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# Genetic information and insurance: some ethical issues

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**SUMMARY**

Life is risky, and insurance provides one of the best developed ways of controlling risks. By pooling, and so transferring risks, those who turn out to suffer antecedently uncertain harms can be assured in advance that they will be helped if those harms arise; they can then plan their lives and activities with confidence that they are less at the mercy of ill fortune.

Both publicly organized and commercial insurance can organize the pooling of risk in ways that are beneficial for all concerned. They provide standard ways of securing fundamental ethical values such as solidarity and mutuality. Although policy holders do not know or contract with one another, each benefits from the contribution of others to a shared scheme for pooling and so controlling risk. Although there is a limit to the degree to which commercially-based insurance, where premiums depend on risk level, can go beyond mutuality towards solidarity, in practice it too often achieves a measure of solidarity by taking a broad brush approach to pooling risk.

However, the ordinary practices of insurance, and in particular of commercial insurance, also raise ethical questions. These may be put in simple terms by contrasting the way in which an insurance market discriminates between different people, on the basis of characteristics that (supposedly) determine their risk level, and our frequent abhorrence of discrimination, in particular on the basis on religious, racial and gender characteristics. Are the discriminations on which insurance practice relies upon as standard acceptable or not?

The increasing availability of genetic information, which testing (of individuals) and screening (of populations) may provide, could lend urgency to these questions. Genetic information may provide a way of obtaining more accurate assessment of individual risks to health and life. This information could be used to discriminate more finely between the risk levels of different individuals, and then to alter the availability and the costs of health, life and unemployment insurance to them. Since all of these forms of insurance bear very directly on the way most people live, it will matter to them how (if at all) insurers take account of genetic information. Will use of this information improve or damage the capacity of insurance to provide confidence in the face of uncertain harms, and help if they happen? Will it discriminate in acceptable or in unacceptable ways? Will it support or damage the sorts of mutuality and solidarity various sorts of insurance schemes have successfully institutionalized?

## 1. ACTUARIAL 'FAIRNESS'

Insurance practice assumes that individuals differ, and in particular that their experiences will differ in ways that cannot be foreseen for each individual, although patterns of difference across large numbers of cases can be foreseen. The combination of individual uncertainty and group predictability makes it worthwhile for individuals to insure, yet possible for insurers to sell policies profitably.

As actuarially relevant information is accumulated, the possibility of defining more distinct risk pools and of assigning individuals to them more accurately may also increase. Insurers who have access to such information can decide to offer those whom they assign to lower risk pools lower premiums, and those whom they assign to higher risk pools higher premiums. Yet, as the information for differentiating risk pools increases, a policy of differentiating premiums proportionately may lead to uncomfortable results. Would it be acceptable, for example for premiums to differ on the basis of characteristics such as race or religion (whenever these factors are actuarially significant), or to differentiate premiums on the basis of left-handedness (which is apparently actuarially significant information), or on the basis of income level, charging the poor more when all other risk factors are constant? Equally, would it be ethically acceptable to discriminate premiums on the basis of genetic traits?

At present many health and life insurers in the UK rely on supposedly more 'neutral' information, such as selected facts about age, sex, smoking, past and present health, family health and present lifestyle, supplemented in some cases by a medical examination. Until recently there has been no possibility of answering more direct questions about future health. The availability of genetic information might change that.

