# Genetics and Human Behaviour: the ethical context

## **PUBLIC CONSULTATION DOCUMENT**



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#### The Council's terms of reference are as follows:

- 1 to identify and define ethical questions raised by recent advances in biological and medical research in order to respond to, and to anticipate, public concern;
- to make arrangements for examining and reporting on such questions with a view to promoting public understanding and discussion; this may lead, where needed, to the formulation of new guidelines by the appropriate regulatory or other body; and
- 3 in the light of the outcome of its work, to publish reports; and to make representations, as the Council may judge appropriate.

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# Terms of reference of the Working Party on Genetics and Human Behaviour: the ethical context

- To define and consider ethical, social and legal issues arising from the study of the genetics of variation within the normal range of behavioural characteristics.<sup>1</sup>
- 2 To survey the current field of research, in particular, to review:
  - a the evidence for the relative importance of genetic influences;
  - b the basis for characterisation and measurement of behaviour;
  - c the relationship between normal variation in behaviour and disease processes.
- 3 To consider potential applications of the research.
- 4 To consider:
  - a the ethics of undertaking research on the genetics of normal variation in behavioural characteristics<sup>2</sup> on human participants;<sup>3</sup>
  - b the implications of applying the findings of such research through the development of genetic tests to establish particular characteristics in practical contexts including education, employment, insurance, legal proceedings;
  - c the particular impact of the findings of a genetic test on the individual, including an individual child or fetus, on family members, and on various social groups;
  - d the broader impact of genetic knowledge on the perception of those with relevant behavioural characteristics, including questions about stigma.

<sup>&</sup>lt;sup>1</sup> And to identify the issues which are additional or complementary to those dealt with in the Council's report on **Mental Disorders and Genetics: the ethical context**.

<sup>&</sup>lt;sup>2</sup> Including, for example, research on intelligence, antisocial behaviour, sexual orientation and addiction.

<sup>&</sup>lt;sup>3</sup> Including ethnic groupings, criminal offenders, and children.

### 1 Introduction

The Nuffield Council on Bioethics, an independent body, has begun an inquiry into the ethical issues raised by research into behavioural genetics. A Working Party has been established for this purpose and will publish a report in early 2002. The terms of reference of the Working Party, and a list of members, is attached.

We would welcome your comments on the ethical, social and legal implications of research into genetics and human behaviour. This consultation paper discusses some of the issues raised by research in behavioural genetics and poses a number of questions. It would be appreciated if you were able to frame your response around these questions.

This paper starts by explaining the background to current debates about behavioural genetics. Section 3 sets out what is meant by behavioural genetics and explains some of the biological terms and concepts. Section 4 addresses the fundamental question of whether there are some forms of scientific knowledge, which we ought not to pursue. Section 5 outlines the possible applications of research in behavioural genetics and Section 6 highlights a number of specific ethical issues that need to be considered.

### 2 Background

Competition between biological and environmental explanations of human behaviour has existed for many years. With the dramatic advances in our knowledge of genetics and the sequencing of the human genome, the focus has moved once again towards understanding behaviour in biological terms. However, there are some important differences between genetic information about disease and illness, and genetic information about behavioural traits. In medical genetics, the identification of an alteration (mutation) or absence of a particular gene can sometimes be associated directly with a particular disease, such as cystic fibrosis or Huntington disease. In such 'single-gene disorders' it could make sense to say that the gene mutation, or the absence of the gene, 'causes' the disease. But for most diseases, and probably all behavioural traits, the relationship is a great deal more complex.

While acknowledging the scientific difficulties, some researchers are attempting to locate specific genes or groups of genes associated with behavioural traits and to understand the complex relationship between genes and the environment. Such research gives rise to a range of ethical, legal, social and practical questions. Some concerns are based on the currently hypothetical possibility of testing for behavioural genetic characteristics, and the implications of this, not least in terms of discrimination and eugenics.

The central precept of eugenics is the idea that the physical, mental and behavioural qualities of the human race can be improved by selective breeding. This means encouraging people who have 'desirable' traits to have children and discouraging, or preventing, those who do not. This belief was at least partially responsible for the appalling events of the 20th century in Nazi Germany, and the compulsory sterilisation programmes for mentally handicapped people in North America and Northern Europe. The memory of these human rights abuses can still cast a shadow over today's genetic research. This is perhaps particularly true in the field of behavioural genetics, where concerns of social prejudice and racism are very real.

### 3 What is behavioural genetics?

The key aims of research in behavioural genetics are to discover whether genetic influences contribute to normal variation in human behavioural or personality traits and to identify specific genes that influence these traits. Such research is concerned with behavioural characteristics that we all share to varying degrees, rather than intrinsically abnormal traits. For example, some research suggests that there is a genetic influence on novelty-seeking, or the extent to which an individual prefers to engage in exciting or risky activities. We can imagine someone who enjoys hang-gliding or snowboarding, and another person who is happier playing board games. Even though these preferences are very different, we consider this to be part of the normal variation in personalities that distinguishes individuals from each other.

