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Towards a Human Rights-Based Legal Framework for Genetic Technology in Indonesia

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Abstract

The lack of specific legal provisions addressing the misuse of genetic information in Indonesia raises critical concerns regarding potential violations of the right to privacy and genetic-based discrimination. This study aims to examine the extent to which Indonesia's legal framework protects human rights in the era of genetic technology. Employing a normative legal research method, the study utilizes statutory and conceptual approaches to analyze relevant laws, including the 1945 Constitution, the Human Rights Law, and the Personal Data Protection Law. The findings reveal that while Indonesia's existing legal framework provides foundational human rights protections, it fails to explicitly regulate genetic data as a distinct category requiring heightened safeguards. Key issues include the absence of mechanisms for informed consent, vague data governance, and a lack of explicit prohibitions on genetic discrimination. As genetic testing expands—particularly in health, research, and insurance sectors—the risk of rights violations becomes more imminent. The study recommends comprehensive reform through the creation of dedicated legislation, establishment of an independent oversight body, and adoption of progressive legal principles such as autonomy, non-discrimination, and precaution. Without such reforms, Indonesia risks falling behind in ethically and legally navigating genetic innovation while compromising constitutional human rights guarantees. Without such reforms, Indonesia risks falling behind in ethically and legally navigating genetic innovation while compromising constitutional human rights guarantees.

Kurangnya ketentuan hukum yang secara spesifik mengatur penyalahgunaan informasi genetik di Indonesia menimbulkan kekhawatiran serius terkait potensi pelanggaran hak atas privasi serta diskriminasi berbasis karakteristik genetik. Penelitian ini bertujuan untuk mengkaji sejauh mana kerangka hukum Indonesia melindungi HAM dalam era perkembangan teknologi genetik. Dengan menggunakan metode penelitian hukum normatif, studi ini menerapkan pendekatan perundang-undangan dan konseptual untuk menganalisis berbagai regulasi yang relevan, termasuk UUD NRI 1945, UU Hak Asasi Manusia, serta UU Pelindungan Data Pribadi. Temuan penelitian menunjukkan bahwa meskipun kerangka hukum Indonesia saat ini telah menyediakan perlindungan dasar terhadap hak asasi manusia, regulasi tersebut belum secara tegas mengatur data genetik sebagai kategori khusus yang memerlukan perlindungan lebih kuat. Beberapa isu utama yang ditemukan antara lain ketiadaan mekanisme persetujuan berdasarkan *informasi (informed consent), ketidakjelasan tata kelola data, serta belum adanya larangan eksplisit terhadap diskriminasi genetik. Seiring dengan meluasnya penggunaan tes genetik-terutama dalam sektor kesehatan, penelitian, dan asuransi-risiko terjadinya pelanggaran hak semakin meningkat. Penelitian ini merekomendasikan dilakukannya reformasi hukum secara komprehensif melalui pembentukan regulasi khusus, pendirian lembaga pengawas independen, serta penerapan prinsip-prinsip hukum progresif seperti otonomi, non-diskriminasi, dan prinsip kehati-hatian. Tanpa adanya reformasi tersebut, Indonesia berisiko tertinggal dalam menghadapi inovasi genetik secara etis dan legal, sekaligus berpotensi mengorbankan jaminan hak konstitusional warga negara.*

Keywords: Genetic Privacy, Human Rights, Genetic Discrimination, Legal Regulation.

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INTRODUCTION

The advancement of genetic technologies in Indonesia is accelerating rapidly, particularly in the fields of medical biotechnology, agriculture, and genetic engineering (Gelamntara, 2024). Innovations such as CRISPR-Cas9, genetic modification of staple crops, and genetic testing for medical purposes demonstrate immense potential for enhancing human well-being (Hidayati & Arifin, 2025). In the health sector, these technologies pave the way for personalized genetic-based treatments and gene therapies (Sibarani, 2024). However, without robust, rights-based regulatory frameworks, these advancements are vulnerable to misuse and may jeopardize fundamental human rights. Consequently, this progress brings with it profound ethical and legal challenges—particularly concerning potential violations of human rights in the context of genetic technologies (Suhendra et al., 2024).

