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# A Comparative International Overview

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The possibility of using genetic information and testing in life insurance underwriting has stimulated legislative and policy discussion at all levels, international, regional, and national. Even in countries with universal health care, the debate on genetics and life insurance has included potential restrictions on the use of genetic information, since life insurance is closely linked to the acquisition of primary, modern socioeconomic goods (e.g., homes, cars, loans). In Europe, where for the most part universal health care systems are in place, the debate on life insurance is equally active: "Public anxiety focuses on two main areas: that people will be pressured into having unwanted genetic tests in order to obtain insurance, and that genetic testing will create an underclass of people ..." (Read 2002, p. 5). Life insurance appears to be a uniform need, closely linked as it is to family responsibilities. Thus, in many European countries access to it is seen as a basic socioeconomic good, a right, not a privilege. In contrast, the debate in the United States centers on genetics and access to health insurance. Hitherto, scant attention has been paid to issues surrounding life insurance per se.

Life insurance contracts rest on the principle of utmost good faith. This means that all relevant information known to the applicant must be declared. Selection among different risks allows the insurer to limit and rate the premium. To achieve this goal, the applicant must give all information requested by the insurer, and voluntary false declaration voids the contract.

In the insurance contract, rational, scientifically sound and empirically supported discrimination is permissible. Discrimination among risks is considered ethically problematic only where there is no sound actuarial basis for the manner in which the risks are classified, or individuals of the same risk class are treated differently.

> Hence the more information available to the insurers the better, the more precise the discriminations the greater the actuarial fairness of the system. (Anderlik and Rothstein 2001)

It is common practice to ask applicants to fill out a personal and family history health questionnaire. Because life insurance is built on mutuality, risk spreading, and pooling, undeclared or false information leading to an assessment of risk that is not actuarially sound both affects the premium and skews the pool. Taking out a large policy at a favorable premium based on genetic information that is not shared with the insurer creates asymmetry of information known as adverse selection. If this practice becomes widespread, "then the whole of mutuality-based insurance collapses" (Read 2002, p. 4). The European Committee of Insurance (1998), referring to the importance of obtaining all relevant information pertaining to the risk, stated: "[T]o assess the risk in full knowledge of the facts, the insurer most dispose of the means to evaluate the components of the risks. The Committee is therefore opposed to any measure depriving insurers of relevant or significant information on the candidate's health." Finally, mutuality based systems should be distinguished from solidarity based schemes of universal health systems in Europe. The latter are usually compulsory with fixed rates set by the government.

The European Union imposes three principles: free circulation of tests, freedom to establish the enterprise, and freedom to offer services. Free circulation of genetic tests raises questions about their technical accuracy. Quality assurance is both for registration and for marketing. Another question is the relevance of such tests to life insurance. Free establishment requires states to welcome on their territory the insurance companies of other member states as registered and controlled by their original state. Any company can commercialize its products in the European Union market. However, in the life insurance industry, it is the law of the insured person's country that applies to the contract, not the law of the country of the insurer. This may foster either a narrower or broader vision in deciding what constitutes discrimination based on health reasons.

Even though several European organizations have clearly taken a stand against genetic discrimination, the position paper of the European Committee of Insurance of 1998 was not so categorical. On the one

hand, as concerns the importance of being correctly informed on the state of health of a proposer (applicant), it states that "[a] questionnaire including a series of questions on the proposer's health [is routine and] no European insurer requires a genetic test." On the other hand it says, that "to assess the risk in full knowledge of the facts, the insurer must dispose of the means to evaluate the components of the risks. [The] CEA is therefore opposed to any measure depriving insurers of relevant or significant information on the candidate's health."

