Genetic Discrimination

A Critical Discourse Analysis of Legislation in North America

by

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Table of Contents

Abstract

My research examines the legal and societal dimensions of genetic discrimination in North America, focusing on the Genetic Information Non-Discrimination Act in the U.S. and the Genetic Non-Discrimination Act in Canada. Using Fairclough's Critical Discourse Analysis and Pistor's theory of legal coding, I explore how legal frameworks and discursive practices in North America construct genetic information as a governable object that is protected, rendered usable, and valuable within biomedical innovation. Amid advances in genomic technologies and rising concerns over data misuse, legislative efforts have emerged to protect individuals. However, such protections are narrow in scope, primarily covering employment and health insurance. By analyzing legal texts, policy documents, and media narratives, this research illustrates how genetic information is discursively constructed as a form of capital, turning patients into health consumers and economic value sources. It also highlights how discourses of self-responsibility and empowerment often mask deeper neoliberal logics of autonomous individuals and the commodification of genetic data. Through a multilevel examination of this phenomenon at textual, discursive, and social levels, my dissertation reveals how genetic discrimination laws protect against certain harms while simultaneously legitimizing the marketization of genetic data. My research also illustrates the dual role of legislation that protects individuals from discrimination while embedding genetic data within the structures of market mechanisms. The findings contribute to ongoing debates about privacy, health equity, and the use of genetic information.

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INTRODUCTION

My research explores the legal, ethical, and societal dimensions of genetic discrimination, providing an analysis of the legislation in North America following Fairclough's (1989, 1992, 1995a, 2003) Critical Discourse Analysis (CDA) approach and Pistor's (2019) analysis of capital as a framework. Through my dissertation, I explain how legal frameworks and discursive practices around the Genetic Information Non-Discrimination Act in the U.S. (GINA) and Canada's Genetic Non-Discrimination Act (GNA) construct genetic information as a governable object that is protected, rendered usable, and valuable within biomedical innovation and market expansion.

My analytical focus is on the dual role these laws play: both safeguarding individuals and supporting the infrastructure of the bioeconomy. Building on Pistor's (2019) theory of legal coding, I analyze how law functions as an enabling infrastructure for capital, selectively encoding rights, privileges, and protections that render intangible resources, such as genetic information, into commodifiable and enforceable assets. In this approach, law is a productive force that shapes capitalist expansion by crafting enforceable, transferable rights for capital (Pistor, 2019, pp. 4-6).

The socio-legal approach deployed herein treats law not merely as a closed normative system but as a socially constructed product of institutional design and discursive formation, shaped by broader political, economic, and ideological forces (Fitzpatrick, 2002; Cotterrell, 1998; Ewick & Silbey, 1998). This perspective recognizes that legal meaning is continuously produced and negotiated through institutional practices, cultural narratives, and power relations (Silbey, 2005), positioning law as an active component in the reproduction of social structures rather than a neutral arbiter. By examining legal language, policy discourse, and media narratives, I show how ideas about risk, responsibility, and ownership become normalized.

I also consider how advancements in genomic knowledge and technologies have profoundly influenced the organization and delivery of healthcare within a neoliberal knowledge-based economy. This economic model is characterized by market-oriented policies and an emphasis on individual responsibility alongside the valorization of information and innovation as principal economic drivers. Developments in the biotechnology field embody market rationalities, reinforce individualized models of health governance, and facilitate the commodification of biological information (Rose, 2007; Clarke et al., 2003; Lemke, 2011).

My dissertation is situated within the broader context of neoliberal capitalism, not as a monolithic or totalizing ideology, but as a historically specific political-economic project that gained traction in the late 20th and early 21st centuries as states sought to restructure social, economic, and legal systems in the face of crises and shifting global power dynamics (Clapp, 2021; Kotz, 2015; Jessop, 2012; Pistor, 2021). In this sense, neoliberalism functions as a strategic policy toolkit emphasizing deregulation, privatization, and market-based governance while selectively reinforcing legal and institutional mechanisms conducive to capital accumulation and elite interests. Within this context, the knowledge-based economy has emerged as a central vehicle for advancing the commodification of information under the guise of innovation and efficiency, including genomic data, which can be defined as the vast and complex information derived from sequencing and analyzing DNA (National Human Genome Research Institute, 2022). Genomic data has been increasingly used to identify disease risks, guide personalized treatments, and fuel biomedical research, while at the same time serving as a critical resource for pharmaceutical, biotechnology, and data industries, raising profound implications for the commercialization of health.

The neoliberal push toward privatizing health services and fostering high-tech innovation sectors (Jessop, 2002) did not create the legal tools for assetization from scratch; rather, it capitalized on and intensified pre-existing legal infrastructures already primed to encode knowledge and discoveries as proprietary capital (Pistor, 2019, 2021). As Pistor (2021) observes, the post-war welfare state, once oriented toward social solidarity and redistribution, was gradually dismantled in favor of market logic, enabling a new round of private wealth accumulation and institutionalized inequality reminiscent of European pre-revolutionary conditions.

This process aligns with Pistor's (2019) broader thesis that capital is a legal code, selectively endowed with attributes that empower certain assets to function as wealth-generating capital. These legal codes, embedded in property, contract, trust, and corporate law, do not emerge anew under neoliberalism but are instead reactivated and reconfigured to suit shifting economic conditions. For example, as neoliberalism accelerates the financialization of knowledge, legal coding transforms intangible assets such as genetic data into investable commodities by creating enforceable rights through patents, data contracts, and intellectual property regimes (Pistor, 2019). Property rights, such as patents on genetic sequences, licensing agreements, and proprietary control over biobank resources, grant exclusive economic and legal authority to actors like biotechnology firms, shaping who can access, use, and commercialize genetic information. This selective legal coding, in turn, exacerbates inequalities by concentrating wealth and control within those who command the legal expertise and institutional access necessary to navigate and shape these codes.

Moreover, the liberal legal order, as Pistor (2019) emphasizes, is inherently contradictory: it simultaneously protects private property rights while purportedly advancing social goals, a tension that neoliberal policy exploits by framing deregulation and privatization as pathways to

social and economic progress. Yet, this very legal order, which "single-mindedly focused on protecting private rights on one hand, and the use of law to advance social goals on the other," is fundamentally structured to preserve and extend capital accumulation (Pistor, 2019, p. 217). Thus, neoliberalism functions less as a radical break and more as an intensification of the capitalist legal system's intrinsic dualism, enabling the transformation of genetic data into proprietary capital and reinforcing entrenched patterns of wealth and power (Pistor, 2019).

As I illustrate in my dissertation, codifying genetic information as both a health resource and a form of capital has fostered the emergence of a bioeconomy that relies on the commodification of genetic data as a source of economic value (Rose, 2007; Jessop, 2002; Birch & Tyfield, 2013; Pistor, 2019). As healthcare increasingly integrates genetic knowledge and technologies, the growing popularity of genetic testing has begun to reshape both medical practice and the role of patients. Individuals who receive genetic risk results often respond by engaging in preventive behaviors such as diet modification, increased screening, or sharing genetic information with family members, illustrating a shift toward patient empowerment and self-management within precision medicine (Kaphingst et al., 2012; McGowan et al., 2010; Gerdes et al., 2021).

Building on the observation that neoliberalism is not a static project that has evolved alongside inegalitarian social formations, the role of legislative intervention in the governance of genetic data remains structurally uncertain. The legal effort to regulate genetic discrimination, often justified as necessary to establish public trust, may not have been strictly required for data extraction or commodification. Genetic data could circulate through institutional and commercial infrastructures regardless of the presence of specialized protective legislation. At the same time, this raises a more fundamental question about the historical moment in which such legislation

emerges. Contemporary genetic discrimination laws are enacted in contexts where redistributive commitments and collective protections have been significantly weakened.

Within this context, my critique of the account of the individual as a "knowledgeable manager of genetic information" is not a comment on feasibility or rationality, but a structural one (Arribas-Ayllon et al., 2008; Schicktanz, 2018). Expecting individuals to meaningfully manage complex, opaque, and asymmetrical data environments is increasingly unrealistic in systems characterized by concentrated corporate power and extensive data infrastructures. This raises the possibility that legislative frameworks premised on individual rights, consent, and responsibility may be fundamentally misaligned with the conditions they seek to regulate.

While I do not underestimate the role of law as a governance mechanism, I reveal grounds for skepticism toward specialized, narrowly scoped legislation, such as GINA and the GNA. While some actors continue to prefer targeted genetic legislation for its symbolic clarity and specificity, my analysis suggests that such laws may function more effectively as instruments of reassurance and legitimation than as mechanisms of structural accountability. In this sense, I do not question whether legislative intervention should be abandoned or reaffirmed. Instead, I try to clarify the conditions under which different legal strategies operate, and the limits they face in an increasingly inegalitarian political economy.

The discourse of patient empowerment, central to predictive genetic testing, encourages individuals to manage their health risks based on genetic predispositions proactively. At the same time, this discourse aligns with neoliberal themes of self-responsibility, in which individuals are expected to use genetic information to make responsible lifestyle choices or seek preventive care (Juengst et al., 2012; Hurlbut et al., 2020; Prainsack, 2018). Advances such as targeted cancer

therapies (Ginsburg & Phillips, 2018), population-based risk prediction (Bycroft et al., 2018), and pharmacogenomic dosing exemplify how genetic data is increasingly applied to tailor interventions. These developments are presented as improving clinical outcomes and promoting individual well-being through preventive interventions and risk prediction (Bloss et al., 2013). Following the Human Genome Project (HGP), the rise of direct-to-consumer (DTC) genetic testing extended access to these technologies beyond clinical settings, allowing individuals to obtain unprecedented insights into their predispositions for conditions such as genetically related cancers and Type 2 diabetes (Visscher et al., 2017).

Genetic testing companies offer consumers insights into their ancestry and health risks while profiting from selling aggregated genetic data to pharmaceutical companies. For instance, the now-defunct 23andMe has entered multiple commercial data-sharing agreements. In 2018, the company signed a $300 million deal with GlaxoSmithKline (GSK) to provide access to its genetic database for drug discovery and development. This reflects the dual aspect of bioeconomy developments, where patients are promised empowerment through access to their genetic data. At the same time, they also become sources of economic value through the commodification of genetic data. The rise of these biotechnological developments also raised concerns about the potential misuse of genetic information by employers and insurers, such as employment discrimination, denial of insurance coverage, and increased surveillance of individuals deemed "*genetically at risk*," which may hinder individuals from participating in genetic testing or research (Rothstein, 2005; Hudson et al., 2008; Otlowski et al., 2012).

A central theme is how market pressures shape arguments for protecting individuals against discrimination, particularly in employment and insurance contexts. Public debates around these

statutes reflect a tension between promoting innovation in genomics and ensuring that individuals can pursue genetic testing without fear of adverse consequences. These protections are positioned as safeguarding both individual autonomy in health decision-making and the maintenance of a robust pool of genomic data, which is framed as essential for advancing medical research and the collective good (Joly et al., 2021b; Bombard & Heim-Myers, 2018; Bélisle-Pipon et al., 2019). The legal promise *"you will not be punished in employment/health insurance*" reduces fear and function to increase uptake of testing and expands the data pool. That expanded pool is then available for innovation and commercial strategies, especially when protections do not fully constrain secondary data markets, such as life insurance, consumer genomics, and partnerships with pharmaceutical companies.

To analyze these dynamics, I integrate Fairclough's CDA with Pistor's theory of legal coding, offering an interdisciplinary framework to investigate how GINA and the GNA regulate, construct, and justify genetic discrimination across legal, institutional, and media discourses. This approach moves beyond conventional legal or bioethical analyses by examining law as both a discursive and material force that encodes genetic information as capital and embeds it within market logics (Pistor, 2019). By situating legislation within this framework, my dissertation highlights how neoliberal ideologies are naturalized through legal and policy language (Fairclough, 1989, 1992, 1995a, 2003; Jessop, 2005), thereby obscuring the political and economic interests underpinning genetic discrimination frameworks.

GINA and the GNA can be understood within this lens as instruments that simultaneously protect and commodify genetic data. On one hand, they aim to prevent the misuse of genetic information by employers and insurers, fostering public participation in genetic testing and

research. On the other hand, by confining protections largely to employment and health insurance contexts, they leave certain forms of genetic data vulnerable to exploitation, such as in life insurance or consumer data markets, thereby legitimizing the treatment of genetic insights as tradable assets within neoliberal frameworks. Consequently, such legislation foregrounds the commodification of genetic data, intensifies inequities in access to emerging technologies, and amplifies the burden of self-responsibilization under neoliberal governance. By critically unpacking these dynamics, I aim to contribute to broader debates on:

a) social justice, by revealing how regulatory regimes can reproduce structural inequalities;
b) healthcare access, by demonstrating the distributive limitations of market-driven genomic innovation; and,
c) the ethical governance of biotechnological knowledge, by questioning the normative assumptions that underpin the treatment of genetic information as a form of capital.

To summarize, my work offers a novel analysis, combining the scholarship of Fairclough and Pistor, of how ideas are adjudicated into positive law by focusing particularly on discourse and the role of institutional actors as part of the discourse. It situates legal discourse as a key site where norms, values, and power relations are negotiated, interpreted, and codified, demonstrating how law both shapes and is shaped by social and institutional practices (Fairclough, 1995, 2003). This combined theoretical approach illuminates how genetic information is commodified and translated into legal norms, making it particularly apt for analyzing the intersection of law, institutions, and economic value. Below, I outline the structure of the dissertation, providing a roadmap of the objectives, theoretical foundations, and analytical approach.

Chapter 1 provides a concise overview of the GINA and the GNA situating these statutes within their broader legislative and policy contexts. Chapter 2 (Literature Review) offers a critical review of scholarship on genetic discrimination's legal, ethical, and social dimensions. It traces the emergence of genetic discrimination as a policy concern and examines scholarly debates on how legal frameworks aim at influencing public trust, delineating institutional responsibilities, and mediating corporate interests in the governance of genetic privacy. Chapter 3 (Theory and Methodology) outlines the theoretical framework and methodology guiding the dissertation. I explain how Fairclough's CDA and Pistor's theory of legal coding are used to examine how legal responses to genetic discrimination reflect broader neoliberal and market-driven ideologies within the bioeconomy.

Chapter 4 (Textual Analysis: Micro-Level) applies Fairclough's CDA to analyze how genetic discrimination is constructed in legal texts. It focuses on word choices, modality, and agency in legislation and policy pamphlets, examining how legal language frames risks, responsibilities, and protections, revealing neoliberal notions of individual autonomy and self-regulation. Chapter 5 (Discursive Practice Analysis: Meso-Level) explores how GINA and GNA are produced, distributed, and interpreted by different stakeholders, including government agencies, advocacy groups, and the media. It examines intertextuality, showing how earlier anti-discrimination policies and economic discourses shape these laws, and evaluates how different groups interpret and engage with genetic discrimination laws. Chapter 6 (Social Practice Analysis: Macro-Level) shows how laws to provide protections against genetic discrimination are located within broader economic and political structures and how they reflect and reinforce neoliberal governance, market-driven healthcare, and the legal coding of genetic data as capital. Following

Pistor, this chapter also examines how biotechnology and corporate interests influence genetic discrimination laws, shaping and influencing public trust and participation in genetic testing.

Chapter 7, as the conclusion, evaluates findings from the textual, discursive, and social practice analyses. It explains the implications of legal frameworks examined in reinforcing neoliberal arguments, positioning genetic information within biocapitalism, a system where biological materials and processes are transformed into economic assets and sources of profit through scientific and technological innovation (Birch, 2017). It also highlights how legal protections serve both ethical concerns and corporate interests, shaping the future of genetic privacy and personalized medicine.

Chapter 1. GENETIC DISCRIMINATION ACTS: CONTEXT

To provide context in this chapter, I briefly introduce two key legislative frameworks that address the issue of genetic discrimination: GINA (in the U.S.) and GNA (in Canada), both of which I re-visit in subsequent chapters. Both pieces of legislation emerged within broader socio-political debates about privacy, fairness, and the appropriate use of genetic information in increasingly data-driven health systems. Although enacted in different national contexts and through distinct political trajectories, GINA and the GNA share a common focus on safeguarding individuals from misusing genetic information by employers, insurers, and other institutional actors. At the same time, both laws are shaped by the political-economic conditions in which they were introduced, reflecting efforts to balance individual rights with the perceived need to sustain biomedical innovation, data circulation, and public trust in genomic technologies.

By critically examining these laws in detail in subsequent chapters, it becomes possible to trace how genetic risk is discursively constructed as a matter of both individual rights and collective social order, and how the regulation of genetic information reflects enduring tensions between innovation in biomedicine and the preservation of fundamental principles of equality and non-discrimination. This contextual overview, therefore, sets the groundwork for the analytic chapters that follow, which move beyond legislative intent to examine how genetic discrimination law functions as a mode of governance once enacted. In doing so, the analysis attends to the legal, discursive, and institutional mechanisms through which responsibility is allocated, protections are delimited, and legitimate uses of genetic information are defined. This approach allows for an examination of how law not only constrains certain practices but also actively structures the conditions under which genetic data is governed, circulated, and rendered socially acceptable.

1.1) The Genetic Information Non-Discrimination Act

GINA was enacted in the United States in 2008 in response to growing concerns about the potential misuse of genetic information in employment and health insurance contexts. Essentially, this law was intended to allow patients to take advantage of genetic testing in clinical and research settings without fearing genetic discrimination (Chapman et al., 2020, p. 3). Signed into law by President George W. Bush after Congress passed it by near-unanimous votes, 414–1 in the House and 95– 0 in the Senate, GINA was hailed as a landmark achievement in federal protections against genetic discrimination. Massachusetts Democratic Senator Ted Kennedy, for example, called it the "*first civil rights bill of the new century of the life sciences*" (Kaye, 2010, p.51).

The legislation represented the culmination of thirteen years of efforts. he genetic discrimination bill was first introduced in the House of Representatives in 1995 by Representative Louise Slaughter, a Democrat from New York with academic training in microbiology and public health. Slaughter consistently argued that protections against genetic discrimination were necessary to ensure public participation in genetic testing and research, which she believed could ultimately reduce health care costs by enabling earlier detection, monitoring, and prevention of disease. In the U.S. Senate, the legislation was sponsored by Olympia Snowe, a Republican from Maine. Snowe emphasized that the rapidly expanding availability of genetic tests—numbering more than 1,100 at the time—would be rendered effectively useless if individuals avoided testing or research participation due to fears of discrimination. She argued that legal protections were essential to encourage engagement with genetic technologies that could help individuals identify and manage increased genetic risks through preventive interventions and medical surveillance. Together, these arguments framed genetic discrimination legislation not only as a civil rights

measure, but also as a prerequisite for the effective integration of genetic testing into biomedical research and clinical practice.

Multiple versions of the bill were approved at different times by both the House of Representatives and the Senate; however, the legislation was never passed concurrently by both chambers in the same session, as required for submission to the president for signature. While the original bill focused only on health insurance, subsequent versions expanded the scope to include employment discrimination. Passage was achieved by collaborating with an unusually diverse coalition of stakeholders, including patient advocates, consumer groups, medical professionals, researchers, and the medical products and pharmaceutical industries (Suter, 2018).

GINA was largely pre-emptive in nature: unlike Title I of the Americans with Disabilities Act (ADA) or Title VII of the Civil Rights Act of 1964, which were enacted to address documented patterns of discrimination, GINA was intended to prevent genetic discrimination from ever becoming a pervasive problem (Roberts, 2010). Rapid advances in genetics research, alongside federal funding of HGP starting in 1990, heightened concerns that employers and insurers could misuse genetic information to predict health risks or define individuals according to their genetic makeup. Consequently, GINA was designed to prevent potential discrimination and address public fears that might discourage participation in genetic testing, research, or precision medicine (Suter, 2018).

Since the 1960s, most anti-discrimination laws in the United States have adopted a civil rights model, treating all individuals as essentially equal (Suter, 2018). Title VII of the Civil Rights Act and the Age Discrimination in Employment Act prohibit employment decisions based on race, sex, age, and other factors. In contrast, the Americans with Disabilities Act (ADA) requires

reasonable accommodations for individuals with disabilities (Rothstein, 2008). Applying the Title VII model to genetic information may be insufficient to protect individuals with genetic susceptibilities or other accommodation needs, some of which are not yet fully understood. Considering genotype alongside other biological factors is central to future precision medicine, potentially creating tensions between modern medicine and existing civil rights laws (Rothstein, 2018a).

GINA comprises two main titles: Title I, which addresses health insurance, and Title II, which addresses employment. Title I—Genetic Non-discrimination in Health Insurance—was implemented through amendments to several key federal statutes to ensure comprehensive application. Section 101 amended the Employee Retirement Income Security Act of 1974 (ERISA) to prohibit employer-sponsored group health plans from discriminating on the basis of genetic information. Section 102 amended the Public Health Service Act (PHSA) to extend nondiscrimination protections to health insurers and plans outside ERISA. Section 103 amended the Internal Revenue Code of 1986 to bind tax-favored group health plans to the same restrictions. Section 104 amended Title XVIII of the Social Security Act to prohibit discrimination in the sale of Medicare supplemental (Medigap) policies (U.S. Government Publishing Office, 2008). These amendments embedded GINA's requirements across the federal health insurance landscape. Under these provisions, insurers may not use genetic information to determine eligibility, coverage, underwriting, or premium-setting decisions, nor may they request or require individuals or their family members to undergo genetic testing (U.S. Government Publishing Office, 2008).

Title II similarly prohibits employers from using genetic information in employment decisions such as hiring, firing, promotions, pay, and job assignments, and prevents employers

from acquiring genetic information about employees or applicants, providing both antidiscrimination and privacy protections (Suter, 2018).

A significant feature of GINA is its broad definition of "genetic information," which includes not only the results of genetic tests of an individual but also the genetic tests of family members, the manifestation of disease in family members, participation in clinical research, and requests for genetic services. This expansive definition reflects Congress' intention to fully protect individuals against discrimination based on genetic predisposition, recognizing the impossibility of drawing precise boundaries between genetic and non-genetic medical information (Suter, 2018).

Despite these protections, GINA's scope is limited. It does not cover life, long-term care, or disability insurance, nor does it protect symptomatic individuals. Title I does not preclude insurers from making decisions based on manifested disease, and Title II explicitly excludes protection for information about manifested conditions, leaving the ACA (Affordable Care Act) and the ADA as the primary federal safeguards in those circumstances (Rothstein, 2018a; Suter, 2018). This distinction means that GINA covers asymptomatic individuals at risk of genetic conditions, whereas the ADA covers individuals whose conditions have already manifested, leaving a coverage gap for individuals with subclinical markers or early symptoms of gene-associated diseases (Rothstein, 2018a; Suter, 2018). Emerging medical technologies, laboratory tests, and sophisticated imaging that detect incipient disease may further complicate this gap.

The practical limits of GINA are also reflected in its limited use: from 2009 to 2015, only twenty-four non-frivolous employment discrimination complaints were filed with the Equal Employment Opportunity Commission, most concerning alleged discrimination based on family health information (Rothstein, 2018a). The judicial interpretations of GINA's broad definition of

genetic information remain divided, as some courts adhere strictly to the statutory language. In contrast, others narrow the definition to information predictive of future disease (Suter, 2018). It is argued that the narrower approach conflicts with Congress's intent to adopt a (Suter, 2018). Evans (2019) contends that, despite its narrow scope, GINA's broader impact as a "genomic civil rights law" stems from Congress' definitions of protected genetic information, the appointment of a federal regulator with broad enforcement authority, and its safeguarding of rights that prevent discrimination, protect privacy, and support meaningful participation in society, including free speech, access to information, association, scientific inquiry, and political engagement.

GINA treats genetic information as uniquely deserving of protection, yet the distinctions it draws between genetic and non-genetic medical information are increasingly difficult to justify in practice (Rothstein, 2008, 2018a; Suter, 2018). Advances in genomics, epigenetics, and precision medicine have blurred the line between what is "genetic" and what is environmental or lifestyle-related (Shostak, 2003), raising questions about the ongoing relevance of a legal framework that singles out genetic information for special treatment. Non-genetic biomarkers, epigenetic modifications, or other predictive health indicators may be as private, predictive, and immutable as genetic information, yet they fall outside GINA's protections. Similarly, the differentiation between presymptomatic genetic risk and manifested disease can appear arbitrary. Both categories of information may inform an employer about future health care costs or job performance, but only the former receives the full suite of privacy protections under GINA (Rothstein, 2018a; Suter, 2018).

From a practical standpoint, GINA's privacy protections introduce compliance challenges for employers and healthcare providers. Health records often contain interwoven genetic and

nongenetic information, making it difficult to segregate genetic data when providing records post-conditional offer fully (Clayton et al., 2019). Employers may receive information that they are prohibited from using, creating legal and operational burdens. While GINA's approach seeks to minimize the difficulty of proving discriminatory intent, it does so by imposing a level of privacy protection for genetic information that has no parallel for other medical conditions (Feldman, 2012). This asymmetry may limit employers' ability to provide proactive interventions or accommodations that could prevent disease onset and improve employee health outcomes. For example, an employee with a genetic predisposition to musculoskeletal disorders could benefit from early ergonomic interventions if employers were allowed to use this information responsibly, yet GINA's structures effectively prevent such anticipatory measures (Rothstein, 2018a).

Moreover, the special treatment of genetic information raises ethical questions about fairness and equity. Suppose privacy and non-discrimination protections are extended to genetic risk. In that case, employees with early-stage or manifested conditions, or those facing predictive health risks from non-genetic biomarkers, may be left more vulnerable. In effect, GINA creates a hierarchy of protection that privileges some types of sensitive health information while leaving others less protected, even when the practical consequences for individuals are similar. This selective protection may inadvertently exacerbate inequalities and undermine public trust in genetic testing and precision medicine initiatives.

GINA's design reflects a fundamental tension between privacy, non-discrimination, and health promotion as it prioritizes avoidance of discrimination over proactive health management (Joly et al., 2020). In contrast, frameworks like the ADA permit the responsible use of health information to facilitate reasonable accommodations and prevent adverse outcomes, embodying

an anti-subordination approach that can actively protect individuals while enabling them to benefit from workplace interventions (Rothstein, 2018a). Reconciling these competing priorities, protecting individuals from discrimination while enabling the preventive and therapeutic use of predictive health information, remains a critical challenge for future policy development, as Suter (2018) indicates. From this perspective, GINA and analogous state-level statutes in the United States were enacted not primarily to remedy genetic discrimination, but to address public apprehension regarding the potential misuse of genetic information (Joly et al., 2020; Wauters & Van Hoyweghen, 2016). GINA prohibits employers and health insurers from using genetic data in employment or coverage determinations. However, the legislation adopts a deliberately circumscribed scope, leaving unregulated domains, such as life insurance, where the potential for discriminatory practices based on genetic information remains unaddressed, highlighting a deliberate prioritization of employment and health insurance contexts over broader protections.

Taken together, this historical overview of the GINA suggests it was enacted primarily as a preemptive protective measure to alleviate public concern that genetic information could be misused in employment and health insurance contexts and thereby discourage participation in genetic testing and research. At the same time, the structure and scope of GINA reveal a secondary, less explicit function: by narrowly defining prohibited uses while leaving broader data practices intact, the Act helps stabilize the conditions under which genetic information can be generated, shared, and utilized within healthcare and biomedical innovation. This dual orientation—protective in intent yet enabling in effect—provides the foundation for the next chapter's analysis of how enacted genetic discrimination law operates discursively and institutionally as a form of governance.

1.2) The Genetic Non-Discrimination Act

GNA, enacted in Canada in 2017, represents a federal legislative response to concerns about the potential misuse of genetic information in employment, insurance, and contractual contexts. Its origins can be traced to nearly two decades of advocacy and policy deliberation, culminating in the introduction of Bill S-201, a Senate Public Bill sponsored by Senator James S. Cowan in December 2015. Cowan's initiative reflected growing awareness among policymakers and the public of the risks associated with unregulated access to genetic information and the absence of comprehensive federal protections. Bill S-201 received royal assent in May 2017, addressing gaps in Canadian law and aligning domestic protections with international approaches, such as GINA. GNA defines key terms, including "genetic test," which analyzes DNA, RNA, or chromosomes for purposes such as predicting disease, vertical transmission risks, or monitoring, diagnosis, and prognosis; "disclose," which includes authorizing disclosure; and "health care practitioner," referring to a person lawfully entitled under provincial law to provide health services (Government of Canada, 2017). These definitions provide the foundation for the Act's protective measures.

GNA establishes prohibitions against coercion and misuse of genetic information. It is prohibited for any person to require an individual to undergo a genetic test as a condition of receiving goods or services, entering into or continuing a contract, or being offered or continuing specific contractual terms. Similarly, refusal to engage in these activities based on an individual's decision not to undergo testing is prohibited. The Act also forbids requiring disclosure of previously conducted genetic tests or refusing engagement based on refusal to disclose results. Collection, use, or disclosure of genetic test results without the individual's written consent is

likewise prohibited. Sections 3 to 5 of the Act do not apply to physicians, pharmacists, other health care practitioners providing services, or persons conducting medical, pharmaceutical, or scientific research involving participants, thereby balancing protections with operational needs in healthcare and research sectors (Government of Canada, 2017). Section 7 establishes criminal liability for contraventions of Sections 3 to 5. Indictable offences may result in fines of up to CAD 1,000,000, imprisonment for up to five years, or both, whereas summary offences carry fines of up to CAD 300,000, imprisonment for up to twelve months, or both (Government of Canada, 2017).

The GNA introduced amendments to the Canada Labour Code (CLC) under Division XV.3 (sections 247.98–247.99) to strengthen protections further. Employees are granted the right not to undergo genetic testing (section 247.98(2)) and not to disclose or be required to disclose results (section 247.98(3)). Employers are prohibited from taking disciplinary actions, including dismissal, suspension, demotion, or financial penalties, based on an employee's refusal to undergo testing, refusal to disclose results, or the results themselves (section 247.98(4)). Third parties are prohibited from disclosing test results to an employer without the employee's written consent, and employers may not collect or use genetic test results without consent (sections 247.98(5)–(6)). Employees who believe their rights have been violated may submit complaints to an inspector within 90 days (sections 247.99(1)–(2)), with unresolved complaints proceeding to adjudication (sections 247.99(5)–(6)), and adjudicators empowered to order remedies such as reinstatement, compensation, or other corrective actions (section 247.99(8)).

The GNA also amended the Canadian Human Rights Act (CHRA) by adding "genetic characteristics" as a prohibited ground of discrimination (section 3(1)). Section 2 outlines the Act's purpose to ensure equal opportunities without discrimination on specified grounds, now explicitly

including genetic characteristics. Section 3(3) establishes that refusing to undergo or disclose the results of a genetic test constitutes discrimination based on genetic characteristics, thereby expanding federal human rights protections to encompass genetic information and related actions.

Policy objectives underlying the GNA focus on preventing both direct and indirect genetic discrimination and promoting public confidence in genetic testing and participation in genomics research. By prohibiting coercion and restricting unauthorized use or disclosure of genetic information (Joly et al., 2020), GNA encourages participation in genetic testing and research (Bombard & Heim-Myers, 2018) while providing uniform standards across federally regulated sectors where protections had previously been incomplete or inconsistent. Implementation challenges have emerged, particularly regarding the federal government's jurisdiction to enact criminal prohibitions. The Quebec government questioned whether sections establishing criminal offences fell within federal criminal law powers, arguing that the Act's primary purpose, encouraging access to genetic testing, did not constitute a valid criminal law objective. A five-judge panel of the Quebec Court of Appeal concluded that provisions regulating contracts and services did not align with a criminal law purpose. However, sections amending the CHRA and CLC were not challenged. The case was subsequently appealed to the Supreme Court of Canada, highlighting ongoing legal and jurisdictional questions that may influence enforceability.

GNA was enacted as a protective intervention aimed at preventing coercion and misuse of genetic information while promoting public confidence in genetic testing and participation in genomics research. At the same time, the Act's structure—combining criminal prohibitions with amendments to labour and human rights legislation, alongside notable exclusions and jurisdictional constraints—reveals a secondary function. By delineating specific prohibited practices while

leaving broader data uses and commercial arrangements largely unaddressed, the GNA helps stabilize the legal environment in which genetic information can circulate across healthcare, employment, and research contexts. As with the GINA, this dual orientation provides a foundation for the subsequent chapter's examination of how enacted genetic discrimination law operates as a mode of governance, rather than solely as a statement of legislative intent.

In comparative perspective, the GNA aligns with international approaches aimed at preventing genetic discrimination while protecting privacy. Like GINA in the United States, it focuses on presymptomatic genetic information, recognizing its predictive potential, sensitivity, and implications for employment and access to services. Yet GNA differs in establishing criminal penalties, reflecting a more prescriptive enforcement approach than the civil remedies typical of U.S. frameworks.

Chapter 2. LITERATURE REVIEW

This chapter reviews the scholarly literature on genetic discrimination, focusing on how the concept has been defined, debated, and operationalized within legal and policy contexts. It also examines discussions of the legal frameworks developed in North America to address genetic discrimination, with particular attention to how broader neoliberal and market-oriented ideologies shape these responses. The review identifies several recurring themes and conceptual frameworks in the literature, including *genetic exceptionalism*, *patient empowerment*, *self-responsibility*, and *genetic determinism*.

These concepts function as key framing devices through which risks associated with genetic information are understood and governed. They recur across legal, ethical, and policy scholarship, reflecting shared assumptions about autonomy, responsibility, and the role of law in regulating emerging biotechnologies. Central to scholarly debates on the development and deployment of genetic technologies, these concepts inform how law and policy define the problem of genetic discrimination and justify particular regulatory approaches.

In what follows, I examine these core concepts in greater detail and critically engage with the socio-legal and policy literature to situate my analysis of genetic discrimination law within a broader socio-political and economic context. This review provides the theoretical and conceptual foundation for the subsequent analysis of legal texts, highlighting the discursive and ideological conditions under which genetic discrimination has been framed as a problem requiring legal intervention. This chapter also sets the foundation for Chapter 3, where I explain how I will apply Pistor's (2019) legal theory of coding capital and Fairclough's CDA to examine how genetic data is utilized as a commodifiable asset.

2.1) The Human Genome Project and shift towards market-driven healthcare

The Human Genome Project (HGP) is widely regarded as a milestone in the history of genetic science because it marked the first coordinated, large-scale effort to map the entire sequence of human DNA—approximately 3 billion base pairs—and to identify all human genes. Funded by the US Department of Energy (DOE) and the National Institutes of Health (NIH) from 1990 to 2003, the HGP aimed to map and understand all the genes of human beings, and in particular, to isolate causal links between specific genes and particular diseases (Collins et al., 2003). This unprecedented initiative laid the foundation for a genomic revolution by producing a reference genome that has since become integral to biomedical research, disease understanding, and the development of personalized medicine.

The HGP also exemplified a broader epistemic shift in life sciences, replacing phenotype-based models with genotype-driven inquiry (Hilgartner, 2017). When latter efforts proved inadequate for comprehending the complexities of common disorders such as cancer and heart disease (Rabinow & Rose, 2006, p. 213), genetic research focused on identifying specific individual molecular differences and developing diagnostic and therapeutic technologies. New technology and research, such as the HGP, have institutionalized assumptions that genetic factors may contribute to disease susceptibility by shaping the perception of risk in addition to promising features for individualized diagnosis and treatment options (Rose, 2007; Green et al., 2015; Ashley, 2016).

The HGP also facilitated the increasing fusion of biology with computational and data-intensive methods, catalyzing the emergence of bioinformatics and the field of systems biology (Green et al., 2015). This laid the groundwork for a paradigm shift in healthcare, where genetic

information increasingly informs individualized risk assessment, diagnosis, and treatment through predictive genetic testing. In this context, the biotechnology sector, driven by neoliberal, knowledge-based economic logics, has become a site of rapid innovation and intensified commodification of genetic information and technologies (Jessop, 2002; Rajan, 2006, 2008; Rose, 2007; Birch, 2017). Market-driven ambitions are also inherent in the biotechnology sector, fueled by advancements in genomic knowledge and diagnostic and therapeutic technologies. The advent of new technologies in genetic research has led to significant changes in healthcare and personalized medicine, particularly regarding genetic tests based on individual genetic profiles. For instance, Khoury et al. (2009) present genomic technologies as a means to enhance the precision and effectiveness of population-level interventions. Genetic testing has been heralded as making it possible for people living with or who are susceptible to genetically related health conditions to receive appropriate health care and manage their conditions (Adjin-Tettey, 2013, p. 579). It has also been claimed that access to genetic information will empower individuals and families to make informed decisions to mitigate future risks based on genetic dispositions (Lautenbach et al., 2013; Rose, 2007; National Cancer Institute, n.d.).

The transformation of healthcare through genetic developments, biotechnology, and the knowledge-based economy reflects a broader shift towards neoliberal governance and market-driven healthcare. As Birch (2006) notes, biotechnology is shaped not solely by scientific progress but by neoliberal ideologies. The commodification of life sciences is framed within policies that prioritize market competitiveness over public welfare. This extends to healthcare, where genetic technologies are marketed as solutions for economic growth and social challenges such as aging populations. Drawing on Pistor's (2019) theory of legal coding, I will show how laws governing genetic information function not merely as regulatory instruments but as mechanisms that *code*

genetic data into economic assets that can be owned, traded, and privatized. This legal infrastructure enables the commodification of life sciences and reconfigures public health objectives for economic competitiveness. Under this model, governments, healthcare institutions, and medical professionals have increasingly adopted market-oriented approaches to medicine and healthcare delivery, integrating emerging technologies within what Gottweis et al. (2009) term a "*global techno-managerial paradigm*" that emphasizes efficiency, innovation, and techno-scientific solutions.

Governments increasingly collaborate with biotech firms to finance genetic research and implement new healthcare solutions (Petersen & Krisjansen, 2015; Rajan, 2006; Birch, 2022). This expands genetic healthcare but also subjects it to market imperatives, which risks prioritizing commercially viable treatments over public health needs. While promoting bioscientific innovation, the state simultaneously adopts market logics, fostering commodification and privatization. This restructuring of healthcare practices generates both possibilities, such as the advancement of precision medicine, and significant risks, including the intensification of health inequalities, genetic determinism, and the exploitation of genetic data.

These transformations reframe patients as autonomous consumers responsible for managing their own care, aligning healthcare delivery with broader market logics of choice, efficiency, and individual responsibility (Rose 2007; Clarke et al. 2003; Lupton 2012). The individual is framed as a health consumer, responsible for self-management through genetic testing and personalized medicine (Fairclough, 2002). Interaction occurs between multiple actors in this regard: biotechnology corporations, governments, legal institutions, patients, and healthcare providers.

2.2 Molecularization, geneticization and managing genetic risk

Scholars have also noted that the changes described above are part of a broader transformation in biomedicine, often described as *molecularization*, a process in which disease is understood at the molecular level, particularly through genetic markers (Rose, 2007; Lippman, 1991). Rose and Rabinow (2006) describe how genomics reconfigures the concept of risk, embedding it within the individual body and genome, which in turn legitimizes preventative and therapeutic strategies tailored to presumed genetic predispositions. Moreover, the literature on "geneticization" (Lippman, 1991; Nelkin & Lindee, 2010) critically examines how genetic explanations increasingly dominate public and medical discourse, shaping perceptions and policies regarding health and disease. This individualized framing of risk and treatment, often aligned with the rise of personalized or precision medicine, has been institutionalized through state-funded projects like the HGP, which not only mapped the human genome but also helped solidify genetic causality as a dominant paradigm in contemporary biomedicine (Juengst, 2012; Tutton, 201).

The emphasis on the early detection of disease in health practices demonstrates how risk has become a central concept, shaped over the years by the impact of neo-liberalism on health policies and practice (Lupton, 1995). Through new technologies, even if the individual does not manifest a particular condition, the concept of illness has been further expanded based on the concept of *carrier status*[1] (Armstrong et al. 1998). Carrier status has gained importance with the

[1] Carrier status refers to an individual's genetic condition concerning specific genetic mutations or variations associated with particular diseases. In the context of genetic risk or conditions, being a carrier signifies that a person has inherited one copy of a mutated gene that, under certain circumstances or in combination with another mutated gene (inherited from the other parent), could lead to the expression of a genetic disorder. Carriers themselves may not manifest the symptoms of the associated condition because they have one normal copy of the gene to compensate. However, carriers have the potential to pass the mutated gene to their offspring, increasing the risk of the condition in the next generation.

proliferation of individual-level genetic testing practices through which individuals can learn about their status as well as potential genetic risks and the likelihood of passing on conditions to their children. Though new technologies shift the understanding of risk, they are also seen as opportunities to shape individual and family decision-making around family planning, preconception testing, tests of carrier status, or assisted reproductive technologies.

While genetic testing is often framed as a tool of empowerment and progress, this discourse can mask the complex relationship between social, environmental, and political factors that shape health outcomes. For instance, Prainsack (2017) argues that the emphasis on personalized and genomic medicine redirects attention away from upstream factors such as housing, income inequality, and systemic racism, which have a demonstrably greater impact on population health. Similarly, Fullwiley (2007) highlights how genetic explanations of disease risk, particularly in racialized populations, can depoliticize health disparities by attributing them to biological difference rather than to structural inequities in healthcare access or environmental exposures. This framing, often reproduced in policy and commercial genomics, contributes to what Roberts (2011) calls "the fatalism of the gene," wherein social interventions are deprioritized in favor of individualized, biotechnical solutions. The emphasis on genetic explanations for disease mechanisms highlights individual responsibility at the expense of collective accountability and may contribute to the overmedicalization of everyday life (Lippman, 1991; Clarke et al., 2003; Rose, 2007; Lupton, 2012).

With the availability of direct-to-consumer genetic tests and the increasing deployment of these tests in clinical practice, health is increasingly a matter of individual rather than state responsibility (Rose & Novas, 2005; Petersen, 2006; Tutton & Prainsack, 2011). In this setting,

citizens are asked to take responsibility for securing their own well-being. This expectation reflects neoliberal ideals of self-responsibilization: citizens are urged to be "*informed consumers*" to assess personal risk, and to manage their future health proactively. This includes seeking genetic counseling, participating in research, purchasing private health insurance, and engaging with advocacy networks. As Rose (2007) and Fairclough (1995a) argue, discourse does not merely reflect social realities; it constitutes them. The discourses of genomic medicine reconfigure individuals as "*biocitizens*," morally obligated to manage their biological futures through market-based strategies, as Rose and Novas (2005) portrayed. This transformation embeds health governance within a framework of market rationality, where the ethical imperative to care for oneself is inseparable from consumerist logics by recasting citizenship as a form of entrepreneurial self-governance shaped by genomic risk and neoliberal discourse (Rose, 2007; Petersen, 2010; Novas & Rose, 2000; Prainsack, 2017).

Genetic counseling is a key tool in managing genetic risk (Prince & Roche, 2014). The Canadian Association of Genetic Counsellors (CAGC), for example, highlights the benefits of consulting a genetic counselor in cases such as prenatal testing for genetic conditions in babies; assessing family history of cancer or inherited conditions; evaluating histories of miscarriages, infertility, or mental and physical disabilities; and for couples of certain ancestries to identify conditions prevalent in their communities, typically through a referral from a health care provider. Genetic counseling occurs before and after genetic testing (upon referral by a health care professional) at different life stages (e.g., planning for pregnancy, during pregnancy, caring for children, and managing your health (US Centers for Disease Control and Prevention – CDC). The U.S. National Society of Genetic Counsellors portrays genetic counselling as informing citizens about their genetic risk (including risks for unborn children), presenting treatment options and

information, and supporting decision-making (U.S. National Society of Genetic Counsellors – NSGC).

Such discourses emphasize the potential of genetics to promote health and improve the quality of life (Rantanen 2009 et al., p. 303), and to 'empower' individuals to make informed choices across various aspects stemming from one's connection with familial heritage, their offspring, and well-being. Understanding the complexities of managing genetic testing requires a nuanced examination of the risks involved in the interplay between individual choices and discourses shaping them. This highlights how genetic counseling serves as a means of disseminating medical information as a form of risk and functions within broader socio-political discourses that frame genetic knowledge as a tool for personal responsibility, informed decision-making, and the management of future health risks (Novas & Rose, 2000; Kerr et al., 1997).

Fairclough's (1995a) analysis reveals how discourse constructs knowledge regimes. The hyped narratives of precision medicine and early disease detection often obscure the socio-structural limitations of their implementation. Bhasin et al. (2022) show that a significant proportion of cancer patients, especially those with lower educational attainment or from ethnic minorities, misunderstood their genetic test results, despite counseling. This reveals a disjuncture between the discourse of empowerment and the lived realities of patients' engagement with genetic information and risks associated with this information, emphasizing that access to genetic testing does not guarantee equitable interpretation or benefit. Such findings problematize the neoliberal ideal of the self-managing genetic subject and support calls for more culturally and structurally responsive counseling interventions (Fairclough, 1995a; Rose, 2013; Jessop, 2005). The sociolegal literature on this point, particularly with respect to the structural and institutional dimensions of

genetic information governance, highlights the complex interplay between law, policy, and social norms.

2.3. The spectre and concept of genetic discrimination

Among the hype and potential of genetic advancements, significant ethical, legal, and social issues have been flagged (Chadwick, 2013; Juengst et al., 2016; Rothstein, 2005), with *genetic discrimination* being one of the most frequently cited issues in this regard (Wauters and Van Hoyweghen, 2016). At a basic level, genetic discrimination was initially defined as "*discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the 'normal' genome of that individual*" (Billings et al., 1992, p. 477). Referring to discrimination against an individual or their family members based on real or perceived genetic differences, there is some concern that public fear of such discrimination may hinder uptake of genetic testing and participation in genetic research (Bombard & Heim-Myers, 2018; Geelen et al., 2012). Such fears predominantly stem from the potential misuse of genetic information by third parties, such as insurance companies and employers, who might use this data to the detriment of individuals, denying them coverage or employment based on their genetic predisposition to certain diseases or conditions. Ultimately, however, it is important to understand genetic discrimination as a *social construct*, a category whose meaning is negotiated through discourse, law, and public concern.

Below, I review existing research on genetic discrimination as well as several scholarly approaches to the concept that demonstrate different understandings across legal, ethical, and societal viewpoints. Divergent framings of genetic discrimination shape and influence legal and policy responses—and, importantly, how these framings reflect broader ideologies about risk,

identity, and fairness in the genomic era. This theoretical groundwork is essential to critically assess the legislation under review and discourses surrounding genetic discrimination in North America.

Definitions of *genetic discrimination* have been considered from various legal, ethical, societal, and policy perspectives, and extend beyond exclusion from health insurance and employment to broader societal implications, including stigma, familial discrimination, and unequal treatment in healthcare and social interactions (Otlowski et al., 2012; Joly et al., 2013). Socio-legal scholarship highlights cultural and jurisdictional variability in definitions of genetic discrimination (Knoppers & Joly, 2007). Although some jurisdictions define discrimination narrowly while others adopt broader conceptions that encompass social and cultural harms (Joly et al., 2020), legal scholars emphasize how antidiscrimination laws typically emphasize *genetic exceptionalism*, as discussed further below (Rothstein, 2005; Lemke, 2004; Suter, 2001).

2.3.1. Geneticization and genetic exceptionalism: scholarly critiques and debates

Beyond legal and policy frameworks, societal norms and perceptions of genetic risk inform how individuals experience and navigate genetic discrimination. Lippman (1991) introduced the concept of "*geneticization*" to describe a reductionist discourse that frames genetics as the primary model for understanding health and disease. This discourse not only influences biomedical practices but also shapes cultural attitudes and values surrounding health and identity. Building on this, Stempsey (2006) argues that genetic diagnostics is ethically distinct because it operates within a framework of genetic reductionism and a neo-ontological concept of disease, which signifies a conceptual shift that redefines how we understand illness, personhood, and moral responsibility. However, this reductionist framing stands in contrast to anti-discrimination and human rights–

based approaches, which often have broader and more flexible applications. For example, the Canadian Genetic Non-Discrimination Act not only regulates insurance and employment practices but also amended the Canadian Human Rights Act and the Canada Labour Code, thereby embedding genetic discrimination within a wider rights-based framework. This contrast underscores the tension between narrow biomedical and market-driven logics of genetics on the one hand, and more expansive human rights–oriented protections on the other.

From a human rights and civil liberties perspective, genetic discrimination is typically viewed as a violation of equality and dignity. Scholars like Otlowski (2005) and Gostin (1991) argue that genetic discrimination should be treated no differently from racial or gender-based discrimination. Discrimination based upon actual or perceived genetic characteristics, it is argued, denies an individual equal opportunity and is as unjust as that based on race, gender, or disability. Gostin (1991) adds that discrimination violates fundamental principles of human rights, which undermines public health goals. In this way, a civil rights perspective considers moral and ethical dimensions of genetic discrimination as well as social values and public health outcomes. Such a perspective advocates legal measures to ban genetic discrimination and greater focus on moral and ethical dimensions and focuses on fairness and equal treatment of individuals within legal frameworks.

The privacy of genetic information has also been discussed within a human or civil rights perspective, particularly from those who critique a more individualistic approach to human rights. Eltis (2007, p. 283) ties this to the potential risk of discrimination since biobanking may inadvertently affect ethnic or other vulnerable groups. From this perspective, it is argued that we need to recognize the multiplicity of interests at stake and the interplay of intersectionalities when

making policy decisions. In this context, biobank governance should be seen not just as a matter of regulation, but as a strategy that coordinates interactions across multiple domains, scientific, medical, economic, legal, and sociopolitical, reflecting the complex landscape in which genetic data is collected and used (Gottweis & Lauss, 2012). An individualistic approach in human rights frameworks can impede the integration of crucial structural considerations and intersectional complexities, hindering the development of comprehensive legal protections.

The notion of *genetic exceptionalism* indicates that genetic information is fundamentally different from other health information and therefore requires special treatment (Rothstein, 2005). Proponents of genetic exceptionalism argue that genetic data is uniquely powerful, not only in shaping an individual's future health trajectory but also in affecting familial and broader population groups (Joly et al., 2021a, p. 174). For instance, Andrews (1995) argues that genetic data can reveal not just an individual's medical risks, but also those of their biological relatives, and therefore needs stronger legal safeguards to prevent discrimination and ensure informed consent in genetic testing and data sharing. These perspectives highlight the tension between viewing genetic data as uniquely sensitive and requiring special legal protections (such as Andrews, 1995; Collins &McKusick, 2001) and the view of integrating it within broader health information frameworks for equitable privacy and anti-discrimination measures (for instance Rothstein, 2005; Green & Botkin, 2003).

Indeed, legal scholar Murray (2019) critiques the notion that genetic data is uniquely sensitive, arguing that this framing lends legitimacy to genetic determinism and distracts from more holistic understandings of health and identity. Contrary to proponents of "*genetic exceptionalism*" which advocates for the distinct legal treatment of genetic data, Murray (2019, p.

14) argues that genetic information is, in fact, not "*uniquely powerful and uniquely personal*" and that "*we are not obliged to accord it special status or unique privacy protection*." In this sense, regulatory frameworks based on genetic exceptionalism may, paradoxically, create and exacerbate stigmas associated with genetic disorders while obscuring a holistic approach that considers societal dimensions of genetic discrimination. Rothstein and Anderlik (2001) echo this point, arguing that separating genetic information from other health data in healthcare applications denounces genetic difference and undermines efforts to build inclusive, equitable health systems.

Other scholars argue that genetic exceptionalism disproportionately elevates genetic factors above environmental, occupational, and social determinants of health (e.g., Conrad, 1999). Viewing genetic data as unique may divert attention from broader social and environmental issues impacting health. Shostak (2003) critiques the increasing focus on genetic explanations for health outcomes, emphasizing that this trend "*directs scientific, biomedical, and public health attention both inward, to the gene/genome, and outward, to particular places*" (p. 2328). Such a focus may overshadow the role of environmental and social determinants of health, therefore limiting a comprehensive understanding of disease causation and prevention (Shostak, 2003; Vilhelmsson, 2017; Chadwick, 2013).

Genetic-specific legislation may not only inadvertently emphasize the stigma associated with genetic disorders (Rothstein, 2005) but risks deepening structural inequities by isolating genetic discrimination from the broader landscape of health-related biases. The policy implications of this debate are substantial. Thus genetic-specific protections rooted in an exceptionalist framework (i.e., rather than integrating genetic protections within comprehensive anti-

discrimination measures), risks diverting attention from systemic barriers to healthcare, employment, and insurance access, limiting the effectiveness of anti-discrimination efforts.

This critique is central to the work of scholars such as Lemmens (2000) and Wolf (1995). Lemmens (2000, p. 349) argues that focusing on genetics is an imperfect way of protecting an already insufficient degree of access to health care, overshadowing more fundamental issues related to the nature of insurance, access to health care, and unequal distribution of wealth. In a similar vein, Wolf (1995) argues a primary focus on ensuring uniform treatment within the existing system fails to question the system itself and obfuscates connections between problems of genetics, race, and gender, and so helps emphasize the status quo (Wolf, 1995, p. 346). Thus, both Lemmens (2000) and Wolf (1995) argue that the focus on genetic discrimination within existing healthcare and insurance frameworks fails to address deeper structural inequalities related to access, wealth distribution, and systemic biases tied to race and gender, reinforcing the status quo rather than challenging the broader social determinants and distributive justice of access to care.

Critics such as Suter (2018) and Clayton et al. (2019) have drawn attention to how laws like GINA and GNA are rooted in *genetic exceptionalism,* which is the idea that genetic information is fundamentally different and thus requires special legal protections. Since the launch of HGP in 1990, scholars and policymakers have deliberated whether genetic information warrants distinct legal treatment from other health data due to its predictive, hereditary, and forensic characteristics (Murray & Livny, 1995; Rothstein, 2005; Rabinow & Rose, 2006; Knoppers & Chadwick, 2005; Juengst et al., 2016). Collectively, these critiques underline the need for policy frameworks that move beyond genetic exceptionalism to embrace a more integrated approach to anti-discrimination. This means embedding protections against genetic discrimination within

broader legal instruments that already address inequality based on disability, health status, and socio-economic marginalization. Doing so would reduce the risk of reinforcing the stigma attached to genetic differences and promote a more just and equitable model of health governance.

Moreover, *genetic determinism*, the belief that genes alone dictate health outcomes, downplays the influence of environmental, social, and behavioral factors and encourages overmedicalization (Lippman, 1992; Nelkin & Lindee, 2010; Hedgecoe, 2001; Conrad, 2007; Hansson et al., 2018). As such, Davison et al. (1994) warn that predictive testing may offer false certainty, lead to unnecessary interventions, and increase patient anxiety. Similarly, Hedgecoe (2004) critiques the hype surrounding genetic tests, noting that their clinical utility is often overstated in media and policy discourse. Fortun (2001) calls this the "speculation-driven world" of genomics, where promise outpaces evidence and shapes public perception.

This overvaluation of genetic knowledge is not without consequence. As individuals are encouraged to act on uncertain or probabilistic risk, they become subject to new forms of surveillance and moral evaluation. in the context of genetic testing, patient empowerment stands for individuals' ability to make informed decisions about their health based on their genetic information as a tool for proactive health management. Polzer (2005) highlights how genetic testing is framed within a discourse of *personal responsibility*. Being framed as an empowering tool, genetic testing can function as a mechanism of social regulation, shifting the burden of health from the state to the individual (Polzer, 2005). This perspective reveals the dual nature of patient empowerment in genetic testing. While it offers individuals greater control over their health decisions, it also highlights the neoliberal idea of *self-responsibility,* shifting healthcare responsibilities from healthcare systems to individuals.

Despite portraying patients as agents of choice within a discourse of empowerment as agents of choice (i.e., *rational individuals*), critics caution about the overvaluation of genetic knowledge and the deterministic tendencies it fosters. Beliefs in *genetic determinism,* understood here as attributing human traits primarily to genes and granting them greater causal power than scientific consensus supports, can foster overly simplistic one-to-one understandings of how genes relate to traits or diseases, often ignoring the complex interplay of multiple genes, proteins, and environmental influences (Gericke et al., 2017). Such views risk reinforcing existing social boundaries and inequalities by presenting genetic explanations for categories like gender or race as scientifically justified, reflecting a naturalistic fallacy that can be mobilized to support various political or ideological agendas. Indeed, the extensive optimism related to genetic testing can overestimate the value of genetic knowledge (Kerr et al., 1998). This understanding often obscures the complexity of disease mechanisms and highlights a reductionist perspective

Surbone (2011) notes that genetic testing for cancer risk has created a moral imperative to act, not just for oneself but for one's family. As Surbone (2011, p. 63) illustrates, genetic testing for cancer predisposition and genetic links in high-risk families would appear to be associated with moral obligations that go beyond those related to individual autonomy. Likewise, research by Hallowell (1999) on patients who receive genetic counselling for hereditary breast and ovarian cancer illustrates how women who are identified as at-risk assume responsibility for their own and others' genetic risks and perceive themselves as having an obligation to others, the risks faced by family members, to manage these risks. Therefore, new diagnostic technologies intertwined with ideas of responsibility as a moral technology of self and a commitment to the external world can be seen to generate new personal and collective responsibilities, but also new forms of

discrimination. This illustrates how genetic knowledge can impose new moral responsibilities and deepen existing gendered burdens of care.

2.3.1. Patient experiences and fear of genetic discrimination

Genetic discrimination arises from knowledge of genetic information, including an individual's genetic tests and family history of disease and/or genetic tests. As a result, the concern is that individuals may face bias and exclusion based on their genetic predispositions, even in the absence of any present symptoms or medical conditions. Some empirical studies over the past two decades have documented real-world instances of genetic discrimination in areas such as employment, health and life insurance, and social interactions (Otlowski et al., 2012; Joly et al., 2013; Wauters & Van Hoyweghen, 2016). For example, individuals with known genetic mutations for conditions like Huntington's disease, BRCA1/2-linked breast cancer, or hereditary cancer syndromes have reported insurance denial, employment disadvantage, and social stigma. Despite legal efforts to mitigate these risks, such as GINA in the United States and GNA in Canada, the literature reveals that fears of discrimination remain widespread and continue to influence individuals' decisions about whether to undergo genetic testing (McGowan et al., 2010; Suter, 2018; Joly et al., 2013; Chapman et al., 2020). This demonstrates that genetic discrimination is not a hypothetical concern but a documented social reality that can have material consequences.

