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Legal Perspectives on Genetic Data Ownership and Consent

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The rapid evolution of genetic technologies, particularly in genomics and personalised medicine, has given rise to complex legal and ethical issues regarding the ownership and consent of gene information. As genetic information becomes an increasingly valuable resource for research, healthcare, and commercial purposes, there are concerns that traditional legal doctrines are struggling to keep pace with the evolving issues of privacy, autonomy, and proprietary interests. This article critically analyses the legal boundaries surrounding the ownership of genetic information and the standards of informed consent in jurisdictions worldwide, with a focus on the Indian legal landscape in light of global developments. The core question centres on whether genetic data should be treated as personal property, a form of intellectual property, or as part of the common heritage of humanity. The paper explores existing legislative frameworks, such as the General Data Protection Regulation in the European Union.[1] The Health Insurance Portability and Accountability Act in the United States,[2] and the regulatory void in India, especially in the context of the Personal Data Protection Bill[3] and the draft Digital Information Security in Healthcare Act (DISHA).[4] It analyses court rulings on privacy and proprietary rights issues using classic court decisions like Moose v MGH and Puttaswamy v Union of India.[5] It also explores ethical issues regarding genetic surveillance, commercialisation, and the rights of indigenous people. Lastly, it supports a rights-based and consent-sensitive strategy that recognises the distinctive nature of genetic information and the need for rigorous legislative safeguards. In balancing and

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[1] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data (General Data Protection Regulation) [2016] OJ L119/1
[2] Health Insurance Portability and Accountability Act 1996
[3] Personal Data Protection Bill 2019
[4] Draft Digital Information Security in Healthcare Act 2018
[5] *Justice KS Puttaswamy (Retd) and Anr v Union of India and Ors* (2017) 10 SCC 1

reconciling individual freedom, public concern, and scientific progress, this study finds a way to fair and enforceable terms for the regulation of genetic information in the age of digital technology.

Keywords: *genetic data ownership, informed consent, data privacy, legal frameworks in genomics.*

INTRODUCTION

The twenty-first century has witnessed a historically unprecedented boom in the gathering, analysing, and commercialising of genetic information. Human genome mapping and its follow-up technological innovations have transformed our health, disease, identity, and knowledge.[6] Genetic information is, therefore, now at the intersection of science, commerce, and human rights, raising intricate legal questions of ownership of such information and on what terms it can be used. In contrast to other types of personal data, genetic data is embedded biologically, uniquely identifiable, closely linked with the individual and their relatives, and occasionally with entire groups.[7] The stakes for its ownership and consent are, therefore, extremely high.

Genetic information means the data collected from a person's DNA, which contains the blueprint for all biological functions. It can reveal suspicion of disease, physical traits, and behavioural tendencies.[8] The possibility of extracting such personal data has made genetic information highly desirable to many players, including pharmaceutical companies, research institutions, insurers, and government agencies. However, overriding crises over privacy, discrimination, consent, and exploitation offset the data's worth.[9] In this context, legal systems across the globe are being asked to define the scope and nature of genetic data

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[6] Eric T Juengst, 'Self-Critical Federal Science? The Ethics Experiment within the U.S. Human Genome Project' (1996) 13(2) Social Philosophy and Policy <https://doi.org/10.1017/S0265052500003460> accessed 01 June 2025

[7] Bartha Maria Knoppers and Ruth Chadwick, 'Human Genetic Research: Emerging Trends in Ethics' (2005) 6(1) Nature Reviews Genetics 75 <https://doi.org/10.1038/nrg1505> accessed 01 June 2025

[8] 'Genomic Data Sharing Policy' (*National Human Genome Research Institute*) <https://www.genome.gov/about-genomics/policy-issues/Genomic-Data-Sharing> accessed 22 May 2025

[9] Sonia M Suter, 'Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy' (2004) 72(4) George Washington Law Review 737 <https://pubmed.ncbi.nlm.nih.gov/16506342/> accessed 01 June 2025

ownership, the standards for informed consent, and the rights of a person in controlling the use and dissemination of their genetic material.[10]

This article attempts to define the legal issues of ownership of genetic information and consent in detail. It begins by recognising the nature and uniqueness of genetic information. It persists by drafting theoretical and jurisprudential underpinnings of ownership claims, either established on property law, intellectual property, or personal autonomy. The article analyses statutory frameworks such as the European Union's General Data Protection Regulation,[11] the United States' Health Insurance Portability and Accountability Act,[12] India's proposed Digital Personal Data Protection Act and DISHA.[13] It also draws upon landmark judicial pronouncements like Justice K.S. Puttaswamy (Retd.) v Union of India (2017),[14] the Indian Supreme Court affirmed the fundamental right under Article 21 of the Constitution, which is the right to privacy, offering a constitutional basis for genetic data protection.

In addition, the article deals with the ethical and social dimensions of genetic data gathering, such as its effects on indigenous groups, the potential for genetic surveillance, and the commodification of human biological information. Given the rise of direct-to-consumer genetic testing services such as 23andMe and AncestryDNA, people tend to relinquish control of their genetic information anonymously in return for personalised reports, posing questions regarding the sufficiency of consent processes in commercial contexts. These advances require establishing a syncretic legal framework that identifies the double character of genetic data as highly private and scientifically valuable.

The Indian debate regarding genetic information is nascent, with no all-encompassing legislation regulating its ownership or consent mechanism. Existing regulations are scattered and insufficient, creating a legal vacuum that leaves individuals vulnerable to misuse. The more recent Digital Personal Data Protection Act, 2023 and the earlier draft Personal Data Protection Bill, 2019, are early efforts at a regime for regulation.[15] They are, however, short of meeting the special intricacies of genetic data. Additionally, the envisaged DISHA

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[10] Graeme Laurie et al., *Genomic Research and Biobanks: Legal and Governance Issues* (CUP 2020)

[11] General Data Protection Regulation 2016

[12] Health Insurance Portability and Accountability Act 1996

[13] The Digital Personal Data Protection Act, 2023 and Draft Digital Information Security in Healthcare Act 2018

[14] *Justice KS Puttaswamy (Retd) and Anr v Union of India and Ors* (2017) 10 SCC 1

[15] Personal Data Protection Bill 2019

framework for the regulation of personalised digital health data continues to be in draft and has not been promulgated as law.[16]

Against this background, the core argument of this article is that any pragmatic legal regime for recognition needs to be grounded in a rights-based approach that puts individual autonomy, informed consent, and distributive justice at the forefront. Genetic data cannot be thought of purely in terms of property rights. Nevertheless, it must also consider identity, family implications, and collective interests. Consent mechanisms must be strong, dynamic, and context-dependent, understanding the dynamic nature of data utilised in research and business contexts.

