Genetic Testing In Europe

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INTRODUCTION

Preliminary remarks

Progress made in predicting illness will alter information on the risk of illness. Whereas formerly we all shared the same uncertainty insofar as our health was concerned and believed ourselves to be equal in the face of illness, we now know that we do not all have the same chances.

The genetic revolution at the root of this upheaval will, of course, have important consequences for private insurance, and in particular at the level of the insurer/policyholder relationship. This revolution is thus no longer just scientific, but equally ethical and social.

Like all new knowledge, genetics arouses fear, primarily because of the abuse it could lead to, but also because of ignorance and the erroneous opinions and unfavorable prejudices that surround it. It is therefore not surprising that some people are desperate to limit certain of its applications.

Such a reaction is understandable as emerging technologies quite often generate fear: for example, in the UK, at the beginning of the automobile era, an Act for further regulating the Use of Locomotives on Turnpike and other Roads for agricultural and other Purposes, which took effect on 5 July 1865, stipulated that:

Every Locomotive propelled by Steam or any other than Animal Power on any Turnpike Road or public Highway shall be worked according to the following Rules and Regulations:

Firstly, at least Three Persons shall be employed to drive or conduct such Locomotive...

Secondly, one of such Persons, while any Locomotive is in Motion, shall precede such Locomotive on Foot by not less than Sixty Yards, and shall carry a Red Flag constantly displayed, and shall warn the Riders and Drivers of Horses of the Approach of such Locomotive and shall signal the Driver thereof when it will be necessary to stop, and shall assist Horses, and Carriages drawn by Horses, passing the same...

Fifthly, ever such Locomotive shall be instantly stopped, on the Person preceding the same, or any other Person with a Horse, or a Carriage drawn by a Horse, putting up his Hand as a Signal to require such a Locomotive to be stopped;

Concerns of the public

The arguments against genetic testing that are most frequently cited are as follows:

- Genetic testing entails an invasion of privacy, to the extent that insurers may be seeking access to confidential information that applicants themselves do not want to know and that may affect multiple family members.
- Genetic testing could cause insurance applicants to be rated up or denied insurance, even for risk factors beyond their control.
- Genetic testing might entail classifying people at birth or even before, and possibly lead to entire families being disqualified for insurance.
- As people do not believe that insurers are using personal information for insurance purposes only, they fear that genetic testing could lead to job discrimination, stigmatization and social exclusion.

Concerns of private insurers

Most insurers are aware of the problems that arise because of developments in genetics and of the fears that this science inspires in the public at large.

Their main concern is that if they are prohibited from having access to pertinent information at the time
of underwriting or when the policy is renewed, the consumers will use genetic information to abuse the insurance system, taking advantage of private knowledge of the risks they are submitting for coverage.

In addition, insurers feel that, if they are prevented from requiring applicants to undergo too broadly defined genetic tests, they may in the near future, as technology evolves, no longer be able to order standard medical tests routinely performed today (because these tests, according to the definition adopted in the legislation, will then be considered as genetic).

Insurers have good reasons to be concerned: in many countries, restrictive legislation is already in force or pending.

**LEGISLATIVE ASPECTS IN EUROPE**

**European Union**

On 16 March 1989, the European Parliament adopted a Resolution on the Ethical and Legal Problems of Genetic Engineering. Two principles refer to insurance:

**Principle 19**

Insurance companies have no right to demand that genetic testing be carried out before or after the conclusion of an insurance contract nor to demand to be informed of the results of any such tests which have already been carried out and that genetic analysis should not be made a requirement for the conclusion of an insurance contract.

**Principle 20**

The insurer has no right to be notified by the policyholder of all the genetic data known to the latter.

The Explanatory Report to the Resolution contains the following requirements:

- Genetic analyses which provide information on the future health prospects and the life expectancy of the person to be insured may not be a requirement for the conclusion of an insurance contract. It has not been usual in the past to categorize insurance risks on the basis of hereditary factors and this must remain the case in future. If risks are categorized on the basis of genetic forecasts, the policyholder will suffer a considerable diminution of his individual rights as, unless he wishes to refrain from concluding the contract, he will have to allow his future health to be investigated. The freedom to remain ignorant of genetic information concerning his future, or even not to allow such information to be collected, is a major aspect of self-determination for the individual, is central to his identity and must remain outside the sphere of business organizations' information interests.

