

**Genetic Screening, Health care and the Insurance Industry:
Should genetic information be made available to insurers?**

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Introduction

The UK government recently introduced a 5 year moratorium preventing the insurance industry from using genetic tests or requiring the disclosure of genetic tests (DH, 2001) for most insurance policies to provide “a five year breathing space to work with the industry to get things right.” Test can still be used for high cost policies (life insurance policies up to £500,000 and long term care assurance and income protection up to £300,000). This paper sets out the policy context and seeks to model the trade-offs between the potential losses faced by insurers from adverse selection by insurees (which will increase premiums reducing consumer welfare) and the detrimental health effects that may result from people refusing to undergo tests because of fears about the insurance implications.

Role of information in insurance

Medical information plays an essential role in insurance risk valuation. (McGleenan T, 1999a; O’Neill O, 1998; Zimmerman SE, 1998) This information can be obtained through questions on the proposal form, medical history, examinations and/or medical tests, all with appropriate authorization from applicants. In the same way, genetic information can be accessed through the proposal form; through medical records and family history; through the results of genetic testing for clinical or research purposes, and/or by asking the applicant to undergo genetic testing. Developments in genetics and predictive medicine mean that genetic screening has become a powerful diagnostic tool, especially in single gene diseases where the risk of developing a disease can be predicted with reasonable accuracy. Consequently, the insurance industry wants to have access to this information without restrictions that would make the risk assessment process unworkable. (Zimmerman SE, 1998)

Insurance companies are concerned about the possibility of adverse selection because of positive predictive genetic screening results. They argue that they should be able to require the disclosure of any genetic information that has been obtained for other reasons (i.e. clinical or research). (McGleenan T, 1999a; O’Neill O, 1998) Those persons with positive genetic results will have a relative increased risk for a specific disease, and they may take advantage of this information and insure at unfair rates. Furthermore, adverse selection could put at risk the viability of the insurance market. They base their argument on the

adverse selection suffered by the industry with HIV positive patients in the 1980s and the MIRAS crisis in 1983 (McGleenan T, 1999a). In the latter case, the promotion of endowment mortgages with life insurance repayment guarantees with simplified forms that contained no requests for medical information led to take up by those in poor health and hence to losses for insurers. However, Macdonald (2000, 1997) developed models to examine the impact of adverse selection in the case where insurance companies do not use the genetic information in life insurance underwriting. He maintains that the resultant increment in costs can be borne by the industry if the numbers of policies the adverse selectors are buying is limited and if a cap is put on the value of the policies that can be bought without testing. Fenn (2000) has modelled the potential impact of adverse selection on health insurance markets in the absence of genetic tests and found that the effects could be substantial. His modelling does suggest, however, that high coinsurance rates would provide a way of enabling insurers to discriminate against adverse selectors. Insurers would offer full cover policies at high premiums (in the expectation of attracting adverse selectors) and policies offering partial cover with high co-payments for care at lower prices, in the expectation that these would not be attractive to adverse selectors who knew they would need the health care. Such contracts would however be attractive to those with a low known risk of high cost disease.

Disclosure and Regulations: an overview

The better a risk can be identified, the more insurable it is. Genetic screening would provide relevant information for risk rating; that is, it would have actuarial significance. (McGleenan T, 1999b) However, it may lead to discrimination and hence to people not taking up tests that will be of value in health care because they fear the insurance implications. In response to this, various legislative initiatives have been proposed which attempt to tackle the possible social harms that a wide implementation of genetic testing would bear.