This article is written in the following structure: Part II explains the definition of genetic data and its scientific, legal, and ethical idiosyncrasies. Part III analyses the different legal theories and models regarding the ownership of genetic data. Part IV concerns comparative legal regimes across jurisdictions, namely GDPR, HIPAA, and Indian legislative proposals. Part V discusses judicial trends and landmark cases defining the legal meaning of consent and ownership. Part VI addresses ethical issues regarding vulnerable groups and the commodification of data. Part VII suggests recommendations for a holistic, consent-based legal system specific to the Indian context, and Part VIII ends with a look at the future of genetic data regulation.

UNDERSTANDING GENETIC DATA: SCIENTIFIC AND LEGAL DIMENSIONS

The legal discussion regarding genetic data ownership and consent needs to start by defining genetic data, why it is intrinsically different from other types of personal data, and how its particular nature affects legal interpretation and regulation. Genetic data refers to any information concerning the inherited or acquired genetic traits of a natural person that provides specific information regarding the physiology or health of such person and which arises, specifically, due to an examination of a biological specimen of the concerned person.[17]

Legal Definitions of Genetic Data: At its core, genetic data is derived from deoxyribonucleic acid (DNA), the molecular blueprint that dictates biological structure and function in all living organisms. Each human carries approximately 3 billion base pairs of DNA, which

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[16] Draft Digital Information Security in Healthcare Act 2018

[17] General Data Protection Regulation 2016, art 4(13)

determines a range of traits from the colour of the eye to susceptibility to certain diseases.[18] The Human Genome Project (HGP), which concluded in 2003, planned the entire sequence of the human genome, allowing researchers to identify the genetic basis of numerous conditions and traits.[19] This development has opened new frontiers in personalised medicine, forensic science, and ancestry research.[20]

Its immutability and shared nature set genetic data apart from other forms of personal information. Unlike passwords or financial data, genetic information cannot be changed, and it inherently implicates not just the individual but their blood relatives and, in some cases, entire ethnic or geographical communities. This interconnectedness introduces a collective dimension to what is typically treated as an individual right in data protection law.[21]

Legal Definitions and Classifications: Different legal frameworks classify genetic information differently, based on their legislative objectives. For example, the EU GDPR classifies genetic information categorically under the special category of personal information under Article 9, which is afforded more protection due to its sensitive nature. According to the GDPR, genetic data is confidential data relating to the inherited or obtained genetic characteristics of a natural person, which gives uncommon information about the physiology or the health of that natural person (GDPR, art 4(13)). Similarly, under the United States' Genetic Information Non-discrimination Act (GINA), genetic data encompasses information about a person's genetic tests, the genetic tests of the family members, and the incidence of a disease or disorder in family members.

In the Indian context, however, there is no explicit statutory definition of genetic data. The draft Personal Data Protection Bill, 2019, now superseded by the Digital Personal Data Protection Act, 2023, includes sensitive personal data, which can reasonably be interpreted to encompass genetic information but does not provide a categorical definition. The draft DISHA Bill attempts a more targeted approach by referring to digital health data, which includes physical and mental health information. Still, he lacks a clear delineation of genetic information as a distinct category.

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[18] Bruce Alberts et al., *Molecular Biology of the Cell* (6th edn, Garland Science 2014) ch 4

[19] Francis S Collins et al., 'Finishing the euchromatic sequence of the human genome' (2004) 431 Nature 931

[20] 'The Human Genome Project' (*National Human Genome Research Institute*) <https://www.genome.gov/human-genome-project> accessed 21 May 2025

[21] Graeme Laurie, *Genetic Privacy: A Challenge to Medico-Legal Norms* (CUP 2002)

CHARACTERISTICS THAT COMPLICATE OWNERSHIP AND CONSENT

Several intrinsic features of genetic data complicate its governance within existing legal paradigms:

Permanence and Immutability: As soon as genetic data are gained and sequenced, they do not change throughout one's life. This stability makes it easier to abuse and increases the stakes for protecting data.[22]

Identifiability: Genetic data can uniquely identify individuals, even from anonymised data. Studies have demonstrated that individuals can be re-identified from aggregated genomic data by correlating it with publicly available information, undermining privacy assurances.[23]

Familial and Collective Nature: One person's genetic data reveals information about their relatives and, by extension, about entire communities. This challenges the individualistic foundation of most consent models and raises questions about communal rights over genetic information.[24]

Value for Research and Commerce: Genetic data is valuable for pharmaceutical companies, data brokers, and researchers. The ability to link genetic data with health records and behavioural data provides powerful insights for drug development and introduces ethical concerns about commodification and exploitation.[25]

Asymmetry of Knowledge and Power: People are usually not well-equipped with the technical acumen to grasp the consequences of sharing their genetic information. An imbalance like this compromises the principle of informed consent, particularly in cases such as direct-to-consumer genetic testing, where commercial interests can dominate ethical considerations.[26]

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[22] Mark A Rothstein, 'Is De-Identification Sufficient to Protect Health Privacy in Research?' (2010) 10(9) American Journal of Bioethics 3

[23] Yaniv Erlich and Arvind Narayanan, 'Routes for Breaching and Protecting Genetic Privacy' (2014) 15(6) Nature Reviews Genetics 409 <https://www.nature.com/articles/nrg3723> accessed 01 June 2025

[24] Laurie (n 21)

[25] Roger Brownsword and Han Somsen, 'Law, Innovation and Technology: Before We Fast Forward – A Forum for Debate' (2009) 1(1) Law, Innovation and Technology <https://doi.org/10.1080/17579961.2009.11428364> accessed 01 June 2025

[26] Sarah Chan, 'More than Cautionary Tales: The Role of Fiction in Bioethics' (2009) 35(7) Journal of Healthcare Ethics <https://doi.org/10.1136/jme.2009.031252> accessed 01 June 2025

INTERSECTION WITH OTHER LEGAL CONCEPTS

Genetic data operates at the intersection of multiple legal domains, including privacy law, property law, bioethics, and human rights. Whether an individual has a property right over their genetic data, whether it is a manifestation of their personhood, or whether it should be treated as part of the commons are questions that significantly affect the regulatory approach.

In privacy law, particularly following the landmark case of Justice K.S. Puttaswamy (Retd.) v Union of India, the Indian Supreme Court under Article 21 of the Constitution recognised the right to privacy as a fundamental right. This decision laid a constitutional foundation for protecting genetic data, arguably the most intimate personal information. The judgment emphasised informational privacy and decisional autonomy, both of which are major in the context of genetic data.

