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## **Genetics and insurance: an actuarial perspective with a difference**

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### SUMMARY

This response focuses on genetic tests and insurance. Many individuals or organisations capable of commenting technically on insurance discrimination have a commercial interest in promoting such discrimination. Technical expertise is therefore directed to the promotion of discrimination for commercial ends, but little technical expertise is applied to counteract it. This paper attempts to redress the balance. Its central section comprises a point-by-point rebuttal of some of the myths and half-truths which are promulgated by those wishing to legitimise insurers' access to genetic test results. Further material is available at [www.guythomas.org.uk](http://www.guythomas.org.uk).

### **1. Introduction**

One of the difficulties which the Human Genetics Commission (HGC) will encounter in consultation on genetic testing in insurance is that many individuals and organisations with a technical knowledge of insurance also have a vested interest in promoting discrimination for commercial ends. The main purpose of this paper is to point out some of the myths and half-truths which characterise commercial lobbying on this subject.

I am a Fellow of the Institute of Actuaries and a former principal examiner for the fellowship examinations of the actuarial profession. Further details of my actuarial background are given at the end of the paper.

Whilst this paper is informed by my actuarial knowledge, much of it is not specifically actuarial. This is because the main insight I derive from my actuarial knowledge is that the purely actuarial issues in relation to genetics and insurance are not very compelling.

Section 2 of this paper identifies salient starting points for discussion of genetic testing in insurance in the UK. Section 3 briefly considers the activities of the Genetics and Insurance Committee. Section 4, the central and longest section of the paper, considers point-by-point the myths and half-truths which are promulgated by those seeking to legitimise genetic testing in insurance. Section 5 answers some objections and counterpoints. Section 6 briefly outlines two previous issues, AIDS and disability, where actuarial issues have sometimes been misrepresented or exaggerated for commercial ends. Section 7 contains recommendations and a postscript.

### **2. Starting points**

Some salient starting points in relation to genetic testing in insurance are public attitudes, international comparisons, the history of eugenics, and actuarial issues.

### *Public attitudes to insurers' access to genetic test results*

There appears to be very strong public opposition to insurers' access to genetic test results. Apart from the MORI survey conducted for HGC, the British Survey of Social Attitudes is another authoritative survey which revealed very similar results.<sup>1</sup>

These results appear to be internationally robust. All reports I have seen or heard from other countries indicate overwhelming public opposition to, and distrust of, insurers' access to genetic test results.

The insurance industry's stock response to this observation is that "education" is required to promote acceptance of genetic discrimination. The notion seems to be that if insurers explain their reasons for wanting access to genetic test results, people will change their minds. However, experiments conducted by the American Council of Life Insurance suggest that, at least for the moment, "education" makes very little difference to people's views: the insurers can explain all they like, but people still remain deeply opposed to insurers' access to genetic test results.<sup>2</sup>

Thus the objection to insurers' access to genetic tests is very strong, and (at least for the moment) it does not seem very susceptible to "education." The HGC's consultation document notes this strong opposition but then states (9.2) that "any response to this issue must be informed by facts". Overwhelming public opposition to insurers' access to genetic test results is one of the facts.

### *International comparisons*

A second starting point is to note that the UK government currently appears to be pursuing an approach which is unique in Western Europe, and highly unusual anywhere in the world, in seeking to legitimise and promote the use of genetic tests in insurance. Most countries in Europe, and most of the United States, have effected some restrictions on insurers' access to genetic tests.

### *History of eugenics*

The history of eugenically motivated discrimination in many countries refutes the suggestion that genetic discrimination is harmless until proven otherwise. History places a heavy burden of proof on those who would assert that 'mild' forms of genetic discrimination (such as denial of insurance) will not lead to more 'severe' discrimination in other social contexts. It is possible that with time this burden of proof could be discharged; but this cannot be merely assumed.

Apart from the views of the general public as mentioned above, it is clear that groups representing disabled people have acute concerns about the eugenic connotations of reference to genetic tests in social contexts such as insurance or employment.<sup>3</sup>

### *Actuarial issues*

Notwithstanding everything above, there is a potential actuarial justification for permitting insurers' access to genetic test results. The potential justification is that such access is *essential to the viability of private insurance markets*. But there is currently little evidence, for any class

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<sup>1</sup> 16<sup>th</sup> Annual Survey of Social Attitudes, p165.

<sup>2</sup> Jones, CS (1999). The current state of genetic testing, an insurance industry perspective on the rush to legislate. *North American Actuarial Journal*, 3,1, pp 56-66.

<sup>3</sup> See for example: British Council of Disabled People (2000). *The new genetics and disabled people*. Paper available at <http://www.bcodp.org.uk/general/genetics.html>.

of insurance, that this either is or will become the case. Recent actuarial studies suggest that even under the most unfavourable assumptions, ignoring genetic tests *and family history* would have little effect on most insurance markets.<sup>4</sup>

*Why is the UK pursuing an unusually discriminatory course?*

Given the above starting points, an obvious question is: why is the UK government set on the unusual course of promoting the use of genetic tests in insurance? Can the UK government credibly claim that the approach of most other countries is wrong?

