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GENETIC PRIVACY AND DNA REGULATIONS: INDIA'S LANDSCAPE[1]

AUTHORED BY - AMOL YADAV

Abstract

This research paper conducts a thorough examination of the intricate relationship between genetic privacy and DNA regulations, recognizing the substantial value inherent in genetic information. Genetic data divulges essential insights into an individual's health, ancestry, and susceptibility to specific diseases. With the rapid advancement of genetic testing and sequencing technologies, the paper underscores the escalating concerns surrounding the safeguarding of this sensitive information.

The research delves comprehensively into multiple facets of genetic privacy, encompassing legal and ethical dimensions, potential perils associated with unauthorized access or misuse of genetic data, and the broad-ranging consequences for individuals, families, and society at large. It scrutinizes the existing regulatory frameworks governing DNA data, ranging from national legislations to institutional policies. Moreover, the study scrutinizes the dynamic landscape of DNA regulations, encompassing issues like consent requisites, data sharing, storage protocols, and the establishment of DNA Data Banks. The study also examines the impact of genetic information in diverse domains, such as law enforcement, healthcare, and employment.

By drawing from interdisciplinary perspectives spanning law, ethics, genetics, and technology, this research critically evaluates the effectiveness and sufficiency of current DNA regulations in preserving genetic privacy. It accentuates potential gaps and hurdles necessitating resolution to ensure robust protection of individuals' genetic information, while concurrently accommodating societal interests like research advancement and public safety. Furthermore, the paper explores emerging technologies, including genome editing and direct-to-consumer genetic testing, and their implications for genetic privacy and regulation. It dissects the ethical quandaries posed by these innovations and offers insights into potential policy responses and governance models.

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[1] Authored by Amol Yadav, Jamia Millia Islamia.

In summation, this research paper furnishes an all-encompassing overview of genetic privacy and DNA regulations, illuminating the intricate complexities and challenges intertwined with the preservation of genetic information. It underscores the imperative for comprehensive legal and ethical frameworks that harmonize the progression of genetic research with the preservation of individual privacy rights.

Background

In India, genetic privacy and DNA regulations have gained prominence due to the sensitive nature of genetic information and its impact on individual privacy and rights. The DNA Technology (Use and Application) Bill is the key legislation governing these concerns. The bill underscores the significance of obtaining consent for DNA sample collection, except in severe offense cases. It also proposes the formation of a DNA Regulatory Board to oversee accreditation of DNA laboratories, ensure adherence to quality standards, and implement data protection protocols. Provisions for the removal of DNA profiles, including those of suspects and undertrials, based on police reports, court orders, or written requests are included in the bill. The legislation aims to strike a balance between harnessing DNA technology for criminal investigations and safeguarding individual privacy and rights, offering clear guidelines, consent requirements, and oversight mechanisms.[2]

Genetics is a branch of biology devoted to the study of genes, heredity, and variations in living organisms. It investigates genes' structure, function, and transmission, the fundamental units of heredity that transfer traits from parents to offspring. Genes are segments of DNA (deoxyribonucleic acid) that carry instructions for an organism's construction and maintenance. DNA, present in the cells of all living beings, holds genetic information crucial for organism development, operation, and reproduction.

Genetic data comprises information derived from gene and variation studies. It encompasses DNA gene sequences, the presence or absence of specific genetic markers, and other data collected from individuals or populations. Genetic data aids in understanding inherited traits, genetic disorders, evolutionary relationships, and the influence of genetics on health and disease.[3] Advancements

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[2] Srivastava, Ankit, et al. "Impact of DNA evidence in criminal justice system: Indian legislative perspectives." *Egyptian Journal of Forensic Sciences* 12.1 (2022): 51.

[3] Jana, Achin, and Kavita Singh. "Forensic DNA Profiling In India: An Emerging Human Rights Hazard." Indian Journal 1.1 (2022): 22.

like DNA sequencing have enabled the collection of extensive genetic data from individuals. This data facilitates the identification of genetic variations linked to specific traits or conditions, population genetics research, and personalized medical treatments based on an individual's genetic makeup. Handling genetic data with care is vital to address privacy, security, and ethical concerns, as it contains sensitive information about individuals' biological attributes and potential health risks.