Finally, central to the debate is the definition of genetic information as distinct from other medical data. "Clear definitions of terms used in genetics, insurance and employment should be developed, so that different professions and their clients have a common understanding of the issues" (European Society of Human Genetics 2000). That organization subsequently defined genetic information as:

> [I]nformation that derives directly from the variation between people that exists in their chromosomes or DNA, or information that is being used to infer that a specific genetic variation or genetic influences might be present. The former includes cytogenetic and DNA test results and very specific biochemical changes, whilst the latter category of genetic information includes family history, clinical diagnosis, imaging, clinical chemistry test results, etc. (European Society of Human Genetics 2000)

It is interesting to compare this broad definition with the more restrictive definition of what constitutes genetic testing given by the insurance industry. For example, the Investment and Financial Services of Australasia (IFSA) defines it for the purpose of its policy on genetic testing and insurance as "the direct analysis of DNA, RNA, genes or chromosomes for the purposes of determining inherited predisposition to a particular disease or group of disease but excluding DNA, RNA, gene or chromosome tests for acquired disease" (IFSA 1999). The Life Office Association of South Africa (2001), Association of British Insurers (ABI 1997) and Irish Insurance Federation (2001) have a similar view of what should be considered as a genetic test. The ABI (2001) also points out that "[W]hile there may be little or no conceptual distinction between molecular genetic information and other forms of predictive healthcare data, the popular perception appears to be that there is an important difference." The ABI differentiates between the impact of information resulting from molecular genetic testing and that from family pedigree information. The Canadian Institute of Actuaries (2000) goes further by

stating: "[a] genetic test is a test to determine the presence or absence of particular variations in a person's genetic code." In short, "[d]istinctions between genetic and non-genetic information can be difficult to sustain, since most medical information can in one sense be considered genetic" (McGlennan 2000).

Yet, by distinguishing information coming from genetic tests from other genetic information or even other health information, guidelines of the insurance industry narrow the protection against genetic discrimination of an applicant. Insurers would probably argue, however, that if all genetic data were to be included within a given prohibition, the guidelines would become too general and unworkable (Lemmens 2000). Among their major concerns is the fact that a broad definition of genetic testing undermines currently accepted underwriting tools. Finally, any definition written into law today will most likely be applied to the next wave of demand for extending the prohibitions to long-term care insurance or for disability income insurance (Baker 2002).

In our overview of comparative positions in Europe, Australasia, and Asia, we discern five avenues that could or already do constrain access by life insurers to genetic information. The first is a human rights approach found mainly at international and regional levels. It includes an overriding prohibition on discrimination based on genetic characteristics or features. Within this approach, one can also include that of the Human Genome Organization (HUGO) Ethics Committee (1998), which recommended a broader interpretation of prohibited discrimination based on personal health data.

The second approach is found largely at regional and national levels. It limits the use of genetic testing or genetic test results to health care or research purposes. Outside of those therapeutic purposes, it forbids any other use of such information. A good example of this can be found in the 1992 European Convention on Human Rights and Biomedicine (1992) which states: "Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counseling."

The third avenue requires that insurers be prohibited by law from performing genetic tests or inquiring about results of previously performed tests as a precondition for concluding or modifying an insurance contract. This approach is popular at international, regional, and national levels. Estonian legislation provides a good illustration, stipulating that: "Insurers are prohibited from collecting genetic data on insured persons or persons applying for insurance cover and from requiring insured persons or persons applying for insurance cover to provide tissue samples or descriptions of DNA" (Estonia 2001). An important distinction must be made among different instruments favoring prohibition in that some allow the insurer to have access to the applicant's genetic information with full informed consent, whereas others will not allow any access by the insurer even with consent of the applicant.

The fourth approach involves moratoria in which limitations on the use of genetic information for life insurance purposes come from the initiative of insurers themselves, although sometimes with government support. The strength of moratoria varies greatly from one country to another. Some insurers limit themselves to agreeing not to require genetic testing of applicants, whereas in other countries the results of previous tests will not be demanded. Some insurance moratoria have a ceiling over which it no longer applies; others apply to genetic information derived from research but not to clinical genetic test results.

A fifth approach is the status quo. The decision is not to legislate and to let the insurance industry decide what would constitute relevant genetic information for life insurance underwriting. All these approaches have strengths and weaknesses. Indeed, ultimately, the question is that of the responsibility of insurers as corporate citizens in modern societies where a universal health care infrastructure exists. Table 8.1 summarizes the laws of various countries.

