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Centre for Market and Public Organisation
University of Bristol
Department of Economics
Mary Paley Building
12 Priory Road
Bristol BS8 1TN

Tel: (0117) 954 6943
Fax: (0117) 954 6997
E-mail: cmpo-office@bristol.ac.uk

Acquisition and disclosure of genetic information under alternative policy regimes

Deborah Wilson

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Deborah Wilson [1]

[1] *CMPO, The University of Bristol*

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Abstract

A current policy issue is whether, and if so under what circumstances, insurance companies should be given access to genetic test results. The insurance industry argues for mandatory disclosure in order to avoid problems of adverse selection; genetic interest groups argue for a moratorium or legislation preventing such disclosure; a third option would be a voluntary consent law. The purpose of this paper is to investigate the impact of alternative policies on individuals' incentives to both acquire genetic information and to disclose it to insurers. The theoretical framework used to inform this analysis is provided by the 'games of persuasion' literature, in which one agent tries to influence another agent's decision by selectively withholding her private information regarding quality. The application of the theoretical framework to this policy context yields surprising results. Individuals have the incentive to acquire genetic information and to disclose the test results if disclosure is voluntary. If, however, they are obliged to disclose the results of any genetic tests they have taken, their incentive may be not to acquire such information. I discuss the policy implications of these findings both from the point of view of the insurance industry and from a public health perspective.

Keywords: genetic information, disclosure, insurance

JEL Classification: D8, I1

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Address for Correspondence
Department of Economics
University of Bristol
12 Priory Road
Bristol
BS8 1TN
Carol.Propper@bristol.ac.uk
D.Wilson@bristol.ac.uk

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Acquisition and disclosure of genetic information under alternative policy regimes.

1 Introduction

The number of inherited diseases for which genetic tests are available is increasing at a rapid rate[1]. A current policy issue across Europe and the US is whether, and if so under what circumstances, insurance companies (and/or employers) should be given access to the results of such genetic tests. Despite the range of developments in relation to genetic information and insurance, the question of the appropriate policy response remains open (Godard et al, 2003). Should insurers be allowed to use genetic test results as part of the underwriting process? If so, should disclosure of test results be mandatory or voluntary? Or should regulation prevent any such disclosure? The insurance industry argues for mandatory disclosure, primarily to avoid the problem of adverse selection, while genetic interest groups argue for some form of moratorium or legislation to prevent the use of genetic test results. There is a balance to be found here between the interests of the insurance industry on one hand, and public health concerns plus the maintenance of insurance opportunities on the other.

The purpose of this paper is to investigate what may happen under alternative policy regimes regarding the disclosure and use of genetic information, from the point of view of the incentives for individuals to take a genetic test and disclose the results. The analysis is informed by an application of a theoretical model from the economics of information literature to this policy question. Specifically I consider a model from the games of persuasion literature, in which one agent tries to influence another agent's decision by selectively withholding her private information regarding quality. The results from the application of the theoretical model are surprising: individuals have the incentive to acquire genetic information and to disclose the test results if there is *not* a mandatory disclosure rule in place. If, however, they are obliged to disclose the results of any genetic tests they have taken, their incentive may be not to acquire such information.

These findings have implications for policy, both from the point of view of the insurance industry, and from a public health perspective: a mandatory disclosure rule may create the incentive for individuals *not* to test and therefore *not* to disclose the information. This has particular implications if the genetic condition is treatable, as treatment opportunities will not be exploited if the individual does not take the test. Moreover, the insurance industry's insistence that a mandatory disclosure law is required to prevent adverse selection is misplaced: this analysis suggests that information symmetry could be achieved under a policy of voluntary disclosure.

The rest of the paper is structured as follows. The next section discusses genetic information and the policy context and motivates the use of the specific theoretical framework to inform the debate. Section 3 outlines the intuition behind the model, applying it to the case of acquisition and disclosure of genetic information under alternative policy regimes. Section 4 discusses the results and their applicability under different assumptions. Section 5 concludes.

[1] In November 2004 there were 321 such diseases, representing a 25% increase from the previous year (BBC News Report, 17 November 2004, available from www.bbc.co.uk).

