Vol. 15 No. 2 ISSN: 0976-3570

Navigating the Genetic Labyrinth: Reconciling Individual Genetic Autonomy with Collective Health Imperatives in International Policy

Dr. Shuvro Prosun Sarker[1]
Akash[2]

Abstract

Genetic information serves as a crucial resource for scientific inquiry, clinical diagnostics, and establishing personal identity. Yet, this same data harbours potential threats to individual and collective privacy rights, with the capacity to disclose intimate details susceptible to discriminatory or exploitative misuse. It is, thus, imperative to scrutinise the role of international law in safeguarding genetic data privacy and curtailing discrimination predicated on genetic profiles. This article delves into the evolution of privacy rights concerning genetic data, as demarcated by international legal frameworks. It examines the delicate balance between genetic data confidentiality and anti-discrimination efforts, questioning whether the pursuit of communal benefits is compromised by rigorous privacy protections. The discourse posits that international legal tenets can inform the formulation of privacy measures that reconcile the communal imperative for technological advancement with the privacy entitlements of individuals and kinship groups. Furthermore, it advocates for the adoption of optimal practices to fortify genetic data privacy and impede genetic-based discrimination within the ambit of international law. These practices may encompass the implementation of stringent data anonymisation protocols and comprehensive informed consent processes at the national level.

Keywords: genetic data, privacy rights, anti-discrimination, international legal frameworks, communal benefits, kinship groups, data anonymisation, national-level implementation.

---

[1] Assistant Professor, Grade – I, RGSoIPL, IIT, Kharagpur, West Bengal, India.

[2] Junior Research Fellow, RGSoIPL, IIT, Kharagpur, West Bengal, India.

I. Introduction

The scientific community today heavily relies on a line of cells known as HeLa, which were taken from a cervical cancer patient named Henrietta Lacks almost a century ago. Lacks was a Black woman who received treatment at one of the few hospitals in the USA that allowed people of colour at that time. Her cells were perpetually self-replicating and in a manner incapable of perishing, making them ideal for countless scientific discoveries. However, her cells and medical records were widely circulated among the research and biomedical fraternity without her consent or recognition of their source.[3] Lacks died shortly after and was more or less lost in oblivion. Her identity and genomic sequence were also revealed to the public without her family's permission, and they were never compensated for the profits made from her cells.[4]

The use of genetic data for scientific research, clinical studies, investigation of crimes[5], identification of victims, tracing relatives and lineage, etc., can advance science, medicine, and society.[6] However, genetic data also poses significant risks to the privacy and rights of individuals and groups, as it can reveal sensitive and personal information that may be used for discrimination or exploitation. Studies have shown that people have concerns about the manner in which their genetic data is used and prefer health officials or researchers over the government or any private entity when deciding to grant consent or show willingness to share genetic data.[7] The Henrietta Lacks case highlights legal and ethical issues

---

[3] Katharine Lang, *The Story of Henrietta Lacks and the Uniqueness of HeLa Cells*, (2023), https://www.medicalnewstoday.com/articles/the-stolen-cells-of-henrietta-lacks-and-their-ongoing-contribution-to-sci ence (last visited Jan 18, 2024).

[4] Henrietta Lacks: Science Must Right a Historical Wrong, 585 NATURE 7 (2020), https://www.nature.com/articles/d41586-020-02494-z (last visited Jan 18, 2024).

[5] E. Wyatt Jones, *Privacy and Property: Constitutional Concerns of DNA Dragnet Testing*, BRIDGEWATER COLLEGE DIGITAL COMMONS (2023).

[6] LIBBY COPELAND, LOST FAMILY Prologue (2020).

[7] Nanibaa'A. Garrison et al., *A Systematic Literature Review of Individuals' Perspectives on Broad Consent and Data Sharing in the United States*, 18 GENETICS IN MEDICINE 663 (2016), https://linkinghub.elsevier.com/retrieve/pii/S1098360021043963 (last visited Dec 30, 2023); Zhiyu Wan et al., *Sociotechnical Safeguards for Genomic Data Privacy*, 23 NAT REV GENET 429 (2022), https://www.nature.com/articles/s41576-022-00455-y (last visited Dec 29, 2023).

surrounding genetic data use, where a cancer patient's cells were utilised without her consent for scientific research, highlighting the disregard for genomic data privacy. This case raises concerns about unauthorised use of genetic material and calls for international law to protect the rights of individuals whose genetic data is used for research. This study explores the concept of privacy within the international legal framework, focusing on its multifaceted meanings and implications. It adopts a broad definition of privacy, including individuals' rights over their personal information and their freedom to decide who can access, use, or share it. It also covers the protection of genetic data, which is unique to a person and indicative of their general physiology and health. This concept is essential in understanding the protection of personal information. The General Data Protection Regulation (GDPR) of the European Union (hereinafter EU) provides such a definition of genetic data[8]and is one of the instruments that aims to regulate "the collection, processing, and transfer of genetic data" in a way that respects the privacy and rights of individuals[9]. However, GDPR is not the only instrument defining genetic data, and there is a need to understand what genetic data or information means vis-à-vis the fear of discrimination based on it and whether the enforcement of the right to privacy is sufficient to curtail the issues arising out of discrimination based on genetic data.

The international community encounters various challenges that necessitate periodic attention from international law. The Universal Declaration of Human Rights (UDHR) in its Preamble recognises the fact that the basic human rights available to all, along with a dignified existence of an individual sans any discrimination of any kind, are all essentials to promote progress in society and improve standards of living in order to advance the sense of freedom.[10]In recent times, international law has made advancements in tackling matters concerning consent, privacy, and genetic information-based discrimination. However, it is crucial for the international community to come together and address the

---

[8] Council of The European Union, *General Data Protection Regulation*, 4(3) (2016), https://gdpr-info.eu/.

[9] Art. 4(3) of The GDPR defines "genetic data" as *"personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question."*

[10] UN GENERAL ASSEMBLY, *Universal Declaration of Human Rights*, (1948).

discussion regarding the conflict between personal and societal well-being. This study determines whether current international legal frameworks adequately allow for adaptation in domestic law, or if these frameworks lack due effectiveness and relevance. The latter concern is in line with the perspective of Austinian positivist thinkers who believe that international law lacks the necessary enforcement mechanisms. This study also aims to determine existing challenges and gaps arising due to international legal conventions,

and to offer some suggestions and best practices for enhancing genetic data privacy and preventing genetic information-based discrimination (GD) in international law.

