



# Practical Importance of Genetic Research Results when Developing an Insurance Product for Personal Insurance: International Experience

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**Abstract:** *This article considers the practical importance of genetic research results when developing an insurance product. The modern science, which allows obtaining information not only about the current state of health, but also about the risks of various diseases, challenges the possibility of using genetic information in insurance. The main goal of the study is to consider the possibility to use genetic information when concluding a personal insurance agreement for assessing the risks of an insured event, taking into account long-term obligations of insurance companies. The methods of collecting and studying singularities, generalization methods, scientific abstraction methods, and method of inquiry into regularities were used in the article. It has been concluded that it is necessary to use a differentiated approach when using genetic information in insurance. Full protection against genetic discrimination requires to completely prohibit insurance companies to use any information about genes, gene products, or inherited characteristics as a basis for refusing or limiting insurance coverage. The only area where it is allowed to use genetic information is medical insurance because it is impossible to postulate the right to life insurance without genetic testing if the agreement provides a broader insurance coverage. In order to maintain a balance of interests between insured persons and insurers, it seems acceptable to use genetic information when concluding voluntary life and health insurance agreements that, above all, provide annuity payments. It is necessary to use genetic information in insurance when assessing the risks of real occurrence of a genetic disease. This approach will allow to practically minimize risks of insurance companies and to take into account the interests of an insured person.*

**Index Terms:** *confidentiality, equity, genetic information, insurance, underwriting.*

## I. INTRODUCTION

The physical and mental health of an individual largely depends on genetic factors that can determine a predisposition to certain diseases. About 200 genetic disorders had been revealed by 1990. As on today more than 1,500 diseases have been identified as genetic ones. Due to this, the issue on using genetic information when concluding a personal insurance agreement for assessing the risks of an insured event is raised more and more often, taking into account long-term obligations of insurance companies to make payments to insured persons in case of diseases that cause full or partial loss of their ability to work, and require compensating for medical, social, and personal services provided as a result of this.

The discussion is getting truly international. This is proved by the desire to develop common approaches to solving the issue on protecting human rights due to the prospects to obtain and use genetic information, especially because due to modern high-performance methods used to analyze a genome and transcriptome, in the next few years a breakthrough is expected in the area of diagnostics personalization. In this context, issues on the voluntary nature of genetic testing, the possibility to maintain control over access to the test results, conditions for disclosing them to third parties, including insurers, as well as taking protection measures by genetic character are essential. It is obvious that the possibilities of genetic research inevitably influence the insurance practice [1]. Genetic testing and disclosing its results to an insurance company may cause a number of adverse effects: impairment of an individual's privacy rights, discrimination against certain categories of citizens (e.g., refusal to conclude health insurance agreements or a considerable overestimation of the insurance cost) [2]. In this regard, it is necessary to note that a lot of states have adopted the legislation restricting the use of genetic information by insurers.

This requires assessing the practical importance of genetic research results when developing an insurance product for personal insurance and the feasibility of providing insurers with genetic information about insured persons.

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## II. LITERATURE REVIEW

Many researchers devoted their works to researching a gene and its impact on insurance, e.g.: Alper Joseph S. and Beckwith Jon devoted their works to genetic and nongenetic medical tests in terms of the consequences for anti-discrimination legislation; Launis V. wrote about the use of genetic test information in insurance: an argument from indistinguishability; Brockett Patrick and L.Tankersley E. [3] researched problems of the genetic revolution in terms of citizens' insurance; Christianson David J. studied the insurance of income on disability associated with genetic diseases; Gemma A. Bilkey, Gareth Baynam and Caron Molster considered changes in employers' use of genetic information and nondiscrimination for the US health insurance; Joly Yann, Knoppers Bartha M. and Godard Béatrice considered issues on genetic information and life insurance for citizens; in his work Karen H. Rotenberg [4] studied details of the problems related to genetic information and medical insurance; and many other authors developed this theme. However, there has never been a definite approach to insuring the individuals predisposed to genetic diseases. It is necessary to accurately determine how to insure citizens who are at risk under genetic testing.

## III. METHODS

### A. General Description

Methodologically the study was based on dialectic, teleological, axiological, logical, formal-legal, and system-structural methods.