As a nation that upholds the values of human dignity, Indonesia must ensure that the development of genetic technologies proceeds in a manner that balances scientific progress with the protection of fundamental individual rights (Sibarani, 2024). From a human rights protection perspective, Indonesia already possesses several legal instruments, including the 1945 Constitution of the Republic of Indonesia (UUD NRI 1945) and Law No. 39 of 1999 on Human Rights (Human Rights Law). The Constitution enshrines several provisions directly linked to human rights protection, including Article 28G(1), which guarantees the right to personal and family security, including protection against threats—particularly relevant in the context of the use and storage of genetic data. Furthermore, Article 28H(1) affirms every citizen's right to a healthy environment and access to healthcare services, which is increasingly significant in light of the medical applications of genetic technology. Most crucially, Article 28I(1) recognizes the right to life and human dignity as non-derogable rights—imperative to safeguard in the face of technological evolution.

These constitutional guarantees are echoed and reinforced in the Human Rights Law. Articles 4 and 9(1) emphasize the right to life and to the improvement of quality of life as inherent and inviolable rights that must be shielded from any harmful interference. Additionally, Articles 16 and 17 enshrine the right to equality before the law and protection from degrading treatment—both of which are critical in the era of rapidly developing technologies. Thus, Indonesia's legal framework provides a solid constitutional and statutory foundation for the protection of human rights amid scientific progress.

In strengthening this foundation, however, Indonesia must confront the emerging complexities introduced by genetic technologies, which pose novel legal and ethical challenges beyond the scope of traditional human rights protections. Although existing constitutional and statutory provisions affirm fundamental rights such as privacy, equality, and human dignity, they do not yet provide explicit safeguards tailored to the sensitive nature of genetic information. The absence of clear regulatory standards for informed consent, data governance, and restrictions on genetic-based discrimination risks creating legal ambiguities that may undermine these constitutional guarantees. As genetic testing becomes more prevalent in healthcare, insurance, employment, and research, the need for specialized legislation that defines, protects, and supervises the use of genetic data becomes increasingly urgent. Therefore, the current legal framework-while normatively strong—requires proactive refinement to ensure that Indonesia remains capable of addressing the ethical implications and human rights risks associated with genetic innovation.

Among the most prominent human rights violations in the age of genetic technology is the infringement of the right to privacy, particularly regarding the handling of individual genetic/biological data (Cadizza et al., 2024). Genetic information is inherently sensitive, containing an individual's immutable biological identity (Rustan M et al., 2025). Individuals with genetic predispositions to certain conditions may face discrimination in access to healthcare, education, or employment opportunities (Gelinsky & Hilbeck, 2018). Therefore, comprehensive legal safeguards are indispensable to ensure that the development of genetic technology is pursued responsibly and with full respect for human rights. Human rights principles such as the right to privacy and freedom from discrimination must serve as the normative foundation for any application of advanced technologies (Nazar et al., 2022). Human rights protection in this context is not intended to hinder innovation, but rather to ensure that technological progress remains aligned with the preservation of human dignity (Nainggolan et al., 2024).

Although previous research has addressed various aspects of genetic technology, critical areas remain underexplored. For instance, a study by Yanju Chen examined the use of CRISPR techniques, revealing promising prospects in genetic therapy but raising complex ethical dilemmas (Chen et al., 2020). Karine Peschard and Shalini Randeria have analyzed how genetic technology applied to crop seeds has led to corporate monopolies that undermine farmers' rights (Peschard & Randeria, 2020). Jochen Menz compared legal approaches across different countries regarding the regulation of genetically modified crops (Menz et al., 2020). Meanwhile, Alex Hoose investigated the development of genetic technologies from the standpoint of legal and biosecurity challenges (Hoose et al., 2023).

This study holds substantial significance in identifying the latent threats to human rights posed by genetic technological advancements in Indonesia and proposes more comprehensive regulatory solutions. By adopting a more integrative legal approach, Indonesia can formulate policies that equitably balance technological progress with the protection of civil liberties. Nevertheless, this study faces certain limitations in empirically measuring the impact of regulations, largely due to the limited number of documented human rights violations in the application of genetic technologies in Indonesia. Furthermore, it is essential to account for the socio-cultural dimensions that may influence public acceptance of new regulations in this field.