There are those who have argued that if it is possible to differentiate risk pools using actuarially valid information of any sort, then insurers ought to

discriminate between individuals who are assigned to distinct pools. Quite early in the AIDS epidemic the point was put as follows: 'an insurance company has the responsibility to treat all its policy-holders fairly by establishing premiums at a level consistent with the risk represented by each individual policy holder' (actuarial 'fairness' has been widely advocated in the US, e.g. Clifford & Iuculano (1987); more recently the same view has been taken by insurers in the UK, e.g. Leigh (1996)). The principle of actuarial 'fairness' is of course familiar: what is distinctive about this assertion of the principle is the insistence that insurers have an obligation to set premiums by it. According to this view of the claims of actuarial 'fairness', it would be unfair for insurers not to insist on testing for HIV or for adverse genetic factors, and proper for them to charge those testing positive larger premiums where the risk so indicates, or to refuse them insurance. Equally, it would be proper to refuse to pay out on grounds of non-disclosure if individuals did not reveal results of tests taken. The number of separate risk pools and levels of premium which might be created by following a policy based on actuarial 'fairness' would depend on genetic knowledge, actuarial diligence and the commercial implications of differentiating or not differentiating more or fewer distinguishable risk levels. It is readily imaginable that people with certain adverse genetic factors would be denied insurance of certain sorts, or priced out of it, if this policy were followed.

There are contexts in which actuarial 'fairness' is well established and uncontroversial. For example, there are both ethical and commercial arguments in favour of using an actuarial conception of fairness in motor insurance. Surprisingly, this is not universal practice. There are jurisdictions (e.g. Switzerland) in which the costs of the risk represented by inexperienced and young drivers is shared among all drivers. One solid ethical argument is that differentiation of premiums for individuals by reference to their risk level rewards good driving, deters risky driving and by denying insurance in some cases helps prevent catastrophic driving; another is that differentiation of premiums by risk levels encourages ownership of safer, less powerful cars.

The commercial arguments in favour of actuarial 'fairness' in the motor insurance market are even plainer. Companies that pursue this conception of fairness can offer cheaper policies to lower risk clients; if they did not do this they might lose those clients to other companies who did so. If they adjust premiums to individual risk they will avoid adverse selection, although they would not pick many cherries (unless, of course, rivals fail to adjust premiums to risks). In motor insurance an actuarial conception of fairness is supported both by ethical and by commercial considerations.

However, in other areas ethical and commercial considerations may pull in different directions. The claim that it is unfair not to differentiate risk levels as far as information permits, and charge individuals in proportion to their presumed risk, has been challenged by various writers (e.g. Daniels 1990; Murray 1992). The challenges with which I am familiar do not dispute that reliance on an actuarial conception of fairness has commercial advantages, not only for motor but for other forms of insurance, and that departing from it could have commercial dangers.

The commercial dangers are of two distinct sorts. First, competitive danger: if some firms do not fully use available actuarial knowledge in setting premiums, while their rivals do so, the rivals will gain the most lucrative customers and the firms that do not use the full range of actuarially significant information will suffer adverse selection. Like other competitive concerns, this one could be addressed by ensuring a uniform regulatory regime that precluded uses of certain sorts of information by all competitors. I will return to this point later.

Second, non-competitive danger: if certain sorts of information were not used in fixing premiums, clients who had access to such information might profit, for example by insuring their lives for large sums in the knowledge that their families would benefit. Here the risk for an insurer arises not because competitors are using different underwriting policies, but because clients are imposing a form of moral hazard. I will return to this point also.

Before these commercial issues are considered in more detail, some of the ethical problems of relying on an actuarial conception of fairness in health and life insurance should be set out. A range of these ethical problems can be pinpointed by considering how life and health insurance differ from motor insurance. One basic difference is that provision for illness and dependants, access to accommodation and the possibility of earning one's living are not optional activities like driving. The availability of health, life and unemployment insurance is basic to people's ability to lead their lives. This contrasts with the unavailability of motor insurance, which can be a major inconvenience to an individual, but does not undercut any basic needs. It can be a social disaster, indeed a human tragedy, if people are priced out of health insurance, as current debates in the US make vivid. However, the availability of health and life insurance would be compromised if those with ill health and shorter lives, who most need such insurance, were least able to obtain it. Insurance based solely on actuarial 'fairness' requires those with the worst prospects to pay more than anybody else for life or health insurance. It may even deny health and life insurance to some of them. Commercially it may be ideal to insure only the healthy and the long-lived. Ethically this would be disastrous, and an insurance system would be superior if it did not exclude or penalize the least fortunate. Actuarial 'fairness' seeks to place the costs of misfortune on the unfortunate, and this is ethically quite different from placing the costs of bad driving on bad drivers.

