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Genetics and insurance in the United Kingdom 1995–2010: the rise and fall of "scientific" discrimination

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Around the millennium there was extensive debate in the United Kingdom about the possible use of predictive genetic tests by insurance companies. Many insurance experts, geneticists, and public policymakers appeared to believe that genetic test results would soon become widely used by the insurance industry. This expectation has not been borne out. This article outlines the history of exaggerated perceptions of the significance of genetic test results to insurance, with particular reference to the United Kingdom, suggesting reasons why they arose and also why they have declined. The article concludes with some speculation about how policy on genetics and insurance might develop in future.

Keywords: genetics; insurance; discrimination; adverse selection; loss coverage; moral panic

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 greatly receded.

The decline in comment reflects a consensus in many countries 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. In the United Kingdom, a ban on the use of genetic tests in insurance has been extended to 2017, subject to review in 2014. The Genetics and Insurance Committee (GAIC), established by the UK government in 1999 to approve the use of genetic tests in insurance, approved one test in 2000; but thereafter insurers made no further applications for approval of tests, with the result that GAIC became inactive, and was formally disbanded in 2009. Laws restricting the ability of insurers to use genetic tests have also been enacted in many European countries,

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Table 1. Occurrences of "genetics and insurance" in English language news items worldwide, by year.

Year	Number of mentions	Year	Number of mentions
1997	14	2004	18
1998	11	2005	28
1999	42	2006	37
2000	114	2007	29
2001	140	2008	15
2002	21	2009	8
2003	54	2010	17(*)

Source: Nexis UK proprietary database [accessed 18 June 2011].
Notes: (*) All 17 mentions in 2010 arise from one news event: the mistaken inclusion of the Genetics and Insurance Committee (GAIC) in a list of quangos recommended for disbandment. GAIC had in fact already been disbanded in 2009. Apart from this, the database shows no press comment on genetics and insurance in 2010.

including Austria, Belgium, Denmark, France, Norway, Sweden, and the Netherlands. The claims by many insurance experts and public policymakers around the millennium that genetic test results would soon become widely used in insurance can now be seen by all as exaggerated or misconceived. This article examines the history of this misconception, with particular reference to the United Kingdom, suggesting reasons why it arose and also why it has declined.

Several previous authors in this journal have examined insurers' and policymakers' responses to the issue of genetics and insurance. Van Hoyweghen *et al.* (2005) characterize insurers' response as passing through three phases: first treating the issue as a public relations problem; then an appeal to science as a bulwark against regulation; and finally an acceptance that science did not provide robust justification for insurers' ideological preference for implementing any technically feasible discrimination, and that politically negotiated solutions between that preference and wider social preferences were unavoidable. Van Hoyweghen and Horstman (2009) record the efforts of global reinsurers to develop an evidence base to provide better justifications for recommendations in the rating manuals which they provide to direct insurers. The survey of Joly *et al.* (2010) of regulatory policy on genetics and insurance in 47 countries emphasizes the role of contextual factors in each country in influencing policy, in particular legal traditions, the social role of insurance, and the interplay between private and public healthcare systems. Liukko (2010) describes the distinctive terms of public debate in Finland, where the focus is primarily on ensuring the privacy of genetic test results, rather than their potential effects on social solidarity.

The rest of this article is structured as follows. The next section gives a brief history of public policy towards genetics and insurance in the UK. The article then gives a critique of the actuarial ideology which led to the use of genetic tests by insurers being promoted by policymakers around the millennium. The article then considers why this ideology attracted much support from policymakers despite its flaws, and then why it has more recently lost some of its earlier salience.

The final section speculates on the possible course of future public policy on genetics and insurance.

History of public policy towards genetics and insurance in the UK

A convenient starting date for a history is 1995, the year in which the UK Parliament Science and Technology Select Committee published a report *Human genetics: the science and its consequences* (Select Committee, 1995) which represented the first substantial attention given to the matter by legislators. The report made dramatic predictions of the effect which genetic information would soon have in the insurance industry:

> Many of our witnesses were very concerned that the availability of genetic information might have profound effects on the insurer as well as the insured. (paragraph 235)

> Dr Barr told us: "My experience as someone who studies the economics of insurance is to say that if the effectiveness of genetic testing spreads as widely as we are told, then that will have very major implications for insurance very quickly." (paragraph 237)

> . . . the great majority of our witnesses, including those with expertise in genetics, think that such information could have major implications for the industry in a relatively short time. (paragraph 247)

The Select Committee recommended that the insurance industry be given one year to produce proposals for dealing with genetic tests which were acceptable to Parliament, and that if it did not do so, the government should legislate.

The government rejected this recommendation and instead formed another committee, the Human Genetics Advisory Commission (HGAC) and asked it to make recommendations. In December 1997 the HGAC recommended a two-year moratorium on the use of tests by insurers (HGAC 1997).