This research focuses on examining two core issues: first, the potential for genetic privacy violations and genetic discrimination arising from the increasing use of genetic technologies, particularly in sectors such as healthcare, research, and insurance; and second, the legal and human rights challenges faced by Indonesia in regulating these technologies. The study highlights how the absence of explicit legal provisions governing genetic data, inadequate mechanisms for informed consent, and unclear data governance frameworks amplify the risks of privacy breaches and discriminatory practices. At the same time, Indonesia′ s current legal system—while providing general human rights protections-has not yet evolved to address the complex ethical and juridical implications posed by advancements in genetic science. This dual analysis underscores the urgent need for a robust, specialized regulatory framework to safeguard individual rights in the era of genetic innovation.

METHOD

This research adopts a normative legal methodology, which seeks to analyze and interpret the applicable legal norms governing the use of genetic technologies (Disemadi, 2022b). The study is grounded in two complementary approaches: the statutory approach, which involves examining legislation relevant to human rights and genetic data regulation—such as the 1945 Constitution of the Republic of Indonesia (UUD NRI 1945), Law No. 39 of 1999 on Human Rights, and Law No. 27 of 2022 on Personal Data Protection—and the conceptual approach, which utilizes contemporary legal scholarship to explore the theoretical and doctrinal underpinnings of emerging legal challenges (Tan, 2021).

The data analyzed in this study consist of secondary legal materials, including primary legal sources such as statutory texts, constitutional provisions, and government regulations. These were obtained through an extensive literature review, encompassing legal books, academic journal articles, and official documents. The collected data were then subjected to a qualitative descriptive analysis, identifying key legal themes and normative patterns within the existing legal framework (Marzuki, 2011). This method enables a critical and structured examination of how Indonesian law addresses the human rights implications of genetic technology development, while also offering insights into potential normative gaps and reform needs.

RESULTS AND DISCUSSION

The Potential for Genetic Privacy Violations and Genetic Discrimination Arising from the Use of Genetic Technologies

The development of genetic technologies encompasses a set of scientific methods for analyzing, modifying, and utilizing the genetic information of humans, animals, or plants for medical, forensic, and industrial purposes (Kerans, 2022). These technologies represent one of the most revolutionary achievements in modern science and technology, significantly impacting numerous facets of human life (Bilyaro et al., 2024). Breakthroughs in this field continue to open new opportunities across sectors. Global trends reveal a sharp rise in the adoption of genetic technologies. According to Grand View Research, the global market for genetic testing is projected to reach USD 11.71 billion in 2024 and grow substantially to USD 39.25 billion by 2030, at a CAGR of 22.5% (Grand View Research, 2025). Similar estimates are presented by Biospace, projecting a market size of USD 91.30 billion by 2034 (Nova Advisor, 2024). Other research firms, such as Mordor Intelligence, Global Market Insights, and Precedence Research, forecast varying but equally significant growth. Additionally, Research Nester anticipates the market will reach USD 73.99 billion by 2037, with the Asia-Pacific region contributing up to 36% of the global share (Research Nester, 2025). Public adoption of genetic testing is also rising rapidly; by 2025, over 40 million individuals worldwide are expected to have used at-home DNA testing kits, mainly for genealogy and preventive health (Levy, 2024). Data from MIT Technology Review and NCBI reported at least 26 million direct-to-consumer (DTC) genetic test users as of 2019 (Resnick, 2019), while KnowYourDNA estimated a current global user base of 38.5 to 50 million (Sandoval, 2024). In the U.S. alone, surveys indicate that 21% of adults have taken a home DNA test, and 27% have family members who have done so (Orth, 2022). These figures underscore the growing societal acceptance of genetic technology and its broad implications for both medical and social domains.