- The policyholder must not be required to inform the insurer of all the genetic data on his health prospects known to him when the contract is concluded. Whilst, in an insurance contract, the contracting parties must have the same information with regard to the probability of the event insured against, the insurer cannot claim any right to protection in respect of estimates concerning possible risks, risk which may manifest themselves in the distant future or the identification of predispositions which will only be activated under certain environmental conditions. Such factors must be taken into account for most people. The onset of an illness at some point in the future is a risk which health insurance must cover as the purpose of such insurance is to cover future risks and not to exclude them as cleverly as possible.

Comments: This Resolution had obviously no legal authority in the member States of the then European Community but it sensitized people to the problems which would arise as a result of the developments in genetics. When reading the Resolution, it is not really clear whether private insurance as a whole or only private medical expense insurance was targeted: Principles 19 and 20 do refer to insurance whereas from the Explanatory Report it appears that only private insurance "which provides financial assistance in the event of illness" is concerned.

**Council of Europe**

On 10 February 1992, the Committee of Ministers of the Council of Europe adopted the Recommendation No. R (92) 3 on Genetic Testing and Screening for Health Care Purposes. Its Principle 7 refers to insurance and stipulates:

Insurers should not have the right to require genetic testing or to enquire about results of previously performed tests, as a precondition for the conclusion or modification of an insurance contract.

All members of the Council of Europe adopted this Recommendation, with the exception of the Netherlands, the representative of which reserved the right of the Dutch government to comply or not with Principle 7.
Belgium

Belgium was the first European country to incorporate the above Recommendation in its new law of 25 June 1992 on Non-Marine Insurance Contracts. The following two articles refer to genetics.

Article 5 - Obligation to declare

The policyholder is obliged to declare exactly, at the time of completing the contract, any particulars known to him/her which he/she could reasonably be expected to consider as constituting risk assessment elements for the insurer. However, he/she does not have to disclose details which are already known to the insurer or which the insurer should reasonably be expected to know. GENETIC DATA CANNOT BE TRANSMITTED.

Comments: The applicant is apparently prohibited from declaring any genetic data, even if it would be to his or her advantage. Interestingly, it is not the use of genetic data by the insurer which is prohibited, but its transmission by the applicant! A rather strange way to treat consumers!

It must, however, be said that the legislators had little choice if they really wanted to prohibit insurers from charging higher premiums, let alone denying coverage on the basis of unfavorable genetic data. For by implicitly allowing genetic data to be transmitted, they would in effect create ipso facto a subgroup of quasi substandard applicants: those unable to provide favorable genetic information!

Article 95 - Medical information

The physicians nominated by the insured shall submit to the insured, at his or her request, the medical certificates necessary for the completion and execution of the contract. The medical examinations necessary for the completion and execution of the contract are only to be based on PAST MEDICAL HISTORY ESTABLISHING THE INSURANCE APPLICANT'S PRESENT MEDICAL STATE AND NOT ON GENETIC ANALYSIS TECHNIQUES CAPABLE OF DETERMINING HIS OR HER FUTURE STATE OF HEALTH.

Comments: Strictly speaking, this article implies that the applicant's cholesterol level or blood pressure cannot be used in the underwriting process as these measures are obviously predictive in nature!

Council of Europe (continued)

In July 1994, the Council of Europe published a draft Bioethics Convention, which was modified at the beginning of 1995; three articles refer to insurance:

Article 17 (Tests predictive of genetic diseases)

Tests which are predictive of genetic diseases or that may identify a genetic predisposition to a disease may only be performed for health purposes or for scientific research linked to health purposes.

The Explanatory Report to the Convention contains the following remarks:

- 118. Article 17 prohibits predictive tests for reasons other than health or health-related research, even with the assent of the person concerned. This covers the field of insurance, for example. An insurance company will not be entitled to subject the conclusion or modification of an insurance policy to the holding of a predictive genetic test. Nor will it be able to refuse the conclusion or modification of such a policy on the ground that the applicant has not submitted to a test, as the conclusion of a policy cannot reasonably be made conditional on the performance of an illegal act.

- 119. Predictive genetic testing in the case of employment or private insurance contracts does not have a health purpose and would imply a disproportionate infringement on the rights of the individual to privacy.

Article 18 (Communication of results)

The communication of results of genetic testing outside the health field may only be allowed in accordance with the provisions of Article 2 paragraph 2 [see below] of this Convention and in accordance with the national legislation about data protection.

