

Research Article

Analyzing Discrimination Based on Genetic Information: Review, Critique and Proposal

Akash * 

Rajiv Gandhi School of Intellectual Property Law, IIT Kharagpur, India

Shuvro Prosun Sarker 

Rajiv Gandhi School of Intellectual Property Law, IIT Kharagpur, India

ABSTRACT: This paper analyses and critiques existing literature on discrimination based on genetic information collected during genetic tests of individuals and the legal issues attached therewith. Genetic variations, which can lower or raise disease risk, result from the inheritance of parental genes. Subjecting individuals to stigmatization based on their unique ancestry or genetic status raises legitimate concerns. The literature review reveals that the issue of discrimination based on genetic information has occurred in countries like the United States and Canada. Accordingly, concerns regarding new forms of discrimination arising from the collection of information during genetic testing have grown over the decades in the wake of technological advancements in biotechnology, health, and allied sciences, as several studies have revealed. On the contrary, more material sufficiency in India necessitates consulting data from various disciplines. A conceptual framework is proposed to examine the theoretical foundations of non-discrimination provisions, compare genetic information non-discrimination legislation in the United States and Canada to India, and evaluate the practicality of implementing such laws in India. The initial testing of this framework suggests that due to insufficient legislation, there may be a need for enforceable measures to mitigate genetic information-related discrimination in India. The research problem requires qualitative research to gain an in-depth comprehension of experiences, phenomena, and context. This paper makes two main contributions: establishing a comprehensive background to allow comparisons by scholars and policymakers on the matter and helping to further the debate on the subject to generate value-based research regarding the ethical, legal, and social impacts of genetic research and anti-discrimination laws.

KEYWORDS: Non-discrimination, Genetics and law, Literature review, Genetic discrimination

I. INTRODUCTION

The law, a universal institution, faces several difficulties in our complex, pluralistic world due to ongoing transformations, ethical dilemmas, and the building of political consensus. From information technology to artificial intelligence, to biotechnology, the technological revolution has brought developments across many fields. These developments have changed individual

*Corresponding author, email: shuvro@rgsoipl.iitkgp.ac.in

Submitted: 2 October 2023 | Reviewed: 13 March 2024 | Revised: 18 March 2024 | Accepted: 28 March 2024

behavior, human relationships, and the labor market over time. Even so, the new age offers complex challenges for legal solutions to develop properly. Notwithstanding moral conundrums and political obstacles, the law tries to fit this new reality while safeguarding personal liberties. In this milieu, we continue to expect the law to safeguard the fundamental rights of individuals in spite of existing difficulties. The law must ensure that the technological advances that take place exist humanely and ethically.¹

Advancement in genetics is the latest example of technological advances that raise complex legal and ethical questions. With the ability to manipulate genes and potentially alter the course of human evolution, the law must grapple with issues such as genetic discrimination (GD), privacy concerns, and the boundaries of reproductive rights. Additionally, emerging technologies like artificial intelligence and automation are transforming the labor market, posing challenges to employment laws and worker protections. As society navigates these advancements, the law must balance promoting innovation and safeguarding fundamental human rights.

The term “genetics” refers to the scientific study of genes and heredity—of how certain qualities or traits are passed on from parents to offspring as a result of modifications in the DNA sequence.² As per the National Human Genome Research Institute, a gene is the most fundamental part of any living organism, which forms the segment of DNA that contains instructions and information for building one or more molecules that help the body work.³ Genes are responsible for the development of various traits in living beings. Variations in these traits are responsible for distinctions in individuals belonging to the same species. Because genes from parents are passed down to the children, some diseases cluster in families, like other inherited traits. Slight differences in DNA can lead to incorrectly formed proteins that cannot perform their functions.

¹ Luís Roberto Barroso, “Technological revolution, democratic recession, and climate change: The limits of law in a changing world” (2020) 18:2 *International Journal of Constitutional Law* 334–369 at 335.

² National Institute of General Medical Sciences, , online: *Genetics* <<https://www.nigms.nih.gov/education/fact-sheets/Pages/genetics.aspx>>.

³ *Ibid.*

Such differences, termed “genetic disorders,” can influence how a person’s body will respond to certain medications or their likelihood of developing a disease.⁴

Researchers can use DNA sequencing to identify variations in a person’s genome.⁵ The Genetic Information Non-discrimination Act (hereinafter GINA) of the United States of America, under section 201, has defined the term “genetic test” as the “*analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.*”⁶ Furthermore, the term “genetic information” (GI) concerning any individual would include information about their genetic tests, or the genetic tests of family members, and the manifestation of a disease or disorder in family members of such an individual. However, this information will exclude particulars about the sex or age of any individual.⁷

The information gathered through genetic tests can be used to identify and classify the individual. Genetic data is personal data and carries two different types of consequences. Firstly, on the level of an individual, the person concerned can understand their genetic constitution. Such knowledge could help them predict, avoid, or minimize hereditary diseases. Per contra, if this information is passed on to a potential employer, an insurance company, or any third party likely to either benefit or suffer a loss from such genetic screening, the individual may then be subject to selective treatment. This could encourage, if not suppress, discriminatory practice against the individual, similar to racism or casteism (as prevalent in the Indian subcontinent). Secondly, on the level of a group or collective, genetic data could be assimilated as a stock of stored knowledge about individual genetic conditions and benefit society to prevent or mitigate potential medical or pathological threats, promoting beneficial research, et cetera. This would no doubt result in sacrificing the individual identity. It may also lead to consequences such as a “moralistic urge” for total

⁴ M Otlowski, S Taylor & Y Bombard, “Genetic Discrimination: International Perspectives” (2012) 13 *Annu Rev Genomics Hum Genet* 433–454 at 437.

⁵ National Institute of General Medical Sciences, *supra* note 2.

⁶ Genetic Information Non-discrimination Act 2008

⁷ GINA, s 201

openness or a complete abandonment of individual privacy.⁸ Therefore, the concern is to prevent discrimination based on GI and ensure the privacy of the individual's genetic data.

II. LEGAL MEASURES

The idea behind considering legal measures to prevent discrimination based on GI is that when some disease is not visible in the present, the same cannot become an excuse to distinguish from individual to individual due to a future apprehension. For example, a person who tests positive for a genetic predisposition to a certain disease may be denied employment or promotion because employers fear the potential increase in healthcare costs. This individual may be highly qualified and capable of performing their job, but their GI leads to discrimination. Furthermore, individuals with genetic predispositions may also need help obtaining affordable health insurance coverage, leading to financial burdens and limited access to necessary medical care. Contrast this to a situation where an individual with a genetic predisposition to a certain disease remains healthy throughout their life, defying the employer's fears of increased healthcare costs. For example, let us consider a scenario where an individual has a genetic predisposition to developing diabetes. Despite this genetic risk, if the person leads a healthy lifestyle with regular exercise and a balanced diet, they can minimize their chances of developing the disease. In this case, it would be unfair for an employer to deny employment or health insurance coverage based solely on the individual's GI, as their choices and behaviors significantly impact their health outcomes.

Concerns about discrimination based on GI in employment and health insurance sectors have been debated for quite some time. This debate was at its peak in the United States between 1995 and 2008.⁹ Until 2008, despite a limited number of recorded instances of discriminatory practices based on GI, research

⁸ Derek J Chadwick et al, eds, *Human Genetic Information: Science, Law and Ethics: Symposium on Human Genetic Information: Science, Law and Ethics, held at the Haus der Universität, Bern, Switzerland, 20 - 22 June 1989*, Ciba Foundation Symposium 149 (Chichester: Wiley, 1990) at 96.

⁹ Cheryl Erwin, "Behind the Genetic Information Non-discrimination Act of 2008" (2009) 109:12 *AJN*, *American Journal of Nursing* 46–48, online: <<https://journals.lww.com/00000446-200912000-00026>> at 46.

indicated that a significant proportion of individuals with genetic diseases, ranging from 6% to 27% based on various studies, perceive themselves to have encountered instances of discrimination based on GI concerning health insurance or job issues. Many individuals claimed employment termination or denial of health insurance coverage based on their genetic status while being asymptomatic for the disorders they were predisposed to develop.¹⁰ Despite persistent calls from professionals in the medical and legal fields, the enactment of federal legislation in the country took time.

