Should genetic information be disclosed to insurers?

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YES The main argument for disclosing genetic information to insurers is that there are no good reasons for not disclosing it. If we accept that life or health insurers can legitimately seek and obtain other kinds of health information that predicts insurance risk, then we should also accept that they can seek genetic information that is predictive in the same way. There is no reason for treating genetic information differently.

What is the purpose of insurance?

The main purpose of life or health insurance is to spread the costs of expensive but unpredictable events across the pool of the insured, thereby converting a possibly catastrophic loss to a predictable regular expenditure. The actuarially fair price is the price that adequately reflects my risk plus the administration costs. This is, for instance, the reason that the price of car insurance reflects the value and type of the car, the age and sex of the driver, and the postcode of the owner, since all of these predict the chance of theft or damage and the cost of the potential loss.

In life insurance the actuarially fair price is the price that accurately reflects my likelihood of dying within the insured period and the amount I am insured for. Because my personal risk cannot be estimated with precision, insurers set premiums for groups of people with broadly similar risks.

Genetic information is not special. It is not inherently more specific, predictive, sensitive, or private than other kinds of health information

What information should insurers be allowed?

We could have a system for life and health insurance that denied insurers access to any kind of health information. This would mean that they could differentiate premiums only according to very general risk markers (age, sex, place of residence, occupation, etc). If we think that life or health insurance is a basic social good that is essential for citizens in modern societies, such a system is attractive. It will mean that healthy people subsidise unhealthy people, but that may be acceptable as an expression of social solidarity or equality. If we choose to have such a system, or a hybrid system where you can get basic insurance without surrendering any health information but have to give this information for more extensive policies (along the lines of the current UK policy on genetic information[1]), we choose it not because health information is special but because we think that justice or solidarity demands risk sharing between healthy and unhealthy people.

If, however, we allow insurers to obtain some kinds of health information (body mass index, cholesterol concentration, results of a physical examination, etc) we no longer have any principled reasons for excluding genetic information. Genetic information is not special. It is not inherently more specific, predictive, sensitive, or private than other kinds of health information.[2]

It is also extremely difficult to define what counts as genetic information. Genetic information can be obtained without anything we would usually classify as a genetic test (is taking a family history a genetic test?). The most common genetic test is probably routine blood typing in hospitals, but does that mean that knowledge of my blood type is one of the pieces of knowledge that an insurer may not seek?

We may have good reasons to allow insurers access only to information that is properly validated and for which there is sufficient evidence that it predicts risk, but this is again a consideration that applies across the whole range of health information. It is true that many so called genetic risk factors are not well validated, but the same is true of other risk factors measured by non-genetic means.

Other considerations

It is often argued that if we allow insurers access to genetic information it will deter people from having genetic tests that are relevant to their health care. This may well be true, but the same is true for other health information (similar discussions were had about HIV testing) and it does not provide a reason to treat genetic information differently.

Another worry is that insurers may not interpret genetic information correctly and deny people insurance or levy inappropriate premiums based on faulty calculations of risk.[3] This is again an obvious risk but is no reason to single out genetic information. Genetic information is not more inferentially fertile than any other kind of information and not more liable to misinterpretation. Again the earlier debates about HIV are instructive. It was claimed, probably correctly, that residence as a single man in certain areas of major cities was interpreted as a risk factor for homosexuality and HIV infection. Even if the only information we allowed insurers was the name of the person seeking insurance, surely a rather restrictive requirement, sound (but not necessarily true) probabilistic inferences could be made concerning age, sex, ethnicity, social status, etc.[4 5] Because so many kinds of information can be interpreted wrongly or in discriminatory ways a better solution to the problem is to allow people to challenge decisions to deny coverage for life or health insurance, forcing insurers to make their reasoning transparent.

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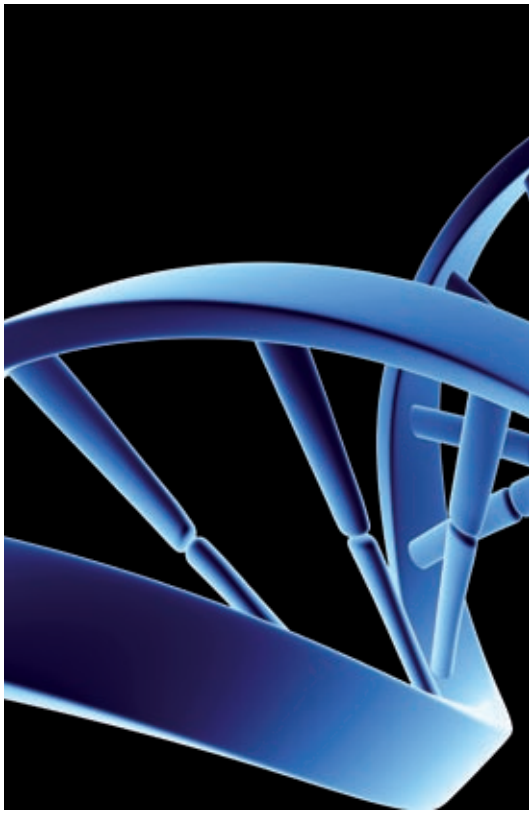
References are in the full version on bmj.com