The following comments on Article 18 can be found in the Explanatory Report:

- 121. People should have unhindered access to genetic testing which may serve their health purposes. In order to be able to take advantage of these techniques in the health care setting, external factors which might interfere with people's free choice to use genetic services in health care should be barred....

- 122. Therefore it is important to prevent third parties from making use of genetic information which the individual has acquired by making use of genetic services in health care. This holds in particular when the attainment of social goods is involved (for instance, employment, life, health and disability insurances). Therefore, the communication of results of genetic testing acquired in the framework of health care for other purposes is forbidden, notwithstanding the free contractual relationship. Otherwise, the individual could refuse to undergo a test and obtain essential information about his or her health because of the fear of consequences....

- 123. Furthermore, the individual who has knowledge of his or her genetic constitution could try to use this unduly, in particular in the case of private insurance
contracts. It is left to national law, taking into account especially the notion of good faith and the general principle forbidding the abuse of law, to specify the appropriate solutions.

Article 2, paragraph 2 (Primacy of the human being)

No restrictions shall be placed on the exercise of the rights contained in this Convention other than such as are prescribed by law and are necessary in a democratic society in the interest of public safety, for the prevention of disorder or crime, for the protection of public health or for the protection of the rights and freedoms of others.

The Council of Europe’s Steering Committee on Bioethics is still discussing the final version of the draft Convention to be submitted to the Parliamentary Assembly (at the beginning of 1996?). If adopted, this Convention would represent the first international text on bioethics to have legal effect in the Council of Europe’s member States that would ratify it (and which would consequently have to transpose it into their national law within a prescribed time, possibly without reserving the right to comply or not with certain articles of the Convention!).

There is no doubt that insurance companies operating in countries which would adopt the Convention would be seriously exposed to antiselection. It is therefore extremely urgent that they undertake all that is possible to amend this draft, particularly the wording of articles 2, 17 and 18. To do so, the most efficient way is probably to have in each country the insurance industry respond as a whole (through its professional association) and address its reply to the local representative of the Council of Europe.

France

The Laws No 94-653 concerning respect for the human body and No 94-654 concerning donation and use of parts and products of the human body, medically-assisted reproduction and prenatal diagnosis stipulate that:

- The genetic study of an individual’s characteristics can only be carried out for medical purposes or scientific research.
  The individual’s consent must be obtained before carrying out the study. (Art. 16-10 of the Civil Code and Art. L. 145-15 of the Public Health Code).
- The use of information about an individual which has been obtained by studying his genetic characteristics other than for medical purposes or scientific research is punishable with one year’s imprisonment and a fine of FRF 100 000 (Art. 226-26 of the Penal Code).

While the original bill which gave rise to the above laws was discussed in the French Parliament at the beginning of April 1994, the French Federation of Insurance Companies made the announcement that for a period of 5 years, its members would not use genetic information when determining applicants’ insurability, even if favorable genetic information was brought by the applicants! The purpose of this 5-year period, which coincides with the 5-year period upon expiry of which the said laws are to be revised, is to study the technical, social, economic and ethical problems which will necessarily arise as developments in genetics occur, with a view to reaching not later than 1999 a consensus with regard to the use of genetic testing in insurance-related matters.

On 7 November 1995, i.e. slightly more than one year after the laws were enacted, the National Consultative Committee on Ethics (Comite Consultatif National d’Ethique) published a report entitled Génétique et médecine: de la prédiction à la prévention.

The recommendations contained in this report are the result of a detailed analysis of the existing laws and pinpoint the matters which need to be discussed further as well as those aspects for which additional measures would probably be necessary. The report insists on the fact that the request of a genetic test by an insurance company with a view to assessing the risks submitted to it would severely jeopardize the basic principles of equality and solidarity! In other words, to deny insurance coverage because the results of a genetic test ordered by an insurance company show that an applicant possesses in his/her genome a gene which would predispose him/her to a disease constitutes a serious violation of human rights! As a consequence, the Committee considers it necessary to continue to prohibit insurers from requesting a genetic test.

With regard to the use of existing genetic information, the report is more cautious and states that:

In reality, whether in insurance or in employment, all the economic mechanisms inherent in ‘liberal’ Western society will sooner or later lead to a widespread use of genetic information. It seems that in the longer term, only a general debate about the role played by solidarity in society at large is capable of forestalling the expected serious consequences entailed in the development and more frequent use of genetic tests in everyday life.

