

RIGHT OF PRIVACY OF GENETIC INFORMATION IN CRIMINAL CASES

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INTRODUCTION

Genetic Information is the information about every individual's genetic heritage. It can tell a lot about the possible risks of any genetic disorder. Hence, the right to privacy is essential while dealing with genetic information, especially in criminal cases where every argument is recorded and proof of the tests is presented as well. As the right to privacy for all is mentioned under the umbrella act of Article 21, every individual has the right to privacy and violating it can lead to some serious punishment.

In this article, I have attempted to discuss what exactly genetic information is and the process by which genetic testing happens as well as the risks and benefits involved. I have attempted to explain what DNA is and how it helps in criminal proceedings. I have also mentioned the right to privacy and its involvement in criminal cases.

GENETIC INFORMATION

Cells are the building blocks of the human body. There are many different types of cells that have different functions. They form all the organs and tissues of your body. The same deoxyribonucleic acid, or DNA, is found in almost every cell in a person's body. DNA is the material that carries hereditary information in humans and in almost all other organisms.

The code for the construction and maintenance of an organism is contained in DNA. Just as cells are known as the building blocks of organisms, nucleotides are known as the building blocks of DNA. "Each nucleotide is named depending on its nitrogenous base. The nitrogenous base can be a *purine*, such as adenine (A) and guanine (G), or a *pyrimidine*, such as cytosine (C) and thymine (T)."¹

Base pairing occurs between a purine and a pyrimidine. Thus, adenine (A) would pair with thymine (T) and guanine (G) would pair with cytosine (C), which are all complementary pairs. "The sugar and phosphate of the nucleotides form the backbone of the structure,

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¹ 'Storing Genetic Information' (*LibreTexts*) <<https://bio.libretexts.org/@go/page/35708?pdf>> accessed 13 May 2023

whereas the nitrogenous bases are stacked inside.”² The twisting of the two strands around each other results in the formation of uniformly spaced major and minor grooves.³

“In one sense, almost all information about a person’s health and physical well-being can be called *genetic information*. A casual glance reveals information about a person’s gender, race, height, weight, and other features that are related, in whole or in part, to that person’s genetic inheritance.”⁴ Genetic information can be used to medically provide information on a person’s blood pressure, diabetes, cholesterol levels, etc.

Genetic information is passed from generation to generation through inherited units of chemical information (in most cases, genes).⁵ By reproducing, species maintain a 'bank' of genetic information linking individual members and successive generations. There may be variations in the form of hair colour, and skin colour as well as some characteristics that cannot be seen may also be passed on.

PROCESS OF GENETIC TESTING

Before going through the process of genetic testing it is essential to the risks, benefits, informed consent and the counseling process. “The process of educating a person about the test and obtaining permission to carry out testing is called informed consent. *Informed* means that the person has enough information to make an educated decision about testing; *consent* refers to a person's voluntary agreement to have the test done.”⁶ However, informed consent can only be given by an adult who understands the medical conditions but in the case of a child, the parent or guardian gives the consent on behalf of the child.

It is extremely important for either the doctor or the genetic counselor to explain the test, clear all doubts and questions and make sure the consent is then signed willingly and doubt-free. Information about what the test is, its purpose and the condition for which it is being performed is therefore part of informed consent. Further includes what the test results mean

²‘Storing Genetic Information’ (*LibreTexts*) <<https://bio.libretexts.org/@go/page/35708?pdf>> accessed 13 May 2023

³‘Storing Genetic Information’ (*LibreTexts*) <<https://bio.libretexts.org/@go/page/35708?pdf>> accessed 13 May 2023

⁴Australian Law Reform Commission, *Essentially Yours: The Protection of Human Genetic Information in Australia* (ALRC Report 96) ch 3(3.2)

⁵Education Victoria, ‘Genetic Information in the Victorian Curriculum: Science’, [2018] <[https://www.education.vic.gov.au/school/teachers/teachingresources/discipline/science/continuum/Page/s/geneticinfo.aspx - top](https://www.education.vic.gov.au/school/teachers/teachingresources/discipline/science/continuum/Page/s/geneticinfo.aspx-top)> accessed 15 May 2023

⁶MedlinePlus, ‘Understanding Genetic Testing: Informed Consent’ <<https://medlineplus.gov/genetics/understanding/testing/informedconsent/>> accessed 15 May 2023.

and the benefits and the risks of undergoing the particular test as well as acknowledging that the person undergoing the test has discussed it with a health care provider.

Genetic tests are performed on a sample of blood, hair, skin, amniotic fluid (the fluid that surrounds a foetus during pregnancy), or other tissue.⁷The buccal smear is often used, where a cotton swab is used to collect cells from the inside of the cheek. This swab sample is then sent to the laboratory to look for changes in the DNA or chromosomes of the suspected condition. The reports are then sent to the doctor or the patient.

