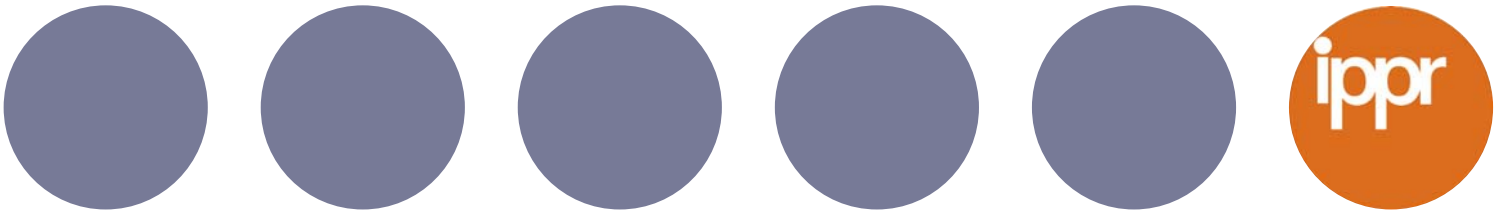

Brave new choices?

Behavioural genetics and public policy
a discussion document

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Executive summary

The rapid advancement of science, and particularly genetic science, is opening up new fields of knowledge to investigation, ethical debate and public policy development. As part of ippr's Rethinking Social Justice project, this paper considers recent advances in behavioural genetics – the study of how genes influence behaviour – and suggests how this research may be both useful and of concern to those interested in a fairer society and greater equality of opportunity.

The paper starts by outlining the current state of knowledge, before asking whether future research will enable more personalised and effective public (and private) services. It also outlines concerns that future findings may raise.

It does not discuss 'medical' genetics – the study of how genes influence disease – nor is it concerned with familiar debates around GM foods or human cloning.

The state of genetic knowledge

Current scientific consensus tells us that genes play an important role in shaping people's behaviour. However, it is important not to overstate the effect that they have; our personalities are not determined by our genes. It will never be possible to predict how someone will act by looking at a genetic test result.

Yet this does not mean that research into behavioural genetics is unrevealing. We know a great deal about how some genes affect some kinds of behaviour. For example, some studies looking at obesity have found genes that appear to increase people's appetite, some have found genes that seem to affect how easy it is for people to give up smoking and others have (more controversially) found links between a particular gene and antisocial behaviour.

Our understanding is still in its infancy but it is possible that research will have practical implications for public policy within fifteen years time. This presents an opportunity to start a public debate about the role of behavioural genetics in public policy and promote discussion that aims to ensure that scientific advances are used in the most constructive way possible, with fairness as a key concern.

More effective services?

One hope is that future findings will enable government services to be more personalised and effective. This is because a behavioural genetic test could provide additional information about which services would benefit an individual most, thereby helping people and professionals to make well-informed decisions. The most obvious application is in aiding people to choose programmes for overcoming substance addiction but there may well be others, depending on the findings of future research.

While it is vital that no-one should ever be required to take a behavioural genetic test or be discriminated against as a result of choosing not to take one, it may be that giving people the option of doing so could help improve the basis on which they make important decisions about their lives.

Should we be worried?

As well as holding the potential for improving people's lives, this form of scientific progress raises new ethical and moral choices. How we respond to these is crucial.

There is enough time before behavioural genetic tests become practically useful to set up appropriate mechanisms to ensure that they are used fairly and to promote a more socially just society. But the government must start to take action now.

The most important concern is the potential of creating a new 'genetic divide'. Different groups in society may have differential access to behavioural genetic tests if they are only available through the market. Those who are already better off may be able to benefit more.

This inequality may be compounded by the way different social groups use information. Much of the debate around choice in education and healthcare reflect the concern that the middle classes may take advantage of information asymmetries. More crudely, the clear socio-economic differences in rates of smoking, where the evidence base is clear, dramatic and uncontroversial, suggest that the middle classes would benefit most from access to behavioural genetic information. While this problem is common to many policy areas – particularly healthcare related ones – it should be recognised that it is particularly significant in this case.

Other areas of concern that this paper considers are:

- Responsibility.
  Will our ideas about people's responsibility for their actions change? Will this affect criminal justice proceedings?

- Unequal benefits.
  Will some people or groups benefit unfairly from advances in behavioural genetics? What could be done to reduce this inequality?

- Protecting information.
  What is the best way to ensure that people's genetic information is securely protected?

- Genetic discrimination.
  Could behavioural genetic tests be used to discriminate against people, particularly in insurance and employment? What should be done about this?

- Eugenics.
  Will people be able to select the personalities of their children? What is an appropriate response?

- Public attitudes.
  Will people begin to think of behaviour as something that has a 'medical' solution? What should be done to prevent this?

It is vital that debate on these issues is as democratic, accessible and open as possible. Informed public concerns and opinions should be paramount in influencing decisions that are made about the acceptable use and boundaries of genetics in public policy. There is currently no forum in which such a debate is possible.

Recommendations

In the light of these concerns, this paper makes the following recommendations:

A new 'People's Science Forum'
A standing deliberative forum should be established that looks at the policy implications of emerging scientific knowledge from a moral and ethical standpoint. Its first task should be to consider behavioural genetics. The forum would consist of a body of people that met for a period of several days, during which they would hear evidence from expert witnesses. With the

help of neutral moderators, members would then talk together, explore options, weigh each others' views and consider costs and trade-offs, before coming to an agreed viewpoint and set of recommendations. The emphasis would be on collaboration and constructive criticism, with the aim of reaching mutual consensus. This would allow differing viewpoints to be heard in a fair and balanced way.

No such body currently exists in the UK. While small scale public consultations and citizen's juries are convened on an *ad hoc* basis for some policy decisions, there is no standing body to which government departments can submit proposals for public scrutiny in a deliberative context. Establishing a People's Science Forum would enable better public involvement in a range of scientific areas. Members could be drawn by lot from the electoral register for each session.

The key challenge in setting up this body would be to ensure that it was integrated sufficiently into the legislative process to ensure that it made a real difference to legislation. One option here would be to create a statutory obligation for government to produce a report detailing how it has used the recommendations of the People's Science Forum in drafting legislation.

Other immediate recommendations
Against genetic discrimination

- The terms of reference of the Genetics and Insurance Committee (GAIC) should be extended to specifically include behavioural genetic tests.
- The terms of reference of the GAIC should include a consideration of the likely fairness of the impact of genetic tests, considering whether a test under consideration will have a discriminatory effect against some socio-economic, ethnic or other group.

Towards a better public understanding of behavioural genetics

- The Science Media Centre should include information about behavioural genetics in its *Genetics in a Nutshell* press briefing. This should highlight the fact that the notion of a 'gene for' is potentially more misleading in describing research concerning behaviour than other research.
- Existing online resources explaining genetics should be updated to include features on behavioural genetics.

Within five years
Maintaining a fair legal system

- The HGC Horizon-Scanning Sub-Group should carry out an information gathering session on the future implications of behavioural genetics for criminal responsibility.

