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Phil. Trans. R. Soc. Lond. B 1997 **352**, 1103-1106
doi: 10.1098/rstb.1997.0091

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The likely financial effects on individuals, industry and commerce of the use of genetic information

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SUMMARY

In this paper I look at the financial implications of genetic testing, particularly in the employment and pensions fields. I have generally not covered life insurance, as that is covered in other papers in this Discussion Meeting. However, the issues are similar, although the emphasis is different. Inevitably there is an element of speculation involved; genetic testing is in its infancy and so we cannot predict either what information we will be able to obtain through genetic testing, nor the uses that may be devised for this information.

1. LIMITATIONS OF GENETIC TESTING

We do not know what genetic testing may tell us. However, we can determine some limitations to the ability of genetic testing to improve our ability to predict mortality and morbidity. These limitations can be determined in two ways: there are other influences on mortality and morbidity besides genetics; and there are other sources of information (already available) that may give us some or all of the information that could be obtained from genetic testing.

Table 1 shows the proportion of deaths by cause for 1993. The major causes of death are diseases of the circulatory system and neoplasms, which together account for over three quarters of all deaths. We know that the incidence of these diseases is affected by environment and behaviour, so the most that the genetic information can do is show a propensity to a particular type of circulatory disease or neoplasm. Whether and how that disease develops will be influenced by the person's environment and lifestyle.

There has been much discussion about cancer genes. What such genes tell us may depend on how specific they are. For example, with prostate cancer, we know that all men will get this if they live long enough. Genetic information will only help if it tells us that (i) someone is likely to develop prostate cancer at an unusually early age or (ii) they will develop a particular type of prostate cancer.

Another group of diseases may be loosely described as the infectious diseases (e.g. tuberculosis, malaria, AIDS). At best, genetic information could tell us about people's susceptibility to these diseases, but even the most susceptible person will not develop the disease if he or she never comes into contact with it.

Accidents are a significant cause of death, particularly at young ages. The main influence here is environment and behaviour. It is difficult to conceive that being accident prone is a genetic characteristic.

What is conceivable is that there is a genetic propensity to dangerous pursuits, which would then increase the risk of accidental death. However, once the person has grown to adulthood one does not need genetic testing to decide whether they are likely to indulge in dangerous pursuits, one can simply look at their record.

2. MONOGENIC DISEASES

Although a large number of diseases have been identified as monogenic, they are all rare. However, these are diseases where it is clear what genetic information might tell us. With a monogenic disease the genetic test will tell us whether a person has the gene which means they will get the disease. Without the genetic test it is not possible to make such a determination until the clinical signs of the disease appear. But we may already know, without genetic testing, that the person has a significant chance (usually 50%) of developing the disease. This knowledge of course derives from the knowledge of the parents' health.

In effect, enquiries about parental health give significant genetic information, and what the genetic testing will do is render this information more precise.

3. THE EMPLOYMENT RELATIONSHIP

When considering employment, it is important to recognize that the employment relationship is very variable, depending on the nature of the job, and the preferences of both employer and employee. At one extreme there is pure casual labour, such as fruit pickers, where the employer has no real interest in the employee's state of health.

With permanent employment the employer is more likely to be seeking a long-term relationship and so

Table 1. *Proportion of deaths by cause for 1993, for persons aged between 45 and 64, which is the key age range for employment purposes*

	male	female	all
diseases of the circulatory system	44	27	38
neoplasms	35	52	41
diseases of the respiratory system	7	7	7
accidents or other external causes	5	3	4
diseases of the digestive system	4	4	4
diseases of the nervous system and sense organs	1	2	2
endocrine, metabolic and immunity disorders	1	2	1
all other causes	3	3	3
total	100	100	100

Source: OPCS Series DH2 No. 20 Table 2.

Table 2. *Annual incidence of death and major sickness per 10000 persons in UK males of working age*

age	death	sickness
25	8	72
30	9	99
35	11	126
40	18	155
45	33	192
50	62	249
55	110	350
60	184	554

Sources: ELT No. 14 CMIR No. 12.

may not take on new employees if their health is doubtful. However, this should not be overemphasized.

For most jobs, employers do not insist on intensive health testing of prospective employees, because the extent of the employer's investment in a new employee is not great enough to warrant such expense. Commonly the prospective employee is simply asked to make a declaration about his or her state of health. Of course, if the person has had an investigation about his or her state of health then this process will pick it up.