The European insurance industry bases its contracts in the principle of *uberrimae fides*. (McGleenan T, 1999b; Fenn P and Diacon S, 1998) By this means, any information that is known to an applicant and may influence the underwriting process - so the insurer's judgement whether or not to take the risk - must be notified to the insurer. Failure to so doing can result in the contract being declared voided. In the UK, according to the Marine Insurance Act, section 18(2), (Depicted in McGleenan T, 1999b: 76) this information will be considered

materially relevant. However, there are different models as to the exact nature of the duty of materially relevant information disclosure. (McGleenan T, 1999b). For example, the Insurance Code in France introduces an element of proportionality into the resolution of disputed insurance claims. If individuals deliberately hide materially relevant information from insurers, the contract is held to be void. However, if there is no wilful nondisclosure, in the event of a claim the insurance company pays the proportion of the claim which would have been charged with full information. This approach tries to protect against the possibility of adverse selection and avoids any unfair resolution where an honest mistake has been made.

The insurance system in the United States works under a *duty to investigate model*. Most States function in the (more or less) absence of disclosure obligation in insurance contracts. Therefore, the insurer should properly investigate the risks brought by a particular application. This approach moves costs of acquiring risk information from the proposer to the industry, what is seen as fair since consumers are not supposed to have the same level of expertise as the insurer.

Several countries have negotiated agreements or legislated specifically on genetic information and insurance, mostly to prevent any type of genetic discrimination. (Gaulding J, 1995; McGleenan T, 1999b; Morrison PJ *et al.*, 1999; Rosén E, 1999) In Europe, some nations (e.g. Netherlands, UK and Sweden) have a moratorium for the implementation of genetic information in underwriting procedures based on agreements and insurance industry self-regulation. These states have also adopted a ceiling value under which no genetic information will be required. Other countries (e.g. Austria, Belgium, France, and Norway) have enacted stringent laws against the use of genetic test results by insurers. Furthermore, some of these nations (i.e. France, Norway and Sweden) have introduced legislative sanctions.

In the UK, the government approach to the relevant issues in genetic testing and insurance is based on negotiation. (McGleenan T, 1999b) Interim solutions has been agreed between a self-regulated insurance industry and the government supported by the Human Genetics Advisory Commission (HGAC). (McGleenan T, 1999b; Morrison PJ *et al.*, 1999; Rosén E, 1999)

The Association of British Insurers (ABI) released a code of practice for genetic testing (<http://www.abi.org.uk/INDUSTRY/abikey/genetics/gentest99/gentest99.asp>), where they agreed that insurers should not ask applicants to undergo a genetic test in order to obtain insurance. However, existing test results should be informed to the insurance firm when it asks a relevant question. These results need not to be disclosed if application for life insurance is up to £300,000. It is also stated that insurers will take into account genetic test results only when they have been found reliable³ and relevant to the insurance contract. Consequently, genetic information may be used to increase premiums, although it cannot be used for preferred underwriting. The code also says that the insurer must procure proposer's informed consent before using any information obtained through genetic testing, and this information must be kept confidential and not be used for anything other than those purposes explained clearly to the applicant; this includes the prohibition of using genetic test results in the estimation of a related family member's premium. In other words, an applicant will not be requested to disclose any other persons genetic test result, and one person's genetic information will not influence another person's application. Finally, the code contains a description of the legal practice and procedure to be adopted by a tribunal if there are any complaints from insurance applicants.

The HGAC, a non-statutory advisory body to report to the government on different aspects in genetics, published a report (<http://www.dti.gov.uk/hgac/>) which recommended a three-year moratorium on the use of genetic information. (HGAC; McGleenan T, 1999b; Morrison PJ *et al.*, 1999; Rosén E, 1999) They concluded that genetic testing technology is currently in an early stage and testing for multifactorial diseases will not generate any actuarially relevant information. (McGleenan T, 1999b) They considered the issue of adverse selection based on genetic information and insurance, and found that the evidence was not conclusive and that life insurance could cover the resultant adverse selection of nondisclosure of an adverse genetic result.⁴

³ The standard of reliability is based on NHS use or validation by an expert body. (McGleenan T, 1999b)

⁴ McDonald (1997, 2000) showed that there is adverse selection when an applicant has a positive genetic result, but the insurance industry can withstand it if the sums insured are not above a ceiling.