II. Genetic Data through the Lens of Privacy

The issue of privacy, which has always been a concern in the realm of information technology, is once again brought to the forefront due to the increasing collection of highly sensitive data and the unavoidable occurrence of data breaches. The privacy of highly sensitive genetic data is under threat due to the lack of adequate legal and ethical regulations in the field of precision medicine.[11]In 2001, Justice Langa emphasised that the intensity of privacy increases as it gets closer to the personal sphere of human life and decreases as it gets further away from this core. This highlights the complexities of privacy rights.[12] It is the law that recognises the right to privacy and associates human dignity with it to award it significance. Therefore, privacy without dignity is mere words in the law that lack ethos. This implies that human dignity lies in the person's ability to decide whether or not and to what extent they wish to extend their personal sphere. Therefore, the decision behind sharing the genetic data of a person may be based on several factors, but it is ultimately personal. [13] This means that there exists a personal

---

[11] Wallace J. Hopp, Jun Li & Guihua Wang, *Big Data and the Precision Medicine Revolution*, 27 PRODUCTION AND OPERATIONS MANAGEMENT 1647 (2018), http://journals.sagepub.com/doi/10.1111/poms.12891 (last visited Dec 29, 2023).

[12] Langa, J., Investigating Directorate: Serious Offences v. Hyundai Motor Distributors Ltd. 2001 (1) SA 545 (CC) (2001).

[13] David Eugene Johnson & Debora Jane Shaw, *The Dangerous Use of Genetic Information*, 21 JICES 533 (2023),

choice behind decision-making, which is protected legally by the right to privacy, also encompassing the right to be left alone.

As a broad term, privacy is difficult to define substantially because it cannot be consolidated into a single conception.[14] However, privacy in common usage may refer to the concealment of information, as in having control over one's personal information. It may also refer to enjoying peace and tranquillity within one's own space as against the world at large, or it may even be connected with freedom or liberty within one's own sphere in a broader sense.[15] Privacy encompasses various aspects, including the desire to be left alone, protecting individuality, secrecy, limiting self-access, and promoting control over personal information, among others.[16] The debates over the years have raged and ebbed, but we are left with the overall understanding that privacy is a complex idea.

As individuals, it is our expectation for certain matters to remain private and confidential. When this expectation is projected under any law and sanctions are attached to the violation of such a law, a right to privacy is created. This right has an element of power associated with it, as under the law, privacy becomes a product of the collective view of the broader societal makeup.[17]

The right to privacy, in a narrower sense, connotes any bunch of rights that causes an individual to be protected from the prying eyes of the public. This idea should make sense, especially in the present age, where information technology touches every aspect of human life. As Justice D. Y. Chandrachud observes, privacy "allows each human being to be left alone in a core."[18] Where an individual's

---

https://www.emerald.com/insight/content/doi/10.1108/JICES-06-2023-0089/full/html (last visited Jan 30, 2024).

[14] Daniel J. Solovet, *Conceptualizing Privacy*, 90 CALIFORNIA LAW REVIEW 1087 (2002), https://www.jstor.org/stable/3481326.

[15] Richard A Posner, *The Economics of Privacy*, 71 THE AMERICAN ECONOMIC REVIEW 405 (1981), https://www.jstor.org/stable/1815754 (last visited Dec 8, 2023). Richard A Posner, 'The Economics of Privacy' (1981), 71 The American Economic Review 405 <https://www.jstor.org/stable/1815754> accessed 8 December 2023.

[16] Solovet, *supra* note 14.

[17] *Id.*

[18] J. S. Khehar , C.J.I. et al., Justice K. S. Puttaswamy (Retd.) and Anr. v. Union of India and Ors., AIR 2017 SC 4161 2 (2017).

autonomy is necessarily conditioned by their relationship with the society, the right to privacy preserves their liberty while allowing them to grow in their core.[19] In other words, if we consider that the data containing an individual's genetic attributes must belong to that individual and it is that individual alone who must decide whether to share the data with any other party or not, then in order to ensure their autonomy and liberty, genetic data must be protected against misuse at all costs, for any unauthorised use of that data without prior information and consent of the individual would result in their right to privacy getting infringed. It is submitted that before this could happen, it is necessary for the person to have sufficient awareness that his or her genetic information is confidential and should be protected as something exceptional. This is to avoid any potential misuse that could lead to negative consequences such as being stigmatised, causing disruptions in family relationships, or experiencing loss of employment or insurance coverage.[20] Several studies suggest today that the *"commercialisation"* of patient or research participants' data is a way of obtaining funding by medical centres.[21] Besides data getting outsourced for profits[22], there have been occurrences of using DNA samples for purposes other than what it was intended for in the first place. The case of Havasupai Native Americans is an instance where a DNA sample collected for research on type-2 diabetes was used by the Arizona Board and State University for several other genetic studies.[23] In 1990, a leukaemia patient sued University of California

---

[19] J. S. Khehar , C.J.I. et al., *supra* note 18.

[20] Wan et al., *supra* note 5.

[21] Kayte Spector-Bagdady et al., *"My Research Is Their Business, but I'm Not Their Business": Patient and Clinician Perspectives on Commercialization of Precision Oncology Data*, 25 THE ONCOLOGIST 620 (2020), https://academic.oup.com/oncolo/article/25/7/620/6443480 (last visited Dec 29, 2023).

[22] Justin Sherman, *How Shady Companies Guess Your Religion, Sexual Orientation, and Mental Health and Sell That Data to the Highest Bidder.*, SLATE, Apr. 2023, https://slate.com/technology/2023/04/data-broker-inference-privacy-legislation.html (last visited Jan 5, 2024).

[23] Nanibaa' A. Garrison, *Genomic Justice for Native Americans: Impact of the Havasupai Case on Genetic Research*, 38 SCIENCE, TECHNOLOGY, & HUMAN VALUES 201 (2013), http://journals.sagepub.com/doi/10.1177/0162243912470009 (last visited Dec 29, 2023).

doctors who used his spleen, blood, and other bodily substances to create a patented cell line. The court observed that the defendant doctors were aware of the "competitive, commercial, and scientific advantages" of the tissues collected from Moore, and continued to capitalise on the unique genetic material collected from Moore without his knowledge or consent.[24] Again, the 2003 case where parents of children with Canavan disease sued a physician and his research group for patents on the Canavan gene. The Canavan Families shared their children's samples, unaware that the physician and his research group were attempting to enforce their patents against entities offering Canavan testing.[25] Questions were also raised in these cases regarding the nature of the right the person has over their genetic data.

One view holds that genetic data must be treated as an ordinary set of information, such as the medical record of the person or the database of financial information, and the right to property should be recognised on the principle of utilitarianism and ownership over the same. However, this view has been criticised as being narrow and restrictive, since such an approach would harm future research by creating exclusive entitlements. Therefore, a contrasting view has proposed that instead of creating additional rights, simply strengthening provisions on privacy and confidentiality of data and informed consent will be much more effective.[26] The main focus is on protecting genetic information from potential privacy breaches, regardless of its nature or degree of personal data. Discriminatory actions can be based on an individual's genetic information, making it crucial to address privacy concerns to mitigate the threat of genetic discrimination.

---

[24] Moore v. Regents of the University of California, (1990).