Most factors that make ill health or early death more likely are not chosen. In particular, the contribution of genetic make-up to ill health or death is not chosen, and may be only partly mitigable, or even bleakly irremediable. So, using genetic information to assign individuals to risk pools and to price health or life insurance can be doubly damaging to those who suffer

unavoidable misfortune. Even if it were reasonable to differentiate premiums for health and life insurance on the basis of avoidable lifestyle factors (e.g. smoking, mountaineering), it would not follow that it was reasonable to differentiate them on the basis of unavoidable genetic risk. Of course, the disanalogy between health and life insurance and motor insurance must not be pushed too far. Some aspects of ill health and some sorts of premature death are wholly or partly self-inflicted, such as those produced by smoking. Here, selectively higher premiums may have an ethical purpose: they reward healthier living and penalize unhealthy living. But there would be no ethical purpose or merit in penalizing those with adverse genes. To hinge levels of premium for insurance against serious misfortunes (e.g. being ill, early death) on the possession of these unavoidable characteristics is to insist that commercial considerations should automatically trump ethical considerations. A decision to endorse this order of priorities is not an axiomatic truth, but one that has to be established or rejected.

In particular, we should consider whether actuarial considerations are all there is to fairness, and whether discrimination on the basis of genetic characteristics will (among other things) amount to or lead to unacceptable discrimination. Since certain genes (including those for cystic fibrosis, sickle cell anaemia, thalassemia) are more frequent in certain racial or ethnic groups, or among people of certain provenance, actuarial 'fairness' can easily lead to thinly disguised racial and ethnic discrimination. The fact that the genetic information can be used to define risk levels and fix premiums is not enough to show that it ought to be used, or that doing so would be acceptably non-discriminatory.

Some critics of an actuarial conception of fairness have argued that it is also ultimately self-defeating, and indeed specifically commercially self-defeating. If this were true, commercial and ethical arguments might point in the same direction. The argument is that if information which permitted very accurate assignment to numerous distinct risk pools became available, and premiums were adjusted to reflect this, the point of insuring would be undercut. Insuring is worthwhile because we pool risk with others, whose actual experience may be very different from our own. If genetic information permitted very accurate prediction of patterns of ill health or of age of death, then uncertainty would be greatly reduced. Health and life insurance based on actuarial conceptions of fairness would no longer involve significant risk pooling, and there would no longer be significant benefits in paying for life or health insurance. It would be rational to self-insure for everything except accidents. In this case the too extensive elimination of uncertainty would have destroyed the basis of certain sorts of insurance market: from a commercial point of view a pursuit of actuarial 'fairness' which is too successful would simply kill the goose that has laid so many golden eggs. Although the human needs which health and life insurance now meet would be unchanged, the costs of insuring for any given individual would be such that it became rational to provide for oneself.

However, this degree of accuracy of assignment to risk pools is of more theoretical interest than practical importance at present (Abbott 1996). The more likely difficulty with any attempt to assign individuals to risk pools on the basis of current, quite fragmentary genetic knowledge is that many assignments would be inaccurate. The inaccuracy has many different sources including lack of knowledge about (i) the degree of association of disease with possession of certain genes; (ii) the time of onset and severity of disease associated with certain genes; (iii) the environmental factors and interventions which may modify the effects of certain genes; (iv) the different subgroups within the population sharing a certain gene; and (v) whether the combined effects of two or more adverse genes is likely to be cumulative. Where genetic risk factors are not individually associated with very high risks, such ignorance can make assignment to risk pools uncertain and undermine any appeal to an actuarial conception of fairness.