Human behaviour is vastly complex, and it is wrong to speak of a 'gene for' a specific trait. There is no evidence of a simple correlation between one gene and one trait. Rather, a number of genes may be involved in an individual's susceptibility to possessing a particular trait. But there will also be environmental influences on both behaviour and genes, and genetic influences on both the environments we seek out and the activity of other genes. So even if some genes are associated with certain types of behaviour, the contribution they make may be individually very small, and the precise effect they have on any particular person may be very difficult to predict. A further complication is that one gene, or group of genes, is likely to affect more than one trait. For example, in 1999 researchers in the US developed a genetically altered mouse that had an improved memory. But in 2001, another group of researchers discovered that mice whose genes had been altered in this way also suffer more from long term pain.<sup>4</sup>

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<sup>&</sup>lt;sup>4</sup> This effect is called *pleiotropy*.

It is also important to note that, as well as the difficulties that arise in identifying and interpreting the influence of genetic factors, it can be just as hard to define and measure behavioural traits themselves.

Behavioural genetics is thus a complicated and often controversial area of genetic research. Various traits with behavioural connotations are currently being researched by behavioural geneticists in the UK and abroad, including intelligence, aggression, antisocial behaviour, anxiety, novelty-seeking, alcoholism, addiction, obesity, and homosexuality.

In humans, three research methods have traditionally been used: family, twin and adoption studies. Such studies allow estimations of *heritability*, which is a statistic showing what proportion of the variation in a population for a particular trait can be attributed to genetic factors. This can only tell us about the influence of genes on whole populations, not on individuals. Then, if heritability estimates suggest that genes do have a significant influence, the next step is to try and identify the specific gene or genes that may be involved. This would enable researchers to make observations about particular individuals. A list of research methods used in behavioural genetics is attached at **Annex A**.

It has been argued that some of the research methods used in behavioural genetics are flawed. Although animal models have been extremely useful in much medical genetics research, they have been subject to criticism as to the validity of inferring from animal behaviour to human behaviour. Statistical assessments such as calculations of heritability have been criticised on the grounds of incorrect interpretation and superficiality. On the other hand, the sequencing of the human genome now enables attempts at determining direct correlations between genetic variation and behaviour to be made, rather than relying on indirect measures such as heritability.

### 4 Why study behavioural genetics?

Although research in behavioural genetics gives us information about genetic influences on behaviour, it can also assist in investigating the contribution of environmental influences, and in understanding how the brain works. Understanding more about normal variation can also help us to learn more about those with particular disorders or problems. For example, identifying genes that influence normal variation in mood could be important in finding gene variants that increase the risk of clinical depression.

Some commentators have suggested that by focusing on genetic explanations of human behaviour, social and environmental factors will be ignored. Ultimately, this could have an effect on social welfare policies, for example by reducing the motivation to improve the environment and surroundings of disadvantaged people and seeking genetic 'solutions' to existing problems instead.

There are numerous concerns about the use which could be made of genetic information about behaviour, many of which are outlined later in this paper. In the light of these concerns, one question which arises is whether such research should be carried out at all. This is part of a broader concern about whether scientific research is morally neutral. It is sometimes suggested that even if there are genetic causes or associations with behavioural or personality traits, it is in general better that we should not know about them, particularly if there is no useful or desirable use which can made of the information. However, many people believe that the suppression of any research is an unacceptable form of censorship. They argue in favour of freedom of inquiry and suggest that if there are facts about ourselves, we ought not to be prevented from finding out what they are.

One example of this dilemma is research in behavioural genetics which attempts to establish genetic causes for differences in behaviour between ethnic groups. For example, in the recent past, it has been suggested that there is a genetic explanation of the finding that black Americans score on average lower marks on IQ tests than white Americans. This conclusion has been subsequently heavily criticised, but illustrates the sensitivity of this type of research.

- 4.1 What do you think are the likely advantages and disadvantages of research in behavioural genetics?
- 4.2 Do you think that behavioural genetics has special features?
- 4.3 Should there be limits to scientific inquiry in this field?
- 4.4 In your view, will research in behavioural genetics have a negative or positive impact on research into social and environmental issues?

# 5 How will findings in research in behavioural genetics be translated into practice?

If genes that influence particular behavioural traits are identified, it could become possible to test for the presence of variations in these genes in individual people. No such tests currently exist and there is disagreement about whether they could ever be developed because of the complexity of human behaviour, the very weak contribution of individual genes or groups of genes to overall susceptibility, the subtle interaction of genes with the environment, and the unpredictability of human development. However, it remains possible that tests which indicate susceptibility to a particular trait might be developed, even if they do not yield predictions of a definite outcome. Such hypothetical tests can be divided into three broad areas:

- i) genetic testing undertaken for the purpose of gaining knowledge
- ii) genetic testing undertaken for the purposes of intervention or treatment
- iii) genetic testing undertaken for the purposes of selection

The first category covers testing to learn more about genetic influences on behaviour. In these cases, the information is not used to change anything, merely to increase our understanding about human behaviour.

