PHILOSOPHICAL TRANSACTIONS OF THE ROYAL SOCIETY B BIOLOGICAL SCIENCES

# Social and psychological issues associated with the new genetics

Sally Macintyre

*Phil. Trans. R. Soc. Lond. B* 1997 **352**, 1095-1101
doi: 10.1098/rstb.1997.0090

# Social and psychological issues associated with the new genetics

SALLY MACINTYRE

*MRC Medical Sociology Unit, 6 Lilybank Gardens, Glasgow G12 8RZ, UK*

**SUMMARY**

This paper discusses two prevailing views—optimistic and pessimistic—about the potential benefits and risks arising from developments in human genetics and argues that we do not yet have enough evidence to assess which elements (if any) of either view are likely to be correct.

## 1. INTRODUCTION

Many social and psychological issues are raised by developments in the science and applications of human genetics. In this paper I will focus mainly on those issues raised by predictive genetic testing and, to a lesser extent, on those raised by testing for carrier status for recessively inherited disorders. This is because these may have particular implications for the insurance industry in this country.

Durant and colleagues have distinguished between two discourses in which the new genetics are often described, the 'discourse of great promise' and the 'discourse of concern' (Durant *et al*. 1996). Both among groups of the lay public and in press reporting, one can discern first, enthusiastic accounts of the great promise of recent scientific developments, and second, less sanguine discussions of many ethical, legal and social concerns raised by these same developments. Other authors have summed up the contrast between the optimistic and pessimistic views with titles such as 'Mapping the human genome: friend or foe?' (McLean 1994).

## 2. THE DISCOURSE OF GREAT PROMISE

Some of the most optimistic views about the potential power and benefit of genetic testing and screening are to be found in official reports, not in the tabloid press as is sometimes assumed. The House of Commons Science and Technology Committee's report on Human Genetics (House of Commons Science and Technology Committee 1995), the two reports to the NHS Central Research and Development Committee (CRDC) (Department of Health 1995*a*, *b*) and the report of the Health and Life Sciences Panel of the recent Technology Foresight exercise (Office of Science and Technology 1995) all illustrate the discourse of great promise. In the former we find statements such as that from the Royal College of Physicians to the effect that 'the transformation of medical practice by genetic science represents the change from empirical to rational management of disease and hence its significance can hardly be exaggerated' or that, as the role of genes in common diseases is increasingly understood, genetic medicine could mean that 'treatment, as conventionally understood, will, eventually, become an action of last resort, used only when the proactive approach of predict/prevent fails' (House of Commons Science and Technology Committee 1995). Indeed, the potential medical benefits then listed by the Commons Select Committee include:

1. better understanding of the genetic and environmental components of psychiatric, mental and neurological disorders, leading to more effective treatments (para 67)
2. quicker, cheaper, more accurate and sophisticated diagnosis of common diseases (para 68)
3. targeting of 'at risk' individuals and the tailoring of treatment to take account of genetic factors (para 68)
4. better understanding of disease mechanisms, leading to 'the social and economic benefits of unequivocal diagnosis and rationalisation of treatment' (para 69)
5. rational drug design, in which chemicals are designed so that they precisely fit the molecules implicated in disease (para 70)

An even more extensive list of potential benefits was given in the report on the genetics of common diseases to the NHS Central Research and Development Committee (Department of Health 1995*b*), which stated that: 'Almost all major susceptibility genes, and some genes conferring protection, will be identified in the next 5–10 years', and that this will lead to:

1. better understanding of the pathophysiology of common diseases
2. a new taxonomy of disease
3. opportunities to prevent some diseases and for earlier and more effective treatment of others
4. more accurately targeted therapies
5. fewer side effects from therapy
6. more effective use of health care resources.

Similarly enthusiastic views were expressed in the report of the Health and Life Sciences Panel of the Technology Foresight exercise, which stated that: 'Identifying the genetic risk factors for major diseases, and the genes associated with good health and immunity and clarifying the relative importance of these and environmental risk factors could have

profound effects on the treatment and prevention of disease. For instance it might be possible to target sectors of the population at risk or by individualising risk, to enhance the effectiveness of preventive measures. The knowledge would certainly be useful in developing new treatments and perhaps in selecting treatment strategies on an individual basis' (Office of Science and Technology 1995, p. 34).