Genetic data privacy and operation of consumer genetic tests

Genetic data privacy aims to prevent unauthorized access and use of an individual's genetic information, especially in light of advances in science and technology that make it easy to obtain and extract personal data from DNA samples. This conflicts with individuals' privacy rights. The confidentiality of genetic information is vital because it contains the blueprint for an individual's physical and biological makeup. A person's gene sequence can potentially reveal intimate details about their private life, even providing insights into their future. Therefore, it is essential to protect an individual's privacy whenever their genetic information is utilized, whether for research, medical purposes, or any other reason.

Consumer genetic tests, typically administered by healthcare professionals, involve DNA sample collection, analysis, and result explanation. In contrast, direct-to-consumer DNA tests (DTC) do not require consultation with healthcare professionals. DTC companies offer genetic tests online, on television, or through other channels. Customers provide a DNA sample, which the company analyzes and sends results via email or regular mail. These tests assess the risk of developing serious diseases based on an individual's genes or DNA.[4] DTC genetic testing serves various purposes, including ancestry tracing and identifying distant relatives. However, many individuals use DTC tests to check for potential health issues.

How do companies handle genetic data obtained from consumers?

These testing kit manufacturers should take effective precautions to protect the database containing the genetic information because they are in possession of their customers' highly confidential data. Because there is always a risk of a hack or data breach, they should take the concerns about the security of the genetic data of their customers extremely seriously. The

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[4] Bondre, Ameya, Soumitra Pathare, and John A. Naslund. "Protecting mental health data privacy in India: The case of data linkage with Aadhaar." *Global Health: Science and Practice* 9.3 (2021): 467-480.

majority of customers who purchase direct-to-consumer DNA tests (DTC) consent to this sharing of their personal information. These businesses only share data with third parties with explicit permission. Companies always promise not to reveal the identities of their users when information is given with their consent. Privateer's policies vary amongst businesses. To protect their privacy, the users must read them before accepting them.[5]

Companies that handle genetic data from consumers must prioritize stringent privacy and security measures to safeguard the sensitive information they possess. This entails addressing various aspects of data protection:

- *Informed Consent*: Prior to collecting genetic data, companies typically obtain informed consent from consumers. This process ensures that consumers fully comprehend how their data will be utilized, shared, and stored. It should offer clear information on testing purposes, potential risks, benefits, and the implications of results.
- *Anonymization and De-identification*: To preserve privacy, genetic data is often anonymized or de-identified, removing personally identifiable information (PII) like names and addresses. This precaution prevents direct linkage of data to specific individuals.
- *Secure Data Storage*: Genetic data is securely stored in databases or servers with robust access controls. Encryption, firewalls, and regular security audits are essential to thwart unauthorized access, hacking, or data breaches.
- *Data Sharing and Consent Options*: Companies should provide consumers with choices regarding the sharing of their genetic data. Some may opt for data use in research or sharing with third parties, while others may demand strict limitations. Transparency in presenting these options empowers consumers to make informed decisions.
- *Data Use and Sharing Policies*: Companies must maintain transparent policies detailing how genetic data is employed and shared. These policies should clarify usage purposes (e.g., research, product development) and specify third-party recipients (e.g., research institutions, pharmaceutical firms). Furthermore, they should outline procedures for consumers to opt out of data sharing if desired.
- *Regulatory Compliance*: Compliance with relevant privacy and data protection regulations is imperative. The General Data Protection Regulation (GDPR) in the European Union and the Health Insurance Portability and Accountability Act (HIPAA) in the United States, among

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[5] Graeme Laurie. *Genetic Privacy: A Challenge to Medico-Legal Norms*. 1st Ed. Cambridge University Press. 2002.

others, set forth guidelines governing the collection, storage, and handling of personal and health-related data, including genetic information.