[25] Greenberg v. Miami Childrens's Hospital Research Institute, 264 F. Supp. 2d 1064 (S.D. Fla. 2003) (2003).

[26] Richard A. Spinello, *Property Rights in Genetic Information*, 6 ETHICS AND INFORMATION TECHNOLOGY 29 (2004), http://link.springer.com/10.1023/B:ETIN.0000036157.14807.b0 (last visited Dec 7, 2023).

III. Balancing Genetic Privacy and Public interest

A. The Debate on Genetic Exceptionalism

Thomas Murray, in 1998, had coined the term "genetic exceptionalism" to describe the perspective that genetics presents unique and specific concerns, drawing inspiration from the previous concept of "HIV exceptionalism."[27] The issue of handling genetic data differently from other medical or health data is a significant and divisive policy question. Opponents argue that genetic discrimination is equivalent to health status discrimination and is essential for effective insurance administration.[28] However, the proponents advocate for the treatment of genetic data differently from other health data, calling for legislative measures to address exceptional discrimination. These opposite views exist because being able to distinguish between genetic data and other health-related information based on the subtle distinctions that fundamentally exist is a daunting task, and creating a precise definition of "genetic information" is necessary.[29] Alternatively, it has been argued that GD is a moral issue where individuals with a genetic predisposition to a disease are denied coverage or charged higher insurance rates, similar to health discrimination.[30] In fact, according to this alternate view, there is no good reason to tell the difference between people who are genetically more likely to get sick and people who actually get sick. However, this view does not hold that anti-discrimination laws are wholly unnecessary. Anti-discrimination laws are seen by them as a step in the right direction, with a subsequent law protecting everyone from health discrimination as the next step.

The issue of whether to prohibit GD is pertinent to evaluating the need for protective laws in varying contexts where individual assessment is common,

---

[27] Thomas H. Murray, *Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 101 (Mark A. Rothstein ed., 2000).

[28] Rothstein, *supra* note 35.

[29] According to Rothstein, this necessity is justified because administering different treatments for genetic conditions can increase negative perceptions and reinforce the idea that genetics solely dictates an individual's characteristics and behaviours.

[30] Hellman, *supra* note 27.

such as insurance.[31] It is submitted that the distinction between individuals who are ill and those who are healthy in insurance appears unjust, as the individual with a genetic predisposition may not require healthcare services due to a lack of apparent illness. Insurers estimate the probability of a particular insured individual filing claims for reimbursement within the policy duration. However, the distinction between an individual who is already ill and one who may potentially fall ill is merely a matter of degree, rather than a fundamental distinction. Genetic information, like other types of information, is utilised by insurers to determine personalised rates and forecast the probability of an individual making claims on their insurance policy within a specific timeframe. Although genetic science may provide more accurate forecasts of future health, it will never achieve flawless predictability. Unforeseen occurrences, such as accidents, and external factors acting on genetic predispositions introduce a significant level of uncertainty. The issue of whether GD possesses distinct moral characteristics compared to discrimination based on health or illness can also be raised in other scenarios as well, such as instances of employment discrimination. GD can be influenced by family circumstances, where judges may determine that a child should be placed with one parent if there is a genetic susceptibility to early-onset Alzheimer's disease. Similarly, potential adoptive parents may be turned down if they carry a gene associated with Huntington's disease, or they may be required to undergo genetic testing before the adoption is finalised. GD should not be prohibited in these contexts, as it poses ethical concerns regarding the morality of treating individuals based on their genetic predispositions.[32]

Critics argue that laws specifically targeting genetic information have been deemed insufficient in their ability to effectively prevent the negative consequences resulting from the utilisation and divulgence of genetic data. Additionally, they perpetuate the negative perception of genetic disorders and disregard the societal issues linked to genetic privacy and discrimination. The primary concern regarding GD in health insurance pertains to the equitable distribution of healthcare access. Balancing employer and employee rights in

---

[31] instances may involve individuals purchasing health insurance policies and the insurance markets for life, disability, and long-term care, etc.

[32] *Id.*

managing access to health data and determining relevance of current or future health conditions to job opportunities is crucial in employment.[33] Healthcare finance systems without individual medical underwriting are immune to GD, but individual underwriting in insurance products is equivalent to discrimination due to risk classification. Hence, it is exceedingly challenging to formulate efficacious strategies to mitigate GD within a discriminatory framework. It is necessary for society to determine whether specific social opportunities have significant social implications. If they do, a system should be established to eliminate any form of risk categorisation. Group-based health insurance should be mandatory for all participants and should incorporate various risk-spreading mechanisms. In contrast, life insurance may permit individual underwriting in specific situations.[34] Nevertheless, there is one alternative that is certain to be unsuccessful: the implementation of special underwriting or the provision of access to health information that is widespread, indeterminate, isolated from other health information, and incapable of being treated distinctively.

The examination of genetic material can also be approached from the perspective of property rights[35], taking into account considerations of ownership and genetic privacy in relation to each other.[36] One perspective in this context argues that genetic source material, which includes samples of human tissue and genetic data, should be granted ownership rights. This elucidates that the foundation of this concept is rooted in the exclusive "rights of sources." The primary objective of this is to ensure the protection of privacy, as the extensive availability or unauthorised acquisition of this information can endanger privacy rights. Genetic exceptionalism advocates for individuals to have property rights over their genetic information to ensure confidentiality. However, excessive restrictions on

---

[33] Mark A. Rothstein, *Genetic Exceptionalism and Legislative Pragmatism*, 35 HASTINGS CENTER REPORT 27 (2005), http://muse.jhu.edu/content/crossref/journals/hastings_center_report/v035/35.4rothstein.pdf (last visited Sep 14, 2023).

[34] *Id.*

[35] Vera Bergelson, *It's Personal but Is It Mine? Toward Property Rights in Personal Information*, 37 U.C. DAVIS L. REV. (2005), https://core.ac.uk/download/pdf/45678038.pdf.

[36] E. Wyatt Jones, *supra* note 3; Jonathan F. Will, *Comment: DNA as Property: Implications on the Constitutionality of DNA Dragnets*, 65 LAW REVIEW (2003), http://lawreview.law.pitt.edu/ojs/lawreview/article/view/25 (last visited Jan 30, 2024).

data collection and dissemination could negatively impact future biomedicine and genetics research.[37] Therefore, it is submitted that at least two distinct reasons require that genetic information be treated separately from any other forms of information. A specialized legal framework offers increased protection for human rights, but it's also crucial from a utilitarian standpoint to mitigate anxiety, foster scientific investigation, and improve the overall well-being of individuals and society by expanding knowledge.