If shown to be correct, such optimistic predictions would indeed imply enormous social, economic and health service benefits, with a revolution in our ability to understand, predict, prevent and treat disease. A brave new world and a discourse of great promise indeed, and one with major implications for life insurance, health insurance and liability insurance.

Peter Harper has pointed out that in the course of a single year, 1995, views seemed to shift from an optimistic one emphasizing the large-scale beneficial effects of the new possibilities for genetic screening and testing, to more pessimistic ones emphasizing the difficulties and potentially detrimental effects of such screening and testing services (Harper 1995). What issues are raised in the discourse of concern?

## 3. THE DISCOURSE OF CONCERN

Many authors have expressed much more cautious views about the likely social benefits of genetic medicine, and in particular screening and testing (Wilfond & Fost 1990; Clarke 1996). Expressed within the 'discourse of concern' are the following social and psychological issues:

(*a*) geneticization of society
(*b*) underestimation of the role of environmental factors in disease
(*c*) discrimination (in insurance, employment and more generally)
(*d*) changed attitudes to parenthood, and commodification of babies
(*e*) diversion of care, treatment and resources away from disabled people or people with genetic abnormalities
(*f*) screening for conditions for which there is no effective treatment
(*g*) uncertainty about whether lifestyle changes would occur as a result of screening, and about whether they would be effective.

### (*a*) *Geneticization*

The process of geneticization has been described by several authors. Abby Lippman has defined it as: 'An ongoing process by which differences between individuals are reduced to their DNA codes, with most disorders, behaviours and physiological variations defined, at least in part, as genetic in origin. … Using the metaphor of blueprints, with genes and DNA fragments presented as a set of instructions, the dominant discourse describing the human condition is reductionist, emphasizing genetic determination' (Lippman 1991, pp. 18–19).

The concern here is that our social values and cultural assumptions may come to be viewed through what Troy Duster has described as the 'prism of heritability … a way of perceiving traits and behaviour that attributes the major explanatory power to biological inheritance' (Duster 1990, p. 164). Such a way of viewing the world may, it is argued, change our ways of thinking about and dealing with issues such as personality, personal autonomy and responsibility for actions, education, the environment and social change. Obesity, homosexuality and poor exam performance may all come to be seen as reducible to our DNA.

### (*b*) *Underestimating the role of the environment*

A related concern is that such geneticization may lead us to underestimate the role of the social and material environment not only in influencing general traits such as personality, criminality and educational achievements, but also in influencing disease and physical traits. Wilkie has pointed out that while there is a genetic component to height and that, on average, Scottish people may be shorter than English people, his generation of Glaswegians is much taller than his father's generation as a result of better diets in the postwar era compared to those experienced by his parents' generation during their youth in an era of unemployment and depression, not as a result of rapid genetic change (Wilkie 1993). The risks of diseases with a strong genetic element can be greatly influenced by the environment. Non-insulin dependent diabetes mellitus (NIDDM), for example, is known to be highly determined by genetic factors, but the prevalence of the disease in a population has been found to change dramatically with economic growth and cultural change, and some places have gone from being virtually free of the disease to having very high rates in a short period of time (Zimmet *et al*. 1978; Orchard *et al*. 1986). Similarly, it has been pointed out that although there may be a genetic component to heart disease, the rapid change in the social class distribution of coronary heart disease (CHD) in the UK (from being more prevalent in higher social classes to being more prevalent in lower classes), and the recent declines in the prevalence of CHD in nearly all industrialized countries, cannot be attributed to changes in the gene pool. Rather they suggest a major role for living standards and environment (Rose & Marmot 1981). Enthusiasm for the potential of the new genetics may lead us to underplay the importance of these environmental factors, which from a public health perspective may be extremely important. In particular, Clarke has expressed the fear that commercial pressures for susceptibility testing for common disorders 'will promote the notion that genetic endowment and chosen lifestyle together determine future health, while the importance of material circumstances (especially poverty) in creating ill health will be glossed over' (Clarke 1996, p. 35).

### (*c*) *Discrimination*

A third concern is about discrimination (in the workplace, in insurance, or more generally) against those who are at risk of, or carriers of, genetic disorders.




