GENE TESTING AND GENETIC DISCRIMINATION IN INSURANCE

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ABSTRACT

As technology has become part of our life, all essential hereditary data may be accessible to everyone through numerous sources, utilizing them there is a chance of discrimination in insurance and employment. The fear of disclosure of genetic information to insurers or employers will force the insured to avoid gene testing which necessary for medical purposes. On the other hand, the lack of proper legislation to regulate this matter can affect the insurance company and give rise to adverse selection as the customers can take advantage of privacy and deny the predominant facts about them during the formation of the policy which will in later stage demand the insurance company to pay higher coverage. This article centers on the concept of gene testing, the risks and benefits associated with it, and its part in Insurance which may prompt genetic discrimination. Genetic discrimination in the field of insurance can bring a huge impact on society. The importance of a proper legal framework for preventing the mandate on the disclosure of genetic results and genetic discrimination towards insurance is analyzed. The methodology utilized draws out the current position and practices followed by different countries and also a short report on the current situation of India around here.

Keywords: Genetic discrimination, Gene testing, Insurance, legal framework

Introduction

Gene testing has become an increasingly important part of human life for diagnostic or predictive health information. This information can assist individuals in making behavioral or other changes to minimize the threat and symptoms associated with genetic disorders, and in some cases, can aid in the earlier initiation of treatment. Despite all these advantages people are concerned about the risk that genetic information may be used for discriminatory purposes, potentially affecting insurance and employment. Insurers may choose to use the insured's genetic details to set premiums (to achieve "actuarial fairness") or to limit coverage of people that have a high genetic risk of developing conditions in some situations.[1] The insurers and employers might seek to obtain the genetic information through a clinical setting or by Direct-to-Customer (DTC) genetic test, those results whether accurate or not can be under mandatory disclosure.[2] People are in the fear of genetic discrimination as a result of unwanted disclosure of genetic test results. In the field of clinical care, 28% of declining participants invoked the fear of insurance discrimination, and a majority of patients in a study about breast cancer-genetics tests refuse to participate in research if the results could be given out to insurers.[3] These disclosures might lead to genetic discrimination. The risk might increase if the insurers seek other kinds of personal data to determine the genetic status of a person for constructing and pricing their policies.

Genetic Testing

The tests that are initiated in the clinical area, which may be done for diverse purposes on clinical genetics, including the diagnosis of:

i. Genetic disease in children and adults,
ii. Identification of future disease risks,
iii. Prediction of drug responses and

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[1] Bombard, Y., King Wong, E. &Lemmens, T. *Insurance and genetic information. in Encyclopedia of Life Science,* John Wiley & Sons, 2017, available at <https://onlinelibrary.wiley.com/doi/10.1002/9780470015902.a0005203.pub3> (last visited on Mar. 18, 2021)

[2] Tiller, J. &Lacaze, P. *Australians can be denied life insurance based on genetic test results, and there is little protection. The Conversation* 2017, available at <http://theconversation.com/australians-can-be-denied-life-insurance-basedon-genetic-test-results-and-there-is-little-protection-81335> (last visited on Mar. 18, 2021)

[3] Dalpé, *G.* et al. *Breast cancer risk estimation, and personal insurance*: a qualitative study presenting perspectives from Canadian patients and decision-makers. Front. Genet. 8, 128 (2017).

iv. Prediction of risks of disease to future children.[4]

Different Forms of Genetic Testing

The following forms of gene testing are available in clinical practice, depending on a patient's specific medical problem. The most common include:

- *Prenatal testing* to detect changes in fetus genes or chromosomes before birth.
- *Newborn screening*s are used to identify highly penetrated genetic disorders that can be treated early in life.
- *Diagnostic or confirmatory genetic* testing to identify or confirm a specific genetic condition in an asymptomatic individual.
- *Carrier screening* to identify unaffected individuals as carriers for a specific autosomal recessive disease.
- *Predictive and pre-symptomatic testing* for estimating the risk of developing an adult-onset disease or predicting future disease onset.
- *Pharma co-genetic testing* to guide individual drug dosage, selection, and response.
- Pre-implantation genetic testing to reduce the risk of having a child with a particular genetic or chromosomal disorder.
- *Nutri genetic testing* to study the effect of genetic variations on the interaction between diet and health or on nutrient requirements.[5]

These are few types out of 1000 varieties of genetic testing practices used around the world.