Within ten years
Towards more effective and fair policy

- Government should be actively considering offering behavioural genetic tests in very limited circumstances – where the benefits clearly outweigh potential disadvantages – to improve the way services are delivered to individuals. This should be done through deliberation with the general public (through the People's Science Forum); policy experts; and scientific, legal and ethical advisors.
- Depending on how far and fast science progresses, government should consider setting up a Genetics and Social Policy Committee, with the remit of exploring and monitoring the application of (behavioural) genetics for improving the provision of public services.
- Government should conduct a review into the use of privately bought behavioural genetic tests with the aim of considering whether these should be offered with public subsidy through the healthcare system.

Towards a more equitable use of information

- The Cambridge Genetics Knowledge Park should undertake a consultation exercise into the best way to communicate the benefits of behavioural genetics with a focus on encouraging awareness among traditionally hard to reach groups.

Introduction

This paper considers recent research in the field of behavioural genetics – the study of how genes can influence behaviour – and discusses the implications this has for policy.

While scientific interest in how genetic inheritance is linked to behaviour has been marked since at least the beginning of the eighteenth century, the molecular methods for finding genes associated with human behaviour have only been used since the early 1990s and our understanding still in its infancy. Research is only just beginning to reveal genuine and useful insights about the complex interplay between genes, behaviour and environment.

In the long term, advances in behavioural genetics will almost undoubtedly affect many policy areas, including criminal justice, healthcare, education, welfare and employment. Yet relatively little thinking has been done about the potential implications of this research for a society that is concerned with fairness, equality of opportunity and a good standard of living for all. Media and public attention has been focused on issues such as cloning, 'designer' babies and GM crops, with relatively little emphasis on the links between genetics and behaviour.

This presents an opportunity to start a debate about the role of behavioural genetics in public policy and promote discussion that aims to ensure that scientific advances are used in the most constructive way possible with fairness as a key concern.

Government, policymakers and other interested parties can aim to pre-empt scientific advances by thinking ahead about the possible implications, uses and political and ethical difficulties research will raise, enabling them to formulate appropriate responses. While it is important to recognise the limits of what can be achieved by speculating about future findings, pre-emptive discussion and public debate can help by raising awareness, considering popular opinion and putting appropriate consultative bodies in place.

This paper aims to promote this debate, as part of ippr's Rethinking Social Justice project. While the details of future policy depends on the detailed findings of future research, there are steps that need to be taken now. This paper takes a broader look at the relevant issues for those concerned with a fair, equal and prosperous society and makes recommendations for action.

The paper begins by outlining current government policy regarding behavioural genetics in Section 1. Then Section 2 looks at the state of knowledge in behavioural genetics, highlighting recent research that suggests how scientific advances may be useful for public policy. It discusses the extent to which genes influence behaviour and the likely limits to the predictive power any future genetic test could have.

The final sections draw out the implications for public policy. Section 3 considers whether research will enable better solutions to existing policy problems, using examples related to antisocial behaviour and some forms of social exclusion. Section 4 asks whether future findings create new concerns for policy makers and what appropriate responses to these could be. It also makes specific recommendations. The most important of these is the establishment of a People's Science Forum for improving upstream public involvement in policy development concerning emerging scientific issues. Section 5 outlines how this should operate and what its remit should be.

1 Current government policy

Government is concerned with future advances in genetics and has set up responsible and forward-looking mechanisms to advise policymaking. One result of this was the white paper in June 2003, which focused on realising the potential of genetics in the NHS (DoH 2003).

There are three main governmental advisory bodies directly concerned with policy development for genetics in the UK. These are:

1. *The Human Genetics Commission* (HGC). This was created to advise government on how new developments in human genetics will impact upon people and healthcare. Its remit is to give Ministers strategic advice on the 'big picture' of human genetics, with a particular focus on social and ethical issues. The HGC does carry out some public consultation work through citizen's juries, although this tends to be small scale.

2. *The Foresight Healthcare Panel*. Foresight is funded by the Office of Science and Technology with the aim of increasing UK exploitation of science. The Foresight programme has a dual remit of identifying potential opportunities for the economy or society from new science and technologies, and considering how these could address key future challenges for society. It is currently engaged on a project concerning how scientific and technological advancement may impact on our understanding of addiction and drug use over the next 20 years.

3. *The Genetics and Insurance Committee* (GAIC). The Government made a manifesto commitment to tackle the issue of genetic discrimination and has negotiated a moratorium with the insurance industry that will last until 2006. Under the moratorium, insurers may not use genetic test results in setting premiums for life insurance policies up to £500,000 or for critical illness, long term care and income protection policies up to £300,000. Above these limits, insurance companies are only allowed to use results of genetic tests that have been approved by the GAIC. To date, the only genetic test that has been approved by the committee is for Huntingdon's disease for life insurance policies over £500,000. The Committee also monitors compliance with the moratorium and investigates any complaints that cannot be resolved by the insurance company or the Association of British Insurers (DoH 2003).

In addition to these bodies, the House of Commons Select Committee on Science and Technology and the House of Lords Select Committee on Science and Technology have a remit to look at these issues. Furthermore, the Department of Health (DoH) and the Department of Trade and Industry (DTI) are jointly supporting the development of five genetics knowledge parks over five years from 2003. The knowledge parks will carry out research into the genetic components of major diseases, the implications of genetics for NHS services and broader ethical, social and legal issues.

2 The State of Knowledge

Genetic science is advancing rapidly and it can be hard to keep track of the latest developments. Fortunately, policymakers do not need to have comprehensive knowledge of all scientific developments within a newly developing field. What is important is that they ask the right questions and think carefully about what the answers mean. As far as thinking about the future implications of behavioural genetic research is concerned, the key questions are:

- Do genes influence behaviour? If so, to what extent?
  This would tell us how effective predictive genetic tests could be in theory.

- Is it possible to predict someone's personality or behaviour from their genes? If so, to what extent?
  Even if it was known that behaviour was largely determined by genes, the mechanisms might be so complex that no predictive test could be developed. This would give us a good idea of how powerful predictive tests could be in practice.

- Do people react differently to different interventions (such as criminal sentencing, educational environments, drug treatments or mentoring programmes) depending on their genes? If so, is it possible to predict how and to what extent?
  This would tell us whether genetic tests could help people to choose more effective and personalised services.

The rest of this section outlines what current research tells us about each of these questions and suggests what this could mean for policy. It explores the technological possibilities of behavioural genetic tests but does not consider whether we should in fact want to exploit these. This question is discussed in Section 3.

Genes account for 30 to 50 per cent of the differences in behaviour between individuals

Much of people's behaviour and personality are formed in childhood. How this happens is partly determined by their genes and partly by the environment they grow up in and the experiences they have (Marcus 2003). What is important is how these three factors interact, which is why debate about whether 'nature' or 'nurture' is more important tends not to get anywhere – nature is part of nurture and nurture is part of nature.

A useful way to think about the way genes work is as sources of options that are switched on or off by experiences and environment during childhood. Genes do not *determine* how the brain grows independently of experience; they *influence* how the brain grows in response to experience. Wilson (1998: 37) explains that:

"genes prescribe epigenetic rules, which are the neural pathways and regularities in cognitive development by which the individual mind assembles itself. The mind grows from birth to death by absorbing parts of the existing culture [including environment and experience] available to it, with selections guided through epigenetic rules inherited by the individual brain."

As such, it would be surprising if there were extremely strong links between genes and behaviour. Environment and experience clearly play crucial roles.