From the property law standpoint, no uniform global consensus exists on whether individuals own their genetic data. Some argue that since individuals generate the data, they have a proprietary claim akin to intellectual property rights. Others assert that once de-identified and used for research, data becomes a resource that should be governed by public interest considerations rather than private ownership.[27]

THEORETICAL FOUNDATIONS OF GENETIC DATA OWNERSHIP

The issue of ownership of genetic information is legal, philosophical, and ethical. While the common law tradition tends to look for simplicity through contract and property rights, genetic information defies such easy classification. Ownership claims over genetic data invite a deeper inquiry into its unique characteristics, the interests of individuals and society, and the appropriate limits of commodification. In this section, we explore the major theoretical models that have been invoked to conceptualise ownership of genetic data, namely, the property-based model, the personality or autonomy-based model, and the public trust or common heritage model.

Property-Based Model: The property model treats genetic data as a form of intangible property, akin to intellectual property. Proponents of this approach argue that since genetic

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[27] Barbara Prainsack, 'The "We" in the "Me": Solidarity and Health Care in the Era of Personalised Medicine' (2018) 43(1) Science, Technology, & Human Values <https://www.jstor.org/stable/26580368> accessed 01 June 2025

data is generated from an individual's biological material, that individual should have ownership rights similar to those over tangible property. This model is appealing in commercial and contractual contexts, especially in the biobanking industry or when individuals provide biological samples to research institutions or companies.

Supporters often draw analogies to intellectual property law, where creators or originators of knowledge have proprietary rights over their creations. Under this logic, the genetic data derived from an individual's DNA should belong to them and require their consent for any subsequent use. A notable illustration of this argument can be found in Moore v Regents of the University of California, where the California Supreme Court held that individuals do not retain property rights over their cells once removed, even if those cells are later used for profitable scientific research.[28] While the court refused the claim on property, the case initiated a worldwide discussion concerning the rights of people over their biological tissue and the profits derived therefrom.

The commodification of genetic data has been critically examined by many scholars who warn against treating human biological materials as marketable assets. In her theory of market-inalienability, Margaret Radin argues that specific aspects of personhood, such as bodily integrity and genetic identity, should not be commodified. She believes that commodifying some aspects can lead to dehumanisation and moral damage. In like manner, Michael Sandel criticises the expansion of market values into spheres previously driven by ethical or civic reasons. He cautions against commodification, weakening the moral fabric of society. In biomedicine, scholars like Donna Dickenson challenge the idea of genetic information as property, arguing that viewing genes this way undermines collective interests and erodes principles of solidarity and justice. Genetic information, where the rights of the individual, commercial interests, and public goods tend to enter into conflict.

But the imposition of property law on genetic information poses some challenges. First, genetic data is not merely a product of an individual's body; it is also shared with relatives and communities, complicating the identification of a single owner.[29] Second, property rights are often alienable and transferable, while rights over one's genetic identity arguably should

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[28] *Moore v Regents of the University of California* [1990] 793 P 2d 479 (Cal)

[29] Laurie (n 21)

not be. Third, treating genetic data as property risks commodifying human identity, leading to ethical concerns about consent, exploitation, and inequality.[30]

Autonomy and Personality-Based Model: A second model centres around individual autonomy and the protection of one's identity instead of ownership per se. This model is informed by the philosophical ideas of Hegel and Kant, who interpreted personhood as always being tied to having dominion over one's body and self. In the legal domain, this is reflected in the doctrine of informational self-determination, the right of individuals to control the collection, use, and dissemination of their personal information.

This model gained judicial recognition in Justice K.S. Puttaswamy (Retd.) v Union of India,[31] the Indian Supreme Court explicitly linked privacy to individual dignity, liberty, and autonomy. Applying this to genetic data implies that individuals have a right to decide who can access their genetic information, how it can be used, and for what purposes. Notably, this right continues even after the data has been disclosed, requiring provisions for continuous consent, revocation of consent, and minimisation of data.

The autonomy model sidesteps the traps of commodification while reasserting the primacy of consent. It acknowledges that genetic information, in contrast to other forms of property, is inherently embedded in the identity, family, and future decisions of the individual. But this model also poses practical difficulties, especially in situations such as biobanking or research, where dynamic, informed consent for each new purpose of genetic data is practically cumbersome.

Public Trust and Common Heritage Model: A third approach treats genetic data, especially in anonymised and aggregated forms, as a public resource that should be governed in the interest of society. This model is often invoked in public health and scientific research contexts, where data sharing can yield significant social benefits. For example, genomic research on cancer or rare diseases requires large datasets that can only be obtained through the collective contributions of genetic data.

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[30] Susanne B. Haga and Laura M. Beskow, 'Ethical, Legal, and Social Implications of Biobanks for Genetics Research' (2008) 60 Advances in Genetics <http://dx.doi.org/10.1016/S0065-2660(07)00418-X> accessed 01 June 2025

[31] *Justice K.S. Puttaswamy (Retd.) v Union of India* (2017) 10 SCC 1

Proponents argue that treating genetic data as a public good facilitates equitable access, collaborative research, and global health benefits. This perspective is echoed in the UNESCO Universal Declaration on the Human Genome and Human Rights (UDHGHR) (1997), which defines the human genome as the heritage of humanity. Here, no one or entity can assert sole proprietorship over genetic information that inherently pertains to everyone and all alike.

Yet, the model of public trust has to be well-balanced with civil liberties. There is a risk that extending privilege to the public interest would desecrate privacy rights, especially where there is unclear or lacking consent. Moreover, minority groups will be disproportionately harmed from data exploitation with little benefit conferred, serving to perpetuate already present inequalities. Therefore, even within a public trust framework, principles of fairness, transparency, and community participation must be rigorously upheld.

Towards a Hybrid Approach: Given the limitations of each respective model, legal scholars increasingly advocate for a hybrid framework that incorporates elements of property, autonomy, and public trust. Such a framework would acknowledge the individual's right to control access to their genetic data (autonomy), allow for limited proprietary claims in commercial contexts (property), and encourage data sharing for legitimate public purposes under stringent safeguards (public trust).

For example, in the case of genomic studies, a hybrid model might mandate general but educated consent for data use, allow for specific commercial uses under licensing agreements, and provide for data governance structures that have representatives from impacted communities. This would be seen as an adequate reflection of the complicated nature of genetic information and the multiple interests involved.

COMPARATIVE LEGAL FRAMEWORKS ON GENETIC DATA: EU, US, AND INDIA

It is imperative to know how various jurisdictions go about regulating genetic data to assess the efficacy of prevailing legal regimes and arrive at best practices. The European Union (EU), the United States (US), and India have different paradigms of legal regulation along these lines, based on their respective constitutional ideologies, policy agendas, and historical backgrounds. This section explores the regulatory frameworks governing genetic data in these three regions, focusing on issues of ownership, consent, privacy, and enforcement.

