Genetics & Life and Health Insurance International Aspects*

by Yves Chiche**

The insurance industry's medical services have always used genetic notions such as hereditary diseases or family history of genetic disorders. The insurance contract being a bilateral contract, this implies – according to the legal definition – good faith from both parties. In other words, the applicant is indeed supposed to inform the insurer of all elements known by him which could help the insurer to better apprehend the risk covered.

My purpose, here, is not to make a list of all the different aspects of insurance in relation to life and health. These are fully described by the laws pertaining to insurance contracts. Nor do I intend to make an inventory of common insurance practices, but rather, as regards developments in genetic research, I plan to outline the various stands taken internationally concerning genetic testing. Before going ahead, I would like to remind you of the terms in which the issue presents itself in Europe as well as in the United States.

The insurer, by nature, operates a mutualisation of risks. Therefore, he has to estimate the nature and the scope of each individual risk which he expects to cover. This is true for all types of risks and, obviously, in Life insurance as well as in Health insurance.

At this stage, I would like to point out that, today, insurers' and reinsurers' medical services are already commissioned to examine the medical files of applicants for Life or Health insurance and this, without any genetic test being available.

The use by insurers of genetic test results would enable them to improve medical selection. On the other hand, if insurers do not have access to genetic tests an applicant may have taken, it would favour anti-selection or a situation where today's exclusions would have to be maintained.

This anti-selection – so dreadful for insurers – is the outcome of the unequal access to data between insurers and policy-holders, which could put insurers out of business.

In Life insurance, 95% of applicants are merely accepted by filling in a medical questionnaire. Less than 1% of risks are uninsurable in other words the occurrence of such risks is certain and non-random.

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In Health insurance, the risk assessment is trickier. This is due to:

- the existence or not of public health schemes;
- the fact that the risk is part of a group policy or just an individual policy;
- the access to the medical data available which differs greatly from one country to the next (later, we shall deal with the attitude of English policy-holders regarding genetic testing).

In practice, the tendency worldwide is to have few exclusions but adequate rating, adapted to each case.

We must, indeed, keep in mind that, generally speaking, insurance is taken out at a relatively young age.

Lastly and in order to end this discussion of the background surrounding the issue of genetic testing in relation to the insurance industry, let me remind you that an individual's genetic identity is not fixed once and for all; indeed genetic mutations do exist.

Therefore, we can only speak of genetic pathology when a genetic constituent is so important that it reliably foreshadows the occurrence of an illness, assuming there are no extraordinary environmental factors.

Concerning the international aspects, it is clear that we are dealing with a fragmented situation, nevertheless, two main tendencies appear:

- one observed in the United States and
- another observed in Europe.

The different views expressed have helped us move towards a shared pattern of conclusions. Looking at the various stances has furthered our grasp of the problem.

In the United States, today, we can notice that most insurers use genetic test results. In order to avoid abuses, associations have put forward some recommendations which I will list in a moment.

The Health Insurance Association of America carried out a survey showing that none of the insurers who took part in the interview requests that clients undergo genetic testing. But one in four stated that, when already taken, the results of genetic tests should be made available to insurers so as to avoid the unequal access to data and therefore anti-selection.

This survey also included a question on the relative weight given by companies to insurance branches involved. It brings out that – in the opinion of American insurers – Individual Disability insurance is a main concern to 58% of them, Individual Medical Expense insurance to 92%, and lastly, Individual Long-Term Care insurance – new and growing product – to 47%.

A thorough analysis of the survey reveals that in 79% of cases, the knowledge of genetic test results does not change underwriting terms.

Furthermore, 66% of the companies responding indicated that they would decide to use genetic test results if genetic testing was accepted and in use in the medical community.

In addition to this survey, the National Institute of Health and the Department of Health and Human Services have formed a task force and have enacted some recommendations. These two organisms share common characteristics in their way of thinking, functioning something like an ethics committee, with the intention of governing the use of the genetic testing knowledge in the American society.

First recommendation:

Information related to the past, present or the foreseeable future of one's health (including genetic data) should not be used to deny coverage or health services.

Second recommendation:

Insurers should consider putting a moratorium on the use of genetic testing in the determination of their coverages.

Third recommendation:

To put into practice a basic programme of prevention aiming at advising people, uncovering illnesses and at curing possible genetic diseases.

Moreover, it is to be hoped that insurers will make a significant effort to train professionals for a better understanding of genetic data.