To understand why the UK is proceeding down the unusual road that it is, one needs to note that in many European countries, the insurance industry appears to have less influence than it does in the UK. A great deal of technical expertise is being applied to promote acceptance of insurers' access to genetic test results in the UK, but it is more difficult to identify any technical expertise which is being applied to counteract it. The quango known as the Genetics and Insurance Committee, whose ostensible purpose is to provide independent oversight of the insurance industry, has been captured by the insurance industry and is providing only a semblance of scrutiny.

### **3. Genetics and Insurance Committee (GAIC)**

Every aspect of the GAIC's terms of reference and practical operation appears to have been arranged to suit the insurance industry: its establishment without consideration of the social aspects of genetic testing; its strategy of developing a framework to "approve" tests whilst ensuring that consideration of the social consequences is deferred for as long as possible; its avoidance of the actuarial question of whether testing is necessary for the financial stability of insurance markets; its low thresholds for the approval of tests; and the disdain with which it treats technical criticism or enquiries from critics such as myself. This capture of the regulatory agenda by the insurance industry has some similarities to the so-called "self-regulation" of insurance industry sales practices in the late 1980s.

The GAIC suits the insurers very well because it lends spurious authority to an approval process which considers testing purely *from a commercial insurer's point of view*. In approving tests for insurance use, the GAIC requires that the test should be capable of demonstrating, at least for some ages, an increased risk of at least +50% for life insurance, and +25% for other types of insurance. These thresholds represent the minimum levels of increased risk for which insurers find it commercially viable to go to the trouble and expense of applying premium loadings. In other words, the GAIC approves tests *if they could be of any possible commercial benefit to the insurance industry*.

The GAIC does *not* consider the social policy perspective of whether insurers' access to test results is *necessary for the viability or stability of the insurance market*. If this criterion were used, it is very unlikely that insurers' access to any test results would currently be approved.

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<sup>4</sup> Macdonald, AS & Pritchard, D (1999). Genetics, alzheimers disease, and long-term care insurance. To appear in *North American Actuarial Journal*. See summary of results in paragraph 8.6. Also *Research Report No 2 of the Swiss Re / Heriot-Watt genetics initiative*: The genetics of breast and ovarian cancer II: a model of critical illness insurance. See summary of results at p28. These detailed results are perhaps unhelpful to the insurers' desire to avoid any form of effective regulation, and so some effort has been made to present a more helpful 'spin.' This is discussed further in section 4 below. Both the papers are available at <http://www.ma.hw.ac.uk/~angus/girc/publications.html>.

Separate from the GAIC's defective terms of reference, there is a credibility problem arising from the fact that all Committee members with insurance or actuarial expertise appear to have interests in promoting genetic discrimination for commercial ends. Professor Sandy Raeburn is a paid adviser to the ABI, and a member of their Genetics Committee. Dr David Muiry, a nominee of the Faculty & Institute of Actuaries, is an employee of Swiss Reinsurance, the company which prepared the main supporting paper for the first application to the GAIC. The third member with insurance expertise, Tony O'Leary, is managing director of GE Frankona Reassurance, chairman of the ABI's Life Assurance and Medical Affairs Committee, and also a member of the ABI Genetics Committee. Some of the views which he brings to the GAIC were outlined in an article<sup>5</sup> in the insurance trade press.<sup>6</sup>

An illustration of the effects of these conflicts of interest was the GAIC's public response (or rather, non-response) to the actuarial review of the application for approval of the use for life insurance of a genetic test for Huntington's disease. This actuarial review was prepared by Professor David Wilkie, who is an eminent consulting actuary, and who is not employed by an insurance company. Whilst affirming that the GAIC's weak criterion of a +50% mortality loading appeared to be satisfied by the test, Professor Wilkie was remarkably critical of the poor quality of the ABI's evidence. He made numerous technical criticisms and stated that the primary paper prepared by Swiss Reinsurance in aid of the application would not be accepted for publication in a reputable journal without very substantial revision and considerable reworking. Yet these criticisms were completely covered up when the Committee announced its decision to "approve" the test, presumably because any reference to them would have put a commercially unhelpful gloss on the GAIC's "approval."

#### **4. Myths, half-truths and unsubstantiated assertions**

I now consider some of the myths, half-truths and unsubstantiated assertions which are used by organisations lobbying on behalf of the insurance industry to promote acceptance of genetic discrimination.

**Myth:** "*adverse selection is an unambiguously negative phenomenon*"

Insurers and actuaries talk a great deal about *adverse selection* or *anti-selection*.<sup>7</sup> In the context of genetic tests, these phrases refer to the notion that individuals who know from a genetic test result they have a predisposition to illness or premature death might be more likely to purchase insurance, or to purchase in larger amounts, than those who perceive themselves to be at lower risk. The idea is obvious, and intuitively plausible; but whilst they assert the concept for lobbying purposes, insurers and actuaries often pay curiously little attention to the *empirical* question of to what extent it actually occurs.

Adverse selection (or as I prefer to call it, self-selection) is presented in commercial lobbying as an unambiguously negative phenomenon. But this is an insurance company's commercial perspective. From a public policy viewpoint, *self-selection is at first order a positive*

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<sup>5</sup> *Financial Adviser*, 14 December 2000, pp49-50.