Where an employer is particularly interested in the health of the employee is for jobs where there is a substantial investment in training (e.g. fighter pilots) or for very senior positions. Nevertheless, it is notable that, for example, heavy smokers manage to get jobs without significant difficulty, despite their substantial extra risk, both for mortality and sickness.

For an employer, sickness represents a much greater risk than death because it is so much more common. Table 2 compares (for UK males) the incidence of death with the incidence of major sickness (defined as sickness leading to more than 4 weeks off work).

4. HEALTH OF THE WORKING-AGE POPULATION

The population of working age is generally healthy. Of males age 20, more than 75% will survive to age 65. The proportion is even higher for females, and for males at older ages. Moreover, of the 25% who fail to make it to age 65, many die of accidental causes. Thus any improved ability to predict mortality prior to age

65 can only affect a relatively small part of the population.

5. EMPLOYEE BENEFITS

It is common for employers to provide a range of benefits for their employees. These benefits may include some or all of the following:

1. Sick pay, covering short periods of absence and often providing for the full salary to be paid.

2. Permanent health insurance, covering longer periods of absence and providing a benefit in the region of 50–75% of salary, plus pension contributions.

3. Death benefit, which, during employment, often consists of a substantial lump sum (typically between two and four times salary) and a spouse's pension; on death after retirement, a spouse's pension of about 50% of the deceased member's pension is normally payable.

4. Retirement pensions, which constitute much the most costly benefit; a pension of two thirds of salary payable from age 65 after a full career will require contributions of about 15% of salary each year and, in a typical scheme, most of that cost would be met by the employer.

5. Healthcare benefits covering the costs of hospitalization and medical care provided privately; these benefits normally cease to be provided on retirement.

Many of these benefits may be insured with an insurance company. However, whether or not the benefit is insured, it is common for most employees (other than the very highly paid) to be covered automatically, without having to provide any information about their health. This is possible because the insurance company is taking on a risk for a group of lives and so can rely on getting a reasonable spread of risk. It can also be argued that the employee's main reason for joining the employer is to get a job, not to exploit a benefits package. The moral hazard often discussed in the context of direct insurance is less relevant. Taking the benefits package as a whole, the most important risks are of improved pensioner mortality and poor investment returns.

In recent years there has been some trend towards flexible remuneration packages, under which employees get some measure of choice as to which employee benefits they take. Where the employee has a choice, then some measure of individual underwriting

is likely to be required; the extent of the underwriting depends on the extent of the individual choice that is offered.

6. EMPLOYERS' USE OF CURRENT INFORMATION

There is already a substantial amount of information available that can be used in assessing whether a particular individual has unusually high risk of either sickness or death. This information includes (not in any particular order)

1. past medical history
2. parental medical history
3. age
4. lifestyle (diet, exercise, smoking, drinking, dangerous pursuits, etc.)
5. results of medical examination and clinical tests.

The costs of any health investigation by an employer are significant. As noted above, the population of working age is generally healthy. So if an employer investigates every prospective employee it will have to pay the investigation costs for all of them, but in only a few will the investigation show anything at all.

For some jobs (e.g. very senior jobs, or jobs with a very high training investment) it is worthwhile for employers to do a detailed investigation of prospective employees. However, for most jobs employers will not go to such lengths because it is not worth the cost of obtaining and assessing the information.

Where an employer does get information of a health risk, it does not follow that it withdraws the job offer. Heavy smoking is an easy risk to assess, and a known high risk for both sickness and mortality. But heavy smokers still get jobs, without particular difficulty. The same applies to other health risks. The decision for the employer, where there is a known health risk, is whether the value that the employee will give to the firm justifies the risk. In very many cases, the employer is prepared to take the health risk. One example is that voters in many countries have been prepared to elect to high office people with known and quite significant health risks.

There are some jobs in which health risks would be unacceptable. For example, fighter pilots need to be in excellent health. They are very expensive to train, so a person is unlikely to be taken on for such training if he or she is in a high-risk category.

