Human
Genetics
Commission

Public attitudes to human genetic information

People's Panel Quantitative Study conducted
for the Human Genetics Commission

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We are entering a new era in human understanding since the completion of the human genome project. Barely a day goes by without news stories about the implications – positive and negative – of the rapid advances in genetics.

The Human Genetics Commission (HGC) launched a major public consultation on the future use of personal genetic information last year. As part of this work we commissioned MORI to carry out a detailed survey of people's attitudes, using the People's Panel, which was established by the Government to facilitate research of this type. This is a fascinating and wide-ranging piece of work and one that will help HGC greatly when considering these matters. We are glad to have been able to use such a valuable resource as the People's Panel.

First and foremost the findings of this survey clearly show that people have strong views on the ways genetic information is used now and on the ways it should be used in the future. The results cover a range of issues and show what people see as the benefits of the advances being made in the field of genetics, and what they see as causes for concern. In general there is a high level of public support for some uses of genetic information, for example: to improve the diagnosis of diseases and to better understand who is at higher risk of common diseases, to develop treatments for genetic disorders, and to identify or eliminate possible offenders from police enquiries. However, this is balanced by concerns about how genetic information will be protected from inappropriate use, in particular concerns over the use of genetic information by insurance companies, employers or use by parents to choose their child's characteristics.

This is a comprehensive study, which gives HGC a chance to look at attitudes to many of the different aspects of this complicated area. We wanted to make sure we heard from a diversity of people. Views vary between groups of people and this is reflected in the report's sub-group summaries. The survey included additional booster interviews among Black and Asian respondents to ensure statistical relevance.

The HGC has a clear remit to involve the public in all areas of its work and this report is a useful tool to help us do this. We need to know which areas people think are important for future consideration and what people's key concerns are so we can reflected these when drawing up our advice to Ministers.

This survey forms part of a wider consultation process. And the findings confirm what we have already heard about the importance people place on getting the basic principles right in this area - obtaining consent, confidentiality and using genetic information appropriately. We know that people are worried that developments in genetics might lead to discrimination or exploitation, and that people feel they are not as well informed as they would like to be. We went to Newcastle last year to talk to people about the uses of genetic information and published ‘Whose hands on your genes?’ which sought detailed views on all of these issues.

We have been impressed by people's enthusiasm to be involved in this process and are fully aware of their interest in this subject. This is an issue that people want to know more about and need to know their views are being heard. The report gives us a good overview of attitudes to the uses of human genetic information and highlights key areas for HGC to take forward in the future.

Human Genetics Commission
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Further copies are available by writing to:

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This document, and further information on the HGC, is available at: www.hgc.gov.uk and the report is also available at www.servicefirst.gov.uk/index/pphome.htm.

Public Attitudes to Human Genetic Information

People's Panel Quantitative Study conducted for the Human Genetics Commission

October - December 2000

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Introduction

This volume contains the summary findings of a quantitative survey of a representative sample from the People's Panel conducted by MORI Social Research on behalf of the Human Genetics Commission.

The Human Genetics Commission is the UK Government's advisory body on how new developments in human genetics will impact on people and on health care. 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 aim of this research project was to:

- Examine the public's general understanding of genetics, and human genetic information;
- Look at the public's perception of how human genetic information can, and should be used;
- Explore attitudes to the use of genetic testing;
- Examine views on access to, storage and use of human genetic information, with specific questions on forensic use, use by insurance companies and employers and medical databases.

The People's Panel is a study established by the Modernising Public Services Group at the Cabinet Office in Summer 1998. It is a randomly recruited panel of the general public, aged 16 and over, that is representative of the UK population. At original recruitment in 1998, 5,000 members of the public were recruited. Since then a further 1,000 members have been recruited to the Panel, with an additional 830 members from ethnic minority communities. Over the life-time of the Panel 725 members have asked to leave, giving a total size of 6,105.

1,038 interviews were conducted with members of the People's Panel between 6th October and 17th December 2000. The results have been weighted to the profile of all adults in the UK. (The marked-up questionnaire is included in the appendices).

This main sample was supplemented with additional booster interviews among Black and Asian respondents to ensure sufficiently large base sizes for separate analysis. This gives an unweighted total of 114 Black respondents, and 107 Asian respondents.

The table below shows the number of respondents by ethnic group interviewed in the main sample, and in the booster interviews.

QA To which of the groups on this card do you consider you belong?

	Main sample *N*	Additional booster *N*
White		
British	931	0
Irish	22	0
Any other white background	19	0
Mixed		
White and Black Caribbean	1	4
White and Black African	0	2
White and Asian	1	0
Any other mixed background	2	1
Asian or Asian British		
Indian	4	41
Pakistani	3	38
Bangladeshi	1	20
Any other Asian background	0	0
Black or Black British		
Caribbean	6	73
African	6	22
Any other Black background	2	5
Chinese or other ethnic group		
Chinese	2	0
Any other background	4	5
Refused/not stated	34	0
Total	1,038	211

Source: MORI

The report draws comparisons between Black, Asian and White respondents. As defined above, ‘Black’ refers to those respondents who define themselves as ‘Black or Black British’, ‘Caribbean’, ‘African’ or from ‘Any other Black Background’. By Asian respondents, we mean those respondents who define themselves ‘Asian or Asian British’, ‘Indian’, ‘Pakistani’, ‘Bangladeshi’ or from ‘Any other Asian Background’. (This definition of ‘Asian’ does not include Chinese respondents who are recorded separately). By White respondents, we are referring to those who define themselves as ‘White’, ‘British’, ‘Irish’, or from ‘Any other white background’.

Interpretation of Survey Findings

Findings are subject to the normal tolerances for sample surveys, and although these tolerances are small for relatively large sample sizes, it should be noted that some findings (for example, those of ethnic minority Panel members) are drawn from small sub-groups for which the tolerances may be high. Care should, therefore, be taken when interpreting findings based on answers from a small number of respondents.

Where percentages do not add up to 100, this may be due to computer rounding, the exclusion of “don’t know” categories, or multiple answers. Throughout the report, an asterisk (*) indicates a value of less than 0.5% but not zero.

“Net” figures refer to the percentage of people expressing one view minus the percentage holding the opposite view; thus the “net agree” figure is based on the proportion agreeing minus the proportion disagreeing.

The report discusses regional differences of opinion based on the sample sizes listed below:

- North (292 respondents)
- Midlands (102 respondents)
- South (502 respondents)
- Scotland (70 respondents)
- Wales/Northern Ireland (72 respondents)

The report also discusses the views of those with high, medium or low levels of genetic knowledge. These are derived groups based on respondents ability to correctly identify sickle cell anaemia, huntingtons disease, cystic fibrosis, and eye colour as totally inherited characteristics:

- High – all those correctly identifying at least three out of four (sickle cell anaemia, huntingtons disease, cystic fibrosis or eye colour) as totally inherited

- Medium – all those identifying only one or two out of four (sickle cell anaemia, huntingtons disease, cystic fibrosis or eye colour) as totally inherited

- Low – all other respondents

Publication of the Data

This project forms part of a wider programme of People's Panel research. Results may be reproduced free of charge, in any format, without requiring specific permission. This is subject to the material not being used in a derogatory manner or in a misleading context. The source of the material must be acknowledged as Crown copyright and the title of the document must be included when being reproduced as part of another publication or service. Any report using these figures must also include the web-address where the full results can be found (http://www.servicefirst.gov.uk/index/pphome.htm).

The full report is also available on the Human Genetics Commission website, http://www.hgc.gov.uk.

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Summary

- The findings from the study reveal broad support for the advances becoming available through the responsible use of human genetic information. There is an acknowledgement that these developments offer real opportunities for medical and forensic progress, but certain areas are perceived as ‘out of bounds’, with stringent control on the use and storage of genetic information.

- Respondents have a general understanding of genetics and human genetic information. While many associate these with phrases such as the ‘foundation of living matter’, and ‘blueprint of the human body’, others mention high profile applications, or related subjects such as genetically modified food and cloning. There is also a broad understanding of the balance between nature and nurture in determining a range of human characteristics or illnesses.

- Nine in ten agree that new genetic developments will bring cures for many diseases. However, despite this comprehension of the potential benefits a third are concerned that research on human genetics is tampering with nature, and is unethical, and half fear that if others have access to their genetic information they will know too much about them.

- The public support the use of human genetic information to improve the diagnosis of diseases, to develop targeted drugs, and to better understand people’s susceptibility to certain diseases. 94% think it should be used to identify or eliminate possible offenders from Police enquiries, and four in five supports its use to establish paternity, or other family relationships. Over two-thirds back the use of genetic information to develop techniques to correct defective genes for individuals and for future generations, and for the study of ancestry. However, while being aware that the use of genetic information to choose the physical and mental characteristics of offspring, to set the level of insurance premiums, and to research biological and chemical warfare is possible, only small minorities think it is desirable.

- Respondents overwhelmingly back the public ownership of new developments that make use of human genetic information – irrespective of whether the development time and investment has been commercially or publicly funded.

- There is support for the use of genetic testing for personal informative purposes – such as assessing whether a child is likely to develop genetic disorders in later life – but opinion is more divided on issues that will determine an outcome, such as using tests to help parents have a baby of the sex of their choice, or decide if children with disabling conditions are born.

- Respondents were presented with a number of situations – when a doctor tests a patient for an inherited disease, when a person wants to find out if they are related to somebody, and when a doctor tests a couple planning to

have a family and finds they have a family history that means their children are likely to have an inherited disability or life-limiting illness. In each situation, at least seven in ten feel that this a situation in which it would be appropriate to identify someone's genetic information, and a purpose for which they would be willing to provide genetic information. However, in none of these scenarios would respondents think it appropriate to subsequently share the genetic information with other organisations.

- There is considerable concern about how employers might use human genetic information. Seven in ten think it is inappropriate for an employer to see the results of an existing or potential employee's genetic test that determines whether they are prone to an inherited disease or disability. Half think it inappropriate for an employer to see employees, or potential employees, test results to determine whether they may become a risk to colleagues or members of the public they come into contact with in their job. Respondents do, however, feel it is appropriate for employers to have access to information that indicates whether or not employees or potential employees may be sensitive to certain substances they may come into contact with in their job.

- Respondents reject the suggestion that insurance companies should be able to ask to see the results from genetic tests to assess premium levels. When asked to consider the appropriateness of providing test results, a majority think it is inappropriate, irrespective of the type of policy that is being applied for. However, those policies that have a more direct relationship to an applicant's health are more likely to be thought instances where it would be appropriate to provide this information to insurance companies.

- There is almost universal support for the Police to take DNA samples from those people charged with murder or sexual offences. On balance, respondents also think it is appropriate to take samples from those charged with burglary or drink driving, while majorities think it inappropriate for the Police to take DNA samples from those charged with fraud and shoplifting. However, opinion is evenly split on whether or not such samples should be retained on the Police genetic database after an individual has been acquitted. While respondents would support Police powers to access non-Police genetic databases so they can cross-check information, only one in six feel others, such as social researchers, should be able to access the Police genetic database.

- Issues of consent and access are vital to respondents. Nine in ten agree that permission should always be sought prior to blood or tissue being used in genetic tests. Furthermore, four in five feel that fresh consent should be required before new research is conducted on existing samples. Nine in ten agree that information should only be included on a database where an individual has given consent, and three in five say that commercial organisations should only have access to human genetic information if the individuals cannot be identified. Family doctors, the NHS and Police are most likely to be trusted to use database information responsibly.

- Three-quarters say they receive too little information on the rules and regulations about biological developments, and seven in ten have little or no confidence that the rules and regulations are keeping pace with new research developments.

Sub-group Summaries

The summaries below bring together the significant findings within each of a number of key groups – by gender, age, ethnicity, region, genetic knowledge, whether or not respondents have children in household, and the influence of religion on the way they live their lives.

Gender

When asked to consider what they understand by ‘genetics’, women are twice as likely as men to say ‘the inherited elements of human cells’, and significantly less likely to mention genetically modified food.

Women are significantly more likely to think that human genetics research is tampering with nature and is therefore unethical (women 37% agree, men 28% agree), and that if others have access to your genetic information they will know too much about you (women 59% agree, men 49%).

Respondents were asked to consider the balance between nature and nurture in determining a range of characteristics. Women are significantly more likely than men to say body height and weight is determined by nature, whereas men place greater emphasis on environmental factors. Women are also more likely than men to say that cystic fibrosis, thalassaemia and sickle cell anaemia are inherited conditions. Men are more likely than women to think high blood pressure is influenced by environmental factors.

While both sexes support the public ownership of developments using new genetic information, men are significantly more likely to say that commercial organisations that have invested time and money in the development should be able to own and profit from them. In contrast, if a public organisation has invested in the development, men are less likely to think they should own the development, and charge for its use.

When presented with the scenario of a doctor testing a couple planning to have a family and finding they have a family history that will mean their children are likely to have an inherited disability or life-limiting illness, men are twice as likely as women to say this is an inappropriate reason to identify human genetic information.

Respondents were asked to consider the use of genetic test results by employers. Men are significantly more likely than women to think it appropriate for employers to see the results of tests that indicate whether an employee or potential employee may be sensitive to certain substances that they will come into contact with in their job.

If applying for an health-related insurance policy, women tend to be more likely than men to think it is appropriate to share genetic test results with the insurance company.

Respondents were presented with a range of crimes and asked for each whether it was appropriate or inappropriate for the Police to take DNA samples from people charged with those crimes. For each crime – drink-driving, shoplifting, murder, sexual offences, fraud, burglary – men were more likely, or equally likely, than women to advocate the taking of DNA samples.