### The Human Rights Approach

UNESCO's Universal Declaration on the Human Genome and Human Rights states, "No one shall be subjected to discrimination based on genetic characteristics ..." (UNESCO 1997, article 6). By embodying the general antidiscrimination principle but extending the traditional list of

**Table 8.1**
Restrictions on the Use of Genetic Information by Insurers for Life Insurance Underwriting (as of August 2003)

| Country | Moratorium[a] | Legis-lation[b] | Guide-lines[c] | Convention on Human Rights and Biomedicine[d] | Other |
|---|---|---|---|---|---|
| Austria | No | Yes | No | | |
| Australia | Partial | No | Yes | | A bill on genetic privacy was introduced in 1998 but has not been accepted |
| Belgium | No | Yes | No | | |
| Bulgaria | No | ? | ? | Ratified the Oviedo Convention 8/1/03 | |
| Canada | Partial | No | Yes | | |
| Chile | No | No | Yes | | |
| Cyprus | No | No | No | Ratified the Oviedo Convention 7/1/02 | |
| Czech Republic | No | No | No | Ratified the Oviedo Convention 10/1/01 | |
| Denmark | No | Yes | Yes | Ratified the Oviedo Convention 12/1/99 | |
| Estonia | No | Yes | No | Ratified the Oviedo Convention 6/1/02 | |
| Finland | Yes, unlimited amount Exp: none | No | Yes | | |

| | | | |
|---|---|---|---|
| France | Yes, unlimited amount<br>Exp: 2004 | Yes | Yes |
| Germany | Yes, limited amount<br>Exp: 2006 | No | Yes |
| Georgia | No | Yes | No |
| Greece | Partial | No | Yes |
| Hungary | No | No | Yes |
| Iceland | No | No | No |
| India | No | No | Yes |
| Ireland | Yes, limited amount, some conditions excluded<br>Exp: 2005 | No | No |
| Israël | No | Yes | No |
| Italy | No | No | Yes |
| Japan | No | No | Yes |
| Luxembourg | No | Yes | Yes |

| | | |
|---|---|---|
| | A parliamentary commission declared that insurers should not use genetic test results | |
| Ratified the Oviedo Convention 3/1/01 | | |
| Ratified the Oviedo Convention 12/1/99 | | |
| Ratified the Oviedo Convention 5/1/02 | | |
| | A bill has been presented but has not been enacted | |
| | Guidelines for genetic testing to be adopted shortly by Ministry of Health | |
| | Association of Life Insurance Medicine has code of practice in preparation | |

ed)

| Moratorium[a] | Legis-lation[b] | Guide-lines[c] | Convention on Human Rights and Biomedicine[d] |
|---|---|---|---|
| No | No | No | Ratified the Oviedo Convention 11/26/02 |
| No | Yes | Yes | |
| Partial | No | Yes | |
| No | Yes | Yes | |
| No | No | Yes | Ratified the Oviedo Convention 8/13/01 |
| No | No | No | Ratified the Oviedo Convention 8/1/01 |
| No | No | No | Ratified the Oviedo Convention 12/1/99 |
| No | No | Yes | |
| No | Yes | No | Ratified the Oviedo Convention 12/1/99 |
| No | No | No | Ratified the Oviedo Convention 12/1/99 |
| Partial | No | Yes | |

| Other |
| --- |
| Task force established by the Ministry of Health has prepared key guidelines addressing genetic testing |
| Bill should be drawn up shortly specifically addressing human genetics |

| | | | | | |
|---|---|---|---|---|---|
| South Korea | No | No | No | | Bill prohibiting discrimination in insurance and employment has been presented |
| Spain | No | No | No | Ratified the Oviedo Convention 1/1/00 | |
| Sweden | Yes, limited amount<br>Exp: Dec 2004 | No | Yes | | |
| Switzerland | No | Yes | Yes | | |
| Turkey | Yes | No | No | | |
| United Kingdom | Yes, limited amount, some conditions excluded<br>Exp: 2006 | No | Yes | | |