The second category might cover procedures such as testing criminals in order to provide 'corrective' treatment, interventions to prevent the development of addictive behaviour or 'tailored' interventions, that is the implementation of different social interventions for people with different gene variants. The interventions that could be used may be genetic, but are more likely to involve medical techniques or attempts to modify relevant aspects of the environment. In theory, this category could also apply to interventions or treatments before birth such as gene therapy during pregnancy.

The third category encompasses prenatal testing and techniques such as preimplantation genetic diagnosis. It could also include genetic personality profiles carried out by employers when selecting employees and the use of genetic information about behavioural and personality traits by insurers. Prenatal genetic tests for single gene disorders such as Huntington disease and cystic fibrosis are already made available to parents.

- 5.1 Should genetic tests for behavioural traits and personality characteristics be developed? Why, or why not? Does this apply to all types of behavioural trait?
- 5.2 Would the pre-natal selection of behavioural and personality traits within the normal range be morally acceptable?

<sup>&</sup>lt;sup>5</sup> Pre-implantation diagnosis is a relatively new technique that involves testing the DNA of embryos that have been created by IVF (in vitro fertilisation), and implanting in the woman embryos that do not have particular genetic diseases such as Huntington disease or cystic fibrosis.

# 6 What are the ethical, legal, practical and social implications of these applications of research in behavioural genetics?

### Health, normality and enhancement

The identification of genetic or physiological influences on behaviour has implications for our current understanding of the difference between health and illness. Unlike genetic diseases such as cystic fibrosis and Huntington disease, behavioural traits are present, to a greater or lesser degree, in everyone. Attributions of disease or abnormality tend to arise when an individual is thought to express an extreme form of a trait, such as aggression. But setting the boundary at which the expression of a trait is extreme is very difficult and open to accusations of arbitrariness. Moreover, it has been suggested that research in behavioural genetics may lead to a tendency to medicalise certain traits, even though they had previously been thought of not as medical problems but as aspects of an individual's character that can be shaped by that individual and by the environment.

A related issue is the question of the enhancement of our capabilities. The desirability of enhancing our capacity to resist disease is relatively uncontroversial. This is the objective of preventive medical procedures and much social welfare. However, the enhancement of our behavioural and personality traits is more controversial. A fundamental concern is that our choices about which traits to enhance will be directed by society's different and changing views and values about the relative importance and desirability of particular characteristics. As one commentator puts it, 'Are we so confident in the wisdom of our conceptions of normality and perfection that we are prepared to use new genetic technologies to achieve them?' 6

A further problem is the distinction between enhancement and treatment. This is illustrated by a hypothetical example: imagine that we can increase the IQ of an individual with a learning disability into the 'normal' range (usually stated to be between 70 and 130 IQ points) by altering their genetic makeup. Would it be morally wrong also to use the same genetic technology to increase the IQ of an individual who already had an IQ within the 'normal' range? Would such a genetic intervention on a 'normal' individual be any different, morally speaking, than sending that individual to a particularly good school with the intention of increasing his or her intellectual performance?

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<sup>&</sup>lt;sup>6</sup> Erik Parens, *Enhancing Human Traits*, Hastings Center Studies in Ethics, 1998. Note that this question could equally be asked of some environmental 'technologies'.

The answer to such questions will have important implications for the use of and access to potential applications of the results of both research in behavioural genetics and environmental research.

- 6.1 What, in your view, might be the effect of research in behavioural genetics on our understanding of health, illness, disability and abnormality?
- 6.2 Is there a moral difference between the *correction* of a trait thought to be the result of a genetic abnormality or defect, and the *enhancement* of that same trait for a 'normal' individual? If so, why?
- 6.3 Is the genetic enhancement of behavioural or personality traits morally different to enhancement by *non-genetic* means such as education or medical intervention?

### Antisocial behaviour and responsibility

One of the central anxieties concerning any biological explanation of human behaviour arises from the belief that we are only morally responsible for those actions that we could have chosen not to perform. In the context of behavioural genetics, the concern is that since we do not choose our genes, then insofar as our genes influence our behaviour, we are not truly responsible for those aspects of our behaviour: we are at the mercy of our genetic inheritance. This argument is controversial and involves important assumptions about the nature of free will, the possibility of physical and genetic determinism, and the nature of causation. A similar argument has already been used on a few occasions, unsuccessfully, in defence of individuals who have committed criminal offences.