In Indonesia, genetic testing remains largely confined to research institutions rather than commercial clinical laboratories, rendering it limited in reach and accessibility. However, several foundational steps have been taken, such as a national program focusing on cancer genetics, indicating growing attention to the application of genomics in healthcare, particularly oncology (Illumina, 2023). Genetically inherited disorders remain a significant health challenge in Indonesia, as evidenced by an increase in infant mortality due to birth defects from 10.7% in 2010 to 12.5% in 2019. Despite this, the use of genetic testing in hospitals is still rare due to a lack of specialists, inadequate infrastructure, high costs, and limited public awareness (Hermanto et al., 2024). By 2025, Indonesia had begun utilizing polygenic risk scores (PRS) to predict disease risks based on multiple genetic factors—an early sign of precision medicine tailored to the genetic profile of the Indonesian population (Siswanto et al., 2025). However, alongside its immense benefits, genetic technology also raises significant legal and ethical concerns (Cadizza et al., 2024). Thus, while these technologies offer revolutionary medical solutions, their implementation must remain strictly guided by ethical and legal principles.

Table 1. Legal Framework Governing Genetic Technology in Indonesia

Regulation	Article	Content
Law No. 21 of 2004 on the Ratification of the Cartagena Protocol on Biosafety	Article 1	Enacts the Cartagena Protocol as part of Indonesia's national legal framework
	Article 2	Declares Indonesia's full adherence to all provisions of the Protocol, including the precautionary principle
	Article 10	Requires the establishment of a Biosafety Clearing House (BCH) for international exchange of biosafety data
	Article 17	Mandates consultation and information sharing among Parties on the use of Living Modified Organisms (LMOs) for food, feed, or environmental release
	Article 19	Obligates Parties (including Indonesia) to build scientific, technical, and institutional capacity for risk assessment and biosafety management
Presidential Regulation No. 39 of 2010 on the Biosafety Commission for Genetically Engineered Products	Article 1	Establishes the Biosafety Commission as a non-structural body reporting directly to the President
	Articles 2–4	Define the governance, location, and membership structure of the Commission
BPOM Regulation No. 19 of 2024 on Supervision of Genetically Engineered Food Products	Article 1	Defines terms such as food, genetic engineering, genetically modified products, genome editing, etc.
	Article 5	Requires safety approval for genetically modified food products
	Article 12	Regulates quality, nutrition, labeling, and advertisement of genetically engineered food

Source: Legal Materials/Secondary Data

Despite the presence of these regulatory instruments, Indonesia's legal framework still lacks comprehensive and technical provisions specifically addressing genetic technology usage. There is no clear regulation governing procedures for collecting, storing, utilizing, or sharing genetic data (Disemadi, 2022a). This regulatory gap opens the door to potential human rights violations—particularly regarding the right to privacy—such as unauthorized collection or coercive consent for DNA data use. At the same time, genetic information may be misused to discriminate against individuals in insurance, employment, or access to public services based on predisposed genetic risks. Both the right to privacy and freedom from discrimination are constitutionally protected rights under the 1945 Constitution (Armiwulan, 2015). The right to privacy extends beyond conventional personal data and includes highly sensitive genetic information (Ferianto et al., 2020). Such data can reveal a person's predisposition to inherited diseases, mental disorders, or other biological traits. Unfortunately, not all institutions handling this data apply the precautionary principle or adhere to strong data protection measures (Virginia, 2024). Consequently, there is a real risk of third-party misuse—by corporations, the state, or individuals—resulting in data breaches, unwarranted surveillance, or decisions made using genetic data without the subject's knowledge or consent (Lesle, 2015). If the State fails to protect this genetic information, it may amount to a constitutional rights violation, particularly the right to security and freedom from threats as stipulated in Article 28I(4) of the 1945 Constitution, which declares: "The protection, advancement, enforcement, and fulfillment of human rights are the responsibility of the state, especially the government."

The unauthorized storage, processing, and dissemination of genetic data without the informed and explicit consent of the individual concerned constitutes a potential violation of the right to personal protection (Indrayati, 2021). This right is explicitly guaranteed in Article 28G(1) of the 1945 Constitution of the Republic of Indonesia (UUD NRI 1945), which states: "Every person shall have the right to protection of self, family, honor, dignity, and property under their control, and shall have the right to security and protection from fear to do or not do something which is a human right." Further, Article 32(1) of Law No. 39 of 1999 on Human Rights (Human Rights Law) affirms: "The freedom and confidentiality of an individual's communication may not be disturbed, except by order of a court or other lawful authority under legislation." These provisions confirm that genetic information—being deeply personal and biologically identifying—falls within the scope of "confidential" data protected by law. Any use or collection of such data without proper consent amounts to a violation of the right to privacy. Article 29(1) of the same law also guarantees: "Every person has the right to the protection of self, family, honor, dignity, and property." As genetic data constitutes a form of personal property in the form of biological information, any misuse may qualify as a human rights violation.