When asked whether the DNA samples should be kept or removed from the Police genetic database after the individual has been acquitted of the crime, men are significantly more likely to say the information should be removed from the database. They are also more likely than women to say that other researchers should have access to the Police genetic database for purposes such as social research.

Respondents were asked to consider the use of medical genetic databases. Men were significantly more likely than women to say they would trust the family doctor, or the NHS, to use the information held on such databases responsibly. They are also more likely than women to trust an expert government scientific advisory committee to be responsible users.

Men are more likely than women to advocate that rules and regulations on human genetic information storage and usage should be made independently of party politics, and that there should be random spot checks of all regulated activities. In contrast, women are more likely than men to say that if those who made the decisions on regulations were independent, or declared their interests, it would give them greater trust in the system of controls.

Age

When unprompted, younger respondents are far more likely to understand ‘genetics’ as relating to the regeneration or improvement of growth, ‘chromosomes’, or genetically modified food. In contrast, older respondents are more likely to mention ‘the blueprint of the human body’.

Those respondents who are most likely to have young children (respondents aged 25-34) are also more likely than other age groups to agree that new genetic developments will mean children who are healthier and free from inherited disabilities. Those aged 25-64 are more likely than others to say that genetic techniques should not be made available to parents so that they can choose the gender of their baby.

When considering the balance between nature and nurture in determining a range of characteristics, those aged under 25 are significantly more likely than others to say depression is determined by environmental factors, whereas older respondents place greater emphasis on inherited causes. Younger people are also more likely to say epilepsy is an inherited condition, whereas older respondents are more likely to think environmental factors are influential. Older respondents are more likely to see intelligence as an inherited characteristic, whereas younger respondents place greater emphasis on nurture.

Opinion on whether or not couples at risk of having a child with a serious genetic disorder should be discouraged from having children of their own differ greatly by age. Over half of those aged 55+ agree couples should be discouraged, whereas among those aged 16-24 only 5% agree.

Older respondents are more likely than those under 25 to think commercial organisations should be able to own and profit by any new ways of using human genetic information they develop.

When asked to consider how human genetic information could and should be used, those aged 65+ are significantly more likely than other respondents to say that it should be used in the setting of insurance premiums. Those under 25 are less likely than older respondents to say genetic information should be used to establish paternity and other family relationships.

Those aged 65+ are more likely to think an employer should be able to see the results from a genetic test to determine whether an employee, or potential employee is likely to become prone to an inherited disease or disability. They are also more likely than other age groups to think insurance companies should be able to ask to see the results of genetic tests to assess whether premiums should go up or down. While a third of those aged 55+ think it appropriate to share the results of genetic tests with an insurance company if you are applying for motor insurance, this falls to 1% among those aged under 25 who think it appropriate.

Older respondents are consistently more likely to back the taking of DNA samples for a given crime than younger respondents. Whereas 64% of those aged 65+ support the taking of samples in cases of drink-driving, only 38% of those aged under 25 do. Similarly, among those aged 65+ 56% think DNA samples should be taken from those charged with fraud, while only 24% of the under 25s would support this. Those under 25 are also significantly more likely than older respondents to say that the genetic information should be retained on the database after the individual has been acquitted. Furthermore, they are more likely than older respondents to say it is appropriate for the Police to have access to other genetic databases to cross check information.

When considering the responsible use of information held on medical databases, younger respondents are more likely than others to say they would trust health and pharmaceutical companies, or industrial scientists.

Those aged 35-54 are significantly less likely than other age groups to agree that fresh consent from an individual should be required before new research is conducted on existing samples held on a database. While respondents aged 16-25 are less likely than older respondents to agree that commercial organisations should have access to human genetic information only if individuals can't be identified.

Older respondents tend to have greater confidence than those under 55 that the system of rules and regulations is keeping pace with biological developments and research. Younger respondents want those the rules and regulations made in an environment that is free of party politics, and involves people who are independent or declare their interests. In contrast, older respondents place greater emphasis on the system being seen to be open and fair.

Ethnicity

Black and Asian respondents are significantly less likely than white respondents to agree that new genetic improvements will bring cures for many diseases (78% and 76% respectively, compared to 89% among white respondents). Black and Asian respondents are also far less likely to believe that genetic improvements will deliver healthier children free from inherited disabilities. Asian respondents are more likely to think human genetic research is unethical than other respondents.

Across a broad range of questions Asian respondents reflect a considerable trust in others, or institutions, whereas Black respondents do not. Black respondents are significantly more likely than white or Asian respondents to agree that if others have access to your genetic information they will know too much about you.

Respondents were asked to consider the balance between nature and nurture in determining a range of characteristics. White respondents are significantly more likely than Black and Asian respondents to say that cystic fibrosis is an inherited condition. In contrast, Black and Asian respondents are more likely than white respondents to say diabetes and high blood pressure are inherited conditions. Black respondents are significantly more likely than others to say sickle cell anaemia is an inherited condition, rather than due to environmental factors.

Black and Asian respondents are less likely than white respondents to agree with the statement that genetic techniques should not be available to parents so that they can have a baby of the sex they choose. Black respondents are also more likely than white respondents to agree that couples at risk of having a child with a serious genetic disorder should be discouraged from having children of their own.

Black respondents are significantly more likely than others to say that publicly funded researchers should be able to own innovative developments in the use of human genetic information, and charge for its use, rather than the information being publicly owned and free to use.

When asked to consider how human genetic information could and should be used, Black and Asian respondents are significantly more likely than others to say that it should be used in the setting of insurance premiums. Asian respondents are also less likely than white respondents to think that genetic information should be used to develop techniques to correct defective genes for individuals. Black and Asian respondents are also significantly more likely than others to say human genetic information should be used to research biological and chemical warfare, or to determine the physical and mental characteristics of children –

whereas they are less likely than white respondents to support its use by the Police in identifying offenders.

Respondents were presented with a range of scenarios and asked for each whether they thought it was appropriate to provide genetic information for the purpose, whether they would be willing to do so, and whether they thought the information should be shared. While Black and Asian respondents were no more or less likely to think the purpose appropriate, or to be willing, they were significantly more likely to think that the information gathered should subsequently be shared with other organisations.

Asian and Black respondents tend to be more likely than other respondents to think it is appropriate for an employer to have access to the results of genetic tests to see if employees may become a risk to colleagues or members of the public they come into contact with in their job, or if they are likely to become prone to an inherited disease or disability.

On balance, Black and Asian respondents are more likely than white respondents to agree that insurance companies should be able to ask to see the results of genetic tests to assess whether premiums should be up or down. Asian respondents also tend to be more likely to think it appropriate to share test results with an insurance companies, irrespective of the type of policy you are applying for.

While overwhelmingly supportive, Black and Asian are significantly less likely than others to think it is appropriate for the Police to take DNA samples from anyone charged with murder or sexual offences. Asian respondents are significantly more likely than others to support the right for Police to take DNA samples from people charged with drink-driving offences. In contrast, Black respondents are less likely than white and Asian respondents to support the idea of DNA samples from those charged with shop-lifting.

When asked what should be done with the information after the individual has been acquitted of the crime, Black respondents are significantly more likely than Asian respondents to say the information should be removed from the Police database. Black respondents are also more likely to say it is inappropriate for the Police to have access to other genetic databases to cross check information – but more likely than others to support the right for others to have access to the Police genetic database for purposes such as social research.

Black and Asian respondents are less likely than others to identify family doctors, or the NHS, as responsible users of information held on medical databases. They are, however, marginally more likely than white respondents to trust people tracing a family tree, or the Government, to use the information responsibly. Black respondents are less likely than others to agree that commercial organisations should have access to human genetic information anonymously held on medical databases.

Asian respondents are significantly more likely than Black or white respondents to be confident that the rules governing biological research are keeping pace with the speed of developments, and also less likely to say they receive too little information on the subject. Black and Asian respondents are more likely than white respondents to say that they would trust a system of rules and regulations for human genetic information storage and usage if it involved legally enforceable rules. Asian respondents are less concerned than others that system of controls and regulations monitors developments and uses, and is prepared to restrict them if there are well-founded concerns.

Region

While nine in ten respondents agree that new genetic developments will bring cures for many diseases, this falls to 72% among respondents from Wales and Northern Ireland. Those respondents living in the Midlands are significantly less likely to agree that genetic developments will mean children who are healthier and free from inherited disabilities.

Scottish respondents are significantly more likely than those in the North, Midlands, Wales or Northern Ireland to think that human genetics research is tampering with nature and unethical.

When considering the balance between nature and nurture in determining a range of characteristics, Scottish respondents are significantly more likely than those elsewhere in the UK to say body height and weight is determined by nature, rather than nurture.

Scottish, Welsh and Northern Irish respondents are more likely than others to agree that people should be encouraged to be tested in young adulthood for disorders that develop in middle age or later in life. However, those in Northern Ireland are significantly more likely than others in the UK to disagree with the statement ‘genetic techniques should not be made available to parents so that they can have a baby of the sex they choose’.

When asked to consider how human genetic information could and should be used, respondents from Wales and Northern Ireland were significantly less likely than those elsewhere to say it should be used to assess health damage and risk from chemicals and radiation. Those in Scotland are significantly more likely to support the use of genetic information to establish paternity and family relationships, while those in the Midlands are more likely than others to say genetic information should be used by parents to choose the physical and mental characteristics of their children.

Respondents from Wales and Northern Ireland are significantly less likely to feel it is appropriate, or to be personally willing, to be tested by a doctor for an inherited disease. They also, together with respondents from the North, are less likely to think it is appropriate to provide genetic information to test whether, as a couple, you have a family history that will mean your children are likely to have an inherited disability or life-limiting illness.

When presented with a range of crimes and asked for each whether it was appropriate or inappropriate for the Police to take DNA samples from people charged with those crimes, respondents from Northern Ireland and Wales tend to be less likely than others to support the Police power to take DNA samples.

When considering the responsible use of information held on medical databases, respondents from Wales and Northern Ireland are less likely than others to say they would trust GPs, the NHS, the Police, academic scientists, or an expert government scientific advisory committee to use the information in a responsible manner.

Those living in the North of England are significantly more likely to say they have a ‘great deal’ or a ‘fair amount’ of confidence in that the rules and regulations are keeping pace with biological developments, while those in the Midlands are significantly more likely to feel they receive too little information about biological regulations.

Genetic Knowledge

Respondents with a high level of knowledge of genetics (those who correctly identified at least three of sickle cell anaemia, huntingtons disease, cystic fibrosis or eye colour as wholly inherited characteristics) have markedly different views from less well informed respondents across a whole range of issues. Firstly, they are more likely than others to understand genetics as meaning ‘the foundation of living matters’, and ‘Make up of DNA’. In contrast those with low levels of genetic knowledge are more likely than others to mention cloning or ‘Dolly the Sheep’. Again, when asked what they understand by the phrase ‘human genetic information’ those with high levels of genetic knowledge are more likely than others to mention ‘DNA/testing of DNA/fingerprinting’ and ‘research/identifying genetic problems’.

Knowledgeable respondents are more likely to agree that new genetic developments will bring cures for many diseases (high level of genetic knowledge 92% agree, medium 89% agree and only 75% agree among those with low levels of knowledge), and that new genetic developments will mean healthier children. In contrast, those who know least about genetics, are most likely to agree that genetic research in tampering with nature, and therefore unethical.

There is greater awareness of the potential use of human genetic information to set insurance levels among those with high genetic knowledge – however they are also more likely to oppose its use in this way. Only nine per cent of those with high levels of knowledge of genetics think genetic information should be used for research into biological and chemical warfare, whereas this increases to a quarter among those who know little about genetics. In contrast, seven in ten (72%) of those with high levels of genetic knowledge say it should be used to study evolution, ancestry and population, but this falls to only 57% among those with lower levels of knowledge.

Opposition to the use of genetic information by parents to choose the physical and mental characteristics of children is higher among those who are more knowledgeable about genetics (86%).

Those who have a low level of genetic knowledge are more likely than others to agree that couples at risk of having a child with a serious genetic disorder should be discouraged from having children.

Those who have a low level of genetic knowledge are more likely than others to agree that parents have a right to ask for their child to be tested for genetic disorders that develop in adulthood. They are also less insistent that permission be sought before blood or tissues are used in a genetic test.

Those with low levels of genetic knowledge tend to be more likely to think it appropriate for an employer to have access to employees or potential employees genetic information to assess their suitability. They are also more likely to agree that insurance companies should be able to ask to see genetic test results to determine premiums, and for the Police to take DNA samples from individuals charged with a crime.

Desire for more information on the regulation of biological developments is in inverse proportion to the existing knowledge of respondents – with those with low levels of knowledge about genetics more likely than others to say they already receive ‘the right amount’ of information on the rules and regulations of biological developments.

Those with Children in Household

Those with children living in their household are significantly less likely than those without children, to think that human genetic information should be used to develop techniques to correct defective genes for individuals. They are also less likely to think genetic information should be used to establish paternity and family relationships.

Opposition to the use of genetic information by parents to choose the physical and mental characteristics of children is higher among those with children in household (83%). They are also less likely than others to support the right of parents to ask for their child to be tested for genetic disorders that develop in adulthood.

Those with children in their household are more likely than others to say that samples from acquitted individuals should be kept on Police databases.

They are less likely than others to agree that fresh consent is required from individuals for each subsequent use of the existing human genetic sample.

Religious Influence

Those who say they have a religion or faith – particularly those who say it has an influence on the decisions they make - are significantly more likely to agree that human genetic research is unethical.

Those whose religion is influential in their decision-making are less likely to agree that new genetic developments will mean healthier children free from inherited disabilities. They are also significantly less likely to support the use of genetic information to establish paternity or other family relationships.