Consumers should diligently review a company's privacy policy and terms of service prior to undergoing genetic testing to gain clarity on data handling practices. If uncertainties persist, reaching out to the company directly to seek clarification on data privacy and security practices is advisable. Companies must be vigilant in upholding these measures to maintain trust and ensure the confidentiality of consumers' genetic data.[6]

Effectiveness of de-identification of genetic data

De-identification stands as a pivotal process for safeguarding individual privacy, particularly when it pertains to the use of genetic data in research. This method involves removing certain identifiers, such as names and phone numbers, from the data to protect the anonymity of participants in human trials. Genetic testing companies routinely employ de-identification procedures to erase names, aiming to ensure the confidentiality of genetic information. However, it's important to acknowledge that complete de-identification may not provide an absolute safeguard due to the distinct nature of each person's genetic data, which could potentially be traced back to them, compromising their anonymity. Moreover, when an individual's genetic information is utilized in research, there's often a necessity to disclose some details about that individual, inadvertently revealing their identity. Consequently, de-identification alone cannot guarantee unwavering privacy protection.[7]

In contrast to de-identification, the concept of re-identification poses a significant threat to the privacy of genetic information. Researchers, through specialized techniques, can re-identify individuals from data previously assumed to be anonymised. This undermines the confidentiality of genetic data.

Nonetheless, achieving complete de-identification of genetic data is a formidable challenge, and the risk of re-identification or privacy breaches remains. Several considerations shed light on the effectiveness of de-identification:

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[6] *Ibid.*

[7] Garfinkel, Simson. *De-identification of Personal Information:*. US Department of Commerce, National Institute of Standards and Technology, 2015.

- *Genetic Identifiability*: Genetic data inherently contains unique information that may still be traceable to an individual or their relatives even with personally identifiable information (PII) removed. Various means, like cross-referencing with publicly available databases or matching with familial genetic data, can facilitate re-identification.
- *Auxiliary Data*: De-identified genetic data can potentially be re-identified when combined with other auxiliary data sources. Access to datasets containing genetic or biographical information enables adversaries to correlate and re-identify individuals.
- *Data Aggregation*: Combining de-identified data from multiple sources increases the risk of re-identification. As more data accumulates, the potential for patterns or overlaps in the data rises, aiding attackers in linking de-identified records to specific individuals.
- *Evolving Re-identification Techniques:* Re-identification methods continually evolve, with advances in data analysis and genetics research potentially simplifying re-identification from de-identified genetic data in the future.
- *Insider Threats and Data Breaches*: Despite robust de-identification practices, there's an enduring risk of insider threats or data breaches that can compromise data privacy and security. This underscores the necessity of stringent security measures and ongoing monitoring to thwart unauthorized access.

While de-identification serves as a valuable privacy measure, it is not foolproof. Consequently, there's a growing recognition of the need for additional safeguards, including stringent data access controls, encryption, and comprehensive data sharing policies, to ensure the protection of individuals' genetic data. Such multifaceted approaches are essential to mitigate the evolving risks associated with genetic data privacy.

Concept of genetic privacy

Genetic privacy encompasses an individual's right to maintain strict control over the confidentiality and security of their genetic information. This ensures protection from unauthorized access, usage, or disclosure without explicit consent. The significance of genetic privacy arises from genetic data's potential to reveal intimate health details, ancestry, disease susceptibility, and even familial genetic traits. Genetic data's inherent identifiability, due to unique genetic markers, poses re-identification risks despite de-identification efforts, like removing personally identifiable information (PII) to protect privacy.[8]

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[8] *Supra* note 2, at 2.

Establishing robust safeguards and legal frameworks is essential to ensure genetic privacy. This involves implementing informed consent procedures, transparent data collection, storage, sharing guidelines, and fortified security measures against unauthorized access and breaches. Existing regulatory frameworks, like the General Data Protection Regulation (GDPR) and Health Insurance Portability and Accountability Act (HIPAA), provide crucial directives for safeguarding genetic privacy.[9]

Balancing the benefits of genetic research and personalized healthcare with genetic privacy preservation requires ongoing dialogue among individuals, researchers, healthcare providers, and policymakers. Ethical considerations, informed consent, data sharing practices, and transparency must be addressed. Upholding genetic privacy safeguards individuals' rights and fosters trust in responsibly using genetic data for scientific and healthcare advancements.

Genetic privacy is a multifaceted concept that manifests differently in various contexts:

- *Privacy in Research:* Genomic research must navigate a delicate balance between the need for extensive data sharing to advance scientific knowledge and the imperative to safeguard the privacy of research participants, particularly in identifiable populations or groups facing unique privacy challenges.
- *Privacy in the Clinic*: The widespread adoption of genomic testing in clinical settings has brought about significant clinical benefits for patients but also introduced new privacy concerns related to the misuse of genetic information.
- *Genetic Privacy in Society*: Genetic and genomic information plays a pivotal role in law enforcement, the legal system, and forensic contexts, raising crucial questions about privacy and security. Direct-to-Consumer (DTC) genetic testing has gained popularity, resulting in vast databases of consumer genetic data with inadequate regulation, thus heightening privacy concerns. Additionally, surreptitious DNA testing poses privacy threats, and certain companies offer genetic analyses from various biological samples without proper consent, further complicating the landscape of genetic privacy.

