

Genetic testing and insurance

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Last October the Genetics and Insurance Committee (GAIC), part of the UK Department of Health, announced its decision to allow life insurers in the UK to use genetic test results for assessing the risk of Huntington's disease (HD)¹. Though the announcement was specific to life insurance and HD, the committee is already looking at other insurance products, including private medical cover, and other diseases, including breast cancer. The GAIC's mandate is simply to establish whether the results of certain genetic tests are sufficiently accurate for use by insurers². However, since the committee's decision indicates the possible direction of future regulation of insurance and genetics in the UK, it is of concern that ethical considerations were not addressed. Here we discuss the wider impact of the decision, contrast the regulatory approach in the UK with that in other countries and draw some conclusions about the future of genetics and insurance.

IMPACT OF THE DECISION

The use of genetic information by insurers creates severe disincentives for genetic testing in general. Fears of discrimination or isolation, and now the recognition that insurance may not be available, will cause some individuals to forgo a test that would be medically beneficial. All genetic testing centres in the UK are reported to have encountered refusal to undergo a test because of concern about future insurability³. Although the GAIC's decision applies to HD only, the committee's intention to review tests for other diseases, coupled with the *perceived* threat, might dissuade some individuals from undergoing *any* genetic tests⁴. Such a deterrent effect, if large, would be devastating for patients, the research community and preventive medicine.

The new pressure on individuals at risk of genetic disease could affect their interaction with healthcare providers in other ways. Instead of engaging in discussions with their doctors or other health professionals, they may decide to have the tests done privately: in the USA numerous for-profit laboratories already allow individuals to purchase genetic tests without any input from primary

care physicians or genetics counsellors⁵. Genetic testing outside the doctor–patient relationship could have severe implications both for the health of the patient and for the provision of health services. Patients might feel obliged to conceal the results from their physicians and families, with dire consequences for early detection and prevention. While the former UK Advisory Committee on Genetic Testing (ACGT) established a voluntary set of practice guidelines for the suppliers of medical genetics services direct to the public, there are no clear laws or enforceable controls on the conduct of such tests⁶.

The Association of British Insurers (ABI), which played an important part in the formation of the GAIC and in its proceedings, has pointed out that the disclosure of HD test results may benefit some individuals since those with normal test results can then avoid the higher premiums that would otherwise be calculated solely on the basis of family history⁷. However, this poses a dilemma for anyone with a family history of the disease—to go untested and pay exceptionally high premiums (if an insurer can be found at all) or to undergo a test and risk being excluded from the insurance market altogether. Such a conundrum may unfairly tie genetic test results to all risks, including those unrelated to health. Insurers might offer alternative life policies with specific exclusions and riders related to the disease, so that these individuals can still obtain protection against risks unrelated to genetic make-up (for example, the risk of an automobile accident), but according to the GAIC report such policies would be based on clinical and actuarial data that have yet to be collected.

THE ROLE OF THE GAIC

The authority of the GAIC decision over the practices of the insurance industry is questionable, and will be put to the test as genetic technology expands and insurance competition grows. Because the GAIC is a non-statutory body it does not directly regulate the use of genetic information by the insurance industry. The ABI, through its code of practice, says it will abide by GAIC decisions⁸; however, while the ABI code prohibits insurers from requiring a genetic test as a condition of contract, it does not prohibit insurers from requiring the disclosure of genetic test results during the application stage. The code of practice requires insurers to discontinue the use of results from a particular genetic test if and when the GAIC finds the test to be unfit

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for insurance underwriting, at which point insurers have pledged to reassess individuals affected by the use of genetic tests.

Such a system of retrospective review places the burden of proof on the GAIC. Moreover, the voluntary code of practice within the industry could easily break down: if just a few insurers began requiring the disclosure of all genetic test results, others would be forced to follow suit to avoid accepting a disproportionate share of high-risk individuals⁹.