A country like the United States has a long history of discrimination,¹¹ even as programs for genetic testing have raised questions about whether they represent values consistent with the history of racial and social eugenics in the West.¹² The Constitution of the United States guarantees equal protection before the law and ensures due process. The Fourteenth Amendment to the U.S. Constitution ratified in 1868, added fundamental principles such as citizenship and equal protection under the law to the U.S. Constitution, guaranteeing full citizenship rights and privileges for all formerly branded slaves. The Amendment guarantees equal protection under the law and serves as the basis for civil rights claims.¹³ It does not, however, specifically address discrimination based on GI.¹⁴ It was only in May 2008 that the Genetic Information Non-discrimination Act (GINA) was finally approved by Congress and signed into law by President George W. Bush. Despite excluding those with known genetic diseases or those currently displaying symptoms or undergoing treatment, the law remains crucial in safeguarding a susceptible group from discriminatory practices.¹⁵

¹⁰ Erwin, *supra* note 9.

¹¹ *Racial Discrimination in the United States*, by Anjana Malhotra et al (ACLU - Human Rights Watch, 2022).

¹² Ruth Hubbard & Mary Sue Henifin, “Genetic Screening of Prospective Parents and of Workers: Some Scientific and Social Issues” (1985) 15:2 Int J Health Serv 231–251, online: <<http://journals.sagepub.com/doi/10.2190/U1MJ-Y6YR-D01R-1UQ4>> at 234, 235.

¹³ See U.S. Const., Amendment XIV (1868).

¹⁴ William E Nelson, *The Fourteenth Amendment: From Political Principle to Judicial Doctrine* (Cambridge, Massachusetts: Harvard University Press, 1995) at 19 The author points out that the early days of adoption of the fourteenth amendment saw debates about abolishing slavery. It is subtly pointed out that the americans were of the opinion that blacks and whites were fundamentally unequal, especially in a genetic and social sense.

¹⁵ Erwin, *supra* note 9.

Subsequently, in 2017, following the prevailing debate in the United States, the Genetic Non-Discrimination Act (GNDA) was enacted in Canada. The Act received royal assent on May 4, 2017, and is critical for promoting the health of Canadians and advancing genomics research.¹⁶ However, its constitutionality was contested in the courts, leading to uncertainty and confusion among the public and medical community.¹⁷ Hon'ble Justice Kasirer had observed regarding the primary goal of the GNDA that the sections of the said Act may have “an indirect effect of preventing genetic discrimination from occurring in the first place, the primary objective of the provisions is not to prohibit or even to prevent genetic discrimination.”¹⁸ Nevertheless, the Act prohibits the requirement of genetic testing or disclosure of genetic test results as a condition of employment or insurance. The validity of the GNDA was upheld by the Supreme Court of Canada in 2020, although there were dissenting opinions.¹⁹ The adoption of a clear and coherent genetic non-discrimination policy in Canada has been a contentious issue, creating an opportunity for future policy changes.

III. INDIA AND CONCERNS ABOUT DISCRIMINATION

The future, given rapid technological advancements, only shows a rise in genetic testing and the availability of information. However, more needs to be said about the ethical, legal, and social issues (ELSI) attached to genetic tests in India. This is evident from the fact that there needs to be more research addressing ELSI concerns in India. Furthermore, unlike the United States and Canada, India has no specific legally binding provision to address discrimination based on GI. The current legal framework, at the very outset, protects biometric information. The Information Technology Act, 2000 (21 of 2000); the Aadhaar (Targeted Delivery of Financial and Other Subsidies, Benefits, and Securities) Act, 2016; and the Aadhaar and Other Laws (Amendment) Act, 2019; all

¹⁶ Yann Joly et al, “Erring in Law and in Fact: The Supreme Court of Canada’s Reference re Genetic Non-Discrimination Act” (2021) 99:1 Can B Rev 172–192, online: <<https://heinonline.org/HOL/P?h=hein.journals/canbarev99&i=172>> at 176.

¹⁷ *Canadian Coalition for Genetic Fairness v Attorney General of Canada and Another*, [2020] 2020 SCC OnLine Can SC 2 .

¹⁸ *Ibid* at para 247.

¹⁹ 2020 *Canadian Coalition for Genetic Fairness v Attorney General of Canada and Another*, *supra* note 17.

mention “biometric information,” that covers “biological attributes of an individual” capable of being specified under regulations,²⁰ and stored under a Central Data Repository.²¹ The Information Technology Rules prevent the collection and disclosure of biometric information and do not go beyond.²² The Digital Personal Data Protection Bill 2022 recently became an Act.²³ The said law does not explicitly mention genetic data but does include personal data as information that needs to be protected. The Digital Personal Data Protection Act (DPDPA) aims to protect the right to privacy of an individual while empowering them to grant or withdraw their consent.²⁴ To an extent, GI privacy may be ensured in the wake of this law.

The question arises about the meaning of discrimination based on GI and whether its definition should be inclusive or specific to a particular sector. Even as existing laws and statutes define and safeguard against the misuse of biometric information, these legal documents do not explicitly mention genetic materials. GINA and GNA may be protecting individuals against discrimination based on GI, but these acts have steered clear from delving into the depths of the question of defining GD. GD refers to withholding rights, benefits, or opportunities from someone based on data acquired through genetic testing.²⁵ The counter-question is, should the definition cover genetic particles such as finer mRNA or other RNA particles, which might carry more GI embedded within? These stores of GI are a part of genetic data, primarily when DNA libraries and advanced sequencing techniques, also known as direct-to-consumer genetic testing (DTC-GT) services, are well known worldwide.²⁶

One may then ask whether India needs a specific law to protect against GI-based discrimination or whether the existing policy framework is sufficient to address discrimination, then delve into the definition aspect. To address the ‘whether’ before the ‘what,’ one may look at the laws that deal with biomedical

²⁰ *Aadhaar (Targeted Delivery of Financial and Other Subsidies, Benefits and Securities) Act*, 2016, s 2 (g).

²¹ *Ibid*, s 2(h).

²² Ministry of Electronics and Information Technology, *The Information Technology Rules*, (2011).

²³ *The Digital Personal Data Protection Act*, 2023.

²⁴ *Act No. 22 of 2023*.

²⁵ Erwin, *supra* note 9.

²⁶ Hannah Kim et al, “Genetic discrimination: introducing the Asian perspective to the debate” (2021) 6:1 npj Genom Med at 54.

testing since genetic testing is concerned with improving overall human health and tackling diseases deemed incurable in the past. At the very least, this would be a justification if a future law on non-discrimination was enacted—improving overall human health. Therefore, while it is debatable whether there is a need to address the legal issues associated with genetic research, problems arising from biomedical research on human subjects have been covered in India by the ICMR Guidelines.²⁷ These guidelines may provide a reference point to bring this discussion forward. Although Section 10 of these guidelines highlights general issues concerning “Human Genetic Testing and Research,” and Section 10.12.2 addresses concerns about the misuse of GI leading to discrimination, one cannot deny that ethical guidelines cannot carry the force of a legally binding act to prevent against discrimination and remain non-binding, as is seen by the principle of non-maleficence under Section 8.²⁸ Similarly, other policy regulations, including the National Health Policy of 2017 and the Biotech-PRIDE Guidelines (Department of Biotechnology) of 2021, are merely morally binding and have no legal binding. Therefore, the existing laws in India may not be sufficient in dealing with the ethical and legal concerns attached to information gathered through genetic testing that could lead to discrimination. However, this question cannot be answered with finality before exploring the existing legal structure in much detail.

Whether there is a need to introduce a legal provision against discrimination based on GI despite the existing ethical doctrines and laws warrants an elaborate discussion given the anti-discrimination provisions of the Indian Constitution. Given the discussion mentioned earlier, however, it may be necessary first to explore the feasibility of a legislative provision or an act presently absent in India. If the existing provisions sufficiently address the problem, then specific legislation may be optional. However, if such legislation should be introduced because of the inadequacy of current provisions, its potential structure is a concern. One point is clear, though: the aim of any legally binding anti-discrimination provision should be to create necessary deterrence for ensuring human dignity and bodily autonomy and the prevention of discrimination

²⁷ Indian Council of Medical Research, *National Ethical Guidelines for Biomedical and Health Research Involving Human Participants* (2017).