Observational studies of relatives, such as twins, can help show the extent to which genes affect behaviour. One body of research compares the differences between identical twins who have been separated at birth and brought up in different adopted families (Gray 2002). The studies

rely on the fact that since such twins are genetically identical, any differences must be due to environment and experience, which allows estimates to be made for how important genes are.[1]

Although this research can reveal how strong the genetic influence is on personality, talent and behaviour, it does not lead directly to predictive information about individuals, nor does it give reliable estimates of how strongly predictive a genetic test might be, were it to be developed. This is because the genetic effect might be extremely complex, involving many genes interacting with each other and the environment.

Studies following similar methodology has shown that the genetic contribution to personality is substantial for many different personality attributes, such as Neuroticism, Agreeableness and Conscientiousness.[2] There is wide consensus that the difference in behaviour between individuals is 30 to 50 per cent determined by genes and 50 to 70 per cent determined by environment and experience (Gray 2002).

This is relevant for policy because it means that behavioural genetic tests will not be able to predict an individual's personality (except possibly in very extreme cases) to a great degree of accuracy. It is extremely unlikely that behavioural genetics will develop to the point where it is possible to predict an individuals behaviour from their genes; the scenarios laid out in blockbuster films like *Gattaca* and *Minority Report* will remain science fiction.

One upshot of this is that such genetic tests will often be less revealing than existing non-genetic tests, such as IQ tests and personality questionnaires, and existing methods of determining individuals at risk of social exclusion or other undesirable outcomes.[3] At the most, behavioural genetic tests will be an additional tool for policymakers; they are far from being a panacea for all social problems.

This is an important finding. When considering the implications of future technological and scientific advances it is often easy to be drawn into speculation that goes beyond what can be practically expected or is supported by research.

Yet this does not mean that advances in behavioural genetics will be irrelevant for policy. In some specific situations, genetic tests may have enough predictive power to make policy more effective helping to improve people's lives, despite the fact that this power will be relatively limited. The areas that will benefit most immediately are those in which most research is concentrated. Accordingly, it will be helpful to consider the state of knowledge in some specific fields.

A gene for appetite?

A substantial scientific effort is underway into trying to understand the genetics of obesity and diabetes, with more than 250 genes currently under investigation. Research published last year suggested that one way genes may affect people's risk of becoming obese is by affecting their appetite (Boutin *et al* 2003).

The study showed that people with a particular version of a gene called GAD2 were more likely to be obese. This gene seems to stimulate overeating by speeding up production of a chemical

[1] This is clearly a simplification of the methodology. Studies use complex statistical models to isolate relevant environmental and genetic factors.
[2] The standard model of personality used by behavioural genetics researchers has five 'dimensions of personality'. These are: Neuroticism, Extraversion, Agreeableness, Conscientiousness and Openness to Experience. These are usually capitalised to distinguish the terms from those in everyday use.
[3] The link between intelligence and behaviour is under analysis by Plomin *et al* at the Institute of Psychiatry in London. This paper does not discuss the implications of this research as the science in controversial and the other examples used provide more tangible indications of possible policy implications.

messenger in the brain called GABA, or gamma-amino butyric acid. When combined with another molecule, GABA stimulates us to eat which means that people who produce too much of it have larger appetites than those who produce less and so are more likely to be obese, as they may still feel hungry even when they are full.

Environment, genes and antisocial behaviour

A substantial body of research has also been carried out into the genetic component of antisocial behaviour. This is partly because there is good data on people involved in antisocial behaviour, collected through the criminal justice system, and partly because there may be implications for policy.

Recent estimates of heritability for antisocial behaviour from cluster around 40 per cent (Rhee *et al* 2002). This means that the identical twin of someone who has displayed antisocial behaviour is nearly twice as likely as the average to show similar signs themselves, controlling for other factors.

One revealing study, published in August 2002, investigated the link between the gene encoding monoamine oxidase A (MAOA), which affects the production of a protein involved in the metabolism of serotonin in the brain, and antisocial behaviour in a group of 500 male children in New Zealand (Caspi *et al* 2002).

The study examined the genotypes of the boys and identified a variant in the MAOA gene that was associated with high levels of MAOA activity in the brain, and another that was associated with low levels.

The researchers found that by age 11, 36 per cent of the children in their study had been maltreated (8 per cent severely).[4] Of these, the 12 per cent that had the gene associated with low levels of MAOA accounted for 44 per cent of their generation's total convictions for assault and other violent crimes. As adults, 85 per cent of the severely maltreated children who also had the gene for low MAOA activity experienced antisocial outcomes, such as violent criminal behaviour; the combination of maltreatment and the genetic variation magnified the odds by nine times. (Those children who were maltreated but had the other version of the gene were relatively unlikely to develop behavioural problems).[5]

Much more work needs to be done in this area, before we are able to draw firm scientific conclusions. However, the New Zealand study does provide an indication of what future research may be able to show: some people may be more at risk of being affected by certain adverse experiences than others and the degree to which they are affected may depend on their genes. This may have important implications for policy development as behavioural genetic tests could provide additional information about which environmental factors are most influential in how people's personalities and behaviour develop. Since much policy is focused on affecting the environment in which people live and the (educational) experiences they have, better understanding of the way people are affected by their environment at an individual level could enable much more personalised policy measures.

[4] Defined as experiencing frequent changes in primary caregiver, rejection by the mother and physical or sexual abuse

[5] Care should be taken when interpreting this study, as it has been the subject of some criticism in the scientific community, and its results are fairly controversial. It has been noted, for example, that low levels of MAOA are associated with impaired cognitive ability, and that it may be this that correlates more generally with antisocial behaviour. In other words, the link between MAOA and antisocial behaviour may be less direct than the research seems to suggest. However, it still provides a useful thought experiment for possible implications of behavioural genetic research for public policy.

How effective services are for an individual may depend on their genes

As well as influencing how sensitive people are to environmental factors when they are growing up, genes may also influence how effective different types of treatment or intervention are for different individuals. Some interesting findings come from studies looking at smoking.

Researchers in Japan have shown that people with one variant of a gene involved in processing nicotine find it harder to give up smoking, possibly because they are unable to break down nicotine in the body, and suffer greater withdrawal systems by giving up – as their body is less used to low nicotine levels than other smokers (Minematsu *et al* 2003). People with the specific variant appear to require more help to give up smoking, which may include closer monitoring and drugs for depression. In addition, lower doses or longer dosing intervals are needed when using nicotine replacement therapy.

A second study, in the UK, found that nicotine patch therapy for smoking has negligible effect on women with a certain gene type (Yudkin *et al* 2004). Researchers looked at a gene that controls a brain receptor for dopamine, a neurotransmitter that is associated with pleasure and addiction. The gene comes in two variants, known as the T and CC alleles. The researchers found that there was a high response to nicotine patches among women with the T variant, but almost no response in women with the CC variant.

These advances have led to a surge in companies developing genetic tests for private consumers. For example, the NicoTest – launched in December 2004 by g-Nostics – can be carried out in the same way that diabetics self-test for blood-sugar (www.nicotest.com). The test gives a 'metabolic profile' which shows how quickly a smoker is able to clear nicotine from their body, helping to determine the right dose in Nicotine Replacement Therapy. In theory, it could also be used to check which children have a particular addictive gene and are at risk of becoming addicted to nicotine in the future.

