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Editorial

Insurance, genetic testing and familial cancer:

Recent policy changes in the United Kingdom

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In the United Kingdom, concerns about the consequences of genetic testing and the eligibility for life assurance have worried families wanting to pursue genetic testing for later onset disorders such as familial cancers and neurological disease. The recent history and development of the insurance and genetic testing guidelines in the UK is interesting and relevant, because it is the only country in Europe to have had a recent major change in insurance recommendations. Insurance companies have driven the changes, which culminated in the agreement of the UK Government and the Association of British Insurers on a five-year moratorium announced at the end of October 2001. This review details the events leading to the introduction of a moratorium, and the implications for families with a family history of a familial cancer.

BACKGROUND

A family history of cancer is now universally recognised as a major risk factor for developing cancer and demand for appropriate clinical services is fuelled by publicity in both the popular media and the professional literature. Within the past few years, cancer genetic clinics have sprung up in almost every major medical centre and all are hard pressed to cope with the numbers of referrals[1-3]. The insurance implications of genetic testing are complex and this review serves to reflect recent changes in government policy and in the thinking of the insurance industry in the United Kingdom. The situation in the USA is different as within a private healthcare system, insurers often encourage or fund genetic testing as they can see the preventative value of such tests in helping initiate cancer screening programmes. The situation in the Republic of Ireland is *de facto* the same as the UK as most insurers in Ireland have head offices in the UK or vice versa and operate the same policy on genetic testing and insurance.

INSURANCE ISSUES

Fisher predicted the use of genetic information in assessing insurance risks as long ago as 1935[4]. Several cancer genetic tests are now available routinely. For testing in familial breast and ovarian cancer, the main tests asked for are BRCA1 and BRCA2, and less frequently PTEN and TP53. In familial colorectal cancer, familial adenomatous polyposis coli (FAP) and hereditary non-polyposis colon cancer (HNPCC) tests are in common use. Huntington's disease (HD), an autosomal dominant neurodegenerative disorder, has been a role model for this type of testing in adult genetic diseases. Several ethical and legal problems already have been recognised[5,6]. Clearly, there is a difference between more highly penetrant autosomal dominant diseases such as HD, and such diseases as breast and colon cancer. Life tables and penetrance have been worked out for HD and it is possible to predict the age of death within a narrow range. Cancers due to single genes such as breast cancer, which constitute only 5-10% of a predominantly non familial common cancer, present more difficulty, as few accurate lifetime risk tables are available or are difficult to compile with limited accurate penetrance data[7,8]. If genetic tests such as BRCA1 and BRCA2 are used in insurance, they should only be used in conjunction with other information.

DEFINITION OF A GENETIC TEST

A genetic test has been defined as *"an examination of the chromosome, DNA or RNA to find out if there is an otherwise undetectable disease related is genotype, which may indicate an increased chance of that individual developing a specific disease in the future"*[9].

The UK advisory committee on genetic testing (ACGT) definition[10] defines it as *"a test to detect the presence or absence of, or change in, a particular gene or chromosome"*.

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Family history data has been used for years and is generally accepted by insurance companies although there may be considerable inaccuracy in family history data. Using such history without good validated reasons is bad practice and should be challenged - further evidence needs to be collected to demonstrate whether such use is really fair or effective.

In the UK, 95-97% of life insurance policies are accepted at no increased premium. Only about 1% are declined, and 2-4% are rated up[11, 12]. There is no analysis of these figures for specific diseases. The main reason for refusal or 'loaded' premiums is the above average sum assured, and not the type of 'high risk' individual assessed. Risks for insurers will be small if the policy value is low[13], for example under £100,000.

THE RECENT UK POLICY DEVELOPMENTS IN INSURANCE AND GENETIC TESTING

In the UK the main concern is about the consequences of cancer genetic testing on the eligibility for life assurance[14,15]. The recent history and development of the insurance and genetic testing situation in the UK is interesting and relevant, because it is the only country in Europe to have had a recent major change in insurance recommendations. Insurance companies have driven the changes. Before 1995, the insurance industry paid little attention to progression of genetic testing. A House of Commons Science and Technology Select Committee reported on human genetics in 1995,[16] and included insurance issues. The committee found a lack of published research on underwriting and adverse selection, with the insurance industry relying on the principle of the 'right to underwrite'.

