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# GENETIC PRIVACY, DISCRIMINATION AND THE LAW IN INDIA

**Abstract**

Genetic testing is thriving as its predictive abilities and accuracy are growing. However, genetic discrimination could pose a major threat to the genetic revolution. The knowledge of an individual's genetic makeup imposes particular duties and concerns both for its custodian and its subject. Awareness of a genetic defect in an individual may have serious consequences for his/her whole family. This article critically examines how disclosure of such sensitive information can become an impediment in getting employed and obtaining health insurance. How an individual is treated by society should not be dictated by their genetic variations. Discrimination based on an individual's genetic predisposition will be detrimental to employees and policyholders. There is an imminent need for legislation on discrimination against genetic information, particularly in employment and insurance. The DNA Technology (Use and Application) Regulation Bill, 2018, has significant limitations that may affect the incredible potential of genetic testing in India.

**Keywords:** Genetic testing, employment, health insurance, DNA technology, genetic discrimination

# Introduction:

Genetic testing in India has evolved to a great extent in the past decade ([**1**](#_bookmark0)). Genetic testing can be instrumental in predicting whether or not a person is likely to develop a particular disease. The fall in the cost of DNA testing and its growing recognition would cater to a larger public. The test results will also prove beneficial in the “prevention, management, and treatment of disease” ([**2**](#_bookmark1)). Most people these days are self-diagnosing themselves by searching their medical symptoms on the internet ([**3**](#_bookmark2)). Such people have been termed as cyberchondriacs. Most definitions of “cyberchondria include excessive or repeated online searches for health-related information and anxiety about health” ([**4**](#_bookmark3)).

A personalized genome test enables an individual to assess what his/her medical condition will be in the future. With the advancement of science and technology, the results of DNA testing can provide us extremely vital information about the likelihood of a disease. DNA testing will prove beneficial in predicting and preventing potential risks of a disease. The results give us a chance to be aware of our susceptibilities in advance and prevent it. Also, we will be able to make more informed medical and lifestyle decisions based on these predictions.

Such tests have sparked public curiosity because they are increasingly accurate and can help determine how long a disease will run its course. The underlying issue is if DNA testing is capitalizing the curiosity of people ([**5**](#_bookmark4)). An individual's genetic information is more private than his/her general medical information and needs to be protected. The misuse of personal data could threaten individual liberties ([**6**](#_bookmark5)).

In Privacy and Freedom, Alan F. Westin has accurately defined privacy: “Privacy is the claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others” ([**7**](#_bookmark6)). This choice to determine for themselves entails consent. Consent is fundamental in deciding what and how much a person is ready to reveal about his personal information.

The fact that we now have access to quick and low-cost genetic testing will increase demand of personalized genome tests, commercial production, and distribution of the DNA testing kits, eventually making it cost-effective to introduce genetic testing in several non-medical settings, including employment and insurance ([**8**](#_bookmark7)).

The commercial interests in this incredible science of DNA testing are enormous ([**8**](#_bookmark7)). The predictions regarding potential genetic risks and the fall in the cost of genetic testing will constitute a huge incentive to conduct genetic testing by insurance companies and employers ([**8**](#_bookmark7)).

The fundamental issue is not about the access to genetic information; it is what we choose to do with that information. If the answer to this very pertinent question reveals that this sensitive information is going to be misused in order to discriminate against an individual, then such an act should be considered unlawful. It is essential to prevent the misuse of genetic data as its disclosure could adversely affect opportunities in insurance, employment, education, etc ([**9**](#_bookmark8)).

Discrimination is usually in the form of denial of employment opportunities, health insurance, or social stigma. In India, where caste, gender, racial and religious discrimination are already posing hurdles, genetic discrimination will be a significant concern.

# What constitutes Genetic Data?

Genetic data differs from medical information as genetic data is a unique combination which is hard to be kept confidential and can disclose sensitive information ([**10**](#_bookmark9)). Also, it can be easily accessible since people “constantly slough off hair, saliva, skin cells, and other trails containing our DNA” ([**10**](#_bookmark9)).

