

Genetics and insurance

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GLOSSARY

Adverse selection The possibility that customers know more than the insurer about their individual risks, and use that information in insurance buying decisions.

Community rating A mandatory requirement for the insurer to charge the same price to all customers, without risk classification or actuarial fairness.

Deterrent effect The possibility that fear of the insurance consequences of having a genetic test result may discourage people from taking clinically useful tests.

Family history The ages at death and causes of death of an insurance buyer's parents, siblings and possibly other close relatives.

Loss coverage The proportion of loss events (say deaths) in a population which is compensated by insurance. An index of the social benefit of insurance to the population as a whole.

Risk classification The process of assigning customers to classes according to the insurer's assessment of their risk, with all members of each group then charged a price reflecting the assessed risk.

Statistical discrimination The application of group averages (say average claim rates for women) to make decisions about individual cases (say the insurance price to be charged to a particular woman).

SYNOPSIS

This article first gives an account of the basics of insurance. It then summarises the considerations which have led to restrictions in many countries on insurers' ability to ask questions about results of predictive genetic tests. The effect of such restrictions on insurance prices has been investigated in various actuarial simulations, which generally indicate that to a first approximation they make little difference to insurance prices. Issues which are raised as arguments for insurers' access to test results are outlined. One of these issues, adverse selection, is examined in more detail. Regulatory approaches in a number of countries are summarised.

I. Introduction

In the years around the millennium there was extensive discussion in many countries of the possible use of predictive genetic tests by insurance companies. Table 1 shows the annual number of mentions of the phrase “genetics and insurance” in English language news items in one online database. It can be seen that the peak in comment around the millennium has now largely receded.

Table 1: Occurrences of “genetics and insurance” in English language news articles

Year	Number of mentions	Year	Number of mentions
1997	14	2003	54
1998	11	2004	18
1999	42	2005	28
2000	114	2006	37
2001	140	2007	29
2002	21	2008	15

Source: Nexis UK database

The decline in comment reflects a consensus around legislative or quasi-legislative initiatives which have restricted the ability of insurers to ask questions about any predictive genetic tests prospective customers may have taken, at least for some types of insurance. For example in the United States, the Genetic Information Non-discrimination Act became law in 2008. The Act prohibits health insurers from denying coverage or charging higher premiums to a healthy person solely on the basis of genetic predisposition to develop a disease in the future.

The prohibition in the Genetic Information Non-discrimination Act (and most similar legislation in other countries) applies only to predictive tests, and not to diagnostic tests. Predictive tests are those which are made on an individual with no symptoms, usually because a relative is affected by the condition for which the test is made. Diagnostic tests are those which are made because an individual already has symptoms. Generally, people buying health or life insurance are obliged to disclose past illnesses and treatments, including diagnostic tests, in response to the insurer’s questions (this obligation is discussed further below). Any special consideration for genetic tests therefore relates only to tests which are predictive. References in this article to genetic tests are generally to be understood to mean only predictive tests, not diagnostic tests.

II. Basics of insurance

The essence of insurance is that in exchange for a small up-front charge, an insurer agrees to make a much larger later payment if a specified adverse event occurs – for example, the death of the life insured in life insurance. In insurance terminology the up-front charge is known as a premium, and the payment if the adverse event occurs is known as a claim; the insurance agreement is known as a policy. The insurer’s result on a single policy is very uncertain – a small profit of the premium less costs if there is no claim, or a very large loss if a claim occurs. But the insurer achieves relative certainty by selling a large number of policies on independent risks. By the law of large numbers, the expected aggregate claims paid by the insurer on the portfolio as a whole become more and more certain as the number of policies increases. Provided the insurers’ aggregate premiums exceed expected aggregate claims (plus costs), the insurer can be relatively certain of making a profit.