UK insurers have said that they may seek approval to use the results of genetic tests for cancer from next year. **Søren Holm** believes they should have to pass the results on to insurance companies, but **Richard Ashcroft** argues that the risks of disclosure justify privacy in most cases

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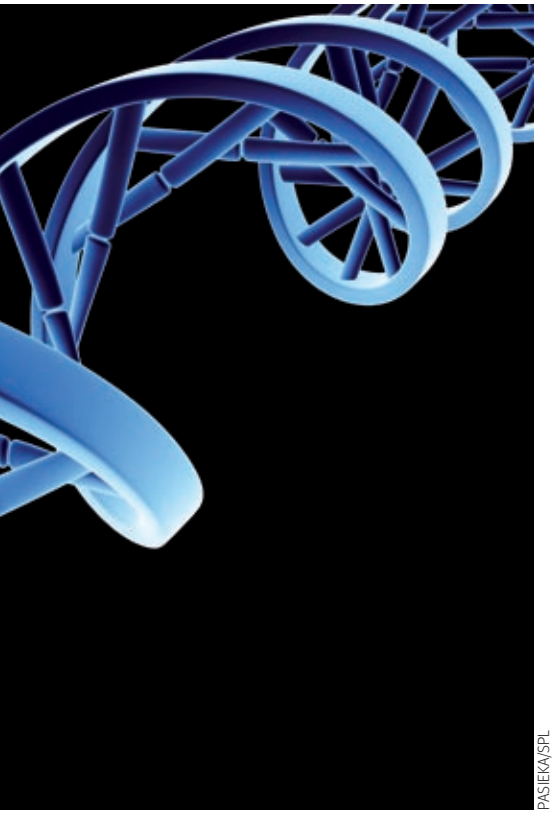
NO A strong case can be made for requiring people who have had genetic tests to disclose that fact to insurers when they purchase life, critical illness, or health insurance policies. There are essentially three arguments for this position: that genetic information is not essentially different from other kinds of health information, that non-compulsory insurance depends on full and truthful disclosure by the applicant to protect the integrity of insurance underwriting and risk pooling, and that because insurance is a private arrangement between freely contracting parties, each party is entitled to set the terms of the contract in negotiation.

I would accept all of this. Indeed, it is the consensus in both the academic and the policy literature that under ideal conditions we have no reason to treat genetic information differently from any other kind of health information.[1] Nevertheless, most jurisdictions do impose restrictions on insurers' power to request and use genetic test information, and I think this is justified.[2]



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Risk of discrimination

The central issue here is unfair discrimination. Two forms of unfair discrimination should concern us. Firstly, we have the irrational discrimination that arises from false beliefs about genetic information. The insurance industry has occasionally been guilty of this sort of discrimination, and there have been important controversies about insurance sales, underwriting, and management of claims in HIV and, subsequently, in relation to genetic information.[3-5]

The moratorium on use of genetic test information can be justified on the grounds of protection from irrational discrimination

As with the use and abuse of genetic information in employment, it is important to note how genetic information can be misunderstood, or its importance overestimated, and therefore used in discriminatory ways that would not be justified on sound actuarial grounds.[6] For instance, if a woman were to test positive for a mutation in the BRCA1 gene, a naive insurance salesperson might think that she represented a poor risk for life insurance, even though the actuarial advice might be that this made little difference to her life expectancy.[7] The point is sometimes neglected in the defence of "freedom to underwrite" that what is theoretically justified may be undermined by the less than perfect behaviour of people working under pressure. The moratorium on use of genetic test information apart from in carefully regulated exceptions may not be justified on actuarial grounds, but it can be justified on the grounds of protecting consumers from irrational discrimination.

Social justice

The second form of discrimination is more troubling. Use of complete information (including genetic information) in underwriting could lead to a situation that is actuarially fair but socially unfair.[8 9] Actuaries are, reasonably enough, concerned that if they are barred from using genetic test information they will misprice risks. The result could be that the premiums collected would not cover the payments made and, in particular, that people would have an incentive to buy policies to cover risks known to them but unknown to the insurer (adverse selection). This could potentially lead to the collapse of life insurance companies, or even the industry itself. Not only would this be unfortunate for the insurance companies it would arguably be unfair to the other consumers of insurance products, who would be paying higher premiums to subsidise people whose policies were artificially cheap and, in the worst case, would not receive pay-outs they were due because the insurer was insolvent (although because of reinsurance this is unlikely).

All of this is true and important, and actuarial fairness therefore matters morally as well as commercially. But it is not the whole of fairness. If the point of insurance is to cover the costs of ill luck, the only sort of ill luck you could not insure against would be the misfortune to have a late onset serious genetic disorder.[10] Arguably such people would need insurance more than most yet would be less able than most to get it. There are various ways around this—for instance, ensuring adequate welfare state support or making some insurance compulsory for all. But these are only partial remedies and would arguably not cover all the economic losses many people with inherited disorders would face.

This raises an important question of policy. Insurers could argue that it is not fair to them to have to carry the burden of the social problem of genetic ill luck. However, in the face of the scientific uncertainties of interpreting genetic information (especially for complex disorders), the occasionally discriminatory practice of insurance workers, and the lack of readymade solutions to the social justice problem, it is reasonable in the medium term to maintain the current UK moratorium on the use of genetic information in underwriting, save in those exceptional cases licensed by the Genetics and Insurance Committee.[11]

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