

**Report to the Human Genetics Commission**  
**on Public Attitudes to the Uses of Human**  
**Genetic Information**

**GEORGINA VOSS**

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# Public attitudes to the uses of human genetic information

## Human Genetics Commission

### EXECUTIVE SUMMARY

The Human Genetics Commission is undertaking work in the next 18 months to investigate public opinion on the uses of human genetic information and genetic databases. It is therefore important to know what current opinions in this area are, and how they have changed over the past 10 years.

This report examines work that has been carried out over the past decade in the area of public attitudes to genetic information in the UK. Particular focus was made on the views of young people and ethnic minorities, as these were groups identified as being underrepresented in current work. Work done in other countries was also looked at, to provide comparison with UK data, and in areas where UK research hadn't been carried out.

Over the past 10 years, knowledge (both self-defined and tested) has improved in the UK and other countries. It is difficult to quantify how attitudes have altered with this change; those who are most informed about bioscience have the most polarised, but consistent views. Those with lesser knowledge have less reliable and consistent views due to their lack of prior thought in this area. What can be said is that, although the medical benefits of many aspects of biotechnology meet with widespread approval, there are still many reservations. Practical fears include those related to privacy of information (particularly with reference to employers and insurers), informed consent and use of prenatal screening. Ethical concerns include the worry of "tampering with nature", altering organisms, and destroying the concept of individuality. Attitudes to the prospect of a large-scale genetic database being set up fit into all of these categories, gene therapy is looked upon favourably.

Young people have a more "risk-taking" attitude and better knowledge. The degree of risk-taking seems to be linked to age; between the mid- and late-teens, concerns about the practical aspects of biotechnology increase. Knowledge however, is generational, and is influenced by improved bioscience education, the prominence of popular science-fiction media and encouragement in schools to discuss the ethical side of science.

Very little work has been done in the UK into the opinions of ethnic minorities. What work has been done implies that there are greater concerns in ethnic minorities about privacy of genetic information and prenatal testing. There seems little value in transposing work done in other countries in this area to the UK, given the very different racial experience, history and values.

There is much scope for future research in this field. Only one large study has been performed on attitudes to genetic databases, and very little on how the public defines genetic information. The issue of self-defined knowledge versus tested knowledge should also be investigated. Given the recent publicity surrounding the Human Genome Project, there is ample opportunity for work to investigate the change in public awareness and attitudes since its publication.

**Public attitudes to human genetic information**  
**Human Genetics Commission**

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# Public attitudes to genetic information

## Human Genetics Commission

### REPORT

#### Introduction

- The purpose of this report was to discover, by means of a literature review, what work has been done in the UK investigating public attitudes towards genetic information, and how these attitudes have changed over the past decade
- Particular attention was also given to the views of young people and ethnic minorities, as these have been identified as groups whose views are underrepresented, or less well studied.
- By informing the HGC which research has already been done, it will then be possible to design studies using, amongst others, the people's panel, which will not duplicate work already performed.

#### Selection of material

- UK material was selected if it contained research, or analysis of research done about public understanding and attitudes to genetic information and biotechnology. Much of this work was contained within studies of public understanding of science as whole and public attitudes to medicine.
- Extensive studies have been performed in the past 10 years about issues surrounding the genetic alteration of agriculture, especially with the current issues surrounding transgenic crops. However, very few of these issues overlap with those of human genetics. The only literature selected from that field was that containing work done about biotechnology and knowledge of genetics without reference to food or agriculture.
- Much work has been done in other countries in this field. Work from outside the UK was selected on 2 grounds:
  - if it contained research done over a period of time, to give an indication of changing attitudes over the past 10 years
  - or
  - if it contained work that had not also been carried out in the UK, to give an indication of what the answers to those questions in the UK might be.
- Comparisons were also made between attitudes and knowledge in the UK and in other countries towards genetic information, although clearly we aren't able to extrapolate from these results.