2 Genetic information : issues and current policy

It actually proves difficult to find a precise – and agreed – definition of 'genetic information'. How we conceptualise genetic information and the related term genetic testing will have significant social and policy implications, however (Zimmern, 2001). In their recommendations regarding its use, the European Society of Human Genetics (2003, page S11) use the term genetic information to refer to "information that derives directly from the variation between people [which exists] in their chromosomes or DNA, or information that is being used to infer that a specific genetic variation or genetic influences might be present". The former includes DNA test results and very specific biochemical changes; the latter includes family history and clinical diagnoses.

Macdonald (2004a) discusses some of the complications of drawing up a precise boundary around what can be classified as genetic information, and in particular the overlap between it and family history. While information obtained by directly examining an individual's DNA is clearly genetic, there are many, less clear cut, cases. For example, mutations in the BRCA1 and BRCA2 genes confer a high risk of breast cancer, but account for only a small proportion of cases. So is family history of breast cancer 'genetic information'? Moreover, the relative predictive power of genetic testing and family history will depend on the condition being considered (Zimmern, 2001). While directly obtained DNA-based genetic information may be more predictive for high penetrance inherited disorders such as Huntingdon's disease, the converse is likely to be true for common, complex diseases, such as cardiovascular conditions. Here we need to distinguish monogenic from multifactorial conditions. With the former, mutation in a single gene guarantees onset of the condition and hence a genetic test result is highly predictive. Such conditions are rare, however; in the majority of cases "genes and environment and their complex interaction together give rise to the huge variety of human variation and disease. The singling out of the genetic factor as the most important or significant is entirely unjustified in most instances" (Zimmern, 2001, page 13).

Even within the category of monogenic disorders there is a range of possible outcomes for an asymptomatic individual who receives a positive test result. A mutant gene is not a disease (Godard et al, 2003). There is a range of "patterns of inheritance and expression" which affect the level of risk imposed by the presence of a mutation (Low et al, 1988, page 1633). There may still be a large degree of uncertainly regarding when the individual will contract the disease and, when she does, to what degree of severity or treatability. Evaluation of such risk is of course central to the link between genetics and insurance. In Macdonald's (2003a) terms, while molecular genetics has raced ahead, the related discipline of genetic epidemiology is one of those following in the wake of the laboratory science. Advances in genetic epidemiology, however, are necessary for the development of evidence-based underwriting in relation to insurance contracts involving genetic information, however defined. Neither insurers nor the media should therefore assume that the discovery of a new gene mutation implies the creation of new insurance risk categories (Macdonald et al, 2003a).

The current constraints on evidence-based underwriting with regard to genetic information is one reason why we may consider genetic information as different from other pieces of information in terms of whether insurers should have access to it, at least in the short term. There are several other differences between genetic and 'conventional' health data (Hendriks, 2002, page 87). Genetic information "is not strictly individual but shared familial or collective information, is permanent, can not – given the fact that treatment options are still in

their infancy – be altered and has unprecedented social consequences. It also raises complex questions with respect to [disclosure to] relatives and the right not to know". While some commentators argue that it should be treated no differently from other medical information (see, for example, Pokorski, 1994; 1997), the general consensus is that the differences are substantive enough to necessitate specific attention and policy response (Greely, 1992; Daniels, 1994; Zimmerman, 1998; McGleenan and Wiesing, 2000). Of course, the extent to which genetic information is different, or should be treated differently from 'conventional' health data depends on how it is defined; for example, whether family history information is included within the definition. These concerns are reflected in the range of legislative responses regarding insurer (and employer) access to genetic information.

