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GENETIC PROFILING IN LIFE INSURANCE UNDERWRITING: A CRITICAL ASSESSMENT OF PRIVACY RIGHTS AND REGULATORY DISCRETION UNDER IRDAI

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ABSTRACT

The increased use of genetic profiling by insurance companies in deciding the risk profile for life insurance policies is indeed a very critical change in the practice of assessing risks. It not only helps improve actuarial efficiency but also has some serious legal and ethical consequences. The lack of regulation of genetic testing in life insurance underwriting in the country is indeed an alarming state of affairs, where there are no legal or policy guidelines set forth by IRDAI. In this paper, the focus would be on the consequences of genetic profiling on constitutional rights of citizens as protected under Articles 14 and 21 of the Constitution of India.

The study will explore whether the use of genetic profiling and subsequent use of this information for assessing risk in life insurance leads to a breach of individual rights of citizens as enshrined in Articles 14 and 21 of the Constitution of India. In other words, it is essential to understand the extent to which life insurance companies are involved in discriminatory practices such as denial of insurance, higher premiums or exclusion clauses in insurance.

Ultimately, the paper argues for a balanced regulatory approach that restricts the misuse of genetic data while allowing limited, ethical use for underwriting purposes. It recommends stronger data protection measures, clearer regulatory guidelines, and the adoption of a moratorium-based model to ensure fairness, transparency, and protection of individual rights in the evolving insurance landscape.

Keywords: Genetic profiling, life insurance, underwriting, privacy, IRDAI, discrimination, data protection

INTRODUCTION

The rapid development of biotechnology and genomics has led to changes in traditional methodologies for risk assessment, especially in areas like insurance. Genetic profiling, as an example, has revolutionized life insurance policies because insurance companies can now evaluate current health status as well as a person's propensity to certain illnesses in the future. The use of genetic tests in making predictions and classifications will enhance the insurer's understanding of risk through better actuarial calculations and reduce uncertainty. Despite the positive impacts brought about by science, it is evident that new ethical and legal challenges have been created, primarily related to basic rights of privacy, dignity, and equality.[468]

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[468] Tom Baker and Kyle D. Logue, *Insurance Law and Policy: Cases and Materials* (5th edn., Wolters Kluwer 2017)

Similarly, the use of genetic information in insurance underwriting creates very significant issues related to the issue of privacy and respect for human dignity. Information about genes is particularly intimate and immutable and exposes intimate details about the person whose genetic makeup is being investigated. As per the Indian Constitution, privacy was recognized to be a fundamental right through Article 21. Hence, the use of genetic information in insurance underwriting can easily infringe upon this fundamental right.[469]

In addition to privacy concerns, genetic profiling may result in discriminatory outcomes that conflict with the constitutional guarantee of equality under Article 14. Insurers may deny coverage, impose higher premiums, or include exclusion clauses based solely on genetic predispositions rather than actual medical conditions. Such practices risk creating a form of "genetic discrimination," where individuals are penalized for factors beyond their control. Judicial intervention has played a key role in addressing these concerns, particularly through the decisions of the Delhi High Court, which have emphasized that exclusion of genetic disorders in insurance policies is arbitrary and violative of fundamental rights.[470]

Nevertheless, there have been some shortcomings in the regulatory scheme. IRDAI, which is the main regulatory body responsible for overseeing the insurance industry, has made certain directives regarding claims based on genetic diseases. Such initiatives are merely defensive and by no means amount to a comprehensive legal framework addressing issues arising out of the use of genetic information in underwriting insurance policies. Consequently, this paper aims at determining whether genetic screening of potential clients by life insurance companies is consistent with the constitution or whether there is enough regulatory discretion within IRDAI to solve these challenges.

LITERATURE REVIEW

Scholarly literature highlights the growing concern over genetic discrimination in insurance markets. Studies indicate that the use of genetic data can lead to denial of coverage, increased premiums, and exclusion clauses, thereby undermining the social purpose of insurance

Mark A. Rothstein argues that genetic discrimination represents a fundamental challenge to equality and fairness in insurance, particularly when predictive information is used rather than actual health conditions. International organizations such as the OECD have emphasized the need for regulatory intervention to balance innovation with ethical considerations.

