

# Future impact of genetic screening in occupational and environmental medicine

Roger G Rawbone

## Abstract

**New genetic technologies open up the possibility of predictive screening, both for individual genetic risk factors for susceptibility to workplace hazards and for late onset (both single gene and multifactorial) hereditary disease. Although the initiative for testing may lie with employers and employees there are many potential stakeholders—from family members and workplace colleagues to insurers and society in general. The role of the occupational health professional will not only involve the contextual interpretation of genetic test results but also the myriad of associated ethical and moral questions. This paper considers a range of ethical issues with which the occupational health professional may be confronted as genetic technology advances.**

(Occup Environ Med 1999;56:721-724)

Keywords: genetic screening; occupation

Dear

*Thank you for attending our final selection panel and pre-employment medical examination which, as you know, involved an obligatory DNA analysis. I regret having to inform you that although you made a strong impact at interview you have been unsuccessful in your application on the basis of predicted genetic susceptibilities.*

*Your DNA profile showed that although you have the potential for innovation and creativity, features which were apparent from your initial interview, you have at the same time a high risk of developing a manic-depressive psychosis which would seriously impair your performance, and in the position to be filled, potentially put colleagues at risk. As well as this, however, you have a genetic susceptibility to develop liver disease on exposure to several metals which are found throughout our premises.*

*I regret that, on the basis of these results, we cannot offer you employment but wish you success in the future.*

*Yours faithfully,*

Fact or science fiction? By 2002 the entire human genome will have been sequenced, and thereafter, subsequent research will rapidly advance our understanding of disease mechanisms. Although genetic variability will remain only one factor in determining how a person will react to the workplace environment the current uncertainties associated with the relevance and accuracy of genetic test results will be improved, and tests will become more reliable allowing the identification of suscepti-

bility to specific hazards. Together with “DNA chip” technology<sup>1</sup> and the increasing commercial availability of DNA typing this will permit widespread predictive testing and risk stratification at pre-employment or pre-placement assessment. This potential for mass genetic screening with identification of workplace susceptibilities and predisposition to disease, in essentially healthy people, raises ethical and moral issues which may ultimately impact throughout the practice of occupational medicine.

## Test relevance

Although the focus of this paper is on the ethical issues surrounding workplace genetic screening an initial comment on the relevance of the test methods is appropriate in so far as if the methodology provides results which cannot be fully interpreted in the context in which they are being used then this uncertainty has to be at least considered alongside the potential outcomes in terms of use to humans.

The extent to which people may be considered to be at higher risk, through any screening programme, depends on the relevance of the test; that is, both on the strength of the association between a positive result and the risk of developing the adverse health effect and on the intrinsic variability of the test method. The most useful measure for assessing the performance of a test in a population is its predictive value—that is, the proportion of people with true positive reactions, which is related not only to the validity (sensitivity and specificity) and reliability of the test but also to the prevalence of the factor in the population being studied.

It is possible, as an example, to show that even if a reliable selection test is used that has a 90% sensitivity and a 90% specificity for identifying people with a specific genetic trait, which, however, has a relatively low prevalence of 5% in the population of concern, then only 32% of the people with a positive result will be truly positive, with the other 68% showing false positive results and therefore, in the current context, being needlessly excluded from employment.<sup>2</sup> For many genotypes the population frequency may be lower causing even higher false positive rates.

The fact that developing genetic technologies have the potential to enable testing for a battery of conditions which might affect a person's future work performance on a single drop of blood, together with the fact that the use of such tests in pre-employment screening may give rise to discrimination or to the restriction of a person's liberty to pursue their chosen career, then a full consideration of the method-

**Health and Safety  
Executive, Magdalen  
House, Stanley  
Precinct, Bootle,  
Merseyside L20 3OZ,  
UK**  
R G Rawbone

Correspondence to:  
Dr Roger G Rawbone,  
Health and Safety Executive,  
Magdalen House, Stanley  
Precinct, Bootle, Merseyside  
L20 3OZ, UK.

Accepted 13 July 1999

ology becomes justified and occupational health professionals will need to be able to understand and interpret the results in the context of specific workplace factors.