The government again rejected this recommendation, and instead in April 1999 established a Genetics and Insurance Committee (GAIC) to approve the use of specific genetic tests in insurance. The terms of reference of GAIC were developed by consultation with the insurance industry; its rationale was essentially to approve tests if they might be of any commercial value to insurers, subject to insurers demonstrating the clinical and actuarial relevance of particular tests. GAIC was not asked to consider any wider implications of genetic discrimination for social policy or public health. The expectation of government and insurers appears to have been that with these terms of reference, several tests would quickly be approved, and genetic discrimination normalized.

In practice the GAIC project soon faltered, largely because evidence for actuarial relevance could not be produced to a standard which would withstand any critical scrutiny. GAIC gave one approval in November 2000, for the use of a test for Huntington's disease in relation to life insurance, but this approval attracted

much critical commentary about the standard of evidence. Minutes of a subsequent meeting of GAIC itself acknowledged the strength of this criticism:

> The quality of actuarial evidence produced for the first application [the test for Huntington's disease, approved by GAIC] continued to cause concern … It was recognised that there is a lack of good quality, peer-reviewed actuarial evidence relevant to genetic disorders and to GAIC.[1]

Meanwhile, representatives of insurers, giving evidence in early 2001 at another parliamentary enquiry by the Science and Technology Select Committee, stated that they were already using genetic tests without approval from GAIC, in defiance of what the government understood had been agreed when the GAIC was established. This defiance was strongly criticized in the Select Committee's report (Select Committee 2001). Separately on 1 May 2001 the Human Genetics Commission, which had been established by the government to consider wider (non-insurance) implications of advances in genetic knowledge, issued a statement calling for legislation to restrict the use of genetic tests by insurers, and claiming that: "The existing system of self-regulation has failed."[2]

The government rejected this call for legislation. However faced with an increasing likelihood of eventual legislation, in October 2001 insurers agreed with the government a voluntary ban on the use of genetic test results in setting insurance premiums, unless the tests had been approved by the GAIC. For tests approved by GAIC, an insurer could use test results only for large policies providing cover above a threshold (a capital sum of £500,000 for one person, in the case of life insurance, or £30,000 per annum for insurance which paid out as an income). The Association of British Insurers stated that around 97% of new policies fell below these limits. This ban was initially to last until 2006, but it was repeatedly extended, most recently (in April 2011) for six years until 2017.

New criteria for approval of tests were promulgated by GAIC in 2002, in more detail than before, but still within the same broad paradigm: GAIC would approve any tests which were commercially useful to insurers and for which clinical and actuarial relevance could be demonstrated, with no consideration of any wider social or public health implications. Applications for approval of three further tests – for Alzheimer's disease, breast cancer, and ovarian cancer – had been submitted by insurers as early as December 2000. But GAIC never gave a decision on these applications, and the Association of British Insurers eventually withdrew them. Over the next few years, minutes of meetings of GAIC repeatedly noted the stated intentions of the insurers to re-submit the applications. However, no applications were in fact re-submitted by insurers. GAIC therefore had little work to do, and was eventually disbanded in 2009. The policy outcome by 2011 – a voluntary ban on the use of genetic tests until at least 2017 – was quite incongruent with the strong enthusiasm of insurers and the UK government in the late 1990s to promote the use of genetic tests.

In my view it was already obvious in the late 1990s that for the foreseeable future, access to genetic test results would not be essential to insurers. There were two ways of appreciating this. First, mathematical investigations of the effect on insurance prices of ignoring genetic tests, even with the most pessimistic assumptions, suggested that costs would be very small relative to the variations which occur in insurance prices for many other reasons (e.g. Macdonald 1997, 2000). Second, by simple observation of the practice of insurance in different countries, one could see that successful insurance markets operated under a variety of conventions for risk classification. Some markets (such as life insurance in the UK) operate with very fine classification of risk; others (such as health insurance in Ireland) operate with almost no risk classification. Generally, the varying degrees of risk classification in different markets were not well explained by technical rationales; instead the differences appeared to be largely attributable to market culture and accidents of history.

To an informed observer who appreciated how financially insignificant genetics was likely to be to insurance companies, the rhetoric widely used around the millennium to advance genetic discrimination could seem disturbing. Claims that genetic test results would have a devastating effect on insurance were routinely made, and widely accepted by insurers, scientists, and policymakers as a justification for imposing new forms of discrimination against the unfortunate. These claims were closely analogous to the enthusiasm of many eminent scientists for eugenic discrimination in the first half of the twentieth century (Kevles 1985, Thomson 1998). The banal truth was that genetic test results were not likely to be of any great consequence in insurance for many years, and perhaps forever; but actuarial ideology obfuscated this reality for many years.