B. Can the Enforcement of Privacy Rights Address the Threat of Discrimination?

The debate on safeguarding individual privacy has two main lines: traditional, advocating for citizens' right to privacy, and far-sighted, addressing discriminatory behaviour based on genotype characteristics. In the United States, the Fourth, Fifth, and Fourteenth Amendments ensure privacy for individuals with personal information affecting their intimate existence, as per the Constitution.[38] The Indian Constitution also contains Fundamental Rights under Part III[39] that aim at preserving the life and personal liberty of "every person."[40] In 2017, the Hon'ble Supreme Court of India had held that *"the right to life and personal liberty includes the right to privacy as an integral part guaranteed under Part III of the Constitution."*[41] Thus we see that the traditional meaning of the right to privacy is protected and ingrained in the constitutional fabric of democratic nations. The presence of a strong constitutional basis allows for a privacy-based solution to GD that addresses both privacy and anti-discrimination to ensure the realisation of the promises shown by advancements in genomics.[42]

Information is a commodity, and companies over the years have collected, maintained, and stored records of personal information left behind by people. In

---

[37] Spinello, *supra* note 26.

[38] See United States of America: Constitution, (1787), https://www.refworld.org/docid/3ae6b54d1c.html.

[39] See The Constitution of India (1950), https://www.refworld.org/docid/3ae6b5e20.html.

[40] *Id.* at 21.

[41] J. S. Khehar , C.J.I. et al., *supra* note 18 at 40, 119, 134, 183, 186, 187, 188.

[42] Anita Silvers & Michael Ashley Stein, *Human Rights and Genetic Discrimination: Protecting Genomics' Promise For Public Health*, 31 JOURNAL OF LAW, MEDICINE AND ETHICS 377 (2003).

the present era, where the internet is easily accessible, everyone using the same leaves behind "digital footprints," which include the minutest details about them, including their tastes, habits, sexual orientation, etcetera, and can be used as breadcrumbs to trace the person.[43] The computer revolution has made this intrusion of privacy even more dramatic as companies gained the ability to distribute this information far and wide. Thus, a direct-marketing industry that trades in personal information as a commodity in the secondary market is a reality, with billions of dollars' worth of trade being carried out daily.[44] Few common examples to illustrate this complexity would be credit card companies develop and maintain lifestyle profiles on their cardholders, or telecom companies keep a record of users' calling patterns, or manufacturers of goods track habits and choices of their customers. Credit reporting agencies also keep records of data on household status (someone is married or unmarried is fact of value) of individuals or their pending legal disputes.[45] Thus the scale of erosion of individual privacy is huge, and at the same time it is so ubiquitous that its outcomes are hard to determine. In such a case, the individual neither owns his personal information nor does he have a recognised personal interest in it once the information is retrieved.[46]

The increasing access to genetic information has led to the unauthorised use of previously private information. This has led to social implications, as personal information can be used without consent or in ways that an individual does not agree with. Individual-level data, particularly those identifying individuals, carries a higher risk of harm compared to summary data from multiple participants. Data breaches can reveal sensitive health information, potentially damaging an individual's reputation or causing loss of insurance, employment, or financial advantages.[47] It is a fact that genomic research often includes additional data, such as demographic information, social and behavioural health

---

[43] Joel R. Reidenberg, *Privacy in the Information Economy: A Fortress or Frontier for Individual Rights?*, 44 FEDERAL COMMUNICATIONS LAW JOURNAL 195 (1992).

[44] Vera Bergelson, *supra* note 57.

[45] Joel R. Reidenberg, *supra* note 65.

[46] Vera Bergelson, *supra* note 57.

[47] Ellen W. Clayton et al., *A Systematic Literature Review of Individuals' Perspectives on Privacy and Genetic Information in the United States*, 13 PLoS ONE e0204417 (2018), https://dx.plos.org/10.1371/journal.pone.0204417 (last visited Jan 2, 2024).

factors, and molecular or clinical information about phenotypes. This data can be obtained from electronic health records after eliminating identifiable information. However, there is debate over the feasibility of removing identifying information or making genomic data anonymous. Researchers have demonstrated the ability to re-identify individuals whose data was used for genomics research, even without the usual identifying information.[48]

The most effective approach to neutralising discrimination is a stringent and dual-pronged privacy approach. This involves suppressing genetic predisposition information to prevent discrimination based on it. The next step is prohibiting the use of acquired information, despite efforts to impede transmission through legal provisions that provide penalties and solutions.[49] It is proposed that the regulation of informed consent would allow for the regulation of the flow of acquired information. Consider a linear river system with multiple tributaries originating from it (Fig. 1).

---

[48] Wan et al., *supra* note 5.

[49] Iulia Voina Motoc, *The International Law of Genetic Discrimination*, *in* NEW TECHNOLOGIES AND HUMAN RIGHTS 222 (Thérèse Murphy ed., 2009), https://academic.oup.com/book/8616/chapter/154577381 (last visited Dec 29, 2023).

