anti-discrimination in place of the privacy framework, see Hagendorff (2019).

well as a Federal Privacy Board. Industry lobbying and federal policymaker uncertainty about the law's consequences limited the statute's provisions to federal agencies (Newman 2008: 52, 57). The Federal Privacy Board, meanwhile, drew the ire of government agencies that resented its proposed oversight (Regan 1995: 77). Government representatives signaled their wariness during hearings that the bill's "unfathomable reach and consequences…[are] staggering, indeed, both in potential scope and cost." [29] Business representatives across multiple sectors emphasized government's lack of knowledge about the problem, arguing that policymakers' unfamiliarity with private sector data practices risked prematurely introducing disruptive new regulations.

Although businesses had not anticipated such public blowback over their consumer data practices, which policymakers criticized as riddled with inaccuracies and jeopardizing access to jobs and crucial services, they quickly mobilized to quash additional federal efforts to regulate information privacy in the private sector. In a meeting with the U.S. Chamber of Commerce in September 1975, lawyer Francis Gregory, Jr. warned that "the entire business community may be saddled with the most burdensome general Federal legislation imaginable, unless business leaders familiarize themselves with the privacy issue, consider the effect of the various proposals on their companies, and forcefully present their views and conclusions through the mass media and in private communication to the Privacy Commission, the Congress, and the American public" (Gregory 1975). Arguing for self-regulation, industry representatives agreed to leave the door open for future private sector legislation only if industry could not live up to its self-regulatory promises.

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[29] *Privacy: Collection, Use, and Computerization of Personal Data: Hearings before the Ad Hoc Subcom. on Privacy and Information Systems, Committee on Government Operations*, 93rd Congress 2 (1974).

Even as new federal regulatory agencies were established during the 1970s to protect consumers from dangerous products, unsafe workplaces, hazardous roads, and environmental pollution, efforts for federal regulation of information privacy faltered.[30] Why did Congress create these new agencies while the Federal Privacy Board failed? The plan for a national privacy regulatory agency with economy-wide regulatory powers was a casualty of timing and the activism of both government and business interests. Backed by some of the leading privacy advocates, both government and business interests insisted that self-regulatory approaches in the private sector were preferable to government intervention. Although the public still distrusted businesses, the costs of sweeping economy-wide privacy rules quickly became unpalatable to both business and the new administration. When Ford assumed the presidency in August 1974, inflation was approaching twelve percent. Declaring inflation "domestic enemy number one" in his address to Congress on August 6, 1974, Ford was wary of the potential inflationary impact of instituting more regulations on industry. Concerned that a Federal Privacy Board would function as a "super-regulator" over the public and private sectors and "second-guess citizens and agencies," the president indicated that he would veto any legislation that included the creation of an independent privacy regulatory body (Ford 1974: 7; Bennett 1992: 198; Flaherty 1992: 312).

While the entirety of the private sector bristled at prospects of "comprehensive" government laws about data use, both policymakers and industry representatives agreed that the particular sensitivity of medical records required a more targeted legislative approach. Congress pared down the Federal Privacy Board to a temporary Privacy Protection Study Commission (PPSC). In 1977, the PPSC released its report, *Personal Privacy in an Information Society*, in

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[30] These included the Environmental Protection Agency (1970), the National Highway Traffic Safety Administration (1970), the Consumer Product Safety Commission (1972), and the Occupational Safety and Health Administration (1973)

which it "warned that disclosure of sensitive medical information could…prevent an individual from being hired, promoted or licensed to practice a profession" (CQ Almanac 1980). A flurry of bills in the early 1970s and 1980s tried to address consumer protections for medical records. Privacy-oriented members of Congress, such as Ed Koch (D-NY) and Richardson Preyer (D-NC), introduced legislation to implement the Privacy Protection Study Commission's recommendations for medical records privacy. Several members of Congress sponsored the Federal Privacy of Medical Information Act (H.R. 5935) in November 1979 to give patients a right of access and correction to their medical records. The Carter administration, which had launched its own Privacy Initiative and established an Interagency Review of Privacy Policy, submitted its own bill to protect the privacy of medical records in 1979 (Becker 1978: 4; Flaherty 1992). Despite federal studies warning about misuse of health information and urging by the Carter Administration to enact stronger data protections, Congress made little progress (Becker 1978: 4; Flaherty 1992). Persistent conflicts among health-related data users, business opposition, and the absence of concerted public interest advocacy on the issue posed a formidable obstacle to legislative action, even as patient records were considered particularly sensitive.

The failure of Congress during the 1970s to pass any meaningful statutes governing personal health data in the private sector contributed to the proliferation of health status discrimination in two ways. First, the delay bought insurers valuable time to build their data capacities to address an emerging problem. The rising cost of health care during the 1970s incentivized a strategic turn by employers and insurers to contain costs and provided justification to collect more health-related data. Second, the failure to establish a national regulatory agency for data governance left regulating personal health data misuse to multiple agencies and jurisdictions. While the Federal Trade Commission experienced a resurgence during this period in its consumer protection role, regulating insurance was not traditionally in its wheelhouse and

protecting patients was considered separate from consumer protection. Officials agreed that potential misuse of health data by insurers was a problem, but there were no significant or successful efforts to regulate health data at the national level over the next twenty years.

Historically under the purview of state regulators, private health insurance experienced a downturn in coverage in 1980. This turn of fortunes jolted federal policymakers to consider federal intervention. Federal policymakers concluded that declining coverage stemmed from rising costs of health care and that government financing, largely through the reimbursement structure of Medicare, drove a significant part of inflation (Hacker 2002: 251-252). As the cost of health care increased throughout the 1980s, the predominant question became one of cost control: who was responsible for addressing rising costs, and what kinds of policy interventions were necessary? While some argued that medical underwriting generated significant administrative costs that exacerbated rising costs, others argued that cost-intensive medical technology and the pricing practices of healthcare providers were important contributors to inflation. Most influential in health policy reform during the 1980s, however, was an argument that cutting costs in health care should be delegated to private sector actors and individuals.

In the context of health care, rationalization refers to the process by which healthcare services and resources are made more efficient and cost-effective while maintaining or improving the quality of care. This is achieved through decisions about how resources are allocated, service centralization, incorporating "evidence-based" practices, improving the sharing of patient information through EHR and interoperable information systems, and cost control measures such as negotiating with healthcare providers, implementing price transparency, and encouraging competition. Market reform advocates argued that shifting more of the responsibility for healthcare costs from the government to individuals and private firms would incentivize

consumers to be more judicious in their healthcare consumption and prod corporate actors including employers, insurers, and providers to be more efficient in their allocation of health services and products. In this argument, consumers' individual decisions created a problem of "overconsumption" of unnecessary care while corporations could reduce uncertainty in health care by becoming private "planners" in distributing care (Pollitt 1982; Gottschalk 2000: 59-61; Quadagno 2006: 16; Morgan and Campbell 2011).

The result was new policies to individualize healthcare expenses and to encourage health sector actors to pursue fiscal responsibility. The introduction of HMOs in 1973 "combine[d] private enterprise and state sponsorship in a way that encourage[d] both physicians and (to a lesser extent) consumers to organize themselves in the pursuit of cost control" (Pollitt 1982: 245). While market-friendly reforms promoted individual consumer choice, they also increased competition fueled strategies by firms and consumers to find cheaper plans, which in turn motivated insurers to segment consumers and limit coverage to bring down the cost of plans. Large employers, unhappy with the rising costs of purchasing insurance, turned to self-funding insurance as "fringe benefits" to cover their own workers. Self-insurance allowed employers to skirt state regulations mandating certain services and pay from their own funds rather than go through a third-party administrator.

The shedding of high-risk members by large employers choosing to self-insure in a context of extensive state mandates meant that insurers now faced the prospect of covering those with the most expensive illnesses. Healthier individuals are considered the most desirable members in both employers' and carriers' insurance plans, while individuals who need extensive health care are often subject to exclusions from coverage. Small employers, unable to afford self-funding insurance for their workers, purchased coverage in the small-group market. Insurance carriers

either avoided the riskier small-group market entirely or offered underwritten plans that excluded high-risk individuals (Quadagno 2006: 140). Adverse selection in the private insurance market was exacerbated by the plethora of state mandates during the 1980s that required insurers to cover a huge variety of services in their benefit plans (Quadagno 2006: 141). Thanks to ERISA's preemption clause for self-insurance, employers that self-funded coverage for their workers were exempt from state-level health insurance regulations and coverage mandates. Insurers, made financially vulnerable by fleeing employer purchasers and rising requirements from state mandates, were further motivated to narrow eligibility requirements in their plans and limit coverage for expensive medical conditions (Hacker 2002: 260).[31] Firms that were unsuccessful in managing cost inflation failed financially, and subsequent Congressional investigations cast a harsh, unflattering light on mismanagement and fraud in the insurance industry.

Cost-cutting efforts in the private sector contributed to a decline in overall insurance coverage in the early 1980s. Risk-shedding by self-insured employers and insurer incentives to refine their underwriting techniques excluded more individuals from coverage, while shifting employment arrangements since the mid-1970s towards a more contingent workforce meant that fewer workers could claim employment's insurance benefits (Hacker 2002: 261). Small firms, facing expensive plans and rapidly increasing premiums, reduced their benefits or eliminated coverage entirely for their employees (Quadagno 2006: 141). Although self-insurance by employers grew to cover the majority of workers as a proportion of insured Americans, overall

[31] See Eibner et al (2011) for an empirical assessment of self-insurance by employers and its potential effects on adverse selection in private insurance markets after the ACA. In this study, the authors find that self-insured plans and fully-insured plans on the private insurance market are largely comparable in their pricing, benefit generosity, and claims denial rates. They argue that this is because self-insured employers still tend to purchase stop-loss coverage (which is regulated differently than marketplace plans) given the higher financial risk that employers bear with self-insurance.

coverage declined and reversed the gains from public health insurance expansions from prior decades, making the U.S. a cross-national outlier in health coverage and costs (Hacker 2002: 261; Peterson 2005: 220).[32]

Political Debates over Health Status Discrimination

Beginning in the late 1980s and 1990s, states began to respond to insurance coverage problems by tackling the issue of health status discrimination. States passed bans on the use of certain health status criteria in insurance decisions and issued requirements for community rating, though these were limited to a small handful of states.[33] Concerns about coverage exclusions also resulted in state-level mandates to cover specific services and treatment, though according to the National Federation of Independent Business (NFIB), these mandates "seldom surfaced as a result of constituent demand" but rather were initiated by special interest groups such as providers hoping to cement coverage for their services (Quadagno 2006: 141). Coverage mandates exacerbated the increase in healthcare costs, as providers who flocked to offer the covered services and increased costs for employers. In response, corporate purchasers began to shift the cost burden of providing benefits onto their employees; they introduced cost-sharing schemes with high deductibles and copays, reduced coverage for expensive illnesses, "churned" members by

[32] As a third-party payer concerned about cost control, the government also turned to contracts with managed care for health care reviews, especially as the cost of Medicare ballooned (Altman and Shactman 2011: 36). Several laws in the 1980s, including the Tax Equity and Fiscal Responsibility Act (P.L. No. 97-248) in 1982 and the Balanced Budget and Emergency Deficit Control Act in 1985 (P.L. No. 99-177), aimed to contain the costs of Medicaid and Medicare by emphasizing fiscal responsibility.

[33] Prior to the ACA's implementation in 2014 that introduced guaranteed issue for individual plans sold on the Marketplace, five states (Maine, Massachusetts, New Jersey, New York, and Vermont) had passed rules during the 1990s for guaranteed issue in individual (non-group) health insurance policies. Some states – Kentucky, New Hampshire, and Washington – later abandoned or loosened their community ratings regulations to stabilize their insurance markets (Sasso 2011).

switching policies just as the most expensive people were about to complete the waiting period, and dropped coverage altogether (Hacker 2002: 260; Quadagno 2006: 141, 160).

The burden of these cost-saving strategies fell most heavily on those with the poorest health status. During the 1980s, this meant individuals who had been diagnosed with HIV/AIDS. Gay rights advocates challenged medical underwriting by lobbying state legislatures to block the use of individual sexual orientation information and HIV antibody blood tests in insurance. Insurers fought back, narrowing the ability of regulations to protect individuals with HIV/AIDS but simultaneously launching the issue of data-driven discrimination into the national public spotlight (Stone 1993: 309-310). Some states, such as New York, adopted prohibitions on health insurance exclusions of the sick; in response, some insurers left the state (Steinmetz 1993). Although state anti-discrimination laws sought to protect vulnerable groups, namely those with HIV, from insurance exclusion, these state protections of HIV-related health data did not extend to rules for the use of health information systems more generally, nor did it block insurers from seeking data proxies to assess health status. Furthermore, state laws banning the use of AIDS-related health data had difficulty reaching employer-provided ERISA plans, which were exempt from state regulations.

Laws banning discrimination on the basis of race and gender from the 1960s had contributed to a transition by insurers, employers, and other private data users to more impersonal data proxies. The development of health "risk factors" and credit scoring systems using variables such as occupation, residential location, and consumer behavior correlated closely with banned demographic criteria (Lauer 2015: 240; Bouk 2015: 241). Of these proxies, pre-existing condition clauses became a particularly useful feature of insurance plans that allowed insurers to exclude risky, expensive individuals without incurring scrutiny for categorical

discrimination. Moreover, the use of these exclusions had the potential to individualize coverage problems among those who needed it most; compared to race or gender criteria, pre-existing condition exclusions were a quieter way for insurers to discriminate against riskier enrollees by making exclusions seem personal to one's own health conditions. The insurance industry insisted that excluding "pre-existing conditions" was a matter of smart business; James Dorsch, an attorney the Health Insurance Association of America (HIAA), the main trade association for commercial insurers, described health insurers covering pre-existing conditions as "selling fire insurance on a burning building" (Gottschalk 1986). Vague in definition and broad in scope, "pre-existing conditions" could be used by insurers in both individual and large group policies to set the plan's terms of service. Individuals with illnesses or disabilities of all sorts could fall into the net of pre-existing conditions, subject to discriminatory practices that denied them offers, priced their premiums, and excluded coverage for their conditions. By the 1990s, pre-existing condition clauses became common practice and were upheld by state courts (Stone 1993). Pre-existing condition clauses in many large and mid-sized employer groups plans also fell outside of the scope of state regulators given ERISA's preemption clause.

These strategies for cost reductions by insurers and employers had downstream effects that exacerbated the problem of inadequate coverage. Employers, worried about how individuals with pre-existing conditions could cause their entire group's premium to rise or coverage to be impacted, avoided hiring people with expensive medical conditions or fired those who developed them (Roberts 2012: 8). Meanwhile, state and federal politicians interested in addressing public concerns about private coverage through regulations were wary of arguments that federal mandates and new regulations would make insurance too costly for employers and thus drive more reductions in coverage (Hacker 2002: 258). In the individual insurance market, those with pre-existing conditions were charged a higher premium rate while healthy applicants were "rated

down" and charged lower premiums, resulting in those with the highest need receiving sub-standard offers and paying higher premiums for less coverage (Roberts 2012: 1167; Lueck 2020a). Studies bear this out; in a 2001 KFF survey, researchers asked 19 health insurers in the individual market to evaluate and rate their plan offers for seven hypothetical applicants. They found that people were often rejected if they had breast cancer in the past, and the hypothetical applicant who had HIV was rejected by all of the surveyed health insurers (KFF 2020). Thus, while rationalization by private insurers and for-profit hospitals did help to contain costs for employers and public insurance programs, it came at the expense of growing numbers of the uninsured.

The Emergence of Protections on the Basis of Health Status

EHR was still in its infancy during the 1980s and early 1990s, but anti-discrimination fights over the use of HIV-related data for insurance exclusion laid the groundwork for government regulation of health status information as a related issue of health coverage and cost. Not only did AIDS activists bring the issue of health status discrimination to the public's attention, the sensitivity of health data in the emerging data trade made health data regulation a Congressional concern. The Institute of Medicine (IOM) in 1994 warned that "computer-based health data have become a very valuable commodity" and health data organizations "may find it difficult indeed to resist economic benefits from allowing access to their data files by third parties" (Donaldson and Lohr 1994: 4). In addition to the economic temptations of electronic health data, national legislators feared that private insurers would use health status to identify and dump high-risk AIDS patients onto public insurance plans (Stone 1993: 309).

As states transitioned from paper to electronic health records, a patchwork of state health data privacy laws emerged. At the state level, health data privacy laws during the 1970s had largely focused on statutory requirements of confidentiality between the patient and provider, with

provisions requiring medical providers to report data to state authorities for public health purposes (PPSC 1977: Appendix 19; Wallace 1977). During the early 1990s, some state legislatures adopted health status anti-discrimination laws, but most focused on obtaining consent for disclosures with various allowable exceptions. Others continued to rely on old pen-and-paper procedures, including "quill-pen statutes" that required the use of paper-based records and prohibited electronic copies to ensure privacy in medical records (Donaldson and Lohr 1994: 3; Barefoot 1998: 300-302). These discrepancies among state consumer data protections and the absence of expectations and standards for health information systems motivated researchers and representatives of the medical records industry to support federal preemption of these state laws (Waegemann 1993: 20).