Rothstein (1994) found evidence of "*differential treatment*" based on phenotype; the most common focus here was exclusion from insurance, employment, and health care. While discrimination may be defined as a type of distinction that is or should be socially unacceptable (e.g., from a civil rights perspective), the actuarial perspective used in the insurance sector appeals to the rationality or irrationality of actuarial bases around different risk classifications (Rothstein

& Anderlik, 2001, p. 354). In an actuarial approach, discrimination would only be considered unacceptable if it is not based on sound actuarial principles, or, in other words, irrational. For the insurance sector, then, discrimination in the form of using genetic information in risk calculation is rational and justified through the actuarial perspective. The insurance industry uses genetic information to evaluate applicants and establish insurance premiums, leading to public concerns about not being able to obtain different types of insurance coverage. For instance, Lynch et al. (1997) observe concerns of discrimination by insurance companies among family members in the US with hereditary breast/ovarian carcinoma (HBOC) syndrome who underwent genetic testing for BRCA mutation. As such, genetic discrimination could potentially contribute further to practices that exclude segments of the population from access to basic social necessities such as healthcare, insurance, housing, reproductive freedom, and employment (Joly et al. 2013). More recently, Joly et al. (2021b, p. 952) proposed that individuals belonging to a genetically determined high-risk group could face more restrictive and potentially discriminatory public health measures, such as continuing to undergo shielding or self-isolation measures for a longer period than the rest of the population under pandemic conditions.

Despite legal efforts to mitigate these risks, such as GINA in the United States and GNA in Canada,, studies show that fears of discrimination continue to influence individuals' decisions about whether to undergo genetic testing (Penziner et al., 2008; Bombard et al., 2011). Additional empirical studies on genetic discrimination in the literature reveal varied patient experiences. These studies position genetic discrimination as a documented social reality that can have material consequences. Adjin-Tettey (2013) highlights how fears about exclusion in insurance access continue to shape patient decision-making, especially where legal protections remain inconsistent. Allain et al. (2012) researched the impact of the GINA on individuals' decisions regarding genetic

testing for BRCA1/2 mutations. They found that many patients were unaware of GINA's protections and still feared insurance discrimination. Erwin et al. (2010) documented real-world cases of discrimination among those at risk for Huntington's disease (HD). They observed that 46.2% of 433 individuals they studied that were at risk for HD in North America and Australia reported experiencing genetic discrimination, again including but extending beyond insurance and employment, to being denied approval for child adoption or denied housing and mortgage.

The literature also reveals the importance of considering familial and social dynamics in discussions of and research on genetic discrimination (Featherstone et al., 2020; Hallowell, 1999; Nelkin & Lindee, 2010; Sharp & Foster, 2002). Within this framework, risk perception becomes a product of both individual and collective understandings, influenced by societal norms and attributions of responsibility (Gibbon, 2006; Kerr, Cunningham-Burley, & Amos, 1997; Conrad, 2001). These perceptions are further complicated by integrating genetic data into healthcare systems and social life. For instance, Ashkenazi Jewish women in Canada with genetic risk for breast cancer expressed concerns in one study about potential impacts of this information not only for insurance discrimination, but on marriage prospects for family members and scrutiny of the Jewish community; they were also concerned about potential risks to confidentiality, accuracy, and interpretability of results (Phillips et al., 2000). The authors highlight the need for nuanced policies and ethical frameworks that address individual health concerns and broader societal implications and cultural contexts surrounding the integration of genetic data into healthcare systems.

Similarly, Bombard et al. (2011) interviewed individuals with gene mutations related to HD about their concerns about discrimination in family, social, government, health-care domains, insurance, and employment. They documented participants' apprehensions of differential treatment

ranging from increased surveillance by employers, experiences of social avoidance and pity, as well as altered medical advice from health-care professionals. These cases highlight the multidimensional nature of genetic discrimination, which extends beyond employment and insurance to include interpersonal, cultural, and institutional harms. Treloar et al. (2004) and Erwin et al. (2010) argue that familial and social stigma should be recognized as forms of genetic discrimination.

Indeed, across the world, there has been less attention, in public policies and regulatory efforts, to genetic discrimination outside of insurance and employment contexts (Wauters and Van Hoyweghen, 2016; Joly et al., 2013; Joly et al., 2020). Joly et al. (2020, p. 504). Legislative constructions of genetic discrimination treat genetic information is treated less as a social or ethical concern and more as an economic variable that must be managed within risk-bearing institutions. Such a focus reproduces a neoliberal orientation in which law functions primarily to protect market transactions and commercial stability, while leaving unaddressed the broader social and relational consequences of genetic information. Excluded from this construction are other sites where discrimination may manifest—such as education, housing, access to social services, or even family law—contexts in which genetic knowledge can carry profound personal and social repercussions.

Using a human rights perspective, Erwin et al. (2010) argue that genetic discrimination should be more inclusive of a broad range of discriminatory activities, including denial of rights, privileges, opportunities, or other adverse treatment based solely on genetic information. This wider framing would also include interpersonal contexts, such as familial discrimination, social stigma, or exclusion in everyday life. Expanding the definition in this way highlights that genetic discrimination is not limited to institutional or economic settings but also operates within social

and relational domains. However, recognizing such a broad spectrum of harms would potentially attract additional or different legislative responses, as laws designed primarily to regulate insurance and employment contexts may be insufficient to address the social, cultural, and interpersonal dimensions of discrimination that Erwin et al. (2010) identify. Along similar lines, Treloar et al. (2004) likewise suggest familial discrimination should be included in the scope of genetic discrimination on the grounds that prejudicial attitudes or discrimination may be experienced by members of families who are not themselves at direct genetic risk.

Penziner et al. (2008) explored experiences of presymptomatic persons with positive Huntington's disease gene tests, documenting impacts on their partnerships, family planning, self-image, and identity within the family. These fears often led to test refusal, as also seen in Penziner et al. (2008), who found that predictive testers for HD felt compelled to withhold results from employers or insurers. Studies by Bombard et al. (2011) and Phillips et al. (2000) further illustrate how genetic information can impact family dynamics, marriage prospects, and social standing, especially in tight-knit cultural communities. As legal protections do not always translate into perceived safety, patients can be left to navigate a fraught ethical and emotional terrain.

The cases illustrated above, where individuals were denied housing, child adoption, or fair treatment by healthcare providers based on genetic risk, point to the intersection of biomedical knowledge with social power. The impact of genetic risk does not stop at the individual but extends to family members, who may also face stigma or exclusion. This expands the concept of harm beyond legal or institutional settings and acknowledges how genetic discourse permeates personal relationships, social norms, and collective identities (Gibbon & Novas, 2008). An expanded concept of harm is crucial, especially given the growing role of private actors, such as

biotechnology firms, insurers, and tech companies, in collecting, storing, and profiting from genetic data. While companies like 23andMe (now defunct) promote individual empowerment through knowledge, they also operate within a data economy that commodifies genetic information (Langlois, 2006; Geiger & Gross, 2021). This in turn raises concerns about consent, data privacy, and the future use of genetic material, especially as predictive analytics and algorithmic decision-making become more common in healthcare and insurance (Kaye et al., 2015; Dove et al., 2016; Mittelstadt et al., 2016).

Scholars such as Wauters and Van Hoyweghen (2016) and Lemke (2013) have also called for greater attention to subtle, interactional, and indirect forms of discrimination, those that occur in everyday life, often unintentionally, and are harder to document. This can include disrespect and stigmatization; however, it also includes structural constraints on autonomy and decision-making, (Lemke 2013). Such scholars highlight the need to look beyond visible acts of exclusion and examine the broader social but also the structural and systemic mechanisms (Somek, 2011) through which *genetic disadvantage* is perpetuated.

2.4) Genetic information as moral technology, and the limits of existing legislation

Biotechnological innovation is tightly linked to neoliberal discourses that promote individual responsibility and self-management (Rose, 2007; Novas & Rose, 2000; Lemke, 2011). As Lemke (2013) points out, genetic information functions as a *moral technology*, a form of knowledge that redefines what it means to be a responsible individual in society. Rather than relying on collective welfare systems or structural interventions, as described by scholars such as Surbone (2011) and Lemmens (2000), individuals are expected to optimize their health through informed choices, lifestyle changes, and strategic decision-making, including undergoing genetic

testing and modifying behavior based on perceived risk. The need for a stronger public oversight or limits on secondary data use regardless of consent are not included in these accounts. From this perspective, individuals are expected to take responsibility for their health choices as active and responsible customers of medical services and products associated with genomic knowledge, ranging from new pharmaceuticals to genetic tests. This process transforms citizens into *biocitizens*, a concept developed by scholars such as Rose (2007), who argue that individuals are increasingly defined by their biological risks and responsibilities. In the context of genetic medicine, being a good citizen means managing one's genetic future, contributing data to biobanks, and participating in research. These expectations are embedded in public health discourse and emphasized by legislation that positions genetic testing as a form of proactive, responsible behavior.

Importantly, these new responsibilities are unevenly distributed. Not everyone has equal access to genetic testing, counseling, or the resources needed to act on genetic information, as racial and socioeconomic disparities, limited healthcare infrastructure, and shortages of trained genetics professionals create systemic barriers that reduce awareness, uptake, and effective use of genetic services (Roberts & Middleton, 2018; Armstrong et al., 2005). For example, Kaphingst et al. (2012) conducted research using a genetic susceptibility test to examine how patients aged 25 to 40 understand, recall, and respond to direct-to-consumer genetic risk information. Many participants resisted deterministic interpretations. However, racialized and less-educated respondents were more likely to misunderstand results. These disparities reflect broader patterns of health literacy inequality, as individuals with lower educational attainment or socioeconomic status are more likely to misinterpret or misuse genetic information, illustrating how social inequality shapes the capacity to navigate genetic discourse (Gollust et al., 2012; Roberts et al.,

2017). This highlights the necessity of culturally competent genetic counseling and the dangers of assuming universal genetic literacy. These disparities are not merely informational gaps but manifestations of broader socio-cultural and economic stratification, which shape how individuals engage with and act upon genetic knowledge.

Similarly, Baker et al. (2022) analyzed *MyCode Community Health Initiative,* a large-scale genomic research program based in the USA with a strong emphasis on community engagement to explore how integrating genetic data into routine healthcare affects individuals' lives. Baker et al. (2022) found that familial communication about genetic risk is mediated by emotional closeness. Those without strong family or community networks may not benefit from opportunities for cascade testing (i.e., genetic testing to relatives of a person identified as having a specific genetic mutation associated with a hereditary condition), potentially widening gaps in preventive care. These findings emphasize the argument that social support and cultural competence are essential to realizing the benefits of genomic medicine and avoiding pitfalls. They reflect how access to genetic knowledge is stratified. The concern is not simply about literacy but about *justice*. As the *MyCode Community Health Initiative* shows, family communication of genetic risks is mediated by emotional proximity and social capital. Those without such networks may not benefit from cascade testing (Baker et al., 2022).

More recent research continues to indicate that fears of stigma and discrimination, particularly around insurance, are still prominent even where legislative protections exist, and continue to deter people from undergoing genetic testing (Fraser et al., 2023, in New Zealand) or applying for life insurance (Tiller et al., 2023, in Australia). These concerns are especially

pronounced among marginalized groups, whose trust in healthcare institutions may already be low due to historical injustices and ongoing structural inequalities.

In North America, a Canadian survey conducted by PricewaterhouseCoopers (Martin, 2000) found that despite strong attitudinal support for the application of genetic testing and information, and with 91.6% expressing willingness to share their genetic data with their personal physicians, only 13.6% expressed willingness to share such information with government agencies, suggesting deep-seated concerns about how genetic information could be used by institutions beyond the clinical setting.

Moreover, despite strong uptake of and satisfaction with some genetic testing initiatives such as The Screen Project (a direct-to-consumer initiative offering BRCA1 and BRCA2 testing: Narod et al., 2021), one qualitative study suggested that awareness of Canada's GNA remains low, and that many lacked confidence in its ability to protect them from discriminatory practices (Gopalakrishnan et al., 2024). Moreover, the American Genetic Information Nondiscrimination Act (GINA)'s gaps with regards to life, disability, or long-term care insurance are notable, given how discrimination in these sectors can loom large in patient's decision-making; for this reason, some states attempted piecemeal remedies through legislation of varying strength (Williams, 2024).

Finally, broader attitudinal surveys suggest that public trust in genomic medicine hinges on the actors controlling access to genetic information. Savic-Kallesøe et al. (2021), drawing on the "*Your DNA, Your Say*" research, found that Canadians place the highest trust in doctors and nonprofit researchers, while exhibiting markedly less trust in governments and private industry. This finding is consistent with the reluctance noted in earlier surveys to grant government agencies

access to genetic data, and it helps explain why, even with formal legal protections, the spectre of discrimination persists.

This body of evidence illustrates a paradox. While publications in Canada and the U.S. generally welcome the medical benefits of genetic testing, persistent mistrust and experiences of discrimination in insurance and other domains continue to shape behaviour. Laws like GINA and GNA represent important symbolic and legal interventions but have not fully mitigated perceived or enacted risks. The result is a policy landscape in which uptake of genetic testing remains influenced not only by clinical utility but also by broader social, economic, and institutional uncertainties.

This reality reveals the limitations of formal legal protections, such as GINA and the GNA, which may exist on paper but fail to address the broader social conditions and considerations that shape people's willingness and ability to access genetic services. Moreover, these laws often do not address concerns related to non-institutional forms of discrimination, such as familial stigma, social exclusion, and emotional coercion (Joly et al., 2013; Otlowski et al., 2012; Lemke, 2013).

A comprehensive approach to genetic discrimination and stigma is imperative not only to account for individual harms but also to interrogate the broader structural and discursive conditions that shape them. As Fairclough (1995, 2003) argues, discourse analysis enables researchers to examine how language mediates social practices, including the ways dominant narratives normalize exclusionary outcomes even without overt violations. Building on insights from scholars such as Rothstein (2005) on genetic exceptionalism and Shostak (2003) on the dominance of genetic explanations that subordinate gene–environment relationships, in the rest of this dissertation I situate genetic discrimination laws within wider processes that simultaneously

protect against certain harms while embedding genetic data into structures of biocapitalism (Birch, 2017).

Somek (2017) offers a provocative critique which echoes an actuarial view, arguing that genetic discrimination is rational within a market mentality. From this perspective, insurers and employers act in their financial interest by assessing genetic risk, and anti-discrimination laws are attempts to correct market failures. However, this perspective raises serious ethical concerns. The rise of biotechnology in the context of neoliberal economics intersects with advancements in genomics, fostering industrial interests in patenting scientific discoveries and promoting new diagnostic technologies (Prainsack, 2018). As Somek (2017) warns, allowing such practices to continue would erode social solidarity, as the logic of the market begins to replace values of inclusion and mutual support that are widely understood to underpin democratic societies like the USA and Canada. While Somek (2017) brings *market-correcting* mechanisms into attention in his scholarship, anti-discriminatory regulations have been supported by business in biotechnology to ensure that regulatory protections are set to remove barriers for individuals to undertake genetic testing, therefore fostering investments in genomics fields. From Somek's (2017) perspective, legislation such as GINA and the GNA is not simply protective but also promotional: it builds consumer confidence and legitimizes the growing genetic testing market.

Biotechnology firms strategically support such regulations because they stabilize the market environment, ensuring a steady supply of genetic data necessary for product development, personalized therapies, and predictive analytics. This illustrates how neoliberal governance frames rights-based legislation as compatible with, and even essential to, market growth, effectively

turning protections into tools that enhance market participation rather than challenge its underlying logic (Birch & Tyfield, 2012; Rose, 2007).

A more detailed examination of the association between genomic markets and legislation is, however, beyond the scope of my dissertation. I intentionally focused on analyzing legislative texts and their discursive functions through the combined lens of Fairclough's CDA and Pistor's legal assetization theory, to maintain a clear and in-depth analysis of the discursive formations.

The material reviewed above highlights how genetic discrimination is not merely a legal or medical issue, but a broader social phenomenon influenced by systemic inequalities, market forces, and normative assumptions about health and risk. Laws like the 2008 GINA and the 2017 GNA appear to attempt to push back against this market logic by prohibiting the use of genetic information in employment and health insurance decisions, as will be more fully discussed in subsequent chapters. However, they stop short of addressing structural factors such as the privatization of healthcare, uneven access to preventive services, or corporate control of genetic databases. These types of laws may actually reinforce *genetic essentialism* by treating genetic conditions as fundamentally distinct and genetic data as inherently risky (Lemke, 2005).

As the discourse surrounding genetic research and biobanking evolves, scholars have increasingly emphasized the intricate relationship between genetic data and broader health information (Rothstein and Anderlik, 2001, for instance). Furthermore, separate treatment increases the stigma attached to genetic conditions and lends legitimacy to and reinforcing *genetic reductionism* and *determinism* (Lemke, 2005; Lippman, 1992; Nelkin & Lindee, 2010). It is crucial to assess the implications of integrating genetic data into healthcare, on societal perceptions, stigma, and genetic essentialism (Tutton, 2014; Prainsack, 2017; Khoury et al., 2009). These are

key issues that this dissertation addresses by analyzing how legislative and policy discourses narrowly construct and regulate genetic information, often with little attention to their broader social and ethical consequences (Strydom, 1999).

In the context of genomic medicine, dominant discourses reconfigure how people come to understand themselves as at risk, as responsible, and as morally accountable for managing their biological futures. The discourse surrounding genetic knowledge not only informs but actively produces new subjectivities: patients begin to internalize neoliberal imperatives of self-governance, health optimization, and risk aversion (Rose, 2007; Novas & Rose, 2000; Rabinow, 1997; Petersen, 2011). What was once a clinical option becomes a moral duty by transforming genetic testing into a form of biocitizenship in which individuals are expected to understand and act upon their genetic profiles, often without adequate institutional support. Indeed, the expectation that individuals should manage their genetic risks both for themselves and others contributes to new social obligations and, in some cases, new forms of discrimination.

2.5) Policy responses to genetic discrimination

Fairclough's (2010) approach to CDA and Pistor's (2019) legal theory of assetization help us understand how laws and policies function as discursive practices embedded within broader socio-political contexts. Rather than treating legal texts as neutral or technical, this analysis examines how institutional frameworks operationalize concerns around genetic privacy, risk, and fairness, while simultaneously reflecting and reinforcing ideological currents such as genetic exceptionalism, market rationality, and the valorization of biomedical innovation. While genetic laws are often positioned as safeguards to protect individuals from potential misuse of their genetic data, they also serve as mechanisms to foster public trust (Feldman, 2012) and facilitate

participation in genetic testing and biobank research - aligning with the interests of state-led innovation agendas and biotechnology markets (Dressler & Terry, 2009; Samuel & Farsides, 2018). Viewed through the lens of "*legal coding*", such law and policy frameworks do not merely respond to ethical concerns but also encode genetic data with legal protections that enable its circulation within medical, economic, and research infrastructures and transform it into a form of capital (Pistor, 2019).

That said, before delving into the analysis further, in this subsection I provide a brief overview of some of the dominant policy responses to genetic discrimination (including the legislative responses noted in Chapter 1). Policymakers in several countries, including Canada, have responded to concerns about the particular threat of genetic discrimination with legislation to ban genetic discrimination since the 1990s (Rothstein, 2005; Otlowski et al., 2012; Wauters & Van Hoyweghen, 2016). In Canada, this concern culminated in the passage of the GNA in 2017, although policy discussions around genetic discrimination date back much earlier, particularly in relation to human rights and anti-discrimination frameworks (Knoppers & Joly, 2004). In the U.S., the absence of a universal healthcare system makes access to personal insurance highly dependent on employment, intensifying concerns about genetic discrimination (Hudson et al., 2008; Rothstein, 2005). Early cases of discrimination related to monogenic diseases prompted a patchwork of state laws addressing genetic discrimination in different contexts (Otlowski et al., 2012; Hudson et al., 2008). Advocacy from patient groups and genetic researchers eventually led to federal interventions, including the Americans with Disabilities Act, the Health Insurance Portability and Accountability Act (HIPAA), and the Affordable Care Act (Baruch & Hudson, 2008; Joly et al., 2013). Despite these legislative efforts, the U.S. framework remains fragmented,

particularly in the domain of life insurance, where protections remain largely at the state level (Rothstein, 2018b; Otlowski et al., 2012).

Unlike the U.S., Canada's universal healthcare system has historically mitigated the urgency for genetic discrimination legislation by providing broad access to healthcare regardless of genetic risk, thereby reducing the immediate economic and social pressures that drive demand for such laws (Knoppers & Joly, 2004; Otlowski et al., 2012; Wauters & Van Hoyweghen, 2016). However, recent shifts in political momentum have pushed for legislative solutions, culminating in the passage of the GNA, which establishes clearer protections against genetic discrimination in employment and insurance by amending the Canada Labour Code and reinforcing provisions under the Canadian Human Rights Act.

The nuanced differences between the U.S. and Canadian approaches highlight how responses to genetic discrimination are shaped by underlying healthcare structures—largely individual-funded in the U.S. and publicly funded in Canada—rather than solely by evidence of discrimination. While the U.S. framework reflects a pre-emptive strategy shaped by concerns about private insurance and employment practices, Canada's trajectory reveals how universal healthcare initially absorbed such pressures, only later giving rise to legal protections amid shifting political contexts. Yet in both systems, neoliberal logics of risk management, individual responsibility, and the marketization of genetic information remain influential, framing genetic data simultaneously as a liability and as a valuable resource. From a critical discourse perspective, this suggests that national differences in funding models do not preclude convergence around dominant narratives that legitimize the integration of genetics into health and market systems, while public fears of

discrimination continue to shape individual decision-making (Caulfield et al., 2008; Muller et al., 2024; Chapman et al., 2020).

Among the legal and policy responses to these concerns, international organizations have established the need for broad protections against genetic discrimination, emphasizing *genetic privacy* as a fundamental human right. UNESCO's 1997 Declaration on the Human Genome and Human Rights states that "no one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms, and human dignity." While this reflects a growing international consensus on the importance of protecting identifiable genetic information and preventing discrimination, such conventions remain non-binding until domestically implemented, limiting their practical effect and leaving national governments to determine the scope and enforceability of protections.

The discussions surrounding genetic discrimination cover multifaceted concerns regarding fair use, data privacy, protective legal frameworks, and societal ramifications (Gostin,1991; Billings et al., 1992; Brothers & Rothstein, 2015). There have, in particular, been concerns about stigmatization and equitable access to services wherein the risk of genetic disease might become a deeply discrediting attribute. These expressions of concern are shaped by different institutional positions, professional responsibilities, and normative frameworks—from ethical imperatives and legal protections to lived experiences of vulnerability. The framing of genetic risk as a "*deeply discrediting attribute*" is particularly resonant with Goffman's (2009) conception of stigma, and is often mobilized to argue for preventive legislation, public education, and anti-discrimination safeguards in both U.S. and Canadian contexts. Central to public and academic discussions is the fact that insurance companies and employers can make decisions based on genetic information,

which contrasts with the principles of equality, privacy, and individual rights. This is especially problematic as the predictive value of diagnostic technologies has also been questioned due to concerns raised by scientists, physicians, and bioethicists based on the limited diagnostic value of genetic testing (for instance, Surbone, 2011, highlights the relatively stronger role of environmental factors in carcinogenesis).

In addition to responding to perceived ethical concerns in the public about genetic testing and research, however, a key policy-making aim is to promote *personalized medicine*, which tailors diagnostics and interventions based on individual genetic profiles (Juengst et al., 2012; Prainsack, 2017; OECD, 2009b). By providing legal protections against genetic discrimination, policymakers seek to remove barriers that might deter individuals from genetic testing and research opportunities, in this way facilitating personalized medicine. Some have even argued that participation in genetic research, in this sense, is an ethical duty (Bélisle-Pipon et al. 2019; Juengst et al., 2016). Legal protections against genetic discrimination in this way align with state efforts to realize personalized medicine's potential benefits.

Among the laws prohibiting genetic discrimination since the 1990s, GINA in the United States stands out as particularly impactful. This act purports to protect individuals from discrimination based on genetic predispositions but also regulates the privacy of genetic information in order to prevent its misuse (Chapman et al., 2020). According to Joly et al. (2020), GINA and similar laws with specific legal prohibitions forbid requiring an individual to undergo genetic testing, prohibit access to already existing genetic information about an individual, or prohibit the use or processing of genetic information by a designated entity. This approach is common in countries that have adopted a broad human-rights–based statutory prohibition, for

instance in France, and countries that have adopted a moratorium with government oversight to prevent genetic discrimination in specific domains, as in the United Kingdom and Australia (Joly et al., 2020, p. 494). In general, GINA is acknowledged as a landmark effort globally to prevent genetic discrimination despite its limitations, such as the lack of coverage for life, disability, and long-term care insurance.

GINA was followed by federal initiatives aimed at integrating genetics into mainstream medicine. For example, during his time in the Senate, Barack Obama introduced the Genomics and Personalized Medicine Act of 2008. Although not enacted, the bill proposed extensive funding and infrastructure to expand genomics research, improve diagnostic tools, and promote pharmacogenomics, a field that connects genetic profiles with drug response to improve patient safety and treatment effectiveness. The proposed law also sought to establish biobank governance, privacy frameworks, a genomics workforce strategy, and public education programs, indicating a broad vision for integrating genomic medicine into the U.S. healthcare system.

Post-GINA, agencies such as the Food and Drug Administration (FDA), Centers for Medicare & Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH) have developed companion initiatives supporting genetic testing regulation, laboratory standards, and public health surveillance. These include the oversight of laboratory-developed tests, adverse event reporting systems, and efforts to integrate pharmacogenomic data into clinical decision-making by the Clinical Laboratory Improvement Amendments (known as CLIA of 1988). The CLIA is the U.S. federal regulatory standards that apply to all clinical laboratory testing performed on humans. Collectively, these developments

mark a shift from merely preventing discrimination to actively enabling the infrastructure of genomic medicine (U.S. Congress, 2008).

Following the passing of GINA in 2008, Canada discussed enacting legislation to prevent genetic discrimination. GNA received royal assent on May 4, 2017. However, the Government of Québec challenged the constitutionality of certain provisions, referring the question to the Québec Court of Appeal for an advisory opinion and arguing that the Act was beyond federal jurisdiction over criminal law. The GNA was on hold until July 10, 2020, when the Supreme Court of Canada in Reference re Genetic Non-Discrimination Act, 2020 SCC 17, [2020] 2 S.C.R. 283, upheld the Act as constitutional. In doing so, the Court acknowledged that protecting an individual's right to privacy over genetic information constitutes a valid federal criminal law purpose. As the decision stated, "t*he provisions are supported by a criminal law purpose because they respond to a threat of harm to several overlapping public interests traditionally protected by the criminal law — autonomy, privacy, equality, and public health*." This ruling affirmed that the protection of genetic information is not merely a matter of market regulation or individual preference, but a matter of broader public concern situated within Canada's constitutional framework. Building on this constitutional recognition, GNA proscribes imposing genetic testing, or obtaining access to or requiring disclosure of information obtained from genetic tests, as it relates to the provision of goods and services. However, the GNA provides an exception for medical personnel and researchers and allows certain activities, such as the use or disclosure of genetic test results, where written consent of the individual concerned is provided.

Similarly, GNA and the Canadian Genomics Strategy (CGS), which was launched in 2025, illustrate the increasingly explicit alignment of genomics with national economic objectives. CGS,

supported by a $175.1 million federal investment, emphasizes the commercialization of genomic technologies, the cultivation of interdisciplinary workforce capacities, and the enhancement of data infrastructure and sharing across diverse sectors, including healthcare, agriculture, and environmental management (Government of Canada, 2025). Within this framing, law operates not only as a safeguard against potential harms but also as a crucial instrument for enabling economic innovation and scientific advancement. As Pistor (2019) underscores, legal frameworks actively participate in the codification of intangible resources—such as genetic data—into capital assets, thereby structuring the conditions for their circulation within market economies.

This dynamic situates genomics within what Brabazon (2016) and Jessop (2002) describe as the neoliberal juridical project, whereby legal regimes extend and entrench market logic into new and previously non-commodified domains, including the life sciences. The transformation of genetic information into a legally protected and tradable asset is therefore not incidental but central to the political economy of genomics, reflecting the juridical infrastructure required for markets to function. In this respect, Canadian initiatives like the CGS parallel U.S. developments, illustrating how legislative and strategic policy frameworks not only regulate risk but also narrate genomics as a cornerstone of the knowledge economy. As Lemke (2011) and Cloatre and Pickersgill (2015) argue, this institutional embedding of genomics within broader economic and policy structures highlights the dual role of law: both as a mode of governance and as a constitutive force that integrates scientific practices into national and transnational economic imaginaries.

Some analyses present national legislative efforts in the United States and Canada as reflecting a “growing recognition” of genomics as both a health innovation and an economic driver (OECD, 2018; Government of Canada, 2025; Canadian Institutes of Health Research, 2022;

Hasanzad et al., 2022). However, a critical perspective reveals that the commercial and market-driven dimensions of genomic science have been deeply entrenched since its inception. From the earliest phases of HGP onward, private biotechnology firms and their political representatives actively framed genomics as a lucrative frontier for profit and competitive advantage (Jessop, 2005; Hedgecoe, 2004; Birch & Tyfield, 2012). This longstanding commercial orientation challenges narratives that portray the economic value of genomics as a recent development, instead highlighting how neoliberal governance strategies have consistently sought to align public policy with market expansion and commodification of biological data (Jessop, 2002; Rose, 2007). Thus, claims of a "growing recognition" risk obscuring the persistent influence of corporate interests and the neoliberal rationalities shaping genetic innovation and regulation.

In the U.S., the Genomics and Personalized Medicine Act of 2008 was proposed to accelerate genomics research and its clinical applications by coordinating federal agency efforts and investing in biobanking, workforce development, and pharmacogenomics (U.S. Congress, 2008). Although this bill was not enacted, it represented a pivotal moment of alignment between scientific advancement and regulatory foresight. Francis S. Collins, then Director of the National Human Genome Research Institute (NHGRI), emphasized before the 110th Congress that the success of personalized medicine hinged on the passage of legislative protections like GINA, arguing that only by alleviating fears of genetic discrimination could public participation in genomics research thrive (Dressler & Terry, 2009). According to Hudson et al. (2008), these developments reflect what Thomas Jefferson once advocated: "*Laws and institutions must go hand in hand with the progress of the human mind… as new discoveries are made… institutions must advance also and keep pace with the times"*. However, this optimistic framing also reflects the broader tendency within biomedical and policy discourse to hype genomic technologies as

inevitable solutions, often downplaying persistent ethical, social, and economic challenges that complicate equitable access, meaningful public engagement, and the real-world impact of personalized medicine (Rose, 2007; Jasanoff, 2005; Fortun, 2001).

These legislative and regulatory initiatives were not only framed as legal safeguards, but also as strategic economic instruments designed to cultivate public trust and thereby stimulate investment and innovation in the rapidly expanding genetic technology sector. The global genomics market, valued at approximately USD 32.65 billion in 2023, is projected to grow at a compound annual growth rate of around 16.5% from 2024 to 2030, driven by growing demand for gene therapy, personalized medicine, drug discovery, increasing cancer incidence, and a significant increase in demand for consumer genomics in recent years (Grand View Research, n.d.). This explosive growth underscores how genetic data is increasingly commodified and integrated into neoliberal market logics, as scholars like Birch and Tyfield (2012) argue, where public policy functions to de-risk investment and maximize biocapital accumulation. Furthermore, the framing of GINA and related policies as essential to unlocking the economic potential of genomics reflects a neoliberal governance strategy that intertwines scientific progress, ethical regulation, and market expansion (Rose, 2007; Jessop, 2002). However, this convergence also raises critical concerns about the privatization of genetic information, uneven access to benefits, and the shifting of risk onto individuals, which remain largely under-examined in policy discourse. Thus, while GINA aimed to prevent genetic discrimination and build public trust (Feldman, 2012), it simultaneously facilitated a market environment where genetic data is a valuable asset within a competitive global bioeconomy (Birch et al., 2010).

Additional apparent objectives underlying these regulations are also outlined in the literature, which extend beyond merely prohibiting genetic discrimination. They include reducing apprehension surrounding discrimination that might dissuade individuals from undergoing genetic testing or engaging in genetic research (Wauters &Van Hoyweghen, 2016). For instance, personalized medicine with new diagnostic and treatment approaches customized to individual genetic characteristics necessitates patient involvement in clinical research. As noted earlier, by addressing fears of genetic discrimination, the provision of assurances and legal safeguards is hoped to encourage individual participation in clinical research, ultimately advancing the goals of personalized medicine, which relies on individual genetic profiles for tailored diagnostics and treatments.

However, the effectiveness of these laws is complicated by the conceptual framework of genetic exceptionalism, which underpins much of the legislation. As Rothstein (2005) observed, policymakers have often treated genetic information as distinct from other health data due to its predictive capacity, familial implications, and symbolic power. As earlier alluded to, policies designed to safeguard individuals from genetic discrimination often operate within the framework of genetic exceptionalism, treating genetic data as fundamentally different from other health information. Building on earlier debates sparked by HGP about the unique features of genetic data and whether they warrant special treatment, proponents of this perspective emphasize that genetic information carries unique risks of misuse, requiring specialized protections (Joly et al., 2021a).

What emerges from this reasoning is a fragmented regulatory environment, in which legal protections become tightly centered on genetic information rather than integrated into broader frameworks of health protection. In privileging genetics, GINA in the United States and GNA in

Canada exemplify how legislative responses have carved out narrow protections around DNA and genetic testing while largely neglecting other determinants of health. This has important distributive consequences: individuals who experience discrimination on the basis of chronic illness, disability, or social marginalization remain outside the scope of these protections, even though such conditions can generate harms similar to those attributed to genetic information. By isolating genetics as a special category, the law not only reinforces genetic exceptionalism but also obscures the wider socio-environmental and occupational contexts that structure health disparities. However, critics argue that this legislative approach reinforces the idea that genetic conditions are fundamentally distinct from other health risks, potentially contributing to their exceptional treatment in law and policy. Critics argue that genetic-specific legislation may unintentionally emphasize stigma by suggesting that genetic information is uniquely risky or shameful. Murray (2019) advocates for integrating genetic information into broader data privacy and antidiscrimination policies, avoiding the trap of affirming genetic determinism and masking social context. The belief that legal protection alone against genetic discrimination is sufficient neglects the structural conditions that generate these conditions.

At this point, *legal coding theory* (Pistor, 2019) is especially illuminating. While laws like GINA and GNA appear to offer safeguards, they simultaneously facilitate the assetization of genetic data. By assigning genetic information a legally protected status, these laws enable its safe circulation through research institutions, healthcare systems, and biotechnology markets. This legal encoding transforms genetic data into capital strategically usable, tradable, and monetizable by aligning public health policy with the logic of innovation and economic growth. In this light, policies that protect privacy also serve to legitimize data-driven capitalism.

These dual policy considerations of protection and facilitation are particularly clear in national initiatives like the proposed *Genomics and Personalized Medicine Act of 2006- S.3822 (GPMA)* in the U.S. and CGS. Although the bill for GPMA was not enacted, it introduced critical proposals: biobank governance, national data infrastructures, incentives for pharmacogenomics, and a genomics-ready workforce. It also called for interagency collaboration between the U.S. Food and Drug Administration (FDA), the National Institutes of Health (NIH), the Centers for Medicare & Medicaid Services (CMS), and the Centers for Disease Control and Prevention (CDC), which later materialized through related efforts such as the integration of pharmacogenomic data into clinical guidelines and the establishment of genetic test registries (National Institutes of Health, n.d.). GINA and its associated policies are attempts to legislate the collection, use, and disclosure of genetic information in ways that protect individuals from discrimination while accommodating evolving scientific capabilities and social expectations regarding genetic testing and personalized medicine (Juengst et al., 2012; Tutton, 2012; Evans, 2019).

These policies function as legal infrastructures that both protect individuals from genetic discrimination and enable the integration of genetic data into market and healthcare systems (Pistor, 2019; Juengst et al., 2012; Tutton, 2012; Evans, 2019). Through this dual function, genetic information is transformed into a form of biocapital, subject to market dynamics and facilitating its commodification within biotechnological and healthcare industries. For example, initiatives such as national biobank governance, pharmacogenomic incentives, and interagency coordination in the U.S. demonstrate how legislation creates infrastructures that allow genetic data to circulate as both scientific and economic resources. However, in focusing on these assets, such policies often sideline structural determinants of health, including socioeconomic inequality, racial discrimination, and unequal access to care, reflecting a form of genetic exceptionalism that

prioritizes innovation and market objectives over broader social justice concerns (Krieger, 2005; Rothstein, 2005). This highlights the tension inherent in these frameworks: while advancing scientific progress and patient protection, they also reinforce economic rationalities that can obscure persistent health inequities.

Consequently, while these frameworks promote narratives of scientific progress and patient empowerment, the laws themselves illustrate the mechanisms through which biomedical innovation is mobilized to advance economic objectives. For example, provisions in GINA prohibit employers and health insurers from requesting, using, or disclosing individuals' genetic information, while also allowing consented use of genetic data for research purposes. Similarly, proposals in initiatives like proposed GPMA or CGS establish legal and institutional infrastructures—such as regulated biobanks, standardized data-sharing protocols, and interagency collaborations—that enable genetic information to circulate as both a scientific resource and a marketable asset (Pistor, 2019; Juengst et al., 2012). This process of assetization embeds market rationalities into healthcare governance, shaping how genetic data is collected, stored, and used, while simultaneously framing individuals as both beneficiaries and participants in these systems. At the same time, the legislative focus on regulating genetic data narrowly—as opposed to addressing broader determinants of health such as socioeconomic inequality, racial discrimination, or access to care—demonstrates a form of genetic exceptionalism (Rothstein, 2005; Krieger, 2005), where the social justice dimensions of healthcare are marginalized. In this way, translating genetic science into legal frameworks simultaneously safeguards individuals from discrimination and facilitates the commodification of genetic information, revealing the inherent tension between protective intent and market-oriented outcomes.

The focus on *genetic exceptionalism* in policymaking may lead to gaps in antidiscrimination efforts. While these laws aim to prevent unfair treatment based on genetic predispositions, they often do not extend to individuals who face similar discrimination due to chronic illnesses, disabilities, or other health conditions. In doing so, they fail to integrate genetic protections into a more comprehensive anti-discrimination framework (Rothstein, 2008). Moving forward, a more inclusive policy approach that considers genetic information alongside other health and social factors would be necessary to ensure equitable protections for all individuals, rather than reinforcing distinctions between genetic and non-genetic conditions that are socially and legally constructed rather than inherently meaningful. This observation raises speculative but important questions for future research. While current genetic non-discrimination statutes (e.g., GINA, GNA) are narrowly tailored to genetic information, there is a broader debate in legal and philosophical scholarship about the scope and purpose of anti-discrimination protections.

Scholars like Fredman (2011) have argued that anti-discrimination law is historically rooted in rectifying specific forms of structural oppression (e.g., race, gender, disability), often justified by historical injustices and entrenched power imbalances, which *may* not apply to inheritable or biologically influenced characteristics, including genetic predispositions to certain diseases or conditions ("traits"). Similarly, Khaitan (2015) cautions against expanding protected characteristics without rigorous normative justification to avoid diluting the remedial purpose of such laws. While this caution might appear to support narrow laws and reinforce genetic exceptionalism, it is more accurately interpreted as a call for careful reasoning: protections should target clear social harms and remedial goals rather than automatically extending to all traits. Future work could explore whether and how genetic predispositions could be integrated within a more unified anti-discrimination framework, or whether their treatment under "exceptionalist" models

remains conceptually warranted. This also invites engagement with the literature on health and the *limits* of anti-discrimination law in addressing health inequities (Kirkland, 2025; Fredman, 2011), and broader critiques of rights-based approaches in health justice (Farmer, 2004).

There are intrinsic risks to legal frameworks that manifest and reproduce genetic exceptionalism. Specifically, genetic-specific laws emphasize the stigma of genetic disorders by treating them differently from non-genetic conditions and ignore the underlying social problems (Rothstein, 2005, p. 30). Genetic anti-discrimination policies aim to protect individuals from exclusion in employment, insurance, and healthcare while fostering participation in genetic research. However, the legislative focus on genetic exceptionalism highlights genetic determinism and neglects broader social and environmental health factors, as mentioned earlier.

Anti-genetic discrimination legislation provides some protection for individuals to undertake genetic testing, which is a key component of individual autonomy in health decisions and contributes to genomics data repositories for risk calculations. Exploring genetic discrimination using theoretical understandings of discourse helps illuminate how ideas like genetic exceptionalism and genetic reductionism, patient empowerment, and rational individuals diffuse into legislative efforts. These legislative frameworks, while formally instituted to prevent genetic discrimination, simultaneously entrench a regulatory architecture that privileges market expansion and individualized responsibility over collective rights and structural reform (Rose, 2007; Pistor, 2019). By framing protections through the lens of individual autonomy and consumer choice, such policies shift the burden of risk management onto individuals, obscuring the broader social and institutional determinants of health disparities (Rothstein, 2005; Krieger, 2005). In Chapter 4, I build on this critique by analyzing the discursive practices through which these

regulatory logics are stabilized and reproduced—via industry advocacy, professional organizations, media narratives, and policy consultations (Birch & Tyfield, 2013; Mamo & Fishman, 2013).

To summarize, this analysis explores how ethical discourse is operationalized not to challenge power imbalances but to legitimize market-oriented reforms, converting ethics into a governance tool that facilitates the commodification of genetic information (Petersen, 2015). As described, far from serving purely protective purposes, anti-discrimination policies function as key components of the bioeconomy, providing legal certainty and ethical legitimacy to the commercial exploitation of genetic data (Jessop, 2007; Birch, 2022). This chapter argued that such dual policy considerations—protection and facilitation—are integral to neoliberal health governance, where ethical principles are increasingly subsumed under bioeconomic rationalities. The following chapter extends this critique by tracing how genetic discrimination is constructed, contested, and negotiated across legal, media, and professional domains, revealing the co-production of ethical justifications and market imperatives (Fairclough, 1995; Pistor, 2019).

Chapter 3. THEORY AND METHODOLOGY

3.1) Overview

In this chapter, I will discuss in detail the key theoretical perspectives that inform my approach for analyzing genetic discrimination laws, GINA and GNA, alongside the methodological assumptions and data sources underpinning my research. Building upon existing insights into the social construction of genetic information and its commodification (Rose, 2007; Reardon, 2017; Gibbon & Novas, 2008), and applying theories of Fairclough and Pistor, my research demonstrates how genetic discrimination is framed and regulated within legal frameworks, public discourse, and media representations. Specifically, I analyze the conceptualization and regulation of genetic discrimination to reveal how legal, institutional, and media discourses construct and govern this issue by mobilizing concerns around the concepts of genetic privacy, risk, and fairness (Pistor, 2019; Salter & Salter, 2017). This analysis is situated within broader ideological contexts, including genetic exceptionalism (Rothstein, 2004), market rationality to foster biotechnology (Rose, 2007; Jessop, 2002), and biomedical innovation (Novas & Rose, 2000).

Drawing on CDA (Fairclough, 1995; Wodak & Meyer, 2009), I examine how language and discursive practices within legal frameworks, public discourse, and media representations both reflect and reproduce broader power structures. By analyzing public perceptions alongside the legal codifications of genetic discrimination (Pistor, 2017; Bridges et al., 2017; Sherwin, 2011), my dissertation illuminates how laws, policies, and cultural narratives interact to shape societal attitudes and legislative responses. In particular, the research focuses on how the discourse

surrounding genetic discrimination and its legal regulation constructs norms, legitimates market-oriented policies, and embeds neoliberal ideologies within healthcare governance.

In the previous chapter, I introduced the literature on genetic and anti-discrimination frameworks, examining both protective and market-oriented perspectives. Building on this, a broader review of the literature reveals that, from an anti-discrimination or human rights perspective, the laws under consideration primarily focus on safeguarding individuals against certain forms of genetic or health-related discrimination, while from a market perspective, they simultaneously aim to facilitate the development and commercialization of genetic technologies. Taken together, this preliminary analysis suggests that the scope of these laws is relatively narrow, reflecting selective attention to specific dimensions of protection (e.g., prohibiting employment or insurance discrimination) and market facilitation (e.g., enabling the use and exchange of genetic information in research or commercial contexts). At this level, it also appears that the laws are shaped by broader neoliberal and market-oriented ideologies, privileging certain economic and individual rights considerations over more expansive social or ethical concerns. This framing sets the stage for the next section, where Fairclough's and Pistor's theoretical approaches will be employed to examine more deeply how law can be commodified and shaped through discursive and institutional processes. This chapter sets the foundation for the subsequent analysis by outlining the theoretical lenses, methodological strategies, and data sources.

3.2) Theoretical perspective

In this section, after introducing Pistor's (2019) framework as well as my critical understanding of the neoliberal discursive framing of biotechnology, I will explain how I will integrate and apply Fairclough's CDA in this dissertation. Through an institutional lens, my

analysis also explores how institutional actors such as governmental agencies and professional bodies contribute to the creation of these legal texts and what institutional interests drive the development of legal texts such as GINA, GNA, and related policies. These legal texts are not simply legislative artifacts but are the products of complex institutional processes in which regulatory agencies, expert committees, and advocacy coalitions play central roles. For instance, in the U.S., federal bodies such as the NHGRI, the Department of Health and Human Services (HHS), and the Equal Employment Opportunity Commission (EEOC) contributed scientific and ethical justifications that informed the scope of GINA (Rothstein, 2008; Hudson et al., 2008). As Petersen (1996) indicates, institutions increasingly govern through the regulation of individual conduct, encouraging self-regulation and personal responsibility. Advocacy groups, most notably the Coalition for Genetic Fairness, were instrumental in lobbying for the Act by framing genetic discrimination as both a public health and civil rights issue (Hudson et al., 2008). Similarly, in Canada, the passage of GNA was driven by sustained advocacy from the Canadian Coalition for Genetic Fairness and shaped by debates within federal and provincial institutions about jurisdiction and constitutional authority (Knoppers & Joly, 2018). Professional bodies such as the American College of Medical Genetics and the National Society of Genetic Counselors also helped translate clinical and scientific concerns into policy priorities, highlighting the institutional interplay between medical expertise, legal infrastructure, and political action.

Katharina Pistor is a prominent legal scholar, widely recognized for her interdisciplinary work at the intersection of law, finance, and economics. Pistor (2019), in her book *The Code of Capital: How the Law Creates Wealth and Inequality,* examines how legal systems contribute to the creation and distribution of wealth, particularly through the structuring of financial markets and property rights, and offers a framework for understanding how legal systems transform assets

into capital by coding them with protections and privileges. This framework helps identify how legal coding processes facilitate the commodification of genetic data, with attention to the institutional actors who participate in shaping policy and law.

Pistor (2019) offers a granular account of how *legal coding* through contracts, property rights, trusts, collateral law, and corporate structures endows assets with critical attributes such as priority, durability, convertibility, and universality. These attributes make assets suitable for integration into financial markets and accumulation processes. This legal-institutional lens is particularly powerful when examining intangible assets such as genetic data, which are not inherently ownable or tradable. Through intellectual property regimes, privacy laws, and data contracts, such information is legally coded into investable capital. Thus, Pistor's framework is essential for understanding not only how capital is constructed and maintained but also how legal regimes underpin the commodification of biosocial life in the genomic era.

Pistor (2019) argues that capital is constituted through the legal coding of assets, transforming anything from land to data into capital through institutionalized legal protections. According to Pistor (2019, p. 2), capital is composed of two essential elements: an asset and its legal coding. Pistor (2019, pp. 6-8) shows how modern legal systems have evolved to serve mobile capital rather than local democratic accountability, allowing actors to "code capital" across jurisdictions. While the asset can be anything, tangible or intangible, such as land, ideas, or financial claims, it is the process of legal coding that transforms it into capital by selectively granting attributes such as priority (legal recognition above others), durability (protection over time), universality (enforceability across contexts), and convertibility (capacity to be exchanged or generate economic value) (Pistor, 2019, p. 3).

As Pistor (2019) argues, these attributes are not inherent in the assets themselves but are conferred through legal coding, through a modular and adaptable set of legal devices, including contract law, property law, collateral frameworks, and corporate structures. These types of legal modules can operate much like a computer code, combining to grant certain assets superior legal protection and enforceability. This legal code is enforced by the state, which makes the legal devices' power both formidable and consequential, especially in times of crisis when competing claims over assets emerge (Pistor, 2019, pp. 15–16).

Pistor's conception aligns with broader sociological understandings of capital as theorized by Bourdieu. For Bourdieu (2018), capital is not a singular economic resource but exists in multiple forms—economic, cultural, social, and symbolic—all of which are convertible and deeply embedded within institutional structures. Social capital, for instance, consists of networks and social relationships that provide individuals with access to resources and opportunities. Cultural capital, particularly in its embodied form, is tied to the individual's body and dispositions, and requires time and personal investment to acquire. In its objectified state—such as books, instruments, or artworks—it derives its value only in relation to embodied cultural capital. When institutionalized, through mechanisms like academic credentials, cultural capital becomes formally recognized and can be exchanged or converted into economic capital. As Bourdieu puts it, capital is "accumulated labor that, when appropriated on a private, that is, exclusive, basis by agents or groups of agents, enables them to appropriate social energy in the form of reified or living labor" (2018).

In this sense, Pistor's framing of capital as a legal construct parallels Bourdieu's assertion that capital is not merely a material resource but an institutionalized form of power that derives its

value from systemic structures of validation and control. The key distinction lies in the locus of institutionalization: while Bourdieu emphasizes the symbolic and cultural mechanisms through which power is reproduced, Pistor foregrounds the constitutive role of legal infrastructures. For Pistor, the law does not simply reflect economic relations but actively constructs them by selectively endowing assets with the legal attributes necessary for wealth creation. This includes not only priority, durability, universality, and convertibility, which give asset owners a guarantee to convert their asset into state money when they can no longer find private takers (Pistor, 2019, pp. 7–14). Importantly, these legal codes remain largely invisible during times of normalcy and only come to the fore in moments of economic distress—when, for example, liabilities exceed assets, and not all claimants can be made whole (Pistor, 2019, pp. 15–16).

Institutional economists like Veblen define capital as an asset's "income-yielding capacity," and Commons emphasizes that capital relies on the legal expectation of beneficial behavior from others, such as enforceable claims on future returns (Pistor, 2019). Despite their valuable insights, Pistor (2019) argues that Veblen and Commons do not fully capture the active role of law in constituting capital, and she makes explicit how legal systems create, enforce, and stabilize these expectations, transforming assets into tradable, income-generating instruments with recognized rights and future value. Other similar theoretical frameworks, including Marxist value theory, Science and Technology Studies, and Actor-Network Theory, also offer valuable insights into processes of commodification, the socio-material construction of knowledge, and the distributed agency of technological systems (Marx, 2024; Haraway, 1997; Latour, 2005).

Marx, for instance, illuminates the transformation of ordinary objects, including labor, into capital through processes of commodification, driven by surplus value extraction and rooted in

class-based social relations. However, as Pistor (2019) argues, Marx correctly identifies that commodification is man-made but underestimates the "legal coding" required to complete this transformation, particularly the role of legal institutions in endowing assets with enforceable rights and future income potential. Similarly, Haraway (1997) emphasizes the co-construction of humans and technologies, showing how knowledge and scientific practices are deeply entangled with social and material relations, which shape what can be commodified or valued. Latour (2005), through Actor-Network Theory, further illustrates how agency is distributed across both human and non-human actors, highlighting that technological systems, scientific objects, and legal frameworks collaboratively enact the processes by which assets acquire economic and social significance.

Just as Marx identifies commodification as a social process but underestimates the role of legal structures, Haraway and Latour highlight that knowledge, objects, and technologies are produced and valued through networks of human and non-human actors, but they do not fully account for how legal frameworks formalize these valuations into enforceable rights or tradable assets. Pistor's analysis (2019), therefore, bridges this gap by showing that the transformation of socio-technical networks into capital requires deliberate legal infrastructures that assign property rights, regulate exchanges, and stabilize future income potential. Yet these insights, while foundational, often remain at a general level and lack the modular legal specificity Pistor provides. In the view of the author, they lack the legal-institutional specificity necessary to account for how intangible assets like genetic data can be rendered ownable, tradable, and investable. In contrast, Pistor (2019) provides a detailed account of how legal coding endows assets with qualities that enable their integration into circuits of accumulation. Thus, her legal coding framework is essential for understanding not only how capital can be constructed but also how legal regimes are essential to the commodification of biological material in the genomic era.

Pistor's perspective is useful in analyzing the capitalization of genetic information, where legal instruments such as intellectual property rights, contracts, and data protection regimes function as codifying mechanisms that secure control and future value extraction. This work expands on Pistor's line of analysis to explore the legal coding of genomic-specific legal instruments, namely GINA and GNA.

As Pistor (2019) notes, even human labor and ideas, typically excluded from traditional definitions of capital, can be transformed into capital through *legal engineering*. Freelancers may capitalize their labor by incorporating themselves, while ideas are commodified through IP law, illustrating how law enables the conversion of non-capital into capital (Pistor, 2019, pp. 11–13). Similarly, genetic data—whether derived from individuals, populations, or biobanks—can be transformed into capital assets when encoded with legal rights, including patents on gene sequences, licensing agreements, or data ownership claims. This matters because these legal codifications not only determine who can access and profit from genetic information but also shape the priorities and inequalities within healthcare and research. As will be discussed, even legislation aimed at protecting individuals from discrimination can simultaneously facilitate the commercialization of genetic data, illustrating the tension between protective intent and market-driven outcomes.

This conversion exemplifies what Pistor (2019, pp. 4–6) describes as the *legal code of capital*, where legal tools are used not only to recognize property but to engineer its longevity, transferability, and monetization. Genetic material, for example, when framed through IP and contract law, is no longer just biological information—it becomes an asset that can be traded, licensed, securitized, or used as a basis for speculative investment (Pistor, 2019, pp. 113-120).

Legal coding ensures that this data can be partitioned, shielded from external claims, and subjected to rent-generating schemes, particularly in the biotech and pharmaceutical industries (Pistor, 2019, pp. 124-129). In this way, the legal infrastructure does not merely facilitate scientific advancement—it actively shapes the assetization of life.

Moreover, it should be mentioned that as genetic information is increasingly stored, processed, and commodified in digital form, the digital coding of law becomes central (Pistor, 2019, pp. 183-189). Digital coding refers to the structuring and management of data through software architectures, algorithms, and platform infrastructures, which govern how genetic information is accessed, shared, and utilized. In this sense, digital coding shapes the lifecycle of genetic data, including how it is reprocessed, analyzed, and integrated into decision-making systems. The convergence of these two forms of coding occurs when digital platforms rely on legal protections, such as patents, licensing agreements, or contractual permissions, to regulate the circulation and monetization of genetic information. As Pistor (2019, p. 186) notes, mastering digital coding allows actors to operationalize the legal code of capital, effectively embedding market logic into digital infrastructures and facilitating the commodification of genetic data.

Legal coding is now interacting with digital code, raising important questions about who controls the rules of access, exchange, and ownership in the data economy. “In other words, legal rules might be embedded in the technology itself, potentially reducing the relevance of overt legal infrastructure such as statutes, regulations, or court-enforced contracts in governing data access, exchange, and ownership. The rise of digital platforms for storing and processing genomic data illustrates how digital architectures now co-determine the economic life of genetic assets (Pistor, 2019, pp. 218–222). Smart contracts, algorithmic governance, and data access protocols are all part

of this new regime, where legal and digital codes converge to create new opportunities for capitalization but also new asymmetries in power and access (Metcalf & Sadowski, 2024).

As introduced in the preceding chapters, my dissertation examines how legal and policy frameworks aim to protect individuals from potential harms associated with genetic information while simultaneously enabling its commercial and scientific use. In this context, digital technologies have made genetic data increasingly traceable, portable, and interoperable across platforms, raising new questions about privacy, consent, and the management of risk. Consumer-facing tools—such as direct-to-consumer (DTC) genetic testing kits and wearable health devices—integrate into broader digital health infrastructures, facilitating the continuous generation, tracking, and exchange of genomic data (Prainsack, 2017; Phillips, 2016). These technologies simplify the submission of biological samples, the receipt of results, and the sharing of data, often with limited awareness of downstream uses or long-term implications. As Lupton (2016, 2013a) notes, such tools foster *self-tracking modes* embedded within regimes of *dataveillance*, where personal data—including genetic profiles—are monitored, predicted, and regulated under the guise of individual empowerment and optimization. By situating these technological developments within the broader legal and policy landscape, this discussion highlights the risks that protection-focused legislation seeks to address, setting the stage for analyzing how laws mediate the tension between individual safeguards and broader commercial or research interests.

Platforms like 23andMe and AncestryDNA illustrate how digital coding transforms genetic information into both research and commercial assets, integrating tracking mechanisms, analytics, and predictive modeling to generate behavioral insights and marketing value (Benjamin, 2019; Mozersky et al., 2021). Once uploaded, genetic data enters a dynamic digital lifecycle, constantly

reprocessed, reinterpreted, and recontextualized by algorithms, researchers, or third-party partners (Wachter et al., 2017). Because genomic data is inherently unique and durable, it is particularly vulnerable to reidentification, and digital traceability amplifies these risks by making data linkages faster and harder to detect (Knoppers & Joly, 2018). Moreover, the normalization of API-based access and smart-contract permissions means that individuals may lose meaningful control over how their data circulates, even when platforms claim user consent and transparency (Zuboff, 2023).

These practices exemplify how digital coding creates new forms of risk—to privacy, autonomy, and equitable use of genetic information—and highlight why legal coding and protective legislation (such as GINA or Canada's GNA) have become necessary. In other words, the very capacities that make genetic data valuable for research, innovation, and commercial purposes also generate vulnerabilities that protective laws aim to address, situating this discussion squarely within the study's broader themes of risk, protection, and the regulation of genetic information in a market-oriented context.

Applying Pistor's framework more directly, if we view this type of genetic information as a form of *capital*, it is being *legally coded* to offer *protection* to individuals, while the simultaneous commodification of it through instruments like patents serves the interests of the biotechnology and healthcare industries. Genetic data is basically information derived from an individual's DNA that reveals inherited traits and health predispositions. By legally coding genetic data as a valuable and protected asset, for instance, GINA protects individual rights and facilitates the collection of genetic data, which is key for the development of personalized medicine.

The legal codification of genetic data through intellectual property law illustrates how scientific discoveries can be transformed into privatized forms of knowledge, generating new

enclosures of biological information. As Pistor (2019, p. 130) notes, the patenting of genetic sequences exemplifies how legal engineering converts biological materials into sources of private wealth, effectively transforming them into a form of capital. In the biotechnology sector, patents have allowed corporations to monopolize access to genetic information by securing exclusive rights to diagnostic methods, synthetic DNA sequences, and other genomic tools. A salient example is the BRCA1 gene, associated with increased risk of breast and ovarian cancer and identified through publicly funded research. While naturally occurring genes themselves cannot be patented, companies such as Myriad Genetics were able to obtain patents on the cDNA sequences and screening tools used to detect BRCA1 mutations.

This distinction relies on the judicially created "product of nature" doctrine, which maintains that unmodified elements of nature are not patentable, whereas inventions resulting from human intervention—such as synthetically created or isolated sequences—can be (Conley & Makowski, 2003; Conley, 2009; Lucchi, 2013). Under this doctrine, the line between discovery and invention hinges on human agency: anything made, altered, or isolated through human intervention falls within the scope of patentability, while naturally occurring entities remain outside it (Lucchi, 2013). However, as Conley and Makowski (2003) observe, this doctrine has produced considerable legal ambiguity and inconsistency, particularly concerning isolated genes and DNA sequences, as courts have struggled to define precisely when isolation transforms a natural substance into a patent-eligible invention.