<sup>6</sup> This account of the commercial interests of GAIC members is believed to be correct, but may be incomplete. As part of my preparation for this paper, I wrote to the GAIC on 7 January seeking a copy of any 'register of interests', but as of 26 February I have received no reply of any kind.

<sup>7</sup> Note that this very vocabulary betrays the actuaries' bias: 'adverse' selection in fact means *adverse to the insurer*. From a public policy viewpoint, the phenomenon may be highly positive, as I discuss below. 'Self-selection' would be better term.

*phenomenon*: it means that the right people, people who are more likely to suffer loss, are choosing to buy insurance.

Self-selection is potentially a negative phenomenon only in its *second order* effects. Specifically, it can become a negative phenomenon if it reaches a degree which causes insurance markets to break down. Insurance markets break down when the following cycle of events occurs to a material extent:

- the price of insurance increases so much that the ‘better’ risks opt out of insurance;
- hence the pool of insured people decreases in number, and shifts towards ‘worse’ risks;
- insurers further increase premiums to reflect the ‘worse’ pool of risks; and
- the cycle repeats, leading to a spiral of increases in premiums and declines in numbers of people covered.

This is a theoretical possibility, although it is not clear to what extent it actually happens<sup>8</sup>. But the correct perspective, *from a public policy viewpoint*, is that self-selection is generally a positive phenomenon unless and until it becomes so severe as to make insurance markets break down. *From a public policy viewpoint*, a high degree of self-selection in insurance purchase is *desirable*.

Thus the critical actuarial question for public policy is not whether self-selection occurs, but what degree of self-selection causes insurance markets to break down? *This question is not being considered by the authorities in the UK. It should be.*

Any balanced discussion of ‘adverse’ selection should also note the converse phenomenon of *propitious selection*. This is the notion that insurance may be a complement, rather than a substitute, for other risk-avoiding measures. For example, people may buy critical illness insurance or medical insurance because they are health-conscious, conscientious “worriers” (propitious selection), rather than because they have foreknowledge of a future illness from a genetic test (adverse selection). Propitious selection works in favour of insurance companies; but in their lobbying they never mention it.<sup>9</sup>

More generally, insurance industry lobbying can create the impression that everyone who buys life or health insurance must do so because of foreknowledge of illness or early death. But in reality people may buy insurance for reasons such as conscientiousness about providing for their family, or tax planning, or because they happen to meet a sales person. These reasons are quite unrelated to foreknowledge of illness.<sup>10</sup>

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<sup>8</sup> The short answer is that it is quite difficult to give examples where it has happened. One rare exception is where insurers are not permitted to discriminate on the grounds of age, as for example in some private health insurances in Australia. This really does seem to lead to problems. Empirically, age discrimination seems more necessary than other forms of insurance discrimination. Rather conveniently, many people might be persuaded to regard age as different from all other classification factors, because ‘it happens to everyone’.

<sup>9</sup> As with adverse selection, it is quite difficult to give empirically validated examples, but some are discussed in: Hemenway, D. (1992) Propitious selection in insurance. *Journal of Risk and Uncertainty*, 5, pp247-251.

<sup>10</sup> The classic industry adage ‘insurance is always sold, never bought’ also tends to belie the notion that self-selection is the overwhelming and pervasive problem it is depicted as for lobbying purposes.

**Half-truth:** “restrictions on discrimination lead to higher costs for consumers”

Another much used lobbying strategy is to assert that any restriction on insurance companies’ ability to discriminate leads to “increased premiums for consumers”. When insurers advance this argument they never mention an obvious corollary. The corollary is that unless insurers make monopoly profits, *increased insurance premiums must mean proportionately increased claim payouts*. The insinuation that policyholders or consumers *in aggregate* are always disadvantaged by restrictions on discrimination is false. Restrictions on discrimination lead to a *redistribution* of costs and benefits among a pool of life or health insurance policyholders.<sup>11</sup>

Restrictions on discrimination may also cause some change in the membership of the insurance pool: “superfit” lives may leave the pool and resort to self-insurance, and more “poor risks” may be accepted into it. For an insurer, this shift in coverage towards lives who are more likely to claim may be negative; *but from a public policy perspective, it is positive*. The superfit are likely to be better able to pay for themselves (both because they *are* fit, and because they tend to be more affluent) than the people the insurance industry would exclude if permitted to do so.

In addition, although restrictions on discrimination by insurance companies may cause some policyholders to pay slightly higher premiums than they would pay in the absence of restrictions, if you asked these policyholders it is unlikely they could say they had suffered any *perceptible* loss. Insurance premiums vary for many reasons not related to the risk represented by the individual policyholder. Policyholders generally *do not know* the what proportion of the premium represents their pure risk cost, and the insurance industry would for various reasons resist any requirement to tell them.<sup>12</sup>

From a social perspective, insurance is most effective if there is broad pooling, with large transfers from the fortunate to the less fortunate. Lobbying by some actuaries can have the malign effect of making this more difficult. This is because some actuaries tend to make a habit of proclaiming that fortunate people *will be*, or even *should be*, unwilling to “subsidise” the premiums of the less fortunate.