European Union: The GDPR's Robust Regime: The EU has possibly the most elaborate data protection legal system anywhere in the world, enshrined in the General Data Protection Regulation that took effect in May 2018. The genetic information is categorised by GDPR as a special category of personal data under Article 9(1) and so demands special protection for its processing.[32] Informed, specific, and freely given consent is a cornerstone in legal processing under the regulation and also confers strong rights over personal data on individuals.

Definition and Scope: Under Article 4(13) of the GDPR, genetic data is defined 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.[33]

This broad definition covers a wide range of genetic materials, including DNA, RNA, and even epigenetic markers.

Consent Mechanisms: The GDPR says that consent must be free, specific, informed, and unambiguous (Art 7). For sensitive data such as genetic information, explicit consent is required. Moreover, data subjects must be allowed to withdraw consent at any time, and such withdrawal must be as easy as giving it.[34]

The regulation also gives the concept of data minimisation (Art 5(1)(c)), which requires that only data essential for the intended purpose should be collected, thus limiting unnecessary exposure of genetic information.

Rights of Data Subjects –

The GDPR provides data subjects with a range of rights that are particularly relevant to genetic data:

Right to Access: Individuals can obtain information about whether and how their genetic data is being used.[35]

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[32] General Data Protection Regulation 2016, art 9(1)

[33] General Data Protection Regulation 2016, art 4(13)

[34] General Data Protection Regulation 2016, art 7

[35] General Data Protection Regulation 2016, art 15

Right to Erasure (Right to be Forgotten): Under certain conditions, individuals can request the deletion of their data.[36]

Right to Data Portability: Individuals can request their data in a machine-readable format to transfer it elsewhere.[37]

Right to Object: Individuals can object to processing based on public interest or legitimate interest grounds.[38]

Despite its strengths, the GDPR has limitations when applied to communal or familial aspects of genetic data, as it is primarily centred on individual rights.

United States: Fragmented and Sectoral Approach: Unlike the EU's unified framework, the US legal system adopts a sector-specific approach to data protection. While there is no single federal law that governs genetic data across all contexts, several statutes provide partial protections.

HIPAA and Genetic Information: The Health Insurance Portability and Accountability Act (HIPAA), 1996, governs the disclosure and use of protected health information (PHI) by covered entities like insurance firms and hospitals. In 2013, the HIPAA Privacy Rule was modified to incorporate genetic information into the definition of PHI, thereby providing privacy protections for genetic information in health care settings.

However, HIPAA applies only to entities that fall within its regulatory ambit and does not cover data collected by direct-to-consumer genetic testing companies such as 23andMe or AncestryDNA, unless they engage in activities falling within the healthcare domain.[39]

Genetic Information Non-discrimination Act (GINA): Signed into law in 2008, GINA forbids genetic information discrimination in employment and health insurance. GINA's definition of genetic information is sweeping, encompassing genetic tests and family medical

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[36] General Data Protection Regulation 2016, art 17

[37] General Data Protection Regulation 2016, art 20

[38] General Data Protection Regulation 2016, art 21

[39] 'Summary of the HIPAA Privacy Rule' (*U.S. Department of Health and Human Services*) <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html> accessed 22 May 2025

history. Yet GINA does not cover life, disability, or long-term care insurance, which leaves large holes in protection.[40]

Consent and Ownership: US law generally does not treat genetic data as the property of the individual. In Moore v Regents of the University of California (1990), the court ruled that once cells are removed from an individual's body, they no longer retain property rights over them.[41] Consent is treated more as a contractual agreement than a fundamental right, and enforcement mechanisms vary widely depending on the sector. The absence of a federal law comparable to the GDPR means that individuals in the US lack a consistent, enforceable right to control their genetic data across all contexts.[42]

India: A Fragmented Legal Landscape in Transition: India currently lacks a comprehensive legislative framework explicitly governing genetic data. However, several developments in privacy law and draft legislation indicate a growing recognition of the need for stronger protections.

The Puttaswamy Judgment and Privacy Rights: In Justice K.S. Puttaswamy (Retd.) v Union of India, a 9-judge bench of the SC unanimously held that under Article 21 of the Constitution, the right to privacy is a fundamental right. The judgment includes a strong articulation of informational privacy, laying the groundwork for future legislation on genetic data protection.

Digital Personal Data Protection Act, 2023: The DPDP Act, enacted in 2023, is a landmark towards the regulation of data in India. Though it does not classify genetic data categorically, it does make the sensitive personal data a concept and has provisions for consent, data minimisation, limitation of purpose, and individual rights. Key features relevant to genetic data include:

1. Consent must be informed, specific, and freely given.
2. Data principals have the right to access, correct, and erase their data.
3. Data fiduciaries are obligated to process data fairly and lawfully.

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[40] U=The Genetic Information Non-Discrimination Act 2008

[41] *Moore v Regents of the University of California* [1990] 793 P 2d 479 (Cal SC)

[42] Andrew D Selbst and Solon Barocas, 'The Intuitive Appeal of Explainable Machines' (2018) 87(3) Fordham Law Review 1085, 1104 <https://ir.lawnet.fordham.edu/cgi/viewcontent.cgi?article=5569&context=flr> accessed 01 June 2025

However, the Act lacks sector-specific rules for health and genetic data, and many operational details are left to be prescribed by future rules and regulations.

DISHA (Digital Information Security in Healthcare Act): DISHA, while still a draft, attempts to create a paradigm for the secure transmission and preservation of digital health information. It makes a broad sweep and makes provisions regarding consent, access, and sharing of information. Encouraging as the draft is, it has yet to be legislated, and there is a legislative lacuna in the meantime.

The Digital Information Security in Healthcare Act (DISHA) was drafted and released for public consultation in March 2018 by the Indian Ministry of Health and Family Welfare. However, this 2018 version has not been enacted, and to date, it has not been re-tabled in Parliament or formally revived in any legislative session. In practical terms, DISHA has lapsed and remains inactive, with no further progress since the initial draft stage.