The practical implications of this ambiguity were profound. By securing exclusive rights to cDNA sequences and associated testing methods, companies like Myriad Genetics restricted the number of laboratories that could offer BRCA1 screening services, allowing the company to charge

high prices and exercise substantial control over access to critical health information. This situation exemplifies how legal codification can privatize knowledge originally generated through public funding, creating barriers to access and raising ethical and social concerns. More broadly, these dynamics illustrate the process through which scientific developments—when encoded within legal frameworks—become economic assets, requiring regulatory attention not only to govern commercial interests but also to protect individuals from discrimination, inequity, and restricted access to healthcare resources.

Pistor's discussion of intellectual property rights and the enclosure of knowledge is also particularly relevant to laws to ban genetic discrimination, which I examined in my dissertation. Pistor (2019), particularly in the chapter titled "*Enclosing Nature's Code*", explains how litigation battles over gene patents and diagnostic tools have framed genetic material as an *asset* rather than a shared scientific resource. As described by Pistor (2019, pp. 113-116), the expansion of intellectual property rights through patents and patent litigation has allowed corporations to monetize genetic information while limiting access for researchers and patients. Legal systems thus assign exclusive rights to genetic sequences through gene patenting, for instance, privatizing knowledge that was once considered part of the "natural world" (Pistor, 2019, pp. 120-121).

This legal codification process effectively privatizes forms of knowledge and biological material that were once considered part of the public or natural domain. A salient example, discussed by Pistor (2019, pp. 112–114), is the case of Association for Molecular Pathology v. Myriad Genetics, Inc. In this landmark 2013 case, Myriad Genetics held patents on the BRCA1 and BRCA2 gene sequences, mutations of which are strongly associated with increased risk of breast and ovarian cancer. These patents granted the company exclusive rights not only to isolate

the genes but also to develop and commercialize diagnostic tests based on them. This legal monopoly potentially enabled Myriad to restrict other laboratories from conducting similar tests, thereby controlling access to critical health information and generating substantial revenue. The case illustrates how legal coding through patent law can transform naturally occurring biological sequences into proprietary, income-generating assets.

While the U.S. Supreme Court ultimately invalidated Myriad's gene patents in the 2013 case, ruling that naturally occurring DNA cannot be patented, the case remains emblematic of how legal infrastructure can potentially enable the capitalization of genetic knowledge, even when such claims provoke significant ethical, legal, and social controversy. Importantly, the Myriad case demonstrates that even when legal claims are ultimately struck down, the process of legal coding itself reveals how law can be structured to convert knowledge and biological material into assets, shaping who can access, control, and profit from genetic information. This dual policy consideration—to enable commercialization while simultaneously prompting debates about protection, equity, and ethics—highlights the tension at the heart of genetic regulation: laws are not only instruments of protection but also mechanisms that facilitate market-oriented uses of scientific knowledge, illustrating the intertwined processes of assetization, regulatory oversight, and neoliberal governance.

Critical understanding of the neoliberal discursive is also a key starting point for my analysis (Jessop, 2005; Birch, 2006). As just described, Pistor's (2019, p. 7) analysis of legal coding indicates that law acts as an enabler of capital mobility and wealth concentration, and diagnostic and therapeutic technologies based on genomic knowledge have driven industrial aspirations to patent scientific discoveries and market these new technologies. These efforts

include both marketing strategies of direct-to-consumer genetic testing strategies by biotechnology companies and public health programs to educate and increase awareness, for example, about cancer, and such diffuse genomic knowledge into society (Matloff & Caplan, 2008). The sequencing of the human genome and subsequent genetic research produce material consequences, such as the development of personalized medicine, gene editing technologies, and genetically driven diagnostic and therapeutic tools (Collins et al., 2003; Rose, 2007; Jasanoff, 2005; Hood & Rowen, 2013; Juengst et al., 2016). These innovations not only reflect scientific progress but also reshape social institutions, healthcare practices, and ethical frameworks, demonstrating the co-production of science and society.

Based on these subsequent actions, genetic healthcare discourse is constructed through powerful linguistic representations that emphasize progress, inevitability, and necessity. Phrases such as the "knowledge-based bio-economy (KBBE)," the "biotech revolution," and the "transformative potential of genomics" convey a sense of technological inevitability and the naturalization of market expansion (Hilgartner, 2007; Gottweis, 2005; Fortun, 2008; Birch, 2017). The advancements in genetics are framed as essential and inevitable responses to contemporary challenges, such as ageing populations, chronic diseases, and environmental sustainability (Rose 2007; OECD, 2009a; Tutton, 2016).

Yet these transformations are not purely technological or scientific; they are deeply embedded in legal infrastructures that enable the capitalization of genetic information. As Pistor (2019) argues, it is not innovation alone that turns ideas or biological matter into capital, but the legal coding that inscribes these with the four attributes of proprietary rights, priority, durability, universality, and convertibility. In the digital age, this transformation is amplified through

simultaneous digital coding, which increasingly governs the access, circulation, and monetization of genomic data. For example, digital platforms and biobanks—organized repositories that collect, store, and manage biological samples and associated data for research and clinical purposes—as well as algorithmically driven diagnostics, rely on both legal protections (such as patents and licensing agreements) and software architectures to structure control over genetic assets (Kaye et al., 2009). Together, legal and digital codification processes underpin the assetization of genetic material, facilitating its transformation into speculative capital within bioeconomic markets (Pistor, 2019).

This process reflects a distinctly neoliberal discursive orientation, in which law and technology actively reframe biological material as marketable property and legitimate objects of investment. Genetic science is thus narrated not only as a natural response to global challenges but as an economic opportunity structured through juridical and digital infrastructures that normalize market expansion into the life sciences (Brabazon, 2016; Jessop, 2002). At the same time, the extent to which genetic resources are successfully capitalized remains contingent upon these coding practices; without legal and digital inscription, their translation into capital assets would be impossible.

The narrative of inevitability and innovation in genomic discourse that emerges out of the discursive construction of genetic knowledge as a solution to challenges in public health and economic growth is not merely symbolic. These discursive frames play an instrumental role in preparing the ground for legal and institutional interventions that enable the capitalization of genetic resources. This is where Pistor's (2019) theory of legal coding is particularly useful. Again,

Pistor argues that *capital* is not an inherent quality of an asset but is *constructed* through legal mechanisms that endow it with certain attributes.

The discursive construction of genetic knowledge as a vital solution to public health and economic development legitimates the use of legal infrastructures to transform genomic information into proprietary, income-generating assets. The genomic bioeconomy that emerges at the intersection of discursive, digital, and legal coding is therefore shaped not only by how knowledge is framed but also by how it is operationalized through technology and law. While discursive coding shapes public perception and institutional priorities, digital coding facilitates the technical implementation of these priorities, such as automated data access rules, algorithmic governance, and networked exchanges, effectively embedding certain legal and economic logics within technology. Legal coding assigns enforceable rights and obligations, enabling private actors to control, commodify, and extract value from genetic data.

Following Pistor (2019), the rise of digital coding does not replace legal coding; the coercive authority of the state and the legal system remain crucial for scaling social and economic relations beyond tight-knit groups. Digital code may operationalize or enforce rules, but the underlying decisions it encodes are still fundamentally shaped by legal frameworks. Private law, backed by the state's coercive powers, allows parties to turn genomic data and related knowledge into capital, assets that generate secure, tradable wealth, while providing flexibility in organizing exchanges beyond immediate social networks (Pistor, 2019, p. 189). Thus, the bioeconomy relies on a tripartite coding process, but legal coding retains a central, irreplaceable role in verifying and enforcing the rules that make capital creation possible.

This coding process illustrates how assets like genetic information are rendered capital not merely by virtue of their scientific utility, but through a socially and institutionally mediated process of valuation, ownership, and control. In this way, Pistor's legal theory complements and deepens the sociological analysis of genomics by highlighting the critical role of law and legal infrastructure in institutionalizing market relations around biological life, all of which has direct implications for how genetic data is governed, accessed, and commercialized. For example, the structuring of legal rights over genomic information shapes who can collect, use, and profit from such data, while discursive and digital coding influence public perception, institutional priorities, and the technical mechanisms through which data flows and transactions occur. Together, these intersecting coding processes illuminate how the genomic bioeconomy is constructed, maintained, and contested across scientific, social, and legal domains.

As discussed in Chapter 2, transformations in healthcare under a neoliberal economic model are often framed through the language of competitiveness, innovation, and efficiency (Lupton, 1995), emphasizing market-driven rationales for policy and practice changes. This model has compelled governments, healthcare institutions, and medical professionals worldwide to adopt new approaches to medicine, healthcare delivery, and the integration of emerging technologies into medical practice. Health policy began to align with what Gottweis et al. (2009) describe as a "*global techno-managerial paradigm*," which highlights market-driven solutions, efficiency, and the application of techno-scientific innovation to healthcare. As Tutton (2016, p. 10) clarifies, "*initiatives such as the British Government's introduction of personal health budgets for people with chronic illness with the aim of enabling them to customize their own health management*" illustrate how neoliberal principles are reshaping healthcare systems. Fairclough, whose theory is discussed in more detail below, would describe this as a managerial example, as it reflects a shift

toward individualized governance, responsibility (Fairclough, 2002), and the use of technocratic tools for optimizing care delivery. It should be noted, however, that this also resonates with market-oriented logics by introducing consumer-like choice into public services. As a result, publicly funded healthcare systems increasingly functioned as extensions of the market, where technical tools became central to the delivery and understanding of care.

I contend that managerial discourse is consistent with a neoliberal discourse. While this literature underscores a broad sociopolitical transformation in healthcare, its relevance to my dissertation lies in how it frames the discursive and legal conditions under which genetic discrimination laws have emerged. The construction of genomics as an efficient, innovative solution to healthcare challenges, emphasized by proponents such as Khoury et al. (2009), helps legitimize both its integration into public health and the creation of legal frameworks that support its commercialization. This is where Pistor's (2019) legal theory of capital and Fairclough's (1992, 2003) CDA provide essential analytical tools. Pistor's framework helps explain how legal infrastructures support this discursive shift by coding genetic information as capital. The neoliberal emphasis on innovation and efficiency legitimizes the use or creation of legal mechanisms, such as data ownership rights, contractual consent frameworks, and privacy regimes, that enable private actors to control and profit from genetic data. Laws that prohibit genetic discrimination, while ostensibly protective, may also function to stabilize public trust and maintain the legitimacy of expanding data markets, particularly when framed through discourses of individual rights and equality- more fully examined below.

Alongside these market-oriented reforms, public services such as healthcare were actively positioned by state actors, international policy organizations (e.g., the OECD, WHO, and European

Commission), and public–private partnerships as key platforms for embedding scientific and technological innovation into everyday life (Stirling, 2008; Jasanoff, 2004). These actors framed healthcare not merely as a site of care delivery, but as a strategic domain for promoting national competitiveness, biomedical innovation, and economic growth (OECD, 2009a; Rose, 2007; Tutton, 2016). The biomedical-economic growth (OECD, 2009a) positioning reflects a broader neoliberal logic in which public institutions are reimagined as facilitators of market expansion and innovation networks (Mazzucato, 2013; Jessop, 2005; Birch et al., 2010). In the context of genomics, this shift enabled the integration of genetic technologies into healthcare under the guise of modernization, cost-effectiveness, and individualized care—discursively aligning public health objectives with the economic imperatives of the bioeconomy (Tutton, 2016; Birch, 2017; Green et al., 2023).

Applying Pistor, by naming these institutional actors, such as biotechnology corporations, financial institutions, government agencies, regulatory bodies, legal institutions, healthcare providers, and patients, we can uncover the political and economic interests that underlie the integration of emerging technologies into health systems. This enriches the sociological analysis and complements and unlocks the second theoretical framework: Fairclough's CDA. Fairclough's CDA helps to trace how institutional language constructs the alignment between biomedical innovation, market priorities, and healthcare governance as a natural or expected outcome, even if it is not necessarily inevitable or universally desirable. Pistor's legal theory elucidates how such discursive framing is operationalized through legal infrastructures that render genetic information a capitalizable asset that, in turn, provokes additional legal responses to address emergent inequalities.

By framing patients as self-responsible consumers within healthcare markets, these reforms exemplify how genetic discrimination laws operate within and reinforce the discursive and legal structures of a neoliberal political economy (Rose 2007; Clarke et al. 2003; Lupton 2012). These shifts are not merely empirical developments but are deeply embedded in discursive and legal structures. Building on Pistor (2019), these legal frameworks reveal the contested process of transforming genetic information into commodifiable assets. Policymakers, legal authorities, and industry actors collectively shape the conditions under which market priorities can take precedence over public health concerns. By leveraging patents and proprietary technologies, biotechnology firms exert significant influence over healthcare practices, controlling access to genetic data in ways that advance commercial objectives.

The trajectory toward individualized healthcare mentioned earlier involves multiple legal and institutional mechanisms, including intellectual property law, as well as the coordinated actions of diverse actors—biotechnology corporations, governments, legal institutions, healthcare providers, patients, policymakers, and industry stakeholders. Applying Pistor's (2019) framework, this shift reflects a transformation in power relations within the healthcare sector, as diagnostic tools, screening technologies, and gene-based treatments increasingly rely on genetic information. Biotechnology corporations, through patents and proprietary technologies, effectively convert patients into data subjects, rendering their genetic information a form of capital (Waldby & Mitchell, 2006; Cooper & Waldby, 2014). This transformation can generate new inequalities, as access to gene-based treatments may be limited by intellectual property regimes, high costs, or other barriers (Pistor, 2019). These developments are not neutral; they are also discursive choices that reproduce hegemonic ideologies—particularly neoliberalism—by embedding scientific

innovation within market logic and promoting the commodification of healthcare through both digital and legal coding.

I conduct a CDA of legal responses to genetic discrimination, drawing on Fairclough's methodology to identify the dominant genres, discourses, and styles that shape the development of personalized medicine within the framework of a knowledge-based political economy. Fairclough's CDA provides a way to analyze not only the language of individual texts but also how those texts are situated within, and contribute to, broader social processes. This involves examining legislative documents, professional publications, and media sources to understand how they mediate and represent the policy environment.

As Fairclough (1995, 2003) emphasizes, discourse analysis goes beyond describing linguistic features; it investigates how language both reflects and shapes social practices. A central concept in his approach is the "order of discourse"—a network of social practices through which particular ways of acting, representing, and being are organized and maintained. CDA thus moves back and forth between detailed textual analysis and the examination of this wider order of discourse. Within this, "interdiscursive analysis" is a key tool for exploring how elements of genres (ways of acting), discourses (ways of representing), and styles (ways of being) are combined within texts to achieve specific effects. In Fairclough's framework, the relationship between social structures (semiotic systems or languages) and social events (texts) is mediated by social practices (orders of discourse). Social fields, institutions, and organizations are, in turn, constituted as networks of such practices (Fairclough, 2013, p. 11). This approach makes it possible to trace how the discourse around genetic discrimination is constructed, contested, and stabilized across

different institutional and communicative contexts, and how it serves broader political-economic imperatives.

In short, Fairclough's CDA provides insights into how texts are shaped by linguistic structures and social practices. This approach enables a deeper understanding of the complexities surrounding genetic discrimination and the regulatory efforts aimed at addressing it within contemporary societies heavily dependent on mediated communication (Fairclough, 2003). Specifically, CDA methodology facilitates a multi-layered analysis of texts—ranging from legislative documents to professional publications and media sources—highlighting how these texts actively construct and mediate social practices and *power relations*. Given the complex and mediated nature of genomic governance, where scientific, legal, and economic interests intersect, Fairclough's CDA provides the tools to critically interrogate how discourses *produce and reproduce inequalities* and regulatory strategies. It thus enables a nuanced understanding of how genetic *discrimination* is framed, contested, and managed within contemporary societies increasingly reliant on mediated communication and market logics. Because of that, this dovetails with the application of Pistor's theory, which focuses on assetization. With CDA, the focus is on the legal and policy texts as they pertain to genetic discrimination within the ideological and institutional contours of neoliberal governance (Brown, 2015; Rose, 2007).

Indeed, employing Fairclough's framework facilitates a nuanced analysis of how diverse genres—encompassing legislative statutes, regulatory instruments, and media representations—interact with distinct discourses such as risk management, individual empowerment, and the commodification of genetic data (Fairclough, 2003; Lemke, 2011). Furthermore, it enables the interrogation of stylistic features that vary across these texts, from the formalistic register of legal

language to the more persuasive and accessible tone of public communication (Fairclough, 2013). The concept of the "order of discourse" proves instrumental in situating these textual practices within broader socio-institutional networks encompassing biomedical research, legal regulation, and market-driven health governance (Pistor, 2019; Rose, 2007). Consequently, Fairclough's CDA offers a robust methodological lens through which to elucidate the complex ways in which language functions not merely as a passive reflection but as an active agent in the production and reproduction of power relations and ideological constructs within the regulatory landscape of genetic discrimination (Fairclough, 1995a; Lemke, 2011).

It is also important to note that Fairclough (2001a, 2003) emphasizes that discourses are not isolated but are shaped by other social practices and structures reproducing or challenging the social order. CDA, in this context, aims to uncover how discursive practice, the processes through which texts are produced, distributed, and consumed within social contexts, has a role in defining and regulating social practice (Fairclough, 2001a, 2003). This approach views social reality as conceptually mediated, with objects of critical social analysis understood as both material and semiotic in nature (Fairclough, 2001a, 2003, 2013). Fairclough's approach highlights that existing social realities are not merely given but are humanly constructed constraints, shaped and sustained through discourse. It also foregrounds the ideological nature of discourse (Fairclough, 2013). Consequently, the critique of ideology lies at the heart of CDA (Fairclough, 2018). This is particularly relevant in the context of capitalist economies, which depend on continuous growth, as this is inherent to the nature of capital. However, it is not only the actual pursuit of growth that is essential; equally important is the widespread discursive belief that such growth is necessary, an assumption so deeply embedded that it appears self-evident and beyond critique, mere common sense (Fairclough, 2018, pp. 45–47). For instance, policies to cut public expenditure and public

services entail material–structural factors associated with the character of capitalism, but they also entail semiotic factors such as the causal power of common sense that help bring about the material effects (Fairclough, 2013).

By applying CDA to texts such as the GINA and GNA, this project demonstrates how these laws are embedded in and contribute to neoliberal ideologies that prioritize market logic, individual responsibility, and data commodification, while obscuring structural inequalities and collective rights. Thus, Fairclough's framework enables a critical unpacking of how genetic antidiscrimination law functions not only as a legal instrument but also as a discursive practice that shapes social realities under neoliberal capitalism.

Furthermore, Fairclough (2001a, p. 128) explains genres that regulate action and interaction in organizations, including neo-liberal economic discourses internationally disseminated and enacted by organizations; he also elaborates the styles of key figures in the new capitalist order, such as entrepreneurs and political leaders. Fairclough et al. (2002) explain the resonance of emergent semiotic properties within orders of discourse using the illustrative example of Blair's *White Paper On Competition*, according to which the government must promote competition, stimulating enterprise, flexibility, and innovation by opening markets as a response to new technologies. Similarly, one can consider how investments into human genetics have been facilitated and fostered within and through neo-liberal discourses in a knowledge-based economy that relies on high-growth sectors, including biotechnology (Jessop, 2002, 2005, 2007). In this sense, the legal coding of capital is best understood as operating within, and being reinforced by, the broader discursive orders described by Fairclough (2001a) and Jessop (2002, 2005, 2007). The neoliberal genres and styles that circulate through organizational practices and policy texts provide

the legitimating narratives through which legal mechanisms acquire their social force (Fairclough, 2001a; Fairclough et al., 2002; Jessop, 2002, 2005, 2007). What Pistor (2019) identifies as the constitutive functions of law—granting assets durability, priority, convertibility, and universality—do not occur in isolation but are discursively sustained within a knowledge-based economy that valorizes competition, innovation, and growth.

The concept of a knowledge-based economy indicates qualitative change in economies and societies such that economic and social processes are knowledge-driven and designed to remove obstacles to the new economic order, which is also discourse-driven (Fairclough, 2001b). These legal and policy frameworks to promote this economic model can be seen as part of the broader shift toward a Schumpeterian competition state, in which the role of governance is to foster technological innovation and competitiveness rather than merely regulate or protect (Jessop, 2002). In this sense, regulatory efforts to ban genetic discrimination, namely GINA and GNA, can be understood as being primarily discourse-driven and aimed at preventing potential barriers for individuals to undergo genetic testing, which is crucial for the advancement and discoveries in the biotechnology sector. While such an interpretation risks suggesting an inevitable trajectory where discourse analysis merely reflects the unfolding of neoliberal logics, CDA should not be reduced to a method that advances a theory of inevitability. Rather, as Chouliaraki and Fairclough (2010) emphasize, CDA is a mode of critical inquiry in which theory and methodology are inherently linked, providing tools for investigating how discourses are constituted, contested, and stabilized. This makes CDA not simply descriptive of dominant discourses, but also a framework that can account for the dialectics of discourse and social practice, illuminating spaces of resistance and alternative articulations. In this regard, CDA can be viewed as a theory-informed method (Chouliaraki & Fairclough, 2010) that allows the analysis of how legal frameworks like GINA and

the GNA both reinforce neoliberal knowledge-economy discourses and simultaneously open up terrain for contestation around genetic information, privacy, and equity.

These laws not only aim to mitigate fears of discrimination that might otherwise dissuade individuals from participating in genetic testing, as discussed further below; rather, through applying CDA, we see how they can also function to construct a normative framework that encourages individual compliance and trust in biotechnological innovation. As examined in the following analysis, by framing genetic testing as a safe and non-discriminatory practice, these legal instruments can help to remove social and institutional barriers that might otherwise hinder the flow of genetic data essential for research, development, and commercialization in the biotechnology sector. In this sense, anti-discrimination laws may operate not solely as protective measures but also as strategic discursive tools that align with the knowledge-based economy's imperatives for growth and innovation. Forthcoming chapters will explore how such measures embed genetic testing within neoliberal discourses of personal responsibility, risk management, and consumer empowerment by aligning public perceptions with the economic interests of biotech industries while managing potential social resistance. This discursive framing, as will be demonstrated, plays a central role in facilitating the expansion of biotechnology as a high-growth sector by encouraging individual participation and enabling the accumulation of genetic data as a valuable economic asset (Jessop, 2005; Fairclough, 2001b; Pistor, 2019).

To summarize, Fairclough's CDA also offers a framework for examining how language shapes and reflects social power, ideology, and inequality within society. CDA is not just a method for analyzing language but a broader lens for understanding how language both reflects and highlights social structures. Fairclough (1989: p. 22) explains that CDA operates on the premise

that language is inherently "socially constitutive and socially shaped," meaning that texts do not exist in isolation but instead contribute to the formation and maintenance of social identities, relationships, and systems of knowledge. This theoretical perspective critically informs the present research, which again analyzes legal and policy texts addressing genetic discrimination within the context of neoliberal governance and knowledge economies (Brown, 2015; Rose, 2007). Employing Fairclough's CDA enables a comprehensive interrogation of how diverse textual genres—including legislative instruments, regulatory frameworks, and media narratives—intersect with discourses that emphasize risk management, individual responsibility, and the commodification of genetic information (Fairclough, 2003; Lemke, 2011). Moreover, this framework facilitates the analysis of discursive styles ranging from the highly formalized language of legal texts to the more accessible and persuasive rhetoric employed in public communication (Fairclough, 2013). The concept of the "order of discourse" is especially instrumental in situating these texts within expansive networks of social practices that encompass biomedical research, legal regulation, and market-driven health governance (Pistor, 2019; Rose, 2007). Consequently, Fairclough's CDA provides a critical methodological lens that elucidates the dynamic processes through which language functions as a constitutive element of power, ideology, and social inequality—processes that are central to understanding how regulatory discourses both reflect and reproduce neoliberal logics within the governance of genetic discrimination

The three-dimensional approach of Fairclough (1989, 1995a) will also be used to identify how legislative texts, media coverage, and professional publications *mediate* public debates and policy decisions surrounding genetic discrimination. *Textual analysis* examines how single words and grammatical formulations participate in the construction and reconstruction of social structures (Fairclough, 2003). *Discursive practice analysis* examines the processes through which the

production, distribution, and consumption of texts come into being. *Social practice* explores the connection between discursive practice and society, where both discursive and non-discursive elements are identified, and the focus is on how social practice challenges the existing order of discourse (Fairclough, 1993; 2003). These processes are perceived as a form of social practice, forming a link between the text and the social surroundings.

3.3) Methodology and Data Collection

In the following sections of this chapter, I introduce the methodological approach of CDA after outlining its theoretical underpinnings. I will explain how CDA is applied to legislative texts, policy documents, and media representations to uncover the ideological structures embedded in legal discourses on genetic discrimination. This approach operationalizes the theoretical framework of this work combining Pistor's theory of legal coding and Fairclough's CDA to critically examine how dominant ideologies are embedded in legal texts, policy documents, and media representations and to engage with the central research question: How do specific legal frameworks and public discourses surrounding genetic discrimination in North America reflect and reinforce neoliberal ideologies and the commodification of genetic information?

My dissertation employs a qualitative research design, using Fairclough's CDA, and examines features of specific legal and policy texts for the linguistic and rhetorical, such as vocabulary, framing, modality, and intertextuality to uncover how dominant discourses around genetic risk, personal responsibility, and innovation are produced, circulated, and legitimized within broader neoliberal structures of governance. Pistor's (2019) framework of legal coding serves as the second methodological pillar, enabling a critical examination of how the specific legal mechanisms (including statutory language, regulatory frameworks, and property rights) function

to transform genetic information into capital assets and embed them within market-driven health systems.

Rather than collecting primary data through surveys or interviews, my research is situated within CDA and draws on a purposive sample of publicly available legislative texts (e.g., GINA and GNA), federal and provincial policy documents related to genomics and personalized medicine (e.g., CGS, Health Canada white papers, and CIHR policy frameworks), advocacy publications from organizations such as the Canadian Coalition for Genetic Fairness, and media sources including national news coverage, opinion editorials, and public education materials. These documents are treated as data because, within the CDA tradition, discourse is not limited to spoken or interview-based language but includes all forms of text that reflect and reproduce institutional ideologies and power structures (Fairclough, 1995; Wodak & Meyer, 2016). By analyzing how genetic risk, innovation, and responsibility are framed across these particular genres, I interrogate how law and policy shape social meaning and reinforce neoliberal approaches to genetic governance (Fairclough, 2003, 2013; Jessop, 2005). The decision not to engage directly with individual actors, such as patients, clinicians, or policymakers, is a deliberate one, rooted in both epistemological and ethical considerations.

Again, Fairclough's CDA (1993, p. 135) refers to an approach that systematically examines the often-hidden connections between language use, such as texts, events, and discursive practices, and broader social and cultural structures. This method investigates how discourse both emerges from and is shaped by power dynamics and ideological struggles. It also considers how the obscured nature of these connections helps to sustain power and reinforce dominant norms. Accordingly, this analysis can help us understand how public health campaigns, corporate

advertising, and media representations construct genetic literacy as a form of *civic duty,* pressuring individuals indirectly to engage with genetic testing and personalized health strategies (Rose, 2007; Prainsack, 2017). Being framed as empowering, this practice can inadvertently lead to moralizing judgments where individuals are held accountable for genetic risk factors beyond their control (Reardon, 2017).

As a methodological alternative, CDA facilitates a nuanced examination of how subjectivities, social relations, and institutional formations are discursively produced, stabilized, and contested within legal, policy, and media texts, obviating the need for direct engagement with research participants. Within this framework, subjectivity is conceptualized as the contingent and historically situated positioning of individuals within discursive regimes that render them intelligible as, for example, responsible genetic subjects or entrepreneurial health consumers—positions that are constituted through interpellative practices and anchored in broader ideological formations (Foucault, 1980; Butler, 1997; Fairclough, 2003). Social relations are approached as discursively mediated configurations of power and hierarchy that are enacted, legitimized, or resisted through language, and that structure access to resources, authority, and recognition (van Dijk, 2009; Wodak & Meyer, 2016). Similarly, institutions are understood not merely as static bureaucratic entities, but as sedimented discursive constructs that derive authority and coherence through the iterative performance of linguistic and symbolic practices (Laclau & Mouffe, 2014; Fairclough, 1992). Through the application of CDA, I research how these dimensions are articulated in texts that govern genetic information, revealing how market efficiency, self-responsibilization, and techno-scientific progress are embedded in, and reproduced by, the legal and discursive infrastructures of genomic governance. As Wodak and Meyer (2016) point out, CDA is particularly well-suited to uncovering "*discursive practices that construct, maintain and*

legitimize social inequalities" (p. 2). By focusing on institutional and legal texts, this method provides an on-point critical framework for exploring how dominant ideologies, such as neoliberalism, genetic exceptionalism, and individualized risk management, are stabilized and disseminated through public discourse.

This approach is also appropriate given my focus on the regulation and commodification of genetic information, since these issues are deeply embedded in legal and institutional language. As Titscher et al. (2000) note, qualitative discourse analysis is especially effective in cases where the objective is to understand how abstract social phenomena, such as biopolitical governance or legal rationality, are encoded in language and shape collective imaginaries and practices. Widdowson (1998, pp. 368-369), who warns that CDA analysts may conflate their own interpretations with objective meaning and risk imposing ideological readings onto texts, states that its value lies in its ability to expose how power and ideology become naturalized in institutional discourse. Engaging directly with individuals might offer insight into lived experience, but it would not necessarily illuminate perspectives on the institutional configurations and ideological logics that structure genetic governance at the legal-policy level (Fairclough, 1989; Wodak & Meyer, 2016).

Moreover, CDA provides a way to account for the power-driven nature of language in shaping subject positions, such as the "empowered patient," the "responsible consumer," or the "at-risk subject" notions. Without assuming that individuals passively absorb discourse, CDA situates these subjectivities within broader social and institutional arrangements. As van Dijk (2009, p.78) states, discourse analysis enables researchers to examine how ideologies are "*discursively reproduced in ways that are often taken for granted or rendered invisible*".

CDA is suited to uncovering hidden sub-discourses and institutional preoccupations that may not be explicitly stated in texts but still guide the reader's perception. Fairclough (1995a) highlights how sub-discourses (which are not the main focus of a text) can reveal important tensions, exclusions, and silences. This is particularly relevant in the context of genetic discrimination, where issues like consent, data ownership, or racial and socioeconomic disparities may be downplayed or rendered invisible. These silences are not merely incidental; they reflect ideological operations that sustain dominant biomedical and neoliberal framings of genetics. For instance, the rhetoric of patient empowerment often masks structural inequalities and obscures the limited agency many individuals have over how their genetic data is collected, shared, and commercialized (Lemke, 2011; Tupasela, 2007). Similarly, discussions around consent frequently overlook the power asymmetries between individuals and institutions, particularly in contexts where genetic data is extracted under broad or opaque terms (Cohen, 2012; McGuire & Beskow, 2010; Brown & Baker, 2012). Fisher (2013) argues that the conventional notion of voluntary consent fails to consider how structural and socio-economic forces limit true autonomy, resulting in what the authors term "*structural coercion*" that challenges the legitimacy of consent in such contexts.

Moreover, racialized populations may be disproportionately targeted or excluded in genomic research, reinforcing systemic inequities under the guise of scientific neutrality (Benjamin, 2019). The absence of these dimensions from dominant discourses underscores Fairclough's point: what is left unsaid can be just as revealing—and politically consequential—as what is explicitly articulated. As Cummings et al. (2020, p. 100) point out, CDA's activist dimension is also significant: by critically examining existing discourses, the method supports the identification of new narratives and arguments that can counteract "social wrongs." In this case,

CDA both helps analyze how genetic discrimination is constructed in policy and informational materials and also provides a pathway to envisioning more inclusive and equitable alternatives in genetic governance.

I employ Fairclough's (1989, pp 110-111) ten questions for my textual analysis framework, which provides a structured approach to analyzing lexical choices, grammatical structures, and textual organization. Through an analytic approach outlined in Table 1, in this chapter, I explore how language is used to define risks, enforce compliance, and allocate responsibility within genetic privacy laws and associated policy publications.

Analytic question as per Fairclough (1989)	**Application**	**Analytic implications**
	Sentence-level analysis	
The experiential value of words: how lexical choices reflect particular worldviews or ideologies	Examine the classification schemes that are drawn upon in these legal texts and how terms like "genetic privacy," "discrimination," "protection," and "consent" are used to construct genetic testing as a risk or a right.	Whether and how genetic information is framed as an inherently vulnerable category of data requiring strict legal protection and/or as a resource that should be managed by individuals and institutions.
Rewording or overwording: when certain terms appear excessively or repetitively to emphasize particular ideas	Repeated references to "safeguards," "rights," and "privacy protections" in legal documents may indicate an emphasis on government responsibility, whereas an overuse of terms like "informed consent," "voluntary participation," or "self-monitoring" might shift the burden onto individuals.	

Ideological significance of meaning relations (e.g., synonyms, antonyms)	Analyzed to determine whether texts contrast "protection" with "risk," or "privacy" with "openness"	Differing policy priorities can be assessed
Who is assigned agency (and/or is it unclear?)	Agency is unclear in the legal framework when laws use passive constructions devoid of specific actors, which obscure responsibility, whereas phrases like "the government prohibits employers from requesting genetic data" assign explicit institutional agency.	Passive formulations can contribute to an "impersonal authority" that distances responsibility from regulatory bodies.
Nominalization: a process that turns actions into abstract nouns	E.g., "the collection of genetic data" instead of "employers collecting genetic data."	This grammatical feature can create a sense of inevitability or neutrality, making policies appear as natural facts rather than social or political decisions. In examining whether processes are what they seem, this study explores whether and how genetic discrimination is framed as an unintentional consequence of genetic testing practices rather than an act of deliberate exclusion by insurers or employers.
Modality: the degree of certainty or obligation expressed in a text, particularly through the use of modal verbs such as "must," "shall," "may," and "should."	Legal texts may use high-modality expressions like "shall not" and "prohibited", which indicate strict enforcement, or whether they rely on weaker formulations like "should ensure" or "are encouraged to comply", which suggest voluntary adherence.	The strength of legal language shapes how binding and enforceable protections against genetic discrimination appear in different contexts.
Expressive modality: the degree of speaker (or legal text) commitment to a claim.	If a legal text states, "Individuals may experience discrimination in the absence of regulation," it implies a possibility rather than certainty, making the issue seem less urgent. In contrast, if the law asserts, "Without regulation,	Examining these variations provides insight into how serious genetic discrimination is constructed as a policy problem.

	genetic discrimination will occur," it makes a stronger, more definitive claim.	
Relational modality: who is addressed and how relationships between institutions and individuals are framed.	How legal texts position different actors, government agencies, employers, insurers, and individuals by analyzing the use of pronouns such as "we," "you," and "they." For instance, the use of "we" in advocacy documents (e.g., "We must protect genetic privacy") fosters collective responsibility, while phrases like "The government shall ensure compliance" emphasize institutional authority.	Reflects how power dynamics are established.
Connection value of text: how closely social actors are integrated within the protective framework	How a text structures the inclusion or exclusion of social actors within frameworks of protection and responsibility. For instance, in GNA, the frequent use of passive voice in phrases like "discrimination shall be prohibited" removes clear agents of enforcement, which distances institutional actors from responsibility. The absence of explicit subjects such as "the government" or "regulators" in key provisions minimizes the state's role and emphasizes individual action. This linguistic choice positions individuals as autonomous managers of their genetic data, reinforcing the notion that protection is a personal duty rather than a collective or institutional obligation.	Reflects how authority and responsibility are redistributed among social actors within institutional texts.

Neutral expressions	For example, an insurance policy stating that "genetic test results may be considered in certain underwriting processes" obscures the fact that insurers might deny coverage based on genetic risk factors.	Neutral expressions soften legal restrictions or obligations. Identifying these linguistic strategies helps reveal the extent to which genetic privacy laws genuinely protect individuals versus allowing room for industry discretion.
Analysis of the structure of a text		
How sentences are linked together	Whether texts rely on coordination (e.g., "Employers must not collect genetic data, and individuals have the right to privacy") or subordination (e.g., "Although individuals have the right to privacy, insurers may still request certain health data").	The latter structure qualifies or weakens the strength of genetic privacy protections by making them contingent on other conditions.
Logical connectors (e.g., "therefore," "however," and "in contrast")	If a law states, "Genetic discrimination is a growing concern; therefore, legislation is necessary," it presents regulation as a direct and necessary response to a problem. However, if a text says, "While genetic discrimination is a concern, industry self-regulation has been effective," it suggests that formal legal intervention may not be needed.	Helps identify how arguments are framed

In sum, by applying Fairclough's ten key questions in this chapter, I examine how genetic discrimination is defined, how responsibility is assigned, and how policy solutions are framed within legal and advocacy texts. The analysis explores whether and how legal discourse highlights individual responsibility or promotes institutional accountability, whether and how protections are framed as absolute rights or conditional safeguards, and whether and how laws employ strict mandates or leave room for discretionary compliance.

Although I do not include interviews or ethnographic engagement, it does not treat texts as detached from social practice. On the contrary, a three-dimensional framework (Fairclough, 1992, 2003) links texts to the discursive and social contexts in which they are produced and consumed. In this way, my dissertation configures its methodological approach around a critical analysis of institutional discourses that shape, and are shaped by, the political economy of genetic data. This approach aims at providing insights into systemic inequities and the commodification of health without relying directly on personal narratives.

In doing so, this research brings pressing issues into focus. The increasing responsibilization of individuals under genetic risk discourse, the privatization of genomic knowledge, and the structural inequalities in access to emerging biotechnologies are often overlooked when studies center primarily on individual experiences or perceptions with an emphasis on insurance and employment discrimination as part of the received positive law (Rose, 2007; Lemke, 2011; Benjamin, 2019; Joly et al., 2013). This narrower focus can obscure broader political-economic and institutional forces shaping genetic governance, including data commodification, racial inequities, and neoliberal health reforms. This methodology enables my research to explore how law and policy are discursive sites where power, market logic, and ethical tensions converge beyond being regulatory instruments.

In other words, the use of Fairclough's CDA as a methodological framework offers more than a tool for dissecting language. It provides a critical lens through which to reveal how power operates through discourse. CDA's three-dimensional model of textual analysis, discursive practice analysis, and social practice analysis enables this research to examine what is said in legislation and policy texts, who produces it, how it is received, and what broader societal structures it

highlights or challenges. This methodological approach is particularly appropriate for a study of genetic discrimination, as the regulation of genetic data is shaped by legal language that appears neutral or technical on the surface in spite of immense ideological and political implications embedded in it (Fairclough, 2002).

Social practices are networked together, and social events are causally shaped by networks of social practices. Social practices define particular ways of acting, and although actual events may more or less diverge from these definitions and expectations (because they cut across different social practices, and because of the causal powers of social agents), they are still partly shaped by them. The way practices are networked together can change over time. For example, in British universities, the practices of management have begun to dominate traditional practices of teaching (Fairclough, 2003, pp. 23-24). Importantly, these networks are not static; they are historically and ideologically contingent, subject to reconfiguration over time. This observation is crucial for understanding how neoliberal ideology has restructured the field of genetic governance. Neoliberalism, characterized by its emphasis on market rationality, privatization, individual responsibility, and the minimization of state intervention, increasingly conditions the organization of social practices, including those within healthcare, law, and science (Brown, 2015; Rose, 2007). Fairclough's framework allows us to trace how these ideological shifts are discursively realized: legal texts, public communications, and institutional policies recontextualize genetic testing practices in ways that privilege consumer choice, data ownership, and individual accountability, while backgrounding concerns related to equity, collective rights, or structural vulnerability (Prainsack, 2018). This transformation mirrors Fairclough's example of how managerial practices have come to dominate traditional academic ones in British universities, illustrating how one set of social practices can marginalize others within a shifting ideological terrain.

Modern societies involve the chaining and networking together of different social practices across various domains of social life (e.g., the economy, education, family life) and across different scales (global, regional, national, local) (Fairclough, 2003). Social events are causally shaped, though not absolutely determined, by these networks. Texts play a crucial role in these networking relations, as the orders of discourse associated with social practices specify particular chaining and networking relationships between different types of text. This conceptualization is directly applicable to the analysis of genetic discrimination legislation. Laws such as GINA and GNA do not operate in isolation but are embedded within broader discursive and institutional networks that link biomedical science, legal governance, and economic practices. These texts (legal statutes, regulatory guidelines, public communications) are not merely reflective of policy intentions; they are active sites where the logic of neoliberal governance has materialized. Through textual analysis, one observes how genetic data is framed not only as a site of risk and protection but also as a marketable asset and a responsibility of the individual, revealing a discursive convergence between legal norms and market rationality (Rose, 2007; Pistor, 2019).

The transformations of new capitalism can be seen as transformations in the networking of social practices, including changes in discourse orders and in the chaining and networking of texts and genre chains. The process of globalization has further intensified this phenomenon, enhancing the ability of certain actors to shape the actions of others across time and space. This capacity increasingly depends on complex processes of textual mediation and the interplay of diverse text types, facilitated by new communication technologies such as the Internet. The power to mediate and control these processes has become a key dimension of contemporary power structures. In this regard, Fairclough's concept of *networking social practices* is particularly evident in the case of genetic healthcare, where discursive and institutional forces converge to shape the regulation,

communication, and distribution of genomic knowledge and access. The governance of genomic technologies is not confined to the biomedical domain; rather, it involves a complex interplay of legal, economic, and media discourses that collectively shape how genomic knowledge is produced, disseminated, and accessed. For instance, legal frameworks such as GINA and the GNA do not simply prohibit discrimination—they also normalize a discourse of individual risk management and responsibilization, aligning healthcare practices with market logics of insurance, cost-efficiency, and data commodification (Rose, 2007; Pistor, 2019; Lemke, 2011).

CDA also recognizes the role of discourse in constituting subject positions such as the empowered patient, the responsible consumer, or the at-risk individual, which are central to how genetic testing is promoted, legislated, and received. Through this methodology, I am able to explore how these subjectivities are constructed in law, advocacy documents, and media narratives, and how they reflect and reproduce broader neoliberal rationalities. For example, by analyzing grammatical constructions such as active/passive voice and modality in legal texts, I examine the distribution of agency and responsibility across different actors, either on patients, institutional actors, or the state. CDA has sometimes been criticized for being interpretive in nature and for its potential for researcher bias (Breeze, 2011). This project mitigates such limitations by grounding the analysis in interdisciplinary literature and drawing connections across multiple levels of texts, including legal, institutional, and media, such as the GINA and GNA. The inclusion of Pistor's theory of legal coding also strengthens the methodological approach by offering a macro-level understanding of how legal systems materially shape markets, institutions, and the social life of genetic data.

The choice of CDA as a methodology helps analyze existing discourse and also to critically evaluate the ideologies that legitimize certain legal structures and regulatory approaches. It focuses on the socially constructed nature of legal texts and their role in normalizing specific ways of thinking about genetic risk, privacy, and discrimination. Through this lens, law can be examined as a dynamic and contested discursive site where societal values, scientific knowledge, and economic interests meet.

Analyzing genetic laws through the lens of CDA allows us to uncover how legal discourses align with and emphasize institutional power structures. For instance, laws governing access to genetic technologies often mirror and reproduce the priorities of the biomedical industry, public health authorities, and government agendas. These discourses may prioritize population-level health surveillance, biomedical innovation, or commercial interests over individual rights or community-based ethics. By examining these texts, CDS scholars can identify how dominant narratives, such as those emphasizing genetic determinism or bioeconomic utility, become institutionalized through legal language, marginalizing alternative ways of understanding genetics, such as Indigenous knowledge systems or disability perspectives.

Furthermore, a CDA approach highlights how genetic laws help to naturalize and legitimize social inequalities under the guise of scientific objectivity and legal neutrality. For example, discourses around consent, data ownership, and genetic privacy often assume a liberal, individualist subject who has the power and knowledge to navigate complex legal frameworks, an assumption that excludes structurally disadvantaged populations. By interrogating the language of these laws, CDA exposes how certain forms of citizenship, health, and identity are normalized while others are rendered invisible or problematic. In doing so, it enables a more reflexive and just

approach to policymaking that accounts for the socio-political implications of genomic governance.

The inclusion of materials at each analytical level was methodologically guided by the purpose of uncovering how discourses on genetic discrimination are constructed, circulated, and embedded within broader social structures. At the micro-level (textual analysis), legislative texts such as the GINA and GNA, along with official explanatory policy pamphlets, were selected to expose how linguistic formulations shape the normative understanding of rights, responsibilities, and protections, thereby providing insight into the institutional codification of genetic privacy within formal governance structures. For the meso-level (discursive practice analysis), the selection of advocacy group publications, professional association position papers, and media coverage was justified by their role in mediating between formal legal texts and broader public discourse. These materials were included because they actively participate in the production, circulation, and consumption of discourse, often influencing policy debates and shaping public sentiment. By focusing on organizations such as the Canadian Coalition for Genetic Fairness, the American Society of Human Genetics, and key media sources, the analysis captures how various social actors interpret, contest, and reinforce legal frameworks, thus elucidating the dynamic interplay between institutional interests and public narratives. At the macro-level (social practice analysis), biotechnology sector reports, government strategy documents (e.g., CGS), and industry white papers were included to trace how genetic information becomes embedded within economic structures and policy infrastructures. These materials are justified within Fairclough's macro-level analysis as they illustrate how discourse connects to wider political-economic arrangements, particularly through the commodification and assetization of genetic data. Including these texts facilitates a critical examination of how neoliberal market logics are naturalized in the governance

of genetic technologies, how innovation is prioritized over equity, and how bioeconomic imperatives shape regulatory frameworks.

First, textual analysis will be used to examine the linguistic and rhetorical features of documents such as the GINA and GNA, as well as media articles and policy pamphlets. This includes attention to lexical choices, modality, transitivity structures, and grammatical formulations that construct meanings around risk, privacy, and individual responsibility (Fairclough, 2003). Second, the discursive practice dimension will focus on the intertextual and interdiscursive processes through which these texts are produced, circulated, and consumed. For example, I analyze how media representations of genetic testing recontextualize scientific discourse, or how policy pamphlets draw from both legal and commercial genres to construct the genetic subject as an informed consumer. This level of analysis considers how texts draw upon and reshape existing discourses (e.g., patient empowerment, biosecurity, neoliberal individualism) and genres (e.g., law, public health communication, journalism) (Fairclough, 1995a; 2003). Third, the social practice dimension will explore the broader socio-institutional and ideological contexts in which these texts are situated. This involves analyzing how regulatory discourses on genetic discrimination are embedded in neoliberal rationalities, particularly in relation to biocapital, basically the process by which biological materials and information are transformed into economic assets within capitalist markets, the assetization of genetic data, and individualized risk governance (Reardon, 2017; Birch, 2017; Rose, 2007; Pistor, 2019). Here, both discursive and non-discursive elements (such as institutional structures, economic interests, and political strategies) will be considered to understand how regulatory practices surrounding genetic information reinforce or contest dominant power relations and the existing order of discourse (Fairclough, 1993; 2003).

Through analysis of these three levels, Fairclough's CDA provides a robust framework for examining the relationship between texts, social events, and the structural elements of society—particularly as they relate to the discursive construction of genetic discrimination in contemporary governance. Fairclough (2001a, 2003) argues that texts are not merely the products of linguistic structures but are also shaped by broader social practices and institutional configurations. Networks of social practices, including legal, biomedical, and economic practices, define particular ways of acting, representing, and being, and are central to how power is enacted and sustained in discourse. In the case of genetic discrimination, texts such as legislative frameworks (e.g., GINA, GNA), policy pamphlets, and media representations are shaped not only by their linguistic composition but also by wider contextual forces—economic interests in biotechnology and data markets, prevailing cultural norms of self-responsibility, and ideological commitments to market-based health governance.

By employing Fairclough's three-dimensional model—textual analysis, discursive practice, and social practice— I critically investigate how regulatory texts construct the genetic subject as an autonomous, risk-managing actor, while also embedding these constructions within broader neoliberal discourses of the knowledge-based economy (Jessop, 2005; Fairclough, 2001b). At the textual level, the analysis focuses on how key lexical and grammatical choices in legal texts reflect ideological assumptions about empowerment, risk, and consumer choice. At the level of discursive practice, I explore how these texts are produced, circulated, and interpreted across institutional settings such as health ministries, biotech firms, and media outlets, revealing how legal and scientific discourses are hybridized to legitimize policy directions. Finally, at the social practice level, the research interrogates how these discourses are situated within and contribute to broader social structures—particularly the neoliberal imperative to eliminate regulatory "barriers"

to innovation and data accumulation in the biotechnology sector. Following Fairclough (2001a), this research thus aims to uncover dominant discourses that shape the development of genomic medicine under the banner of the knowledge-based economy and to analyze how these discourses are operationalized in regulatory efforts that ostensibly aim to prevent genetic discrimination but may, in fact, reproduce structural inequalities under the guise of neutrality and progress.

Fairclough's approach to CDA places emphasis on connecting micro-level textual analysis, such as vocabulary, grammar, and sentence structure, with macro-level social contexts and ideologies. Fairclough (1989: pp.113-120) outlines how examining vocabulary choices can reveal underlying ideologies, as even neutral vocabulary can reveal the ideological stance of the author and convey implicit power relations. For example, in the analysis of legislation or media texts on genetic discrimination, rhetorical or textual choices such as "protection" versus "restriction" or "right" versus "safeguard" can indicate whether the text frames genetic information as a personal asset, a privacy issue, or an economic commodity. Fairclough (1989: pp.120-132) also highlights grammar and sentence structure by indicating that active versus passive constructions can highlight or hide agency, which shapes how responsibility and power dynamics are perceived. This structural choice is important when examining legislative language around genetic discrimination, where the subject position can significantly influence the interpretation of responsibility and authority within the text. Fairclough (1989: p.112) introduces three concepts of "experiential," "interactional," and "expressive" values within texts, which help analysts assess how language constructs identities, relationships, and viewpoints. *Experiential value* pertains to how language choices reflect the producer's perspective on reality and the ideological framing of information. In the context of genetic discrimination acts like GINA and the GNA, experiential value manifests in the ways legislation frames genetic information as both a private right and a potential risk requiring legal

protection. For example, in GINA, the phrase "genetic information shall be maintained on separate forms and in separate medical files and be treated as a confidential medical record" highlights an implicit assumption that genetic data is inherently sensitive, reinforcing the idea that it requires exceptional handling compared to other personal data.

Interactional value relates to how texts establish and maintain social relationships between different groups, often by indicating authority, obligation, or deference. In legal texts, interactional value is reflected in the use of imperatives and modal verbs that dictate permissible actions. In GINA, for instance, the provision "No employer shall request, require, or purchase genetic information with respect to an employee" envisions a hierarchical dynamic between employers and employees, reinforcing the employee's right to privacy. This structure indicates that the state, acting through the law, positions itself as the final arbiter in employment practices. Furthermore, the use of legal prohibitions highlights the power relations between the law as enforcer and the regulated parties. An example of identifying interactional value in a text can be seen in the GNA's statement: "*It is prohibited for any person to require an individual to undergo a genetic test*". Here, the passive construction "It is prohibited" avoids direct attribution of responsibility, making the legal principle appear as an objective, universal truth rather than a directive issued by a governing authority. This linguistic choice highlights the legitimacy of the law while downplaying any potential resistance from stakeholders who might contest these regulations.

Lastly, *expressive value* indicates the attitudes, stances, or evaluations embedded in a text, often reflecting implicit judgments or ideological positions. In GINA and the GNA, expressive value can be found in the use of terms such as "discrimination" and "protection." These words evoke strong ethical connotations, framing genetic privacy as a fundamental right that must be

safeguarded against unethical corporate or institutional actions. For instance, the phrase in the GNA, "*Every employee is entitled not to undergo or be required to undergo a genetic test*", expresses a stance that genetic privacy is an absolute right rather than being just a regulatory requirement. The use of "entitled" indicates a positive value of individual autonomy, aligning the legislation with broader human rights discourses. Together, these values shape how the acts construct genetic privacy, positioning the state as a protector of individuals while defining corporations and employers as entities that must be regulated. By examining the linguistic choices in these Acts through the lens of experiential, interactional, and expressive values, it is possible to see how power, agency, and ideological stances are embedded within legal discourse. This reveals how legal language not only codifies rights and responsibilities but also subtly constructs hierarchies of authority, legitimizes particular institutional roles, and naturalizes ideological assumptions about individual responsibility, corporate risk, and state intervention in the governance of genetic information (Fairclough, 2001a, 2003; Pistor, 2019; Rose, 2007; Tiersma, 1999).

With the concept of *semiotic mediation*, Fairclough (2003) refers to how signs and symbols, such as legal language, medical terminology, or media phrases, mediate social practices and structures. This notion is central to understanding how discourse links social structures to social practices through meaning-making. For instance, the phrase "genetic empowerment" can mediate public perceptions of healthcare responsibility, encouraging individuals to view genetic testing as a proactive personal duty, even though this aligns with broader neoliberal discourses of self-governance. Similarly, an order of discourse refers to the structured network of discourses operating within a social institution or field, such as healthcare, law, or media, that determines what is sayable and how (Fairclough, 1992). For example, in public health discourse, genetic testing is

often framed as a "preventive measure," whereas in insurance discourse, it might be seen as a "risk factor." These competing discourses reflect different institutional orders of discourse that assign meaning to genetic data depending on context and power relations. To uncover how these meanings are produced, stabilized, or contested across domains such as law, healthcare, and media, I apply Fairclough's three-dimensional CDA framework, which helps explain how language functions within and across institutional settings to sustain particular ideological positions.

Fairclough (1989: pp.120-132) also highlights grammar and sentence structure by indicating that active versus passive constructions can highlight or hide agency, which shapes how responsibility and power dynamics are perceived. This structural choice is important when examining legislative language around genetic discrimination, where the subject position can significantly influence the interpretation of responsibility and authority within the text. As I will explore in my findings chapter, in GINA and GNA, many provisions are phrased in passive constructions that remove direct agency, therefore depersonalizing responsibility and reinforcing a neutral one. For instance, GINA states that "genetic information shall be maintained on separate forms and in separate medical files and be treated as a confidential medical record." In this statement, the passive voice avoids specifying who is responsible for enforcement. This contrasts with active formulations in GNA, such as "*No employer shall dismiss, suspend, lay off or demote an employee…because the employee refused a request by the employer to undergo a genetic test*", which explicitly assigns responsibility to the employer. By constructing sentences in this way, the acts shape the perception of power relations, positioning institutions as regulators while making individual actors accountable for compliance. An example of this distinction could be: "Employers must ensure that genetic information is not misused in hiring decisions" (active) versus "Genetic

information must not be misused in hiring decisions" (passive), where the latter removes explicit responsibility.

Fairclough's CDA allows us *to examine what a text explicitly communicates and the "hidden" meanings and assumptions.* This approach is particularly useful in understanding legislative and media discourse on genetic discrimination, where language shapes public perception and policy approaches to complex issues of privacy, ethics, and economic interest. Through CDA, it is possible to uncover how these texts emphasize specific ideologies and power structures, to understand genetic discrimination better (Fairclough, 1989: p. 140). For instance, in GNA, the phrase "*it is prohibited for any person to require an individual to undergo a genetic test*" illustrates genetic privacy as an absolute and universally accepted principle, but the passive construction obscures the specific actors responsible for enforcing this prohibition, which highlights the state's authority and downplays potential resistance from insurance or employment sectors.

Fairclough (2001a) places weight on the active role of discourse in constructing the social world, and his CDA evaluates social life as interconnected networks of social practices along economic, political, and cultural dimensions; importantly, every practice has a semiotic element. The related concept of *intertextuality* (Fairclough, 1992, pp.104-106) shows how an individual text draws on and reproduces elements and discourses of other texts, combining elements from different discourses in ways that can change the individual discourses and thereby also the social and cultural world (Philips & Jorgensen, 2002, p.7). I*ntertextuality*, or how texts reference each other, helps establish authority and create continuity within a broader discourse (pp. 104-106). As I will present in my findings section, GINA-related texts frequently refer to other civil rights laws and

healthcare protections, putting GINA within a larger tradition of anti-discrimination legislation. In my analysis, I will be attentive to how GINA-related texts draw on intertextual reference to position GINA within a broader tradition of anti-discrimination and privacy legislation. For instance, references to the Civil Rights Act of 1964 and the Health Insurance Portability and Accountability Act (HIPAA) position GINA as part of a legacy of legislative protections, reinforcing its credibility (OHRP Guidance, 2018; Genetic Engineering & Biotechnology News, 2008). These intertextual connections increase the authority of GINA, establishing it as consistent with existing civil rights and privacy laws (Fairclough, 2003)

Fairclough (2013) also shows how particular conceptualizations of mediation and ideology can be accommodated within CDA. For instance, in his analysis of the World Economic Forum and neo-liberalism, Fairclough (2003) explains how the forum mediates between organization and civil society with desirable value assumptions of "choice and liberty" and "participation" among others, whereas "trade barriers" are undesirable, positioned within a neo-liberal value system. Therefore, Fairclough's analysis underscores the importance of critically examining how ideologies are perpetuated and contested through mediated discourse, offering insights into the complexities of power dynamics within socio-political frameworks. Drawing on this approach, I will be attentive to how genetic discrimination laws and related policy texts mediate between institutional actors (e.g., government, private sector, civil society) through ideologically loaded concepts such as "empowerment," "privacy," and "choice." I will examine how these discourses embed normative assumptions that reflect broader neoliberal logics, and how they may legitimize particular power relations under the guise of anti-discrimination protections.

Employing a critical socio-legal and discourse studies perspective, my research delves into legal frameworks designed to prevent genetic discrimination. As a broad framework for this work, socio-legal studies, through its cross-disciplinarity, concerns the intersections of law and society and the ways in which law and society are co-constitutive and co-existent, and therefore inseparable (Davies, 2019, p. 88). Law is not merely a reflection of existing power dynamics; rather, it actively shapes and highlights institutionalized power structures, serving as a key mechanism through which authority is maintained and exercised (Deakin et al., 2016). As Pistor (2019) argues, *legal coding* is central to the construction of economic and social hierarchies; the law selectively grants protections and privileges that define access to resources, capital, and rights. This perspective on the function of law is crucial for understanding genetic discrimination, as it highlights how legislative frameworks both reflect societal norms about what is deemed unacceptable and actively shape broader social structures by determining whose rights and interests are prioritized and protected.