Comparative literature reveals that jurisdictions like the United States and European Union have adopted protective frameworks to limit misuse of genetic data. However, Indian scholarship points to a lack of specific legislation and over-reliance on general constitutional principles

RESEARCH METHODOLOGY

In the case at hand, a doctrinal and comparative analysis will be used to evaluate how genetic profiling is utilized in life insurance underwriting in India with regard to privacy and regulation. Doctrinal analysis is done through examination of constitutions, laws, and court judgments, specifically Puttaswamy vs Union of India, as well as regulatory guidelines provided by Insurance Regulatory and Development Authority of India.

Another methodology that the study uses is the comparative method, as it takes into account the international context through laws like GINA in the US and GDPR in the EU. Moreover, the study makes use of secondary sources of information, which include literature from scholars and policy makers. It is important to note that the study is qualitative in nature, which means that it does not make use of any empirical data..

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[469] Justice K.S. Puttaswamy (Retd.) v. Union of India, (2017) 10 SCC 1
[470] Genetic Information Nondiscrimination Act, 2008 (USA)

GENETIC PROFILING CONCEPT IN INSURANCE

Genetic profiling denotes the practice of examining one's DNA to find any genetic disorders, mutations or even predispositions towards certain medical conditions.[471] With respect to the underwriting process in life insurance, such genetic information holds a lot of promise as it allows for making predictions about future health issues, thereby allowing the insurer to make accurate judgments without having to rely only on existing health problems or one's family history.[472] Thus, genetic profiling can become a valuable tool for underwriting purposes.

On the other hand, the introduction of genetic profiling to the field of insurance poses many ethical and legal questions, since this type of information, unlike medical, tends to be predictive. This means that the data obtained through genetic profiling does not guarantee the presence of health problems but, instead, only provides some indication of their occurrence.[473] Therefore, people can face discrimination in the insurance industry due to the possibility, rather than actual existence, of health problems.

Moreover, genetics can be considered highly private and confidential, representing a fundamental part of someone's individuality. Genetic testing in underwriting may have a number of issues concerning the infringement on privacy, consent, and confidentiality. Unauthorized usage of such information may constitute a violation of the right to privacy as determined in Justice K.S. Puttaswamy (Retd.) v. Union of India.[474] There also exists the issue of the possibility of genetic discrimination in the form of the denial of coverage or increased premiums. Genetic discrimination may be considered contrary to the social role of insurance and represent an obstacle to the concept of risk pooling.[475]

Therefore, even though there are many technological benefits associated with genetic profiling, its application should be controlled to guarantee its compliance with equity, privacy, and human dignity.

PRIVACY RIGHTS AND GENETIC DATA

Genetic information ranks among the most private type of personal information because it provides insight into not only the current state of the person’s health but also his/her future predispositions to certain diseases, as well as information on family traits.[476] For this reason, genetic information is protected by the right to informational privacy, which guarantees that a person’s information is not collected, stored, or disseminated without his/her explicit consent. In regard to insurance underwriting, genetic information poses numerous ethical problems because individuals have to disclose their genetic information without clear guarantees regarding its use.[477]

The right to privacy as enshrined in Article 21 of the Indian constitution has been extensively explained by the Supreme Court of India in the case of Justice K.S. Puttaswamy (Retd.) v. Union of India to include the right to informational privacy and the control over personal information that needs to be shared. This case stresses on the autonomy that must be provided to people in terms of their personal information where they can choose to disclose or not disclose certain sensitive information like genetic information.

Further, collection of genetic data without proper and voluntary consent violates autonomy, which forms an essential part of constitutional law as well as bioethics. The individual may be coerced into disclosing his genetic data due to unequal bargaining position in insurance contract, and thus consent

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[471] Nuffield Council on Bioethics, *Genetic Screening: Ethical Issues* (2006) 10–15

[472] OECD, *Genetic Testing and Insurance: Policy Issues* (OECD Publishing, 2004) 25–30

[473] Mark A. Rothstein, “Genetic Discrimination in Insurance,” (2008) 13 *Harvard Journal of Law & Technology* 1, 15–18

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

[475] Kenneth S. Abraham, *Insurance Law and Regulation* (5th edn., Foundation Press 2010) 20–25

[476] OECD (2004) 80–85

[477] Nuffield Council on Bioethics, *Genetic Screening: Ethical Issues* (2006) 35–40

becomes questionable, along with opening up the possibility of misuse of genetic data for discriminating against them.

Also, lack of adequate provisions relating to data protection in respect of genetic data is a problem in India, although general principles of data protection involve elements of confidentiality and purpose limitation. Thus, in the absence of clarity on treatment of genetic data under existing data protection provisions in the insurance sector, it is necessary that genetic data be considered sensitive personal data and accorded appropriate level of protection, just like GDPR.