A critique of actuarial ideology

What is meant by "actuarial ideology" here? In relation to genetics and insurance, actuarial ideology around the millennium encompassed the following beliefs:

(1) People with knowledge of their genetic predisposition to illness will seek to buy much larger amounts of life insurance than people without such predispositions ("adverse selection").
(2) This adverse selection will have a large effect on insurance prices.
(3) Adverse selection is always a negative effect, which should be deprecated, minimized or avoided as a matter of public policy.

This ideology is characterized as "actuarial" because in the author's judgment it summarizes the views of the overwhelming majority of actuaries around the time of the millennium. But the ideology was not unique to actuaries: it was also embraced by many geneticists, government ministers, and other opinion-formers and policymakers. Official public statements by representatives of the Actuarial Profession (e.g. Actuarial Profession 1999a, 2001) tended to qualify the

uncompromising formulation of the ideology stated above, "softening" it with some references to ethical and social issues, probably because actuaries recognized that for public relations purposes it would be diplomatic to acknowledge such concerns. A very few actuaries publicly and unequivocally disagreed (e.g. Moultrie and Thomas 1997, Thomas 2001). But this was a minority view, and the view of most actuaries towards it in the late 1990s was succinctly expressed by one as follows:

> In my view, *only a fool or a rogue would disagree* with this principle . . . I believe that, from a theoretical viewpoint and assuming that [life insurance] offices act responsibly, *we are invariably right.* This is not arrogance because, *looked at objectively, anyone would have to concede the arguments*. (Leigh 1996, p. 2; emphasis added)

In my view each of the elements (1) to (3) in the ideology above was misconceived or exaggerated. The following sections elaborate on these misconceptions.

Adverse selection: the fallacy of the one-shot gambler

Around the millennium it was often suggested that people with knowledge of genetic predisposition to illness would wish to buy large amounts of insurance. For example, a press release from the UK Actuarial Profession in July 1999 stated as follows:

> Bans [on insurers using genetic test results] have already been imposed in some countries, such as Denmark, Netherlands, Norway and a number of states of the USA (eg California), leaving the way open for people with knowledge of their genetic condition to take advantage of insurance companies, thus pushing up the cost for everyone.[3]

The press release did not elaborate on what was meant by people "[taking] advantage of" insurance companies. However, the natural interpretation is that a person with private knowledge of their genetic status could benefit by buying large amounts of life insurance. This is the concept of over-insurance as an attractive investment. For many people, it has some intuitive plausibility. But more careful consideration, using realistic probabilities and premiums, suggests that in most realistic scenarios, over-insurance is probably *not* an attractive investment. This is for two reasons: (1) life insurance pays out only in the event of low-probability (in gambling terminology, long-odds) events; and (2) the life insurance purchaser is a "one-shot gambler" who can make their bet on these odds only once.

For example, suppose that an insurer offers me a term life insurance premium based on an assumed risk of dying of $p = 2\%$ over the term of an insurance policy (say the next 10 years), but I have taken a genetic test which privately tells me my real risk is three times the normal level, that is $p^* = 6\%$. If I "invest" in over-insurance, then my private knowledge means I pay a "favorable" price (2% rather than 6%). But despite the "favorable" price, on a one-shot gamble it is still overwhelmingly likely (94% likely, on the true probabilities) that I shall just forfeit the premium.

This one-shot gamble against long odds seems to me a relatively unattractive proposition. It would remain unattractive for a wide range of plausible probabilities and premiums. It may be worth buying a "normal" level of insurance for the usual reasons, such as paying off a mortgage, or provision of adequate security for one's family in the unlikely and adverse scenario of early death. But the notion of over-insurance based on a private genetic test as an attractive investment generally does not make sense for realistic probabilities and premiums.

For over-insurance to be attractive as an investment, either (a) the gamble needs to be repeated across many independent trials, or (b) odds of a payout need to be relatively short. As an example of (a), if I could buy life insurance on 1000 independent lives on the terms above, then that portfolio of bets would be an attractive investment.[4] As an example of (b), if I privately know I already have a terminal illness from which I am 70% likely to die during the period of the insurance, then over-insurance on the terms above is probably attractive.[5] But neither of these scenarios corresponds well to a purchaser of life insurance with some private genetic knowledge, for whom the bet against the insurer is on long odds and can be made only once.

Adverse selection: a relatively small effect on insurance prices

Around the millennium the claim was frequently made that if insurers were not permitted to use genetic tests, this would lead to a very large rise in average insurance prices, or even the collapse of some insurance markets. For example in response to a consultation by the Human Genetics Commission, the Actuarial Profession commented as follows (emphasis added)[6]:

> The insurability of long term care costs by insurers *may not be sustainable* unless either insurers are permitted to make use of some pre-existing genetic test results, or some much more extensive rating framework is adopted.
>
> Contracts which offer benefits when the insured becomes ill (eg critical illness policies, income protection and long term care) are likely to be more specific to the issue of specific risk propensities and restriction on underwriting could prove very damaging to the public. *There could be a substantial reduction in consumer choice through products becoming dearer or even the withdrawal of some types of product*.