PHILOSOPHICAL TRANSACTIONS OF THE ROYAL SOCIETY B BIOLOGICAL SCIENCES

Billings *et al*. (1992) have discussed the fear that: 'As large numbers of individuals submit to or are coerced into genetic testing, in order to obtain employment or insurance cover, a new social class and category—the "asymptomatic ill"—may be constructed. Although they are healthy, persons in this new group may find that they are treated as if they were disabled or chronically ill by various institutions of our society' (Billings *et al*. 1992, p. 479).

There are several subvariants of the issue of genetic discrimination. One is that carrier status may be regarded in a similar light to homozygote status for recessively inherited conditions. The often-quoted experience of the sickle-cell carrier screening programme among African-Americans illustrates the possibility of carrier screening programmes designed to benefit particular groups actually disadvantaging them. Following the National Sickle Cell Anaemia Control Act in 1972, in some US states Blacks were required to take the sickle cell test before being permitted entry to school or being issued with a marriage licence, and carrier status could lead to loss of employment, increased insurance premiums, inappropriate medical therapy and delay in adoption of children. It was not until 1981 that the Air Force Academy lifted its flying ban on African-Americans who were carriers of sickle cell (Bradby 1996). A case has been reported of the brother of an individual with Gaucher disease who was tested and found to be an unaffected carrier, but who was refused a government job because of his carrier status (Billings *et al*. 1992).

Another subvariant of the discrimination issue is that misunderstandings about the clinical variability of many genetic conditions may lead to discrimination against people without regard to the severity of their condition or its relevance for the particular activity (e.g. the example of a man turned down for car insurance because of Charcot-Marie-Tooth disease). 'In these and other cases, having a particular genotype is equated with the presence of a severe illness and the lack of effective treatments' (Billings *et al*. 1992, p. 479).

A third issue identified by Billings *et al*. is the double bind in relation to testing in which some people who may be at risk of genetic disorders are placed. 'Discrimination may ensue as a result of a decision to forego testing and thereby not determine whether they (or their future children) will develop the disease. Discrimination may also occur if they opt for such testing and the results reveal a genotype associated with disease' (Billings *et al*. 1992, p. 480). Individuals are faced with a 'damned if you do, damned if you don't' scenario similar to that experienced in relation to HIV testing: take the test and if found to be negative find yourself discriminated against as someone who has been tested, and if found to be positive find yourself discriminated against as someone who is positive; and if you do not take the test to avoid discrimination, you may forego the benefits of testing.

A fourth issue, raised in part by the sickle cell experience, is that particular diseases associated with already low status or discriminated-against population groups may themselves take on the discreditable attributes of those population groups, or come to be seen as further reasons for discrimination. The association of some recessive disorders (for example sickle cell, thalassaemia, Tay Sachs) with ethnic minority groups may have these effects, and the disorders may themselves become overassociated with these groups in the minds of public and social institutions such as the medical and insurance professions. For example, neonatal screening programmes in the US have detected sickle cell anaemia among Hispanics, Italians and other ethnic groups as well as Blacks, but found that non-Blacks may be surprised by or resist this diagnosis. 'The common belief that they (Hba and Hbc) occur in Blacks results in a reluctance to consider the diagnosis or to accept it when made, because to do so implies racial intermixing' (Mack 1989, quoted in Marteau & Anionwu 1996). Members of these ethnic minorities at high risk for a condition may be pressured to take tests for carrier status, while they may not be available to members of other ethnic groups at lower risk. However, it has been pointed out that the relationship between risk and ethnic origin is becoming increasingly complex. For example, in the UK and US more births of infants with Tay-Sachs disease now occur among non-Jews than among Jews. The view that cystic fibrosis (CF) occurs only in Whites (rather than being more common among Whites) is still prevalent, though inaccurate, as is the view that sickle cell anaemia occurs only in Blacks (a view which led to settlement of £175 000 to a family of an affected child, where the white partner of a carrier was not offered testing but was later found to be a carrier for haemoglobinopathy) (Marteau & Anionwu 1996). Incidentally, the example of sickle cell anaemia can be held up as a cautionary tale to those expressing the 'discourse of great promise'; although the genetics of the disease have been understood, and carrier testing available, for some time, there is little evidence that this has had the radical benefits (either via prevention or treatment) that would be implied in the illustrations of the 'discourse of great promise' given above.