Building on this foundation, I draw on Pistor's (2019) theory of legal coding to understand how legal frameworks selectively endow protections, privileges, and entitlements that stratify access to rights, capital, and resources. Law, in this view, is not a neutral arbiter but a constitutive force in producing and stabilizing economic and social hierarchies. Pistor argues that legal institutions "code" capital by assigning legal attributes—such as priority, durability, and convertibility—that transform assets into wealth, and this logic extends beyond financial instruments to encompass forms of human capital and data, including genetic information (Pistor, 2019, pp. 4–5, 42–45). This theoretical framing is particularly relevant for the analysis of genetic discrimination legislation, where legal protections ostensibly aim to guard against the misuse of genetic information but may also reproduce normative assumptions about risk, identity, and

deservingness (Lemke, 2011; Rose, 2007). Such laws do not merely prohibit certain forms of discrimination—they also participate in the broader political economy of "*biovalue*" and data governance, framing certain uses of genetic data as legitimate and others as deviant (Rajan, 2006).

By integrating this critical socio-legal approach with discourse analysis, I treat laws to prevent genetic discrimination—namely GINA and GNA—as discursive formations that reveal how concepts like fairness, privacy, and genetic risk are mobilized to construct regulatory legitimacy. Drawing on Fairclough's CDA (2003, 2013), I examine how these legal texts are embedded in wider discursive practices that normalize market-driven logics of self-responsibility and individual choice under the guise of anti-discrimination. This approach allows for a critical interrogation of how such laws function ideologically: whose interests they serve, what kinds of genetic subjectivities they construct (Rothstein, 2005; Nelkin & Lindee, 2010), and how they participate in the commodification and governance of genetic data (Benjamin, 2019; Jasanoff, 2005). Through this theoretical framework, my research critically analyzes not only what these laws prohibit, but also what they permit, prioritize, and render invisible in the legal-political architecture of the genomic era.

The law can be conceptualized as akin to a dependent variable, for instance, law as affected by other social forces, processes, and institutions, or as an independent variable, such as how the law affects other social institutions and the "acted upon" (Menkel-Meadow, 2019, p. 39). I applied Fairclough's CDA to examine how GINA and the GNA discursively construct notions of genetic risk, privacy, and fairness, situating these constructions within the broader sociopolitical and economic order. Specifically, I analyze legal texts, policy documents, and public communications as instances of social practice that embed ideological assumptions, drawing on Fairclough's three-

dimensional model (text, discursive practice, and social practice) to interrogate how legal language both reflects and shapes institutional logics. This includes identifying intertextual references to civil rights, market-based healthcare values, or privacy frameworks; tracing how genetic subjects (e.g., consumers, patients, citizens) are positioned within these texts; and critically evaluating how such positioning reinforces or contests neoliberal ideologies of self-responsibility, risk management, and data commodification.

Through this approach, I investigate not only what the law says but also how it says it, and what this reveals about the power relations, institutional interests, and social imaginaries underpinning genetic governance. Fairclough (2003) states that discourses are both shaped by and help shape social practices and structures, thereby reproducing or transforming the social order. His three-level model of CDA enables the examination of the interplay between textual features, discursive practices, and broader social structures, highlighting how meaning is constructed through socially situated processes that are both material and semiotic. Therefore, in analyzing legal responses to genetic discrimination, this methodology provides a framework to understand how texts, including legislative frameworks and regulatory efforts, are shaped by linguistic structures and various social elements such as economic interests, cultural norms, and power dynamics.

3.4) Data Sources

I analyze existing legal frameworks, GINA and GNA, aiming to unravel the underlying ideologies and discourses shaping legislative efforts in this area, by scrutinizing the interplay between linguistic structures (e.g., the vocabulary, framing, and rhetorical devices used in legal texts), social practices (such as how institutions, governments, insurers, employers—interpret and

implement these laws), and the internal logic and conventions of the legal system itself (e.g., how law codifies concepts like "discrimination," "risk," and "genetic information"), my research examines how legal language not only reflects but actively constructs social meanings and regulatory norms. This approach allows me to explore how laws against genetic discrimination operate not just as protective tools, but as discursive mechanisms that frame certain subjects as at risk, prioritize specific interests (e.g., data privacy over structural inequality), and potentially reproduce existing social hierarchies.

I will further discover and synthesize existing research evidence through a multi-step discourse analytical approach grounded in Fairclough's CDA and informed by socio-legal and political economy perspectives (Dezalay & Garth, 2002; Davies, 2019). Specifically, I will conduct a close textual analysis of key legal and policy documents—namely GINA and GNA and associated regulatory guidelines, policy briefs, and public-facing materials—to identify dominant linguistic patterns, intertextual references, and value-laden terminology that construct genetic risk, fairness, and rights. I will then situate these texts within their broader institutional and sociopolitical contexts to examine how discourses of individual responsibility, market efficiency, and data privacy are reproduced or contested across domains (e.g., legislative debates, bioethics literature, and advocacy discourse). This includes a targeted analysis of how the legal focus on insurance and employment reflects a particular framing of genetic discrimination—one that foregrounds economic harm and individual risk over structural or systemic concerns such as racial, gendered, or social disparities in genetic data governance. By mapping these discursive boundaries and their ideological underpinnings, I aim to uncover the socio-political assumptions shaping legislative priorities and how these assumptions may marginalize alternative conceptions of justice, equity, or collective rights.

This approach includes examining the reasons for and implications of the narrow focus of genetic discrimination legislation that emphasizes insurance and employment. While existing legal and bioethical scholarship has explored the development and limitations of GINA and GNA, much of this work remains doctrinal or policy-oriented, often treating the law as a static response to technological advances or narrowly focusing on biomedical ethics, individual privacy, or procedural justice (e.g., Hudson et al., 2008; Rothstein, 2005). What is often missing is a critical interrogation of the discursive and ideological foundations of these laws—how dominant narratives around risk, choice, fairness, and responsibility shape and are shaped by legal texts and institutional responses. My research is expected to help fill the gap in scholarly literature using a critical approach to antidiscrimination laws in North America, illustrating dominant and nondominant genres and discourses that diffuse into laws, using socio-legal and CDA alongside existing scholarship and empirical research, to problematize public responses to genetic discrimination, including advocacy and professional and legal responses. In this way, it is hoped that I contribute to establishing a novel approach to analyzing the legal framework of genetic discrimination in the North American context. The novelty of my dissertation lies in its interdisciplinary and critical methodological approach, which goes beyond doctrinal or compliance-focused legal analysis to treat genetic discrimination law as a discursive site where competing values and power relations are negotiated. By drawing on Fairclough's CDA and Pistor's theory of legal coding and situating these within the broader socio-political economy of genomics governance, I bring a systemic, critical, and ideologically attuned lens to the analysis of North American genetic discrimination laws.

A key data source for my dissertation includes legislation, policy pamphlets, and texts produced by lobby groups and key stakeholders, alongside a range of other materials that reflect

how genetic discrimination is constructed and contested across different discursive sites. This selection follows directly from the theoretical framework: Fairclough's CDA (1995, 2003) emphasizes the importance of analyzing how language and discourse mediate social practices and institutional power, making legislative texts, public-facing materials, and stakeholder narratives essential for tracing the ideological and institutional dimensions of genetic governance. In parallel, Pistor's (2019) theory of legal coding provides a lens for examining how legal instruments—such as statutes, regulatory documents, and advocacy outputs—serve as mechanisms through which genetic information is commodified and embedded into market systems. These texts are thus treated not merely as content but as constitutive elements of the socio-legal and economic infrastructure surrounding genetic data, enabling a critical investigation of how genetic discrimination is discursively and legally produced, justified, and resisted.

In addition, the analysis draws on 18 articles published between 2004 and 2024 from prominent mainstream news outlets. These sources were selected using a purposive sampling approach (Bryman, 2016), guided by their relevance, reach, and discursive influence in shaping public understandings of genetic discrimination and related legal and biotechnological debates. The selection criteria included: high circulation or viewership indicative of agenda-setting potential (McCombs & Valenzuela, 2020); thematic relevance to genetic privacy, antidiscrimination protections, and biotechnological regulation; and representation of both general news media (e.g., The New York Times, CBC News) and specialized science and industry publications (e.g., Genetic Engineering & Biotechnology News), to ensure both breadth and depth of discursive coverage. This sampling strategy was aimed at capturing the intersection of public discourse and institutional power, consistent with Fairclough's (1995) emphasis on analyzing media as a site of ideological production within CDA. These outlets were also selected based on

their reach and influence in shaping public discourse on genetic discrimination, legal protections, and the intersection of biotechnology and market-driven narratives. The selected articles cover legislative developments, ethical debates, industry perspectives, and the broader societal implications of genetic privacy and anti-discrimination protections.

Another critical component of this methodology involves tracing how developments in genomics and biotechnology, particularly public-private partnerships and translational research initiatives, contribute to the shifting discursive domain in which genetic discrimination is negotiated. This analytic focus is theoretically grounded in Fairclough's (1995, 2003) conceptualization of discourse as both a reflection of and a mechanism for restructuring social practices and institutional arrangements. Within this framework, biotechnological initiatives are not treated as neutral or purely technical advances but as discursive events that encode ideological positions—especially those aligned with neoliberal rationalities, such as marketization, innovation-driven governance, and responsibilized subjectivity. Concurrently, drawing on Pistor's (2019) theory of legal coding, these developments are interpreted as processes through which legal and institutional infrastructures are mobilized to convert genomic data into capital assets, often through contracts, proprietary standards, and regulatory design. For example, initiatives such as the partnership between Intermountain Health, Fabric Genomics, and the Broad Institute, which aim to integrate rapid whole-genome sequencing into clinical care for critically ill infants, illustrate the material and institutional dimensions through which genomics is embedded into healthcare systems. These case exemplars reflect technological acceleration and foreground ethical, legal, and social tensions that influence how genetic information is valued, regulated, and contested.

By incorporating such concrete examples, the methodology expands beyond legislative texts and policy statements to engage with the socio-technical infrastructures that shape, and are shaped by, legal discourse. These developments, such as translational genomics initiatives and public-private collaborations, are approached not merely as contextual factors but as discursively and institutionally productive arenas in which meanings around genetic risk, privacy, and discrimination are constructed, stabilized, or contested. Methodologically, this entails conducting a multi-layered discourse analysis that attends to how language, legal form, and institutional arrangements coalesce to produce particular normative understandings of genetic data. Drawing on Fairclough's (2003) model of CDA, the analysis interrogates both the textual features of these discourses (e.g., framing, modality, interdiscursivity) and the broader social practices they instantiate. Simultaneously, Pistor's (2019) legal coding framework is applied to examine how legal instruments, contracts, and regulatory architectures function to convert genetic information into proprietary or monetizable assets. This dual approach reveals how the commodification and normalization of genomic data not only shape public discourse but also delineate the operational boundaries of anti-discrimination protections in law.

Using Fairclough's CDA, I examine vocabulary, grammar, and structure to uncover the underlying ideologies, social assumptions, and power relations embedded within GINA and GNA. Particular attention will be paid to how these linguistic choices reflect and reproduce underlying ideologies, social assumptions, and institutional power relations. I will be especially sensitive to lexical choices that frame genetic information in terms of risk, responsibility, or consumer rights; grammatical constructions that obscure or foreground agency (e.g., use of passive voice); and intertextual references that link legal discourse to scientific, economic, or moral narratives. This approach will allow for a critical examination of how legal texts participate in constructing

normative understandings of genetic data and in delineating the scope and limits of antidiscrimination protections.

These analyses are presented in Chapter 4, after which I examine how the discourse is taken up in secondary sources, focusing on how the acts were represented and debated in the public sphere by state institutions, non-state actors, and lobby groups. These groups include the U.S. Department of Health and Human Services; *the Canadian Association of Genetic Counsellors (CAGC)*, Genetic Alliance, American Society of Human Genetics, Canadian Coalition for Genetic Fairness, Huntington Society of Canada, the Canadian Biotech Company "*Sequence Bio*", and the Biotechnology Industry Organization, among others. A brief introduction to these key actors and groups is provided below. The selection is theoretically grounded in Fairclough's (1995, 2003) model of interdiscursivity and orders of discourse, which conceptualizes discourse as constituted through interactions among multiple institutional voices operating within and across domains such as law, science, medicine, and the market. These groups represent key discursive nodes where genetic legislation is reframed for different audiences— patients, professionals, investors, or the general public—and thus offer insight into how legal meanings are socially negotiated. In parallel, this focus aligns with Pistor's (2019) theory of legal coding by illuminating the role of advocacy groups, industry actors, and professional organizations in shaping the legal infrastructure and commercial pathways through which genetic data is codified, valued, and mobilized. A brief introduction to each of these actors and their relevance is provided below.

The *U.S. Department of Health and Human Services (HHS),* established in 1953, has played a significant role in enforcing healthcare laws, including GINA. By supporting legislative efforts and public education initiatives, HHS aims to ensure that genetic information is protected and used

ethically. Through agencies such as the Office for Civil Rights and the National Institutes of Health, HHS collaborates with stakeholders to shape policies that prevent misuse of genetic data in employment or insurance contexts. This involvement is believed to align with the agency's broader mission of enhancing and protecting public health. Similarly, CAGC, founded in 1987, represents professionals providing genetic counseling services in Canada. The organization's advocacy for GNA appears designed to advance genetic counseling practices and ensure equitable access to genetic healthcare. Through collaboration with policymakers and public awareness campaigns, the CAGC highlights the role of counseling in navigating complex genetic information.

The *Genetic Alliance*, a U.S.-based advocacy group established in 1986, focuses on transforming healthcare systems through the integration of genetic research and personalized medicine. By lobbying for privacy protections and conducting public education initiatives, the Genetic Alliance aims to bridge the gap between genetic advancements and societal concerns. Its coalition of patient advocacy groups, healthcare providers, and researchers indicates a comprehensive approach centered around fostering ethical use of genetic data.

The *American Society of Human Genetics (ASHG)* is a professional organization founded in 1948 that advances research and application in human genetics. The ASHG's support for GINA and emphasis on ethical policies highlight its position on safeguarding genetic information while promoting scientific innovation. Its educational resources and advocacy efforts appear intended to ensure that both professionals and the public understand the implications of genetic data usage.

Coalition for Genetic Fairness (CGF) was formed in 1997 as a diverse coalition, including groups like the Genetic Alliance, Council for Responsible Genetics, Facing Our Risk of Cancer

Empowered (FORCE), the American Civil Liberties Union (ACLU), and many patient advocacy organizations, working together to advance a federal genetic non-discrimination law in the U.S.

In Canada, *the Canadian Coalition for Genetic Fairness* (CCGF) emerged in the early 2000s as an advocacy group against genetic discrimination. The CCGF's lobbying for GNA and its role in raising public awareness reflect their stated commitment to protecting individuals from unfair treatment based on genetic information. The coalition's partnerships with patients, healthcare professionals, and organizations are designed as a multifaceted approach to addressing genetic privacy issues.

The *Huntington Society of Canada* was founded in 1973 to improve the quality of life for those affected by Huntington disease (HD). HD is a fatal hereditary brain disorder with symptoms of Alzheimer's, Parkinson's, and ALS. In 2009, as part of the Canadian Coalition for Genetic Fairness, the Huntington Society of Canada met with policymakers on Parliament Hill to raise concerns about genetic discrimination. Representing families affected by Huntington disease, the Society advocated for stronger protections of genetic test information and the need for legislative action.

On the industry side, *Sequence Bio,* a Newfoundland and Labrador-based biotechnology company established in 2013, leverages population genetics to develop personalized medical treatments. While focused on innovation, Sequence Bio also supports protective legislation like the GNA to ensure ethical practices in research and data usage. Its transparency and advocacy efforts are designed to build public trust in genetic research.

Lastly, the *Biotechnology Industry Organization (BIO),* now the Biotechnology Innovation Organization, was founded in 1993 to represent global biotechnology stakeholders. BIO's advocacy for balanced policies that protect genetic privacy while fostering innovation illustrates its dual commitment to advancing biotechnology and addressing ethical concerns. By promoting education and collaboration, BIO states that it aims to ensure that the benefits of biotechnology are realized responsibly.

In this chapter, I outlined the theoretical and methodological foundations, combining Fairclough's CDA with Pistor's legal coding framework to investigate how legal, institutional, and media discourses construct and regulate genetic discrimination. Fairclough's CDA enables a layered analysis of texts by examining language and textual features, discursive practices of production, distribution, and consumption of texts, and broader social structures, including power, ideology, and institutional interests. Through this lens, I critically assess dominant discourses, such as genetic exceptionalism, patient empowerment, and neoliberal rationality, that shape public understanding and legislative responses to genetic privacy. Pistor's concept of *legal coding* complements this by showing how law transforms genetic data into capital, embedding it in a system of ownership and value aligned with market logic. Together, these approaches reveal the underlying power dynamics and ideologies encoded in laws like GINA and the GNA, as well as in the advocacy and industry discourse that surrounds them.

Chapter 4. TEXTUAL ANALYSIS-MICRO LEVEL

4.1) Overview

This chapter examines how certain legal texts construct the meaning of genetic discrimination and frame the protections offered by legislation, focusing on the linguistic and discursive features that shape these constructions. Drawing on Fairclough's (1992, 2003) model, this analysis constitutes a micro-level investigation into the lexical choices, grammatical structures, modality, and framing devices used in legal language. By analyzing how genetic discrimination is represented in GINA and GNA, as well as the associated policies and pamphlets, through particular word choices, passive constructions, and legal definitions, this chapter explores how the law encodes specific ideologies and assumptions about risk, responsibility, and protection, thereby contributing to broader discursive formations within the regulatory landscape of genomic governance. This analysis reveals the ideological underpinnings of genetic privacy laws, exposing how language shapes public perceptions, policy enforcement, and the balance between privacy and industry interests. By systematically analyzing vocabulary, grammar, and textual structures, this research provides insight into the broader sociopolitical context of genetic non-discrimination laws in the United States and Canada.

For the micro-level analysis in this chapter, I conducted a CDA of GINA and GNA under the legislation sub-header below, focusing on the textual and linguistic features that construct meanings of genetic discrimination, risk, and protection. This includes analyzing lexical choices, grammatical patterns, and modality to reveal how these legal texts position individuals and institutions within discourses of responsibility and privacy. Additionally, I analyzed policy documents and pamphlets from HHS and CAGC to explore how regulatory bodies and

professional organizations frame genetic privacy and discrimination in the following section. This close analysis of textual features aligns with Fairclough's (1992, 2003) micro-level dimension of discourse analysis, which interrogates how language choices in texts both reflect and reproduce broader ideological assumptions.

From a CDA perspective, laws to ban genetic discrimination are not neutral texts. They are embedded with specific ideologies, classifications, and representations of human identity and agency. As Fairclough (1989) asserts, the law operates as a form of language that shapes and legitimizes social norms. In the case of genetic regulation, the language used in legal texts plays a critical role in defining who is considered a legitimate subject of genetic testing, whose data can be stored and used, and under what conditions. These categorizations often reflect broader societal values about health, normalcy, risk, and worthiness, which are rarely questioned but carry significant implications for marginalized groups.

4.2) Legislation

GINA emerged as a landmark federal law in the United States, addressing growing societal concerns about genetic discrimination. Signed into law by President George W. Bush after a near-unanimous Congressional vote, GINA sought to prevent discrimination based on genetic information in health insurance and employment contexts. GINA was introduced to tackle a dual concern: the potential for employers and insurers to use genetic information discriminatorily, and the public's fear that such misuse might discourage the uptake of genetic testing and innovation in personalized medicine. The legislation provides explicit protections, prohibiting employers and health insurers from using genetic data to make hiring, firing, coverage, or premium decisions.

Crucially, it defines “genetic information” broadly, encompassing the results of genetic tests and family medical history, which recognizes the interconnected nature of genetic and medical data.

GINA’s primary audience includes individuals undergoing genetic testing, employers, and health insurers, making it a foundational framework for navigating the ethical and economic implications of genetic data in a rapidly evolving genomic landscape. However, its scope is not without limitations. By focusing solely on health insurance and employment, GINA leaves gaps in protections for life, disability, and long-term care insurance, which continue to raise questions about the comprehensive efficacy of genetic discrimination safeguards. These gaps highlight tensions between preventive legislative measures and the evolving nature of genetic science, and also broader neoliberal dynamics where individual risk management, market-based logic, and competing interests between public health goals and private sector priorities shape the scope and limitations of genetic discrimination safeguards.

GINA is unique among anti-discrimination laws because it was enacted proactively, aiming to address the potential misuse of genetic information before it became a widespread issue. This contrasts with laws like the Civil Rights Act of 1964 or the Americans with Disabilities Act (ADA), which responded to documented histories of discrimination. GINA’s forward-looking nature purportedly reflects an acknowledgment of advancements in genomic research, particularly HGP, which raised questions about the potential for genetic determinism and the misuse of genetic data.

While GINA’s primary stated goal is to foster trust in genetic testing and research by protecting against discrimination, its effectiveness in achieving this is debated (Suter, 2018; Evans, 2019). The law has contributed to a significant reduction in public fears regarding employment and health insurance discrimination based on genetic information. However, by excluding protections

for life, disability, and long-term care insurance, GINA leaves significant gaps that could still deter some individuals from undergoing genetic testing, particularly those who might face high personal or financial risks if such data were misused.

The variety of groups supporting GINA reflects its multifaceted motivations. Patient advocacy groups, such as the Genetic Alliance, were instrumental in raising awareness about the ethical and social implications of genetic discrimination. Researchers and healthcare professionals, motivated by concerns that public fear might hinder the adoption of genetic testing, also played a critical role. Notably, the medical products and pharmaceutical industries supported the legislation, recognizing the value of genetic testing in advancing precision medicine and ensuring public confidence in genetic research (Allison, 2008).

On the opposing side, lobbying efforts by certain sectors, such as life and disability insurance providers, limited GINA's scope (Tenenbaum and Goodman, 2017). These industries argued that health insurance is fundamentally different from other forms of insurance, which operate on risk assessments. As a result, GINA's protections were confined to health insurance and employment, leaving significant areas of potential genetic discrimination unregulated. Suter (2018) underscores that GINA's broad definition of "*genetic information,*" which includes family history, reflects Congress's intent to prevent discrimination and encourage public participation in genetic testing and research. However, its focus on presymptomatic conditions and exclusions for manifested conditions limits its effectiveness in fully addressing genetic discrimination.

GNA passed despite opposition from influential stakeholders like the insurance industry and even the federal government[2]. It was seen as a victory for patient advocacy groups and healthcare providers, as well as by key players in the biotechnology sector. Patient organizations, such as the Canadian Cancer Society, welcomed the legislation as a crucial safeguard against genetic discrimination, fostering greater access to genetic testing without fear of adverse consequences (Bombard & Heim-Myers, 2018). Companies like Sequence Bio had publicly championed the legislation, emphasizing its transformative potential for healthcare and research. Sequence Bio, a biotechnology firm based in Newfoundland and Labrador, explicitly lauded Senator Cowan for his leadership and acknowledged the act as a legacy benefiting Canadians for generations. Chris Gardner, CEO and President of Sequence Bio, framed the legislation as a cornerstone for fairness and equality, while also emphasizing its importance for advancements in healthcare and innovation (Sequence Bio, 2017). This endorsement sought to highlight mutual benefits for both patients and the biotechnology industry stemming from the GNA's provisions.

From a stakeholder perspective, GNA aims to serve multiple interconnected interests. For patients, the act was designed to alleviate fears of discrimination, empowering them to pursue

[2] An attempt by the Liberal government to significantly narrow the scope of the genetic discrimination bill was defeated by a cross-party coalition of MPs, despite Justice Minister Jody Wilson-Raybould raising constitutional concerns. Alberta Liberal MP Randy Boissonnault had moved to remove key provisions of the bill—such as penalties for genetic discrimination and protections for job applicants—but his motion was defeated in a voice vote. Wilson-Raybould has stated that the bill likely encroaches on provincial jurisdiction, particularly over the insurance industry, although the bill does not name the industry directly (CBC News, 2017b). In addition, Wilson-Raybould wrote to the Council of the Federation seeking provincial input, and three provinces—British Columbia, Manitoba, and Quebec—have expressed concerns about the bill. The government's shift in position may also be linked to external influences. Public lobbying records suggest that senior officials in the justice minister's office were likely engaged in multiple discussions over the past year with the Canadian Life and Health Insurance Association and Manulife Financial regarding the bill. Liberal MP Sean Casey, formerly the parliamentary secretary to the minister of justice, was also reportedly lobbied by the insurance association on at least six occasions. These factors may have contributed to the government's current opposition to the bill.

genetic testing without apprehension regarding its potential misuse. For biotechnology companies like Sequence Bio, the legislation creates an environment conducive to research and innovation. By protecting participants' genetic information, the act addresses a critical barrier to research recruitment: the fear of genetic discrimination. As noted by Senator Cowan, Canadians had previously declined genetic tests that could improve their health due to concerns over discrimination (Cowan et al, 2022). By removing these fears, the GNA was intended to encourage greater public engagement in genetic research, which is crucial for the development of personalized medicine and novel drug therapies.

Applying theoretical frameworks of Pistor's theory of legal codification and Fairclough's CDA to GNA reveals their broader implications for stakeholder dynamics. Pistor's notion of legal codification as a means of asset creation is particularly relevant here. The GNA transforms genetic information into a private asset, safeguarded by stringent legal protections, by fostering trust among research participants and ensuring ethical standards in the biotechnology sector. Fairclough's analysis, as detailed further in this chapter, reveals how the Act balances individual rights with collective benefits, framing genetic data as both a personal right and a public good. This framing aligns the interests of diverse stakeholders, including patients, researchers, and the biotechnology industry.

Biotechnology companies have a vested interest in the GNA for several reasons. First, the act's protections facilitate a participant-centric approach to research, a value emphasized by Sequence Bio and other industry leaders. Ensuring participants' privacy and addressing their ethical concerns are critical for building trust and securing consent, which are foundational for successful research endeavors. Second, the GNA enhances Canada's reputation as a leader in

ethical genomics, attracting global investments and collaborations in biotechnology. Empirically, this legal-institutional architecture has coincided with a period of substantial investment and international collaboration. CGS and the Canadian Precision Health Initiative, a $200 million program to build Canada's largest genomic data resource, explicitly promote ethical genomics as a competitive advantage (Government of Canada, 2025). Genome Canada's track record—$1.5 billion invested since 2000, attracting $2.1 billion in co-funding, including from international sources—demonstrates the sector's ability to leverage public funding into globally networked projects (Genome Canada, 2025). Similarly, Ontario Genomics has mobilized over $2.06 billion in total investment, facilitating commercialization and investor readiness for genomic companies (Ontario Genomics, n.d). This reputation fosters international collaborations and attracts investment by providing regulatory clarity and aligning with global ethical standards. Companies like Sequence Bio benefit directly from such a regulatory environment, as it fosters innovation while ensuring compliance with world-class privacy standards.

The GNA seeks to mitigate entrenched inequities in access to genetic testing and personalized healthcare by legally prohibiting discrimination based on genetic information. In theory, this legal protection enables individuals to engage in preventive care and disease management without fear of adverse social or economic consequences. However, from a sociological and critical legal perspective, the efficacy of the GNA in redressing such inequities is shaped by broader structural conditions, including systemic healthcare inequalities and the commodification processes within the biotechnology sector. Fairclough's CDA highlights how legal texts both reflect and reproduce power relations through language, suggesting that legislation like the GNA operates within discursive frameworks that can both challenge and reinforce existing social hierarchies (Fairclough, 2013). Complementing this, Pistor's theory of legal codification

explains how law transforms social relations into tradable assets, illuminating the ways in which genetic data and related protections become embedded within neoliberal market logics (Pistor, 2019). Thus, while the biotechnology industry benefits from expanded genetic testing participation essential to developing targeted therapies, the GNA's capacity to ensure equitable access and outcomes remains contingent on intersecting policy, economic, and social factors.

Stakeholder interests in the GNA's development and implementation are multifaceted and, at times, conflicting. While patient advocacy groups and the biotechnology sector supported the legislation, the insurance industry opposed it, citing concerns about its impact on actuarial practices (Adjin-Tettey, 2021). The act's focus on criminalizing discrimination rather than regulating specific sectors reflects a deliberate effort to navigate these tensions and ensure constitutional validity. The removal of a provision exempting high-value insurance contracts from the act's prohibitions was a strategic move to strengthen its legal standing and avoid framing it as an industry-specific regulation.

The enactment of the act represents not only a legal intervention but also a reflection of broader sociotechnical dynamics governing genetic science and individual rights. Sociologically, the GNA emerges at the intersection of risk governance and bio-citizenship, where individuals are increasingly encouraged to engage with genetic technologies while being assured protection from potential discrimination (Rose, 2007; Lemke, 2011). The legislation seeks to address public concerns about the misuse of genetic data in employment and insurance, aiming to foster trust in genomic innovation and encourage broader participation in personalized medicine (Adjin-Tettey, 2021). Yet, critical analysis reveals tensions inherent in this legal framework. GNA reflects a neoliberal responsibilization of health, where individuals are positioned as both consumers of

genetic services and managers of their own biological risks (Prainsack, 2017). Simultaneously, the Act's narrow focus, excluding family medical history, reveals a reductionist approach to genetic risk that sidelines the social determinants of health and familial contexts (Lippman, 1991). Moreover, jurisdictional disputes, particularly Quebec's constitutional challenge[3], and addressing practical limitations, such as the Act's exclusion of family medical histories[4] from its protections. While the GNA symbolizes a legal alignment with scientific progress, it simultaneously exposes the limits of law as a tool for equity, revealing how legal reforms may serve more to stabilize market confidence in biotechnology than to dismantle structural inequalities in access to health resources (Rose, 2007).

In conclusion, both GINA and GNA were seen as landmark achievements in protecting patient rights and privacy and fostering innovation in genomics, balancing the interests of various stakeholders. Further in-depth and contextualized examination of the legislation is needed, however, starting with the CDA analysis of the legislation, as outlined earlier.

[3] Quebec launched a constitutional challenge to the Genetic Non-Discrimination Act, arguing that it exceeded the federal government's authority under the criminal law power in section 91(27) of the Constitution Act, 1867. The Quebec Court of Appeal agreed, ruling that sections 1 to 7 of the Act were ultra vires, or beyond Parliament's jurisdiction. Notably, the Attorney General of Canada supported Quebec's position in the reference. However, the Canadian Coalition for Genetic Fairness, an intervener in the case, appealed directly to the Supreme Court of Canada. In a narrow 5–4 decision issued on July 10,2020 the Supreme Court overturned the Quebec Court of Appeal's ruling and upheld the constitutionality of the Act, affirming it as a valid exercise of federal criminal law power.

[4] GNA in Canada offers protections against the misuse of genetic test results, but it notably does not explicitly extend these protections to family medical history. Under the GNA, individuals cannot be required to undergo genetic testing or disclose the results of such tests as a condition for accessing goods, services, or entering into contracts, such as with insurers or employers (GNA, SC 2017, c.3). However, the Act's language is limited to "genetic test results", and does not specifically include information derived from a person's family medical history, which can often be used as a proxy for genetic risk. This omission is significant because family medical history has long been used by insurers and other entities to assess risk. According to the Canadian Life and Health Insurance Association (CLHIA), life and health insurers in Canada routinely ask applicants about their family health history, especially in the absence of genetic test results. This means that despite the GNA's intent to protect individuals from genetic discrimination, insurers and employers may still use family medical history in ways that could disadvantage individuals based on perceived genetic risks.

4.2.1) Critical Discourse Analysis

GINA and GNA both incorporate common ideological notions of privacy, protection, and rights and also contain linguistic elements that embed neoliberal values, emphasizing individual responsibility over institutional accountability in managing genetic information. By examining the vocabulary, grammar, and structure through Fairclough's CDA framework (1989, 1989, 1992, 1995a, 2003), it is possible to uncover how these acts construct genetic privacy as a protected right and identify it as an asset that individuals are responsible for managing within market-driven social relations.

At the core of both GINA and GNA lies the conceptualization of genetic privacy as a protected right, emphasized by language that evokes notions of ownership and individual control. Terms such as "*protection*," "*consent*," and "*choice*" dominate these Acts' vocabularies, constructing genetic information as a commodity-like asset over which individuals have exclusive rights. For instance, the GNA explicitly prohibits unauthorized use, collection, or disclosure of genetic test results, criminalizing these actions unless written consent is provided. Similarly, GINA prohibits employers and insurers from requesting genetic information, emphasizing that individuals alone hold the authority to disclose or withhold this data.

Fairclough's framework (1989, 1989, 1992, 1995a, 2003) highlights how this language of ownership and control operates within neoliberal paradigms, shifting responsibility for managing privacy risks onto individuals rather than institutions an structural mechanisms. By framing genetic information as an individual's private property, the acts promote a self-regulatory ethos, where individuals are expected to safeguard their genetic data against potential misuse. This emphasis

aligns with broader neoliberal logic that valorizes personal autonomy and accountability, often at the expense of systemic interventions or institutional accountability.

The ideological framing of genetic information as both a private right and a market asset serves multiple, often conflicting, interests. For individuals, the acts provide critical protections against discrimination, empowering them to access genetic testing and participate in research without fear of repercussions. These protections align with the interests of patient advocacy groups and civil society organizations that have long called for stronger safeguards against genetic discrimination. The acts' linguistic emphasis on individual responsibility and consent reflects broader neoliberal trends in governance, where regulatory frameworks prioritize self-management over institutional oversight. This approach aligns with what Pistor (2019) describes as the codification of assets through legal mechanisms, transforming genetic information into a form of private property that can be leveraged within market-driven contexts. By positioning genetic privacy as an individual right, the acts emphasize the notion that individuals, rather than institutions, bear the primary responsibility for managing the risks associated with genetic data.

However, the acts also serve the interests of corporate stakeholders, particularly in the biotechnology and insurance sectors, by creating a predictable regulatory environment that enables the commodification and utilization of genetic data within legal parameters. By emphasizing individual consent as the primary mechanism for accessing genetic information, the Acts facilitate the integration of genetic data into market systems without challenging the power dynamics that govern these systems. Biotechnology companies, for example, benefit from increased public trust and participation in genetic research, while insurers gain clarity on the boundaries of permissible data usage.

Both GINA and the GNA use similar vocabulary, with terms like "*discrimination*," "protection," "*genetic information*," and "*rights*" positioning genetic data as uniquely sensitive and deserving of legal safeguards. Through specific examples drawn from their texts, we can see how these terms function to delineate the acts' scope, articulate their protective goals, and reflect their underlying ideological commitments. Both acts prioritize the prevention of genetic discrimination, framing it as a critical societal harm. GINA, for example, explicitly prohibits employer practices that "*limit, segregate, or classify employees...because of genetic information*" (Sec. 202(a)(2)). This phrasing underscores the act's intent to eliminate inequitable treatment based on genetic characteristics in employment contexts. Similarly, the GNA states that individuals are entitled to be free from being required to undergo or disclose genetic tests as a condition of "*providing goods or services*" or "*entering into or continuing a contract*" (Sec. 3(1)). Here, the term "discrimination" operates not just as an abstract concept but as a concrete prohibition against exploitative practices across diverse societal domains.

They also invoke "*protection*" to assure individuals that their genetic data is shielded from misuse. GINA highlights confidentiality, requiring employers to maintain genetic information as part of a "*confidential medical record*" and limiting its disclosure to specific conditions, such as an "*employee's written request or compliance with legal obligations*" (Sec. 206(a)-(b)). The GNA mirrors this protective stance by criminalizing unauthorized collection, use, or disclosure of genetic test results, imposing "*penalties of up to $1 million or five years of imprisonment for violations*" (Sec. 7(a)). This use of "protection" signals the dual objectives of deterring wrongful practices and fostering public trust in genetic testing and research.

The term "*genetic information*" is rigorously defined in both acts to specify the protected scope. GINA includes "*information about...genetic tests*" and "*the manifestation of a disease or disorder in family members*," emphasizing its relevance to personal and familial contexts. The GNA adopts a similarly expansive definition, encompassing tests analyzing "*DNA, RNA or chromosomes for purposes such as the prediction of disease*". By anchoring their provisions in this precise terminology, the acts emphasize the idea that genetic data is not just personal but fundamentally sensitive, warranting special treatment under the law.

Both acts situate genetic privacy as a fundamental right that must be upheld in various societal interactions. GINA highlights this by making it "*unlawful*" for employers to "*request, require, or purchase genetic information*" except under narrowly defined conditions. The GNA similarly frames its prohibitions as rights-based entitlements, stating that every employee has the right "*not to undergo or be required to undergo a genetic test*" and "*not to disclose or be required to disclose the results of a genetic test*". These provisions reflect the alignment with broader human rights frameworks, emphasizing individual autonomy and dignity.

The linguistic construction of these terms reflects a neoliberal framework that places primary responsibility on individuals to manage and safeguard their genetic information. By codifying genetic privacy as a personal right rather than a collective or institutional obligation, the acts implicitly position individuals as the central agents in navigating and mitigating risks associated with genetic data. This focus on individual responsibility aligns with market-driven logic, facilitating the integration of genetic information into commercial systems under regulated conditions. Moreover, this language serves the interests of multiple stakeholders, including employers, insurers, and biotechnology companies. While ostensibly limiting these entities' ability

to misuse genetic data, the acts also provide them with a clear regulatory framework that enables the ethical use of genetic information in research and innovation. For example, exceptions for health care practitioners and researchers in the GNA illustrate how the acts balance protective measures with the promotion of scientific and economic advancement.

These word choices imply a shared foundation that recognizes genetic information as distinct and valuable, in need of specific protection to prevent misuse. For instance, the repeated use of the word "*prohibit*" in GINA's text and supporting documents frames genetic data as sensitive, requiring legal protection against potential misuse by employers or insurers. This terminology also constructs genetic data as different from other personal information, resonating with the concept of genetic exceptionalism, where genetic information is viewed as uniquely private due to its implications for health, identity, and family (Fairclough, 2003). In this vein, both Acts convey that genetic information is a valuable commodity tied to individual agency, self-reliance, and autonomy.

The framing of genetic data as uniquely sensitive and in need of special protection is emphasized through multiple linguistic and structural choices in both GINA and the GNA. Beyond the frequent use of the word "*prohibit*," these texts embed the concept of genetic exceptionalism through explicit legal prohibitions, the delineation of genetic information as distinct from other personal data, and the construction of genetic privacy as a right that must be safeguarded. For example, GINA states that "*it shall be an unlawful employment practice for an employer… to discriminate against any employee with respect to compensation, terms, conditions, or privileges of employment, because of genetic information with respect to the employee*." The phrase *"unlawful employment practice*" highlights the severity of genetic discrimination and differentiates

genetic data from other forms of employee information that might not receive the same level of legal scrutiny.

Similarly, the GNA highlights this distinction by mandating that "*it is prohibited for any person to require an individual to undergo a genetic test as a condition of providing goods or services*" and further specifying that genetic test results cannot be "*collected, used, or disclosed*" without explicit written consent. This phrasing, especially the consistent use of "*require*" and "*disclose*" in a legal context, constructs genetic data as a potential liability, one that individuals must actively protect. Moreover, the GNA's amendments to the Canada Labour Code and Canadian Human Rights Act further institutionalize this framing by legally recognizing genetic characteristics as a protected category alongside race, sex, and disability. This structural placement elevates genetic data to the same level of fundamental human rights protection, reinforcing its exceptional status.

Tracing this framing across other sources, legislative debates, and advocacy materials surrounding the Acts often stress genetic information's predictive power and its implications for personal and familial health. For instance, Senator Jim Cowan, in supporting Bill S-201, argued that "*Canadians have been declining genetic tests that could have improved their health, fearing discrimination and the implications for themselves and loved ones*". This statement underscores the perceived vulnerability of genetic data, aligning with Fairclough's (2003) notion that discourse not only describes but actively constructs social realities. By repeatedly associating genetic information with risk and protection, these texts do not merely regulate access to genetic data but shape the broader public understanding of genetic privacy as an individual responsibility tied to market-driven social relations.

The framing of genetic information as an asset that individuals must own and manage aligns with neoliberal values of self-governance, emphasizing personal responsibility over collective or institutional accountability. In both GINA and GNA, the vocabulary reflects experiential value, as terms like "*privacy*" and "*rights*" construct genetic data as a highly personal resource, intrinsically tied to individual identity and autonomy, one that must be actively controlled and safeguarded by the person to whom it belongs (Fairclough, 1989, p.115). This linguistic framing positions genetic information as something akin to property, reinforcing the notion that individuals should be proactive in protecting their genetic privacy rather than relying on systemic protection.

Additionally, the expressive value embedded in the language of these Acts conveys a particular stance on genetic privacy; while both explicitly prohibit genetic discrimination, they also imply that the onus of privacy management falls primarily on individuals rather than institutions or governments. This suggests that while legal mechanisms exist to prevent discrimination, individuals are ultimately positioned as the custodians of their own genetic data, responsible for navigating risks associated with genetic testing and disclosure. By embedding this perspective, the Acts subtly align with market-driven ideologies that favor self-regulation and personal responsibility, framing privacy as something that must be actively maintained by the individual rather than a fundamental right ensured through broader structural protections.

GINA in particular uses terms such as "*employee*," "*employment*," and "*health insurance*" frequently, with a focus on the impact of genetic discrimination on an individual's economic life (U.S. Government Publishing Office, 2008). The frequent use of terms such as "*employee*," "*employment*," and "*health insurance*" in GINA underscores the law's emphasis on the economic

consequences of genetic discrimination (U.S. Government Publishing Office, 2008). This sector-specific vocabulary aligns with a neoliberal perspective, which prioritizes privacy protections primarily within economic transactions rather than as a broader human right. While this terminology might initially appear to reflect experiential value, with the insight of lawmakers' focus on professional and financial domains, it more accurately demonstrates expressive value, conveying an implicit stance on the role of genetic privacy in society (Fairclough, 1989). The sector-specific vocabulary in GINA underlines the significance of genetic privacy within market interactions, foregrounding individual rights as especially valuable for economic participation.

GINA's framing suggests that genetic privacy is particularly important insofar as it affects an individual's economic security, reinforcing the idea that privacy protections are necessary primarily within employment and insurance settings, rather than in all aspects of life. This perspective reflects a cultural attitude (Fairclough, 1989, p.118) that values privacy as a means of ensuring economic participation rather than as an inherent right. The law constructs individuals as economic actors, whose ability to work and access insurance must be safeguarded against discrimination by positioning privacy as a functional necessity rather than a universal principle. By embedding this logic, GINA subtly highlights a market-driven approach to rights, where protections are justified based on their relevance to economic engagement rather than broader ethical or social considerations.

In contrast to this economic foregrounding in GINA, GNA relies more on broader terms such as "*person*," "*individual*," and "*testing*" (Genetic Non-Discrimination Act, 2017), signifying a wider application of the Act across social contexts without focusing on employment or insurance specifically. In contrast to this economic foregrounding in GINA, GNA relies more on broader

terms such as "*person*," "*individual*," and "*testing*" (Genetic Non-Discrimination Act, 2017), signifying a wider application of the Act across social contexts without focusing on employment or insurance specifically. For example, Section 3(1) of the GNA states: "*It is prohibited for any person to require an individual to undergo a genetic test as a condition of providing goods or services to that individual*". This wording extends the Act's protections beyond economic settings and into broader societal interactions, emphasizing universal safeguards against genetic discrimination, regardless of whether the individual is an employee, consumer, or participant in public life. This might, from one perspective, be interpreted as reflecting a commitment to egalitarian principles, positioning genetic privacy as a right that extends beyond economic roles to include all social interactions.

Without a focus on institutional protections or sector-specific frameworks, GNA continues to position individuals as the managers of their genetic data across all interactions. Since structural decisions in text-crafting reveal ideological values (Fairclough, 1989), by structuring the GNA as a universal safeguard, this act highlights the neoliberal notion of genetic privacy as a private concern that individuals must navigate independently. This might, from one perspective, be interpreted as reflecting a commitment to egalitarian principles, positioning genetic privacy as a right that extends beyond economic roles to include all social interactions. However, without a focus on institutional protections or sector-specific frameworks, the GNA continues to position individuals as the primary managers of their genetic data, emphasizing personal responsibility over systemic oversight. This echoes a theme previously identified in the analysis of GINA, where the burden of protecting genetic privacy is placed on individuals rather than institutions. Both acts, despite their differences in scope, ultimately reflect a neoliberal framework that prioritizes individual autonomy over collective or state-driven protections.

Structural choices in legal texts reveal underlying ideological commitments (Fairclough, 1989), and the GNA's use of universal terms such as "*person*" and "*individual*" rather than context-specific categories like "*employee*" or "*insured*" exemplifies a deliberate discursive strategy to extend protections beyond institutional confines. However, this universal framing aligns with neoliberal governance's emphasis on individual responsibility, situating genetic privacy as a personal asset that individuals must actively manage themselves (Rose, 2007; O'Malley, 2012). Such framing reflects an understanding in which individuals internalize risk management and assume accountability in navigating complex socio-legal landscapes without robust institutional enforcement. This approach is consistent with broader trends in health governance that valorize self-care, empowerment, and risk awareness, privileging biomedical individualism and the commodification of genetic data as private property requiring active stewardship (Lemke, 2011; Prainsack, 2017; Rabinow & Rose, 2006). Moreover, this discourse echoes Beck's (1992) risk society thesis, whereby governance responsibilities shift from the state to individuals who must negotiate risks in fragmented regulatory environments (Lupton, 2013b). Furthermore, the commodification of personal data in biomedicine reveals how genetic privacy is increasingly treated as a form of capital, reflecting broader market logics that transform biological information into extractable and tradable assets. Consequently, while the GNA projects inclusivity through universal language, it simultaneously reinforces a neoliberal logic of self-governing, risk-aware subjects, obscuring the structural inequalities embedded in access to protections and framing genetic privacy less as a collective right and more as an individualized, market-mediated asset (Clarke et al., 2003; Sadowski, 2019).

The difference in scope between GINA and GNA can also be understood through their legal and political contexts. GINA, passed in the U.S., emerged in response to concerns about

discrimination in employment and insurance, reflecting the American reliance on employer-based healthcare and the need to ensure economic security through anti-discrimination protections. Its narrower focus serves the interests of employees and insured individuals, protecting their ability to participate in the workforce and access insurance without genetic bias. However, by emphasizing employment and insurance discrimination rather than systemic state-level oversight, GINA highlights the neoliberal notion that individuals are responsible for negotiating privacy risks within economic transactions, rather than expecting collective or regulatory intervention.

By contrast, GNA in Canada takes a broader approach, extending protections beyond employment and insurance to any contractual or service-based interaction, including consumer relationships and everyday transactions. This expansion could reflect Canada's public healthcare model, where genetic discrimination in insurance is a less pressing concern than in the U.S. Instead, the Act serves a wider range of social interests by addressing potential risks in sectors such as education, housing, and access to services. While this broader scope appears to offer stronger legal safeguards, it still operates within a neoliberal logic. Genetic privacy is framed as an individual responsibility, and individuals must remain vigilant in managing their own genetic risks across multiple domains. Rather than mandating proactive institutional safeguards, GNA relies on legal prohibitions that require individuals to assert their rights after a violation occurs, further reinforcing an individualistic rather than systemic approach to genetic privacy.

Despite differences in scope, both GINA and GNA reflect a neoliberal paradigm in which individuals, not the state or institutions, are positioned as the primary actors responsible for managing their genetic privacy. While GINA highlights privacy within employment and insurance markets, and GNA extends protections across multiple social domains, both Acts construct genetic

privacy as an individualized concern rather than a collective or structural issue, reinforcing the broader ideological framework of self-reliance and personal risk management in neoliberal governance.

The linguistic aspect of modality in both acts underscores this individual responsibility. GINA and the GNA both use high-modality expressions like "*shall not*" and "*prohibited*" to establish firm restrictions, which convey a high level of authority and deterrence (U.S. Government Publishing Office, 2008; Government of Canada, 2017). GINA places restrictions primarily on employers, insurers, and other entities involved in employment and healthcare, including employment agencies, labor organizations, and joint labor-management committees. It prohibits these groups from using genetic information in hiring, firing, job assignments, and insurance eligibility decisions (U.S. Government Publishing Office, 2008). GNA, on the other hand, imposes restrictions more broadly, applying to any person or entity that requires genetic testing as a condition for providing goods, services, or entering into contracts. However, it also includes employers and insurers by prohibiting them from compelling individuals to undergo genetic testing or disclose genetic information (Government of Canada, 2017).

For example, GINA (2008) states, "*An employer shall not disclose genetic information concerning an employee or member except as provided under this title*." Similarly, the GNA (2017) enforces categorical prohibitions, stating, "*It is prohibited for any person to require an individual to undergo a genetic test as a condition of providing goods or services to that individual*." The forceful nature of these prohibitive statements conveys the legislative intent to eliminate genetic discrimination by explicitly restricting certain actions. The linguistic aspect of modality, which refers to the degree of certainty, obligation, or possibility expressed in language (Fairclough, 1989),

underscores the emphasis on individual responsibility in both Acts. Modality is particularly relevant in legal texts, as it signals the strength of legal mandates and the extent of enforcement. In this case, GINA and the GNA both use high-modality expressions, such as "*shall not*" and "*prohibited*," to establish firm restrictions (U.S. Government Publishing Office, 2008; Government of Canada, 2017). These expressions convey a strong sense of obligation and deterrence, making it clear that genetic discrimination is legally unacceptable. The use of such authoritative language highlights the notion that compliance is non-negotiable, yet it also subtly shifts the responsibility to individuals, who must assert their rights and take legal action if these prohibitions are violated. This reliance on strict legal language aligns with the broader neoliberal logic present in both Acts, where regulation exists, but enforcement largely depends on individuals navigating the legal system to protect their genetic privacy.

Fairclough (1989: p.127) identifies such strong modality as common in legislative discourse, where it serves to enforce compliance and assert power. Although both acts provide a definitive protection against discrimination, this strong modality also has the effect of distancing institutional responsibility, placing the burden of responsibility on individuals. In other words, although the frequent use of high-modality language establishes a strict legal framework, the approach foregrounds what is not allowed rather than offering resources or support. For instance, GINA states: "*A health insurance issuer shall not request, require, or purchase genetic information for underwriting purposes*" and "*It shall be an unlawful employment practice for an employer to discriminate against an employee because of genetic information*". Similarly, the GNA declares: "*It is prohibited for any person to require an individual to undergo a genetic test as a condition of providing goods or services*". These statements clearly establish prohibitions but do not outline what institutions must do to ensure compliance or how affected individuals can access support if

their rights are violated. The absence of explicit enforcement mechanisms, oversight bodies, or procedural guidance leaves the burden on individuals to be aware of their rights and pursue legal recourse independently.

This legal structure aligns with a neoliberal, individualistic approach to privacy, wherein protections are defined in legal terms, but their practical enforcement is left to individuals. Rather than embedding proactive safeguards, such as mandatory workplace policies, employer education on genetic rights, or state-funded legal aid for discrimination cases, the acts assume that legal deterrence alone is sufficient. The reliance on individuals to initiate action, whether by challenging employers or insurers or seeking legal remedies, reflects a broader shift of responsibility from institutions to individuals. In this sense, while high-modality language projects authority, it simultaneously distances state and corporate accountability, reinforcing the idea that individuals are the primary custodians of their own genetic privacy.

The grammar used in both Acts further supports the individualization of responsibility, particularly in the use of active voice and sentence structure, such as in statements like "*An employer shall not fail or refuse to hire*…" (GINA), which assigns accountability to employers, positioning them as entities that must respect genetic privacy in employment decisions (U.S. Government Publishing Office, 2008). Fairclough (1989:124) argues that active constructions in legal language encourage a sense of personal responsibility, aligning with neoliberal principles that shift protective duties from institutions to individuals. GINA highlights employers' obligations and positions employees as responsible agents to monitor potential infringements as well. In this sense, GINA frames genetic privacy as something that employees themselves must actively safeguard, rather than regulation only. GINA establishes clear obligations for employers, explicitly stating

that they "*shall not request, require, or purchase genetic information with respect to an employee or a family member of the employee*". This provision places a legal restriction on employers, signaling that they are bound by law to avoid genetic discrimination. However, while GINA mandates employer compliance, it does not describe direct mechanisms for government enforcement or proactive monitoring beyond legal penalties for violations. Instead, employees are positioned as the first line of defense in protecting their genetic privacy.

For instance, GINA states that individuals who believe they have been discriminated against "*may file a charge with the Equal Employment Opportunity* Commission (*EEOC*)". This statement suggests that enforcement is reactive, which means government agencies only intervene once an individual files a formal complaint. There is no structural provision for routine audits, workplace training, or employer reporting requirements, reinforcing that employees themselves must recognize, document, and report violations. In this way, GINA, while legally binding for employers, assumes that employees bear the responsibility of vigilance, shifting much of the burden to the individuals affected.

This framing aligns with a neoliberal emphasis on self-governance, where individuals must manage risks and navigate institutional policies largely on their own. While GINA ensures that employees have the legal right to genetic privacy, it does not create a regulatory framework to actively monitor employer compliance. It does not ensure state intervention either before harm occurs. Although the government serves as an arbitrator in discrimination cases, it is the employee's responsibility to detect violations and initiate legal action in the end.

GNA also uses active constructions in a similar way, such as "*No person shall require an individual to undergo a genetic test*". This rhetorical choice highlights a sense of universality and

neutrality, suggesting the law applies to all actors, regardless of their specific roles or industries. The lack of sector-specific language in GNA reflects its general tendency towards broader application and a more universal mandate against genetic discrimination than GINA. However, this broad phrasing also implies that individuals bear responsibility for managing their privacy in various contexts. In this way, GNA encourages a self-governing approach, which aligns with neoliberal values that prioritize autonomy and self-responsibility. While both GINA and GNA place responsibility on individuals to some extent, the GNA's broader and more universally applicable language also increases this individual burden. Unlike GINA, which targets employment and insurance contexts, GNA uses general terms such as "*person*", "*individual*", and "*testing*", without specifying the institutions responsible for compliance. This lack of sector-specific focus makes genetic privacy an issue that applies to various social and economic interactions. This approach also supports the idea that individuals must navigate and protect their genetic privacy independently.

While GINA defines clear obligations for employers and insurers, providing an institutional framework for violations, GNA does not specify who is accountable for preventing discrimination beyond prohibiting it. Instead, it states that "*no person shall require an individual to undergo a genetic test as a condition of providing goods or services*". This phrasing does not establish which institutions or regulatory bodies are tasked with overseeing compliance, which might make enforcement uncertain.

As a result, GNA implies individual responsibility, but it does so more than GINA by omitting certain institutional obligations and legal pathways. Without sectoral constraints or enforcement mechanisms, the Act constructs genetic privacy as an expansive but personally

managed concern, which highlights the neoliberal principle that individuals must protect their own data through multiple aspects of their lives. This broader framing contrasts with GINA, which confines its application to employment and insurance. For these two domains, institutional oversight and dispute resolution mechanisms exist.

Fairclough's concept of *connection value* is particularly relevant to understanding how neoliberal themes manifest in the GNA's structure. As noted above, the GNA minimizes the state's role in actively managing genetic privacy, positioning individuals as self-reliant custodians of their own genetic data. According to Fairclough (1989: p.112), *connection value* in a text's structure reflects how closely social actors are integrated within the protective framework. In the GNA, the limited explicit or direct emphasis on governmental or institutional intervention in protecting genetic data highlights neoliberal ideals that value self-regulation over collective governance. By seeing genetic privacy as a responsibility to be navigated by individuals, the GNA supports a neoliberal structure that limits institutional responsibility, encouraging individuals to act as independent custodians of their own data. Rather than outlining specific enforcement mechanisms or institutional oversight, the Act broadly prohibits discrimination without detailing who is responsible for ensuring compliance or providing recourse. This omission highlights the idea that individuals must actively manage their own genetic privacy, rather than relying on regulatory structures to protect them.

The *expressive value* in both acts further illustrates neoliberal framing by constructing genetic data as a personal asset that individuals must actively manage. The emphasis on protecting genetic data within employment and insurance in GINA, for instance (noted above), constructs privacy as a market-oriented personal asset, aligning with neoliberal views that prioritize economic

freedom and stability. GNA also portrays genetic data as a private and personal asset that individuals must protect across all contexts, highlighting a view of privacy akin to a property asset that individuals should guard vigilantly. This *expressive value* (Fairclough, 1989) resonates with neoliberal ideologies, which emphasize privacy as an individual responsibility rather than a collective or state-managed right. By configuring genetic privacy as an asset, both GINA and the GNA subtly align with neoliberal discourses that promote autonomy and individual responsibility within a market-driven society. (Rose, 2007; Rabinow & Rose, 2006; Prainsack, 2017). This aligns with broader processes of biomedicalization that commodify health data and prioritize individualized empowerment over collective protections (Clarke et al., 2003).

4.3) Policies and Pamphlets:

CDA offers a valuable framework for analyzing policy documents and pamphlets on genetic discrimination because it reveals how language is used to produce and emphasize power relations (Fairclough, 2013). As Fairclough highlights, CDA is particularly effective in identifying dominant, marginal, oppositional, and alternative discourses within texts (Fairclough, 2003). These documents are not merely descriptive or neutral; rather, they are tools through which institutions like governments, health agencies, and advocacy groups shape public understanding of complex issues such as genetic risk, privacy, and fairness. By focusing on how key terms and narratives are framed, CDA enables a deeper understanding of how policy texts either emphasize or challenge broader ideological assumptions, such as genetic determinism or market-based health solutions, that influence legal and ethical decision-making.

Three texts produced by two organizations, the *OHRP Guidance on GINA* (2009) by the HHS and the *Fact Sheets* by CAGC, offer further insights into how these particular groups are also

shaping the public discourse on genetic privacy and discrimination from distinct cultural and ideological perspectives. Just as in the legal Acts themselves, the rhetorical choices in these texts frame genetic privacy in particular ways and reveal their underlying ideological orientations. I will focus on these documents because HHS and CAGC play key roles in shaping public discourse on genetic privacy and discrimination, each contributing distinct perspectives based on their institutional mandates and national legal frameworks. While both organizations advocate for genetic privacy protections, their approaches reflect differences in regulatory oversight, policy implementation, and professional advocacy, shaped by the enactment of GINA and GNA.

As further background, the HHS, through the Office for Human Research Protections (OHRP), plays a central role in ensuring the ethical and regulatory oversight of genetic research in the U.S. This includes issuing guidance documents and policies that emphasize federal commitments to preventing genetic discrimination in both clinical and research settings. The OHRP's guidance on GINA (2009) serves as a key document clarifying the legal and ethical responsibilities of researchers, ensuring that individuals participating in genetic research are protected from discrimination based on their genetic information.

In line with GINA's enactment in 2008, the OHRP guidance focuses on integrating ethical safeguards into research protocols while ensuring compliance with federal regulations. The document clarifies how GINA intersects with existing human subject protections under the Common Rule (45 CFR 46) and highlights that genetic information should not be used in ways that could result in employment or health insurance discrimination. The regulatory language in the OHRP guidance reflects a compliance-oriented approach, where genetic privacy is framed primarily as a matter of institutional responsibility, regulatory oversight, and informed consent

mechanisms. This positioning suggests that legal frameworks and structured regulatory compliance, rather than individual agency, serve as the primary mechanisms for preventing genetic discrimination.