Comparative Insights: The EU's GDPR provides the strongest and most integrated architecture for genetic data protection, based on personal rights and informed consent.[43] The US system, although progressive in some areas, is plagued by fragmentation and sectoral constraints. India is at a legislative juncture: with a strong constitutional foundation of privacy and developing legal tools, India can create a framework of rights-based instruments specific to its socio-cultural and technological environment.[44]

JUDICIAL TRENDS AND INTERPRETATIONS: CONSENT AND PRIVACY IN CASE LAW

Judicial rulings in the jurisdictions have had a great impact on the legal understanding of ownership and consent in genetic information. The courts are best positioned to describe the boundaries of informational privacy, bodily autonomy, and the acceptability of data use without overt individual ownership. This section analyses notable decisions from India, the United States, and the European Union to illustrate evolving judicial thought and its implications for genetic data governance.

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[43] Dr. Orla Lynskey, *The Foundations of EU Data Protection Law* (OUP 2015) 211–50

[44] *Justice K.S. Puttaswamy (Retd) v Union of India* (2017) 10 SCC 1

India: Expanding the Scope of Privacy –

Justice K.S. Puttaswamy (Retd.) v Union of India:[45] This path-breaking judgment of the Indian Supreme Court interpreted the right of privacy under Article 21 of the Constitution as a constitutional right. The judgment labelled informational privacy as a fundamental part of freedom of the individual, noting that privacy of private information is cardinal to the autonomy and dignity of the individual. Although the case did not specifically involve genetic data, its reasoning laid the constitutional foundation for privacy claims relating to biometric and genetic information.[46]

The Court acknowledged that informational privacy includes a person's right to control the dissemination of personal data. Justice Chandrachud's opinion emphasised that privacy is not surrendered merely by sharing data with another entity, and that consent must be meaningful, informed, and capable of being withdrawn. This doctrine has wide implications for genetic data, which is inherently sensitive and often collected by third parties for purposes beyond the individual's understanding or immediate control.

District Registrar and Collector, Hyderabad v Canara Bank:[47] Although ruled before Puttaswamy, this ruling also upheld informational privacy under Article 21. The Court held that unauthorised access to personal files by the State without permission infringes on the right to privacy. About genetic information, this supports strict procedural protections before state or private entities access a person's genetic information.

United States: Property versus Privacy –

Moore v Regents of the University of California:[48] This widely cited case involved a patient, John Moore, whose spleen cells were used to develop a patented cell line without his knowledge. Moore sued for property rights over the cells and the profits derived therefrom. The California Supreme Court rejected his property claim but acknowledged a breach of fiduciary duty and a failure to obtain informed consent.

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[45] *Justice K.S. Puttaswamy (Retd) v Union of India* (2017) 10 SCC 1

[46] Anupam Chander, 'The Racist Algorithm?' (2017) 115(6) Michigan Law Review 1023, 1042

[47] *District Registrar and Collector, Hyderabad v Canara Bank* (2005) 1 SCC 496

[48] *Moore v Regents of the University of California* [1990] 793 P 2d 479 (Cal)

Although the court overturned ownership in the conventional sense, it emphasised the necessity of informed consent in biomedical settings. This case has influenced bioethical arguments, meaning that people do not own their genetic tissues once they have been removed from their bodies, but do own how things are done to them.

United States v Kincade:[49] Here, the court validated the constitutionality of storing and collecting DNA samples from parolees according to the Fourth Amendment. Although the court favoured law enforcement concerns, the dissent cautioned against genetic monitoring and abuse of state authority. This decision reflects the US courts' willingness to allow exceptions to genetic privacy in specific contexts, especially where public safety is involved.

European Union: Emphasis on Autonomy and Consent –

Nowak v Data Protection Commissioner Case:[50] In this CJEU case, the Court believed that answers provided during a professional examination and comments of examiners thereon constituted personal data. Not being per se genetic data, this broad definition of personal data under the GDPR reiterates that any data that identifies or pertains to a person must enjoy legal protection. Implying, genetic data, being inherently traceable, falls under the purview of GDPR protection and therefore requires high levels of consent, transparency, and accountability in its collection and use.

Catt v United Kingdom:[51] In this case, the European Court of Human Rights examined the retention of data by the police and reiterated that individuals have the right to know how their data is being used, especially when it is retained without their consent. Though not directly related to genetic data, this jurisprudence supports the view that consent is not just procedural but a substantive right grounded in personal autonomy.

KEY TAKEAWAYS FROM COMPARATIVE JURISPRUDENCE

India has made significant strides post-Puttaswamy in recognising the primacy of individual consent and informational privacy. However, judicial application to genetic data remains indirect and interpretive.

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[49] *United States v Kincade* [2004] 379 F.3d 813 (9th Cir.)

[50] *Nowak v Data Protection Commissioner* Case C-434/16, EU:C:2017:994

[51] *Catt v United Kingdom* [2019] ECHR 76

The United States, despite its constitutional protections, tends to favour institutional and commercial interests, especially in cases involving research or public safety, and has refrained from recognising property rights in genetic data.

European Courts have shown the most commitment to autonomy and consent, handling genetic information as a very sensitive type of personal data with related rights and protections under the GDPR.

Together, these decisions reveal a global judicial trajectory that, while diverse in approach, is moving toward a greater recognition of individual rights over personal and genetic information. Courts are increasingly aware of the complex ethical, legal, and social dimensions involved in the collection and use of genetic data, although legislative clarity still lags.

The policy vacuum around genetic information in India tends to represent two kinds of regulatory orientations. Firstly, the denial of ownership suggests that individuals do not retain proprietary rights over their genetic data, viewing such information rather as being within the commons or a shared good, particularly in the context of public health or research. This stance eschews market-based management by anti-commodification critiques.

Conversely, acknowledging failure of consent emphasises the insufficiency of current mechanisms of consent, whereby people tend to consent to data use without comprehensively appreciating the extent, risks, or prospective utilisation. This is not necessarily denying ownership but suggests that the presently designed consent does not guarantee authentic autonomy or protection of data. So, the issue is not so much who the owner of genetic information is, but rather if the legal infrastructure of consent is strong enough to secure individual rights in an age of widespread genomic data exchange.

ETHICAL AND PHILOSOPHICAL DIMENSIONS OF GENETIC DATA CONSENT

The issue of ownership of genetic data and consent cannot be moved to the limits of the legal establishment. Ethical thinking must provide the base for legislation and policies, particularly where scientific developments outrun legislation and regulations. Consent in genetic data is not a ritual process but an ethical obligation to respect the autonomy, dignity, and trust of the individual. Philosophical underpinnings of consent, subtleties in the genomic setting, and ethical issues faced in practice are the matters of discussion in this section.