Shortly after the publication of the report, the UK Government gave the ABI one year to formulate proposals that would meet demands for access to insurance. At the same time, they announced the formation of a Human Genetics Advisory Commission (HGAC). The HGAC was established in December 1996 as a non-statutory advisory body to report to the government on various developments in genetics. It concentrated on insurance as its first task. The insurance industry in 1997 announced the appointment of a genetics adviser and drafted a code of practice. The first HGAC report was published in December 1997[13]. The report recommended a two-year moratorium on genetic testing. Its conclusions are shown in Table 1. The Association of British Insurers (ABI), a body representing around 95% of insurers in the UK, also reported their recommendations at the same time as the HGAC[8]. The ABI code of practice for genetic testing came into effect in January 1998. The code had several important features (Table 2) and applied to all insurance, including life, permanent health, critical illness, and long-term care and medical expenses. Most 'relevant' UK insurance is predominantly life insurance linked to personal pensions, and property insurance (mortgage cover). As the UK National Health Service provides free health care, health insurance is less frequently purchased than in the USA, although there has been a recent increase in sales of personal health insurance cover policies. The situation

TABLE 1:

Recommendations on genetic testing & insurance of the Human Genetics Advisory Commission of the UK (1998).

1. A permanent ban on the use of genetic testing is not appropriate. Recommendation is for introduction of a moratorium on genetic testing for at least 2 years.
2. There is not sufficient predictive ability of genetic tests at the moment to allow accurate risk assessment.
3. The life insurance industry could currently withstand limited adverse selection if nondisclosure of test results was current policy.
4. There is a perception of unacceptable discrimination - this may deter testing that may lead to beneficial treatment.
5. Arrangements for confidentiality of data are adequate under current practice.
6. No company should require taking of a test as a prerequisite of obtaining cover.
7. Increased research and collaboration between industry and science is required to improve knowledge of actuarial implications of genetic factors.
8. There should be a robust appeals procedure as part of any new system.
9. Recommendations are primarily relating to life insurance but the principles above should appl apply to other types of health insurance.

TABLE 2:

Association of British Insurers code of practice for genetic testing (1998).

1. Insurance companies will not insist on genetic tests.
2. Genetic test results will only affect insurance if they show a clearly increased risk of illness or death. A low increase in risk will not necessarily affect the premium.
3. Insurance companies will always seek expert medical advice when assessing the impact of genetic test results on insurance.
4. Insurers may take account of a test result only when reliability and relevance have been established.
5. Applicants for insurance will not be asked to take a genetic test, but existing test results should be given to the insurance company when it asks a relevant question, unless it has said this information is not required.
6. Existing genetic test results need not be disclosed in applications for life insurance up to £100,000* which are directly linked to a new mortgage for the purchase of a house to be occupied by the applicant(s).
7. An applicant will not be required to disclose the result of a genetic test undertaken by another person (such as a blood relative), and one person's test information will not affect another person's application.
8. The reason for an increased premium or rejection of an insurance application will be provided to the applicant's doctor on request.
9. Insurers will not "cherry pick" by offering a "preferred life" lower than normal premiums on the basis of their genetic test results.
10. An independent adjudication tribunal is being set up to consider complaints, which are unresolved.
11. Each year chief executives will need to demonstrate how they have complied with the code.

* Extended to £300,000 for all classes of insurance in May 2001 and to £500,000 for life insurance in October 2001

differs greatly from the USA insurance market, which is dominated by private health insurance.

The Government responded to the HGAC in late 1998 and although it didn't accept the proposed moratorium, it established a genetics and insurance advisory committee (GAIC in April 1999 in an attempt to validate genetic tests proposed by the Association of British Insurers. The ABI had listed matrices of autosomal dominant, autosomal recessive and X-linked recessive diseases for potential validation. Initially a list of around 30 tests was drafted, and then shortened to eight Autosomal dominant diseases. Adult polycystic kidney disease was then dropped as a test as ultrasound scanning was found to be reliable and easier to institute than a genetic test The list of seven conditions (see Table 3) includes Huntington's disease, multiple endocrine neoplasia (MEN-2), breast cancer (BRCAI & 2 genes), familial adenomatous polyposis coli (FAP), Alzheimer disease, hereditary motor and sensory neuropathy (HMSN) and myotonic dystrophy. The list was never openly published.

TABLE 3.