- The quality of the work chosen varies; some pieces were carried out over several years by professionals in this field and some were carried out to supplement newspaper reports. These differences in standards can be seen in the account technique summaries at the end of this report.

## Public attitudes in the UK

### Knowledge and attitudes to science

***General positive attitudes towards science but split views on specific issues. Those who know more have more polarised views caused by the better developed attitudes that they hold. Those who know less (as defined poll by poll) have very variant and unreliable attitudes due to their lack of prior thought about the topic. Most favourable opinions are held towards medical science research and others that affect day-to-day life.***

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- Durant's work on public understanding of science in Britain (Durant *et al*, 1992, PUS 1) indicated that the general public's greatest interest and respect is for medical science. Increased knowledge of science led to greater discrimination between "scientific" disciplines (eg. Medicine) and "nonscientific" disciplines (eg. History). Between different scientific disciplines, greater knowledge led to less discrimination between chemistry and physics and between biology and astronomy.
- Though no relationship was seen between scientific understanding and interest in medicine, those with higher understanding showed a more philosophical approach to science; those with lower understanding had a more utilitarian viewpoint.
- Although views on science are mixed, in 1988 (Evans G & Durant J), there was overall support for research, and the general view was that not enough money was being spent on research. Those with low levels of scientific understanding showed less consistent and less discriminatory attitudes to science; the more consistent views held by the well-informed included lower support for "morally contentious" issues, such as genetic engineering and embryo testing.
- Little change was seen a year later - a survey carried out for New Scientist (16th December 1989) in 1989, with closed questions, showed 44-45% supporting the statement "science does more good than harm" – no change from 1985. 37-38% thought that the benefits:harm ratio was about equal.
- Views taken in Scotland in 1990 (Scotinform Ltd, 1991) also support the idea of medicine being the most "favoured" science – the advances that the public most want to see in the future are cures for cancer, AIDS and heart disease. The greatest medical achievement of the 20th century chosen (from a list) was antibiotics.
- As seen before, the science that the public feels would be most beneficial is that that would affect everyday life (eg. Safe cars) rather than impersonal achievements (eg. Proof of the Loch Ness monster).
- The general public was asked specific closed questions about science in 1988 and 1997 (Imperial College/ LSE/ Nuffield Foundation); the proportion of correct answers rose by 11% in those 9 years.

## Information sources and trust

***Although the media is not a trusted source, it is where most information is gained from and remembered. There is strong feeling that Government should provide more information relating to the new genetics, although government itself isn't trusted to regulate biotechnology. Medical research and doctors gain consistent high trust (although this is pre Harold Shipman, Rodney Ledward etc).***

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- Attitudes seen in biotechnology focus groups were compared with the actual media articles cited in these groups (Cunningham-Burley *et al* "The Social and Cultural Impact of the New Genetics" 1998). Although lay people used media articles to justify their opinions, the actual articles were less critical of biotechnology than the views expressed.
- Eurobarometer 46.1 (1996) and 52.1 (1999) gave the medical profession as the most trusted source of information for biotechnology, with consumer organisations and environmental pressure groups also gaining high trust. The UK has the lowest trust in its government to provide funds and support for sound biotechnology research(34%) of any European country.
- With respect to accepting information, the more persuasive a news piece is, the less it matters how trusted the source it came from is. Equally, the more trusted a source is, the less it matters how persuasive the actual information is. The source itself is a high determinant of public response to information about genetics. (Frewer *et al*, "PUS" 8, 1999)
- Trust in hypothetical sources doesn't correspond to trust in the actual context for the same source. The perceived degree to which different information sources have positive attitudes about biotechnology doesn't influence the quality or attitude to the information. The provision of information increased risk perceptions. (Frewer *et al*, "PUS" 3, 1994)
- Broadsheet readers are more knowledgeable about biotechnology than tabloid readers (Gunter *et al*, University of Sheffield, 1998).
- People who have direct interests and experience with biotechnology and its effects are unsure as to which information source to accept. Pressure and conservation groups gain the highest trust, Government has the lowest trust. (Martin *et al*, "Attitudes of selected public groups in the UK to biotechnology" 1992).
- A comparison of media reportage and public attitudes to the Human Genome Project in 1992 (Durant *et al*, 1993) showed that, whilst the media made many references to the science of genetics (eg. "genes", "DNA"), there was little reference to the applications of such terms, such as the HGP. This selective reporting was mirrored in the public attitudes seen.
- The terminology used by information sources was often misunderstood. (Cragg Ross Davidson, 2000). There was strong faith in government and the medical profession to provide clear and reliable information on the new genetics.