However these comments were generally not supported by the emerging results of actuarial simulations of insurance markets where genetic test results are known to customers, but unknown to insurers (e.g. Macdonald 1997, 2000, Viswanathan *et al.* 2007, Macdonald and Tapadar 2010, Macdonald and Yu 2011). The results of these simulations can be succinctly stated: to a first approximation, preventing insurers' access to genetic test results will probably lead to only a tiny increase in average insurance prices, seldom rising above 1%.

The increases of less than 1% just quoted are negligible compared to other variations in insurance prices between insurance companies in the prices which are

quoted for any particular risk. For example, if a person obtains quotes from several UK life insurance companies, the best six quotes will typically differ by 20% or more.[7] Prices also tend to vary cyclically over time, not because of changes in risk assessment but because of changes in the level of competition in the market, for example when major reinsurers decide to enter or leave the market for a particular product. An index of prices for critical illness insurance in the UK fell around 25% between 1999 and 2002; then rose more than 50% in 2003 after two of the largest reinsurers withdrew from this market; and then gradually declined again from 2005 onwards.[8] In the context of these large cross-sectional and inter-temporal variations, insurers' access to genetic test results is unlikely to have the significance which has often been claimed.

Adverse selection: not necessarily adverse

The previous section highlighted that adverse selection attributable to genetic tests is likely to have only a small effect on average insurance prices. It is conceivable that this may one day change: genetics may eventually become more predictive, and adverse selection may start to have a larger effect. But even if this scenario materializes, it does not follow that the use of genetic tests by insurers would be necessary or even helpful from a public policy viewpoint. Insurers always frame adverse selection as a problem to be deprecated, avoided or minimized, and most policymakers seem to accept this without question. But a little thought shows that adverse selection may not be adverse from the viewpoint of society as a whole.

The usual argument made by insurers regarding adverse selection is as follows. Any restrictions on risk classification 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 numbers insured will fall. Insurers suggest, either explicitly or implicitly, that any adverse selection and any fall in numbers insured must be regarded as a bad outcome from a public policy viewpoint. But this argument 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 (those likely to suffer loss) buy insurance.* From a public policy perspective, a degree of so-called "adverse" selection in insurance can often be beneficial.

This insight can be illustrated by a simple numerical example. Suppose that in a population of 1000, 16 people die every year. Suppose everyone takes a genetic test, with the result that 200 people know they have a risk of dying four times higher than the other 800 people. Assume that everyone can buy either one unit of life insurance or none (this simplifies the presentation, but it is not necessary). If test results are disclosed, insurers will charge different prices to standard and

Table 2. Insurers use genetic test results: 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: $\left(\frac{deaths\ insured}{total\ deaths}\right)$	50%	

high risks. 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.

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 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 four 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 it is often asserted 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 in the population as a whole are now compensated by insurance (compared with 8 of 16 before). A moderate degree of adverse selection has led to higher loss coverage – a good outcome.

Table 3. Insurers banned from using genetic test results: 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: $\left(\frac{deaths\ insured}{total\ deaths}\right)$	56%	

Table 4. Insurers banned from using genetic test results: 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: $\left(\frac{deaths\ insured}{total\ deaths}\right)$		44%	

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.

Which of Tables 3 or 4 represents the more likely outcome if insurers are banned from asking about genetic test results? 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 – essentially a measure of the responsiveness of each group's insurance purchasing behavior to changes in price. These dependencies are explored in recent papers in the insurance and actuarial literature (Thomas 2007, 2008, 2009). These suggest that given plausible elasticities of demand, some restrictions on risk classification are likely to increase loss coverage. Under the loss coverage criterion, public policy on risk classification can be seen as a question of degree: what degree of restriction on risk classification is required to induce the optimal degree of adverse selection, which maximizes the loss coverage? For example, restrictions on the use of genetic test results may increase loss coverage; and perhaps further restrictions, extending to say family history, may also increase loss coverage; but if the use of age as a risk factor was also restricted, this might "go too far," reducing loss coverage.

Reasons why actuarial ideology was initially embraced by policymakers

Despite adverse selection having only small (and perhaps socially beneficial) effects as described above, the view that insurance companies should be allowed to use genetic test results appeared to be widely accepted by UK public policymakers and opinion-formers for some years around the millennium. We now suggest some reasons why this view gained wide acceptance.