Adverse selection

To meet the aim of aggregate premiums exceeding expected aggregate claims, the insurer's premiums need to be based on some sort of risk classification. Usually, risk varies between different potential customers. At one extreme, the insurer may ignore all variations between customers in risk, and set a single premium rate based on the expected average risk across all customers for a particular type of insurance. At the other extreme, the insurer can make a qualitative assessment of each individual risk, and set individual premiums to reflect these assessments. The former approach is cheap and simple, but in a competitive market it is vulnerable to adverse selection. This refers to the possibility that customers know more about their individual risks than the insurer, and use that knowledge in insurance buying decisions – tending to buy less insurance (or none) if their risk is low, or buying more insurance if their risk is high. This tendency can be exacerbated if a competing insurer differentiates its premium rates, offering lower prices to lower risks (say, those with a favourable genetic test result) and higher prices to higher risks (say, those with an adverse genetic test result). Lower risks may then tend to defect from the first insurer to take up the cheaper offer of its rival. This leaves the first insurer with a higher proportion of high risks than its original assessment, so that unexpected losses are made.

The threat of adverse selection in a market where insurers can compete by offering different risk classifications pushes all insurers towards using finer risk classifications. But finer classification of risk tends to imply higher costs of gathering information about potential customers; and an over-complicated and intrusive classification process may discourage some customers, leading to lost sales. The actual degree of risk classification in an unregulated market is then a balance between these two factors: the threat of adverse selection with less risk classification, and the extra costs and complication with more risk classification.

In life insurance, the questions asked by the insurer for risk classification normally include age, sex, occupation, use of tobacco, alcohol and other recreational drugs, dangerous pastimes, and various medical questions. The medical questions cover all hospital admissions, doctor consultations in the past 5 years, any current medication, and family history. Family history means the ages at death and causes of death of the applicants' parents, siblings and possibly other close relatives. Although family history is genetic information, proposals to restrict insurers' access to the results of genetic tests often implicitly assume that family history will continue to be available. However, in some European countries such as Norway, Sweden and the Netherlands, a ban on insurers asking for genetic information also bans questions about family history.

Community rating

Adverse selection is a threat, at least in theory, to any insurer which does not adequately differentiate between risks in a market where other insurers do. But it does not follow that adverse selection is an insuperable problem in a market where all insurers are prevented from using certain factors to differentiate between risks, or even prevented from using any form of differentiation. In such markets each insurer simply makes a risk assessment at the portfolio level, taking account of any higher propensity of higher risks to buy more insurance. This undifferentiated approach is known as community rating. For reasons explained later in this article, accepting a degree of adverse selection can sometime produce a better outcome from a public policy perspective than a greater degree of risk classification. Community rating is often mandated in health insurance (for example, in Ireland, in Australia, and in several US states). Modified community rating, where some limited risk classification is permitted (*eg* perhaps by age only, and no other factors) is also common. In life insurance, on the other hand, community

rating is not mandated, and so a greater degree of discrimination between risks is more common, reflecting insurers' balancing of competitive pressures versus risk classification costs, as referred to earlier.

Utmost good faith

Where community rating is not mandated and insurers set premiums by reference to individual risk characteristics, there is an obvious incentive for a potential insured to deny or conceal characteristics which suggest higher risk. Recognising this possibility, the law of insurance generally requires 'utmost good faith' from the insured: all questions asked by the insurer must be answered fully and honestly. In some jurisdictions, any non-disclosure may entitle the insurer to refuse to pay a subsequent claim, even if the claim arises from an unrelated cause. For example, following the insured's death in an accident, the insurer might refuse to pay out because the insured inadvertently failed to disclose an unrelated episode of depression when applying for the insurance many years ago. This unreasonable principle, which largely derives from very old statute and case law, has been criticised by the United Kingdom's Law Commission and by the courts, but has been relaxed only to a limited extent by industry codes of practice and decisions of the Financial Ombudsman. In other jurisdictions, for example many US states, the unreasonable principle has been limited by "no contest" clauses, which limit the insurer's ability to contest the policy on the basis of non-disclosure to a limited period (say two years) after the policy is sold. This history of statute and case law supporting insurers' right to all information has conditioned insurers' response to the novel issue of genetics and insurance.