The Personal Data Protection Law (Law No. 27 of 2022 – PDP Law) strengthens this protection. Article 4(a–b) grants every data subject the right to "protection of their personal data" and "the right to complete, update, or correct errors and inaccuracies in their data." Article 20(1) affirms that personal data processing must be based on valid consent from the data subject. Genetic data falls under the category of "specific personal data" per Article 58(2), requiring stricter safeguards. Article 65(1) stipulates criminal penalties for those who knowingly disclose personal data without lawful consent. Therefore, if genetic data is collected, analyzed, or shared by hospitals, laboratories, or biotechnology firms without explicit and informed consent, such actions not only violate the PDP Law but also contradict fundamental privacy protections under the Human Rights Law. Genetic data, as permanent biological identifiers, affects not only individuals but also their families and descendants. Its misuse thus raises serious legal consequences (Alifah, 2024).

In addition to privacy violations, the use of genetic technologies poses risks of discrimination, particularly when genetic information is used to differentiate treatment between individuals (Faqih et al., 2023). For example, people with a genetic predisposition to certain diseases may face discrimination in employment, healthcare, education, or insurance access (Aziz & Hidayah, 2020). Such practices directly violate Article 28I(2) of the 1945 Constitution, which guarantees: "Every person has the right to be free from discriminatory treatment on any basis and is entitled to protection from such treatment." Genetic-based discrimination represents a new form of injustice, and when conducted by the state or formal institutions, it becomes even more alarming (Mulyaningrum et al., 2023). Moreover, the misuse of genetic technologies can deepen social inequalities, fostering a society stratified by "ideal" genetic traits (Sutandar & Iqbal, 2022). This is not only inconsistent with social justice principles but also violates Article 28D(1) of the Constitution, which upholds: "Every person has the right to recognition, guarantees, protection, and legal certainty that is fair, and equal treatment before the law." Hence, the state bears the responsibility to prevent discriminatory practices in the application of genetic technology and to ensure that its use serves universal, inclusive human benefit, rather than functioning as a tool of exclusion. Without robust preventive measures, genetic technologies may ultimately undermine the core values of human rights enshrined in the Constitution (Cadizza et al., 2024).

This potential infringement is also addressed in Law No. 39 of 1999 on Human Rights, particularly Article 3(3), which affirms: "Every person has the right to the protection of human rights and fundamental freedoms without discrimination." This means that genetic information, as part of one's biological identity, must not be used as a basis for unequal treatment—such as denying jobs or insurance based on genetic predisposition. Furthermore, Article 4 of the Human Rights Law declares that the right to life, personal freedom, freedom of thought, religion, legal equality, and freedom from torture or retroactive legal enforcement are non-derogable. Thus, genetic discrimination may amount to a violation of these absolute rights—especially equality before the law.

In the context of the PDP Law, Article 4 affirms the right of data subjects to access and control their personal data. Article 13(1) prohibits the collection of personal data without valid consent, and Article 65 enforces criminal sanctions for its misuse. Since genetic data qualifies as specific personal data, it is entitled to the highest level of protection. Any use for commercial purposes or social filtering is thus in direct conflict with legal protections. Without stringent oversight, the misuse of genetic information could allow companies or institutions to manipulate or restrict access to rights and services, thereby violating both the non-discrimination principle under the Human Rights Law and data protection obligations under the PDP Law.