The convergence between the rights to privacy and genetic information requires a sound legislative framework in order to promote the idea of consent, prevent abuse, and protect the dignity and integrity of the individual. The utilization of genetic information in insurance policy-making can result in gross infringement of one’s constitutional rights.

REGULATORY ROLE OF IRDAI

The hallmark characteristic of the IRDAI regulatory regime is the extensive scope for discretion in regulating underwriting practices. Such discretion was deemed indispensable because the insurance industry is dynamic and changing, and the rigid statutory norms might not have been sufficient to cover all kinds of risk scenarios that can arise.[478]On the other hand, although such discretion is necessary, its overuse could lead to regulatory unpredictability.

In the case of underwriting, IRDAI has predominantly embraced a principles-based regulatory regime as opposed to a rules-based approach. While broad principles of fairness, openness, and non-discrimination have been articulated, there has been no specific set of guidelines for cutting-edge technological innovations such as genetic screening and profiling.[479] In essence, such silence on the part of the regulator has given immense discretion to insurers regarding the use of such data.

Thus, insurers operate in a fairly non-structured environment while handling genetic information. Some insurers, driven by moral principles and reputation issues, might avoid using genetic information at all. On the other hand, some insurers might interpret disclosure requirements broadly and try to use genetic information in underwriting.[480] This disparity in behavior undermines uniformity as one of the core objectives of sectoral regulation. The role of a regulator is to maintain the level of consistency in the activities of market participants.[481] In the case of genetic information, this goal is compromised due to the lack of guidelines.

Another problem connected with the non-structure of the regulation process is arbitrariness. When there is no code that describes the process of evaluation of risk, insurers may use their internal policies, the implementation of which may be arbitrary to some extent.[482] This creates difficulties for claimants, who cannot contest insurance claims made against them since they do not have any understanding of the criteria used by the insurance company.

Another significant factor that needs consideration relates to accountability. Even though IRDAI has supervisory authority to request information and conduct investigations, these measures tend to be reactive and not preventive.[483] Without having pre-established criteria, it will be challenging for the regulator to determine whether a specific underwriting strategy can be considered prejudicial or discriminative. As a result, regulation may become less effective in protecting consumers' rights.

It should also be noted that there is an increased complexity associated with using

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[478] Insurance Regulatory and Development Authority Act, 1999, § 14

[479] IRDAI (Protection of Policyholders’ Interests) Regulations, 2017

[480] Avtar Singh, *Law of Insurance* (Eastern Book Company, 2018)

[481] M.N. Srinivasan, *Principles of Insurance Law* (LexisNexis, 2017)

[482] IRDAI (Health Insurance) Regulations, 2016

[483] Insurance Regulatory and Development Authority Act, 1999, § 33, §34

genetic data because of its probabilistic nature. Genes cannot ensure that an individual will have a specific disease but only suggest a tendency to contract it.[484] This type of data might lead to incorrect conclusions about risks and unnecessary refusal to extend insurance benefits. The lack of regulation leaves insurers free to act more cautiously towards their customers.

In a legal sense, the wide-ranging discretion available to the insurer and the regulator needs to be checked through the fundamental rights provided for in the constitution of India, mainly the right to equality and the right to privacy.[485] Any misuse of genetic data would be a violation of these two basic rights. However, in the absence of any regulatory guidelines on this matter, it is difficult to enforce the said rights.

While discretionary power has a significant role in IRDAI's functioning, it is evident that the existing regulatory discretion does not have enough structure when it comes to underwriting and genetic data.[486]

RISK OF GENETIC DISCRIMINATION

The growing trend in using genetic information for underwriting purposes in life insurance poses significant problems in relation to the potential threat of genetic discrimination this is a discriminatory act toward people in terms of differences in their genetic makeup compared to their health condition.[487] Genetic information is by nature predictive and probabilistic; in other words, it can reveal merely the probability of having particular diseases in the future. Nevertheless, insurers may make use of such information while deciding whether to cover someone, charge more premium or apply exclusion clauses for specific diseases.[488] Thus, people will be discriminated against not for their existing health problems but for their potential threats that can eventually never become real.

Furthermore, genetic discrimination is likely to impact those who are otherwise healthy but possess genetic predispositions and thus find themselves in a disadvantaged position regarding securing financial safety.[489] In addition, such discriminatory measures could lead to a situation where there emerges an "underclass" of genetically disadvantaged people who are systematically denied insurance coverage due to circumstances out of their control. Not only does this pose ethical questions but goes against the overall purpose of insurance, serving as a social security and risk management system.