Statistical discrimination

Average rates of insurance claims vary by characteristics such as sex, disability, race and probably genetic markers. Statistical discrimination is the application of group averages to make decisions on individual cases. For example, making all comparisons at the same age, it is well documented that women have more sickness than men, but also lower mortality than men; and that white Americans have lower mortality than African Americans. Therefore insurers charge women more than men for health insurance, but less for life insurance; and they would probably (if the law did not prevent this) charge African Americans more than white Americans for life insurance. This is statistical discrimination. It is not denied by insurers that there are some men who live long lives, and some women who have little sickness; the discrimination is based on the average characteristics of the groups applied to individual cases.

Statistical discrimination is often strongly deprecated by contemporary social opinion, and in many jurisdictions it has been outlawed in most contexts. For example, sex discrimination is outlawed in many jurisdictions in employment contexts. Laws banning sex discrimination by employers generally make no distinction between an employer who avoids hiring women based on casual prejudice ("taste-based" discrimination), and an employer who produces statistical evidence that women as a group are less successful in a particular role (statistical discrimination). Sex discrimination laws demand that individual men and women are considered on their individual merits, not on the average merits of their group. The contradiction of this type of law with risk classification in insurance is fundamental: all risk classification is statistical discrimination. Special provisions or exceptions for insurance risk classification are therefore common in this type of law, at least for sex and disability, although usually not for race. Much of the controversy about insurance risk classification arises from the fact that insurers have special exemptions which allow them to practise statistical discrimination, despite society's disapproval of the practice in many other contexts.

Importance of insurance

Private insurance plays an important role in most developed societies in mitigating misfortune of many kinds. This importance is another reason why insurance risk classification is often a subject of public attention and controversy. The level of reliance on private insurance for various needs depends partly on the available alternatives in each society. For example, in the UK, health insurance has low prevalence: less than 10% of the adult population holds health insurance, because the State-financed National Health Service is a comprehensive free-at-the-point-of-use alternative which covers most needs. On the other hand, life insurance, which pays out a fixed sum if the insured person dies, has much higher prevalence: about 50% of the adult population in the UK holds some life insurance. This probably reflects the fact that UK social security benefits make little provision for maintaining a family's income if the breadwinner dies. In the past, it was often difficult in the UK to obtain a mortgage to buy a house without accompanying life insurance, which increased the prevalence of life insurance, although many lenders have relaxed this requirement in recent years. Critical illness insurance, which pays out a fixed sum if the life insured is diagnosed with any of a list of serious illnesses, has an intermediate prevalence – higher than health insurance, but lower than life insurance. In the US, health insurance has much higher prevalence than in the UK: most of the US population has health insurance, because there is no comprehensive alternative for persons under age 65. Life insurance and critical illness insurance have prevalence more similar to that in the UK.

III. Should insurers be able to access genetic test results?

Broad surveys of non-experts generally suggest that the majority of the population opposes insurers having access to genetic test results. For example, the British Social Attitudes Survey asked a question about whether genetic tests should be used by insurance companies to accept or refuse people for life insurance, in 1998 and 2000 (the question has not been asked since, presumably reflecting the declining interest as mentioned in the introduction). The ratio of negative answers ('definitely should not' plus 'probably should not') to positive answers was approximately 4:1 in 1998, and 5:1 in 2000. Similar results have been seen in surveys in many countries, including a number conducted on behalf of the insurance industry. This broad opposition is also reflected in legislative activity in many countries.

These public surveys and legislative activity suggest wide acceptance of the idea of genetic exceptionalism (for further discussion within the encyclopaedia please **see also** Kakuk, P. Genetic exceptionalism). Applied in the insurance context, genetic exceptionalism is the idea that the results of predictive genetic tests can be distinguished from other types of medical information, and should receive greater protection from disclosure. This distinction rests on several features: compared with other types of medical information, genetic test results may be perceived as more predictive, or more personal, or carrying greater implications for other family members, or less within the individual's control. The validity of genetic exceptionalism is often questioned. Geneticists point out that it is difficult to draw a clear distinction between tests which are genetic and those which are not. Insurers point out that many other types of test result (for example, blood pressure or cholesterol) which are routinely made available to insurers are highly predictive; and in most jurisdictions, insurers are permitted to request and use information about family history, which is genetic. These difficulties of definition create practical difficulties for any policy restricting insurers' access to genetic information: where do we draw the line?