Federal protections against discrimination in insurance can be traced back to the 1964 Civil Rights Act, which prohibited discrimination on the basis of race and gender. It was not until the late 1980s and 1990s that Congress began formalizing protections against discrimination on the basis of health status.[34] Sponsored by Senator Lowell Weicker (R-CT), the Protection and Advocacy for Mentally Ill Persons Act (PAIMI) in 1986 established rights and protections for individuals with mental illnesses, including the confidentiality of medical records against disclosures that would be "detrimental to such individual's health."[35] The protections offered in PAIMI, however, did not prevent insurers from using such health records in determining coverage. Courts during this time upheld pre-existing condition exclusions, even in cases in which

[34] Federal standards for health insurance plans were first established in the Public Health Service Act of 1944 (P.K. No. 78-410). The PHSA (1944) was the first time that the federal government brought together various statutes about the Public Health Service, which began as a federal system of marine hospitals to become the collective of public health agencies (9 of the 12 agencies in HHS are part of the Public Health Service, including NIH, the FDA, and CDC) into a single, comprehensive legislation (Willcox 1944).
[35] Protection and Advocacy for Mentally Ill Persons Act, P.L. No. 99–319, Section 106 b(1) (1986)

there had been no diagnoses prior to the policy date (Stone 1993: 305, fn 13). In these cases, the courts held that insurance contracts could use broad language in their exclusion policies and defined the onset of pre-existing conditions as when illnesses first manifested and became "capable of diagnosis" rather than when they were officially diagnosed.[36]

Health Status Discrimination in the Americans with Disabilities Act (1990)

Grassroots energy and congressional support for federal protections for people with disabilities gained momentum through the 1980s. Senator Weicker, whose son had Down's Syndrome, championed federal protections for those with mental and physical disabilities (Young 1997: 52). In April of 1988, Weicker and Congressman Tony Coelho (D-CA) introduced the Americans with Disabilities Act (ADA).[37] The result of sustained activism by disability rights advocates and sympathetic Congressional members, the ADA (1990) instituted comprehensive anti-discrimination protections for people with certain physical and mental health-related conditions in private and public employment, services, accommodations, transportation, and telecommunications. In recognition of the link between health data and discrimination, the ADA took a "two-pronged approach" to preventing health status discrimination by protecting the confidentiality of medical information about disabilities through individual privacy rights and prohibiting discriminatory acts.[38]

Unlike in the case of experience rating and fragmented patient groups, the disability community took a unified approach during the ADA debates. Advocacy organizations during this

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[36] These court cases include *Hannum v. General Life and Accident Ins. Co*., 745 W.W. 2d 500 (Tex. App. 1988) and *Dear v. Blue Cross of Louisiana*, 511 So. 2d. 73 (La. App. 1987).
[37] Americans with Disabilities Act, P.L. No. 101-336 (1990).
[38] The ADA only specifies the confidentiality of medical records collected as part of an employment entrance exam, as it does not apply to health insurance (PL 101-336, 104 Stat. 332).

time argued that "[n]o subgroup of people with any type of physical or mental disability, or perceived disability, no matter how politically impotent or how stigmatized, will be sacrificed" (Young 1997: 66). This organizational wherewithal, however, could not overcome the unwillingness of both Congress and disability advocates to include health insurance in the ADA's protections.[39] The decision to exclude the content of coverage from the ADA's restrictions against health status discrimination reflected a "conscious decision not to disrupt traditional underwriting practices by insurers" (Crossley 2005: 16). Disability advocates recognized that affordable health care was a major problem for people with disabilities, but political considerations by both disability interest groups and Senator Weicker, whose sponsorship of the bill was critical to its survival, led advocates to conclude that including health insurance was impractical. Advocates also worried that including health insurance in their anti-discrimination claims created a rift with civil rights advocates, since it created a protection that was not stipulated for any other social group. Anti-discrimination for health status could thus redefine disability and "medicalize" the community by using coverage expansions rather than civil rights law to address discrimination.[40] Meanwhile, health insurers were a major industry presence in Connecticut and thus part of Senator Weicker's political constituency (Young 1997: 39, 52-53). Rather than forbid

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[39] Anti-discrimination measures were limited to Title II of the Americans with Disabilities Act and the Rehabilitation Act of 1973 (P.L. No. 93-112), which applied only to insurance plans that were either employer-sponsored, public programs, or federally-assisted (Rosenbaum 2009: 102). While explicit discrimination of people with disabilities by insurers was prohibited, such as the physical accessibility of an insurance office, a "safe harbor" was established in the ADA to exempt the content of insurance from anti-discrimination protections. Risk management practices in insurance like classification and underwriting were explicitly carved out in Titles I through IV (Jones and Sarata 2008: 12). Despite the ADA's insurance safe harbor stipulation for actuarial justification for discrimination, courts stretched what was allowed under the ADA in favor of insurers. For example, although the Equal Employment Opportunities Commission (EEOC) has interpreted the ADA to apply to genetic information, in both the statute and in regulatory and judicial interpretations, the ADA permits insurers to use disability information for risk management (Jones 1996: 3-4; Jones and Sarata 2008: 12; Crossley 2005: 91-92). The statute also allows exclusions of coverage for certain conditions "so long as the exclusion applies to all plan members" (Rosenbaum 2009: 109).

[40] I thank Heather Swadley, JD, PhD for this insight.

health status discrimination in health insurance, the ADA expanded the insurance market as insurers created new products for disability insurance in response to new legislation (Cox 1994).

While neither the PAIMI nor the ADA extended anti-discrimination protections for people with disabilities to the content of health insurance, the statutes represented the first formal federal recognition of health status discrimination as a national policy problem. With the exclusion of the content of health insurance from both laws, anti-discrimination proponents concerned about health care focused instead on targeting the behavior of individual market actors. They advocated for greater consumer choice of providers to avoid discriminatory treatment rather than proactive consumer protections about the content of insurance (Schlesinger 2005: 99).

The Path to Protections

The shift towards delegated healthcare rationalization incentivized the federal government to address data-driven discrimination on the basis of health status. In the following sections, I show that the federal government's foray into regulating data-driven discrimination in health insurance was the result of converging interest group behaviors about the importance of federal intervention in health data systems to promote private efforts for healthcare rationalization.

Federal policymakers become active in regulating data-driven discrimination in EHR because cost-cutting goals defined in the 1970s and 1980s made both provider and consumer trust in a private healthcare system critical for the continued success of delegated rationalization policies. As employers turned to self-insured plans and insurance companies to stricter underwriting and coverage limitations, Congress feared that health status discrimination by commercial health insurers would increasingly push the costs of covering expensive illnesses to public insurance plans. Insurers also worried about taking on the burden of expensive members

as the lack of federal regulation would encourage non-competitive behavior by carriers and employers.

Bringing consumers, providers, and insurers all on board to cut healthcare costs required Congress to ensure that private insurers had the technological capacity needed to control costs without incentivizing them to dump high-risk members, while assuring both providers and consumers that the patient-provider confidentiality expectations would be respected when collecting and sharing patient-related information. Thus, instead of expanding coverage or banning underwriting altogether, the federal government would regulate the data used in underwriting models to allay consumer and provider fears of participating in the private, modernized, and cost-efficient health insurance system.

Agenda-setting for Federal Intervention

Despite the initial hesitance for federal intervention in private sector data practices, beginning in the 1990s federal policymakers began to move into a more robust consumer protection role against health status discrimination. Attempts to provide a legislative solution to the twin problems of data privacy and data-driven discrimination gained traction in Congress as health reform rose to the top of the Clinton administration's policy agenda. Federal policymakers had previously resisted intervening in private health insurance, but several developments – namely the regulatory gap from ERISA, the growing potential of EHRs, and the increased visibility of health status discrimination to consumers – changed federal policymakers' approach to health data reform during the late 1980s and early 1990s.

The passage of ERISA in 1974 and its regulatory preemption opened up a regulatory vacuum that left most private plans outside of state regulatory jurisdiction. As part of the broader

policy to delegate healthcare rationalization to the private sector, ERISA incentivized employers to shoulder more of the risk in covering healthcare costs of their employees while giving them the leeway to provide health insurance in the most efficient way that they saw fit. The rise of ERISA plans, which by 1993 covered approximately 85% of people with medical insurance, meant that more employer-provided plans could be considered exempt from state regulations protecting consumers, such as those with AIDS, from discrimination in health insurance (Schultz 1993; Olender 2002: 108). ERISA's regulatory preemption also made it difficult for consumers to contest claims denials or other problems they encountered with coverage.[41] Although consumers were largely unsuccessful in their complaints, state insurance regulators were active in pushing insurance reform onto the Congressional agenda. Represented by the National Association of Insurance Commissioners (NAIC), state insurance regulators were active in pushing Congress to reform the private insurance market's consumer protections (Atchinson and Fox 1997: 148).[42] By preempting state insurance regulations, ERISA had weakened the ability of state insurance regulators to carry out their role as consumer protection advocates.

The ERISA regulatory vacuum existed for more than a decade, but the changing health information environment in the 1980s made federal intervention more urgent. Although EHRs had been introduced in the 1970s and adoption was slow, improved computerization of health records in the late 1980s increased the potential of EHRs to become a nationwide health information system. In a series of studies in the mid-1980s and early 1990s, the Institute of Medicine (IOM) argued for the widespread adoption of EHR, which the IOM considered an

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[41] ERISA plans are subject to federal regulations overseen by the Department of Labor.
[42] *Health care reform: reforming the small business marketplace and the individual health insurance market: Hearings on Bill 104 S. 1028, Before the Subcommittee on Health and the Environment. Committee on Energy and Commerce*, 104th Congress 2 (1996) (prepared statement of Paul R. Huard, Senior Vice President, Policy and Communications, National Association of Manufacturers).

"essential technology" for the advancement of the medicine. The IOM called for funding technological development while addressing issues with security and standardization (IOM 1991; Evans 2016: 553).

Health researchers and the health industry also found the impending technological transition promising. Standardized clinical data could be collated into large datasets for tracking public health outcomes, drug development and side effects, as well as opportunities to improve the cost-efficiency of patient care (Pryor 1993: 54). The healthcare industry was particularly interested in linking computerized patient records across hospitals, offices, medical centers, individual practices, and software vendors to create and use "cradle-to-grave" records of patients (OTA 1993: 8). Insurers have had access to centralized paper medical records since the early 20th century, but the development of EHR promised easier access to larger datasets and more accurate, complete records for payment determinations and other activities (Donaldson and Lohr 1994: 4). Lastly, Congress was interested in advancing EHRs; a national health information infrastructure, in addition to improving public health surveillance, could help address the growing cost of Medicare amidst concerns about waste and fraud in the system.[43]

The pressure for a widespread transition to EHR placed the issue of regulating consumer health data on the federal policy agenda. The federal government engaged in fact-finding missions to explore the changing health information environment. The Assistant Secretary for Planning and Evaluation established a Task Force on Privacy to investigate private sector health records, convening a conference on the topic with representatives from academia, policy research, trade

[43] Although the Privacy Act of 1974 covered federal use of information, most health-related data is held by private entities. Private health information systems were built to address Medicare's huge informational needs and became entrenched (Barefoot 1998: 294).

associations, and insurers. Congress commissioned a study by the Office of Technology Assessment (OTA) and held numerous congressional hearings about health information privacy and the computerization of medical records (OTA 1993; Donaldson and Lohr 1994).[44]

From the public's perspective, health reforms that delegated cost-cutting responsibilities to private actors made discrimination by private actors more salient. With echoes of the 1977 PPSC report, federal policymakers during a 1993 conference on medical privacy recognized that improved ease of access to electronic health information about HIV infection, genetic predisposition for illnesses, drug and alcohol abuse, and mental illness "[could] affect a person's access to insurance, employment, or other opportunities" (Ellwood et al 1993: 13). The biggest backlash from the public to data-driven discrimination came through their experiences with managed care. Commercial insurers and managed care organizations quickly became "public enemy number one" among a public that was increasingly concerned about third-party access to their personal information and fearful that cost-cutting of services would lead to substandard health care or denied claims (Regan 1995; Quadagno 2006: 163). The backlash to cost containment measures in private health insurance, led by a coalition of consumers and physicians unhappy with incursions on their autonomy forced a partial retreat from managed care (Quadagno 2006: 162; Altman and Shactman 2011: 37).

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[44] In hearings before the Subcommittee on Technology and the Law of the Committee on the Judiciary in October 1993 and January 1994, it was clear that technology for EHR had already developed to allow physicians to create a computerized "portable medical record" for patients. According to testimony from Sherman Hope (Brownfield Rural Health Clinic), Richard Hope, M.D., and Richard Haddock (Lasercard Systems Corporation), Brownfield Rural Health Clinic had improved efficiency and patient care by adopting a "ChartCard" that could store up to 2,000 bytes of information per patient. Haddock attributed the slow adoption of health cards in the U.S. compared to Europe and Japan to "questions on electronic records legality, and secondly, the wide use of magnetic card [of which magnetic stripe technology cannot offer secure data storage for patient information] for financial services in the U.S." (See *High-tech privacy issues in health care: Hearings before the Subcommittee on Technology and the Law of the Committee on the Judiciary,* 103rd Congress 1-2 (1993-1994): 8-15, 26).

Policymakers invoked public opinion surveys of data privacy concerns when discussing the challenges facing EHR, including an oft-cited series of studies by Equifax on consumer privacy sentiments. Yet the political unpopularity of insurers and consumer privacy concerns did not translate into consistent political mobilization by consumers for stronger protections against health status discrimination. For one, public interest groups split on the issue. Generalist consumer groups had actively avoided advocating for data privacy protections during the height of the public interest movement because they feared it would clash with their priority for greater corporate transparency (Newman 2008: 173, fn 68). Privacy advocates such as the ACLU continued to lobby Congress on protections and to testify during hearings about the values of personal privacy into the 1990s, but the momentum for the public interest lobby had significantly weakened.[45] In addition, some groups were more sensitive to the data privacy and discrimination nexus than others. The majority of consumers had employer-sponsored insurance and were generally satisfied with their coverage, even if they were taking on an increased share of the cost and risk (Gottschalk 2000: 121-122). Although data-driven discrimination could affect large swaths of people, it was particularly damaging for those in poor health.[46] The narrowing coverage in health insurance was most burdensome for those who were already politically-marginalized.

The patients' rights movement, which emerged in the mid-1990s during the health reform debates as the main political voice for patients, was actively involved in promoting medical privacy

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[45] The fears of consumer groups about the "double-edged sword" of privacy protections were not unfounded. Businesses have used data privacy laws to block data requests from government regulators and to shield their practices from scrutiny.

[46] Prior to the ACA, insurers used lists of up to four hundred different pre-existing conditions to reject applicants and deny coverage on the basis of disease or mental and physical conditions, including pregnancy (KFF 2012; Roberts 2012: 1166). Minor issues, such as allergies or acne, could also be considered a pre-existing condition and affect offers of insurance (KFF 2020). In 2016, for example, more than a quarter of adults under the age of 65 were estimated to have conditions that might be considered pre-existing and subject to denial in the individual marketplace without the ACA's regulatory restrictions (Lueck 2020a).

but refrained from protesting data-driven discrimination. In the context of managed care, "the new patients'-rights movement [sought] to shift power not from physicians and hospitals to patients but from managed-care companies, insurance companies, and health care facilities to patients and their physicians" (Annas 1998: 696). Fears of discrimination were channeled into activism through the courts to designate "protected groups" while data-driven discrimination by health status proved too broad of a definition for "disability" in the ADA. The Patients' Bill of Rights, first proposed in 1997 by Edward Kennedy (D-MA) and John Dingell (D-MI) on behalf of Clinton's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, included a right to patient-provider confidentiality, but it did not include any provisions for equity of treatment on the basis of medical need (Annas 1998: 697; Schlesinger 2005: 119). The biggest concern of consumer and patient advocates on medical privacy was instituting patient consent agreements and increasing patient access to their own health records. These consent and access requirements would manifest as largely-perfunctory procedures to assuage patient concerns rather than true protections against data-driven discrimination.[47]

Nonetheless, although consumers did not actively push for protections, federal policymakers were motivated to ensure consumer participation in the transition to a rationalized healthcare system. As Gerald Britten, the Deputy Assistant Secretary for Program Services at HHS noted at a 1993 conference on medical records and privacy, "a key element in this strategy [to reduce administrative costs in health care] is the expanded use of automated health care

[47] Patient consent forms have become longer and more detailed, as patients have to sign consent agreements allowing insurers to access medical records in order to medically underwrite their individual plans (Lueck 2020a). In addition, despite early successes in protecting HIV-related information from insurance exclusion, HIV/AIDS patients continue to struggle with health status discrimination in health insurance and have alleged that insurers "were discriminating by placing all drugs that treat HIV on the highest formulary tier with the highest patient copay" (Guo et al 2017).

information systems…The greatest impediment to development of electronic data systems may be concern for individual privacy" (Ellwood et al 1993: 12-13). These concerns emerged from all corners of the health sector. Securing consumers trust in EHR systems and alleviating their concerns about potential discriminatory treatment would be critical for consumer participation in the transition to modernized health information systems.

Fair Health Information in the Clinton Health Reform

The election of major Democratic health reformers moved health reform from the state to the federal level. The electoral victories of Harris Wofford (D-PA) to Congress in 1991 and Bill Clinton as president in 1992 opened a window of opportunity for federal action on health policy (Stone 1993: 311; Hacker 1996; Hacker 2002: 261). Announced in September 1993, the Clinton administration's health reform proposal emphasized the potential of advancements in health information technology to tackle coverage shortfalls by improving system-wide efficiency and cutting healthcare costs. In preparation for a technological transition, Representative Gary A. Condit (D-CA-18) introduced the Fair Health Information Practices Act (103 H.R. 4077) with co-sponsors John Conyers (D-MI-14) and Nydia Velazquez (D-NY-12) on March 17, 1994 to "establish a code of fair information practices for health information." By establishing standards for data privacy and expectations for protection against misuse, the federal government could facilitate the adoption of a national health information network and potentially automate the exchange of health information for more cost-efficient care (OTA 1993: 23). By July, Condit's bill had been rolled into the Health Security Act (H.R. 3600) as part of comprehensive health reform.

Although Democrats were historically more often associated with consumer protection regulations, the issue of protecting consumers from health status discrimination appealed to Republican legislators as well. Iversen and Rehm (2022) argue that governments representing the

political right have been more hostile than left governments to "regulatory roadblocks [limiting] private insurers' access to medical information" (73) because left parties tend to represent constituencies that experience more discrimination on the basis of poor health.[48] Left parties, however, do not have the monopoly on constituencies with higher health status risks. Before Clinton, President George H.W. Bush's health reform plan in 1992, while taken as a "defensive posture" by the Republican administration to stave off other major reform proposals, prohibited the use of health status to deny insurance coverage even if it still allowed rates to vary by health status (Stone 1993: 311; Peterson 2005: 209). The more ambitious Health Security Act reform by Democrats failed, but consumer health status protections in HIPAA passed after Republicans had secured a majority in Congress in the 1994 elections.[49] Addressing health status discrimination through consumer data protections is a politically easier route than either expanding public health insurance or banning underwriting altogether, and politicians of both parties benefited from efforts to reform health insurance to protect consumers.

Interest Fragmentation over Healthcare Financing

The failure of the Health Security Act left both the issues of healthcare financing and health data systems unresolved. Congressional proponents of health policy reform aimed to make a small but significant dent in health policy by salvaging the bill's health data components and federal consumer protections. The first efforts to legislate medical records privacy after the defeat of the

[48] This is because poor health is correlated with lower income and lower income groups, which tend to make up a bigger part of left party constituencies, while right parties represent more affluent constituencies.
[49] Even Starr (2013) overlooked the protections formalized in HIPAA when he claimed that "no [federal] legislation to protect the privately insured made it through Congress when Republicans were in the majority and took the side of the insurance industry on key issues" (Starr 2013: 144).

HSA failed due to insufficient support from privacy advocates and industry interests, but there was strong consensus for the need for federal intervention.

The Health Insurance Portability and Accountability Act (HIPAA) of 1996, also known as the Kennedy-Kassebaum Act, was "the first time that the federal government entered the field of regulation of insurance companies" (Patel and Rushefsky 2002: 264).[50] Like the Consolidated Omnibus Budget Reconciliation Act (COBRA) passed several years prior, the broader issue of HIPAA dealt with the issue of "job lock."[51] Afraid to leave their jobs in fear of losing health insurance, "job lock" diminished the willingness of workers to move jobs. Congress viewed health status discrimination as an issue immobilizing labor and stifling economic competition and growth.[52] In addition to its portability rules, HIPAA established the statutory basis for regulations about health data and limits to its discriminatory use in health insurance. As the first federal consumer protection law against health status discrimination, the statute prohibited discrimination on the basis of health status in eligibility for coverage and cost of coverage in the group (but not individual) market, including in ERISA self-insured plans that had previously been exempt from state-level consumer regulations of benefits. These new protections changed eligibility rules in insurance enrollment and introduced anti-discrimination on the basis of health status into health insurance. HIPAA arguably provided more expansive anti-discrimination protections than the ADA, given its ability to reach ERISA plans and its more generalized definition of health status. It was still limited by leaving the content of insurance coverage and direct issues of cost virtually untouched, and the exclusion of the individual market created a

[50] Health Insurance Portability and Accountability Act, P.L. 104–191 (1996).
[51] Consolidated Omnibus Budget Reconciliation Act, P.L. No. 99-272 (1985).
[52] The issue of pre-existing conditions was also an issue of portability rather than of coverage more generally. When people developed a condition and moved to a new company, the new company would not cover their newly-developed (but now "pre-existing") condition.

regulatory gap that would later motivate the Affordable Care Act's consumer protections (Quadagno 2006: 196; Rosenbaum 2009: 110). Nonetheless, HIPAA formalized expectations for federal protections against data-driven discrimination in health insurance.