The 'discourse of great promise' tends to suggest that genetic testing and screening will be of benefit to the individuals concerned and to society because it will permit more rational targeting of preventive and therapeutic actions. The implication is that testing/screening will benefit both individuals found to be positive and those found to be negative, because knowledge is a good thing; those found to be negative will be relieved of uncertainty and the threat of disease in themselves and or their offspring, and those found to be positive will be empowered to plan their lives accordingly and to take preventive or palliative actions.

Studies to date on carrier screening and testing programmes, on predictive testing for adult onset disorders and on other non-genetic screening programmes suggest that this is an oversimple picture. Studies of the emotional and cognitive effects of carrier testing tend to find different results according to the social context and condition in question. Individuals found to carry a gene from Tay Sachs were found to have a less optimistic view of their future health than those found not to be carriers (Marteau *et al*. 1992), but

no such effects, at least in the short term, have been reported for those detected as being CF carriers, (Bekker *et al*. 1994; Meidzybrodzka *et al*. 1995). Similarly, among those who had participated in a sickle-cell carrier screening programme, non-carriers perceived carriers in a more negative light than did carriers, seeing them as being less happy, healthy and active than non-carriers (Woodridge & Murray 1989). However, carriers and non-carriers of CF had similar and positive perceptions of being a carrier (Evers-Kiebooms *et al*. 1994). One might speculate that conditions seen as common to the majority population may evoke less negative stereotypes of carriers, among both carriers and others, but more research needs to be done on this issue.

In the area of predictive testing for adult onset disorders it has tended to be assumed that 'those receiving low-risk results will react positively and those receiving high-risk results will react negatively' (Michie *et al*. 1996, p. 455). Studies have shown the picture not only to be more complex than this, but to contain surprising aspects. For example, studies of those tested for a genetic predisposition to Huntington's disease have found guilt and depression among those found not to be at risk (Huggins *et al*. 1992), and thay have also found distress after testing to be lower than before both for those with high and low risk result (Wiggins *et al*. 1992). Some of those found not to carry the gene may experience 'survivor guilt' in relation to siblings, and family dynamics may change in unpredictable ways. Persons shown on the basis of genetic tests to be at low risk of breast and ovarian cancer, and of familial adenomatous polyposis (FAP), have expressed disbelief and continued anxiety, regard themselves as still being at higher risk than the general population and wish to continue with intensive surveillance even if it is unpleasant (Michie *et al*. 1996). So testing may not allay anxiety among those found to be at low risk, who may become the 'worried well' and add to the health service or insurance industry problems posed by the 'symptomless ill'.

Social, psychological and health care responses to being defined as 'at risk' of a particular disorder have already been studied in other fields, such as hypertension, high cholesterol and screening for breast cancer. There is some evidence from such studies that asymptomatic risk identification may create a new type of social identity (neither well nor ill, but at risk) that can have deleterious effects on social and psychological functioning and not necessarily lead to lifestyle changes of the sort recommended by doctors (for a review see Davison *et al*. 1994).

### (*d*) *Changed attitudes to parenthood and babies*

Programmes of carrier screening are usually justified on two grounds: reduction of birth incidence of specified disorders, and reproductive choice. The public health goal of reducing birth incidence can potentially conflict with individual goals of choice and autonomy. It is often implicitly assumed that 'reproductive choice' will mean that parents will decide to abort fetuses found to have genetic disorders, but if we are to take the concepts of choice and autonomy seriously we have to allow for the possibility of parents deciding to carry an affected fetus to term. One concern is that this choice will increasingly be eroded by pressures, including those from insurance companies, to abort. A case has been reported of a family in the US who had health insurance through a health maintenance organization (HMO) and whose first child, who had cystic fibrosis, had health care paid for by the HMO. Prenatal tests on the second child showed it to be homozygous for CF but the parents decided to proceed with the pregnancy. The HMO considered withdrawing or limiting health care coverage for the pregnancy, post partum and paediatric care, as well as for the already affected child (Billings *et al*. 1992). There are fears that insurance companies will pay for abortions of affected fetuses but not for their care if born, and that society in general, and the medical, caring and insurance professions, may become intolerant of parents who decline testing or who, having had a positive prenatal diagnosis, decide to take the pregnancy to term.