The dialectical method of cognition, which has the universal and general nature, made it possible to work out a general search and regulations strategy when planning the study based on the cognition of the interrelation and interdependence of phenomena and processes that are important for solving the scientific problem. In the most concentrated form, this idea was implemented through the use of the teleological research method related to the interpretation and study of problematic issues through the goal setting and taking into account goals and strategies of developing and ensuring the optimal regime of legal regulation of relations associated with genomic studies and use of their results in insurance.

### B. Algorithm

Taking into account the fact that the acquisition and use of genetic information inevitably affects the human right to privacy, the axiological method that implies the analysis of the above public relations in terms of moral, ethical and social values was of particular importance when carrying out this study.

The use of the logical method made it possible to correlate the conceptual framework used in medicine with the categories that are important for insurance and jurisprudence. It was supplemented with the formal legal method that determined the implementation of such system for processing and analyzing the existing legal norms and current legal practice that allowed assessing the normative legal concepts and constructions, identifying peculiarities of legal phenomena and prospects for their regulation. This predetermi

ned the use of various methods of interpreting the norms of law, as well as the study of factors and conditions that determined the development of a legal mechanism for using data on the human genome.

The system-structural approach made it possible to identify and assess the legal regulation of obtaining and using genetic information.

Taking into account the novelty of the subject matter for the Russian jurisprudence, the comparative legal method is of special importance for the study. It allows identifying positions on the possibility of using genetic information in foreign legislation, science and practice of insurance companies to determine prospects.

### C. Flow Chart

The study used certain algorithms that made it possible to obtain results (Fig. 1)

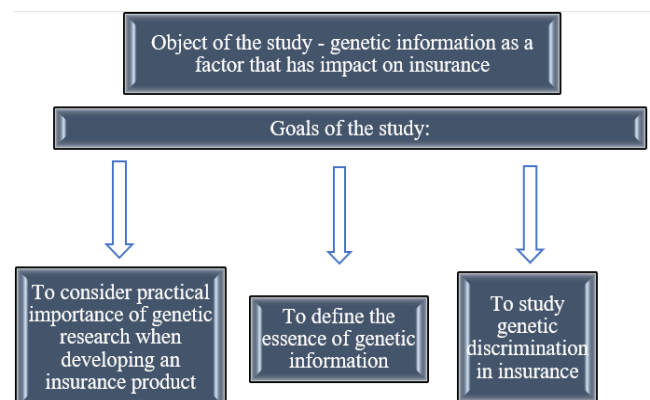


Fig. 1. Study Algorithm

## IV. RESULTS

The modern science, which allows obtaining information not only about the current state of health, but also the risks of various diseases, challenges the possibility of using it in insurance [5]. The term "genetic information" is interpreted quite broadly and covers information for any person about the results of genetic tests of such person, genetic tests of his/her family members, as well as occurrence of relevant diseases or disorders (Act to prohibit discrimination on the basis of genetic information with respect to health insurance and employment).

The legislator does not provide the right to independently obtain information about the insurant's health, which is understandable, taking into account that information about the health belongs to a special category of personal data, and their processing is possible either with the written consent of the subject or in the cases expressly provided by law [6].

It is necessary to distinguish between collective and individual insurance. In case of individual insurance, insurers have more discretionary powers in terms of agreeing insurance conditions and controlling them. The participation in the collective insurance system is initially related to membership in the relevant group, and is terminated due to dismissal. It is necessary to note that the collective insurance, in the form it exists, in particular, in the United States does not protect against genetic discrimination.

The problem is that many such programs are based on self-insurance agreements, which releases them from the state insurance laws, and therefore does not protect the insureds. Moreover, in 2017 so-called employee health preservation programs were introduced. The adopted law – the Preserving Employee Wellness Programs Act (PEWPA) – allows employers to circumvent the employee's rights to the confidentiality of genetic information upon request as a part of a wellness program, which involves the use of genetic information, including for preventive purposes. The situation is aggravated by the fact that the PEWPA allows employers to introduce incentives and penalties for the participation in such programs, which can be considered as a considerable encroachment on the individual's rights to genetic information protected in accordance with other laws [7].

It is important to take into account the specifics of life and health insurance agreements concluded for a limited period and subsequently renewable, and agreements involving a long-term relationship between the insured and the insurer, where the latter has the obligation to make annuity payments in case of an insured event defined by the agreement.