Genetic Discrimination

The insurance companies that have a profit motive have a clear rationale to set up the base eligibility or premiums depending upon the genetic information, the fairness of the practice is still controversial. The customer is treated differently regarding their genetic test results. This varied treatment for the individuals who are likely prone to any genetic

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[4] William C. Shiel Jr. *Medical definition of genetic testing*, *Medicine* Net Blog, available at <https://www.medicinenet.com/genetic_testing/definition.html>. (last visited on Mar. 18, 2021)

[5] *International Society of Genetic Genealogy* Wiki, available at <https://isogg.org/wiki/List-of-DNA-testing-companies> (Accessed on Mar18, 2021)

disorder as believed from the results of their genetic test is known as genetic discrimination. The US insurance industry has two conflicting ideologies:

i. The more a person is genetically predisposed to disease; the insurance company with a lesser motive towards profit will only have the desire to take such a person as its customer.

ii. The more a person is predisposed to disease, they will likely have a desire for comprehensive health insurance, this is known as *adverse selection*.[6] Whether charging a higher premium on genetic bases ethical? It differs from each society's political philosophy. On a communal level, ethics depends on society's principles, Libertarians may believe that health discrimination based on genetics by for-profit entities is fair, either higher user must pay more or the insurance industry must turn in to free-market, another view is that every individual must have access to basic healthcare, is a just society.[7]

Benefits and Risk in Genetic Testing

Genetic testing helps in the identification of disease risk and earlier diagnosis of the disease for asymptomatic people that can help in getting the specialized treatment in the earlier stage of the disease. Potential new treatments can be accessed by screening the person’s genetic profile. Preventative therapies guided by genetic tests could help in decreasing the expense of healthcare costs in the end-stage of the disease.[8] There is a ray of hope that individuals, once informed about their genetic tendencies, may be encouraged to change lifestyle behaviors such as smoking, poor physical activities, and other unhealthy habits, and enter into wellness programs.

The risk in genetic testing may include the complication that insurers might be threatening the public with genetic information that could be used to anti-select. If an

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[6] American Academy of Actuaries, *Risk Pooling: How Health Insurance in the Individual Market Works* (2017), available at <https://www.actuary.org/content/risk-pooling-how-health-insurance-individual-market-works-0> (last visited on Mar. 21, 2021)

[7] Carolyn Riley Chapman, Kripa Sanjay Mehta, Brendan Parent, Arthur L Caplan, *Genetic discrimination: emerging ethical challenges in the context of advancing technology*, Law and Bioscience, available at <https://academic.oup.com/jlb/advance-article/doi/10.1093/jlb/lsz016/5651192> (last visited on Mar.22.2021)

[8] *Genetic-testing-in-insurance*, available at <https://www.rgare.com/docs/default-source/newsletters-articles/genetic-testing-in-insurance---challenges-and-opportunities---dec-2016.pdf?sfvrsn=acce399f_0> ((last visited on Mar. 21, 2021)

insurer is considered to be misusing test results or if insurers choose genetic testing services that either cannot deliver or produce incorrect results, it can suffer a negative image and face legal challenges. Insurers must also follow strict privacy and confidentiality policies when it comes to genetic information, or face the negative public and regulatory views.[9]

Ethical Issues in Gene Testing and Insurance Industry

The Contract of Insurance is governed by the principle of *uberrimae fide* which mandates utmost good faith between both the parties ie., the insurer and the insured. Utmost good faith is the disclosure of material facts and circumstances associated with a risk insured within a policy. Hence, non-disclosure of material facts by the parties whether fraudulent or innocent, shall render the contract voidable at the option of either of the parties.[10]

A) *Ethical Issues Governing Insurance Companies*

Adverse selection occurs when people have undergone testing and conceal the test results from insurers.[11] If the insured person does not disclose information that is an essential insurer to know, then this breaks the equilibrium of the relationship and the probability of adverse selection arises. If insurers are prohibited from having access to pertinent information, the policyholders could use genetic information to abuse the insurance system, taking advantage of private knowledge of the risks they are submitting for coverage.[12] As a consequence of the lack of information between insurers and insured persons, the insurance companies may be forced to adjust premiums.