Genomes are, in the words of Murray, "future diaries" ([**11**](#_bookmark10)). It is a challenging task to keep our genetic codes private as we are always vulnerable to the use of it. The data collected could reveal about our genetic susceptibilities, risk factors, and other characteristics. This makes it easier for health insurers or employers to calculate risks based on genetic information as it helps them predict how an individual may fare in his/her future. The major problem with genetic information is that an individual who undergoes a DNA test also discloses sensitive information about his/her family ([**10**](#_bookmark9)). This could result in an invasion of privacy and anonymity being under threat. One of the major ethical issues in genetics today is “Confidentiality vs. duties towards relatives at genetic risks” ([**12**](#_bookmark11)). There are several complex ethical questions in this field with hardly any answers.

# Genetic Discrimination:

“Genetic discrimination occurs when people are treated differently by their employer or insurance company because they have a gene mutation that causes or increases the risk of an inherited disorder” ([**13**](#_bookmark12)). The threat of being discriminated on the basis of a genetic trait is a major concern for people considering to undergo a DNA test.

Concerns regarding genetic discrimination or discrimination based on health information are prevalent ([**14**](#_bookmark13)). Several countries like USA, UK, Australia and Canada have already recognized genetic discrimination in health insurance or employment. In USA, The Genetic Information Nondiscrimination Act (GINA) was passed in 2008 to restrict the access of issuers of health insurance and employers to individuals’ genetic information and prohibit genetic discrimination ([**15**](#_bookmark14)). In addition to GINA, Health Insurance Portability and Accountability Act (HIPAA) is a federal law that required the creation of national standards to protect sensitive patient health information from being disclosed without the patient’s consent or knowledge ([**16**](#_bookmark15)). India is not governed by any such legislation yet.

There are extremely high chances of genetic data being abused at the hands of potential employers or health insurance companies. The Supreme Court of India has explicitly stated that “any act of genetic discrimination, specifically by insurance companies, violates the basic tenets of Right to Equality under Article 14 and the Right to Health and healthcare guaranteed under Article 21” ([**17**](#_bookmark16)).

“A meaningful right to health care must include access to services for the diagnosis, treatment, and prevention of genetic disorders” ([**12**](#_bookmark11)). Priority should be given to provide genetic services like DNA tests and genetic counseling alongside other health facilities as it is a matter of public health policy in every country ([**12**](#_bookmark11)).

# Genetic Testing in India:

DNA technology could be extremely advantageous due to its multiple uses. It is irrefutably a ground-breaking technology in today's world ([**18**](#_bookmark17)). DNA testing is gaining popularity in India as people have started to acknowledge how beneficial it could be in the long run ([**19**](#_bookmark18)). The size of India's DNA industry, which is estimated at Rupees 300-400 crore, has been growing at a rate of 30% annually ([**19**](#_bookmark18)).

However, the potential abuse of genetic information can lead to discrimination and invasion of privacy. “Data sharing is not in opposition to privacy and should be conducted in a responsible way such that it does not infringe on the privacy rights of individuals and groups” ([**20**](#_bookmark19)).

The direct-to-consumer (DTC) market is at its inception in India. DTC is rapidly evolving as India has a large consumer market, and people are curious about tracing their ancestry, family relationships, and lifestyle choices ([**21**](#_bookmark20)). Companies like MedGenome and Mapmygenome provide genetic counseling and insights into health, fitness, nutrition, and wellness ([**19**](#_bookmark18)). These

companies may reveal if a disease runs in your family, but they don’t tell you whether or not you are going to develop that disease. Although DNA tests have become inexpensive over the years, one of the problems we are facing is that we don’t have enough labs to assess large volumes of data. Moreover, there are significant privacy risks involved in the absence of a regulatory framework or binding guidelines governing these companies ([**21**](#_bookmark20)).

# Discrimination in Health Insurance Settings:

“The more an individual is genetically susceptible to a disease, the less insurers desire that individual as a customer. The more an individual is susceptible to a disease, the more they desire comprehensive health insurance – this concept is known as adverse selection” ([**22**](#_bookmark21)).