Source: Table prepared by Yann Joly.
Notes:
[a] Partial: the insurer will not ask the applicant to undergo genetic testing but may request results of genetic tests already taken by the applicant.
Ceiling: the insurer will not ask the applicant to undergo genetic testing or request results of genetic tests already taken by the applicant unless the insurance policy asked for is over a given amount.
Unlimited: the insurer will never ask the applicant to undergo genetic testing or request results of genetic tests already taken by the applicant.
[b] This category covers any legal protection restricting access to genetic information by insurers.
[c] This covers any guidelines made by scientific or professional organizations regarding the restriction on the use of genetic information.
[d] States that have ratified this Convention are bound by it. The Convention forbids any kind of discrimination against a person based on genetic heritage. Genetic testing should be permitted only for health or research purposes.

prohibited grounds to include genetic characteristics, UNESCO considers such characteristics to be as inherent to the person as gender, age, and race. This approach is extended to personal data when it stipulates that: "Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions set by law" (UNESCO 1997, article 7). It being in the very nature of a declaration to be proclamatory, it remains for other more binding instruments to reiterate such principles and to foresee their application with appropriate sanctions at the regional or national level. Nevertheless, the terms "genetic characteristics" and "genetic data" are telling in that they underscore the concept that the notions of mental or physical handicap and privacy of personal data are not sufficiently robust to include genetic information.

It bears noting that at the regional level, the Council of the European Union mirrored UNESCO's approach in prohibiting discrimination based on genetic features (Council of European Union 2000). Similarly, the Council of Europe's Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine prohibits discrimination on grounds of genetic heritage (Council of Europe 1997a).

Prohibition against genetic discrimination and the need to preserve the confidentiality of genetic data and ensure their protection from access by insurers has received support from several international professional bodies (International Huntington Association 1994; Human Genetics Society of Australasia 1999). This approach is undermined, however, because life insurance is seen as a private contract sanctioned under national laws covering risk assessment and selection, subject only to the marketplace or to rules of professional practice and thus exempt from the general prohibition.

The HUGO Ethics Committee offers a variant in that it explicitly considers genetic information to be "like other medical information" and requiring human rights protection as such. This is consistent with the Council of Europe's Recommendation on the Protection of Medical Data, which includes genetic data in the concept of medical data (Council of Europe 1997b). The European Group on Ethics in Science and New Technologies of the European Commission (1999) also limits itself to stating that as concerns insurers "[s]uch third parties must in no case

have direct access to personal health data." As mentioned, however, most countries do not consider it discriminatory to inquire about a person's health condition in the private contract of life insurance underwriting. In fact, as seen under the principle of mutuality, if prohibited from doing so, insurers would not be able to classify risk and the system would collapse. Thus, if health information is relevant and exists and the applicant is aware of it, it will have to be communicated.

### The Therapeutic Approach

The Council of Europe's 1997 Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine simply states that any genetic test "may be performed only for health purposes" (article 12), thereby thwarting specific requests by insurers for testing. The confidentiality of data is included under the general "right to private life in relation to information about his or her health" (Council of Europe 1997a, article 10).

The Convention on the Human Rights and Biomedicine has been ratified by a number of European countries. Indeed, Cyprus, the Czech Republic, Denmark, Estonia, Georgia, Greece, Hungary, Lithuania, Moldova, Portugal, Romania, San Marino, Slovakia, Slovenia, and Spain have agreed not only that genetic testing can be performed only for health purposes or for scientific research linked to health purposes, but also that any form of discrimination based on genetic heritage is prohibited. The Convention came into force in January 2000 after having been ratified by five states. Ratification procedures differ in each country, but normally involve parliamentary approval. Before ratification each state has to bring its laws into line with the Convention. This may require no change, a change to domestic legislation, or new laws. Domestic laws must include legal sanctions and require compensation for individuals who have suffered undue harm after medical treatment or research. As mentioned, genetic tests solely for insurance purposes or for exclusion solely on the basis of genetic heritage would be prohibited. Georgia, for example, made its internal legislation conform to the convention by including its restrictions concerning genetic material in a new Law on Patients Rights (Georgia 2000). It is interesting to note that even though neither Norway nor France ratified the Convention, both include in their

legislation a prohibition on the study of the genetic characteristics of a person in the absence of medical or research purposes, thus mirroring the therapeutic approach of the Convention.