When considering the range of specific insurance policies, those whose religion is influential in the decisions they take, are more likely than others to think it appropriate for the insurance company to know the results from existing genetic tests. They are also more likely than others to think it is appropriate for the Police to take DNA samples from individuals charged with a crime.

Main Findings

Overall understanding of Genetics and Genetic Information

The public have a very broad and general conception of the meaning of 'genetics'. Respondents were asked to suggest what, if anything, they understood by the term 'genetics', and they cited a range of relevant, and related, issues.

Almost one in four spontaneously mentioned genetically modified food. Other frequent responses focused on genetics as the 'foundation of living matter' (18%), 'blueprint of the human body' (14%) and cloning (13%). The breadth of responses reflects a very general understanding of both genetics, as well as the popular perceptions of its uses, and misuses.

Q1 When I say 'genetics', what, if anything, springs to mind?

	%
Genetically modified food/products/messing about with food	23
The foundation of living matter/organisms	18
Regeneration/improving growth	15
Genes/information/science of genes/genetic make-up	14
Make-up of human genes/blueprint of human body/physical characteristics	13
Inherited elements of human cell/hereditary traits/illnesses	13
Cloning/Dolly the Sheep	13
Make-up of DNA/chromosomes	13
Genetic engineering/modification of cells/structures	11
Modern technology	10
Medical research/science/experimentation	9
Trying to create a super race	9
Crop modification/crops	8
People/races/nationalities	7

(Answers below seven per cent not shown)

Source: MORI

Other less frequently mentioned perceptions of 'genetics' include 'Hitler and Mengele' cited by five per cent, 'Having babies to help/save brother/sister' mentioned by four per cent, and the 'Growing of spare body parts', four per cent.

A range of responses also made reference to the fact that it was an area of medical advance, and that a range of new technologies are becoming available.

Younger respondents (aged under 25) are more likely than others to mention genetically modified foods, and one in three mention 'Make-up of DNA/chromosomes' in comparison to only 1% among those aged over 65.

Those who have completed A-Levels or higher educational qualifications are more likely to give responses such as genetically modified foods, the foundation of living matter, and inherited elements of the human cell. In contrast, one in five respondents with no formal qualifications are unable to give a response to this question.

Those with high genetic knowledge (who correctly identified at least three of sickle cell anaemia, huntingtons disease, cystic fibrosis or eye colour as wholly inherited characteristics) are more likely than others to understand genetics as meaning 'the foundation of living matters', and 'Make up of DNA'. In contrast those with low levels of genetic knowledge are more likely than others to mention 'Dolly the Sheep'.

Respondents were asked what they understood by the more specific phrase 'human genetic information'. This drew a range of responses.

Q2 And when I say 'human genetic information', what, if anything, springs to mind?

	%
DNA/testing of DNA/fingerprinting	18
Make-up of human genes/characteristics/genetic info of the body	15
Research/identifying genetic problems/illnesses in humans/hereditary problems	10
Cloning/cloning body parts/Dolly the Sheep	9
Inherited genes/physical attributes/characteristics	7
Selective breeding/having baby of your choice/choosing sex of child	5
Chromosomes of the body	4
Human Genome Project/Factor	4
Genes/definition of genes	4

(Answers below four per cent not shown)

Source: MORI

Some attempted to define the phrase – DNA was mentioned by 18%, and 'make-up of human genes' by 15% - while others tried explain it by reference to how genetic information has been used – 'identifying genetic problems' was mentioned by 10%, cloning by 9% and 'selective breeding' by 5%. Four per cent spontaneously mention the Human Genome project, and two per cent say test tube babies, and IVF.

Those with high levels of genetic knowledge are more likely than others to mention 'DNA/testing of DNA/fingerprinting' and 'research/identifying genetic problems'.

One in five respondents did not feel able to answer this question – this rises to 37% among those with no formal educational qualifications.

Attitudes towards Genetic Developments

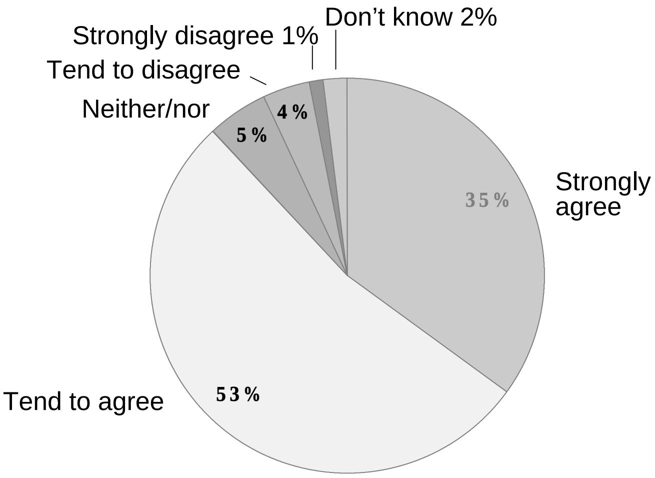
Respondents were asked a number of broad attitudinal questions to establish their overall views of genetic developments. These suggest majority support for the current advances – however, a significant minority are concerned with the implications of the developments.

Four in five (88%) agree that new genetic developments will bring cures for many diseases (35% agree strongly, and 53% tend to agree). Only a small minority, five per cent, disagree with the statement. The contrast between the knowledge of advances and the concerns regarding the implications is highlighted when we compare these results with recent Eurobarometer data showing that only 37% agree that ‘genetic engineering will improve our lives’[1].

While the majority of all demographic groups agree that genetic developments will bring cures for many diseases, some sections of population are less convinced than others. Black and Asian respondents are significantly less likely to agree (78% and 76%, respectively), as are those living in Wales and Northern Ireland (72% agree). Interestingly, those describing themselves as having a religion or faith are more likely to agree with the statement than atheists and agnostics. Those with higher levels of genetic knowledge are more likely to agree that new genetic developments will bring cures for many diseases (high level of genetic knowledge 92% agree, medium 89% agree and only 75% agree among those with low levels of knowledge).

Overall attitudes to new genetic developments

Q4 Please tell me to what extent you agree or disagree …. New genetic developments will bring cures for many diseases?



Base: All respondents (1,038)

Source: MORI

Similarly, almost three-quarters agree that new genetic developments will mean healthier children free from inherited disabilities. Only eight per cent disagree. Again, Black and Asian respondents are less likely to agree (61% and 56% agree,

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[1] ‘The Europeans and Biotechnology’ Eurobarometer 52.1 (1999)

respectively), as are those whose religion influences the decisions they make. In contrast, those who know more about genetics are more likely to agree that new developments will mean healthier children.

However, despite this widespread belief in the positive medical impact of new genetic developments a third of respondents believe that research on human genetics is tampering with nature and, as such, is unethical. One in eight strongly agree, and one in five tend to agree.

While the overall balance of opinion (of those agreeing, less those disagreeing) is –8, there are large differences in opinion between different demographic groups. Women are significantly more likely than men to agree that human genetics research involves unethical tampering with nature – as do Asian respondents, those in social classes C2DE, or with lower educational attainments. Those who say they have a religion or faith – particularly those who say it has an influence on the decisions they make – are significantly more likely to agree that human genetic research is unethical. Those who know least about genetics, are most likely to agree that genetic research in tampering with nature, and unethical.

There is also broad concern that if others have access to your genetic information they will know too much about you. Half agree with this sentiment, while almost three in ten disagree, giving a balance of opinion of +27. Women, those in social classes C2DE, and Black respondents are more likely than others to be concerned that access to an individual's genetic information allows others to know too much about them.

Q6 Please tell me to what extent you agree or disagree … Research on human genetics is tampering with nature and is therefore unethical?

	Agree %	**Disagree** %	**Net agree** ±%
All	*33*	*41*	*-8*
Gender			
Male	28	46	-18
Female	37	35	+2
Social class			
AB	27	50	-23
C1	34	47	-13
C2	31	32	-1
DE	37	34	+3
Ethnicity			
White	32	42	-10
Black	40	37	+3
Asian	59	13	+46
Educational attainment			
No formal qualifications	45	32	+13
GCSE level	31	44	-13
A-level	24	41	-17
Degree or above	22	54	-32
Religion			
Those with a religion	36	40	-4
Agnostic and Atheist	22	44	-22

Source: MORI

Nature vs Nurture

One in six respondents say they have an inherited condition or illness. Most frequently mentioned are heart disease or Angina, Asthma, Psoriasis, sight problems, diabetes, arthritis, or thyroid problems. A quarter say members of their family also have inherited conditions or illnesses. In addition to the conditions mentioned above, nine per cent of respondents mention cancer as an inherited condition or illness of a family member.

Respondents were presented with a list of nineteen different characteristics and asked to estimate the determination of each characteristics, using a scale of 1 to 5, where 1 is a totally inherited characteristic and 5 is a totally environmental characteristic. The chart below illustrates the mean scores for each characteristic.

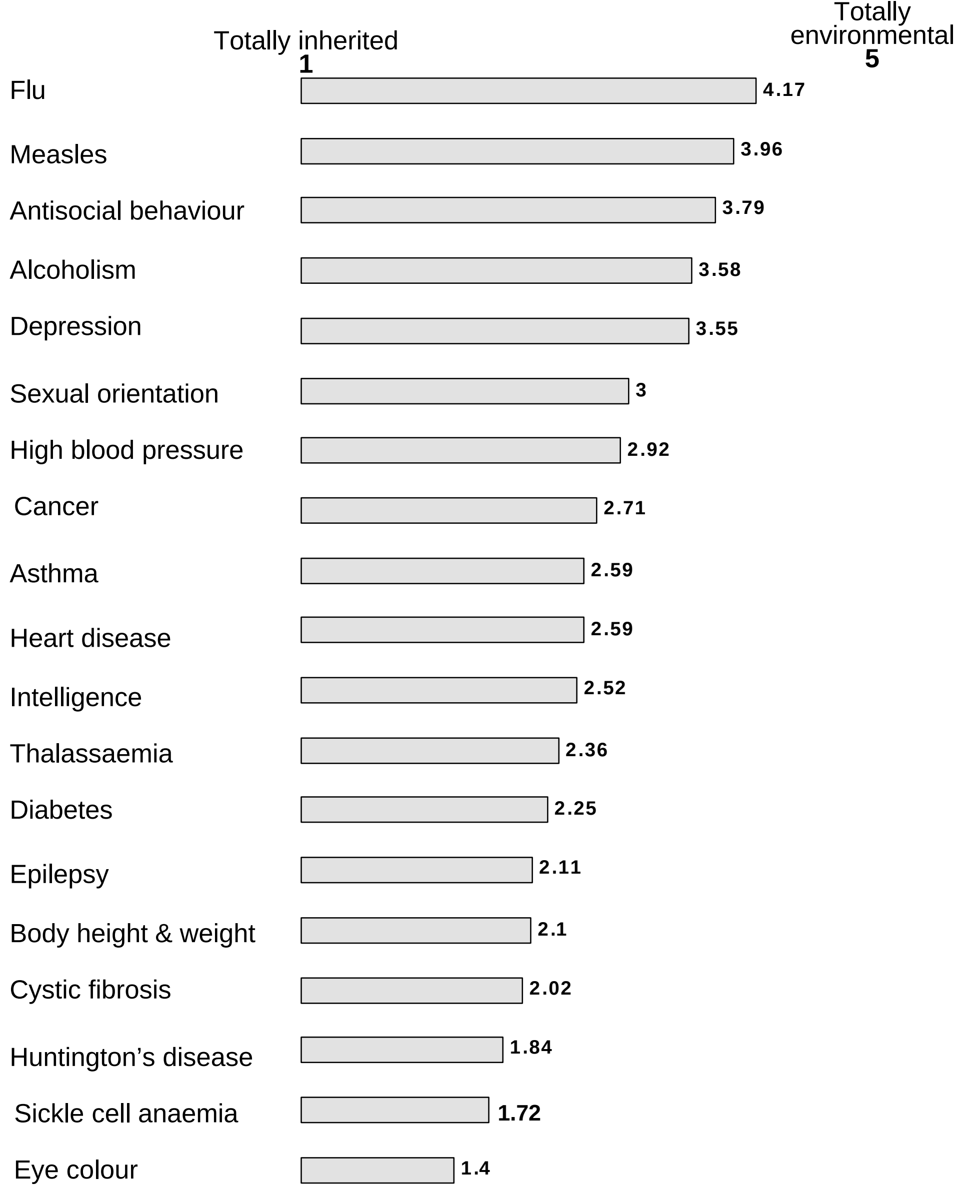
Characteristics such as eye colour, sickle cell anaemia and Huntington's disease are seen as very largely inherited characteristics, whereas those such as flu, measles and antisocial behaviour are seen as dependent on environmental factors. The remaining characteristics are seen as a mixture of both nature and nurture.

Women are significantly more likely to say body height and weight is determined by nature, i.e. inherited, than men who are likely to place greater emphasis on environmental factors.

Older respondents are more likely to see intelligence as an inherited characteristic, whereas younger respondents tend to take more account of nurture in developing intelligence.

Q12- Q30 I am now going to read out a list of characteristics which may come about because they are inherited (nature) or because of environmental factors (nurture) such as lifestyle, upbringing etc. or because of a combination of these.

For each, please tell me how each characteristic comes about from 1, if you think it is totally inherited, to 5 if you think its development is entirely dependent upon environmental factors.



Base: All respondents (1,038)

Source: MORI

Genetic Testing

Respondents were presented with a number of statements relating to the use of genetic tests. In general, there is support for use of genetic testing for personal information purposes, but opinion is more divided when considering uses that will lead to an immediate intervention.

Three-quarters agree that people should be encouraged to be tested in young adulthood for disorders that may develop in middle age or later in life. Eleven per cent disagree. Those who describe themselves as having a disability are significantly more likely to agree (81%).