Moreover, genetic risk may not be of the simple additive sort that can be relied upon in computing motor insurance premiums, where having a bad driving record and driving a powerful car are independent risk factors, and the two together create a greater risk factor. Genes that are usually adverse might, for all we now know, add no risks in certain contexts and combinations. Genes with known adverse effects have, after all, survived and may still confer survival advantage. Too confident a reliance on current information may lead to risk assessments which, with hindsight, will be judged actuarially quite unfair. An AIDS comparison may be helpful – it has recently been found that some people who live a high-risk lifestyle appear to be HIV immune. If their risk level were assessed using only lifestyle evidence they might be refused insurance on the basis of falsely presumed vulnerability to an illness to which they appear to be immune (Hill & Littman 1996).

The limits of current information may be considerable, even for genes which have been found to be the basis of statistically highly probable adverse events. For example, although BRCA1 mutations are the basis of a very strong predisposition to breast cancer it appears that 15% of those with mutations in this gene do not suffer breast cancer before age 70. If BRCA1 mutations were used to determine risk levels in the absence of understanding of the interacting factors (whether genetic or environmental), this more fortunate 15% might be denied insurance or have to pay a great deal more for it. Equally, of the less fortunate 85%, many will enjoy long years of adult life without breast cancer.

Actuarial 'fairness' based on imperfect knowledge may assign some cases (e.g. HIV risk or BRCA1 risk) to risk pools where they may not belong, or may deny cover to those with genes for a late-onset disorder who, if fuller information were available, would be assigned a long life expectation. These illustrations, moreover, are cases where current knowledge is relatively good, and probabilities of genetically based illness are relatively high. Much genetic information is expected to establish statistically weaker predispositions. This

suggests that we should be very cautious in extrapolating from an individual's having some genetic risk factor to conclusions about that individual's health and life risks.

Let us suppose that the actuarial difficulties were overcome, and that relatively complete information was available about ways in which adverse genes, taken in combination, contribute to an individual's risk of ill health or premature death. Insurers would then have the information that would make it possible for them to compute what was actuarially 'fair'. But, it would still be necessary to ask whether unregulated actuarial 'fairness' is an ethically acceptable standard for health and life insurance.

## 2. HEALTH INSURANCE, GENETIC INFORMATION AND GENETIC DISCRIMINATION

The fact that the NHS provides health care free at the point of delivery for all in the UK has meant that the very intense debates about ethics and health insurance that are current in the US have not, so far, become urgent here.

US debates have now reached the stage of outlawing what is being called 'genetic discrimination' in health insurance. The conceptions of discrimination invoked are various. The 1993 report of the National Institutes of Health concluded that genetic information should not be used to deny health care cover. The Health Coverage Availability and Affordability Act (Sciencescope 1996), which President Clinton signed in August 1996, forbids insurance companies from treating genetic information (both test results and family history) as indications of a 'pre-existing condition' for group health insurance in the absence of any diagnosis of actual disease. For example, if breast cancer has been diagnosed, a health insurance premium for a group scheme may reflect this fact, either by excluding treatment for breast cancer or by raising premiums. If, on the other hand, a test had revealed a BRCA1 mutation then, although this mutation is associated with rather high risks of breast cancer (51% by age 50 and 85% by age 70; see Eeles 1996), it would not be permissible to use this information in determining premiums in a group scheme or to exclude coverage of treatment for breast cancer. The particular aim of the US Act is to ensure that people are not disqualified from health insurance when they change jobs, a juncture at which it is common to have to switch between health insurance policies.