Another possibility is that if we are given genetic information about our behavioural predispositions we may be expected to take *more* responsibility for our behaviour by making use of genetic tests, interventions, or preventive measures that may be available.

- 6.4 Are there implications of research in behavioural genetics for our general responsibility for our own behavioural and personality traits?
- 6.5 What are the implications for criminal justice, and the legal process generally, of research in behavioural genetics in the areas of aggression and antisocial behaviour?

### Labelling and discrimination

It has been suggested that genetic explanations of behavioural traits such as homosexuality will make them more easily understandable and less frightening or 'strange' to the general public. However, it is also possible that the opposite response might occur; individuals who display a particular type or level of behaviour may be viewed as genetically and behaviourally abnormal, and discrimination may increase unless these individuals receive 'corrective' treatment. Similar discrimination could also be directed at ethnic groups if research in behavioural genetics reveals genetic differences in the occurrence of particular behavioural traits.

Discrimination may not only be a problem for individuals who currently exist. If diagnostic tests are developed for behavioural traits, it may even be theoretically possible for parents to select an embryo or fetus according to its behavioural characteristics as outlined in Section 5. This could lead to enhanced discrimination against people whose parents do not make use of such technology, whether for ethical or financial reasons.

- 6.6 In your view, might research in behavioural genetics heighten or reduce discrimination, stereotyping and social discrimination between groups?
- 6.7 What do you think will be the impact of genetic knowledge about behavioural traits on the individual, on families and on communities?

### Privacy, confidentiality and consent

Information about genetic influences on an individual's personality may be of interest to third parties. Employers already use psychometric tests to assess the personalities and intelligence of potential employees and might also want to have information about their genetic susceptibility to certain behavioural traits. Insurers may wish to know whether an individual has a genetic susceptibility to aggression or novelty-seeking. There may also be implications for the provision of education if techniques for assessing genetic contributions to an individual's intelligence are developed. These questions have so far only received widespread attention in relation to genetic disease, but they are equally relevant in behavioural genetics. They raise important issues about privacy, confidentiality and consent.

6.8 How might health professionals, governments, employers, insurers, education authorities and others use genetic information concerning human behaviour?

- 6.9 Are there any circumstances when such information should be available to third parties either with or without the consent of the individual?
- 6.10 How can we ensure that consent to the disclosure of such information is properly informed and freely given?

### Public education

Media coverage of advances in behaviour genetics research has been accused by some of being simplistic and misleading. Scientists themselves must also take responsibility for accurately informing the public. There is a danger that inaccurate reporting will contribute to mistaken beliefs about the nature and cause of particular behavioural traits and could encourage discrimination and stigma. The media is one of the most important means by which the general public receives information about scientific issues and will therefore have a key role to play in informing people about new developments.

6.11 Given the complex and sensitive nature of research in behavioural genetics, how can members of the public best be informed about it?

### Policy issues

In view of the dilemmas that research in behavioural genetics may raise, it could be suggested that legislative or regulatory controls may be needed to monitor both the research and any practical applications that may be developed. Unlike medical genetic tests and interventions which are aimed at curing disease, future developments in behavioural genetics are likely to take place primarily in the private sector or the non-health sector rather than in the public sector. This may make regulation more difficult.

- 6.12 Do you think that research in behavioural genetics might require new codes of practice or new regulatory controls? What in your view should be the nature of such codes of practice or controls?
- 6.13 Do you think that genetic tests for behavioural traits might require new codes of practice or new regulatory controls? What in your view should be the nature of such codes of practice or controls?
- 6.14 How much priority would you accord research in behavioural genetics in the competition for necessarily limited research funds?

### Annex A

# Techniques used in research in behavioural genetics

1	Studies involving families, twins and adopted children
2	Linkage studies of inheritance using families. This method involves identifying regions of DNA inherited by family members with a particular trait and which might therefore influence the development of the trait
3	Linkage studies using sibling-pairs (brothers and sisters). Siblings with particular behavioural traits rather than whole families are used. This reduces problems with data analysis and eliminates the need to specify the mode of inheritance of the trait
4	Association studies which examine populations to identify whether a particular form of a gene is associated with a particular trait
5	Candidate gene studies which examine genes with functions of particular interest
6	Studies of individual gene structure and function that contribute to knowledge of basic neurobiology
7	Animal studies
8	Quantitative trait locus (QTL) analysis is a set of techniques originally developed in plant and animal studies for identifying genes which influence a characteristic

### Genetics and Human Behaviour: the ethical context

### Details of respondents

Please complete and return with your response

This response may be included in the list of Yes / No those who have commented

This response may be quoted in the report Yes / No

This response may be made available to other Yes / No researchers interested in the topic

If you have answered 'yes' to any of the above questions, please indicate your name and/or the title of your organisations as it should appear in print:

Please return your response by 31 July 2001 to:

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