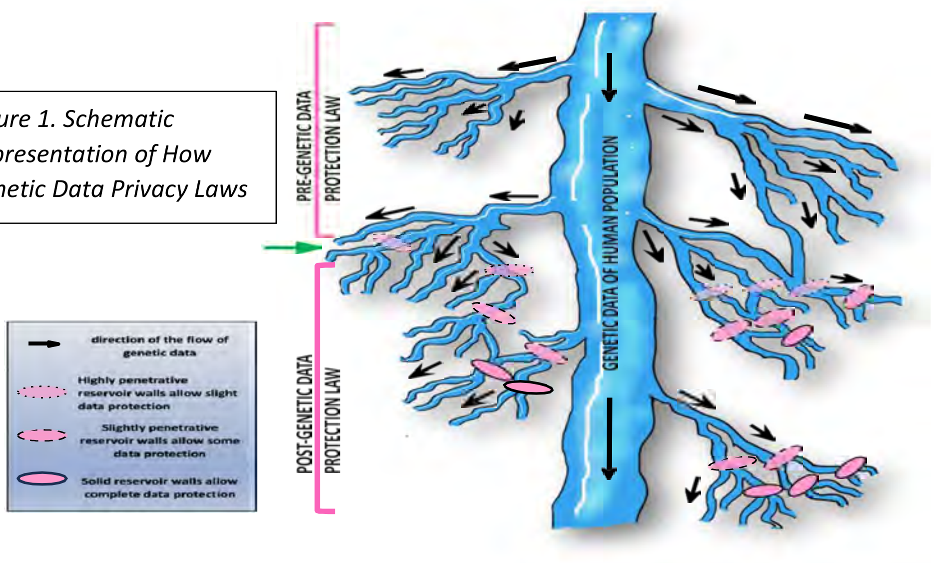

Figure 1. Schematic Representation of How Genetic Data Privacy Laws

In Fig. 1, the river waters (shown in blue colour) represent the genetic data of the human population (central Stream), with emerging streams, each representing specific family systems or lineages originating from the river. Arrows represent the direction of the flow of water. The riverbanks symbolise ongoing human effort to document genetic information. The length of the streams increases as more individual genetic data gets added in the genealogy through the merging of two streams (symbolising the union between a male and female from two lineages). Dams can regulate the flow of the streams, allowing control over water flow. Dams serve as an analogy for data privacy laws governing the genetic data of families. In the past, with a relatively low risk of information misuse, the water in the streams flowed freely, allowing access to genetic information for non-family members. However, as dams or data privacy laws are introduced, the remaining individuals can control the flow of water or genetic information by exercising informed consent. Thus, Figure 1 also depicts the importance of data privacy laws in today's society. Furthermore, any genetic information of the individual and their family is securely stored within an impervious structure of the dam, shown by the solid walls of a reservoir (Fig. 1). The robustness of such a wall is contingent upon the individual's understanding and conscious recognition of the significance of the information being held. A clear understanding indicates that the individual is cognisant of the fact that personal data must be preserved. Thus, an awareness about their right to privacy and data protection laws ensures that individuals are able to give their informed consent. On the contrary, an unauthorised dissemination of genetic information without proper consent would constitute leakage, as seen by the penetrative reservoir walls in Fig. 1, which will fail to provide robust data protection. The walls become weak with a lack of knowledge. Once the information has been disclosed, it is irretrievable, since the flow of water is unidirectional, as indicated by solid arrows. Thus, laws must endeavour to fill any unauthorised gaps or gullies that are formed. Legislation that is revised from time to time guarantees effective safeguards for an individual's right to privacy and autonomy in relation to their genetic data. At the same time, prior to envisioning an idealistic scenario where the barriers of the dam will ultimately be impervious and genetic data completely safeguarded, it is prudent to understand that a right to privacy cannot be entirely unrestricted and there needs to be a balance between the rights of an individual and the larger public good. Thus, a regulation must be flexible enough to address such a problem. This is because genetic information can also be utilised to create technology that would have advantageous implications for society, particularly in areas like public health.[50]

IV. **Examining International Legal Instruments**

A. Genetic Privacy, Discrimination and Consent under International Law

The controversy surrounding genetic technology development is not new, with the potential harm resulting from genetic discoveries causing global turmoil during the Nazi regime and the emergence of the "eugenics" movement in the early 1900s. Francis Galton coined the term "eugenics" to describe the science of improving human stock through narratives related to the cultivation of race.[51] According to Galton, "the investigation of human eugenics" involves studying conditions in which humans of "a high type" are produced.[52] To state simply,

---

[50] Wan et al., *supra* note 5.

[51] FRANCIS GALTON, INQUIRIES INTO HUMAN FACULTY AND ITS DEVELOPMENT 17 (2nd ed. 1907), https://galton.org/books/human-faculty/.

[52] *Id.* at 30.

Eugenics refers to the selection of the best specimens of the human race and allowing them to multiply so as to replace the lesser or inferior stock of humans over time. In 1910, the Eugenics Record Office was established in New York in the USA, where trained field workers maintained huge records of family histories and where, reportedly, people would visit to ascertain the eugenic appropriateness of marriage proposals.[53] In 1927 the U.S. Supreme Court, in *Buck v. Bell,*[54] deemed a Virginia law that allowed the sterilisation of specific inmates with a hereditary form of mental illness or intellectual disability to be constitutional. Justice Oliver Wendell Holmes made the observation that it is sufficient to have three generations of intellectually disabled individuals, thus permitting the sterilisation of an 18-year-old named Carrie Buck. Thus, the highest court in the USA had once permitted a classification system based on genetics. Eugenics, a movement that allowed for the determination of genetically superior individuals, was shocking at the time.[55] However, between 1933 and 1945, the Nazis used human experiments to "cleanse" the German people of those deemed "unworthy of life."[56] This led to the adoption of the Universal Declaration of Human Rights (UDHR) in 1948 and the International Covenant on Civil and Political Rights (ICCPR) in 1966, which protects against torture, cruelty, and inhuman treatment.[57]

Thus, the issue of discrimination arising out of creating a superior race based on the knowledge of a person's genetic attributes became a global concern. Genetic data can reveal sensitive and personal information that may be used for discrimination or exploitation, and discrimination based on such data. Therefore, GD is explicitly prohibited by several significant international documents, such as the Universal Declaration on the Human Genome and Human Rights (UDHGHR), the International Declaration on Human Genetic Data (IDHGD),

---

[53] Motoc, *supra* note.

[54] Oliver Wendell Holmes, Jr., Buck v. Bell 1927 SCCOnline US SC 105 (1927).

[55] By the 1920s, eugenics had become a global movement.

[56] Eugenics and Scientific Racism, GENOME.GOV (2022), https://www.genome.gov/about-genomics/fact-sheets/Eugenics-and-Scientific-Racism (last visited Dec 30, 2023).

[57] INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS, (1966), https://www.refworld.org/docid/3ae6b3aa0.html (last visited Jan 4, 2024). *Article 7* of the ICCPR covers these grounds but expressly mentions medical and scientific experimentation.

and the Convention on Human Rights and Biomedicine. The documents emphasise equality and human dignity, requiring states to protect citizens by enacting laws against GD. Human rights recognised internationally evaluate policy decisions and choices in applying scientific knowledge, reflecting the commonality of the GD problem.[58] The study of genetics and biotechnology in terms of human rights requires acknowledging the fundamental liberty of scientific investigation and the entitlement *"to enjoy the benefits of scientific progress and its applications,"* [59] as outlined in Article 15 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR). However, this freedom and right have limitations.

The adherence to specific bioethical standards is a prerequisite for the legitimacy of the assertion of scientific research freedom, as these standards serve as a counterbalance.[60] Governments have an affirmative responsibility to intervene in scientific, technological, and economic endeavours to protect human rights from misuse or distortion of research and market freedoms. This aligns with Article 28 of the Universal Declaration of Human Rights, which emphasises the importance of establishing a social and international system that enables the realisation of rights and freedoms outlined in the Declaration. It urges governments to actively work towards creating a societal framework that fosters the establishment and protection of human rights.[61] Article 7 of the Universal Declaration of Human Rights (UDHR) guarantees equal protection from discrimination, ensuring that all individuals are entitled to the same level of protection. The International Covenant on Civil and Political Rights (ICCPR) acknowledges the UDHR as the foundation of freedom, justice, and peace. The covenant also states that individuals can only enjoy rights and freedoms in the absence of fear and that no one shall be subjected to medical or scientific experimentation without their free consent.[62] The UDHR (under Article 5) and

---

[58] See the detailed discussions of Prof. Otlowski et al., Otlowski, Taylor, and Bombard, *supra* note 37.
[59] INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS, *supra* note 79.
[60] Francioni, *supra* note 82.
[61] *Id.*
[62] INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS, *supra* note 79 at Preamble.

the ICCPR (under Article 7), both mandate member states to prevent degrading cruelty or experimentation against consent.