It is necessary to note that the differentiation of the approach to the insurer right to obtain it depending on the type of insurance can be traced in the US law. Thus, in the state of Arkansas, in order to determine the right of any person to any insurance coverage, define insurance premiums, limit, renew, terminate the coverage or any other underwriting solution in connection with the offer, sale or renewal or prolongation of the policy, no insurer should require, directly or indirectly, from any person or his/her family member to obtain a genetic test, as well as stipulate the provision of the policy by the requirement to carry out genetic testing. This is not related to determining a higher insurance rate or insurance, or restrictions on the coverage of such policy based on the occurrence of any genetically determined condition, disease or disorder. In addition, an exception is determined for the insurance agreements that provide for annuity payments, including due the disability and the need for external care (Arkansas Code Title 23).

The problem of using genetic information is considered from different perspectives. A number of authors analyze it in terms of ensuring the autonomy of an individual, privacy, confidentiality, and justice [8].

In the context of genetic testing, respect for the individual's autonomy is considered as recognition of the right to make a reasonable, independent judgment about the need in its implementation, obtaining detailed information on test results. Obligatory genetic testing can have devastating consequences for the people who consider a genetic disease as an integral part of their nature, and can cause an inferiority complex. Autonomy is also seen as the person's right to determine his/her own fate, relying or not relying on genetic information, and to avoid the interference of other people in important life decisions, regardless of whether they are based on genetic information or other factors. Respect for autonomy also implies the right of individuals to control the future use of genetic material submitted for analysis with a specific purpose. From a legal point of view, this is about preserving the individual's physical integrity.

In terms of personal privacy, it is possible to speak about two components: on the one hand, the exercising of the right to make independent decisions on genetic research, and on the other hand, – restricting access to such information without the will of a certain person. As for ensuring the confidentiality of genetic information, here it is necessary to take into account that some information may be unprotected, and the legislation may provide positions on the possibility to use such information without the will of a certain person. Experts are fairly concerned about the confidentiality of genetic information [4]. The attention is drawn to the fact that if there is no comprehensive legal regulation, insurers can ground obtaining of such information by their need to check the circumstances of an insured event.

This is a relevant issue to comply with the principle of justice in the context of ensuring the balance of the insured's and insurer's interests. One of the most important issues is to define whether genetic disorders or a genetic predisposition to certain diseases are a basis for restricting access to certain social benefits, such as health insurance. The practice of medical underwriting in health insurance reflects what is often called "actuarial justice", based on the need to group entities with similar risks for the insurer to predict his costs and determine fair and sufficient insurance premium rates. Although the actuarial justice can be intuitively attractive, it is generally believed that it does not comply with the principle of justice from a moral and social point of view [9]. The main argument in favor of eliminating genetic discrimination in the health insurance system is the need to exercise the right to health care that cannot be made dependent on any merit, public contribution, or ability to pay. Social justice requires the provision of medical services to maintain, rehabilitate, or compensate for the loss of normal functioning of the body in order to ensure fair equality of opportunities.

At the same time, it is impossible not to note a different point of view. According to it, the use of genetic information for insurance purposes should be allowed because in some sense it does not differ from nongenetic medical information in any appropriate respect, therefore, it would be inconsistent to prohibit the first one, while allowing the latter [9]. In addition, the attention is drawn to the fact that the use of genetic information for life insurance is not something fundamentally new because insurers have been able to request information on the applicant's family history of diseases for decades. A genetic test based on scientific knowledge only simplifies the mechanism of risk assessment [10].

It is also suggested that since it is impossible to a priori assume that a genetic predisposition to diseases will have worse health consequences than their absence, it is impossible to claim that genetic discrimination will become a serious problem in the health insurance system in the free market [11]. In a word, the idea of the injustice of imposing the responsibility for consequences of the "genetic lottery" on the people who cannot choose their genotype cannot be regarded as an adequate substantiation for the inaccessibility of genetic information [12].

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Taking this into account, it is concluded that the problems arising from genetic discrimination can only be solved by changing the entire health care system [13], and the benefits that can be obtained by providing insurers with an access to the relevant genetic data may justify more active role in the use of such information by insurance companies.

In general, it is possible to state the gradual formation of a differentiated approach to the issue about the use of genetic information in insurance. The prohibition on genetic testing is primarily considered as legitimate in case of exercising the right to health insurance that is the moral right of everyone in a civilized society because in terms of social policy, the need in basic health care differs greatly from the need to replace income and protect assets which is characteristic of personal insurance. At the same time, it is recognized that it is impossible to postulate the right to life insurance without genetic testing if the concluded agreement provides a wider insurance coverage [14].