HIPAA proved to be a much more popular approach than comprehensive health reform, passing 421 to 2 in the House and 98 to 0 in the Senate. Compared to the 1970s when federal policymakers were first taken off-guard by the rise in computerized information systems and data privacy concerns, the slow development and diffusion of EHR systems arguably bought federal policymakers time to build experience and knowledge about best practices in regulating emerging technologies and preventing their most egregious harms. The Office of Technology Assessment (OTA), which was authorized in 1972 and funded in 1974, conducted a study, *Protecting Privacy in Computerized Medical Information* in 1993 that was extensively cited throughout the medical privacy debates (OTA 1993). This capacity to understand the problem and make recommendations did not last, however. Although Republican legislators supported health system reforms that could tackle costs, they railed against the regulatory expertise arguably needed to design and implement these cost-saving measures. House Republican legislators characterized the OTA as wasteful, duplicative of other government functions, and hostile to their party's interests. The defunding of the agency in 1995, after the Republican takeover of Congress, closed the main hub of federal expertise on technology regulation.

Without the guidance of the OTA's technical expertise, the perspectives of well-resourced interest groups on federal data regulation became paramount. As they strengthened their political presence in Washington during the 1970s, organized business opted for a general anti-regulatory stance against federal rules on data-driven discrimination in the private sector. As noted in the debates over the 1974 Privacy Act, these early efforts to regulate consumer information fell by the

wayside as private sector interests lobbied for regulatory exemptions. Similarly, spooked by the prospect of a public insurance plan in the lead-up to the creation of Medicaid and Medicare, both large and small private insurers including Metropolitan, Prudential, Equitable as well as Blue Cross and Blue Shield plans had voluntarily addressed data-driven discrimination by expanding coverage to "the chronically ill or over-age, previously classed as uninsurable" during the late 1960s and 1970s. The industry was unequivocal about its purpose for regulatory preemption, with one representative baldly stating that insurers would "plug all the gaps so there will be no vacuum into which the Federal Government can move" (Decormis 1961).

By the 1980s, fault lines began to fracture industry groups over health financing but brought them closer together on the issue of federal action on health data. The American Medical Association (AMA) organizationally fragmented as physicians split over the Clinton Health Security plan, forming hundreds of special-purpose medical associations (Quadagno, 2006: 192). The AMA, once the premier representative for the medical profession, could only claim 40% of all practicing physicians by the early 1990s (Peterson 2005: 217). Health reform in the 1990s also divided insurers, as federal reform signaled a threat to small insurers and an opportunity to large ones. The result was a "civil war" among insurers as larger insurers supported the move towards HMOs and small, traditional insurers feared for their survival (Steinmetz 1993). While large insurers were enamored by the prospect of mandated private insurance, provisions in the bill that would have prohibited health status discrimination in coverage decisions and restrictions on risk rating threatened smaller "specialty" insurance firms more than their larger counterparts. In 1991, the large commercial insurer Cigna left the industry's main lobby group, the Health Insurance Association of America (HIAA), and Aetna, Travelers, Prudential, and MetLife quickly followed. Organizationally fragmented over Clinton's healthcare reform, health insurers split into the "Gang of Five" against smaller insurers, represented by groups like the Council for Affordable Health

Insurance, who argued that the shift to HMOs would stifle market competition. Meanwhile, employers that had been active in crafting the contours of the modern benefits system struggled to put forward a coherent position on health policy reform, even as they buckled under increasing healthcare costs (Smyrl 2014). General business associations failed to present a united voice, as organizations representing both providers and employers could not reconcile their clashing priorities.

After years of promoting health reform, advocates wanted to avoid coming away empty-handed after the failure of the HSA. Preemptively regulating health data systems presented a relatively undisruptive path to incremental reform. Extending limited consumer protections against data-driven discrimination while preserving private health insurance and pushing technological solutions offered a way for politicians to respond to reformers without alienating private insurers or inflicting painful, direct cost-cutting measures. More importantly, however, as the organizational capacities of interest groups transformed over the decades, so did their positions on the federal government's role in regulating health information. No single interest or individual ushered through health information laws. Instead, despite their fragmentation over medical financing, interest groups reliant on health information systems became more closely aligned on their policy preferences towards federal intervention in health data.

Interest Convergence in the Health Insurance Portability and Accountability Act

In the wake of computerization of the financial industry during the mid-1960s, the Fair Credit Reporting Act (FCRA) passed in 1970 outlined consumer privacy protections of financial records to prevent discrimination in lending. By the early 1990s, no parallel federal law existed in health care. During the 1970s, a huge variety of users of medical records, ranging from "public health agencies, medical and social researchers, employers, social welfare programs, insurance

companies, government agencies, educational institutions, law enforcement agencies, credit investigation agencies, licensing agencies, and the media" had balked at the potential consequences of federal data regulations and lobbied successfully against proposed data privacy legislation (Regan 1995: 104). The temporary Privacy Protection Study Commission (PPSC), on which the executive vice president of Aetna served as a member, reported in its 1977 final report that sharing personal data had become inevitable in the modern information economy. The dangers of discrimination and exclusion abounded, and the commission asserted that individuals deserved a right to access and correct their records (Regan 1995: 85). Despite these recommendations from the PPSC, none of them translated into concrete policies (Igo 2018: 261).

In contrast, by the 1990s, these various data users became increasingly interested in federal intervention in health information systems. The delegation of healthcare rationalization to the private sector during the "market turn" energized providers, employers, and private insurers towards supporting federal intervention in the transition to a more efficient EHR system. During the HIPAA debates, the digitalization of medical records was still largely confined to academic settings. Although EHR had the potential to improve the efficiency of health care, EHR's diffusion into healthcare systems was slow (Patel and Rushefsky 2002: 158). Hospitals and medical centers were hesitant to bear the large upfront costs required to adopt the new technology. Even at the time of HIPAA's passage, "only a handful of hospitals and few physician offices used EHRs" and according to one estimate, 90% of medical records were still in paper files in 1999 (CQ Almanac 2000). Nonetheless, the focus on fiscal responsibility in the healthcare system and technology's contribution to these goals meant Congress would need providers' participation and trust in a standardized and integrated population-wide information system. Medical providers had once maintained largely individualized relationships with their patients, but with the development of EHR, providers hoped to improve the quality of patient care by

sharing patient records across providers. Cost-savings were also attractive. Dr. Roger Bulger, the President of the Association of Academic Health Centers in 1993, pointed to per-patient-visit savings resulting from the speed at which computerized medical notes could be read compared to deciphering the chicken-scratch of handwritten doctor's orders (Bulger 1993: 16).

Many observers of health reform have concluded that the medical profession, whose leading representative organization fragmented and whose membership had dramatically declined, became irrelevant in the debates over health policy reform (Swenson 2021; Peterson 2005: 217). As policymakers looked to dampen medical inflation, they became less receptive to arguments by medical and health service providers to expand coverage or mandate services. However, the medical profession was not so much irrelevant in health policymaking as its specific role in system reform had changed. Rather than exercise influence over the financing of health care, providers were critical to the successful transition to modernized health information systems. Data quality was paramount in rationalized health care (Bode 2019: 136-137; White 2004: 862-863); although providers became organizationally weakened, their role in extracting and providing accurate patient information meant that the demands of providers for better privacy protections and assurances for consumer protection in emerging health data technology could not be ignored (Battistella 1972: 343).

The emergence of managed care in the 1970s intensified clashes between providers and insurers over access to patient information. In efforts to combat waste, fraud, and abuse, HMOs and health plans would "routinely interview mental health providers by phone to ascertain whether a patient really requires treatment, and some sen[t] their own nurses into hospitals to review patient charts" (Barefoot 1998: 287, fn 33). Doctors, whose practices and patient records were reviewed by managed care, feared a greater loss of autonomy over their medical and price-

setting practices as healthcare financing moved towards a "prepaid" basis and away from fee-for-service (Starr 2013: 54-55). Health providers thus aligned themselves with the interests of patients and consumers against managed care (Quadagno 2006: 162-164). Providers also supported community rating of insurance premiums and bans on pre-existing condition exclusions, given that insurer practices of experience rating and exclusions were cost-cutting measures that affected coverage of physician services. Moreover, providers and especially psychiatrists working with sensitive mental health records worried that electronic data-sharing required in managed care's reviews could jeopardize the confidentiality assumed in the patient-provider relationship. If privacy were not properly protected, patients would be less willing to seek treatment as a result. The American Psychiatric Association (APA) was active in blocking "compromises" in the failed 1980 Medical Privacy Act bill, and the APA pushed for stronger privacy protections for mental health patients during and after the HIPAA debates (Barefoot 1998: 306, fn 185).

Employers, meanwhile, had relied previously on voluntary measures to govern their use of individual health data but turned to supporting federal intervention to bolster employee trust. Few states imposed statutory requirements for health information privacy on employers; a legislative survey of state health confidentiality laws showed that only nine states had done so by 1996 (Barefoot 1998: 349). As employers increasingly provided self-insured plans and managed their own wellness programs to encourage preventative care, they became both frequent generators and users of employee health information. Representatives from IBM, testifying as both an information technology company and as a self-insured employer covering half a million workers nationwide, supported federal rules that were comprehensive yet flexible. Arguing for strong employer involvement in federal rules, IBM representatives emphasized that "employers' benefit plans generate and use much of the health information that flows through the health care

system today" and that, as trustees of individual health information, employers supported federal rules that were flexible but could assure employees of their medical privacy.[53] Later, during debates over HIPAA, employers again appealed to federal preemptive rules for state health insurance benefit standards and regulatory rules. As the National Association of Manufacturers (NAM) testified in hearings for HIPAA, "National uniformity has been crucial to the private, free-market success in providing the vast majority of Americans with health benefits from employers that voluntarily sponsor health plans."[54]

While insurers had previously preferred state laws, the changing infrastructure of healthcare delivery facilitated a repositioning of insurers towards supporting greater federal intervention. During the late 1970s and 1980s, both health and life insurers expressed concerns that federal privacy legislation would disrupt the underwriting and claims processes "to the detriment of insurance applicants and policyholders alike."[55] As part of the push for rationalized care, private insurers merged and acquired managed care organizations throughout the early 1990s (Austin and Hungerford 2010). As insurers consolidated and health care turned towards interstate computerized networks, insurers became increasingly aware of the appeal and need for standardized, shared health data systems (OTA 1993: 119; Barefoot 1998: 29, fn 208). Although their concerns about preserving the industry's risk classification capacities remained, insurers recognized the need for federal rules to govern networked health information systems. In

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[53] *The Fair Health Information Practices Act: Hearings on H.R. 4077, Before the Subcom. on Information, Justice, Transportation, and Agriculture*, 103rd Congress 2 (1994) (statement of Richard Barker (IBM) and Martin Sepulveda (Occupational Health Services).

[54] *Health care reform: reforming the small business marketplace and the individual health insurance market: Hearings on Bill 104 S. 1028, Before the Subcommittee on Health and the Environment. Committee on Energy and Commerce*, 104th Congress 2 (1996) (prepared statement of Paul R. Huard, Senior Vice President, Policy and Communications, National Association of Manufacturers).

[55] Meletzke and Pattison, letter for *Privacy of Medical Records.*

describing Aetna Health Plan's uses of health data, a representative argued that the private sector shared the same privacy concerns about health data as the government and supported a "consensus" approach to data governance (Brooks 1993: 34-35). If insurers had not yet fully realized the value of EHR during the 1990s, the value of the technology became clear in the 2010s, when advances in hardware increased capacities for data storage and processing power so that the cost of EHR adoption dramatically decreased (Miller and Tucker 2009; Evans 2016: 549; Magee 2018; Iversen and Rehm 2022).

There is some scholarly disagreement on the extent to which the largest lobbies for private health insurers opposed the different consumer-oriented components of HIPAA. Despite their support for federal data governance, insurers were arguably more concerned about stemming the encroachment of public insurance options than by stricter federal consumer protections. Private insurers had taken an increasingly active role to promote federal consumer protections in exchange for maintaining a private system of health insurance. In the 1990s, insurers signaled their willingness to abandon some of the industry's discriminatory enrollment practices in response to bad press about pre-existing condition exclusions and the prospect of nationally-mandated health insurance in the Clinton Administration (Kaufman 1994). In the shadow of the failed Clinton reform and the evaporation of the mandate, some insurers backtracked on their initial warmth towards ratings restrictions and consumer protection provisions.

Although insurers rallied to protect their ratings practices after the failure of the employer mandate, they generally welcomed more federal health insurance regulations to even the playing field with self-insured plans. The Independent Insurance Agents of America and the Blue Cross and Blue Shield Association strongly supported the HIPAA bill in its meetings with the White House, and although the Group Health Association of America (which later became the American

Association of Health Plans) and Health Insurance Association of America warned that the bill's portability reforms would cause premiums to go up in the individual market, they did not strongly oppose the HIPAA bill or its consumer data protection components (Atchinson and Fox 1997: 148; Quadagno 2006: 196). Congress took heed of insurers' concerns and revised the final version of HIPAA to apply primarily to group plans. Even so, policymakers were reluctant to enact strict ratings restrictions to control the cost of group plans, resulting in plans that covered pre-existing conditions but at unaffordable rates or limited in their benefits design (Crossley 2005: 75-76; Rosenbaum 2009: 106). The most controversial implications of the law – and the continued uncertainty over the substance of health data protections – were then left to regulators.

Interest Divisions over the HHS Privacy Rule

After HIPAA, Congress stalled in further defining consumer protections in health information systems as competing approaches and conflicting interests among privacy advocates and industry stymied legislative action. The convergence of interest groups on federal legislative intervention and the relatively easy passage of HIPAA in 1996 masked the continuing conflict over the details of health information regulation. During the health reform debates, Representative Condit had described his 1994 fair health information bill as "one of the only noncontroversial parts of health reform" (Condit 1995). This lack of controversy was overstated. Although interests agreed about federal intervention, extensive hearings in April and May of 1994 struggled to identify a uniform set of fair information practices for health data (Conyers et al 1994). After the failure of the Health Security Act, to which Condit's fair health information bill had been included, Condit reintroduced a similar "fair health information" bill in 1995 (104 H.R. 435), 1997 (105 H.R. 52), and again in 1999 (106 H.R. 1941) without success or any Republican support. Even as HIPAA in 1996 had outlined general goals for data protection and banned the use of pre-existing condition exclusions

in eligibility, the statute included exclusions for risk management activities in insurance. Insurers also found ways around the pre-existing condition exclusion bans, drawing the ire of members of Congress, state insurance commissioners, and the National Association of Health Underwriters which accused companies of anti-competitive behavior and unfair trade practices (Pear 1997).

HIPAA gave Congress a deadline – August 1999 – to pass legislation about medical privacy and data protections. In the meantime, it outlined vague recommendations for individual rights, standardized procedures, and use and disclosure rules. Although legislators instinctively understood the sensitivity of medical records and the threat of privacy intrusions, there was significant disagreement over the details. Multiple competing bills from members of the same party demonstrate the lack of agreement over how to translate abstract notions of sensitivity, protection, and privacy into law. Law enforcement, which had been a major obstacle in federal medical privacy legislation during the 1980s, successfully argued for exemptions that would preserve their access to medical records. HIPAA's privacy rules also did not prevent the government from accessing and reviewing medical records to combat waste and fraud in Medicare, the third-largest payer for healthcare services and treatment.

Although interest groups agreed of federal intervention to standardize consumer protections, they split on whether federal legislation should preempt state laws. Health insurers, the managed care industry, and researchers supported a preemptive federal standard for national health information infrastructure that would facilitate a nationwide health information infrastructure; meanwhile, patient advocacy and consumer groups including the APA, the Consortium for Citizens with Disabilities, and the ACLU pushed for states to retain the ability to

pass more stringent protections (CQ Almanac 2000).[56] Industry and privacy interests alike preferred a legislative solution, but with Congress unable to find a compromise, the authority for defining medical privacy and data protections passed to regulators at the Office of Civil Rights at the Department of Health and Human Services (HHS) (Barefoot 1998: 316).

Issued by HHS in 2000, amended in 2002, and implemented in 2003, the Privacy Rule established guiding principles for the collection, use, and disclosure of medical records by individuals and entities -- doctors, hospitals, pharmacies, insurers, and other related businesses -- operating within the healthcare system. The privacy rule implemented the fair information practices and protections in HIPAA but did not allow individuals to sue and avoided imposing strong limitations on data collection "presumably because HHS did not want to tell health care providers what information to collect while treating patients" (Mulligan and Linebaugh 2019: 12; Gellman 2022: 23, 39). Likewise, although state attorneys general have been leading consumer protection advocates at the state level since the late 1960s, they have been less activist about enforcing restrictions on the use of consumer data. State attorneys general have been entrepreneurial in unfair trade practices, deceptive commercial practices, and data security and data breach notification laws, but "[b]ecause norms surrounding use restrictions are not well settled, attorneys general are proceeding with caution" (Citron 2017: 753, 773).

Most frustratingly for the industry supporters of federal intervention, the HIPAA regulations did not allow federal preemption of state laws, leading to the proliferation of varying protections at the state level.[57] The Clinton Administration, siding with privacy advocates, agreed

[56] Researchers are governed by the Federal Common Rule, which requires that researchers obtain informed consent before working with human subjects. The debates over researcher access to individual health data is a related issue that is beyond the scope of this chapter.
[57] Section 164(c)(2) of HIPAA.

that states should retain the ability to pass more stringent data protection laws. Although the "patchwork" of state health data laws had been identified as a problem by both lawmakers and health industry interests, the Clinton Administration justified its position based on precedents in privacy law and expressed an interest in learning from states as "policy laboratories" about their experiences with data privacy governance (Barefoot 1998: 354).

The privacy rules by HHS, which applied only to electronic and not to paper health records, covered only a small portion of health records years after the regulations were implemented. The proliferation of differing state privacy laws contributed to the sluggish adoption of EHR throughout the 2000s so that by 2005, only half of U.S. hospitals had adopted an EHR system (Miller and Tucker, 2009: 2; Rosenbloom et al. 2019: 1116). As part of the American Recovery and Reinvestment Act, the Health Information Technology for Economic and Clinical Health Act (HITECH) in 2009 amended HIPAA to encourage adoption of EHR throughout the healthcare system through federal subsidy incentives for Medicare and Medicaid (Goldstein and Thorpe 2010; Iversen and Rehm 2022: 76).[58] Federal law also needed to acknowledge a rapidly changing healthcare environment in which health data users had expanded far beyond traditional health care entities like hospitals, health insurers, and service providers. In addition to encouraging EMR adoption, HITECH also extended HIPAA's "Privacy Rule" regulations about healthcare data to a new set of "industry-adjacent business associates" and increased the civil penalties for violations. Nonetheless, privacy rules remained a federal floor and preserved the ability of states to pass stricter protections.[59]

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[58] American Recovery and Reinvestment Act, P.L. No. 111-5, Title XIII (2009).
[59] Whether the scope of HIPAA's regulatory liability applies to new entrants of the healthcare market, such as tech companies and biometric wearables, remains hotly contested.