However, despite these doubts, there are two pragmatic reasons for giving some weight to genetic exceptionalism when discussing policy on genetics and insurance. First, the idea is widely embraced by legislators and the broader public, and so any discussion or policy which does not

acknowledge any special status for genetic test results may fail to address widespread public concerns. Second, whilst it may be true that the disclosure of non-genetic information to insurers may sometimes be just as negative for the individual as disclosure of an adverse genetic test result, this does not necessarily mean that compulsory disclosure of new types of negative information is optimal policy. Genetic exceptionalism potentially prevents new forms of harmful discrimination being added to existing harms.

We now discuss some of the arguments which underlie the widespread opposition to insurers' access to genetic tests.

Deterrent effect (collateral harm)

Some people who are offered a predictive genetic test may decide not to proceed because they fear that an adverse result will later lead to difficulty in buying life or health insurance. If insurers are allowed to ask for past genetic test results, this fear could be justified. As explained in the previous section, insurance is very important in many jurisdictions in healthcare and home purchase, and the law gives insurers unusual powers to demand medical and other sensitive information about applicants for insurance. This context helps to explain why many people are fearful of the insurance consequences of undergoing a genetic test.

The negative effect of insurers' access to genetic test results on the take-up of tests and treatments can be described as the "deterrent effect" or "collateral harm" of insurers' practices. Note that this deterrent effect depends more on *beliefs* about testing, rather than reality, and so it can be significant even if the beliefs are ill-founded (for example, a person's belief that an adverse result from a particular test will lead to refusal of insurance, whereas in reality it might lead only to a modest increase in premiums). Where taking a genetic test could potentially lead to therapeutic treatment, the deterrent effect involves a clear harm to the people who are deterred from testing. For many people, the possibility that the deterrent effect may reduce access to therapeutic treatment – leading perhaps, for example, to avoidable early cancer deaths – seems a compelling argument for restricting insurers' access to tests.

There is some credible survey evidence for the deterrent effect, for example as follows.

- In a study in Pennsylvania reported in 2003, 55% of women who attended for breast cancer clinical risk assessment rated fear of life insurance discrimination a moderately or very important factor in deciding whether to take a BRCA1/2 test, and the women who expressed concern were one-third less likely to proceed with the test.
- In a study in Australia reported in 2009, screening tests were offered to 106 people from 25 families thought to be at increased risk of bowel cancer. When the participants were initially offered the tests, 80% were in favour. But willingness to undergo the test fell to 50% when participants were informed that insurance policies may be affected by the results. This is significant because for those at high genetic risk, screening and removal of polyps reduces the risk of bowel cancer by more than 50%.
- Where a test is taken, communication of the results to healthcare professionals and others may be inhibited by worries about insurance. For example, a substantial minority of people who request tests for Huntington's disease in the UK want no information provided to their general practitioner (family doctor).

Spillover effect

Because of the pervasive importance of insurance in meeting needs such as healthcare and family protection, insurance practices tend to spill over into other areas of life. For example, employers sometimes require new employees to make a declaration of health or occasionally to undergo a medical examination, which is modelled on the approach (and often carried out by the same medical service agencies) used by insurers. If information about genetic test results is available to insurers, why should it not also be available to employers or higher education institutions, to driver licensing authorities, to social security officials and to other State agencies? Permitting genetic discrimination by insurers seems likely to legitimise genetic discrimination in other social contexts. Even if there were a political will to limit use in particular contexts (say employment), this may be difficult to enforce, if the procurement and use of the information becomes everyday practice for insurers.

Locus of control

Many risk factors used by insurers are matters of choice which are perceived to be controllable by the individual, at least to some degree. For example, driving fast cars or participation in dangerous sports such as skydiving are seen as matters of choice, and most people agree with the proposition that if such choices imply higher risk, they should be penalised by higher insurance prices. Use of tobacco and other harmful recreational drugs are also seen largely in this way, albeit with slightly less clarity because of the issue of addiction. Obesity is often seen as a matter of choice, although here metabolic considerations complicate the picture considerably. But nobody has a choice about their genetic profile. Many people who accept that skydivers or smokers should be penalised by insurers think that it is unfair that an individual should be penalised for any adverse features in their genetic profile.