- The MORI poll for the OST showed most trust in doctors (71%) to make decisions regarding genetics for them, with government getting 35% trust (43% mistrust).
- Lemkow's focus groups in 1992 felt that there was insufficient accurate, understandable and easily accessible information on the new genetics. It was felt that there should be the right to information on biotechnology and its applications, which is objective, autonomous and free of interference of industry or economic pressure groups.
- There is less trust in organisations associated with biotechnology from older people (Sparks et al, "Agriculture and Human Values" Winter 1994)

## **Knowledge and understanding of biotechnology, genetics and inheritance**

### ***DNA and genes***

***Improved knowledge of DNA and genes over the past 10 years, but this is still minimal. The GM food debate seems only to have confused the issue (ie. possession of genes), although publicity surrounding the Human Genome Project should hopefully have corrected misunderstandings about this. Genes still seen more as vague inheritable concept than solid physical entities.***

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- Closed questionnaires carried out in 1992 showed that only 43% of the general public knew that DNA was associated with living things; 46% didn't know what it was (Durant *et al*, 1992, PUS 1). According to work carried out by Imperial College and LSE however, basic knowledge of DNA rose from 48% to 81% between 1988 and 1997.
- There is still much confusion over the nature of genes. In the 1996 Eurobarometer survey, one-third of the UK general public thought that only genetically modified tomatoes contained genes, not ordinary tomatoes, with the same proportion saying that they didn't know; however, this was 2 years before the media hype surrounding Arpad Putzai's research.
- The UK is happy to accept a genetic explanation of Darwinian evolution; in Eurobarometer 56.1, 56% agreed with the statement "More than half of the genes of human beings are identical to those of chimpanzees" (compared to 48% for Europe).
- The UK is also more likely to admit to not knowing about genetics; their responses ("don't know") were higher than the European average for the following: "Ordinary tomatoes don't contain genes, GM tomatoes do", "If a person eats GM food, their genes could be modified as well", "It is impossible to transfer animal genes to plants". However, the number of affirmative responses to these questions (35%, 24% and 47%) indicates a gap in knowledge about basic concepts of DNA-based genetics.

### ***Genetics and "gene technology"***

***Awareness of biotechnology has increased over the past 10 years, but support has declined. Anything perceived as manipulating genes is perturbing and "unnatural". Dolly the sheep raised awareness of the potentials of the new genetics more than the research interests behind her creation. Cloning still identified as "creating identical humans" for unspecified purposes, with no real genetic knowledge.***

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- Genetics is clearly a perturbing area for the general public – the Eurobarometer split surveys showed less support for "genetic engineering" than "biotechnology".
- Self-defined knowledge of genetics of the Greater London general public increased between 1993 and 1997 (Wellcome, "The People Decide", 1997). In 1997, 56% said that they were "very" or "reasonably" knowledgeable about genetics, compared to 47% in 1993 and the proportion of those being "not at all" knowledgeable fell from 20% to 9%. However, at the debate where the 1997 poll was taken, a quarter of the audience didn't

answer this question, possibly because they were unsure as to how to quantify their knowledge.