On 17 February 2005, the US Senate approved "A bill to prohibit discrimination on the basis of genetic information with respect to health insurance and employment"[2]. The bill, which at the time of writing (April 2005) had yet to be approved by the House of Representatives, includes provisions to prevent health insurance premiums being raised or eligibility rules changed on the basis of genetic information, as well as preventing employment or training opportunities being denied an individual as a result of genetic information. Godard et al (2003) provide an overview of current legislative practices across Europe with regard to use of genetic information by insurance companies. Table 1 (page S128) provides a summary of policy responses as of 1 January 2003. There are three general types of policy:

(1) Prohibition of any use of genetic information by insurers outright (Austria, Belgium, Denmark, Estonia, France, Luxembourg, Norway);
(2) Legislation prohibiting its use below a certain amount of coverage (Sweden, the Netherlands, the UK);
(3) Moratoria; which are either indefinite (Finland, Germany), or for a limited number of years (France, Switzerland), or limited to policies which do not surpass a certain value (Sweden, the Netherlands, the UK).

The current UK policy illustrates several of the key issues. In the UK there has been a moratorium on the use of genetic information, agreed by the Government and the Association of British Insurers (ABI), since November 2001, and which was due to run until 2006[3]. In a concordat published in March 2005 this voluntary moratorium has been extended until November 2011, subject to a review in 2008 (Department of Health, 2005). The precise terms of the moratorium are as follows (Department of Health, 2005, page 4):

> "(i) Customers will not be required to disclose the results of predictive genetic tests for policies up to £500,000 of life insurance, or £300,000 for critical illness insurance, or paying annual benefits of £30,000 for income protection insurance (the 'financial limits'). More than 97% of policies issued in 2004 were below these limits in each category.
>
> (ii) When the cumulative value of insurance exceeds the financial limits, insurers may seek information about, and customers must disclose, tests approved by the GAIC for use for a particular insurance product, subject to the restrictions in the Concordat."

[2] http://www.wellcome.ac.uk/en/genome/geneticsandsociety/hg15n031.html (accessed 17/03/05).
[3] The ABI is the trade organisation for Britain's insurance industry. It has over 400 member companies which provide over 97% of the insurance business in the UK (Department of Health, 2005).

The UK moratorium therefore covers three broad classes of insurance, and relates to a narrow definition of genetic information: predictive genetic tests are those which examine the structure of chromosomes or detect abnormal patters in the DNA of specific genes. The principle of disclosure continues to hold for diagnostic and non-genetic medical tests, as well as for all other information relevant to insurance underwriting, including family history. For applications over the financial limits, customers can be asked to disclose the (adverse) results of predictive genetic tests which have been approved by the Genetics and Insurance Committee (GAIC), whose core duty is to evaluate predictive genetic tests with regard to their reliability and relevance to particular types of insurance. Currently, only the test for Huntingdon's Disease has been approved[4]. The GAIC additionally monitors compliance to the moratorium. Individuals can voluntarily choose to disclose favourable predictive genetic test results in order to over-ride family history information. Most insurance companies will take such test results into account, even if it has not been approved by the GAIC, provided it is from a reputable source.

The current UK policy is therefore a voluntary moratorium with regard to a narrow definition of genetic information, limited to policies below a certain value. Even above that value, only externally validated predictive test results may be used in underwriting. The insurance industry is willing to take part in this moratorium because the number of policies affected by non-disclosure of predictive test results is low.

There are various types of moratoria which may be imposed on insurance market(s). Each introduces some form of information asymmetry between customer or enrolee and insurer, the extent of which depends on the precise form of the moratorium. We can distinguish lenient from strict moratoria, where the key difference is in the use – or not – of favourable (negative) test results. Under a lenient moratorium, an insurer is able to use a genetic test result that shows a mutation to be absent in order to charge standard premiums to an individual who has previously been charged higher than standard premiums, usually because of her particular family history (Macdonald, 2004a). A strict moratorium does not allow favourable test results to be used in underwriting. The UK insurance market is therefore currently operating under a lenient moratorium. In Belgium, there is a strict moratorium on both positive and negative test results; while in Sweden neither genetic test results nor family history can be used in underwriting (Macdonald, 2004b).

The moratorium in the UK is now in place until 2011, subject to a review in 2008. It was imposed in order to create the time and space to determine a longer term policy regarding the use – or not – of genetic information by insurers, during a time when the rapid advances in genetic technology were creating public concern that such information may be (mis)used. As Macdonald (2004a, page 1) states:

> "It is taken for granted that geneticists will soon be able to tell us pretty accurately what diseases we will get, and when we will get them; and that insurers will make rather precise use of this information in order to filter out anyone who might be likely to claim under a life or health insurance policy. Both of these ideas are gross exaggerations, but as long as they are believed by large sections of the media and the public, insurance will continue to be seen as a problem".