List of seven conditions and genetic tests recommended by the ABI as relevant for insurance purposes genetic tests of ABI

Condition	**Genes tested for**
*Huntington disease	HD
*Early onset familial Alzheimer disease	APP, PS1 and PS2
*Hereditary breast and ovarian cancer	*BRCA1 and BRCA2*
Myotonic Dystrophy	*MDPK*
Familial adenomatous polyposis	*APC*
Multiple endocrine neoplasia	*RET*
Hereditary motor and sensory neuropathy	*PMP22*

* Reduced to only these three by end December 2000

The role of GAIC was in validating the tests proposed by the ABI. It deemed a test suitable for use in assessing insurance proposals if it met three conditions:

1. Technical relevance - is the test technically reliable and does it accurately detect the specific changes sought for the named condition?
2. Clinical relevance - does a positive result in the test have any implications for the health of the individual?
3. Actuarial relevance - do the health implications make any difference to the likelihood of a claim under the proposed insurance product?

The first condition for validation, Huntington's Disease, was approved in October 2000 as reliable and relevant for the purposes of life insurance policies. The insurance companies accepted this ruling and disclosed that they would not use tests, which were not received for approval by GAIC by the end of 2000. Two more conditions were submitted and are currently being processed - early onset familial Alzheimer disease and hereditary breast/ovarian cancer. Regrettably, the insurance companies took the view that although they had withdrawn other tests including the cancers FAP and MEN-2 as they felt genetic testing by middle age was not going to add much to family history and clinical examination, they refused to allow the results of negative (i.e. not carrying a family mutation) tests which would have been advantageous in securing normal rates in those penalised by family history of these disease. Although there was a large amount of public opposition to the first approval of HD by GAIC, the role of GAIC has been useful in that it forced the ABI to consider the topic seriously, rather that its' previous view that no problem existed. It also put the onus on insurers to produce facts and a case to submit evidence to GAIC regarding reliability and for just these reasons, 5 of the 8 tests have now been dropped. GAIC has all types of insurance as its remit and not just life insurance, which is most problematic in the UK and has forced the consideration of health and critical illness and long term care issue onto the agenda (issues which are particularly relevant in the USA).

Other issues including ethical and social issues in relation to insurance are not covered by GAIC and are the remit of the Human Genetics Commission (HGC). The HGC was established in May 1999 following a major government reorganisation of committees and it absorbed several predecessor committees including the HGAC, which stopped functioning in December 1999. In December 2000, the HGC published a consultation on public opinion on several issues and showed that there was strong opposition to the use of genetic test results by insurance companies[17]. This was confirmed in a MORI opinion survey published by the HGC in March 2001[18] and the HGC concluded that the level of public concern over the issue required a response. This information coincided with the new House of Commons Committee on Science and technology report[19] also in March 2001. The committee took both oral and written evidence from several bodies including the insurance companies within and outside the ABI. The report was severely critical of the insurance companies and the conclusions (including recommending a two year moratorium) are listed in table 4.

The HGC published a statement in May 2001 recommending interim recommendations on the use of genetic information in insurance (Table 5). These included an immediate moratorium on the use of genetic tests by the insurance companies for a period of not less than 3 years. This would allow time for a full review of evidence and regulatory options. The use of family history information was allowed but the HGC specified that they would discuss this and address how insurers use family history information. They also placed a ceiling on the recommended moratorium of £500,000, to protect the insurance industry from significant financial loss. They recommended that legislation might be needed to enforce the moratorium because of the failings of the current system. The ABI responded by issuing on the same day, an extension to their existing moratorium to include all classes of insurance up to £300,000 (previously only mortgage related policies up to £100,000).

The UK government response to both the House of Commons select committee report and the HGC interim recommendations was published on 23rd October 2001[20]. The key features are summarized in table 6. The Government and the ABI have announced a 5-year moratorium on the use of genetic test results by insurers. The moratorium will apply to life insurance policies up to £500,000 and critical illness, long-term care insurance and income protection up to £300,000 for each type of policy. In policy applications above these limits, the insurance industry may use genetic test results where these tests have been approved by GAIC. Legislation

TABLE 4.