Furthermore, the HHS approach aligns with broader federal efforts to standardize genetic privacy protections across different sectors, particularly in the context of biomedical research and personalized medicine. While GINA prohibits genetic discrimination in employment and health insurance, it does not extend protection to life insurance, disability insurance, or long-term care insurance, leaving certain areas of genetic data usage unregulated. This regulatory gap has prompted ongoing discussions within the HHS and allied organizations about the limitations of GINA and the need for broader protection in the era of expanding genomic technologies.

In contrast to the HHS, CAGC functions primarily as a professional and advocacy organization, emphasizing public awareness, legislative change, and professional ethics in genetic counselling. The CAGC's Fact Sheets and position statements highlight the ethical and social dimensions of genetic discrimination, calling for comprehensive legal protections that prevent the misuse of genetic test results by employers, insurers, and other institutions. The CAGC's discourse aligns with a rights-based approach, advocating for government intervention to protect individuals from potential genetic-based discrimination.

Following the enactment of GNA in Canada in 2017, the CAGC intensified its advocacy efforts, positioning genetic discrimination as a public policy issue that requires active legal enforcement. GNA, unlike GINA, applies more broadly, making it a criminal offense for any entity, including employers, insurers, and service providers, to require genetic testing or disclose genetic test results without explicit consent. The CAGC played a key role in pushing for these legislative

changes, arguing that Canada lagged behind other G8 nations in protecting its citizens from genetic discrimination.

The CAGC's Fact Sheets frame genetic privacy as a matter of social justice and public protection, frequently using high-modality phrases such as "must be protected" and "should not be used unfairly" to emphasize the non-negotiable need for legal safeguards. This language constructs genetic discrimination as an urgent issue, positioning the government and public as joint stakeholders in ensuring equitable access to genetic services without fear of discrimination. The CAGC's advocacy also underscores the importance of transparency in genetic data usage, calling for stronger governmental oversight rather than relying on industry self-regulation.

The contrast between HHS and CAGC reflects fundamental differences in the governance of genetic privacy between the U.S. and Canada. The HHS, as a federal regulatory body, focuses on ensuring compliance within research and healthcare settings, reinforcing the institutional responsibility of researchers, healthcare providers, and insurers to prevent genetic discrimination. Its OHRP guidance on GINA (2009) is framed within a regulatory and biomedical discourse, where genetic information is treated as a protected category within clinical and research protocols.

CAGC, as a professional and advocacy body, engages in broader social discourse, framing genetic privacy as a human rights issue that demands legislative intervention. Its Fact Sheets and public statements emphasize collective responsibility, government accountability, and the ethical obligation to prevent discrimination, reinforcing the need for active legal enforcement rather than voluntary compliance. Unlike HHS, which highlights institutional oversight, the CAGC places greater emphasis on legal protections that apply universally across all sectors, including employment, insurance, and public services.

Moreover, while GINA and GNA share similar objectives, the scope and implementation of these laws differ significantly. GINA focuses on preventing discrimination in employment and health insurance, maintaining a balance between privacy protections and economic interests, while GNA enforces criminal penalties against any entity that improperly collects, uses, or discloses genetic information. The HHS approach to GINA aligns with a compliance-based model, whereas CAGC's advocacy for GNA aligns with a rights-based framework that prioritizes public protection over industry considerations.

Both HHS and CAGC contribute to shaping the discourse on genetic discrimination and privacy, but they do so through different institutional lenses. The HHS, as a government agency, enforces regulatory compliance in research and healthcare, ensuring that GINA's protections are integrated into biomedical practices. The CAGC, as an advocacy organization, mobilizes public and legislative support to push for broader genetic privacy protections beyond the healthcare sector.

These differences highlight how regulatory and advocacy bodies influence genetic privacy laws, either through institutional oversight and structured compliance (HHS) or through legislative lobbying and public mobilization (CAGC). As genomic technologies continue to evolve, these organizations will likely play critical roles in shaping future debates on genetic data governance, ensuring that genetic privacy remains a central concern in both scientific research and public policy.

From a CDA perspective, these contrasting approaches illustrate how discourse both reflects and reproduces institutional power, shaping not only the legal scope of genetic privacy but also the social meanings attached to it. The HHS frames genetic information through a compliance-oriented, biomedical discourse that emphasizes regulation and institutional responsibility, which

aligns with neoliberal logics of governance where risks are managed through institutional oversight rather than collective rights (Fairclough, 2003; Rose, 2007). CAGC advances a rights-based discourse that foregrounds social justice, equity, and public protection, yet it too is situated within a neoliberal policy environment where appeals to fairness and human rights must be articulated in ways that resonate with market-oriented health systems and legislative agendas (Joly et al., 2021a). CDA reveals how the rhetorical choices in these texts legitimize particular framings of genetic discrimination—either as a technical matter of regulatory compliance or as a universal human rights issue—while simultaneously constraining alternative possibilities. In this way, policy and advocacy documents are not neutral but discursive practices that reproduce dominant neoliberal assumptions about responsibility, risk, and market-driven innovation, even as they contest or reframe their implications in different national contexts.

4.3.1) Critical Discourse Analysis

The OHRP guidance document is segmented into procedural sections outlining responsibilities for researchers and regulatory bodies, underscoring a compliance-focused tone invoking ideas of regulatory order and scientific progress, as well as structured oversight of genetic information within a scientific framework. The document mandates that Institutional Review Boards (IRBs) carefully evaluate genetic research proposals to ensure adherence to the protections outlined in GINA, demonstrating a structured approach to oversight. For example, it states, "IRBs should consider the provisions of GINA when assessing whether genetic research satisfies the criteria required for IRB approval of research, particularly whether the risks are minimized and reasonable in relation to anticipated benefits and whether there are adequate provisions in place to protect the privacy of subjects and maintain the confidentiality of their data" (OHRP, 2009). By

positioning genetic privacy as a part of a larger regulatory system, the text draws on and highlights the belief that scientific advancement is central to societal development (Fairclough, 1989: p.140). In doing so, it highlights how discourse on genetic privacy serves as a mechanism for legitimizing and promoting developments in genetics, positioning them as essential steps toward broader scientific and technological progress.

In the OHRP document, terms like "research," "consent," and "protected health information" further help frame the discussion around genetic discrimination within a scientific and regulatory context, with a focus on ethical oversight in scientific progress. This reflects what Fairclough (1989: p. 113) describes as "ideologically controversial" vocabulary, while the term "protected health information" constructs genetic data as integral to medical research rather than personal identity. Such language aligns with an ideological perspective that prioritizes scientific advancement within a structured regulatory framework, suggesting that while privacy is valuable, it is secondary to the societal benefits of research (Fairclough, 1989: p.120). This framing prioritizes genetic data's role in biomedical research over its connection to individual identity and privacy. It positions privacy concerns as subordinate to the societal benefits of scientific advancement, reflecting a neoliberal discourse that balances ethical considerations against innovation imperatives. This aligns with Pistor's analysis, where she argues that legal frameworks transform assets like genetic information into capital through mechanisms such as intellectual property rights, thereby embedding them within economic systems that prioritize value extraction over individual rights (Pistor, 2019). Thus, the language used in regulatory texts not only legitimizes but also naturalizes the subordination of individual privacy within a governance framework focused on promoting research as a public good.

Unlike GINA and the GNA, which primarily frame genetic privacy as an issue of individual rights and economic participation, the OHRP document situates genetic information within a scientific and regulatory framework, emphasizing oversight and compliance rather than personal autonomy. While both acts use strong modality to prohibit genetic discrimination, their focus remains on restricting employer and insurer actions, reinforcing a neoliberal model where individuals must navigate privacy concerns within existing institutional structures. In contrast, the OHRP document does not center on individual rights or economic protections but instead constructs genetic data as a resource essential for research and medical progress.

This difference reflects the distinct goals of the entities responsible for each text. GINA and the GNA, created by lawmakers, are shaped by political and economic considerations, ensuring protection against discrimination while maintaining a model of self-regulation. The OHRP document, on the other hand, is designed for researchers and regulatory bodies, prioritizing ethical oversight and structured governance. The use of terms like “protected health information” and “consent” signals an institutional perspective, where genetic privacy is framed as something to be managed within the broader goals of advancing medical knowledge rather than as an inherent personal right. By emphasizing structured oversight, the OHRP document subtly implies that privacy concerns should not obstruct scientific progress, a contrast to the acts that foreground privacy as a safeguard against discrimination.

The CAGC Fact Sheet uses words like “rights,” “protection,” and “dignity,” shifting the focus slightly from regulation towards a human rights-based perspective on genetic discrimination. With the language emphasizing protection from discrimination, it reflects collective rights and individual dignity above scientific utility, with terms like “dignity” invoking social values and

identities centered on equity and universal rights. Moreover, the combination of scientific and ethical vocabulary in this text creates a sense of balance, which constructs genetic data as requiring protection both for individual privacy and the advancement of healthcare. By framing genetic privacy in terms of personal dignity and rights, the fact sheet appeals to ethical considerations, reinforcing the idea that individuals deserve autonomy over their genetic information beyond institutional mandates.

For example, the CAGC Fact Sheet explicitly states: "*There is a law – the Genetic NonDiscrimination Act, GNA for short – that makes it illegal for third parties, such as employers and insurance companies, to ask for your genetic test results*." Here, the emphasis on "illegal" underscores a protective stance while also signaling the authoritative power of the law. However, unlike legal statutes that focus on enforcement mechanisms, this statement places the individual at the center of discourse, suggesting that the law serves to uphold their fundamental rights rather than merely regulate institutional behaviour.

Similarly, the document highlights personal protection by stating: "*It is illegal to collect, use, or disclose your genetic test results without your written consent*." The phrase "your written consent" highlights individual agency, positioning genetic privacy as a personal right rather than an institutional obligation. This wording contrasts with GINA and GNA, which often center on employer or insurer responsibilities rather than individual empowerment. By emphasizing consent, the fact sheet conveys genetic privacy as something individuals actively control, rather than something passively safeguarded by institutions.

Analysis of the grammar and sentence structures across these texts also reveals how they distribute agency and portray power relations. In the OHRP guidance, passive constructions such

as “genetic information is protected under GINA” minimize human agency, framing the law as an overarching regulatory structure or “impersonal authority” (Fairclough, 1989). Positioning institutional power in this way implies that individuals’ actions are subordinated to the institutional framework of the legal system, which is a distant but still authoritative regulator. The OHRP guidance adopts a detached, procedural tone, describing protections in generalized terms: “GINA restricts the use of genetic information as soon as GINA becomes effective for a particular plan or insurance policy.” This passive construction erases direct reference to who is responsible for enforcing these protections, suggesting an automatic, institutionalized mechanism that individuals do not need to directly engage with. In contrast, both GINA and the GNA structure their legal language in a way that necessitates individual awareness, consent, and action, reaffirming the neoliberal model in which individuals, rather than institutions, are expected to police their own rights.

This linguistic divergence reflects the broader ideological context in which these documents were written. The acts, as legislative tools, adopt legalistic but participatory language that places genetic privacy within the sphere of personal responsibility and market-based interactions, whether in employment or insurance. Meanwhile, the OHRP guidance, as a research and regulatory document, highlights a structural, compliance-focused framework, where legal protections are viewed as passive safeguards within the broader scientific and ethical regulatory environment.

While both frameworks acknowledge the importance of genetic privacy, they present different models of agency. The Acts push individuals toward self-regulation, while the OHRP guidance distances the individual from responsibility, reinforcing the idea that institutional

oversight and structured compliance will ensure protection. This divergence is critical because it influences how individuals perceive their role in protecting their own genetic information, whether as autonomous actors navigating a neoliberal system or passive beneficiaries of institutional oversight.

In a different approach, the CAGC Fact Sheets, produced by a professional and advocacy body, actively emphasize institutional power in statements such as "the GNA protects Canadians against discrimination," positioning the law as an active defender of rights and reinforcing the idea of a proactive government dedicated to citizen welfare. Unlike the OHRP guidance, which frames oversight through procedural compliance, or GINA and the GNA, which place responsibility largely on individuals, the CAGC situates both citizens and institutions within a network of ethical and legal obligations. As a professional organization, its goals extend beyond guidance to shaping public understanding, advocating for legislative improvements, and promoting professional ethical standards. By emphasizing terms like "rights," "protection," and "dignity," the CAGC constructs genetic privacy as a collective and moral concern, highlighting social values alongside scientific considerations.

From a CDA perspective, this approach illustrates how discourse actively distributes agency and legitimizes institutional authority. The CAGC frames government oversight as a proactive force rather than a distant regulatory mechanism, demonstrating that even professional advocacy texts are implicated in broader ideological and neoliberal debates over responsibility, governance, and the commodification of genetic information (Fairclough, 2003; Rose, 2007). Through its rhetorical choices, the Fact Sheets reinforce the idea that genetic privacy is both an individual right and a matter of public interest, revealing how language in professional advocacy

can shape social understanding, influence policy, and mediate the balance between ethical imperatives and broader structural or market-driven considerations.

Chapter 5. DISCURSIVE PRACTICE ANALYSIS-MESO-LEVEL

5.1) Overview

I situate this second phase of analysis within the processes through which texts are produced, distributed, interpreted, and consumed, by analyzing media and public discourse surrounding genetic testing and discrimination stemming from different stakeholders. Pistor's framework is important here in identifying how legal coding processes facilitate the commodification of genetic data, as influenced by institutional actors who shape policy and law. Focusing my analytic lens on the institutional context, in this chapter, I will show how governmental agencies, professional bodies, and advocacy groups contribute to the creation of these legal texts while unpacking the institutional interests behind GINA and similar legislation.

Intertextuality is a particular focus at this level of analysis to show how different texts (e.g., legislation, media reports, and advocacy publications) influence each other. For example, I question whether and how GINA benefits from earlier debates on genetic privacy or legal texts in anti-discrimination. In this level, I also analyze the interpretation and reception of this legislation, with a focus on how these laws are received by different groups, including patients, healthcare providers, and biotech companies, and on exploring disparities in the way genetic discrimination may be understood by stakeholders. For instance, professional publications by genetic counselors may frame genetic testing as empowering, while others may highlight the risks of privacy violations.

This level of analysis helps illuminate how legal discourse is shaped by social, economic, and political interests and how various actors contribute to the legal and ethical framework surrounding genetic testing.

5.2) Lobby groups

Various lobby groups are actively involved in efforts to present genetic privacy as essential in North America (the selected texts of the lobby groups are included in Table 2). Analysis of the structure of each text in this section reveals these groups' distinct orientations toward genetic nondiscrimination as well as their perceived role and relationships with government, the public, and genetic information. For example, the Genetic Alliance's structured, procedural response to specific policy inquiries reflects its formal advocacy role that conveys trust in regulatory processes while placing itself as a policy partner, supporting genetic privacy as a matter for regulatory protection. The CCGF's "Genetic Fairness" document takes an informative approach, with headings like "Why Genetic Privacy Matters" to inform readers of the importance of genetic protections. This structure aligns the CCGF with values of transparency and collective responsibility, positioning the organization as an educator, encouraging public awareness of genetic privacy policy.

Table 2 Lobbying Group Sources

Entity	**Document Title**
The American Society of Human Genetics	Protecting Canadians against Genetic Discrimination
Genetic Alliance-US Department of Labor	Genetic Alliance Response to Request for Information

Canadian Coalition for Genetic Fairness	Genetic Fairness One Step Closer to Canadians Making Informed Decisions About Their Health – Without Fear
Canadian Coalition for Genetic Fairness	Proposal to Protect Canadians from Genetic Discrimination
Sequence Bio	Changing the discriminating eye of the law
Huntington Society of Canada	Genetic Discrimination and the GNDA
Bio Technology Innovation	BIO's Letter Supporting S.358, the Genetic Information Nondiscrimination Act (GINA)

The use of the absolute recommendations and action steps in the CCGF's "Proposal to Protect Canadians" creates a persuasive, authoritative tone, prioritizing government intervention in protecting public rights, in which the CCGF takes a position of moral authority. Lastly, Sequence Bio's blog post, structured informally as a narrative, explains genetic discrimination through real-world implications, reflecting a neoliberal approach that highlights (corporate) accessibility and industry self-regulation. The format is approachable yet professional, appealing to both public and industry stakeholders by combining advocacy with (corporate) accessibility.

The Genetic Alliance strategically employs rights-based and security-focused language to frame genetic information as a highly sensitive and personal category of data that requires strong safeguards against institutional misuse (Genetic Alliance, 2008). Terms such as "rights," "access," "security," and "protection" are used throughout the text to construct genetic privacy as both a legal entitlement and a necessity for personal well-being. This framing presents genetic discrimination as a direct threat to individuals' autonomy and highlights the need for proactive measures to prevent its misuse. For instance, the document asserts that: "*The protections of the Genetic Information Non-discrimination Act represent a crucial step in this journey, and we expect the public will benefit from the use of genetic information to inform their healthcare decisions,*

provided that clear protections in health insurance and employment are in place." (Genetic Alliance, 2008). The phrase "clear protections" underscores the necessity of formalized legal safeguards, reinforcing the idea that individuals cannot be solely responsible for protecting their genetic data. Instead, privacy is framed as a structural concern of ensuring that institutions uphold protective measures. The use of "benefit" also implies that these legal protections serve a functional role, enabling individuals to access genetic testing without fear of discrimination.

Through this framing, the Genetic Alliance constructs privacy as both a right and a practical necessity, advocating for legal guarantees that extend beyond personal responsibility. Another lobby group, the American Society of Human Genetics (ASHG), highlights the GNA's importance in protecting patient privacy and promoting genetic counseling in their public materials (ASHG, 2020). By emphasizing "patient autonomy" and "informed decision-making," these documents align with the professional ideologies of health advocacy and patient rights.

By focusing on "patient autonomy" and "informed decision-making," ASHG aligns its discourse with broader health ethics principles that emphasize individuals' ability to make choices about their genetic testing without coercion or fear of discrimination. This perspective is evident in its coverage of the law's impact on clinical care and research participation. Dr Ronald Cohn, medical geneticist and President and Chief Executive Officer of the Hospital for Sick Children, told parliamentary committee members about ill children who could not be helped without genetic testing but whose parents, while desperate to help their children, could not consent to genetic testing for fear of genetic discrimination. Dr. Cohn states that *genetic discrimination interferes with our ability to provide high-quality, safe, and best-standard clinical care to our patients, something that, in part, can be paralyzing for us as healthcare providers* (Cowan et al, 2022). Here, the

language of medical professionalism underscores that protecting patient privacy is not merely a legal issue but a fundamental ethical obligation of the healthcare system. The phrase “paralyzing for us as healthcare providers” suggests that, prior to the GNA, clinicians were hindered in their ability to provide optimal care, not due to a lack of scientific knowledge, but because of systemic fears surrounding genetic discrimination. This framing shifts the conversation from an abstract policy debate to a human-centered narrative that prioritizes patient well-being.

Moreover, ASHG (2020) highlights trust in genetic services as essential for both patient care and scientific progress. This is reflected in the testimony of Dr. Cohn, who described research in which families of children with serious medical conditions were offered free whole-genome sequencing. Initially, many families were “elated at the prospect of something that might lead to a diagnosis of their children’s conditions,” but then, “because of fear of genetic discrimination, over 35 percent of the families concluded they had to decline to participate.” This passage frames fear of genetic discrimination not as a hypothetical concern but as an active deterrent to medical research and clinical advancements. The contrast between initial enthusiasm and ultimate reluctance identifies the absence of legal protections as directly impacting individuals’ healthcare decisions. ASHG’s discussion of these cases in the text aims to validate the need for legal and institutional guarantees to protect genetic privacy, ultimately aiming to restore public confidence in genetic medicine.

ASHG’s narrative also aligns patient rights with broader public health benefits, positioning genetic protection as essential to fostering participation in research that could lead to medical breakthroughs. This ideology is particularly evident in the following excerpt from an interview with Barbara Kagedan who is a lawyer and served as a policy advisor to Canadian Parliamentarians

and Cabinet Ministers for over 25 years, including serving as Director of Policy to Senator Jim Cowan, the leading sponsor of GNA: "It is tremendously satisfying to know that this very short law (it is only three pages long) has cleared the path for all Canadians to benefit from the incredible advances in genetic science" (ASHG, 2020). The phrase "cleared the path" suggests that GNA is not just a safeguard but an enabler of scientific progress, eliminating the legal and ethical concerns that once deterred participation in genetic research. By emphasizing that genetic testing decisions should be personal choices free from external pressure, ASHG appeals to the bioethical principle of informed consent, ensuring that individuals can navigate genetic healthcare without institutional constraints.

In contrast to regulatory documents that frame genetic privacy as a compliance issue, ASHG's language in public materials constructs genetic protections as a means of empowering individuals. This distinction aligns with a patient-centered approach to healthcare, in which privacy is not merely a legal safeguard but a prerequisite for trust in medical services (Prainsack, 2017; Mamo & Fishman, 2013). By integrating real patient experiences, ethical concerns, and professional perspectives, ASHG defends the GNA and confirms the role of legal protections in advancing both scientific innovation and patient autonomy.

The discursive practices of these various lobbying organizations aim to reassure patients about the privacy and ethical use of their genetic information by fostering trust in genetic services**.** This is achieved not only through explicit claims about legal protections but also through rhetorical choices that position institutions as both advocates and enforcers of ethical medical practices. For example, ASHG (2020) states that "fear of genetic discrimination is not an issue for their patients" following the passage of the GNA, implying that institutional oversight has successfully eliminated

this barrier to care. This construction frames the law as an active force that has already improved patient confidence, rather than as a policy still subject to limitations or legal challenges. The phrase "not an issue" erases lingering concerns patients might have, presenting genetic privacy protections as fully realized and effective. In doing so, ASHG draws on and reinforces a narrative that encourages individuals to engage with genetic testing and research by positioning regulatory mechanisms as sufficient to ensure ethical practices.

Collectively, lobbying texts construct genetic privacy as a fundamental right by implying that individuals need legal guarantees to access healthcare and employment without the risk of genetic discrimination. Asserting the importance of individual rights against institutional overreach invokes what Fairclough (1989: p.114) describes as a text's "experiential value", in this case, where "rights" and "protection" signal the need for strong legal safeguards. This highlights a vision of society where government intervention protects personal privacy, resonating with the values of individual autonomy and resistance to corporate or governmental abuses. By coding genetic information within anti-discrimination laws, governments and advocacy groups shape the conditions under which individuals engage with genetic testing and research. This legal coding does not merely protect individuals; it also facilitates the integration of genetic data into the biotechnology and healthcare industries.

According to Pistor (2019), capital is not an inherent property of assets but is created through legal coding that selectively grants protections and privileges to certain forms of property. This perspective helps to explain why organizations like Genetic Alliance advocate so strongly for legal protections while simultaneously supporting expanded access to genetic testing and research. By securing legal rights around genetic information, these organizations contribute to the

stabilization of genetic data as a valuable asset within the biotechnology sector. The legal protections, therefore, do not simply serve as a shield for individual privacy but also function as an enabling mechanism that makes genetic data more accessible and reliable for institutional actors, including researchers, pharmaceutical companies, and insurers who must navigate evolving legal landscapes.

Similar to the Genetic Alliance, the Canadian Coalition for Genetic Fairness (CCGF), in its "Genetic Fairness" document, uses terms like "informed decisions," "freedom," "dignity," and "privacy," framing genetic information as central to personal identity and agency (CCGF, 2018). The ways these organizations use these terms in their texts underscores the construction of genetic privacy as essential for individual welfare, equity, and full societal participation without discrimination. In the CCGF's "Proposal to Protect Canadians," terms like "protection," "rights," "safeguard," and "access" highlight the need to protect individuals from discrimination**,** framing genetic privacy as a universal right necessary for fair access to services. The *expressive value* (Fairclough, 1989) is one that views genetic discrimination as an infringement on dignity and autonomy, reflecting priorities on universal rights and protections.

The Huntington Society of Canada's document titled *Genetic Discrimination and the GNA* constructs genetic discrimination as a pressing ethical and legal issue, using authoritative language and moral appeals to justify legislative intervention. By defining genetic discrimination with concrete examples, the text frames it as a systemic injustice, stating: "Genetic discrimination occurs when people are treated unfairly because of actual or perceived differences in their genetic information." This experiential framing (Fairclough, 1989) presents discrimination as a tangible social harm rather than an abstract concern, reinforcing the necessity of legal protections. The

document further strengthens this argument with emotive anecdotes, such as a father refusing genetic testing due to employment fears, positioning a lack of protection as forcing individuals to choose between their health and economic security.

The text broadens the issue to a collective national concern, stating: "All Canadians are affected by genetic discrimination." This inclusive language fosters a sense of shared responsibility, framing genetic privacy as a public good rather than an individual concern. The use of high modality statements such as "Genetic discrimination is real" and "Genetic discrimination is unjust" eliminates ambiguity, positioning the Huntington Society as a moral authority advocating for systemic change. By citing national statistics, such as "*91% of Canadians felt that insurance companies should not be allowed access to their genetic information*", the text further constructs public consensus in favor of the GNA, reinforcing the law's legitimacy.

The document further legitimizes the GNA by emphasizing its legislative process and legal victories. Phrases like "Bill S-201 passed 3rd reading" and "received Royal Assent" highlight its democratic legitimacy, portraying it as a widely accepted policy rather than a contested law. Additionally, it positions advocacy groups as key actors, stating: "*Our community members had the courage to tell their stories and influence the protection of genetic test information*." This shifts the narrative from government-led action to grassroots activism, reinforcing the power of public engagement in shaping policy.

The text also acknowledges legal challenges, particularly the Québec government's attempt to invalidate the GNA, which it frames as a threat to genetic privacy. Statements like "CCGF was the appellant in the case heard at the Supreme Court" construct a clear opposition between provincial resistance and national protection, reinforcing the GNA's importance. The final ruling,

described as "*upholding the Genetic Non-Discrimination Act, is presented as a decisive victory, eliminating uncertainty about the law's validity*".

The closing section shifts to individual responsibility, advising people to educate healthcare providers and ensure compliance with the law. The directive "*Educate your own healthcare provide*rs" suggests that legal protections require active enforcement by individuals, aligning with neoliberal advocacy models that emphasize self-advocacy over government enforcement. While the GNA is framed as a landmark victory, the document from the Huntington Society highlights the idea that patients must remain vigilant in protecting their own rights, reflecting broader trends in patient-centered activism.

The Canadian biotechnology company, Sequence Bio's "*Changing the Discriminating Eye of the Law*," article uses terms like "innovation," "progress," and "transparency" to present genetic information as an asset requiring protection and as a resource for biomedical advancement (Sequence Bio, 2018). For instance, the article states, "Genetic testing is becoming more common, and more and more useful. Understanding our genetic makeup is changing how we are prescribed medicines, how we determine our likelihood for disease, and leading to groundbreaking research". Here, genetic information is described as a tool for scientific and medical progress, supporting its role as an essential component of healthcare developments. By linking genetic testing to "groundbreaking research" and "the right treatment and care," the company highlights its interest in fostering public trust in genetic science while advocating for legal protections that ensure public participation in genetic testing.

This vocabulary reflects a neoliberal emphasis on individual rights alongside the importance of responsible data use for societal benefit. This company's use of terms like

"innovation" suggests that genetic data, while needing protection, should also be employed for scientific progress. This framing positions genetic information as a valuable asset within the bioeconomy, aligning with market-driven values that consider personal data both a right to be safeguarded and a resource for advancement. The article explains that "this legislation will not only protect Canadians from discrimination and promote the use of genetic tests for healthcare (i.e., precision medicine), but it will also support world-class, Canadian-led medical research and innovation, which will positively impact all Canadians in the future." This statement identifies a dual function of genetic privacy protections: they reassure the public about ethical concerns while ensuring that genetic data can continue to fuel advancements in medical science. The company is advocating for individual autonomy and simultaneously constructing genetic data as a critical resource for Canada's bioeconomy.

Analysis of these key texts produced by lobby groups further shows how each positions individuals, institutions, and government bodies in relation to genetic privacy. For instance, the Genetic Alliance frequently uses active constructions, such as "we support policies that ensure" and "our commitment is to protect," which positions the organization as an active advocate for genetic privacy; in other words, making the Genetic Alliance's lobbying role explicit. By presenting itself as a proactive intermediary between the public and government, the Genetic Alliance establishes a power dynamic where it advocates for the public, reflecting a belief in the role of private organizations in influencing public policy.

The CCGF's "Genetic Fairness (2017)" document uses inclusive, despite being vague to some extent, phrases like "Canadians need" and "we must protect," towards a sense of collective responsibility and agency for genetic privacy and non-discrimination. Language that invokes

solidarity in the reader is geared to promoting shared responsibility (Fairclough, 1989). The document frames the government and public as joint stakeholders in ensuring equitable access to genetic information, with values of collective welfare and government accountability. The government is positioned as an ally instead of a distant authority, responsible for upholding citizens' rights.

In the CCGF's "Proposal to Protect Canadians (2015)," the high modality phrases like "must not" and "should ensure" reflect a more distinctively authoritative stance, highlighting the text's call for government action. Through conveying a sense of urgency and non-negotiable obligations (Fairclough, 1989), the rhetoric positions the CCGF as a moral authority that expects the government to protect genetic privacy and prevent the harms of discrimination immediately and through legislative intervention. The use of urgent, prescriptive language reflects a more urgent approach, which suggests that legislative progress requires a stronger push. The CCGF presents itself as a moral authority, expecting the government to act decisively to prevent genetic discrimination, which suggests a transition from advocacy to policy negotiation, reinforcing the expectation that government intervention is a necessary and immediate response to an identified

risk.

Turning to Sequence Bio, this biotech company's blog (available to the general public) balances active and passive rhetorical structures, assigning responsibility across both individual researchers and regulatory bodies. Passive constructions, such as "research must be conducted responsibly," emphasize ethical standards without specifying agents, which may be used to convey impartiality (Fairclough, 1989). Presenting the idea of balanced agency/responsibility implies a neutral regulatory environment where both individuals and institutions uphold genetic privacy,

resonating with a neoliberal ideology that values self-regulation within industry, while acknowledging a need for some oversight.

BIO letter (2008) in support of GINA appeals to policymakers by positioning the biotechnology industry as both an advocate for patient rights and a driver of economic and scientific progress. This dual positioning reflects a calculated discursive move that aligns with Fairclough's (1989) concept of experiential value, where the language used in the text reflects the broader ideological and institutional interests of the industry. The letter states: "Passage of genetic non-discrimination legislation will ensure that patients can enjoy the benefits of medical advances that are occurring through our enhanced knowledge of genetics, without fear of discrimination." Here, the phrase "enjoy the benefits of medical advances" constructs GINA as a patient-centered initiative, while this framing serves a strategic function by reinforcing the industry's interest in maximizing participation in genetic testing and research. This language aligns personal empowerment with market expansion, positioning individuals as both beneficiaries and participants in the commercialization of genetic data (Rose, 2007; Prainsack, 2017). The absence of regulatory barriers is presented as a condition for scientific progress, implying that delayed or restricted implementation of genetic non-discrimination laws could slow down biomedical innovation. This positioning reflects a neoliberal discourse in which regulation is necessary only to the extent that it facilitates market expansion. The letter highlights the role of personalized medicine, which aligns with broader market-driven discourses to promote biotechnology as an essential component of modern healthcare by stating: "We are beginning an era of personalized medicine, where each individual's health care is shaped according to his or her individual genetic make-up."

As part of the discursive framing of GINA, policymakers themselves also used optimistic and future-oriented language to emphasize its potential benefits. Representative Judy Biggert, a co-sponsor of the bill, echoed the language and arguments of lobby groups of the time when they stated: "*This bill unlocks the great promise of the Human Genome Project by alleviating the most common fear about genetic testing. It will accelerate research... and allow Americans to finally realize the benefits and health care savings offered by gene-based medicine."* (Hudson et al. 2008, p. 2663). This framing positions GINA not only as a legal safeguard but as a key enabler of biomedical innovation and economic efficiency, an interpretation that resonates with neoliberal discourses prioritizing market growth and technological advancement.

BIO links genetic research to the promise of improved healthcare outcomes, constructing GINA as an enabler of innovation rather than merely a legal safeguard. The future-oriented rhetoric suggests that personalized medicine is an inevitable and necessary progression, and GINA serves as a crucial step toward realizing this vision. This deterministic framing of technology highlights the neoliberal principle of self-regulating markets, where public policy must align with scientific and economic imperatives (Dean, 2010; Jessop, 2002; Lemke, 2001; Rose, 2007). The letter also uses fear appeals to justify the necessity of GINA, warning that public anxiety over genetic discrimination "may greatly slow down or impede the promise of personalized medicine." The use of the modal verb 'may' introduces a contingent threat, presenting regulation not as an imposed necessity but as a proactive measure to prevent a potential crisis. The phrase "slow down or impede the promise" reinforces a dichotomy between scientific progress and inaction, pressuring policymakers to prevent economic stagnation by supporting GINA.

Part of the industry's broader lobbying efforts also involves the key strategy of co-opting privacy concerns. The BIO letter (2008) states: "BIO has long supported national policies to ensure that individuals' personal medical information, including genetic information, is safeguarded against misuse." This statement allows BIO to position itself as an ethical actor, reinforcing a corporate social responsibility narrative while simultaneously advocating for industry-friendly regulation. By emphasizing "safeguarded against misuse" rather than strict regulation, the language suggests that industry-driven measures may be preferable to heavy-handed government intervention. This reflects Fairclough's (1989) concept of relational value, where the text establishes a power dynamic that positions the biotech industry as a key partner rather than a regulated entity.

The BIO letter exemplifies a neoliberal lobbying discourse, where regulation is framed as a facilitator rather than a constraint, aligning with the broader logic of "competitive regulation" that prioritizes market innovation and self-regulation over restrictive state intervention (Dean, 2010; Jessop, 2002; Lemke, 2001; Rose, 2007). By emphasizing scientific progress, economic growth, and voluntary industry compliance, the letter constructs GINA as a necessary and industry-friendly measure. The discursive strategy of blending patient rights with market imperatives allows BIO to present itself as a key stakeholder in shaping genetic privacy policy, reinforcing the notion that corporate and public interests are mutually reinforcing.

5.3) Media Articles:

The analysis here draws on 18 articles between 2004 and 2024 from prominent mainstream news outlets such as CBC News, The New York Times, The Washington Post, Fox News, NBC News, The Wall Street Journal, as well as Genetic Engineering & Biotechnology News, among

others (the full list is available in Table 3). These outlets were selected based on their coverage and influence in shaping public discourse on genetic discrimination, legal protections, and the intersection of biotechnology and market-driven narratives. The 18 included articles cover legislative developments, ethical concerns, industry interests, and the broader societal implications of genetic privacy and anti-discrimination protections.

Table 3 Media Sources

Media Outlet	**Title**
The Conversation	Canada's Genetic Non-Discrimination Act has only had a limited impact on the use of genetic information by life insurers
CBC News	Door will open to genetic discrimination if act protecting Canadians is overturned, genomics expert says
CBC News	Genetic anti-discrimination law protects patient privacy without sacrificing research
CBC News	Senate passes bill to keep genetic test results private
CBC News	Liberal backbenchers defy cabinet wishes and vote to enact genetic discrimination law
CBC News	Supreme Court of Canada upholds genetic non-discrimination law
CBC News	MPs reject liberal government's attempt to gut the genetic discrimination bill
CBS News	Guarding Against Genetic Discrimination
Fox News	Congress Sends Bush Anti-Genetic Discrimination Bill
Genetic Engineering & Biotechnology News	GINA Provides Bioindustry Boost
Global News	MPs to debate controversial bill on genetic testing after intense lobbying
NBC News	Senate passes genetic discrimination ban
New York Times	Opinion | A Ban on Genetic Discrimination

New York Times	Opinion | My Medical Choice by Angelina Jolie
New York Times	Once Again, Scientists Say Human Genome Is Complete
Time Magazine	Can You Be Fired for Your Genes?
The Wall Street Journal	Hands Off My Genes
The Washington Post	Act Now to Prevent Genetic Discrimination

Media coverage of early genetic discoveries from the 1990s onwards, most notably HGP (1990–2003), focused on the scientific and public health benefits rather than the commodification of genetic data. News reports often celebrate these breakthroughs as milestones in human knowledge, emphasizing collective progress rather than private ownership. For instance, media coverage of HGP presented the sequencing of DNA as a triumph for humanity, reinforcing the idea that genetic information was a public good, freely accessible for medical research. The New York Times (2003) quotes the leaders of the public consortium of academic centers who state, "*We have before us the instruction set that carries each of us from one cell through adulthood to the grave*". This language of "*instruction set*" highlights the neutrality and universality of the project, masking the reality that corporate entities were already filing patents on genetic sequences.

Before the passage of GINA in 2008, media narratives largely framed patients as vulnerable individuals in need of legal protection rather than as active participants in shaping policy. Mainstream coverage emphasized personal stories of genetic discrimination, often using emotional language. For instance, CBS News reported in 2008 that GINA would provide relief by ensuring that: "*people learning through genetic testing that they might be susceptible to devastating diseases wouldn't also have to worry about losing their jobs or their health insurance*." (CBS News, 2008). This statement suggests that patients were previously unable to exercise control over their genetic information, reinforcing a narrative of helplessness that positioned the law as their only defense.

Similarly, the Washington Post (2005) states that without national protections, individuals may decline to participate in genetic research studies or may compromise their health by refusing testing of their genomes, thereby halting the field and promise of genetics. Such framing aligns with Pistor's (2019) argument that the enclosure of genetic knowledge within legal frameworks serves not only to protect individuals but also to stabilize emerging markets by reducing uncertainty and risk for insurers, employers, and biotech firms.

As Pistor (2019) notes, even before the full genome was mapped, efforts to enclose and commercialize genetic data had already begun through intellectual property laws. From the early stages, media coverage also reflected the growing private sector interest in genetic data, highlighting Celera Genomics' high-profile sequencing race (Wall Street Journal, 2000) by setting the stage for ongoing debates about patents, ownership, and access. Indeed, as genetic testing and biotechnology investments continued to expand in the early 2000s, media narratives increasingly focused on the commercialization of genetic data. This shift coincided with corporate lobbying and legal battles over patents (Pistor, 2019). Despite the media coverage on the commercialization of genetic data, a common theme emerges, as Time Magazine (2012) indicates: the implementation of legal protections does not mean there will not be plenty of companies looking to benefit from genetic information, but if they use it, they may well have to pay.

A major turning point in media mobilization occurred in 2013 when Angelina Jolie's OpEd, "My Medical Choice," was published in The New York Times. Jolie revealed that she underwent a double mastectomy after testing positive for the BRCA1 gene mutation, stating that the cost of genetic testing is beyond the means of many women, denying them the choice she had. (New York Times, 2013). Her Op-Ed transformed public debate, shifting media coverage from scientific

discourse towards a greater focus on personal agency, affordability, and corporate monopolization. The Supreme Court's ruling against Myriad Genetics' attempts to patent BRCA gene mutations soon followed, marking a rare victory for patient advocates against biotech enclosure. However, as Pistor notes (2019), Myriad's monopoly did not truly collapse. The company continued to profit by leveraging trade secrecy laws to maintain control over its vast genetic database, showing that legal enclosures do not end with patents; they evolve through new legal strategies. This example demonstrates how media can temporarily mobilize public resistance, but corporate power often adapts, reinforcing long-term enclosures through alternative legal mechanisms.

Following the passage of GNA in Canada in 2017 and the continued enforcement of GINA in the U.S., media narratives shifted to a greater focus on long-term implications, loopholes, and continued activism. For example, in the wake of Québec's legal challenge to GNA, CBC News reframed the debate as a constitutional struggle, stating that Québec argues that the law is unconstitutional, claiming that genetic privacy regulation falls under provincial jurisdiction (CBC News, 2018). This jurisdictional framing diverted attention from patient rights to legal technicalities, potentially demobilizing public advocacy by shifting the debate away from individual concerns toward legal proceduralism. However, patient advocacy groups continued to push back, using moral and civil rights arguments to maintain momentum. The New York Times (2009) echoed this perspective, arguing that people with family histories of certain diseases have had difficulty in buying health insurance. This critique highlights Pistor's assertion (2019) that legal enclosures are not static but continually contested, with regulatory frameworks often evolving not to eliminate corporate control but to redefine its boundaries.

In more recent years, the media has increasingly framed genetic information as both an economic asset and a privacy risk, reflecting broader concerns over data security, consumer rights, and corporate power. This multifaceted framing aligns directly with Pistor's theory of legal coding (2019), where assets are not merely economic but also legally constructed to serve different stakeholders (scientists, businesses, and regulators). While some media coverage highlights the economic value of genetic breakthroughs, others focus on privacy concerns and misuse of data. The CBC News reports on real-life cases where genetic testing has been used unethically, stating that some employers and insurers have required genetic tests without patients' knowledge, raising fears about discrimination." (CBC News, 2018). This reflects growing awareness of how genetic data, once enclosed through patents, is now being controlled through corporate trade secrets and private databases, reinforcing Pistor's argument that legal enclosures evolve rather than disappear. Media coverage questions the ethical implications of corporate control over genetic data in recent articles.

Media articles use specific lexical choices, grammatical structures, and rhetorical techniques to shape the reader's perception of genetic discrimination laws. The use of high-modality language highlights the urgency of genetic protections. For instance, NBC News (2008) quotes a member of the US Senate describing GINA as "*the first major new civil rights bill of the new century*," positioning it as a necessary and historic legal intervention.

The use of passive voice also influences agency. Advocacy-driven media tend to use active constructions to highlight government action (e.g., "Congress passed the bill to protect citizens" in Fox News, 2008). In contrast, industry perspectives often employ more neutral constructions on the impact of the legislation instead of their corporate interests, such as "t*he Canadian Life and*

Health Insurance Association warns of higher costs and reduced coverage if passed " (Global News, 2017). This narrative renders opposition seem more neutral and organic, with a focus on impact on individuals, rather than corporate-driven.

The language used in media articles can shape public perception of genetic discrimination laws. For example, CBS News frames GINA as a proactive measure rather than a reactionary policy, stating: *"people …wouldn't also have to worry about losing their jobs or their health insurance."* (CBS News, 2008). The phrase "wouldn't have to worry" constructs genetic nondiscrimination laws as protecting people from fear of harm as well as from the harm itself, positioning legal protections not as regulatory burdens but as enablers of patient empowerment. This aligns with consumer protection discourse, which reassures individuals that they can access genetic testing without economic or professional repercussions. Business-oriented media outlets such as The Wall Street Journal focus on risk and economic uncertainty, warning that genetic privacy laws could create significant burdens on businesses (Wall Street Journal, 2000). Here, corporations, not patients, are framed as the primary stakeholders, with regulation positioned as a potential disruption to actuarial models and market efficiency.

Media narratives often frame genetic privacy laws as enablers of scientific progress, ensuring that patients are willing to undergo genetic testing. Some articles, particularly from business-oriented outlets (e.g., The Wall Street Journal, Genetic Engineering & Biotechnology News)**,** frame genetic data as a market commodity that should be regulated with caution to avoid economic harm. The Wall Street Journal (2000) states that genetic privacy is as vital a principle as other forms of private property. It is also added that if people do not trust that their genetic information will remain private, they would avoid testing and miss out on advances in medical

care; while allowing individuals to keep their genetic results confidential may disrupt the insurance industry, since people could selectively buy coverage based on their risks, that's a challenge for insurers (Wall Street Journal, 2000). These arguments reinforce the neoliberal assumption that markets, rather than laws, should determine data access. Regulatory debates, then, are not just about fairness but about who gets to control genetic information and how it is economically valued.

Regulations like GINA and GNDA transform genetic data into a legally protected category, restricting its commercial use. The New York Times (2009) argues that without strict protections, insurers will exploit genetic data, stating that advances have been made in genetic testing; however, employers and insurance companies have used it to penalize people. This highlights how legal coding, described by Pistor (2019), shapes genetic data's economic and ethical dimensions. Without regulation, genetic information remains a market asset available for corporate use; with regulation, it becomes a protected legal entity, ensuring public trust.

Mainstream media frequently constructs governments and lawmakers as the primary agents of responsibility using a top-down narrative where state intervention is necessary to protect citizens from discrimination and market exploitation. In coverage of the GINA in the U.S., Fox News states: "*Congress sent President Bush a bill Thursday forbidding employers and insurance companies from using genetic tests showing people are at risk of developing cancer, heart disease or other ailments to reject their job applications, promotions, or health care coverage, or in setting premiums*"(Fox News, 2008). Here, the active construction ("Congress sent") attributes agency to lawmakers, positioning them as proactive defenders of genetic privacy. By contrast, insurance companies and employers are passively referenced, avoiding explicit attribution of blame. This passive structure minimizes corporate responsibility, making discrimination appear as a systemic

issue rather than a result of deliberate industry practices. Similarly, The Washington Post highlights state-led intervention, stating: "*Act now to prevent genetic discrimination*." (The Washington Post, 2005). The imperative "act now" further highlights government responsibility, aligning genetic non-discrimination laws with the broader civil rights tradition, where legislative action is positioned as the necessary means to ensure fairness. The use of imperative language to urge action also reinforces the idea that genetic discrimination is an imminent threat requiring immediate regulation.

In contrast to government-framed narratives, corporate actors often distance themselves from direct accountability, shifting responsibility to the market, legal ambiguity, or unintended consequences. The Wall Street Journal (2000) warns that GINA could create burdens on businesses such as the insurance industry, where regulation is constructed as a hypothetical economic disruption rather than a moral or legal necessity. Similarly, in Canada, the insurance industry opposes Bill S-201, with the Canadian Life and Health Insurance Association (CLHIA) arguing the possibility of higher premiums for all Canadians (CBC News, 2017c). This statement shifts responsibility away from insurers by implying that regulation, not corporate practices, would lead to increased financial burdens. This framing discourages regulatory intervention, suggesting that market-based solutions are preferable. The insurance industry further highlights this logic by downplaying the existence of discrimination.

Media narratives also construct individuals as both empowered agents and potential victims, shaping public perceptions of genetic testing and consumer choice. Initially, patients were passive subjects of discrimination. The dominant antagonist in media narratives is corporate overreach, particularly employers and insurers who might use genetic data unfairly. Time

Magazine (2012) states that "*even though this sort of medical information should remain private, employers and insurance companies will have strong financial incentives to get access to it — and to use it to avoid people who are most likely to get sick*". The passive victim vs. active corporate oppressor narrative amplifies the necessity of GINA as a moral safeguard. But over time, media coverage helped transform them into active political agents advocating for legal protections. At the same time, corporate actors have used the legal coding of genetic data to maintain control, often framing regulation as a threat to economic stability and innovation. As Pistor's analysis shows, these legal enclosures are not static but continuously contested, with media playing a critical role in both exposing and reinforcing the power dynamics at play.

Regulation is often framed not as a restriction but as an enabler of scientific progress, reinforcing the neoliberal logic that market stability, rather than just ethical considerations, justifies privacy protections. NBC News (2008) highlights the consequence of lacking adequate genetic privacy legislation to alleviate public concerns, noting that: "*there are more than 1,100 genetic tests available today…but these are absolutely useless if fear of discrimination discourages people from taking tests or participating in clinical trials*." With an optimistic tone about the premises of genetic testing, the New York Times (2009) states that an added benefit is that the law advances genetic science, which cannot conduct research without people willing to undergo testing. However, while individuals are positioned as empowered participants in genetic testing, they are also depicted as vulnerable to discrimination if laws are insufficient. The emphasis on the "fears" in the CBC News (2018) article indicates a passive victimhood, reinforcing the need for external legal protections rather than individual agency. The Washington Post's more activist stance, urging immediate legislative action, indicates the shift from patient vulnerability to political urgency. These examples explain how media can both reflect and shape the momentum of legislative efforts,

framing regulation not as a burden but as a necessity to protect both civil rights and scientific progress.

Rather than simply restricting businesses, genetic privacy laws are framed as mechanisms that ensure public trust in genetic testing, allowing biotech firms to expand research. Genetic Engineering & Biotechnology News argues: "*We expect that the use of predictive genetic testing and screening procedures in personalized medicine will inevitably become a more common practice and an integral part of medical care*." (Genetic Engineering & Biotechnology News, 2008). The phrase "inevitably become" implies that genetic testing is a predetermined economic trajectory, reinforcing Pistor's assertion that regulation is often used to formalize existing industry practices rather than radically transform market structures.

Whereas media and policymakers frame genetic discrimination legislation as a means for consumer protection, for biotech companies like Sequence Bio, the legislation serves their business interests by increasing public participation in genetic research while stabilizing the genetic data market. Their lobbying efforts aim to increase genetic testing participation, secure legal certainty for research investments, and prevent public backlash over genetic data misuse (Allison, 2008). As CBC News (2017a) highlighted, individuals feared that genetic tests could be used against them: "*Some patients refuse genetic testing, worried that insurers will use the results to deny coverage*." By addressing these concerns, legislation provides legal assurances that genetic data will not be misused by encouraging more people to undergo testing and share their genetic information. This highlights how anti-discrimination laws play a strategic role in facilitating genetic research and sustaining biotech industry interests. Biotech firms heavily invest in genetic research, and uncertain

legal frameworks create business risks. Biotech companies frame genetic research as beneficial for public health, but their ultimate goal is to secure exclusive control over valuable genetic datasets.

Breakthroughs in genetic research are often celebrated as pivotal moments in medical history. Articles in CBC News (2016, 2017a) and the Conversation (2024) emphasize genetic testing as a pathway to personalized medicine and early disease detection. CBC News (2017a) describes genetic protections as enabling a new era of medical research where individuals can participate without fear of discrimination. A belief in genetic science as inevitable and progressive reinforces the idea that we must regulate it wisely rather than question its direction. Again, as Pistor (2019) argues, legislation serves to "code" genetic data as an asset rather than fundamentally questioning the ethics of its use. Both media and legislation position genetics as a transformative force while ensuring that regulations do not disrupt biotech industry interests.

Media narratives treat genetic information as uniquely powerful, often ignoring the limitations of genetic interventions. Evans et al (2001) indicate that genetic risk is probabilistic, not deterministic; yet uncertainties contrast against the presentation of predictive genetic testing in the popular media, which often fosters an illusion that genetic risk is highly predictable and determinative. Many conditions, such as Alzheimer's and breast cancer, involve multiple genetic and environmental factors. Common diseases like cancer and cardiovascular conditions, genetic risk assessments are more complex and less definitive (Burke, 2002). This oversimplification of genetic risk in media narratives highlights genetic determinism, potentially misleading the public and policymakers while downplaying the critical role of environmental, lifestyle, and social factors in disease development.

The debate over genetic discrimination laws is shaped by a conflict between public protection and corporate interests. Governments and civil rights organizations advocate for legal protections, while insurance companies and biotechnology firms seek to preserve their ability to use genetic information for financial and research purposes. Analyzed through Fairclough's CDA and Pistor's legal coding theory, it is observed that genetic non-discrimination laws are not just about protecting individuals from bias. They also reshape the economic and legal status of genetic data. While governments and privacy advocates push for stronger protections, the insurance and biotech industries navigate a delicate balance between regulation and commercial interests. Ultimately, genetic privacy legislation represents a power struggle over the legal and economic control of personal data, where the boundaries between privacy rights and corporate interests remain contested.

Chapter 6. SOCIAL PRACTICE ANALYSIS- MACRO LEVEL

6.1) Overview

Within Fairclough's (1995a) framework, discourse is understood as a form of social practice—but it is important to clarify that discourse does not reduce social practices solely to their discursive elements. Rather, social practices encompass a complex interaction of discursive and non-discursive elements, including norms, institutional rules, material conditions, and power relations. Discourse both shapes and is shaped by these broader social practices, forming a dialectical relationship. Fairclough emphasizes that social practices are the sites where language use (discourse) and other social factors are articulated together, enabling researchers to analyze how discourse mediates social structures without collapsing those structures into discourse alone. Therefore, the object of research in CDA involves examining how discursive practices interrelate with other social practices and institutional arrangements, revealing the ways in which power, ideology, and social structures are reproduced and contested through language and action.

In this last analysis chapter, I will explain how the legislative efforts to ban genetic discrimination in North America can be conceptualized as more than legal documents, but as social practices embedded in and shaped by the neoliberal, market-driven transformation of healthcare (Fairclough, 2003; Jessop, 2002; Petersen, 2015). These laws interact with biotechnological advancements and the commercialization of genetic knowledge beyond providing protection against discrimination. In doing so, they in turn contribute to shaping the actions, beliefs, relationships, and discourses that constitute the healthcare landscape.

In the first part, I will explore how genetic data is legally and economically coded into capital through the roles of various institutional actors such as biotech firms, hospitals, regulators, and insurers, showing how personal DNA is transformed into valuable assets via contracts, intellectual property law, and public-private partnerships. Then, I will examine how these legal frameworks do more than prevent discrimination; they actively enable the commodification and assetization of the genome, highlighting the power dynamics involved in ownership and control of genetic information. Next, I will analyze the discourses of empowerment and innovation surrounding genomics, revealing how these narratives serve to legitimize the commercialization of intimate biological data and obscure the underlying market motives. Following this, I will discuss real-world risks exemplified by cases like the bankruptcy of 23andMe, which expose the fragility of protections once genetic data becomes market capital. Finally, I will address the broader political economy questions of who sets the rules, who benefits, and who is marginalized as genomic data becomes a form of capital, emphasizing the responsibilities of institutions in managing the ethical and governance challenges of this evolving landscape.

Genomics discourse frequently positions precision medicine as empowering and transformative. However, actual patient experiences tend to reveal a more ambivalent and complex reality. As the Jackson Laboratory (2024) outlines, genetic testing in cancer care can produce a *spectrum of emotional reactions, including anxiety, guilt, and confusion, especially when results are uncertain or poorly contextualized*. This challenges the dominant narrative of genomics as unambiguously beneficial. Instead, it exposes how the hype surrounding precision medicine often neglects the emotional, ethical, and interpretive burdens placed on patients, particularly in the absence of comprehensive counseling and support. As Brown and Michael (2003, p. 4) argue, future-oriented promises of biotechnology often serve as “organizing dynamics” in emerging

health technologies, even when those promises have yet to materialize in clinical practice. As Fairclough (1995a, pp. 35–36) explains, dominant discourses can construct knowledge and shape social expectations by embedding ideologies that become naturalized—that is, detached from their social origins and presented as commonsensical or rooted in the nature of things. Such discourse constructs not only knowledge but expectations that may not align with clinical or personal realities. Dominant narratives shape hopes and fears, encouraging participation in genetic testing despite ambiguous utility; high public or patient expectations can blur uncertainty about long-term outcomes.

Hype regarding the premises of genetic technologies can further generate a sense of inevitability. From Pistor's perspective, this hype mechanism helps normalize speculative investment in genetic infrastructure. In this regard, the discursive construction of genetic testing as an essential indicator for predicting diseases reshapes public expectations, institutional priorities, and legal frameworks. The discourse surrounding GINA and GNA is infused with the language of rights, choice, and empowerment. Fairclough states that such textual features often manifest dominant ideologies, in this case, neoliberal individualism (Fairclough, 1995a). Media representations frame the legislation as moral victories that protect rights and choice while downplaying their limitations.

Another overlooked aspect of the genomic discourse is the institutional framing of privacy and consent. Legal frameworks such as GINA are frequently celebrated for safeguarding individuals from genetic discrimination, yet they are less equipped to address the complexities of ongoing data governance. Dressler and Terry (2009) express concern that "the promise of privacy" offered by laws like GINA may not align with the practical realities of data sharing and institutional

use of genomic data. Their analysis highlights how institutional actors tend to treat informed consent as a one-time procedural event, rather than as part of an ongoing ethical relationship that evolves alongside data use. This perspective underscores the *structural vulnerabilities that arise when responsibility for data protection is shifted to individuals under the guise of choice*. As Dressler and Terry (2009) caution, institutional reliance on informed consent often fails to account for the long-term trajectory of genomic data circulation, particularly its use in secondary research, biobanking, or commercial applications. They argue that while GINA offers protection against overt forms of discrimination, it does not resolve deeper tensions around privacy, control, and the downstream uses of genetic information. This gap reflects broader neoliberal patterns in which individual consent is emphasized over institutional accountability, masking the power asymmetries that underpin contemporary genomic data infrastructures.

Despite being framed as a protective measure, GNA legitimizes and promotes genetic testing by removing barriers to access and participation in genomic research (Bombard & HeimMyers, 2018). Likewise, as Hudson et al. (2008) argue, GINA serves as a foundational legal mechanism designed not only to protect individuals but also to promote public trust in genetic research and clinical testing. This is particularly important in the context of personalized medicine, where the success of scientific innovation depends on individuals' willingness to share genetic data. As noted earlier in this dissertation, both laws serve as a structural intervention that enables participation while implicitly *facilitating the commodification of genetic information under legal safeguards*. In this way, GINA functions as both a rights-based measure and a tool for building the conditions necessary for the expansion of genomic markets.

Extending this concept of discursive social practice further, the *geneticization of health* reconfigures individuals as morally and socially responsible for knowing and acting upon their genetic risks. For instance, Baker et al. (2022) observe that patients tend to accept genetic results as part of their health management, with many undergoing behavior change or taking cascade testing as a form of familial responsibility. To the extent that this evidences a broader cognitive-behavioural shift, this illustrates how discourse and legal frameworks together construct a normative expectation of genetic responsibility, embedding individualized risk management into broader social and institutional practices.

The legislative and discursive context around genetic discrimination reinforces various social practices, including the normalization of self-monitoring behaviors, patient-driven data sharing, and the growth of direct-to-consumer (DTC) testing. It is possible to observe these practices when patients share the results of their genetic testing with relatives, seek online information, or undergo prophylactic surgeries (Kaphingst et al., 2012; Baker et al., 2022). These are not just responses to technological change but are actively shaped through institutional, regulatory, and cultural mechanisms. Legislation such as GNA and other regulatory frameworks help constitute a discursive environment where genetic testing becomes normalized, desirable, and increasingly integrated into routine care, in addition to the promises of protecting individual rights against discrimination. Emerging from a broader discourse of genetic responsibility and innovation, these practices exemplify how social relations are reorganized through law, policy, and the ideological framing of genomic technologies.

The rise of DTC testing following HGP, for instance, fueled by the idea of empowerment through personalized solutions and control over wellbeing, has occurred with minimal oversight.

Individuals' encounter with genetic testing in a framework that fosters biocapitalism, contributing to data extraction with a belief that they are acting autonomously. The Food and Drug Administration (2019) warns of the potential risks to patients and providers acting on genetic test data that has not been demonstrated to promote the safe and effective use of drugs. Patients may act on genetic information in ways framed by commercial discourse shaped by marketing strategies rather than clinical need.