The Government's response to the ABI Code of Practice and the recommendations made by the HGAC was to use a Genetics and Insurance Advisory Committee (GAIC)⁵ to validate genetic tests proposed by the ABI (McGleenan T, 1999b; Morrison PJ *et al.*, 1999) and to accept the recommendation of a moratoria. (McGleenan T, 1999b) As we noted above this is for five years. Tests can still be used for high cost policies (life insurance policies up to £500,000 and long term care assurance and income protection up to £300,000).

In the US, a different approach towards regulating genetics and insurance has been developed, mainly focused on privacy, i.e. the genetic dimension of the information. McGleenan (1999b: 90) maintains that the US experience is particularly instructive for a legislative approach directed towards the restriction of the methodology used to obtain the information (e.g. genetic testing), rather than '... the negative social consequences that may arise from the application of the existing systems of insurance and insurance law to genetic information'.

Accordingly, in many States, legislation seeks to prohibit insurers from requiring genetic test results or from requiring applicants to take genetic test. Most of these bills are enacted in order to protect individuals from being denied health insurance. However, there are considerable differences between States. Genetic and genetic-law definitions are not homogeneously defined, leading to contradictions or misinterpretations. (Gaulding J, 1995; McGleenan T, 1999b; Rosén E, 1999) The key Health Insurance Portability and Accountability Act (HIPAA) was enacted at Federal level, prohibiting health plans from using pre-existing health status factors for modifying health insurance contracts, limiting coverage or denying health-care. It also prevents insurers from asking individuals for genetic disclosure without written authorization. However, definitions here differ from those often used at State levels, increasing the complexity of the legislative framework.

Genetics and Genetic Tests

The clinical classification of genetic disorders can be arranged into *somatic cell disorders*, *chromosomal disorders*, *single gene disorders*, and *multifactorial disorders*. (Mueller RF and

⁵ The primary function of GAIC is to validate genetic tests proposed by the ABI and to inform policy at the Department of Health. (McGleenan T, 1999b; Morrison PJ *et al.*, 1999)

Young ID, 2001; Rimoin DL, Connor JM and Pyeritz RE, 1997; Thompson MV, McInnes RR and Willard HF, 1991) The last three categories have implications for the insurance industry.

Diseases based on any alteration in the number or structure of the chromosomes are *chromosomal disorders*. In the past only visible alterations under the light microscope were included, but with recent developments on modern diagnostic techniques (e.g. FISH), small amounts of missing material can be identify. The latter permitted to include a 'new' type of disorder into this group: 'microdeletion disorders'. Since symptoms are usually present from an early age, the implications for insurance companies are limited. They can offer health and life insurance on the basis on a known diagnosis. (Hauser G and Jenish A, 1999)

Single gene disorders are the result of mutations in one or both alleles of any gene in the cell (i.e. gene on an autosome, sex chromosome, or in mitochondria). This type of disarrangement usually exhibits obvious and characteristic pedigree patterns. From the insurance risk point of view, (Macdonald, 1997) a monogenic disease would reveal the most likely cause of death, and even more, it would restrict the probable age of death to a narrow range; hence these represent an increased risk for the insurance policy. Pedigree patterns or family trees (family history) for some single gene conditions are already used by the insurance industry for underwriting purposes.

Finally, any disorder that results from the interaction of one or more genes with one or more environmental factors is considered a *multifactorial disorder*. The genetic disarrangement would predispose to the disorder or would produce the disease. However, for most of the multifactorial disorders the nature of the environmental agent, the genetic predisposition and the trigger mechanisms remains unclear. Macdonald (1997) states that for insurance risk purposes what is important is that a multifactorial disorder would indicate a much-advanced time of death, and not the likely cause of death. Because of this, genetic testing might be an important tool for revealing this risk long before any symptoms appear.