It has been reported that geneticists, obstetricians and the general public were more blaming towards mothers who gave birth to a child with Down's syndrome, having declined screening, than they were towards mothers not offered screening who gave birth to affected children (Marteau & Drake 1995). Despite the rhetoric of screening providing informed reproductive choice, the reality may be that we slide towards believing that if it is possible to prevent the birth of a child with a particular genetic disorder then this ought to be done, and that parents who refuse prenatal screening or testing are to blame for having produced an affected child. Another concern is that, as increasingly with so many other areas of our social world, having a baby who is not perfect according to current criteria will come to be seen as being someone's fault and the result of errors of commission or omission, rather than a random occurrence to be accepted and coped with. If it is not seen as being the parents' fault (through either unhealthy behaviours by the mother during pregnancy, or failure to use prenatal screening) then it may be seen as being the fault of the health services. It has been reported that when prenatal screening services are generally available, parents with affected children may blame health professionals either for not offering them screening or for false negative results; and it is suggested that as blaming others for misfortune may lead to poorer adjustment, the availability of prenatal screening may adversely affect adjustment to an affected child (Marteau & Anionwu 1996). There is, therefore, a concern that babies will increasingly become commodified, that is, seen as objects to which adults have a right, and furthermore a right to have a perfect version. An extreme version of concern about attitudes to abortion and blame for less than perfect children was demonstrated in debates about Lord Brentford's private members bill designed to outlaw termination of pregnancy for fetuses diagnosed as having Down's syndrome. In June 1996 anti-abortionists alleged that the government might in future start mass screening for 'low IQ, below average

stature, psychological instability … bringing a less than perfect child into the world will be more than irresponsible … doctors will be sued if anything sub-standard emerges from the womb, teachers will sue if they are required to teach imperfect pupils' (Daniel 1996).

### (*e*) *Diversion of attention from those with genetic disorders*

An argument sometimes following on from this is that advances in genetic science may wittingly or unwittingly change the boundaries of what we now think of as normal, or healthy, or acceptable. Because it may become possible to screen and test for genes for all sorts of human characteristics, it may become acceptable to do so even for conditions that are considered acceptable now. One study found broad agreement between professional groups (geneticists and obstetricians) and the general public over the conditions for which prenatal testing and the option of termination would be approved; the majority of the public and professionals endorsed their use for conditions involving significant degrees of intellectual and physical disability from an early age (Down's syndrome, anencephaly, cystic fibrosis), and did not endorse their use for late onset conditions for which there was treatment but no cure (cancer in early 30s) or for non-disease conditions such as a child of unwanted sex, homosexuality, low intelligence or missing two fingers. Geneticists and obstetricians were more likely than the general public to endorse routinely available screening for serious medical conditions and less likely than the general public to endorse it for homosexuality, child of unwanted sex and two missing fingers (Michie *et al*. 1995).

Just as it is often assumed that people in families with a history of inherited disorders would be the keenest on predictive tests, it is often assumed that those in families affected by inherited conditions would be keenest on prenatal screening, testing and the opportunity for terminating affected fetuses. This is most definitely not the case; some of the most vehement opponents of such programmes are those whose own lives have been touched by genetic conditions.

A concern of advocates for disabled people is that those with inherited disorders will become increasingly marginalized as not deserving to have been born and as not meriting health and welfare expenditure. Tom Shakespeare, who has achondroplasic dwarfism, has argued, for example, that the implications of many present and proposed genetic screening and testing services are that the lives of persons with genetically determined disorders are of no value, and he and Brian Wilson MP (father of a Down's syndrome child) have argued that the resources currently being put into genetic screening and testing, and selective termination, might be better spent on provision for those with the conditions. They argue that 'the problem' is not the condition in question, but society's attitudes towards people with the condition, and lack of educational or health care provision. This argument gains added cogency from the paradox that screening and testing programmes have been instituted for some conditions (such as cystic fibrosis) at the same time as therapeutic advances are increasing the life expectancy and quality of life of sufferers.