Some of the House of Commons Science and technology committee recommendations May 2001

1. Insurance companies should detail exactly what genetic tests they will consider (both positive and negative) for what conditions and under which circumstances as soon as possible.
2. Commercial insurance companies should have access to the same information as applicants, where it is relevant and reliable - but only if there are no adverse consequences for society.
3. It is not certain at present that the information obtained from positive genetic tests is relevant to the insurance industry.
4. Insurers have given test results a predictive significance that cannot at present be justified.
5. Insurers appear to be more interested in establishing their future right to use genetic test results in assessing premiums than in whether or not they are reliable or relevant
6. Insurers must publish more data, which unequivocally supports the changes made to insurance premiums based on positive genetic test results.
7. Insurers should publish clear explanations as to exactly how such factors as early diagnosis and treatment are factored into their actuarial calculations
8. The small number of cases involving genetic test results could allow insurers to ignore all genetic test results until their scientific and actuarial relevance is firmly established.
9. The view that ignoring genetic test results is costly is contradicted by the actions of at least 3 insurers who choose to ignore tests for the short term.
10. We recommend that insurers take into account negative test results.
11. Insurers should explain and publish how they use family history in assessing premiums.
12. Adequate independent research to discern the impact of the use of genetic test results by insurance companies should be carried out.
13. The distinction between research and diagnostic tests should be clearly understood by those seeking to use the results and the statement that results from research will not be used should be incorporated into the ABI code of practice.
14. The ABI must act to convince the government and public that the code of practice is being complied with, and insurers must prove that they are capable of regulating themselves effectively and thoroughly.

TABLE 5.

HGC moratorium recommendations May 2001

1. No insurance company should require disclosure of adverse results of any genetic tests, or use such results in determining the availability or terms of all classes of insurance.
2. Recommendation is for introduction of a moratorium on genetic testing for not less than three years. This will allow time for a full review of regulatory options and afford the opportunity to collect data, which is not currently available. The moratorium should continue if the issues have not been resolved satisfactorily within this period.
3. The moratorium will not affect the current ability of insurance companies to take into account favourable results of any genetic test result, which the applicant has chosen to disclose.
4. HGC will address the issue as to how family history information is used by insurers.
5. An exception is made for policies greater than £500,000. as protection from significant financial loss.
6. Only genetic tests approved by the genetics and insurance committee (GAIC) should be taken onto account for these high value policies. There remains a need for an expert body of this kind.
7. In view of the failings of self-regulation, independent enforcement of the moratorium will be needed. The HGC believes that legislation will be necessary to achieve this.

has not been introduced; however independent monitoring of the ABI code of conduct will take place possibly through an enhanced role for GAIC in monitoring both insurance compliance and customer complaints. It is also to review the composition of the GAIC committee with extension of its' membership. The moratorium has not been extended to use of family history data, and the whole moratorium will be reviewed after 3 years. An important note from the patients' perspective is that the use of negative test results is encouraged by the insurer subject to confirmation in most cases by a geneticist of the relevance of the result.

TABLE 6.

Government and ABI agreed moratorium October 2001

1. There will be a five year moratorium on the use of genetic test results by insurers.
2. The moratorium will apply to life insurance policies up to £500,000 and critical illness, long term care insurance and income protection up to £300,000 for each type of policy.
3. In policy applications above these limits, the insurance industry may use genetic test results where these tests have been approved by GAIC.
4. Legislation has not been introduced, however independent monitoring of the ABI code of conduct will take place through an enhanced role for GAIC in monitoring both insurance compliance and customer complaints.
5. The moratorium has not been extended to use of family history data
6. The whole moratorium will be reviewed after 3 years.
7. The use of negative test results in obtaining normal premiums is encouraged by the insurer subject to confirmation in most cases by a geneticist of the relevance of the result.

THE SITUATION IN OTHER EUROPEAN COUNTRIES

Several European countries have no legislation or guidelines on insurance and genetic testing. Countries that have some guidelines have a moratorium on the use of genetic tests. For example, in France, the moratorium is up to five years, whilst in the Netherlands, it has been extended indefinitely. Once a moratorium has been introduced, it is difficult to find sufficient scientific evidence to justify lifting a ban on the use of genetic testing in underwriting practice[14].

In Austria, the 1994 gene technology law states that employers and insurers are forbidden to obtain, request, accept or use results of genetic analyses. In Belgium, a 1992 Non-marine insurance law allows medical examinations etc. to be based only on past medical history establishing the applicant's medical state, and not on genetic analysis techniques capable of determining future state of health. In Denmark, the amendment to the insurance contracts act 1997, allows insurers only to ask for HIV tests and family history when the sum insured is high and over a certain level. In France, the 1994 French federation of Insurance Companies (FFSA) issued a statement saying that for 5 years, the FFSA will not use genetic information when determining applicants' insurability, even if applicants bring favourable information.