In other respects, the American Council of Life Insurance has recommended to its members:

- that genetic test results should remain confidential;
- that programmes on “how to use genetic tests” should be set up.

This very same association wishes that national legislation and federal standards be implemented after having consulted scientific researchers and insurers, the sole aim being the protection of individuals.

In Europe, positions are more fragmented and it clearly appears that the different studies on the subject have not reached as high a plane as those in the United States.

In Italy,

- A code of practice as regards the use of genetic tests is under consideration by the National Committee of Bioethics.
- Insurers wish to use information concerning the applicant's health.
- The issue has not given rise to much high-level debate.

In Spain, reflections on genetic testing and its implications in insurance have not been carried very far as yet.

As opposed to Southern Europe, Northern Europe has taken steps which bring it to a stance that is similar to the United States' attitude.

Instead of pinpointing each North European country, we will limit our discussion to the following ones: Germany, the United Kingdom, the Netherlands and France.

In Germany,

- No bill but a demand for legislation as regards genetic testing. The issue has little impact on today's consumers because of the usual procedure for buying and selling insurance.
- However, it looks like a consensus, ready to emerge which would allow Health insurers to use genetic test results.
- Life insurers do not use genetic testing today and have no intention of doing so.
- But if an applicant has genetic test results in his possession, life insurers believe that they should be made available to them.

In the United Kingdom,

- No bill.
- Insurers consider that it is far too early to use genetic testing in view of today's knowledge.

Concerning the U.K., a survey has been carried out showing that many policy-holders believe that insurance companies should be allowed access to genetic information if they respect medical secrecy.

This call for confidentiality recalls the one recommended by several American lobbies.

In the Netherlands, the use of genetic testing is being studied by the National Committee of Bioethics.

Some insurers stated that they intended to use genetic testing, which gave rise to a great deal of debate.

In France:**Bioethical laws**

The study of an individual's genetic identity can only be undertaken for medical or scientific research. The person's consent must be obtained prior to the study.

- This draft is scheduled for revision in five years.
- In the meantime, insurers have agreed not to take genetic information into account, even if it is given by the applicant himself.
- A code of practice must be set up.

This quick and non-exhaustive overview provided us with a cross-section of ideas shared by the different associations in the countries mentioned.

Insurers wish:

- To avoid the unequal access to information in order to preserve their ability to prevent the anti-selection stemming from a lack of knowledge of genetic test results.
- One fact: the insurance industry's medical services are carried out by professionals who are bound by medical secrecy, a fact that is not often publicised. Nevertheless, the use of medical expertise has allowed us to make insurable what formerly was not.
- Insurance medicine hopes that today's scientific developments will allow us to reduce refusals thanks to gene therapy.
- A clear distinction must be made between prediction and presumption. Too many accompanying factors are involved:
 - uni-factorial diseases,
 - multi-factorial diseases.

Probability to develop a disease in an environment in constant flux.

Insurance medicine takes into consideration the state of health at the time of adhesion and uses the statistics available on groups similar to that of the applicant.

- Statistics on genetic science are at their very beginning but underwriting in medical fields requires observations over the long term.

The outlook generated by these developments regarding the genetic testing issue is, to use the Swiss expression, "it's urgent to slow down"; in other words, to put moratoriums on further developments.

The effect of such moratoriums is always the same:

Insurers must commit themselves not to use genetic testing as long as the government agrees not to ban its access by the means of legislative measures, so as to have enough time to scrutinize the problem in full.

Therefore a careful position consisting in:

- an attempt to become more fully informed;
- evaluating the control and the liability of genetic tests and the way they are put to use:
 - how they are marketed and to whom,
 - the standards regarding their use.
- A consensus for joint efforts among professionals of the scientific and insurance communities.
- In order to work together to have the right concepts enshrined in law at the right time.

Here, it is necessary to point out that for the first time, 182 countries are attempting to reach a consensus. To do so, the International Committee of Bioethics and one of the U.N.'s intergovernmental bodies – UNESCO – are addressing the problem (this was outlined by Noëlle Lenoir, ICB's president and member of the French Constitutional Council).

In fact, 50 experts from the ICB are trying to work out answers to such questions as:

- How can we ensure that genetic testing is under thorough control?
- What limits should be imposed regarding genetic tests and genetic screening?
- How can we ensure the confidentiality of genetic test results or that genetic screening will not endanger the principle of non-discrimination and the human right of equal treatment?

Only such an approach will ensure that this child's confident gaze at the future will be well-founded.