B) *Ethical Issues Governing Policy Holders*

The fear of genetic discrimination by insurers or employers among the public will increase when genetic information is been disclosed to insurers or employers.[13] This

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[10] Law Commission of India, Report No.112.

[11] Sandberg P, *Genetic information and life insurance: a proposal for an ethical European policy*, SocSci Med (1995), available at <https://www.nature.com/articles/5201117>, (last visited on Mar. 21, 2021)

[12] Chuffart A, *Genetics and Life Insurance: A Few Thoughts*. *Zurich*, Swiss Re (1997), available at <https://www.nature.com/articles/5201117>, (last visited on Mar. 24, 2021)

[13] Williams JK, Schutte DL, Evers CA, Forcucci C, *Adults seeking presymptomatic gene testing for Huntington disease*, Image J NursSch (1999), available at <https://www.nature.com/articles/5201117>, (last visited on Mar. 28, 2021)

fear has been observed in groups of people with a family history of Huntington disease who needs pre-symptomatic genetic identification, people attempted to avoid insurance or employment discrimination by withholding the decision to take up a test from their primary care providers. People also feel insecure to share the result with their general practitioner considering the fear of disclosure to insurance companies.[14]

International and National Policies on Genetic Testing

Many national and international committees are evolved to safeguard individuals from genetic discrimination.

i. The UNESCO Universal Declaration on the Human Genome and Human Rights (1997) states that 'no one shall be subjected to discrimination based on genetic characteristics that are designed to encroach on human rights, civil liberties, and human decency, or have the effect of infringing on these rights, freedoms, and dignity.
ii. The 1997 Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being about the Applications of Biology and Medicine specifies in Article 11. This specifies that "Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited".

There are three different approaches in respect of insurance and genetic test results at a national level:

1. Prohibition of any use of genetic information by insurers outright;
2. Legislation prohibiting this below a certain amount of coverage;
3. Moratoria;[15]

1. Prohibition of any use of genetic information by insurers

Austria, Belgium, Denmark, Estonia, France, Luxembourg, and Norway have opted for this solution. In Belgium, a unique feature of the legislation is that it prohibits the use

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[14] Kaufert PA, *Health policy and the New Genetics,* Soc-Sci Med (2000), available at <https://www.nature.com/articles/5201117>, (last visited on Mar. 29, 2021)

[15] Evans JP, Skrzynia C, Burke W, *The complexities of predictive genetic testing*, 322 2001. available at <https://www.nature.com/articles/5201117> , (last visited on Mar. 29, 2021)

of genetic information even in places where it can benefit the applicant. The rationale is to protect privacy.

2. Legislation prohibiting this below a certain amount of coverage

This is followed in Sweden, Netherlands, and United Kingdom. In the United Kingdom, the government had set up the Genetics and Insurance Committee (1998) whose primary function is to assess the validity of genetic tests that Insurance providers must be able to consider when determining premiums.

3. Moratoria

Moratoria are either indefinite (Finland, Germany), or for a limited number of years (France, Switzerland), or still limited to insurance policies that do not surpass a certain value (Sweden, Netherlands, United Kingdom).

Current Scenario in Gene Testing and Insurance – United States, France, Switzerland, Canada, United Kingdom and Australia

United States

In the year of 2008, the Genetic Information Non-discrimination Act (GINA) was adopted. Title II of GINA prohibits both the acquisition and the use of genetic information for employment and health insurance.[16] Health insurers are prohibited from using genetic information to forecast eligibility or determining premiums, to mandate applicants to undergo genetic testing, or to impose pre-existing condition exclusions. Although the statute covers the manifested conditions of a person's relatives, it does *not* cover an individual's genetic conditions. The law's primary focus is therefore individuals who are pre-symptomatic or asymptomatic.

