Why disclosure of genetic tests for health insurance should be voluntary

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Whether the disclosure of genetic (and non-genetic) information should be mandatory or prohibited is of pressing policy concern. At present there are two opposing camps – the insurance industry argues for mandatory disclosure to avoid problems of adverse selection, and genetic interest groups argue for legislation preventing such disclosure on the grounds of discrimination and that mandatory disclosure would lead people not to have tests, and therefore not benefit from potentially beneficial treatments. Policy has to balance both of these sides of the debate, as reducing adverse selection and encouraging maximum take-up of tests are both important for public health. In this paper we outline why voluntary disclosure is optimal, and that allowing people to decide whether or not to disclose the results of a test actually creates the incentive to both seek the test and to disclose the results, which both reduces the potential for adverse selection and increases the incentives to undergo relevant tests.

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Introduction

The disclosure of genetic test results – and the associated issue of patients wishing to undergo these tests – is of pressing policy concern in many countries. For instance, in the USA, although individual States have their own legislation pertaining to genetic testing, all place severe restrictions on insurance companies using genetic tests to set premiums (1). Similarly, European countries largely follow the European Union directive that genetic information should not be used to ‘discriminate’ (2).

At present in the UK there is a voluntary code of practice, by which insurance companies cannot compel disclosure of a genetic test result (3). This was due to expire in 2006, but in March 2005 was extended until November 2011; subject to review in 2008 (4). This prevarication indicates some equivocation in the mind of government over policy in this area, but a decision needs to be made before advances in genetic testing create moral hazards (5).

The authors have previously suggested that genetic testing should be treated on an equal basis with non-genetic testing and information (6). However, whether the disclosure of genetic and non-genetic information should be mandatory or prohibited was not addressed at that time, and so it is to this issue that we now turn.

Current standpoints on mandatory disclosure

There are, broadly speaking, two opposing camps in this debate. First, the insurance industry argues for mandatory disclosure to avoid problems of adverse selection. Their concern is that a restriction on disclosure creates information asymmetry between the potential insuree and insurer (7). This creates an unstable market; if insurers are unaware of the (genetic) information the insuree holds it may not be
possible for them to operate risk pooling required for a mutuality-based system (6). That is, those at low risk will not pay the higher pooled-risk price, leaving an ‘adverse selection’ of high risk people. As the low-risk population drop out of the market, the problem of a shortfall of premiums over payout will exacerbate the problem until the market collapses (of course, markets seldom collapse, insurance companies simply withdraw from the market, with effectively the same result) (3). It is therefore important to the entire population to ensure that adverse selection does not occur (to an unmanageable extent).

Second, the genetic interest groups (such as Genewatch (8)) argue for legislation preventing such disclosure on the grounds of discrimination, and the wider public health argument that mandatory disclosure would lead people not to have tests and therefore not benefit from potentially beneficial treatments.

Clearly policy will have to balance both of these sides of the debate, as minimizing adverse section (and hence ensuring coverage) and ensuring adequate take-up of tests are both important to public health (9). In this respect we suggest here that voluntary disclosure is optimal. Allowing people to decide whether or not to disclose the results of a test actually creates the incentive to both seek the test and to disclose the results, which both reduces the potential for adverse section and increases the incentives to undergo relevant tests.

**Why it pays to be open and honest**

In any market there is a flow of information between buyer and seller. Crucially, to be relevant to the decision-making process of buyer and seller this information must be verifiable (10). This is easily seen if we consider buying a car. Here the
information asymmetry is with the seller, who knows more about the car than the potential buyer. The seller of the car wants the potential buyer to believe that the car is worth buying at the price he wants. He therefore tries to convince the potential buyer by selectively providing information concerning the car's speed, fuel consumption, service history and other features. Although the seller can ‘spin’ this information by selectively providing or withholding it, or by being precise or vague, that it is something which can be confirmed externally means that it will be ‘true’.

What is interesting from market analysis is that withholding non-favourable information is not always the optimal strategy. Again, this has intuitive appeal in our car market example. The car seller wants to convince the potential buyer that the car is ‘worth’ the asking price, and therefore of at least equal quality to alternative cars available. However, the potential buyer knows that this is what the seller is seeking to do and so approaches the negotiation with scepticism. It is this scepticism that is the key to the market functioning optimally, such that any information that is withheld or presented in a vague manner is assumed to suggest the worst; that the seller is not forthcoming with a precise odometer reading must mean that the car has been ‘clocked’. The seller’s optimal strategy is actually, therefore, to disclose all relevant information.

We can easily translate this into the insurance market context (11). Here the information asymmetry is with the potential insuree, who knows more about their likely risk than the insurer. Thus, the insuree seeks to secure the lowest possible premium by selectively revealing information to present themselves in the ‘best’ light (i.e. as having a low risk). As family and medical history is externally verifiable, the potential insuree cannot be dishonest, but may select what is reported and may be
more or less vague. Such selective disclosure will, following the argument above, not be optimal concerning genetic tests, as insurers will assume that no test result means that unfavourable results may be being withheld. In this case, the potential insuree’s optimal strategy is full disclosure – they will be no worse off disclosing the most adverse result possible, and can only be better off disclosing any other result. Importantly, this is an equivalent incentive both to disclose the results of tests that have been undertaken and to undergo tests that have a bearing on the decision of the insurer concerning coverage.