In essence, the multifaceted nature of genetic privacy underscores the need for comprehensive safeguards, ethical considerations, and regulatory frameworks to ensure the responsible use and

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[9] Siddhant Gupta, Bagmisikha Puhan. *Genetic privacy and the DNA regulation bill*, Lexology, 1st Mar. 2021, https://www.lexology.com/library/detail.aspx?g=a0ba5f39-930f-45a5-b02c-ebd1b72f3aa9. Accessed on 21st Sept. 2023.

protection of genetic data across various domains.[10]

Genetic databases

Genetic databases serve as vital repositories housing genetic information derived from various sources like research studies, clinical genetic testing, and direct-to-consumer genetic testing services. Their primary objective is to bolster genetics research, foster the discovery of novel genetic variations, and offer insights into genetic underpinnings of diverse traits, diseases, and conditions. These databases are instrumental in advancing genetics research, personalized medicine, and comprehending the genetic foundations of ailments. They empower scientists and researchers to scrutinize extensive datasets, discern genetic trends, and investigate correlations between genetic variants and particular traits or maladies. Moreover, they contribute to the development of fresh diagnostic tools, precise therapies, and targeted interventions.[11]

Nevertheless, the utilization of genetic databases gives rise to pivotal ethical and privacy concerns. Upholding individual consent, safeguarding data privacy, and instituting secure data storage and sharing protocols are imperative for maintaining public trust and thwarting unauthorized access or misappropriation of genetic data. Regulatory frameworks, such as the GDPR and HIPAA, offer directives for responsible genetic data collection, storage, and usage to ensure privacy and safeguard individuals' rights.[12]

Uses of genetic information

Genetic information serves crucial roles in diverse fields, including healthcare, research, forensics, and personalized services, with key applications including[13]:

- *Disease Diagnosis and Treatment*: Genetic information aids in diagnosing genetic disorders and tailoring treatment plans. By identifying specific gene mutations or variations, healthcare providers can make precise diagnoses, select optimal therapies, and predict disease progression.

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[10] Heather Widdows, Caroline Mullen. *The Governance of Genetic Information: Who Decides?*. 1st Ed. Cambridge University Press. 2009.

[11] Bishop, Martin J. *Genetic databases*. Academic Press, 1999.

[12] Clayton EW, Evans BJ, Hazel JW, Rothstein MA. The law of genetic privacy: applications, implications, and limitations. Journal Law Biosci. 14;6(1) (2019):1-36

[13] Hall, Mark A., and Stephen S. Rich. "Laws restricting health insurers' use of genetic information: impact on genetic discrimination." *The American Journal of Human Genetics* 66.1 (2000): 293-307.

- *Precision Medicine*: Precision medicine customizes medical treatments based on genetic profiles. Analyzing genetic data enables healthcare professionals to understand individuals' disease susceptibilities, forecast treatment outcomes, and prescribe more effective, less side-effect-prone treatments.
- *Genetic Counselling*: Genetic information guides genetic counselling, where experts advise individuals and families on hereditary diseases and associated risks. Genetic test results assist in risk assessment, family planning decisions, and emotional support.
- *Research and Scientific Discoveries*: Genetic information fuels scientific research by uncovering genetic foundations of traits, diseases, and population dynamics. Researchers analyze genetic data to identify variations, explore gene-environment interactions, comprehend disease origins, and develop potential treatments.
- *Ancestry and Genealogy*: Genetic testing and analysis reveal individuals' genetic lineage and ancestry. Ancestry tests compare genetic markers to reference populations, unveiling ancestral geographic origins and cultural ties.
- *Forensics and Identification*: Genetic data, especially DNA profiling, plays a vital role in forensics and criminal justice. DNA samples are matched with databases to identify individuals, establish connections in criminal cases, locate missing persons, resolve paternity disputes, and identify disaster victims.

However, the utilization of genetic information raises ethical and privacy concerns. Preserving individuals' privacy, obtaining informed consent, and implementing robust security measures are imperative to ensure responsible and ethical use of genetic data.