Privacy and the “right not to know”

Genetic information is often perceived as unusually private, personal and sensitive. The demand for genetic test results by an insurer may be seen as an infringement of privacy. Many people believe that an individual with a family history which suggests the possibility of genetic disease has a “right not to know”, that is to choose not to take a genetic test, and to live in hope rather than in the shadow of confirmed predisposition to disease. Insurers recognise this right not to know, at least in the sense that they ask only to know the results of genetic tests already taken, and do not explicitly ask people with a relevant family history to undergo testing before quoting for their insurance. However, the infringement of the right not to know can be more subtle than a straightforward request from the insurer to take a test. Suppose that an individual has a family history of genetic disease, so that an insurer refuses to provide insurance, or quotes a very high price; and that the individual also knows that the insurer offers standard terms to those with the same family history but a favourable genetic test result. Informed consent then becomes compulsory consent: although the insurer never explicitly asks for the test, the individual has to take it to buy insurance. Genetic test results often also have implications for the tested person’s relatives. “Compulsory consent” as just described may also infringe the relatives’ right not to know.

Perceived analogies with racism and 20th century scientific eugenics

It is noticeable that when advocating that discrimination on the basis of genetic test results should be allowed, insurers and other experts frequently make rhetorical appeals to “science” as a justification for genetic discrimination. The pervasive influence of these appeals can be seen in the regulatory machinery which has been established since 1999 in the UK – a government-sponsored Genetics and Insurance Committee, comprised of geneticists and insurance experts with a brief to approve specific genetic tests for use in insurance based on scientific evidence. Even people who might regard specific proposals (say the use of a particular genetic test by insurers) as unobjectionable are often made uneasy by the rhetoric of “science” as a justification for new forms of discrimination. This unease may be amplified by the fact that in ten years, only one test (for Huntington’s disease) has actually been approved, which suggests that the “science” may not be compelling even on its own terms. For some people, this is reminiscent of the disasters of Nazi racial science and other abuses in the 20th century of scientific eugenics, for example forced sterilisations in several Scandinavian countries and a number of US states. Discrimination on the basis of genetic profiles can also be perceived as discrimination on the basis of heritage or identity, rather than personal merit or achievement. To some people, this has uncomfortable parallels with racial discrimination.

IV. Actuarial studies of genetics and insurance

The previous section outlined a number of arguments for placing some restriction on insurers’ access to genetic test results. Insurers put forward a range of arguments for permitting access to tests, ranging from the ideological to the financial; the more ideological arguments will be described in the next section. But insurers’ potentially most compelling argument is a financial one: the argument that if insurers cannot charge higher prices to people with adverse genetic test results, they will have to charge higher prices to everyone. Note that this is not necessarily a bad thing in principle: in a competitive market, the logical corollary of higher insurance prices is higher claim payouts, with the benefit going particularly towards people with adverse genetic test results. However, it is useful to know how much difference a ban would make to average insurance prices. Would it increase prices by 0.1% or 1% or 100%?

Many simulations have been made by actuaries of insurance markets where genetic test results are known to customers, but unknown to insurers. The results can be succinctly stated: to a first approximation, preventing insurers’ access to genetic test results will probably lead to only a small increase in average insurance prices, almost certainly less than 10%. The reasons for these results appears to be that any tendency for those with adverse genetic profiles to buy more insurance is diluted (i) for severe monogenetic disorders, by the rarity of these disorders (ii) for multifactorial disorders, by the modest and often ambiguous implications of any particular genetic profile for an individual’s risk level.

These broad conclusions are subject to a number of provisos. First, if insurers are also banned from asking about family history, a larger increase in prices might result. Second, the results assume that people with adverse genetic profiles do not choose (or are not allowed) to buy unusually large amounts of insurance. This is satisfied by insurers’ current practice of “financial underwriting”, that is, verifying that the cover requested by an applicant is reasonable compared to their income and needs (*eg* a person on a low income does not require millions of pounds of life insurance). Third, small insurance markets with products focusing on particular illnesses (*eg* critical illness insurance in some countries) might be more affected. Nevertheless, to a first approximation, an increase in insurance prices of less than 10% is a reasonable estimate for the effect of a ban on insurers’ access to genetic test results.