Attempting to curb discrimination in a commercial industry like health insurance is economically, morally and legally hard to achieve ([**6**](#_bookmark5)). The pertinent question is whether individuals with genetic and non-genetic tendencies should be treated equally. It is debatable whether or not “genetic-specific safeguards are fair to the entire population” ([**6**](#_bookmark5)). But then, is it justified to exclude an individual who is affected by a genetic predisposition. To safeguard individual choices and privacy of genetic information from third parties is crucial ([**12**](#_bookmark11)).

The only judgment that specifically deals with genetic discrimination in health insurance is M/S *United India Insurance vs. Jai Parkash Tayal* ([**23**](#_bookmark22)). The facts of this case are as follows ([**23**](#_bookmark22)):

The Respondent/Plaintiff (hereinafter plaintiff) took a mediclaim insurance policy for himself, his wife and daughter from the Appellant/Defendant (hereinafter defendant). The policy was renewed every year regularly for eight years. The sum insured in this mediclaim policy is Rs. 5 Lakh per individual.

However, the problem arose when the insurance company denied the plaintiff’s claim for his heart ailment Hypertrophic Obstructive Cardiomyopathy (HOCM) on the grounds of being a genetic disorder. The plaintiff bought the policy in 2004 and was hospitalized twice between 2004 and 2006, and his claims for the same heart ailment were honored twice by the defendant i.e., the Insurance Company. The Plaintiff was again hospitalized in 2011. He then claimed an amount of Rs.7, 78,864/- from the defendant. However, the third claim was rejected on the ground that genetic ailments are not payable as per the policy genetic exclusion clauses. The plaintiff argued that the exclusion of genetic disorders was not a part of the initial policy that he bought. The exclusion clause was later added in the contract unilaterally, without notifying him and that the said exclusions should not bind him.

# The two pertinent questions that arose during the hearing were:

* Whether the exclusion in relation to genetic disorders is valid or legal? ([**23**](#_bookmark22))
* Whether the exclusionary clause relied upon by the Insurance Company could be applied to the facts of the present case? ([**23**](#_bookmark22))

# Detailed Analysis of the High Court’s Verdict:

The Court looked into the meaning of the term “genetic disorders” while answering the first question. Genes are primarily responsible for the numerous individual traits a person possesses. All of us have genetic variations. Genes pass on both positive traits and medical abnormalities from one generation to another. In some cases, genes are also carriers of certain diseases. Such conditions or diseases are known as genetic disorders. Inherited traits can be categorized into dominant and recessive traits, which further lead to disorders in a human being ([**23**](#_bookmark22)).

According to the National Human Genome Research Institute ([**24**](#_bookmark23)), genetic disorders can be subdivided into: Monogenetic disorders, Multifactorial inheritance disorder and Chromosome disorders. In all probability, medical conditions could be partially caused by genetics, but lifestyle, dietary, and environmental factors may also cause them ([**25**](#_bookmark24)). Our looks vary because of our genetic variations as no two individuals have the same genes. Even identical twins have epigenetic differences. Our environment is capable of influencing our genome through epigenetic modifications ([**26**](#_bookmark25)). Without doing a detailed genetic test, the cause of a disease cannot be determined.

The High Court specifically noted that the exclusionary clauses include even the most common ailments like cardiac diseases and diabetes ([**23**](#_bookmark22)). India currently ranks second highest ([**27**](#_bookmark26)) in the world for people diagnosed with diabetes ([**28**](#_bookmark27)). The numbers are staggering and it is predicted that we will have over 134 million diabetics by the year 2045 ([**29**](#_bookmark28)). The Court observed that a vast majority of the population will remain uninsured and will not be able to avail health insurance benefits if general exclusions are not prohibited. The Court thus considered such exclusions in health insurance policies constitutionally vulnerable.