Status of Genetic Privacy in India

The Delhi High Court issued a landmark decision in 2018 against United India Insurance Company's discrimination in health insurance based on the presumption that a person's heart illness is caused by a hereditary disorder. Due to the lack of appropriate genetic testing and reasonable differentiation, the court ruled that this type of discrimination was illegal and violated the concept of fair treatment under the law. The order was later partially overturned by the Supreme Court. This demonstrates how urgently India needs legislation to outlaw genetic discrimination. In a time when genetic testing is common, it is essential to stop discrimination and guarantee "fair justice under the law".

Article 14 of the Constitution, which ensures equal treatment under the law, forbids genetic discrimination. In the *Justice KS Puttaswamy (Retd.) & Anr. v. Union of India*[14] case, the Supreme Court of India unanimously declared the Right to Privacy to be a Fundamental Right protected by Article 21. Genetic discrimination ought to be viewed as an infringement on privacy rights since everyone's genome is a subject of personal privacy. The Delhi High Court's decision has established a precedent, and it is now up to the legislature to enact legislation that fulfils the pledge to outlaw genetic discrimination. The majority of nations currently have anti-genetic discrimination laws. For instance, the Genetic Information Non-discrimination Act (GINA), passed in 2008 in the United States, safeguards people from genetic discrimination in employment and healthcare. GINA has some restrictions, though, as it doesn't cover things like housing, mortgage financing, education, or other insurances like life, long-term care, and disability. Guidelines for the use of genetic information for insurance reasons have been adopted by the Council of Europe.[15]

The recently passed "*Genetic Non-discrimination Act*" in Canada forbids employers and insurers from seeking DNA testing or results. Until 2019, insurers in the United Kingdom voluntarily abide by a moratorium that was decided upon by the government and the Association of British Insurers. Given the current state of the world, India should not fall behind but rather develop its own legislation to enforce the ban of genetic discrimination, using the best elements from around the globe.

Recent Developments

In a recent ruling of *Aparna Ajinkya Firodia v. Ajinkya Arun Firodia*[16], the Supreme Court recognized the right of children to protect their genetic information in DNA tests, stating that such tests should not be conducted without their consent.

This judgment was made in response to a petition filed by a man who questioned the paternity of his second child, alleging his wife's involvement in an adulterous relationship. Based on the specific circumstances of the case, the apex court concluded that no negative assumptions could be made due to the mother's refusal to subject the child to a paternity test.

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[14] (2017) 10 SCC 1

[15] Bondre, Ameya, Soumitra Pathare, and John A. Naslund. "Protecting mental health data privacy in India: The case of data linkage with Aadhaar." *Global Health: Science and Practice* 9.3 (2021): 467-480.

[16] Civil Appeal No. 001308 / 2023

"Children have the right not to have their legitimacy questioned frivolously before a Court of Law. This is an essential attribute of the right to privacy", the bench of *Justices V Ramasubramanian and B V Nagarathna* observed.

The court held that Genetic information holds deep personal significance, providing valuable insights into an individual's core being. It empowers individuals to make informed decisions regarding their health, privacy, and identity. In the context of divorce proceedings, children possess the right to safeguard their genetic information from DNA testing as an integral aspect of their fundamental right to privacy. This right is explicitly protected under Article 21 of the Indian Constitution.

It is crucial that children are not made the focal point of disputes between spouses. The recognition of privacy, autonomy, and identity rights is not limited to the domestic sphere but also extends globally through the United Nations' Convention on the Rights of the Child. The Convention acknowledges individuals' ability, including children, to exercise control over their personal boundaries and determine their identity in relation to others. It emphasizes that children should not be deprived of this entitlement to shape and comprehend their sense of self solely due to their status as children.

