

After the moratorium? Acquisition and disclosure of genetic information under alternative policy regimes.

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Abstract

There is currently a moratorium on the use of genetic information in the underwriting process for both health and life insurance. This moratorium is in place until 2006 and subsequent policy regarding insurers' access to genetic information is the subject of ongoing debate. The insurance industry argues for a mandatory disclosure rule in order to avoid problems of adverse selection; genetic interest groups argue for a continuation of the moratorium; a third option would be a voluntary consent law. The purpose of this paper is to investigate the impact of alternative disclosure 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.

After the moratorium? Acquisition and disclosure of genetic information under alternative policy regimes.

1 Introduction

There are currently 321 inherited diseases for which genetic tests are available. This represents a 25% increase in the past year¹. In the UK there is a moratorium in place on the use of genetic test results by insurance companies in their calculation of an individual's premiums. The moratorium is due to run until 2006. There is an ongoing debate regarding what policy should be implemented after that date. Should the moratorium be continued? If so, in its present form? Or 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? The insurance industry argues for mandatory disclosure, primarily to avoid the problem of adverse selection, while genetic interest groups argue for a continuation of the moratorium. 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 we may expect to 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 According to a BBC News Report on 17.11.04, available from www.bbc.co.uk.

2 Genetic information : issues and current policy

It is first important to be clear about what precisely is meant by the term ‘genetic information’. Williams and Clow (1999, page 12) distinguish genomics from genetics. Genomics is “the study of the genome as a whole – the sequence of DNA nucleotides in the cell and how this provides the information for the cell to function and reproduce itself”. Genetics is “the study of individual genes and their roles in cell functioning and reproduction”. They continue, “[m]utations in specific genes often produce, or contribute to, diseases, thus defining the disease as a ‘genetic disease’. Therefore, genetic research can be considered as a category (perhaps the most critical category) of genomic research”.

Macdonald (2004a) discusses some of the complications of drawing up a precise boundary around what can be classified as genetic information. 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’? The picture becomes more complicated when we consider more complex, multifactorial, conditions, in which several genes, behaviour and/or the environment may play a part. In these cases, to what extent is familial clustering genetic information?

Even if we consider the term genetic information in a narrow sense, meaning the results of a genetic test which detects the presence of a genetic marker in an asymptomatic individual, there is a range of “patterns of inheritance and expression” which affects the level of risk imposed by the presence of such a gene (Low et al 1998, page 1633). Even within the category of single gene disorders, where mutation in a single gene guarantees onset of the condition, there is a range of possible outcomes for an asymptomatic individual. There may still be a large degree of uncertainty regarding when she will contract the disease and, when she does, to what degree of severity or treatability. The link between the presence of a mutation and the consequences in terms of risk are not well established for the majority of conditions. This 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.

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 the disclose [sic] of 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). This is reflected in the current policy debates on whether insurers should be given access to an individual’s genetic information.

So what is the current UK policy emphasis regarding this question? Here I will concentrate on the regulation of the life and health insurance markets. In the UK there is a moratorium on the use of genetic test results, agreed by the Government and the Association of British Insurers (ABI), which is in place until 2006². The moratorium applies to life insurance policies up to £500,000 and critical illness, long term care insurance and income protection up to £300,000. Over these limits, the insurance industry may only use the results of genetic tests which have been approved by the Genetics and Insurance Committee (GAIC). Currently only the test for Huntington's Disease has been approved (see <http://www.advisorybodies.doh.gov.uk/genetics/gaic/> for more on this). The GAIC additionally monitors compliance to the moratorium, following complaints that previous self-regulation by the insurance industry has not been sufficient (Kmietowicz 2001). It is recognised, however, that this moratorium is not a permanent solution; rather it provides the space and time to develop a longer term policy. The UK emphasis on both treating genetic information as a subset of health information and on preventing its use by the insurance industry is mirrored in other European countries as well as in the US (where legislation additionally covers employers' access to genetic data): see Rosen (1999), Josefson (2000) and Hendriks (2002) for more discussion on this.