While studies like these are most obviously relevant for healthcare, they are also important for public policy because they show the potential of genetic science to provide additional information about which treatments or programmes will be most effective on an individual basis. This could make policy measures more effective by helping to reveal which services are most suited to a particular individual in overcoming a particular kind of difficulty.

Behavioural genetics could influence public policy within 15 years

Of course, it is important to be realistic about how soon genetic tests could really be used. There are still many problems for scientists working in behavioural genetics to overcome, but this does not mean that the implications of advances should not be considered until they are practically feasible.

There are several reasons why behavioural genetic research is particularly difficult:

- Many medical disorders are the result of one genetic defect. It seems likely that most behavioural traits are the result of many genes interacting, which is significantly more complex.
- The genetic (rather than environmental or experiential) component of behavioural traits is harder to isolate than for many medical conditions.
- The descriptions that we use to describe behaviour are relatively imprecise, particularly when talking about criminal or antisocial behaviour. Our terminology is defined by vague symptoms rather than causes. It seems likely that most behavioural traits that we have descriptive terms for are likely to have a many–many causal relationship with underlying genetic determinants; there could be many genetic causes of violent

tendencies and many more kinds of violent tendencies than we had realised. A significant methodological problem here is that we simply do not know what it is we are trying to measure in many cases; our descriptions of different types of behaviour do not distinguish between behaviours precisely enough.

A salient example here is the study of schizophrenia, which is known to have a strong genetic component: it runs in families and is highly correlated between identical twins that have been separated at birth. Despite significant research efforts looking at the genetics of schizophrenia, no specific genetic correlations have been found.

Scientific knowledge about the behavioural impact of genetics is currently limited in both predicting which individuals are at risk of certain types of behaviour and predicting which factors are likely to be particularly influential for a given individual. It does not appear that this knowledge will be available to policymakers at a practical level within the next fifteen years. However, the scientific community is generally optimistic that such knowledge will be found. It is currently at the limits of feasibility but it is worth pointing out that we have significantly under-estimated the problem solving abilities of science in the recent past, particularly with reference to genetics.

The earliest that consensus is likely to emerge about the links between some specific personality traits and specific genes is in around fifteen years time. It is crucial that policy mechanisms are in place by this time to ensure such knowledge is used in the best way.

The rest of this paper asks what the progressive response to behavioural genetic knowledge should be. Will it enable government services to be more effective? Should we be worried? What can we do now to ensure that research findings have the greatest benefit?

3 More effective services?

Environment, drugs and genes

Policy often aims to influence people's behaviour through affecting the world in which they live. This can vary from broad macroeconomic policy to targeted support services.

Yet there are other ways that people's behaviour can be influenced. One is pharmacologically – through drugs that influence mood. Some forms of behaviour are 'treated' using drugs; one obvious example is the prescription of Ritalin for children diagnosed as having Attention Deficit Hyperactivity Disorder (ADHD) – although the widespread prescription of Prozac is another case in point. Advances in behavioural genetics will reveal the neurophysiological mechanisms behind various types of behaviour and could contribute to the development of drugs which work in this way.

A further way of influencing behaviour would be by 'genetic intervention', directly altering people's DNA. This is still far from feasible given current levels of scientific understanding but it might be possible within decades.

While debate around the suitability of these is certainly necessary, this paper is not concerned with genetic or pharmacological 'treatments'.

In 2021 we will probably know enough about the links between genes and behaviour to make a real difference in the way that government services are developed and delivered. While it is important not to draw unwarranted conclusions or speculate too wildly, it is useful to consider what practical use new findings may have.

Predicting the political future is notoriously unreliable. Yet it seems likely that we will face many of the same issues as we face today, with some new challenges raised by new concerns. Policymakers will still be interested in 'what works', meaning that considering how behavioural genetic advances could affect services as they are currently organised is a useful and revealing exercise.

As highlighted above, the use of behavioural genetics lies in its potential to provide detailed, personal information about individuals. This is particularly interesting as a significant recent move in the provision of public (and private) services is a shift towards greater personalisation, tailoring services to people's individual needs, which is generally both more effective and more efficient.

Behavioural genetic knowledge has the potential to increase government's ability to personalise services and how we decide to allow or restrict use of the information it provides is crucial. The key concerns are that *individuals remain free to choose whether or not they provide this information and suffer no discrimination or disadvantage from withholding their genetic information, and that any use of genetic information is equal and equitable* – advances in behavioural genetics should not benefit one group in society more than another.

With these principles in mind, the rest of this section will discuss whether behavioural genetics could in fact make services more effective, before outlining a useful life-stage model for thinking about its public policy implications.

The earlier the better?

Tackling the causes of many types of social problem is more effective than treating the symptoms. This is particularly true in education, health and crime policy. A recent report calculated that if one in ten young offenders received effective early preventative intervention the annual saving would be in excess of £100 million (Audit Commission 2004) and social theorists argue that the timing of services is of paramount importance (Yaqub 2001).

Effective early intervention depends on being able to identify individuals who would benefit from appropriate targeted help from the state, business and third sectors, before the problems they face become insurmountable or entrenched. Government has devoted significant resources to identifying these individuals through measures including Youth Offending Teams, Connexions and behaviour improvement programmes in schools, and developing programmes to support them, such as SureStart and Positive Activities for Young People.

- SureStart aims to aid services development in disadvantaged areas alongside financial help for parents to afford childcare.
- Positive Activities for Young People (PAYP) provides a broad range of constructive activities for 8 to 19-year-olds at risk of social exclusion, aiming to develop young people's interests, talents and education, and engage them in community activities with an aim of making them less likely to commit crime. Activities based on arts, sport and culture take place both during the school holidays and out of school hours throughout the year.

The effectiveness of these programmes partly depends on them being targeted to the right areas and (through this) to the right individuals, yet it is often difficult to predict who is at greater risk. Many of the signs are well known; experiencing difficulty at school, youth offending, lack of parental support and truanting are all correlated with reduced life chances, but these are far from perfect indicators.

This might suggest that behavioural genetic tests could be used to help identify which individuals are most at risk of developing anti-social behaviour and which environmental factors would make this most likely. While this would raise many ethical and moral difficulties, it is not a likely scenario. It is important to remember that the accuracy of any such tests would be extremely limited in most cases and existing ways of identifying individuals at risk would almost always be more effective. This is a finding that is to be welcomed as there are serious moral concerns here related to respect for people's dignity and rights.

Although behavioural genetic tests should not and could not be used in selecting which individuals receive state services aimed at reducing risks of social exclusion, this does not mean that they cannot play a role in public service provision. The potential use of behavioural genetic tests is more likely to lie in helping individuals to choose the services that are most effective for their needs, by providing them with additional information. This is the issue that debate should concentrate on.

More personalised services?

Government offers many different types of service to tackle social exclusion and improve people's life chances. Taking the example of substance addiction, there are an enormous variety of services that are on offer to help people to participate in society in a useful and productive

way. Much of the effectiveness of these services depends on the user being enrolled in a suitable programme (NTASM 2004). For some, care planned counselling is more appropriate than structured day programmes or residential rehabilitation services, while for others, the reverse may be true.