In Asia, this approach has also been recommended. In 1999, the Japanese Society for Familial Tumors (JSFT) presented draft guidelines stating that: "research should only be performed for the advancement of diagnostic, therapeutic and prophylactic procedures, as well as the understanding of the etiology and pathogenesis of the disease" (Kimura 1999). It also added that "the right to have access to genetic information belongs to the participant" and that "[t]he maintenance and confidentiality of genetic information should be strictly controlled in order to protect the privacy of the participant." The guidelines also stipulate that insurance companies should not inquire about genetic data. The Council Committee of Ethics of the Japan Society of Human Genetics (2000) also produced guidelines stipulating that even where consent is obtained "the utmost care is needed so that this information is not used as a source of discrimination."

### The Prohibitive Approach

The third approach, which specifically restricts by law requests for genetic testing or access to results by insurers as a condition for issuing a life insurance policy, seems to be the most comprehensive. International organizations and

> [g]overnments favoring this approach recognize that even though predictive genetic testing is not yet widespread, significant quantities of genetic information are already held in data banks and could be sought by insurers. A potential difficulty faced by an individual who is asked to consent to the disclosure of genetic information by an insurance company is that since the implications of such disclosure cannot be fully understood in advance, the consent given cannot be regarded as truly informed. (McGlennan 2000, p. 48)

Absent an explicit statutory prohibition on individual consent, this approach is somewhat limited in that if the individual consents, the private law of contracts governs it and the information cannot be withheld. Considering the latter, we saw that general legal obligations of disclosure by the applicant found in the law on insurance contracts would apply. Examples of such limitations can be found in the World Health Organization's 1998 Proposed International Guidelines on Ethical Issues in

Medical Genetics and Genetic Services, which state: "Genetic data should not be given out to insurance companies, employers, schools or governments, other than after the full informed consent of the person tested." The 1999 World Health Organization Statement on Cloning in Human Health reported that "[i]ndividuals have the right to retain control over their genetic material and the information derived from it. Access and use must be defined through consent, contract or law. Genetic information should not be used as the basis for refusing employment or insurance. Exceptions would have to be legally defined." Thus, only a statutory prohibition mentioning that individual consent is not an exception avoids the consent issue or the specific contractual rules of insurance.

It is interesting to note that on the regional level, the European Council Health Committee (1999) added a nuance to the concept of a total prohibition under law. The report stated, "[i]n order to take into account the legitimate interest of the insurer, who in all fairness, wishes to reduce the risk of adverse selection, it would be foreseeable to apply an exception to the non-disclosure of previous genetic test results to the insurers if the coverage desired is much higher than the financial status of the applicant" (p. 20). This proportionate approach is equitable in that it fulfills mutuality while avoiding adverse selection.

The prohibitive approach is particularly popular among European countries. Austria, Belgium, Denmark, Estonia, France, Luxembourg, The Netherlands, Slovakia, Sweden, and Switzerland have enacted laws specifically restricting access to genetic information. Except for Switzerland, the prohibition is total and cannot be set aside by consent of the applicant or rules of insurance law. In short, in most countries, prohibitive protection cannot be lifted even with individual consent. Outside of Europe, Georgia and Israel are the only countries that have legislated to prohibit insurers access to genetic information. In Asia, the Indian Council of Medical Research, without clearly indicating whether specific legislation is necessary, supports the prohibitive approach.

### The Moratorium Approach

Insurers in several countries decided to state publicly that they will neither request life insurance applicants to undergo genetic testing nor divulge results of genetic tests previously undertaken.