Similarly, 78% say that parents have a right to ask for their child to be tested for genetic disorders that develop in adulthood. Again, eleven per cent disagree. Those with children in household are more likely to disagree (14%). Whereas those respondents who have an inherited illness or condition, and those who know little about genetics are more likely to feel this is appropriate.

Reinforcing findings from earlier studies[2], there is a clear rejection of the use of genetic techniques to help parents to have a baby of the sex of their choice. Three-quarters (74%) agree that these techniques should not be made available to parents, while 17% disagree, giving a balance of opinion of +58. Opinion is constant, irrespective of whether or not respondent have children living with them. Those who say they are atheist or agnostic are twice as likely to disagree (28% disagree, compared to 14% disagree among those with a religion). Black and Asian respondents are less likely (60% and 54% agree, respectively) than white respondents (77%) to agree with the statement that genetic techniques should not be available to parents so that they can have a baby of the sex they choose.

On balance, respondents support the use of genetic testing to provide information that may be used by parents to decide if children with certain disabling conditions are born (57% agree with this suggestion, while a quarter disagree). Respondents views are relatively consistent between subgroups, with older respondents and those in social classes C2DE marginally more likely to agree that this is appropriate use of genetic testing.

However, on balance, respondents do not agree that couples who are at risk of having a child with a serious genetic disorder should be discouraged from having children of their own. Three in ten agree couples should be discouraged, while 43% disagree. There is marked difference in opinion by age. Only five per cent of those aged under 25 agree that couples at risk of giving birth to a child with a serious genetic disorder should be discouraged from starting a family – whereas support increases with age and 55% of those aged 55+ feel that these couples should be discouraged. Those who have a low level of genetic knowledge are also more likely to agree that couples at risk of having a child with a serious genetic disorder should be discouraged from having children.

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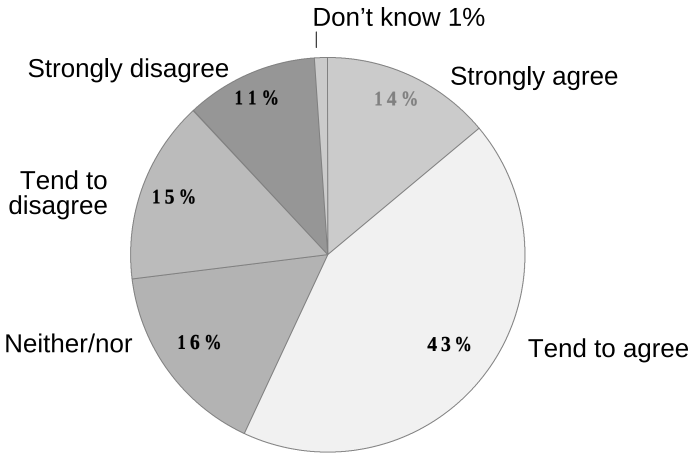
[2] 'Public Understanding of Science' Michie et al 4 (1995)

Use of genetic testing

Q33 Please tell me to what extent you agree or disagree … Genetic information may be used by parents to decide if children with certain disabling conditions are born?



Base: All respondents (1,038)

Source: MORI

Nine in ten agree that their permission should always be sought before their blood or tissues are used in a genetic test, as part of a medical treatment. Only five per cent disagree that permission should be required. Those who know less about genetics than others are less insistent that permission be sought before blood or tissues are used in a test.

Ownership of Genetic Information

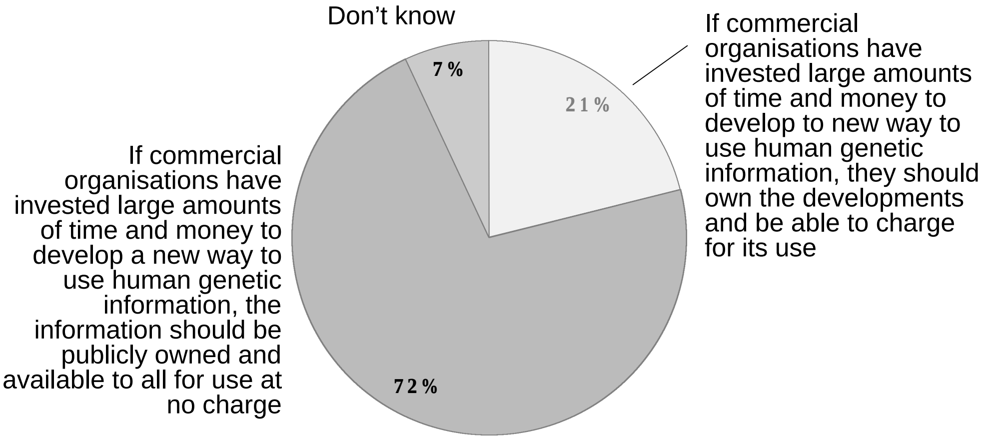
Respondents were asked whether those who develop new innovative ways of using human genetic information should be able to own, and profit from its use. Irrespective of whether or not the organisation is publicly funded or commercially owned, the large majority of respondents support the public ownership of, and free access to, the genetic information.

The issues were put to respondents in one of two ways. Firstly, we asked whether commercial organisations who have invested large amounts of time and money to develop new ways to use human genetic information should own the developments and be able to charge for its use. One in five support this position, and seven in ten feel the information should be publicly owned and available for all to use at no charge.

Men are significantly more likely than women to say commercial organisations should be able to own their developments and profit by its use (supported by 25% of men, but only 16% of women). There are also differences by age, with those aged under 25 significantly less likely to support this position than older respondents. Among respondents aged 16-25 only 5% feel commercial organisations should be able to patent their ideas and charge for their use.

Ownership of Genetic Information

Q37 Looking at this card, please tell me which of these statements comes closest to your personal opinion?



Base: All answering (599)

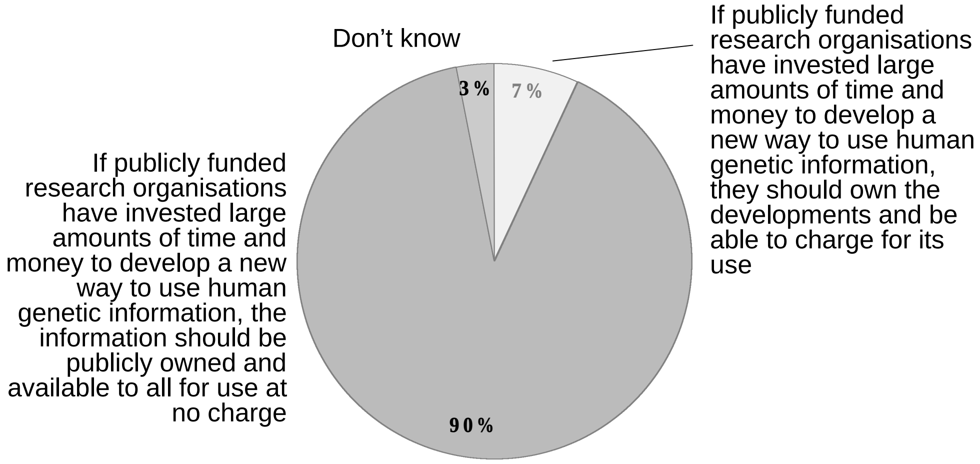
Source: MORI

Attitudes towards this issue harden when the question is posed asking about a publicly funded research organisation rather than a commercial organisation. Support for the developer having rights over the new use of the human genetic information is only seven per cent, with nine in ten saying the information should be publicly owned and available to all for use at no charge. In this scenario, men are now significantly less likely to say that the developing organisation – a publicly funded research organisation – should own the development and charge for its use.

Black respondents are significantly more likely than others to say that the publicly funded researchers should own the information and charge for its use (23%).

Ownership of Genetic Information

Q38 Looking at this card, please tell me which of these statements comes closest to your personal opinion?



Base: All answering (522)

Source: MORI

Uses of Genetic Information

Respondents cite a very wide-ranging list of ways in which they think human genetic information can be used now or in the near future. When asked for their spontaneous thoughts, the most common understanding is that information will be used for the curing of illnesses, and to overcome hereditary conditions, each mentioned by one in five respondents.

One in eight mention cloning (12%) or the use of genetic information to produce ‘designer babies’ (12%). One in ten spontaneously say that human genetic information can be used for catching criminals, and eight per cent specifically mention DNA testing, or fingerprinting. One in ten give a very general response that human genetic information will be used for medical research and scientific experimentation.

Respondents were presented with twelve potential uses for human genetic information, and asked which were ways in which information could be used, and which were ways in which it should be used. Reaction to the twelve potential uses falls into three broad categories – those ways of using information that a large majority think could and should use, those that are possible but should not be used, and a third category where opinion is divided.

Four of the twelve items are considered ways in which we currently can and should be making use of human genetic information – for improvement in the diagnosis of diseases, for the development of targeted drugs, to better understand why people are more or less likely to develop diseases, and to identify offenders or eliminate possible offenders from police enquiries using DNA found at the crime scene. Each of these uses was thought possible, and desirable by nine in ten respondents.

Respondents are equally clear cut about which were ways in which human genetic information should not be used. Three-quarters think that human genetic information can currently be used to determine the physical and mental attributes of offspring, but only one in eight would support its use in this way, and 78% are opposed. Opposition is higher among those with children in household (83%), and also among those who are more knowledgeable about genetics (86%).

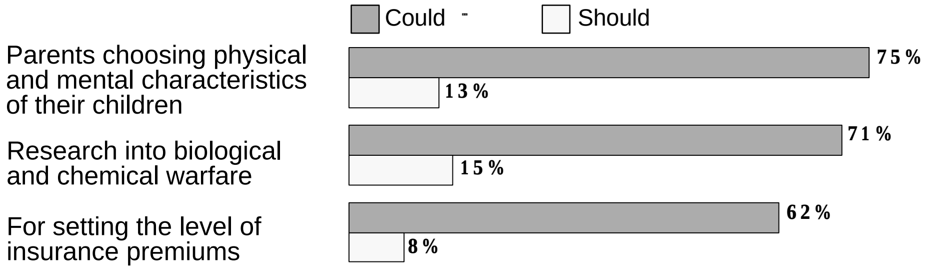
While seven in ten believe human genetic information could be used for research into biological and chemical warfare, there is strong opposition to the suggestion. Fifteen per cent say it should be, and 75% say ‘no’, information should not be used in this way. However, opinion differs significantly by respondents’ knowledge of genetics. Among those with a high level of knowledge only nine per cent think genetic information should be used for research into biological and chemical warfare, whereas this increases to a quarter among those who know little about genetics.

Similarly, two-thirds are aware that human genetic information can be used for setting insurance premium levels, but only eight per cent back its use for this purpose. There is greater awareness of this potential usage among those with high genetic knowledge – however they are also more likely to be opposed to its use in this way.

Appropriate uses of human genetic information

Q8 Please tell me whether or not you think this is a way in which human genetic information could be used?

Q9 And would you say this is a way in which human genetic information should be used?



Base: All respondents (1,038)

Source: MORI

The remaining five ways of using human genetic information mentioned attract more divided opinion. Four in five believe that human genetic information can be used to assess health damage and risk from chemicals and radiation, and a similar proportion would support its use for this, with one in ten are opposed.

Similarly nine in ten are aware that human genetic information can be used to establish paternity and other family relationships, and over three-quarters say the information should be used for this purpose. Eleven per cent disagree with its use in this way. Opposition to the use of genetic information to establish paternity and family relationships rises to 28% among those aged under 25. There are also significant differences of opinion by whether or not respondents are parents – with those with children less likely than others to think genetic information should be used to establish paternity and family relationships. Also those whose religious faith is influential in making life decisions are significantly less likely to support the use of genetic information in this way.

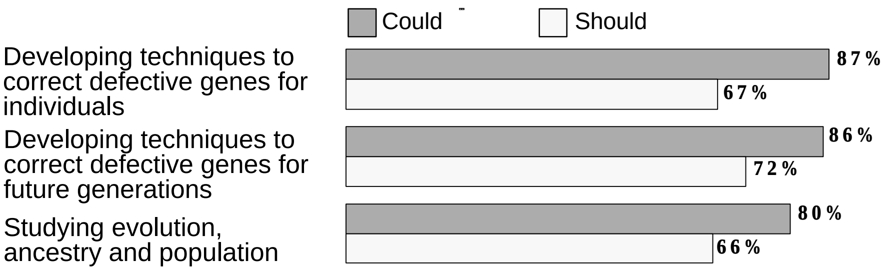
Almost nine in ten believe that human genetic information can currently be used to develop techniques to correct defective genes for individuals, and for future generations. However, while still a majority, fewer think it should be used in this way. Seven in ten would support the use of human genetic information to develop techniques to correct an individual's defective genes. (Those who have children in household are significantly less likely to feel information should be used in this way, than those without children). This drops slightly to two-thirds when using the techniques to correct genes for future generations.

Four in five say human genetic information can be used to study evolution, ancestry and population, and two-thirds think it should be used in this way. One in six disagree. Support for its use to study evolution, ancestry and population varies with genetic knowledge. Seven in ten (72%) of those with high levels of genetic knowledge say it should be used for this, but this falls to only 57% among those with lower levels of knowledge.

Appropriate uses of human genetic information

Q8 Please tell me whether or not you think this is a way in which human genetic information could be used?

Q9 And would you say this is a way in which human genetic information should be used?



Base: All respondents (1,038)

Source: MORI

Respondents were presented with three different scenarios and asked to consider three questions:

- Is it appropriate or inappropriate for someone to provide genetic information for this purpose?
- Would you be willing or unwilling to provide genetic information for this purpose?
- Do you think the genetic information obtained for this purpose should or should not be shared with other organisations?