The price increases of less than 10% just quoted are small compared to other variations between insurance companies in the prices which are quoted for a particular risk. For example, if any person obtains quotes from several life insurance companies, the best six quotes will typically differ by considerably more than 10%. In this context, genetic testing does not have the overwhelming importance which is often supposed.

V. Insurance ideology

In the light of the small and often negligible theoretical effects on insurance prices if genetic tests are ignored, it may seem surprising that so much effort was directed by insurers around the millennium to promoting the use of genetic tests in insurance. Insurers' arguments appeared to be based more on broad principles and beliefs about insurance, rather than on compelling evidence that inability to access tests would have a large financial effect on their business. In advancing broad principles and beliefs, insurers appeared to expect that compelling evidence of large financial effects would soon become available; but the actual results of actuarial studies summarised above (many of them funded by insurers) have not borne this out.

The principles invoked by insurers to justify their access to genetic test results include the following. First, "actuarial fairness": the principle that insurance prices should reflect the cost of each risk, based on all information about the risk. This is widely accepted for risk factors which are within the control of the individual (say smoking), but controversial for risk factors over which the individual has no control (say genetic profile). Second, and related to the first principle, the "right to underwrite": a belief in the autonomy of insurers to accept or reject risks as they see fit, unfettered by regulation or any mechanism for challenge by customers. As mentioned earlier, the history of statute and case law on insurance in many countries has conditioned insurers to expect this autonomy. Third, adverse selection: even the smallest degree of adverse selection is often seen by insurers as a problem, as the "adverse" terminology itself suggests. This last point is further examined below.

VI. Loss coverage: adverse selection is not always bad

Insurers often invoke the mantra of "adverse selection" as an argument against any restrictions whatsoever on the use of genetic tests by insurers. Their argument is that any restrictions will tend to lead to more insurance bought by higher risks, and less insurance bought by lower risks, so that the price of insurance will rise; and as the number of higher risks is usually small relative to the number of lower risks, the overall number insured will fall. Insurers suggest, either explicitly or implicitly, that any adverse selection and any fall in numbers insured, even if small, would be a bad outcome from a public policy viewpoint. But this argument that all adverse selection is bad rests on a mis-measure of the benefit of insurance to the population as a whole. A fall in the number of people insured can be consistent with a higher number of losses compensated by insurance, if more of the "right" people – that is, the higher risks – buy insurance. From a public policy perspective, a degree of so-called "adverse" selection in insurance may sometimes be beneficial.

This point can be demonstrated by simple numerical examples. Suppose that in a population of 1,000, 16 people die every year. Suppose everyone takes a genetic test, with the result that 200 people know they have a risk of dying 4 times higher than the other 800 people. Assume that everyone can buy either one unit of life insurance or none. If test results are disclosed, insurers will charge differentiated prices to standard and high risks, reflecting their different risk levels. Suppose that under these conditions, exactly half of each group buys insurance. Table 2 shows

the outcome: 8 of the 16 deaths in the whole population are compensated by insurance. This 50% “loss coverage” is an index of the social benefit of insurance to the population as a whole.

Table 2 Insurers use genetic tests: no adverse selection

	Standard risk	High risk
Population:	800	200
Risk:	1/100	4/100
Break-even premiums (differentiated):	1/100	4/100
Insurance purchases:	400	100
Deaths compensated by insurance:	4	4
Loss coverage: $\left(\frac{\text{deaths insured}}{\text{total deaths}} \right)$	50%	

Now suppose instead that insurers are banned from asking about genetic test results, and so they have to charge a single “pooled” price to both the standard and high risks. One possible outcome is shown in Table 3. The “pooled” price is more expensive for standard risks, so fewer of them buy insurance (300, compared with 400 before). The “pooled” price is also cheaper for high risks, so more of them buy insurance (150, compared with 100 before). Because there are 4 times as many standard risks as high risks in the population, the total number of policies sold falls (450, compared with 500 before). This is adverse selection, and insurers often assert that it must always be bad. But in this case, the shift in coverage towards high risks more than outweighs the fall in number of policies sold: 9 of the 16 deaths (56%) in the population as a whole are now compensated by insurance (compared with 8 of 16 (50%) before). A moderate degree of adverse selection has led to higher loss coverage – a good outcome.