The landmark verdict states that the insurance company cannot unilaterally modify the contract as the contract terms must be reasonable, non-discriminatory, and constitutional. Further, the claims can be disputed even if the claimant has signed the contract ([**30**](#_bookmark29)). The new inserted exclusionary clause was neither discussed with the plaintiff, nor notified to him. Therefore, there was no ‘consensus ad idem,’ i.e., there was no meeting of the minds of all the parties involved. The plaintiff is not bound by the alteration in the policy as there was no mutual agreement on the same. The Court also recognized the public interest dimension in insurance contracts.

The Delhi High Court revisited a few pertinent case precedents before giving the verdict. In *Biman Krishna Bose vs. United India Insurance*, the Supreme Court held: "A renewal of an insurance policy means repetition of the original policy. When renewed, the policy is extended and the renewed policy in the identical terms from a different date of its expiration comes into force. In common parlance, by renewal, the old policy is revived and it is sort of a substitution of obligations under the old policy unless such policy provides otherwise. It may be that on renewal, a new contract comes into being, but the said contract is on the same terms and conditions as that of the original policy” ([**31**](#_bookmark30)).

Health insurance contracts mainly differ from general insurance contracts because they provide financial security in times of unplanned medical emergencies. The cost of quality treatment in most countries is astronomical and hence unaffordable. The “right to health is a fundamental human right and not a privilege” ([**32**](#_bookmark31)). Health insurance is a necessity, especially in a developing country like India, which is still facing enormous challenges in implementing universal health coverage. The Right to avail health insurance is an integral part of the Right to health and right to healthcare, as recognized in Article 21 of the Constitution ([**23**](#_bookmark22)). Indian Courts have widely opened up the ambit of Article 21 and as a result, several rights find shelter under it ([**33**](#_bookmark32)). One such Right is the Right to health and right to healthcare.

The Hon’ble High Court examined the present case from multiple perspectives such as genetic discrimination in the context of health insurance policies globally, comparative law on genetic discrimination in various foreign jurisdictions which included, USA, Canada, UK, Australia, Estonia, Switzerland, and the EU, the one-sided nature of the contract in the present case, the principles under the Indian Constitution, and the implications all of these will eventually have on the constitutional framework of our nation.

The Court noted that despite the lack of uniformity in the nature of regulation, the jurisdictions had one thing in common, i.e., that discrimination based on genetic disposition conflicts with the human rights and in the context of insurance, exclusion of genetic disorders is heavily regulated. Due weightage is given to maintain confidentiality of the collected genetic data and its preservation.

The Court condemned the exclusion of genetic disorders and ruled that the exclusionary clause had no credibility, was arbitrary and is liable to be set aside ([**23**](#_bookmark22)). The Court also specified that the exclusionary clause is violative of Article 14 of the Constitution of India and such discrimination based on genetic disposition is unconstitutional.

The Court further directed Insurance Regulatory Development Authority of India ([**34**](#_bookmark33)) “to re- look at the Exclusionary clauses in insurance contracts and ensure that insurance companies do not reject claims on the basis of exclusions relating to genetic disorders” ([**23**](#_bookmark22)). The High Court upheld the ruling of the trial court and stated “a person, suffering from a genetic disorder, needs medical insurance as much as others”. A three-judge bench of The Supreme Court has partially stayed this verdict ([**17**](#_bookmark16)).

After a detailed analysis of this landmark verdict which prohibits genetic discrimination in India, one can infer that even though it is somewhat progressive, it may have a

counterproductive effect. On the one hand, the verdict states that it is unconstitutional and discriminatory to exclude an individual based on genetic heritage or disposition ([**23**](#_bookmark22)). However, on the other hand, it is permitting the insurance companies to charge a higher premium on the basis of a genetic disposition.

# Impact of the verdict on Insurance Companies:

Post the Delhi High Court verdict, The Insurance Regulatory and Development Authority of India (IRDAI) issued a circular to all the companies that offered health insurance ([**34**](#_bookmark33)). The circular stated the below mentioned:

1. Claims related to genetic disorders shall not be rejected for any existing health insurance policy ([**25**](#_bookmark24)).
2. Insurance companies can no longer use genetic disorder as an exclusion on their new and existing health insurance policies ([**25**](#_bookmark24)).