[4] See http://www.advisorybodies.doh.gov.uk/genetics/gaic/ for more on this.

In fact it is not clear that a permanent moratorium would be sustainable in a competitive insurance market, given that it imposes an information asymmetry between insurer and (potential) enrolee (Rothschild and Stiglitz, 1976). As these authors state in a later paper, the non-existence of equilibrium in this scenario is an indication that "competition does not mix easily with adverse selection and that competitive markets with adverse selection are often unstable" (Rothschild and Stiglitz, 1997, page 78). The key point is that if insurers are unaware of the genetic information possessed by insured individuals, it may not be possible for them to break even on contracts which pool risk across different genotypes, as low risk individuals will not pay the pooled-risk price, leaving an adverse selection of high risk types. The extent to which this is a problem depends on two factors: the proportion of (informed) high risk types in the population; and the price elasticity of market demand of low risk types (Fenn, 2004). Specifically, as either or both of these factors increase, it is more likely that low risk types will not be willing to cross-subsidise high risk individuals under one pooling contract. They will hence drop out, potentially creating an adverse selection spiral under which the contract is unsustainable. The extent to which this is a problem will vary both across genetic conditions and different insurance markets, as well as across different types of moratoria. Godard et al (2003) argue that adverse selection is primarily a problem only for the very small number of single gene, late onset disorders for which there is a predictive genetic test, the result of which could be concealed from the insurer. Macdonald et al (2003a) state that adverse selection presents different problems for the life insurance and critical illness insurance markets, partly due to the greater maturity of the former. While a moratorium on all genetic test results should present a negligible adverse selection cost to the mortgage-related life insurance market in the UK (Macdonald 2003b), the potential impact on small or emerging markets may be of some practical significance (Macdonald et al 2003b). If the definition of genetic information covered under a moratorium is widened, the degree of information asymmetry and hence the cost of adverse selection would be expected to rise. The terms of the moratorium can be altered to lessen any impact of adverse selection; through the imposition of a financial cap for example, as is in place in the UK (Ossa and Towse, 2004).

There is conflicting empirical evidence on the size of the adverse selection problem in practice. Rothschild and Stiglitz (1997) quote evidence from Cutler (1996) that suggests it is a significant issue for the Federal Employees Health Benefits Program in the US. Pauly et al (2003), however, find that the elasticity of demand is sufficiently low so as not to cause such a spiral in life term insurance markets, again in the US. Macdonald (2004a) estimates the costs of adverse selection for several single gene disorders and concludes that, "overall, it is hard to argue that single-gene disorders could lead to adverse selection that would trouble the [insurance] industry much. Therefore any case to be allowed to use this type of genetic information (including family history) rests mainly on the principle of being allowed to underwrite" (page 29).

The principle of being allowed to underwrite is certainly one of the arguments put forward by the insurance industry in the UK. Tyler (2004) argues that genetic information should be included within the principle of "utmost good faith"[5] (essentially, full disclosure) as a matter of fairness; that not allowing genetic information to be used for underwriting discriminates both between genetic and non-genetic risks, but also between identical risks depending on the diagnostic evidence. Insurers do also rely on the costs argument; that maintaining an

[5] The principle of "utmost good faith" means that applicants have a duty to disclose what they know about their own risk profile, and insurers have a duty to explain the nature of the product being applied for (Tyler 2004).

information asymmetry by preventing their access to genetic information will increase costs, which will be reflected in increased prices and more cautious product design (Tyler, 2004).