In the Netherlands, it is considered that strict regulation will be needed. In 1995, a 5-year moratorium was extended indefinitely and insurers have agreed not to use genetic tests or existing genetic information for policies below NLG 300'000. Individual responsibility is seen as being extremely important. Limitations on the collection and use of genetic information are derived from the medical treatment and medical checks acts.

In Norway, a 1994 biotechnology law allows strict use of genetic tests. It states that it is 'forbidden to request, receive, retain or make use of genetic information from a genetic test result, and it is forbidden to ascertain if a genetic test has been performed'. In 1997, Poland introduced a law, which established a general inspectorate for personal data protection. In Sweden, Genetic discrimination can be subject to penalty by fine or prison sentence up to a maximum of six months. An agreement was reached with the insurance companies in 1999 not to require insurance applications to undergo genetic tests up until 2002. Following a referendum in Switzerland in June 1998, insurers are not allowed to demand presymptomatic or prenatal investigations as a condition of insurance.

There is no legislation in Finland, Germany, Greece, Hungary, Iceland, Italy, Portugal or Spain. In Ireland the situation is similar to the UK and although there is no specific legislation, most Irish insurance companies have organisational links to the ABI and follow the ABI code where possible.

REGULATION OF GENETIC TESTING AND INSURANCE IN OTHER COUNTRIES

In the USA and other countries without national health services the main concern is about health insurance where a positive predictive test would have great relevance although predictive genetic

tests are rarely able to determine the time at which someone will become ill. In the USA most health insurance is purchased on a group basis by employers and the unemployed or low income groups are often not insured. There is no obligation on an employer to insure a high-risk employee who would raise their costs. Thus 31-36 million people in the USA have no health insurance[21]. The most significant legislation is the health insurance portability and accountability act 1996 (HIPAA). This federal law provides some protection from genetic discrimination but only to employer based and commercially issued group health insurance. President Clinton in February 2000[22] signed an executive order forbidding the USA federal government from using genetic information in general employment decisions. Eventually national legislation in the USA is likely in order to prevent discrimination. Indeed this has been proposed for some time[23]. In the interim 28 states have already introduced fairly restrictive legislation, including the recent Massachusetts law, which prohibits genetic discrimination by employers and health insurance agents[24]. Interestingly there does not appear to be any advantage taken of the gap in those states without laws. The situation in the USA is covered partly by the Discrimination act, 1996. Current bills passing through the US government include one on genetic information & non-discrimination in health insurance[25].

Australia has an Insurance contracts act 1984, which allows insurers to take into account existing genetic information as well as family history. Insurers generally are against forcing individuals to take genetic tests. The Life, Investment, and Superannuation Association of Australia (LISA) are currently revising further guidelines in 1997. The genetic privacy and nondiscrimination bill 1998 explicitly prohibits genetic discrimination by insurers. Canada has no legislation. New Zealand issued guidelines in April 1997 on insurance and genetic tests.

BENEFITS OF CANCER GENETIC TESTING

As in Huntington's disease, if the genetic nature of the condition is well enough defined individuals may be unable to obtain insurance because they are at 50% risk, irrespective of DNA tests[6]. This may prompt those at risk to request testing in the hope that their 50% prior risk will be reduced to the point of being able to obtain insurance. This has not been found to be a particularly important reason for opting for a test[26], nonetheless some women who test positive for BRCA1 have had premiums reduced to normal after prophylactic mastectomy and oophorectomy.

The finding of negative test results (i.e. non gene carriers) has been used to lower already high premiums. In the UK, insurance companies cannot insist that applicants should have genetic tests. Many individuals at risk and on a higher premium will organise genetic tests at their own expense. Confirmation by genetic testing of a genetic cause for a cancer in an already affected person does not automatically increase the existing premium, as this may be based on existing family history or current health status, but a negative test result has led to a reduced premium for some applicants.

Some insurers consider that genetic information is not essential for underwriting life insurance, and are not requesting information about genetic tests. Most applicants who were requested to provide further information were not rated at a higher premium or rejected. Some companies consider they can absorb this small extra load. Overall only 1 in 20 policies are actually claimed on death, which is not an excessive amount.

EVIDENCE OF DISCRIMINATION

A survey of European genetic centres involved in breast cancer testing showed that all the UK centres surveyed had had patients who refused testing because of fear of penalty or being unable to obtain insurance. Two (40%) of the UK centres had experience of patients who refused genetic testing because of fear of employment discrimination[27]. Interestingly, although Norway has extremely strict laws, and there is no particular need to discuss insurance issues prior to testing, instances of refusal of testing due to both fear and employment were seen. This may reflect anxiety because of strict legislation, as people may consider there must be something behind the legislation. The non-UK centres did not appear to have any major discrimination problems.