In the absence of explicit decisions by the GAIC, insurers are left to judge for themselves the relevance of certain genetic tests. However, evidence in the UK and the US indicates that insurers do not possess a clear and consistent operational policy regarding the use of genetic information and may not be sufficiently knowledgeable about genetic science in general^{10,11}. The implications of such findings are especially troubling in the case of multifactorial diseases, for which the genetic and non-genetic determinants are difficult to differentiate for the purposes of determining the probabilities of an insurance claim.

WIDER IMPLICATIONS

As the technology behind genetic testing improves, it is possible that genetic tests for other illnesses will meet the GAIC's criteria for use by insurers. While insurers may still choose not to make testing a condition of contract, the required disclosure of existing test results would no doubt affect a greater number of individuals over time. As science continues to discover the idiosyncrasies of the human genome and its links to physical and psychological ailments, genetic testing may well lead to the identification of some genetic abnormality in a large fraction of the public. According to the ABI, insurers will use test results only for the seven diseases approved by the ABI genetics advisor in November 1998 for use in risk assessment—Huntington's disease, myotonic dystrophy, familial adenomatous polyposis, multiple endocrine neoplasia, familial Alzheimer's disease, hereditary breast cancer and hereditary motor sensory neuropathy. Will this policy withstand the growth of medical genetics or the demand for genetic tests?

There are also issues of data security. The results of a genetic test may reveal several different risk factors, but the obligation to disclose may involve only one disease such as HD. Patients will want guarantees that other confidential information will not be disclosed. In addition, as the pharmaceutical and biotechnology industries develop preventive treatments targeted at patients with identifiable genetic risk factors, the reimbursement claims to private medical insurance companies for such treatments may reveal genetic information which could be used to determine future premiums. In research, too, a balance

will have to be struck between the privacy of patients and necessary access to data. The growing use of genetic testing will require a re-examination of health information management protocols to prevent the misuse of test results.

Even more than the life insurance market, private medical insurers should be concerned about recent developments. A person who has undergone genetic testing, and knows himself or herself to be at excess risk, may purchase exceptional medical cover. In response, private medical insurers will be forced to use genetic test results for risk assessment, and place a stronger emphasis on individual risk rating—even, quite possibly, within group purchasing schemes. This trend will have an inflationary effect on the price of insurance overall, since those with negative test results may be less willing to purchase insurance where their risk is pooled with others. As good risks leave the private medical insurance market, the number of bad risks will grow and insurers will be forced to raise premiums.

Might these trends be countered by some form of social provision? The insurance industry in the UK has not traditionally accepted, explicitly or implicitly, the notion of shared risk across widely disparate risk groups, and both premiums and benefit amounts vary according to the risk posed by an individual applicant's risk category¹². Nevertheless, it is possible to envisage support for the subsidization of life insurance whereby modest premium increases would be levied to ensure cover for the small minority of people requiring special consideration. As the British Society of Human Genetics points out, there is nothing new in the idea that private firms should incur reasonable costs to enable disadvantaged individuals to be treated more equally relative to others; it is embodied both in the US and in the UK by equal employment regulations and laws protecting the disabled¹³.

INTERNATIONAL PERSPECTIVES

Internationally, the UK stands alone in its policies towards insurers. Many other countries have intervened to regulate the use of genetic testing so that patients do not lose the benefits (see Table 1). In some instances, testing is explicitly regulated with regard to technical quality, counselling and disclosure of results (Austria, Netherlands, and Norway). In others, the regulation has focused on the insurance industry, detailing what genetic information can and cannot be used for risk assessment (Denmark, Sweden and the USA). Through its Civil Code, France has enacted human rights regulations that limit the use of genetic tests to medical and scientific research purposes. As part of its new health reforms, Greece has announced plans to prohibit the use of genetic tests by insurers. Even in the USA, where the private health insurance industry is a powerful lobby,

