UK insurers postpone using predictive genetic testing until 2011

Susan Mayor *London*

Insurance companies in the United Kingdom have agreed to postpone using information from genetic tests that predicts risk of disease when they set insurance premiums. The postponement, announced by the Department of Health, will last until after 2011.

The health secretary, John Reid, announced that the government had negotiated an agreement with the Association of British Insurers, the trade organisation for insurance companies in the United Kingdom, to extend the current voluntary restrictions on the use of predictive genetic test results by insurers by five years, to November 2011.

The agreement is part of a new framework, the *Concordat*

and *Moratorium on Genetics and Insurance*, agreed between the association and the government with the aim of ensuring that insurers' use of genetic information is "transparent, fair, and subject to independent oversight."

The framework states that no one will have to disclose the result of a predictive genetic test unless it is first approved by the government's Genetics and Insurance Committee and if the insurance is for more than £500 000 (\$960 000; €715 000) for life insurance or £300 000 for critical illness and income protection insurance. More than 97% of insurance policies are for less than these amounts.

Only a small number of

predictive genetic tests are currently potentially of interest to insurers. These include tests for the BRCA1 and BRCA2 genes, associated with inherited breast and ovarian cancer, and the HD gene, which is implicated in Huntington's disease.

The only predictive genetic test currently approved by the Genetics and Insurance Committee for insurance purposes is the test for Huntington's disease for life insurance.

Figures from the NHS show that 500-600 predictive genetic tests are done each year for Huntington's disease, and 40-50% of these are positive. A total of 4635 tests for BRCA1 and BRCA2 genes were done in 2004. About 1000 of these were predictive genetic tests on women with a family history of genetic breast or ovarian cancer, and 45-50% were positive.

Antonia Bunnin, director of policy and campaigns with the charity Breakthrough Breast

Cancer, said, "Our research shows that nearly a third of these women would not take the genetic test if insurance companies were able to access this data, potentially putting their health at risk. Choosing to take a genetic test is a difficult enough decision to make without the added fear that insurance companies may use this information against them."

Mr Reid agreed: "Choosing to have a predictive genetic test can be life saving, and nobody should be put off having such a test because of fears it will be used against them by insurers."

The new framework also states that genetic tests taken as part of a research study do not have to be disclosed to insurers. This removes a potential obstacle to patient recruitment in genetics research. □

Concordat and Moratorium on Genetics and Insurance is available at www.dh.gov.uk

Do it yourself cancer gene testing raises concerns

Anne Harding *New Jersey*

A US company is offering genetic tests for susceptibility to breast and ovarian cancer direct to consumers. Representatives of DNA Direct insist that the counselling and testing that they provide is identical with what a woman would get at a cancer centre—with the exception that she receives test results and counselling by telephone and online, rather than in person. But critics say that the approach puts women and their doctors at risk of not getting the whole story.

The company offers a single point mutation test for \$586 (£306; €439); a screen for three mutations found among women of Ashkenazi Jewish ancestry for \$627; and complete sequencing for \$3312.

"What we are offering at DNA Direct is basically what would be offered at any healthcare provider as standard care for individuals with a personal history or a medical history that would be indicative of hereditary breast cancer,"

Katherine Rauen, the company's consulting medical director, told the *BMJ*.

A woman orders the test online, after which she gets a call from a genetic counsellor who takes a medical and family history. The woman receives a test kit in the mail that she takes to a local laboratory. Results take about three weeks and are given over the telephone by a certified genetic counsellor. The woman also receives a personal report and referrals to community resources.

The company also sends consumers a letter with tips on talking about the results with their doctor and a letter that they can print out for their doctor explaining the results and their implications.

"We like to think that we are part of the team," said Dr Rauen, a paediatrician and medical geneticist. Dr Rauen says that DNA Direct's services are appropriate for people without access to a cancer centre or to a doctor with adequate knowledge of genetic testing. And for women who dislike going to the doctor, Dr Rauen added, the test can be a first step.

But one medical geneticist fears that it is a step in the wrong direction. "I think it's poor patient care," Georgia Wiesner, the director of the Center for Human Genetics, run jointly by Case

Western Reserve University and University Hospitals of Cleveland, told the *BMJ*.

Dr Wiesner argues that the process of getting tested for breast cancer susceptibility and working out what to do with the results contains so many subtleties and requires such personalisation that

it cannot be handled adequately by telephone or via the internet.

Telephone counselling cannot take the place of having a genetic counsellor on hand, in person, agrees Wendy Mason, who manages the helpline for the Susan G Komen Foundation, a US breast cancer charity. □

Some doctors argue that genetic test results, which can be analysed using autoradiograms (above), contain so many subtleties that they cannot be handled adequately by telephone or via the internet