- A questionnaire defining gene technology as "...involving the transfer of genetic material from one living thing to another" (Sparks et al, "Agriculture and Human Values", Winter 1994) indicated that the responders had heard little of biotechnology before the survey; this view may have been coloured by the ill-defined preface.
- A MORI poll performed in 2000 gave 65% of the general public confused and unclear as to the meaning of "gene cloning" with 20% unable to attempt an explanation as to what it might be; Eurobarometer 46.1 showed a double increase in knowledge of cloning since 1991.
- In 1992, focus groups in London (Durant et al, 1993) showed no prior knowledge of the Human Genome Project, despite high levels of interest and knowledge in related areas (eg. Forensic testing), and good knowledge of basic laboratory DNA techniques.
- Frewer's work on public attitudes to applications of genetic engineering ("Science, Technology and Human Values", Winter 1997) showed that there was more concern with the ethics behind genetic engineering than the actual products. Despite confused ideas as to the nature of "genetics", there was still strong opposition to the use of animal or human genetic material.
- Although 55% of the general public surveyed had heard of biotechnology (Gunter et al, 1998, Sheffield University), 25% had not. In discussions held, one-third couldn't give the risk-benefit balance for biotechnology; in later discussions this fell to one-fifth, with an increase in those saying that risks outweighed benefits.
- Awareness of cloning has increased strongly after Dolly the sheep. HCC De-Facto found, in 1998, awareness was very high, particularly in Scotland. Although the public knew that Dolly had been created, very few knew who by, or why – most theories as to why (from closed questions) were to do with advancing human cloning. The 1998 MORI/ OST survey also indicated that a common view of Dolly was that of an ovine precursor to human cloning.
- Eurobarometer 52.1 showed a fall in "biotechnology/genetic engineering will improve our lives" (50 to 45%, 43 to 37%). The UK had the lowest opinion of biotechnology in Europe, although 38% couldn't spontaneously give examples of. "modern biotechnology". The UK also gave the low opinions for applications of biotechnology that other European countries found favourable, such as scientific health research.
- Despite it's more positive response than "genetic engineering", "biotechnology" is still seen as an all-encompassing, possibly corporate-owned concept, rather than a tool of scientific research. There is a near-even split between those who would sign a petition against biotechnology and those who wouldn't (39% and 38%), and those who would participate in debates on biotechnology (41% each way).
- Despite holding such strong views on biotechnology, 81% of Europeans don't think that they are adequately informed about biotechnology.

- In focus groups held by Cragg Ross Davidson (2000, MRC/ Wellcome), genetics research was seen as less familiar than medical research, with a certain mystique surrounding it. Those participants knowing little of the methodology or its applications were wary; those knowing more had more favourable views.
- Ability to understand the concepts is not a problem, as seen in focus groups held in 1992 (Lemkow).
- In 1999 The Royal Association for Disability and Rehabilitation (RADAR) looked at the views of people who are disabled (57% of the sample size) and who have experience of disabilities:
  - Half of those surveyed had equal hopes and fears for what future genetic research would bring. Of those who said they were “horrified” by genetics, 69% were disabled. 73% felt that developments in genetics would bring both benefits and problems to the lives of disabled people.
  - 58% of those questioned felt that gene patenting was wrong, but 38% said that it was right and “necessary to fund research”.
  - 76% thought that cloning research using human embryos should be illegal (19% didn't).
  - The general feeling of this poll was that not enough was known about the genetic issues to be able to comment fully on them.

## **Gene Therapy**

***Is it clear that the public actually know what gene therapy is? When offered the choice to “magically” cure/ prevent disease, there is a positive reaction, although when it is explained, the reaction is more negative. Any answers given at this time are surely speculative, given the current limited gene therapy available.***

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- The 1999 British Social Attitudes survey offered closed question options on various types of gene therapy/ alteration. Those most acceptable were preventative – lower susceptibility to breast cancer and heart disease were the most favourable choices (72% and 68%). Altering physical attributes – height and weight – were less favourable, and altering mental attributes of IQ and sexuality were the most opposed.
- However, these results came from answers from highly speculative questions. Work (Huntingdon's) has shown that responses to questions about theoretical events can be very different to those about actual events.
- A MORI poll (2000), after an explanation of gene therapy, gave 75% of the general public willing to let their children undergo gene therapy for disease (with the Scottish being most positive and Londoners being most negative). 75% also agreed with the statement “gene therapy plays an important part in the future of medical research”. Three-quarters thought that gene therapy would be acceptable if tightly controlled.