Austria


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It is forbidden for employers and insurers, including their representatives and employees, to obtain, request, accept or in any other way make use of the results of genetic analyses on their employees, candidates, policyholders or insurance applicants.

Norway

According to Law No 56 of 5 August 1994, concerning medical use of biotechnology, genetic tests can only be performed for medical diagnostic and/or therapeutic purposes (Chapter 6-2). Furthermore, Chapter 6-7 stipulates … it is forbidden to request, receive, retain or make use of genetic information concerning a third person if such information is the result of a genetic test. It is forbidden to try to ascertain whether a genetic test has been performed.

Interestingly, Chapter 6-7 also mentions that information resulting from a diagnostic genetic test is not subject to the prohibition given above.

The Netherlands

A 5-year moratorium, expired in 1995, was extended indefinitely a few months ago with the provision that it can be canceled at any time with a 2-year notice period. Insurers have agreed to abstain from ordering genetic tests or using existing genetic information for policies below a certain level (NLG 300'000). The exact wording of the moratorium is currently being discussed with representatives of patients’ organizations.

These contacts with patients’ organizations have been imposed by the government as a prerequisite for self-regulation, the government’s preferred position.

Interestingly, one party, which ironically forms part of the present coalition, found that the moratorium was not going far enough and introduced a private member’s bill: the Medical Examinations Act (Wet op de Medische Keuringen - Wetsvoorste). This bill will be discussed very soon at the Dutch Parliament; if it is adopted, insurers will be prohibited from:

• asking questions and ordering medical tests which constitute a disproportionate invasion into privacy, whatever the sum insured is to be. More specifically, insurers would not be allowed to request that an applicant undergoes a medical test, the result of which could indicate that the applicant is suffering from a severe incurable disease (eg. HIV infection). The reason given for this prohibition is that people have a right not to know that they may one day suffer from a severe and incurable disease. It is noteworthy that the bill is also seeking to include non-hereditary diseases (which should not come as a surprise as the purpose of the bill is truly to grant access to insurance to HIV+ people).

• medically underwriting employees applying to any pension scheme (includ death and disability benefits) set up by an employer,

• having access to existing genetic information when the sum assured is below NLG 300'000 and/or when the annuity assured represents less than 70% of the applicant’s income!

Needless to say, such irrational and discriminatory developments are rather alarming, not least because they may spread throughout the European Union.

United Kingdom

In July 1995, the House of Commons’ Select Committee on Science and Technology produced a report on Human Genetics. The Committee

• proposed the creation of a Human Genetics Commission to regulate medical uses of genetics and advise on other issues including the use of genetic information for employment and insurance purposes

• expressed fears that the need to disclose genetic information to insurers could deter people from taking genetic tests which might be desirable either for their health, or because they aided in research

• recognized the insurers’ concern over anti-selection and their responsible attitude

• believed that it would be possible to find ways to regulate the use of genetic information in insurance which would both protect the interests of society in enabling as many people as possible to obtain insurance and protect the insurance companies themselves

• recommended that the complacent insurance industry be allowed one year in which to propose a solution for dealing with genetic information acceptable to Parliament and that, if it fails to do so, a solution should be sought, by legislation if necessary.

The government’s response to the Committee (January 1996) can be summarized as follows:

• The existing network of more targeted advisory bodies is already largely effective and a Human Genetics Commission is therefore unnecessary

• An Advisory Committee on Genetic Testing will be established to ensure that genetic tests are supplied safely and used ethically

• The insurance industry’s attitude has been responsible
Legislation is not appropriate now or in the foreseeable future

A deadline to propose an acceptable solution should not be imposed on the insurance industry

More work needs to be done to define the problems before the search for a solution can begin

The dialogue between the ABI and leading geneticists is to be welcomed and encouraged as such discussions might lead to an industry-wide code of practice

The government will follow these discussions and review whether it needs to take action. It hopes to see substantial progress within 12 months.

Following this response, a sharp conflict of views has arisen between the British government and a key group of Members of Parliament over the extent to which the government should take responsibility for mitigating the potentially harmful effects of new discoveries in human genetics and their social implications (Nature, 18.2.96, p. 195).

Interestingly, none of the bills/laws which have been introduced in Europe gives a definition of what constitutes

- a genetic test, or
- genetic information.