As such, the discourse of empowerment as heralded by DTC companies and public health campaigns masks the commercial logics underlying these interactions, where data is commodified and returned to individuals as both risk and responsibility (Rose, 2013). Additionally, even though the clinical utility of genetic tests is not certain, these tests are framed through promotional narratives of innovation, early detection, and personalized prevention (American Society of Clinical Oncology, 2022; Jackson Laboratory, 2024). These discourses pass through institutional practices, marketing materials, and even clinical guidelines, transforming individual choices into moral obligations.

Notably, despite legal protection against genetic discrimination, individuals rarely consult healthcare providers about DTC test results. Kaphingst et al. (2012) found that only 1% of participants shared their multiplex test results with a provider, revealing how commercialization sidelines clinical dialogue. The study assured participants that their test results would not be shared with healthcare providers; however, some patients may have avoided discussing them due to concerns about privacy or the possibility of discrimination if the information became part of their medical records (Kaphingst et al., 2012; p. 685). This lack of engagement illustrates the structural transformation of healthcare communication, where corporations mediate what were once

clinician-patient interactions.

Social practices around genetic testing reconfigure relationships between the state, corporations, and individuals. Patients are reimagined as genetic citizens and data providers in a way that gives healthcare institutions and biotech firms influence over healthcare decisions, treatment plans, and data ownership. GINA and GNA shape traditional social roles: the state as a market facilitator, the individual as a responsible consumer, and the corporation as an ethical innovator. As the theory of 'roll-out neoliberalism' indicates, these laws do not dismantle market structures but instead legitimize them, embedding corporate logic within the governance of genetic information (Peck & Tickell, 2002).

Within this commercialized context, traditional social relations in healthcare are being reorganized around neoliberal market logics. The role of genetic counselors, for instance, has shifted from being neutral mediators of clinical meaning to service providers embedded in systems that prioritize efficiency, scalability, and consumer satisfaction (Lambert et al., 2022). Counselors are expected to translate complex genomic information into consumer-friendly narratives, often in time-constrained environments where psychosocial support is marginalized.

In the context of Canada, *the absence of consistent legal recognition and regulation for genetic counselors further compounds this shift*. As Shugar et al. (2017) emphasize, the lack of a protected title and standardized licensure enables individuals without formal training to provide genetic counseling, in this way risking patient harm and eroding public trust. This legal ambiguity highlights the precarious position of certified professionals, whose roles remain underdefined and undervalued within institutional hierarchies. It also limits their integration into multidisciplinary healthcare teams, despite the rising demand for genomic literacy and the need for ethical navigation

in the age of precision medicine, both of which are critical to advancing health equity in genomics and precision medicine implementation (Khoury et al., 2022).

The way genetic knowledge is changing our social relationships points to a bigger shift toward privatization in which getting clear, reliable information often depends on what people can afford. The trust in professionals is also tied to how well they fit within a profit-focused healthcare system. While some scholars, such as Dorsey et al. (2013), contend that limited awareness of genetic nondiscrimination legislation, specifically GINA, contributes significantly to persistent concerns about genetic discrimination, this perspective may represent an incomplete understanding of the phenomenon. Legislation on genetic discrimination does not simply function as a regulatory tool but becomes part of a broader semiotic system for normalization through which genetic testing is depicted as rational, desirable, and inevitable. Such normalization enables the embedding of genomic practices into routine healthcare, labor expectations, and even kinship structures. The expansion of screening programs restructures genetic counseling workflows, and the rise of genomic literacy initiatives in clinical education has become a common practice in this regard.

The expansion of screening programs has restructured genetic counseling workflows, while the rise of genomic literacy initiatives in clinical education reflects broader efforts to institutionalize genetic knowledge (Petersen & Bunton, 2002). These developments align with the process of *biomedicalization*, where health and illness become increasingly defined and managed through technoscientific innovations (Clarke et al., 2003). As Rose (2007) illustrates, the politics of life itself are increasingly governed by molecular understandings of the body, which reconfigure how individuals and populations are managed. Through these mechanisms, social relations are

reorganized in ways that obscure the political-economic interests at stake and render biocapital accumulation both invisible and routine (Rajan, 2006).

In the genomic era, individuals are increasingly positioned through labels such as "genetically at risk," which shapes their sense of self, their health behavior, and their interactions with institutions (Kerr, 2004; Hedgecoe, 2004). The experience of receiving a genetic result is not just clinical; it is discursive, psychosocial, and political. Empirical studies such as Baker et al. (2022) reveal that while many individuals ultimately adjust to their genetic results, initial reactions often include shock, fear, or guilt, particularly when no prior family history exists to prepare them. These responses are not purely internal as they are conditioned by the social meaning of genetic risk.

Being labeled as genetically "at risk" for conditions such as Huntington's disease, BRCA-related cancers, or Alzheimer's may carry consequences far beyond clinical implications. Such individuals may be perceived as burdens on healthcare systems, liabilities to insurers, or less desirable in employment and intimate relationships (Bombard & Heim-Myers, 2018). These discursive constructs of genetic risk can create *new forms of social discrimination*, as noted in Bombard et al.'s (2011) national study on Huntington's disease, where participants reported experiencing rejection in contexts ranging from insurance to adoption. Consequently, individuals may refuse testing or conceal their results, paradoxically limiting their access to preventive care (National Cancer Institute, n.d.).

The implications of genetic labeling are especially pronounced in racialized contexts. Genetic research, even when well-intentioned, has at times emphasized essentialist ideas by overstating the biological basis of racial categories. As Bolnick (2008) illustrates, practices such

as individual ancestry inference often rely on predetermined racial groupings, which obscure the fluid and overlapping nature of human genetic diversity and also risk legitimizing race as a natural, biological division, despite its sociopolitical origins and implications. This practice, known as "*racialized genetics*", can obscure the structural and social determinants of health, such as poverty, stress, and access to care, which are more robust predictors of health disparities than genomics alone (Krieger, 2005).

Historically marginalized communities, such as African Americans and Indigenous populations, often carry deep mistrust toward medical genetics due to prior unethical practices like the Tuskegee Syphilis Study or Canada's forced sterilization programs (Nelson, 2016; TallBear, 2013). As Nelson (2016) illustrates, the mistrust is rooted not only in historical injustices but also in the contemporary commodification and politicization of genetic data. Nelson (2016, pp.153160) explores how African American communities have engaged with genetic ancestry testing as a tool for reclaiming identity and historical continuity, yet she also notes the ambivalence and anxiety that accompany these interactions. While some embrace the potential for empowerment, others view genetic testing as a form of biological surveillance or state-sanctioned racial profiling. These concerns are heightened by fears that DNA could be used to emphasize biological essentialism or justify discriminatory policy, echoing past abuses cloaked in scientific legitimacy.

Similarly, Kim TallBear (2013), in *Native American DNA*, examines how genetic science has been used to define Indigenous identity in ways that often conflict with Indigenous epistemologies and kinship systems. TallBear (2013, pp. 27-56) argues that the use of DNA to determine tribal belonging or to authenticate ancestry imposes colonial and scientific frameworks that disregard Indigenous governance and self-definition. TallBear (2013, pp. 97-123) points out

that while geneticists may frame their work as objective and neutral, it frequently aligns with settler-state interests by undermining Indigenous sovereignty and reinforcing racialized notions of authenticity. Even when genetic interventions are technically available, they may remain socially inaccessible or outright rejected due to long-standing fears of erasure, misrepresentation, or appropriation.

Nelson (2016) and TallBear (2013) reveal that genetic technologies are never merely scientific tools; instead, they are also instruments of power, shaped by and shaping histories of racialized governance, institutional violence, and contested belonging. Their insights reveal how social accessibility, cultural trust, and historical context profoundly condition the uptake and interpretation of genetic testing in marginalized communities. As a result, genetic interventions may be rendered socially inaccessible, as communities justifiably perceive them through the lens of historical trauma, institutional mistrust, and the ongoing risk of surveillance, appropriation, or systemic exploitation. Feminist and critical race approaches similarly foreground the intersections of power, history, and embodiment, highlighting how genetic data governance must attend to structural inequalities that are obscured by rights-based individualism. Sherwin (2011) critiques the abstraction of the individual in genetic ethics, arguing for a relational and socially embedded model of autonomy. Bridges et al. (2017) emphasize how systemic racism and historical exploitation shape contemporary biomedical practices, calling for governance frameworks that explicitly confront and redress these embedded power imbalances.

This dynamic extends to the reproductive sphere, where prenatal or carrier screening can echo eugenic ideologies under the guise of health optimization. As Shildrick (2009) warned, discourses surrounding “genetic prevention” may implicitly pathologize disability, rendering

certain lives as less desirable or even unworthy. The increasing normalization of selective reproduction risks reinforces social hierarchies based on able-bodiedness, race, and class, particularly when genetic information is framed as objective truth, divorced from socio-political context (Daack-Hirsch & Campbell, 2014). In this way, the scientific medical applicability of genomic technologies becomes inseparable from broader cultural practices of exclusion and valuation.

Under such conditions, subjectivities are not merely formed; instead, they are managed. As Rose (2007) argues, genomics participates in a broader "politics of life," wherein individuals are encouraged to understand and govern themselves through risk profiles and molecular identities. Patients become reflexive consumers of risk, responsible not only for their own health futures but also for communicating genetic information to family members and making ethically loaded reproductive choices. This self-governing logic is both liberating and coercive, positioning health as a moral obligation and genetic ignorance as a failure of responsibility. The discursive construction of genetic identity influences personal belief and reshapes social practices, institutional interactions, and moral expectations. It fosters a regime in which biology becomes destiny, not through determinism alone, but through the powerful cultural narratives that structure how genetic knowledge is interpreted, internalized, and acted upon.

Genetic non-discrimination laws circulate within genre chains involving scientific publications, media reports, marketing materials, and legal documents. Media portrayals often emphasize genetic exceptionalism, portraying genetic information as uniquely powerful and in need of special protection, which in turn justifies its commodification. Discursive practices emphasize the idea that genetic testing is both safe and essential, driving its integration into

everyday life. The logic of risk has become personalized and privatized. As Rose (2013) notes, individuals are interpellated as responsible genetic subjects. The National Cancer Institute (n.d.) and Mayo Clinic (2024) emphasize lifestyle change as a response to genetic risk. However, the pressure to act "responsibly" can translate into self-surveillance, guilt, or anxiety, especially when medical guidance is inaccessible or inconsistent (Gibbon et al., 2014; Petersen, 2015).

Genetic information can significantly influence how people see themselves and their future. In the *MyCode* study, Baker et al. (2022) observed that participants often reinterpreted their identity and life plans after receiving genetic results. While such responses may encourage preventive health actions, they also reflect the influence of a neoliberal rationality that highlights self-management and personal responsibility. Genetic testing is increasingly framed not just as a medical tool, but as a moral duty, an act of self-knowledge and empowerment. However, as Rose (2013) cautions, this framing can mask the uncertainty and anxiety it produces, shifting the burden of health to individuals under the flag of informed choice. This reveals the need for regulatory frameworks that not only prohibit discrimination but also respond to the evolving social practices surrounding genetic testing and particularly the unequal capacities individuals have to interpret and act upon genetic risk.

This subsection has shown how genetic information reshapes individual identities and responsibilities, reinforcing neoliberal ideals of self-management while obscuring the emotional and social burdens it may impose. Building on this, the next section turns to the concept of biocapital to examine how genetic data is not only a site of personal meaning but also a source of economic value and political negotiation within the genomics industry.

6.2) Biocapital and Politics of Genomics

Power in the genomic era is increasingly exercised through privately controlled infrastructures and the mediation of meaning. Patients are increasingly positioned as recipients of care and as bio-data producers in a way that encourages them to contribute genetic information. Their contribution is monetized through research, legal codification, and commercial partnerships. This scenario aligns with the definition of *"biocapital"* provided by Birch and Tyfield (2013, p. 308) in which economic value is extracted not just from the latent qualities of the biological material, but from "*knowledge labor*" required to make genetic data actionable. Birch and Tyfield (2013) argue that value is not extracted solely from the biological material itself (e.g., genetic samples or sequences), but critically from the "knowledge labor" that makes this biological material scientifically and economically actionable (p. 308). "Knowledge labor" refers to the scientific, technical, and interpretive work involved in analyzing, interpreting, and applying genetic data. This includes activities such as sequencing, annotating, modeling, and integrating genetic information into medical or commercial frameworks. Unlike traditional forms of labor tied to physical production, knowledge labor emphasizes the cognitive and epistemic effort needed to transform raw genetic data into usable, commodified forms that can drive innovation in areas like pharmaceuticals, personalized medicine, and insurance risk profiling. Thus, in the bioeconomy, it is the combination of biological material and the knowledge infrastructures surrounding it, scientific expertise, databases, and regulatory practices that generate biocapital. This conceptualization helps illuminate how the commodification of life operates through both material and immaterial means, reinforcing the centrality of intellectual and institutional power in the contemporary life sciences.

The analysis of biocapitalism shows how individuals are encouraged to view their genetic information as both a personal tool and a societal contribution, fostering a false sense of empowerment (Birch & Tyfield, 2013). Patients undergo testing to feel proactive, while unknowingly contributing to databases owned by private corporations (Lupton, 2016; Sharon, 2017). In this context, legal protections (e.g., GINA, GNA) serve more as psychological reassurance than material control over one's genetic data.

As Jessop (2005) argues, the strategic-relational state increasingly governs through a governance mechanism enabling markets, setting rules, and legitimizing new domains of accumulation without directly intervening in classical redistributive ways. The GNA exemplifies this shift: while positioned as a rights-based safeguard against discrimination, it simultaneously underwrites the expansion of a genomic marketplace by reassuring citizens and consumers that participation in genetic testing is risk-free. This legal assurance reduces the perceived friction between individual autonomy and data commodification, facilitating the extraction of biovalue through voluntary data sharing, clinical testing, and research enrollment.

In this context, the state operates not as a neutral regulator but as a market enabler by supporting infrastructures and discourses that expand the genomic frontier while displacing accountability to the individual (Peck &Tickell, 2002). Through policy endorsement and symbolic legal protections, the state helps normalize genetic testing and embeds it into healthcare delivery, educational frameworks, and kinship responsibilities. This legitimizes new forms of medical surveillance and labor restructuring under the guise of empowerment and innovation, making participation in genomic regimes appear both inevitable and benign.

Legislative protection against discrimination has driven investment in biotechnological infrastructure by creating a regulatory environment that encourages innovation while aiming to mitigate social risks (Gottweis & Zatloukal, 2007). Hospitals, clinics, and private companies incorporate genetic testing into routine care, creating physical and digital systems for collecting and storing genomic data. HGP was initially framed as a collective scientific endeavor aimed at advancing public knowledge and healthcare; however, the subsequent growth of proprietary genetic databases marks a shift toward the commodification of genetic information, where access and control become concentrated in private hands (Boyd & Crawford, 2012). As Birch and Jessop highlight, the Knowledge-Based Economy (KBE) transforms healthcare into an innovation sector (Jessop, 2005; Birch et al., 2010). Patents, licensing agreements, and IP regimes become integral to healthcare delivery, reshaping the material world of medicine around commercial imperatives whose governance is fragmented and often opaque. In these ways, GINA and GNA contribute to the consolidation of a genetic infrastructure that serves both public health and private profit. Jessop (2005) and Birch et al. (2010) describe this as the Knowledge-Based Bioeconomy (KBBE), wherein public policy drives innovation in genomics while failing to redistribute its benefits equitably. Hospitals increasingly rely on commercial labs, while DTC companies build proprietary databases with minimal oversight (FDA, 2023). This infrastructural shift fosters dependency on commercial platforms and weakens state capacity for oversight (Birch et al., 2010). Genetic data becomes a material resource.

The optimistic reception of anti-genetic discrimination laws by the biotechnology industry, framed as a way to alleviate fears and encourage participation in genetic studies, illustrates how legal protections can function not only as regulatory shields but also as market enablers (Allison,

2008). This dual role becomes more apparent when interpreted through legal and discursive frameworks that analyze the socio-economic structuring effects of law. Indeed, GINA helped lay the groundwork for legal legitimacy and market confidence in the early stages of the genomic economy. From a legal coding perspective, GINA represents a strategic effort to structure trust through legal safeguards that transform genomic participation into a manageable risk, in this way enabling capital formation (Pistor, 2019). However, as public hesitation continues to limit widespread participation, the expected surge in data availability has not fully materialized. This tempered uptake reveals the limits of law as merely a protective mechanism.

Instead, GINA and GNA should be seen as a social practice embedded in broader neoliberal rationalities. They do not simply reflect a protective intent but help normalize the integration of individual genetic data into bioeconomic frameworks. As Fairclough (1995a) argues, law functions as a discursive institution as it both shapes and is shaped by prevailing ideological structures. In this case, GINA is not just a legal response to fears of discrimination, but a discursive act that highlights the logic of individualized responsibility, risk management, and data-driven innovation. Similarly, Jessop's (2005) view of the strategic-relational state helps explain how laws like GINA emerge through selective institutional responses that prioritize market facilitation over systemic transformation. While GINA was crafted to protect individuals, it also strategically enables market structures by inviting participation within the confines of an innovation-led economy.

Fairclough's (2003) concept of *networking social practices* is evident in the case of biotechnological developments in healthcare. GINA and GNA facilitate the entanglement of clinical medicine with biotechnology, consumer markets, and data governance. The knowledge economy is not a backdrop but a driving force behind this integration. Healthcare practices are

increasingly coordinated with commercial practices, media narratives, and legal frameworks. This creates a unified discourse of innovation and inevitability. As Birch et al. (2010) note, competitiveness and growth are discursively tied to the bioeconomy, positioning biotech advancement as a moral and economic imperative.

Texts related to genetic developments often form genre chains that reflect and reproduce the transformations of new capitalism (Fairclough, 1995a; Jessop, 2005). Scientific articles feed into corporate brochures, which are echoed in regulatory debates and public health campaigns. These chains normalize genetic testing and the commodification of life itself. Jessop (2005) and Fairclough (1995a) argue that genre changes are central to neoliberal transformations. The integration of medical, legal, and commercial genres reflects a shift toward flexible, post-Fordist production models in healthcare, where patients are both consumers and commodities.

Biotechnologies transform not just diagnostics but economic structures. As Birch (2006) and Peck (2010) suggest, innovation-driven policy regimes treat the human body as a site of value extraction. HGP once framed genetic knowledge as a public good. Today, genomic value is realized through private data monetization, regulatory arbitrage, and speculative capital. DTC testing companies employ algorithms that transform raw sequence data into consumer insights. Yet the scientific opacity of these algorithms raises concerns about transparency, equity, and accuracy. Regulatory gaps persist despite FDA interventions (FDA, 2023), highlighting tensions between innovation and public accountability.

GINA and GNA exemplify how the state has shifted its role, not to constrain market forces, but to actively support and enable the expansion of market-driven approaches to genetic information and biotechnology. These legal frameworks lend legitimacy to the commodification

of genetic information by framing regulatory interventions as protective measures for individual rights. In the Canadian context, Bombard and Heim-Myers (2018) emphasize that the GNA plays a pivotal role in enabling research participation; however, its constitutional fragility exposes how easily rights-based protections can be compromised by market-oriented pressure.

At the same time, institutional boundaries become increasingly porous, with universities, biotech firms, and hospitals forming hybrid research-commercial partnerships. As Adair et al. (2009) and Weymann et al. (2022) demonstrate, resource allocation for predictive genetic testing is often driven more by economic imperatives than by public health priorities. This blurring of roles reflects the deeper contradictions of neoliberal governance. Even under the banner of "progressive" neoliberalism, health policy is routinely leveraged to serve trade objectives and industrial growth rather than to safeguard collective well-being (Crawford, 2021). In this context, regulatory fragmentation, illustrated by provincial challenges to the GNA, reveals the limits of state intervention and also the strategic ways in which states enable the genomic economy.

These contradictions in governance not only reveal tensions within health policy but also lay the groundwork for how legal protections function as infrastructural tools that embed genetic data into circuits of biocapital accumulation. It is within this broader architecture that we must evaluate how GINA and GNA, while ostensibly anti-discrimination laws, also normalize the commodification of life itself under the guise of innovation and empowerment.

Weymann et al. (2022) underscore this dilemma in their research on genomic testing in Canada. They found that despite public enthusiasm, regulatory and infrastructural bottlenecks prevent equitable integration. The legal recognition of genetic counselors remains inconsistent across provinces, as Lambert et al. (2022) state, further undermining effective governance and

increasing the potential for patient harm (Shugar et al., 2017; Knoppers et al., 2025). This situation calls for a rethinking of the role of public regulation in a biotech-driven healthcare system. As Little et al. (2008) and Battista et al. (2011) note, the long-term sustainability and ethical implementation of public health genomics require coordinated governance frameworks that safeguard against undue commercial influence.

The broader social practices shaped by GINA and GNA reveal significant ethical and political tensions. While these laws aim to prevent discrimination, they leave unaddressed the structural inequalities exacerbated by genetic capitalism. Patients face hidden forms of exploitation through data extraction and surveillance, particularly in employer-sponsored testing schemes and DTC platforms. This reflects the dual role of the neoliberal state: regulating the excesses of the market while enabling its expansion (Jessop, 2008; Birch & Tyfield, 2013). The ethical narrative of protecting individual rights masks a deeper economic logic that prioritizes accumulation over equity. Neoliberal ideologies reshape not just discourse but the very institutions of health. As Sanders et al. (2023) argue, neoliberal globalization has led to health policies increasingly aligned with market efficiencies rather than equitable care. Privatization, deregulation, and public-private partnerships are key trends that redefine access to care and resource allocation.

This logic is evident in the rollout of genetic technologies. For instance, Adair et al. (2009) found that resource allocation decisions for genetic testing in Canada are often shaped by economic and political pressures, favoring cost-efficiency over patient-centered care. Similarly, Puddester et al. (2023) reveal that Canada's genomic nursing policy reflects a regulatory vacuum, where rapid expansion of genetic applications outpaces legal oversight. Chernomas et al. (2018) offer a compelling critique: neoliberal capitalism extends its influence on the evolutionary level by

altering survival conditions through systemic inequality. In healthcare, this plays out in genetic discrimination risks disproportionately affecting marginalized populations who lack the socioeconomic capital to navigate complex biomedical markets. This critique is reinforced by Fitzgerald-Butt et al. (2014), whose study on parents of children with congenital heart defects highlights gaps in genetic knowledge that are strongly associated with income and education levels. Despite positive attitudes toward genetic testing, many parents, particularly those from lower socioeconomic backgrounds, struggled to understand genetic information and access appropriate counseling. This underscores how structural barriers, shaped by neoliberal priorities, perpetuate inequalities in access to and understanding of genetic technologies, leaving vulnerable populations more exposed to the risks of genetic misinterpretation and discrimination. Moreover, neoliberal healthcare reforms have turned patient-centered care into an empty slogan. As one research on PrEP implementation shows, profit-driven systems disincentivize holistic care because "to do so in a patient-centred way is not particularly lucrative" (Sinno et al., 2024). This reflects the broader commodification of health, where what counts as care is what can be monetized.

The social practices surrounding GINA and GNA illuminate a profound disjunction between the protective ideals these laws promote and the political-economic realities they inhabit. While anti-discrimination frameworks may offer symbolic and procedural safeguards, they operate within a broader neoliberal order that commodifies health, stratifies access, and privileges corporate accumulation over equity. Rather than dismantling the structural conditions that enable genetic exploitation, these laws often stabilize them, embedding genomic data practices within market logics that disproportionately burden the most vulnerable. As neoliberal globalization continues to redefine healthcare through efficiency, privatization, and profitability, genetic rights risk is invoked to build trust. However, this is insufficient to redress the deep-seated inequities of

the bioeconomy. A more transformative approach would require moving beyond individualistic protections toward collective frameworks that foreground justice, solidarity, and the public governance of genomic futures (Prainsack, 2018).

6.3) Legal Frameworks and Assetization

Pistor (2019) explains how law itself becomes a mechanism for assetization, turning data, including genetic information, into capitalizable assets. Within this logic, the GINA and GNA are less about restricting corporate reach and more about codifying the legal conditions for accessible data circulation. By ensuring that individuals are not penalized for participating in genetic testing, it paradoxically invites greater engagement with genomic technologies, which then feed knowledge-driven innovation ecosystems. These institutional mechanisms, such as legislative assurances, discursive normalization, and infrastructural support, enable the embedding of genetic practices into everyday life while rendering the underlying political-economic transformations opaque. Through this multi-scalar reorganization, biocapital accumulation becomes not only routinized but legitimized as a public good.

The enactment of GINA and GNA can be seen as institutional actions to regulate interactions between individuals, corporations, and healthcare providers. On the one hand, these laws prohibit discriminatory practices in employment and insurance. On the other hand, they facilitate trust in genetic testing and data sharing. This dual function causes a new genre of social interaction in which patients are channelized to participate in genetic testing through assurance of legislative protections. The regulations on genetic discrimination have also paved the way for new practices of genetic testing by encouraging individuals to take up the tests through the rhetoric of

choice and autonomy. As Jessop (2008) points out, the state's interventions are strategically selective. These laws regulate discrimination, not commodification.

Pistor's theory of legal coding posits that assets become "capital" through legal institutions that endow them with attributes like priority, durability, and convertibility. This process has historically transformed land, debt, and intellectual property into wealth-generating assets – and today it increasingly encompasses "nature's own genetic code and the data we produce in the digital age". Genetic information, once merely personal or scientific data, is being legally reconfigured into an asset class or biocapital. This analysis examines how a network of institutional actors – biotech firms, hospitals, regulators, insurers, and others – facilitates the legal and economic encoding of genomic data into capital. It explores how tools like informed consent contracts, data-sharing agreements, and intellectual property (IP) rights serve as assetization mechanisms, how public-private partnerships commercialize patient genomes, and how national and international bodies provide an enabling legal infrastructure. Throughout, we adopt a critical political economy lens to show that, amid discourses of innovation and patient empowerment, a commodification of genomic data is underway that privileges capital accumulation.

Crucially, these laws are not neutral safeguards. From the perspective of Pistor's (2019) theory of the legal coding of capital, the GNA and GINA function as enabling infrastructures that turn genetic information into monetizable assets. While they prohibit overt discrimination, they simultaneously codify the conditions under which genetic data can circulate, particularly through informed consent contracts, data-sharing agreements, and IP protections that operate in the background of healthcare delivery and research. The requirement for written consent under Section 5 of the GNA, for example, ostensibly protects individuals but also legitimizes the collection and

commodification of their data under lawful pretexts. This formal legal structure, as Pistor notes, is key to assetizing intangible resources by ensuring that genetic data, once collected, becomes usable and tradable within innovation-driven economies.

GINA similarly enables commodification through its carefully delineated protections and exceptions. For instance, Title II of GINA prohibits employers from using genetic information in hiring or firing decisions but permits the collection of such information under wellness programs with voluntary consent. This framing embeds genetic data into employer-sponsored healthcare structures, transforming employee participation into a site of data extraction. Such provisions encode consent within contractual relations that authorize commodification while appearing to promote autonomy, what Pistor calls the paradox of legal coding, where law simultaneously protects and unlocks economic value. By limiting liability while enabling circulation, GINA institutionalizes data as a monetizable asset embedded in the fabric of employment and insurance governance.

These legislative frameworks reflect a broader neoliberal shift in the role of the state, from a provider of direct services to a meta-governor that sets the conditions for private accumulation. Rather than directly owning or managing genetic databases, governments create legal environments that support their growth. Pistor (2019) underscores how legal coding allows capital to multiply without the need for material production, relying instead on law's capacity to structure and legitimize ownership, exclusivity, and transferability. The GNA and GINA, in this context, are part of the legal architecture that underwrites the genetic bioeconomy, quietly transforming genetic information into capitalizable, contract-bound assets within the evolving landscape of precision medicine.

In this way, the restructuring of social relations around genetic knowledge reveals a deeper logic of privatization: where access to reliable interpretation is uneven, and professional authority is contingent on alignment with commodified healthcare delivery. Legal frameworks such as GINA and GNA serve as pivotal tools in the neoliberal transformation of healthcare, simultaneously disciplining actors and enabling markets through selective intervention and legitimizing norms.

Discourses of genetic knowledge do not merely describe reality but also construct it. As Fairclough (1995a) indicates, discourse is a form of social action. Genetic legislation, counseling, and commercialization form a discursive ensemble that normalizes new roles (e.g., genetic consumer, bio-citizen), restructures institutions, and reshapes subjectivities. The expansion of genetic testing reflects a broader shift toward biopolitical governance, where life itself becomes the object of regulation and accumulation (Rose, 2013). In this context, GINA and GNA serve not as ultimate safeguards, but as moments within a neoliberal genealogy of regulation, where protection and commodification proceed hand in hand. To resist the subsumption of healthcare by the knowledge industry, critical attention must be paid to how genetic discourse constructs legitimacy, authority, and value.

From a social practice perspective, genetic discrimination legislation like GINA and GNA represents a complex dialectic of protection and commodification. These laws function within a neoliberal governance structure that encourages genetic innovation while embedding corporate logics into the fabric of healthcare. Fairclough's framework reveals how legislation, discourse, and institutional practices work together to normalize the extraction and commodification of genetic data. The discourse of rights and choice masks deeper processes of biocapital accumulation, transforming patients into both consumers and producers in the knowledge-based bioeconomy

(Fairclough, 1995a; Birch et al., 2010; Jessop, 2008). Ultimately, the genetic healthcare regime is not merely a scientific advancement but a socially constructed and politically charged practice that reshapes how we understand, regulate, and experience health in the 21st century.

Legal frameworks governing genetic privacy do not operate in isolation. Rather, they function within and are shaped by broader institutional ecologies where biotech corporations, hospitals, and public agencies co-produce the conditions for genetic data to be legally transformed into economic capital. Following Pistor's (2019) concept of "legal coding," this process involves layering legal protections, contractual arrangements, and intellectual property frameworks that imbue genetic data with the properties of an asset, exclusive, durable, and marketable. Genetic data, once generated through clinical or research settings, is rarely static. Instead, it is actively mobilized through informed consent forms, licensing agreements, and data-sharing contracts that distribute access and ownership across a fragmented field of public-private actors.

In Canada, GNA prohibits coercive access to genetic test results and seeks to ensure voluntary participation (Government of Canada, 2017). However, its structure also opens space for contractual mechanisms that facilitate data commodification. For example, Section 5 of the Act protects against unauthorized use of test results, but it simultaneously validates their use upon written consent. This transforms consent into a legal instrument that enables transfer and circulation. According to Pistor (2019), such arrangements are hallmarks of assetization: law does not merely regulate an asset but constructs it by assigning control rights that can be transferred, licensed, or monetized.

Legal instruments are pivotal in turning raw genomic information into proprietary assets. Informed consent contracts are one such tool: they not only obtain patient permission for data use

but also often transfer certain rights or access to institutions. For example, in a new genome initiative involving 17 health systems and the data company Truveta, patients are asked during routine lab tests to consent to the analysis of their leftover blood samples and linkage of that data to anonymized health records (Reuters, 2025).

Data-sharing agreements and licensing contracts concretize the asset value of genomic datasets by controlling access and IP. A case in point is the collaboration between 23andMe and pharmaceutical giant GlaxoSmithKline (GSK). Initially an exclusive R&D partnership, this has evolved into a non-exclusive data licensing arrangement where GSK paid $20 million for one year of access to de-identified, aggregate genomic data from 23andMe's database (KTRV, 2023). Under this contract, GSK can mine genetic insights for drug discovery, and while GSK will own any new drug compounds discovered, 23andMe is entitled to downstream royalties. The contract transforms consumers' DNA information (acquired via consent) into an income-generating asset: GSK treats the data as a valuable input for product development, and 23andMe treats it as licensable property. In Pistor's terms, the agreement grants legal priority and convertibility onto the data – 23andMe has priority rights (others must pay to use it) and convertibility (data access rights are converted into revenue).

Intellectual property (IP) regimes are equally central to this coding process. Patents and exclusive licenses turn genetic inventions and data-derived insights into intangible property that can be owned or traded. For example, St. Jude Children's Research Hospital, a leading pediatric center, developed a novel DNA amplification technology (*Primary Template Amplification, PTA*) through research on childhood cancer. In 2020, St. Jude granted an exclusive worldwide license to a startup, BioSkryb Genomics, to use this technology in developing diagnostics (BioSkryb, 2020).

This licensing contract – a form of IP transfer – exemplifies how a hospital's scientific discovery (rooted in patient-derived data and samples) is encoded as private capital**.** BioSkryb's license secures *priority* (no competitors can use the PTA method without permission) and *durability* (the technology is legally protected over a term of years) in exchange for financial terms to St. Jude. As BioSkryb's CEO noted, this expanded license allows them to create "first-in-class" diagnostic products from the St. Jude innovation.

In this way, the hospital's genetic data and know-how are assetized via IP, migrating into a commercial domain where they can generate profits as proprietary diagnostics. Such arrangements are commonplace in biotechnology: gene sequencing companies like Illumina rely on extensive patent portfolios to secure market exclusivity, and research institutions frequently spin off genetic findings into private startups under license. Law bestows legally-backed exclusivity on these genomic assets, which is essential for attracting investment and realizing capital value.

GINA and GNA illustrate the broader transformation in which legal instruments are not merely reactive tools of protection but active enablers of market formation. Framed in the language of choice, autonomy, and anti-discrimination, these laws invite public trust while quietly embedding genetic data into circuits of capital accumulation. Pistor's concept of legal coding exposes how these frameworks construct genetic data as assets, durable, exclusive, and tradable through consent regimes, IP protections, and contractual arrangements. Far from limiting commodification, such legal architecture authorizes and legitimizes it. As discourse, infrastructure, and policy converge, patients are not only safeguarded but enrolled into a neoliberal genetic economy as data producers and consumers. To meaningfully resist the enclosure of health within market logics, critical attention must be paid to the legal, discursive, and institutional mechanisms

that naturalize biocapital, and to how alternative regulatory frameworks might challenge the privatization of life itself.

6.4) Strategies for Genomic Data and Commercialization

The evolution of genomic data into capital is encouraged and steered by national and international institutions that craft the enabling environment. Governments, quasi-public agencies, and global bodies provide legal codes, strategies, and standards that normalize the commodification of genomic information while safeguarding ethics and public interest. Taylor and Whitton (2020) critically examine the UK's 2018 Data Protection Act, which introduces a "public interest" test permitting the secondary use of personal health data without explicit consent—and even in the face of direct objection—so long as the reuse is framed as serving the public good. While this trade-off is legally structured as legitimate, Taylor and Whitton caution that it is only ethically defensible if "all practicable steps are taken to maximise preservation of individual control," including proactively seeking consent and respecting refusals in all but exceptional cases. In practice, however, these safeguards are often eroded, allowing individual autonomy to be overridden by institutional imperatives for data access. This illustrates how legal frameworks, while appearing neutral or pro-public, often facilitate the systemic extraction and commodification of genetic data—undermining genuine informed consent and collective governance. These frameworks illustrate Pistor's (2019) account of law as the "master coder" shaping markets and assets at a collective level, with state actors being involved in further acceleration of this dynamic.

At the national level, a clear example is the Canadian Genomics Strategy (Government of Canada, 2025), which is explicitly designed to "*drive innovation and foster economic growth*" through investments in genomics (Newswire, 2025). The federal government earmarked C$175

million over seven years to accelerate the commercialization and adoption of genomics across sectors. The official discourse highlights translating research into *"real-world applications"* like personalized medicine and advanced diagnostics, and emphasizes Canada's global leadership and prosperity as key outcomes

CGS connects genomic innovation with economic competitiveness, outlining a national plan to link healthcare policy with trade, investment, and industrial development goals (Innovation, Science and Economic Development Canada, 2025). The Strategy aligns with OECD (2015a) recommendations on biotech-driven growth and reflects what Jessop (2005) terms the "*Schumpeterian workfare state,*" which is a regime where welfare provision is subordinated to innovation-based competitiveness. Through CGS, Canada is developing and investing in a valuable national asset. The pan-Canadian Genome Library project, funded by the Canadian Institutes of Health Research, is another example of investments into genomics. In this initiative, the language of a "library" suggests openness, but access will be stratified via legal contracts, illustrating Pistor's point that even ostensibly public assets are coded with private-law features to facilitate capital creation.

CGS also exemplifies how state-led investment in genomics not only drives scientific advancement but also aims to accelerate commercialization and economic growth, which highlights the dual role of public funding as both an enabler of innovation and a facilitator of market formation. Much of the funding under this strategy flows through Genome Canada, a public intermediary that co-funds projects with industry. Genome Canada's mandate under the strategy includes a $96M investment in its Genomic Applications Partnership Program (GAPP) to *"turn world-class research and innovation into solutions that save lives, bolster supply chains and fuel*

economic growth", explicitly working with Canadian companies to build industries (Genome Canada, 2025). Such policies further institutionalize the economic logic underpinning genomics, reinforcing the discourse of innovation while masking biocapital' s underlying equity and ethical tensions.

In this way, the legal coding process is supported by institutions like Genome Canada, which actively promotes partnerships between public research institutions and biotech companies. Public-private partnerships (PPPs) have become a key interface through which genomic data moves from clinical settings into commercial value chains (OECD, 2015b). The Genome Canada–AdMare BioInnovations alliance, for instance, channels public genomic data into commercial development pipelines under intellectual property terms designed to attract private investment (Genome Canada, 2024). Similarly, Genome BC's initiatives have fostered ventures where provincial funds support biotech infrastructure and sequencing efforts, ensuring that the state becomes a co-producer of genomic capital (Genome BC, 2021).

This is legal coding via public policy: taxpayer money is channeled into creating genomic assets (data, patents, startups) that are given legal form (through contracts and grants), favoring private sector uptake. The Strategy also allocates funds to improve data infrastructure and access – e.g., coordinating large-scale data management nationally– which addresses the **"**convertibility**"** attribute of data-as-capital: easier data sharing and integration increases its utility and exchange value. In essence, Canada is writing into policy a blueprint to convert genomic science capacity into national wealth. By funding big data initiatives and incentivizing PPPs, the state is standardizing the legal-institutional conditions (such as IP frameworks, data access rules, benefit-sharing agreements) under which genomic data is collected and monetized. Notably, this is

accompanied by innovation-friendly regulatory stances; for example, Canada's drug and health agencies are adapting to precision medicine by considering genomic evidence in approvals and reimbursement. The creation of a *Canadian Drug Agency* is aimed at better evaluating costly gene therapies and coordinating drug funding for rare diseases (Council of Canadian Academies, 2020).

The Canadian Agency for Drugs and Technologies in Health (CADTH) publication titled CADTH Horizon Scan 2023: Watch List illustrates how CADTH, as a federal health technology assessment body, acts as a knowledge broker between research, policy, and practice. Its role exemplifies how governments and public institutions mediate the adoption of private innovations into public health systems, shaping both clinical use and policy discourse. This publication illustrates how technological innovation, particularly in genomics, is reshaping clinical practice and forcing health systems to grapple with issues of infrastructure, equity, and regulatory legitimacy.

All these moves lower legal barriers and uncertainties, making genomic data more readily exploitable by firms, which is precisely how law codes capital. Regional genome centers and nonprofit innovation agencies echo these priorities. Genome BC**,** one of six regional Genome Canada centers, explicitly frames genomics as an economic engine. In a 2023 statement, Genome BC (2023) touted that its investments "*stimulate economic growth within BC*"*,* yielding jobs, GDP gains, and tax revenue. It highlights how partnering with industry and leveraging co-funding "amplifies" the impacts of initial public investments.

The translation of research innovations into commercial success is a core metric of success – early support for local companies that later achieved global success (like AbCellera in biotech) is celebrated as returns that *"benefit all British Columbians"*. This kind of institutional discourse

and programmatic strategy confirms that national intermediaries view genomic data and innovations as assets to be cultivated and capitalized. By building capacity (talent, infrastructure, datasets) and aligning with private sector needs, they provide the legal and logistical substrate for biocapital. Even intellectual property policies are tuned to this goal: tech transfer offices, patent-friendly research grants, and streamlined licensing processes ensure that knowledge from publicly funded genomic research can swiftly enter markets. Pistor's notion of legal modules conferring priority and durability is evident – e.g., a Genome BC program might help secure a patent (durability) for a genomic diagnostic and facilitate a startup license (contractual priority), in this way coding the discovery as investible capital rather than a public good.

The national asset is being built through PPP structures: public funds leverage private tech and vice versa, ensuring that once the data is in hand, both public researchers and industry innovators can exploit it, with governance by bodies like Genome Canada. Initiatives like the Illumina-NTU Hospital agreement in Taiwan, Genome Medical's linkages with private payers in the USA, and the pan-Canadian genome library project funded by the Canadian Institutes of Health Research all embed proprietary interests within public research mandates (Illumina & NTU Hospital, 2024; Canadian Institutes of Health Research, 2023). These PPPs often rely on public legitimacy to access population-scale data while privatizing the benefits via licensing, exclusive data access, or pre-commercial technologies.

While CGS highlights federal investment and commercialization, Husereau et al. (2022) state that in Ontario, systemic inefficiencies, such as fragmented governance, lack of coordination, and unclear funding pathways, continue to limit access and delay implementation of advanced genetic testing. Husereau et al. (2023) further demonstrate that despite recent efforts to centralize

genetic services in Ontario through the Provincial Genetics Program, the province still lacks several foundational conditions for system readiness, including a unified evaluation framework, integrated data systems, and transparent funding models, hindering its ability to deliver genome-based testing at scale and with equity. This shows that public investment alone is insufficient without structural reform and provides empirical support to Mazzucato's (2013) argument that public funds and infrastructure are essential to de-risking innovation, yet value capture remains uneven. Ontario's struggles with test adoption show how policy and funding frameworks can inadvertently favor commercial or elite research hubs, while failing to deliver equitable health benefits system-wide.

Hospitals are also central actors in this landscape. Hospitals and public health institutions hold the raw asset of patient genomes**,** while private firms contribute technology or funding to extract and monetize that asset. Often using the banner of improved healthcare, these partnerships are structured by legal agreements that balance research, care, and commercial interests, transcoding clinical data into economic capital**.** They frequently enter into formalized agreements with genomics startups, transferring biospecimens and patient data under confidentiality and IP clauses. For example, Fabric Genomics' collaboration with Intermountain Children's Health, a large not-for-profit hospital system in the USA, integrates sequencing into pediatric diagnostics while enabling the company to refine its algorithms using institutional datasets (Fabric Genomics, 2024). BioSkryb's partnership with St. Jude Children's Research Hospital offers a similar example in the same country. Presented as a clinical collaboration, the structure of the agreement grants exclusive commercialization rights over derived applications and datasets (BioSkryb, 2023). These agreements exemplify how hospitals, once caretakers of health data, become infrastructural agents in the capitalization of genetic information.

The mix of public investment and private gain in genetic research reflects broader dynamics in innovation economies, where state support both funds and legitimizes the commercialization of emerging biotechnologies. Chapman et al. (2020) explain how growing public and institutional investment in genetic research strengthens the scientific legitimacy of precision medicine, while enabling private actors to capitalize on emerging markets. This is an endorsement of public-to-private value extraction aligning with Mazzucato's account of innovation economies (Mazzucato, 2013). Their analysis reveals how federal support functions not only as a funding mechanism but also as a legitimizing force that facilitates the commercialization of genetic technologies.

In their research, Almeling and Gadarian (2014) found that 65% of Americans believe clinicians should be involved in explaining genetic test results, contrary to the DTC model that marginalizes medical professionals. Moreover, 82% of respondents rated the GINA as important, reinforcing the idea that public trust hinges on regulatory assurance. These findings show that common ideas about trust and professional credibility have become deeply rooted, influencing how people think genomic data should be managed. These discourses also help conceal the structural reorganization of healthcare around commercial imperatives. The public may favor clinical oversight and legal protections, but these sentiments are deployed to facilitate broader participation in systems of data extraction. In this way, the rhetoric of empowerment becomes a consent that is legally encoded and economically instrumentalized.

The broad consent waives patients' exclusive control, enabling their genomic data to be pooled into a large database – an asset that Truveta and its partners can leverage for research and product development. Similarly, consumer genetics firms embed far-reaching consent in their terms of service. 23andMe, for instance, has over 80% of its customers opt in to research uses of

their DNA data, allowing the company to aggregate and commercialize one of the world's largest private genomic datasets (KTRV, 2023). This consent-based data trove becomes a monetizable asset when paired with data-sharing agreements.

In this legal-institutional ecosystem, the GNA and GINA function as enabling devices in a market-oriented genomic infrastructure. They authorize the conditions under which genetic information circulates, shaping the institutional and legal logics of biocapital accumulation. Public trust is managed through discourses of protection and empowerment, even as the infrastructure quietly aligns with market imperatives. Empirical research on public opinion by Almeling and Gadarian (2014) reveals that a majority of Americans (57%) support increased federal government spending on genetic research. This widespread endorsement suggests that public institutions can leverage popular legitimacy to justify and sustain investments in genomic infrastructure. From an economic analysis perspective, such public support provides the political capital necessary for states to make long-term investments that de-risk innovation for private partners. In effect, taxpayer-funded research and infrastructure become indirect subsidies for commercial R&D, enhancing the competitiveness of domestic bioeconomies.

PPPs often involve national research initiatives and consortium-building, blurring public research and private enterprise. In Canada, the federal government's Canadian Precision Health Initiative recently committed $81 million to create a pan-Canadian genomic dataset of 100,000 genomes, with the goal of driving precision medicine (Sick Kids, 2025). A portion of this funding ($11.7M) was awarded to projects at The Hospital for Sick Children (SickKids) to sequence 10,000 pediatric genomes and contribute to a federated "*Pan-Canadian Genome Library*". This public investment is contingent on partnerships and co-funding, as Genome Canada requires that its grants

be matched by other institutions and industry partners**.** In these projects, SickKids collaborates with universities and companies. The Center for Applied Genomics at SickKids will generate data as part of CGEn, Canada's national sequencing platform. The legal arrangements involve multi-party data sharing agreements defining how 100,000 genomes can be accessed and by whom, such as academic researchers and private pharma, under certain conditions.

Illumina-NTU Hospital, such as public-private agreements, formalize the transfer of patient genomic data into shared research assets, with implications for future commercial use. The hospital will use Illumina's high-throughput sequencing platforms to generate vast amounts of genomic data, focusing on cancers, rare diseases, and neurological disorders. Critically, both parties acknowledged that by "*accumulating large-scale genomic data, a future genetic database may be established*", which will "promote the development of the biomedical industry and nationwide precision health. In other words, this PPP explicitly aims to convert patients' sequences into a long-term data asset fueling both public health research and private-sector innovation. Illumina gains a major data-generating customer and potentially access to the anonymized dataset for algorithm training or variant discoveries, while NTU Hospital gains technology and know-how to become a national precision medicine leader.

The Memorandum of Understanding between these parties legally encodes each party's rights, for instance, clauses on data sharing, publication, and any IP arising from new gene discoveries. We see here how state hospitals and biotech firms co-produce biocapital: the hospital recruits patients under informed consent, Illumina provides sequencing as a service, profiting from equipment and kits sold, and the resulting database of more than 10,000 genomes becomes an asset underpinning future commercial diagnostics or therapies in Taiwan's bioeconomy.

The partnership between Intermountain Health, genomics startup Fabric Genomics, and the Broad Institute seeks to integrate rapid whole-genome sequencing for critically ill infants and constitutes another good example. Announced in 2024, this collaboration aims to deliver sample-to-report genome services for newborns with congenital conditions. Fabric Genomics provides AI-driven genome interpretation software, Broad supplies sequencing through its clinical labs, and Intermountain supplies the patients and clinical context. The partnership is framed as purely clinical to "improve outcomes and enhance the quality of care" *for* children. However, it undeniably has a data dimension. Each sequenced genome and clinical annotation adds to Fabric's knowledge base by improving its algorithms and databases, which are proprietary assets. Intermountain builds an internal repository of pediatric genomic data linked to outcomes. The legal framework includes data use agreements ensuring patient data flows to the analysis platform and perhaps research clauses for secondary use. What started as an effort to improve patient care by diagnosing rare diseases quickly has also turned into a way to make money. The more genomes they study, the more useful and valuable Fabric's software and knowledge base become, which can help bring in investors or new customers. This demonstrates how PPPs *"*make whole genome sequencing (WGS) and diagnosis accessible to healthcare systems*"* that lack in-house capacity, while folding patient data back into commercial innovation.

Another PPP example is the 2025 Truveta Genome Project in the U.S., which brings together a health data startup (Truveta), 17 major nonprofit hospital systems, and corporate investors, including Regeneron (a pharmaceutical company) and Illumina. In this deal, the health systems collectively took a $320 million equity stake in Truveta in exchange for contributing data and participation in what is projected to be the world's largest genomic database. The goal is to

rapidly accumulate 10 million patient exomes, protein-coding genomes, linked to clinical records, creating a resource to *"accelerate drug discovery and transform patient care"*.

Legally, each hospital system presumably signs data-transfer agreements and updated patient consent protocols in which patients are asked to allow use of leftover samples for genomic sequencing. In return, those non-profit hospitals gain equity and access to the aggregated insights. Regeneron invested $120M and Illumina $20M into Truveta, effectively purchasing ownership stakes and data rights to this future biobank. Here, the coding of data into capital is especially literal: by pooling their patients' genomic data, the hospitals receive shares in a for-profit entity valued at over $1 billion (Reuters, 2025). Regeneron obtains preferred access to a massive research database to feed its drug pipeline that could lead to lucrative new therapeutics. The entire endeavor is embedded in humanitarian terms, such as exploring why some non-smokers get lung cancer, finding targets for untreatable diseases, but it is fundamentally an exercise in asset creation. Truveta's legal architecture, including contracts with data donors and IP policies for discoveries, transforms millions of individual health records and genomes into a capitalized data platform, owned by a consortium and geared toward monetization in pharma and healthcare markets, as in this example. PPPs facilitate biocapital accumulation at scale: hospitals contribute the raw inputs under legal agreements that ensure they and their corporate partners capture the future value generated from patient data**.**

One common narrative is that sharing genomic data will *"*accelerate breakthroughs in health*"* and *"*improve patient outcomes*."* Hospital-business partnerships are often announced as purely positive for patients. In the Fabric Genomics–Intermountain press release, the terms are

"precision diagnosis," "game-changer for the children and families we serve", and *"improve outcomes"*. There is no mention that a private company will also gain from the data generated. Similarly, Truveta spoke of answering scientific unknowns and cited public health mysteries, such as lung cancer in never-smokers, to justify assembling 10 million genomes.

This humanitarian framing presents data aggregation as a social good, implying that broad consent is a moral obligation to help cure diseases. It conceals the fact that Truveta is a for-profit entity and that the data becomes a proprietary asset once donated. The empowerment discourse is especially evident in direct-to-consumer and insurance contexts. MassMutual's genomics program was introduced under the banner *"Empowering Health Insights"*, focusing on how giving policyholders personal risk information "may help them lead longer, healthier lives"(HIT Consultant, 2024). The program's success was measured by participants' intent to take preventive action.

Both empowerment and innovation are portrayed as ends in themselves, aligned with the public interest. The idea that genomic data is being commodified – turned into exchangeable units of information traded between corporations – is not part of these narratives. Economic growth rhetoric is also pervasive, especially in policy contexts. In announcing CGS, officials highlighted creating a "more prosperous future for Canadians" and securing "economic growth" through genomics (Newswire, 2025).

Genome Canada (2025) proudly notes that its investments "fuel economic growth across sectors" and explicitly ties genomics to job creation, revenue, and competitiveness. This bioeconomy narrative serves to rally political and public support by promising collective economic benefits – genomics will boost the economy much like information technology did in prior decades.

While likely true to some extent (a thriving genomics sector can contribute to GDP), this narrative again obscures the distribution of benefits. Economic growth can be concentrated; profits from genomic innovations often accrue to biotech and pharma shareholders, and high-value data assets may be owned by private entities. Yet by conflating national interest with genomic industry growth, these discourses justify extensive public support (funding, favorable laws) for the assetization process. The concept of biocapital accumulation, private capital expanding by enclosing genomic data, is repackaged as *"Canada remaining at the forefront of a rapidly evolving field"* and *"delivering… breakthroughs in health… and sustainability*" (Newswire, 2025). In other words, the commodification is painted as a win-win scenario: it's *"innovation"*, not market appropriation of a public resource.

From a critical political economy perspective, these discourses function ideologically to naturalize the commodification of human genomic data. By emphasizing health empowerment and innovation, they create consent among the public and policymakers for the expansion of genomic data markets. The narrative of *"*doing good by sharing data*"* dampens potential resistance from those concerned about privacy or exploitation. It also deters people from asking whether genomic advances could be achieved under less commodified models. Importantly, these narratives also help ease the passage of legal reforms that facilitate data commercialization. For instance, when a government justifies a genomics initiative in terms of curing diseases and economic competitiveness, lawmakers are more inclined to pass supportive measures such as funding, weaker privacy constraints for research use, and genomic IP incentives. Therefore, discourse and law work hand in hand: the discourse justifies the law that codes the asset, and the law, in turn, highlights the discourse by producing the promised innovations, which are showcased as success stories.

Institutional actors consistently employ uplifting rhetoric around genomic data, including empowerment, curing illness, inclusive innovation, and national progress. This serves to obscure the underlying process in which individuals' genetic information is transformed into assets controlled by intermediaries and monetized largely outside the contributors' control. A critical lens reminds us that while the benefits touted are real, such as new diagnostics and targeted drugs, they are enabled by a legal-political process that concentrates ownership and capital. The challenge, as Pistor (2019) states, is that the legal coding of capital often perpetuates inequality. In the genomic arena, that could translate to disparities in who reaps the rewards of the genomic data gold rush.

6.5) Global Legal-Institutional System and Genomic Data Governance

Legal coding is further emphasized by global governance bodies like the Global Alliance for Genomics and Health (GA4GH), which produces data standards and ethical guidelines designed to facilitate cross-border data exchange while maintaining the asset integrity of genomic information (GA4GH, 2023). These standards serve dual functions: ensuring interoperability and embedding property-like control into data architectures, making the data legally and technically portable across jurisdictions.

As outlined in the National Human Genome Research Institute's (2024) fact sheet, HGP is celebrated as a historic scientific milestone that unlocked new frontiers in biomedical research and personalized medicine. Positioned as a universally beneficial achievement, HGP is a discursive and infrastructural anchor for the entire genomics ecosystem. It legitimizes contemporary investments, such as CGS and CADTH's policy foresight, while also obscuring the underlying shift from public good to private capital. On the international stage, standards bodies and consortia

also help harmonize the legal-infrastructural conditions for genomic data exchange, which in turn underpins its commodification.

The Global Alliance for Genomics and Health (GA4GH)**,** for example, has developed a "Framework for Responsible Sharing of Genomic and Health-Related Data." This framework sets forth ethical and legal principles agreed upon by stakeholders from research, industry, and government. Even the language in ethical frameworks can be co-opted. Terms like "*data sharing*", "*open science*", and "*collaboration*" in GA4GH and OECD guidelines carry positive connotations of communal effort, masking the reality that what is being shared is often then privatized downstream. A scientist or patient advocacy group might champion open genomic data for accelerating research, while a company quietly applauds it for lowering its cost of acquiring data.

The GA4GH (2023), for example, sets a reassuring tone that suggests that as long as privacy and consent are addressed, all sharing is good. This narrows the ethical discussion to micro-level issues like consent protocols, encryption methods, and deflects questions about macro-level issues like: Who owns the aggregated data? Who can profit from it? Are donors meaningfully rewarded or just the companies? The power dynamics that Pistor hints at – where legal systems favor certain claimants of capital – lurk behind the scenes. Most participants become rule-takers rather than rule-makers in this system. Yet institutional discourses seldom address that asymmetry. Instead, they often imply a unity of interests: that what is good for genomic businesses and researchers (i.e., more data, more freedom to use it) is good for society at large. By promoting a common approach to consent and data governance, GA4GH lowers transaction costs for data sharing across borders. This is crucial for companies that rely on large, diverse datasets – a pharmaceutical company or genome analytics firm can more easily merge data from multiple countries if those sources all

follow GA4GH's standardized consent clauses and privacy safeguards. In effect, GA4GH functions as a private legal harmonization body: it cannot make law, but its soft-law standards often get embedded in national regulations or institutional policies. For instance, the framework highlights a human-rights approach and "foundational principles" to guide data-sharing contracts and oversight. One can view this as encoding a "universality" attribute for genomic data, facilitating recognition of data use rights across jurisdictions. Notably, GA4GH involves industry partners in setting the rules, ensuring the resultant norms don't impede data flows that companies desire.

Similarly, the OECD (2009b) has issued guidelines that shape genomic data's legal status. Its 2009 *Recommendation on Human Biobanks and Genetic Research Databases* urged member countries to establish governance that both protects participants and promotes research. The OECD (2009b) recommended broad consent models and data access procedures to enable international collaboration on genomic data. Such guidance encourages nations to adjust laws on data protection, research ethics, and even liability to make large biobanks feasible and linkable. More recently, OECD (2021) recommendations on "enhancing access to data" call on governments to maximize the benefits of data by sharing it for innovation while managing risks.

In practice, this has led to a policy trend of treating health data as a resource to be "open" for biotech development. The European Union's General Data Protection Regulation (GDPR) even has research exemptions and mechanisms like pseudonymization that allow secondary use of genetic data without fresh consent, under certain conditions (World Economic Forum, 2020). All these measures reflect an international consensus that data liquidity is key to innovation – a stance very much in line with industry interests. The legal technicalities, such as data transfer agreements

under Privacy Shield, are part of the *legal coding* that makes a person's genetic sequence in one country convertible into a unit of global biocapital that can be pooled, compared, and mined by actors worldwide.

National genomics strategies and international frameworks together establish a pro-commodification policy regime**.** They do so by funding the generation of genomic assets, by smoothing legal barriers to data aggregation, and by reassuring the public through ethical guidelines that genomic data can be shared "responsibly." This regime encodes genomic data with the qualities that Pistor identifies as crucial for capital: it gains priority through IP and exclusive agreements supported by policy, durability through long-term infrastructure and legal protections, convertibility through standardized rules enabling data exchange and monetization, and a form of universality through international norms that allow data assets to transcend local jurisdictions.

6.6) Institutional Assetization: Insurance, Consumer Genomics, and Pharma

Beyond the research realm, genomic data is being integrated into the workflows and value calculations of insurance companies, direct-to-consumer (DTC) genetic testing firms, and pharmaceutical R&D pipelines. These integrations represent the downstream phase of assetization. Once genomic information is coded into an exploitable resource, it can be plugged into various actuarial, diagnostic, and drug development systems to extract value. Institutional actors in these domains bring their own legal-economic practices to bear, further entrenching genomic data as capital.

The insurance industries are deeply implicated in partnership in genomics. Although initially critical of GNA's restrictions (Insurance Business Canada, 2016), many insurers now

collaborate with genomics firms to develop actuarial models that utilize de-identified but behaviorally predictive data (Joly et al., 2016). Meanwhile, U.S. firms like 23andMe and AncestryDNA have established expansive IP portfolios around consumer data, leveraging legal frameworks that allow genetic information to be aggregated, anonymized, and monetized through partnerships with pharmaceutical companies (Fast Company, 2017).