Not surprisingly, genetic interest groups such as Genewatch[6] argue that the moratorium should at least be continued, if not strengthened to additionally prevent insurers (employers) using family history in their calculation of premiums (employment decisions) (Genewatch, 2001). They argue that the poor predictive capacity of genetic testing means its use in underwriting constitutes discrimination, and that the fear of such discrimination will deter individuals from taking a test and therefore from not benefiting from potential treatment opportunities. This position has also recently found support from the geneticist and Nobel laureate Professor Sir John Sulston, who sits on the Human Genetics Commission and who has proposed legislation to outlaw discrimination (by employers and insurers) on the basis of a person's genetic make-up (Sample, 2004).

Any policy regarding access to genetic test results needs to consider both the insurance industry and the public health perspective, which in turn means addressing the concerns of those who fear an unfair increase in discrimination on the basis of genetic information. In addition, such a policy must be able to deal with the dynamics of a rapidly changing area, in which tests are continually being developed for an increasing number of inherited diseases. I argue therefore that we need to consider the incentives for and impact of both acquisition and disclosure of genetic information under alternative policy regimes.

An analytical framework in which both acquisition and disclosure can be incorporated is provided by the games of persuasion literature. In the next section, therefore, I outline the relevant theoretical models in some detail, before discussing the implications of their predictions in Section 4.

3 Theoretical framework: games of persuasion

In games of persuasion a piece of private information can be proved or verified through the sending of a message. Consider a situation involving a seller of a product and a prospective buyer. The seller has some private information regarding the quality of his/her product and wants the buyer to believe the quality to be high. In a game of persuasion the informed seller attempts to influence the uninformed buyer's decision whether or not to purchase the product by strategically providing or concealing relevant information on its quality. A key assumption of these models is that the information provided by the seller may be precise or vague, but it must be truthful, i.e. the seller can choose to conceal information, but any report s/he does make must be verifiable (equivalently there are sufficient penalties against lying that his/her incentive is to be truthful) (Koessler, 2003). Examples of this theoretical framework in different contexts are provided by Milgrom (1981), Grossman (1981), Milgrom and Roberts (1986).

The central result from these models is that strategic concealing of (non favourable) information does not always work. The intuition behind this result is as follows. The seller wants to convince the buyer that her product is high quality in order to increase demand. Anticipating this strategy, the buyer interprets any vague claim (any information withheld) as revealing that the true quality is at the lowest level consistent with the claim being truthful,

[6] http://www.genewatch.org .

i.e. the buyer adopts a stance of extreme scepticism. The agent's best response to such extreme scepticism is to disclose all relevant information, i.e. to precisely disclose true quality (Matthews and Postlewaite, 1985). The argument behind this fully revealing equilibrium is known as the unravelling argument (Koessler, 2003)[7].

If we place this theoretical framework into the current context, we can consider the relationship between a potential enrolee and an insurer; the enrolee trying to influence the decision of the insurer regarding the premiums to be charged by selectively providing information regarding her genetic make-up, or the results of genetic tests. The enrolee may report or conceal any of these, but is not able to misreport them, i.e. any report she chooses to make must be truthful. This seems a reasonable assumption in the case of genetic test results, which are medically verifiable. One implication is that a voluntary consent law will not be sustainable. Given the unravelling argument above, selective disclosure of only favourable genetic test results will lead insurers to believe that unfavourable results are being withheld. Given this extreme scepticism, the enrolee's best response in equilibrium is full disclosure, thus nullifying the impact of a voluntary consent law[8].

It is not enough to consider the incentives for an individual already in possession of genetic information, however, given the increasing availability of predictive genetic tests. One key issue is the incentive to acquire such information, particularly in those cases in which early detection can lead to effective treatment in an asymptomatic individual. It is necessary, therefore, to extend the theoretical framework by adding an additional stage to the game of persuasion: that of the decision by the enrolee to take the genetic test or not. A model by Matthews and Postlewaite (1985) provides the framework for us to incorporate this extension[9].

Matthews and Postlewaite (1985) model a game of persuasion between a monopoly seller and a buyer. They assume that the seller is not exogenously informed of product quality, but has to decide whether or not to acquire such information. They additionally assume that there is a costless test which will fully reveal quality. As in the one-stage games above, the seller may choose to conceal information, but anything she does reveal must be truthful.