The Moral Basis of Consent: Autonomy and Dignity: At the heart of modern bioethics lies the autonomy principle, according to which individuals can make informed decisions on issues based on their lives and bodies. Grounded in Kantian ethics, this principle states that every individual is an end in themselves and should never be treated as a means to an end.[52] Informed consent makes this ideal a reality in medicine and research, allowing people to have a say in the intervention on them.[53] Genetic information, as a type of personal data from the body, engages autonomy fundamentally. It discloses not only the present health state, but also future risk, familial features, and possible predispositions. As such, informed consent in this realm must ensure that individuals understand the breadth of what they are consenting to, including possible future uses, risks of re-identification, and implications for family members. Anything less undermines both the ethical and legal validity of consent.[54]

Further, the principle of dignity supports a robust consent framework. Human dignity is undermined when people are used as sources of data without active voice in how their genetic information is utilised. Therefore, consent is more than a safeguard; it is a realisation of the person's moral value and autonomy.[55]

CHALLENGES IN OBTAINING GENUINE INFORMED CONSENT

Despite its centrality, genuine informed consent is difficult to achieve in the context of genetic data for several reasons:

Complexity of Information: Genomic science is necessarily technical. Even highly educated individuals may not have the specialist knowledge that they need to appreciate what it is that they are agreeing to regarding the gathering and utilisation of genetic information. This

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[52] Immanuel Kant et al., *Groundwork of the Metaphysics of Morals* (OUP 2019); Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* (7th edn, OUP 2012)

[53] Ruth R. Faden and Tom L. Beauchamp, *A History and Theory of Informed Consent* (OUP 1986) 15–20; Tom L Beauchamp, 'Informed Consent: Its History, Meaning, and Present Challenges' (2011) 20(4) Cambridge Quarterly of Healthcare Ethics <https://doi.org/10.1017/s0963180111000259> accessed 01 June 2025

[54] Ellen Wright Clayton et al., 'The law of genetic privacy: applications, implications, and limitations' (2019) 6(1) Journal of Law and the Biosciences <https://doi.org/10.1093/jlb/lsz007> accessed 01 June 2025

[55] Ruth Macklin, 'Dignity Is a Useless Concept: It Means No More Than Respect for Persons or Their Autonomy' (2003) 327 British Medical Journal 1436 <https://doi.org/10.1136/bmj.327.7429.1419> accessed 01 June 2025

establishes a knowledge asymmetry between the data subject and the data controller, which can cause consent to be uninformed in substance.[56]

Unforeseen Future Uses: Genetic data, once collected, may be used for purposes not foreseeable at the time of collection, such as future medical research, commercial applications, or law enforcement. This raises the issue of open-ended or broad consent, where participants agree to unspecified future uses. While practical for research, this undermines the individual's control and contradicts the spirit of informed consent.

Familial and Group Implications: Genetic information is relational—it can provide information not just on the individual but also on biological kin. Sharing genetic information, therefore, may involve others who are not present and have not given consent. This tests the individualistic conception of consent and raises ethical concerns about collective rights and intergenerational privacy.

Power Imbalances and Vulnerability: In many contexts, such as clinical trials or public health programmes, individuals may feel coerced or pressured into giving consent. Vulnerable populations, such as economically disadvantaged groups or indigenous communities, may be particularly susceptible. Ethical consent requires not only voluntariness but also an awareness of power dynamics and socio-economic context.

ETHICAL FRAMEWORKS IN GENOMIC RESEARCH

Ethical codes and statements have long attempted to protect human dignity in research. Instruments such as the Nuremberg Code (1947), the Declaration of Helsinki (1964), and the Belmont Report (1979) have all highlighted the need for voluntary and informed consent in medical research. More recently, the Universal Declaration on Bioethics and Human Rights (2005) by UNESCO reiterates that consent must be based on adequate information, be freely given, and be revocable.[57]

In the context of genetic research, many ethics boards now recommend dynamic consent, an interactive, ongoing process that allows participants to update their preferences and receive information about how their data is used. Dynamic consent tools use digital platforms to

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[56] Bartha Maria Knoppers, 'Framework for Responsible Sharing of Genomic and Health-Related Data' (2014) 8(1) The HUGO Journal <https://doi.org/10.1186/s11568-014-0003-1> accessed 01 June 2025

[57] Universal Declaration on Bioethics and Human Rights 2005

engage participants continuously, thereby aligning with the principles of transparency, respect, and autonomy.[58]

Ethical Tensions: Individual Rights v Public Good: One of the key ethical challenges of regulating genetic information is weighing the rights of the individual against the common good. Genetic studies can have great social value, like the identification of disease biomarkers, better public health, and the creation of tailored drugs. Rigid consent regimes interfere with such large-scale data collection and sharing on which these advantages will depend.

This has resulted in some ethicists arguing for public interest exceptions, circumstances under which data can be used without explicit consent, as long as the use is for a legitimate social purpose and there are suitable safeguards. This strategy has risks of undermining trust; however, if people feel that their data is usable without consequence.

Moreover, justice and equity are of central ethical concern. Historically disadvantaged groups might be overrepresented in research databases yet underrepresented in benefit sharing. Ethical regulation has to guarantee equitable access, communal involvement, and benefit-sharing to avoid exploitation.

Indigenous and Cultural Perspectives: In the majority of indigenous and tribal cultures, genetic ownership is deeply interwoven with cultural identity and collective heritage. To illustrate this point, Maori society in New Zealand and indigenous Native American groups in the US have asserted collective rights to genetic resources and information, dismissing the Western focus on individual consent and property rights.

These communities advocate for free, prior, and informed consent (FPIC) as recognised in the UN Declaration on the Rights of Indigenous Peoples (2007). FPIC emphasises community engagement, cultural respect, and the right to say no to data collection or use that conflicts with communal values. Incorporating such models into national frameworks represents an important step toward ethical pluralism and cultural sensitivity in genomic governance.

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[58] Jane Kaye et al, 'Dynamic Consent: A Patient Interface for Twenty-First Century Research Networks' (2015) 23(2) European Journal of Human Genetics <https://doi.org/10.1038/ejhg.2014.71> accessed 01 June 2025

Moving Toward Ethical Governance Models: To build ethical frameworks that uphold dignity, autonomy, and justice, legal frameworks must transition beyond minimalist procedural consent. There must be an ethics-by-design approach in which ethical safeguards are directly infused within data systems and institutional processes. This includes:

1. Developing consent processes that are interactive, comprehensible, and revocable.
2. Giving information about the uses of data, storage, and sharing.
3. Affording fairness to research benefits and access to genomic technologies.
4. Building public trust through engaging, being accountable, and inclusive governance.

Reforms under these conditions can bridge the gap between morality and law so that governance of genetic data is not only legally good but also morally good.