²⁸ *Ibid.*

against an individual. Before entering the depths of this issue, one must consider the existing literature showing the paradigm shift in assessing the overall debate.

IV. EXISTING LITERATURE AND GAPS

A. Foundational Research And Early Insights

The National Symposium on “Genetics and the Law” was held in May 1975. The proceedings, published in 1976 as a book edited by Professor George Annas, present the intersection of genetics with various aspects of law, ethics, and society, including issues related to fetal rights, personhood, and the moral dilemmas of scientific advancements.²⁹ The work explores the discretionary nature of genetic counseling procedures and the potential risks and liabilities associated with genetic screening.³⁰ The recent advancements in medical technology have highlighted the conflicts between genetics and the law, particularly regarding informed consent and confidentiality.³¹ The paper, presented by Alan Dershowitz,³² is relevant as it explores this conflict by citing the instance of using the XYY karyotype as a defense in criminal trials worldwide. XYY karyotype refers to a genetic condition where a male has an extra Y chromosome, resulting in a total of 47 chromosomes instead of the usual 46. According to the author, the trial defense argues that individuals with XYY karyotype are more prone to aggressive and violent behavior due to their genetic makeup. Therefore, they should not be held fully responsible for their actions. The paper questions the validity of this defense and argues that there is no specific evidence to support the claim that the XYY karyotype leads to criminal behavior. It also raises ethical concerns about using genetics as a defense in criminal trials. The author explains that “predictability” refers to the ability to predict an individual's behavior based on their genetic makeup. The

²⁹ Aubrey Milunsky & George J Annas, eds, *Genetics and the Law* (Boston, MA: Springer US, 1976) at 93.

³⁰ *Ibid* at 3.

³¹ *Ibid* c preface.

³² Alan M Dershowitz, “Karyotype, Predictability and Culpability” in Aubrey Milunsky & George J Annas, eds, *Genetics and the Law* (Boston, MA: Springer US, 1976) at 63.

paper further argues that such predictions are unreliable and can lead to unfair treatment of individuals based on their genetics.³³

In the United States, the desire for prediction led to an astounding variety of health screening tests becoming popular during the mid-1960s. Nevertheless, disapproval started to emerge towards the end of the decade due to their lack of cost-effectiveness and absence of substantiation for their efficacy in benefiting the majority of patients. In 1985, Hubbard and Henifin produced their study, *Genetic Screening*,³⁴ exploring the idea of genetic screening for predictability using genetic tests for “screening apparently healthy people (or their future offspring) for potential diseases.” By stating this, the authors seem to imply a difference between treatment of overt health problems and predictability for potential diseases using genetic testing. Authors have pointed out that almost four decades ago, genetic testing had gained support, for instance, to determine environmental risks in individuals, including fetuses, pregnant women, and employees. However, such testing raises medical, ethical, economic, and social issues.³⁵ The paper concludes that while gaining deep insight into one's health status can be beneficial, screening procedures intrude on the privacy of healthy people. If screening processes are technically complex, they frequently inform the person or agency who screens rather than those who are screened. In a social setup where physicians exercise much more influence than most of their patients, preventive screening can lend itself to coercion.³⁶ Thus, the paper describes a time when questions began to be raised about the intrinsic advisability of asking healthy people to have their health validated by experts. However, a few screening programs still exist to detect cancer, but they have a specific target population who are believed to be facing the risk of a potentially incurable disease.

The research papers, followed by discussions held during the 149th Symposium of Ciba Foundation in 1990, were compiled under *Human Genetic Information: Science, Law and Ethics*.³⁷ In particular, the portion by Walter Ch. Zimmerli lays bare the talks on information paradigms in the era of technological

³³ *Ibid.*

³⁴ Hubbard & Henifin, “Genetic Screening of Prospective Parents and of Workers”, *supra* note 12.

³⁵ *Ibid.*

³⁶ *Ibid.*

³⁷ Chadwick et al, *supra* note 8.

advancements in bioscience. The author has concluded that, in theory, everyone has the right to know everyone else's genetic makeup. However, the flaws that arise from such a presumption are identified and addressed by raising arguments and confronting those arguments with higher-order norms of modern ethics. The discussion that follows is on the right to know, the many degrees of genetic knowledge available, and the long-term utility of the same. The overall conclusion of this discussion points out the flip side of the debate relating to *“the obligations that the information gatherers have to make information available, other than to the individuals immediately concerned.”*³⁸ Diana Brahams, through her *“brief summary,”* has discussed *“some of the key legal issues raised by human genetic information and research as viewed from a British common law standpoint,”*³⁹ thereby pointing at the need for a proper legislative framework in the field. This has set the baseline and allows for insights into much research from the inception of the debates on the current topic.

Mark Rothstein, while making comments at the annual meeting of the ABA Section of Science and Technology in California as far back as 1992, presents a logical approach to the possibility of individuals being considered as commodities for the benefit of companies and interested third parties in the backdrop of the Human Genome Project. The basis of the argument in this paper is that *“[a] greater ability to differentiate between individuals, even at the molecular level, comes with the ability to draw distinctions between individuals.”*⁴⁰ The idea that the ability to monetize information allows for discrimination based on such information is the basis of this paper.

Bringing the discussion forward, a pilot study was undertaken in 1992 by the authors of *Discrimination as a Consequence of Genetic Testing*. The paper describes the term GD as discrimination against an individual or their family because of a perceived or actual deviation from the “normal” human genotype.⁴¹ The authors have detailed the findings of a case history research conducted to determine the

³⁸ *Ibid.*

³⁹ *Ibid.*

⁴⁰ Mark A Rothstein, “DISCRIMINATION BASED ON GENETIC INFORMATION” (1992) 33:1 *Jurimetrics* 13–18 at 13.

⁴¹ Paul R Billings, Mel A Kohn & Marvin R Natowicz, “Discrimination as a Consequence of Genetic Testing” (1992) 50:3 *American Journal of Human Genetics* 476–482 at 476.

prevalence of genetic prejudice. In numerous social organizations, including the health and life insurance sectors, the authors discover evidence of some form of GI-based discrimination using the aforementioned concept and severe criteria for a case selection. It is recognized that people who are otherwise healthy and receive a genetic diagnosis or who may never even face serious disability may be stigmatized and denied services or entitlements. The pre-existing and prospective genetic screening programs need assessment by members of the public and specialists alike belonging to the fields of medical, scientific, legal, and social policy. They may require modifications to prevent the creation of a new social underclass based on GD called the "asymptomatic ill."⁴² Additional in-depth research on the relevance and nuances of GD is suggested.

Rothstein's 1994 paper titled, *The Use of Genetic Information for Nonmedical Purposes*,⁴³ strings together the concerns raised by himself and Billings in 1992. This paper discusses the use of GI for nonmedical purposes in the context of the Human Genome Project and the increasing knowledge of human genetics. It briefly mentions the various medical uses of GI, such as diagnosis, reproductive planning, disease prevention, treatment, and research, but states that these topics are beyond the scope of the lecture. The paper draws on the author's expertise and knowledge in the fields of genetics and law to provide insights and recommendations regarding the responsible use of information about an individual pertaining to genetics. The paper utilizes a literature review approach to discuss the use of GI for nonmedical purposes. For this, the author analyses and synthesizes information from various sources to explore the potential nonmedical uses. The author also highlights concern about the potential misuse of GI as vast amounts of data are accumulated on individuals and in aggregate. The three main ways in which third parties can gain access to any person's genetic data are identified: through clinical records, genetic data banks, and genetic testing or family histories. The paper identifies eight specific areas of possible use of GI, including identification, employment, insurance, commercial transactions, domestic relations, education, criminal justice, and tort

⁴² Billings, Kohn & Natowicz, *supra* note 41.