Error of magnitude

At its simplest, policymakers' endorsement of genetic tests in insurance can be seen as reflecting an error of magnitude: the misconception that genetic test results would imminently become highly material to insurers, when in fact they would remain quite inconsequential. The error of magnitude can be attributed to several factors which encouraged insurers to over-state the significance of genetic tests to their business. First, a precautionary principle of taking any perceived threat seriously. Second, a political calculation that claims of large effects would be more likely to achieve insurers' desired policy outcomes. But in my opinion, the notion of insurers publicly exaggerating for political purposes effects which they privately knew were very small over-states the rationality of insurers' reactions. A third, probably more significant, cause of the error was moral panic by many insurance experts concerning the perceived "threat" to the insurance industry of people with genetic predispositions (this is elaborated later in the article).

Public relations campaigns

As noted by van Hoyweghen *et al.* (2005), for some years the insurance industry appeared to assume that a public relations campaign could persuade policymakers that insurers should be allowed to use genetic test results. It was suggested that those who argued against genetic discrimination in insurance on ethical or social grounds were misunderstanding or disregarding the arithmetical facts of insurance. Insurers' efforts to "educate" the public benefited from a strong hierarchy of credibility: because insurance is a technical field in which most people feel uninformed, insurers themselves were generally perceived as the most credible sources of information. It was easy for insurers to insinuate that critics lacked technical knowledge, or were discredited by their own disadvantaged status as persons affected by genetic conditions.

Scientism

Van Hoyweghen *et al*. (2005) notes that after initially viewing genetics as a problem of public misunderstanding which could be solved by "education," insurers' second approach was to claim that science could justify genetic discrimination. These claims were very prevalent around the millennium, and for some years they appear to have been accepted by the UK government and others; the establishment of GAIC was predicated on this model of "scientific" discrimination. The hope that actuarial research would provide robust justifications for discrimination led insurers to take an increased interest in (and provide more funding for) such research. As it became clear that actuarial research would not in fact give robust justifications for genetic discrimination, insurers' interest in such research appears to have declined. Rather than justifying genetic discrimination, research has tended to cast fresh doubt on long-established practices, not just in relation to genetics but also in other areas of underwriting (van Hoyweghen 2010).

Cognitive regulatory capture

The apparent concern of UK policymakers to legitimize the use of genetic tests by insurers reflected the fact that policy was substantially shaped by the insurers themselves. There were many manifestations of this. In the initial GAIC, all members with insurance expertise were employees of insurance companies, rather than academics or independent consultants. Two of the initial members of GAIC were also working with the Association of British Insurers on preparing the applications which GAIC was supposed to assess.[9] Parts of GAIC's annual reports were sometimes drafted and supplied to GAIC by insurance companies.[10]

The perception of cognitive regulatory capture is also supported by government papers from the period 1999–2001, which I obtained in 2009 and 2010 from the Department of Health by means of requests pursuant to the Freedom of Information Act. Communications from the Association of British Insurers (ABI) in these papers indicate that the concept of tests being validated by a body such as GAIC was originally suggested to the government by the ABI itself, and in establishing the committee the government largely followed the ABI's proposals.[11] On 22 July 1999, the chairman of GAIC wrote to the responsible minister noting that "You will understand that there is strong pressure from the industry members of the committee to validate these and indeed other tests that are currently in use by some insurance companies."[12] On 12 August 1999, an official at the Department of Trade and Industry wrote to a colleague that "There must be a real risk to the credibility of GAIC if the test for Huntingdon's does not pass."[13] The "credibility" of GAIC to policymakers apparently depended on its supporting the insurance industry.

When it became apparent that GAIC was nevertheless struggling to approve tests, ways were suggested to relax the criteria it had set to a level which insurers might be able to meet. On 25 October 2000, the Government Actuary, writing on behalf of the Actuarial Profession, urged that a lower standard of actuarial evidence should be accepted by GAIC: "It seems, therefore, that the remit of GAIC may be to accept a somewhat lower burden of proof than fully developed academic research results to back each submission."[14] This search for a way to lower standards of evidence required from insurers in some publicly acceptable way persisted until the end of GAIC's life: as late as 2008, GAIC minutes noted a planned meeting with the Association of British Insurers to discuss ways of relaxing the GAIC requirements in order to "to speed up tests being brought to the Committee."[15]

Moral panic

The concept of moral panic (Cohen 1973) is normally understood as a phenomenon affecting a broad public. The term refers to hostility expressed by a large number of people towards a stigmatized minority group which is believed to threaten the social order. The concern expressed in a moral panic is disproportionate to any actual threat represented by the minority. Social issues which have been suggested

as attracting moral panics include Satanic ritual abuse (Victor 1993), pedophilia (Jewkes 2004) and human trafficking for prostitution (Davies 2009). In the case of genetics and insurance, a similar phenomenon could be said to have afflicted the community of insurance experts, which we might characterize as expert panic: a strong (but factually disproportionate) belief among many experts that a minority group with genetic predispositions represented an existential threat to the insurance industry.