Despite internal divisions and its failure to secure federal preemption of state laws, the insurance industry as a whole successfully asserted its preferences for continued access to health data. The HIPAA rules included exceptions to its health data-sharing rules with third parties for health plans making eligibility, enrollment, or underwriting and risk rating determinations (Mulligan and Linebaugh 2019: 11). Health insurers have become deeply integrated in general health care delivery in the United States (Webel 2018; Kelly 2023). In crafting consumer protections and data regulations, regulators were aware that restricting insurers too much in their risk discrimination strategies could lead to the collapse of the private health insurance system (Sasso 2011).

Though they were still in their political infancy during the HIPAA debates, the development of EHR also gave rise to new health technology interests. Large private vendor EHRs came to dominate the field while academic EHR systems declined (Evans 2016: 551). In response to the IOM's early reports about health record systems, the Institute's Committee on Improving the Patient Record recommended the creation of a public-private Computer-Based Patient Record Institute (CPRI). Formed in 1992 as a member-based association, the CPRI included representatives from the U.S. Chamber of Commerce, the AMA, and the American Medical Record Association (AMRA) (Dick 1992: 295). The organization consistently promoted the adoption of computer-based patient records and served as the primary go-between for the healthcare industry, information systems businesses, and regulators on health data policy recommendations (Tang and Hammond 1997).[60] The private EHR company, Epic Systems, established in 1979, became a go-to vendor for new health information technology. By 2019, the company dominated the EHR market and covered almost two-fifths of the 880,000 hospital beds in the United States

[60] In 2002, CPRI merged with the Health Information and Management Systems Society (HIMSS).

(Jennings 2021). As hospitals and healthcare systems responded to HITECH and transitioned to EHRs, Epic Systems became a vocal supporter of patient data privacy, a position that some criticized as furthering the company's efforts to keep health data systems proprietary and non-interoperable, or "closed."

Discussion

The consumer movement led by Ralph Nader, which had reached its peak in the mid-1970s, suffered a major defeat in 1978 with its failure to establish a federal consumer protection agency. The electoral incentive of pursuing consumer protections became less clear; although new legislative proposals for consumer protections had tended to match electoral cycles in the 1960s, this pattern disappeared by the 1980s (Trumbull 2012: 65). The enthusiasm for protecting individuals against businesses faded from the national agenda as other concerns such as inflation, fraud, and national security came to dominate discussions about regulation. A conservative backlash to regulation grew as detractors derided the growth of the "nanny state." Yet while the federal government underwent a "deregulatory turn" in economic and social regulations, its regulatory approach towards health data turned toward increasing federal intervention in consumer data privacy and anti-discrimination protection.

Why have federal policymakers pursued privacy and anti-discrimination provisions in health insurance, despite the fact that "discrimination is endemic in all health insurance" and such provisions can exacerbate costs (Blake 2016: 239)? A core observation in studies of political economy is that regulatory policy often serves to maintain the market rather than challenge it (Barma and Vogel 2022). Consumer financial protections, for instance, are arguably designed such that they are better at maintaining a preferred economic system of consumption than proactively protecting consumers (SoRelle 2020). Likewise, the "business case" for anti-

discrimination regulations argues that such laws on the books increase consumer confidence and thus increase consumer demand for a regulated industry's goods and services. Although protections against data-driven discrimination and consumer-oriented regulations had the potential to increase costs, they were ultimately meant to ease the transition to more cost-effective health information systems.

This chapter investigated why the federal government gradually assumed a stronger consumer protection role against health status discrimination over time and why different interest groups of private data users eventually agreed to it. Beginning in the late 1980s and early 1990s, private health insurers faced growing scrutiny over their use of consumer health data. Yet, consumers were not particularly proactive in advocating for consumer protections in health insurance. Where, then, did federal consumer protections against health status discrimination come from? Contrary to expectations that industry resists regulation while consumers promote protections, consumer protections against health status discrimination are the result of industry negotiations rather than consumer advocacy. As a result, consumer protections against health status discrimination have both reaffirmed public trust in private insurance while remaining limited and full of loopholes over the multi-decade course of policy development.[61]

With the passage of HIPAA and subsequent rule-making by HHS, healthcare entities faced new regulations on their data practices. I trace the factors leading to federal protections against

[61] Although intended to protect patients' control over their information and improve access to health insurance, health privacy and anti-discrimination regulations had uncertain effects. While privacy protections were meant to assure consumers of the security of new EHR systems and hasten their adoption, HIPAA's rules and regulations also discouraged some healthcare entities from adopting EHR (Miller and Tucker 2009). To address these problems, the Health Information Technology for Economic and Clinical Health Act (HITECH) in 2009 explicitly included incentives to encourage EHR adoption. More recent evidence suggests that the privacy assurances may not have their intended effect. For example, see Masters et al (2022) who argue that privacy assurances can increase patient lying about their medical history.

data-driven discrimination to the central role that federal policymakers delegated to private actors to rationalize health care during the 1970s and how it changed the behavior of interest groups towards federal intervention in the private health sector. Health policy in the U.S. has been an "area of social welfare [that] was long left to the management—and the financial responsibility—of private-sector actors within a structure established by public regulation" (Smyrl 2014: 14). I argue that policy development of consumer protections against data-driven discrimination are more reflective of the early political engagement of industry interests in shaping "fair health systems" than of any grassroots mobilization by consumers or their organized public interest advocates.

The turn to rationalization during the 1970s and 1980s changed the context of consumer health information. Federal policymakers were increasingly receptive to the private sector's efforts to dampen medical inflation through improvements to the private system of healthcare delivery and payment. The government's reliance on private insurers, consumers, corporate purchasers, and providers to rationalize healthcare services and products led to more federal protections against health status discrimination in service of bolstering and preserving this arrangement. These changes had subsequent effects on the behavior and relative power of interest groups in policymaking about successive health data technologies. Efforts to institute protections for health information would not take hold until the absence of protections was widely perceived as a major threat to the functioning of delegated rationalization.

Conclusion

With the turn to delegated rationalization, the stakes of federal regulation and its effect on the development of health data technologies became clearer to insurers, providers, employers, emergent health tech players, and consumers. Private insurers have also been more than happy

to emphasize that the problem of coverage can be better solved through the growth in the private market than through an expansion of public insurance. Health insurers become convinced, despite the stark partisan polarization over health financing and the fragility of policy change, that new federal consumer protection regulations could facilitate their ability to access valuable data for cost management. Cost-cutting goals also appealed to employers, consumers, and providers, the latter of which became arguably more important in determining the direction of health data policy given their crucial role in collecting accurate patient information. While they were not necessarily better organized, as evidenced by the fragmentation of major industry groups on the issue of medical financing, health interest groups converged during the 1990s towards greater federal involvement in regulating a national health data system.

Although the consumer protections in HIPAA marked a key moment in health policy history, it has received considerably less attention than the financing aspects of health reform. The existing work on data and discrimination in health care analyzes consumer protections from the legal perspective, focusing on how regulations can be interpreted and their legal precedents and implications. This chapter focused specifically on the political history of data-driven discrimination leading up to HIPAA and health data privacy law. Welfare state institutions built in the past can shape the behaviors of organized interests in modern technological reforms.

In the midst of EHR development, misuse of rising genetic technology posed a looming threat of data-driven discrimination. Of the bills proposed on protecting against genetic discrimination, HIPAA was the least comprehensive. HIPAA provided that genetic information could not be used by group health insurers, including HMOs, as asymptomatic "evidence of disease" used to exclude individuals from coverage or to charge them a higher premium. However, the law excluded employer self-insured plans and individual insurance from the genetic

information ban (Cooper 2000: 14). HIPAA's Privacy Rule also allowed for exemptions to the sharing of genetic information "if the data have been de-identified" despite arguments by researchers that the individual nature of genetic sequences made true anonymization impossible (Kulynych and Greely 2017: 95-96; Harbord 2019: 282). At the state level, multiple states during the late 1990s passed laws providing protections against genetic discrimination in health insurance. In some of these states, protections extended to the individual market while other states provided protections limited to specific diseases such as cancer. A tiny handful of states, in the meantime, enacted anti-discrimination laws banning the use of genetic information in health, disability, and life insurance (Cooper 2000: 29).

In the following chapter, I turn to examine the development of federal consumer protections against discrimination on the basis of human genetics. In this final empirical case of the dissertation, I show how social policy goals established before the discovery of the human genome contributed to regulatory change to protect individuals from genetic discrimination.

CHAPTER 5: GENOMICS AND THE POLITICAL HISTORY OF GINA (1980-2008)

Introduction

In this last empirical chapter, I focus specifically on the development of human genomics and the politics of federal genetic anti-discrimination regulation in health insurance. The discovery of links between human genes and disease ushered in a new era of health-related research and technology, but it raised yet another specter of data-driven discrimination on the basis of health status. Although genomics represented a potentially valuable source of health information, the federal government intervened to ban the collection and use of genetic information in employment and insurance with the Genetic Information Non-discrimination Act (GINA).[62]

Introduced in the House on January 16, 2007 by Representative Louise Slaughter (D-NY-25) and 143 co-sponsors and enacted a year and a half later, GINA (2008) is still the one and only dedicated federal law that governs human genomics. Nicknamed the "first civil rights act of the twenty-first century" by its sponsors, GINA protects the privacy of individual genetic data from employers and insurers by limiting its use in both domains. GINA consists of two main titles that address the use of genetic information – one for health insurers in coverage and pricing determinations (Title I) and the other for employers by prohibiting their collection and use of genetic testing of employees (Title II). Although prior federal efforts against data-driven discrimination had implied privacy protections for genetic information, GINA explicitly addressed the use of genetic information in insurance and employment.

For almost two decades, multiple efforts to enshrine genetic anti-discrimination in health insurance had consistently failed. Congress demonstrated its wariness towards health status anti-

[62] Genetic Information Nondiscrimination Act, P.L. No. 10-233 (2008).

discrimination by narrowing the definition of disability in the ADA and further excluding health insurance from its protections. The wrangling over HIPAA after the failure of the Clinton health reform resulted in partial protections against genetic discrimination, as health insurers warned about the potential collapse of their markets in the face of too-strict regulations. Recognizing genomics as a potentially valuable source of individual health risk information, health insurers lobbied against proposed regulations that would further limit their underwriting capabilities.

Why, then, did Congress pass GINA in 2008 and make off-limits a potentially useful source of health status data after many years of failed efforts? Although GINA passed with the support of both parties, I argue that the statute's relatively easy passage through Congress represents not a bipartisan agreement over the ethics of genetic discrimination but rather the convergence of myriad interests over a decade of wrangling over how to ameliorate public fears about genetic data misuse while preserving private health insurance. In this chapter, I trace the political history of GINA to understand why the federal government introduced bans on the use of genetic data in health insurance decisions. I argue that changes to welfare state arrangements during the 1980s and 1990s gradually pushed key interest groups closer together in the fight over genetic information, influencing the extent to which their fortunes became increasingly intertwined over safeguarding health information technology. More precisely, as the potential value of genetic information for rationalized healthcare systems became clearer, interest groups became supportive of government measures towards genetic information anti-discrimination policy to bolster consumer confidence in the new technology.

Although HIPAA arguably addressed the problem of data-driven discrimination in health systems, supporters of genetic anti-discrimination law feared that existing law was not enough. In much the same way that health-related information during the privacy debates of the 1970s

was deemed particularly sensitive compared to other types of personal data, genetics became understood as a uniquely sensitive form of health data deserving of targeted protections. In contrast to medical records, genetic data provided an individualized "fingerprint" that could not be anonymized. The ability of genetic information to identify individuals and provide life-altering predictions about future disease posed a particular challenge to an information privacy regime reliant on de-identification and patient consent.

Unlike in the cases of experience rating and EHR, the specter of genetic discrimination was far more effective in activating consumers concerned about data-driven discrimination. Consumer groups and patient advocates, especially groups concerned about breast cancer, mobilized to demand stronger anti-discrimination protections in health data governance. More broadly, however, consumer fear of discrimination led to privacy-protective behaviors in the healthcare market that worried legislators, physicians, and representatives from the insurance industry, employers, and growing biotechnology firms. Researchers invested in the success of genetic technology feared the loss of public support and funding for their work. The system of delegated rationalization, which relied on efficient and accurate health information systems, required robust public trust to secure the participation of consumers, patients, and providers. Federal intervention on behalf of consumers was therefore an attempt to bolster this delegated arrangement, even in the face of emerging genetic technology that arguably threatened the logic of private insurance.

The Promises and Perils of Human Genomics

It is hard to overstate the revolutionary nature of genetic technology in the late 1980s and 1990s. A recent estimate of the impact of the Human Genome Project estimates that the project contributed to research on "1,660 human diseases with documented genetic roots; 7,712 approved

and experimental pharmaceuticals; and 704,515 scientific publications between 1900 and 2017" (Gates et al 2021: 212). During the 1980s, scientists discovered the relationship between specific genes and single-gene illnesses, most notably Huntington's Disease, and genetic markers for gene patterns that suggested increased vulnerability to cancer and other serious health conditions. Accelerating these discoveries was the effort to map the entirety of the human genome that began in the mid-1980s. Initially an effort by scientists at the U.S. Department of Energy to understand the genetic effects of radiation from the atomic bombings of Hiroshima and Nagasaki, the Human Genome Project (HGP) was a collaboration between the National Institutes of Health (NIH) and the U.S. Department of Energy. The HGP expanded to "allow researchers to create brand new opportunities for preventive medicine, lay the foundation needed to develop and better target effective therapeutics, and provide unprecedented information about the origin and migration of human populations."[63] From 1990 to its completion in 2003, the HGP represented a massive federal investment of $3 billion to map and sequence human DNA for improving human health. Private companies, namely Celera Genomics, Inc. founded by former NIH gene researcher J. Craig Venter, joined the race to map the human genome, while partnerships with European and Japanese researchers turned the project into an international endeavor.

The discovery of genetic links to specific human health conditions had huge implications for medical research, but this rapid technological development was accompanied by the specter of genetic discrimination. Identifying genes and their defects could help medical researchers pinpoint underlying causes of diseases such as heart disease, cancer, diabetes, and hypertension (Watson 1989). The development of genetic information as health data also introduced a potent

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[63] *Genetic Information and Health Care: Hearings on S. 89, Before the Committee on Labor and Human Resources*, 105th Congress 2 (1998) (statement of Dr. Francis Collins, Director, National Human Genome Research Institute, National Institutes of Health).

new proxy into the toolbox of health insurers and employers concerned about rising healthcare expenses. More specifically, data about genetic predispositions represented a form of health status information about pre-existing conditions uniquely identifiable to an individual. Both the public and policymakers feared that, if left unregulated, insurers and employers could use genetic data to target individuals for exclusion and classify large numbers of people as having pre-existing conditions, leading to discrimination against those likely to develop costly health conditions.

As the HGP unfolded, changes in information technology and the identification of more genes linked to various diseases transformed the potential of genetic medicine. Further aided by simultaneous advancements in computer technology that rapidly shortened the time to discovery, genetic researchers at private companies such as SmithKline Beecham identified disease-affiliated genes, including those associated with Alzheimer's, alongside the publicly-funded HGP (Patel and Rushefsky 2002: 117). Not only could genetic research aid in diagnosis and treatment, it opened up the possibility for more precise and personalized pharmaceuticals. By identifying disease-causing genes, drugs could be developed to target specific pathways of disease and incorporate variations in individual genetics to such an extent that treatments could be personalized.

The Ethics of Genetics

Although scientists and researchers were adamant that public policy ultimately be conducive to technological innovation, internal divisions prevented them from having a sustained influence on federal regulatory intervention. Despite the promises of genomic research, the HGP was not without its opponents. In 1990, the National Center for Human Genome Research collected fifty-five letters from faculty at medical schools and natural sciences departments around the U.S. opposing the project (NHGRI 1990). Opposition from academic and scientific researchers

targeted the cost and centralization of the project, which some scientists feared would siphon public resources away from more-promising research endeavors and disincentivize investigator-initiated projects (Roberts 1989; Hilgartner 2018: 124). Internationally, European efforts to fund national collaborations with U.S. genomic researchers ran into criticisms of insufficient preparation for ethical considerations. The apprehension was particularly strong in West Germany, where the shadow of eugenics motivated advocates to argue for better ethics protocols (Dickson 1989).

Although criticized for the lack of ethical considerations, leaders of the HGP were well-aware of the ethical quandary of mapping the human genome from its inception, even if they were unsure of the statutory protections or regulations that would be required. To tackle discrimination, genetic researchers emphasized the need to preemptively and actively correct misconceptions about genetic determinism to combat ideas about a "genetic underclass" and a resurgence in eugenics thinking.[64] Regulating genetic information was part of larger debates about the privacy of health records, but researchers and advocates alike emphasized the uniqueness of genetic information from other medical records, given the potential for discrimination on the basis of not-yet-manifested health conditions. Most importantly, while medical records could be de-identified for population-level research, complete genetic sequences provided a unique individual "fingerprint" of personal information that made de-identification procedures largely infeasible.

[64] The roots of the eugenics movement during the early 20th century can be traced back to Sir Francis Galton's writings in the 1880s. Galton, inspired by the work on natural selection by his first cousin Charles Darwin, proposed the idea of "selective breeding" to improve the human race (Cooper 2000: 34).

Anticipating a complexity of issues raised by the public, HGP Director James Watson prioritized the institutionalization of an ethics component to the project and allocated three-percent of its budget towards a working group. Led by Nancy Wexler, the president of the Hereditary Diseases Foundation at Columbia University, the working group was tasked to "develop a detailed plan for addressing the ethical issues" of human genetic research (Watson and Jordan 1989; Watson 1989; Thompson 1989). The resulting Ethical, Legal, and Social Implications (ELSI) program in the HGP was not the first formal bioethics commission in the federal government, but it became "the best funded bioethics enterprise in history" (Hilgartner 2018: 123).[65]

The ELSI normalized the institutionalization of ethics into technological innovation projects, though its effectiveness in setting federal genetic anti-discrimination policy is questionable. As in prior debates about information privacy and discrimination during the 1970s, employment and insurance were areas of particular concern. Given the ability of genomics to predict health risks, health insurance coverage became an early target for government protections. Employers provided an ever-larger proportion of health insurance coverage, and protection from genetic discrimination by employers similarly rose to the top of the anti-discrimination agenda.[66] In the area of insurance, the ELSI committee identified life and health insurers as particularly interested in accessing genetic information, even if private insurers did

[65] Prior to the ELSI, Congress created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in 1974 after the Tuskegee Syphilis Study scandal, followed by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in 1978.

[66] In comparison, the issue of genetic discrimination in employer-provided and private health insurance was not prominent in countries where there is national universal healthcare. Instead, the concerns in the UK about genetic discrimination, for instance, centered around discrimination in life and disability insurance, not health insurance (Parthasarathy 2004).

not yet use genetic tests to determine coverage. As alternatives to anti-discrimination and national coverage, several states created special "risk pools" during the 1980s with higher premiums for individuals deemed "uninsurable" per underwriting in the group and individual markets given their pre-existing conditions.[67] Members of the ELSI looked to these potential solutions and suggested during the committee's first workshop that "alternate sources of health insurance for people with genetic diseases" such as "government co-payment, employer benefits or self-insurance systems, or combinations of these" be considered (ELSI 1990: 7).