In reality, most people probably give very little thought – or at least, much less than an actuary does! – to how their insurance premiums are calculated, and what degree of cross-subsidy to the less fortunate is implied. Most people have other things to think about. However, when “experts” (such as the actuaries) insinuate that fortunate people *will be*, or even *should be*, unwilling to accept any subsidy of the less fortunate, *the insinuation makes it more likely that this problem will actually occur*. This is particularly so if the experts make (wholly spurious) claims that they have a professional expertise or “science” which tells society that it should penalise or exclude the unfortunate. Sadly actuaries often do this, almost always with the effect of promoting the interests of insurance companies and fortunate people like themselves, and harming the interests of the less fortunate.<sup>13</sup>

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<sup>11</sup> Typically the redistribution is away from healthy or privileged and individuals towards the less healthy or less privileged. People in a position to pontificate about insurance matters tend to belong to the former group!

<sup>12</sup> In a different context, the Faculty and Institute of Actuaries has recently published a briefing statement *Price variations at renewal* which states that it would be “too complicated” to tell policyholders the proportion of their premium which represents a pure risk cost (as distinct from expenses, commissions, and profit loading).

<sup>13</sup> The influence of actuaries and actuarial ideas can have a malign effect on the unfortunate across a wider perspective. There are very many situations where one can envisage that people who are disadvantaged in some way – by disability, for example – would be better off if less attention were paid to actuarial arguments, and more attention to ordinary humanity. I do not suggest that harming disabled people is the intention of actuarial lobbying, but it is often the foreseeable effect.

**Half-truth:** “insurance discrimination represents competition between insurers, which benefits consumers”

Many types of commercial competition do benefit consumers, but some do not. An unusual feature of insurance products is that as well as competing in the usual ways for service industries – price, level of service, product differentiation, recruitment of employees – the insurers also compete in risk selection. That is, they compete in selecting the “good risks,” and avoiding “bad risks”. *From a social policy perspective, this "selection competition" is essentially negative:* it may create an insurance underclass, and does **not** make a clear positive contribution to the aggregate welfare of consumers. Public policy should discourage or reduce this “bad” competition, and encourage “good” types of competition – that is, those which are more clearly beneficial to consumers e.g. on expenses and level of service.<sup>14,15</sup>

**Half-truth:** “insurance is relatively unimportant in UK society”

*For the time being* this is more or less a whole truth. For example, the existence of the National Health Service makes insurance much less important in healthcare in the United Kingdom than in the United States. Present UK social welfare provisions mean that there is less reason why I or anyone else should be concerned about insurers’ practices in the UK than in the United States.

But that is only the first half of the story. The second half of the story is that the *same people* and the *same organisations* which lobby for unfettered discrimination in insurance also conduct a constant and insidious campaign to undermine public support for the institutional fabric of UK social welfare, and to promote the perception that it should be largely replaced by private insurance.

The insurance industry tries to have it both ways: it lobbies for unfettered discrimination on the pretext that UK circumstances make insurance relatively unimportant, and then in other contexts it works assiduously to undermine those circumstances. It is the *combination* of these political agendas which is profoundly sinister.

**Myth:** “insurers do not want to initiate genetic tests, they just want access to tests already taken”

In public the insurance industry continually asserts that it would never seek to initiate genetic tests not already taken by an applicant. Organisations such as the Genetic Interest Group appear to accept this at face value.

There are two reasons to doubt the validity and durability of this policy of self-restraint. The first is that there are many ways in which insurance practice can create financial or social pressure to undergo testing short of actual compulsion. Indeed the notion of compulsion is a red herring: it is difficult to envisage how anybody can be *forced* to buy an insurance policy except by state diktat. It is **entirely foreseeable** that when insurers do seek to initiate genetic testing, they will argue

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<sup>14</sup> This is discussed in Moultrie, TA & Thomas, RG (1997) The right to underwrite? An actuarial perspective with a difference. *Journal of Actuarial Practice*, 5, 2, pp125-147. A version is available at [www.guythomas.org.uk](http://www.guythomas.org.uk). There are some instances where “selection competition” could be seen as socially positive through its signalling function: for example, insurers’ competition to avoid insuring houses subject to flooding sends a useful signal to society that new houses should not be built on flood plains! But this ‘signalling’ concept has very limited applicability in life or health insurance.

<sup>15</sup> In a slightly different context, another type of competition between insurers which generally does **not** benefit consumers is competition bidding up levels of commissions paid to agents – from a consumer perspective this type of competition is a major structural problem of the insurance industry, as the Consumers’ Association has pointed out.

that nobody is *compelled* to purchase insurance, and therefore nobody is compelled to take genetic tests!<sup>16</sup>

The second reason to doubt the validity of self-restraint is what insurance policymakers and opinion formers say, and occasionally write, in forums or media which they perceive are not for widespread public consumption. For example, Mr Spencer Leigh, an actuary and underwriting consultant, writes as follows in a recent edition of the professional magazine *The Actuary*<sup>17</sup> (all italics are mine):

“The *current* UK position is *to state* that insurance companies will not, *at present*, request genetic tests. This is sensible but *largely window-dressing* as the tests are expensive....*Before long, however, the cost of tests will be reduced.*”

Mr Leigh goes on to deride the current ABI Code of Practice in relation to mortgage-linked insurances as ‘a curate’s egg which makes little sense.’ He further notes that the ABI has a credibility problem because of its obvious self-interest, and therefore recommends that

“The Institute of Actuaries, with its more independent stance, could put these issues to the media and demonstrate that the arguments are not as one-sided as they think. The Institute has issued one statement, but next time round more thought needs to be given as to how it can be perceived positively. I realise I am advocating spin-doctoring, but without suitable guidance, we will lose our case.”