Despite the public messaging never state it, the insurer benefits financially from those preventive actions. The individualization of benefit in the form of "*you get to know your DNA and take charge of your health*" avoids discussing the collective asset being built, such as a dataset of risk scores and improved mortality projections for the insurer. In consumer genomics, 23andMe long marketed its service as empowering people to *"discover insights about your health, traits and ancestry."* Only in recent years, after some public scrutiny, has it become more transparent about the research uses of data. Still, the collaboration with GSK was pitched as a way *"*to leverage genetic insights for innovative new medicines*"*(GSK, 2018). A positive spin suggesting drug development will be faster and more tailored to patient needs, rather than emphasizing that 23andMe sold access to its users' data.

Insurance companies**,** especially in life and health insurance, have begun cautiously incorporating genomics into their business models. While the use of genetic test results in underwriting is controversial and regulated (e.g., many countries ban using predictive genetic data to raise premiums or deny coverage), insurers have found other avenues to leverage genomics. One approach is through wellness and risk awareness programs. For example, Massachusetts Mutual Life Insurance (MassMutual) partnered with UK-based Genomics Plc. to offer *free polygenic risk score testing* to certain policyholders as a pilot program (HIT Consultant, 2024). In 2024, this

partnership expanded after a successful trial in which over 70% of participating life insurance customers said they planned health-related preventative actions based on their genomic risk report. MassMutual frames this as *"enabling policyowners to gain knowledge about their health…to lead longer, healthier lives"*. The program analyzes millions of genetic variants from a saliva sample to predict risk for eight common diseases, such as heart disease, diabetes, and certain cancers.

Legally, the insurer is careful to separate this from underwriting. The test is voluntary and offered after the policy is in place, and they emphasize data privacy. Yet the actuarial logic is clear. If policyholders act on genetic risk insights, such as treating high cholesterol earlier or getting cancer screenings, their health outcomes may improve, potentially lowering claims and extending life, which delays life insurance payouts. From a capital perspective, insurers are turning genomic data into a predictive asset, part of their data-driven risk management. Legal coding is evident in how the partnership is structured. Genomics Plc. likely retains ownership of the genetic data and risk algorithm, possibly using it to improve their predictive models, which they can market to others, including perhaps to reinsurers or healthcare providers. MassMutual likely gains deidentified aggregate data about risk prevalence in its pool, or at least the positive PR and customer engagement. This is a subtle commodification. Customers' DNA is analyzed not for direct profit but to refine risk projections and encourage behavior that protects the insurer's capital by mitigating future liabilities. Other insurers are exploring similar routes. Globally, reinsurance firms like Swiss Re have published research supporting the use of genetic information in insurance as long as it is ethical, noting it "*can reduce morbidity and mortality, and improve health, benefiting both customers and insurers*".

The legal discourse in insurance is shifting from outright prohibition of genetic data use to controlled incorporation under consent. Over time, one can envision regulatory changes allowing more explicit use of polygenic risk scores in life insurance pricing, which would directly transform those scores into financial capital factors. Already, in jurisdictions without strict genetic discrimination laws, some life insurers offer discounts if an applicant's genetic test, for example, showing no high-risk mutations, is favorable (American Council of Life Insurers, 2022). These developments are essentially about plugging genomic data into the actuarial code that governs insurance capital, in this way monetizing predictive genomic knowledge in pricing and product design.

Consumer genetic testing firms like 23andMe and AncestryDNA pioneered the model of turning personal genetic data into business assets, and they continue to expand that model through partnerships. As discussed, 23andMe's primary source of capital now is not the one-time sale of test kits, but the ongoing utilization of its 13-million-person DNA database for research and collaborations with pharmaceutical companies. By 2023, 23andMe had over 40 drug discovery programs in its pipeline, some in partnership with GSK, that were genetically informed by its database (23andMe).

In effect, the company vertically integrated from DTC data collection into therapeutics, showcasing how genomic data can be recycled into multiple value streams. The legal foundation for this is complex but revealing: 23andMe's consent and privacy policy grants it broad rights to use and share de-identified user data for R&D; the collaboration agreements with pharma carve out IP ownership; as we saw, GSK owns drugs it discovers, while 23andMe may get royalties (KRTV, 2023). Even securities filings highlight the database as an intangible asset. This

multilayered legal scaffolding transforms something inherently personal – one's DNA – into part of a large, impersonal capital asset that can be repeatedly leveraged. Smaller consumer genomics firms are following suit, often focusing on niche data such as Helix and Nebula, which collect exome or whole-genome data for subscribers and then partner with researchers and pharmaceutical companies for analysis.

A significant point is how data governance choices can expand the capital utility of genomic data. By keeping data de-identified and in aggregate form, companies avoid privacy laws that would restrict the sale of personal data, in this way enabling licensing deals like the 23andMe–GSK $20M agreement. In other words, privacy law exceptions are themselves a legal coding mechanism. They allow genetic datasets to be treated more like tradable commodities than sensitive personal information. International guidelines like those from OECD and GA4GH often endorse this approach by promoting anonymization and data sharing for "*legitimate research interests*", a framing that consumer genomics companies use to justify profitable data transfers. Meanwhile, users are enticed by discourses of empowerment, "*find out about your health risks and ancestry*", to give up data that ultimately feeds into biocapital networks. The balance of power, however, tilts toward the companies and their partners, who aggregate millions of individual decisions into a powerful asset under centralized control.

Pharmaceutical companies have rapidly embraced genomic data as part of their R&D and marketing pipelines, through both partnerships and acquisitions. The motive is clear: genetics can identify drug targets, stratify patients for trials, and eventually serve as companion diagnostics to sell precision therapies. We have already seen examples like GSK's tie-up with 23andMe and Regeneron's investment in Truveta. Another prominent model was Regeneron's earlier

collaboration with the Geisinger Health System in the U.S., the DiscovEHR project, where Regeneron's Genetics Center sequenced over 250,000 Geisinger patient exomes in exchange for shared discovery rights. This led to new findings, such as genes linked to chronic diseases that Regeneron could patent or use in drug development, while Geisinger received some funding and the promise of future clinical benefits. The Regeneron–Truveta deal of 2025 scales this approach nationally. It exemplifies pharma's willingness to directly invest capital to obtain genomic assets, treating data sourcing as part of their R&D investment portfolio.

Pharmaceutical companies often insist on IP ownership or exclusive licensing of any discoveries, as GSK did with 23andMe, underscoring how they view genomic data as a wellspring of proprietary innovation. They also integrate genomic analytics into their in-house research; many big pharma now have dedicated genomics units and collaborate on international projects like the UK Biobank, a public resource that pharmaceutical companies pay to access under license. The recent bankruptcy of 23andMe and the possibility that its vast genetic database, which contains information from roughly 30 million individuals, could be sold; indeed, Newfoundland and Labrador's privacy commissioner encourages people to go onto the 23andMe website, log in, and delete their information and accounts to protect their genetic information (CBC News, 2025). This example illustrates the precarious nature of genomic data governance and its commodification. It also shows the enduring commercial value of such data, which remains attractive to potential buyers, including insurance and pharmaceutical companies, even amid legal and ethical

uncertainties.

In diagnostics and precision medicine, pharmaceutical and diagnostic companies collaborate to develop genomic tests that predict how patients will respond to specific drugs. For

example, large genomics companies like Illumina and Myriad Genetics work with drug makers to create FDA-approved tests that must be used before prescribing certain cancer therapies. These arrangements again turn population genomic data into a dual product: the drug and the required genetic test. Patents or regulatory exclusivities may cover both, maximizing capital extraction from the underlying genomic insight. Even healthcare delivery organizations like Genome Medical (a tele-genetics services firm) collaborate with pharma on initiatives such as sponsored testing programs (Genome Medical). In these programs, a pharma company might pay for genetic testing in patients who might be eligible for a trial or a targeted drug, effectively using genomic data to drive product utilization. Genome Medical's role is to provide genetic counseling and infrastructure, making it easier to funnel patients and their data into pharma pipelines.

Insurers indirectly play a role here too: by deciding which genomic tests and precision medicines to reimburse, they influence how valuable certain genomic data points are. For instance, if insurers broadly cover a $5,000 genomic tumor sequencing test for cancer patients, the data from those tests collected by labs like Foundation Medicine or Caris becomes highly valuable. It can be sold to pharma companies looking for biomarker insights or new targets. We see an ecosystem where insurance coverage decisions, provider adoption, and pharma R&D demand coalesce to integrate genomic data into the core valuation systems of healthcare.

Through these examples, we observe that genomic data flows into multiple institutional circuits of capital – insurance risk models, consumer data platforms, drug discovery engines – each governed by distinct but overlapping legal arrangements. What unites them is the drive to extract economic value from information about human DNA. A life insurer treats genomic risk scores as a form of capital to manage by enhancing the value of its pool by reducing unknown risks, a

consumer genomics firm treats its database as a capital asset to license and leverage, and a pharma company treats genetic variants as intangible capital, leading to lucrative patents on drug targets.

In all cases, the law mediates these transformations: insurance law and genetic nondiscrimination laws set outer boundaries, contracts and consents enable data transfers, IP law secures exclusivity on discoveries, and regulatory approvals certify genomic tests and drugs for the market, contributing to their profitability. Each actor operates within its institutional logic, but together they are constructing an integrated genomic-industrial complex where personal genetic data is a raw input into value production.

Across these domains, a striking feature is the discourse used by institutional actors to justify and frame their activities. The language of patient empowerment, medical breakthrough, and economic innovation pervades policies and press releases, often obscuring the underlying commodification of genomic data. CDA reveals that these narratives play a legitimating role, assuring stakeholders that the capitalization of genetic data is universally beneficial and ethically sound, even as they sideline concerns about privacy, equity, or exploitation.

6.7) Conclusion

The legal coding of genetic data into capital is a multifaceted process facilitated by a web of institutional actors. Biotech firms, hospitals, regulators, insurers, and global organizations each play roles in rendering the human genome legible to law and valuable to markets. Informed consent agreements and data-sharing contracts serve as micro-level code that converts personal DNA information into institutional assets, while IP law secures monopoly rights over genetic inventions.

Public-private partnerships create pipelines that move genomic data from bedside to database to marketplace, **"***assetizing*" patient data behind the scenes. National strategies and international frameworks provide macro-level code, aligning laws and infrastructures with the needs of a burgeoning bioeconomy, and smoothing the path for genomic data to flow and aggregate. Downstream, the integration of genomic profiles into insurance risk calculations, consumer platforms, and pharmaceutical research demonstrates how thoroughly genetic data is being absorbed into capital circuits and valorized.

Throughout these developments, Pistor's (2019) insight that capital is made through the creative force of law was powerfully affirmed in the genetic domain. The legal architecture surrounding genetic data does far more than protect against discrimination through statutes like GINA and GNA. It enables the assetization and commodification of the genome through contracts, licensing frameworks, and IP regimes. Institutional actors convert genetic information into exclusive, tradable, and income-generating capital assets with the attributes of longevity, universality, and liquidity. These legal coding processes are not neutral, but they shape access, control, and profit distribution in ways that benefit powerful actors while marginalizing others. We have seen law's alchemy at work: transforming an inexhaustible natural resource, the information in our DNA, into exclusive, tradable, and income-generating assets. Each actor studied wields specific legal tools to attach desirable capital attributes to genomic data: exclusivity, longevity, exchangeability, and universality of recognition. In doing so, they also shape power relations by deciding who owns and controls humanity's genetic patrimony in its datafied form.

Finally, this analysis underscores the importance of looking at past uplifting institutional rhetoric. The discourses of empowerment, innovation, and public good, while highlighting genuine

potential benefits of genomics, also function to legitimize what is fundamentally a commodification process**.** Drawing on Fairclough's CDA, it becomes clear that such narratives can mask the real targets of regulatory and institutional design: the creation of market value from human biological data. These discourses sanitize and legitimize the expansion of commercial interests into intimate biological domains, portraying profit-driven motives as benevolent public advancement.

The recent bankruptcy of 23andMe provides an ample illustration of the risks embedded in this system. Despite public assurances and privacy policies, the potential sale of its 30 million-user genetic database illustrates how fragile protections are once genetic data has been folded into market logics. This case makes visible the commodification of genomic data not as a hypothetical concern, but as a real and present danger. Especially when institutions collapse, and the only thing left of value is the genetic capital accumulated.

Large-scale genomic initiatives are often celebrated as collective endeavors, yet the legal coding ensures that the collective resource is carved into private property slices. Critical political economy reminds us to ask: Who decides the rules of this coding? Who gains the most from the capital created? And who might be left out or exposed to new risks as their genomes become enmeshed in profit-driven systems? These questions gain urgency as genomic data continues to proliferate. The institutions facilitating genomic biocapital have a responsibility not only to extol progress, but also to address the inequities and governance challenges that arise when the code of life becomes a code of capital**.**

Chapter 7. CONCLUSION and DISCUSSION

7.1 Summary

In conclusion, my dissertation reveals the ambivalent character of genetic anti-discrimination legislation, namely GINA and GNA, as both protective and productive mechanisms within the neoliberal governance of life through techniques of privatization, responsibilization, and optimization (Rose, 2007). While these laws are rhetorically positioned as safeguards for privacy and equality, they also enable the expansion of market and legal infrastructures (Jessop, 2005; Pistor, 2019) that commodify genetic information (Waldby & Mitchell, 2006; Rabinow &Rose, 2006). Through Fairclough's CDA, I demonstrated how legal texts frame genetic data as an individualized, ownable asset, responsibilizing subjects to manage their genetic risks in alignment with neoliberal ideals. Complementing this analysis, Pistor's (2019) theory of legal coding offers a structural explanation for how genetic data is transformed into an economic asset: not by its intrinsic value, but through legal encoding, the assignment of exclusionary rights, control mechanisms, and durable claims over the use and circulation of data. These legal attributes render genetic information capital-ready, embedding it within systems of private property and market exchange.

Together, these findings demonstrate the dual function of genetic discrimination legislation: safeguarding individual rights while simultaneously embedding genetic information within systems of market exchange and biocapital. Pistor (2019) shows that law plays an active role in the creation of capital by endowing assets, whether land, debt, or data, with features such as priority, universality, and convertibility. In the case of GINA and GNA, the law frames genetic data as possessable, excludable, and tradeable through the codification of consent, ownership, and

access rights. Rather than opposing market logics, these protective laws facilitate the orderly functioning of genetic markets under the guise of individual empowerment and privacy protection.

At the heart of legislative discourse is a neoliberal narrative privileging personal autonomy and self-regulation. Terms such as "choice," "protection," and "consent" create an illusion of empowerment, masking limited enforcement mechanisms while shifting regulatory burdens to individuals (Rose, 2007; Petersen, 2011). Instead of comprehensive institutional safeguards, GINA and GNA rely heavily on individuals' awareness of their rights and capacity to seek legal recourse, aligning with neoliberal rationalities based on the self-governing, risk-aware subject. As Pistor (2019) notes, legal structures frequently operate under the appearance of neutrality while systematically favoring those with the resources and expertise to leverage them. In the case of genetic non-discrimination laws, enforcement is delegated to the individual, who must understand their rights, initiate legal action, and bear the risks of navigating complex regulatory frameworks. This mirrors Pistor's (2019) observation that legal rights are not evenly distributed tools, but scalable instruments of capital, accessible primarily to institutional actors such as insurers, biotechnology firms, and data brokers.

I have further explored how these legislative instruments construct a subject who must navigate complex legal frameworks with minimal institutional support, which reinforces a broader pattern of risk individualization (Petersen, 1996; Novas & Rose, 2000). The legal discourse, as analyzed through CDA, reveals how modality and agency are distributed to produce compliance while depoliticizing institutional power (Fairclough, 1995a, 2003). High-modality verbs like "shall not" and passive constructions such as "information shall not be used" create the appearance of strict regulation while concealing the responsibilities of corporate actors and the state. This

ideological illusion frames laws as neutral and universally applicable, yet the very legal code constructs genetic privacy as a market-compatible right, subject to the same logics of control, liability, and transaction as any other commodified asset.

The framing of privacy through possessive constructions such as "*your genetic data*" and the legal emphasis on individual consent naturalize genetic information as private property. This language, as Fairclough (1992) suggests, performs a constitutive function. It does not merely describe existing realities but constructs new social relationships and expectations. Individuals are configured as data custodians, consumers of health information, and contributors to biocapital economies. In doing so, the law mobilizes discourse to align citizens' identities with market logics (Rose, 2007). In this sense, the law, through both its language and its coding practices, mobilizes discourse to align citizens' identities and responsibilities with the demands of financialized bioeconomies (Pistor, 2019). Rather than resisting commodification, genetic discrimination laws actively support it by embedding genetic information in legal and economic structures that privilege capital accumulation under the guise of individual empowerment and autonomy.

In this sense, citizens are configured as custodians of their genetic identities, consumers of health information, and contributors to biocapital economies (Rose, 2007; Novas & Rose, 2000; Birch, 2017). GINA and GNA must also be situated within their broader historical contexts. Emerging after HGP, both sets of legislation respond to public anxieties about genetic determinism and the potential misuse of predictive information. Their forward-looking orientation in attempting to pre-empt discrimination rather than address embedded patterns makes them fundamentally speculative, distancing them from traditional civil rights legislation (Rothstein, 2018b). This positioning makes them vulnerable to being co-opted by commercial interests framing genetic

testing as a morally imperative, future-oriented practice essential to innovation and personalized medicine (Rose, 2007; Lippman, 1991).

The literature on genetic privacy highlights the dual consequences of laws on genetic discrimination. While promoting targeted safeguards, genetic exceptionalism reifies the idea that genetic identity is a dominant factor in individual worth and social risk. Scholars such as Rothstein (1994, 2005, 2008), Lemmens (2000), and Murray (2019) critique the piecemeal nature of genetic legislation by arguing that it conceals broader determinants of health and stigmatizes those with genetic predispositions. These critiques align with CDA's aim of exposing ideas and values embedded in dominant discourses. My dissertation also examines how genetic risk has redefined health as an individual responsibility, creating new expectations for individuals to understand and act on their genetic profiles. This shift obscures social determinants of health and reinforces moralizing discourses of self-governance, challenging traditional welfare state ideals (Rose, 2007; Petersen, 1996; Dean, 2010; Jessop, 2005).

I have evaluated the rise of genetic discrimination concerns in the context of biotechnological advances and HGP, emphasizing how genetic risk has redefined health as a matter of individual responsibility. This shift has created new forms of identities, biocitizenship (Petersen, 2011; Novas & Rose, 2000; Cooper, 2008). Questions raised in this context include how biocitizenship challenges traditional welfare state ideals and the extent to which empowerment rhetoric may induce anxiety among those receiving genetic information.

Applying micro-level CDA to legal texts, we see how language choices distribute responsibility and reflect ideological assumptions (Fairclough, 2003, 2013). Words like "protection" and "choice" appear empowering, yet they often operate in documents that lack clear

enforcement mechanisms. GINA and GNA rely on individuals to detect violations and pursue legal action, a structure aligned with neoliberal ideals of self-governance. Lexical choices and high-modality verbs (e.g., "shall not") project authority while obscuring enforcement gaps. The use of nominalization and passive voice (e.g., "collection of data") further shifts accountability from institutions to abstract processes. Comparative analysis of advocacy documents reveals contrasting discursive strategies. While U.S. guidance from the Department of Health and Human Services emphasizes compliance and research facilitation, Canadian sources like CAGC stress dignity, rights, and institutional responsibility. These differences underline varying national discourses around state responsibility, market regulation, and individual autonomy (Jasanoff, 2005; Gottweis & Lauss, 2012; Hurlbut et al., 2020).

At the meso-level, analysis of stakeholder discourses, including lobbyists, advocacy groups, and media, demonstrates how genetic privacy is simultaneously framed as a right and an asset. Organizations such as Genetic Alliance, ASHG, and CCGF mobilize moral discourses of dignity and protection. In contrast, biotech lobbyists like BIO and Sequence Bio intertwine rights-based language with pro-innovation messaging. Media narratives initially celebrated genomic science but have shifted toward exposing data commodification, often portraying lawmakers as protectors and corporations as both innovators and extractors of value (Fairclough, 1995b). These narratives influence public trust and obscure power asymmetries embedded in data governance. This level of analysis highlights how lobbyists' institutional affiliations influence the framing of genetic privacy, how media coverage shapes public perceptions of benefit distribution, and how discourse navigates the tension between individual rights and systemic data extraction (Hilgartner, 2007). The uncertainty embedded within legal texts and media reports stabilizes genomic data as

a proprietary capital resource while concealing its commodification behind narratives of trust and progress (Pistor, 2019; Rajan, 2006).

At the macro level, we turn to how laws like GINA and GNA are embedded in broader neoliberal health governance. In this regard, my dissertation revealed how legal discourse intersects with economic and institutional structures, reconfiguring roles and normalizing genetic testing. These laws, while framed as safeguards, foster public-private partnerships and facilitate genomic market expansion. CGS, Genome Canada's funding initiatives, and U.S. partnerships like Truveta (Reuters, 2025) illustrate how public institutions co-produce genomic capital with industry actors, transforming patient data into assets. GINA and the GNA are promoted as protective measures designed to secure individual rights and privacy, and their discursive configurations also function to facilitate the legal coding of genetic data as a valuable asset. These laws present themselves as frameworks to eliminate discrimination and foster public trust in genetic science. However, this protective framing conceals the function that these laws serve in stabilizing emerging markets in genetic data (Pistor, 2019; Rajan, 2006). By creating standardized categories of "genetic information," establishing legal boundaries for data collection and use, and delineating ownership and consent parameters, such legislation plays a foundational role in transforming personal genetic data into legally tradable, governable capital (Birch, 2017; Pistor, 2019).

The contradiction lies in the dual purpose these laws serve: they present genetic data as highly sensitive and in need of exceptional safeguards; they also construct a legal environment that makes such data reliably accessible for commercial and institutional use, with the promise of consent and ethical conduct. This alignment with what Pistor (2019) terms the "*legal coding of capital*" enables the integration of genetic information into broader circuits of value creation by

transforming it from embodied biological material into datafied, extractable resources governed by enforceable rights and obligations. Consent mechanisms and privacy protections become less about limiting access and more about legitimizing circulation within established legal and economic infrastructures (Cohen, 2012).

In this context, public-private partnerships, such as in Genome Canada–AdMare BioInnovations alliance, initiatives for community engagement like *MyCode Community Health Initiative* (Baker et al., 2022), can be seen as strategic discursive tools that normalize participation while diffusing responsibility. These initiatives are framed as enhancing equity and trust, yet they often operate within institutional settings that are already embedded in commodification logics. Therefore, legislation advertises equity, empowerment, and individual agency. Its implementation reinforces individualized responsibility for privacy management and participation, instead of addressing the issues about how genetic data is collected, monetized, and governed (Benjamin, 2019; Cohen, 2012; Prainsack, 2017).

By encoding genetic information with attributes of both property and personal identity, GINA and GNA contribute to the neoliberal restructuring of health governance by transforming protective legal discourse into enabling infrastructure for bioeconomic development (Pistor, 2019; Birch, 2017; Rose, 2007). The mechanisms that are meant to protect genetic subjects, such as consent forms, anonymization protocols, and non-discrimination clauses, are often what make data legally actionable and commercially viable (Pistor, 2019). This contradiction is structural: it reflects a broader pattern in which legal instruments perform a dual function, offering nominal protections while facilitating the conditions under which commodification can occur.

Through this lens, it is possible to see that the protective aims of genetic legislation serve not simply to shield individuals from harm, but to stabilize the socio-legal environment necessary for genomic markets to function. These laws incorporate economic logic by embedding data flows within legal frameworks that grant predictability, legitimacy, and enforceability to capital interests (Pistor, 2019; Birch, 2017; Jessop, 2002). The language of rights, privacy, and choice is co-opted into a system where governance is oriented toward risk management and market facilitation (Rose, 2007; Jasanoff, 2005). The resulting legal landscape is one in which the symbolic assurance of protection masks the material expansion of value extraction from genetic life.

In doing so, law participates in the naturalization of market logic within healthcare, reinforcing the notion that genetic information is a valuable personal asset to be protected by the individual and selectively shared under market-mediated terms (Fairclough, 2002; Pistor, 2019). Under Pistor's (2019) framework, this is a clear instance of legal coding: a process whereby legal instruments convert otherwise non-economic phenomena, such as personal health data, into capital by assigning them exclusionary rights, enforceable boundaries, and mechanisms for circulation. GINA and GNA do this subtly, through defining what genetic information is, who can access it, and under what conditions it may be withheld or shared. These acts give genetic information the attributes of an asset: excludability, transferability, and calculability.

This codification is not just symbolic; it underpins a massive infrastructure of data collection, biobank development, and algorithmic modeling. In this trajectory, patient-subjects are framed as vulnerable individuals to be protected and as indispensable data sources whose biological material feeds innovation (Gottweis, 2005; Prainsack, 2017). The contradiction lies in the fact that while these laws rhetorically position individuals as empowered agents who are

capable of making informed choices, they enable institutional actors to build platforms, tools, and markets on the basis of those same data.

The gap between rhetorical protection and material enforcement is not incidental. It reflects broader neoliberal governance structures where risk is individualized, and systemic protections are eroded in favor of self-regulation and market participation. Pistor (2019) helps clarify how these protections are selectively granted. Legal coding creates capital not through equal application but through differentiation. For example, protections under GINA exclude life and disability insurance, while GNA's criminal provisions are rarely invoked. These selective boundaries ensure that some actors, such as biotech firms, research institutions, and insurers, can continue to operate with substantial latitude, while individuals are left to navigate increasingly complex risk landscapes with little institutional support (Rothstein, 2008; Hudson et al., 2008).

This contradiction becomes especially evident in the policy documents and advocacy texts surrounding these laws. Organizations like HHS in the U.S. or Canada's CAGC use discourses of consent, privacy, and dignity, but often fail to disrupt the core economic mechanisms that incentivize the capture and commodification of genetic information. Thus, while the genre of legal-political texts may suggest regulatory control and public accountability, their interdiscursive function is often to facilitate trust, stabilize industry relationships, and legitimize the continued expansion of data economies (Fairclough, 2003; Birch, 2017; Jessop, 2007).

Media coverage plays a pivotal role in normalizing and legitimizing this duality. Early narratives surrounding initiatives like HGP emphasized the collective benefits of scientific progress, framing genetic information as a public good. However, as biotechnology advanced, media discourse shifted toward market-oriented framings, describing genetic data as a high-value

economic asset that requires legal and technological safeguards. High-profile events, such as the Myriad Genetics BRCA patent case and Angelina Jolie's public engagement with genetic testing (New York Times, 2013), amplified public concern about affordability, access, and monopolization. These events pave the way for the media narratives that portrayed genetic data as both deeply personal and highly commodifiable, aligning with Pistor's (2019) argument that the legal system plays an active role in coding data into capital through mechanisms such as trade secrecy, IP law, and regulatory exceptions.

Media texts also reveal shifting agentive roles. Initially, individuals are depicted as passive subjects in need of legal protection from potential corporate misuse of genetic data. Over time, as legal protections become institutionalized, individuals are reimagined as self-governing subjects who are empowered, informed, and responsible for managing their genetic risks (Rose, 2007). This discursive shift mirrors the neoliberal governance logic that underpins both GINA and GNA, whereby laws aim less to mandate institutional responsibility than to encourage voluntary compliance and consumer confidence. In media narratives, regulation is often portrayed not as a constraint on corporate power, but as a facilitator of market stability. Media articles routinely indicate that "regulation is necessary to enable innovation" or "ensure public trust," suggesting that legal protections are instrumental not for redistributing power or addressing structural inequality, but for creating the conditions necessary for the expansion of genetic testing and personalized medicine. These framings align with Pistor's (2019) claim that legal mechanisms, rather than being neutral tools of fairness, are foundational to the construction of new markets. They give legitimacy to certain actors, such as biotech firms, insurers, and researchers, while shaping the boundaries of permissible economic activity.

Furthermore, media discourses contribute to the naturalization of genetic determinism, often presenting genetic predispositions as predictive and actionable truths. Such portrayals overlook the probabilistic nature of genetic risk and the influence of social determinants of health (Nelkin & Lindee, 2010; Shostak, 2003). In doing so, they help establish a biomedical gaze that prioritizes individual-level interventions over structural approaches to health equity. This aligns with Fairclough's (2003) concept of recontextualization, where scientific knowledge is appropriated and restructured within public discourse to support dominant ideologies, here, the ideology of market-based self-management (Jessop, 2007). Media narratives do not just reflect public concerns; they shape public trust, regulatory priorities, and the broader discursive terrain of genetic governance. They participate in the process of legal coding by framing genetic data as both a protected right and a strategic economic asset. Through their coverage, they stabilize the emerging order in which genetic information is managed not only as a privacy concern but also as a valuable commodity embedded in complex, contested infrastructures of power, law, and capital. These findings underscore the necessity of treating media not just as a vehicle of information, but as an influential discursive site that co-produces the conditions under which genetic rights are defined, challenged, and ultimately commodified (Fairclough, 1995b; Jasanoff, 2005).

As a result, the law becomes a site of discursive closure, where the ethical debates conceal the material dynamics of accumulation. At this point, the CDA is particularly helpful in uncovering the discursive alignments between legislation, policy making, and corporate communications by showing how these different genres reinforce a dominant narrative of genetic exceptionalism, personalized health responsibility, and innovation-as-public-good, while masking alternative narratives grounded in justice and equity (Rose, 2007; Rothstein, 2005).

7.2 Contribution of the Dissertation

This research contributes to critical socio-legal scholarship by revealing the hidden commodification pathways embedded in genetic anti-discrimination laws. Through the combined use of Fairclough's discourse analysis (1989, 1992, 1995a, 2003) and Pistor's (2019) legal coding, it highlights how genetic privacy laws operate within the broader dynamics of capitalist accumulation. Rather than being purely protective instruments, GINA and GNA act as facilitators of market expansion, legitimizing the transformation of human biology into capital assets (Pistor, 2019). This dual role of law reflects a systemic alignment of governance with neoliberal economic rationalities, where individuals are responsibilized, institutions evade structural accountability, and markets thrive under the guise of protection (Rose, 2007). Reimagining genomic governance requires a radical departure from rights-based individualism toward collective, equity-driven legal and institutional frameworks that prioritize public welfare over private gain.

Overall, I highlight the need to understand genetic discrimination not just as an ethical or legal concern, but as a discursive and material phenomenon produced within a knowledge-based political economy (Jessop, 2007; Birch, 2017). In this context, genetic testing is not neutral; it generates new moral obligations and expectations while reinforcing structural inequities in access, literacy, and social support (Novas & Rose, 2000; Lippman, 1991; Lemke, 2013). The commodification of health data transforms patients into both consumers and data providers, while legal instruments ostensibly designed to safeguard individual rights simultaneously function as mechanisms of legal coding that enable corporate access to and control over genetic material, facilitating the accumulation of biocapital within global markets (Pistor, 2019; Birch, 2017; Zuboff, 2023). My dissertation concludes that genetic anti-discrimination laws have dual

functions: being protective instruments on the one hand, and being deeply implicated in the commodification of life itself on the other hand (Rose, 2007). While they offer symbolic and procedural safeguards, they stabilize the neoliberal conditions that allow for the enclosure of genomic data into proprietary markets. Fairclough's CDA (1989, 1992, 1995a, 2003) shows how discourse masks the commodification of genetic data through empowering narratives, while Pistor's (2019) framework reveals how legal tools encode data with attributes of capital.

Importantly, my research contributes to the broader literature by offering a novel methodological synthesis of discourse analysis and legal theory. By integrating Fairclough's CDA with Pistor's concept of legal coding, I highlight how language reflects and reinforces ideological power and also how law functions as a material infrastructure that facilitates economic transformation. This synthesis provides a critical framework for future scholarship in several domains. It expands the field of policy analysis by illustrating how genetic law must be examined not only through doctrinal or institutional lenses but through discursive and economic ones. It also opens new avenues for health research by showing how legal and regulatory environments shape patient experiences, health behaviors, and trust in genomic technologies (Jasanoff, 2005; Reardon, 2017; Tutton & Prainsack, 2011; Samuel & Farsides, 2018).

The need to move beyond market-driven governance toward alternative approaches becomes evident. This shift includes reimagining genetic data not as proprietary information but as a public good managed through democratic, transparent, and equitable systems (Prainsack, 2017; Gottweis, 2005; Kaye et al., 2012). Such a shift necessitates a collaboration involving legal scholars, public health experts, ethicists, sociologists, and patient advocates to ensure that the promises of genomic medicine do not deepen existing disparities and foster solidarity, dignity, and

equitable access for all. It also questions a re-evaluation of the dominant legal and policy assumption that "informed consent" functions as an adequate mechanism for protecting individuals within complex bioeconomic systems (Hallowell, 1999; Hedgecoe, 2004; Knoppers, 2014). In practice, consent often operates more as a tool of legal compliance than substantive empowerment, legitimizing the circulation of data without addressing underlying power asymmetries (Brown & Baker, 2012; Fisher, 2013). Strengthening institutional accountability beyond individual legal action would require the development of collective oversight mechanisms, participatory governance structures, and greater institutional transparency to rebalance relationships among individuals, states, and commercial actors.

My dissertation underscores the broader societal implications of genetic data governance within capitalist political economies. Institutions, through legal coding and discursive practices, socially construct the very meaning of genetic identity, embedding it in market logics. As Pistor's (2019, p.7) analysis of capital coding indicates, law acts as an enabler of capital mobility and wealth concentration. Genetic data is incorporated into the same legal machinery that allows elites and corporations to transcend territorial accountability, echoing broader patterns of financialization and privatization (Jessop, 2002; Birch, 2017). Legal mechanisms (consent, anonymization, non-discrimination) render genetic data legible, transferable, and economically actionable. This reinforces power asymmetries, contributing to social stratification where marginalized populations face higher risks of genetic surveillance and discrimination, while privileged groups benefit from capitalized healthcare products.

Structural power asymmetries remain largely unaddressed within rights-based legal frameworks governing genetic data. By centering protection on individual consent and non-

discrimination, responsibility for managing genetic risk is effectively shifted onto individuals, obscuring the structural and institutional conditions under which genetic data is produced, circulated, and exploited. Complaint-based enforcement mechanisms further limit institutional accountability, placing the burden of proof and action on affected individuals while allowing powerful public and private actors to operate with minimal oversight. At the same time, transparency gaps in public–private data partnerships restrict meaningful public scrutiny, reinforcing asymmetrical access to information and decision-making power. In this configuration, legal protection functions less as a mechanism of redistribution or justice than as a stabilizing force that secures participation in genomic markets while leaving extractive and exclusionary structures intact. Without substantive reform, genetic data governance risks reproducing, and intensifying, existing health and social inequalities. A social justice–oriented approach, therefore, demands a fundamental transformation in how genetic resources are governed: not as private, alienable assets subject to market logics, but as public goods embedded within frameworks of collective ownership, shared responsibility, and care.

7.3 Future Research

Future research would benefit from interrogating the role of law as a social constructor of market realities in health governance. Building on Pistor's theory (2019), researchers would empirically map how legal codification of genetic data shapes capital flows and institutional behavior in different jurisdictions. Expanding beyond North American contexts to include European, Indigenous, and Global South perspectives can reveal alternative governance pathways. A mixed methods approach combining discourse analysis, legal sociology, and ethnography could

offer richer insights into how genetic subjects experience legal protections in practice, and how power asymmetries manifest in healthcare delivery.

My dissertation shows how governance is built, how responsibility is individualized, how market access is normalized, and how protections are scoped and operationalized. My research question is not how individuals experience genetic governance, but how governance itself is constructed and stabilized. Laws, policies, and institutional narratives are performative texts which create categories, rights, and obligations that shape downstream experiences. Ethnography would show navigation, while my study shows architecture. The primary limitation is that a text-centered approach cannot directly capture lived experience or implementation practices. CDA shows how governance is encoded and legitimized, not how individuals navigate it day to day. My decision for the theoretical and methodological approach is not based on a belief that institutional ethnography is incapable of addressing institutional power. Rather, it was based on the specific level and object of analysis I prioritized. Institutional ethnography, following Smith (2005), excels at tracing how people's everyday work is coordinated by texts and institutions. My project, however, is focused less on how actors navigate governance and more on how governance itself is legally and discursively constructed at the level of statutes, policy frameworks, and institutional narratives. I explicitly treat lived experience as a future direction.

A further avenue of inquiry is the exploration of alternative legal discourses, such as those rooted in Indigenous legal traditions, feminist jurisprudence, or critical race theory, that could reshape the field of genetic governance. These frameworks challenge the liberal individualism and property-centric assumptions underlying current genetic privacy laws. Indigenous legal systems, for instance, often emphasize collective stewardship of biological and environmental resources,

offering powerful models for community-based governance of genetic information (Kukutai & Taylor, 2016). Indigenous data sovereignty initiatives, such as the First Nations' OCAP principles in Canada, assert communal ownership and governance over genomic data to ensure transparency and benefit-sharing within communities (First Nations Information Governance Centre, n.d).

Feminist and critical race scholars argue that genetic data governance must address structural inequalities obscured by rights-based individualism, emphasizing relational autonomy (Sherwin, 2011) and the enduring impact of systemic racism in biomedical practice (Bridges et al., 2017). Incorporating these perspectives could help shift the focus from protection as a defensive stance to justice as a proactive and structural perspective, generating a more inclusive, reflexive, and ethically grounded model of genetic governance. If genetic data is embedded within systems of capital accumulation, then its governance needs to be understood not just in ethical or procedural terms, but in material and structural ones.

Another important direction for future research is the empirical examination of corporate practices surrounding genetic data; that is, how corporations commodify and use data, and operationalize legal and discursive frameworks in practice. Future studies could investigate how genetic data is collected, processed, shared, monetized, and governed within corporate settings, including biotechnology firms, data intermediaries, insurers, and platform-based health companies. Such research could draw on analysis of corporate disclosures, contracts, data-sharing agreements, regulatory filings, governance policies, and compliance documents, as well as interviews with industry, regulatory, and oversight actors. This would illuminate organizational logic, risk management strategies, and accountability mechanisms that shape genetic data use beyond formal legal protections. Importantly, this line of inquiry would allow researchers to assess whether and

how existing legal frameworks constrain corporate behavior or primarily function to legitimate and stabilize data-intensive business models. Such work would complement the present study by tracing how governance frameworks are enacted, negotiated, or circumvented within organizational settings.

The role of discourse in shaping public perceptions of trust and risk also emerges as a critical area of inquiry. Legal and policy narratives surrounding genetic privacy frequently invoke empowerment, dignity, and safety, even as they coexist with structural logics of extraction and enclosure (Benjamin, 2019; Jasanoff, 2005; Hilgartner, 2017). This discursive strategy helps sustain public compliance and participation in genetic testing programs, even under conditions of surveillance and potential exploitation (Rose, 2007; Gibbon & Novas, 2008). Counter-discourses grounded in solidarity, public ownership, and epistemic justice could offer alternative frameworks to challenge the dominant individualization of genetic privacy. Implications for health equity and social justice are also significant. The assetization of genetic data often benefits biotech firms, insurers, and research institutions, raising concerns about the lack of redistributive mechanisms to ensure that communities contributing genetic material share in the resulting material and therapeutic benefits (Waldby & Mitchell, 2006; Pistor, 2019; Reardon, 2017). Addressing these inequities would involve granting marginalized groups greater control over the use, storage, and valuation of their genetic information.

7.4 Limitations

While I provide an analysis of genetic discrimination laws in North America, several limitations need to be acknowledged. First, the analysis is based on publicly available legal texts, policy documents, and selected advocacy materials. These sources offer rich insight into how

discourse shapes legal meaning and social perception (Fairclough, 1995a). However, they may not fully capture how these laws function in practice or how they are experienced by individuals subject to them (Ewick & Silbey, 1998). There remains a gap between the discourse of law and its lived realities to explain how genetic privacy is navigated in healthcare settings, how consent is operationalized in medical practice, or how individuals understand and exercise their rights.

The analysis is intentionally confined to two specific legal instruments within North American legal and political-economic contexts. The dissertation does not claim to provide a comprehensive account of genetic discrimination law across jurisdictions, nor does it seek to reconstruct the legislative processes or political negotiations through which these statutes were enacted. Instead, its contribution lies in demonstrating how, in these two cases, protection-oriented law functions as governance infrastructure once enacted, and how law and discourse together shape the political-economic conditions under which genetic data is regulated, circulated, and valorized. Framed in this way, the dissertation should be understood as a starting point rather than a comprehensive account. My dissertation does not explore comparative legal frameworks from other jurisdictions, such as the European Union's General Data Protection Regulation (GDPR), which may offer different models of protection, enforcement, and data governance. However, it offers a transferable analytic framework that can be applied to other legal domains, jurisdictions, or data-intensive technologies. Including such comparisons in future research could deepen the analysis by highlighting potential alternatives or variations in how genetic information is legally coded and commodified.

My dissertation draws on a three-level (macro, meso, and micro-levels) analysis; it does not include empirical interviews or ethnographic data from stakeholders such as genetic

counselors, patients, biotech executives, or policymakers. As a methodological alternative, interviews and ethnographic approaches would tell how people navigate governance based on the research question and direction. Such data would provide valuable perspectives on how legal discourses are interpreted and rearticulated in everyday practice. Interviews and ethnographic approaches are valuable for understanding how people navigate legal systems, but they would not be able to show how governance itself is constructed for the scope of my research. Instead, a text-centred approach that I employ in my dissertation allows me to trace how power is organized and how genetic information becomes a regulated and economically meaningful object.

There are methodological constraints in the use of CDA itself. While CDA helps reveal power relations and ideological formations within texts, it is interpretive in nature and can risk privileging certain readings over others (Widdowson, 1998). Despite these limitations, I offer a helpful framework for analyzing genetic governance's legal, discursive, and economic dimensions. Future research would benefit from expanding the empirical base, incorporating diverse legal traditions, and exploring participatory forms of regulation to build more equitable and transparent systems for managing genetic information.

7.5 Discussion

In light of these findings, critical questions emerge that extend the analytical scope of my study and open pathways for reimagining the role of law in the governance of genetic information. The extent to which legal frameworks, despite their protective rhetoric, function more as enablers than constraints of genetic data extraction and commercialization is one such question (Pistor, 2019; Jasanoff, 2005; Waldby & Mitchell, 2006; Hilgartner, 2017). In addition, the extent to which current legal frameworks adequately address structural power imbalances in the governance of

genetic information also bears exploration. Protections such as those granted by GINA and GNA often displace systemic responsibility onto individuals, raising the need to consider how law could be reconfigured to recognize the collective, relational, and uneven ways in which genetic risks and data are distributed. Expanding the legal definition of discrimination to include indirect, algorithmic, or institutional forms of harm could offer a more accurate reflection of the evolving realities of datafied health governance (Wachter et al. 2017; Joly et al. 2014). Addressing the cumulative effects of genetic profiling in insurance markets, healthcare triage systems, and social policy would be an important step toward a more comprehensive legal framework. As indicated by Pistor (2019), these laws help constitute the conditions under which genetic information is transformed into capital through mechanisms like consent that facilitate data flow within regulated markets. While appearing to provide safeguards, the legal structures simultaneously stabilize the infrastructure required for commodification. This raises the concern that law is not simply lagging behind innovation but actively participating in shaping the genomic economy.

From a regulatory perspective, I identify urgent areas for policy reform as well. These include a clearer institutional accountability for genetic data use, expanding protections against indirect discrimination, strengthening oversight in public-private partnerships, and ensuring that informed consent mechanisms are meaningful and enforceable. It highlights that genetic information needs to be reimagined not as a privatized commodity but as a shared social resource. By applying CDA and legal coding theory to this field, this research contributes to a critical rethinking of the role of legislative framework in the bioeconomy. In this sense, this research carries significant policy and legal implications, highlighting the urgent need to critically reassess existing frameworks governing genetic data. The findings call for a reconsideration of the normative assumptions underpinning genetic privacy laws. Rather than serving solely as protectors

of individual rights, laws often function as vehicles for market expansion, facilitating the construction of legal infrastructures that enable the accumulation of biocapital.

As Pistor (2019) demonstrates, modern legal systems have evolved to serve mobile capital rather than local democratic accountability, allowing actors to strategically "code capital" across jurisdictions (pp. 6–8). Within genomic governance, this manifests as flexible legal frameworks that prioritize corporate interests while placing disproportionate regulatory burdens on individuals through consent requirements and self-enforcement mechanisms. In contrast, governance frameworks that engage donors, researchers, policymakers, and the public foster more democratic forms of oversight, helping to ensure that biobanks reflect societal values and expectations (Kaye et al., 2012, p. 60). By contrast, governance frameworks that actively engage donors, researchers, policymakers, and the public can foster more democratic forms of oversight, thereby ensuring that biobanks operate in ways that more accurately reflect societal values and expectations (Kaye et al., 2012). Policies that focus narrowly on formal rights often overlook the deeper economic dynamics at play, leading to regulatory capture wherein the state inadvertently facilitates market expansion (Pistor, 2019). Drawing on such analyses, there is a pressing need for legal reforms that move beyond protectionist rhetoric to enhance institutional accountability, critically assess the expansion of speculative markets in genetic data, and explore redistributive approaches aimed at addressing structural inequities (Birch, 2017; Pistor, 2019).

Reimagining the law as a redistributive force rather than merely a tool for risk management demands moving beyond current frameworks that treat genetic data as privately owned and individually managed assets. Instead, genetic information should be reconceptualized as a shared social resource. This paradigm shift is reflected in emerging legal and policy frameworks

emphasizing transparency, collective responsibility, and equitable access. For example, the European Union's General Data Protection Regulation (GDPR) embeds principles of transparency and accountability to ensure data use aligns with societal interests beyond individual control (European Parliament, 2016). Similarly, the Open Science Movement advocates FAIR (Findable, Accessible, Interoperable, Reusable) data principles that promote equitable access and reuse of genomic data to advance public health and scientific knowledge (Wilkinson et al., 2016). On a global scale, the Global Alliance for Genomics and Health (GA4GH) has developed governance frameworks emphasizing responsible data sharing with enforceable agreements prioritizing equity and reciprocity among stakeholders (Knoppers, 2014). Additionally, public-private partnerships such as the UK Biobank incorporate enforceable equity clauses designed to prevent data monopolization and ensure broad, equitable distribution of research benefits to support long-term public health objectives (UK Biobank, 2015). Together, these examples illustrate how legal frameworks can evolve beyond minimal protection to actively regulate data ownership and use, embedding redistributive justice into genomic information governance.

Genetic discrimination laws in North America are grounded in a negative rights framework. They prohibit certain actions by employers, insurers, and other actors, but they do not compel the state or private institutions to provide protections, oversight, or infrastructure beyond complaint-based enforcement (U.S. Government Publishing Office, 2008; Government of Canada, 2017). This reflects broader neoliberal legal traditions in which positive rights are less developed, particularly in settings that do not operate as expansive social welfare states. From this perspective, the absence of enforceable positive obligations, such as a right to have a robust genetic data protection, proactive regulatory oversight, or institutional safeguards. is not accidental but structural. My dissertation shows how protection is framed as an individual entitlement rather than

a collective guarantee, limiting the capacity of law to redistribute risk or impose affirmative duties on powerful actors. Future research could examine whether a more explicitly positive rights approach, for example, framing genetic data protection as a right that obliges governments to regulate, monitor, and intervene, could alter governance outcomes, and under what conditions such an approach might emerge. Together with corporate practices research, these directions extend my dissertation's contribution by moving from an analysis of how governance is constructed to an examination of how it is operationalized and contested, at the intersection of law, corporate power, and human rights.

From a public health perspective, the current legal and discursive frameworks surrounding genetic testing risk exacerbating health inequities by reinforcing broader trends such as digitalization and individualization of healthcare, which often shift focus away from structural determinants of health and disproportionately affect marginalized populations (Lupton, 2016; Prainsack, 2017; Phillips, 2016). My research reveals how genetic testing is promoted through empowerment narratives while systematically shifting responsibility to individuals, aligning with neoliberal models of health governance (Lupton, 2013a; Petersen & Bunton, 2002; Rose, 2007). Fairclough (2003) explains how discourse can construct participation as a choice when, in reality, it is shaped by institutional power. The legal codification of genetic data fosters commercial pathways for data extraction rather than prioritizing collective health needs. As scholars like Roberts (2011) and Nelson (2016) argue, an overemphasis on genetic risk obscures social determinants of health, potentially diverting attention and resources from structural public health interventions. The law's complicity in transforming public health resources into private commodities, facilitated by public-private partnerships and expansive genomic data sharing, has raised concerns regarding public health equity (Lupton 2012; Prainsack 2017). This trend

underscores the need for reform efforts such as the de-commodification of genetic resources, the adoption of collective benefit-sharing frameworks, and stronger regulatory oversight of private actors involved in genomic medicine (Benjamin, 2019; Tutton, 2012; Birch, 2017).

The findings of my dissertation highlight the importance of examining the influence of international standards, guidelines, and principles, such as those promoted by the OECD. These transnational frameworks, frequently developed in collaboration with corporate stakeholders, help institutionalize normative understandings of genetic privacy, ownership, and access that reflect market logics. While the OECD (2015a) frames data governance in terms of privacy and innovation, its guidelines often prioritize interoperability and commercial utility, reinforcing a neoliberal logic that privileges market facilitation over local governance, cultural specificity, and Indigenous data sovereignty. Pistor (2019) shows how legal systems serve as infrastructures for capital accumulation, encoding assets like genetic data through jurisdictional arbitrage, contractual flexibility, and proprietary protections, thereby enabling capital mobility at the expense of democratic accountability. This is reflected in global governance regimes that prioritize investor confidence over redistributive justice.

If current governance frameworks continue to be dominated by commercial logics, challenges to safeguarding equity and access in genomic healthcare are likely to persist (Reardon, 2017; Benjamin, 2019). International standards would continue to play a pivotal role in either reinforcing or constraining corporate control over genetic resources. The regulatory frameworks that evolve beyond narrow protections and adopt collective governance models to emphasize justice, solidarity, and the public interest may create opportunities for a more robust oversight of data-sharing agreements, greater transparency in public-private partnerships, broader protections

against indirect and systemic discrimination, and the development of participatory oversight mechanisms (Tutton & Prainsack, 2011). Interdisciplinary collaboration from various disciplines, including legal theory, ethics, public health, and sociology, would play a crucial role in supporting these shifts and shaping more inclusive approaches to genomic governance (Knoppers & Chadwick, 2005; Prainsack, 2018). Such developments could counteract the trend of subsuming human genetic material into capital, reframing it instead as a shared and collectively managed resource. Whether regulatory reforms can move from market facilitation toward advancing collective justice will depend on how these structural and institutional dynamics interact (Pistor, 2019; Hilgartner, 2017).

Taken together, this analysis demonstrates that genetic discrimination law in North America operates less as a barrier to exploitation than as a stabilizing infrastructure for the genomic economy. Through rights-based protections, consent mechanisms, and narrowly defined notions of discrimination, law simultaneously mitigates overt harms while enabling the extraction, circulation, and capitalization of genetic data. Rather than focusing on structural power asymmetries, these frameworks individualize responsibility, obscure institutional accountability, and normalize market participation as a condition of protection. As my dissertation shows, governance of genetic technologies is not only shaped by technological developments but constituted through legal coding and discursive framing that privilege commercial utility. The challenge, therefore, is not simply to strengthen existing protections, but to rethink the role of law in genomic governance, moving beyond complaint-based, negative rights models toward collective, redistributive, and institutionally accountable frameworks. Without such a shift, genetic governance risks continuing to reproduce the inequalities it purports to prevent, embedding

genomic innovation more deeply within neoliberal regimes of extraction and commodification instead of working towards equitable public health outcomes.

More broadly, I encourage scholars, policymakers, and other stakeholders to rethink the dual role of legal frameworks: as barriers to discrimination and as co-constructors of the commodification of genetic knowledge under the bioeconomy. Genetic information is not simply a sensitive form of personal data; instead, it is a contested social resource whose governance will shape the future of healthcare, equity, and citizenship (Novas & Rose, 2000; Rabinow & Rose, 2006; Prainsack, 2017). Moving forward, a new approach to policy making in the regulation of genomic knowledge and technologies to prevent genetic discrimination may be needed to address the flaws of prevailing logics of privatization and commodification.

BIBLIOGRAPHY

Legislation:

Government of Canada. *Genetic Non-Discrimination Act 2017*.

U.S. Government Publishing Office. *Genetic Information Non-discrimination Act of 2008.*

Policies/Pamphlets:

Canadian Association of Genetic Counsellors (2018**).** *Genetic Non-Discrimination Act (formerly Bill S-201) Fact Sheet*.

Canadian Association of Genetic Counsellors (2018). *Genetic Non-Discrimination Act (GNA).*

US Department of Health and Human Services "Genetic Information Non-discrimination Act

(GINA) OHRP Guidance (2009**).** *Guidance on the Genetic Information Non-discrimination Act:*

Implications for Investigators and Institutional Review Boards.

Lobbying Groups:

American Society of Human Genetics (2020). *Protecting Canadians against Genetic Discrimination.*

Bio Technology Innovation (2008). *BIO's Letter Supporting S.358, the Genetic Information Nondiscrimination Act (GINA).*

Canadian Coalition for Genetic Fairness (2017). *Genetic Fairness One Step Closer to Canadians*

Making Informed Decisions About Their Health – Without Fear.

Canadian Coalition for Genetic Fairness (2015). *Proposal to Protect Canadians from Genetic Discrimination.*

Genetic Alliance-US Department of Labor (2008). *Genetic Alliance Response to Request for Information.*

Huntington Society of Canada (2020). *Genetic Discrimination and the GNDA.*

Sequence Bio (2017). *Changing the discriminating eye of the law.*

Media Articles:

CBC News (2016). *Senate passes bill to keep genetic test results private.*

CBC News (2017a*). Genetic anti-discrimination law protects patient privacy without sacrificing research.*

CBC News (2017b). *Liberal backbenchers defy cabinet wishes and vote to enact genetic discrimination law.*

CBC News (2017c). *MPs reject liberal government's attempt to gut genetic discrimination bill.*

CBC News (2018). *Door will open to genetic discrimination if act protecting Canadians is overturned, genomics expert says.*

CBC News (2020). *Supreme Court of Canada upholds genetic non-discrimination law.*

CBS News (2008). *Guarding Against Genetic Discrimination.*

Conversation (2024). *Canada's Genetic Non-Discrimination Act has only had a limited impact on the use of genetic information by life insurers*.

Fox News (2008). *Congress Sends Bush Anti-Genetic Discrimination Bill*

Genetic Engineering & Biotechnology News (2008). *GINA Provides Bioindustry Boost*

Global News (2017). *MPs to debate controversial bill on genetic testing after intense lobbying*

NBC News (2008). *Senate passes genetic discrimination ban*

New York Times (2003). *Once Again, Scientists Say Human Genome Is Complete*

New York Times (2009). *Opinion | A Ban on Genetic Discrimination* New York Times (2013). *Opinion | My Medical Choice by Angelina Jolie* Time Magazine (2012). *Can You Be Fired for Your Genes?*

Wall Street Journal (2000). *Hands Off My Genes*

Washington Post (2005). *Act Now to Prevent Genetic Discrimination*

Secondary Sources:

Adair, A., Hyde-Lay, R., Einsiedel, E., & Caulfield, T. (2009). Technology assessment and resource allocation for predictive genetic testing: A study of the perspectives of Canadian genetic health care providers. *BMC Medical Ethics, 10*(6).

Adjin-Tettey, E. (2013). Potential for genetic discrimination in access to insurance: is there a dark side to increased availability of genetic information? *Alberta Law Review*, *50*(3).577.

Adjin-Tettey, E. (2021). Striking the Right Balance: Does the Genetic Non-Discrimination Act Promote Access to Insurance? *McGill Journal of Law and Health*, *14*(2), 978-986.

Allain, D. C., Friedman, S., & Senter, L. (2012). Consumer awareness and attitudes about insurance discrimination post enactment of the Genetic Information Non-discrimination Act. *Familial Cancer*, *11*, 637-644.

Allison, M. (2008). Industry welcomes Genetic Information Non-discrimination Act. *Nature Biotechnology*, *26*(6).

Almeling, R., & Gadarian, S. K. (2014). Public opinion on policy issues in genetics and genomics. *Genetics in Medicine*, *16*(6), 491-494.

American Council of Life Insurers (2022). *Life Insurance Companies and Genetic Information*.

https://www.acli.com/-/media/public/pdf/about-the-industry/risk-classification/risk_ classification_genetic_ testing_q_and_a_v3.pdf#:~:text=,Genetic

Andrews, L. B. (1995). Genetic privacy: from the laboratory to the legislature. *Genome Research*, *5*(3), 209-213.

Armstrong, D., Michie, S., & Marteau, T. (1998). Revealed identity: a study of the process of genetic counselling. *Social Science & Medicine*, 47(11), 1653-1658.

Armstrong, K., Micco, E., Carney, A., Stopfer, J., & Putt, M. (2005). Racial differences in the use of BRCA1/2 testing among women with a family history of breast or ovarian cancer. *Journal of the American Medical Association*, *293*(14), 1729-1736.

Arribas-Ayllon, M., Sarangi, S., & Clarke, A. (2008). Managing self-responsibility through other-oriented blame: family accounts of genetic testing. *Social Science & Medicine*, *66*(7), 1521-1532.

Ashley, E. A. (2016). Towards precision medicine. *Nature Reviews Genetics*, *17*(9), 507-522.

Baker, A., Tolwinski, K., Atondo, J., Davis, F. D., Goehringer, J., Jones, L. K., Pisieczko, C. J.,

Sturm, A. C., Williams, J. L., Williams, M. S., Rahm, A. K., & Buchanan, A. H. (2022). Understanding the patient experience of receiving clinically actionable genetic results from the MyCode Community Health Initiative, a population-based genomic screening initiative. *Journal of Personalized Medicine*, *12*(9), 1511.

Baruch, S., & Hudson, K. (2008). Civilian and military genetics: nondiscrimination policy in a post-GINA world. *The American Journal of Human Genetics*, *83*(4), 435-444.

Battista, R. N., Blancquaert, I., Laberge, A. M., Van Schendel, N., & Leduc, N. (2011). Genetics in health care: an overview of current and emerging models. *Public Health Genomics*, *15*(1), 34-

45.

Bélisle-Pipon, J. C., Vayena, E., Green, R. C., & Cohen, I. G. (2019). Genetic testing, insurance discrimination and medical research: what the United States can learn from peer countries. *Nature Medicine*, *25*(8), 1198-1204.

Benjamin, R. (2019). *Race after Technology: Abolitionist tools for the new Jim code*. Polity Press.