Based on these lines of maintaining human dignity and equality, the UDHGHR, which recalled the UDHR and ICCPR, was adopted by the United Nations Educational, Scientific, and Cultural Organization (UNESCO) in 1997. The UDHGHR encourages ethical research on the implications of scientific and technological progress in biology and genetics, promoting human progress while upholding human rights and fundamental freedoms. It emphasises the potential of research on the human genome to enhance individual well-being but prohibits discrimination based on genetic characteristics.[63] This sentiment is bolstered by several provisions aimed at preventing GD. For example, under Part A it is declared that the human genome constitutes the heritage of all humanity.[64] It talks about human dignity through the lens of the human genome. Article 2(a) ensures all individuals are treated with dignity and impartial rights, regardless of their genetic attributes, emphasising the importance of respecting their uniqueness and diversity rather than reducing them to their genetic characteristics.[65] Part B emphasises the requirement of *"prior, free, and informed consent."*[66] The UDHGHR's legislation prohibits discrimination based on genetic traits, aiming to violate basic rights and liberties. It also upholds confidentiality under Article 7. The legislation also recommends strict regulations for research on the human genome, as outlined in Articles 10, 11, and 12 under its Part C.[67] It further outlines principles of "solidarity and international cooperation" in Part E, specifically in Articles 17, 18, and 19. Article 17 mandates states to support vulnerable individuals, families, and populations affected by genetic diseases or disabilities, advocating for research to treat, prevent, and identify genetically determined diseases. Article 18 mandates states to facilitate the dissemination of scientific knowledge about the human genome and foster

---

[63] UNESCO, *supra* note 87 at Preamble paras 4, 6.
[64] *Id.* at 1.
[65] *Id.* at 2(b).
[66] *Id.* at 5(b).
[67] *Id.* at Part C-Research on the Human Genome.

cooperation between developed and developing nations, particularly in the field of genetics.[68]

UNESCO adopted the IDHGD in October 2003. The IDHGD aims to establish principles for States to formulate policies and legislation on genetic data collection, processing, use, and storage, while ensuring its application in criminal investigation, detection, and prosecution. Article 5 and Article 1(c) outline the main purposes of genetic data "collection, processing, use, and storage" while ensuring compliance with international human rights law in domestic law and parentage testing.[69] Article 3 lays down that an individual's identity is not solely determined by genetic traits but also by various factors such as education, environment, personal connections, and cultural connections. It also asserts the importance of promoting equality and eliminating prejudice. Article 7 focuses on the preservation of human dignity and rights, emphasising the need to avoid discrimination or stigmatisation based on genetic data. This includes population-level genetic studies and studies examining the relationship between genetics and behaviour. It is crucial to interpret these studies cautiously to prevent any violation of individual rights and fundamental freedoms.[70] The text emphasises the importance of obtaining consent before collecting genetic data, proteomic data, or biological samples from individuals. Article 8 requires prior, free, informed, and express consent without financial or personal gain. This applies to both invasive and non-invasive procedures, as well as their use and storage. Restrictions on consent should only be imposed by domestic legislation in accordance with international human rights law, with strong justifications. Consent for medical and scientific research is revoked when data becomes permanently separated from an identifiable individual. If consent is revoked, the use of the data should cease unless permanently disassociated. If the person's desires are not entirely unrelated, they should be followed. If it is unfeasible or presents a potential hazard, the data and samples should be permanently disassociated or destroyed. Moreover, article 11 highlights the importance of genetic counselling in providing non-directive, culturally tailored, and ethically

---

[68] *Id.* at 19.

[69] INTERNATIONAL DECLARATION ON HUMAN GENETIC DATA, 1(a). Contains the aims of this declaration (2003), https://www.refworld.org/docid/4042241f4.html (last visited Jan 11, 2024).

[70] *Id.* at 3.

meaningful genetic testing services.[71] Furthermore, Article 14 addresses the need for protecting the privacy and confidentiality of biological, proteomic, and human genetic samples in accordance with national and international human rights standards. It advises against sharing or disclosing this data unless there are strong public interest reasons or explicit consent. The data must be handled with utmost confidentiality, even if unlinked samples may be associated with an identifiable individual. This is followed by article 15, which deals with the need for uprightness and precision in handling biological samples, demonstrating prudence, truthfulness, and moral uprightness; considering ethical, legal, and social consequences; and ensuring data integrity and security.[72] Thus, the IDHGD is considered the paramount international instrument regarding genetic privacy with its objective of protecting human "genetic data, proteomic data, and biological samples" from external access or disclosure. It states that such permissions should only be granted when there is a compelling public interest or when consent is provided in accordance with domestic and international human rights laws. The document emphasises the need for confidentiality in handling these sensitive data.

In 1993, UNESCO Director-General Federico Mayor established the International Bioethics Committee (IBC) to draft the preliminary version of the UDHGHR, which was officially approved in November 1997.[73] IBC published the IDHGD in 2003 and the Universal Declaration on Bioethics and Human Rights (UDBHR) in 2005.[74] The UDBHR addresses ethical concerns related to technologies, medicine, and life sciences, providing a comprehensive framework for biomedical activities.[75] Article 6 emphasises the importance of prior, free, and

---

[71] *Id.* at 9.

[72] INTERNATIONAL DECLARATION ON HUMAN GENETIC DATA, *supra* note 94.

[73] Roberto Andorno, *The Role of UNESCO in Promoting Universal Human Rights. From 1948 to 2005* (2018), https://www.zora.uzh.ch/id/eprint/158412 (last visited Jan 11, 2024).

[74] The 2005 declaration by UNESCO is a comprehensive framework of principles for all biomedical activities but does not specifically deal with genetic privacy or discrimination based on genetic information.

[75] INTERNATIONAL BIOLAW AND SHARED ETHICAL PRINCIPLES: THE UNIVERSAL DECLARATION ON BIOETHICS AND HUMAN RIGHTS, (Cinzia Caporale & Ilja Richard Pavone eds., 1 ed. 2018), https://www.taylorfrancis.com/books/9781317114406 (last visited Jan 11, 2024).

informed consent for medical interventions and scientific research. It allows for exceptions based on ethical and legal standards, as well as international human rights law. In cases involving groups or communities, additional legal agreements may be sought, but individual consent should always be the primary basis. Article 7 provides special protection for those unable to give consent.[76] The "Report of the IBC on Updating its Reflection on the Human Genome and Human Rights" (IBC Report), published in 2015, identifies five domains where ethical dilemmas have emerged in the field of genetics and biomedicine.[77] These include direct-to-consumer genetic tests, precision/personalised medicine, biobanks, non-invasive prenatal testing, and emerging techniques for engineering gametes and editing the human genome. The report aims to adapt the existing international legal frameworks to changing times. It further mandates the need for respecting the autonomy and privacy of an individual.[78] The report emphasises the need to balance ethical challenges related to genetic technology advancement with the need for research and individual freedom. The 2009 IBC report on consent highlights the lack of clarity on how to apply the principle of consent in practice and different contexts, presenting numerous challenges in biomedical, social, and cultural settings.[79] The report provides a comprehensive framework on informed consent, outlining its contents, conditions, and methods, and highlighting the necessity for its withdrawal.[80] The report discusses the application of consent and the roles of states in this process. It emphasises that consent is a fundamental principle in the legal system, guiding decisions by individuals and families, strengthening cultural beliefs about self-governance, and enabling ethical choices. It also plays a crucial role in preserving political freedom by allowing

---

[76] UNIVERSAL DECLARATION ON BIOETHICS AND HUMAN RIGHTS, (2005).