Another problem associated with using genetic information for underwriting purposes is the violation of the basic concept of risk pooling underlying insurance mechanisms.[490] Indeed, insurance is based on the ability to spread risk among multiple people. Genetic information, however, leads to the formation of risk segmentation as people are increasingly divided into small risk classes. The result is the potential exclusion of those who belong to the highest risk categories from obtaining insurance at all.

Moreover, the concern of genetic discrimination might result in reluctance among individuals to have genetic testing and take part in research studies.[491] Such an effect has significant public health repercussions since genetic testing has become very important in diagnosing, preventing, and treating certain diseases. Refusal to undergo tests owing to the fear of possible discriminatory practices in terms of access to insurance policies will be detrimental to progress in the sphere of preventive medicine.

To summarize, the problem of genetic discrimination underscores the necessity to

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[484] OECD, *Genetic Testing and Insurance: Policy Issues* (OECD Publishing, 2004)

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

[486] Justice B.N. Srikrishna Committee, *Report on Data Protection Framework in India* (2018)

[487] Mark A. Rothstein, "Genetic Discrimination in Insurance," (2008) 13 *Harvard Journal of Law & Technology* 1, 15–18

[488] OECD, *Genetic Testing and Insurance: Policy Issues* (OECD Publishing, 2004) 70–75

[489] Nuffield Council on Bioethics, *Genetic Screening: Ethical Issues* (2006) 85–90

[490] Kenneth S. Abraham, *Insurance Law and Regulation* (5th edn., Foundation Press 2010) 15–18

[491] OECD (2004) 95–100

introduce comprehensive measures to regulate the use of genetic information by insurers. Finding a balance between individual security and insurance company functioning is of vital importance.[492]

COMPARATIVE EVALUATION OF REGULATORY APPROACHES

Comparatively analyzing the regulation of genetic information usage by the US, UK, and EU, one can note that fundamentally different approaches towards regulation exist in all three states/countries/organizations. While the United States operates on the legislative basis, with special attention being paid to sector-specific regulation of genetic information usage in the field of insurance – mainly by means of GINA; however, the latter leaves much to be desired with respect to regulating genetic information usage for health, disability, and life insurance purposes.[493]

On the contrary, the UK employs a co-/self-regulation approach, as it relies on codes such as the Code on Genetic Testing and Insurance, implying cooperation between the government and the insurance companies.[494] This way, the state tries to strike a balance between its oversight and self-regulation of the insurance sector, making sure that its framework evolves alongside the scientific advances and changes in the market.

Lastly, the European Union applies a rights-based regulatory approach that is based on the principles of privacy and data protection. Thus, genetic information becomes categorized as sensitive personal data that receives legal protection in accordance with GDPR regulations.[495]

There are various pros and cons associated with each of these models. For example, the regulatory regime in the USA offers clear guidance in the form of statutes. It is particularly applicable to the health insurance industry. Yet, the model is too fragmented. In other words, while people are not subjected to genetic discrimination in the health insurance context, they still can experience it in other areas of life.[496]

Finally, the EU model ensures effective protection of the individual. It includes legal obligations and requirements, which guarantee that genetic information will not be used improperly.[497] At the same time, excessive regulations can impede risk assessment and, hence, create room for adverse selection.[498]

SUGGESTIONS AND FINDINGS

- **Enacting Special Law for Genetic Discrimination**

There is a need for India to enact a special law that addresses the problem of genetic discrimination with respect to the insurance sector. This can be done through enactment of laws such as the GINA of America. Such a law must define genetic information and the limitations regarding its utilization.

- **Formulation of Clear IRDAI Guidelines**

The Insurance Regulatory and Development Authority of India must promulgate comprehensive and binding guidelines regarding the application of genetic information in insurance underwriting. The guidelines must cover the following:

- If genetic tests are mandatory
- Bounds on the duty to disclose
- Criteria for risk evaluation
- Prevention of capricious rejection of insurance claims

This would eliminate any vagueness and ensure uniformity in the process.

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[492] Justice B.N. Srikrishna Committee, *Report on Data Protection Framework in India* (2018) 215–220

[493] Mark A. Rothstein, "Genetic Discrimination in Insurance,"12-15 (2008) 13 *Harvard Journal of Law & Technology* 1,

[494] HM Government & Association of British Insurers, *Code on Genetic Testing and Insurance*5–7 (2018),

[495] Paul Voigt & Axel von dem Bussche, *The EU General Data Protection Regulation (GDPR): A Practical Guide* 34–38 (Springer 2017).