> The attractions of this strategy for the insurance industry are apparent. From the perspective of public relations, it enables the insurance industry to appear sensitive to public concern and responsive to criticism. This option has also a prestige enhancing effect for an industry in so far as it reflects a strong sense of moral responsibility on the part of the industry in question. In reality, it may well be the case that the current round of moratoria does not represent such a major concession to public opinion given that there are very few actuarially relevant and accurate genetic tests available. (McGlennan and Wiesing 2000, p. 374)

Insurance associations of Australia, Canada, Finland, France, Germany, Greece, Ireland, New Zealand, South Africa, Sweden, Turkey, and the United Kingdom have all adopted some form of moratorium. It can be self-regulated or a collaboration between major insurance associations and the government, as is the case in the United Kingdom and Sweden.

A derivative in the approach that is popular among several countries is a partial moratorium initiated by the industry. Major actuarial organizations of Australia, Canada, Greece, New Zealand, and South Africa have all stated their opposition to mandatory genetic testing for insurance. Yet they consider it acceptable to access existing test results of an applicant after obtaining consent. The IFSA claims that it will nevertheless "take account of the benefits of special medical monitoring, early medical treatment, compliance with treatment and the likelihood of successful medical treatment when assessing overall risk" (1999). Most associations also give the applicant, or the doctor, reasons for any adjustment made on insurance premiums related to the result of a genetic test.

Although insurers' associations of most countries that have moratoria agree that insurers should not demand that an applicant take a genetic test in order to obtain insurance, only in Finland, France, Germany, Ireland, Sweden, and the United Kingdom have insurers made a stronger commitment. These associations agreed not to ask an applicant for results of previous genetic tests but limit their engagement in various ways. A popular technique is for insurers to provide a time limit of usually no more than five years to the moratorium. This allows them to take some time to understand fully the process of underwriting or to renew the moratorium.

Another interesting feature of this approach is the possibility of a ceiling. Underscoring any intervention by government or insurers in Europe is the recognition that both social security and universal health care are in place. As mentioned, life insurance, while seen as a necessary socio-

economic good in modern society, is still a private contract subject to general rules. Thus, where the amount of life or disability insurance asked for exceeds a certain amount, results of genetic tests have to be supplied. The ceiling serves to distinguish the function of life insurance from social, state-sponsored schemes that are compulsory and based on solidarity as opposed to mutuality. Furthermore, a ceiling has long been a more general feature of medical testing and life insurance. It reduces the potential effects of adverse selection by permitting the insured to transfer risk only within narrowly constrained boundaries. It is assumed that the risk of adverse selection only truly comes into play with large amounts of capital. Individuals who know they are at higher risk might take out high-value policies that would have to be funded by other policy holders. This means that adverse selection can still occur within such a ceiling system, but actuarial models suggest that consequent increases in premiums would be negligible. For applicants, it permits acquisition of social goods such as cars and housing. Finally, a ceiling can also be proportionate to personal income levels as opposed to a set amount.

As concerns the combination of moratoria with government approval, the United Kingdom is illustrative. In 1997, the Association of British Insurers produced a code of practice in which not only were insurers barred from requesting genetic tests or requiring disclosure, but underwriters were not allowed to take into account what they knew about a given family. The subsequent creation of the Genetics and Insurance Committee had as its purpose the evaluation of tests proposed by insurers. Even though ultimately the committee considered that the test for Huntington disease is reliable and actuarially relevant, the controversy was such that the government imposed a further five-year moratorium on the use of genetic tests for insurance. In short, whereas the committee decision was accurate, the public was not ready for such transparency. We say transparency because it is obvious that insurers will obtain the same information by legitimate examination of family histories. Indeed, if one comes from a family with a history of this disease, one has a 50% chance of developing it, a factor that will be considered by insurers in any event and is known by family members. If one has the disease, like all the other medical conditions that are expressed, this will be taken into account. Thus, paradoxically, the true advantage of genetic testing would be to prove that one is risk free so as not automatically to

pay the high premium. This moratorium gives the insurance industry the time to gather sufficient data. Even more salutary, it does not have the untoward effect of discouraging citizens from participating in genetic research or from testing. In any event, contrary to popular perception, other than in the case of monogenic conditions, research results are rarely of sufficient clinical significance (U.K. Forum 2001). The advent of predictive testing for genetic risk factors such as breast cancer tests for women, only make this time interval all the more important.