## Prenatal/ genetic screening and termination

***Attitudes held by specific groups to prenatal testing and termination are similar. Strongest support is for testing for severe disabilities; lowest is for gender/sexuality.***

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- There is a division of opinion about the reasons for prenatal testing (Michie *et al*, “Public Understanding of Science” 4 1995). Opinions were gauged from the general public, ethicists and scientists. Strongest support came for prenatal testing for cystic fibrosis, Down’s syndrome and anencephaly. Lowest support was for testing for unwanted gender and homosexuality, although the general public had a more positive view on this than scientists and ethicists.
- Divides are also seen in the 1999 BSA survey. The more religious groups are opposed to testing, even when there is reason (eg. Family history) to suspect a genetic problem. (NB. The wording of these questions implies that the test itself may cause risks). Ethnic minorities are also less in support of universal prenatal testing (25%) than whites (50%).
- Termination is more acceptable if the results of prenatal testing indicate severe mental or physical impairment, than indication of Huntington’s or restricted height. Those with experience of a genetic condition are more in favour of termination when prenatal testing indicates a genetic condition.
- The MORI/OST poll (1998) indicates that only a quarter of respondents sited genetic screening as a benefit of scientific development (advances in human health were the biggest benefit).
- There are strong splits in the views of those who are differently abled around screening and termination. 50% don’t care if their child is disabled or not. There is a near-even split between those who would undergo some prenatal screening, all prenatal screening or no prenatal screening if pregnant.
- Treatable genetic conditions (eg. Cleft palette) were not considered suitable reasons for termination, although there were mixed opinions about more severe genetic conditions. Termination for gender reasons was strongly rejected.
- It is worth noting that the differences between theoretical and real testing; although surveys suggested that a majority of at-risk Huntindon’s patients would undergo genetic testing when it became available, only 10-15% have done so (Bloch *et al*, 1992; Tyler *et al*, 1992; Crauford *et al*, 1989).

## Attitudes to uses of Genetic Information

### *Insurance and employment*

***A general wariness of “big business” has led to strong negative views of use and possible abuses of genetic tests in work and insurance. The right to privacy is a key issue. NB. These were the only five reports found that contained work on public attitudes to genetics, employment and insurance. “Genetic testing” in such reports was commonly defined as testing for gene/s for specific conditions.***

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- In 1992, support for genetic testing of humans for non-medical purposes was low (Frewer *et al*, “Science, Technology and Human Values” Winter 1997), with objections raised about the ethical implications of such work.
- The 1999 BSA indicated that the public believe that the employers don’t have the right to either see the results of genetic tests already taken (72%), take test results into consideration when the candidate applies for a job (70%) or make job applicants take genetic tests (83%). Answers from interviewees with a genetic condition were 10% more negative than this.
- 75% also thought that insurance companies shouldn’t be allowed to use genetic tests when determining premium rates.
- During debate, three-quarters of people felt that genetic tests should only be available through a doctor, possibly implying that they should not be available through a private medical team in an employers/insurers pay.
- Concern was expressed in workshops (Lemkow L, “Public attitudes to genetic engineering”, 1992) about genetic screening at work in relation to the right to privacy.
- There has been general concern throughout most surveys about the relationship between private companies and genetic research, extending to an overall dislike of the perceived selfishness of “big business”.
- RADAR’s work in 1999 showed strong opposition to either employers or insurers gaining access to genetic tests (91% and 90% respectively). Many of those involved in this survey reported high levels of discrimination about their, or their family’s genetic condition. (NB. In this survey, the definition of a genetic condition was wide, and included short-sightedness, homosexuality and height).
- The Citizen’s Jury held by the ABI in 1997 gave some interesting results. It was felt that insurers should only have access to genetic test results if they were negative, didn’t raise premiums and were tests for monogenetic diseases, and that there should be a moratorium on the use of genetic tests for multifactorial diseases.
- There was overall approval for the ABI code of practice with reference to genetic testing. Recommendations for the code were that there should be an independent body monitoring it, further clarity and more detail needed about who would have access to the information.