⁴³ Mark A Rothstein & Mark A Rothstein, "The Use of Genetic Information for Nonmedical Purposes" (1994) 9:1 *The Journal of Law and Health* at 109.

litigation. The author also examines the concerns and ethical considerations surrounding the ability of third parties to use GI.⁴⁴

Another 1996 survey of 332 people in the United States examined issues and perceptions of consumers who are part of genetic support groups because someone in their family has been diagnosed with one of 101 different genetic disorders.⁴⁵ As per the result of the survey, 25% of respondents or affected family members believe they have been denied life insurance, 22% believe they have been denied health insurance, and 13% believe they have been denied or let go from their job because of their genetic disorder. Nine percent of respondents or family members refused genetic testing for fear of genetic discrimination; 18% did not disclose their genetic information to insurers; and 17% did not disclose information to employers. Given the extent to which prejudice is felt, additional data was required to fully understand the situation.⁴⁶ Therefore, it is imperative to discuss another 1996 study conducted by Billings and others.

The paper titled, *Individual, Family, and Societal Dimensions of Genetic Discrimination*, is a case study investigation on the extent and relevance of experiences linked with GD, defined as the differential treatment of individuals based on real or imagined disparities in their genomes.⁴⁷ The study discovered that GD can occur in a variety of institutions, including insurance firms, healthcare providers, adoption agencies, and schools, with serious effects on individuals and their families. Insurance companies can discriminate when individuals are denied coverage or charged higher premiums based on GI, leading to limited access to healthcare services and financial burdens. Healthcare providers may discriminate when healthcare professionals treat individuals differently based on their GI, leading to disparities in healthcare delivery and quality of care. Further, concerning adoption agencies, discrimination can manifest when individuals are denied adoption opportunities or face additional scrutiny based on genetic

⁴⁴ *Ibid.*

⁴⁵ E Virginia Lapham, Chahira Kozma, & Joan O Weiss, "Genetic Discrimination: Perspectives of Consumers" (1996) 274:5287 Science 621–624, online: <<https://www.science.org/doi/10.1126/science.274.5287.621>> at 621.

⁴⁶ E. Virginia Lapham, Chahira Kozma, & Joan O. Weiss, "Genetic Discrimination", *supra* note 45.

⁴⁷ Lisa N Geller et al, "Individual, family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis" (1996) 2:1 Sci Eng Ethics 71–88, online: <<http://link.springer.com/10.1007/BF02639319>> at 72.

conditions, impacting their ability to form families and experience parenthood.⁴⁸ Furthermore, discrimination can even take place when schools and educational institutions make decisions regarding enrolment, accommodations, or treatment of students based on GI, potentially limiting educational opportunities and fostering stigma.⁴⁹ These instances of GD can have significant consequences for individuals and their relatives, including emotional distress, social isolation, financial burdens, and limited access to healthcare and educational opportunities.

Another work by Australian researcher Sandy Taylor the importance of studying the ethical, legal, social, and psychological implications of the availability of predictive genetic technology⁵⁰. The author has undertaken a case study of individuals suffering from Huntington's disease being discriminated against in employment settings. Overall, the paper emphasizes the need for increased awareness, interest, and advocacy in addressing the potential GD associated with predictive genetic technologies, particularly in the context of inherited illnesses like Huntington's Disease. The paper, however, does not address the potential intersection of GD with other forms of discrimination, such as race or age discrimination.

Paul Steven Miller's work, *Genetic Discrimination in the Workplace*, addresses the issues regarding GD in the workplace and the necessity for protection against it. It analyses the application of current federal statutes to GD, specifically the Americans with Disabilities Act (ADA).⁵¹ The overall conclusion is that as genetic technology progresses and reveals individuals' genetic predispositions, new safeguards will be required to ensure that genetic knowledge is not misused in the workplace. The author cites the case of *Norman-Bloodsaw v. Lawrence Berkeley Laboratory* 135 E3d 1260 (9th Cir. 1998). In this case, the Ninth Circuit

⁴⁸ *Ibid* at 76.

⁴⁹ *Ibid* at 80–81.

⁵⁰ Sandy Taylor, "A Case Study of Genetic Discrimination: Social Work and Advocacy Within a New Context" (1998) 51:4 Australian Social Work 51–57, online: <<https://www.tandfonline.com/doi/full/10.1080/03124079808411245>> at 51.

⁵¹ Paul Steven Miller, "Genetic Discrimination in the Workplace" (1998) 26:3 J Law Med Ethics 189–197, online: <https://www.cambridge.org/core/product/identifier/S1073110500013048/type/journal_article> at 189–190.

Court of Appeals observed that genetic testing for syphilis, sickle cell trait, and pregnancy without explicit notice and informed consent violated prevailing medical standards and constituted discrimination based on sex, race, and disability. The court also recognized a claim under Title VII, based on differential medical examinations for African Americans and women, constituting an adverse effect. The court upheld the dismissal of ADA claims, stating that no job-related action was taken and also that the scope of the genetic tests did not violate the ADA.

Although ADA provides some protection against workplace discrimination based on genetic predispositions, no court has directly addressed this issue. The paper proposes that state and federal legislation be enacted to provide extra safeguards in this burgeoning field. The idea is to ensure that one's genotype does not replace one's qualifications at work. Despite the significant point that discrimination based on GI exists, the paper does not provide empirical data or studies on the prevalence or extent of GD in employment. Neither does it discuss the potential impact of GD on scientific research or the willingness of individuals to participate in genetic studies.

An empirical study by the authors of *Genetic Discrimination in Life Insurance*, seeks to collect empirical evidence on GD in the insurance sector in the United Kingdom and to assess how society will manage future GI from polygenic multifactorial conditions tests.⁵² In 1996, the Wellcome Trust undertook a postal survey to collect the first empirical evidence on genetic prejudice in the UK and assess how society will deal with GI from tests for polygenic, multifactorial illnesses. The survey focused on how the insurance industry, the medical profession, employers, and social services treated families with genetic disorders. The survey's preliminary findings concentrate on the life insurance aspects, as private insurance is used to help deliver housing in the UK. The study found that insurers did not consistently treat people in support groups for genetic disorders, suggesting error rather than a coherent industry-wide policy

⁵² L Low, S King & T Wilkie, "Genetic discrimination in Life Insurance: Empirical Evidence from a Cross-sectional Survey of Genetic Support Groups in the United Kingdom" (1998) 317:7173 BMJ 1632–1635, online: <<https://www.bmj.com/lookup/doi/10.1136/bmj.317.7173.1632>> at 1632.

of GD. Insurers are concerned about adverse selection and believe that access to genetic test results can help prevent it and provide information about age-specific mortality rates. The results highlight the need for further investigations to establish the nature and sources of GD.

All these aforementioned instances show that GD is a prevalent cause for concern, especially between 1975 and 1998. This was when the debate became relevant, and research in the area saw significant growth. However, the next phase sees further advancement in the discourse.

V. PARADIGM SHIFT

Zweig and Davis explore the central idea of their work around the quote of Albert Einstein declaring that “*the progenitor of modern science once proclaimed that knowledge is important, but the imagination is more so.*”⁵³ The relevance of imagination is understood when dealing with a unique problem, and this work's theme is unique in many ways. *Genetic Technologies and Courts of Law*, as the work is titled, delves into the unregulated nature of genetic testing worldwide, including in the United States. This is a pre-GINA era work before the federal law was introduced in 2008. The authors have highlighted that basic scientific knowledge and technological expertise are shared resources between nations. Thereby, disputes, if any, could arise across the courts of these nations, compromising the rule of law. The globalization of civil and criminal conflicts that may occur in the wake of genetic testing, causing extra-judicial disputes, is a problem that has been dealt with in this work. Consequently, the case-by-case study presented in this paper will endow a broader perspective, allowing a multi-faceted approach to this study.

In her paper, Deborah Hellman states that an individual's genetic and health data are distinct, and GI does not always accurately predict an individual's health outcomes.⁵⁴ While genetic data focuses specifically on an individual's GI, health data encompasses a broader range of information related to an individual's

⁵³ Franklin M Zweig & Andre M Davis, “Genetic Technologies and Courts of Law” (2000) 3:4 *Community Genetics* 215–220 at 215, 216.