This condition-by-condition approval within a general moratorium agreed to by government together with the industry can be called reflective. This means that use of genetic tests in insurance is subject to oversight by government advisory bodies. It constitutes a policy option that mitigates the problems generally associated with genetics and insurance. In fact, the issue of actuarial relevance has become central to the debate on the topic. The position taken by the insurance industry (e.g., ABI in the U.K.) is that genetic test results will, in certain circumstances, be actuarially relevant. Moreover, if such information is useful to the applicant, it can also be useful to insurers. Insurers maintain that there is no difference between genetic information and other forms of data to which they have established access. Genetic information is one additional factor to be evaluated. In an area of rapidly developing technology, such a reflective system can react to changing circumstances. It implies that rational, scientifically sound, and empirically supported discrimination is permissible, as is the case under general antidiscrimination legislation.

### The Status Quo Approach

As seen earlier, the life insurance system is based on mutuality. Insurers have to be able to rate risk appropriately to avoid the possibility of adverse selection. It could be maintained then, that insurers are best suited to decide whether a genetic test is sufficiently accurate or if a genetic condition is sufficiently serious to warrant mandatory disclosure. After all, they are on the edge of technologies that improve the latest diagnostic tools leading to discoveries (for example, implications of hypertension and obesity on mortality). Some of the most qualified experts in the fields of genetics work for insurance companies. Should

it be up to the insurance industry to decide what is or is not actuarially relevant?

This approach seems to predominate in Asia. Japan and China have well-developed genetic testing technologies, and nothing restricts insurers from using resultant information. In this region, the dilemma has not yet aroused intense reactions by either governments or industry seen in Europe. In Singapore and Korea, the potential danger of imposing genetic testing before obtaining life insurance was brought up by several professional groups, but little legislative action has taken place. Several Asian countries have access to public health care, but life insurance in many of these countries is considered a luxury rather than a necessity.

It should be noted that the Japanese life insurance industry has shown increasing interest in genetic information. In a survey of companies, over half revealed they would like to adopt genetic testing of potential policy holders (Takagi 2000). Controversy surfaced, however, when children screened positive for two genetic disorders (Folling disease and phenylketonuria) were denied coverage, prompting protests from the Japanese Medical Association, which claimed the ban had no medical basis.

## Conclusion

Taking the approaches in turn, there is no doubt that, at this time, the human rights approach when applied to the arena of life insurance is limited in its potential and may unwittingly encourage discrimination. The terms "genetic characteristics" and "genetic data" are telling in that they underscore the fact that the notions of mental or physical handicap or of the privacy of personal or medical data under current legislation are not sufficiently robust to include genetic information. Indeed, we contend that singling out genetic features or data can only exacerbate the perceived abnormality of genetic conditions or at-risk status, thereby contributing to further stigmatization and discrimination. General antidiscrimination legislation also fails to address the fact that fair insurance practices usually constitute an exception to such legislation. Insurance is seen as a private contract sanctioned by law as a risk-assessment business subject only to the marketplace or rules of professional practice.

The therapeutic approach at a minimum avoids the pitfalls of the human rights approach by addressing the purpose of testing rather than

singling out genetics and so draws a much wider net. In fact, prohibition on genetic testing outside of therapeutic purpose would allow the inclusion of social attributes within the prohibition, as would mere perception of being at risk for a genetic condition. We mean that unless considered scientifically validated, such tests would not be performed for insurance purposes nor would mere perception of at-risk status be sufficient. Thus, tests for social attributes such as agression would be precluded. Nevertheless, the value of the therapeutic approach is also limited in that the results of persons participating in genetic research are not adequately protected, the status of research records being uncertain. Furthermore, once a test is performed, its result would have to be communicated if requested by the insurer. This not only affects individual participation but also the request of another family member for pedigree or linkage analysis since familial data are shared by underwriters. Obviously, the legitimate and traditional use of family history questionnaires also thwarts this approach.