Instead of pushing for health insurance reforms, the ELSI aimed to reassure people of the privacy of their DNA while correcting misconceptions to protect researchers from public backlash. As Senator Domenici explained, "A very large portion of the money under genome research goes to ethics panels to try to determine that we do not jump into the wrong body of water and drown the whole program."[68] The ELSI tread lightly in the health reform debates of the 1990s and refrained from participating in state debates about genetic anti-discrimination legislation (Yesley 2008: 4-5). Francis Collins, Watson's successor as director of the HGP at the NIH, explicitly stated that he would not advocate to replace the system of private health insurance or the individual market's reliance on underwriting.[69] Internal conflicts over whether the group should be offering broader policy recommendations led Collins to restructure the group in the mid-1990s (Hilgartner 2018: 125). In the months preceding the introduction of GINA in Congress, key

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[67] These state risk pools, supported by insurers who were unwilling to take on high-risk individuals without government subsidies, were adopted in thirty-five states until the ACA banned health status discrimination in health insurance markets.

[68] *Genetic Information and Health Care: Hearings on S. 89, Before the Committee on Labor and Human Resources*, 105th Congress 2 (1998) (statement of Pete Domenici, a U.S. Senator from the State of New Mexico).

[69] Collins, statement for *Genetic Information and Health Care*.

individuals involved in the ELSI program criticized the group as largely ineffective in influencing bioethics policymaking given the absence of an established policymaking channel and the group's lack of independence from the NIH and the Department of Energy (Yesley 2008; Hilgartner 2018: 125). Even so, other participants of the ELSI took credit for GINA passage in 2008. In a letter to the editor of *Nature Medicine*, Paul Billings, a member of the Secretary's Advisory Committee on Genetics, Health and Society in HHS, wrote that GINA represented "[t]he first policy initiative of the Ethical, Legal and Social Issues [ELSI] component of the Human Genome Project [that] has finally engendered a landmark postgenomic law" (Billings 2008).

Although researchers agreed on the need for legislation to protect individuals, significant differences in their approaches prevented them from taking a forceful stance on genetic anti-discrimination policy. Collins, though he aimed to avoid the ire of private health insurers, encouraged Congress to adopt national protections as concerns about genetic data misuse remained salient despite state legislative efforts to counter public fears.[70] Other scientists who endorsed a legislative approach to genetic privacy supported provisions that allowed individuals to sue to enforce their privacy rights. Dr. Lander, the Director of the Whitehead Institute/MIT Center for Genome Research and an advisor to the NIH, noted at the White House 8th Millennium evening in 1999 that the current law did not recognize the right to genetic privacy: "I think we're going to have to protect it with a lot -- to recognize that right, to let you sue for that right and to make sure that everyone respects that right… I really, for my part, endorse the efforts to pass such legislation. I really call on everyone to get to it" (Lander 1999).

[70] Collins, statement for *Genetic Information and Health Care*.

The right to sue health plans and private health data users would prove to be highly controversial. At the initiative of a presidential commission, the proposed "Patient Bill of Rights" in 1997 was enthusiastically received by the public, Congress, and state policymakers but quickly fell victim to disagreements over the actual substance of rights. In particular, private health insurers lobbied aggressively against the "right to sue a health plan for malpractice" ("Health Insurers Gain A Huge New Lobby," *NYTimes* 2003). Meanwhile, other researchers agreed on the need for anti-discrimination legislation but did not consider genetic information an existential threat to health insurance. Dr. Gibbs of the Baylor Center in the HGP, for instance, characterized the industry use of genetic information as "real potential…for insurance to be better managed through this kind of knowledge….You'd still need to have legislation in place to prevent the exclusion of different groups who are at risk, but in a large sense, there's a positive thing going on here, and that is that management of risk will become better articulated" (Cooper 2000: 15).

Political Debates over Genetic Discrimination (1980-2000)

In the years leading up to GINA, the gap between various interest group stakeholders in health information technology gradually closed. Although they had been largely inattentive to health status discrimination in years prior, consumers were broadly mobilized by concerns about genetic discrimination, especially as new scientific discoveries made the issue relevant to a broader population. Industry interests in insurance and employment, the two domains most subject to public criticism, were initially adamant that existing protections made additional genetic anti-discrimination laws redundant. Public apprehension of data misuse proved difficult to dispel, and providers and physicians observed firsthand the negative effects of potential genetic discrimination on the quality of health care and information systems. As the HGP neared its goal

of sequencing the human genome, Congressional leaders converged on the need for federal legislation.

Consumer Backlash to Personal Responsibility

The discovery of genomics challenged the "personal responsibility" approach that characterized healthcare rationalization policies, politically mobilizing consumer and public interest groups that chafed at the discrepancy between individual responsibility and hereditary risks. Market reforms in health care and their emphasis on individual consumer choice altered the relationship of individuals with the state, turning patients into consumers and placing upon them the burden of making good choices on the market (Campbell and Morgan 2011). Consumers excluded from the market as the result of government regulations become particularly aware of the government's role in their exclusion. As a result, they can organize and lobby for government intervention to remedy a market problem (Thurston 2018; Krippner and Hirschman 2022).

During the 1980s, consumer concerns about budding genomics research was limited to a few groups. The policy of rationalization in health care that had taken hold during the 1970s and 1980s gradually pushed responsibility for cost containment to the choices of private individuals, insurance businesses, and employers. During this time, consumer and patient campaigns against health status discrimination in health insurance was led by groups with rare diseases. AIDS groups protested against the ERISA exemption of employer-provided insurance in the courts as evidence emerged that employers dropped workers with AIDS from their plans. Observers of the fight over AIDS-related blood tests drew parallels between the denial of insurance coverage for AIDS carriers and rapidly-developing genetic testing capabilities for the broader population (Ricklefs 1987; Stipp 1990). The Council for Responsible Genetics (CRG), formed in 1983, began lobbying to support victims of genetic discrimination. Although advocates for patients with single-

gene diseases emerged to join forces with AIDS activists, public concern over data-driven discrimination in health care was still limited to these relatively small, and often marginalized, interest groups.

Meanwhile, efforts to regulate health status data were driven by state policymakers' concerns about market stability. California, for instance, banned the use of HIV antibody tests in health and life insurance underwriting in 1985 (Stone 1993: 313). Other states, however, sided with insurers as insurers pushed back in the courts, successfully challenging state regulators over the use of HIV tests in underwriting by arguing that certain types of health status discrimination were actuarially fair (Crossley 2005: 110-111). State insurance regulators defended their role as state-level consumer protection advocates on issues of genetic information in debates over federal legislation. The National Association of Insurance Commissioners (NAIC) lobbied against federal preemption of state laws, arguing that federal legislation on genetics could further complicate the existing patchwork of state health information privacy laws and hamper their ability to stabilize state insurance markets.[71] Nonetheless, state activism on consumer protections for health status was arguably driven by concern among legislators that discriminatory enrollment practices in small group and individual markets were evidence of market failure (Crossley 2005: 111). Rather than ban discrimination more generally, regulations did not apply to the growing share of self-insured employer-provided plans that ERISA's preemption clause had unleashed, and states avoided regulating the pricing, underwriting, and coverage policies of insurers together, as such

[71] *Genetic Information and Health Care: Hearings on S. 89, Before the Committee on Labor and Human Resources*, 105th Congress 2 (1998) (statement of Jack Ehnes, on behalf of the National Association of Insurance Commissioners (NAIC)).

a “triple-threat” in insurance regulation would prevent insurers from managing their financial risks.

Although rationalization can individualize risks and thus fragment consumer interests, it energized consumer interest groups to demand better protections against genetic discrimination. The rapid advancement of genomics in the 1990s threw into question the culpability of individuals for their personal health status. The discovery of genetic “determinants of health” challenged the ideas of personal responsibility that justified healthcare rationalization policy, mobilizing consumers on a much broader basis than experience rating or specific disease exclusions had done previously (Stone 1993: 309). Some scholars argue that Clinton’s health reform effort failed in 1994 because voters were generally content with their employer-provided health insurance (Gottschalk 2000; Mettler 2011). While voters may have been generally satisfied by their employer-provided health insurance, they certainly did not take it for granted during the genetic revolution. Reliance on the private provision of health insurance, through private insurance or employer-sponsored plans, had the effect of amplifying the threat that genetic discrimination by employers and insurers posed to health coverage. Proponents of genetic anti-discrimination law argued that discrimination on the basis of genetic data constituted unfair treatment based on circumstances beyond one’s control, even for groups typically considered responsible for their poor health status. In hearings about genetic information in health care in 1998, Senator Paul Wellstone (D-MI) observed that “in both mental health and substance abuse…more and more, we are beginning to see neurological and biochemical connections. So that in some areas that people

do not normally think of, these are large numbers of people who are going to be affected for the worst, in a very real life or death manner" by genetic discrimination in health care.[72]

Although evidence of genetic discrimination in practice was mixed, public concerns persisted. Genetic researchers supported educational campaigns to dispel misconceptions about genetics, yet consumer and public interest groups mobilized to support a more forceful government stance. Identity movements and disease-oriented patient groups could appeal to immutable or shared characteristics to organize groups, but the prospect of discrimination on the basis of genomics could bring together both consumers with "better" and "worse" health status given their shared uncertainties about their genetic risks. Civil rights groups, which had been largely uninterested in health status discrimination during the 1980s, banded together with patient rights groups to form the Coalition for Genetic Fairness (CGF) in 1997. The CGF lauded GINA's main sponsor, Representative Louise Slaughter (D-NY-25), and her insistence that "[w]e all have bad genes, even health insurance company executives" (AScribe 2007; The Nation's Health 2008). Formed initially by civil rights and advocacy organizations such as the National Workrights Institute with healthcare professional associations including the National Society of Genetic Counselors, the coalition expanded to include industry representatives and employers in 2005 (CGF 2008). Throughout debates on GINA, the CGF argued that everyone could be subject to discrimination because genetic abnormalities were universal. These arguments have had staying power. Several years after the passage of GINA, support for genetic anti-discrimination laws remained strong and widespread among the American public (Almeling and Gadarian 2014).

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[72] *Genetic Information and Health Care: Hearings on S. 89, Before the Committee on Labor and Human Resources*, 105th Congress 2 (1998) (comments by Paul Wellstone, a U.S. Senator from the State of Minnesota).

Articulated by ethicists, the fear of a genetic "underclass" based on genetic test results spurred widespread public involvement on the issue of genetic discrimination. The uncertainty of diagnoses and the potential for genetic tests to produce both predictive risks and false positives expanded the issue of genetic discrimination to a much larger, interested public. Consumers were encouraged to attend to the accuracy of their risk profiles for insurance products and pricing, and their concerns about genetic discrimination stemmed from fears that they would be categorized incorrectly or discriminated against for taking genetic tests as a preventative measure to preempt expensive diseases.

Scientists led by geneticist Dr. Mary-Claire King identified the connection between the BRCA1 gene and breast cancer in 1994. The discovery of hereditary factors for breast cancer in the mid-1990s suddenly changed genetic discrimination from an issue affecting people with "rare diseases" to a significant proportion of the population (NHGRI 1997; Jones 1996; Parthasarathy 2004; Hurst 2014).[73] The Genetic Alliance, an international coalition of genetic disease groups, and disease-oriented groups such as the Polycystic Kidney Research Foundation and the National Breast Cancer Coalition (NBCC) organized for protections given that "members dread the thought of losing their insurance or becoming unable to acquire coverage…[and] avoid testing completely largely due to fear that a positive test result would adversely affect their insurability for life or health insurance."[74] Significant media coverage of the HGP also raised the public profile of genetic

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[73] In the U.S., 1 in 8 women will likely develop breast cancer in her life. Cancer is the second leading cause of death in the U.S. (CDC 2023).

[74] *Potential for Discrimination in Health Insurance Based on Predictive Genetic Tests: Hearing before the Subcom. on Commerce, Trade, and Consumer Protection of the Committee on Energy and Commerce*, 107th Congress 1 (2001) (statement of Mary E. Davidson, Executive Director, Genetic Alliance, Inc.); *Genetic Information and Health Care: Hearings on S. 89, Before the Committee on Labor and Human Resources*, 105th Congress 2 (1998) (statement of Christine Brunswick, Vice President, National Breast Cancer Coalition). Even after the passage of GINA, consumers avoided genetic testing in part due to fear of discrimination in health insurance (Allain et al 2012).

discrimination throughout the 1990s and early 2000s. In establishing a genetic basis for many diseases, genomics challenged the personal responsibility mantras that had once dominated conversations about health reform and mobilized consumer and public interest groups to demand stronger government protections against genetic discrimination.

A strategic turn on the part of commercial health insurers in the 2000s to focus on consumers rather than providers in managing costs heightened consumer sensitivity to genetic discrimination. Rationalization policies during this time moved away from the "supply-side" strategy of managed care that dominated the industry from 1980 to 2000 and towards the "demand-side" of patient behavior. Rather than manage the practices of physicians, which had created backlash from physicians and patients, commercial insurers moved to diversify their products and prices to attract different consumers (Robinson 2004). This change in insurer strategy moved rationalization policy towards an even greater emphasis on personal responsibility of individual consumers. In this context of shrinking benefits and individualized plans, consumers became more concerned about genetic information and its regulation for ensuring adequate coverage. Alongside the CGF, the Council for Responsible Genetics (CRG) proposed a Genetic Bill of Rights and lobbied state and federal legislators to regulate insurer and employer use of genetic information (Parthasarathy 2004: 335; CRG 2010).[75]

In previous disruptions of health information technology, a broad-based interest in privacy and anti-discrimination failed to emerge as different groups faced dramatically varying stakes in the consumer protection debate. Genomics, however, made data-driven discrimination a widespread concern. In contrast to experience rating and potential discrimination from

[75] Sophia M. Kolehmainen, the director of the human genetics program at CRG, was one of the most vocal and active advocacy groups pushing for government regulation of genetic information.

electronic health records, genomics motivated consumer and public interest advocacy groups to play a more active, broader role in preventing data-driven discrimination. Despite the potential for genetic differences to further segment consumers by their health risks, the persistent uncertainties in understanding genetic risks helped consumer and public interest groups to hold together. These groups survived to lobby for anti-discrimination protections until the successful passage of GINA in 2008. Consumer groups generally fragmented in the policymaking process after GINA, as the CGF changed directions to focus on public educational campaigns and the CGR unsuccessfully lobbied for expansions of GINA to life, disability, and long-term care insurance (Peikoff 2014). Rationalization policies set decades earlier and adjusted over the years made the discrepancy between genomics and expectations for personal responsibility in healthcare costs even more stark. Specifically, policy approaches to cost containment in health insurance that emphasized the individual nature of healthcare coverage and personal responsibility for costs made consumers more sensitive to their risk profiles and aware of the "unfairness" of genetics in data-driven discrimination. Rationalization policies thus positioned consumers to become politically active on federal and state regulations when personal responsibility was thrown into question by genetic discrimination.

Insurer Efforts to Inform and Educate

Initially, insurers were adamant that they retain their ability to access genetic data and staunchly resisted federal genetic anti-discrimination legislation. Although the health insurance industry is diverse, including commercial firms, nonprofit and for-profit plans, and managed care or HMO-like organizations, the industry considered the promises of emerging genetic science for insurance too tantalizing, even if it had not yet adopted genetic data use. In a 1989 report by representatives of the Lincoln National Life Insurance Company for the American Council of Life Insurance, the

authors argued that "fairness, sound insurance principles, and the public interest will require life and health insurers to use genetic tests to determine insurability and prices" (Stone 1993: 299-300). Representatives of the leading trade group for health insurers brushed off early concerns about genetic discrimination as the media coverage of the HGP intensified. In discussing the need for insurers to know about genetic test results, Jude Payne, the senior policy analyst for the Health Insurance Association of America (HIAA), explained "While some people might consider that discrimination, the insurance industry would consider it standard policy" (Stipp 1990).

During the 1990s, members of Congress proposed at least a dozen bills about genetic information, including the Genetic Privacy and Nondiscrimination Act of 1995, the Genetic Information Nondiscrimination in Health Insurance Act of 1995, the Genetic Fairness Act of 1996, and the Genetic Confidentiality and Nondiscrimination Act of 1996. Many of these efforts were spearheaded by Representative Kennedy, who also introduced the Kennedy-Kassebaum bill that would become HIPAA (Jones 1996: 6). As federal legislation appeared, the health insurance industry pushed back. Even as the industry had signaled an openness towards federal underwriting restrictions during the Clinton health reform debates in exchange for the federal mandate, they were unwilling to preemptively cut off access to emergent genetic technology. Accused by Congress of using genetic information as a "pre-existing condition" for determining insurance coverage, insurers argued that these claims of genetic discrimination were anecdotal and fed "misinformation" and "unjustified public fears about insurers' use of genetic information" in the underwriting process (Jones 1996: 2).[76] In multiple hearings about genetic data in health

[76] *Potential for Discrimination in Health Insurance Based on Predictive Genetic Tests: Hearing before the Subcom. on Commerce, Trade, and Consumer Protection of the Committee on Energy and Commerce*, 107th Congress 1 (2001) (statement of Donald A. Young, Interim President, Health Insurance Association of America (HIAA)).

care, the HIAA argued that federal legislation on genetic anti-discrimination would increase the costs of health insurance, create artificial fragmentation in the medical record, and was generally "a misguided effort to fix a problem that does not exist, [such that] Congress may in fact be stifling innovation and improvements in health care quality against the best interests of millions of American patients."[77] Health insurers also attempted to preempt federal legislation, instituting professional guidelines and company policies about consumer genetic data to address consumer privacy fears even as they argued for the right to conduct their own genetic tests in order to circumvent applicants hiding their results (Knoppers 1999: 41-43).

Split Employers Strike Back

Like insurers, employers were subject to immense scrutiny for their use of genetic information. Insurers and employers thus joined forces to lobby against genetic data use legislation. Employers took on a larger role in healthcare coverage through ERISA plans, which meant that established insurance companies increasingly played an administrative role as self-insuring employers assumed the financial risk of paying for their employees' healthcare claims (Austin and Hungerford 2010: 23). Genetic screening provided a tool for employers to avoid costly members, a practice that some employees challenged in court under the ADA.[78]

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[77] Young, statement for *Potential for Discrimination in Health Insurance; Protecting health information: legislative options for medical privacy: Hearing of the Subcommittee on Government Management, Information, and Technology of the Committee on Government Reform and Oversight,* 105th Congress 2 (1998) (statement of Charles N. Kahn, Chief Operating Officer and President-designate of the Health Insurance Association of America (HIAA)).

[78] In 2000, Terri Seargent filed an EEOC claim against her employer after testing positive for a genetic condition. In 2001, workers at the Burlington Northern Santa Fe Railway (BNSF) challenged workplace genetic testing for carpal tunnel syndrome. In both cases, which were heavily cited during hearings for GINA, the EEOC ruled in favor of the employee and signaled that it would "continue to respond aggressively to any evidence that employers are asking for or using genetic tests in a manner that violates the ADA" (Jones and Sarata 2008: 8).