Bhasin, P.G., Durana, T., Kyaw, N.Y.W., Natarajan, V., Best, J., Wu, A., Toom, S. and Xu, Y., (2022). The perception and emotional reaction to genetic test results in cancer patients in an immigrant enriched hospital. *Journal of Clinical Oncology*, 40(16_suppl), e24128.

Billings, P. R., Kohn, M. A., De Cuevas, M., Beckwith, J., Alper, J. S., & Natowicz, M. R. (1992).

Discrimination as a consequence of genetic testing. *American Journal of Human Genetics*, *50*(3), 476.

BioSkryb. (2023). *BioSkryb and St. Jude Children's Research Hospital partner*.

https://www.bioskryb.com/news/bio-skryb-and-st-jude-children-s-research-hospital-partner/

Birch, K. (2006). The neoliberal underpinnings of the bioeconomy: the ideological discourses and practices of economic competitiveness. *Genomics, Society and Policy*, *2*(3), 1.

Birch, K., Levidow, L., & Papaioannou, T. (2010). Sustainable capital? The neoliberalization of nature and knowledge in the European "Knowledge-based Bio-economy." *Sustainability, 2*(9), 2898–2918.

Birch, K., & Tyfield, D. (2013). Theorizing the bioeconomy: Biovalue, biocapital, bioeconomics. *Science, Technology, & Human Values, 38*(3), 299–327.

Birch, K. (2017). Rethinking value in the bio-economy: Finance, assetization, and the management of value. *Science, Technology, & Human Values*, *42*(3), 460-490.

Bloss, C. S., Schork, N. J., & Topol, E. J. (2011). Effect of direct-to-consumer genomewide profiling to assess disease risk. *New England Journal of Medicine*, *364*(6), 524-534.

Bolnick, D. A. (2008). Individual ancestry inference and the reification of race as a biological phenomenon. In B. A. Koenig, S. S.-J. Lee, & S. S. Richardson (Eds.), *Revisiting Race in a Genomic Age* (pp. 70–88). Rutgers University Press.

Bombard, Y., Veenstra, G., Friedman, J. M., Creighton, S., Currie, L., & Avard, D. (2011). Perceptions of genetic discrimination among people at risk for Huntington's disease: A cross sectional survey. *British Medical Journal,* 342, d4374.

Bombard, Y., & Heim-Myers, B. (2018). The Genetic Non-Discrimination Act: critical for promoting health and science in Canada. *Canadian Medical Association Journal,* 190(19), E579E580.

Bourdieu, Pierre. (2018). The Forms of Capital. In M. Granovetter (Ed). *The Sociology of Economic Life* (pp. 78–92). Routledge

Boyd, D., & Crawford, K. (2012). Critical questions for big data: Provocations for a cultural, technological, and scholarly phenomenon. *Information, Communication & Society, 15*(5), 662–679.

Brabazon, H. (2016). *Neoliberal Legality.* Routledge.

Breeze, R. (2011). Critical discourse analysis and its critics. *Pragmatics: Quarterly publication of the International Pragmatics Association (IPrA)*, *21*(4), 493-525.

Bridges, K. M., Keel, T., & Obasogie, O. K. (2017). Introduction: Critical race theory and the health sciences. *American Journal of Law & Medicine*, *43*(2-3), 179-182.

Brothers, K. B., & Rothstein, M. A. (2015). Ethical, legal and social implications of incorporating personalized medicine into healthcare. *Personalized Medicine*, *12*(1), 43-51.

Brown, N., & Michael, M. (2003). A sociology of expectations: Retrospecting prospects and prospecting retrospects. *Technology Analysis & Strategic Management, 15*(1), 3–18.

Brown, B. J., & Baker, S. (2012). *Responsible Citizens: Individuals, health, and policy under neoliberalism*. Anthem Press.

Brown, W. (2015). *Undoing the Demos: Neoliberalism's Stealth Revolution*. Zone Books.

Bryman, A. (2016). *Social Research Methods*. Oxford University Press.

Burke, W. (2002). Genetic testing. *New England Journal of Medicine*, *347*(23), 1867-1875.

Butler, J. (1997). *The psychic life of power: Theories in subjection*. Stanford University Press.

Bycroft, C., Freeman, C., Petkova, D., Band, G., Elliott, L. T., Sharp, K., ... & Marchini, J. (2018). The UK Biobank resource with deep phenotyping and genomic data. *Nature*, *562*(7726), 203-209.

Canadian Agency for Drugs and Technologies in Health (2023). *CADTH Horizon Scan: 2023 Watch List*. https://www.cda-amc.ca/sites/default/files/Tech%20Trends/2023/ER0013%20-%202023%20Watch%20List%20Final.pdf

Canadian Association of Genetic Counsellors (n.d). *What is Genetic Counselor?* https://www.cagc-accg.ca/doc/what%20is%20a%20genetic%20counsellor%20-%20english.pdf Canadian Institutes of Health Research. (2022). *Sequencing Our Future: Institute of Genetics Strategic Plan 2022–2027*. https://cihr-irsc.gc.ca/e/52973.html

Canadian Institutes of Health Research. (2023). *Government of Canada invests $15M in first-ofits-kind pan-Canadian genome library*. https://www.canada.ca/en/institutes-healthresearch/news/2023/10/government-of-canada-invests-15m-in-first-of-its-kind-pan-canadiangenome-library.html

Caulfield, T., McGuire, A. L., Cho, M., Buchanan, J. A., Burgess, M. M., Danilczyk, U., ... & Timmons, M. (2008). Research ethics recommendations for whole-genome research: consensus statement. *PLoS Biology*, *6*(3), e73.

CBC News (2025, March 29). *N.L.'s privacy commissioner urges people to delete data from 23andMe after bankruptcy declare*d. https://www.cbc.ca/news/canada/newfoundland-labrador/nl-privacy-23andme-protect-data-1.7496034

Centers for Disease Control and Prevention (n.d). *Genetic Counselling*. https://www.cdc.gov/genomics/gtesting/genetic_counseling.htm

Chadwick, R. (2013). Ethical issues in personalized medicine. *Drug Discovery Today: Therapeutic Strategies*, *10*(4), e171-e174.

Chapman, C. R., Mehta, K. S., Parent, B., & Caplan, A. L. (2020). Genetic discrimination: emerging ethical challenges in the context of advancing technology. *Journal of Law and the Biosciences*, 7(1), lsz016.

Chernomas, R., Hudson, I., & Chernomas, G. (2018). Can neoliberal capitalism affect human evolution? *Review of Radical Political Economics, 50*(2), 325–332.

Chouliaraki, L., & Fairclough, N. (2010). Critical discourse analysis in organizational studies: Towards an integrationist methodology. *Journal of Management Studies*, *47*(6), 1213-1218. Clapp, J. (2021). *Naming Neoliberalism: Exposing the spirit of our age*. Stanford University Press

Clarke, A. E., Shim, J. K., Mamo, L., Fosket, J. R., & Fishman, J. R. (2003). Biomedicalization:

Technoscientific transformations of health, illness, and US biomedicine. *American Sociological Review*, *68*(2), 161-194.

Clayton, E. W., Evans, B. J., Hazel, J. W., & Rothstein, M. A. (2019). The law of genetic privacy:

applications, implications, and limitations. *Journal of Law and the Biosciences*, *6*(1), 1-36.

Cloatre, E., & Pickersgill, M. (Eds.). (2015). *Knowledge, Technology and Law*. Routledge.

Cohen, J. E. (2012). *Configuring the Networked Self: Law, code, and the play of everyday practice*. Yale University Press.

Collins, F. S., & McKusick, V. A. (2001). Implications of the Human Genome Project for medical science. *Journal of the American Medical Association*, *285*(5), 540-544.

Collins, F. S., Morgan, M., & Patrinos, A. (2003). The Human Genome Project: lessons from largescale biology. *Science*, *300*(5617), 286-290.

Conley, J. M., & Makowski, R. (2003). Back to the Future: Rethinking the Product of Nature

Doctrine as a Barrier to Biotechnology Patents (Part II). *Journal of the Patent and Trademark Office Society*, *85*, 371.

Conley, J. M. (2009). Gene Patents and the Product of Nature Doctrine. *Chicago-Kent Law Review, 84*, 109.

Conrad, P. (1999). A mirage of genes. *Sociology of Health & Illness*, *21*(2), 228-241.

Conrad, P. (2001). Genetic optimism: Framing genes and mental illness in the news. *Culture, Medicine and Psychiatry*, *25*, 225-247.

Conrad, P. (2007). *The Medicalization of Society: On the transformation of human conditions into treatable disorders* (Vol. 14, p. 204). Johns Hopkins University Press.

Cooper, M. (2008). *Life as Surplus: Biotechnics and the transformations of capital*. Washington University Press

Cooper, M., & Waldby, C. (2014). *Clinical Labor: Tissue donors and research subjects in the bioeconomy*. Duke University Press.

Cotterrell, R. (1998). Why must legal ideas be interpreted sociologically? *Journal of Law and*

Society, *25*(2), 171-192.

Council of Canadian Academies (2020). *From Research to Reality. Expert Panel on the Approval and Use of Somatic Gene Therapies in Canada*. https://cca-reports.ca/wp-content/uploads/2019/08/Report-From-Research-to-Reality-EN.pdf#:~:text=%5BPDF%5D%20Report,can%20improve%20the%20ability

Cowan, J. S., Kagedan, B. L., Graham, G. E., Heim-Myers, B., & Bombard, Y. (2022). Health care implications of the genetic non-discrimination act: protection for Canadians' genetic information. *Canadian Family Physician*, *68*(9), 643.

Crawford, K. (2021). *The Atlas of AI: Power, politics, and the planetary costs of artificial intelligence*. Yale University Press.

Cummings, S., De Haan, L., & Seferiadis, A. A. (2020). How to use critical discourse analysis for policy analysis: a guideline for policymakers and other professionals. *Knowledge Management for Development Journal*, *15*(1), 99-108.

Daack-Hirsch, S., & Campbell, C. A. (2014). The role of patient engagement in personalized healthcare. *Personalized Medicine*, *11*(1), 1-4.

Davies, M. (2019). Doing critical-socio-legal theory. In Cloatre, Creutzfeldt, N., Mason, M., & McConnachie, K. (Eds), *Routledge Handbook of Socio-Legal Theory and Methods* (pp. 83-96). Routledge.

Davison, C., Macintyre, S., & Smith, G. D. (1994). The potential social impact of predictive genetic testing for susceptibility to common chronic diseases: a review and proposed research agenda. *Sociology of Health & Illness*, *16*(3), 340-371.

Deakin, S., Gindis, D., Hodgson, G. M., Huang, K., & Pistor, K. (2017). Legal institutionalism:

Capitalism and the constitutive role of law. *Journal of Comparative Economics*, *45*(1), 188-200.

Dean, M. M. (2010). *Governmentality: Power and rule in modern society*. SAGE Publication

Dezalay, Y., & Garth, B. G. (2002). The internationalization of palace wars. *Lawyer, Economists, and the Contest to Transform Latin American States. Chicago/Londres: Universidad de Chicago*.

Dorsey, E. R., Darwin, K. C., Nichols, P. E., Kwok, J. H., Bennet, C., Rosenthal, L. S., ... & Oster, E. (2013). Knowledge of the Genetic Information Nondiscrimination act among individuals affected by Huntington disease. *Clinical Genetics*, *84*(3), 251-257.

Dove, E. S., Townend, D., Meslin, E. M., Bobrow, M., Littler, K., Nicol, D., ... & Knoppers, B. M. (2016). Ethics review for international data-intensive research. *Science*, *351*(6280), 13991400.

Dressler, L. G., & Terry, S. F. (2009). How will GINA influence participation in pharmacogenomics research and clinical testing? *Clinical Pharmacology & Therapeutics*, *86*(5), 472-475.

Eltis, K. (2007). Genetic Determinism and Discrimination: A Call to Re-Orient Prevailing Human

Rights Discourse to Better Comport with the Public Implications of Individual Genetic Testing. *The Journal of Law, Medicine & Ethics*, *35*(2), 282-294.

Erwin, C., Williams, J. K., Juhl, A. R., Mengeling, M., Mills, J. A., Bombard, Y., ... & IRESPOND-HD Investigators of the Huntington Study Group. (2010). Perception, experience, and response to genetic discrimination in Huntington disease: The international RESPOND-HD study. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, *153*(5), 10811093.

European Parliament. (2016). *Regulation (EU) 2016/679 (General Data Protection Regulation).* https://eur-lex.europa.eu/eli/reg/2016/679/oj/eng

Evans, J. P., Skrzynia, C., & Burke, W. (2001). The complexities of predictive genetic testing. *British Medical Journal*, *322*(7293), 1052-1056.

Evans, B. J. (2019). The Genetic Information Nondiscrimination Act at age 10: GINA's controversial assertion that data transparency protects privacy and civil rights. *William and Mary Law Review*, *60*(6), 2017.

Ewick, P., & Silbey, S. S. (1998). *The Common Place of Law: Stories from everyday life*.

University of Chicago Press.

Fabric Genomics. (2024). *Fabric Genomics partners with Intermountain Children's Health*.

https://fabricgenomics.com/2024/03/fabric-genomics-partners-with-intermountain-childrenshealth/

Fairclough, N. (1989). *Language and Power*. Longman.

Fairclough, N. (1992). *Discourse and Social Change.* Cambridge.

Fairclough, N. (1993). Critical discourse analysis and the marketization of public discourse: The universities. *Discourse & Society*, *4*(2), 133-168.

Fairclough, N. (1995a). *Critical Discourse Analysis: The Critical Study of Language*. Longman.

Fairclough, N. (1995b). *Media Discourse.* Edward Arnold.

Fairclough, N. (2001a). Critical discourse analysis as a method in social scientific research.

Methods of critical discourse analysis. In Wodak, R., & Meyer, M. (Eds). *Methods of Critical Discourse Analysis*. (pp. 121-138). Sage.

Fairclough, N. (2001b). The dialectics of discourse. *Textus*, *14*(2), 231-242.

Fairclough, N. (2002). *New labour, new language?* Routledge.

Fairclough, N., Jessop, B., & Sayer, A. (2002). Critical realism and semiosis. *Alethia*, *5*(1), 2-10.

Fairclough, N. (2003). *Analysing Discourse*. Routledge.

Fairclough, N. (2013). Critical Discourse Analysis. In Handford, M., & Gee, J. P. (Eds.). *The Routledge handbook of discourse analysis*. (pp.9-20). Routledge.

Fairclough, N. (2018). CDA as Dialectical Reasoning. In Flowerdew, J., & Richardson, J. E.

(Eds.). (2013). *The Routledge Handbook of Discourse Analysis*. (pp.44-60). Routledge.

Farmer, P. (2004). *Pathologies of Power: Health, human rights, and the new war on the poor* (Vol.

4). Univ of California Press.

Fast Company. (2017). *Genetics companies start to speak up about genetic discrimination*.

https://www.fastcompany.com/4002379/genetics-companies-start-to-speak-up-about-geneticdiscrimination-2

Featherstone, K., Atkinson, P., Bharadwaj, A., & Clarke, A. (2020). *Risky Relations: Family, kinship and the new genetics*. Routledge.

Feldman, E. A. (2012). The Genetic Information Nondiscrimination Act (GINA): public policy and medical practice in the age of personalized medicine. *Journal of General Internal Medicine*, *27*(6), 743-746.

First Nations Information Governance Centre. (n.d.). *OCAP®: Ownership, Control, Access and Possession*. https://fnigc.ca/ocap-training/

Fisher, J. A. (2013). Expanding the frame of" voluntariness" in informed consent: structural coercion and the power of social and economic context. *Kennedy Institute of Ethics Journal*, *23*(4), 355-379.

Fitzgerald-Butt, S. M., Klima, J., Kelleher, K., Chisolm, D., & McBride, K. L. (2014). Genetic knowledge and attitudes of parents of children with congenital heart defects. *American Journal of Medical Genetics Part A*, *164*(12), 3069-3075.

Fitzpatrick, P. (2002). *The Mythology of Modern Law*. Routledge.

Food and Drug Administration. (2019). *FDA issues warning letter to genomics lab illegally marketing genetic test claims to predict patient outcomes*. https://www.fda.gov/news-

events/pressannouncements/fda-issues-warning-letter-genomics-lab-illegally-marketing-genetic-test-claimspredict-patients

Fortun, M. (2001). Mediated speculations in the genomics futures markets. *New Genetics and Society*, 20(2), 139-156.

Fortun, M. (2008). *Promising Genomics: Iceland and deCODE genetics in a world of speculation*. Univ of California Press.

Foucault, M. (1980). *Power/knowledge: Selected interviews and other writings.* Pantheon.

Fraser, H., Gamet, K., Jackson, S., Shelling, A. N., Lacaze, P., & Tiller, J. (2023). Genetic discrimination by insurance companies in Aotearoa New Zealand: experiences and views of health professionals. *The New Zealand Medical Journal (Online)*, *136*(1574), 32-52.

Fredman, S. (2011). *Discrimination law*. Oxford University Pres

Fullwiley, D. (2007). The molecularization of race: Institutionalizing human difference in pharmacogenetics practice. *Science as Culture*, *16*(1), 1-30.

Geelen, E., Horstman, K., Marcelis, C. L., Doevendans, P. A., & Van Hoyweghen, I. (2012). Unravelling fears of genetic discrimination: an exploratory study of Dutch HCM families in an era of genetic non-discrimination acts. *European Journal of Human Genetics*, *20*(10), 1018-1023.

Geiger, S., & Gross, N. (2021). A tidal wave of inevitable data? Assetization in the consumer genomics testing industry. *Business & Society*, *60*(3), 614-649.

GeneOnline News. (2024, Oct 16). *Illumina and NTU Hospital sign collaboration agreement to launch large-scale whole genome sequencing project*. https://www.geneonline.com/illumina-and-ntu-hospital-sign-collaboration-agreement-to-launch-large-scale-whole-genome-sequencing-project/

Genome BC. (2021). *Genome Quebec announces investment of $4.5M*. https://research.chusj.org/en/Media/News/2021/Genome-Quebec-announces-an-investment-of$4-5-M-in.

Genome BC. (2023). Growing economic impact through strategic partnerships. https://www.genomebc.ca/blog/growing-economic-impact-through-strategic-partnerships#:~:text=Genome%20BC%E2%80%99s%20investments%20in%20projects,in%20projects%20and%20associated%20platforms

Genome Canada. (2024). *Genome Canada and AdMare BioInnovations Partnership*. https://genomecanada.ca/partnership-admare/

Genome Canada. (2025). *Genome Canada to accelerate high-tech commercialization through national genomics strategy*. https://genomecanada.ca/ cgsannouncement/#:~:text=,5M%20investment%2C%20Genome.

Genome Medical (n.d). *Programs*. https://www.genomemedical.com/programs/invitae/biopharma/#:~:text=Invitae%20Sponsored%20Testing%20,disorders%20and%20who%20meet

Gerdes, A. M., Nicolaisen, L., Husum, E., Andersen, J. B., Gantzhorn, M. D., Roos, L., & Diness, B. R. (2021). Direct to consumer genetic testing in Denmark—public knowledge, use, and attitudes. *European Journal of Human Genetics*, *29*(5), 851-860.

Gericke, N., Carver, R., Castéra, J., Evangelista, N. A. M., Marre, C. C., & El-Hani, C. N. (2017). Exploring relationships among belief in genetic determinism, genetics knowledge, and social factors. *Science & Education*, *26*(10), 1223-1259.

Gibbon, S. (2006). *Breast cancer genes and the gendering of knowledge*. Palgrave Macmillan.

Gibbon, S., & Novas, C. (2008). *Biosocialities, Genetics, and the Social Sciences*. Routledge

Gibbon, S., Joseph, G., Mozersky, J., zur Nieden, A., & Palfner, S. (2014). *Breast cancer gene research and medical practices: Transnational perspectives in the time of BRCA*. Routledge.

Ginsburg, G. S., & Phillips, K. A. (2018). Precision medicine: From science to value. *Health Affairs*, 37(5), 694–701.

Global Alliance for Genomics and Health (2023*). Framework for responsible sharing of genomic and health-related data*. https://www.ga4gh.org/framework/#:~:text= The%20sharing%20of%20 genomic%20and,will%20facilitate%20responsible%20research%20conduct.

Goffman, E. (2009). *Stigma: Notes on the Management of Spoiled Identity*. Simon and Schuster.

Gollust, S. E., Wilfond, B. S., & Hull, S. C. (2003). Direct-to-consumer sales of genetic services on the Internet. *Genetics in Medicine*, *5*(4), 332-337.

Gopalakrishnan, R., Sam, J., Butkowsky, C., Reble, E., Clausen, M., Rajeziesfahani, S., ... & Bombard, Y. (2024). “Should I Let Them Know I Have This?”: Multifaceted genetic discrimination and limited awareness of legal protections among individuals with hereditary cancer syndromes. *Public Health Genomics*, *27*(1), 240-254.

Gostin, L. (1991). Genetic discrimination: the use of genetically based diagnostic and prognostic tests by employers and insurers. *American Journal of Law & Medicine*, *17*(1-2), 109-144.

Gottweis, H. (2005). Governing genomics in the 21st century: between risk and uncertainty. *New Genetics and Society*, *24*(2), 175-194.

Gottweis, H., & Zatloukal, K. (2007). Biobank governance: trends and perspectives. *Pathobiology*, *74*(4), 206-211.

Gottweis, H., Salter, B., & Waldby. C. (2009). *The Global Politics of Human Embryonic Stem Cell Science*. Palgrave Macmillan.

Gottweis, H., & Lauss, G. (2012). Biobank governance: heterogeneous modes of ordering and democratization. *Journal of Community Genetics*, *3*(2), 61-72.

Government of Canada (2025). *Government of Canada launches Canadian Genomics Strategy to drive innovation and foster economic growth*. https://www.canada.ca/en/innovation-scienceeconomic-development/news/2025/02/government-of-canada-launches-canadian-genomicsstrategy-to-drive-innovation-and-foster-economic-growth.html

Grand View Research. (n.d.). Genomics Market Size, Share & Trends Analysis Report By Product, By Technology, By Application, By End Use, By Region, And Segment Forecasts, 2019 - 2026. https://www.grandviewresearch.com/industry-analysis/genomics-market

Green, M. J., & Botkin, J. R. (2003). Genetic exceptionalism in medicine: clarifying the differences between genetic and nongenetic tests. *Annals of Internal Medicine*, *138*(7), 571-575.

Green, E. D., Watson, J. D., & Collins, F. S. (2015). Human Genome Project: Twenty-five years of big biology. *Nature*, *526*(7571), 29-31.

Green, S., Prainsack, B., & Sabatello, M. (2023). Precision medicine and the problem of structural injustice. *Medicine, Health Care and Philosophy*, *26*(3), 433-450.

GSK (2018). *GSK and 23andMe sign agreement to leverage genetic insights for the development of novel medicines*. https://www.gsk.com/en-gb/media/press-releases/gsk-and-23andme-signagreement-to-leverage-genetic-insights-for-the-development-of-novelmedicines/#:~:text=GSK%20and%2023andMe%20sign%20agreement,new%20medicines%20and%20potential%20cures

Hallowell, N. (1999). Doing the right thing: genetic risk and responsibility. *Sociology of Health & Illness*, *21*(5), 597-621.

Hansson, M. G., Bouder, F., & Howard, H. C. (2018). Genetics and risk–an exploration of conceptual approaches to genetic risk. *Journal of Risk Research*, *21*(2), 101-108.

Haraway, D. (1997) *Modest_Witness@Second_Millennium. FemaleMan©_Meets_Oncomouse: Feminism and Technoscience*. Routledge.

Hasanzad, M., Sarhangi, N., Naghavi, A., Ghavimehr, E., Khatami, F., Ehsani Chimeh, S., ... & Aghaei Meybodi, H. R. (2022). Genomic medicine on the frontier of precision medicine. *Journal of Diabetes & Metabolic Disorders*, *21*(1), 853-861.

Hedgecoe, A. (2001). Schizophrenia and the narrative of enlightened geneticization. *Social Studies of Science*, *31*(6), 875-911.

Hedgecoe, A. (2004). *The Politics of Personalised medicine: Pharmacogenetics in the clinic*. Cambridge University Press.

Hellman, D. (2003). What makes genetic discrimination exceptional? *American Journal of Law & Medicine*, *29*(1), 77-116.

Hilgartner, S. (2007). Making the bioeconomy measurable: Politics of an emerging anticipatory machinery. *BioSocieties*, *2*(3), 382-386.

Hilgartner, S. (2017). *Reordering Life: Knowledge and control in the genomics revolution*. MIT press.

HIT Consultant. (2024, Apr 9). *MassMutual leverages genomics for personalized risk assessments*. https://hitconsultant.net/2024/04/09/massmutual-leverages-genomics-forpersonalized-riskassessments/#:~:text=,expansion%20follows%20a%C2%A0successful%20research%C2%A0collaboration%20in

Hood, L., & Rowen, L. (2013). The Human Genome Project: big science transforms biology and medicine. *Genome Medicine*, *5*, 1-8.

Hospital for Sick Children (SickKids). (2025). *Genome Canada awards SickKids $11.7 million to advance Precision Child Health.* https://www.sickkids.ca/en/news/archive/2025/genome-canadaawards-sickkids-$11.7-million-to-advance-precision-child-health/#:~:text=The%20funding%20is%20part%20of,enabled%20precision%20health%20for%20Canadians

Hudson, K. L., Holohan, M. K., & Collins, F. S. (2008). Keeping pace with the times—the Genetic Information Nondiscrimination Act of 2008. *New England Journal of Medicine*, *358*(25), 26612663.

Hurlbut, J. B., Metzler, I., Marelli, L., & Jasanoff, S. (2020). Bioconstitutional imaginaries and the comparative politics of genetic self-knowledge. *Science, Technology, & Human Values*, *45*(6), 1087-1118.

Husereau, D., Sullivan, T., Feilotter, H. E., Gomes, M. M., Juergens, R., Sheffield, B. S., ... & Jacobs, P. (2022). Optimizing the delivery of genetic and advanced diagnostic testing in the province of Ontario: challenges and implications for laboratory technology assessment and management in decentralized healthcare systems. *Journal of Medical Economics*, *25*(1), 9931004.

Husereau, D., Villalba, E., Muthu, V., Mengel, M., Ivany, C., Steuten, L., Spinner, D.S., Sheffield, B., Yip, S., Jacobs, P. and Sullivan, T., (2023). Progress toward health system readiness for genome-based testing in Canada. *Current Oncology*, *30*(6), 5379-5394.

Illumina & NTU Hospital. (2024). *Launch of large-scale whole genome sequencing project*. https://www.geneonline.com/illumina-and-ntu-hospital-sign-collaboration-agreement-to-launchlarge-scale-whole-genome-sequencing-project/

Innovation, Science and Economic Development Canada. (2025). *Government of Canada launches Canadian Genomics Strategy*. https://www.canada.ca/en/innovation-science-economicdevelopment/news/2025/02/government-of-canada-launches-canadian-genomics-strategy-todrive-innovation-and-foster-economic-growth.html

Insurance Business Canada. (2016). *Insurance industry criticizes genetic nondiscrimination bill*. https://www.insurancebusinessmag.com/ca/news/breaking-news/insurance-industry-criticizesgenetic-nondiscrimination-bill-44767.aspx

Jackson Laboratory. (2024). *Patient reactions to genetic test results.* The Jackson Laboratory. https://www.jax.org/education-and-learning/clinical-and-continuing-education/clinicaltopics/cancer-resources/patient-reactions

Jasanoff, S. (Ed.). (2004). *States of Knowledge*: *The co-production of science and social order.* Taylor & Francis.

Jasanoff, S. (2005). *Designs on Nature: Science and democracy in Europe and the United States*. Princeton University Press.

Jessop, B. (2002). *The Future of the Capitalist State*. Polity.

Jessop, B. (2005). Cultural political economy, the knowledge-based economy, and the state. In A. Barry & D. Slater (Eds.) *The Technological Economy* (pp. 144–166). Routledge.

Jessop, B. (2007). Knowledge as a fictitious commodity: insights and limits of a Polanyian perspective. In A. Bugra & K. Agartan (Eds.) *Reading Karl Polanyi for the twenty-first century Market economy as a political project* (pp. 115-133). Palgrave Macmillan.

Jessop, B. (2008). *State Power: A Strategic-Relational Approach*. Polity Press.

Jessop, B. (2012). Neoliberalism. In G. Ritzer (Ed.), *The Wiley-Blackwell Encyclopedia of Globalization*.

Joly, Y., Ngueng Feze, I., & Simard, J. (2013). Genetic discrimination and life insurance: a systematic review of the evidence. *BMC Medicine*, *11*, 1-15.

Joly, Y., Burton, H., Knoppers, B. M., Feze, I. N., Dent, T., Pashayan, N., & Chowdhury, S. (2014). Life insurance: genomic stratification and risk classification. *European Journal of Human Genetics*, 22(5), 575–581.

Joly, Y., Dupras, C., Pinkesz, M., Tovino, S. A., & Rothstein, M. A. (2020). Looking beyond GINA: policy approaches to address genetic discrimination. *Annual Review of Genomics and Human Genetics*, *21*, 491-507.

Joly, Y., Dalpé, G., Gallois, H., Knoppers, B. M., & Turp, D. (2021a). Erring in Law and in Fact: The Supreme Court of Canada's Reference re Genetic Non-Discrimination Act. *Canadian Bar Review*, *99*, 172.

Joly, Y., Huerne, K., Arych, M., Bombard, Y., De Paor, A., Dove, E. S., ... & Dalpe, G. (2021b). The Genetic Discrimination Observatory: confronting novel issues in genetic discrimination. *Trends in Genetics*, *37*(11), 951-954.

Juengst, E. T., Flatt, M. A., & Settersten Jr, R. A. (2012). Personalized genomic medicine and the rhetoric of empowerment. *Hastings Center Report*, *42*(5), 34-40.

Juengst, E., McGowan, M. L., Fishman, J. R., & Settersten Jr, R. A. (2016). From "personalized" to "precision" medicine: the ethical and social implications of rhetorical reform in genomic medicine. *Hastings Center Report*, *46*(5), 21-33.

Kaphingst, K.A., McBride, C.M., Wade, C., Alford, S.H., Reid, R., Larson, E., Baxevanis, A.D. and Brody, L.C. (2012). Patient understanding of and responses to multiplex genetic susceptibility test results. *Genetics in Medicine, 14*(7), 681–687.

Kaye, D. H. (2009). GINA's Genotypes. *Michigan Lae Review First Impressions*, *108*, 51-57

Kaye, J., Heeney, C., Hawkins, N., De Vries, J., & Boddington, P. (2009). Data sharing in genomics—re-shaping scientific practice. *Nature Reviews Genetics*, *10*(5), 331-335.

Kaye, J., Gibbons, S., Heeney, C., & Smart, A. (2012). *Governing Biobanks: Understanding the interplay between law and practice*. Bloomsbury Publishing.

Kaye, J., Whitley, E. A., Lund, D., Morrison, M., Teare, H., & Melham, K. (2015). Dynamic consent: a patient interface for twenty-first century research networks. *European Journal of Human Genetics*, *23*(2), 141-146.

Kerr, A., Cunningham-Burley, S., & Amos, A. (1997). The new genetics: professionals' discursive boundaries. *The Sociological Review*, *45*(2), 279-303.

Kerr, A., Cunningham-Burley, S., & Amos, A. (1998). Drawing the line: An analysis of lay people's discussions about the new genetics. *Public Understanding of Science, 7*(2), 113–133.

Kerr, A. (2004). *Genetics and Society: A sociology of disease*. Routledge.

Khaitan, T. (2015). *A Theory of Discrimination Law*. OUP Oxford.

Khoury, M. J., McBride, C. M., Schully, S. D., Ioannidis, J., Feero, W. G., Janssens, A. C. J., ... & Xu, J. (2009). The scientific foundation for personal genomics: recommendations from a National Institutes of Health–Centers for Disease Control and Prevention multidisciplinary workshop. *Genetics in Medicine*, *11*(8), 559-567.

Khoury, M. J., Bowen, S., Dotson, W. D., Drzymalla, E., Green, R. F., Goldstein, R., ... & Bunnell, R. (2022). Health equity in the implementation of genomics and precision medicine: a public health imperative. *Genetics in Medicine*, *24*(8), 1630-1639.

Kirkland, A. (2025). *Health Care Civil Rights: How Discrimination Law Fails Patients*. University of California Press.

Knoppers, B. M., & Joly, Y. (2004). Physicians, genetics and life insurance. *Canadian Medical Association Journal, 170*(9), 1421-1423.

Knoppers, B. M., & Chadwick, R. (2005). Human genetic research: emerging trends in ethics. *Nature Reviews Genetics*, *6*(1), 75-79.

Knoppers, B. M. (2014). Framework for responsible sharing of genomic and health-related data. *The HUGO journal*, *8*(1), 3.

Knoppers, B. M., & Joly, Y. (2018). Introduction: the why and whither of genomic data sharing. *Human Genetics*, *137*(8), 569-574.

Knoppers, T., Haley, C. E., Patrinos, D., & Zawati, M. N. H. (2025). “Protection for the public, better use of resources and clearer lines”: Interviews with genetic counselors and their colleagues on the need for regulation in Quebec. *Journal of Genetic Counseling*, *34*(2), e1960.

Kotz, D. M. (2015). *The Rise and Fall of Neoliberal Capitalism*. Harvard University Press.

Krieger, N. (2005). Stormy weather: race, gene expression, and the science of health disparities. *American Journal of Public Health*, *95*(12), 2155-2160.

KRTV News. (2023, Oct 30). *Drugmaker pays 23andMe $20 million for access to user DNA information*. https://www.krtv.com/drugmaker-pays-23andme-20-million-for-access-to-user-dnainformation#:~:text=extending%20its%20five,of%20new%20drugs%20and%20medications

Kukutai, T., & Taylor, J. (2016). *Indigenous Data Sovereignty: Toward an agenda*. ANU press.

Laclau, E., Mouffe, C. (2014). *Hegemony and Socialist Strategy: Towards a radical democratic politics*. Verso Books.

Lambert, D. M., Patrinos, D., Knoppers, B. M., GenCOUNSEL Study, & Zawati, M. N. H. (2022). Genetic counselors and legal recognition: A made-for-Canada approach. *Journal of Genetic Counseling*, *31*(1), 49-58.

Langlois, A. (2006). The governance of genomic information: will it come of age? *Genomics, Society and Policy*, *2*(3), 49.

Latour, B. (2005). *Reassembling the Social: An introduction to actor-network-theory*. Oxford university press.

Lautenbach, D. M., Christensen, K. D., Sparks, J. A., & Green, R. C. (2013). Communicating genetic risk information for common disorders in the era of genomic medicine. *Annual Review of Genomics and Human Genetics*, *14*(1), 491-513.

Lemke, T. (2001). 'The birth of bio-politics': Michel Foucault's lecture at the Collège de France on neo-liberal governmentality. *Economy and Society*, *30*(2), 190-207.

Lemke, T. (2005). Beyond genetic discrimination. Problems and perspectives of a contested notion. *Genomics, Society and Policy*, *1*, 1-19.

Lemke, T. (2011). *Biopolitics: An Advanced Introduction.* NYU Press.

Lemke, T. (2013). *Perspectives on Genetic Discrimination*. Routledge.

Lemmens, T. (2000). Selective justice, genetic discrimination, and insurance: should we single out genes in our laws. *McGill Law Journal*, *45*, 347-412.

Lippman, A. (1991). Prenatal genetic testing and screening: constructing needs and reinforcing inequities. *American Journal of Law & Medicine*, *17*(1-2), 15-50.

Lippman, A. (1992). Led (astray) by genetic maps: The cartography of the human genome and health care. *Social Science & Medicine*, *35*(12), 1469-1476.

Little, J., Potter, B., Allanson, J., Caulfield, T., Carroll, J. C., & Wilson, B. (2008). Canada: public health genomics. *Public Health Genomics*, *12*(2), 112-120.

Lucchi, N. (2013). Understanding genetic information as a commons: From bioprospecting to personalized medicine. *International Journal of the Commons*, *7*(2).

Lupton, D. (1995). *The Imperative of Health: Public health and the regulated body*. Sage.

Lupton, D. (2012). *Medicine as Culture: Illness, Disease and the Body in Western Societies. (3rd ed.).* Sage.

Lupton, D. (2013a). The digitally engaged patient: Self-monitoring and self-care in the digital health era. *Social Theory & Health,* 11(3), 256-270.

Lupton, D. (2013b). Risk and emotion: towards an alternative theoretical perspective. *Health, Risk & Society,* 15(8), 634-647.

Lupton, D. (2016). The diverse domains of quantified selves: self-tracking modes and dataveillance. *Economy and Society, 45(1), 101-122.*

Lynch, H. T., Lemon, S. J., Durham, C., Tinley, S. T., Connolly, C., Lynch, J. F., ... & Narod, S. (1997). A descriptive study of BRCA1 testing and reactions to disclosure of test results. *Cancer: Interdisciplinary International Journal of the American Cancer Society*, *79*(11), 2219-2228.

Mamo, L., & Fishman, J. R. (2013). Why justice? Introduction to the special issue on entanglements of science, ethics, and justice. *Science, Technology, & Human Values*, *38*(2), 159175.

Martin, S. (2000). Most Canadians welcome genetic testing. *Canadian Medical Association Journal*, *163*(2), 200.

Marx, K. (2024). *Capital: Critique of Political Economy, Volume 1*. Princeton University Press.

Matloff, E., & Caplan, A. (2008). Direct to confusion: lessons learned from marketing BRCA testing. *The American Journal of Bioethics*, *8*(6), 5-8.

Mayo Clinic. (2024). Understanding test results. *Center for Individualized Medicine*. https://www.mayo.edu/research/centers-programs/center-individualized-medicine/patientcare/understanding-test-results

Mazzucato, M. (2013). *The Entrepreneurial State: Debunking Public vs. Private Sector Myths*. Anthem Press.

McCombs, M., & Valenzuela, S. (2020). *Setting the Agenda: Mass media and public opinion*. John Wiley & Sons.

McGuire, A. L., & Beskow, L. M. (2010). Informed consent in genomics and genetic research. *Annual Review of Genomics and Human Genetics*, 11, 361–381.

McGowan, M. L., Fishman, J. R., & Lambrix, M. A. (2010). Personal genomics and individual identities: motivations and moral imperatives of early users. *New Genetics and Society*, *29*(3), 261290.

Menkel-Meadow, C. (2019). Uses and abuses of socio-legal studies. In Cloatre, Creutzfeldt, N.,

Mason, M., & McConnachie, K. (Eds)., *Routledge Handbook of Socio-Legal Theory and Methods*. (pp. 35-57). Routledge.

Metcalf, K., & Sadowski, J. (2024). Asserting the public interest in health data: On the ethics of data governance for biobanks and insurers. *Big Data & Society*, *11*(4), 20539517241290215.

Mittelstadt, B. D., Allo, P., Taddeo, M., Wachter, S., & Floridi, L. (2016). The ethics of algorithms: Mapping the debate. *Big Data & Society*, *3*(2), 2053951716679679.

Mozersky, J., McIntosh, T., Walsh, H. A., Parsons, M. V., Goodman, M., & DuBois, J. M. (2021). Barriers and facilitators to qualitative data sharing in the United States: A survey of qualitative researchers. *PLoS One*, *16*(12), e0261719.

Muller, C., Gallacher, L., Keogh, L., McInerney-Leo, A., Boughtwood, T., Gleeson, P., ... & Tiller, J. (2024). "Uninsurable because of a genetic test": a qualitative study of consumer views about the use of genetic test results in Australian life insurance. *European Journal of Human Genetics*, *32*(7), 827-836.

Murray, T. H., & Livny, E. (1995). The Human Genome Project: ethical and social implications. *Bulletin of the Medical Library Association*, *83*(1), 14.

Murray, T. H. (2019). Is genetic exceptionalism past its sell-by date? On genomic diaries, context, and content. *The American Journal of Bioethics*, *19*(1), 13-15.

Narod, S. A., Gojska, N., Sun, P., Tryon, A., Kotsopoulos, J., Metcalfe, K., & Akbari, M. R. (2021). The screen project: guided direct-to-consumer genetic testing for breast cancer susceptibility in Canada. *Cancers*, *13*(8), 1894.

National Cancer Institute. (2024). *Genetic testing for inherited cancer risk.* https://www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet

National Human Genome Research Institute (April 5, 2022). *Genomic Data Science* *https://www.genome.gov/about-genomics/fact-sheets/Genomic-Data-Science*

National Human Genome Research Institute (June 13, 2024). *Human Genome Project: Fact Sheet.* https://www.genome.gov/about-genomics/educational-resources/fact-sheets/human-genomeproject

National Institutes of Health Report (n.d). *Report on NIH Collaborations with Other HHS Agencies for Fiscal Year 2021.* https://dpcpsi.nih.gov/oepr/crs/summary/2021

National Society of Genetic Counselors (n.d). *About Genetic Counselors* https://www.nsgc.org/About/About-Genetic-Counselors

Nelkin, D. (1987). *Image Makers: Selling Science. How the Press Covers Science and Technology.* Freeman.

Nelkin, D., & Lindee, M. S. (2010). *The DNA Mystique: The gene as a cultural icon*. University of Michigan Press.

Nelson, A. (2016). *The Social Life of DNA: Race, reparations, and reconciliation after the genome*. Beacon Press.

Newswire (2025, February 06). *Government of Canada launches Canadian Genomics Strategy to drive innovation and foster economic growth*. https://www.newswire.ca/news-releases/government-of-canada-launches-canadian-genomics-strategy-to-drive-innovation-andfoster-economic-growth-833365142.html#:~:text=Government%20

of%20Canada%20launches%20Canadian,foster%20economic%20growth%20%20Fran%C3%A7ais

Novas, C., & Rose, N. (2000). Genetic risk and the birth of the somatic individual. *Economy and Society*, *29*(4), 485-513.

O'Malley, P. (2012). *Risk, uncertainty and government*. Routledge-Cavendish. Ontario Genomics (n.d). *Impact of Genomics.* https://www.ontariogenomics.ca/impact-ofgenomics/

Organisation for Economic Co-operation and Development (OECD). (2009a). *The Bioeconomy to 2030. Designing a Policy Agenda*. https://www.oecd.org/en/publications/the-bioeconomy-to-2030_9789264056886-en.html

Organisation for Economic Co-operation and Development (OECD). (2009b). *Recommendation of the Council on Human Biobanks and Genetic Research Databases*. https://legalinstruments.oecd.org/en/instruments/OECD-LEGAL-0375

Organisation for Economic Co-operation and Development (OECD). (2015a). *Data-Driven Innovation: Big Data for Growth and Well-Being*, OECD Publishing, https://doi.org/10.1787/9789264229358-en.

Organisation for Economic Co-operation and Development (OECD). (2015b). Public-private Partnerships in Biomedical Research and Health Innovation for Alzheimer's Disease and other Dementias. OECD Science, Technology and Industry Policy Papers, No. 20. *OECD Publishing*.

Organisation for Economic Co-operation and Development (OECD). (2018). *Health at a Glance: Indicators of Health Systems*. OECD Publishing.

Organisation for Economic Co-operation and Development (OECD). (2021). *Recommendation of the Council on Enhancing Access to and Sharing of Data*. https://legalinstruments.oecd.org/en/instruments/OECD-LEGAL-0463

Otlowski, M. (2005). Exploring the concept of genetic discrimination. *Journal of Bioethical Inquiry*, *2*, 165-176.

Otlowski, M., Taylor, S., & Bombard, Y. (2012). Genetic discrimination: international perspectives. *Annual Review of Genomics and Human Genetics*, *13*(1), 433-454.

Peck, J., & Tickell, A. (2002). Neoliberalizing space. *Antipode, 34*(3), 380–404.

Peck, J. (2010). *Constructions of Neoliberal Reason*. Oxford University Press.

Penziner, E., Williams, J. K., Erwin, C., Bombard, Y., Wallis, A., Beglinger, L. J., Hayden, M.R. and Paulsen, J.S. (2008). Perceptions of discrimination among persons who have undergone predictive testing for Huntington's disease. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, *147*(3), 320-325.

Petersen, A. R. (1996). Risk and the regulated self: the discourse of health promotion as politics of uncertainty. *The Australian and New Zealand Journal of Sociology*, *32*(1), 44-57.

Petersen, A., & Bunton, R. (Eds.). (2002). *The New Genetics and the Public's Health*. Routledge.

Petersen, A. (2006). The genetic conception of health: is it as radical as claimed? *Health*, *10*(4), 481-500.

Petersen, A. (2011). *The Politics of Bioethics*. Routledge.

Petersen, A. (2015). *Hope in Health: The socio-politics of optimism*. Springer.

Petersen, A., & Krisjansen, I. (2015). Assembling 'the bioeconomy': Exploiting the power of the promissory life sciences. *Journal of Sociology*, *51*(1), 28-46.

Phillips, K. A., Warner, E., Meschino, W. S., Hunter, J., Abdolell, M., Glendon, G., ... & Goodwin, P. J. (2000). Perceptions of Ashkenazi Jewish breast cancer patients on genetic testing for mutations in BRCA1 and BRCA2. *Clinical Genetics*, *57*(5), 376-383.

Phillips, A. M. (2016). Only a click away—DTC genetics for ancestry, health, love… and more:

A view of the business and regulatory landscape. *Applied & Translational Genomics*, *8*, 16-22.

Philips, L., & Jorgensen, M. W. (2002). *Discourse Analysis as Theory and Method*. Sage.

Pistor, K. (2019). *The Code of Capital: How the law creates wealth and inequality.* Princeton University Press.

Pistor, K. (2021). Ideology and Institutions in the Evolution of Capital. *Analyse & Kritik*, *43*(1), 23-40.

Polzer, J. (2005). Choice as responsibility: Genetic testing as citizenship through familial obligation and the management of risk. In Bunton, R. and Petersen, A. (Eds.). *Genetic Governance: Health, Risk and Ethics in the Biotech Era*. (pp. 79-92). Routledge.

Prainsack, B. (2017). *Personalized Medicine: Empowered Patients in the 21st Century?* NYU Press.

Prainsack, B. (2018). The “we” in the “me” solidarity and health care in the era of personalized medicine. *Science, Technology, & Human Values*, *43*(1), 21-44.

Prince, A. E., & Roche, M. I. (2014). Genetic information, non-discrimination, and privacy protections in genetic counseling practice. *Journal of Genetic Counseling*, *23*, 891-902.

Puddester, R., Limoges, J., Dewell, S., Maddigan, J., Carlsson, L., & Pike, A. (2023). The Canadian landscape of genetics and genomics in nursing: A policy document analysis. *Canadian Journal of Nursing Research*, *55*(4), 494-509.

Rabinow, P., & Rose, N. (2006). Biopower today. *BioSocieties*, 1(2), 195-217.

Rabinow, P. (1997). *Essays on the Anthropology of Reason*. Princeton University Press.

Rajan, K. S. (2006). *Biocapital: The Constitution of Postgenomic Life*. Duke University Press.

Rajan, K. S. (2008). Biocapital as an emergent form of life: speculations on the fi gure of the experimental subject. In Gibbon, S., & Novas, C. (Eds.). *Biosocialities, Genetics and the Social Sciences* (pp. 157-187). Routledge.

Rantanen, E., Pöntinen, S., Nippert, I., Sequeiros, J., & Kääriäinen, H. (2009). Expertise, empathy and ethical awareness: ideals of genetic counseling based on framing of genetic information in international guidelines. *New Genetics and Society*, *28*(4), 301-316.

Reardon, J. (2017). *The Postgenomic Condition: Ethics, justice, and knowledge after the genome*.

University of Chicago Press.

Registry of Lobbyists. Registration (n.d). *In-house Corporation. Sequence Bio*. https://lobbycanada.gc.ca/app/secure/ocl/lrs/do/vwRg?regId=866485&cno=358632.

Reuters. (2025, Jan 13). *Truveta sells stakes to Regeneron, Illumina in deal to build genetic database*.https://www.reuters.com/markets/deals/truveta-sells-stakes-regeneron-illumina-dealbuild-genetic-database-2025-01-13/#:~:text=NEW%20YORK%2C%20Jan%2013%20,the%20 world%27s%20largest%20genetic%20database

Roberts, J. L. (2010). Preempting discrimination: Lessons from the genetic information nondiscrimination act. *Vanderbilt Law Review*, *63*, 439.

Roberts, D. (2011). *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century*. The New Press.

Roberts, J. S., Gornick, M. C., Carere, D. A., Uhlmann, W. R., Ruffin, M. T., & Green, R. C. (2017). Direct-to-consumer genetic testing: user motivations, decision making, and perceived utility of results. *Public Health Genomics*, *20*(1), 36-45.

Roberts, J., & Middleton, A. (2018). Genetics in the 21st Century: Implications for patients, consumers and citizens. *F1000Research*, *6*, 2020.

Rose, N., & Novas, C. (2005). Biological citizenship. *Global assemblages: Technology, politics, and ethics as anthropological problems*, *1*, 439-63.

Rose, N. (2007). *The Politics of Life Itself: Biomedicine, power, and subjectivity in the twenty-first century*. Princeton University Press.

Rose, N. (2013). The human sciences in a biological age. *Theory, Culture & Society, 30*(1), 3–34.

Rothstein, M. A. (1994). Genetic discrimination in employment: ethics, policy and comparative law in Swiss Institute of Comparative Law (Ed.), *Human Genetic Analysis and the Protection of Personality and Privacy*. Schulthess Polygraphisher Verlag.

Rothstein, M. A., & Anderlik, M. R. (2001). What is genetic discrimination, and when and how can it be prevented? *Genetics in Medicine*, *3*(5), 354-358.

Rothstein, M. A. (2005). Genetic exceptionalism & legislative pragmatism. *Hastings Center Report*, *35*(4), 27-33.

Rothstein, M. A. (2008). GINA, the ADA, and Genetic Discrimination in Employment. *The Journal of Law, Medicine & Ethics*, *36*(4), 837.

Rothstein, M. A. (2018a). GINA at Ten and the Future of Genetic Nondiscrimination Law, *Hastings Center Report*. 48.

Rothstein, M. A. (2018b). Time to end the use of genetic test results in life insurance underwriting. *The Journal of Law, Medicine & Ethics*, *46*(3), 794-801.

Sadowski, J. (2019). When data is capital: Datafication, accumulation, and extraction. *Big Data & Society*, *6*(1), 2053951718820549.

Salter, B., & Salter, C. (2017). Controlling new knowledge: Genomic science, governance and the politics of bioinformatics. *Social Studies of Science*, *47*(2), 263-287.

Samuel, G. N., & Farsides, B. (2018). Genomics England's implementation of its public engagement strategy: blurred boundaries between engagement for the UK's 100,000 Genomes Project and the need for public support. *Public Understanding of Science*, *27*(3), 352-364.

Sanders, D., De Ceukelaire, W., & Hutton, B. (2023). *Health Policies and Health Care in the Context of Neoliberal Globalisation*. Oxford University Press.

Savić-Kallesøe, S., Middleton, A., & Milne, R. (2021). Public trust and genomic medicine in Canada and the UK. *Wellcome Open Research*, *6*, 124.

Schicktanz, S. (2018). Genetic risk and responsibility: reflections on a complex relationship. *Journal of Risk Research*, *21*(2), 236-258.

Sharon, T. (2017). Self-tracking for health and the quantified self: Re-articulating autonomy, solidarity, and authenticity in an age of personalized healthcare. *Philosophy & Technology*, *30*(1), 93-121.

Sharp, R. R., & Foster, M. W. (2002). Community involvement in the ethical review of genetic research: lessons from American Indian and Alaska Native populations. *Environmental Health Perspectives*, *110*(suppl 2), 145-148.

Sherwin, S. (2011). Feminist Perspectives on Genetics, Ethics, and Law. In R. Chadwick & H. Greenspan (Eds.), *The Handbook of Genetics & Ethics* (pp. 265–283). Springer.

Shildrick, M. (2009). *Dangerous Discourses of Disability, Subjectivity and Sexuality*. Palgrave Macmillan.

Shostak, S. (2003). Locating gene–environment interaction: at the intersections of genetics and public health. *Social Science & Medicine*, *56*(11), 2327-2342.

Shugar, A. L., Quercia, N., Trevors, C., Rabideau, M. M., & Ahmed, S. (2017). Risk for patient harm in Canadian genetic counseling practice: It's time to consider regulation. *Journal of Genetic Counseling*, *26*(1), 93-104.

Silbey, S. S. (2005). After legal consciousness. *Annual Review of Law and Social Science, 1*(1), 323-368.

Sinno, J., Daroya, E., Wells, A., Hull, M., Lachowsky, N. J., Tan, D. H., & Grace, D. (2024). "To do so in a patient-centred way is not particularly lucrative": The effects of neoliberal health care on PrEP implementation and delivery. *Social Science & Medicine*, *347*, 116749.

Smith, D. E. (2005). *Institutional ethnography: A sociology for people*. Bloomsbury Publishing.

Somek, A. (2011). *Engineering Equality: An essay on European anti-discrimination law*. OUP Oxford.

Somek, A. (2017). This is about ourselves: Or, what makes genetic discrimination interesting. In N. Stehr (Ed.), *Biotechnology: Between Commerce and Civil Society* (pp. 195-216). Routledge.

Stempsey, W. E. (2006). The geneticization of diagnostics. *Medicine, Health Care and Philosophy*, *9*, 193-200.

Stirling, A. (2008). "Opening up" and "closing down" power, participation, and pluralism in the social appraisal of technology. *Science, Technology, & Human Values*, *33*(2), 262-294.

Strydom, P. (1999). The Civilisation of the Gene: Biotechnological Risk Framed in the Responsibility Discourse 1. In *Nature, Risk and Responsibility* (ed) O'Mahony, P., & Campling, J. (1st ed., pp. 21–36). Springer.

Surbone, A. (2011). Social and ethical implications of BRCA testing. *Annals of Oncology*, *22*, i60i66.

Suter, S. M. (2018). GINA at 10 years: the battle over 'genetic information' continues in court. *Journal of Law and the Biosciences*, *5*(3), 495-526.

TallBear, K. (2013). *Native American DNA: Tribal belonging and the false promise of genetic science*. University of Minnesota Press.

Taylor, M. J., & Whitton, T. (2020). Public interest, health research and data protection law: establishing a legitimate trade-off between individual control and research access to health data. *Laws*, *9*(1), 6.

Tenenbaum, J. D., & Goodman, K. W. (2017). Beyond the genetic information nondiscrimination act: ethical and economic implications of the exclusion of disability, long-term care and life insurance. *Personalized Medicine*, *14*(2), 153-157.

Tiersma, P. M. (1999). *Legal Language*. University of Chicago Press.

Tiller, J., Bakshi, A., Dowling, G., Keogh, L., McInerney-Leo, A., Barlow-Stewart, K., ... & Lacaze, P. (2023). Community concerns about genetic discrimination in life insurance persist in

Australia: A survey of consumers offered genetic testing. *European Journal of Human Genetics*, 1-9.

Titscher, S., Meyer, M., Wodak, R., & Vetter, E. (2000). *Methods of Text and Discourse Analysis*.

Sage.

Treloar, S., Taylor, S., Otlowski, M., Barlow-Stewart, K., Stranger, M., & Chenoweth, K. (2004). Methodological considerations in the study of genetic discrimination. *Public Health Genomics*, *7*(4), 161-168.

Tupasela, A. (2007). Re-examining medical modernization: Framing the public in Finnish biomedical research policy. *Public Understanding of Science*, 15(4), 387–404.

Tutton, R., & Prainsack, B. (2011). Enterprising or altruistic selves? Making up research subjects in genetics research. *Sociology of Health & Illness*, *33*(7), 1081-1095.

Tutton, R. (2012). Personalizing medicine: Futures present and past. *Social Science & Medicine*, *75*(10), 1721-1728.

Tutton, R. (2016). *Genomics and the Reimagining of Personalized Medicine*. Routledge.

23andme (n.d). Power drug development with evidence from the world's largest recontactable genetics community. https://www.23andme.com/en-ca/partner/?srsltid=AfmBOopuQyAY9gpWyaGrsKfg6vPLE677ne24fXMzRh54P7pZGuPSd6C5

UK Biobank. (2015). *Access to Data and Samples*. https://www.ukbiobank.ac.uk/enable-yourresearch/apply-for-access

U.S. Congress. (2008). *Genomics and Personalized Medicine Act of 2008, H.R. 6498, 110th Cong*

Van Dijk, T. A. (2009). *Society and Discourse: How Social Contexts Influence Text and Talk*. Cambridge University Press.

Vilhelmsson, A. (2017). Value-based health care delivery, preventive medicine and the medicalization of public health. *Cureus*, *9*(3).

Visscher, P. M., Wray, N. R., Zhang, Q., Sklar, P., McCarthy, M. I., Brown, M. A., & Yang, J.

(2017). 10 years of GWAS discovery: biology, function, and translation. *The American Journal of Human Genetics*, *101*(1), 5-22.

Wachter, S., Mittelstadt, B., & Floridi, L. (2017). Why a right to explanation of automated decision-making does not exist in the General Data Protection Regulation. *International Data Privacy Law*, 7(2), 76–99.

Waldby, C., & Mitchell, R. (2006). *Tissue Economies: Blood, organs, and cell lines in late capitalism*. Duke University Press.

Wauters, A., & Van Hoyweghen, I. (2016). Global trends on fears and concerns of genetic discrimination: a systematic literature review. *Journal of Human Genetics*, *61*(4), 275-282.

Weymann, D., Dragojlovic, N., Pollard, S., & Regier, D. A. (2022). Allocating healthcare resources to genomic testing in Canada: Latest evidence and current challenges. *BMC Medical Ethics, 23*, 37.

Widdowson, H. G. (1998). The theory and practice of critical discourse analysis. *Social Research Methods: A reader*, 366-370.

Wilkinson, M. D., Dumontier, M., Aalbersberg, I. J., Appleton, G., Axton, M., Baak, A., ... & Mons, B. (2016). The FAIR Guiding Principles for scientific data management and stewardship. *Scientific Data*, *3*(1), 1-9.

Williams, J. (2024). Do your genes fit: How life insurance companies discriminate based on genetic test results. *Journal of Biosecurity, Biosafety, and Biodefense Law*, *14*(1), 35-48.

Wodak, R., & Meyer, M. (Eds.). (2016). *Methods of Critical Discourse Studies* (3rd ed.). Sage.

Wolf, S. M. (1995). Beyond "genetic discrimination": toward the broader harm of geneticism. *Journal of Law, Medicine & Ethics*, *23*(4), 345-353.

World Economic Forum (2020). *Genomic Data Policy: Framework and Ethical Tensions*. https://www.weforum.org/publications/genomic-data-policy-framework-and-ethical-tensions/

Zuboff, S. (2023). The age of surveillance capitalism. In *Social Theory Re-Wired: New connections to classical and contemporary perspectives.* (Eds). Longhofer, W. & Winchester, D. (pp. 203-213). Routledge.