The heel prick test, which is performed on newborn babies, involves taking a blood sample by pricking the baby's heel. The result is usually delivered only for a positive test result, for which further tests are done to figure out if a baby has a genetic disorder and can also help in detecting any rare disorders. The reasons for getting a genetic test could be varied like checking if one has a risk of the disease in the future, finding the cause of symptoms of a disease, or choosing the best treatment plan.

RISKS AND LIMITATIONS OF GENETIC INFORMATION

“Genetic testing can provide only limited information about an inherited condition. The test often can't determine if a person will show symptoms of a disorder, how severe the symptoms will be, or whether the disorder will progress over time.”⁸ Depending on the method used for genetic testing there might be very little or some risk associated with it. For example, the buccal smear or the blood sample possess very little risk but on the other hand another genetic testing procedure, namely prenatal diagnostic testing poses a risk of miscarriage as the amniotic fluid sample is required.

The above-discussed risks are those of a physical nature often there might be some mental, social, or financial consequences as well. This could also lead to rifts or closeness between family members. The genetic results are individually received hence proper consultation may not be given and interpretation of the results might affect an inaccurate or incomplete treatment plan. Although a test can detect a genetic change that is the cause of a condition, it often cannot predict how severely the person with the change will be affected. For example,

⁷MedlinePlus, 'How is genetic testing done?'

<<https://medlineplus.gov/genetics/understanding/testing/procedure/>> accessed 15 May 2023

⁸MedlinePlus, 'Understanding Genetic Testing: Risks and Limitations'

<<https://medlineplus.gov/genetics/understanding/testing/riskslimitations/>>accessed 15 May 2023.

some patients diagnosed with cystic fibrosis (CF) have mild symptoms while other patients with CF have severe lung, pancreatic, and intestinal problems.⁹

Many people undergo genetic testing to find out whether they have cancer and while it may help in giving you results on whether one has a risk of cancer, it may sometime also turn out to be wrong. This can lead to a disbalance in the emotional health of the person. There is also a big risk of data leak and one's genetic information may also be used in an unauthorised way. The likelihood of developing many conditions is also influenced by other genetic and environmental factors, lifestyle choices and family medical history.

The result of the test can be either positive, negative or unknown. However, a negative test result does not mean that you won't get the disease and rather tells you that there's a genetic variant present and various factors like food, and lifestyle could very well trigger it. It is essential that no matter what the test results are, one cannot be relaxed about not being able to contract the disease and precaution is always necessary. Even if you receive a negative test report, you still need to take the proper precautions to prevent the disease from occurring.

DNA FUNCTIONS

"Genes carry biological information that must be copied accurately for transmission to the next generation each time a cell divides to form two daughter cells. Two central biological questions arise from these requirements: how can the information for specifying an organism be carried in chemical form, and how is it accurately copied?"¹⁰The discovery of DNA has answered both questions.

In criminal cases, DNA has the most evidential value and helps in confirming who the offender is and makes the process easier. To take an example of a rape scene, the skin under the nails of the victim will help pinpoint the offender by a simple DNA test and can help the victim receive justice quicker. Hence the time it takes to cross off suspected offenders from the list can be cut down and can give a lot of peace to the victim and their families.

As technology keeps increasing and the DNA testing becomes cheaper and quicker, more pressure is placed on institutions to protect the privacy and ethical practice. While looking at the Indian scenario, a conservative view had been taken by the judges in the matter of how valuable DNA evidence is for solving familial dispute cases. The Indian Judiciary system has

⁹Testing, 'Genetic Testing: Benefits, Risks, and Future' <<https://www.testing.com/genetic-testing-benefits-risks-and-future/>> accessed 15 May 2023.

¹⁰Bruce Alberts et al., *Molecular Biology of the Cell, Fourth Edition* (first published 2002, Garland Science)

always faced this dilemma of giving priority to a societal or a biological percentage in matters of parental responsibility. DNA percentage testing can provide evidence that shows that a person has a blood relation or biological connection with a deceased person or can help a person to become a party to the suit.¹¹

In criminal proceedings as well, even though Section 53 of the Criminal Procedure Code, 1973¹² does not specifically talk about DNA, it does however mention the examination of the accused using scientific techniques. Hence, a hair sample, nail, saliva, handprints, etc play a major role in finding who the accused is at a crime scene by a simple method of DNA testing.

RIGHT OF GENETIC PRIVACY

The right to privacy, a fundamental right is included under “Article 21 of the Indian Constitution. Article 21 states that Protection of life and personal liberty: No person shall be deprived of his life or personal liberty except according to procedure established by law.”¹³ Here, life doesn’t mean mere survival but rather living a complete life with meaning and dignity. The case of *Kharak Singh v. State of UP* was the first of its kind “where the Supreme Court held that Regulation 236 of UP Police regulation was unconstitutional as it clashed with Article 21 of the Constitution.”¹⁴ The Court also held that under the right to protection of life and personal liberty, the right to privacy is also a part of it.