### Workplace genetic screening

As the opening letter above shows, the essential debate today, however, lies not so much with the technology itself but in the ways in which it might be used, with concerns that genetic testing could open the door to discrimination and abuses of civil rights as well as detracting from attention paid to overall safety in the workplace. Interestingly a study from the United States by Draper<sup>3</sup> has shown that employers and employees have opposing views on the validity of pre-employment genetic screening and of genetic monitoring—that is, genetic testing in a health surveillance programme. Employers tend to support screening as a way of selecting employees, but they generally oppose monitoring, whereas employees oppose screening, but tend to favour monitoring.

This support for genetic screening by employers could be interpreted as reflecting a position that if developing health problems were due to a genetic susceptibility in the workforce then this would in some way diminish their own responsibilities, whereas employees who do not want to lose their jobs or be identified as high risk would prefer, at least in the short term, to see the cause of any potential for ill health as originating in the workplace.

Genetic susceptibility to workplace hazards is not, however, the only issue. Employers might use genetic screening for single gene disorders and complex traits to determine whether prospective employees have the required physical or psychological capabilities for the job. Although single gene disorders—such as Huntington's and Alzheimer's disease—can have a serious impact on people's health and their ability to perform in the workplace, in the case of complex disorders the inherent problem is that the presence of a specific gene will only indicate one risk factor among many. In the case of single gene disorders and complex traits, both because of variable expressivity and incomplete penetrance, the presence of a specific gene does not necessarily indicate the inevitability of disease. Not only may carriers never develop the disease linked to their genes but individual people may compensate for an increase in susceptibility by reducing hazardous environmental influences.

### Interests of employer and employee

Employers invest in their employees, who, when trained and experienced, cannot be easily replaced, and employers, therefore, clearly have an interest in the future health of their workforce. Genetic screening has the potential to identify not only those employees who are at risk but also those who might have future ill health.

On this basis employers may wish to perform genetic tests to exclude susceptible workers and those predicted to have ill health to reduce costs related to occupational health and safety by reducing necessary expenditure on work-

place controls; costs associated with reassignment or ill health retirement; and costs incurred through liability and legal action for compensation. On the other hand there may be some genetic traits which could interest employers by enabling positive selection on the basis of desired psychological attributes or resistance to occupational hazards to improve productivity.

Employers might, however, provide genetic screening for purely altruistic motives, with voluntary testing as part of an overall health programme. For individual employees, knowing whether they have an increased susceptibility for occupational hazards can clearly be of benefit, warning them of the need for preventive measures, both general—such as dietary control or prophylactic medication—and specific—such as environmental workplace controls or protective clothing.

The idea that employers and employees have opposing views on the cause of workplace related diseases may therefore be a somewhat simplistic view and although there may be the potential for conflict between employers and employees this is not clear cut and in many instances genetic testing may be of mutual benefit.

The challenge in formulating workplace policies in relation to genetic screening is to find a balance among all the competing interests with the current emphasis in discussion relating to the importance of the voluntary nature of any testing programme to protect individual privacy.<sup>4</sup>

### The moral dimension

The moral issue underlying genetic screening might thus seem to be one of autonomy versus paternalism: should people be permitted to assume risks to their health, and, if not, what actions should be taken and by whom? It would generally be accepted in today's society that people should have the right to self determination and should be free to accept certain risks providing that they are informed of the implications and the decision does not put others who have not consented at risk.

One particular question highlighted by genetic screening is how far a just system of health care, which would include an equitable distribution of the risk of ill health, could be invoked to prevent susceptible people from a specific workplace environment. If such people are barred to protect their equality of opportunity for health protection in the workplace then we interfere with their opportunity to compete for jobs and careers. Would society's obligation to protect equal opportunity through preventive health care be in conflict with the obligation to ensure equal opportunity in the pursuit of jobs and careers? In his discussion of this question Daniels<sup>5</sup> considers the issue of the moral relevance of individual susceptibility to risk as a special case within the broader question of the moral relevance of detectable individual variation in susceptibility to disease. In this context we would no more discriminate against genetic susceptibility than we would against any specific lifestyle factor.

This raises further questions, however, as many egalitarians make a basic distinction between choice and circumstance. In general terms people should be held to account for choices they affirm but receive compensation for the results of bad luck.<sup>6</sup> In this regard those with a genetic disadvantage should receive compensation from society, through public social insurance schemes, for any resultant ill health. However, whether those with genetic susceptibility who entered employment with a full knowledge of the potential risks would be open to similar compensation under this distinction, or have to rely solely on private insurance schemes, is open to discussion centring on the question of fully informed consent and freedom of choice.