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 strict from lenient moratoria. 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 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)³.

The moratorium in the UK is in place until 2006. 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 (2004, 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”.

² The ABI is the trade organisation which represents approximately 95% of the British insurance industry. Wilson (2001) provides an account of the steps which led to the current UK policy position.

³ Information on other countries' policies can be found in Genewatch (2001).

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) enrollee (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. 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 current debate regarding what UK policy should be after the current moratorium is lifted in 2006. Tyler (2004) argues that genetic information should be included within the principle of “utmost good faith”⁴ (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 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 (<http://www.genewatch.org>) 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

⁴ 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).

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, 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)⁵.

⁵ 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.

If we place this theoretical framework into the current context, we can consider the relationship between a potential enrollee and an insurer; the enrollee 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 enrollee 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 enrollee's best response in equilibrium is full disclosure, thus nullifying the impact of a voluntary consent law⁶.

It is not enough to consider the incentives for an individual already in possession of genetic information, however. 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 enrollee to take the genetic test or not. A model by Matthews and Postlewaite (1985) provides the framework for us to incorporate this extension⁷.

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.

I argue that this framework can usefully inform the relationship between enrollee and insurer. Consider that the enrollee is the seller, and the insurer the buyer. The enrollee 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 will 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) enrollee to test in secret, so that insurers cannot know for sure whether she has information on her genetic risk status 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 enrollee wants insurers to believe that she represents a low risk in order to gain lower premiums.

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 enrollee has two decisions to make. First, whether to take the genetic test; and second, whether to conceal the result.

⁶ Tabarrok (1994) arrives at the same conclusion via a different route.

⁷ What follows has parallels with the analysis of Doherty and Thistle (1996).

Consider first the case when there is no effective disclosure regulation. Given the assumption that the enrollee 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 enrollee 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 enrollee'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 enrollee'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 enrollee will both take the genetic test and disclose its results, thus nullifying the impact of a voluntary consent law. According to this analysis, therefore, the concerns of the insurance industry regarding the potential for adverse selection under such a consent law are misplaced.

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 enrollee has not taken any tests. Effective disclosure rules dispel insurer scepticism over statements of ignorance, hence the enrollee is not forced to take a test in order to dispel such scepticism. In this case, therefore, the enrollee will acquire the information and disclose the results only when she prefers the insurer to be informed. As Matthews and Postlewaite (1985, page 334) state, mandatory disclosure rules are exactly what enrollees that can choose to acquire information should want.

Under disclosure regulation, therefore, the enrollee may optimally choose not to acquire genetic information. An "ignorant" symmetric information equilibrium may therefore result, with neither enrollee 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 [enrollee] 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. 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 the moratorium imposed.

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. This is contrary to the beliefs of the insurance industry regarding what would happen under such a voluntary consent law.

Finally, consider a system of mandatory disclosure, in which the results of any test must be disclosed to the insurer. Again according to the framework provided by the games of persuasion literature, 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.

A mandatory disclosure law does not guarantee a full information equilibrium, 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 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. Of course, 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. This does not seem so relevant in the genetic information context. A genetic test provides precise information on the presence or not of a malfunctioning gene. A separate point, however, is the precision of the prediction regarding future risk status following a positive test result. The link between information and prediction is not precise, even in the simplest cases of single gene disorders (Macdonald 2004a). So I would argue that ignorance is not credible in this instance: insurers know that a genetic test provides sharp information, even though such information may not be translatable (by insurers, actuaries, medics) into sharp predictions of future risk⁸.

So ignorance is credible, and hence individuals may not choose 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 that I want to discuss. 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. 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 risk⁹. 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

⁸ Of course, this lack of precision in prediction of risk provides a separate argument for the continuation of the moratorium.

⁹ 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.

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 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. The purpose of this paper has been to investigate 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.

So what should happen after the moratorium ends in 2006? Any policy 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 the 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 return to the need for 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 the moratorium to be lifted.

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