Changes will also come gradually into the medical field. Genetics will be no more just a specialisation in tertiary care medicine, it will become a common practice for all kind of clinicians to use new medical diagnosis procedures and more accurate therapies. Predictive

genetic tests will allow individuals (and their physicians) to know their susceptibilities and to take measures in order to reduce risk.

It is important to differentiate between family/individual(s) at risk testing and population screening. The former implies that the target population is composed by those individuals who have a (positive) family history of the entity under surveillance, therefore having greater risk. Examples of this are familial cancers, and carrier detection in haemophilia B. On the other hand, population screening is performed on the target population regardless of family history.

Genetic screening is not only of value in medicine and insurance. Employers may want to test individuals trying to identify those at higher risk for industrially related complications. An example of this is screening for deficiency of α_1 -antitrypsine in individuals that work in dusty environments. We do not consider this issue further.

Extent of Overlap between health care and insurance use of genetic information

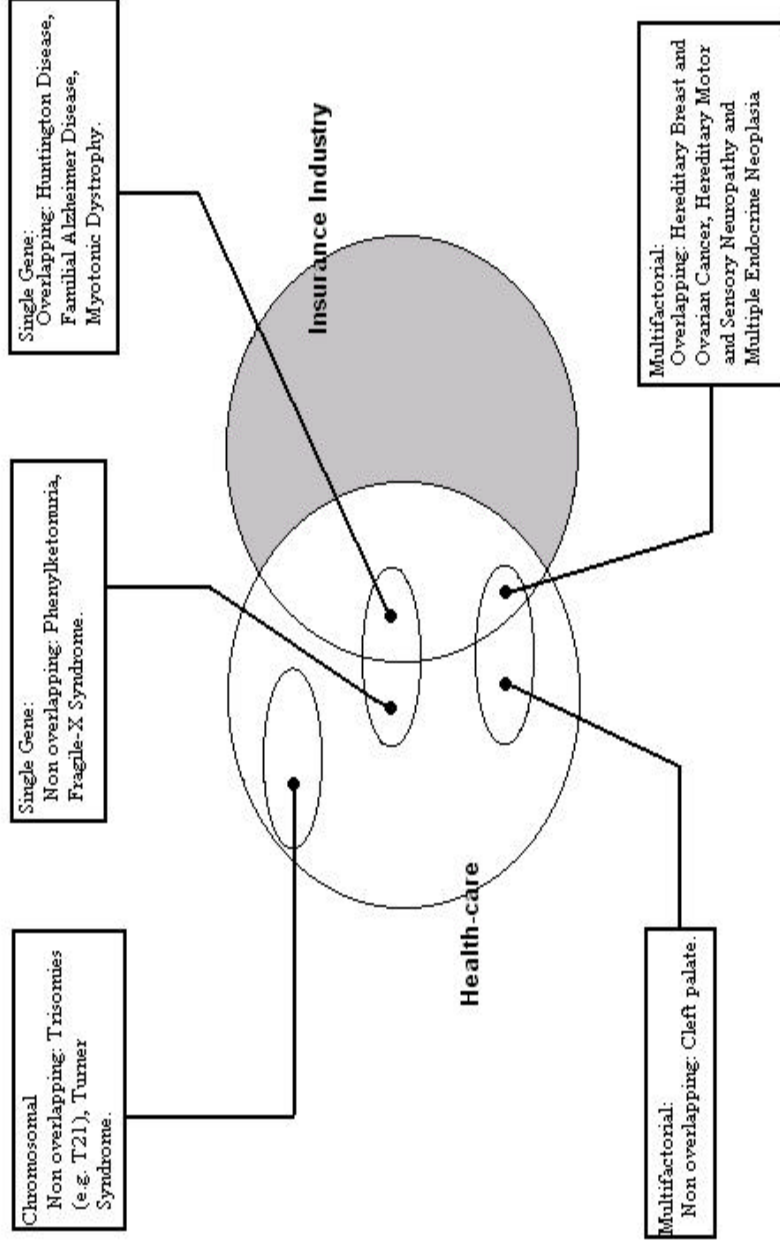
It is possible to depict different circumstances where genetic testing would be relevant for both health care and underwriting, or just significant for health care. We summarise this in Figure 1