Concerned about the effect of genetic anti-discrimination laws on their ability to collect and use health-related information, large employer associations organized as the Genetic Information Nondiscrimination in Employment (GINE) Coalition. GINE, led by the U.S. Chamber of Commerce, lobbied against genetic anti-discrimination legislation as an unnecessary and expensive regulation that would open employers up to litigation (Slaughter 2013: 51-54).[79] Human resources groups such as the Society of Human Resources Management (SHRM) also argued that public fears were unfounded, testifying that employers rarely used genetic information, and genetic anti-discrimination proposals were unnecessarily punitive to employers compared to existing civil rights non-discrimination laws.[80] Both insurers and employer groups pushed back against claims about discrimination made by researchers, arguing that examples of coverage losses or firing decisions were anecdotal. According to industry, consumers and employees were already protected by existing laws such as the ADA and Titles VI and VII of the Civil Rights Act. The ACLU countered that the courts had narrowed the definition of "disability" in the ADA as to exclude people with genetic predispositions from protection.[81]

Large employers lobbied as GINE, but small employers had different priorities. As in questions of medical financing, employers were split on their preferences for genetic anti-discrimination protections given the implications for health insurance costs. Facing both costly

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[79] Other members included the National Association of Manufacturers, the National Retail Federation, and the Society for Human Resource Management.

[80] *Genetic Information in the Workplace: Hearing of the Committee on Health, Education, Labor, and Pensions,* 106th Congress 2 (2000) (statement of Susan R. Meisinger, Chief Operating Officer, Government and Public Affairs, Society for Human Resource Management (SHRM), Alexandria, VA).

[81] *Genetic Non-Discrimination: Implications for Employer Provided Health Care Plans: Hearing before the Subcom. on Employer-Employee Relations*, 107th Congress 1 (2001) (statement of Mary K. Williams, Attorney, Alston & Bird, Atlanta, GA); *Fulfilling the Promise of Genetics Research: Ensuring Nondiscrimination in Health Insurance and Employment: Hearing on S. 318, Before the Committee on Health, Education, Labor, and Pensions,* 107th Congress 1 (2001) (prepared statement of the American Civil Liberties Union (ACLU), Ronald Weich, Legislative Consultant). See also *Sutton v. United Airlines, Inc.* 527 U.S. 471 (1999).

insurance plans and costly genetic screening, smaller employers diverged from large employer associations. Small employers feared that health insurance could become unaffordable for their employees if premiums for the whole group could be based on the genetic tests of one member, even if the member was asymptomatic for genetic disease. In the 1990s, the costs of genetic screening were still considered prohibitively expensive and restrictions on genetic screening for small employers was less of a priority than protections against exorbitant health insurance costs resulting from genetic discrimination.

Providers as Unwilling Information Intermediaries

Since the emergence and adoption of managed care during the 1980s, delegated rationalization in health care has transformed the landscape of medical services provision. Rationalization brought the majority of people covered with private insurance under managed care plans and vertically integrated providers with health insurers and prepaid health plans (Austin and Hungerford 2010: 22).[82] This vertical integration in the healthcare system also moved physicians and insurers closer together in supporting clear protections about genetic data flows even as it created divisions between them in their stewardship of patient data. Although insurers remained largely adamant that a strategy of public education campaigns could dispel public fears, providers developed a strong interest in federal intervention to alleviate patient distrust. Providers worried about the effect of public fears of genetic discrimination on the effectiveness of their practices. Early on in the debates over genetic privacy, providers were attuned to the effects of new health information on their relationship with patients. A 1993 report from the Institute of Medicine

[82] These managed care plans can either be "a managed indemnity plan" or PPO, in which insurers negotiate payments with providers, or "staff HMOs" in which the HMO directly provides care since physicians are salaried by the insurer.

(IOM) discussing changing health information technologies took a strong pro-privacy stance in its recognition of genetic risks (Donaldson and Lohr 1994: 57, fn 4).

Physicians also became unwillingly caught in between patients and insurers over genetic information. The American Medical Association (AMA) recommended doctors to "maintain a separate file for genetic test results so the information is not sent to insurers" in the association's code of ethics (Peikoff 2014). Physicians, as Dr. Judy Garber of the Dana Farber Cancer Institute explained, found themselves in a "terrible place for physicians to sit, really dancing the tightrope around the liability issues on all sides – do we tell, don't we tell, do we write, don't we write, can it be discovered, can we be sued for inadvertent disclosure…physicians…also have obligations to the insurers that they deal with."[83] Physicians employed by Kaiser Permanente's managed care organization, for instance, created a working group on genetic ethics and expressed general support for federal genetic anti-discrimination legislation.[84] Caught in between as information intermediaries, providers allied with consumers and patient advocates in support of genetic anti-discrimination legislation (Slaughter 2013: 53).

As the HGP advanced and gained public salience in the mid-1990s and early 2000s, public concern about health insurance coverage grew. In studies about the public's attitudes towards genetic discrimination, the distrust of health insurers was on full display. Public opinion polls from the mid-1990s showed that the public distrusted the insurance industry more than tobacco

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[83] A*dvances in Genetics Research and Technologies: Challenges for Public Policy: Hearings before Committee on Labor and Human Resources*, 104th Congress 2 (1996) (testimony of Dr. Judy E Garber, assistant professor of medicine, Department of Cancer Epidemiology and Control, Dana Farber Cancer Institute and Harvard Medical School).

[84] A*dvances in Genetics Research and Technologies: Challenges for Public Policy: Hearings before Committee on Labor and Human Resources*, 104th Congress 2 (1996) (testimony of Dr. Kate T. Christensen, Staff Internist, Kaiser Permanente Medical Center, Regional Ethics Coordinator, The Permanente Medical Group).

companies while more than two-thirds of respondents "agree[d] that insurers would do everything possible to use genetic information to deny health coverage" and "80% oppose[d] access to this information by health insurers" (Quadagno 2006: 163; Jones and Sarata 2008: 3). Even the director of the National Human Genome Research Institute, Francis Collins, testified about the dangers of "insidious discrimination" on the basis of genetic data in employment and health insurance.[85] Genetic testing promised early intervention and even the potential preemption of diseases before they could develop into expensive conditions. Yet persistent public fear of genetic discrimination threatened to derail the benefits of the federal government's significant technological investment.

Bipartisan Support for Genetic Anti-discrimination

Genetics is a core intervention in preventive care and precision medicine given the ability to create individualized disease profiles. Researchers describe genetic technology as promoting "cost-effective preventive medicine."[86] Politicians of both parties have long argued for the use of preventive care to address healthcare costs, and genetic testing offered a promising approach. Senator Ted Kennedy (D-MA), a champion of the biotechnology industry who sponsored many genetic anti-discrimination bills, recognized that "[genetic testing] can be used to detect genetic traits in ways which will assist patients in receiving treatment or even taking steps which will prevent the onset of disease long before any symptoms of that disease are apparent" (Perino and

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[85] *Genetic Information in the Workplace: Hearing of the Committee on Health, Education, Labor, and Pensions,* 106th Congress 2 (2000) (statement of Dr. Francis Collins, Director, National Human Genome Research Institute).

[86] *Technological Advances in Genetics Testing: Implications for the Future: Hearings before the Subcommittee on Technology, Committee on Science*, 104th Congress 2 (1996) (statement of Wayne W. Grody, MD, PhD, UCLA School of Medicine, Member, NIH-DOE Task Force on Genetic Testing).

Nussle 2008).[87] Sponsors of genetic anti-discrimination pointed to the utility of genetic tests to tackle spiraling healthcare inflation. Senator Olympia Snowe (R-ME) co-sponsored the precursor bill to GINA, the Genetic Information Nondiscrimination in Health Insurance Act in 1998, arguing that "in the final analysis, there will be cost savings for the insurance companies and for America [from genetic testing]. So we should do all we can to protect the privacy of genetic information."[88] An almost equal number of Republicans and Democrats sponsored these genetic anti-discrimination bills during the 1990s (Kennedy 2007: 13). Even though the empirical evidence is mixed on whether preventive care is more cost-efficient, this argument has persisted as presidential candidates Hillary Clinton, John Edwards, Mike Huckabee, and Barack Obama all referenced preventive care as a way to save money in the health system (Cohen et al 2008). In this way, preventive care was arguably part of a broader strategy towards cost-efficient and "optimized" healthcare services that characterizes rationalization policies.

In the midst of lobbying for protections by consumers and resistance from industry groups, politicians from both parties converged to protect cost-saving genetic technology with consumer protections. Both Democratic and Republican presidential administrations had prioritized federal funding of the HGP, which they viewed as incentivizing future cost-savings and technological development. In 1990, the Reagan Administration sought to increase spending for the project by more than $110 million, even as the administration publicly extolled domestic

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[87] *Fulfilling the Promise of Genetics Research: Ensuring Nondiscrimination in Health Insurance and Employment: Hearing on S. 318, Before the Committee on Health, Education, Labor, and Pensions,* 107th Congress 1 (2001) (opening Statement of Edward Kennedy, Chairman, Committee on Health, Education, Labor, and Pensions).

[88] *Genetic Information and Health Care: Hearings on S. 89, Before the Committee on Labor and Human Resources*, 105th Congress 2 (1998) (statement of Olympia Snowe, a U.S. Senator from the State of Maine). As in the case of the ADA and sponsor Senator Weicker's family experience with disability, Snowe had personal experience with genetically-linked diseases as she lost her mother to breast cancer as a child.

spending cuts. Later, both the Clinton and Bush administrations renewed funding for the project and brought the total cost of the HGP to $3 billion. Observers of the project's significant cost noted at the time that "[Director] Watson sees the project as important to the scientific community, not only because of its ultimate goal [to map the human genome], but also because it will generate new technology along the way" (*Nature* 1989). Public fears about genetic discrimination threatened the goals of delegated rationalization for cost-efficiency, motivating federal policymakers to support greater intervention to better secure the benefits of the government's massive technological investment.

Fulfilling the Promise of Genetics Research (1995-2008)

The first version of GINA introduced in 1995 had 76 bipartisan cosponsors in the House, and later revisions of the bill after the success of HIPAA continued to garner bipartisan legislative support despite legislative stalemate in a divided Congress (Slaughter 2013: 49-53). Bipartisan sponsors of the early genetic information bills worried that delaying protections could lead to the loss of public support for government funding of genetic technology.[89] Even in the pro-business presidency of George W. Bush's administration, the Bush White House publicly called on Congress to pass legislation prohibiting genetic discrimination in health insurance, though Republicans balked at the inclusion of employers in genetic anti-discrimination law and Republican House leadership repeatedly declined to hold hearings on genetic privacy bills as the unintended consequences of anti-discrimination requirements on employers remained uncertain (*The Washington Post* 2001; Jones and Sarata, 2008: 5).

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[89] A*dvances in Genetics Research and Technologies: Challenges for Public Policy: Hearings before Committee on Labor and Human Resources*, 104th Congress 2 (1996) (statement of Connie Mack, a U.S. Senator from the State of Florida).

Given bipartisan support in Congress for federal consumer protections, why did genetic anti-discrimination legislation still take another decade to pass after the initial proposals? Despite the apparent urgency of growing consumer distrust, debates over how to define genetic information in the midst of ongoing technological change and persistent lobbying by industry groups over the scope of legislation created a policymaking context of significant uncertainty and apprehension. Efforts to pass a genetic discrimination bill in the 106th (2001-2002), 107th (2002-2003), and 108th (2003-2004) Congresses failed as legislators wrangled over the breadth of the prohibitions and their potential unintended consequences on health insurance and research (Roberts 2012: 1182, fn 141).[90]

The delay in genetic anti-discrimination law was also a victim of bad timing. An executive order by President Clinton in February 2000 prohibited genetic discrimination against federal employees, while President Bush supported the Genetic Non-Discrimination in Health Insurance and Employment Act proposed in Congress in 2001 (Patel and Rushefsky 2002: 147; Jones and Sarata 2008).[91] By 2001, twenty-eight states had passed laws banning discrimination in insurance on the basis of genetics while thirteen had banned genetic discrimination by employers ("America's next ethical war," *The Economist* 2001; Patel and Rushefsky 2002: 147). The surprise dual attacks on the World Trade Center and the Pentagon on September 11, 2001, slowed momentum for genetic anti-discrimination legislation as Congress pivoted to address homeland security priorities. Other consumer-oriented initiatives in patient rights, which had been steadily

[90] These failed bills include S. 2553, HR 2990, S. 1052, S. 318, HR 602, S. 1995, S. 19, S. 382, S. 16, HR 1910, S. 1053, S. 306, HR 1227, HR 6125.
[91] Executive Order 13145; Genetic Non-Discrimination in Health Insurance and Employment Act, H.R. 602 (2001).

gaining support and presidential attention, similarly fell by the wayside as legislative priorities turned to the "War on Terror."[92]

The completion of the HGP in 2003 reinvigorated the debate over genetic protections and provided the immediate impetus for another serious Congressional attempt at federal regulation. In the early years of the HGP, some observers had dismissed the issue of data-driven discrimination in insurance given the significant expense of genetic profiling to insurers (Friend 1989). By the 2000s, the cost of genetic profiling had dramatically declined. A prototype sequence of the human genome was developed in 2001 and over the following years, technological advancements in computer processing power decreased the price of genome sequencing from $300 million in 2001 to about $200 in 2018 (Iversen and Rehm 2022: 62). In April 2003, the completed human genome sequence was deposited into public databases. The transition of health information systems to electronic medical records in the 2000s vastly increased the amount of data that could be centralized and made available to both private and government entities.

More importantly, interest groups moved closer together in the interim over their support for federal intervention. By the mid-2000s, forceful resistance from insurers against genetic regulations no longer seemed a tenable position for the industry. Unlike during the early years of genetic technology, insurers were also no longer adamant that insurer access to genetic information was necessary for their practices. This change in the insurance industry's position towards genetic data regulation stemmed from two developments in the period after the failure of Clinton's health reform. First, consistent public fear of genetic discrimination provided continued ammunition for criticisms of the logic of private insurance despite both researcher and

[92] Later, digital privacy initiatives suffered a similar loss of momentum when Obama's Consumer Privacy Bill of Rights was derailed by Edward Snowden's revelations of government surveillance in 2013.

insurer efforts to dispel public misconceptions about genetic information technology. Second, the years-long wrangling between legislators and insurers over the definition of genetic information had narrowed down the scope of genetic anti-discrimination to no longer include established practices in insurance markets.

The evaporation of support for Clinton's health reform during the 1990s did not settle efforts to nationalize health insurance or the problem of genetic discrimination. Public fear continued to threaten private insurance. Arguing that genomics posed an existential challenge to the logic of private and employer-provided insurance, Craig Venter, the founder of the genetics research company Celera, warned, "[o]nce we've sequenced all of our genomes, we will all be uninsurable because we all have genes in our genetic code that would indicate a propensity for some disease in the future" (Cooper 2000: 15). Others echoed these dire predictions about health insurance, sowing doubts about the sustainability of private and employer-provided health insurance in the age of genomics (Stipp 1990; Knoppers 1999; Burley 1999). Researchers and legislators alike argued for legislative intervention to protect consumers to protect both genetic technology and insurance. In sponsoring legislation on genetic testing, Jim McDermott (D-WA) emphasized that "[U]nless we prevent this sort of misuse of information, we will undermine the very notion of insurance."[93]

These debates about the feasibility of private insurance in the age of genomics convinced insurers and employers to abandon their staunch opposition and acquiesce to limitations on their

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[93] *Technological Advances in Genetics Testing: Implications for the Future: Hearings before the Subcommittee on Technology, Committee on Science*, 104th Congress 2 (1996) (statement of Rep. Jim McDermott (D-WA)). These predictions for the future of private insurance were not shared across the research community. Norton Zinder, for example, reached the opposite conclusion. As chairman of the NIH genome project advisory committee, Zinder argued instead that "[i]f we screen 100 genes per person, we would find everyone is seriously ill and discrimination would disappear" (Thompson 1989).

access to genetic data. For years, the HIAA had insisted on correcting misinformation about genetic discrimination while lobbying against genetic anti-discrimination regulations, pointing to the need for "the public policy debate [to] be carried on in a way that does not feed unjustified public fears about insurers' use of genetic information" (HIAA 2001: 30). This strategy of public educational campaigns was ineffective. Politicians recognized the political incentives of arguing in favor of genetic anti-discrimination protections against the much-disliked insurance industry, with the added benefit that they could make arguments without fundamentally threatening the system of private insurance. Representatives of the insurance industry thus came to accept the requests by health reformers, consumer advocates, and scientists for a legislative response. Even if redundant, these federal interventions promised to assuage public fears of insurer misbehavior.

Definitional debates also diminished the value of genetic data to insurers. Insurers initially argued that genetic anti-discrimination laws fundamentally threatened insurance practices because genetics and other forms of health data were largely indistinguishable. As legislative efforts persisted, the industry changed its strategy and succeeded in redefining genetics on much narrower terms than originally proposed or envisioned by the sponsors of anti-discrimination protections. Although insurers insisted that they did not use genetic tests for underwriting, they did access genetic test information for other purposes. In testimony to Congress in 1998, a representative of Blue-Cross/Blue Shield cited that "[a]bout 17 percent of Blue-Cross and Blue Shield managed care plans have begun to use the results of genetic testing to trigger early intervention and the most appropriate disease management programs" (Lehnhard 1998: 65). As a relatively new practice, however, genetic testing was much less central to insurers' information interests than other, more traditional types of health data. Insurers were more concerned that definitions of genetic information in anti-discrimination law would come to encompass information about family history, medical records related to hereditary diseases, and

chromosomal indicators for individual sex that they considered critical for accurate risk management. In pointing to competing definitions, representatives of the National Association of Health Underwriters, Blue Cross/Blue Shield, and HIAA argued for the need to "differentiate information that is available only from genetic testing as opposed to general genetic information" and criticized definitions of genetic testing as "unnecessarily broad" (Denise 1998: 51; Lehnhard 1998: 64; HIAA 2001: 29).

The insistence on distinguishing genetic information from other types of health data was strategic. For one, such arguments by industry did not travel to other related legislative debates about health information. In simultaneous debates over confidentiality protections in patient health data, health insurers supported an expansive definition of genetic information. In contrast to its approach to defining genetic information narrowly in anti-discrimination law, HIAA argued in debates over health data privacy legislation that "there are genetic components in almost all health information. Therefore, it would be extremely difficult as a practical matter for health plans and providers to treat genetic information differently than other patient health information" (HIAA 1998: 111). Thus, insurers insisted on narrowing the scope of genetic anti-discrimination law, even as they lobbied for expansive definitions for genetic information in related debates about health data governance.

The Biotechnology Industry Organizes

As legislators and regulators sorted through competing definitions for genetic information amidst rapidly changing technological contexts, the use of genomics became further integrated into existing health information systems. The burgeoning biotechnology industry had a vested interest in protecting government funding of their technology and did not hesitate to blame insurers for the crisis of consumer confidence. Biotechnology firms organized to form the Biotechnology

Industry Organization (BIO) in 1993 and became active in shaping legislation affecting genetic discrimination.[94] Concerned about the burden of new regulations on lab protocols, BIO lobbied against FDA intervention on genetic tests and in favor of a voluntary system of regulatory compliance in genetic testing based on existing professional society standards set by the American Society of Human Genetics, the American College of Medical Genetics, and the College of American Pathologists.

Biotechnology firms, however, recognized that growing public fears about genetic discrimination could fundamentally threaten the growth of their industry. They blamed fears of discrimination on the use of genetic and pre-existing conditions exclusions by insurers. Medical services companies such as the genetic testing company OncorMed instituted their own protocols since "[in] the absence of Federal legislation to protect people from genetic discrimination…[a]ny failure on our part or on the part of any other commercial laboratory to make caution, conservatism, and restraint our watchwords could severely damage the market for our unfolding industry."[95] BIO characterized genetic discrimination in health insurance as "essentially a market failure which justifies Federal action" and argued that protections against insurance discrimination would "assure the public that the great promise of biotechnology research will not be tarnished by abuses of this technology."[96] In response to dwindling consumer confidence in

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[94] The organization was renamed the Biotechnology Innovation Organization (BIO) in 2016. For history about the trade association, see https://archive.bio.org/history.