This framework can usefully inform the relationship between enrolee and insurer. Consider that the enrolee is the seller, and the insurer the buyer. The enrolee must decide whether or not to take a genetic test, given that the resulting information on her risk level ("quality") will influence the insurer's decision regarding whether or not to offer insurance, and, more specifically, at what premium. (I return to the impact of the assumption that testing is both costless and fully revealing below). I focus on the case in which it is possible for a (potential) enrolee to test in secret, so that insurers cannot know for sure whether she has information on relevant genetic test results when the contract is signed. As discussed above, the requirement that any information that is revealed must be truthful can be considered a result of the medical verifiability of genetic test results. The enrolee wants insurers to believe that she represents a low risk in order to gain lower premiums.

[7] Koessler (2003) shows that this perfectly revealing equilibrium does not depend on the information structure as long as the informed party is more informed about the pay-off relevant information than the uninformed party.
[8] Tabarrok (1994) arrives at the same conclusion via a different route.
[9] What follows has parallels with the analysis of Doherty and Thistle (1996). See also Shavell (1994).

Matthews and Postlewaite (1985) derive the outcome of the game under two alternative policy regimes: no disclosure regulation (i.e. a voluntary consent law), and mandatory disclosure. In each case, the enrolee has two decisions to make. First, whether to take the genetic test; and second, whether to conceal the result.

Consider first the case when there is no effective disclosure regulation. Given the assumption that the enrolee may be vague but must be truthful, there are two instances in which she can report ignorance of her genetic status: if she has not taken a test, or if she has done so, but is concealing the results. The insurer cannot distinguish between these two cases. As in the one-stage game outlined above, the insurer's best response is to adopt a stance of extreme scepticism: given that the insurer knows the enrolee has access to genetic testing, a report of ignorance leads the insurer to believe that the risk level is the highest possible, even when it is not. In essence, the enrolee's report of ignorance is not credible, as the insurer knows she has access to genetic testing and therefore that such a report may be hiding a non favourable test result. The enrolee's response to such scepticism is both to acquire the information, i.e. to take the genetic test, and to fully disclose the results to the insurer. Again, therefore, there is a fully revealing equilibrium when we add an additional stage to the game.

So in the absence of disclosure regulation (but in the presence of a truthful revelation mechanism such as medical verifiability) the equilibrium outcome is that the enrolee will both take the genetic test and disclose its results, thus nullifying the impact of a voluntary consent law.

Now consider the case in which effective disclosure regulation is in place, such that individuals are obliged to fully disclose the results of any tests taken. Given such legislation, an announcement of ignorance must mean that the enrolee has not taken any tests. Effective disclosure rules dispel insurer scepticism over statements of ignorance, hence the enrolee is not forced to take a test in order to dispel such scepticism. In this case, therefore, the enrolee will acquire the information and disclose the results only when she prefers the insurer to be informed. Mandatory disclosure rules are exactly what enrolees that can choose to acquire information should want (Matthews and Postlewaite, 1985, page 334).

Under disclosure regulation, therefore, the enrolee may optimally choose not to acquire genetic information. An "ignorant" symmetric information equilibrium may therefore result, with neither enrolee nor insurer having genetic information which may be relevant to premiums. This also has public health implications, which I discuss further below. According to this analysis, it is not the case that disclosure regulation leads to a fully informative symmetric information equilibrium. Indeed, as Matthews and Postlewaite (1985, page 334) state: "Since without disclosure rules the [enrolee] will test and disclose, any change caused by a disclosure rule will be just the opposite of its intent".

4 Implications of alternative policy regimes

Let us first summarise what we may expect to happen regarding both acquisition and disclosure of genetic information under the three alternative policy regimes, highlighting the implications both from an insurance market and a public health perspective. I then discuss the impact of relaxing some of the assumptions underlying the theoretical model.

Consider first a moratorium on the use of genetic test results in underwriting. Individuals are able to acquire genetic information as they choose, given that insurers are not able to gain access to any such test results. Both treatment and insurance opportunities are maintained for individuals, but there is a loss in efficiency for the insurance market resulting from the imposed information asymmetry. As discussed above, the precise cost of this adverse selection may depend on the genetic condition and/or the market being considered, as well as on the form of moratorium and definition of genetic information employed.