The insurance industry in the UK (ABI) recommended ten genetic tests for seven conditions based on the belief that they are technically, clinically and actuarially relevant. (Table 2)

| Condition | Genes Tested for | Type of Genetic Disorder |
|---|-------------------------|---------------------------------|
| Huntington's Disease | HD | Single Gene |
| Familial Alzheimer Disease | APP, PS1 & PS2 | Multifactorial |
| Hereditary Breast & Ovarian cancer | BRCA1 & BRCA2 | Multifactorial |
| Myotonic dystrophy | MDPK | Single Gene |
| Familial adenomatous polyposis | APC | Single Gene |
| Multiple endocrine neoplasia | RET | Single Gene |
| Hereditary motor and sensory neuropathy | PMP22 | Multifactorial |

Table 2. List of conditions and genetic tests recommended by the ABI as relevant for insurance purposes. (Adapted from the House of Commons – Science and Technology – Fifth Report).

Extent of Overlap



Chromosomal disorders usually present symptoms from early stages of life. Examples of these are the trisomies including Down syndrome or other conditions like Turner syndrome, and Klinefelter syndrome. For research, clinical and counselling purposes, genetic testing based on karyotyping or sophisticated techniques like FISH is very important. However, for underwriting purposes, genetic screening for diseases confined to this group is of little significance; all the information can be achieved from filling up an application form or by looking at the medical history of the applicant.

For single gene and multifactorial disorders it is possible to find diseases where genetic testing has minimal implications for underwriting purposes, although very important consequences for health care. This would be the case of Phenylketonuria or Fragile-X syndrome in single gene disorders, and congenital malformations like cleft palate in multifactorial disorders. In diseases like these, a similar approach to that for chromosomal disorders can be taken.

| Disorder | Insurance Industry | | | Health-care (Diagnostic methods) |
|-----------------------|--|--|--|---|
| | Underwriting Implications | Policies | Genetic Determinants for Underwriting | |
| Chromosomal | Minimal | Not available or available with restrictions or exclusions | Medical history | Clinical and lab diagnosis (e.g. Karyotype and FISH). |
| Single Gene | Relative to family risk. | Increased premium or applicants rebuf. | Family history and pedigree. | Selective screening in families at risk. |
| Multifactorial | Important as indicator of a 'much-advanced time of death'. | Increased premium or applicants rebuf. | Population Genetic Screening. | Mass screening Epidemiological surveys Occupational screening Population screening |

Table 3. Implications and associations between genetic disorders, the insurance industry and health-care diagnostic methods.

Currently, the potential overlap between health care and insurance arises in cases where insurers have claimed a genetic test as relevant for applicant's risk assessment. The only genetic tests approved by the GAIC so far are those for Huntington's Disease, where sensitivity and specificity has been calculated in 98.8% and 100%, respectively. Furthermore, the different genotypes associated with this single gene disorder would define the age of onset of the disease and its severity. Myotonic Dystrophy and Familial Adenomatous Polyposis could be also classified under single gene disorders; however, their technical and clinical validity is not as clear as for Huntington's Chorea. (OMIM)

In the case of multifactorial disorders, the GAIC is looking at the possibility of allowing the insurance industry to use genetic tests results for Familial Alzheimer Disease and Hereditary Breast and Ovarian Cancer. These disorders present difficulties for genetic screening, as many factors might be involved, and their relationship with severity and age of onset of the disease is not completely understood. Nevertheless, Familial Alzheimer Disease and Hereditary Breast and Ovarian Cancer have provided (some) evidence of technical and clinical validity. (OMIM)

Finally, some multifactorial disorders (e.g. Coronary Artery Disease and Diabetes Mellitus) can be subjected to genetic test but the evidence suggests there are currently neither technical nor clinical valid. However, if appropriate advances in genetics can be achieved, genetic test results for these diseases might be considered appropriate for the underwriting process in the future.