While both the Human Rights Law and the PDP Law provide a legal umbrella for addressing genetic privacy and discrimination concerns, they reveal certain structural weaknesses when applied to genetic-specific issues. The Human Rights Law remains general in nature, lacking explicit reference to genetic-based discrimination, while the PDP Law lacks detailed technical provisions on genetic data governance, including mechanisms for informed consent, strict limitations on secondary use, and clear prohibitions against discriminatory application. Although the PDP Law classifies genetic data under "specific personal data" alongside health data, it does not explicitly define "genetic" or "DNA information" as a distinctly protected category, leaving room for legal ambiguity. Additionally, Article 13 mandates consent for personal data processing but fails to set rigorous safeguards for genetic data, despite its permanence, familial impact, and complexity in anonymization (Nurnaeni & Bachri, 2025). As a result, there is a serious risk that genetic data may be treated similarly to general health data, despite its significantly higher sensitivity, complexity, and potential for misuse.

Reflecting on Article 3(3) of Law No. 39 of 1999 on Human Rights (Human Rights Law), the principle of non-discrimination is firmly stated: "Every person has the right to the protection of human rights and fundamental freedoms, without discrimination." Similarly, Article 4 emphasizes the right to be recognized as an individual and to equality before the law. However, the Human Rights Law remains highly general in scope and does not address specific issues such as genetic discrimination. It lacks detailed provisions clarifying how these rights are to be applied when genetic information is used in contexts such as employment recruitment, insurance eligibility, or access to public services. As a result, practices such as rejecting job applicants based on genetic predisposition to illness fall into a legal grey area, enforceable only through broad interpretations of the non-discrimination principle. The normative gap between the PDP Law and Human Rights Law—the former lacking explicit protection for genetic data, the latter silent on genetic-based discrimination—creates a legal loophole that could be exploited for commercial or discriminatory misuse of genetic information.

Table 2. Analysis of the Weaknesses in the Human Rights Law and PDP Law on Genetic Technology (Based on Progressive Legal Theory)

Regulation	Article	Provision	Weakness
Human Rights Law	Article 3(3)	Right to non-discrimination	General; does not mention genetic discrimination (not responsive to biotechnological risks)
	Article 4	Right to life, liberty, and equality before the law	No explicit prohibition of genetic discrimination (legal protection remains abstract)
Personal Data Protection Law	Article 4	Right to personal data protection	Does not explicitly mention genetic data (creates legal ambiguity)
	Article 13(1)	Consent for personal data processing	Provides only general consent; lacks specific mechanisms for genetic data processing

Source: Legal Materials/Secondary Data

According to Satjipto Rahardjo's Progressive Legal Theory, law should not be viewed merely as a normative text, but rather as a living and responsive instrument capable of addressing the evolving needs of society (Maruf & Harefa, 2023). When applied to the context of potential legal violations arising from genetic technology, it becomes evident that the Human Rights Law remains too static, lacking specific provisions on genetic information-based discrimination. Although Article 3(3) guarantees the right to non-discrimination and Article 4 emphasizes legal equality, these provisions fall short of being progressive norms that can adequately respond to emerging threats in the age of biotechnology (Faizal, 2016).

The PDP Law suffers from a parallel limitation—it fails to identify genetic data explicitly as a distinct and sensitive category requiring heightened protection. In practice, genetic information is far more sensitive than general health data: it is permanent, difficult to anonymize, and can affect not only the individual but also their descendants. Although Articles 4 and 13 grant data protection rights and stipulate consent requirements, their scope remains generic and underdeveloped. From a progressive legal standpoint, this illustrates the PDP Law's inability to accommodate techno-social developments, such as the growing use of DNA data in healthcare services, biotechnology research, and the insurance industry (Cadizza et al., 2024). Hence, the PDP Law cannot yet be considered a progressive legal framework, as it fails to provide concrete legal responses to the specific risks posed by genetic technology.

Both the Human Rights Law and the PDP Law appear to operate under a positivist legal paradigm, which prioritizes written legal certainty over substantive justice. In practice, this positivist rigidity leaves room for the abuse of genetic data by corporations or state institutions, such as in discriminatory employment or insurance decisions based on an individual's genetic profile. As Satjipto Rahardjo argued, the law must "serve humanity" and not merely rest within the confines of its text, but move dynamically with social changes (Tania et al., 2021). Both laws currently fall short of ensuring that the protection of genetic privacy is human-centered, and neither contains provisions that anticipate the modern risks of genetic privacy invasion and discrimination arising from technological advances. Therefore, a regulatory reform—either in the form of amendments or specific implementing regulations—is urgently needed to establish a legal framework that governs the collection, use, and sharing of genetic data. Such reform must ensure that the law functions as a genuine tool to protect human dignity in the midst of rapid technological and scientific transformation.