Therefore, insurance companies can no longer disapprove any claims related to genetic disorders. Moreover, insurers will not be able to modify a contract unilaterally. IRDAI has also revised its guidelines and made them less ambiguous. The usage of open-ended words like “related to”, “such as” or “etc” in the wording of exclusions and waiting periods in the policy contract has been banned ([**35**](#_bookmark34)).

It is unfair to charge an additional cost for a disease resulting from a genetic predisposition. Individuals should not be charged higher premiums while purchasing health insurance based on whether or not they possess a genetic trait. Such blatant genetic discrimination by insurance companies should be prohibited.

# Discrimination in Employment Settings:

Disclosure of genetic information to employers could raise significant concerns about the confidentiality of such sensitive information. It could be used to discriminate against potential or existing employees based upon their susceptibilities or deny employment ([**36**](#_bookmark35)).

In *Union of India vs. Sanjay Kumar Jain*, the respondent was a Group-C employee of the Western Railways and had applied for promotion to a Group-B post ([**37**](#_bookmark36)). He qualified for the written test and was directed to undergo a medical examination as per para 531(b) of the Indian Railway Establishment Manual. The railway board issued a circular which stated that passing the medical test is a prerequisite before the candidate is called for a viva voce exam. The respondent was declared medically unfit as he was diagnosed visually handicapped. He suffered from external squint and retinitis pigmentosa which affects the eye sight progressively. He was considered unfit for the promotion as he may become visually handicapped in the future. Consequently, the respondent was denied permission to appear for the viva voce test.

The respondent filed an appeal before the Central Administrative Tribunal (hereinafter CAT) challenging this order. After hearing both the parties, the CAT held that the provisions of The Persons with Disabilities Act, 1995 (hereinafter The Act) had not been adhered to ([**38**](#_bookmark37)). The CAT accordingly allowed the application.

The Union of India (hereinafter UOI) questioned the validity of CAT’s order and filed a writ petition, which was dismissed by the High Court. The High Court held that the CAT’s order was in accordance with the provisions of the Act. Following the verdict, The UOI filed an appeal against the order of the CAT and the High Court ([**37**](#_bookmark36)).

The Hon'ble Supreme Court observed that the argument revolved around sub-Section (2) of Section 47 of the Act, which reads as follows:

“Section 47: Non-discrimination in Government employments- (2) No promotion shall be denied to a person merely on the ground of his disability:

Provided that the appropriate Government may, having regard to the type of work carried on in any establishment, by notification and subject to such conditions, if any, as may be specified in such notification, exempt any establishment from the provisions of this section” ([**38**](#_bookmark37)).

The proviso does not operate in the absence of a notification. The Apex Court held that the proviso to the section of the Act was not applicable to the facts of the case at hand. Hence, the Court upheld the order passed by both the Tribunal Court and the High Court. The appeal was thereby dismissed ([**37**](#_bookmark36)).

Although only Section 47, sub Section (2) of The Persons with Disabilities Act was considered relevant while delivering the judgment in the present case, it would be fair to say that the respondent has been a victim of genetic discrimination in the workplace. “Retinitis pigmentosa is a group of rare, genetic disorders that involve a breakdown and loss of cells in the retina” ([**39**](#_bookmark38)).

The facts stated in the judgment declared, “He was considered unfit as he may become visually handicapped in future”. The respondent was denied a promotion on the basis of ‘what may happen’ in the future. It is unfair to be turned down for a promotion on the basis of a genetic disorder. India does not have a long history of cases that primarily deal with genetic discrimination. However, we will find several such cases that entail differential treatment by employers, insurance companies, educational institutions, and for that matter, by anyone who has access to such sensitive information of an individual.

An individual who gives consent to undergo a medical examination or genetic testing does not expect that he/she will have to face discrimination on the basis of their results in health

insurance or employment opportunities. There is a very thin line between medical information and genetic information. To maintain the trust of public in institutions, protection of genetic information should be of utmost importance ([**40**](#_bookmark39)).