There is little discussion in the literature about the actuarial relevance of genetic test results for the underwriting process: any increase in the accuracy of the risk assessment will in principle permit the insurer to determine better whether or not to insure certain event, and at what price to set the premium. However the technical and clinical validity of most of the genetic tests has yet to be determined. The introduction of a moratorium before the insurance industry is permitted to use any genetic test for underwriting purposes seems reasonable on the grounds of the need to allow more time to assess the validity of, and actuarial relevance of any test. However, there is a more important policy issue – that of the potential for use of genetic information in insurance reducing access to health care. In the next section we model the possible gains and losses in health care and insurance markets,

from society's perspective, of policy rules to permit or not permit the use of genetic test information collected for health care purposes in the insurance market.

Modelling the trade-offs

Let us assume that we have a genetic test for certain predictable disease with 100% sensitivity and specificity that has been shown to be technical and clinical valid. The disease has a prevalence of 10%. It is treatable when spotted at pre-presentation in 80% of cases. In the other 20% of cases the patient dies prematurely. We consider firstly the health care implications and then the insurance implications of different disclosure rules.

Health care impact

We begin by assuming that there is a ban on the use of the test information for insurance purposes. Let us assume that our genetic test (which costs £500 including diagnosis and counselling) is offered to a 100,000 population. The whole population chooses to undergo testing with the resultant of 10% being identified as positive (i.e. predisposed to the disease). All 10,000 positive patients are treated at a discounted cost of £10,000. Of these, 60%, 8,000 people, are successfully treated. However, 2,000 of these people would have recovered irrespective of receiving treatment. The other 2,000 patients die prematurely from the disease. Treatment allows average gains per person successfully treated of 16 QALYs (20 extra years of life at 0.8 QALYs per annum). Society has set a £10,000 price for QALY. The value of the health gains is thus 96,000 QALYs, giving a monetary value of health gain of £960m.

The costs of testing 100,000 people is £50m and the costs of treating 10,000 people are £100m. The net benefit of testing is therefore £960m - £150m, i.e. £810m.

Now let us presuppose a policy environment in which, although people can decide whether or not to be tested, (i.e. the insurance industry cannot insist on testing as a condition of having a policy) the insurance industry is allowed to use any insuree acquired genetic information for underwriting purposes. Insurers would then be able to allocate any tested individual to the

right pool (high or low-risk) and offer the appropriate contract for each one so avoiding the problem of adverse selection.

Let us assume that in this case 5% of the population decide not to be tested fearing discrimination. There is a health loss of 5 per cent of the QALYs gained as treatable cases are not detected (£48m at £10,000 per QALY). However there are offsetting savings in testing costs (5000x£500) and in treatment costs (500x£10,000). The net impact on the health care system is a loss of benefit of £48m-£2.5m-£5m equals £40.5m.

Insurance industry impact

Now we consider the insurance industry in both scenarios. Prior to the existence of the test we assume that 80,000 of the population buys life insurance policies worth £100,000 in PV terms in the event of death before a certain age (say 55). The insurer charges an average premium with a present value of £25,000. 20,000 people (25%) are expected to die before the age of 55 from a range of causes including the disease for which the test will become available. The present value of premiums is thus £2,000m and the present value of payouts is £2,000m. The scheme is actuarially fair. As Table 4 shows, there is significant redistribution between those with and without the particular disease (let us call it G) that we will be able to test for. This is the role of an insurance market. Prior to the invention of the test all individuals need access to an insurance market that will provide life insurance in the event of them getting anyone of a number of diseases for which we have no basis to believe they are more or less likely to succumb than their neighbours.