⁵⁴ Deborah Hellman, “What Makes Genetic Discrimination Exceptional?” (2003) 29 *American Journal of Law and Medicine* 77–116, online: <<https://ssrn.com/abstract=401661>> at 77–78.

overall health. Genetic data refers to information about an individual's genetic makeup, including their DNA sequence and variations in specific genes. It provides insights into an individual's inherited traits, susceptibility to certain diseases, and potential treatment response. Genetic data is obtained through genetic testing, which analyses specific genes or the entire genome.⁵⁵ Health data, on the other hand, encompasses a broader range of information about an individual's health, including medical history, current health conditions, symptoms, and lifestyle factors. It includes data collected from medical records, diagnostic tests, and self-reported information. Health data provides a comprehensive picture of an individual's overall health status and is used for diagnosis, treatment planning, and monitoring of health conditions⁵⁶. Ultimately, Hellman argues that because the social meaning of treating people differently based on their genetic makeup is different from the social significance of discrimination based on health or illness, special legislation is warranted to prohibit GD.

Through his paper on genetic exceptionalism, Mark Rothstein explores the conceptual idea behind genetic exceptionalism and legislative pragmatism in the context of passing anti-discrimination laws.⁵⁷ The author has highlighted limited conditions in which passing genetic-specific laws is reasonable. It is asserted that passing genetic-specific legislation, despite its flaws, can be justified in some instances, even if it means abandoning broader policy reform. However, it is argued that genetic exceptionalism as a public policy approach is problematic, as it promotes genetic over generic approaches to regulating health information and may offer little or no protection against discrimination. It criticizes the current federal and state policies for promoting genetic over generic approaches to access and use of health information by third parties. The author acknowledges that more desirable and far-reaching "generic" laws may be politically infeasible, leading legislators to opt for genetic-specific rules. The paper also mentions the difficulty in defining "genetic" and separating genetic information from other medical information in medical records. It concludes

⁵⁵ Hellman, *supra* note 54.

⁵⁶ *Ibid.*

⁵⁷ Mark A Rothstein, "Genetic Exceptionalism and Legislative Pragmatism" (2005) 35:4 *Hastings Center Report* 27–33, online: <http://muse.jhu.edu/content/crossref/journals/hastings_center_report/v035/35.4rothstein.pdf> at 27, 28.

by stating that genetic exceptionalism allows elected officials to avoid fundamental and controversial issues while offering little or no protection against GD.⁵⁸

The Ethics discusses the complex and troubled relationship between law and medicine across the developing and developed world.⁵⁹ Part III of the book deals with the legal issues related to the topic. In Chapter 20, the author, Lena Halldenius, dealt with the issue of GD.⁶⁰ A comparative analysis of the laws in place in countries across Europe, including Iceland, Sweden, Estonia, and the UK, has been done in relevant chapters. Similarly, the authors in *Genetic Resources, Traditional Knowledge and the Law* under Part 3, have discussed the legal developments in exemplary countries, including Kenya, South Africa, and China.⁶¹ A suggestion for a model law has also been made, given approaches to access and benefit sharing. The overall contents of these books advance the study while shedding light on the modern concepts of genetic data and information collection, storage, and distribution across countries, as well as giving an idea about legal developments across countries.

The work of Mark Taylor in *Genetic Data and the Law* sheds light on the various legal concepts of privacy laid down by way of international law⁶². The author has discussed the international legal standards applicable only to genetic data and has proceeded to evaluate the contentious issue of anonymity in Parts I and II of his work, respectively. Chapter 8 of this critical work has also touched on GD. The overall contents promote further clarity on the topic while allowing privacy to become transparent regarding international legal provisions.

Noah Levin has presented exciting facets of the usefulness and the impact of the GINA Federal Act of 2008 in the U.S. The law in place and the criticisms have been carefully studied, and the author has prepared a defense. The author

⁵⁸ *Ibid* at 32.

⁵⁹ Matti Hayry et al, "The Ethics and Governance of Human Genetic Databases: European Perspectives" at 1 See Introduction: some lessons of ELSAGEN for further insight.

⁶⁰ *Ibid* at 170.

⁶¹ Evanson C Kamau et al, eds, *Genetic resources, traditional knowledge and the law: solutions for access and benefit sharing*, 1. publ ed (London: Earthscan, 2009) at 173.

⁶² Mark Taylor, *Genetic Data and the Law: A Critical Perspective on Privacy Protection* (Cambridge University Press, 2012) at 1, Introduction.

observes that the Genetic Information Non-discrimination Act is sweeping legislation and states that sometimes justified discrimination can be helpful.⁶³ The case of the epileptic bus driver, who was convicted of second-degree murder, has been cited as an example. Thus, the author concluded that justifying acts discriminating based on GI is problematic. A detailed analysis of GINA has been presented, which allows an insight into the problem. Given that the object of this study is to suggest framework legislation, a critical analysis of existing legal provisions and their effectiveness will enable a more rationalized approach towards the final objective.

Genetic discrepancies have been recorded as early as the beginning of the 20th century. Given the fresh developments in pathology, as far back as 1909, a new term, “inborn errors of metabolism,” was coined by Sir Archibald Garrod.⁶⁴ Sir Garrod had used the term as a metaphor for “inherited metabolic disorders.” Acknowledging the changes in the concept of disease itself, the author of *Perspectives on Genetic Discrimination* examines the 20th-century idea of “the concept of error.”⁶⁵ Living matter has been conceptualized as “code” or “information” in this manner. According to several empirical investigations undertaken in various nations over the past two decades, new kinds of discrimination, inequality, and stigma have emerged due to advances in genetic knowledge comprising enriched forms of information and code of living matter.⁶⁶ These discriminatory practices spread across varying fields, including but not limited to insurance, labor market exclusions, child adoption, the education system, and the military. Two examples are the scholarly discussion of genetic data privacy and the subsequent regulatory attempts to combat discrimination based on GI. Countries have enacted legislation to safeguard individuals' right to autonomy and genetic privacy, and popular culture has responded with works of fiction like *Gattaca* and literature like *Beggars in Spain*. These works demonstrate the problems that arise when only the genetically enhanced are allowed to hold positions of power in society.⁶⁷ The

⁶³ Noah Levin, “A Defense of Genetic Discrimination” (2013) 43:4 *Hastings Center Report* 33–42, online: <<https://onlinelibrary.wiley.com/doi/10.1002/hast.193>> at 33.

⁶⁴ Thomas Lemke, *Perspectives on Genetic Discrimination*, Routledge advances in sociology 100 (New York, NY: Routledge, 2013) at 1.

⁶⁵ Lemke, *supra* note 64.

⁶⁶ *Ibid* at 2.

⁶⁷ *Ibid* at 3.

book acknowledges that GD, as it is today, is a complicated phenomenon that is not well explored. The overall gist of the work is contained in Chapter 6 of the work, which concludes that the genetic norm—a fiction—often leads to systematic exclusion, stigmatization, and discrimination, neglecting the connections between genetic modes of reasoning and existing forms of exclusion. This erroneous assumption confirms the genetically normal, perpetuating exclusion and stigmatization.⁶⁸

The privacy concerns associated with new genetics and testing in the 1990s have evolved, posing new threats to personal privacy. Consumers now have access to their genetic information, and new concerns have emerged regarding electronic data sharing and surveillance for terrorism and security hazards. This book addresses privacy issues and ethical reasoning, focusing on solidarity and equity. It discusses biobanks, forensic databases, do-it-yourself (DIY) testing, group rights, accountability, sustenance, and the role of the press and digital media. The varying occurrences of GD, as well as philosophical and legal issues, traditional challenges, and emerging instances in the new era of development, have been examined by the authors in *The Right to Know*.⁶⁹ The philosophical and legal debate surrounding the right to know and not to know has evolved significantly since 1997. The Human Genome Project, biobanks, and social and political changes have led to changes in the context of genetic research, personalized health advice, and whole genome sequencing. Individual identity has given way to collective identity in the ownership of GI, with ethical approaches emphasizing solidarity and equity. Jørgen Husted focuses on the issue of uninvited revelation of GI to unwitting relatives, who lose their genetic innocence and right to remain anonymous. He contrasts between two concepts of autonomy: thin and thick.