France

Genetic test reports are only permitted to be used for medical and research purposes in France, where health care coverage is universal and largely funded by the government.[17]

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[16] Genetic Information Non-discrimination Act of 2008, Pub. L. No. 110-233 (2008); United States available at <https://www.gpo.gov/fdsys/pkg/PLAW-110publ233/content-detail.html> (last visited on Mar. 26, 2021)

[17] European Commission, Directorate-General for Research, Quality of Life and Management of Living Resources. *Genetic Testing: Patient's Rights, Insurance, and Employment*: *A Survey of regulations in the*

Under the Penal Code (art. 226-29), using genetic information for other purposes like employment or insurance represents a diversion from medico-scientific purposes which is punishable with 1 year of imprisonment and a €15,000 fine.[18]

Switzerland

Federal Act on Human Genetic Testing is a statute to prohibit genetic discrimination. Insurers must receive approval from individual citizens before conducting an examination. The Swiss regulation prohibits the use of test results only under a certain financial limit (regardless of the type of genetic information and the disease).[19]

Canada

Canada provides publicly funded healthcare to its population, proposals were made to manage genetic discrimination as a prohibited ground of discrimination. Under the new Canadian law, employment and *all* forms of insurance are subject to the law, also holding life and long-term insurance (which are left out of the US GINA).[20] Later in 2018, a new code was introduced, protecting commercial and consumer interests.

United Kingdom

In 2001, the United Kingdom adopted a new approach to contain the issues of genetic discrimination, a hybrid of government regulation and industry self-regulation. It is a non-legislative approach against genetic discrimination by negotiating with the Association of British Insurers (ABI) and signing the Concordat and Moratorium on Genetics and Insurance.[21]

Australia

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*European Union (*Office for Official Publications of the European Communities/Bernan Associates, 2002), available at <https://academic.oup.com/jlb/advance-article/doi/10.1093/jlb/lsz016/5651192>, (last visited on Mar. 27, 2021)

[18] France. Code Pénal (1994), art. 226-26, No.54, 1994(France)

[19] The Swiss Parliament. GenetischeUntersuchungenbeim Menschen: Bundesgesetz— Analysegénétiquehumaine: Loifédérale (The Swiss Parliament, 2018); available at <https://www.parlament.ch/en/ratsbetrieb/amtlichesbulletin/amtliches-bulletin-die-verhandlungen?SubjectId=4235>, (last visited on Mar. 27, 2021)

[20] Gold, K. How *genetic testing can be used against you—and how Bill S-201 could change that*. The Globe and Mail(2016) available at <,https://www.theglobeandmail.com/life/health-and-fitness/health/bill-s-201-aims-to-end-genetic-discrimination-in-canada/article29494782/> (last visited on Mar. 27, 2021)

[21] Government of the United Kingdom & Association of British Insurers. Code on Genetic Testing and Insurance (2018), available at <https://www.geneticalliance.org.uk/wp-content/uploads/2018/10/code-on-genetic-testing-and-insurance_embargoed/> (last visited on Mar. 28, 2021)

Australia's Financial Services Council (FSC), starting in July 2019, a moratorium that will prevent the use of genetic test results from insurance applications. Invoking its undertaking to genetic inclusion, FSC will enable Australians to get insurance, without the need of disclosing adverse test results, up to AUD 500,000 for death and permanent disability, AUD 200,000 for trauma, and AUD 4,000 a month for income protection. The moratorium will be valid for 5 years and reviewed in 2022 to assess its actual impacts.[22]

Current Scenario in India

The Apex court in India has specified that any act of genetic discrimination, especially by insurance companies, violates the basics of Right to Equality under Article 14 and the Right to Health and healthcare guaranteed under article 21. This has been the argument used by most nations, where any such act of discrimination is done by the state, individual, or a corporate body. The detailed analysis of various aspects and dimensions is analyzed in the case of *United India Insurance Co. v. Jay Prakash Tayal*.[23] Additionally, this discrimination is recognized as a violation of fundamental rights which is not only actionable against the state but also other non-state actors. But the Puttuswamy[24] judgment denied this concept of direct horizontal application of privacy right and hence there is a need for a parliamentary law to protect the privacy of an individual against the Non-State Actors.[25]