[95] A*dvances in Genetics Research and Technologies: Challenges for Public Policy: Hearings before Committee on Labor and Human Resources*, 104th Congress 2 (1996) (statement of Patricia D. Murphy, Vice President, Genetic Services, OncorMed, Inc. Gaithersburg, MD).

[96] *Technological Advances in Genetics Testing: Implications for the Future: Hearings before the Subcommittee on Technology, Committee on Science*, 104th Congress 2 (1996) (testimony of Alan Goldhammer, Ph.D. Director of Technical Affairs at Biotechnology Industry Organization); *Potential for Discrimination in Health Insurance Based on Predictive Genetic Tests: Hearing before the Subcom. on Commerce, Trade, and Consumer Protection of the Committee on Energy and Commerce*, 107th Congress 1 (2001) (statement of Craig Venter, President of Celera Genomics on behalf of the Biotechnology Industry Organization (BIO)).

genetic testing, BIO supported provisions and sponsored amendments to Congressional bills including HIPAA to include bans on genetic discrimination. Diverging from insurers, the growing biotech industry also lobbied to prevent regulations from targeting genetic information specifically. Targeted protections would create a unique compliance burden, and the biotechnology industry preferred genetic and health information be governed together.[97]

Biotechnology was growing into a significant industry presence, though its support for genetic anti-discrimination legislation cannot singlehandedly explain the success of federal anti-discrimination protections. Then as now, biotechnology firms were concentrated in Massachusetts. They were active in educating legislators about the need for government genetic information protections. Yet, while other states passed genetic anti-discrimination laws, Massachusetts as "a State that is generally so progressive…has not been able to come to any kind of decisions where this is concerned, and [cannot] plead ignorance."[98]

The Genetic Information Non-Discrimination Act (GINA)

The success of federal consumer protections required the convergence of multiple interests in favor of federal intervention and the receptivity of federal policymakers to pass legislation amidst continuing uncertainty about the law's potential consequences. Reintroduced in 2003, the Genetic Information Non-discrimination Act (GINA) aimed to "allay concerns about the potential for discrimination and encourage individuals to participate in genetic research and to take advantage of genetic testing, new technologies, and new therapies" and "to fulfi[l] the promise of

[97] Murphy, statement in A*dvances in Genetics Research and Technologies*.
[98] Garber, statement in A*dvances in Genetics Research and Technologies*.

the human genome project."[99] Regulatory and bureaucratic agencies joined the chorus in arguing for federal consumer protection legislation to promote public participation in genetic testing (Jones and Sarata 2008: 3-4).[100] Worried that public reluctance towards genetic testing would hinder the cost-saving benefits of genomic technology, federal legislators and policymakers were sensitive to public fears about the potential misuse of their genetic information and focused on strengthening consumer trust while maintaining private insurer capacities to manage their financial risks.

In commenting on the bipartisan support for the bill after GINA's passage, some legislators explained that "GINA was a non-issue for either party. There weren't any people that were discriminated against" (Hochschild 2021: 68). The president of America's Health Insurance Plans (formerly HIAA), which had previously lobbied against the law, described GINA as "strengthen[ing] patients' privacy protections while preserving their access to health insurance plans' innovative prevention and coordination programs that enhance the safety and quality of care" (Vesely 2008). This apparent lack of controversy over GINA disregards the decade of legislator efforts to define genetic anti-discrimination, the significant public consternation over the issue and resources directed towards resolving ethical concerns, and the prolonged

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[99] *Fulfilling the Promise of Genetics Research: Ensuring Nondiscrimination in Health Insurance and Employment: Hearing on S. 318, Before the Committee on Health, Education, Labor, and Pensions,* 107th Congress 1 (2001) (comments by Judd Gregg, a U.S. Senator from the State of New Hampshire).

[100] Research by the Secretary's Advisory Committee on Genetic Testing (SACGT) in 2000 and the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) in 2004 for the Department of Health and Human Services cast public apprehensions as a "deterrent to advances in the field of genetic testing [that] may limit the realization of the benefits of genetic testing." Likewise, in a report jointly authored by the Department of Labor, the Department of Health and Human Services, the Equal Employment Opportunity Commission (EEOC), and the Department of Justice, these agencies made the case for federal legislation to protect individuals against genetic discrimination (Jones and Sarata 2008: 3-4).

negotiation among interest groups that led to their eventual convergence over federal consumer protections.

It became clear over time that GINA's primary purpose was to ameliorate public distrust in genetic information technology while minimizing disruptions to private health insurance. By the mid-2000s, employers had joined other interest groups to support genetic non-discrimination protections. The CGF, which initially included consumer, civil rights, patient, and healthcare groups, welcomed industry groups and employers into its membership in 2005 (Coalition for Genetic Fairness 2011). The smallest employers, those with fewer than fifteen employees, were excluded from the law's provisions. Large employers, fearing an onslaught of lawsuits over genetic discrimination, had lobbied successfully to match GINA's enforcement mechanisms with those of existing civil rights law on discrimination.

This turn in fortunes for GINA can be attributed to the gradual narrowing in scope of its protections. Convinced that GINA could create a "death spiral" for other insurance products, namely life, long-term, and disability insurance given their time-limited disbursement structure compared to health coverage incremental payouts, legislators agreed to amend the proposal in 2003 "with the possibility for future legislation remaining open" (Slaughter 2013: 54). Early iterations of GINA did not make the distinction between potential and actual occurrence of genetic diseases. The biotechnology industry, for instance, argued that genetic information's predictive value for future health status was comparable to other non-genetic diagnostic tests, such as blood tests and cholesterol monitoring or family health history records, and could thus be easily

incorporated into comprehensive medical privacy legislation.[101] Insurers, on the other hand, pushed to differentiate them to narrow the scope of anti-discrimination law.

Major changes to the definition of genetic anti-discrimination over time helped to bring the last reticent opponents on board. Over the course of debates over GINA, insurers successfully negotiated for a definition of genetic information that recognized genetics as health data yet carved out variables such as age or sex given their importance for risk underwriting (Redhead and Sarata 2008). Though insurers and employers lost their ability to collect and use family medical histories, the final law drew a line between asymptomatic and symptomatic genetic information to limit the law's reach (Institute of Management & Administration 2008: 9). Once genetic diseases were no longer speculative and had manifested as a health condition, they became fair game for insurers to use in risk management (Roberts 2012: 1184). By categorizing genetic information in this way, legislators maintained the use of pre-existing conditions in health insurance despite GINA's protections and differentiated between genetic anti-discrimination and health status.[102]

Partisan differences in Congress over the scope of legislation stalled progress on GINA until the Democrats regained control of Congress in 2007. Ongoing concerns about GINA's effect on state genetic anti-discrimination laws persisted, but pressure from the White House and the enthusiasm of bill supporters maintained political momentum. President George W. Bush

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[101] *Technological Advances in Genetics Testing: Implications for the Future: Hearings before the Subcommittee on Technology, Committee on Science*, 104th Congress 2 (1996) (testimony of Alan Goldhammer, Ph.D. Director of Technical Affairs at Biotechnology Industry Organization).

[102] Other aspects of GINA's design preserved insurers' ability to parse out health status risks of their potential plan members. For instance, GINA allowed insurers to offer discounts based on participation in wellness programs, which were designed to incentivize plan members to engage in healthy behaviors and share more personal health data with insurers.

supported laws to prohibit insurers from denying applications for coverage on genetic health information, issuing a White House public statement on January 17, 2007 calling on Congress to pass genetic nondiscrimination legislation to protect consumers from misuse by employers and insurers (Jones and Sarata 2008: 18-19). The main partisan split over GINA occurred over the question of reproductive health and abortion, when Republicans objected to a phrase that could be interpreted as allowing abortion (as genetic discrimination of embryos) during in-vitro fertilization. Modifications to the language in the bill appeased Senator Coburn (R-OK), who had initially blocked the bill from coming onto the Senate floor due to these concerns and questions about employer and insurer liability. GINA was released in April 2008 to garner a unanimous vote in the Senate (Slaughter 2013: 55). Representative Judy Biggert (R-IL-13th), GINA's Republican co-sponsor in the House alongside Louise Slaughter (D-NY-28th), remarked as the bill moved to the White House, "This bill unlocks the great promise of the Human Genome Project by alleviating the most common fear about genetic testing…and allow[s] Americans to finally realize the benefits and health care savings offered by gene-based medicine" (Biggert 2008).

Conceived as a civil rights law, GINA represents a bipartisan, yet limited, federal effort to extend anti-discrimination protections to genetic differences. Enacted May 21, 2008 with votes of 95-0 in the Senate and 414-1 in the House, GINA demonstrated that both parties recognized the value of setting federal standards for genetic anti-discrimination. By amending HIPAA's lack of explicit confidentiality protections for genetic information and extending its protections beyond group plans, GINA limited medical underwriting in health insurance for both group and individual markets including ERISA health plans. The law restricted the collection, use, and disclosure of genetic information across health insurance markets and by employers (Redhead and Sarata, 2008: 2; Rosenbaum 2009: 111; Iversen and Rehm 2022: 93). GINA also narrowed the ADA's "safe harbor" for insurance and addressed the shrinking scope of protections from court

interpretations of disability, though protections continued to exclude life, long-term, and disability insurers from anti-discrimination requirements. The law also did not disallow medical underwriting based on symptomatic health status, an issue that reappeared several years later and motivated new consumer protections in the Affordable Care Act (ACA).

GINA's Implementation and Persistent Problems

As is the case with many laws, the complexity of post-passage implementation remained largely beyond the public's interest. To implement GINA's consumer protection provisions on health insurers, the Privacy Rule that implemented HIPAA's data provisions was amended to clarify that genetic information was considered health information. The Office of Civil Rights (OCR) in the Department of Health and Human Services finalized regulations in December 2009 with very limited public engagement. The OCR received only 25 comments on their proposed rule, while the Equal Employment Opportunity Commission (EEOC) received 43 comments for its rule implementing GINA's genetic anti-discrimination provisions for employers (The Federal Register 2010, 2013).

Republicans and Democrats had both supported GINA in large numbers, but the law was not quite the rejection of data-driven discrimination that supporters had hoped. Although GINA's main aim was to address public fears about genetic discrimination, the majority of patients, physicians, and other healthcare providers remained unaware of the protections afforded by the law (Laedtke et al 2012; Prince and Roche 2014). Polls after the passage of GINA showed that more than half of Americans continued to worry about insurer access to their online health information while individuals concerned about discrimination still practiced "privacy-protective" behaviors by withholding information from their providers and avoiding genetic testing for preventative measures (McGraw 2009: 124; Peikoff 2014). This public hesitance around sharing

genetic information has created problems for providers in accurately assessing care and researchers interested in developing precision medicine.

While the lack of public awareness of GINA hindered its effectiveness, other problems have stemmed from gaps in the law. As mentioned previously, GINA excluded life, disability, and long-term care insurance and left comprehensive protections out of reach (Rothstein 2008; Rothstein and Gerdes 2014). Sponsors "had to settle for what they could get" after more than a decade of Congressional wrangling (Peikoff 2014). GINA also did not cover manifested genetic disorders, and very small employers were excluded from its provisions (Hochschild 2021: 101).[103] A rapidly changing health technology environment also created discrepancies. GINA does not cover direct-to-consumer DNA testing, a market that grew tremendously after the U.S. Food and Drug Administration (FDA) approved home tests in 2017 (FDA 2017; Harbord 2019: 269; Winkler 2024). The emergence of more multi-state, for-profit insurers also changed the ability of genetic regulations to provide comprehensive protections. As many of these for-profit insurers offer health, life, and/or disability coverage together, a single insurance company can face different regulations on data use across their products as genetic information "enters through the back door" (Iversen and Rehm 2022: 93).

There have been ongoing efforts at the state level to close GINA's gaps and continue to address public distrust, especially as health information technologies advance. By the mid-2010s, genetic results could be stored in electronic health records (HER) and made broadly available to researchers and practitioners (Evans 2016: 552; Kulynych and Greely 2017). At the state level, Republicans and Democrats have both promoted stronger consumer protections against genetic

[103] The Affordable Care Act (ACA) filled this gap on manifested genetic conditions by banning discrimination on the basis of pre-existing conditions.

information use by health insurers. In 2020, stricter privacy rules to "close a gap" in GINA were proposed by a Republican and passed with overwhelming support in the Florida legislature. These genetic anti-discrimination and privacy regulations were also specifically motivated by concerns about insurer misuse. As the Republican Speaker-designate of Florida's House of Representatives explained in sponsoring the state's genetic privacy bill, "[I]t was imperative that we take action, in order to protect Floridians' DNA data from falling into the hands of an insurer who could potentially weaponize that information against current or prospective policyholders in the form of rate increases or exclusionary policies" (Hochschild 2021: 68).

Discussion

At the dawn of the millennium, genetic technology promised to bring revolutionary change to medicine. The Director of the HGP envisioned that health information technologies developed by genetic research would be "used to shape a lifetime of personalized strategies for disease prevention, detection and treatment….the vision of the 'quantified self' will be a reality for many of us" (Collins 2014). Yet experts and researchers warned that the promises of technology could not be removed from their legal and political context. As Dr. Vinton Cerf expressed, "[T]he problem is not the technology. And don't let anybody tell you that, well, the solution to this problem [of data governance] is cryptography. It's actually a powerful tool, and it's a good, useful tool to have. But what is really at issue here is how we decide as a society to treat that information" (Cerf 1999: 9). Philip Kitcher, a philosopher in the Human Genome Project's ELSI Working Group, "concluded that the [ethics] program had been 'doomed to fail' from the start because it falsely assumed that the problems raised by genomics could be resolved in 'a politically neutral way'" (Hilgartner 2018: 126). Although a broad variety of interests initially proclaimed their support for the ethical use of genomics, this apparent agreement masked a complicated and

lengthy, high-stakes fight over the definition of ethical use, the scope of anti-discrimination, and who would benefit most from genetic technology and government intervention.

Regulating genetics involves questions about distribution and fairness. Proposed solutions for anti-discrimination on the basis of genetics challenge existing systems of distribution and profit motives in insurance. In an increasingly polarized environment, however, encouraging technological development for better cost-efficiency had bipartisan appeal even amongst political conflicts over data's distributional consequences. Innovations in health data technologies promise "to simplify everyday routines, pool information on patients for teams of providers coordinating care, and probe for signs of waste or fraud" (Jacobs and Skocpol 2016: 24). To maintain a system of delegated rationalization, a broad array of interests and legislators converged to protect consumers from data-driven discrimination. Consumer behavior served as a centrifugal force that could unite disparate groups over the maintenance of public trust in health information systems. In the wake of the passage of GINA, biotechnology executives breathed a sigh of relief. As Paul Billings, CEO of Cellpoint Diagnostics expressed, "the pall cast by discrimination--and its impact on test adoption by the market--may lift from biotech companies offering genetic diagnostics. If effective, the new legislation may improve the prospects for this health-related market and for genetically informed care" (Billings 2008).

Conclusion

In this chapter, I examined the political history of GINA and the relationship between the welfare state and the development of federal rules about the use and abuse of genetic information. Genomics posed a major challenge to ongoing healthcare rationalization policy and its emphasis on individual responsibility in cost containment. In doing so, genomics activated consumer and industry interests in favor of protecting the viability of health information systems even as they

disagreed on their motivations for federal intervention. As Deborah Stone observed, "modern genetic research significantly diminishes the realms of illness where individual responsibility is a reasonable causal story" (Stone 2005: 68).

Over more than a decade, interest groups gradually came to agree over the benefits of federal intervention to bolster public trust in health information systems and to protect a key emergent health information technology. Legislators were concerned about maintaining the viability of the genetic testing and were arguably interested in preventing failure in this market, but insurers initially argued that government intervention in data-driven discrimination would cause market failure in private health insurance. Ultimately, the interpretation of data-driven discrimination's effects on market viability for private health insurance shifted. Eventually, the industry realized that arguing about misinformation and providing evidence or studies against discrimination claims did little to combat their bad reputation among the public or among legislators. Advocates for public health insurance argued against the logic of private insurance as consumers lost confidence in participating in health information systems. While consumers threatened rationalization through their "privacy protective" behaviors, consumer groups played an important role in communicating to legislators about the dangers of declining consumer confidence in the information flows crucial to delegated rationalization.

GINA redefined genetic information as both integral to and yet unique from health status data, limiting the scope of federal protections while insisting on the ethical obligation of anti-discrimination. The law expanded civil rights to genetics but left private insurance largely unscathed, thus casting federal protections against genetic discrimination squarely as an effort to ameliorate public misunderstandings and protect the growth of genetic information technology.

CHAPTER 6: CONCLUSION

A Welfare State View of Data Governance

Health status discrimination can have serious effects on access to care and coverage, health equity, and health outcomes. In this project, I considered an aspect of the welfare state that has been largely overlooked. This dissertation examined the historical trajectories leading to U.S. federal consumer anti-discrimination protection on the basis of health status. Since the specter of health status discrimination was first articulated in the early 1970s, an unusual coalition of private insurers, patient advocates, providers, and employers has coalesced around regulations that maintain trust, participation, and access to a valuable, growing health information system even as they disagree on the meanings and sources of data misuse. I argue that this interest convergence can be traced to the policy of delegating rationalization in health care to private actors and individuals, an approach to health policy that created diverse stakeholders in the governance of health information technologies.

Reforms to address the problem of data-driven discrimination were a gradual process. Attempts to protect consumers against health status discrimination in private health insurance failed during the Bush administration and during the first half of the Clinton administration. In the 1990s and 2000s, the federal government passed laws and regulations that recognized discrimination on the basis of health status as a problem and established privacy protocols in the handling of personal health data. Federal intervention in the protection of health insurance consumers challenged the discretion of private health insurers over their use of personal health status information. It was not until the passage of HIPAA in 1996 that protections against health status discrimination in health insurance were codified at the federal level for the first time. Over the following years, consumer protections for individual health data have expanded to include

genetic information and has been updated to align with developing health information technologies.

Current Issues in Health Data Governance

While I focus on historical cases of health information technology up to the late 2000s, several important developments have since taken place. The ACA subsequently reformed consumer protections in health insurance in a major overhaul of the health system. The regulation of emergent health information technologies, in particular the information explosion in biometrics and wearable health technologies, offer additional cases for future exploration.

Consumer Protections in the Affordable Care Act (ACA)

The Affordable Care Act (2010) introduced new federal consumer protections that limited the ability of insurers to use health status information in their decision-making.[104] To prevent private insurance plans from engaging in risk segmentation, the ACA imposed community rating and prohibited plans from excluding enrollees with pre-existing conditions. The ACA's prohibitions on pre-existing conditions exclusions were heralded as a major development in regulation of the health insurance industry. The laws against health status discrimination were exceedingly popular among voters of both parties and politicians eager to promote their willingness to take on the much-despised private insurance business interests.