Brian Wilson has argued that testing for Down's syndrome and other conditions is a commodity for which a market has to be created, which can only be done through promoting in people who have no experience of the condition in question a fear that the condition is intolerable and merits avoidance through termination. It certainly seems that those with experience of the condition may be less likely than others to undergo testing or opt for termination than those with no direct or indirect experience. He further points out that there is slippage into thinking of Down's as a disease, rather than as a chromosomal abnormality with associated learning disabilities.

> If Down's is a disease then, by implication, it can be prevented—but we know there is only one way to prevent it. Is it society's assumption that this is the best, and final solution? … Is there any wonder that prejudice persists, status is low, or that little attention is given to meeting the needs of children who slip through the net? … Meanwhile, thousands of families get on with the routine business of fighting to give their children with learning difficulties a decent life. … It is the endless drudgery of fighting for basic rights which causes far more distress than anything inherent in having a child with Down's Syndrome. (Wilson 1993, pp. 5–6)

Thus a major concern of many activists and pressure groups is that resources that might be used to improve the quality of life and care for those born with genetically determined conditions or disorders will be diverted into scientific programmes to identify those with these conditions, and into health service programmes to screen and test for them.

### (*f*) *Screening for conditions for which there are no effective treatments*

Long-established principles of screening programmes include those that the condition be an important one, that there should be an effective treatment for it, that the tests are sufficiently sensitive and specific, and that the benefits of screening outweigh the costs (Wilson & Jungner 1968). These principles have recently been endorsed in the UK in relation to screening programmes, albeit with an extension of the sense of 'effective treatment' to include lifestyle changes and reproductive decisions (Calman 1994).

However, there are fears that we may be stretching our definitions of effective interventions too far and that we may be introducing tests because they are possible rather than because they are beneficial. Screening for carrier status for CF, testing for the breast/ovarian cancer gene BCRA1 in affected families and testing for Duchenne muscular dystrophy (DMD) in new born males (Bradley *et al*. 1993) are all available in the UK, the first on a commercial basis. The public may assume that these tests would not be offered unless there were clear-cut benefits or actions that could be taken on the basis of them. (In my own earlier work on tests during pregnancy I found that few pregnant

women knew the purpose or consequences of the many tests they were undergoing but went along with them because 'there must be a reason for them' or 'they must know what they are doing'.) However, the 'effective interventions' possible as a result of positive results for CF carrier status are either prenatal testing and selective abortion, or not marrying (or having children by) another carrier; for DMD they are prenatal testing and selective abortion in subsequent pregnancies, or earlier anticipation of disease in the affected neonate. It has been stated of BRCA1 that: 'We are almost totally ignorant of the effectiveness of any preventive strategies for women at high risk' (King *et al*. 1993, p. 1975) A positive test for Huntingdon's offers no effective medical interventions. There is thus a concern that expensive testing and screening tests may be introduced and used even if there are no unequivocally demonstrated effective treatments.

### (*g*) *Uncertainty about probability and effectiveness of lifestyle changes*

The converse of assuming that negative predictive tests for adult onset disorders will result in unalloyed relief is believing that a positive result may result in beneficial lifestyle changes, particularly for multifactorial disorders where lifestyle factors or environmental exposures influence the occurrence or course of disease (e.g. heart disease). The problem from a personal and public health point of view is that there are two possible responses to both positive and negative test results, as follows:

1. I have inherited a high risk of getting heart trouble so I will be especially careful about smoking, weight, food and exercise.
2. I have inherited a high risk of getting heart trouble so I may as well not bother to follow all this advice about smoking, weight, food and exercise.
3. I have inherited a low risk of getting heart trouble so I will build on that by being careful about smoking, weight, food and exercise.
4. I have inherited a low risk of getting heart trouble and so I don't have to take any notice of all this advice about smoking, weight, food and exercise (Davison *et al*. 1989).

All these reactions are psychologically understandable, but the public health dysbenefits if large numbers of people reacted in the second or fourth way could be enormous (and of course have effects on life and health insurance). The problem at the moment is that we simply do not know what sorts of people, in what circumstances and in what sorts of numbers are likely to react in these different ways. The public health and insurance industry problem is that if people increasingly come to believe that all diseases are genetically predetermined they may become more sceptical about the ability of behavioural or environmental modification to improve health.