Legislation outlawing 'genetic discrimination' is also pending or achieved in at least 20 states within the US. The state legislation variously forbids health insurers from (i) using genetic information in setting premiums; (ii) requiring genetic tests; and (iii) using genetic information of any sort in calculating health, life and disability insurance or in employment decisions (Council for Responsible Genetics press release 1996). New Jersey has passed a particularly comprehensive genetic privacy law, by which genetic information is private and cannot be used for any insurance or employment purpose without written consent, and cannot be used to refuse health insurance even if disclosed (Charatan 1996). If such legislation is passed and can be enforced, health insurers in the US will be permitted to use only restricted sorts of genetic information (e.g. that reflected in existing conditions and family history), and will therefore have to set premiums on the basis of traditional risk factors. The boundary between genetic and non-genetic information is not always clear. It may be clear enough what constitutes a genetic test, but less clear when certain other measures of the effects of genes are used to obtain information. Is a PKU test a genetic test? Is information about actual genetic illness a sort of retrospective genetic test? Is a measure of height a genetic test? If current legislation against genetic discrimination is to be enforceable, it will be urgent to clarify these matters.

However, these restrictions on the use of genetic information would be faced by all insurers, and would not create any of the competitive disadvantages which form part of the reason why an actuarial conception of fairness seems competitively essential.

Yet, under this legislation, US health insurers might complain that they would still face commercial difficulties if clients, who had adverse information about their own genetic status and its future implications, purchased health insurance policies on which a great deal later had to be paid out. The insurers would, it seems, be exposed to 'moral hazard'. They might point out that if it was not for the genetic anti-discrimination legislation they could have avoided insuring those people. However, since health insurance policies pay out only for treatment as needed, it is not obvious why this should be thought of as an unconscionable advantage to the insured. Providers would not be in a situation different from that in which they find themselves prior to the possibility of genetic testing, nor would other policy-holders with good prospects. Anyone who thinks that need is an appropriate basis for the distribution of health care, yet is committed to a commercial system of health insurance, may have to conclude that these commitments can only be reconciled by outlawing genetic discrimination in health insurance. Correspondingly, those who think that need is an appropriate basis for the distribution of health care and doubt whether genetic anti-discrimination legislation will be effective must conclude that universal public health insurance is indispensable.

We do not, of course, know to what extent private health insurance may become more common in the UK, nor if it does, whether there would be those who relied wholly on it, as opposed to the present situation where those with private health insurance can still claim treatment from the NHS—and often do so. It may therefore seem that it is unnecessary to worry much about genetic discrimination in health insurance in the UK at this point. However, if privately purchased 'long-term care' policies become a standard (even a required) means for dealing with care in old age, or if 'critical illness' policies become an increasingly popular way of insuring against serious illness, all of these issues may soon become important in the UK too. A particular worry may be put in simplified




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form, as a concern that if the incidence of Alzheimers and other dementias were predictable, long-term care policies would become unaffordable for those who really needed them, and not needed by those who could really afford them.

Indeed, in so far as people in the UK already buy health insurance, some of the issues that are a matter of urgent public policy debate in the US will also have to be settled here. Could it be acceptable to price health insurance on the basis of an actuarial conception of fairness in the UK? If we did conclude that this is acceptable, would we also think that it was fair to use genetic information for setting premiums while knowledge of genetic risks is still fragmentary, so that one person may be judged at higher risk than another simply because one gene has already been thoroughly studied and another has not? More fundamentally, should our first concern be the fair distribution of health care or the actuarially 'fair' distribution of insurance costs among those who purchase private policies? Is it not a matter for public policy to decide (i) how genetic information should be used; (ii) whether health insurers should be permitted to use the results of tests taken; (iii) to know whether tests have been taken; (iv) to insist that tests be taken; and (v) to determine who should pay for required tests?

In addition, if any genetic information is used in insurance of any sort, complex issues of confidentiality must be faced. Genetic information is unlike other medical information in that an individual who obtains it thereby obtains probabilistic information about his or her blood relatives (in some cases this may be definite information). This fact makes genetic counselling a distinctive and difficult area of medical counselling. Genetic information can bear on reproductive decisions and on family relationships in peculiarly intimate ways. Often, medical and reproductive reasons for seeking genetic information have to be balanced against psychological and familial reasons for choosing not to seek it (Nuffield Council Report 1993). In this very sensitive and still little understood area there are strong reasons for at least postponing any requirement that genetic information be made a condition of any sort of insurability, so compromising the feasibility of choosing to forgo such information.