The passage of the Patient Protection and Affordable Care Act (ACA) in March 2010 and its implementation in 2014 marked a breakthrough in American health policy. Alongside a significant expansion of Medicaid and the creation of the government-regulated individual

[104] Patient Protection and Affordable Care Act, P.L. No. 111-148 (2010); Health Care and Education Reconciliation Act, P.L. No. 111-152 (2010).

marketplace, the statute included significant new federal consumer protections aimed at ending the use of health status by insurers for pricing and coverage decisions. Prior to the ACA, only five states had prohibited insurers from using health status to reject applicants or determine premiums (Claxton et al 2016). These rules about guaranteed issue and renewal, as well as new restrictions for modified community rating and bans on the use of pre-existing condition exclusions, meant that health insurers nationwide could no longer deny coverage based on someone's health history or health status, and they could not charge them more based on their health history or health status.[105]

The ACA's new federal regulations implemented on January 1, 2014 provided protections for Americans with medical conditions by banning private health insurers' use of health status in three aspects of health insurance. Broadly, these regulations included guaranteed issue and renewal for enrollment eligibility and coverage, modified community ratings for pricing premiums, and a ban on pre-existing conditions exclusions in plans about the content of coverage (Corlette et al 2018).[106] The ACA's guaranteed issue rules banned insurers from discriminating against applicants in individual and employer group market plans at the point of enrollment on the basis of health status or other factors. This "guaranteed issue" rule limits discrimination in underwriting and prohibits insurers from excluding any applicants from enrolling or "dumping" members, such as those with pre-existing conditions, after enrollment in a health plan (KFF

[105] These states were ME, MA, NJ, NY, and VT.
[106] The specific restrictions in the statute are: 42 U.S.C. §300gg-4(a) "plans cannot use health status to determine eligibility"; 42 U.S.C. §300gg-12 "plans cannot dump enrollees after they become sick or injured (rescission) unless there is fraud or "intentional misrepresentation"; 42 U.S.C. §300gg-4(b) "plans cannot vary premiums for "similarly situated individuals" based on health status i.e. "similarly situated individuals" is defined in 45 C.F.R. §146.121(d)"; 42 U.S.C. §300gg "plans must use community rating rules for premiums"; 23 42 U.S.C. §300gg-94 "states need to have effective rate review systems, identified by the CMS";42 U.S.C. §300gg–3 and 4 "plans cannot exclude coverage for pre-existing conditions and cannot use genetic info to deny coverage, adjust premiums, or impose pre-existing condition exclusions."

2012). The ACA also introduced new federal ratings regulations that dramatically limited the ability of private health insurers to use medical underwriting in the individual and small business insurance markets and banned them from using genetic tests or information to set premiums (Fernandez et al 2018).[107] Given the established role of states in regulation, the ACA regulations set a regulatory floor rather than a ceiling, allowing states to enact more stringent regulations.

Although regulations could require insurers to enroll all individuals and minimize variations in pricing by requiring community ratings, prior to the ACA insurers could design the content of coverage to minimize financial risks. These design maneuvers included limiting or excluding coverage of pre-existing conditions at the point of enrollment and after, increasing deductibles, limiting network providers, denying coverage, and asserting discretion over coverage decisions (Rosenbaum 2009: 107). ACA regulations banned the use of pre-existing condition exclusions to prevent insurers from engaging in these practices.[108]

The ACA's regulatory reforms were largely passed without much consumer input or attention, though consumers have come to its defense in the years since implementation. Despite their motivations to dismantle the newly passed law, Republicans recognized the political risks of

[107] While states had previously regulated insurance ratings and previous federal laws had addressed underwriting in group plans, the ACA created federal standards that limited the factors that all insurers could use to geographic area, age, tobacco use, and family size (specifically, who in the household was already enrolled). Meanwhile, age (arguably the most valuable risk factor) is still allowed. The ACA's regulations limits price differentiation but preserves use and access to a key predictor of personal health. Further ratings regulations prevent insurers from charging older adults any more than three times that of a younger individual, and tobacco users cannot be charged more than 1.5 times that of a non-user's insurance rate. In addition to specifying explicit allowable criteria, the ACA also banned the use of certain information in rating individual plans, including individual health status and pre-existing conditions, the previous use of health services (also known as "experience rating"), and gender (KFF 2012).

[108] The ACA amended the Public Health Service Act (PHSA) to eliminate the use of preexisting condition exclusions by both group and individual health-insurance providers, including self-insured employer plans. In addition to banning pre-existing condition exclusions, the ACA required plans to offer a standardized and specified package of "essential health benefits" (Mach and Fernandez 2014).

rolling back the anti-discrimination provisions that have benefitted segments of their voting constituency. Despite the uneven benefits of these protections, the ban on pre-existing condition exclusions had widespread bipartisan appeal among voters (Blendon and Benson 2017; Beland et al 2020: 654-655). The popularity of consumer protections against health status discrimination spans across the political parties, with 81% of voters agreeing that pre-existing condition exclusions from coverage by health insurance companies should be illegal.

In the years following the ACA, legal challenges and rollbacks in other parts of the law have nonetheless weakened consumer protections.[109] Exemptions were created and implemented in October 2018 with a new rule that extended the allowable duration of short-term plans from three years to one year with renewals, effectively making plans intended for short-term coverage appear closer to regular plans (Seervai et al 2019). Unlike regular plans that are required to be ACA-compliant, however, these extended short-terms plans were deemed exempt from the pre-existing conditions ban and thus not required to follow ACA requirements (Lueck 2020). This created a "parallel market" of ACA and non-ACA compliant plans, reintroducing discrimination on the basis of health status into private health insurance.

While limited in their scope and sustainability, the new regulations in the ACA nevertheless restricted insurers' information capabilities. These important new health insurance regulations were decades in the making. The immediate success of the ACA was the result of deliberate coalition-building between reformers and industry stakeholders. Ballooning costs in health care had become a financial problem, not only for employers sponsoring coverage for their covering employees and consumers unable to afford coverage, but also for the medical industry

[109] Texas v. United States, 579 U.S. __ (2016).

which lost customers as potential health care consumers were priced out of insurance and avoided health care (Hacker 2010; Mettler 2011: 101; Jacobs and Skocpol 2016; Swenson 2019). As problems of cost and coverage intensified, stakeholders in the health insurance market formed a shared recognition that federal intervention was necessary to address failures of the market. As Hacker (2010) explains, "the industry-backed solution was a simple quid pro quo: accept greater public regulation and involvement in return for greater guaranteed financing" (865).

Throughout the debates over health care reform, from Clinton's failed Health Security Act to the ACA, it was clear that insurers were most concerned about defeating any proposals that would create a formidable public competitor to private insurance products. The regulation of private insurance and rules against health status discrimination, even if antithetical to the insurance business model, were therefore necessary concessions on the part of insurers to maintain a system of privatized health insurance. While the ACA arguably engendered a historic shift in the idea of fairness in health status discrimination and the politics over pre-existing conditions exclusions, the law also reaffirmed the central role of private insurers in the healthcare system (Blumenthal 2018).

By examining the history of consumer protections, however, it becomes evident that coalitions for greater federal intervention began emerging before the ACA debates in ways that were related to medical financing. As in the case of the ACA, regulations to protect consumers in health information systems were in service of securing the central role of private actors and individuals in cost containment health policy. Over time, as the responsibilities of private users of consumer data in the welfare state changed to place more of a burden on individuals and private actors in cost control, interest groups representing these constituencies converged towards a shared interest in federal data governance.

Emergent Health Information Technologies

Sometimes called the twenty-first century's new gold or oil, individual data forms the backbone of the information economy. This data includes accumulated personal records as well as the minute, detailed tracking of individual economic, social, and health behaviors (Zuboff 2015). The potential disruption that robustly enforced individual data rights poses to contemporary data-driven business models makes data governance a mobilizing policy issue for many, if not virtually all, firms in the information economy. Business interests spend significant time and lobbying dollars to shape data regulations that might affect their businesses. For instance, a November 2019 industry survey found that 69% of business respondents were "very actively" looking to shape data privacy policy and 44% of business respondents had named data privacy as a top three policy issue (PricewaterhouseCoopers 2019).

The advent of wearable technology, with its ability to collect vast amounts of biometric and related data, introduces new powerful stakeholders into debates over how to protect consumers against health status discrimination. Previously used in identification systems such as fingerprinting for security systems and access control, biometric data has since expanded to include facial and eye scans, DNA sequences, and voice patterns in consumer products. Meanwhile, wearable devices with monitors and other sensors can track and record health-related data such as sleep patterns, locations, heart rate, and activity levels. The proliferation of data collection techniques across different kinds of commercial entities has created immense strain on existing legal frameworks (Wilbanks and Topol 2016; Terry 2017). The Department of Health and Human Services (HHS) and state insurance regulators are responsible for overseeing rules that govern the use of health data in health care and health insurance, though the FTC has become increasingly involved as the boundaries between health entities and information technology

companies blur with the growth of wearables and biometric data collection (Park 2019; FTC 2021; Pifer 2023).

The adoption of health technology "wearables" has generated intense speculation about the extent to which biometric information has become part of the insurance industry's toolkit. Even where investigative journalists have found evidence of health insurers maneuvering around regulations by finding new sources of personal data and proxies using correlated criteria, it is not entirely clear what health insurers do with the data (Allen 2018). Likewise, recent studies suggest that self-tracking health data may not be as easily translatable to personalized pricing as expected (McFall 2019). In the meantime, the main lobby group for U.S. private health insurers, America's Health Insurance Plans (AHIP), has pushed for better sources of public data and for improving demographics. AHIP has called for more data-sharing and collection of more personal data on a granular level, including more racial categories, details about disability status, sexual orientation, and spiritual beliefs (AHIP 2022). Although improved data and "legibility" can certainly advance health equity, the context of data regulations shapes how and when such data can be used.

Contributions and Implications

Although debates over data governance might seem unique to the twenty-first century, they speak to a longstanding debate in American politics over the proper relationship between the state and society, the process by which fairness and discrimination are defined, and the government's role in regulating economic and technological change. Data regulation represents an understudied case of how the development of the modern welfare state has shaped policies regulating the metrics of inclusion. Specifically, public policy decisions about who administers and delivers components of the welfare state affects the information policy preferences that stakeholders have and defines the nature and scope of government protections.

I see this project contributing to the literature in health policy and data governance in two main ways. By focusing on historical cases of data-driven discrimination on the basis of health status, I show how elements of the delegated welfare state shape regulatory politics over time. This project's attention to relatively understudied historical cases about health information also challenges the tendency in scholarship about data regulation towards overemphasizing the technical challenges of data governance while overlooking its distributional and political conflicts.

The Delegated Welfare State and Regulation

In tracing the paths to federal protections against data-driven discrimination in health insurance, I show that delegated arrangements in healthcare rationalization shaped interest groups and their preferences for government regulation. Laws against discrimination in the welfare state are signals of how a society understands fairness, but they are not necessarily the result of grassroots mobilization. Federal limitations or bans of discrimination on the basis of poor health are arguably surprising in a national welfare state context characterized as adhering to market logics. The American "liberal welfare state" relies heavily on private actors to implement social policies and deliver benefits while placing significant blame on individual choices and behavior for incurring social risks in ways that are highly racialized and gendered (Soss et al 2011; Campbell and Morgan 2011; Lynch 2014). At the same time, these elements of the American delegated welfare state have downstream effects on regulation by shaping the interest groups that emerge. As this project shows, the delegated nature of the welfare state can lead interest groups to support government intervention to protect consumers.

Scholars would do well to recognize the interconnectedness between the welfare state and data governance. Despite the distinction that I draw in this dissertation between older forms of discrimination and contemporary data-driven discrimination, there is significant continuity

between them. Racial and gender discrimination in the welfare state were once understood to be "data-driven" as well. As Thurston (2018) demonstrates in her historical account of credit discrimination, the federal government justified the use of race variables in assessing the riskiness of mortgage loans as a data-driven reflection of the market. Likewise, gender variables were used to classify women as particularly high lending risks before explicit discrimination on the basis of gender in credit was banned. Despite arguments that such discrimination was actuarially sound, the activism of public interest groups and advocacy organizations challenged the fairness of discrimination using race and gender criteria and pressured the federal government to regulate such discriminatory practices. By examining cases of federal governance in health data, I show the process by which data-driven discrimination becomes legally unacceptable.

In this project, I uncover how changes to the welfare state across time shaped the federal government's approach to regulating consumer information. This approach diverges from other literature that focuses on the behavior or institutional capacity of regulatory agencies to explain US approach to data governance. I also break away from the insular nature of scholarship on data governance, which tends to understand technological regulation in the context of digitalization, and emphasize the interconnectedness of information regulation with other, long-standing aspects of the state. There has been significant commentary on the all-encompassing nature of certain policy paradigms, namely the appeal of market thinking in health policy and the centrifugal effect of political orders such as neoliberalism on diverse political actors (Stone 2005; Gerstle 2022). By focusing on the effects of delegated rationalization on interest groups' preferences towards consumer protections in health information systems, this project contributes to a deeper understanding of how institutional contexts affect interest group behaviors in policy change.

Data Governance in Health Policy

Data governance is often understood as a technical problem, yet it is better understood as a political conflict with distributional consequences. This project contributes to the literature on data privacy by focusing on historically-understudied cases of regulation in health information. Data-driven discrimination, or the use of personal information to differentiate between individuals and groups, is particularly pronounced in privatized health insurance. Private insurers rely on data-driven discrimination to determine projected healthcare costs and manage financial risks, but these strategies can perpetuate inequalities in pricing and coverage among those with the highest healthcare needs. By focusing on the governance of health data and cases of data-driven discrimination, this project emphasizes that data governance matters politically because it determines in part who gets what and why.

The protection of health data is unusually strong in the U.S. compared to other types of information regulations in part due to perceptions of its sensitivity to misuse. The domestic politics over data governance and consumer protections in the U.S. have remained under-examined, even as a significant literature in comparative and international political economy has grown to explain the transnational differences in regulatory regimes between the U.S. and the E.U. I argue that this focus on the U.S. as an international laggard overlooks the dynamics of problem definition, interest group lobbying and coalition-building, and the bipartisan nature of efforts to extend consumer anti-discrimination protections to health data during key legislative debates since the 1970s. Data about individuals has become a key ingredient in the functioning of the welfare state, and data governance affects domains far beyond questions about "Big Tech" and the Internet. As private interests have become further embedded in the welfare state and

individuals take on increasing responsibility for managing their risks, the policy preferences of these groups have determined the direction of data policies related to their delegated role.

By examining data governance in health policy, I show that data governance in the U.S. is more political and dynamic than the existing literature tends to characterize it. The cases of consumer protection against data-discrimination in health appear as anomalies given the U.S. reputation as a data regulation laggard. Studies of these "rare" cases in the health policy context, however, provide evidence of how prior policies can affect future policy-making by changing the behavior of interest groups towards federal intervention. In examining the changing role of health information systems over time, I argue that interest groups converge to lobby for subsequent regulatory protections that bolster prior policy decisions and ease their implementation.

Future Directions

This project uncovers the historical trajectory of consumer anti-discrimination protections in health data to show how changes to welfare state arrangements contribute to future consumer protections. A research agenda on the intersection of social and data policy yields promising future inquiries. First, research on regulation is often concerned about the effects of rules on relevant measurable outcomes; evaluative empirical studies of the three policy cases examined here would be useful for policymakers and scholars concerned about real-world effects. Second, while this project is concerned with health data and health insurance, it would be worthwhile to include other information-reliant domains. In particular, technological innovation in financial data engenders political questions and interest group conflicts comparable to health. Third, this project relies on policymaking by the federal government, but a significant portion of regulation occurs at the state level. State-level policymakers, such as state insurance commissioners and

attorneys general, play a key role in consumer protection.[110] Lastly, cross-national comparisons often shed new light on national institutions and their differing effects. A targeted comparative study of health data and consumer protections would provide valuable contributions to the literature in comparative and international data governance.[111]

An assessment of the implementation and consequences of consumer protections against data-driven discrimination would be a valuable contribution. For instance, a significant and ongoing dispute over consumer protections in HIPAA and GINA has targeted the effectiveness of these laws. Critics argue that the U.S. has lagged behind other countries with more stringent data protection regimes, pointing to the weakness of existing laws in preventing the problems they were intended to address. An empirical study on the effects of the consumer protections discussed in this dissertation on discrimination, insurance coverage and premiums, and other public health-related outcomes would take the scholarship on data governance in public health in a fruitful direction.

This project focuses on cases of health data and health policy, but do the dynamics of welfare state arrangements and data governance apply to other policy domains? In other words, does a similar convergence of interests over federal intervention occur when it comes to other types of information, such as regulation of misuse of personal financial data? Regulating third-party use of individual credit information is one of the oldest issues in contemporary U.S. consumer data protection. Today, credit information has evolved from individual dossiers to algorithmic scores that pull from various sources of data, though the most valuable and relevant information still comes from credit card usage and financial behavior (Gellman and Dixon 2014).

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[110] See Citron (2017).
[111] E.g. Parthasarathy (2004).

Future research could compare the development of consumer protections for health status against similar efforts to address discrimination on the basis of "financial health" status, such as in the "off-label" use of credit scores in tenant screening. In tenant screening, the use of credit scores has proliferated as rental markets tighten. As homeownership becomes harder to achieve and rental markets become extremely competitive, landlords have turned to tenant screening companies make decisions about tenant risk. These practices have implications for housing equity, as individuals in poor financial health become trapped in financially precarious housing.

Health insurance regulation is still primarily state-centric, with states taking the lead on passing and enforcing data-related protections. What are the interest group dynamics towards health data governance at the state level? Additional studies could also incorporate a more explicit comparative dimension in examining different jurisdictions. Interest groups organize differently at the subnational versus the national level, and the coalitions and relationships seen among interest groups in Congressional debates and legislative efforts may instead look different when examined across individual states. Some states, namely California, have taken a leading role in determining the direction of data governance. Future research that takes a deep-dive into the local politics of regulation around health data could be illuminating.

Lastly, cross-national comparisons that focus specifically on health data could reveal factors relevant to policy change that are obscured by more generalist approaches to data governance writ large. Although the U.S. relies on delegated governance in health policy, comparable institutional arrangements for health policy in other countries hints at the potential portability of my argument. For instance, the central role of private-sector actors in managing the financial cost of health care in France and Germany could provide an interesting comparative case to the U.S. in health data regulation (Hacker 2002: 276; Smyrl 2014: 14). How has health data

been regulated in other countries with similar or different health insurance systems? Cross-national comparative work shines when uncovering the large-scale, institutional factors that determine the historical trajectories of different policy regimes.

A Final Word

Protections against data-driven discrimination in health information are contingent on the political involvement of interest groups and their gradual convergence over federal protections. The literature on data regulation argues that federal regulation is shaped primarily by pressure politics, agenda-setting scandals, entrepreneurial politicians, or the regulatory capacity of federal agencies. By focusing on the history of data use in the welfare state, I argue that the politics of the changing welfare state – and specifically the changing role of "private data users" in rationalizing health care – is an underappreciated factor that shaped the federal government's approach to consumer data governance over time.

Although data collection continues to be a privacy and security concern, the increased collection of personal information and its accumulation into "Big Data" is not in itself detrimental to social risk protection, if it is used to administer and distribute resources more equitably. Data collection that makes marginalized groups more legible, for instance, is critical for effective social policy program administration. On the other hand, the use of data-driven discrimination can deepen and exacerbate social and economic inequalities. This project is motivated by the problem that "[t]he real question is not whether Big Data can be used to create more differentiated risk pools but whether and to what extent insurance companies will be allowed to use the data in this manner" (Iversen and Rehm 2022: 63). Whether and how governments regulate the most sensitive types of personal data will be crucial in determining whether the most promising health information technologies will foster solidarity or segmentation.

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