The second part of the text discusses contemporary issues in genetics, including ethical debates, forensic databases, and the right to know or not to know. Kadri Simm reviews the ethical debates surrounding large population biobanks and the potential of incidental findings. Robin Williams and Matthias Wienroth discuss

⁶⁸ *Ibid* at 7.

⁶⁹ Ruth Chadwick, Mairi Levitt & Darren Shickle, *The Right to Know and the Right not to Know: Genetic Privacy and Responsibility* (Cambridge University Press, 2014) at 13.

the challenges of providing donor feedback and the need for guidelines in this area. Mairi Levitt argues that individuals must have the correct information to exercise their right to know or not to know and discusses the psychological consequences of making decisions under uncertainty. Barbara Prainsack discusses the risks of knowing one's genome and the importance of respecting traditional knowledge and narratives. The chapter also explores the relationship between science, ethics, and accountability in genomic sciences, addressing issues such as inconvenient truths, traditional knowledge, and the Havasupai case study.

Henk ten Have has discussed the growth of the genetic framework for human existence, which is part of a hegemonic neoliberal ideology. This philosophy empowers autonomous individuals while diminishing the role of the state in health and environmental variables. He identifies areas in which neoliberalism is being criticized, such as changes to the patent system, data sharing, and open-access publishing. He also explores the consequences of privacy protection and the role of traditional and digital media in the argument over the right –to know and the right –not –to know. Allgaier examines media coverage of biotechnology and genetics over the last two decades to demonstrate changes in public opinion and attitudes.

Richard Watermeyer argues that the internet has opened science dialogue to diverse social actors, allowing the public to interact directly with scientists. However, online public dialogue is susceptible to inconsistency and manipulation by online authors. The public's ability to navigate online and make fair assessments remains a challenge. Korthals discusses consumer rights, ethical considerations, and labeling in the food sector. Consumers and organizations can shape the right to be informed through mass media and participation in agricultural processes.⁷⁰

⁷⁰ Chadwick, Levitt & Shickle, *supra* note 69.

VI. LEGAL FRAMEWORKS AND PROTECTIONS

The Library of Parliament's Background Papers, published by the Canadian Library of Parliament, examines pressing policy concerns in detail.⁷¹ Many foretell the rise of the issues they investigate and provide historical context, up-to-date information, and references. The Parliamentary Information and Research Service, which does research on behalf of and offers information and analysis to members of parliament, parliamentary committees, and parliamentary organizations, is responsible for preparing these documents. The report details genetic testing and GI collection and elaborates on the treaties and foreign legislation. Canadian laws consist of basic rights that can be interpreted in order to allow future analysis for handling GD.⁷² The Human Rights Laws, Labour Laws, and the Privacy Protection Regime under the *Personal Information Protection and Electronic Documents Act (PIPEDA)* of Canada, along with the GINA of the U.S., eventually became the inspirations for the Genetic Non-Discrimination Act (GNDA) of 2017. Legislation has been enacted in some areas to ensure patients' privacy and offer them more control over their medical records.⁷³

An approach toward understanding GINA from varying perspectives is needed. To spark debates on the problem of GD in the European Union (EU), the authors of the publication *Genetic Discrimination* have examined transatlantic perspectives and the United States' experience in regulating GI privacy.⁷⁴ It is the first publication examining the need for an EU response and exploring options for regulating GI at the EU level, addressing challenges and potential solutions. This book investigates the ethical and legal issues surrounding genetic testing in the European Union. It examines transatlantic perspectives on GINA and its efficacy in combating GD. The book also examines the implications of GINA for employment and health insurance and the impact of the United

⁷¹ *Genetic Discrimination and Canadian Law (Background Paper)*, by J Walker, 2014-90-E (Legal and Social Affairs Division Parliamentary Information and Research Service, 2014) at 1, 2.

⁷² *Ibid* at 5

⁷³ *Ibid* at 3

⁷⁴ Gerard Quinn, Aisling De Paor & Peter David Blanck, eds, *Genetic Discrimination: Transatlantic Perspectives on the Case for a European Level Legal Response* (London New York: Routledge, Taylor & Francis Group, 2015) at 1–2.

Nations Convention on the Rights of Persons with Disabilities (CRPD) on comparable discussions in the European Union. The book focuses on legislative and policy frameworks of the European Union, emphasizing protection gaps and the potential for particular legislative action.

The work of Yann Joly and others is a comparative review of countries across the world that have adopted public policies to address GD.⁷⁵ The article pinpoints the countries that have specific legislation for addressing GD. The authors have pointed out inherent flaws in the policy approaches of the nations. The rigidity, complexity of implementation, and restricted public view of the existing provisions are a few drawbacks in the countries' policies and legislations. Many genetic disease cases may not be prevented by current approaches, as they were developed for highly heritable monogenetic diseases. Existing norms for other types of genetic diseases and predictive information are inconsistent. Governments often use GI to control immigration and prevent crime, leading to the need for more stringent oversight and accountability frameworks. Legislation may help prevent GD, but stakeholders need to be engaged in genetic technologies and existing protections and express solidarity in integrating genetics into everyday life.⁷⁶ The study concludes with suggestions for effective public policy development.

Any information gathered through DNA sequencing during a genetic test can be stored as an individual's genetic data. The same can be shared with a third party without proper regulatory provisions in place. The United Kingdom's data protection legislation regulates genomic data transfer to third countries, combining domestic and European Union laws. Brexit may impact this legislation, with regulators avoiding consent for processing and considering pseudonymization. The future direction of the UK data protection law post-Brexit remains uncertain.⁷⁷ Adopting more stringent privacy regulations to prevent the collection, use, and disclosure of genetic data without the agreement

⁷⁵ Yann Joly et al, "Comparative Approaches to Genetic Discrimination: Chasing Shadows?" (2017) 33:5 *Trends Genet* 299–302 at 299.

⁷⁶ *Ibid*

⁷⁷ M J Taylor, S E Wallace & M Pictor, "United Kingdom: transfers of genomic data to third countries" (2018) 137:8 *Hum Genet* 637–645 at 637.

of the persons concerned and without appropriate exceptions is one strategy for combating GD in the UK.

It is a fact that increased accuracy and reduced cost of genetic tests have increased the availability of GI dramatically. Mark Rothstein and others have tried to examine the current landscape of genetic data laws in light of rapid developments and ease of availability of info. The manner of sharing, storing, and analyzing the data of diverse individuals has raised a concern about developing broadly applicable legal principles for genetic data privacy.⁷⁸ The article talks about why it might be time to stop trying to control who has access to GI and instead focus on how this data can be used and under what circumstances. The authors have pointed out that it is not practical to expect individuals to exercise complete control over the information disclosure that pertains to their privacy. The opportunities for this are limited since people disregard potential risks and end up voluntarily giving up access to their genomic data. In this light, it is concluded that focusing on the negotiations between the individual and the overall community in a variety of situations is much more practical.⁷⁹ In other words, keeping a balance between societal and individual interests is the more pragmatic path to take for data protection.

As pointed hereinabove, the question of data protection and framework regulation is addressed to an extent by the General Data Protection Regulation (GDPR) of the European Union and Council.⁸⁰ The said covenant acknowledges most of the prevailing concerns for data privacy, with its objective being the processing of personal data, the free movement of such data, and the protection of natural persons concerning such manner of data processing.⁸¹ Dara Hallinan, by way of her remarkable work,⁸² highlights the importance of

⁷⁸ Ellen Wright Clayton et al, “The Law of Genetic Privacy: Applications, Implications, and Limitations” (2019) 6:1 *Journal of Law and the Biosciences* 1–36, online: <<https://academic.oup.com/jlb/article/6/1/1/5489401>> at 5.

⁷⁹ *Ibid* at 36.

⁸⁰ *Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance)*, OJ L 2016Legislative Body: EP, CONSIL.1.

⁸¹ *Ibid*.