The research on smoking described in Section 1 suggests that the effectiveness of different types of treatment may partly depend on genetic factors. As we understand more about the processes by which genes interact with environment to influence behaviour, personality and talent, we will be able to develop more effective and targeted services. There are two strands to this.

- The first is in aiding researchers to understand why certain people respond to some services while others do not, which would enable more useful services to be developed.
- The second is in providing a test which people could choose to take that could help them select the most appropriate services for their needs, by providing them with more information about why they have the needs they do.

This is clearly sensitive ground. While basing services on knowledge about people's families is not new (doctors routinely ask about patients' family histories in an effort to prescribe appropriate treatment and medicine), offering genetic tests related to behaviour is clearly a significant step. What is crucial here is that individuals have the choice of not taking a genetic test and that they do not suffer discrimination as a result of declining. Requiring people to undergo such tests as a precondition to receive services would clearly be unacceptable as well as counter-productive: this could act as a significant deterrent to many people.

Behavioural genetic tests should be seen as just another way of gaining information that can aid tailored, effective service provision. It is here that the real potential of (behavioural) genetics to transform public service provision lies: in giving people the ability to make better, more informed decisions about their lives.

A life stage model

Genes have different effects at different times. Accordingly, a useful way of thinking about the policy implications of behavioural genetics follows the 'life stages' of an individual – birth; childhood; and adolescence and adulthood – as the potential policies in each of these areas will have different foci. The rest of this section analyses each of these stages in turn and suggests examples for further consideration by policymakers.

Birth

Screening for PKU (a simple genetic disease) and hypothyroidism (a complex mixture of diseases with some genetic involvement) is offered to all newborns in the UK. These tests use a pinprick of blood taken from the heel and require parental consent, which parents almost always give: they are interested in the welfare of the child and there are treatments available for these genetic disorders that depend on diagnosis before symptoms become obvious.

Requiring parental consent has both moral and practical advantages and should be regarded as absolutely necessary.[6] Morally, it allows parents to make an informed choice regarding their offspring, reducing imposed intervention by the state where it is unnecessary. Practically, it can improve parental co-operation with any treatment that is diagnosed and the relationship between health workers and parents, helping to avoid potential conflict.

[6] The Human Genetics Commission, working with the National Screening Committee, is conducting an initial analysis of the ethical, social, scientific, economic, and practical considerations of genetic profiling at birth and will report by the end of 2005. An initial discussion document is available (HGC 2004).

Screening at birth for behavioural and personality-related genes could be offered with little additional inconvenience to parents or children (although the cost implications will not be clear for several years). However, there are significant differences between testing for specific, named disorders which have clearly defined treatment scenarios and testing for factors related to behaviour, personality and talent, where 'treatment' is not clearly defined, tests have limited predictive power and parents own ambitions and skills may be tacitly called into question.

The reason why some parents might choose neonatal behavioural genetic testing for their child would be that it would give them additional information about which environmental factors he or she was most sensitive to. This could enable parents to improve their child's life chances by tailoring their home environment to the needs of their child, being particularly vigilant to signs of certain behavioural patterns developing, and seeking advice and guidance more readily.

Considering the research discussed above, which implies links between a variant of the MAOA gene and increased sensitivity to some kinds of risk factors for antisocial behaviour, suggests that a test for the genotype conferring low levels of MAOA activity could be developed. Parents whose children were known to have the genotype could be offered voluntary parenting classes aimed at reducing conflict in the home and given easy access to information about programmes aimed at preventing antisocial behaviour. This might reduce the likelihood of children with the relevant genotype suffering social exclusion later, giving them greater chance in life.

However, informing parents of risk factors may induce fatalism on the part of the parents, which may lead to a higher risk for the child than would otherwise be the case. This is particularly true in situations where the level of education concerning genetic risk factors is low in the general population.

The important point here is that neonatal behavioural genetic tests will almost certainly be available through private providers when they are technologically feasible. Even at this early stage, companies such as Sciona, GeneLink and NuGenix offer genetic tests through the internet.

The question is not whether such tests are acceptable, as it seems there is relatively little that government could realistically do (or morally claim the right to do) to prevent their private sale and use; rather the question is whether such tests should be provided through publicly funded routes. The worry would be that if such tests do enable parents to improve the life chances of their child in a significant way but are only available through private services, it may be that those born into poorer families will be unable to benefit, resulting in reduced social mobility and greater inequality.

Childhood

What happens in childhood can have dramatic effects on later life. Much government policy is devoted to ensuring the best possible start to life: there is a well publicised commitment to ending child poverty within a generation. Few would disagree with the aim of ensuring equality of opportunity for children at birth and many would favour equality of opportunity at five, ten or fifteen.

Offering the option of genetic testing might be useful for policy aimed towards increasing equality of opportunity. Again, much depends on the specifics of discoveries, but based on the research outlined earlier, it is possible to flesh out what some policy options might be.

Over 200,000 prescriptions were issued for Ritalin for Attention Deficit Hyperactivity Disorder (ADHD) in 2002. ADHD is a loosely defined disorder which has the symptoms of impulsive and restless behaviour and may lead to sufferers being inattentive at school and unable to learn or socialise as well as other children. This has dramatic repercussions for children's later life success.

Although relatively little is known about the causes of ADHD or the best way of treating children, it is possible that genetic tests could be developed that revealed different underlying causes of ADHD in different children. For example, diet might be more important for some children than others. This information could then be used to help advise on the best ways for families to provide better help and support for children with ADHD and minimise its negative effects on their lives.

Adolescence and adulthood

Patterns of behaviour and personality have often formed by adolescence and continue into adulthood. At this stage, genes have less developmental effect but continue to influence how adults respond to particular environments and treatments, as shown by the research discussed above in relation to smoking.

While the most obvious benefits of behavioural genetic research may be in relation to services related to drug addiction, there may be other policy implications in areas in which the tailoring of interventions to individuals' personalities forms a crucial part of its effectiveness. Much depends on the specific findings of future research

4 Should we be worried?

The public policy initiatives that behavioural genetic science may enable are difficult and controversial. But they are also some way off. The concerns that recent advances raise are more pressing and require serious care and attention.

This section outlines the main issues for progressives concerned with a fair, socially just society and presents policy recommendations.

Unequal benefits?

Behavioural genetics will enable people to know a great deal of information about themselves, should they choose to undergo genetic tests. As well as medical risk factors that affect diet, health and lifestyle, they will have access to (limited) information about their behavioural, personality and talent propensities.

This knowledge will enable them to make more informed choices concerning their lives. For example, knowing that you have a greater chance of becoming addicted to alcohol might make you more careful in your social drinking, and more prepared to seek help when symptoms develop.[7] However, there is a correlative risk that such knowledge might engender feelings of fatalism or apathy if it is not communicated effectively.

There are two concerns here. The first is that different groups in society may have differential access to behavioural genetic tests if they are only available through private provision. Those who are already better off may be able to benefit more.

The second relates to the way different social groups use information. Much of the debate around choice in education and healthcare reflect the concern that the middle classes may take advantage of information asymmetries and benefit more. More crudely, the clear socio-economic differences in rates of smoking, where the evidence base is clear, dramatic and uncontroversial, suggest that the middle classes would benefit most from access to behavioural genetic information. While this problem is common to many policy areas – particularly healthcare related ones – it should be recognised that it is particularly significant in this case.

