nature genetics
volume 26 no. 3 november 2000

Testing times

On 13 October, the Association of British Insurers (ABI) received a thumbs up regarding the suitability of a genetic test for assessing applicants for life insurance. The Genetics and Insurance Committee (GAIC), recently set up by the United Kingdom Department of Health, approved the use of "normal/abnormal" test results for Huntington disease (HD) in the underwriting of applications for life insurance. This is the first genetic test evaluated by the GAIC. Most insurance companies already request the results, where they already exist, of seven tests. These are for mutant alleles that dispose towards early onset Alzheimer disease, breast cancer, familial adenomatous polyposis coli, and those that cause HD and three other monogenic disorders. The insurance industry, through the ABI, has agreed to act on the advice of the non-statutory GAIC. So the positive recommendation is consistent with insurers' continued requests for results of tests for HD. Were it negative, insurers would (according to the code of practice of the ABI) be obligated to re-calculate premiums established since November 1998, ignoring the test results. Or, in cases where applications were declined, make a reasonable effort to contact applicants and invite them to re-apply.

The role of the committee is to establish a mechanism by which to evaluate the relevance of a genetic test to a particular type of insurance (see side bar), and to use this mechanism for evaluating new genetic tests as they are developed. According to its remit, it is also meant to act as a watchdog by reporting to government ministers on the level of compliance of insurers to its own recommendations. But there are currently no detailed plans as to how the GAIC will monitor compliance, and it is not clear whether it will be able to survey all applicants or accepted policy holders only.

The GAIC is composed of eight people, including two geneticists, Sandy Raeburn (Nottingham Univ.) and Dian Donnai (St Mary's Hospital, Manchester), an epidemiologist (Tim Bishop (Imperial Cancer Research Fund)), two members of Patient Support Organizations, an actuary, an insurance 'practitioner' and the former Assistant Director of the Science Museum. Two were nominated by the ABI, and the others, by the institute of actuaries, the Department of Heath, the Chief Medical Office (of England) and the Genetic Interest Group, a national alliance of organizations whose goal is to promote awareness and understanding of genetic disorders.

Using genetic data to inform decisions that potentially affect the welfare of the individual raises complex, sensitive and profound issues, some of which are relevant to the laws, practices and culture of the country or region in question. The concept of a system that is designed to weigh against those with increased risk, to the advantage of those with decreased risk (and that of the insurer) runs counter to the con-

To obtain approval for a specific test, the applicant must demonstrate that:

- The test accurately measures the genetic information
- An abnormal result in the test has significant implications for the health of the individual
- The health implications make a significant difference to the likelihood of a claim under the proposed insurance product (a minimum 50% increase in mortality risk for life assurance and a minimum 25% increase in morbidity risk for other forms of insurance)

cept that society should ensure that all individuals have access to adequate healthcare and social care regardless of their status (be it genetic, financial or otherwise).

The ABI is sensitive to this principle: it stipulates that the results of genetic tests should not be taken into account when assessing applications for life insurance of less than £100,000 that are linked with mortgage applications. (It is very difficult to obtain mortgages in the UK without first obtaining life insurance.) And yet it defends the use of genetic information in assessing other premiums, including those for insurance against critical illness and loss of income. It points out that the use of genetic data in evaluating applications is related to the established practice of taking into account details of family history, and that genetic information allows them to refine assessment of risk. It places emphasis on the fact that individuals with a family history and a negative (or 'normal') result can be offered policies at standard premiums. Curiously, little is said about the effects of a positive, 'abnormal' result. Chris Smith, an actuary with the insurer Swiss Re, has said that people known to carry a disease-causing allele for HD are normally refused cover. One may therefore predict that those at risk of inheriting a mutated *HD* gene—or a mutated version of any other gene that forms the basis of a test approved by the GIAC—may be more inclined to seek insurance before they seek knowledge of their genetic make-up. Alternatively, they may choose to be tested privately or decline to be tested at all.

According to Tim Bishop, the greatest challenge to the GAIC in assessing the case for the HD tests was judging the extent to which the data supported the case for continued testing. "Many thought that this would be comparatively clear cut, but it was still a significant challenge for the ABI to come up with the appropriate evidence." He points out that much of the data was collected from birth cohorts collected in the first part of this century, and collected without heed to the requirements of actuarial calculation. The necessarily retrospective nature of the data inspires the question: how does one account for the impact of new health technologies on mortality of those carrying mutations that dispose to disease? Whereas it seems that mortality due to mutated *HD* is unlikely have changed significantly over the past century, it is plausible that changes in healthcare policy and procedures may influence the morbidity or mortality of some carrying diagnosed mutations in *BRCA2*.

The insurance industry is predicated on calculating risk, and there is no obvious reason why genetic information should be excluded when other types of information are included, given robust welfare and healthcare systems (the presence of which do not make for a thriving insurance industry). The question that hovers over the fate of those denied insurance as a consequence of genetic status also hovers over the contention that a private healthcare system can replace a public one.

Given the apparent challenges that the GAIC encountered on judging the suitability of what one would have thought to be a 'no-brainer' for predicting reduction in mortality, it will be interesting to observe the fate of an application to use *BRCA2* mutations in assessing insurance premiums. Its probable failure will test the mettle not only of the ABI, but the ability of the GAIC to fulfil its remit in effectively monitoring compliance.