Such definitions are, however, extremely important, as restrictive legislation without a precise definition of these terms may prevent insurers from requesting applicants to undergo standard medical tests or using results of time-honoured tests, thereby encouraging anti-selection!

PRIVATE INSURERS' RESPONSE IN EUROPE: A FEW COMMENTS AND SUGGESTIONS

Also in Europe, the response of private insurers to the advances in genetics must take into account the constantly changing environment in which private insurers operate.

Constraints imposed on the insurers

- The existence of legal barriers
  - already prohibiting insurers from using genetic information (in such a case, the insurers' response is obviously very limited)
  - strictly protecting privacy and severely limiting, or even forbidding, the use or release of sensitive information outside the physician-patient relationships without the individual's consent
    - exposing offenders to high fines and/or imprisonment.
- The rather emotional public perception of genetics, exacerbated by ignorance, erroneous opinions and unfavorable prejudices. Unfortunately, there is very little insurance companies can do to educate the public in genetics.
- The public's lack of knowledge of the principles of insurance. It is astonishing to notice the fundamental ignorance in insurance matters not only of the average consumer but also of the best educated people and the legislators. In the light of the foregoing, one can conclude that insurance companies have not generally done a good job in educating the public, and the public's ignorance constitutes a serious problem: if consumers do not have a good opinion of private insurers and do not understand the basics of private insurance, how should their attention be attracted and their attitudes towards insurance and genetics be amended?
- The usually poor image of private insurance in the public eye. Insurance companies, and their professional association, should be extremely concerned and take appropriate measures to try to improve their image. In this respect, it is worth mentioning the exemplary role of the American Council of Life Insurance which budgeted last year $2,000,000 and completed its Mission Statement as follows:
  The mission of the ACLI is... to engage in public outreach activities to foster a positive public image of the industry...
- The professional associations' general lack of strength and experience in timely identifying, analyzing and reporting issues, as well as in lobbying and providing services for their members' education, information and assistance (e.g. the MAP series, unheard of in Europe).

U.S. insurance companies must therefore be congratulated for having understood long ago that there is a vital need for a strong and proactive professional association and for continuing to provide the ACLI with the means of representing them effectively.

Not surprisingly, in Europe, the most active professional associations are those in the countries which have had the most liberal control authorities (NL and U.K.).
- A change in the function of private insurance,
which has now become a predominant element in everyday life (e.g. access to private health care, obtaining a mortgage loan, paying inheritance tax etc.). Hence, in many cases, denial of coverage may mean exclusion, which from a social and political viewpoint is not acceptable.

At the same time, Europeans are becoming increasingly aware that, simultaneously,
- they are exposed to global risks of a catastrophic nature (e.g. rising unemployment, collapse of pension funds, funding problems of most welfare programs) and are therefore vulnerable,
- their existing social protection may be curtailed and they may therefore have to buy elsewhere supplementary coverages to maintain their current level of protection.

Under these circumstances, it should not come as a surprise that private insurance is increasingly perceived as a right, or to use a fashionable expression, as an entitlement.

- The funding problems of most European social security programs. The majority of European countries have generous social welfare programs, conceived during the years of rapid economic growth following World War II. This era has, however, now ended: many governments are having trouble funding their social security programs and are being forced to re-think the extent of their benefits.

Rather than take the politically unpalatable step of imposing limitations on social security benefits, legislators have attempted (and are still attempting) to mandate that some of the social security benefits be provided by private insurers, thus shifting onto them a portion of the State’s financial burden.

In this context of cost-shifting, it is understandable that European governments are not really enthusiastic at the idea of allowing private carriers to use additional tools to select “the cream of the crops”.

Summarizing: Many European private insurance companies are beginning to understand that society’s demands and expectations have evolved and, consequently, that their response to the advances in genetics cannot follow the traditional pattern.

**Types of products affected by genetics**

Genetics will certainly not affect all types of products in the same manner and private insurers should therefore provide a modulated response in which it should underline that
- genetics may almost exclusively affect individual insurance as members of groups are usually not individually underwritten, and
- “genetic tests”, if ever ordered, would concern only a minority of individuals, i.e. those applying for high levels of cover, for which a medical examination is usually requested.