[77] Charles Dupras, Yann Joly & Emmanuelle Rial-Sebbag, *Human Rights in the Postgenomic Era: Challenges and Opportunities Arising with Epigenetics*, 59 SOCIAL SCIENCE INFORMATION 12 (2020), http://journals.sagepub.com/doi/10.1177/0539018419900139 (last visited Jan 11, 2024).

[78] *Id.* at 7.

[79] IBC, UNESCO, *Report of the International Bioethics Committee on Consent*, 14 JAHRBUCH FÜR WISSENSCHAFT UND ETHIK 227, 7 (2009), https://www.degruyter.com/document/doi/10.1515/9783110208856.227/html (last visited Jan 11, 2024).

[80] *Id.* at 15–18.

individuals to exercise and waive constitutional rights.[81] Consent is crucial for the lawful processing of personal data, as it is a commodity, and the fate of shared or online activities is unknown.[82] The importance of informed consent is emphasised as the fate of our personal data is unclear from the outset.

The aforementioned regulations are supplemented by regional legal instruments and other ethical principles regarding biomedical research, worth mentioning among which is the Oviedo Convention[83]. The Oviedo Convention, enacted in 1997, is a regional measure aimed at protecting individuals from genetic discrimination in biology and medicine, prohibiting any discrimination based on an individual's genetic composition.[84] Article 12 of the Convention stipulates that predictive genetic tests are only permitted for health-related or scientific research purposes, respecting patients' rights to receive information and autonomy to decline information sharing. States must align their laws with the Convention before ratification, potentially requiring amendments or new legislation.[85] The convention clarifies that any legislation that is enacted in this regard should incorporate legal penalties and mandate compensation for individuals who have experienced unwarranted harm as a result of medical treatment or research. The Declaration of Helsinki, established in 1964 by the World Medical Association, is a key ethical principle in biomedical research, significantly influencing the development of international, regional, and national legislation and codes of conduct.[86] This document provides ethical guidelines for physicians involved in biomedical research, including obtaining informed

---

[81] Neil Richards & Woodrow Hartzog, *The Pathologies of Digital Consent*, 96 WASHINGTON UNIVERSITY LAW REVIEW 1461 (2019), https://ssrn.com/abstract=3370433.

[82] Paul M. Schwartz, *Property, Privacy, and Personal Data*, 117 HARVARD LAW REVIEW 2056 (2004), https://www.jstor.org/stable/4093335?origin=crossref (last visited Dec 8, 2023).

[83] The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No. 164) was opened for signature on 4 April 1997 in Oviedo (Spain).

[84] EUROPEAN CONVENTION FOR THE PROTECTION OF HUMAN RIGHTS AND FUNDAMENTAL FREEDOMS, AS AMENDED BY PROTOCOLS NOS. 11 AND 14, 11 (1950), https://www.refworld.org/docid/3ae6b3b04.html (last visited Jan 9, 2024).

[85] *Id.* at 31, 32.

[86] Motoc, *supra* note 1180.

consent from subjects and conducting ethical reviews of research protocols. It aligns with the World Health Organisation's International Ethical Guidelines for Biomedical Research Involving Human Subjects, which emphasise respect for individuals, beneficence, and justice as fundamental ethical principles.[87]

International instruments like the EU's GDPR emphasise the importance of informed consent for processing personal data, stating that lawful processing occurs when the data subject explicitly consents to the processing for specific purposes.[88] The basic understanding behind GDPR is that individuals should be given the opportunity to consent for specific areas of scientific research that adhere to established ethical norms, as the purpose of processing personal data may not always be clear.[89] The Ethical Guidelines for Biomedical Research Involving Human Subjects, revised in 2002 by the Council for International Organisations of Medical Sciences (CIOMS), lay emphasis on the importance of informed consent or legal authorisation for genetic tests of clinical or predictive significance on identifiable individuals' biological samples, as well as the need to maintain confidentiality in genetic research.[90] Moreover, Article 14 of the Additional Protocol to the Oviedo Convention prohibits conducting biomedical research without informed consent. Chapter IV, "Information and Consent," emphasises that participants should be informed about their legal rights and safety measures. Article 13 allows individuals to refuse or withdraw consent without discrimination, and they should be aware of their rights and the safety measures in place.[91]

---

[87] DECLARATION OF HELSINKI: RECOMMENDATIONS GUIDING DOCTORS IN CLINICAL RESEARCH, (1964), https://www.wma.net/wp-content/uploads/2016/11/DoH-Jun1964.pdf (last visited Jan 11, 2024).

[88] Council of The European Union, *supra* note 7. Article 6 talks about the lawfulness of processing personal data.

[89] *Id.*

[90] INTERNATIONAL ETHICAL GUIDELINES FOR BIOMEDICAL RESEARCH INVOLVING HUMAN SUBJECTS, (2002), https://media.tghn.org/medialibrary/2011/04/CIOMS_International_Ethical_Guidelines_for_Biomedical_Research_I nvolving_Human_Subjects.pdf.

[91] ADDITIONAL PROTOCOL TO THE CONVENTION ON HUMAN RIGHTS AND BIOMEDICINE, CONCERNING BIOMEDICAL RESEARCH, (2007).

B. Major Challenges and Limitations in Existing Laws

The international community has created legal instruments to address GD and genetic privacy issues. The Oviedo Convention of the EU and UNESCO's UDHGHR marked the beginning of international law's involvement in these matters. Other international bodies, like ECOSOC, have passed resolutions and directives on genetic privacy and non-discrimination in 2001 and 2004. These resolutions urge states to prevent discrimination based on genetic traits and prevent the use of genetic information in social, medical, or employment contexts.[92] These frameworks and resolutions acknowledge human rights in genetic data collection, processing, and use but face challenges in effective implementation across countries due to limitations in recognising human dignity and rights.

The lack of uniformity and coherence in genetic data frameworks is a major challenge, as they reflect different regional, cultural, and political perspectives. The Oviedo Convention prohibits discrimination based on genetic data, while the UDHGHR allows exceptions for public interest or research purposes. The definitions and scopes of genetic data, genetic privacy, and genetic discrimination vary across different frameworks, creating confusion and ambiguity. For instance, the IDHGD defines human genetic data as the *"information about heritable characteristics of individuals obtained by analysis of nucleic acids or by other scientific analysis,"* [93]while the GDPR, under its recital No. 34, states that genetic data is personal data of any individual resulting from an analysis of his/her biological sample, etc.[94] Thus the major international texts miss out on providing operational definitions in the first place so as to effectively answer the "what" question in relation to the problem at hand.