Second, consider a system of voluntary disclosure, in which it is left to the individual whether or not to disclose genetic test results to her insurer. According to the theoretical framework outlined above, in this case the individual will have the incentive both to acquire and to disclose all relevant genetic test results to the insurer. Treatment opportunities are thus maintained, although potentially at the cost of a reduction in insurance opportunities for those with non-favourable genetic test results which result in higher premiums. An efficient insurance market with full information results, with risk discrimination according to (geno)type. According to this analysis, therefore, the concerns of the insurance industry regarding the potential for adverse selection under such a consent law are misplaced.

Finally, consider a system of mandatory disclosure, in which the results of any test must be disclosed to the insurer. An individual will only acquire genetic information if she prefers that the insurer is informed. If she does prefer the insurer to be informed, then the outcome is the same as under voluntary disclosure. If she does not, however, she will not acquire the information, resulting in an "ignorant" symmetric information equilibrium, in which insurance opportunities are maintained, but treatment opportunities are not exploited. In either case the insurance market will not suffer from adverse selection[10].

A mandatory disclosure law does not guarantee a full information equilbrium, therefore, once we incorporate the decision of an individual whether or not to take a genetic test. Indeed, full disclosure is only guaranteed under a regime of voluntary disclosure, contrary to the arguments put forward by the insurance industry. Central to these results is the issue of the credibility of ignorance. In this framework, enrolees acquire and disclose the information under voluntary disclosure because a report of ignorance is not credible: insurers know enrolees have access to genetic test results and take a report of ignorance as a signal of high risk. A mandatory disclosure law means that such a report can be taken as credible, thus getting rid of the incentive to acquire information simply to dispel insurer scepticism.

Matthews and Postlewaite (1985) also discuss other situations in which ignorance is credible, and thus in which enrolees may not take a genetic test. These are:

(i) if the insurer can observe whether or not the test has been carried out;
(ii) if testing or disclosure is costly;
(iii) if testing reveals no information with positive probability.

Essentially these represent a relaxing of three of the assumptions underlying their model: that enrolees can test in secret; that there is no cost to testing or disclosure; that the test determines true quality. The first situation seems fairly self-explanatory and I will not discuss it further here. It is worth considering the impact of (ii) and (iii) in the context of genetic

[10] Which case pertains depends to some degree on the extent to which insurance companies are able to credibly offer different contractual terms on the basis of their expectation of genetic test results.

information, however, as when these conditions hold the individual may have the incentive neither to acquire nor disclose genetic information, resulting in an "ignorant" symmetric information equilibrium as described above.

So if testing or disclosure is costly, announcements of ignorance are credible. In the genetic context, it is the psychological costs of testing which may be particularly relevant, given the implications of a positive test for family members as well as for the individual, especially in those cases in which the condition being tested for is currently untreatable. Additional costs may result from the perceived threat of discrimination, as discussed above. While both of these are hard to quantify, neither should be underestimated.

Ignorance is also credible if the test reveals no information with positive probability. We need to be clear of what this means in the genetic information context. A genetic test does provide precise information on the presence or not of a malfunctioning gene. A separate point is the extent to which this information can be used in underwriting: as discussed earlier, molecular genetics has raced ahead of genetic epidemiology (Macdonald 2003a). Insurers know that a genetic test does provide sharp information, even though such information may not be translatable into sharp predictions of future risk[11]. This third situation in which ignorance is credible does not hold, therefore, in the genetic information context.

So ignorance is credible, and hence individuals may choose not to acquire genetic information, if there is effective disclosure regulation in place, and/or if the costs of testing are sufficiently high. Under a mandatory disclosure regime, individuals will only test and disclose if they prefer (net of testing costs) to have informed rather than uninformed insurers.