TECHNOLOGICAL INNOVATIONS AND LEGAL CHALLENGES: BLOCKCHAIN, AI, AND SMART CONSENT MODELS

As science advances, so too must the mechanisms that govern it. Rising technologies like blockchain, artificial intelligence (AI), and dynamic consent systems provide new means of controlling, securing, and democratising genetic information. Yet they also pose new legal and regulatory questions. This section explores how these technologies interact with legal concepts of ownership and consent in the context of genetic data and evaluates whether they can genuinely empower individuals or simply deepen existing asymmetries of power and knowledge.

BLOCKCHAIN TECHNOLOGY: TOWARDS DECENTRALISED DATA OWNERSHIP

Blockchain technology has also been hailed as a possible rescuer for genetic data governance. Blockchain is a distributed, tamper-proof record where information is added in blocks connected by cryptographic hashes. Data, once placed, cannot be altered without the agreement of the network, promoting transparency and security.

Blockchain-based systems, while offering transparency and decentralisation, inherently lack **jurisdictional anchoring**, making it difficult to attribute legal responsibility or enforce regulatory compliance across territorial boundaries.

Self-Sovereign Identity (SSI) and Data Control: Using blockchain, individuals can theoretically maintain self-sovereign control over their genetic data. Platforms such as Nebula Genomics and Genomes.io are experimenting with models where data is encrypted and stored in decentralised networks, and access is granted through private keys controlled by the individual. This could allow users to:

1. Monitor who accesses their data.
2. Grant or revoke permissions in real-time.
3. Receive compensation for data sharing.

Legally, this may strengthen de facto ownership, although de jure ownership still lacks clear statutory recognition. The technology supports the ethical principle of autonomy and aligns with GDPR's requirement for consent to be specific and revocable.

Smart Contracts and Dynamic Consent: Smart contracts, self-executing agreements coded into blockchain, can automate consent processes. For example, a smart contract could ensure that a participant's genetic data is only accessed for a specific research project, and automatically revoke access once the project ends. This programmable consent can potentially implement legal and ethical protections as enforceable rules and realise abstract rights as manageable rules. Whether such contracts can be enforced in conventional legal systems and interface with consumer protection legislation is questionable.

ARTIFICIAL INTELLIGENCE (AI): PROMISE AND PERIL

AI and machine learning algorithms are largely used to analyse large genomic datasets for predictive healthcare, personalised medicine, and drug development. While AI offers remarkable efficiencies, it also complicates legal and ethical oversight.

Lack of Transparency (Black Box Problem): AI models, specifically deep learning systems, often operate as black boxes; their internal logic is opaque even to their creators. This poses a major challenge to informed consent, as individuals cannot reasonably understand or anticipate how their data will be processed or what inferences will be drawn.

Bias and Discrimination: AI models trained on non-representative genomic data can perpetuate or exacerbate biases, leading to inaccurate predictions for underrepresented populations. Without inclusive datasets, personalised medicine may become personalised only for some, raising concerns of algorithmic injustice.

Legal Accountability: AI obfuscates lines of responsibility. When an AI system uses genetic information maliciously or inflicts damage, who is responsible: the developer, the data controller, or the algorithm itself? Classical legal categories, like negligence or breach of contract, are poorly suited to handle such questions, leading to the need for new doctrines or industry-specific legislation.

DYNAMIC CONSENT MODELS: HUMAN-CENTRIC DATA GOVERNANCE

Dynamic consent is an interactive, online approach by which individuals can actively manage their engagement in research or health data systems. Participants may:

1. View current data usage.
2. Adjust consent preferences.
3. Obtain feedback on research results.

This model honours autonomy and increases transparency, solving many of the drawbacks of typical one-time consent methods.

Implementation Examples: Projects like EnCoRe (Ensuring Consent and Revocation) in the UK and CTRL (Consent to Research and Learn) in the US have piloted dynamic consent tools with promising results. They demonstrate improved participant trust and ethical compliance.

Legal Viability: Dynamic consent is in line with GDPR's focus on freely given, clear, and specific consent. It is also in line with India's developing rule of law, which increasingly supports data fiduciary accountability and user-oriented consent processes, as enacted in the Digital Personal Data Protection Act, 2023. However, practical challenges such as digital literacy, data access inequality, and the cost of infrastructure must be addressed to ensure equitable adoption.

Legal Gaps and Regulatory Challenges: Despite technological advances, the law continues to lag. Key issues include:

1. Absence of statutory recognition of genetic data as personal or property in many jurisdictions.
2. Inconsistent consent standards across regions and sectors.
3. Ambiguity over secondary uses, especially in commercial and cross-border data sharing.
4. Jurisdictional complexity in decentralised systems like blockchain, which defy traditional notions of territoriality and sovereignty.

Regulators must develop tech-responsive legal frameworks that incorporate principles of data minimisation, purpose limitation, and interoperability. Emerging models such as privacy-by-design and ethics-by-design need to be embedded into data infrastructures from the outset.

Prospects for Harmonisation and Global Governance: Given the cross-border nature of genetic data flows and the global nature of genomic research, there is an urgent need for harmonised standards. International cooperation through bodies such as the OECD, WHO, and WIPO can facilitate:

1. Shared definitions and protections for genetic data.
2. Common principles for consent and data sharing.
3. Dispute resolution frameworks for transnational conflicts.

The Global Alliance for Genomics and Health (GA4GH) provides a promising template by creating technical and policy standards that promote data sharing while protecting individual rights.

Reimagining Ownership in the Age of Technology: The ownership argument about genetic information can be recast in consideration of technological developments. Rather than sole ownership, law scholars increasingly advocate for data stewardship models or trust-based forms of governance, in which custodians maximise the welfare of data subjects. Such models can:

1. Balance individual rights with collective benefits.
2. Ensure ethical data use without requiring absolute property rights.
3. Foster trust in digital health ecosystems.

By integrating law, ethics, and technology, such approaches offer a more nuanced and responsive way to govern genetic data in the digital age.

POLICY RECOMMENDATIONS AND THE WAY FORWARD

The regulation of genetic information is at the nexus of law, technology, ethics, and public health. As our analysis to date shows, existing law is patchy, incoherent, and frequently trailing the advance of science and technology. In protecting individual rights while promoting innovation, it is necessary to embrace a future-oriented, multi-stakeholder approach that reconciles autonomy, accountability, equity, and the public good. This section provides policy recommendations at the legislative, institutional, and international levels to create a future-proof and harmonious framework of genetic data ownership and consent.

LEGISLATIVE REFORMS: DEFINING AND PROTECTING GENETIC DATA

Statutory Recognition of Genetic Data: There is a pressing need to explicitly define genetic data as a special category of personal or sensitive data in legislation. The Indian Digital Personal Data Protection Act, 2023, while progressive in many respects, should be amended to classify genetic information as sensitive personal data, akin to how the GDPR treats it. This classification should trigger higher thresholds for data collection, storage, and processing.