### Interests of other stakeholders

The consideration of the impact of genetic screening primarily on the basis of a balance between interests of employer and employee not only ignores the power relationship between employers and employees with the complex interplay of interests and motives but also the wider social and political repercussions.

A feature of genetic information is that it has the potential to effect third parties; not only the family members of tested employees, but also other workers together with the general public.

It has been argued that the right to be able to make decisions about one's health includes the right not to know whether one carries a gene for a disease (or susceptibility).<sup>7</sup> Although this right can never be absolute (for example, testing can be imposed for reasons of public health, as in controlling the spread of contagious diseases) it might seem reasonable to give people the choice of being informed about their actual health or future illness, particularly where informing the person may have no effect on the disease.

Genetic information, however, is relevant to blood relatives and if tests show genetic disorders or susceptibilities, family members might want to know whether they too are at risk. They might also worry about confidentiality of the information which could be used by their own employers, or insurance companies. Furthermore the interests of future descendants may be of concern when damage to the germ cells of employees could adversely affect the health of their children and other descendants. A final but nevertheless important reason for family members to be concerned about genetic screening is that health concerns and problems among employees are likely to have both wider financial and emotional consequences.

Fellow workers and members of the general public may also be interested in pre-employment genetic screening. It is already accepted that people with certain diseases may be debarred from particular occupations because they could represent a serious danger to others—for example, people who have ever had an epileptic attack can only obtain a vocational licence for the driving of heavy goods or public service vehicles on meeting stringent conditions<sup>8</sup>—and by the same argument employees affected by genetic disorders or suscep-

tibilities could expect to be excluded where their condition might endanger others, as is the case where people with sickle cell trait are not accepted as aircrew or offshore divers.<sup>9</sup> But this argument could be invoked to justify other types of screening, particularly where genetic screening may make it possible to identify people with a high risk of developing serious, late onset conditions. For example, concern has been expressed over the fact that those identified as carriers of the gene for Huntington's disease could become train drivers or airline pilots.

The interest of the general public in workplace genetic screening, however, extends far beyond the potential direct effects on third parties because financial contributions through the tax system pay for health care and workers' compensation schemes. When individual people choose to work in an environment where they are knowingly at an increased risk then society as a whole will end up paying for the consequences; workers who become ill need treatment, take early retirement, and so on.

When genetic screening is an option all these potential interests place the person, in whom there is no evidence to suggest that a particular gene may be present, in a situation where there is the adverse possibility of increasing personal anxieties about health. There are pressures to be screened for genetic risk; demands for disclosure of existing test results<sup>10</sup>; continuing concerns of misinterpretation and uncertainty about the significance of test results; fears of divulgence to third parties; and worries about insurance.

It has to be realised that whatever decisions are made as a result of genetic screening these have an impact somewhere and a person's choice to be exposed to occupational hazards, when aware of an increased susceptibility, will inevitably affect others; money spent to make jobs more accessible to susceptible people not only has commercial implications but also takes money away from other things, including health care and education.

The occupational health professional must be equipped to advise employees on these issues (or to refer to competent specialists) both in relation to immediate concerns and to anticipated future outcomes as well as considering the interests of employers and other stakeholders. The key issue which will face the occupational health professional, in any given situation, will be to determine who's interests are to be given the highest position or legitimacy.

### Regulation

The question then is to what extent, if any, should there be regulation of genetic screening? For those who believe in market freedom the government should not intervene in the contractual relations between employers and employees. Fully informed, autonomous workers know what risks they are prepared to take and the income they want to earn. High risk jobs would attract few workers unless there was a commensurate high level of pay and this would cause employers to improve workplace

facilities to attract more job applicants. According to this view, intervention should focus on the provision of risk information, not on regulation. In relation to genetic testing Epstein has argued<sup>11</sup> that where there is contractual relation in which autonomous parties make decisions on the basis of accurate information employers should have the right to test their own employees and exclude them on the basis of genetic susceptibility. Where individual people fail to reveal genetic information to a potential employer then this would be construed as amounting to fraud.

In an analysis of genetic testing in the workplace Lemmens<sup>12</sup> concludes that such a free market system, based primarily on economic rules and cost-benefit analysis, fails to take adequate consideration either of potential human suffering or a person's self realisation through work or other values equally difficult to measure. There is also little account taken of the long term health consequences for non-susceptible workers who remain in a potentially hazardous workplace.