Responses to public consultations and similar documents produced for public consumption tend to be anodyne, with the actual views of the respondent obscured by a veneer of platitudes. Expert panic is clearer in contemporary articles written for actuaries and other insider groups of experts, rather than platitudes developed for wide public dissemination. One example is an article "The freedom to underwrite" (Leigh 1996) presented to a large audience of actuaries at the Actuarial Profession's headquarters in London in 1996. The article included the following remarks on genetics and insurance (all emphasis has been added):

> My own feeling is that the government should outlaw all forms of home and postal testing . . . *The industry will have terrible problems* if legislation does not take place. (p. 15)

> Recently, some preserved samples from the body of the US politician, Hubert Humphrey, have been tested. It has been discovered that his bladder cancer could have been diagnosed with genetic testing over ten years before he had any symptoms. *Think of the damage individuals could inflict on the industry with such knowledge*. (p. 16)

> *We have to protect ourselves* and our existing policyholders from proposers who know the results of genetic or other tests which reveal a poor outlook. (p. 18)

> Taking this a stage further, a salesman could legitimately visit hospices signing up many of the occupants. Notices might even be placed in doctors' waiting rooms. *Even our most vicious critics should realise that this is untenable*. (p. 23)

> If genetic history is banned on proposals, *adverse selection becomes a major issue*. (p. 23)

> I would agree but it could herald the *end of life assurance as we know it*. (p. 44)

Another example was an article by an insurance company medical consultant "Genetics – the poisoned chalice" (Walker 1996) published in the *Transactions of the Assurance Medical Society*, which included the following remarks (all emphasis has been added):

> *If the genetics lobby wins this battle* then the amount of adverse selection will be such that *the industry as we know it can no longer survive*. (p. 48)

> If the situation arises where the proposer knows the results of his genetic tests but the insurance company has to remain in ignorance of these tests, then *insurance companies and their funds will be unprotected and adverse selection will be rife.* Premiums would

> undoubtedly rise to such an extent as to make the cost of insurance prohibitive for the average individual. *If this happens insurance companies would cease to exist*. (p. 50)

> If we are denied access to genetic information we are being denied access to all medical information and *the life insurance industry would no longer exist*. (p. 51)

Articles such as these suggest a disproportionate perception of a threat posed by people affected by genetic conditions. Interestingly, this was not the first occasion where insurers had panicked about a supposed existential threat from a stigmatized minority. In the late 1980s a similar panic arose in relation to HIV and AIDS. For several years, many insurers refused to provide any life insurance to gay men, and those that did charged greatly increased premiums. But in October 2004, the Association of British Insurers issued guidance that insurers should no longer ask any questions about sexuality on application forms. They also noted that "In the past, life insurance underwriters may have used certain information contained on an application form to make speculative underwriting decisions. Answers to questions about occupation and house co-purchase were occasionally used in assessing HIV risk."[16]

The affectation of tough-minded virtue

Another reason why genetic discrimination was often supported may have been that the support was associated with connotations of tough-minded virtue by the commentator. Faced with the personally tragic problem of genetic predisposition to illness, a natural empathetic response is a desire to help those affected, for example by preventing insurers from using genetic tests. However the essence of actuarial orthodoxy is that this response is short-sighted: the attempt to help will lead to a decline in insurance coverage and eventually the collapse of insurance markets. Essentially actuarial orthodoxy demands immediate pain (genetic discrimination) for supposed long-term gain (the survival of the insurance system).

Although the implied necessity for genetic discrimination was almost always overstated, the moral narrative of immediate pain for long-term gain was appealing to many commentators. Advocacy of immediate pain to secure long-term gain seems to carry a connotation of virtue. But for genetics and insurance, the commentators are almost invariably privileged persons who *do not bear the pain themselves*: the pain they advocate is to be imposed on disadvantaged others. This makes the connotation of virtue illusory: there is no virtue in advocating that pain be imposed on disadvantaged others for the benefit of one's own privileged class.

Reasons why actuarial ideology has fallen from favor

By the middle of the 2000s, the panic concerning genetic tests and insurance around the turn of the decade had largely subsided. The moratorium on genetics and insurance initiated in 2001 was repeatedly extended; as of 2011 it has been

extended at least until 2017. GAIC was disbanded in 2009. Also in 2009, the medical director of one health insurance company wrote that "The most important aspect of the issue is the ethical one . . . by looking at genetic profiles, the insurer is going against the very ethic of the community . . ." (Khemka 2009); the managing director of another health insurance company was reported as stating that the fact that a person had taken a genetic test could be regarded by insurers as a positive indication of health-conscious behavior (Henderson 2009). These views – radically different from those expressed by insurers a few years earlier – suggest a decline in salience of the actuarial ideology discussed above.

What were the reasons for this decline in salience? We suggest the following reasons.

Lack of progress in genetic prediction

When GAIC was established, insurers and policymakers wrongly assumed that very rapid progress would be made in accurate testing for genetic predisposition. The expectation of the early arrival of a world where widely available genetic tests are extremely predictive can be seen as part of the expert panic referred to earlier. This world has not materialized.