In the light of these concerns, we recommend that:

- **The Cambridge Genetics Knowledge Park should undertake a consultation exercise into the best way to communicate the benefits of behavioural genetic with a focus on encouraging awareness amongst traditionally hard to reach groups. This should be done within ten years.**

- **Government should be actively considering offering behavioural genetic tests in very limited circumstances where the benefits clearly outweigh potential disadvantages to improve the way services are delivered to individuals. This should be done through deliberation with the general public; policy experts; and scientific, legal and ethical advisors. This should be done within ten years.**

- **Depending on how far and fast science progresses, government should consider setting up a Genetics and Social Policy Committee, with the remit of exploring and monitoring the application of (behavioural) genetics for improving the provision of public services. This should be done within ten years.**

[7] It seems highly likely that some forms of alcoholism are at least partly genetic. Adopted children born to alcoholic parents are four times more likely to become alcoholic that those born to non-alcoholic parents, even when their adoptive parents do not drink (Rice *et al* 2003).

- **Government should conduct a review into the use of privately bought behavioural genetic tests with the aim of considering whether these should be offered through public subsidy through the healthcare system. This should be done within ten years.**

Responsibility

Thinking about responsibility is important for understanding social justice and political debate has recently focused on balancing rights and responsibilities. Society could not function without a conception of personal responsibility, which informs on the way we hold people accountable for their actions in everyday life. A progressive politics of responsibility needs to recognise the legitimacy of some forms of state sponsored conditionality, that background makes a large difference to people's opportunities and that our responsibilities lie centrally in the public and political spheres (White 2005).

Arguments about the limits of personal responsibility have fascinated thinkers for many years as there seem to be important links between responsibility and fairness. One line of thought argues that the difference between a person being responsible for their situation, and being in a situation by chance or bad luck is sometimes thought to be decisive when considering fairness (Dworkin 1981 and Roemer 1995). The idea is that it is unfair if someone suffers through no fault of their own, through mere bad luck, but that it is not unfair if someone suffers because of their own negligence, lack of foresight or carelessness; society should be more prepared to compensate those who suffer unfairly and care less about those who are responsible for their own suffering. While this argument is not uncontroversial, it does help to show how crucial the concept of personal responsibility has been.

One trouble here is that we often find it difficult to decide when someone is responsible for their actions and hence the degree of support society should offer.

Behavioural genetics seems as if it might be able to shed light on this debate from an evidence based perspective. It is well known that there is a link between certain personality and behavioural traits (such as serious depressive tendencies) and reduced welfare – lower standards of living, less income, greater dissatisfaction and worse opportunities. A better understanding of the underlying cause of those traits might help to clarify how responsible people are for their situation.

Although it might seem that this is an abstract philosophical point, it has important repercussions at practical levels. Most obviously, responsibility is a key notion in criminal justice, but it is also important in a softer sociological sense: enabling people to have greater knowledge about the way their behaviour may be influenced by their genes may alter the way they think about the opportunities open to them. The rest of this section looks in more detail at these areas.

Criminal justice

A key feature of the criminal justice system is a defendant's right to point to mitigating circumstances for a crime, such as provocation or self-defence. It might seem that advances in behavioural genetics could lead to legal defences based on genetic evidence, significantly altering our conception of legal responsibility.

This is an doubtful scenario. Genetic variation in the normal range is unlikely to be considered an excuse for legal purposes, at least for the foreseeable future. Where the defences of insanity and diminished responsibility are applicable, there will be much better psychological evidence than can be provided by genetic tests. As such, they may provide corroborating evidence but will not be the crux on which defences rest as their predictive power is too weak.

However, if progress in behavioural genetics reveals close and clearly identifiable associations between particular genetic variants and particular forms of antisocial acts, there would be a case for a re-examination of the legal implications. It might be that the concept of diminished responsibility, for example, could be expanded to embrace such conditions, perhaps by redefining views of illness. If this possibility were to be considered, thought would have to be given to the potential dangers of unwarranted over-reliance on genetic information and the consequences of reducing responsibility for our actions.

With regard to the sentencing of convicted offenders, the criminal law should be receptive to whatever valid psychiatric and behavioural evidence is available. The taking into account of genetic factors would depend on the degree to which such evidence is convincing and relevant. Credible evidence of influence and a robust test for the genetic factor in question would be essential: the weight to be accorded to such information would be determined by the judge. Currently, environmental, social and psychiatric assessments may be taken into account by judges in determining appropriate sentences. These must also be supported by valid, accurate and reliable evidence.

It would be unwise to assume that genetics will not be able to assist in determining degrees of blame, even if the 'all-or-nothing' question of responsibility is not affected by genetic factors themselves. Such a role would not compromise basic assumptions about responsibility. Exchanges between genetics and the criminal law are at present not very productive given the uncertain nature of the evidence. This is likely to change over the next few decades.

The regular exchange of ideas in this area between researchers in behavioural genetics, criminologists and lawyers could be an effective means of ensuring that legal concepts of responsibility are assessed against current evidence from the behavioural and medical sciences. The Human Genetics Commission (HGC), the body that advises the government on issues concerning genetics, currently has no plans to consider behavioural genetics except for monitoring the activities of other bodies concerned with behavioural genetics.

In the light of these concerns, we recommend that:

- **The HGC Horizon-Scanning Sub-Group should carry out an information gathering session on the future implications of behavioural genetics for criminal responsibility. This should be done within five years time.**

Protecting information

The availability of genetic information about individuals raises serious concerns. Any policy which uses genetic testing requires both the analysis and storage of personal genetic data, which is raises ethical difficulties in the areas of privacy, consent and respect for human dignity.

Genetic information is unlike other personal information as information about one individual in a family is likely to reveal information about another individual in a family. This makes consent a difficult notion; information can be known about someone, whether or not they give their consent. This may lead to particular difficulties: a person may know that they have inherited a gene for late-onset Parkinson's from their parent, but their parent may not know they have this disease. Should the child be allowed to tell the parent? Will it be practically possible to stop them?

Genetic tests will reveal many conditions and disadvantages for which there is no known remedy or cure. It is important that people are fully aware of this, when taking a test. One solution here might be that people give levels of consent, tailoring knowledge to cures.

There is huge potential for abuse of data (see genetic discrimination below). The Human Genetics Commission reported on this issue in 2002 and ippr endorses the recommendations in the HGC's report while raising concern that many of its recommendations have yet to be taken up (HGC 2002).

Genetic discrimination

There is genuine concern that the availability of detailed genetic information about specific individuals, combined with relatively good predictive knowledge about the effects of particular genes, will lead to genetic discrimination; some services or opportunities may be restricted to certain individuals on the basis of their genes.

Worryingly, this restriction is most likely to impact on the disadvantaged. It seems likely that genes do make some difference to success (at least across the population). Those who have genes that predispose them to be more likely to engage in unusual behaviour might be more likely to be economically disadvantaged, and would also be more likely to face higher premiums by insurers or lenders were behavioural genetic tests introduced. They would be doubly disadvantaged.

This is most obviously an issue in terms of healthcare. Where healthcare is provided for by private insurers operating in conditions of open competition, it is in the insurers interest to know as much as possible about individuals; by excluding 'high-risk' individuals from certain premiums, they are able to offer lower premiums to other customers. If behavioural genetic knowledge, or knowledge that relates genes to likely social welfare outcomes (and the attendant health risks associated with these), is available, this discrimination will be possible on a much wider genetic basis than has been previously considered.