While there is uncertainty on these matters, individuals who may have medical or familial reasons to seek genetic information could be placed in a double bind if insurers were to demand that information. If they do not seek information, they may not know what they need to know in order to seek medical treatment or to make reproductive decisions. If they do seek the information, and it is adverse, they may be penalized by higher premiums or even by finding that insurance (health and life) is unobtainable. These issues are quite urgent. There is already considerable discussion about the 'right' age at which young people in whose families adverse genes have been found, or may be suspected, should be encouraged to consider being tested, and about the form that screening programmes for certain genetic conditions should take (Nuffield Council Report 1993, ch. 3). In some cases there may be preventative measures to be taken; in other cases, it is thought that the potentially difficult information that might emerge should be assimilated early in life, perhaps before considering marriage or having children. If, at a later stage of life, the fact of being tested, or receiving adverse genetic information from a test, might be made the basis for refusing or restricting health insurance, or for requiring higher premiums, then the costs of having obtained the information for quite serious reasons could turn out to be enormous (for some striking case histories of loss of insurability as a consequence of having obtained genetic information, see the piece in *The Observer*—The genetic underclass—15 September 1996). Clinical geneticists and genetic counsellors who may have advised in favour of testing in the light of medical or reproductive concerns might turn out (however good their intentions) to have given damaging advice. Yet, at the moment neither clinicians nor counsellors can know whether they should warn those whom they counsel that these problems could arise, or how serious they might turn out to be.

## 3. LIFE INSURANCE AND GENETIC INFORMATION

Since the UK has universal health insurance provided by the NHS, and a level of universal income support for those who do not or cannot work, the most sensitive use of genetic information for insurance purposes here at present may be in life insurance. At a certain stage of life, life insurance is not an optional extra. People need it to purchase accommodation and to protect their dependants. Unemployment insurance, or at least a mortgage protection policy that comes into play during periods of unemployment, could also become very important in the UK, where many people have insecure jobs. Questions about genetic discrimination in life and (to a lesser extent) in unemployment insurance may therefore be of great importance here.

Insurers already seek a range of medical and other information from those wishing to take out life policies. Questions about their own medical history and present medical condition and about family medical history are common; a medical examination is sometimes required. Although these policies create great difficulties for certain individuals (including, of course, for many who live a long time), the practice has been generally accepted. For many people the extended use of genetic information raises various concerns, including: (i) it might make it possible to differentiate individuals and their premiums more sharply; (ii) it might (because of the patchiness of information) be a context for ascribing much higher risks to some individuals than would be ascribed to them in the light of fuller information; and (iii) above all, that the practice of discriminating against those who are most unfortunate, even if actuarially 'fair', is not ethically acceptable. In short, the fear is that the advent of genetic information may worsen the lot of the worst off: actuarial 'fairness', even when used carefully in the light of good information, may be deeply unfair.

Before considering whether actuarial 'fairness' is fair, it helps to find out who needs life insurance. In general, the need is greatest in the middle years of life,

during which people may aim to buy a house or flat and to take on family responsibilities, and thus have young dependants. It is much less common for the very young or old to need life insurance. It follows that genetic information that bears mainly on early or late stages of life may not be important for life insurance purposes.

For example, knowledge of adverse genes for disorders which are lifelong, or which do not reduce life expectation, may be largely irrelevant to the provision of life insurance. Those whose genetic disease is present during childhood will often need no life insurance. If they live long enough to need life insurance, their condition will be considered like any other medical condition, and they will, in any case, have to declare it as a current condition when seeking insurance. It is, of course, not a trivial matter if a group of people with early onset disorders but longish life expectation cannot obtain affordable life insurance. It is, however, a separate issue, since the information which leads to their difficulty is not of a novel sort. On the other hand, people who may be shown to have a genetic predisposition to a very late onset disease, such as Alzheimers, may have a long and healthy adult life, and outlive all need for life insurance, before the disease strikes.