Not only is it currently unclear whether people will modify their behaviour in a beneficial direction on the basis of genetic tests for multifactorial disorders, but it is also unclear how effective any such behaviour modifications might be. For example, a regimen of exercise and healthy diet might reduce risks of heart disease in the general population but be entirely ineffective for those with familial hypercholestraemia. So the goal of identifying those most at risk for genetic reasons to allow them to modify their lifestyle might fail on two counts: people so identified might take a fatalistic view and behave even more unhealthily than before; or they might modify their lifestyle drastically but not alter their risk.

## 4. CONCLUSION

Many of the social and psychological issues raised by the new genetics are not new in principle and have been evident in relation to other screening and testing services. As a sociologist I have seen my task as being to present at this Discussion Meeting a description of two prevailing discourses about the likely benefits and hazards of the new genetics: the 'discourse of great promise' and the 'discourse of concern'. Both are expressed in a variety of settings, from official government reports to the scientific, broadsheet and tabloid press. In outlining them I do not mean to imply my own support for either position. My conclusions are that on the evidence available at the moment, it is impossible to choose between them; there are too many uncertainties about how individuals, families and social institutions will respond to the potential of the new genetics, in addition to uncertainties about the science itself. It is likely, however, that the benefits and hazards of the new genetics will be experienced differentially by different groups in society; for some the discourse of great promise may in fact be realized, for others it may not.

The author is grateful for support from The Medical Research Council, and from the Economic and Social Research Council as part of its Risk Programme (grant number L211252010)

## REFERENCES

Bekker, H., Deniss, G., Modell, M., Bobrow, M. & Marteau, T. M. 1994 The impact of population based screening for carriers of cystic fibrosis. *Br. Med. J.* **31**, 364–368.

Billings, P. R., Kohn, M. A., de Cuevas, M., Beckwith, J., Alper, J. S. & Natowicz, M. R. 1992 Discrimination as a consequence of genetic testing. *Am. J. Hum. Genet.* **50**, 476–482.

Bradby, H. 1996 Genetics and racism. In *The troubled helix*: *social and psychological implications of the new human genetics* (ed. T. Marteau & M. Richards), pp. 295–316. Cambridge University Press.

Bradley, D. M., Parsons, E. P. & Clarke, A. J. 1993 Experience with screening newborns for Duchenne muscular dystrophy in Wales. *Br. Med. J.* **306**, 357–360.

Calman, K. 1994 Developing screening in the NHS. *J. Med. Screening* **1**, 101–105.

Clarke, A. 1996 Population screening for genetic susceptibility to disease. *Br. Med. J.* **311**, 35–38.

Daniel, C. 1996 Every baby a wanted baby? *New Statesman*, 20–22.

Davison, C., Frankel, S. & Davey-Smith, G. 1989 Inheriting heart trouble; the relevance of common sense ideas to preventive measures. *Health Education Journal Theory and Practice* **4**, 329–340.




PHILOSOPHICAL TRANSACTIONS OF THE ROYAL SOCIETY B BIOLOGICAL SCIENCES

Davison, C., Macintyre. S. & Davey Smith, G. 1994 The potential social impact of predictive testing for susceptibility to common chronic diseases; a review and proposed research agenda. *Sociology of Health and Illness* **16**, 340–371.

Department of Health 1995*a* *Report of the genetics advisory group*; *a first report to the NHS central research and development committee on the new genetics*. London: HMSO.

Department of Health 1995*b* *The genetics of common diseases. A second report ot the NHS central research and development committee*. London: HMSO.

Durant, J., Hansen, A. & Bauer, M. 1996 Public understanding of the new genetics, In *The troubled helix*; *social and psychological implications of the new human genetics* (ed. T. Marteau & M. Richards), pp. 235–248. Cambridge University Press.

Duster, T. 1990 *Backdoor to eugenics*. New York: Routledge.

Evers-Kiebooms, G., Denayer, L., Welkenhuysen, M., Cassiman, J. J. & Van den Berghe, H. A. 1994 The stigmatising effect of carrier status for cystic fibrosis? *Clin. Genet.* **46**, 336–343.