These recommendations from Mr Leigh help to debunk the next myth.

**Myth:** “*actuaries do not advocate the interests of any particular group*”

In the light of Mr Leigh’s comments, it is interesting to consider the Faculty & Institute of Actuaries’ briefing statement to which he refers.<sup>18</sup> The preamble to the statement asserts that

“The profession aims to evaluate the financial impact on all groups which are likely to be affected, but does not advocate the interests of any particular group.”

Regrettably, both parts of the above sentence are misleading. The first part is misleading because actuarial thinking and analysis are focused on the finances of insurance companies, not individuals. I am not aware of any area of actuarial literature or analysis which aims to evaluate the financial effects *on individuals* of illness, or being unable to purchase insurance.<sup>19</sup>

The second part is misleading for reasons which follow from the first. The fact that actuarial thinking and analysis are concerned with the finances of insurance companies leads actuaries to advocate the interests of insurance companies. Additionally, of course, actuaries are typically employed by, or advisers to, insurance companies. They have a responsibility to their employers

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<sup>16</sup> Apart from being a foreseeable development, this line of argument is already occasionally used by insurance executives, at least when they think only other insurance executives are listening. See for example: Leigh, S (1996). The freedom to underwrite. *Paper to the Staple Inn Actuarial Society*, at ¶5.51.

<sup>17</sup> Leigh, S (2000). The gene genie. *The Actuary*, October 2000, pp20-21.

<sup>18</sup> The statement is available at [www.actuaries.org.uk](http://www.actuaries.org.uk). This is the second version of the statement; an earlier, more egregious version was withdrawn and revised, taking account of some of my suggestions.

<sup>19</sup> More generally, actuarial thought and analysis tend to be concerned with collective interests rather than individual interests, and with business interests rather than consumer interests. This leads to an antipathy amongst actuaries to the international social trend to legislate for individual human rights. This is discussed in greater detail in my paper: Thomas, RG & Sharp, CD (1998). Actuarial values. *Transactions of the International Congress of Actuaries*, 1, pp95-110. A version is available at [www.guythomas.org.uk](http://www.guythomas.org.uk).



or clients, but no responsibility for the financial or social plight of people who are excluded from insurance, or for wider social problems.<sup>20</sup>

**Myth:** “*insurance risk classification is primarily a scientific matter*”

Another lobbying strategy is to assert that a particular organisation of insurance markets is dictated by “science”. This is the same error as was made in earlier disasters of eugenics. It misconstrues the essential nature of science. The essence of science is that it is positive, and not normative. Science says *nothing* about how insurance (or any other social endeavour) *should* be organised; at best it only *predicts* what is likely to happen if we do organise it in particular ways.

In practice, the choice of risk classification factors has always been mediated by cultural factors as well as by analysis of data. One example of this is the link between lung cancer and smoking. This has been known at least since the early 1960s, yet the insurance industry only began to take account in the early 1980s. One possible reason was that in the earlier period, many senior actuaries were themselves smokers! – a rare example where the adverse risk classification *did* have some personal import on those who determined policy.

Another point from this example is that although the industry often uses parables about smoking status to illustrate the nature of risk classification, for many years after the early 1980s a number of life insurance companies *still* took no account of smoking status. This illustrates again that the use (or not) of particular classification factors is to a considerable extent a matter of culture and habit.

A further example is the possibility of links between ethnicity and mortality or morbidity. There is some evidence for such links and underwriters report<sup>21</sup> that in the 1960s insurance companies in the UK commonly charged so-called ‘racial extras.’ With the advent of the Race Relations Act this practice was necessarily discontinued, without perceptible effect on insurance markets.

**Unsubstantiated assertion:** “*self-selection is a much greater problem in critical illness and long-term care insurance than in life insurance*”

This assertion is frequently made by insurance companies and their advocates in discussion in the UK, but there is very little evidence. As I noted in section 2 above, recent actuarial studies suggest that even under the most extreme assumptions, ignoring genetic tests *and family history* would have little effect on reasonably well developed critical illness insurance markets such as exist in the UK.<sup>22</sup> However this necessarily tentative conclusion is perceived as politically unhelpful to the insurer’s freedom of operation, and so an effort has been made to create a ‘spin’ that these types of insurance present unspecified “greater problems.”

An example of this ‘spin’ was the presentation by the Institute of Actuaries of the results of an investigation of genetic test results and insurance in relation to the BRCA1 and BRCA2 genes. A press release<sup>23</sup> was issued stating that

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<sup>20</sup> The HGC may or may not receive a submission explicitly from the actuaries. On a previous occasion, they directed submissions through the UK Forum for Genetics and Insurance, rather than explicitly on behalf of the profession. (One of the advantages of this is that conscientious objectors such as myself can be deflected by the assertion that the profession made no submission of its own!)

<sup>21</sup> Leigh, S (1996), *ibid*.