Table 3 Insurers banned from using tests: moderate adverse selection leading to increased loss coverage (good outcome)

	Standard risk	High risk
Population:	800	200
Risk:	1/100	4/100
Break-even premium (pooled):	← 2/100 →	
Insurance purchases:	300	150
Deaths compensated by insurance:	3	6
Loss coverage: $\left(\frac{\text{deaths insured}}{\text{total deaths}} \right)$	56%	

However, if the adverse selection becomes too severe, this can lead to a bad outcome. This possibility is shown in Table 4. Only 200 of the standard risks and 125 of the high risks buy insurance, giving a total number of policies sold of 325. The shift in coverage towards high risks is insufficient to outweigh the fall in number of policies sold: only 7 of the 16 deaths in the

population are now compensated by insurance (compared with 8 of 16 in Table 2, and 9 of 16 in Table 3). The high degree of adverse selection has led to lower loss coverage – a bad outcome.

Table 4 Insurers banned from using tests: severe adverse selection leading to reduced loss coverage (bad outcome)

	Standard risk	High risk
Population:	800	200
Risk:	1/100	4/100
Break-even premium (pooled):	← 2.15/100 →	
Insurance purchases:	200	125
Deaths compensated by insurance:	2	5
Loss coverage: $\left(\frac{\text{deaths insured}}{\text{total deaths}} \right)$	44%	

The main point to take from these examples is that even if adverse selection consequent upon a ban on genetic tests leads to a fall in the number of insurance policies sold, this might not be a bad outcome from a public policy viewpoint. This is because adverse selection also implies that insurance coverage is shifted away from lower risks, and towards higher risks. From a public policy viewpoint, this is a desirable shift – more of the right people, the people more likely to suffer loss, are buying insurance. Under moderate adverse selection, the shift in coverage can outweigh the fall in number of policies sold, leading to a good outcome (as illustrated in Table 3). On the other hand, under severe adverse selection, the fall in numbers can outweigh the shift in coverage, leading to a bad outcome (as illustrated in Table 4).

Which of Tables 3 or 4 represents the more likely outcome if insurers are banned from asking about genetic test results? Unfortunately there is no simple general answer. The answer depends on the relative numbers in the high and low risk groups, their relative risks, and an economic quantity known as elasticity of demand for insurance in the higher and lower risk groups. Elasticity of demand is the percentage change in insurance demand for a 1% change in price; it is a measure of the responsiveness of insurance purchasing behavior to changes in price. Simulations suggest that with plausible elasticities of demand in high and low risk groups, a ban on access to test results might often increase loss coverage; but the converse outcome is also possible.

Loss coverage is not the only criterion which public policymakers should consider when setting policy on genetic tests in insurance. The possible deterrent effects and spillover effects and other issues which were discussed earlier should also be considered. However, to the extent that the effects within the insurance market itself are given weight by public policymakers, loss coverage seems a better metric than the insurers' usual metric of number of policies sold. This is because loss coverage focuses on the expected losses actually compensated by insurance ("risk-weighted" insurance demand), which seems a better indicator of the social efficacy or benefit of insurance to the whole population than number of policies sold ("un-weighted" insurance demand).

VII. International differences in the regulation of genetics and insurance

International differences in the regulation of genetics and insurance reflect differences in the social role of each type of insurance in each country, and differences in each country's general political attitudes. Where a particular type of insurance has a very large social role, then some restrictions on insurers' access to genetic test results are usually seen. For example, health insurance has a very large social role in the US, and hence the use of predictive genetic test results to set health insurance premiums or deny cover is banned under federal law. In the UK, the existence of the taxpayer-financed National Health Service means that private health insurance has a smaller social role, and hence there are no statutory restrictions on the use of genetic test results in health insurance (although insurers have adopted a voluntary moratorium). On political attitudes, right-wing governments tend to be more permissive of genetic discrimination than left-wing governments. So in life insurance, for example, most US states and also Australia have tended to have more permissive policies about insurers' use of genetic test results than most European states.