The right to genetic privacy says that every individual’s genetic information is inherent to the individual and strictly cannot be allowed in the public domain without consent. Thus concern regarding the privacy of genetic information has come to the forefront as it contains a lot of sensitive information as well as serves as an identification of any person. Hence, genetic information needs stricter protection under the law which is not present in the Indian legislation system. Although the right to privacy is explicitly mentioned in the Constitution of India, the right to protection of genetic information must also be covered.

However, in the US they have “the *Genetic Information Nondiscrimination Act (GINA) of 2008*. GINA protects individuals against discrimination based on their genetic information in

¹¹Vividh Jain, ‘Application of DNA technology in the administration of justice : problems and prospects’ (*iPleaders*, September 13, 2020) <<https://blog.iplayers.in/application-dna-technology-administration-justice-problems-prospects/>> accessed 15 May 2023

¹²Code of Criminal Procedure 1973, s 53

¹³Constitution of India 1950, art 21

¹⁴Hinaailiyas, ‘Right To Privacy Under Article 21 and the Related Conflicts’ <<https://www.legalservicesindia.com/article/1630/Right-To-Privacy-Under-Article-21-and-the-Related-Conflicts.html>> accessed 15 May 2023

health coverage and in employment.”¹⁵This legislation was much needed and puts a stop to employers using people’s information for the purpose of hiring, firing or promotion. In the United Kingdom as well, under the Criminal Justice and Public Order Act of 1994, *the National DNA Database (NDNAD)* is made.¹⁶ This Act basically authorizes recording a person’s DNA regarding certain offences.

CRIMINAL CASES

Criminal proceedings consist of a case where a crime is done against society and the defendant is brought to the court by the petitioner. A crime can be from anywhere heinous to petty and punishment is given accordingly to prevent a similar type of incident in the future and to punish the culprit. The procedure of a criminal proceeding is a very thorough and lengthy process as it involves various steps to it.

The first thing the victim does when committing an offence is to file an FIR (First Information Report) followed by an investigation by the Police. This is the most important step after the filing of an offence as this is the stage where evidence is collected, witness statements are recorded and the accused is interrogated. It is also at this step that various examinations are made on the victim. This information is then turned in to the court and the proceedings follow.

A criminal case to recall that prohibits genetic discrimination in India would be that of *United India Insurance v. Jay Prakash Tayal*¹⁷. In the above case, the Delhi High Court stated that “Discrimination in health insurance against individuals based on their genetic disposition or genetic heritage, in the absence of appropriate genetic testing and laying down of intelligible differentia, is unconstitutional”, however, a comprehensive analysis of the judgment reveals that it is self-defeating in nature, as on one side it is stating that it is unconstitutional to discriminate against such clients but it is also allowing companies to ask for higher premiums or deny claims if a genetic disorder has been established by appropriate medical testing.¹⁸

It concluded that health care is a basic human right hence discrimination on the basis of genetic information contradicts it and insurance is also heavily regulated to exclude any

¹⁵ Office for Civil Rights, ‘Genetic Information’ (U.S. Department of Health and Human Services) <<https://www.hhs.gov/hipaa/for-professionals/special-topics/genetic-information/index.html>> accessed 15 May 2023

¹⁶Sharad Yadav, ‘DNA technology in Indian legal scenario’ (*iPleaders*, February 19, 2021) <<https://blog.ipleaders.in/dna-technology-in-indian-legal-scenario/>> accessed 15 May 2023

¹⁷*M/s United India Insurance Company Limited v. Jay Prakash Tayal* (2018)

¹⁸Anik, ‘Right Of Genetic Privacy’ (*Vidhikarya*, 11 March 2022) <<https://www.vidhikarya.com/legal-blog/right-of-genetic-privacy>> accessed 15 May 2023

genetic disorders. Hence they concluded that genetic disorders must not be opted out of insurance and must be duly covered as it violates the Right to Health.

However, we still need to ponder the question of the privacy of genetic information. Privacy is important for anyone, be it a victim or the accused. Obtaining genetic information/ DNA testing may be essential for a criminal proceeding but maintaining the privacy of any individual is a right on its own. The systems where genetic information is stored must become hack-proof and steps and measures must be taken to ensure no data leaks happen.

CONCLUSION

Although genetic testing is one of the quicker methods of getting information about the accused in criminal cases we must not forget the privacy of genetic information of the accused. The right to privacy applies to everyone be it a victim, an accused, or a witness. Being able to have that kind of protection on one's data gives one a sense of protection and relief. However, if any leak of data does happen it may result in a change in their emotional wellbeing.

Lots of other countries like the US and the UK have made various laws that record and protect DNA information namely, the "Genetic Information Nondiscrimination Act (GINA)" of 2008 and "the National DNA Database (NDNAD)". Hence, it is time India takes these privacy laws seriously and protects people's DNA or genetic test information.