While setting aside the order, the Apex Court bench made the following observations:

- In divorce disputes, a small child's DNA test should not be routinely ordered. Only in cases where there are no other ways to substantiate the charges of adultery in a marriage dispute may DNA profiling be used as proof.
- Only where there is enough prima facie evidence to overcome the presumption under Section 112 of the Evidence Act may DNA tests of children born during the continuation of a legitimate marriage be ordered. A DNA test cannot be ordered to refute the presumption under Section 112 of the Evidence Act if no claim of non-access has been made.
- In a case where the paternity of a kid is not directly in dispute but is purely incidental to the action, a court would not be justified in mandating a DNA test of a child.
- The Court should not order a DNA test or another type of test to settle a paternity dispute just because one or both of the parties has contested the fact. The Court should order the parties to present evidence to support or refute the paternity claim, and it should only order a DNA test if it is impossible to make an inference from the information presented or if

there is no other way to settle the dispute. In other words, the Court can only order such a test in rare and worthy circumstances where it becomes necessary to do so in order to settle the dispute.

- When ordering DNA tests to establish adultery, the court must take into account the possible effects on the offspring, such as inheritance-related repercussions, social stigma, etc.

DNA testing regulations

The Hon'ble Supreme Court in the case of *Ashok Kumar v. Raj Gupta & Ors.*[17] laid in the judgment that, compelling an unwilling person to undergo a DNA test would be a violation of his/her personal liberty and right to privacy.

> *17. "……The appellant (plaintiff) as noted earlier, has brought on record the evidence in his support which in his assessment adequately establishes his case. His suit will succeed or fall with those evidence, subject of course to the evidence adduced by the other side. When the plaintiff is unwilling to subject himself to the DNA test, forcing him to undergo one would impinge on his personal liberty and his right to privacy. Seen from this perspective, the impugned judgment merits interference and is set aside."*

- *DNA Technology (Use and Application) Regulation Bill*

Union Minister of Science and Technology then, Dr. Harsh Vardhan introduced "The DNA Technology (Use and Application) Regulation Bill, 2019" in the Lok Sabha stating that this Bill was for the regulation of use and application of DNA technology for the purpose of establishing identity of missing persons, victims, offenders, under trials and unknown deceased persons.

"*The DNA Technology (Use and Application) Regulation Bill, 2019*" was primarily designed to increase the use of DNA-based forensic technologies to support and strengthen the nation's justice delivery system. It is well acknowledged that DNA-based technologies are useful for identifying missing people and solving crimes and cases. The Bill aimed to ensure that with the proposed increased use of this technology in this country, there is also the assurance that the DNA test results are reliable and that the data remain protected from misuse or abuse in terms of our citizens' privacy rights by requiring the mandatory accreditation and regulation of DNA laboratories.[18]

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[17] 2021 SCC OnLine SC 848

[18] Kansra, Deepa, et al. "The DNA Technology (Use and Application) Regulation Bill, 2019: A Critical Analysis." *Indian Law Institute Law Review* (2021).

The application of DNA evidence, which is regarded as the gold standard in criminal investigations, will be made possible by the proposed legislation, which will strengthen the criminal justice delivery system. Forensic investigations will be aided by the creation of the National and Regional DNA Data Banks as envisioned in the Bill. The proposed Bill will encourage the creation of a consistent code of practises across all national DNA testing laboratories. With the proper input from the DNA Regulatory Board, which will be established for the purpose, this will help in the scientific upgrading and streamlining of the nation's DNA testing activities. It is anticipated that increased usage of this technological advancement led by science will strengthen the current justice delivery system.[19]

- *Important Factors of the Bill*

The Bill governs the use of DNA technology to establish a person's identity for matters outlined in a Schedule. This includes both civil (e.g., parentage issues, immigration, organ transplantation) and criminal (e.g., Indian Penal Code, 1860 offenses) cases. It also establishes national and regional DNA data banks, each maintaining specific indices:

- Crime scene index
- Suspects' or undertrials' index
- Offenders' index
- Missing people' index
- Unknown deceased individuals' index

The Bill forms a DNA Regulatory Board, mandating accreditation for DNA facilities conducting individual identification analysis. It stipulates written consent for DNA collection, except for offenses with sentences exceeding seven years or the death penalty. Provisions for undertrials, erasing suspects' DNA profiles post-police report or court order, and profile deletion upon written request are included.

The Bill sets regulations for DNA testing in various specified matters, encompassing Indian Penal Code, 1860 offenses and other laws like the Immoral Traffic (Prevention) Act, 1956, Medical Termination of Pregnancy Act, 1971, Protection of Civil Rights Act, 1955, and Motor Vehicles

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[19] Joh, Elizabeth E. "DNA theft: recognizing the crime on nonconsensual genetic collection and testing." *BuL Rev.* 91 (2011): 665.