Thus, in the case where there is no mandatory requirement for disclosure, the potential insuree may not reveal information resulting from a test for one of two reasons: they are deliberately withholding the information or they do not have the information because they have not undertaken the test. Crucially, the potential insurer cannot distinguish between these two reasons and will thus adopt a sceptical view that assumes that the individual is simply withholding the information and must be doing so because they are at high risk, regardless of whether this is actually the case. In this case the insurer will choose not to insure the individual. The incentive for the potential insuree is therefore the seek to have the test, and disclose the result, as this will not make them worse off (any adverse result will simply confirm the position adopted by the potential insurer) but could make them better off (if the result shows their risk status to be lower than the worst case assumed by the insurer in the absence of any test result).

**Why mandatory testing will reduce public health**

Alternatively, if it is mandatory to disclose such information a potential insurer knows that where a potential insuree does not disclose a test result this must mean that they
have not taken the test. This means that the potential insurer does not have to be sceptical at the potential insurees lack of information. However, the optimal strategy under this system is for the potential insuree to choose not to acquire test results. Although this will result in an equilibrium situation, it is not an informed equilibrium, but an uninformed equilibrium (there is no asymmetric information as neither party is more informed in this respect than the other). The implication of this is that this equilibrium will be at a point where the overall level of societal welfare (population health) is reduced compared to the voluntary disclosure equilibrium above.

**Why legislating against disclosure will also reduce public health**

The alternative view at present to mandatory disclosure is, however, not a voluntary system, but rather a system where results are, generally, not to be disclosed by insuree or used by insurer. There are instances where people can voluntarily disclose favourable test results, typically where they militate against a negative family history, and the insurer may use this information to reduce premiums, but this is not widespread practice. Crucially, however, this creates the information asymmetry mentioned above, such that insurees are potentially better informed than insurers (they have the results of a test). That people may undergo genetic tests in this case maintains treatment, and insurance, opportunities for them, but there is an efficiency loss resulting from the imposed information asymmetry; the ‘uninformed equilibrium’ mentioned above.

**Conclusion: why voluntary disclosure is the answer**

In practice, tests are generally carried out on individuals with a family history of a condition involving a significant genetic component, and/or where there is a curative or preventative intervention to ameliorate it; such as Huntingdon’s or Parkinson’s
Disease, or cancers of the breast, ovary or colon (12,13,14,15). These tests may be used for lifestyle planning by the individual or to help manage the condition, such as regular colonoscopies for those having mutations associated with colon cancer.

Taking the example of breast cancer, mutations in BRCA1 and BRCA2 genes increase the risk of breast (and ovarian) cancer (14). Current recommendations from the National Institute of Health and Clinical Excellence are that women should test for these gene mutations if they are at high risk due to familial or medical history, as the test defines the risk more accurately (16). Those testing positive may receive more frequent and regular breast cancer screening, undergo surgery or join preventive trials (e.g. of Tamoxifen). Thus, a woman with a strong family history of breast cancer currently faces a decision whether to: (i) have the test; and (ii) disclose the results.

Under a system of mandatory disclosure, the incentive would be for the woman not to have the test, in case the test confirms their risk (as this will lead to a higher premium). The woman is then disadvantaged in not seeking appropriate care, should the test have been positive. The health service/society similarly suffers from any care being postponed until symptoms develop and care is correspondingly more expensive. The insurance company is also disadvantaged, as are other insurees, as no remedial treatment means a sooner or larger eventual payout on the policy.

Under a system of nondisclosure, the woman may have the incentive to have the test, but not to inform the insurance company. However, this current system of legislation, whilst maintaining treatment and insurance opportunities for the woman, clearly promotes adverse selection. This poses a threat to the long-term viability of insurance markets – especially as genetic tests become more widespread and sophisticated – and
may lead to market collapse, not only disadvantaging those who are now no longer able to obtain this insurance, but also, of course, the woman concerned.

Neither system will thus encourage a full-information equilibrium. Only with voluntary disclosure is the woman’s incentive to both have the test and report the result. Consider her alternatives. If she does not have the test, she cannot receive any lower premium if the test result would have been negative and, further, cannot have appropriate care if the result would have been positive – this disadvantages her, the health care system, society and the insurance company. The incentive is thus to have the test. If the result of the test is negative, then her premium will be reduced from that solely based on her family history and she will be better off. If the test is positive, her premium would be no higher than the ‘worst case’ assumption based on her family history, but she would be better off from seeking appropriate care. Yet, further, the health care system and society would be better off from this earlier treatment, and so would the insurance company. Importantly, no one loses from this situation, and everyone may gain.
References


