

provided by employers who pay around 70 per cent of the premiums. Moreover, the health of individuals is less relevant to employers' groups responsible for managing company health policies as premiums are not set by assessing each policy individually, but by a long-term 'community' average in which low risks subsidize the higher risks.

Nonetheless, Coorsch believes health insurers will agree to relinquish access to genetic information only if they are allowed to continue using other medical information, such as a family history of disease, especially for policies that bring higher risks.

Life insurers agree, but add that genetic tests should be treated in the same way as other medical information, says Spencer Leigh, an actuary and chief underwriter for Royal Insurance in Liverpool, the United Kingdom, who presented a paper, "Freedom to underwrite", at a meeting of the Institute of Actuaries in London last month.

A portfolio of problems

Critics such as Peter Harper, chairman of the Royal College of Physicians' Clinical Genetics Committee, cite various reasons why they disagree. First, they argue that information about predisposition to a disorder is not the same as medical history because such information, unlike certain genetic tests, does not indicate how long a person will live.

Second, they argue that people should not be denied insurance — or charged higher premiums — for a condition for which they are not responsible. Third, there are doubts whether the insurance industry will be capable of handling and interpreting sensitive and complex information.

Fourth, the prospect of increased insurance premiums — or discrimination in employment — may deter people from undergoing genetic tests, thus affecting the impact of genetic testing programmes. Fifth, use by insurance companies of genetic data, for example to up-rate a policy, will violate the wish of someone who has chosen not to know the result of a genetic test.

Other observers, such as Hugh Watkins, newly appointed professor of cardiovascular medicine at the University of Oxford, question the value to underwriters of polygenic data — particularly for disorders such as cardiovascular disease — as the research in this area is "in its very early stages".

Groups such as the UK Nuffield Council for Bioethics, which published a report on the ethics of genetic screening in 1993, add that they recognize the insurance industry's concerns and thus advocate a moratorium — rather than an outright ban — on insurance companies using genetic information.

Many insurance industry officials oppose a moratorium. Some, such as Leigh, regard it as effectively a ban. But they also dispute the reasons advanced for denying them access to genetic information.

Chuffart, for example, who is the author

of a paper entitled "Genetic underwriting", says premiums might not necessarily rise significantly for higher risks if insurers were allowed to use genetic information. "Competition among offices is so intense that there will always be some company willing to offer lower rates," he says.

The charge that it is unfair to put higher premiums on high genetic risks represents a fundamental misunderstanding of the principles of insurance, says Leigh. Chuffart agrees and says companies are businesses and not "social welfare organizations". Chuffart concedes, however, that policyholders would need to be counselled if they were found — against their wishes — to be predisposed to a disease.

Leigh suggests personal circumstances should not be allowed to interfere in business. In motor insurance "someone who lives in a high-risk area is going to pay more" even if he has no option but to live there because he cannot afford to move. "Should he pay less for car insurance because the address isn't one of his choice?" he asks. "It is not the insurance companies that are being unfair, it is life itself."

One of the obstacles here is the absence of quantitative data to substantiate the views of the protagonists. There is very little academic work on genetic testing and life insurance. The insurance industry itself has only recently begun to address it in detail.

On the scant evidence available, it is becoming apparent that insurance companies could be persuaded to ignore polygenic data on the grounds of cost. At the moment, the industry has a well-honed system of estimating life expectancy and mortality, based on tables that are continually updated

by actuarial associations around the world. These tables would have to be recalculated at significant cost if polygenic information were to become the basis for premiums.

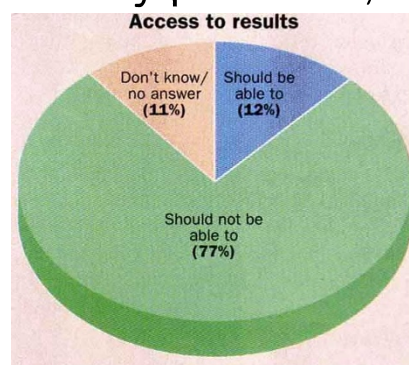
The method of assessment would also have to change. Life insurers do not assess each policy individually, as in motor insurance, but have a standard premium proportional to the probability of death and amount of insurance needed, plus administrative expenses, added to a profit. Companies usually 'load' a premium by a small amount to cover the unpredictable. As a result, 95 per cent of applicants are offered insurance at standard rates, with few medical questions and little administrative work for the office.

Economic implications

Sufferers from monogenic disorders, such as Huntington's disease, fall within the 5 per cent of cases that have to pay more or are denied policies. But sufferers from polygenic disorders, such as heart disease, are likely to be spread within the majority 95 per cent. So if insurance companies want to use polygenic data, they will have to assess each policy individually. "Genetic information will become uneconomic if each applicant has to have an individually tailored policy," acknowledges Paul Smece, head of life insurance at the ABI.

Insurers, however, insist that the potential losses from adverse selection override the fact that genetic information may be of little actuarial value. If data remain off-limits, companies may have to raise premiums to compensate for adverse selection, says Robert Pokorski, vice president of medical research for Swiss Re America, and a ►

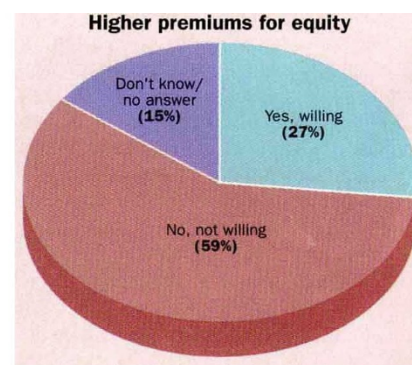
Privacy preferred, but what will it cost?



A clear majority of people do not want insurance companies to have access to the results of genetic tests, according to US public opinion surveys conducted for the American Council of Life Insurance (ACLI).

Most respondents seem to know little about genetic testing, but 77% of those surveyed in 1994 said that life insurance companies should not be allowed access to results (above left).

Individual policy-holders proved



reluctant to pay more for their policies in order to ensure that life cover would be available to everyone at the same rate, regardless of their health and the risk they represent (above right). Only 27% said they would pay more to make a universal rate possible; more than twice that number would not.

The surveys also indicate that the insurance industry "continues to be held in low esteem by the public"; 29% viewed it favourably in 1995. □