There is one further implication of these results. In the above framework individuals have the incentive to acquire and disclose even unfavourable test results under a regime of voluntary disclosure. This links to the analysis of Macdonald (2004a; b) who discusses specific situations where disclosing unfavourable test results may actually be beneficial to an individual in terms of a reduction in premiums. Consider that there is a moratorium in place, under which family history can be used in underwriting premiums, as is currently the case in the UK. He provides the anomalous comparison of an individual aged 30 with a family history of Huntingdon's Disease, who would actually pay a higher premium than an individual of the same age who is known to be a mutation carrier of the relevant gene with 40 CAG repeats, which indicates that the individual is high risk[12]. In this case (and there are similar cases with regard to other genetic conditions) it would be to the advantage of the latter individual to disclose his positive result to his insurer. While this is consistent with a lenient moratorium (in which favourable results can be used to obtain standard premiums), it is actually a non-favourable result that would be being used to reduce premiums. The wider point that Macdonald makes is that the variability of genetic disorders means that not all positive test results are adverse, relative to family history alone. This has implications for the sustainability of a moratorium under which family history can be used in underwriting.

So both under a lenient moratorium which allows the use of family history, and under a voluntary consent law, an individual may have the incentive to acquire and disclose even unfavourable test results. As Macdonald (2004a) discusses, underlying such an incentive is an

[11] Of course, this lack of precision in prediction of risk provides a separate argument for the continuation of the moratorium.

[12] The number of CAG repeats is strongly correlated with the age at onset of the disease; see Macdonald (2004b) for a summary of the mechanism of Huntingdon's Disease.

implied demand for a genetic test: if a test result would change an underwriting decision, is that an implied demand? And what are the consequences of such an implied demand? The fact that these two policy options may put pressure on individuals to take a genetic test may add weight to arguments for either a stronger moratorium – one that doesn't allow the use of family history – or a system of mandatory disclosure, where, in the analytical framework employed here, individuals are able to decide whether or not to acquire the information, depending on whether they prefer (net of testing costs) for their insurer to be informed.

5 Conclusion

There is ongoing debate regarding whether or not insurers should be given access to genetic test results. This paper has investigated the impact of alternative policies regarding such access on the incentives of individuals to both acquire and disclose genetic information, and the potential impact of the resulting information structure from both an insurance industry and a public health perspective. The analysis is informed by an application of a theoretical model from the games of persuasion literature to this specific policy context.

A moratorium maintains both treatment and insurance opportunities for individuals, but imposes adverse selection costs on the insurance industry. A voluntary consent law is not sustainable: the non-credibility of a statement of ignorance creates the incentive to acquire and disclose genetic test results. Treatment opportunities are maintained and there is no adverse selection, but insurance opportunities may be reduced for those with positive test results. A system of mandatory disclosure also prevents adverse selection, but potentially at the cost of a reduction of treatment opportunities for those who prefer, net of treatment costs, for their insurer to be uninformed and who therefore choose not to acquire the information. Mandatory disclosure regulation does not guarantee a full information equilibrium.

Any policy on access to genetic information needs to balance the interests of the insurance industry with public health concerns that any treatment opportunities afforded by early testing should be exploited. A key question therefore is the magnitude of the costs caused by adverse selection. More empirical evidence is required on the impact of such information asymmetry on different insurance markets and with respect to different genetic conditions. If such costs are sufficiently low that they can be absorbed by insurers while maintaining a stable competitive insurance market, the argument for mandatory disclosure from the insurance industry rests on a notion of fairness between genetic and other familial or inherited risk. Such a notion of fairness can, however, be equally used to argue the opposite case, that a moratorium should not be lifted but should be strengthened to include preventing insurers from using family history in writing premiums. Such a moratorium maintains both treatment and insurance opportunities, without creating an implied demand for genetic testing. The current lack of precision regarding the link between a positive test result and a prediction of risk, for even single-gene disorders, reinforces this argument. The stronger the moratorium, however, the greater the potential adverse selection costs and hence the higher likelihood of instability in at least some insurance markets. Again we need evidence on the size of these costs. Given that the analysis in this paper challenges the insurance industry's arguments on the necessity of mandatory disclosure regulation to achieve a full information equilibrium, however, there may need to be particularly strong evidence of unsustainably high adverse selection costs in order for there to be a strong argument for such a moratorium to be lifted.

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