[496] Kenneth S. Abraham, *Insurance Law and Regulation* 102–105 (5th edn., Foundation Press 2010)

[497] Regulation (EU) 2016/679 (General Data Protection Regulation), Art. 9.

[498] Kenneth S. Abraham, *Insurance Law and Regulation*110–112 (5th edn., Foundation Press 2010)

- **Integration with Data Protection Framework**

Genetic information needs to be acknowledged as sensitive personal information within the Indian data protection framework. Proper measures need to be put in place, such as:

- Obtaining informed and express consent
- Purpose limitation
- Data minimization
- Confidentiality obligations

This would ensure compliance with the fundamental right to privacy upheld by Justice K.S. Puttaswamy (Retired) vs. Union of India.

- **Prohibition or Restriction on Use in Certain Insurance Sectors**

India could think about regulating or banning the use of genetic data in critical fields like health insurance. When it comes to life insurance, India can opt for a middle ground, wherein use is permitted under strict regulation, much like in the United Kingdom.

- **Strengthening Consumer Awareness and Protection**

Rights concerning genetic information must be communicated to all insured individuals. This can be done by the following ways:

- Disclosure of information by insurance companies
- Simplification of policies
- Awareness programs

Furthermore, grievance redressal systems need to be improved for prompt solutions.

DISCUSSION

Genetic testing for purposes of insurance underwriting highlights the intrinsic conflict between the concept of fairness according to actuarial principles and that of social justice. From the standpoint of the insurance company, the availability of genetic information increases the precision of the risk calculation, thus allowing for the fairer pricing of the policy as well as mitigating the problem of adverse selection. On the other hand, an excessive use of such predictive information may lead to a situation when insurance stops functioning as an apparatus of pooled risk sharing and starts operating in terms of segregation of risks, which will result in discrimination against high-risk clients.

From the perspective of human rights, any application of genetic information should be thoroughly examined to determine whether it would amount to an infringement of basic rights such as right to privacy, respect and dignity, and equality. There is already a problem of lack of a specific code of regulations in India, thus permitting the discretionary powers of the insurance companies in terms of the interpretation of their duties regarding information and underwriting. Such a scenario creates room for arbitrary decision making that may lead to discrimination against people. A look at the experience of other countries such as the United States, United Kingdom, and the European Union shows that there needs to be a balance in handling the use of genetic information by insurers.

CONCLUSION AND RECOMMENDATIONS

The study concludes that India's existing regulatory framework is insufficient to effectively address the complex legal, ethical, and technological challenges posed by the use of genetic profiling in life insurance underwriting. The absence of a specific statutory framework dealing with genetic discrimination, coupled with the limited and indirect role played by the Insurance Regulatory and Development Authority of India, creates significant uncertainty for both insurers and policyholders. This regulatory gap not only increases the risk of arbitrary underwriting practices but also exposes individuals to potential violations of their fundamental rights, particularly the right to privacy, dignity, and equality. As genetic technologies continue to evolve, the lack of clear legal standards may lead to inconsistent practices, thereby undermining trust in the insurance system and discouraging individuals from participating in genetic testing or seeking necessary medical interventions.

To address these challenges, a multi-layered and balanced regulatory approach is essential. First, India should enact a dedicated legislation specifically prohibiting genetic discrimination in insurance, clearly defining the scope and permissible use of genetic information. Second, the IRDAI must develop comprehensive and binding guidelines governing underwriting practices, including clear rules on genetic testing, disclosure obligations, and limits on the use of predictive data. Third, genetic information should be explicitly incorporated within the ambit of sensitive personal data under data protection laws, ensuring safeguards such as informed consent, purpose limitation, and confidentiality. Fourth, the use of genetic data should be restricted, particularly in essential insurance sectors like health insurance, to prevent exclusion and ensure accessibility. Finally, there is a need to establish independent oversight mechanisms and effective grievance redressal systems to ensure accountability and provide remedies in cases of misuse or discrimination.

Ultimately, a rights-based, transparent, and ethically grounded regulatory framework is crucial to strike a balance between innovation and protection. By adopting such an approach, India can ensure that advancements in genetic science are utilized responsibly, fostering fairness, inclusivity, and public confidence in the insurance sector while safeguarding the fundamental rights of individuals.

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