Where healthcare is provided for by the state, these problems are less pronounced. There is no history of patients in the NHS being prioritised according to whether they have exacerbated their conditions through their behaviour. Importantly, the predictive power of behavioural genetic tests not likely to be strong enough to make this even a theoretical possibility.

The problem of genetic discrimination also arises with respect to employment procedures. Many employers currently use behaviour based selection processes in their recruitment.[8] And 52 per cent of people think that it is very likely genetic information will be used within 25 years, while just 14 per cent think this is a good idea (Sturgis *et al* 2004). While using genetic testing would arguably be immoral, it is not currently illegal in this country.[9] It seems likely that, left unchecked, employers might start to use genetic tests for employees. There are precedents of this from the USA, where a genetic testing by employers is not unusual, although still controversial.[10]

Similar possibilities exist in the fields of education, where genetic tests could be used for the selection and streaming of children, or for deciding which children go on to further education. Alternatively, tests could be used to determine which teaching methods children are likely to respond best to.

[8] Personality questionnaires were used by 40.7 per cent of respondents; 54.5 per cent used general ability tests; 60.1 per cent used tests of specific skills and 44.6 per cent literacy/numeracy tests (CIPD, 2001 and Finkin M W, 2000).
[9] For a summary of the legal position on genetic discrimination see Appendix
[10] In the Equal Employment Opportunity Commission v. Burlington Northern Santa Fe case challenging genetic testing of employees, the defendant railway company admitted to conducting undisclosed genetic testing on its employees after the workers complained of carpal tunnel syndrome ("CTS") stemming from work-related activities. It hoped to use a pilot DNA test to confirm the existence of the condition in conjunction with a comprehensive medical exam (E.D. Wis. 2002)

However, it is crucial to remember that the genetic component of many personality and behavioural traits and talents is likely to be 50 per cent at most, according to current research, and that the way in which genes interact with environment in childhood is likely to be a hugely significant factor. This means that genetic tests may have much more limited application than might be first thought; they may be less accurate predictors of performance in employment and education than those tests which currently exist.

There is currently a moratorium on using genetic tests in insurance until November 2006, with a review planned for November 2004 (Genetics and Insurance Committee 2004). While this does not explicitly include or refer to behavioural genetic tests, and nor does the terms of reference of the Genetics and Insurance Committee (GAIC) – the advisory body to the government on genetic testing and insurance, behavioural genetic tests should be interpreted as falling under the scope of this moratorium. Public opinion is against the use of genetic information for health and life insurance, with 14 per cent of people strongly in favour (Sturgis *et al* 2004), and policy should reflect this concern.

In the light of these concerns, we recommend that:

- **The terms of reference of the GAIC should be extended to specifically include behavioural genetic tests.**
- **The terms of reference of the GAIC should include a consideration about the likely fairness of the impact of genetic tests, considering whether a test under consideration will have a discriminatory effect against some socio-economic, ethnic or other group.**

Eugenics and a genetic underclass

A widespread concern is the possibility of eugenics. The notion of eugenics has a distasteful history, which dissuaded researchers from behavioural genetic study in the 1950s and 1960s (Wilson 1998). The new behavioural genetics will make it technically possible for parents to choose to abort or otherwise avoid having children with certain behavioural risks. This could lead to the creation of a 'genetic underclass'. This is a serious and worrying possibility and a wider debate is certainly necessary around this issue.

Medicalisation of normality

Much reporting about genetic discoveries uses relatively definitive language, giving the impression that genetic links are deterministic when in the vast majority of cases they are relatively small determinants, particularly in relation to behaviour.[11] The concern here is that people's personalities are increasingly talked about as being a result of their genes and that this encourages 'normal' behaviour to be seen in a 'medical' way, as something that can be corrected or treated. This may lead to indirect discrimination and social ostracism of people with unusual behaviour on 'scientific' grounds, which is clearly undesirable.

Education about behavioural genetics is clearly of crucial importance. But so is the way that the media presents findings about genetics. Irresponsible and sensationalist reporting presents a serious concern. While it is unrealistic to expect a sea-change in the way genetic advances are reported, government and other public bodies need to take a proactive role in putting forward the debate about genetics in a clear and calm way. The key message that needs to be communicated is that talking of a "gene for" something is extremely misleading in a behavioural context; at the very most, genes increase someone's chances of behaving in a certain way.

[11] For example, typing "gene for" into Google News brings up articles published within the last 24 hours on a "gene for hard work" and a "gene for repulsion to exercise".

In the light of these concerns, we recommend that:

- **The Science Media Centre should include information about behavioural genetics in its *Genetics in a Nutshell* press briefing. This should highlight the fact that the notion of a 'gene for' is potentially more misleading in relation to research related to behaviour than other research.**
- **Existing online resources explaining genetics should be updated to include features on behavioural genetics. One such is the BBC's *Gene Stories* portal (www.bbc.co.uk/genes).**

5 The people's science forum

The concerns outlined above raise difficult questions that require serious thought. While it is right that the HGC's members are scientific experts and that they consult a panel of people who are affected by genetic conditions, it is also important that broader public opinion is central to policymaking and the formulation of recommendations and legislation.

Greater public involvement can lead to more effective policy. But it can also foster greater trust between citizens and government, which has become a pressing concern over the past few years, as government lost much credibility with the public over its handling of the BSE crisis and foot and mouth disease. The ongoing debate over genetically modified (GM) food shows the strength of public scepticism about the government's ability to regulate and make use of genetic technology. Opinion polls reveal a similar picture. In 2000, 70 per cent of people felt they had too little information about controls on biological developments and 71 per cent had little or no confidence that rules and regulations were keeping pace with scientific developments (MORI 2000). In 2004, 34 per cent of people thought that "those in charge of new developments in genetic science cannot be trusted to act in society's interests (Strugis *et al* 2003). As Wilsdon and Willis (2004) argue, public involvement needs to move 'upstream' in the policy making process if public trust is to be regained.

The issues around behavioural genetics are similar to those arising from many other scientific advances, in that they are complex and some degree of specialist knowledge is needed to form considered and appropriate responses. But this does not mean that informed public debate is impossible. If policy makers are sufficiently forward looking, ethical issues and difficulties can be identified well before any given technology is practically implementable.

Public opinion about the acceptability of some implications of genetic advances shifts rapidly. This may be partly due to growing familiarity with the science and other issues. For example, the proportion of people who thing the disadvantages of GM food outweigh the advantages fell from 57 per cent in 1999 to 33 per cent in 2003. This means that opinion polls and other ways of canvassing public attitudes, which do not reflect the way these develop as people become more familiar with the issues, are unsuitable mechanisms for policy development.

The most suitable form of public involvement is a deliberative forum (Deliberative Democracy Consortium 2004). This is a body of people that meets for a period of several days, during which it hears evidence from expert witnesses. With the help of neutral moderators, members then talk together, explore options, weigh each others' views and consider costs and trade-offs, before coming to an agreed viewpoint and set of recommendations. The emphasis is on collaboration and constructive criticism. This allows differing viewpoints to be heard in a fair and balanced way, as well as enabling people to understand the trade-offs involved and feel their views have been heard and considered.