<sup>22</sup> See footnote 4.

<sup>23</sup> Press release 26 October 2000: <http://www.actuaries.org.uk/pr-rels/2000/ukfgi241000.html>.

“[The results] showed how genetic tests for BRCA1 and 2 could affect the underwriting of critical illness insurance, where an accelerated benefit would normally be payable on diagnosis of cancer. This showed much higher levels of potential impact of adverse selection than for term life insurance, particularly for young and developing critical illness markets.”

The impression given by this press release is that self-selection would very materially impair the viability of the critical illness insurance market. It omits to note that *much higher* levels of self-selection may still be (and in this case are) *immaterial* levels.

The paper on which this press statement was based, *reporting an industry-funded study and looking at the problem from an insurance company’s perspective*, stated that<sup>24</sup>

“Overall, we conclude that adverse selection is only likely to be significant if

- (a) the CI market is very small (smaller than it is in the UK)
- (b) very high sums assured can be obtained without disclosing genetic test results or family history
- (c) the higher penetrances observed in the highest risk families apply more widely.”

On my reading, this suggests that self-selection is a theoretical problem from a commercial perspective, and it may be a practical problem in some very small insurance markets; but it is quite immaterial in the UK critical illness insurance market.

Overall, the unsubstantiated assertion that critical illness and long-term care insurance markets present ill-defined ‘greater problems’ is best understood as a political strategy of the UK insurance industry: make limited concessions on life insurance, but hope to get away with more discrimination on everything else. (Interestingly, the US insurance industry seems to adopt a converse political strategy: they make concessions on health insurance, but hope to get away with everything else.)

**Myth:** “*the ABI Genetics Code of Practice protects customers’ interests*”

The consultation document refers in approving terms to the Association of British Insurers’ Genetics Code of Practice. It does not note the questionable commitment of insurance companies to give practical effect to even these industry-defined standards.

This was illustrated last year when the Alzheimer’s Society carried out a survey of medical questionnaire section of insurance application forms, and found that almost all the forms did not tell applicants of their rights under the Code. More than two years after the alleged introduction of the Code, applicants (and, I strongly suspect, medical practitioners) were not being told of its existence. This “self-regulation” strongly reminds me of the self-regulation of pensions selling practices in the late 1980s: there is an industry-defined rulebook which codifies the industry’s own view of good practice, but a cultural disposition against compliance with these self-defined standards.

**Myth:** “*the UK Forum for Genetics & Insurance provides an independent view*”

This organisation purports to present an independent viewpoint, but in reality its main purpose is to act as a discreet vehicle for the insurance industry to influence public opinion. This reflects its origins: it was established at the instigation of the Faculty & Institute of Actuaries, and its secretariat is located at the London headquarters of the Institute of Actuaries. Its membership does include a number of scientific bodies, but for them insurance is at best a very peripheral and

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<sup>24</sup> Macdonald, Waters & Wekwete, *ibid.*

minor interest. The members with a direct interest are the Faculty and Institute of Actuaries and the Association of British Insurers.

The Forum's public activities appear driven by insurance industry needs. For example, it issued an enthusiastic press release in response to the GAIC's approval of the Huntington's test, extending to 3 pages of text but neglecting to mention any of the extensive criticisms made by the independent actuarial reviewer Professor Wilkie. I would not be surprised if the Forum's executive committees are also dominated by the insurance industry, but at the time of writing I am unable to confirm this, as details of committees and their membership and activities are not shown on the Forum's website.<sup>25</sup>

## 5. Objections and counterpoints

In this section I consider a number of objections and counterpoints to my earlier arguments.

*"Insurance companies already use family history, which is genetic"*

The fact that a practice is widely followed does not make it optimal. As noted in section 4 above, from a social perspective "selection competition" between insurers is largely a negative phenomenon. Social policy should probably discourage selection competition; or at the very least, it should discourage new and intensely controversial forms of selection competition (such as genetic tests).

From the perspective of social policy, it might well be beneficial (and actuarially perfectly feasible) to restrict insurance companies' use of family history. Restricting a longstanding practice such as asking for family history might have a larger impact on insurance markets than restricting a novel practice such as genetic testing, and further consideration of this would be needed. However, an interesting aspect of recent actuarial work on genetics is that it generally assumes no information is available from family history.<sup>26</sup> Furthermore, questions about hereditary disease are already banned in some competitive insurance markets, for example in the Netherlands.

*"Insurance is inherently discriminatory and genetics is no different"*

There are two rebuttals to this. The first is that the necessity for *some* discrimination in private voluntary insurance does not mean that *any* kind of discrimination which insurers desire for commercial reasons should be permitted or endorsed by government. Discrimination in private insurance is a tension between empirical necessity and social consent; it is never a matter of absolute principles. It is difficult to operate private insurance without *some* forms of discrimination, for example discrimination according to age<sup>27</sup>. But other forms of discrimination are much less critical. Attempts to justify any and all discrimination by appeal to some 'principle' which asserts that voluntary insurance can work only with unfettered discrimination are empirically unsustainable.

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<sup>25</sup> Perhaps the details are in the 'members only' section of the Forum's website. (Why does such a forum need a 'members only' section?)