On the other hand, the industry must understand that
- products which are particularly exposed to restrictive legislation are those which guarantee a service considered as a social good such as access to health care, a credit, etc., and
- it will have a difficult time successfully implementing defensive measures to protect its right to underwrite such products.

Let’s now have a quick look at various products sold in Europe:

- **Life products with death benefits**

  In many European countries, the most commonly sold individual insurance contracts have very limited, or even no death benefits. It is therefore understandable that maintaining the right to underwrite risk products does not appear to be the priority No 1 of many European insurers: fiscal advantages attached to life insurance are far more important to preserve, and in order to keep these advantages, a lot of European carriers are prepared to forgo even basic principles of risk classification.

- **Preferred Lives insurance**

  In the US, as well as in the UK and Ireland, most companies are now granting special conditions to Preferred Lives. The initial intention was certainly a valid one, i.e. to apply more efficiently the principles of risk classification and charge policyholders more accurately for the cost of their cover, thereby emphasizing a healthy lifestyle. The practical result of such an approach, however, is that for an increasing number of people, i.e. those which do not qualify as Preferred Lives or those segments of the population which do not retain the interest of product development units, insurance may become more and more expensive, possibly unaffordable, or even unavailable!

Fortunately, this phenomenon has not yet spread to Europe (exception: the U.K. and Ireland) as I fear that such an approach is not without danger; more precisely, I am concerned that the elitist tones of marketing and product design activities aiming at attracting the best risks will
- be considered as unfair discrimination and subject to restrictive regulation/statutes, and
give support to those who pretend that access to private insurance is a right.

As a consequence, European companies, when elaborating their marketing strategy, would be wise to be extremely cautious in order not to provoke an unexpected reaction as I am convinced that systematic use of genetic testing to enhance the efficacy of the risk classification process would not be tolerated!

- **Medical Expense Insurance**
  In Europe, access to health care does not presuppose private medical expense insurance; the vast majority of the population is eligible for comprehensive health care under a social security program and the private insurers' role is essentially to grant supplementary coverages. Hence, the situation in Europe is not at all comparable to that in the U.S., where most restrictive bills/ legislation were/are aiming at guaranteeing access to health care by not allowing insurers to deny coverage on the basis of the result of a genetic test. Therefore, medical expense insurers in Europe may not be exposed to the same pressure as their counterparts across the Atlantic.

- **Critical Illness Insurance**
  Critical Illness policies, which provide a cash benefit to policyholders stricken by an event such as heart attack, stroke, coronary disease requiring surgery, or cancer, are quite popular in the U.K. (but rather a "flop" in other countries). Advances in predictive medicine obviously threaten the existence of such products, in as much as many carriers guarantee for the whole policy duration not only the benefits (e.g. the amount of the benefit or the definition of the events insured against) but also the level of the premiums!

  Critical Illness policies have always been exposed to anti-selection but my feeling is that predictive medicine will enhance carriers' exposure to such a level that radical changes in benefit design will become necessary (e.g. definition of cancer will have to be reviewed) and/or it will no longer be possible to guarantee the level of the premium, thereby rendering these products commercially less and less attractive.

- **L.T.C.**
  Sales of L.T.C. policies are limited in most European countries, because there is no need for such cover (e.g. in the Netherlands), the necessary medical infrastructure does not exist, the fiscal advantages are not sufficient, or for other reasons!

  There is, however, a general need for L.T.C. services and an increasing number of private carriers are perceiving this growing demand. It is also clear that L.T.C. policies will be particularly exposed to anti-selection by those aware of a predisposition to a disabling condition such as dementia. However, before determining the impact genetics may have on L.T.C. insurance, I believe that the following questions should be answered first:

  - is it the role of private insurance to grant first dollar L.T.C. coverage or should not the State be responsible for providing such basic coverage?
  - Whatever the position of the State is, would private insurers be allowed to assess the risks individually and charge a sufficient premium? If the answer is negative, then private insurers might be wise to think now about the consequences which sales of LTC policies might have on the way insurers will be able to underwrite their other individual products in the future.

**Annuities**

Research teams all over the World are looking for markers of longevity. If a genetic test highly predictive of longevity were discovered, insurers who would not obtain the results of such tests could be subject to massive anti-selection: those applicants predisposed to having a very long life (and mainly those) would indeed be delighted to buy guaranteed life annuities priced on the basis of an average life expectancy!