Lack of support from ongoing actuarial research

Insurers would undoubtedly have liked to use genetic tests with the same freedom from regulation as for other types of information. Evidence for their relevance and reliability may be weak, but insurers have traditionally based many of their classifications on weak evidence, prejudice or hunches; for example the speculative stereotypes of occupation and HIV that were mentioned above. However, ongoing actuarial research over the decade from 2010 provided little support for the insurers' claims that access to tests was essential. Macdonald and Yu (2011) synthesized several studies to estimate the overall cost of restrictions on insurers' use of genetic information under various assumptions about market size and customer behavior. They found that these estimates were "all very small, only in the most extreme cases rising above 1% of premiums." (p. 343)

Some commentators suggested that the evidence required by GAIC to approve genetic tests raised questions about the lack of equivalent evidence to support other common practices of insurers (e.g. Macdonald 2000, Daykin *et al.* 2003). This accords with the findings of interviews with executives at two European reinsurance companies (van Hoyweghen and Horstman 2009), which noted that efforts to document a stronger evidence base for ratings, initiated with the hope of de-politicizing the issues of genetics and risk classification, have instead tended to highlight the lack of evidence for many established practices, and so opened new questions about fairness. Faced with demands for a higher standard of evidence, and fearing that the same higher standards might be demanded for other poorly evidenced practices, UK insurers may have decided that the intense scrutiny which

would accompany any further attempt to gain approval for the use of specific genetic tests would not advance their interests.

Lack of public acceptance of GAIC's rationale

The most immediate and obvious sense in which GAIC did not fulfill insurers' and government ministers' expectations was that after the first approval of the test for Huntington's disease in December 2000, no further tests were ever approved. But even if GAIC had approved more tests, it might not have succeeded in its underlying purpose of achieving public acceptance for genetic discrimination. GAIC's (hypothetical) approval of tests appeared to be intended to lend an official imprimatur to genetic discrimination, signaling that the inferior treatment of those affected by genetic predispositions was sanctioned by the State. It was never explained why the State's endorsement of discrimination should be reassuring to people affected by genetic predispositions. For many people, this concept was uncomfortably reminiscent of discredited State-sponsored eugenic projects in the first half of the twentieth century, in the United States, Nordic countries, and Germany. In this sense the concept of State approval might increase rather than reduce alarm about discrimination.

Background changes in permitted risk classifications

In March 2011, the Test-Achats judgment (Case C-236/09) of the European Court of Justice ruled that insurers in the European Union would not be permitted to charge different premiums to men and women after 31 December 2012. This was a significant change for the UK (and for many European states), because different prices for men and women are almost universal in almost all types of insurance, and there are statistically well-evidenced differences between genders for most types of insurance risk. The Court appeared to accept these statistics, but nevertheless reached its judgment on an overriding fundamental right to equal treatment (Mabbett 2011). This development may normalize to some degree the principle of public policy restrictions on risk classification. From the insurers' perspective, the fundamental restriction on the use of gender, one of the most widely used rating factors, may put restrictions on the use of genetic test results into their proper perspective.

How will genetic tests affect insurance in future?

As recounted above, many predictions of the impact of genetic tests on insurance made in the early 2000s have turned out to be greatly exaggerated. Progress to date in predictive genetic testing has been slower than was widely expected a decade ago. However, given the strong ideological commitment to genetic discrimination within the insurance industry, it is possible that insurers may seek to use test results in future. Although GAIC was disbanded in 2009, the Department of Health still intended that a "panel of expert and lay individuals" could be convened to hear any application from insurers to use particular genetic tests. It is possible that insurers will seek to use this mechanism.

Another possibility is that insurers may seek to justify discrimination by rationales different from the evidence-based approach embodied in GAIC. As an example of this, the actuaries Daykin *et al.* (2003) expressed dissatisfaction with the inability of GAIC to progress the insurers' agenda, and referred to hypothetical future applications to GAIC as "specious statistical exercises for which data may not be available for another ten or more years." (p. 817) They suggested that a demonstration of statistical significance should not be required, and that insurers should be allowed to use genetic test results if they could demonstrate "financial vulnerability" to applicants with private knowledge of genetic test results. No definition of "financial vulnerability" was given, but it was suggested that the test should be easier for insurers to satisfy than the GAIC requirements.

Another possibility is that insurers could introduce discrimination gradually and covertly, hoping to avoid regulatory or public attention. There are no legal obstacles to this: the current voluntary ban on use of genetic tests is specifically stated to have no legal force.[17] Covert discrimination may be an attractive option to insurers, given the apparent difficulty of justifying discrimination in ways which meet public scrutiny (e.g. the GAIC process), combined with the strong ideological commitment of insurers to discrimination. The opacity of insurance pricing – in particular the absence of any obligation for insurers to explain that a customer's premium has been loaded for a health or genetic reason – may make covert discrimination difficult to detect.