The first scenario presented to respondents was when a doctor tests a patient for an inherited disease. Nine in ten say it is appropriate to provide genetic information to a doctor to test for an inherited disease, and four in five say they would be personally willing to do so. However, three in five feel that the genetic information should not be shared with other organisations.

Respondents in Wales and Northern Ireland, while small in number, are significantly less likely to feel this is an appropriate use of genetic information, or to be willing to provide genetic information for this purpose. Younger respondents, aged under 25, are twice as likely as other age groups to say that the information should be shared with other organisations. Similarly, Black and Asian respondents are significantly more likely to say the information should be shared.

The second scenario for respondents to consider was if a person wants to find out if they are related to somebody. Seven in ten see this as an appropriate use of genetic information, and would be willing to provide information if asked. Again, despite the support for the purpose, a majority (69%) say this information once used for the intended purpose should not be shared with other organisations. Again, younger respondents are more willing for their genetic information to be shared, as are ethnic minority respondents.

Finally, respondents were asked to consider the situation where a doctor tests a couple planning to start a family and finds their children are likely to have an inherited disability or life-limiting illness. In this scenario, four in five think it is appropriate to identify part or all of the couple's genetic information. Three-quarters say they would be willing to have their genetic information used in this way. But as with the previous two scenarios the consensus is that the information should not be shared (67%).

Q39 When a doctor tests a couple planning to have a family and finds they have a family history that will mean their children are likely to have an inherited disability or life-limiting illness … do you think …

	%
… it is appropriate	82
… or inappropriate for someone to provide genetic information for this purpose	7
It depends	7
Don't know	3
… would you be willing	76
… or unwilling to provide genetic information for this purpose	9
It depends	7
Don't know	7
… do you think the genetic information should	17
… or should not be shared with other organisations	67
It depends	12
Don't know	4

Source: MORI

Men are twice as likely as women to think this is an inappropriate reason to identify genetic information. In contrast, those respondents with the highest educational attainment are more likely than others to think it appropriate. There are also regional differences with those in the North of England, Wales and Northern Ireland more likely to think this inappropriate.

While no more likely to think it an inappropriate reason to identify someone's genetic information, Asian respondents are significantly less likely to say they would be personally willing to provide genetic information for this purpose

(55%). Black respondents are twice as likely as white respondents to say they think the genetic information gathered in this scenario should be shared with other organisations (34%).

Those who know little about genetics are consistently less willing to provide genetic information for the purposes outlined in each of the three scenarios. However, they tend to be more willing for the genetic information to be shared with other organisations.

Uses of Genetic Information by Employers

Respondents appear wary of the use of genetic testing by employers, in keeping with findings from previous studies[3]. Irrespective of whether an employer is enquiring about an existing or a potential employee, half feel it is inappropriate for employers to know the results of genetic tests indicating whether the employee, or potential employee, may become a risk to colleagues or members of the public they come into contact with in their job. Two in five (38%) disagree. Asian respondents, older people, those with low levels of genetic knowledge and those not working are more likely to feel this is an appropriate step for an employer.

Seven in ten feel it is inappropriate for an employer to know the results of a genetic test to see if employees, or potential employees, are likely to become prone to an inherited disease or disability. Again, it is Asian respondents, those aged 65+ and those not working who are more likely to support an employers right to see this piece of genetic information.

There is, however, support for employers to know the results of tests indicating employee, or potential employee, sensitivity to substances they are likely to come into contact with in their job. Two-thirds feel it is appropriate for employers to know this information for existing employees, and three in five say it is appropriate for them to know this about potential employees.

Uses of Genetic Information by Insurers

As mentioned earlier in the summary, the use of human genetic information to set insurance premium levels is thought the least appropriate of the list of different ways of using information put to respondents. Four in five say it should not be used for his purpose.

In keeping with this position, respondents reject the suggestion that insurance companies should be able to ask to see the results from genetic tests to assess premium levels. One in nine agree with the suggestion, while over three-quarters disagree, giving a negative balance of opinion of –67. This is in keeping with data from the 1999 *British Social Attitudes* study[4], where 75% said insurance companies should not be allowed to use genetic tests when determining premium rates, and suggests that opinion is relatively constant on this issue.

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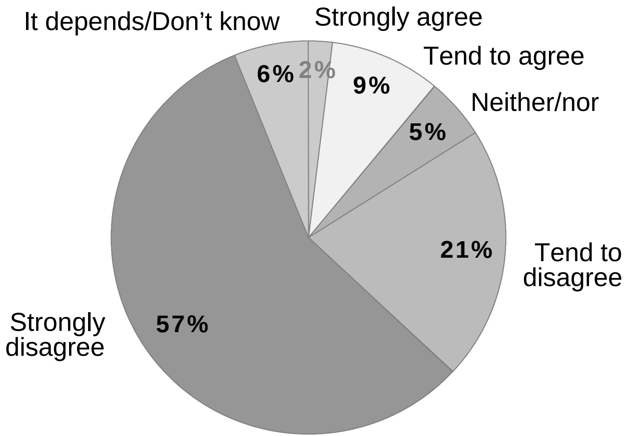
[3] British Social Attitudes: The 16th Report' Jowell et al (1999)

[4] British Social Attitudes: The 16th Report' Jowell et al (1999)

Insurance premiums

Q46 To what extent do you agree or disagree with the following statement:

'Insurance companies should be able to ask to see the results of genetic tests to assess whether premiums should go up or down'



Base: All respondents (1,038)

Source: MORI

Opinion varies considerably by age with a quarter of those aged 65 and over agreeing that insurance companies should have access to genetic tests, while only five per cent of those under 25 agree. Black and Asian respondents are less likely to oppose the suggestion than white respondents. Those with low levels of genetic knowledge are more likely than others to agree that insurance companies should be able to ask to see genetic test results to determine premiums.

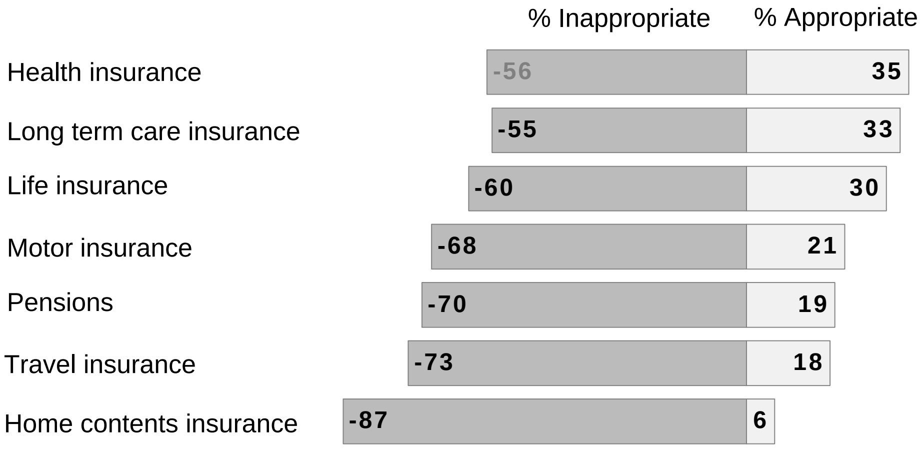
Respondents were asked to consider a range of different types of insurance policies, and to state whether in each case it is appropriate or inappropriate for an insurance company to know the results from a genetic test that an individual has already undertaken when considering an application for a policy.

On balance, respondents reject the need for insurance companies to have access to existing results from genetic tests, irrespective of the type of insurance policy the individual is applying for. However, those policies that have a more direct relationship to the applicants health are seen as situations where it is more appropriate for the insurance company to have access to this information. A third think it appropriate that existing genetic test results are made known to the insurance company when an application is made for health insurance (35%) and long term care insurance (33%), and three in ten think it appropriate when applying for life insurance (30%).

Only one in five think they should have access to an individual's genetic test results when they apply for motor insurance (21%), pensions (19%) or travel insurance (18%). Six per cent think it is appropriate for insurance companies to see this information when people apply for home contents insurance.

Access to genetic information by insurance companies

Q47-Q53 *Please tell me whether you think it is appropriate or inappropriate for an insurance company to know the results from a genetic test that an individual has already undertaken (for example, risk of Huntington’s disease or a rare cancer) when considering an application for each of the following policies?*



Base: All respondents (1,038)

Source: MORI

Older people, women and Asian respondents are more likely to think it appropriate for insurance companies to have access to genetic test results when applying for health or life insurance, than do other respondents. Those who say they have an inherited condition or illness are not significantly more likely than others to think that the provision of this kind of information is inappropriate.

Views on insurance company access to this information when applying for motor insurance vary significantly by age. Possibly reflecting the existing difficulties for young motorists to obtain cost-effective insurance, only one per cent of respondents aged under 25 think companies should have access to genetic test results. This increases to a third among the over 55s.

Asian respondents are more likely than others to feel it is appropriate for companies to know the results of genetic tests when considering an application for a pension policy. When an insurance company considers a travel insurance policy application, women, those aged 65+ and Asian respondents think it appropriate that they have access to genetic test results.

When considering the range of specific policies, those with lower levels of knowledge about genetics, and those whose religion is influential in the decisions they take, are more likely than others to think it appropriate for the insurance company to know the results from existing genetic tests.

Uses of Genetic Information for Forensic Purposes

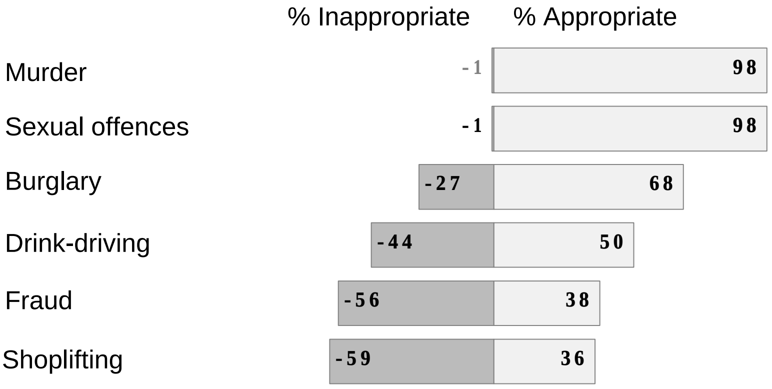
Respondents were asked whether or not they thought it was appropriate for Police to take DNA samples from people charged with a range of different crimes.

Reflecting the serious natures of the crimes, there is overwhelming support that samples should be taken from those charged with either murder or sexual offences. 98% think it is appropriate for Police to take samples in these circumstances.

Access to genetic information by the Police

Q54- Q59 The Police can currently take DNA samples of *__anyone__* *charged with any crime that may carry a prison sentence.*

Please tell me whether you think it is appropriate or inappropriate for the Police to take DNA samples for people charged with … ?



Base: All respondents (1,038)

Source: MORI

Two-thirds think it is appropriate to take a DNA sample from suspects charged with burglary – over a quarter disagree. This gives a balance of opinion of +41 who think this is an appropriate step. While there are no significant differences of opinion by age or by social class, there is a marked difference by gender. Men are significantly more likely than women to say it is appropriate for the Police to take a DNA sample from someone charged with burglary (76% and 62%, respectively). Black and Asian respondents are significantly less likely to think it is appropriate.

While on balance respondents think DNA samples should be taken from those charged with drink-driving offences, opinion is relatively evenly split. Half think it is appropriate, 44% think it is inappropriate.

There are significant differences of opinion by age. While just over a third of those aged under 25 think a DNA sample is appropriate for suspects charged with drink-driving, this rises to 64% support among those aged 65+. Those in social classes DE, those with GCSE level, or no, qualifications, and Black respondents are more likely than others to think the Police should take DNA samples of those charged with drink-driving.

On balance, respondents do not think it is appropriate for the Police to take DNA samples from suspects charged with either shoplifting or fraud. In the case of each crime, almost three in five think it is inappropriate, while just over a third think it appropriate.

Men are significantly more likely than women to think that the Police should take DNA samples from people charged with either of these crimes. Those aged 65+ are significantly more likely than other age groups to say it is appropriate to take samples from suspects charged with shoplifting.

When considering a range of crimes, those with lower levels of knowledge about genetics, and those whose religion is influential in the decisions they take, are more likely than others to think it is appropriate for the Police to take DNA samples individuals charged with an offence.

Use of Genetic Information on Databases

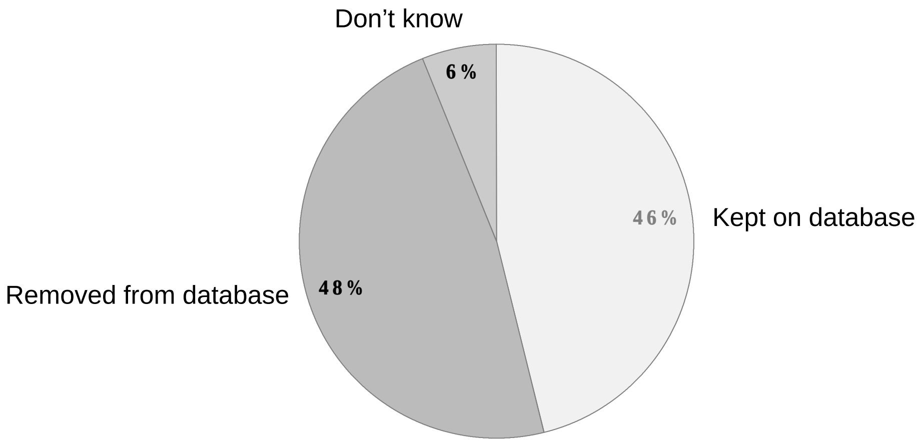
Respondents views on issues of use, access and consent to genetic information being held on databases is determined by the specific details of each specific situation.