Table 4 Insurance outcomes prior to invention of the test

| | Pre-disposition | No pre-disposition | Total |
|----------------------------------|-----------------|--------------------|--------|
| Numbers insured | 8,000 | 72,000 | 80,000 |
| Deaths from disease G | 6,400 | - | 6,400 |
| Deaths from other diseases (17%) | 1,360 | 12,240 | 13,300 |
| Total deaths | 7,760 | 12,240 | 20,000 |
| Cost @ £100K per death | £776m | £1224m | £2000m |
| Revenues @ £25k per person | £200m | £1800m | £2000m |

| | | | |
|-----------------|---------|-------|---|
| Profit / (loss) | (£576m) | £576m | - |
|-----------------|---------|-------|---|

Initially we assume that our genetic test is implemented and offered to the 100,000 population under a system where the insurance industry is allowed to use the genetic information for underwriting purposes, and people can decide whether or not to be tested. This enables us to understand how the insurance market will respond to the genetic information. This is summarised in Table 5.

Table 5 Insurance outcomes with test disclosure or requirement

| | Test positive | Test negative | Total |
|----------------------------------|---------------|---------------|---------|
| Numbers insured | 8,000 | 72,000 | 80,000 |
| Deaths from disease G | 1,600 | - | 1,600 |
| Deaths from other diseases (17%) | 1,360 | 12,240 | 13,300 |
| Total deaths | 2,960 | 12,240 | 15,200 |
| Cost @ £100K per death | £296m | £1224m | £1,520m |
| Premiums required per person | £37,000 | £17,000 | £19,000 |

Points to note are that:

- use of the treatment has significantly reduced the number of deaths (by 4,800);
- this has reduced the average premium from £25,000 to £19,000;
- however, the market will be segmented into two actuarially fair markets, for test positives and test negatives.
- the premiums will be £37,000 and £17,000 respectively.

The market will be segmented as the test negative people will seek insurers who recognise their lower death rate. Insurers in a competitive market will only be able to insure test positive people at a premium that recognises their greater likelihood of dying before the maturity of the policy.

We have to expect that the reduction in premium price for test negatives will increase the demand for insurance. We assume that the Price Elasticity of Demand (PED) for test negative people is 0.5. Thus the price reduction of £8,000 (or 32%) will lead to an increase in demand of 16% or 11,520. Note that of the price reduction £6,000 (or 24%) is due to reductions in overall death rates due to treatment of disease G and £2,000 (or 8%) is due to the segmentation of the market. We assume for simplicity that the PED of the test positive people is 0. In equilibrium the market will thus be as in Table 6.

Table 6 Insurance outcomes with test disclosure taking account of PED

| | Test positive | Test negative | Total |
|----------------------------------|---------------|---------------|-----------|
| Numbers insured | 8,000 | 83,520 | 93,520 |
| Deaths from disease G | 1,600 | - | 1,600 |
| Deaths from other diseases (17%) | 1,360 | 14,198 | 15,558 |
| Total deaths | 2,960 | 14,198 | 15,200 |
| Cost @ £100K per death | £296m | £1419.8m | £1,715.8m |
| Premiums required per person | £37,000 | £17,000 | £18,347 |

Let us now assume that test results do not have to be disclosed and cannot be taken into account by insurers.

We further assume that all of the 10,000 individuals that test positive become adverse selectors and decide to buy insurance policies at a rate of 1.5 times the average £100,000 policy. Let us assume they buy cover that totals, in present value terms, £150,000 instead of £100,000 at low-risk policy rates. They buy this cover at a pro-rata rate on £19,000. The position is as in Table 7.

