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Genetics and Insurance

The knowledge that genetics can provide about our future health could play havoc with the life insurance industry. How can we balance the competing demands of consumers' right to privacy and the insurers' need to assess risks?

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Imagine a moment of decision. Your father died of Huntington's disease, a degenerative brain disorder, and so did his father. There's a strong chance that you, too, carry the genetic mutation that causes Huntington's. Knowing your family history, insurance companies already want to charge you more for life insurance, your family's best protection against losing you too soon. But you still want to get tested, so that you can plan for the eventualities of the disease. Then again, testing positive could render you ineligible for life insurance altogether. It's a classic Catch-22.

Deciding how insurance markets should respond to the growing availability of genetic information requires a lot of science and some moral choices. If genetic information can predict how likely a person is to contract an illness or to die prematurely, possessing that information will affect how consumers and insurers behave. When people take out life insurance policies, they pay in monthly premiums for, say, 30 years. If they die during that period their families receive lump sum death benefits. The premium and the lump sum are calculated on the basis of actuarial assumptions about the population as a whole combined with knowledge of the individual concerned (smoker or not, history of cancer in the family and so on).

We are now faced with a step change in the potential knowledge about the individual taking out a policy. The use of this knowledge should take account of three basic principles: economic efficiency, fairness and privacy. Unfortunately, they frequently conflict. To preserve privacy people ought to be able to keep their genetic information to themselves. But that intrudes on economic efficiency: when consumers know their risks but insurers do not, either companies go bankrupt from paying unexpectedly high claims or premiums have to be raised, discouraging low-risk consumers-in both cases the market collapses. Protecting the market from this new information probably requires insurers to distinguish between people with different genes when they calculate premiums-and that raises concerns about fairness and social solidarity.

The advent of genetic testing has already changed the way insurance companies do business, and governments have been left scrambling in their wake. In Britain insurers are allowed to use relevant tests in calculating premiums. The government's views on privacy are therefore clear; less clear is the approach to those who will now find it more expensive, or impossible, to buy insurance.

The human genome won't necessarily reveal many certainties, but it will reduce the uncertainty that makes risk-pooling worthwhile. When people learn more about their risks, the usefulness and profitability of insurance falls. This is true whether risks are ruled out or confirmed as certainties: on the one hand, residents of igloos never buy fire insurance; on the other hand, owners of demolition-derby cars don't buy car insurance.

The adverse selection problem

Though the test for the single genetic mutation that invariably causes Huntington's disease received the most attention last year-thanks to its acceptance for insurers' use by Britain's Genetics and Insurance Commission (GAIC)-it is not typical. Individuals with the Huntington's gene have trouble obtaining life insurance because they are almost certain to die prematurely, and the disease generally incapacitates its victims in early middle age. But most gene-related health problems come in the form of higher risks, rather than virtually sure things.

Better examples are BRCA1 and BRCA2, genetic mutations that bring women a greater chance of contracting certain cancers. A reasonably conservative estimate is that BRCA-positive women bear a 65 per cent chance of contracting breast cancer or ovarian cancer; the former is often curable, the latter more often fatal. Women who lack the mutation face a cancer risk of about 12 per cent. At age 30, BRCA-positive women can expect to live nine fewer years, on average, than their BRCA-negative counterparts. The GAIC is currently considering allowing insurers to use tests for these genes in determining premiums.

Given their shorter life expectancies, women who test positive for the BRCA mutations are likely to view life insurance policies as a bargain for their families. They will probably pay far less in premiums before collecting a death-benefit than others who insure at their age, as long as the insurance companies don't know the secret of their genes. BRCA-positive women should therefore be more likely to purchase life insurance (or health insurance), and possibly more likely to buy a generous policy.

What happens next? After receiving less revenue before each pay-out, insurers will

have to raise premiums to avoid making losses. That makes life insurance less of a good deal for BRCA-negative women; the BRCA-positive women will start to chase them out of the insurance pool. Every time a BRCA-negative woman leaves the pool, her insurer's average revenue per person drops, and premiums for everyone else must be raised. Fairly soon, the rates will be so high that only BRCA- positive women will want to insure.

This process is called "adverse selection." Because insurers are unaware of the test results, they cannot distinguish the high-risk women from the rest in order to charge them higher premiums. When individuals take advantage of this asymmetry in information, rocketing premiums and shrinking insurance pools result. That seems good reason to give insurers access to genetic information. Some recent research reaches a different conclusion.

A study led by Krupa Subramanian of Temple University, in Philadelphia, examined the BRCA case explicitly. Her team used a simulation to determine what would happen to life insurance markets if 5 per cent of women took genetic tests for BRCA mutations. (This figure seems realistic, given the current cost of the BRCA test of ?1,500 and the reluctance of many people to take tests.) Without any knowledge of the women's BRCA test results, insurance companies could face annual claims six times higher than anticipated and court immediate bankruptcy. But Subramanian also showed that, using family cancer histories for all the women's immediate relatives, insurance companies could reduce the excess costs to a mere 10 per cent of the amount associated with an average woman's claim. And even that discrepancy could be eliminated by preventive procedures undertaken by women who test positive for BRCA.