United India Insurance Co. V. Jay Prakash Tayal

United India Insurance Co. v. Jay Prakash is the only Indian case that expressly prohibits genetic discrimination. However, a thorough examination of the ruling shows that it is self-defeating in nature; on the one hand, it declares that discrimination against such clients is unconstitutional, but it also allows employers to charge higher premiums or refuse claims if a genetic condition has been identified by adequate medical testing.

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[22] Joly, Y., Feze, I. N., Song, L. &Knoppers, B. M. *Comparative Approaches to Genetic Discrimination: Chasing Shadows?* Trends Genet, 299–302 (2017). available at <https://www.cell.com/trends/genetics/fulltext/S0168-9525(17)300331?_returnURL=https%3A%2F%2Flinkinghub.elsevier.com%2Fretrieve%2Fpii%2FS0168952517300331%3Fshowall%3Dtrue> (last visited on Mar. 28, 2021)

[23] United India Insurance Company Limited v. Jai ParkashTayal, (2018) 247 DLT 379

[24] Justice K.S.Puttaswamy(Retd) vs Union Of India, (2017) 10 SCC 1

[25] Sujatha Byravan, *Genetic Discrimination in India, The Hindu*, available at <https://www.thehindu.com/opinion/lead/staying-ahead-of-the-double-helix/article22911354.ece> (last visited on Mar. 28, 2021)

This verdict in *Jai Prakash Tayal v/s United India Insurance Company Limited* appellant Mr.Jai Prakash Tayal had Hypertrophic Obstructive Cardiomyopathy, and his medical insurance claim had been rejected solely because it was inherited. Since hereditary disorders were not covered by the regulation... Earlier the trial court had ruled in favor of Jai Prakash Tayal, holding that there cannot be a discriminatory clause against persons who suffered from genetic disorders and were entitled to medical insurance. United India Insurance Company Limited filed an appeal against the order of the trial court.[26]

"The Insurance Regulatory Development Authority of India has been directed to re-examine exclusionary clauses in insurance contracts and ensure that insurance firms do not deny medical claims based on exclusions," the statement reads. The High Court held that the law and norms of 'genetic disorders' in insurance policies in India were "too broad, ambiguous, and discriminatory" and thus violated the constitutional provisions, stating that "the entire object of taking medical insurance will be defeated if all genetic disorders are excluded."It stated that insurance companies were free to arrange their contracts based on fair and logical factors that were not arbitrary and could not be exclusionary in any case.[27]

Discrimination in Health Insurance based on Genetics is Unconstitutional

Article 14 of the Indian Constitution prohibits discrimination of any kind, including discrimination based on a person's genetic heritage. The Right to Health is a Fundamental Right, as an integral part of Article 21 and the Right to Healthcare is also a basic human right, and the right to obtain insurance is an essential component of that right. As a result, discriminating against people and relying on their genetic status is illegal. In the absence of adequate genetic tests and the establishment of intelligible differentia, the judge ruled that discrimination in health insurance against persons based on their genetic origin was unconstitutional. Hon'ble Justice Pratibha M. Singh stated: The extensive exemption of genetic diseases is, therefore, more than a mutual concern between the insurer and the insured; it also comes under the umbrella of Right to Health.

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[26] *Sujatha,* Supra note 26 at 9

[27] *Sangita Sharma &Sayan Chandra, The Criminal Law Blog, Criminalizing Genetic Discrimination in India,* available at <https://criminallawstudiesnluj.wordpress.com/2020/09/19/criminalizing-genetic-discrimination-in-india/> (visited on Mar.19, 2021, 9.00 PM

It appears that a proper mechanism is needed to prevent genetic discrimination as well as to protect the collection, storage, and confidentiality of genetic data. Insurance companies are free to structure their contracts based on fair and understandable criteria that should not be arbitrary and cannot be exclusionary in any situation. It is the responsibility of legislators to take the requisite measures in this regard, he said.