It is inappropriate for an employer to discriminate on the basis of a genetic predisposition. In Sanjay Kumar Jain’s case, the results of the medical examination predicted that the respondent may lose his vision in the near future. It is essential for the employers to comprehend that one’s genetic inheritance or occurrence of a particular disease in one’s body is not within the control of an individual ([**41**](#_bookmark40)).

If the confidentiality of an individual’s genetic predisposition is not maintained, it will end up stigmatizing the person affected and his/her whole family ([**42**](#_bookmark41)). Further, several people who would otherwise never refuse a genetic test may now fear undergoing one. Invasion of one’s privacy, denial of insurance coverage, employment opportunities, and promotion are valid discrimination concerns ([**43**](#_bookmark42)).

Both employers and health insurers “who have genetic information about individuals can discriminate based on genetic factors, thereby denying individuals an opportunity to earn a livelihood and provide for the financial security of themselves and their family” ([**44**](#_bookmark43)).

# The DNA Technology (Use and Application) Regulation Bill, 2018:

The DNA Technology Bill (hereafter The Bill) ([**45**](#_bookmark44)) aims to regulate the use of DNA technology for establishing the identity of persons in respect of criminal matters (such as offences under the Indian Penal Code, 1860) and civil matters such as parentage disputes, emigration or immigration, and transplantation of human organs. The Bill also establishes a National DNA Data Bank and Regional DNA Data Banks. Every data bank will maintain the following indices: (i) crime scene index, (ii) suspects or undertrials index, (iii) offenders index,

1. missing persons index, and (v) unknown deceased persons index.

The Lok Sabha passed the Bill in 2019 but it failed to get a nod from the Rajya Sabha and therefore lapsed ([**46**](#_bookmark45)).The Bill has been enacted to expand the application of DNA technology and to strengthen the justice delivery system by using DNA to identify certain categories of people, such as – criminal offenders, victims, missing, and deceased persons ([**47**](#_bookmark46)). Under this Bill, a written consent by individuals is required to collect DNA samples from them. Consent is not required for offences with a punishment of more than seven years of imprisonment or death ([**18**](#_bookmark17)).

# Shortcomings of The Bill:

The new proposed Bill is very similar to the Bill drafted by the 271st Law Commission Report in 2017, a month prior to the *Justice KS Puttaswamy vs. Union of India* verdict was passed ([**48**](#_bookmark47)). It seems as if nothing has been done to align this Bill with the standards laid down in the

Puttaswamy case ([**49**](#_bookmark48)). This Bill should not be enacted in the absence of a robust data privacy legislation as it would erode the fundamental Right to privacy ([**50**](#_bookmark49)).

The other concern is related to the information that DNA can reveal about a person. The Bill states that a DNA profile is defined as the result of the analysis of a DNA sample for establishing the identity of a person ([**45**](#_bookmark44)). However, it is a known fact that DNA is capable of revealing further information, apart from identity ([**47**](#_bookmark46)). Such information may include medical or physical characteristics of a person. In order to protect the privacy of an individual, the Bill should have specifically stated that the DNA profile will exclude this information. By failing to impose restrictions on the region of the DNA that can be used for testing and by failing to limit the information that a DNA profile may contain, this Bill will make a large population susceptible to profiling based on their disabilities, medical records, etc. These profiles can be misused for commercial gain, surveillance, and for committing crimes ([**51**](#_bookmark50)). In countries like USA and UK, DNA profiling for criminal investigations use only that portion of the DNA which pertains to the identity of an individual ([**47**](#_bookmark46)).

DNA testing is being used extensively for criminal investigation purposes. Thus, it is not clear why civil disputes have been included in the framework of The DNA Bill. For the use of DNA profiling in criminal investigations, the Bill provides certain safeguards such as consent, storage, and removal of DNA profiles. However, no safeguards have been provided for the use of DNA technology in civil matters. There should be a separation of criminal and civil databanks ([**47**](#_bookmark46)).