A more optimistic possibility is that the insurance industry's ideological commitment to discrimination may gradually weaken over time. Moral panics are typically transient. Matters which seem important to one generation are sometimes matters of indifference to the next. The recent imposition of unisex pricing in Europe will force insurers to find ways of operating without one of their traditional risk classifications, and may also normalize the principle of public policy restrictions on risk classification. As noted earlier in this paper, the UK insurance industry of the 1980s was openly and unapologetically homophobic, with questions about occupation, joint house purchase and taking a HIV test (with a negative result) being used by many insurers to reject applicants who were suspected of being gay; but by 2005 the ABI deprecated these practices as "speculative," and recommended that only positive HIV test results should affect underwriting decisions. Further back in the 1960s, UK insurers openly practiced racial discrimination, charging so-called "racial extras" to some ethnic groups (Leigh 1996); but following the implementation of the Race Relations Act 1968 which effectively banned this practice, insurers have never argued for the Act's repeal.

The analogy of genetic discrimination with racial discrimination is instructive. There are some well-evidenced differences between races in mortality and morbidity.[18] At various historical times and places these differences have been a focus of intense attention, sometimes leading to some State interventions which have come to be widely seen as mistakes (e.g. Nazi racial science; compulsory sickle cell trait screening for African Americans in many US states). More recently it has been

recognized that obsessive attention to racial differences generally does not provide a helpful basis for social policy. In the UK and in many other countries, public opinion is now strongly opposed to focusing on such differences. It is possible that focus on genetic differences will follow a similar historical arc of initial enthusiasm followed by mature restraint.

A GAIC-type process may be able to demonstrate some differences in mortality or morbidity between people with different genetic characteristics, just as some differences could be demonstrated by race; but the fact that it is possible to demonstrate such differences does not make it necessary or helpful to do so. The difficulty in distinguishing genetic from non-genetic information may lead over time to demands for the principle of non-discrimination to be extended to more types of predictive tests (van Hoyweghen 2010). The calculative core of actuarial work – estimating mortality and other risks from past data, and forecasting their evolution in future – can be applied with any scheme of risk classification, including no classification at all (as for example in universal social security schemes). It is possible that the insurance experts of the future may have a weaker ideological commitment to genetic discrimination than those of the past.

Notes

1. Minutes of 9th meeting of GAIC, 19 March 2001. Provided in response to author's Freedom of Information Act request.
2. Human Genetics Commission (2001).
3. Actuarial Profession (1999b).
4. For example: if I "invest" a premium of say £10 on each life (total outlay £10,000), I can expect to win approximately 60 times, collecting 60 × £10 × 50 = £30,000, giving an expected profit of £20,000. This result is subject to random variation. But by spreading my bets across 1000 independent lives I can be 99% sure that I will win between 41 and 79 times, giving a profit between £10,500 and £29,500. This contrasts with the one-shot gamble, where it is overwhelmingly likely that I just lose my £10,000.
5. For example: if I "invest" a premium of say £10,000, this gives a 70% chance of creating an estate of £500,000 for my heirs. This makes it probably worth accepting the 30% chance of losing my £10,000.
6. Actuarial Profession (2001).
7. Some data on the variation of actual life insurance prices in the UK are given in Langkjær-Øhlenschlæger and McGaughey (2001) and Thomas (2005).
8. This is based on an index of guaranteed critical illness insurance premiums compiled by insurance brokers Lifesearch Limited.
9. This is documented in the *First report of the Genetics and Insurance Committee* (GAIC 2001), and the Minutes of the 4th Meeting of GAIC (provided to author pursuant to Freedom of Information Act).
10. See for example Appendices E and F to the *Second report of the Genetics and Insurance Committee* (GAIC 2004), which were drafted by Swiss Re.
11. As stated in a letter dated 3 August 1999 from the Association of British Insurers to the Department of Health. Copy provided to author pursuant to Freedom of Information Act.
12. Letter dated 22 July 1999 from chairman of GAIC to Minister of State for Public Health. Copy provided to author pursuant to Freedom of Information Act.

13. Letter dated 12 August 1999 from an official at the Department of Trade and Industry, provided to author pursuant to Freedom of Information Act.
14. Letter to GAIC from the Actuarial Profession dated 25 October 2000, provided to author pursuant to Freedom of Information Act.
15. As stated in the Minutes of the 28th Meeting of GAIC held on 29 July 2008 (www.hgc.gov.uk [Accessed 10 January 2010]).
16. ABI consumer guide for gay men on HIV and life insurance (www.abi.org.uk [Accessed 26 June 2011]).
17. Paragraph 9 of the *Concordat and moratorium on genetics and insurance* (Association of British Insurers 2005).
18. Crimmins and Saito (2001) examine racial differences in mortality for United States data.

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