While small scale public consultations and citizen's juries are convened on an ad hoc basis for some policy decisions, there is no standing body which government can submit proposals to for public scrutiny in a deliberative context. Establishing a People's Science Forum – a permanent deliberative forum with a rotating membership drawn by lot from the electoral register - would enable better public involvement in policy concerned with a range of scientific areas, including behavioural genetics. This would have the dual benefit of improving public confidence in decision making and making policy more responsive to ordinary people's considered views.

The key challenge in setting up this body would be to ensure that it was integrated sufficiently into the legislative process to ensure that it had a real impact. Without this guarantee, a deliberative forum could be counterproductive as people might disengage from the process or even become disillusioned and lose trust in government. One option here would be to create a

statutory obligation for government to produce a report detailing how it has used the recommendations of the People's Science Forum in drafting legislation.

Summary of recommendations

This paper has raised the following recommendations.

Immediate recommendations

A new People's Science Forum

- A standing deliberative forum should be established that looks at the policy implications of emerging scientific knowledge from a moral and ethical standpoint. Members could be drawn by lot from the electoral register for each session. Its first task should be to consider behavioural genetics.
- The key challenge in setting up this body would be to ensure that it was integrated sufficiently into the legislative process to ensure that it made a real difference to legislation. One option here would be to create a statutory obligation for government to produce a report detailing how it has used the recommendations of the *People's Science Forum* in drafting legislation.

Avoiding genetic discrimination

- The terms of reference of the GAIC should be extended to specifically include behavioural genetic tests.
- The terms of reference of the GAIC should include a consideration of the likely fairness of the impact of genetic tests, considering whether a test under consideration will have a discriminatory effect against some socio-economic, ethnic or other group.

Towards a better public understanding of behavioural genetics

- The Science Media Centre should include information about behavioural genetics in its *Genetics in a Nutshell* press briefing. This should highlight the fact that the notion of a 'gene for' is potentially more misleading in describing research concerning behaviour than other research.
- Existing online resources explaining genetics should be updated to include features on behavioural genetics.

Within five years

Ensuring a fair legal system

- The HGC Horizon-Scanning Sub-Group should carry out an information gathering session on the future implications of behavioural genetics for criminal responsibility.

Within ten years

Towards more effective and fair policy

- Government should be actively considering offering behavioural genetic tests in very limited circumstances where the benefits clearly outweigh potential disadvantages to improve the way services are delivered to individuals. This should be done through deliberation with the general public (through the People's Science Forum) policy experts; and scientific, legal and ethical advisors.

- Depending on how far and fast science progresses, government should consider setting up a Genetics and Social Policy Committee, with the remit of exploring and monitoring the application of (behavioural) genetics for improving the provision of public services.
- Government should conduct a review into the use of privately bought behavioural genetic tests with the aim of considering whether these should be offered through public subsidy through the healthcare system.

Towards a more equitable use of information

- The Cambridge Genetics Knowledge Park should undertake a consultation exercise into the best way to communicate the benefits of behavioural genetic with a focus on encouraging awareness amongst traditionally hard to reach groups.

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Appendix: guiding legal principles[12]

The general legal principles relevant to policy and regulation of the use of genetic information can be derived in the main from three instruments:

- The Convention For the Protection of Human Rights and Dignity Of The Human Being with Regard To The Application of Biology and Medicine (Council of Europe, Oviedo, 4 April 1997) ('the Convention')
- The Universal Declaration on the Human Genome and Human Rights (UNESCO, 11 November 1997) ('the Declaration')
- Charter of Fundamental Rights of the European Union (EU, Nice, 7 December 2000) ('the Charter').

The relevant provisions of these instruments may be summarised as follows:

The Convention

The Convention expressly prohibits any form of discrimination on grounds of genetic heritage. Further, it provides that tests which are predictive of genetic diseases or which serve to identify a person as a carrier of a gene responsible for disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes and subject to appropriate genetic counselling. Interventions on the human genome are prohibited unless undertaken for preventive, diagnostic or therapeutic purposes and only if the aim is not to introduce any modification to the genome of any descendants.

The Convention has not yet been ratified by the UK and has no legal force in this country.

It has been ratified and signed by Bulgaria, Croatia, Cyprus Czech Republic, Denmark, Estonia, Georgia, Greece, Hungary, Lithuania, Moldova, Portugal, Romania, San Marion, Slovakia, Slovenia and Spain. It has also been signed by Finland, France, Iceland, Italy, Latvia, Netherlands, Norway, Poland, Sweden, Switzerland, Macedonia, Turkey and Ukraine.

The Declaration

The Declaration provides that everyone has the right to respect for their dignity and their rights regardless of their genetic characteristics and that such dignity 'makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity' (Article 3).

Research, treatment and diagnosis affecting an individual's genome shall only be undertaken after rigorous and prior assessment of the risks and benefits pertaining thereto. Like the Convention, the Declaration includes an express prohibition on discrimination based on genetic characteristics that is intended to or has the effect of infringing human rights. Genetic data must be held in conditions of confidence, and no research or applications of research concerning the human genome (in particular in the fields of biology, genetics and medicine) should prevail over respect of human rights and the dignity of individuals. The Declaration has no legal force and is intended only as a statement of principles which states are asked to promote.

[12] The information in this section is quoted directly from the Nuffield Council on Bioethics (2004) and is available at http://www.nuffieldbioethics.org/publications/geneticsandhb/rep0000001085.asp

The Charter

In common with the Convention and the Declaration, the Charter contains an express and free-standing provision which prohibits any discrimination based on genetic features. As part of the right to respect for physical and mental integrity, Article 2 provides that, in the fields of medicine and biology, particular respect must be given to prohibition of eugenic practices,(†) in particular those aimed at the selection of persons. The UK, as a Member of the European Union, is a party to the Charter. The Charter is a non-binding instrument which is likely to have only indirect legal force through resort to it by the European Court of Justice as a source of legal principle.

* The Explanatory Report to the Convention (paragraphs 84 to 86) makes clear that genetic testing for employment or insurance purposes or other commercial purposes falls outside the legitimate testing for health care purposes, and is a disproportionate interference with the rights of the individual to privacy. Paragraph 86 provides: 'An insurance company will not be entitled to the holding of a predictive genetic test. Nor will it be able to refuse the conclusion of modification of such a policy on the ground that the applicant has not submitted to a test as the conclusion of a policy cannot reasonably be made conditional on the performance of an illegal act'. The Convention does, however, provide (in Article 26) that the restriction on predictive genetic tests may be overridden where prescribed by law and necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others.

† It is to be noted that the European Group on Ethics in Science and New Technologies, when reporting on the draft Charter insisted (by a majority) that a specific additional provision dealing with eugenic practices be included. The minority considered that there was a difficulty in defining eugenics and the group as a whole recognised that certain current practices might be properly termed as eugenics. The majority, however, insisted on inclusion of a specific prohibition because otherwise 'the Charter would be missing the point if it did not refer to one of the main challenges of human genetics.'[13]

[13] See European Group on Ethics in Science and New Technologies. Citizens Rights and New Technologies: A European Challenge (Brussels, 23 May, 2000). http://www.europarl.eu.int/charter/civil/pdf/con233_en.pdf (18 Jul 2002).