The existing international frameworks for genetic data lack enforceability and compliance, as they are declarations or conventions that require ratification and implementation by domestic laws of most states. The principles and guidelines of these organisations rely on voluntary cooperation and commitment from states

---

[92] UN ECONOMIC AND SOCIAL COUNCIL RESOLUTION 2004/9: GENETIC PRIVACY AND NON-DISCRIMINATION, (2004), https://www.refworld.org/docid/46c455a50.html (last visited Jan 11, 2024).

[93] INTERNATIONAL DECLARATION ON HUMAN GENETIC DATA.

[94] Council of the European Union.

and other actors, but there is no effective mechanism to monitor compliance and accountability, especially in the face of rapid technology development, data flow globalisation, and newer aspects of genetic data-based discrimination. For example, the IDHGD and the UDHGHR both talk about the promotion of the principles set out in their respective texts by way of recommendation to the States who "should" take appropriate measures to "promote" and implement the principles set out by them[95]. Their text does not specify what these measures are or how they will be evaluated.

International legal frameworks for genetic data lack balance and flexibility, failing to accommodate the diverse interests and values of various stakeholders, including individuals, groups, researchers, health professionals, governments, and corporations, regarding the use and protection of genetic data. For example, the protection of genetic data privacy may conflict with the promotion of scientific research, the prevention of GD may conflict with the provisions of health care, and the respect for human diversity may conflict with the pursuit of social justice. These frameworks are also not able to adapt to the changing needs and challenges of the society, as they are often rigid and outdated. For instance, the Oviedo Convention does not address the ethical and legal dilemmas posed by new technologies such as DTC-GT and gene editing, which have emerged since then.

Therefore, there is a need to improve and update these international instruments and to address the challenges and gaps that they face. Some of the possible recommendations and best practices could involve:

i. Developing a global and comprehensive legal instrument for genetic data that is binding, coherent, and consistent and that reflects the universal and shared values and principles of human rights and bioethics. Such An instrument could enhance existing frameworks while addressing new challenges from science and technology advancements. It could establish clear definitions, standards, and procedures for genetic data collection, processing, and use, while protecting privacy and preventing genetic diseases.

---

[95] INTERNATIONAL DECLARATION ON HUMAN GENETIC DATA.

ii. A global, independent oversight body is needed for genetic data, overseeing compliance and accountability of states and other actors and providing guidance for the implementation and interpretation of legal instruments. Such a body could also facilitate the exchange of information and best practices, promote public awareness and education, and foster international cooperation and dialogue on genetic data issues. One possible model for such a body is the International Genetic Discrimination Observatory, which was suggested by some researchers[96] but which needs to be aligned with the comprehensive legal instrument on GD and to have a broader global outreach.[97]

iii. Reviewing and revising the existing legal frameworks for genetic data periodically and regularly and incorporating the latest scientific and technological developments, the best practices and experiences, and the emerging ethical and legal issues and challenges. Such a process could also involve the participation and consultation of various stakeholders, such as individuals, groups, researchers, health professionals, governments, corporations, and civil society.

iv. Adopting a proportional and contextual approach for genetic data that is able to balance the different interests and values of different stakeholders and that can accommodate the diversity and complexity of genetic data and its uses. The approach should consider the unique characteristics of each case, including the type and source of genetic data, its purpose, potential benefits and risks, and the consent and preferences of the data subjects.

---

[96] Yann Joly et al., *Establishing the International Genetic Discrimination Observatory*, 52 NAT GENET 466 (2020), https://www.nature.com/articles/s41588-020-0606-5 (last visited Jul 12, 2023).

[97] Genetic Discrimination Observatory, GENETIC DISCRIMINATION OBSERVATORY, https://gdo.global/en (last visited Jan 28, 2024).

V. **Conclusion**

The paper advocates for ethical and responsible use of genetic information, ensuring privacy and security against misuse or discrimination. It calls for stricter legal and social safeguards to protect individual and group privacy and rights. One of the issues that this paper attempts to address is the potential gap between those who can and cannot access genetic tests and therapies, highlighting socioeconomic inequality and an imbalance of power between scientific and technological actors and traditional government and civil society. The paper suggests that addressing this imbalance requires following the universal principle of human rights, which acknowledges the dignity and worth of every human being, rather than claiming ownership over genes or discoveries. International law frameworks like the IBC, UNESCO's declarations, and the EU's treaties establish standards for protecting personal health information and genetic data. These frameworks should be mandatory and binding, and countries are responsible for cooperating and enacting laws that comply with these standards. International law requires countries to show solidarity and share genetic research findings. Further research is warranted to determine whether countries hoard their findings, preventing others from accessing them. There exists a hidden inequality that affects the lives and rights of millions of people. Addressing this issue is difficult but essential, as it affects millions of lives.

A specialised legislative framework is needed to protect genetic testing and ensure comprehensive protection. Nationally implemented guidelines are crucial for monitoring laws relating to the collection of genetic materials from suspects and database establishment for convicts. Individuals should have the right to access their genetic data and avoid revealing identifiable information that could compromise their privacy. Legislation should define and enforce informed consent, ensuring individuals are fully informed and empowered to make choices about their genetic data. However, this poses challenges for businesses that rely on personal data for improving products, services, or marketing strategies. Further studies can ensure that data-privacy dams are able to regulate information flow and prevent unauthorised or excessive dissemination of genetic data to third parties. The proliferation of genetic data amplifies the urgency to safeguard individual health records with heightened vigilance. The preservation of genetic privacy and mitigation of discrimination underscore the necessity for enhanced public awareness and education. Governments bear a significant responsibility in demystifying the complexities and potential societal impacts of genetic information utilisation. Politicians worldwide need to create a new sense of unity among their people, based on the genetic knowledge that science has revealed. Moreover, enlightening both the public and scientific community about the pivotal role, as well as inherent constraints, of genetic research is indispensable.

The increasing amount of genetic data necessitates increased vigilance in safeguarding individual health records, preserving genetic privacy, and mitigating discrimination. Governments must educate the public about the complexities and potential societal impacts of genetic information utilisation. Politicians worldwide must create unity based on genetic knowledge and educate the public and scientific community about the role and constraints of genetic research. A global dialogue on genetic data privacy and genetic variation (GD) is crucial to address the social and legal implications of genetic information. It should respect genetic prediction constraints and public health while avoiding excessive restrictions that stifle research innovation. Researchers should focus on single family lineages, allowing individuals to control their genetic information and prevent unauthorised use and discrimination. The information should only be shared with close relatives with legitimate interests. Genetic research can offer solutions to economic problems through predictive and preventive medicine, despite ethical challenges.