The further argument that self regulation based on consent promotes autonomy seems to give moral validity to actions simply because they involve choices. But even if that were true can employees be considered "free" when they choose a potentially harmful environment in which to work. High risk jobs, where genetic screening might be of particular importance, are generally characterised by low turnover and are often held by relatively unskilled workers with few alternatives or opportunities. Under these circumstances, consent might be based on economic necessity more than self determination. It might be argued that for the employee voluntary screening is rarely ever voluntary.

Lemmens argues that if this analysis is correct then one may conclude that a restriction of contractual freedom can be considered a valid moral choice to correct an imbalance in power between employers, who may have an interest in maintaining potentially harmful environments, and employees, who seldom have viable alternatives or are in a position to demand better safety standards.

Indeed this is the approach supported in many current reports and recommendations on genetic testing. The Nuffield Council on Bioethics in its recommendations<sup>13</sup>, for example, states that genetic testing should only be allowed within the context of a clearly defined policy with strict criteria and guidelines; it certainly does not suggest that consent, in itself, can justify testing.

### The future

It would seem that in the immediate future there are unlikely to be significant changes in policy from those already defined<sup>14</sup> although the ethical questions raised by the potential of genetic screening in the workplace will continue to be subject to debate. The strategy for reducing occupational ill health will continue

to focus on modification to the workplace and not modification of the work force.

We should perhaps recognise, however, that this may not always be the case. As genes do not usually change during life a DNA test can be performed at any time from conception onwards and there is no single stage of life at which genetic screening is most suitable. Screening may best be offered in a variety of ways and the optimal approach may change as the community becomes more informed. For example, genetic screening for thalassaemia in Cyprus and Sardinia has progressed from the antenatal stage to the premarital stage towards screening in schools. This type of progression may prove to be a common pattern as genetic screening becomes a more established component of primary health care. These questions, however, raise further ethical problems, not only for the specific diseases that do not appear until adult life but also for potential workplace susceptibilities. For example, when should genetic screening be performed for career definition and training?

Looking even further to the future then ultimately genetic technology will have the capability of replacing susceptibility genes. Such technologies could not only be used to improve future generations but also enable parents, or even society, to specify characteristics suitable for specific occupations and thus predetermine a person's life plan. At present the prospect of "designer" children may seem distant but technology and attitudes do not stand still. Will we then see the focus of occupational health and safety in the future shift from "technical prevention" to "modern day eugenics"?

The views expressed are those of the author and do not necessarily reflect the views or policy of the HSE.

- 1 Henn W. Genetic screening with the DNA chip: a new Pandora's box? *J Med Ethics* 1999;25:200-3.
- 2 Van Damme K, Casteleyn L, Heseltine E, et al. Individual susceptibility and prevention of occupational diseases: scientific and ethical issues. *J Occup Environ Med* 1995;37:91-9.
- 3 Draper E. *Risky business: genetic testing and exclusionary practices in the hazardous workplace*. New York: Cambridge University Press, 1991.
- 4 British Medical Association. *Human genetics: choice and responsibility*. Oxford: Oxford University Press, 1998: 170-7.
- 5 Daniels N. *Just health care*. Cambridge: Cambridge University Press, 1985:114-220.
- 6 Dworkin R. What is equality? Part 2: equality of resources. *Philosophy and Public Affairs* 1981;10:283-345.
- 7 Chadwick R, Levitt M, Shickle D, eds. *The right to know and the right not to know*. Aldershot: Ashgate, 1997.
- 8 Taylor JF, ed. *Medical aspects of fitness to drive, 5th ed.* London: The Medical Commission on Accident Prevention, 1995:61-77.
- 9 Fingret A, Emerson PM. Haematological disorders. In: Cox RAF, Edwards FC, McCallum RI, eds. *Fitness for work: the medical aspects, 2nd ed.* Oxford: Oxford University Press, 1995;2:333-4.
- 10 Association of British Insurers. *Genetic testing: code of practice*. London: ABI, 1997.
- 11 Epstein RA. The legal regulation of genetic discrimination: old responses to new technology. *Boston University Law Review* 1994;74:1-23.
- 12 Lemmens T. "What about your genes?" Ethical, legal, and policy dimensions of genetics in the workplace. *Politics and the Life Sciences* 1997;16:57-75.
- 13 Nuffield Council on Bioethics. *Genetic screening: ethical issues*. London: NCB, 1993.
- 14 Human Genetics Advisory Commission Employment Working Group. *The implications of genetic testing for employment*. London: HGACEWG, 1999.