Establishing Legal Ownership or Stewardship Models: Rather than focusing exclusively on ownership in the proprietary sense, legislators should consider data stewardship models where individuals retain control rights, such as consent, access, and benefit-sharing, without necessarily holding full property rights. A fiduciary duty could be imposed on entities that collect or process genetic data, requiring them to act in the best interest of data subjects, similar to the principles of data fiduciaries introduced in Indian law.

Enabling Dynamic and Tiered Consent: Legal frameworks should mandate the use of dynamic consent platforms, especially for research and commercial use of genetic data. Consent should be tiered and modular, allowing individuals to select specific types of data sharing (e.g., for academic research but not commercial profit) and to update or revoke their consent easily. This ensures that consent is not only informed but also ongoing and adaptive.

INSTITUTIONAL REFORMS: OVERSIGHT, REDRESS, AND ACCOUNTABILITY

Independent Genetic Data Authorities: Specialised data protection agencies should establish genomic data divisions or commissions tasked with overseeing compliance, handling grievances, and issuing guidelines. These bodies should include interdisciplinary expertise, lawyers, ethicists, geneticists, and data scientists, to ensure holistic governance.

Ethics Review Boards and Community Participation: All entities conducting genetic data collection or research should be required to clear their protocols with ethics review boards that include community representatives. This ensures democratic legitimacy, transparency, and respect for cultural values, especially when dealing with indigenous and marginalised communities.

Establishing Grievance Redress Mechanisms: A robust grievance redress mechanism should be institutionalised, allowing individuals to seek compensation or redress for breaches of consent or misuse of genetic data. This should include fast-track procedures for vulnerable populations and penalties that are proportionate and dissuasive.

JUDICIAL REFORMS: EXPANDING THE SCOPE OF PRIVACY JURISPRUDENCE

Clarifying Legal Status of Genetic Data in Courts: Courts must recognise genetic data as a distinct category of personal data that warrants enhanced protection due to its permanent, familial, and predictive characteristics. In the Indian context, judicial expansion of the Puttaswamy framework to include explicit reference to genetic data would strengthen the normative foundation for future rulings.

Encouraging Doctrinal Innovations: The judiciary should embrace doctrinal innovations, such as recognising group privacy, intergenerational rights, and data-related harm, to address the unique challenges posed by genetic information. Precedents that incorporate bioethical principles can bridge the gap between law and evolving societal values.

INTERNATIONAL HARMONISATION AND CROSS-BORDER GOVERNANCE

Aligning with Global Standards: India and other developing countries must harmonise their regulatory bases with global best practices like the OECD Guidelines on Human Biobanks, UNESCO's Universal Declaration on Bioethics and Human Rights, and WHO's genomic data guidance. This will enable interoperability and ethical consistency across cross-border research collaborations.

Creating International Agreements on Genetic Data: A multilateral treaty or framework convention, modelled on the Nagoya Protocol or TRIPS Agreement, could be developed specifically for genetic data governance. Such an agreement should address:

1. Cross-border data flows;
2. Consent harmonisation;
3. Benefit-sharing obligations;
4. Respect for indigenous rights.

Promoting Data Solidarity and Equity: International forums should prioritise data solidarity—the idea that the benefits of genomic research must be equitably distributed. Mechanisms such as data trusts, global genomic commons, and benefit-sharing funds can ensure that low- and middle-income countries participate meaningfully and fairly in the genomic revolution.

Public Education and Digital Literacy: Legal and technological reforms must be complemented by efforts to enhance public understanding of genetic data. This includes:

1. Incorporating genomics and data literacy in school and university curricula;
2. Launching public awareness campaigns about rights and risks;
3. Providing access to legal aid for individuals affected by genetic data misuse.

Such efforts can empower individuals to make informed choices and participate actively in governance debates.

Encouraging Ethical Innovation: Ultimately, governments need to create a culture of ethical innovation. This involves encouraging startups and research initiatives that incorporate privacy-by-design, provide open-source consent tools, and build privacy-enhancing technologies (PETs) like homomorphic encryption and federated learning. Public-private collaborations and academic funding can speed this effort. By integrating ethics into innovation, policymakers can avoid the false dichotomy between individual rights and scientific progress, creating a future where both flourish in tandem.

CONCLUSION

The law governing genetic information is at a turning point. As the boundaries of medicine, biotechnology, and the information age are pushed farther afield, the law, too, must keep pace to safeguard not just informational privacy but also human dignity, autonomy, and justice. This article has explored the complex legal, ethical, and technological dimensions surrounding genetic data ownership and consent, with particular reference to Indian and international frameworks.

Ownership of genetic data remains a contested and unsettled legal concept. Whereas proprietary models provide unambiguous entitlements, they do not adequately capture the relational and moral character of genetic information, which is at the same time personal and shared. The stewardship model, where control, accountability, and benefit-sharing are prioritised, looks more appropriate to the changing legal and ethical environment. Consent, meanwhile, is not a static checkbox but a dynamic, context-dependent process. It must be informed, ongoing, and revocable, capable of accommodating changing technologies, purposes, and social expectations.

Indian jurisprudence, notably after Justice K.S. Puttaswamy v Union of India, has laid the groundwork for a rights-based approach to data protection, but much remains to be done. Legislative reform must specifically identify genetic information as sensitive, impose dynamic consent procedures, and create enforceable fiduciary obligations. Institutional innovation, e.g., data authorities and participatory ethics boards with specific mandates, can facilitate greater oversight and democratic participation. At the same time, the law must engage with new technologies like blockchain and AI, which offer opportunities for decentralised control but also introduce new risks.

Globally, harmonisation of standards and transnational cooperation are essential. Genetic data often flows across borders, and so must the principles of fairness, transparency, and equity. International legal tools, following the lead of bioethics and human rights principles, have the power to link countries and communities.

A strong future system for ownership of genetic data must be established on three interdependent pillars: law, ethics, and technology. The law defines the right protections and accountability framework, while ethics secures autonomy, consent, and justice. Technology supplies the means necessary for enforcing secure, transparent, and privacy-preserving data handling. Only through integrating these domains can we balance innovation with human dignity in the governance of genetic data.

Finally, the objective ought not be to curtail the revolutionary potential of genetic science but to ensure that it proceeds in a way that honours individual rights, shields vulnerable groups, and builds public confidence. A future-ready legal framework must integrate law, ethics, and technology, not in silos but in synergy. Only then can society ensure that the genomic revolution serves not just science, but humanity.