The Supreme Court, in a landmark judgment on privacy, declared that privacy is a fundamental right under the constitution ([**49**](#_bookmark48)). It also held that the Right to privacy is intrinsic to life and liberty and thus comes under Article 21 of the constitution ([**49**](#_bookmark48)). Nonetheless, it seems as if the Bill has completely disregarded what was earlier held by the Apex Court. In Puttaswamy, the Apex Court specified that informed consent plays a vital role in the Right to privacy. The Bill has not even defined consent, but it should have been amended to include the definition of consent, in accordance with the privacy judgment ([**50**](#_bookmark49)). Further, it fails to provide standards for consent as there is no provision for notice to the individual who has to undergo a DNA test. When consent is not given, a magistrate can order the collection of DNA samples. Consequently, the Bill allows for uninformed consent to be obtained, perhaps through intimidation.

This Bill fails to impose restrictions on the exact information to be extracted to create the DNA profile in each of the indices. For example- In a crime scene index, two different DNA samples will have to be matched with each other. Whereas, in an unidentified deceased person’s index, merely physical reconstruction of a person will be required.

The government should be obligated to automatically remove all biological material as soon as the purpose of the collection is served ([**50**](#_bookmark49)). They need not wait for a written request as there is lack of awareness in people. An individual should be given the Right to retrieve his/her DNA samples and the removal of DNA profiles should be time-bound. In order to prevent any misuse or potential threats with respect to privacy of genetic information, there should be a time limit imposed for storing such personal data i.e., DNA profiles. If this data is stored for a shorter

period, it will minimize the risk of any external intervention or misuse. Further, The Bill only provides for the removal of information from the DNA Banks and not the DNA laboratories itself, which are the primary source of this data ([**45**](#_bookmark44)).

Finally, the financial assessment of the whole DNA profiling project has been grossly underestimated. The government has allocated a sum of Rupees 20 crores for DNA profiling. The estimated cost of obtaining DNA samples from criminal offenders in India alone could be over Rs 1,800 crore ([**52**](#_bookmark51)).

The DNA Bill has several limitations, both procedural and legal. The clauses in this Bill have been drafted very ambiguously. The security and privacy concerns have also been overlooked. The Bill must be in consonance with the privacy standards laid down in the Puttaswamy verdict, before it is enacted. Moreover, additional privacy safeguards should also be incorporated in the Bill. The DNA bill has been pending for a long time and should be fast- tracked.

# CONCLUSION & RECOMMENDATIONS:

With technology developing at a colossal rate, our Right to privacy is being curtailed. It is extremely important to acknowledge that the results of a genetic test could be a matter of significant concern for the subject and should remain confidential. The right time to have a dialogue on privacy issues and consent is now. It should be compulsory “to obtain informed consent from the patients” so that their interests, such as privacy concerns, are protected ([**1**](#_bookmark0)). The fear of genetic discrimination is intense, and it could have a real impact on diminishing DNA testing. We need good governance, stricter laws, and policy guidelines that not only prevent differential treatment on the basis of a genetic predisposition but also prohibit employers and insurers from requiring genetic tests or using genetic information to discriminate against an individual ([**41**](#_bookmark40)). We have to ensure that there is no misuse of the information gained from genetic testing as disclosure of such sensitive personal information can be detrimental for individuals.

As of now, there is no legislation in India to regulate the use of genetic data or to prohibit genetic discrimination. There is a need for a comprehensive law that regulates the collection, use, and dissemination of personal genetic data ([**10**](#_bookmark9)). We need a law that protects individuals from genetic discrimination under all circumstances and is not just limited to prohibiting discrimination in insurance and employment. It is incumbent on the legislature and the judiciary to ensure non-discrimination on the basis of genetic information. The DNA Technology (Use and Application) Regulation Bill, 2018, has several inconsistencies and should be subjected to further parliamentary scrutiny before it is approved. Moreover, there should be transparency on who has access to our genetic data and accountability in order to protect individuals from abuse of their data. Personal privacy can be highly compromised if genetic information is leaked. The new legislation should not just focus on protecting the information, but overcoming all forms of genetic discrimination.

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