Those with genes that lead to late, but not very late, onset problems may need life cover during adult and productive years, with ordinary adult commitments. From the point of view of life insurers, the worry must be that if there is no obligation to take tests or to disclose the results of genetic testing, life policies may be sold to persons whose risk of death in middle life is higher than it may otherwise appear. Late onset monogenic disorders such as Huntington's (the endlessly repeated example in this context), arise in the middle years of life, although here too there may be many years of adult life before onset. Life insurance matters to Huntington's sufferers. Equally, although many women with BRCA1 mutations will have a long period of adult life before onset, and others may escape the disease entirely, the disease may strike while life insurance is important. Also, genetic predispositions such as those for heart disease, may have their effects during middle life. These are the types of case where it seems that non-disclosure of genetic information may be advantageous to individuals, and disadvantageous to insurers. In particular, if some individuals purchase large policies knowing their risk of early death, insurers, and so ultimately others who had pooled their risks with those individuals, would have to pay.

The question that therefore needs to be addressed directly, is whether actuarial 'fairness' is ethically acceptable as the sole basis for life insurance. The issue is not settled by pointing to the uncertainty of predictions. It is the nature of life insurance that it is often bought by people who die sooner than might have been expected, as well as by people who live longer than might have been expected. The question is rather whether it is wrong to assign people to higher risk pools whenever adverse information about them becomes available, despite the fact that the shorter-lived may also often need some affordable cover at a certain stage of life. If risk pools are relatively broadly defined, needs could perhaps be met within a system based (loosely) on an actuarial conception of fairness; if risk pools are narrowly defined, needs may not be met without using a more substantial conception of fairness which excludes unacceptable forms of discrimination. Once insurers aim to use genetic information to differentiate risk pools increasingly sharply, perhaps for competitive reasons (e.g. to offer lower premiums to 'preferred lives'), then some of the social disasters that are indicated by the phrase 'genetic underclass' may become unavoidable. Once actuarial 'fairness' is based on precise genetic information, we will have sanctioned oblique forms of racial and ethnic discrimination in life insurance. It seems to me that it must be an urgent matter of public policy not to go in this direction.

Nor is it essential to go in this direction. The degree of pooling of risk in a given insurance market is always a matter for policy as well as for calculation. In the past, smoking was not treated as a separate risk factor in computing premiums; now, separate tables are used for smokers and non-smokers. This form of discrimination is widely accepted, perhaps because smoking is seen as a risk factor which people can choose not to incur, just as it is accepted that those who have dangerous pastimes (e.g. diving, mountaineering) be asked to pay more. Age discrimination in life insurance is also standard, and accepted, perhaps because all older policy purchasers will have had opportunities to purchase earlier. Sex is another standard basis of discrimination, although perhaps rather less readily defensible. It seems much less likely that genetic factors can be made the basis of acceptable discrimination. Although it may seem attractive to offer lower premiums to 'preferred lives', it is not obvious whether this would be an acceptable form of discrimination, especially if the definition of 'preferred life' were based on genetic factors rather than current fitness (which may in part reflect lifestyle). Lower premiums for 'preferred lives' are paid for by higher premiums for 'unpreferred lives'. Taken to its logical extreme, offering inducements (lower premiums) for 'preferred lives' requires the progressive elimination of those elements of solidarity that are present within commercial insurance that do not push actuarial 'fairness' to this extreme (and, of course, standard in non-commercial insurance).