Police Databases

Respondents were asked to consider whether or not DNA samples taken from acquitted individuals should, or should be kept on the Police genetic database. Opinion is very evenly split, with 46% saying they feel samples should be kept, while 48% say they should be removed from the database.

Retention of forensic DNA samples

Q60 If an individual is charged with a crime, his/her DNA sample is placed on a Police genetic database. If they are later acquitted of the crime (I.e. not brought to trial or not found guilty), should the DNA sample be kept or removed from the Police genetic database?



Base: All answering (1,038)

Source: MORI

However, opinion varies significantly between different sections of the population, as illustrated in the table below.

While, on balance women favour the retention of the sample for future reference (+5), a majority of men feel samples should be removed after acquittal (-11). There are also significant differences by age with younger respondents more likely to feel that the Police should keep the genetic information on the database, whereas the majority of those aged over 35 disagree. Middle class respondents are more likely to feel samples should be removed from the Police database after acquittal, whereas those in social classes DE favour its retention for future use. Those with children are more likely than others to say that samples from acquitted individuals should be kept on Police databases.

There are also very marked differences by ethnicity. White respondents are fairly evenly split on this issue; 45% favouring retention of samples, and 49% opposed. However, three in five (61%) Black respondents feel that samples should be removed after the individual has been acquitted of the offence they were charged with. In contrast, half (51%) of Asian respondents would support the retention of DNA samples on the Police genetic database.

Q60 If an individual is charged with a crime, his/her DNA sample is placed on a Police genetic database. If they are later acquitted of the crime (i.e. not brought to trial or not found guilty), should the DNA sample be kept or removed from the Police genetic database?

	Kept on database %	**Removed from database** %	**Net kept** ±%
All	*46*	*48*	*-2*
Gender			
Male	43	54	-11
Female	48	43	+5
Age			
16-24	74	23	+51
25-34	47	43	+4
35-54	42	52	-10
55-64	30	64	-34
65+	38	56	-18
Social class			
AB	39	53	-14
C1	41	56	-15
C2	45	48	-3
DE	55	38	+17
Ethnicity			
White	45	49	-4
Black	36	61	-25
Asian	51	36	+15

Source: MORI

There is clear support for Police powers of access to non-Police genetic databases so they can cross-check information. Three in five (61%) think this is an appropriate power – a quarter think it inappropriate. Younger people, those in social classes C2DE and Asian respondents are more likely to support this Police power. Older people, and Black respondents are less likely to think it is appropriate.

Only one in six feel that this power of access to genetic databases should be reciprocal; 17% think that other researchers should have access to the Police's genetic database for other purposes, such as social research. Seven in ten think this would be inappropriate.

Medical Databases

Respondents were asked a range of questions relating to the ownership of, and access to, medical databases of human genetic information.

Health professionals – such as GPs and the NHS – are most likely to be trusted as responsible users of the human genetic information held on medical databases. (The medical profession is also seen as the most trusted source of information for biotechnology).[5]

Nine in ten would trust family doctors to use this information responsibly, and three-quarters would trust the NHS to do so. Three in five (59%) would trust the Police to be responsible users – although this is significantly lower among both Black and Asian respondents (both 37%).

Two in five say they would trust an Expert Government Scientific Advisory Committee, or academic scientists. One in five feel health and pharmaceutical companies, and advisory bodies to the Government would use human genetic information held on medical databases responsibly.

Least trusted to be responsible users are insurance companies (7%), employers (5%), consumer groups (2%) and the general public (2%).

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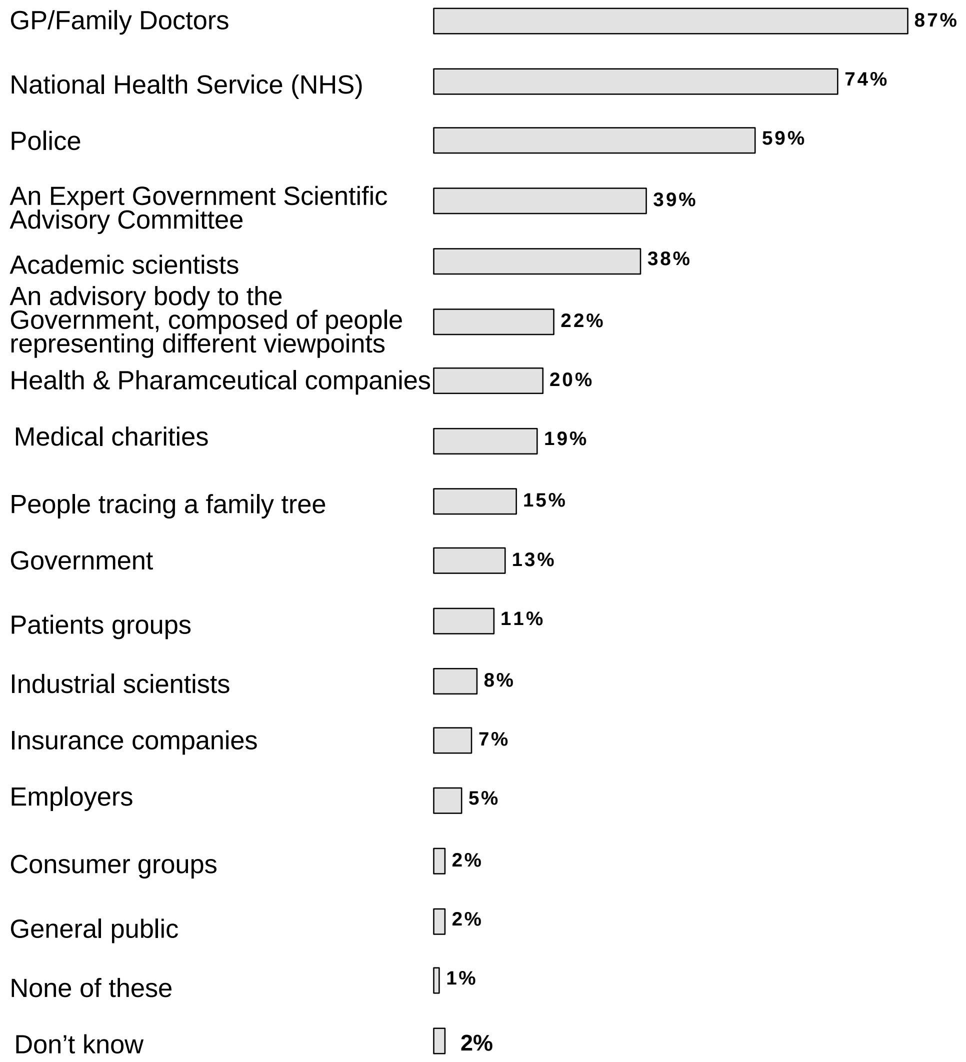
[5] 'The Europeans and Modern Biotechnology' Eurobarometer 46.1 (1996) and 'The Europeans and Biotechnology' Eurobarometer 52.1 (1999)

Use of medical database human genetic information

Q68 Please tell me which, if any, you trust to use the human genetic information held on medical databases responsibly?



Base: All respondents (1,038) Source: MORI

Consistent with their views on the ownership and access to innovative ways of using genetic information, respondents feel that the medical genetic databases should also be publicly owned. Three in five agree that genetic databases should be publicly owned. Almost three in ten disagree, and fifteen per cent don’t express an opinion either way. When asked separately whether genetic databases should be commercially owned the response is clearer. Three-quarters (73%) disagree with commercial ownership of medical genetic databases. This suggests that the rejection of commercial ownership is stronger than the acceptance that public ownership is the best way forward.

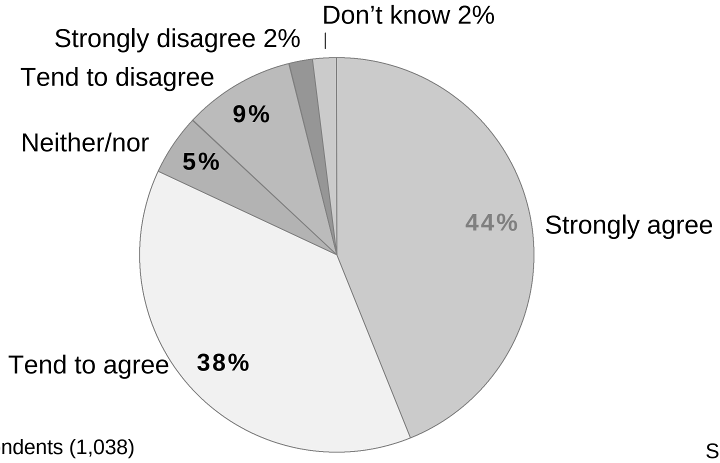
Support for public ownership of medical genetic databases is significantly higher among men, middle class respondents and those with higher educational qualifications (A-level or above). In contrast, Black respondents are more likely than other groups to oppose public ownership of medical databases.

While the majority back public ownership of medical databases, they support stringent regulations on access. Nine in ten agree that information should only be included on the database where an individual has given consent – only six per cent disagree. This rises to 98% among those aged under 25.

Confirming the findings from recent qualitative research[6], four in five agree that fresh consent must be sought from individuals before new research can be conducting on existing DNA samples held on medical genetic databases. Eleven per cent disagree.

Q64 I am going to read out some questions about medical databases of human genetic information, which could allow medical researchers to reach a better understanding of human diseases. Information from these databases can be used to identify individuals.

Please tell me to what extent you agree or disagree…. Fresh consent from an individual should be required before new research is conducted on their existing samples?



Base: All respondents (1,038)

Source: MORI

Respondents with higher educational qualifications (such as A-level, or above), and those with children, are marginally less likely to agree that fresh consent is required for each subsequent use of the existing sample.

Three in five agree that commercial organisations should only have access to human genetic information held in medical databases if individuals can't be identified. One in five disagree. Support for access by commercial organisations if individuals are unidentifiable is lower among those aged under 25 (46%), and among Black respondents (51%).

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[6] Qualitative research to explore public perceptions of human biological samples, Cragg Ross Davidson (MRC/Wellcome) 2000. Depth interviews and group discussions.

Controls and Regulations

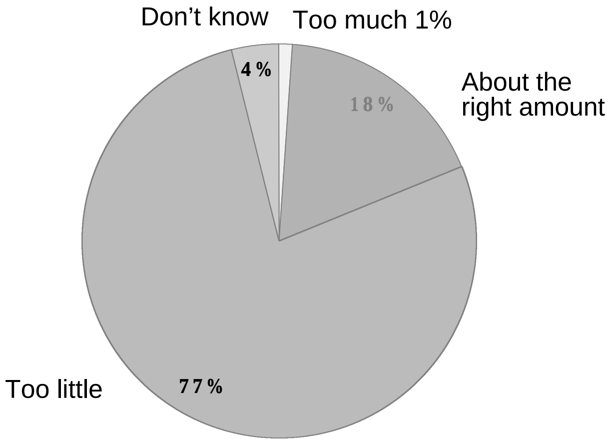
Respondents lack confidence that the rules and regulations governing biological developments are keeping pace with new research and developments. A quarter have a ‘great deal’ or ‘fair amount’ of confidence that regulations are keeping pace – but seven in ten have little or no confidence that this is the case.

Middle-class respondents, and those aged under 25 tend to be less confident of the ability of the regulatory system to keep up with new biological developments. In contrast Asian respondents are significantly more likely than others to have confidence that rules and regulations are up to date.

Three-quarters feel that they currently receive too little information on the rules and regulations about biological developments. Almost one in five say they have about the right amount of information, and one per cent say they receive too much. Older respondents aged 65+ are significantly more likely than other age groups to say they currently receive about the right amount of information on rules and regulations on biological developments, as, ironically, are those with low levels of genetic knowledge.

Regulation of biological developments

Q70 Would you say that you have had too much information on the rules and regulations about biological developments, too little, or about the right amount?



Base: All respondents (1,038)

Source: MORI

Respondents were presented with a list of steps and asked which would give them trust in a system of controls and regulations on how human genetic information is stored and used. Three aspects emerge as key concerns. Over half mention that they would have trust in the system if the rules are made independently of party politics (56%), and that the system can be seen to be fair and open (55%). The third priority is that the system is designed to monitor developments and uses, and is prepared to restrict them if it establishes well-founded concerns (53%).

Independence from party politics is a significantly more important factor when developing a trustworthy system of controls and regulations for men than women (66% and 47%, respectively). It is also of greater concern to middle class respondents (social class AB, 69%), whereas those aged 65+ are less concerned about this aspect of the development of regulatory system (37%).

Older respondents are also less likely than younger people to say that public consultation would give them trust in a system of control and regulations on genetic information storage and use. Unlike white respondents, Black and Asian respondents rate a system that can be seen to be open and fair as most likely to instil trust.

Statistical Reliability

The respondents to the questionnaire are only samples of the total "population", so we cannot be certain that the figures obtained are exactly those we would have if everybody had been interviewed (the "true" values). We can, however, predict the variation between the sample results and the "true" values from a knowledge of the size of the samples on which the results are based and the number of times that a particular answer is given. The confidence with which we can make this prediction is usually chosen to be 95% - that is, the chances are 95 in 100 that the "true" value will fall within a specified range. The table below illustrates the predicted ranges for different sample sizes and percentage results at the "95% confidence interval".

Size of Sample on which survey is based	**Approximate sampling tolerances applicable to percentages at or near**		
	10% or 90% ±	30% or 70% ±	50% ±
100 interviews	6	9	10
200 interviews	4	6	7
500 interviews	3	4	4
700 interviews	2	3	4
1,000 interviews	2	3	3

For example, with a sample size of 1,038 where 30% give a particular answer, the chances are 19 in 20 that the "true" value (which would have been obtained if the whole population had been interviewed) will fall within the range of ±3 percentage points from the sample result.