⁸² Dara Hallinan, *Protecting Genetic Privacy in Biobanking Through Data Protection Law*, first edition ed (Oxford: Oxford University Press, 2021) at 48.

the GDPR and its role as “the keystone of the European data protection law.”⁸³ She discusses the various aspects of GDPR. Chapter 2, which highlights the basics of genetic data and how such data helps generate socially useful information, and Chapter 5, which reviews the baseline for privacy laws against which existing legal systems might be compared, help take this discussion forward.

Inadequately protected data might lead to disastrous results if not handled with care. The idea that a failure to secure data could have catastrophic outcomes is projected by the article titled *The Normative Power of GDPR*.⁸⁴ The authors attempted to compare and contrast GDPR-inspired regulations and bills in South Asian countries with those in Europe. This study examines GDPR-inspired bills in South Asia to determine their suitability for building a worldwide data protection regime. Asian countries are more diversified than European countries, and several are revising their current data protection measures by GDPR. According to the findings, building suitable data protection mechanisms is critical for a consensus-based regional system that would eventually lead to a long-term global data protection mechanism.⁸⁵

VII. EMERGENCE OF THE DEBATE IN INDIA

In 2018, the issue of discrimination based on GI arose before the court of law in India. A single judge bench of the Delhi High Court had observed that any act of gene discrimination, particularly by insurance companies, violates the fundamental precepts of Article 14's Right to Equality and Article 21's Right to Health and Healthcare. Thus, the term “genetic discrimination” was used by the court in stating that citizens are fundamentally protected against such discrimination under the Constitution of the country itself. Most countries have used this argument to argue that any act of discrimination, whether committed by the state, an individual, or a corporate body, is punishable by law. Furthermore, discrimination is recognized as a breach of such a fundamental

⁸³ *Ibid* at 2.

⁸⁴ Vibhushinie Bentotahewa, Chaminda Hewage & Jason Williams, “The Normative Power of the GDPR: A Case Study of Data Protection Laws of South Asian Countries” (2022) 3:3 SN COMPUT SCI 183, online: <<https://link.springer.com/10.1007/s42979-022-01079-z>>.

⁸⁵ *Ibid*.

right, actionable against the state and non-state actors. However, in S.L.P. (Civil) No. 29590/2018, the three judges' bench of the Hon'ble Apex Court was pleased to stay the operation of the aforesaid judgment of the Hon'ble Delhi High Court, thereby putting a stop to the issue for the time being.

The judgment of the Hon'ble Delhi High Court's single bench has been the only one that has explicitly dealt with the problem of GD in India and has explicitly put a stop to the same. However, a detailed analytical view of the judgment reveals that its outcome is self-defeating altogether. For instance, it states that it is unconstitutional to discriminate against such clients, but it allows companies to ask for higher premiums or deny claims if a genetic disorder has been established by appropriate medical testing. Still, the case of *Jay Prakash Tayal* has not succeeded in laying down clear rules for addressing this lacuna. In the current circumstance, there appears to be a single judgment, aggravated by a lack of specific norms and regulations, highlighting the necessity to explore implementing a legal provision for genetic information non-discrimination in India.⁸⁶

This debate may also be addressed in view of the recent privacy act by the Indian Parliament. The DPDPA passed in August 2023, aims to safeguard the "personal data"⁸⁷ of individuals while striking a balance between individual rights and the lawful processing of data.⁸⁸ Under this act, digital or non-digital personal data can be processed with an individual's consent unless they choose to withdraw it⁸⁹ using the "consent manager" established by the Data Protection Board (Board) under the Central Government (CG).⁹⁰ The act draws inspiration from the landmark judgment in the K.S. Puttaswamy case,⁹¹ which affirmed the fundamental right to privacy under Article 21 of the Constitution of India.⁹²

⁸⁶ Sangita Sharma & Sayan Chandra, "Criminalizing Genetic Discrimination in India", (19 September 2020), online: *The Criminal Law Blog* <<https://criminallawstudiesnluj.wordpress.com/2020/09/19/criminalizing-genetic-discrimination-in-india/>>.

⁸⁷ *The Digital Personal Data Protection Act*, 2023, s 2 (n).

⁸⁸ *Ibid* at para Preamble.

⁸⁹ *Ibid*, s 5 (2) (b).

⁹⁰ *Ibid*, s 2 (c) and 2 (d).

⁹¹ *Justice K S Puttaswamy (Retd) and Anr v Union of India and Ors*, AIR 2017 SC 4161 .

⁹² *Ibid* at para 499 (2) (iii).

At first glance, the DPDPA appears to take a distinctive approach to protecting individual privacy. It also ensures that parties violating its provisions face appropriate penalties. However, a notable concern arises: over time, the government may wield significant control over personal data, potentially granting unrestricted discretionary powers in specific situations. For example, Section 36 empowers the CG to request “information” from the Board, Data Fiduciaries, or intermediaries. A legislative analysis reveals an underlying surveillance intent by the CG.

Furthermore, the act grants the CG authority to exempt state agencies from stringent requirements related to handling personal data. This juxtaposition with the Right to Information Act, 2005 (RTI Act) introduces complexities and warrants careful consideration. Specifically, the amendment of Section 8(1)(j) of the RTI Act by Section 44(3) of the DPDPA highlights a conflict between the right to privacy and the right to information. The expanded power of a Public Information Officer (PIO) allows them to reject RTI applications related to personal data.

Interestingly, the DPDPA does not explicitly classify data or mention terms like “genetic data,” “genetic information,” or “genetic disorder” in its text. However, a deeper analysis reveals that the DPDPA intends to protect personal data, whether digital, non-digital, or in the process of digitization. Overall, the DPDPA has extensive reach in terms of safeguarding personal data and informational privacy.

VIII. CONCLUSION

This paper sets a beginning for new research. Genetic variations, which can lower or raise disease risk, result from the inheritance of parents' genes. The broader discourse suggests that individuals should not be subjected to discrimination or bias simply because of their unique ancestry or genetic status, a fundamental biological process vital to their existence. Discrimination based on GI in India has yet to be the subject of significant legal research. Canada and the United States, however, have GI non-discrimination laws (Genetic Non-discrimination Act of 2017 and the GINA of 2008, respectively) that address genetic discrimination in the employment and insurance sectors. These laws

have generated many debates, and academic discourse has followed about their extent and applicability in their respective countries. In the aftermath of genetic advancements, there may be a need for legal protections against GI-based discrimination in India. This scenario has, therefore, led to the rise of several related questions about the key theoretical frameworks relating to anti-discrimination laws and their possible incorporation into the laws against GD, comparing the existing laws and policies in the matter to protect individual interests. The most vital question explores whether there is a requirement for specific legislation to prevent GD in India.

What is clear from the aforesaid debate is that India, unlike the United States and Canada, lacks a legally binding provision to govern genetic testing. This leaves the data entirely at the disposal of the person or agency doing the genetic testing. This concern is not based on fear alone since countries like the United States and Canada have already faced the issue, even though it is unique. Therefore, reason only demands looking at the possibility of the problem gaining ground in India in the coming decades. In this view, exercising foresight while considering fresh perspectives in taking required legislative steps if the situation demands may become necessary to circumvent the problem in the Indian context. Legislation may not simply address one form of discrimination but may include progressive ideas such as procedural safeguards and implementation farsightedness.

On the contrary, introducing more laws while failing to implement them effectively is counterintuitive. In the end, effective policies that are more public-spirited may become as helpful as any stringent law might hope to be. A pragmatic approach is essential. The law may need to be comprehensive, or India may not need a specific law dealing with discrimination based on GI at all if the existing legal provisions prove sufficient.

ACKNOWLEDGEMENTS

The authors would like to sincerely thank the University Grants Commission of India for providing a monthly fellowship that supported this research. Furthermore, they extend their gratitude to the Indian Institute of Technology

Kharagpur, India for providing an environment conducive to growth and innovation.

COMPETING INTEREST

The authors declared that they have no competing interests.

REFERENCES

The Digital Personal Data Protection Act, 2023.

Aadhaar (Targeted Delivery of Financial and Other Subsidies, Benefits and Securities) Act, 2016.

Genetic Information Non-discrimination Act, 2008.

Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance), OJ L 2016.