**Segments of the population in Europe which have been or may be given special treatment**

- **Families at risk from severe and incurable monogenic disorders of late onset**
  In the Netherlands, when discussions took place between the insurance industry and the government with regard to the practical use of the information from the applicant's family history, the industry's statement was that family history alone was never a cause of rejection, except in the case of Huntington's chorea and myotonic dystrophy. The Dutch government then asked the industry to search for a solution, which it did. Not only was the industry able to show that people carrying the Huntington's gene, and a fortiori those at risk from Huntington's chorea, are indeed insurable (providing they are asymptomatic) but it also proved that a certain number of applicants at risk were in fact already enjoying insurance coverages, which then put an end to the discussions.

- **HIV+**
  In France, private insurers were requested, as part of a compromise with the government, to offer special
conditions to HIV+ people applying for mortgage insurance. The underlying argument was that access to home ownership was considered as a right. Noteworthy, this request was subsequently extended to applicants for all types of credit insurance.

In this context, it would therefore not be a surprise if private insurers were again limited in their activities and prohibited from using genetic information, let alone genetic tests, to assess the health of mortgage applicants!

On this topic, the following questions may be worthwhile considering:

- Is access to home ownership a right or rather just “a roof over ones head”?
- When a bank refuses to grant a mortgage or more generally a credit, why are there no complaints?
- If there is a social problem, why should special conditions solely be offered to HIV+ persons? Why should only insurers be requested to solve a social problem?

Carriers of mutations which have an impact on life expectancy and effect a non-negligible proportion of individuals (eg. carriers of BRCA1 mutations).

Insurance carriers will not be prepared (and will probably not be able) to deny coverage to a significant segment of the population. Mathematical models will therefore need to be developed to determine under which conditions carriers of such mutations are insurable.

Such developments are interesting as they reflect a new orientation: simply denying coverage is no longer acceptable, particularly if the underlying activity (e.g. having access to health care or home ownership) is considered as an element of everyday life. I have no doubt that this trend will increasingly manifest itself in the future and that insurers will be expected to develop specific solutions.

**Goal of private insurers**

The insurers’ goal is certainly not to exclude individuals, but to cover risks and to let the greatest number of people obtain and benefit from the cover they need at the fairest price. The public must be made aware of this goal and, as already mentioned, be continuously educated in insurance matters.

It is worth noting that in all European countries surveyed:

- insurers accept more than 95% of individual life applications made to them under normal conditions, that is, without additional premium and without any cover restriction,
- developments in medical science have resulted in an increase (not a decrease!) of this percentage, and some applicants who were once uninsurable are now able to find coverage, though at a higher premium,
- experience shows that the assessment of substandard risks can be fair and equitable (their observed mortality is very close to what had been expected).

Furthermore, experience also reveals that competition among insurers is the best regulator. There will always be innovative carriers ready to take new risks and to insure segments of the population considered as uninsurable until then! For example, in France, at least one carrier successfully specialized in insuring certain cancer patients!

Finally, I do not believe that the percentage of those who are now denied life coverage (about 2% in Europe) will increase because of advances in genetics. On the contrary! There will, however always be a few individuals who will be unable to find the coverage they need and may the therefore unduly suffer and be practically excluded from society. This is obviously not acceptable and an appropriate solution must be found; however, not only at cost of private insurers! If there is a social problem, then a social solution (e.g. through the setting-up of a pool?) must be found, the financing of which should be borne by, for example, the taxpayers!

**Necessity for dialogue**

As soon as possible, insurers, through their associations, should initiate discussions on genetics with all parties concerned: the public at large, the authorities, members of Parliament, the medical profession and in particular geneticists.

Mutual recognition of everyone’s problems and expectations is an necessary condition for working out a solution and eventually reaching a consensus.

**Requesting a genetic test**

It must first be remembered that in Europe there is neither a generally accepted definition of a "genetic test" nor do insurers currently use "genetic tests" (= DNA-based) to screen applicants.

Second, it must be emphasized that European insurers have no intention of changing their procedures, unless

- the number of "genetic tests" administered in
clinical settings, and
• their predictive value
increase significantly.

Taking into consideration the well known difficulty of distinguishing between "genetic" and "non-genetic" tests, I therefore wonder whether simply prohibiting private insurers from requesting applicants to undergo "genetic tests" is an appropriate measure. My feeling is that such a global ban of the use of genetics is excessive and will not work in practice as it will either give rise to endless discussions (if the definition is too vague), or be ineffective (if the definition is too narrow and does not really apply), or put the insurance industry in jeopardy (if the definition is too broad and all tests, including those commonly performed today, are prohibited).