It is a rosy picture-genes remain private, insurers survive and women live longer-but not necessarily an accurate one. For insurers, the long-standing practice of taking family histories will not always be a solution. Don Powell of the Wellcome Trust's Sanger Centre, near Cambridge, the country's leading institute of genome research, adds that most genetic diseases are also dependent on multigenic activity-the conjunction of several faulty genes. Those combinations will be harder to deduce from family histories alone.

On the other hand, it is unclear whether people buy life insurance in the manner predicted by adverse selection. Research by Cathleen Zick at the University of Utah suggests that women who are tested for BRCA are more likely to make a purchase decision based on family history than on test results.

Policy choices

Given the existence of adverse selection, several courses of action are available to policymakers. First, testing could be banned altogether. Alternatively, testing could be allowed, with voluntary disclosure of results-or divulging the results of genetic tests could be mandatory. Perhaps the tests themselves should be mandatory. It is possible to forecast some of the outcomes of these policies.

1. No testing. In this scenario, the informational asymmetry disappears along with the genetic tests. Consumers know no more than insurers, and markets remain as they have been. The downside is that all the positive effects of genetic testing, such as early identification of risks to help in financial planning and preventive care, also vanish. Doctors will also not know whom to treat if a vaccine is developed for a genetic disease.

2. Voluntary testing, voluntary disclosure. Assuming genetic tests become cheaper, as advances in technology guarantee they will, we will end up with a situation in which consumers get tested to show insurers that they do not carry undesirable mutations. (Zick and her collaborators observed exactly this phenomenon; women in their sample who tested negative for BRCA mutations often shared the results with their insurers.) Insurance companies could offer these people standard or even cut-price policies (though the latter would contradict the code established by the Association of British Insurers), safe in the knowledge that their risks were normal. The test for a given disease could quickly turn into a screening mechanism-anyone who does not undergo the test would be presumed to carry the mutation. Eventually, the population would be split into two distinct insurance pools: those who can verify their good genes and pay low premiums; and those who either cannot or decline to be tested, and are obliged to pay high premiums.

3. Voluntary testing, mandatory disclosure. Here insurers can discriminate between their customers on the basis of genes. With costly testing, not everyone would necessarily want to find out the mysteries of their genes. Those who were curious, however, might still be discouraged. Testing positive for an adverse mutation would surely place them in expensive insurance pools-perhaps better not to know at all? In this case, some people whose lives would be improved by early detection of dangerous mutations might not be tested. And of course, people who cherish their privacy might object to mandatory disclosure.

4. Mandatory testing. Any government that decides to test everyone undoubtedly wants to use the information it finds, so this policy should imply mandatory disclosure as well. For such a policy to be cost-effective, testing would have to be inexpensive. The situation closely parallels the second part of case two, in which testing and disclosure were almost, in effect, mandatory. Adverse selection would be expunged,

but not without cost; mandatory testing carries a bevvy of potentially unsavoury side effects. Ethicists warn of a "burden of knowledge" that comes with knowing one's genetic code. Some people, upon learning of an unpromising future, might become despondent. Others might engage in eugenics-refusing to have children with those who carry genetic mutations. This situation has already begun to develop in Turkish and Greek Cyprus. Both countries have had mandatory testing for thalassaemia, a fatal blood disease, for more than two decades.

From the point of view of economic efficiency, case one is almost certainly inferior. To abdicate from all the benefits of genetic science would lead to a huge loss in welfare, now and even more so in the future. Case two would play havoc with insurance markets; many individuals who could benefit from risk-pooling would be driven away. Britain has chosen case three, in which insurance markets-both the consumers and insurers-are protected at a cost to some individuals. Nevertheless, an implicit screening process will evolve. And as tests for more diseases become available, the gaps between insurance premiums for gene-healthy people and untested people will widen.

There are some mitigating factors. First, everyone has some genetic mutations, and usually some bad ones. So insurance premiums are unlikely to vary too much for most of the population once the biggest risks have been identified. Powell expects that day to come within a period of years, especially for many forms of cancer. Second, privacy campaigners will be relieved to know that many insurance industries outside Britain have taken only cautious steps to combat genetic adverse selection. US insurers, for example, have been low-key in lobbying for access to genetic test results. They hope that the medical benefits of genetic research will offset the costs of informational asymmetries.

What about the uninsurables?

At the moment, government's role is a small one. The GAIC establishes whether tests are sufficiently reliable to be used by insurers. The results of accepted tests can then be used to determine who is covered by life or health insurance, and how much they pay in premiums. The Data Protection Act guarantees that this information does not leak out to others.