<sup>26</sup> As far as I can ascertain this is true of all Professor Macdonald's papers referenced earlier. Professor Jean Lemaire did however consider family history and genetic test results separately. Lemaire, J et al (2000). Pricing term insurance in the presence of a family history of breast or ovarian cancer. *North American Actuarial Journal*, 4, 2.

<sup>27</sup> See footnote 8.

The second rebuttal is that many people recognise a fundamental difference between hereditary factors, which are perceived as generally outside the individual's control, and a wide range of other factors of interest to insurers (such as smoking status, or body weight, or participation in dangerous sports) which are perceived as being *at least to some extent, in many cases* within the individual's control. Many people perceive discrimination based on the latter type of characteristic to be more acceptable than discrimination based on unchangeable genetic characteristics.

*"In 10 years' time, sharing genetic test results will be commonplace and unremarkable"*

This is quite possible. It is *possible* that as genetic test results become a more pervasive feature of medicine, and if the development of prophylactic genetic *treatments* keeps pace with pre-symptomatic genetic *testing*, both general public concern and the particular concerns of disabled people may decrease. Under this scenario, it is also *possible* that genetic test results could then be permitted to be used for limited private insurance purposes, without promoting or sanctioning a culture of more pervasive social discrimination.<sup>28</sup> It is *possible* that widespread use of genetic tests could be incorporated into society *without* promoting the hardening of social attitudes towards disability and difference which many people currently fear. This golden scenario could happen; but it all seems rather unlikely to many people at the moment. And if it does happen, any pre-existing restrictions on insurance companies cause no problem: government can relax the restrictions as and when it becomes socially beneficial to do so.

## **6. Previous examples: AIDS and disability**

Although they are not directly related to genetic testing, it is instructive to examine some previous issues where self-selection has been misrepresented or exaggerated for commercial ends.

### *AIDS*

In the late 1980s, the actuarial profession directed much attention to AIDS, and produced numerous papers<sup>29</sup> projecting greatly increased mortality. Term insurance rates were increased very sharply. Many companies refused to provide insurance on any terms to homosexual men. Subsequently, it has become clear that the actuaries' predictions of increased mortality were grossly exaggerated. When one raises this, some actuaries suggest that their exaggerated predictions were socially beneficial, because they helped to promote appropriate public health measures in reaction to the problem. But if one looks back in professional journals to actuarial papers written in the late 1980s, one does not find actuaries were concerned with promoting public health measures. On the contrary, actuarial discussion appears to have focused overwhelmingly on the commercial interests of insurance companies, and was dismissive of the social problem (well recognised in other circles) that insurance company reactions might have a *negative* effect on public health measures (eg by discouraging people from having HIV tests).

I was not an actuary in the 1980s, but one possible motivation of some actuaries' presentations at the time was suggested to me a few years ago by a retired actuary, who in the 1980s was the appointed actuary of a quoted insurance company. He recalled that because of intense competition, term insurance premium rates had been relatively unprofitable for some years. AIDS was apparently seen by some actuaries as a convenient pretext for the industry to achieve a

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<sup>28</sup> As noted in section 4 above, one of the necessary conditions for this benign outcome is that private insurance should remain a minor feature of the fabric of social welfare. Again as noted in section 4, this is a condition which the insurance industry continually seeks to undermine.

<sup>29</sup> For example there were a series of *AIDS Bulletins* presenting projections of the epidemic.

step-change in premium rates which would restore profitability of this class of business to a more satisfactory level. According to the retired chief actuary, meetings were organised between representatives of a number of companies with the objective of agreeing to present a common public relations line to the effect that AIDS necessitated a substantial rise in term assurance premium rates.<sup>30</sup>

The overall effects of the actuaries' "professional" reaction to the AIDS epidemic were: to increase the profits of insurance companies; to promote homophobia; possibly to deter people from seeking testing and medical care; and the social exclusion of many homosexuals in a way which was (in the light of the subsequent drastic reductions of premium rates) wholly unnecessary.

### *Disability*

Under the Disability Discrimination Act 1995 insurers enjoy a number of unnecessarily lenient and broad exemptions. When the Act was first drafted, the proposed exemptions included one which made it lawful for employers to bar newly recruited disabled employees from joining defined benefit pension funds. The justification was an "actuarial" one: it was suggested that disabled people might be more likely to retire in ill health, or die before retirement.

In consultations prior to the Act's implementation, I wrote a number of letters to the Department of Social Security pointing out that this exemption was not necessary for the financial stability of pension funds. There was no significant risk to the overall finances of a pension fund from the possibility of a small number of disabled employees being more likely to retire early or die; the fact that the disabled person was starting a job would normally suggest that their health was at least reasonable; and in any case, the whole *raison d' être* of a defined benefit pension fund is cross-subsidy.<sup>31</sup>

My representations were ignored. However in December 2000, the Disability Rights Commission commissioned a survey of employers and published a report<sup>32</sup> acknowledging that the exemption could be removed, without any perceptible effect on the finances of UK pensions funds. The government's reaction is awaited. In the meantime the effect of the "actuarial" justification has been the unnecessary exclusion and possibly suffering of an unknown number of disabled people.