Criminalizing Genetic Discrimination

It is necessary to review the IPC to see whether such criminalization will be founded on the IPC, 1860. The only provision in IPC which borders on prevention of such discrimination is s.153A,[28] which penalizes any act of promoting violence or hatred based on discriminatory grounds. The section of 153A is broad enough by the usage of the words "any grounds whatsoever". As a consideration, whether any discrimination based on genetic characteristics may be addressed under this clause is a question. Any discrimination can be criminalized only when the act constitutes *"disharmony or feelings of enmity, hatred or ill-will"* in society. Hence, it is the consequence of genetic discrimination that is penalized and not the act of discrimination itself. Hence, it does not prohibit discrimination in the manner done under the SC/ST Prevention of Atrocities Act, 1989.

Genetic Discrimination in Insurance with Reference to Insurance Act, 1938

The Insurance Act of 1938 led to the establishment of the Insurance Regulatory Development Authority (IRDA) to govern India's insurance industry**.** The IRDA guidelines, which were released on February 20, 2013, excluded pregnancy, infertility, congenital, and genetic disorders, but did not define "genetic" disorders. As a result, Indian insurance companies changed the terms of their policies to exclude 'genetic disorders' from coverage. On July 29, 2016, the Insurance Regulatory and Development Authority of India (IRDA) released a new guideline for the standardization of healthcare insurance in India, in which the term "genetic disorder" was removed and only "congenital anomalies" were listed. On February 26, 2018, the Delhi High Court ruled that "genetic disorder" is a vague context that should not be used to exclude insurance claims, and ordered the IRDA to review its exclusionary clauses to prohibit insurance firms from rejecting claims based on an individual's genetic profile.IRDA should review

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[28] Indian Penal Code, 1860, S.153A, No. 45, Acts of Parliament, 1860(India)

the exclusionary provisions to prohibit insurance providers from rejecting claims based on an individual's genetic status. On March 19, 2018, the Insurance Regulatory and Development Authority (IRDA) released a notification instructing all insurance providers not to use "genetic disorders" as an exclusion condition in any health insurance policies. On August 27, 2018, the Honorable Supreme Court of India stayed in the Delhi High Court's judgment's operation.[29]

Conclusion

In an age of widespread genetic testing, India must avoid discrimination and maintain the principle of "equal treatment under the law." Judiciary has set the ball on fire with the judgment of the Delhi High Court, now the legislature must follow the suit to uphold the commitment against genetic discrimination. There about three types of approaches followed around the world in managing the gap between gene testing and insurance. Either the countries follow self-regulation or limitation by law or they might have applied a legal ban. India does not have any specialized legislation enacted by the parliament to govern the section of genetic discrimination in the insurance sector. Neither there is a law to govern the insurer on discrimination nor any law to streamline the important need for the insurer to avoid adverse selection. The privacy and right to insurance of a citizen are to be protected by the government to safeguard its citizen from denial of insurance in the name of genetic discrimination.

Suggestion

There is a need for a specialized and separate act to govern the usage of genetic information in the field of insurance. Discrimination in any must have a proper legal framework to restrain it. Genetic discrimination in insurance and employment will affect the public at large. This will lead to denial of Insurance and Privacy, both of these falls under fundamental rights under the Indian Constitution. We show that the current legal safeguards fall short for a lot of reasons, fail to resolve emerging problems, and are in jeopardy. We must safeguard and uphold broad prohibitions against genetic and health discrimination in health insurance settings, which includes protecting genetic

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[29] The Indian Academy of Medical Genetics, ***Prevention of discrimination based on genetic information*****, Society for Indian Academy of Medical Genetics,** available at <http://iamg.in/PS1.html**.>** (last visited on Mar. 29, 2021)

information privacy rights in the workplace. At the same time, the insurers should not be denied certain information as a basic requirement to form a policy, if they lose business and goes down in number it is again a serious issue to deal with. This will demonstrate the need for an Act from the Parliament to regulate these affairs.