When results are compared between separate groups within a sample, different results may be obtained. The difference may be "real," or it may occur by chance (because not everyone in the population has been interviewed). To test if the difference is a real one - i.e. if it is "statistically significant", we again have to know the size of the samples, the percentage giving a certain answer and the degree of confidence chosen. If we assume "95% confidence interval", the differences between the results of two separate groups must be greater than the values given in the table below to follow.

Size of samples compared	**Differences required for significance at or near these percentage**		
	10% or 90%	30% or 70%	50%
	±	±	±
100 and 100	8	13	14
100 and 500	6	10	11
200 and 200	6	9	10
200 and 500	5	8	8
500 and 500	4	6	6

Social Class Definitions

A	Professionals such as doctors, surgeons, solicitors or dentists; chartered people like architects; fully qualified people with a large degree of responsibility such as senior editors, senior civil servants, town clerks, senior business executives and managers, and high ranking grades of the Services.
B	People with very responsible jobs such as university lecturers, heads of local government departments, middle management in business, qualified scientists, bank managers, police inspectors, and upper grades of the Services.
C1	All others doing non-manual jobs; nurses, technicians, pharmacists, salesmen, publicans, people in clerical positions, police sergeants/ constables, and middle ranks of the Services.
C2	Skilled manual workers/craftsmen who have served apprenticeships; foremen, manual workers with special qualifications such as long distance lorry drivers, security officers, and lower grades of Services.
D	Semi-skilled and unskilled manual workers, including labourers and mates of occupations in the C2 grade and people serving apprenticeships; machine minders, farm labourers, bus and railway conductors, laboratory assistants, postmen, door-to-door and van salesmen.
E	Those on lowest levels of subsistence including pensioners, casual workers, and others with minimum levels of income.

MORI/13722

People's Panel - Independent Commission Study

Marked-up Questionnaire

- Findings based on 1,038 completed interviews with previously recruited People's Panel members.
- Interviews were conducted face-to-face in respondents' homes from 6th October to 17th December 2000 cross the United Kingdom.
- Data are weighted to the known profile of the UK population (sex, age, class, work status, tenure, geographical region, MOSAIC area, car ownership and household composition).
- Data based on all respondents unless otherwise stated.
- Where figures do not sum to 100 per cent, this may be due to computer rounding, multiple responses or the exclusion of 'Don't know' or refused categories.
- An asterisk '*' represents a figure greater than zero, but less than 0.5%.

Sex	%
Male	48
Female	52

Work Status of Respondent	%
Full-time (30 hrs/wk+)	43
Part-time (8-29 hrs/wk)	10
Not working (under 8 hrs)	1
Housewife	10
Retired	23
Registered unemployed	3
Unemployed but not registered	1
Student	6
Other	2

Age	%
16-17	1
18-24	13
25-34	20
35-44	16
45-54	16
55-59	6
60-64	6
65-74	13
75+	7

ASK DEMOGRAPHIC QA OVERLEAF ⇒

Interview Declaration
I confirm that I have carried out this Interview face-to-face with the above name person and that I asked all the relevant questions fully and recorded the answers in conformance with the survey specification and within the MRS Code of Conduct.

Signature: ....

Interviewer Name (CAPS): ....

Interviewer Number:
☐ ☐ ☐ ☐ / ☐
(23) (24) (25) (26) (27) (23-27)

Day of Interview 1 2 3 4 5 6 7
(Mon) (Thur) (Sun) (28)

Date of Interview: ☐☐ / ☐☐ /00

Length of Interview: ☐☐ (minutes) (29-30)

QA SHOWCARD L **To which of the groups on this card do you consider <u>you</u> belong?**
SINGLE CODE ONLY. RECRUIT TO QUOTA

	%
WHITE	
British	86
Irish	2
Any other white background	3
MIXED	
White and Black Caribbean	*
White and Black African	0
White and Asian	*
Any other mixed background	1
ASIAN OR ASIAN BRITISH	
Indian	2
Pakistani	*
Bangladeshi	*
Any other Asian background	0
BLACK OR BLACK BRITISH	
Caribbean	1
African	1
Any other Black background	*
CHINESE OR OTHER ETHNIC GROUP	
Chinese	*
Any other background	*
Refused	*
Not stated	3

PUBLIC UNDERSTANDING OF GENETIC INFORMATION

Q1. **When I say 'genetics', what, if anything, springs to mind?**

	%
Genetically modified food/products/messing about with food	23
The foundation of living matter/organisms	18
Regeneration/improving growth	15
Genes/information/science of genes/genetic make-up	14
Make-up of human genes/blueprint of human body/physical characteristics	14
Inherited elements of human cell/hereditary traits/illnesses	13
Cloning/Dolly the Sheep	13
Make up of DNA/chromosomes	13
Genetic engineering/modification of cells/structures	11
Modern technology	10
Medical research/science/ experimentation	9
Trying to create a super race	9
Crop modification/crops	8
People/races/nationalities	7
Hitler and Mengele/German fascism	5
Change/modification/artificial modification/manipulation	4
Having babies to help/save brother/sister	4
Tampering with genes/nature	4
The body/body parts/spare parts/growing spare parts	4
Togetherness/looking after each other	3
Animals/make-up of animal kingdom/livestock	3
Selective breeding/designer babies/making babies to order	3
Ancestry/where we come from/evolution	2
Mendelism	2
Babies/specialised babies	2
Illnesses/diseases/ways to cure them/gene therapy	2
Make of plants/minerals/vegetation	2
Great advances made/will be able to do amazing things in future	2
Biology/biological manipulation/manipulation of DNA	2

Answers given by less than 2% not listed

Q2. **And when I say 'human genetic information', what, if anything, springs to mind?**

	%
DNA/testing of DNA/fingerprinting	18
Make-up of human genes/characteristics/genetic info of the body	15
Research/identifying genetic problems/illnesses in humans/hereditary problems	10
Cloning/cloning body parts/Dolly the sheep	9
Inherited genes/physical attributes/characteristics	7
Selective breeding/having baby of your choice/choosing sex of child	5
Used to cure/eradicate illnesses/diseases/gene therapy	5
Chromosomes of the body	4
Human Genome Project/Factor	4
Genes/definition of genes	4
Scientific/biological research/experimentation	3
Medical research/developments	3
Test tube babies/IVF/helping childless couples	2
Making perfect babies/screening out impurities	2
Transplants/organ transplants	2
Genetic engineering/ mapping/modification	2
Published information/letting people know what they want them to know	2

Answers below 2% not listed

By human genetic information, we mean the information stored by human genes in every cell that plays an important part in the design and running of the human body and is distinct to each person.

Q3. **From what you may know, in what ways, if any, could human genetic information be used now or in the near future?**

	%
Curing illnesses/diseases/removing genes to eradicate diseases/gene therapy	22
To overcome hereditary diseases/traits	21
For selective breeding/having designer children/choosing sex of child/Eugenics	12
Cloning	12
For catching criminals/solving crimes/forensic purposes	10
Medical purposes/research/scientific research/experimentation	10
DNA testing/identification/ fingerprinting	8
Solving problems of terminal/incurable diseases	7
To eradicate handicaps/deformities/ abnormalities	7
Growing new organs/limbs/spare parts for humans	7
Checking embryos for abnormalities/isolating genes to make healthier babies	6
Identifying diseases/cause of illnesses/diseases/locating carriers of particular diseases	5
To help with transplants (heart/bone marrow etc)	3
To create a super race/perfect humans	3
Insurance companies will check genetic make-up before allowing insurance/to raise premiums	3
Monitoring genetic flaws/isolating genes	2
To improve quality of life/lengthen lifespans	2
Blood tests/cells/blood grouping	2

Answers below 2% not listed

Q4-Q7 SHOWCARD A (R) **I am going to read out a number of different statements. Using this card, for each please tell to what extent you agree or disagree?**
ALTERNATE AND TICK START ☑. SINGLE CODE ONLY.

			Strongly agree %	Tend to agree %	Neither agree nor disagree %	Tend to disagree %	Strongly disagree %	No opinion %
☐	Q4.	**New genetic developments will bring cures for many diseases**	35	53	5	4	1	2
	Q5.	**If others have access to your genetic information they will know too much about you**	19	35	17	22	5	2
☐	Q6.	**Research on human genetics is tampering with nature and is therefore unethical**	12	21	24	29	12	2
	Q7.	**New genetic developments will mean children who are healthier and free from inherited disabilities**	19	54	16	7	1	3

Q8. **I am now going to read out a number of different items. For each, please tell me whether or not you think this is a way in which human genetic information could be used?** READ OUT ITEMS A) TO L) ... (ROTATE AND TICK START ☑)

Q9. **And would you say this is a way in which human genetic information should be used?** READ OUT NEXT ITEM AND REPEAT COULD/SHOULD FORMAT

			Q8 Could be used			Q9 Should be used		
			Yes	No	Don't know/ not stated	Yes	No	Don't know/ not stated
			%	%	%	%	%	%
☐	A)	**Improvement in the diagnosis of diseases**	92	4	4	92	3	5
	B)	**Developing targeted drugs for people**	87	4	9	87	6	7
	C)	**For setting the level of insurance premiums**	62	26	12	8	80	13
☐	D)	**Developing techniques to correct defective genes for individuals**	86	5	9	72	15	12
	E)	**Developing techniques to correct defective genes for future generations**	87	5	8	67	21	13
	F)	**Understanding why people are more or less likely to develop diseases**	93	3	4	90	5	6
☐	G)	**Research into biological and chemical warfare**	71	17	12	15	75	10
	H)	**Assessing health damage and risk from chemicals and radiation**	82	7	11	79	10	11
	I)	**Studying evolution, ancestry and population**	80	10	10	66	18	16
☐	J)	**Identifying offenders or eliminating possible offenders from Police enquiries, using DNA found at the crime scene**	96	1	3	94	3	3
	K)	**Establishing paternity and other family relationships**	90	6	4	78	11	11
	L)	**Parents choosing physical and mental characteristics of their children**	75	17	8	13	78	9

INHERITED DISORDER OR ILLNESS

Q10. **As far as you know, do you, or any members of your family or friends have any inherited conditions or illnesses? By 'inherited condition or illness', I mean a condition that has been passed down to someone through their family.** MULTICODE OK.

	%
Yes, I have an inherited condition or illness	16
Yes, members of my family have inherited conditions or illnesses	24
Yes, I know someone outside my family who has an inherited condition or illness	8
No	60
Don't know	2

ASK Q11 IF YES AT Q10 CODE 1,2 OR 3

Q11. **And what is this inherited condition or illnesses? In giving me your answer, please also tell me whether it is you, a member of your family, or someone else that has these inherited conditions or illnesses. This information will be treated in confidence and individuals will not be identified.** PROBE FULLY AND WRITE IN.

Base:	Respondent (166) %	Family Member (263) %	Friend/ Acquaintance (67) %
Asthma	15	14	2
Heart disease/Angina	14	15	14
Psoriasis	11	6	0
Sight problems/weak eyesight	6	2	0
Diabetes	5	13	1
Arthritis	5	6	2
Thyroid problems/Graves disease	5	4	0
Eczema	4	3	0
Glaucoma	3	4	4
Varicose veins	3	1	0
Allergies/rashes (non-specific)	3	1	1
High blood pressure	2	3	0
Hay fever	2	1	0
Cancer (non-specific)	1	9	14
High cholesterol	1	2	0
Breast cancer	1	2	2
Epilepsy	1	1	12
Dyslexia	1	1	2
Migraines	1	1	0
Kidney problems	1	*	0
Spina Bifida	1	1	0
Ovarian cancer	1	0	0
Colour blindness	*	*	1
Ear problems/deafness	*	1	1
Colitis	*	1	0
Parkinson disease	0	2	3
Muscular Dystrophy	0	2	1
Cystic fibrosis	0	1	4
Blood disorders/disease/clots	0	1	2
Downs Syndrome	0	1	*
Lupus/Systemic Lupus	0	1	0
Mental health/abnormalities	0	1	0
Hodgkinsons Disease	0	1	0
Multiple Sclerosis	0	*	8
Thalassaemia	0	*	1
TB	0	*	7
Haemophilia	0	0	5
Huntingtons Chorea	0	0	1
Crohns Disease	0	0	3
Others	1	0	*
Not stated	29	15	17

Answers mentioned by less than 1% not shown.

NATURE VS. NURTURE

ASK ALL

Q12-Q30 SHOWCARD B (R) **I am now going to read out a list of characteristics which may come about because they are inherited (nature) or because of environmental factors (nurture) such as lifestyle, upbringing, etc or because of a combination of these.**

For each one I read out, please tell me how each characteristic comes about from 1, if you think it is totally inherited, to 5 if you think its development is entirely dependent upon environmental factors.

IF UNSURE: **Please give your best estimate.** READ OUT Q12-Q30. ROTATE ORDER. TICK START. ☑ SINGLE CODE ONLY.

