

NATIONAL COMMISSION OF BIOETHICS

OPINION

ON THE USE OF GENETIC DATA IN PRIVATE INSURANCE

The National Commission of Bioethics considered the issue of the possible use of genetic data in private life and health insurance in several sessions. The Commission has already raised this issue in its recommendation “on the collection and use of genetic data” (2002). Today, the latest developments in genetic testing and the activity observed in international legislation justify its re-examination.

The Commission organised hearings with Mr. Tangopoulos, president of the committee on Life and Health Insurance of the Association of Insurance Companies and Mr. D. Kremezis, expert in insurance law and lawyer.

1. General comments

The question of whether insurers may require insurance applicants to provide, in addition to conventional information on their medical history, the results of genetic testing has been a major issue for National Bioethics Committees and legislative action in many countries. The reason is that although genetic information reveals a mere predisposition for the manifestation of certain diseases, it may lead to discrimination against insurance applicants.

There are currently three trends in relevant legislation. Some states have prohibited the use of genetic information with specific laws, others have decided to refrain from legislating while several have adopted a process of relevant consultation with the insurers during which the latter have pledged not to require nor make use of genetic data (*moratorium*). In Greece the issue has not yet been considered while the life and health insurance legislation is incomplete.

2. Genetic data

a. Definition

Genetic data is data arising from genetic analysis, i.e. analysis of DNA, RNA, chromosomes, proteins or metabolites detecting gene mutations or chromosomal changes

associated with diseases and conducted for medical reasons. According to one opinion, family history is also included in a person's genetic data.

b. Importance of genetic testing

The number of diseases with a strong genetic link, for which genetic testing is available, for predisposition or diagnosis, is increasing. Of the available genetic tests, the most controversial with regards to their use in private insurance are predisposition tests, i.e. tests capable for detecting disease-causing mutations in healthy individuals. The prognostic value of such tests varies significantly. Additionally, the processing and evaluation of the results of genetic testing is by no means a simple task as several factors need to be taken into account such as family history, medical history and lifestyle.

c. Is genetic data different from medical data?

Medical history is considered a legitimate criterion for dividing the insured into groups of equal risk and calculating the respective premium. Based on the current policy of insurance companies the insured are covered for diseases not manifested prior to the conclusion of the insurance contract according to their medical records.

Genetic data, and more specifically the results of predisposition tests (the main focus of the present report), like some other types of medical data, reveal a probable risk but – in most cases - not certainty of future sickness. The difference, at the moment, of genetic as against medical predisposition markers is that the association between most genetic markers and the probability of disease is not well-documented compared to medical markers.

3. Ethical issues

a. Protection of personality and economic freedom

In view of the above, the first emerging ethical issue consists in weighing protection of personality for insurance applicants against freedom of business for insurers.

Disclosure of genetic information – similarly to other health-related information – as a requirement for contracting insurance or as a factor in the calculation of premium goes to the core of personality since this information constitutes sensitive personal data.

Considering that genetic data is in principle unchangeable, to reveal a predisposition for a disease may lead to lifelong “stigmatization” of the applicant, a serious infringement on personality that may take the form of unfair social discrimination.

On the other hand, freedom of business for the insurer is apparently restricted if access to genetic data known to the other party may affect significantly the insurer’s business risk. In the context of freedom of contract, barring access to information which is relevant to the object of the specific insurance could be seen as unfair to insurers since they are exposed to a risk they ignore whereas the other party is aware (and perhaps takes advantage) of.

b. The value of genetic data and the risk of “genetic determinism”

Genetic data is a very useful tool in contemporary medicine. In the context of personalized medicine and pharmacogenomics, in particular, personal genetic data is becoming increasingly important for determining therapeutic treatment. It is therefore of paramount importance that the collection of genetic data, which can contribute to improvement of individual health, is not obstructed for non-medical reasons.

The collection of genetic data for research aiming to identify links between diseases and genetic causes with the ultimate goal to identify new treatment targets is crucial for the advancement of science and, in the long run, for the protection of public health. In this case also, it is critical that participation in such research is not discouraged for fear of use of genetic data or of the findings of research to the detriment of participants.

Despite the significance of genetic data for both personal and public health, its prognostic value should not be overrated in order to avoid the impression that genetic tests are decisive for the individual. The use of genetic data in insurance would reinforce the misleading notion of “genetic determinism”, i.e. the belief that an individual’s genetic make-up absolutely determines their future health or other personal characteristics. Therefore, it is important to safeguard genetic data so that not only genetic testing and participation in research, which could yield many benefits to the individual and to society as a whole, are not discouraged but also to avoid an erroneous use of these data disproportionate to their true value for disease prognosis.

3. General directions

a. The principle

In view of the above analysis, the Commission believes that any settlement of the issue should give serious consideration to the following:

- i) Personal insurance is a value of public interest and not a common commodity.
- ii) Genetic data yields a statistical probability of becoming sick and not a definite prediction; therefore, it should not be overestimated.
- iii) Research of the human genome is primarily beneficial for human health, a fundamental societal right and should therefore not be discouraged.

b. A need for regulation

Starting from this position, the Commission believes that some form of regulation of the use of genetic data in insurance is needed in our country. It points out the following:

i) The fact that Greece has an organized system of social security (where discrimination between the insured is inadmissible) does not diminish the relevance of the issue. For, considering the well-known weaknesses of the social security system, the market of private life and health insurance is steadily expanding and is currently relevant to an important part of the population (11 and 16% respectively in big conurbations¹). The same is true in other countries with well-developed social security systems that have already been studying the question systematically (UK, Germany).

ii) The widespread notion of “genetic determinism” – a result of unwarranted overstatements in recent years based on the achievements of genetics – can easily lead to practices of unfair discrimination. The confusion of “predisposition” as a synonym for “manifestation” of a serious disease, even as a result of public misinformation, unless appropriately regulated, can create insurance market conditions unfavourable for the protection of human rights.

¹ According to data from the “Study on insurance contracts” that was commissioned to TNS-ICAP in 2007 by the Hellenic Association of Insurance Companies and was brought to the attention of the Commission by Mr. S. Tangopoulos.

c. The type of regulation

The Commission is aware of the seriousness of the conflict between the rights and interests of citizens and insurers. It believes, however, that the protection of personality and avoidance of unfair discrimination against the insured outweighs the economic freedom of the insurers. And this because the implications of genetic – as any other biological – discrimination directly relate to human dignity and, consequentially, affect the quality of societal life and the principle of equal treatment in a democratic society. By contrast, the harm to the insurance market by the prohibition of genetic discrimination in the risk calculation is not judged significant. The manifestation of a disease for which there is a predisposition (as estimated on the basis of genetic analysis or family history) is uncertain in most cases and it is impossible to determine the time of such manifestation. So, genetic data is not particularly important for the calculation of risk.

Nevertheless, ways need to be identified that will safeguard the legitimate interests of insurers, especially the risk of willful deception. For that purpose, it seems appropriate to adopt a *moratorium* with a reasonable duration. During this time, insurers must make specific commitments not to use genetic data and the State must pledge to enact legislation – following public dialogue. In the context of such dialogue, it is crucial to put in place a certification system for genetic laboratories and to recognize the specialty of geneticists in order to ensure the quality of genetic analysis and genetic counselling.

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