Act, 1988. It allows DNA testing for civil matters such as parentage disputes, pedigree matters, immigration or emigration cases, assisted reproductive technologies, transplantation of human organs, and individual identity establishment.

- *Key Issues*

The Schedule in the Bill enumerates the types of civil matters where DNA profiling can be utilized, specifically for establishing individual identity. However, it remains uncertain whether the Bill intends to regulate medical or research laboratories that conduct DNA testing for identification purposes. In criminal investigations and cases involving missing persons, the Bill mandates the consent of the individual for DNA profiling. However, the requirements for obtaining consent in civil matters are not explicitly stated.

DNA laboratories are obligated to share DNA data with the DNA Data Banks. Yet, it remains unclear whether DNA profiles for civil matters will also be stored in these Data Banks, raising concerns about potential privacy violations. Under the Bill, DNA laboratories generate DNA profiles, which are then shared with the DNA Data Banks. The process for removing DNA profiles from the Data Banks is specified, but the Bill does not impose an obligation on DNA laboratories to delete DNA profiles. It could be argued that such provisions should be included in the Bill itself rather than being left to regulations.

- *Consent for collecting bodily substances*

When a person is detained for a crime that carries a potential sentence of seven years, the government must get their written permission before taking their bodily fluids. However, if the subject declines to comply, the authorities may ask a magistrate for approval. If the Magistrate is confident that the DNA analysis will support or refute the person's involvement in the alleged crime, they may then order the collection of body materials. Contrarily, agreement is not necessary if the crime involves a sentence of more than seven years in jail or death.

Before collecting body substances from a victim or a relative of a missing person, the authorities must have their written agreement. The parent or legal guardian must provide their written approval if the person is a minor or disabled. If the person refuses, the authorities may go before a Magistrate, who has the power to order the collection of the person's bodily fluids.

- *Removal of DNA profiles*

On the basis of a written request by the person, DNA profiles in the crime scene index or missing persons' index will be taken out of the DNA Data Banks. After a police report has been filed or in accordance with a court order, the DNA profile of a suspect will be deleted. A court order will be used to delete the DNA profile in the event of an undertrial.

- *DNA Regulatory Board*

The Bill institutes a DNA Regulatory Board to oversee DNA Data Banks and laboratories, chaired by the Department of Biotechnology's Secretary as an ex-officio member. The Board comprises 12 additional members, including biological sciences experts, the Director General of the National Investigation Agency, Directors of the Central Bureau of Investigation, Centre for DNA Fingerprinting and Diagnostics, and Central Forensic Science Laboratory, along with a member of the National Human Rights Commission. The Board's primary functions encompass supervising DNA laboratories and Data Banks, ensuring quality control, accrediting DNA facilities, and creating training modules for DNA-related personnel. Additionally, it offers recommendations to the central government on privacy protection related to DNA sample use and analysis. Maintaining the confidentiality of DNA profile information is of utmost importance to the Board, mandating that all data held by Data Banks, laboratories, and relevant entities remains confidential, with DNA data strictly limited to individual identification.

Conclusion

In conclusion, this research paper has explored the crucial and evolving topic of genetic privacy and DNA regulations. The study has delved into the various aspects surrounding the protection of genetic information, including the potential risks, ethical considerations, and legal frameworks involved.

The analysis has highlighted the importance of robust regulations to safeguard genetic privacy, considering the sensitive nature of DNA data and its potential implications for individuals and society. It has become evident that a balance must be struck between the advancements in genetic research, which hold immense potential for scientific and medical progress, and the protection of individuals' privacy rights.

Through an examination of existing DNA regulations and privacy frameworks, the research has identified areas for improvement and suggested recommendations. These include the need for comprehensive legislation addressing genetic privacy, clear guidelines on consent and data sharing, stringent security measures for DNA databases, and the establishment of independent regulatory bodies to oversee genetic research and data handling.

Furthermore, the study has emphasized the significance of public awareness and education regarding genetic privacy, aiming to empower individuals to make informed decisions about the use and sharing of their DNA information. Overall, the research paper emphasizes the critical importance of genetic privacy in the era of advancing genetic technologies. By addressing the regulatory gaps and raising awareness, we can create a framework that protects individuals' privacy rights, fosters trust in genetic research, and facilitates responsible and ethical use of DNA data for the betterment of society.