In the light of the foregoing, I would therefore suggest that insurers be proactive and, together with representatives of the public and the medical profession, define their response to the developments in genetics in a code of conduct, in which they would, among other things, agree on the risk assessment measures (including the tests) that can be performed at underwriting time and on those who could not.

I understand that a code of conduct may not be sufficient to prevent the enactment of restrictive legislation as in Europe also there is a trend to legislate. I have, however, no doubt that such a code would contribute to enhancing the insurers’ image in the public eye and also show the legislators their goodwill and desire to find an acceptable solution.

Having access to existing genetic test results

As for genetic tests, one should first take note that there is no generally accepted definition of “genetic information” and that in Europe also, some people consider family history or cholesterol levels as genetic information.

Generally speaking, for insurers to continue to assess the risks submitted to them individually and to avoid being exposed to anti-selection, there is no option but to consider genetic information just as any other medical information and request access to and the ability to use any and all information pertinent to the risk available at underwriting or renewal time, regardless of the sum assured. Prohibition to do so could have serious financial consequences and jeopardize the solvency of private insurance companies.

The entitlement philosophy may force private insurers to consider a few exceptions to the above principle, and I would have no objection to this; these few exceptions should, however, be carefully selected and precisely defined.

As already mentioned, one of the main concerns of the public is that it does not believe that insurers are using personal information for insurance purposes only. People fear, indeed, that genetic testing could lead to job discrimination, stigmatisation and social exclusion. Therefore, it is essential that insurers focus on confidentiality as a key issue, strengthen their policies and practice, and publicise them widely.

CONCLUSIONS

Right to underwrite/entitlement

The continued ability of private insurers to satisfy the needs of consumers is dependent on their continued right to evaluate and underwrite on the basis of information relevant to the risks to be insured. A limitation or prohibition of the insurers’ right to underwrite would radically modify the environment in which they operate (to the satisfaction of most of their clients) and could force them to withdraw some products from the market, which would then rebound on the consumers, unable to find the cover they need. If a social problem arises, for example when denial of coverage means that an applicant is prevented from having access to certain essential social activities, I agree that such a problem cannot be ignored; my view, however, is that it should not only be the private insurers which should have the obligation to find a solution to this social problem but Society at large. Private carriers are obviously expected to contribute but is there any good reason why the other taxpayers should not be involved?

In addition, in a free market environment like the European Union, any restriction impacting negatively on the price of insurance may induce healthy individuals to seek coverages available outside their countries at lower cost, and/or may attract substandard risks living in another country to buy coverages inadequately priced locally, thereby prejudicing the local industry.

Last but not least, legal constraints on the underwriting process may also affect the way reinsurers operate. If risks submitted to them cannot be assessed individually, they will have no choice but to adjust the way they offer reinsurance.
4.2 Advance in Genetics

In response to the extraordinary developments in genetics, people are beginning to demand that insurers be denied access to genetic information. Such a ban would be dangerous and at the same time inadequate, as well as certain to bring serious, negative effects in its wake.

I share the view that the measures to be taken relate more to a professional code of conduct than to legislation; it would therefore be more appropriate to reach a consensus and define special precautions that could be taken to avoid abuse, as much on the part of the insurers (intrusion into privacy, not respecting the right not to know, systematic use of information for the purpose of exclusion) as on that of the policyholders (use of information to take out insurance under privileged conditions). The problems are, in fact, too complex and the subject is too prone to change to warrant adopting legal regulations a priori, for these will quickly be found to be inadequate and counter-productive.

References

1. Set up in 1949, the Council of Europe is a political intergovernmental organization which currently groups 39 European democracies, is quite distinct from the European Union and has its permanent headquarters (> 1'200 officials) in Strasbourg, France. Among other things, it aims to protect human rights and seeks solutions to problems facing European society (minorities, xenophobia, intolerance, environmental protection, bioethics, AIDS, drugs, etc.).

2. Unofficial translation
3. Unofficial translation
4. Unofficial translation
5. Only available in French
6. Unofficial translation
7. In France, e.g., even the patient cannot force the physician to release medical information to a third party.
8. See e.g. Mr. Fessel’s study entitled “Life Underwriting at Swiss Re”