United States

The Genetic Information Non-discrimination Act, which applies to health insurance only, was described above. For other types of insurance – life insurance, disability insurance and critical illness insurance- regulation in the US is at the state rather than federal level. Only a handful of states restrict insurers' questions about genetic tests. The concept of banning questions about genetic tests for policies below a certain size, but permitting questions for larger policies, which is common in Europe, is generally not used in the US; in the few states with restrictions, these apply to policies of all sizes.

United Kingdom

In 1999 the UK government established a Genetics and Insurance Committee (GAIC) to approve the use of genetic tests in insurance. The terms of reference of GAIC were agreed by consultation with the insurance industry; its brief was essentially to approve tests if they were of commercial value to insurers, subject to insurers demonstrating the clinical and actuarial relevance of particular tests, but with no consideration of any wider social or public health consequences. The expectation by government and insurers appears to have been that in this framework, several tests would rapidly be approved. However, in practice the GAIC process soon faltered, largely because the requirement for evidence of actuarial relevance could not be satisfied at a level which would withstand public scrutiny. One test was approved in November 2000, for the use of a test for Huntington's disease in relation to life insurance, but with much critical commentary. Meanwhile, several major insurers were already using other tests which had not been approved by GAIC, apparently on a presumption that approval was a mere formality. This presumption and GAIC's apparently lax approach to evidence were strongly criticised by the Human Genetics Commission, which had been established by the government to consider wider (non-insurance) implications of advances in genetic knowledge. This led to a hiatus of over a year, after which GAIC was reconstituted with a new membership and asked to start again. New criteria were promulgated by GAIC in 2002, in more detail than before, but essentially still envisaging the approval of any test which was commercially useful to insurers and for which clinical and actuarial relevance could be demonstrated. However, no further applications have been made to GAIC over the remainder of the decade. This appears to be because the insurers do not have evidence of actuarial relevance at a level which could withstand public scrutiny.

In the light of the threat of legislation and the failure of the GAIC process to advance matters as envisaged, the Association of British Insurers instituted a moratorium, that is a temporary ban, on asking questions about genetic test results for any type of insurance. Initially this was until 2006, but it was subsequently extended in 2005 to 2011, and then in 2008 to 2014. This outcome is somewhat surprising in the light of the enthusiasm of insurers and the UK government in the late 1990s for “evidence-based” genetic discrimination.

Other Europe

Several European countries have privacy or anti-discrimination laws which either limit or completely ban insurers from asking for genetic test results. These countries include Austria, Belgium, Denmark, France, Norway, Sweden and the Netherlands. In the last three countries, questions about family history are also banned. In some cases exceptions are made for large policies. In other countries insurers have a voluntary moratorium with a ceiling, similar to the UK. These countries include Finland, Germany, Greece, Ireland, and Switzerland. Sometimes the voluntary moratorium extends to questions about family history, for example in Finland.

Australia

In Australia, government has been more permissive towards genetic discrimination in life insurance than in most other countries. Insurers are allowed to ask for past test results for all sizes of policy in life insurance, but have voluntarily agreed not to ask prospective customers to undergo new tests. Health insurance, on the other hand, has operated for many years on a community-rated basis, with very little classification of risk, and so the question of access to genetic tests has never arisen. This stark contrast between life insurance and health insurance markets in the same country highlights the extent to which policy on genetics and insurance is driven by customs developed in each market, and political factors, rather than by compelling technical rationales.

VIII. Conclusion

A few years ago, in the excitement surrounding the completion of the Human Genome Project, many people seem to have expected rapid progress in the development and take-up of predictive genetic tests, and that within a few years this would have a large impact on insurance. In fact, progress has been much slower than expected, and the impact on insurance so far has been negligible. Some of the excessive forecasts made a few years ago for a rapid transformation of insurance markets were probably driven partly by insurance ideology. Since these forecasts have not been fulfilled, insurers are now more cautious in their predictions, and tend to see the issue of genetics and insurance in less apocalyptic terms than many did a few years ago.

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