Table 7 Insurance outcomes with adverse selection

| | Test positive | Test negative | Total |
|--|---------------|---------------|-------|
| | | | |

| | | | |
|----------------------------------|---------|------------|------------|
| Numbers insured | 10,000 | 83,520 | 93,520 |
| Deaths from disease G | 2,000 | - | 2,000 |
| Deaths from other diseases (17%) | 1,700 | 14,358 | 16,238 |
| Total deaths | 3,700 | 14,358 | 18,238 |
| Cost @ £150K per death | £555m | - | £555m |
| Cost @ £100K per death | - | £1,435.8m | £1,435.8m |
| Total cost | £555m | £1,435.8m | £1990.8m |
| Premiums received | £285m | £1,586.88m | £1,871.88m |
| Actuarial surplus / (loss) | (£270m) | £151.08m | (£118.92m) |

There is now an overall actuarial loss. The response of the insurance company will be to increase premium prices to be able to cope with the adverse selection. Again we assume that the test positive people have $PED = 0$ and the test negative people have a $PED = 0.5$. A new equilibrium is established with a price increase of 5.91% to £20,123.

The new equilibrium is set out in Table 8.

Table 8 Insurance outcomes with adverse selection and a price increase

| | Test positive | Test negative | Total |
|----------------------------------|---------------|---------------|-----------|
| Numbers insured | 10,000 | 81,051 | 91,051 |
| Deaths from disease G | 2,000 | - | 2,000 |
| Deaths from other diseases (17%) | 1,700 | 13,779 | 15,479 |
| Total deaths | 3,700 | 13,779 | 17,479 |
| Cost @ £150K per death | £555m | - | £555m |
| Cost @ £100K per death | - | £1,377.9m | £1,377.9m |
| Total cost | £555m | £1,377.9m | £1,932.9m |
| Premium price | £30,184.5 | £20,123 | |
| Premiums received | £302m | £1,630.9m | £1,932.9m |
| Actuarial surplus / (loss) | (£253m) | £253m | - |

The social loss in the insurance market is thus the loss in consumer surplus experienced by those driven out of the insurance market. Some 2.96% of the 83,520 test negative people, or 2,469 people dropped out of the insurance market, in effect to self-insure. We assume that the welfare loss to these individuals is around half of the previous premium cost of £17,000. This gives a present value loss of $(2,469 \times 0.5 \times £19,000)$ which equals £21m.

Overall net cost

We thus have a negative health care cost from disclosure of £40.5m, but a positive benefit in the insurance market of £21m. The net cost is thus £19.5m. In this case the optimal social policy is non-disclosure.

Discussion

The potential use of genetic testing in insurance markets has raised concerns about discrimination and about people losing access to health care or not taking up tests because of fears of the knock-on implications of test results being used in insurance markets. Governments have, so far, largely sought to restrict the use of genetic information in insurance markets. To date the number of tests available with significant actuarial value is limited. However, this is likely to change, raising more clearly the question as to whether the social costs of adverse selection outweigh the social costs of people not accessing health care for fear of the consequences of test information being used in insurance markets. We have developed an illustrative model to be used as a benchmark for developing other scenarios and for incorporating real data, in order to address the social trade-off between health care impact and insurance market impact of different policies on disclosure and requirement to test.

On the basis of our modelling, the factors that will influence the outcome will include:

- the size of the health effects. A test that identifies a disease with no treatment will only impact on the insurance market and non-disclosure is less likely to be optimal;

- there may be knock-on effects. Whilst a separate policy on disclosure for each test and disease might be most efficient in principle – in practice people may not be trust such a piecemeal policy;
- the size of the deterrents effects of disclosure;
- any cap on the size of policy pay-outs;
- the incidence of the disease;
- the type of insurance, i.e. life, social care, or health care.

Thus, for example, in the case of life insurance, a cap on the size of pay-outs without testing, plus a low incidence of disease may lead to minimal social cost from non disclosure in the insurance market. In this case the risk of losses in the health care system from refusal to test may far outweigh these costs, suggesting a policy of non-disclosure (below a cap) is optimal. In the cases of health insurance and social care insurance, however, for diseases with high treatment or care costs the effects on the market of non-disclosure may be much more significant, making such a policy inefficient from a societal perspective, unless insurers are able to segment the market using different co-insurance rates, or there is an effective risk adjustment mechanism combined with a mandatory requirement to take-out a minimum level of insurance.

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