Is there an alternative? Surely there is. We have lived for many years with a limited degree of actuarial 'fairness', guaranteed by limits on available actuarial information, and even by the policies of insurance companies. Extending actuarial 'fairness' by requiring genetic information may become possible, but it may nevertheless be ethically important to follow policies that can secure deeper forms of fairness and non-discrimination between people. Such policies could ensure that everyone has access to some affordable life insurance. The corollary would be that we would have to accept that there is no right to be offered a premium that is minimal for one's (supposed) individual risk level. It is worth noting that if there were such a right, it could hardly be acceptable for insurance companies to seek profits. On the contrary, in taking out insurance

for meeting basic needs we would have to continue to accept that we pool risks to shed uncertainty and in doing so may not end up with as low a premium as actuarial 'fairness', on its own, might have produced (although, we would also have the assurance that we may have ended up with one that is lower than any based on actuarial 'fairness' alone could have been).

## 4. CONCLUSION

Where genetic information is relevant for insurance purposes, choices will have to be made. It is in no way inevitable, and I have argued that it is not ethically or socially desirable, that those judged to have adverse genetic traits should be assigned to risk pools that jeopardize their access to health or life insurance in the name of actuarial 'fairness'. The reasons for this include, first, currently available information of genetic risk factors is often too little to fix a given individual's level of risk, and specifically of life expectation, with much accuracy. Second, even if an individual's genetically determined risk level is relatively clear, it may either be manifest as a current medical condition, or it may be clear that death will fall in a stage of life for which life (and unemployment) insurance is not important. Third, even when the extra information available from genetic testing is clear and when it bears on the stages of life for which life (and unemployment) insurance may be needed, there are no ethical grounds for treating actuarial 'fairness' as the sole consideration. There are ethical and public policy reasons for thinking that risks should be pooled more widely.

However, if risks are to be pooled more widely, insurers will need protection against undercutting competition by commercial rivals and adverse selection imposed on them by clients. Protection against rivals can be achieved when all are subject to the same regulatory demands. This could be achieved either by legislation that parallels or extends that already used in the US and other countries, and which seeks to control the ways in which genetic information may be used for insurance purposes, or by robust self-regulation. Adequate protection against adverse selection by clients might require (self-imposed or legislated) limits to the amount of life insurance that may be bought at a given age without any requirement of disclosure of genetic information. If adequate cover could not be guaranteed within the limits of commercial viability, there may be a case for considering publicly funded support of the costs of insurance in some cases.

While these very complex issues of public policy are under discussion in the UK, I believe that we would do well to have a temporary moratorium on the use of genetic information for all insurance purposes. This would prevent a drift into practices that may be regretted, or that become a source of confrontation between insurers and the public. Such moratoria and other restrictions are already in operation in Belgium, France, Austria, Norway and the Netherlands (Leigh 1996). Broadly speaking, these countries have adopted policies to ensure that there is no requirement to disclose genetic information as the price for life insurance policies offering cover up to a certain amount. If the relevant ethical and public policy issues are to be properly addressed in the UK similar policies will be needed. Any limit to the amount of insurance available without genetic tests will have to be set by careful consultation with consumer and genetic interest groups: it cannot be based upon pulling a round figure out of the air, since the limit must reflect the cost of the social needs which life insurance is to meet.

It follows, I think, that insurers have no unrestricted right to receive or use genetic information for actuarial purposes, (nor, therefore, can they reserve such a right as sometimes claimed; Leigh 1996). Rather, policies for the disclosure of genetic information to insurers, and for its use by them, need to provide reasonable assurance that (i) access to insurance is acceptably non-discriminatory, (ii) that the utmost protection of the confidentiality of genetic information is assured, and (iii) that reasonable account is taken of the demands of commercial practice. Whether these objectives can be achieved by self-regulation by the insurance industry, or whether they will require legislation remains to be seen. What is clear enough from the experience of other countries is that the issues have to be addressed, and that if self-regulation were to fail, the UK would probably face public demands for legislation against genetic discrimination similar to those that have arisen in many other countries.

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