			Totally inherited (nature) 1	2	3	4	Totally environ mental (nurture) 5	Don't know	Mean
			%	%	%	%	%	%	
☐	Q12.	**Antisocial behaviour**	4	6	27	32	29	2	3.79
	Q13.	**Alcoholism**	5	12	27	27	26	2	3.58
	Q14.	**Asthma**	25	20	31	15	7	1	2.59
	Q15.	**Body height & weight**	32	33	27	3	3	1	2.10
	Q16.	**Cancer**	14	23	41	11	7	4	2.71
	Q17.	**Flu**	4	4	19	15	54	3	4.17
	Q18.	**Cystic Fibrosis**	37	19	17	5	4	18	2.02
	Q19.	**Depression**	6	10	29	27	24	4	3.55
☐	Q20.	**Diabetes**	25	33	26	7	3	6	2.25
	Q21.	**Epilepsy**	27	35	20	5	3	10	2.11
	Q22.	**Eye colour**	75	12	6	2	2	3	1.40
	Q23.	**Heart disease**	18	22	42	12	3	2	2.59
	Q24.	**High blood pressure**	12	19	38	22	7	2	2.92
	Q25.	**Huntington's disease**	36	17	15	2	2	27	1.84
	Q26.	**Intelligence**	20	27	36	12	4	2	2.52
	Q27.	**Measles**	5	8	20	16	46	5	3.96
	Q28.	**Sickle Cell Anaemia**	46	14	9	3	3	24	1.72
	Q29.	**Sexual orientation**	13	14	37	12	14	10	3.00
☐	Q30.	**Thalassaemia**	10	5	9	1	3	71	2.36

GENETIC TESTING

Q31-Q36 SHOWCARD C (R) **I am going to read out a number of different statements. Using this card, for each please tell me to what extent you agree or disagree?**
READ OUT Q31-Q36. ALTERNATE AND TICK START ☑. SINGLE CODE ONLY.

			Strongly agree %	Tend to agree %	Neither agree nor disagree %	Tend to disagree %	Strongly disagree %	No opinion %
☐	Q31.	**People should be encouraged to be tested in young adulthood for disorders that develop in middle age or later in life**	30	44	14	9	2	1
	Q32.	**Parents have a right to ask for their child to be tested for genetic disorders that develop in adulthood**	25	53	10	8	3	*
	Q33.	**Genetic information may be used by parents to decide if children with certain disabling conditions are born**	14	43	16	15	11	1
	Q34.	**In the context of medical treatment, people should always be asked for their permission for their blood or tissues to be used in a genetic test**	62	26	6	4	1	1
	Q35.	**Couples who are at risk of having a child with a serious genetic disorder should be discouraged from having children of their own**	11	20	24	29	14	2
☐	Q36.	**Genetic techniques should not be made available to parents so that they can have a baby of the sex they choose**	56	19	8	9	8	1

OWNERSHIP OF GENETIC INFORMATION

SPLIT SAMPLE Q37 & Q38 – ASK HALF YOUR RESPONDENTS Q37, AND THE OTHER HALF Q38. TICK SPLIT SAMPLE.

☐

Q37. SHOWCARD D1(R) **Looking at this card, please tell me which of these statements comes closest to your personal opinion?** SINGLE CODE ONLY.

Base: All answering (599)

		%
A	If commercial organisations have invested large amounts of time and money to develop a new way to use human genetic information, they should own the developments and be able to charge for its use	21
B	If commercial organisations have invested large amounts of time and money to develop a new way to use human genetic information, the information should be publicly owned and available to all for use at no charge	72
	Don't know	7

☐

Q38. SHOWCARD D2(R) **Looking at this card, please tell me which of these statements comes closest to your personal opinion?** SINGLE CODE ONLY.

Base: All answering (522)

		%
A	If publicly funded research organisations have invested large amounts of time and money to develop a new way to use human genetic information, they should own the developments and be able to charge for its use	7
B	If publicly funded research organisations have invested large amounts of time and money to develop a new way to use human genetic information, the information should be publicly owned and available to all for use at no charge	90
	Don't know	3

USES OF GENETIC INFORMATION

SITUATIONS A-C ON SHOWCARD E (R)

Q39. **On this card are a number of different situations in which an individual or organisation might want to identify a part or all of someone's genetic information or DNA.**

Looking at Situation A/B/C (READ OUT A/B/C/ AS APPROPRIATE. ROTATE ORDER OF READ OUT. TICK START ☑).

☐ Situation A: **When a doctor tests a patient for an inherited disease**

☐ Situation B: **When a person wants to find out if they are related to somebody**

☐ Situation C: **When a doctor tests a couple planning to have a family and finds they have a family history that will mean their children are likely to have an inherited disability or life-limiting illness**

Do you think ... ? READ OUT.

	Situation A %	Situation B %	Situation C %
... it is appropriate	87	71	82
... or inappropriate for someone to provide genetic information for this purpose?	7	13	7
It depends	4	13	7
Don't know/not stated	1	3	3

	Situation A %	Situation B %	Situation C %
... would you be willing	83	73	76
... or unwilling to provide genetic information for this purpose?	8	12	9
It depends	5	12	7
Don't know/not stated	4	3	7

	Situation A %	Situation B %	Situation C %
... do you think the genetic information should	22	15	17
... or should not be shared with other organisations?	60	69	67
It depends	14	11	12
Don't know/not stated	4	5	4

EMPLOYMENT SECTION

I am now going to read out a number of different uses of human genetic information.

Q40-Q42 **And for each of these, please tell whether you think it is appropriate or inappropriate for an employer to know this piece of human genetic information for <u>existing</u> employees?** READ OUT Q40-Q42. ALTERNATE AND TICK START. ☑ SINGLE CODE ONLY.

			Appropriate %	Inappropriate %	It depends %	Don't know %
☐	Q40.	**The results of a genetic test to see if employees may become a risk to colleagues or members of the public they come into contact with in their job**	38	47	10	4
	Q41.	**The results of a genetic test to see if employees are likely to become prone to an inherited disease or disability**	18	71	8	4
☐	Q42.	**The results of a genetic test that indicates that they may be sensitive to certain substances that they will come in to contact with in their job**	67	20	10	2

Q43-Q45 **For each, please tell whether you think it is appropriate or inappropriate for an employer to know this piece of human genetic information about <u>potential</u> employees?**
READ OUT Q43-Q45. ALTERNATE AND TICK START ☑. SINGLE CODE ONLY

			Appropriate %	Inappropriate %	It depends %	Don't know %
☐	Q43.	**The results of a genetic test to see if potential employees may become a risk to colleagues or members of the public they come into contact with in their job**	38	50	9	2
	Q44.	**The results of a genetic test to see if potential employees are likely to become prone to an inherited disease or disability**	18	70	9	2
☐	Q45.	**The results of a genetic test that indicates that they maybe sensitive to certain substances that they will come in to contact with in their job**	60	25	11	3

INSURANCE SECTION

Q46. SHOWCARD F (R) **To what extent do you agree or disagree with the following statement:**

'insurance companies should be able to ask to see the results of genetic tests to assess whether premiums should go up or down' SINGLE CODE ONLY.

	%
Strongly agree	2
Tend to agree	9
Neither agree nor disagree	5
Tend to disagree	21
Strongly disagree	57
It depends	3
Don't know	2

Q47-Q53 **Please tell me whether you think it is appropriate or inappropriate for an insurance company to know the results from a genetic test that an individual has already undertaken (for example, risk of Huntington's disease or a rare cancer) when considering an application for each of the following policies?**
READ OUT Q47-Q53. ROTATE AND TICK START ☑. SINGLE CODE ONLY.

			Appropriate %	Inappropriate %	It depends %	Don't know %
☐	Q47.	**Life insurance**	30	60	6	4
	Q48.	**Health insurance**	35	56	6	3
	Q49.	**Motor Insurance**	21	68	7	4
☐	Q50.	**Pensions**	19	70	6	5
	Q51.	**Long term care insurance**	33	55	8	4
	Q52.	**Home contents insurance**	6	87	2	4
☐	Q53.	**Travel insurance**	18	73	5	4

FORENSIC SECTION

The Police can currently take DNA samples of <u>anyone</u> charged with any crime that may carry a prison sentence.

Q54-Q59 **Please tell me whether you think it is appropriate or inappropriate for the Police to take DNA samples for people charged with...?**
READ OUT Q54-Q59. ALTERNATE START AND ☑ ORDER. SINGLE CODE ONLY.

			Appropriate %	Inappropriate %	It depends %	Don't know %
☐	Q54.	**Drink-driving**	50	44	3	3
	Q55.	**Shoplifting**	36	59	3	3
	Q56.	**Murder**	98	1	1	*
	Q57.	**Sexual offences**	98	1	1	*
	Q58.	**Fraud**	38	56	5	1
☐	Q59.	**Burglary**	68	27	5	*

Q60. **If an individual is charged with a crime, his/her DNA sample is placed on a Police genetic database. If they are later acquitted of the crime (i.e. not brought to trial or not found guilty), should the DNA sample be kept or removed from the Police genetic database?** SINGLE CODE ONLY.

	%
Kept on database	46
Removed from database	48
Don't know	6

Q61-Q62 **I am now going to read out two statements. For each, please tell me whether you think this is appropriate or inappropriate?**
READ OUT Q61-Q62. ALTERNATE ORDER AND TICK START ☑. SINGLE CODE ONLY

			Appropriate %	Inappropriate %	It depends %	Don't know %
☐	Q61.	**Police should have access to other genetic databases e.g. medical databases so they can cross check information**	61	24	12	2
☐	Q62.	**Other researchers should have access to the Police's genetic database for other purposes e.g. Social research**	17	69	10	4

MEDICAL DATABASE SECTION

I am now going to ask some questions about medical databases of human genetic information, which could allow medical researchers to reach a better understanding of human diseases. Information from these databases can be used to identify individuals.

Q63-Q67 SHOWCARD F (R) AGAIN **I am going to read out a number of different statements. Using this card, for each please tell to what extent you agree or disagree with it?** READ OUT Q63-Q67. ALTERNATE AND TICK START ☑. SINGLE CODE ONLY.

			Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	No opinion
			%	%	%	%	%	%
☐	Q63.	**Information should only be included in the database where an individual has given consent**	64	27	2	5	1	1
	Q64.	**Fresh consent from an individual should be required before new research is conducted on their existing samples**	44	38	5	9	2	2
	Q65.	**Commercial organisations should have access to human genetic information only if individuals can't be identified**	24	37	14	11	8	5
	Q66.	**These genetic databases should be publicly owned**	26	32	10	16	12	5
☐	Q67.	**These genetic databases should be commercially owned**	1	7	12	29	44	7

Q68. SHOWCARD G (R). **On this card are a number of different types of people or institutions. Please tell which, if any, you trust to use the human genetic information held on medical databases responsibly? Just read out the letter/s that apply.** MULTICODE OK.

	%
GP/Family Doctors	87
National Health Service (NHS)	74
Police	59
An Expert Government Scientific Advisory committee	39
Academic scientists	38
An advisory body to the Government, composed of people representing different viewpoints	22
Health & Pharmaceutical companies	20
Medical charities	19
People tracing a family tree	15
Government	13
Patients groups	11
Industrial scientists	8
Insurance companies	7
Employers	5
Consumer groups	2
General public	2
Other	0
None of these	1
Don't know	2

Q69. SHOWCARD H (R) **Which, if any, of the things on this card do you personally feel would give you trust in a system of controls and regulations on how human genetic information is stored and used? Please mention up to five. Just read out the letter or letters that apply.** MULTICODE UP TO A MAX OF FIVE.

	%
That rules are made independently of party politics	56
Having a system which can be seen to be fair and open	55
Having a system that monitors developments and uses and is prepared to restrict them if there are well-founded concerns	53
Having random spot checks of all regulated activities	39
Having people making decisions who are either independent or declare their interests	37
Monitoring of social/ethical implications	32
Having a wide range of people with different expertise and interests involved	30
Asking the public for their views	26
Legally enforceable rules	16
Voluntary code of practice	*
Other	27
None of these	1
Don't know	2

Q70. **Would you say that you have had too much information on the rules and regulations about biological developments, too little or about the right amount?** SINGLE CODE ONLY

	%
... too much	1
... too little	77
... or about the right amount	18
Don't know/not stated	5

Q71. SHOWCARD I (R) **How much, if any, confidence do you have that rules and regulations are keeping pace with biological developments and research?** SINGLE CODE ONLY

	%
A great deal	1
A fair amount	23
A little	45
None at all	24
Don't know/not stated	8

Additional Demographics:

Q72. **What is your religion, if any?** IF CHRISTIAN: **What denomination are you?** WRITE IN FULL VERBATIM RESPONSES, AND THEN SINGLE CODE PRECODE FROM LIST.

	%
Church of England	45
Roman Catholic	15
Church of Scotland	5
Church of Wales	1
Church of Ireland	*
Free church/Non-conformist (Methodist, Baptist)	6
Independent Evangelical Churches	1
Other Protestant	1
Muslim	2
Hindu	*
Sikh	*
Humanist	*
Orthodox Christian	*
Buddhist	*
Jewish	*
Other	3
None – Agnostic	7
None – Atheist	10
Refused	1
Don't know/not stated	4

ASK ALL WHO HAVE A RELIGION AT Q72

Q73. SHOWCARD J (R) **To what extent does your religion, or religious upbringing, influence the sorts of decisions that you make about life?** SINGLE CODE ONLY.

Base: All who have a religion (849)

	%
Not at all	33
A little	27
Quite a lot	31
Completely	8
Not applicable	1

ASK ALL

Q74. SHOWCARD K (R) **Using this card, please tell me which, if any, is the highest educational or professional qualification you have obtained? Just read out the letter that applies.**

IF STILL STUDYING CODE '8' AND HIGHEST ACHIEVED SO FAR. OTHERWISE SINGLE CODE ONLY.

		%
D	GCSE/O-Level/CSE	19
G	Vocational qualifications (=NVQ1+2)	8
A	A-Level or equivalent (=NVQ3)	18
E	Bachelor Degree or equivalent (=NVQ4)	14
B	Masters/PhD or equivalent	4
F	Other	11
C	No formal qualifications	23
	Still studying	3
	Don't know/not stated	1

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Further copies of this document are available from:
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PO Box 777
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