Monogenic diseases, being an extreme example, illustrate the issues clearly. With many monogenic diseases an employer, by asking about parents' health, can presently find out that a person has a 50% chance of contracting such a disease. For some jobs this makes the person unacceptable. However, for other jobs the employer is still happy to take him or her on, as it believes the employee will give sufficient value before the disease takes hold. Genetic testing will convert the 50% chance to a 100% chance for some people, but this is unlikely to alter the position of either group of employers. If a 50% chance is acceptable, then 100% is probably still acceptable. What would of course change is that some people would move from 50% to

0% chance, and then they would have opportunities which are currently denied them.

7. GENERAL HEALTH

Genetic testing, particularly in the area of multifactorial diseases, may offer significant opportunities for improving the general health of our population. It seems possible that, through genetic testing, we will be able to identify propensities to particular circulatory diseases or particular neoplasms. This knowledge will enable us to improve the targeting of the resources devoted to preventative medicine. Thus, for example, it may be possible to target our programme of screening for breast cancer towards those whom the genetic testing shows to be at highest risk. As early detection of breast cancer is important for its successful treatment, this could help to reduce both the mortality and the length of sickness arising from this disease.

Other preventative measures include counselling on lifestyle. If genetic testing shows a propensity to circulatory disease, then this may be helpful in persuading the individual to adopt a healthier lifestyle. This may be optimistic, but in my view, if people know the facts about their own health then these facts will at least have some effect in persuading them to take responsibility for it.

A general improvement in health would be beneficial to employers and to the economy generally. Sickness is expensive, both in time spent not working and the cost of treatment. Medical advances that reduce such sickness, i.e. primarily advances in preventative medicine, are therefore of great value in reducing these costs of sickness. While genetic testing is not of itself preventative medicine, it could be used to improve our preventative medicine.

It is in employers' interests to have a healthy workforce. Therefore many employers, particularly larger ones, provide facilities to encourage staff to achieve good health, for example, regular (confidential) medical check-ups and gymnasias. If it could be demonstrated that genetic screening would encourage more healthy lifestyles, it is possible to envisage that employers would fund such screening for their staffs as part of the benefits package.

8. RETIREMENT

By the time of retirement, genetic influences may be relatively less important. Certainly it seems unlikely that genetic information would be particularly relevant in assessing mortality risks for a pensioner. So, as far as the financial aspects of retirement are concerned, the effects of genetic testing will be general, rather than relating to particular individuals. Genetic testing is one factor among many which may lead to a healthier population and one that is living longer. This gives rise to issues in relation to the financing of retirement, which have been widely discussed in other contexts. Genetic testing does not bring in any new issues here.

9. LONG-TERM CARE

One in four of us will need long-term care in the final

period of our lives. Such care is expensive and this, coupled with the fact that most of us will not need it, suggests that insurance cover is an appropriate method of providing for it.

It is possible that genetic testing may give information about a person's prospective need for long-term care. I believe there is some evidence of heredity associated with Alzheimer's disease (which is one of the main reasons why people need long-term care). Genetic testing may clarify some of the links in this area. Although it will only add to the information that is already available from the family history, the additional information could be substantial, with major implications for the ways in which genetic information ought to be used.

As a result of the ageing of the population, the costs of State pension, sickness and healthcare benefits are set to rise in future. A likely response is to encourage (or possibly to oblige) employers to provide minimum levels of cover. This suggests an increased role for private insurance. It also suggests that the discussions on the place of genetic testing need to centre on sickness, medical and long-term care insurance rather than on life insurance.

10. IRRATIONAL REACTIONS

Two important characteristics of humanity that have been of great benefit are the thirst for knowledge and the sharing of new discoveries. From time to time, societies have endeavoured, with varying degrees of success, to suppress or channel one of these characteristics. For example, totalitarian societies have suppressed knowledge; the effect has been a stifling of life, both materially and emotionally.

One difficulty with genetic testing is that it may be ill understood, and so people may react irrationally. In particular, a test that shows a person to have a higher risk of a particular disease may be interpreted as meaning that the person is certain to get that disease. In my view it is not wise to restrict access to information just because people may misuse or misunderstand it. It is better to educate people in the proper use of the information. Humanity has made its greatest progress when knowledge has been freely shared.

I am grateful to my colleague Donald Duval for providing me with an extensive supply of ideas and for allowing me to test my own ideas on him. Responsibility for the views expressed in the paper is, however, entirely mine.