The Digital Personal Data Protection Act, 2023.

Ministry of Electronics and Information Technology, *The Information Technology Rules*, 2011, (2011).

U.S. Const., Amendment XIV (1868).

Justice K S Puttaswamy (Retd) and Anr v Union of India and Ors, AIR 2017 SC 4161 .

Canadian Coalition for Genetic Fairness v Attorney General of Canada and Another, [2020] 2020 SCC OnLine Can SC 2 .

Chadwick, Derek J et al, eds, *Human Genetic Information: Science, Law and Ethics: Symposium on Human Genetic Information: Science, Law and Ethics, held at the Haus der Universität, Bern, Switzerland, 20 - 22 June 1989*, Ciba Foundation symposium 149 (Chichester: Wiley, 1990).

Chadwick, Ruth, Mairi Levitt & Darren Shickle, *The Right to Know and the Right not to Know: Genetic Privacy and Responsibility* (Cambridge University Press, 2014).

Hallinan, Dara, *Protecting Genetic Privacy in Biobanking Through Data Protection Law*, first edition ed (Oxford: Oxford University Press, 2021).

Indian Council of Medical Research, *National Ethical Guidelines for Biomedical and Health Research Involving Human Participants* (2017).

- Kamau, Evanson C et al, eds, *Genetic resources, traditional knowledge and the law: solutions for access and benefit sharing*, 1. publ ed (London: Earthscan, 2009).
- Lemke, Thomas, *Perspectives on Genetic Discrimination*, Routledge advances in sociology 100 (New York, NY: Routledge, 2013).
- Milunsky, Aubrey & George J Annas, eds, *Genetics and the Law* (Boston, MA: Springer US, 1976).
- Quinn, Gerard, Aisling De Paor & Peter David Blanck, eds, *Genetic Discrimination: Transatlantic Perspectives on the Case for a European Level Legal Response* (London New York: Routledge, Taylor & Francis Group, 2015).
- Taylor, Mark, *Genetic Data and the Law: A Critical Perspective on Privacy Protection* (Cambridge University Press, 2012).
- William E Nelson, *The Fourteenth Amendment: From Political Principle to Judicial Doctrine* (Cambridge, Massachusetts: Harvard University Press, 1995).
- Alan M Dershowitz, “Karyotype, Predictability and Culpability” in Aubrey Milunsky & George J Annas, eds, *Genetics and the Law* (Boston, MA: Springer US, 1976) 63.
- Barroso, Luís Roberto, “Technological revolution, democratic recession, and climate change: The limits of law in a changing world” (2020) 18:2 *International Journal of Constitutional Law* 334–369.
- Bentotahewa, Vibhushinie, Chaminda Hewage & Jason Williams, “The Normative Power of the GDPR: A Case Study of Data Protection Laws of South Asian Countries” (2022) 3:3 *SN COMPUT SCI* 183, online: <<https://link.springer.com/10.1007/s42979-022-01079-z>>.
- Billings, Paul R, Mel A Kohn & Marvin R Natowicz, “Discrimination as a Consequence of Genetic Testing” (1992) 50:3 *American Journal of Human Genetics* 476–482.
- Clayton, Ellen Wright et al, “The Law of Genetic Privacy: Applications, Implications, and Limitations” (2019) 6:1 *Journal of Law and the Biosciences* 1–36, online: <<https://academic.oup.com/jlb/article/6/1/1/5489401>>.
- E Virginia Lapham, Chahira Kozma, & Joan O Weiss, “Genetic Discrimination: Perspectives of Consumers” (1996) 274:5287 *Science* 621–624, online: <<https://www.science.org/doi/10.1126/science.274.5287.621>>.

- Erwin, Cheryl, “Behind the Genetic Information Non-discrimination Act of 2008” (2009) 109:12 *AJN*, *American Journal of Nursing* 46–48, online: <<https://journals.lww.com/00000446-200912000-00026>>.
- Geller, Lisa N et al, “Individual, family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis” (1996) 2:1 *Sci Eng Ethics* 71–88, online: <<http://link.springer.com/10.1007/BF02639319>>.
- Hayry, Matti et al, “The Ethics and Governance of Human Genetic Databases: European Perspectives”.
- Hellman, Deborah, “What Makes Genetic Discrimination Exceptional?” (2003) 29 *American Journal of Law and Medicine* 77–116, online: <<https://ssrn.com/abstract=401661>>.
- Hubbard, Ruth & Mary Sue Henifin, “Genetic Screening of Prospective Parents and of Workers: Some Scientific and Social Issues” (1985) 15:2 *Int J Health Serv* 231–251, online: <<http://journals.sagepub.com/doi/10.2190/U1MJ-Y6YR-D01R-1UQ4>>.
- Joly, Yann et al, “Comparative Approaches to Genetic Discrimination: Chasing Shadows?” (2017) 33:5 *Trends Genet* 299–302.
- , “Erring in Law and in Fact: The Supreme Court of Canada’s Reference re Genetic Non-Discrimination Act” (2021) 99:1 *Can B Rev* 172–192, online: <<https://heinonline.org/HOL/P?h=hein:journals/canbarev99&i=172>>.
- Kim, Hannah et al, “Genetic discrimination: introducing the Asian perspective to the debate” (2021) 6:1 *npj Genom Med* 54, online: <<https://www.nature.com/articles/s41525-021-00218-4>>.
- Levin, Noah, “A Defense of Genetic Discrimination” (2013) 43:4 *Hastings Center Report* 33–42, online: <<https://onlinelibrary.wiley.com/doi/10.1002/hast.193>>.
- Low, L, S King & T Wilkie, “Genetic discrimination in Life Insurance: Empirical Evidence from a Cross-sectional Survey of Genetic Support Groups in the United Kingdom” (1998) 317:7173 *BMJ* 1632–1635, online: <<https://www.bmj.com/lookup/doi/10.1136/bmj.317.7173.1632>>.
- Mark A Rothstein, “The Use of Genetic Information for Nonmedical Purposes” (1994) 9:1 *The Journal of Law and Health* 109.

- Miller, Paul Steven, “Genetic Discrimination in the Workplace” (1998) 26:3 J Law Med Ethics 189–197, online: <https://www.cambridge.org/core/product/identifier/S1073110500013048/type/journal_article>.
- Otlowski, M, S Taylor & Y Bombard, “Genetic Discrimination: International Perspectives” (2012) 13 Annu Rev Genomics Hum Genet 433–454.
- Rothstein, Mark A, “DISCRIMINATION BASED ON GENETIC INFORMATION” (1992) 33:1 Jurimetrics 13–18.
- , “Genetic Exceptionalism and Legislative Pragmatism” (2005) 35:4 Hastings Center Report 27–33, online: <http://muse.jhu.edu/content/crossref/journals/hastings_center_report/v035/35.4rothstein.pdf>.
- Taylor, M J, S E Wallace & M Pictor, “United Kingdom: transfers of genomic data to third countries” (2018) 137:8 Hum Genet 637–645.
- Taylor, Sandy, “A Case Study of Genetic Discrimination: Social Work and Advocacy Within a New Context” (1998) 51:4 Australian Social Work 51–57, online: <<https://www.tandfonline.com/doi/full/10.1080/03124079808411245>>
- Zweig, Franklin M & Andre M Davis, “Genetic Technologies and Courts of Law” (2000) 3:4 Community Genetics 215–220.
- Anjana Malhotra et al, *Racial Discrimination in the United States*, by Anjana Malhotra et al (ACLU - Human Rights Watch, 2022).
- National Institute of General Medical Sciences, *Genetics*, online: <<https://www.nigms.nih.gov/education/fact-sheets/Pages/genetics.aspx>>.
- Sangita Sharma & Sayan Chandra, “Criminalizing Genetic Discrimination in India”, (19 September 2020), online: *The Criminal Law Blog* <<https://criminallawstudiesnluj.wordpress.com/2020/09/19/criminalizing-genetic-discrimination-in-india/>>.
- Walker, J, *Genetic Discrimination and Canadian Law (Background Paper)*, by J Walker, 2014-90-E (Legal and Social Affairs Division Parliamentary Information and Research Service, 2014).