Table 1 Comparison of laws and regulations affecting the use of genetic tests

Country	Relevant laws and regulations	Scope	Impact on insurers	Oversight
Austria	1994 Gene Technology Act	Specifically regulates the provision of genetic tests including laboratory quality, test accuracy, consent, counselling, and information access	Use of information obtained by genetic testing – defined as molecular biological investigations of human chromosomes, genes and DNA segments – is prohibited	Austrian Advisory Board on Genetic Technology and the Austrian Minister of Labour, Health, and Social Affairs set guidelines and handle quality assessments
Denmark	1997 Act 413 on Insurance Agreements and Pension funds	Regulates genetic testing in the context of insurance markets	Act 413 prohibits insurers from requiring a test and requesting, obtaining or receiving genetic information	Danish Council on Ethics and the Danish Board of Health (both of the Ministry of Health) interpret existing and proposed laws and offer quality guidelines
Netherlands	1998 Medical Examinations Act	Regulates the use of all medical examinations and health assessments	Insurers cannot require or enquire about genetic tests, and no questions may be asked concerning hereditary disease; an exception is made for high coverage amounts	Dutch Health Council offers guidelines and advises Parliament
Norway	1994 Act Relating to the Application of Biotechnology in Medicine	Specifically regulates the provision of genetic testing, including consent, counselling and information access	Illegal to request, receive, retain or make use of information deriving from genetic tests	An Advisory Group of the Norwegian Board of Health assists in interpretation of the Act and offers quality assurance guidelines
Sweden	1999 agreement between the Swedish Government and the Association of Insurance Companies	Formal agreement between regulators and insurance industry	Use of information obtained by studying one's genetic characteristics is prohibited	National Board of Health and Social Welfare makes recommendations to Parliament and writes quality guidelines
USA	State laws	State regulations specifically address the insurance industry	State prohibitions range from the type of insurance, type of information or the use of information	State Insurance Commissioners; Federal Agencies under the Department of Health and Human Services (National Institutes of Health, Food and Drug Administration, Centers for Disease Control, Office for Protection from Research Risks, and the Health Care Financing Administration)
	1996 Health Insurance Portability and Accountability Act	Federal law addresses group health insurers	Federal law prohibits insurance exclusions on the basis of genetic test results	

regulation of genetic testing has been stricter than in the UK. Over the past decade, 28 States in the US have passed laws that either restrict insurers' use of certain genetic information or completely ban the use of genetic data for underwriting purposes. These laws sought to protect the interests of patients from the outset, by shaping industry norms and attitudes¹⁴.

THE WAY FORWARD

To balance the conflicting interests of patients and insurers is no easy task. The framework developed by the GAIC

satisfies the interests and financial requirements of the insurance industry, but patients are left vulnerable by its reliance on voluntary agreements. As we have discussed here, the issue becomes much more complex when the wider implications of genetic testing are considered. Moreover, while there exists a strong potential for the improper use of genetic testing data¹⁵ there is little evidence of exploitative insurance purchasing by individuals whose genetic test results are protected by law^{16,17}. Perhaps a better solution could be found by reversing the framework used by the GAIC. More specifically, policy-

makers could put the interests of individuals first, and then protect insurers' interest by enquiring into possible exploitative insurance purchasing by individuals knowledgeable about their genetic susceptibility to disease.

The GAIC's task was restricted to an examination of the clinical and actuarial relevance of genetic testing for insurance purposes. The committee was not asked to evaluate the social and ethical implications of genetic testing, since the newly formed Human Genetics Commission (HGC) plans to investigate these issues. However, the HGC has only recently begun work, and so far the insurance industry has made no pledges to abide by its decisions.

Insurers' use of genetic test results may deter individuals from seeking a test, discourage them from disclosing the results to health professionals or family and prevent them from obtaining private medical or life insurance. Among the countries that have pursued genetic testing regulations, the GAIC's decision sets the UK apart and opens the way for the expanded use of genetic information by insurers without proper consideration of the ethical and social implications.

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