There is a natural question whether genetic information should be a part of the underwriting information used by insurers to approve or reject insurance claims. A survey of insurers conducted by the Office of Technology Assessment of the US Congress showed that they recognized its importance in this area. Three quarters of the responding companies stated that “the insurer should be able to determine how to use genetic information when determining risk” and it would be fair to use genetic tests to identify individuals at the increased risk of disease. At the same time, insurers are not apt to consider genetic information as a special type of information. They care about its content that enables them to take a decision on the possibility of insurance coverage rather than its origin source [8].

Supporting insurers, experts note that the countries with universal health care systems ensure the necessary protection for those who need life insurance. Moreover, the use of genetic research in insurance has some advantages because it enables applicants to take advantage of a negative result in order to reduce the high premium based on the family history of the disease. In case of the positive test result, applicants may have to face a slight increase in the premium, and possibly avoid it because their genetic risk has already been taken into account in the family history questionnaire [10].

It is also suggested that the use of genetic information can have positive impact on the entire insurance industry, stimulating actuarial research, which will increase the volume of data and, thus, generally improve the fair risk assessment. Such studies should aim at identifying and supporting the solutions that provide additional opportunities for people with genetic defects and maintain an efficient life insurance system. In addition, speaking about justice, its roots go into the concept of contractual freedom. Accordingly, the insurant is aware that insurance implies the assessment of individual risk and in this sense genetic information will not be misused [15]-[17].

The attempts to solve this problem legislatively have caused the formation of three main approaches implemented by insurers involved:

1) Legislative prohibition to use genetic testing which does not solve the problem and forces the legislator to formulate an exception to the general rule. Thus, the Israel Genetic

Information Law 2000 stipulates that the insurer has the right to ask about the results of genetic research if the agreement is concluded for the amount higher than the one set by the Ministry for Finance for any such insurance (Genetic Information Law). In accordance with the US Act on Nondiscrimination against Genetic Information 2008, when implementing health insurance, insurers cannot use genetic information to take decisions about the possibility of concluding an agreement, insurance coverage, or the amount of the insurance premium. However, these provisions are adjusted by states law in relation to certain types of personal insurance.

2) Use of a moratorium when the restriction on the use of genetic information for life insurance is initiated by the insurers themselves (although sometimes they are supported by the government). At the same time, the protection of genetic information obtained as a result of research does not prevent access to the results of clinical tests. Thus, the genetic testing policy is the domestic industry standard applied by the Australian Investment and Financial Services Association (IFSA). Its compliance is the responsibility of each insurance company that must certify annually that the policy is in compliance with the provisions of the IFSA Code of Conduct and the Code of Ethics that state that in case of noncompliance with the established requirements, the IFSA Council can take a number of disciplinary measures, including public or individual blame and suspension of IFSA membership or exclusion from it.

3) Maintenance of status quo based on the idea about the ability of the insurance market to independently resolve the problems associated with the use of genetic information.

Due to this, the experience of the Association of British Insurers (ABI) must be taken into account, which took the system providing for a combination of a moratorium, codes of conduct and regulation through state monitoring as its basis.

## V. CONCLUSION

Prospects of genetic research greatly challenge health measures. Nevertheless, the results of genetic tests and other genetic information can also be used for discrimination, e.g., to refuse insurance coverage or increase the amount of insurance premiums.

The current legislative regulation does not comprehensively solve the problem related to using genetic research results when forming an insurance product for personal insurance, and creates prerequisites for discrimination in this area. It is still relevant to regulate conditions and limits for using any genetic information, including the one obtained as a result of analyzing family diseases or direct examination beyond the prohibition to carry out genetic tests.

It is necessary to use a differentiated approach to using genetic information in insurance. Full protection against genetic discrimination requires to completely prohibit insurance companies to use any information about genes, gene products, or inherited characteristics as a basis for refusing or limiting insurance coverage.

The only area where it is allowed to use genetic information is medical insurance because it is impossible to postulate the right to life insurance without genetic testing if the agreement provides a broader insurance coverage. In order to maintain a balance of interests between insured persons and insurers, it seems acceptable to use genetic information when concluding voluntary life and health insurance agreements that, above all, provide annuity payments.

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