Both these examples involve a misrepresentation and exaggeration of the actuarial issue of self-selection for potential commercial benefit. The pity of it is that certainly in the latter case, and possibly even in the former case, the commercial benefit was extremely marginal.

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<sup>30</sup> I do not suggest that this was a motivation of *all* actuaries commenting on the epidemic; but it is plausible that it was one factor leading to the profession's exaggerated response.

<sup>31</sup> For example, defined benefit pension funds typically involve a large cross-subsidy from the aggregate workforce to a small number of high earners. Strangely one never hears actuaries arguing that this cross-subsidy to high earners creates insuperable actuarial difficulties, in the same way as they allege for subsidies to the unfortunate!

<sup>32</sup> Disability Rights Commission (2000) *From exclusion to inclusion*. A report of the Disability Rights Task Force on civil rights for disabled people. Page 102.

## 7. Recommendations and postscript

### *Recommendations*

In evaluating submissions relating to insurance, the HGC should recognise that substantial technical and lobbying resources are available to those who wish to promote genetic discrimination for commercial reasons, and virtually no technical resources are available to those who may wish counteract it. The weight of submissions of a ‘technical’ character may be affected by this.

The UK government should reconsider its current approach, which is unique in Europe and possibly the world in its discriminatory character.

There should be a presumption against insurers’ right of access to genetic tests, except for exceptionally large policies, or where insurers can show that ignoring tests would seriously disrupt the financial stability of insurance markets. All evidence to date suggests that under this criterion, little or no access to test results would be justified. It is possible that in many years this situation could change, but that is a possibility which can be addressed if and when it arises.

The definition of ‘exceptionally large’ policies in the previous paragraph should be made by reference to the limits which a company sets in each age range for automatic medical examinations. For example, in the case of life insurance for persons up to age 40, insurers typically set limits between £250,000 and £500,000 on the amount of cover which can be obtained without automatic medical examination. At higher ages, lower limits typically apply.

It may also be desirable for social and privacy reasons to restrict insurers’ access to information about family history, as in the Netherlands; but further work may be needed to assess for which (if any) insurance products this would impair the viability of private insurance markets.

It would be difficult to prevent insurers taking account of ‘negative’ tests (ie those which indicate the absence of a disease-linked mutation), if an applicant chooses to disclose them. However I would prefer that insurers were discouraged from actively promoting this concept, since there is clear potential for it to distort patients’ decisions about seeking or avoiding tests.

The Genetics and Insurance Committee should be disbanded. It should be replaced by statutory regulation based on the principle that insurers’ access to genetic tests should be permitted only where it is *necessary to ensure the financial stability of insurance markets*. This regulation, unlike the GAIC, should be demonstrably independent of the insurance industry.

### *Postscript*

I have to recognise that independent papers such as this one may have only a very limited effect. The historical record is appalling: across many countries and societies, the instinct to exclude and stigmatise on spurious ‘rational’ or ‘scientific’ grounds those who are perceived as different or defective has always been very strong. Whilst at present there is much public opposition to genetic discrimination, this opposition could prove quite fragile – particularly if substantial and sophisticated lobbying and technical resources continue to be devoted to legitimising discrimination. It therefore seems quite possible that there may be a regression towards more hostile attitudes towards the genetically disadvantaged, and probably towards disabled people generally; and that this trend may be more marked in the UK than in other countries, which are apparently more alert to the dangers which history so graphically foretells.

I have written this paper reluctantly. I felt obliged to write by my actuarial insight and my very strong belief that the UK government is currently pursuing a profoundly mistaken path; but it has been a distraction from more enjoyable or remunerative activities, and I have no direct stake in the matter. I will therefore not be joining the circus of conferences and seminars populated by people whose job it is to lobby on behalf of the insurance industry to promote acceptance of discrimination. But I plead with the HGC to apply a heavy discount to the self-serving arguments which they produce.

Guy Thomas  
February 2001

*Further sources*

Further material is available at my website [www.guythomas.org.uk](http://www.guythomas.org.uk), in particular my paper *The right to underwrite? An actuarial perspective with a difference*. The tensions between some actuarial traditions and concepts of human rights are also discussed in one section of my paper *Actuarial values*.

*About the author*

I am an actuary and professional investor. I was formerly an academic and I have published papers on various actuarial topics including underwriting. My paper (not related to genetics) *A nonlinear stochastic asset model for actuarial use* was awarded a prize by the Council of the Institute of Actuaries as the most meritorious paper in the 1999 volume of *British Actuarial Journal*.

I am not employed by an insurance company. To the best of my knowledge neither I nor my family nor any of my close friends have any currently testable genetic predisposition to serious disease. In these senses, I have no stake in the matter of genetic tests and insurance. This paper is motivated by my desire to live in a humane society in which social policy seeks to discourage rather than to promote discrimination against those who are different and less fortunate; and by my sad realisation that the lobbying of the insurance industry and other actuaries is often inimical to this end.

I recognise that this paper is negative in the sense that it debunks some of the slogans which other commentators promulgate, but provides no more than a sketch (in the final section) of what should be done. As an observer with an independent frame of mind but no direct stake in the subject and no occupational obligation to consider it, I do not have the capacity to design a complete blueprint. However I hope that an independent frame of mind coupled with actuarial credentials will represent a useful perspective in submissions to this consultation.