Cases of actual discrimination were documented, all from UK centres. Some examples cited include a 40 year-old female with relatives with breast and ovarian cancer who could not obtain insurance, but was able to do so after preventative mastectomy and oophorectomy, and a 39 year-old female with a BRCA1 family history, who divorced from her husband, was denied insurance and mortgage cover for a new house unless she had a negative BRCA1 test. Cases were also documented in which on application for health

insurance, excessive details of other family history and genetic test results were requested[28].

A postal survey found that up to 33% of respondents in patient support groups may have experienced problems when applying for life insurance[29]. Such findings can easily be overinterpreted due to a high non-response rate by more satisfied customers.

In the rest of Europe where most countries have restrictive legislation there is little evidence of discrimination[28], although in Norway, there is evidence of increased premiums for HNPCC, but not for BRCA1/2[30].

There is little evidence of discrimination in obtaining health insurance in the USA for presymptomatic individuals[23], nonetheless health insurers are unwilling to pay for testing of for instance BRCA1, with only 15% covering the costs[24] and this is likely to increase if the tests are targeted in the high-risk situation, such as a family with a known mutation[31]. Unless more is done to encourage insurers they may not to be prepared to pay for, for example, an FAP predictive test, thus denying those on lower incomes the opportunity for testing in the first place. Further work in the USA has also shown that insurance industry's fears about adverse selection may be groundless. Women testing positive for BRCAl mutations did not take out higher levels of life insurance[32].

In Australia, families with hereditary bowel cancer experienced genetic discrimination. In a survey of families on the hereditary bowel cancer register, Barlow-Stewart found 8% discrimination - predominantly HNPCC related, and included a number of areas including refusal of life insurance, denial of an increase in life insurance for a pre-existing policy, refusal of income protection and trauma insurance, reduction of superannuation and loading on premiums for travel insurance[33]. One interesting case was that of a civil servant who reported that her application for a senior position in the public service was subject to a negative FAP test result. She had to discontinue her application, as she would have been forced to have a test that would have revealed her mutation status. The issue had been picked up following her ticking of a regular colonoscopy box on the health form.

As a result of release of this evidence, the Australian government has initiated several enquiries to determine the direction for future law or other policy development.

HOW CAN PATIENTS WITH A FAMILY HISTORY OF CANCER ENSURE THE BEST POSSIBLE MANAGEMENT OF THEIR CONDITION?

Patients, and their clinicians, should be aware of the regulations on insurance and genetic testing, the relevant contents of the ABI report and the recent moratorium on insurance and genetic testing within the UK. Most of these issues are complex and patients with a history of familial cancer need access to a clinical genetics service either by direct telephone or clinic contact or through secondary contact via their medical practitioner or hospital clinician. This is particularly useful if the risk is being based on family history, as often patients' knowledge of their own family history of cancer may be inaccurate. The introduction of the recent moratorium and the safeguards contained both within it and by external monitoring of the genetic testing aspects by GAIC and the ethical and social aspects by HGC, is an encouraging step. Increased use of normal test results in setting normal premiums and industry competition should improve access to reasonable insurance cover for hereditary illnesses and as not all insurance companies belong to the ABI, good advice is to 'shop around' using an independent advisor who may be able to negotiate very competitive rates.

CONCLUSION

The rapidly evolving practice of clinical genetics is producing many questions to which we do not yet have clear answers. This is nowhere more apparent than in the genetics of common cancers, including breast cancer, which is the fastest growing area of genetic medicine. Worry about misuse of genetic test information by insurers is a real occurrence and the recent discussions between the Government and the insurance industry leading to their moratorium is to be welcomed. Little evidence exists on which to base a lot of risk assessment by insurers on either the predictive power of cancer genetic tests or on the use of family history as a rating factor. Further high quality actuarial research evidence will provide a better understanding of insurance risk estimation and allow better actuarial practice in calculation of insurance premiums in families with a history of cancer.

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CONFLICT OF INTEREST

The author is a member of the Human Genetics Commission. Although his views have shaped the HGC recommendations on insurance submitted to the UK government, the views expressed in this article are those of the author and may not reflect official Government policy.

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