In contrast, explicit legislative prohibitions have the sociopolitical allure of the quick fix but in fact may be overreaching, because even persons from at-risk families or in the general population who test negative cannot profit from their health status. Furthermore, the time is near when genetic testing will include testing for proteins, for gene-drug interactions, and for gene-environment exposure. What then constitutes a genetic test or information? Is it possible to distinguish between the results of these tests and family history questionnaires? Moreover, the line between genetic and medical information is necessarily blurred as genetic factors increasingly appear in common diseases as opposed to single-gene conditions. The latter development also obscures the confidentiality of genetic, medical, or personal data through the protection offered by notions of personal privacy or medical confidentiality.

The moratorium approach offers a diversity of techniques that can be adapted to different cultures and legal systems. It can also include agreements between industry and the government, thereby adding political weight and oversight. Yet, not all countries have a single insurance payer or consortium of life insurers so the extent of coverage may be narrow, to say nothing of the issue of monitoring insurers to see what occurs in actual practice. Furthermore, will the time frame be used for actively validating and updating actuarial tables in this age of genetic complexity

and of little knowledge of the role of environmental factors? Such a time frame should also be used to study the consequences of possible access to genetic testing results. Actuarial fairness is the cornerstone for legitimate discrimination.

We maintain that in the moratorium approach, the system of a set ceiling amount with appropriate levels of minimum coverage for all, or of a ceiling proportionate to level of income replacement value, limits the risk to industry of adverse selection. At best, this may be the most realistic, albeit temporary solution.

Finally, the status quo approach (in other words, bide your time and ride it out) rests on dual assumptions that competitive forces in the market will prevent undue discrimination and that insurers are not currently using or asking for genetic test results. The latter is borne out in the literature, which is beginning to illustrate the absence of actual genetic discrimination in insurance practices. In fact, studies reveal that alleged discrimination by applicants was often based on misunderstanding of normal insurance practices or of genetic information and of the nature of genetic disorders (Wertz 1998–1999). In the same vein, even when those affected with a genetic disorder applied for insurance, the fear of insurers that people would buy an excessive amount of insurance (adverse selection) did not materialize either (Hall and Rich 2000; Barlow-Stewart 2000).

Obviously, misunderstanding and allegations by both sides of the debate argue for more than the continuation of the status quo. Most important, they illustrate that public perception and insurer misgivings require the same form of intervention. What then, should be done?

We suggest both a moratorium, preferably under a ceiling or proportionate approach, in concert with governmental approval through an oversight body. Such a body can constantly update, publish, and integrate scientifically validated information, and through public participation regain not only public trust but also public understanding of the workings of the industry. The positive aspects of genetic testing also must be considered, for example, medical surveillance, early treatment, and its likelihood of success.

More important, we also argue in favor of the adoption of legislation that is not genetic specific. The first possible avenue is to add to human rights legislation that prohibits discrimination based on sex, race, and

physical or mental handicap the phrase "or the perception thereof." This would explicitly include within the purview of the general list of prohibitions at-risk but asymptomatic persons, who often are perceived as being already affected. It would also include social attributes often mistakenly attributed to familial genes.

The second avenue is to reinforce legislated protection of medical data and research data generally. In this way, it is hoped that individuals and families will not fear genetic testing or participation in research since all medical data will be better protected. Access by third parties should be strictly limited by law to certain defined situations and questions (i.e., no fishing expeditions). All medical data, including genetic data, will thereby receive greater protection.

Finally, it goes without saying that exclusion from life insurance remains a *real* risk in the absence of a compulsory and comprehensive health care system based on solidarity. This third avenue is the cornerstone.

It is our hope that by these three avenues, current fears based on perceptions of genetic abnormalities and of the socioeconomic impact on insurance will not further exacerbate stigmatization and discrimination. Indeed, with integration of genetics into more general legislation, it could serve as a tool for larger social and political change. The normalization and integration of genetic information depends on it.

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