But business has filled the vacuum left by government's inaction-it has begun regulating itself. In 1997 the Association of British Insurers adopted a 51-point code of practice dealing with genetic testing. The code prevents insurers from asking that tests be conducted, and from transferring genetic information between the file of a

tested person and that of an untested member of the same family. If genetic tests approved by the GAIC are ever found to be unreliable, customers who were incorrectly charged higher premiums will have their policies reassessed and their extra payments refunded. These guidelines roughly correspond to those set forth by the Nuffield Council on Bioethics, an independent group of eminent persons whose 1993 report on genetic screening was among the first comprehensive examinations of the topic.

This armour protecting the insurer-consumer relationship has some chinks, however. Ian Frater, spokesman for the life insurance business of Britain's largest insurer, Norwich Union, states that genetic test results of family members would be included in the "history" that a potential customer would be expected to divulge. That policy contradicts point 16 of the code, but is closer to the spirit of the Nuffield Council's report. The code also contains a provision that absolves customers of their responsibility to divulge the results of genetic tests in one special case: when the life insurance policy involved carries benefits under ?100,000 and is linked to a mortgage for the purchase of a new house.

In the US, laws passed by roughly two-thirds of state governments have overridden the tenets of such a code: genetic profiles cannot be used to determine premiums or to deny insurance coverage unless a resultant disease has already been diagnosed. Federal law also bars the denial of health or life insurance to workers who are part of their employers' group-insurance plans. (Despite these laws, a survey recently conducted by the Genetic Alliance found widespread evidence of genetic discrimination in life insurance markets.) Britain's system, following case three, has no such prohibitions. Soon it will have a problem. The Huntington's Disease Society of America estimates that one in every 1,000 people carries the Huntington's mutation-so what is Britain to do about all the uninsurables?

This is an obvious point for the state to step in. John Harris, from Manchester University's Centre for Social Ethics and Policy, notes that in Britain, "there is not so much of a right to insurance, but a presumption that it should not be revoked unless there is a very good reason." He believes that a principle exists under which insurance is an important social benefit. If the government conforms to this principle, it will find itself with a number of choices.

First, the government could adopt laws similar to those in place in the US-essentially forcing insurers to accept customers with adverse genes, but preventing customers without health-impeding mutations from separating themselves. This forced pooling would still leave insurers open to the sort of adverse selection problems that are likely to make US legislators reconsider their earlier decisions. The only workable solution in this vein would be to nationalise the system and offer standardised policies based on age and earnings rather than medical status. With the entire pool under one roof and

no choice in policies, adverse selection would simply disappear. Genetic knowledge would become a huge boost to socialisation of insurance.

A different solution, proposed by those economists who favour the preservation of individual choice, is for the government to offer subsidies to those who would otherwise face high premiums or denial of coverage. A person who tests positive for the Huntington's mutation would be assigned a coupon by the government, and any insurer who agreed to cover that person could collect the value of the coupon. No one could obtain a coupon unfairly, since a genetic test would be required as proof of need. Insurers would no longer need to discriminate, since the coupons' values would be set to level the playing field. In addition, the system would remove any disincentive against testing. It amounts to a form of genetic insurance: everyone pays a premium in the form of taxes, so that those who discover costly genetic mutations will be protected.

THE FUTURE

The unlocking of the human genetic code is sure to transform the insurance industry. Only the genetic test for Huntington's is currently approved by the GAIC for use by insurers, but that number will grow, with tests for Alzheimer's and various types of cancer under consideration. As it stands now, life insurers almost never reassess their client's policies after signing a contract. But with advances in genetic science, that is likely to change. Frater suggests that customers' premiums would have to be readjusted if a "miracle cure" were found for the genetic diseases for which they are at risk.

Moreover, the battle for public opinion will intensify. A survey by the government's Human Genetics Commission (HGC), an advisory body, found that 90 per cent of Britons believe that genetic information should be shared only by consent. One could argue that doing business with a given insurer is a choice which must be accompanied by that consent-essentially waiving the right to privacy. But if a right to insurance exists as well, the two come into conflict; exercising one requires the surrender of the other.

From an ethical standpoint, the distinction between a right to insurance and the right to privacy will be crucial. Insurance affords a kind of social protection, but it also links the fortunes of people who have no way of monitoring each others' behaviour. Those who keep adverse genetic information to themselves could engage in adverse selection, or fail to take preventive measures that would reduce the costs of their eventual claims; both actions would harm other members of their insurance pool. Is that a greater injustice than the potential suffering of uninsurables?

Preserving privacy implicitly requires that the insured act in a socially responsibly fashion at the expense of personal gain. That may be too much to expect. Indeed, the British government appears to have decided that it is. But in the next few weeks the HGC will publish a big report on genetic testing and insurance markets which may challenge that assumption. This debate has just begun.