Legal and Human Rights Challenges in the Regulation of Genetic Technologies in Indonesia

The legal framework governing genetic technologies in Indonesia continues to face significant challenges—most notably, a regulatory vacuum. The Human Rights Law (Law No. 39 of 1999) contains only general provisions concerning fundamental rights, such as the right to non-discrimination and equality before the law, without explicitly prohibiting discrimination based on genetic characteristics. As a result, instances of genetic discrimination—such as denial of insurance or employment due to a person's genetic predisposition to certain illnesses—lack a clear legal basis for enforcement or redress (Bilyaro et al., 2024). On the other hand, while the Personal Data Protection Law (Law No. 27 of 2022) provides a framework for the protection of personal and sensitive data, it fails to categorically recognize genetic data as a uniquely sensitive category requiring enhanced safeguards. This omission is critical, given that genetic information is permanent, difficult to anonymize, and carries intergenerational implications. Such a legal gap opens the door to misuse—whether through unauthorized data leaks or decision-making based on DNA profiling without valid consent. Thus, the current regulatory framework remains overly general and insufficiently responsive to the ethical and legal challenges of modern biotechnology.

It is imperative to systematically integrate relevant human rights principles into Indonesia's legal approach to protecting individuals from the misuse of genetic technologies. The right to privacy must serve as a foundational principle, as genetic information is inherently personal, capable of revealing sensitive data such as health risks, ethnic origin, and behavioral tendencies (Bilyaro et al., 2024). Accordingly, the collection and use of genetic data must be governed by strict informed consent procedures and robust legal protection against misuse. Without stringent regulation, violations of genetic privacy may escalate into social discrimination or even criminalization based on genetic traits. The State bears an unequivocal duty to ensure that genetic confidentiality is safeguarded with at least the same rigor as medical data—if not more— given its enduring and far-reaching impact (Carundeng et al., 2022)

Furthermore, the principle of genetic non-discrimination is essential for maintaining social equality. The use of genetic information to determine a person's eligibility for employment, education, or insurance is a violation of human dignity (Indrayati, 2021) and risks creating new forms of social stratification. Legal protection against such discrimination must be codified, as exemplified by the Genetic Information Nondiscrimination Act (GINA) in the United States (Nainggolan et al., 2024). Indonesia must develop a similar legislative instrument to prevent the misuse of genetic technology in critical sectors.

Several core human rights principles must be integrated into the regulation of genetic technology. These include, individual autonomy, justice and mutual benefit, transparency and accountability, the precautionary principle, protection of vulnerable groups, social justice in access to technology, ecological sustainability, public participation, global solidarity, scientific responsibility, information disclosure, respect for diversity, and sustainable development (Muni, 2020). Autonomy must be the cornerstone of any genetic intervention—individuals have the right to self-determination over their genetic data, and informed consent must be an absolute requirement before any testing or research is conducted (Aziz & Hidayah, 2020). Without such consent, any genetic intervention constitutes a human rights violation (Cadizza et al., 2024).

Genetic technologies must deliver equitable benefits. Genetic research outcomes should not be monopolized by elites but must be distributed widely to promote distributive justice. Transparency and accountability are also essential. All genetic technology applications should be conducted openly and subject to independent oversight (Cadizza et al., 2024). Research results must be publicly accessible, and conflicts of interest must be disclosed to maintain public trust. Without transparency, misuse becomes inevitable.

The precautionary principle (Butarbutar, 2023) dictates that the use of genetic technologies must be preceded by rigorous risk assessments, especially for long-term individual and ecological consequences. Technologies like germline editing must be approached with strict limitations . Similarly, the protection of vulnerable groups—including children, persons with disabilities, and Indigenous communities—is non-negotiable. Genetic research involving these populations must involve additional layers of consent (Peiru & Alhakim, 2022). Indigenous peoples must retain the right to reject the collection of their genetic material to prevent exploitation.