Harper, P. S. 1995 Genetic testing, common diseases, and health service provision. *Lancet* **346**, 1645–1646.

House of Commons Science and Technology Committee 1995 *Human genetics*; *the science and its consequencs*. London: HMSO.

Huggins, M., Block, M. & Wiggins, S. 1992 Predictive testing of Huntington's disease in Canada; adverse effects and unexpected results in those receiving a decreased risk. *Am. J. Med. Genet.* **42**, 508–515.

King, M., Rowell, S. & Love, S. 1993 Inherited breast and ovarian cancer. What are the risks? What are the choices? *J. Am. Med. Ass.* **269**, 1975–1980.

Lippman, A. 1991 Prenatal genetic testing and screening; constructing needs and reinforcing inequities. *Am. J. Law Med* **XVII**, 15–50.

Marteau, T. & Anionwu, E. 1996 Evaluating carrier testing: objectives and outcomes. In *The troubled helix*: *social and psychological implications of the new human genetics* (ed. T. Marteau & M. Richards), pp. 123–139. Cambridge University Press

Marteau, T. & Drake, H. 1995 Attributions for disability; the influence of genetic screening. *Social Sci. Med.* **40**, 1127–1132.

Marteau, T., van Duijn, M. & Ellis, I. 1992 Effects of genetic screening on perceptions of health; a pilot study. *J. Med. Genet.* **29**, 24–26.

McLean, S. A. M. 1994 Mapping the human genome–friend or foe? *Social Sci. Med.* **39**, 1221–1227.

Meidzybrodzka, Z., Hall, M., Mollison, J., Templeton, A., Russell, I., Dean, J. C. S., Kelly, K., Marteau, T. M. & Haites, N. 1995 Antenatal screening for carriers of cystic fibrosis: randomised trial of stepwise v couple screening. *Br. Med. J.* **310**, 353–357.

Michie, S., Drake, H., Bobrow, M. & Marteau, T. 1995 A comparison of public and professionals' attitudes towards genetic developments. *Public Understanding of Science* **4**, 243–253.

Michie, S., McDonald, V. & Marteau, T. 1996 Understanding responses to predictive genetic testing: A grounded theory approach. *Psychology and Health* **11**, 455–470.

Office of Science and Technology 1995 *Technology foresight programme*; *report of the health and life sciences panel*. London: HMSO.

Orchard, T. J., Dorman, J. S., La Porte, R. E., Ferrell, R. E. & Prash, A. L. 1986 Host and environment interactions in diabetes mellitus. *J. Chron. Dis.* **39**, 979–999.

Rose, G. & Marmot, M. G. 1981 Social class and coronary heart disease. *Br. Heart J.* **45**, 13–19.

Wiggins, S., Whyte, P., Huggins, M., Adam, S., Theilmen, J., Bloch, M., Sheps, S. B., Schechter, M. T. & Hayden, M. R. 1992 The psychological consequences of predictive testing for Huntington's disease. *New Engl. J. Med.* **327**, 1401–1405.

Wilfond, B. S. & Fost, N. 1990 The cystic fibrosis gene; medical and social implications for heterzygote detection. *J. Am. Med. Ass.* **263**, 2777–2782.

Wilkie, T. 1993 *Perilous knowledge*; *the human genome and its implications*. London: Faber and Faber.

Wilson, B. 1993 Screening for a Down's syndrome baby must not be a precursor to abortion; why finders should be keepers. *The Guardian*.

Wilson, J. M. G. & Jungner, G. 1968 *Principles and practice for screening for disease*. Geneva: WHO.

Woodridge, E. Q. & Murray, R. F. 1989 The health orientation scale; a measurement of feelings about sickle cell trait. *Social Biol.* **35**, 123–136.

Zimmet, P., Arblaster, M. & Thorma, K. 1978 The effect of Westernisation on native populations. Studies on a Micronesian community with a high diabetes prevalence. *Aust. N.Z.J. Med.* **8**, 141–146.




PHILOSOPHICAL TRANSACTIONS OF THE ROYAL SOCIETY B BIOLOGICAL SCIENCES