Social justice in access to genetic technologies is also paramount. Expensive gene therapies must be subsidized for the economically disadvantaged, and diagnostic facilities must be distributed equitably across (Sutandar & Iqbal, 2022; Telaumbanua, 2015) Without this, genetic technologies will only serve the privileged. The ecological sustainability principle requires that agricultural genetic applications consider long-term environmental impacts. The release of genetically modified organisms must be tightly regulated to prevent biodiversity loss (Rusdianto et al., 2022).

Public participation is a vital democratic mechanism. Communities must be involved in policymaking on genetic issues through public forums and inclusive regulation processes (Angkat, 2015; Rustan M et al., 2025). Without this, policies may not reflect societal values. Moreover, scientific responsibility demands that all genetic applications adhere to the highest ethical standards (Muni, 2020). Breaches must be met with strict sanctions. Moral responsibility must never be sacrificed for scientific ambition.

Information transparency is critical to consumer rights. The public must have access to accurate information about genetic technologies (Carundeng et al., 2022). Misleading content must be curbed, and genetic literacy should be promoted through national education. In terms of global solidarity, genetic issues require international cooperation based on equity (Aziz & Hidayah, 2020). Developed countries have a duty to assist the capacity-building efforts of developing nations. Collaboration—not techno-nationalism—is the ethical path forward (Rustan M et al., 2025).

Finally, the principle of respect for genetic diversity underscores the ethical boundaries of genetic manipulation. Technologies must not be used to enforce genetic uniformity or pursue the creation of a so-called "superior human." Genetic uniqueness must be safeguarded as part of humanity's collective dignity (Sibarani, 2024). Practices akin to eugenics must be explicitly prohibited. Therefore, genetic technologies must be applied with long-term sustainability in mind. Regulation must reconcile innovation with ecological and human integrity, ensuring that technological advancement does not come at the cost of dignity or justice.

To address these legal deficiencies, several strategic measures are urgently needed: (1) The enactment of a dedicated regulatory framework that explicitly integrates human rights protections—particularly the rights to privacy and non-discrimination—across all sectors; (2) The establishment of an independent oversight body empowered to monitor genetic research and applications; (3) The enhancement of public legal awareness through education campaigns on genetic rights and data misuse risks; (4) The strengthening of law enforcement capacity to investigate and prosecute cases of genetic privacy violations and discrimination; and (5) The pursuit of international cooperation to adopt global ethical standards while simultaneously protecting national genetic sovereignty. Without these concrete steps, Indonesia risks falling behind in responding to the social and legal implications of genetic technologies—and failing to meet its constitutional and moral obligations to uphold human rights in the face of accelerating scientific innovation.

CONCLUSION

The advancement of genetic technologies in Indonesia presents tremendous opportunities across the health, agriculture, and biotechnology sectors. However, this progress also carries profound and pressing risks to human rights, particularly concerning violations of genetic privacy and the potential for discrimination based on genetic information. Genetic data, by its very nature, is highly sensitive and vulnerable to misuse if not governed by a strict and enforceable legal framework. While Indonesia has established foundational legal instruments such as the 1945 Constitution and Law No. 39 of 1999 on Human Rights, it lacks a specific, explicit, and comprehensive regulation dedicated to the protection of genetic data. This gap signals an urgent and unavoidable need to develop a legal system that is not only adaptive but also resolutely protective in the face of the challenges posed by genetic technology. This research concludes that the protection of human rights in the context of genetic technology must be anchored in fundamental legal principles, including the right to privacy, non-discrimination, informed consent, equitable access, and the precautionary principle. Strategic reforms are essential—ranging from the enactment of specialized legislation, the establishment of an independent oversight body, enhanced public education, and the strengthening of law enforcement capabilities. Moreover, international cooperation is critical to ensure that the use of genetic technology does not compromise national data sovereignty or individual dignity. Only through a comprehensive, rights-based, and integrative legal approach can Indonesia ensure that the rapid advancement of genetic technology aligns with the unwavering protection of the fundamental rights of all its citizens.

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