## Databases

**Only one UK survey was found which specifically focussed on genetic databases (Cragg Ross Davidson, 2000). Opinions are mixed; anything that will advance medical research is good, but there are strong concerns over anonymity and collection of samples. Education about the database and consent are both vital.**

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- The term “human biological sample” is in itself confusing; only a few participants guessed at DNA. It differed to the better-known blood and organ donation in that genetic donation saves lives indirectly through research and the former save lives directly. There were uncertainties as to the nature of the sample use.
- Giving consent was thought of as very important as a measure of respect. The exception is for medical waste; those surveyed were content for leftover surgical material to be used, without consent, for genetic databases. Those familiar with genetic testing (those with experience of genetic conditions) are more relaxed about donating samples. Very few of the focus group had actually donated samples, but said that they would for bona fide “moral” research (ie. not eugenics), and no profit being made from it. The more experience the person had had in donating samples, the less thought they would give to donating further samples for research.
- More trust was held for doctors using the samples than the businesses perceived to be using them.
- Taking biological samples from children was more controversial – although the need for this was understood (studying specifically childhood diseases etc) there was still concern over the physical and psychological effects. Parents showed the most concern; even the prospect of new medical discoveries wasn’t enough to ease concerns. Consent was especially important for children.
- When informed of the plans for the MRC/Wellcome database there was extremely low public awareness, but the principle of the database was favoured.
- **Use of DNA** - knowledge of DNA was partial and inaccurate. The idea that DNA is unique to each individual made it hard to understand how the database could be anonymised. Ethnic minorities were also worried about how it would affect immigration status.
- **Information** - The need for volunteers to provide information about themselves caused concern, with those having experiences of genetic conditions being less worried. The issue of people lying about their personal information was also raised. Access to medical records, thought of as sacrosanct, was seen as intrusive.

- **Confidentiality** – A significant issue. Use of computer to store information was expected and accepted as safe. Worries of insurers and employers gaining access to the records were expressed, leading to fear of discrimination. Insurers were seen as particularly troublesome as they were less regulated by law than employers.
- **Consent** – It was automatically assumed that consent would be required before samples could be taken and used.
- **Nature of research** – The expectation of the groups was that the research using the databases would focus on disease, which was more positively thought of than if the research was to understand the human body better. Studying mental or psychological conditions would be misuse of the collection.
- **Future use** – Problematic. It was known that future use was inevitable, and the problem could be overcome if the consent forms considered this. Repeat consent was offered as a solution to this area.

## Young people

*A consistent feature of knowledge surveys is that younger people know more about genetics and technology than the older generation. Views change over time from abstract and “high-concept” opinions, to more grounded, “real world” views, as illustrated by xenotransplantation. But there is also a generational difference; the younger generation have been encouraged to discuss the social aspects of science more than their parents, through school (eg. PSE [Personal and Social Education], General Studies).*

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- The higher knowledge seen in the younger generation may be due to both the better quality of formal science education received, and the proximity of receiving the education.
- Whether a child enjoys science at school is dependent on a number of factors – those with lower socio-economic backgrounds, parents without arts/humanities-based jobs, encouraging mothers and scientific peers had more encouraging attitudes to science (NB, this work didn't discriminate between biology and physics) (Breakwell et al, PUS 1, 1992).
- Work for the European Commission (Chadwick et al, 1996, University of Central Lancashire) investigated attitudes in the UK, Germany, France and Finland:
  - The British were more concerned than other countries about use of biotechnology and animals, and thought that technology and science would make the world a better place. They were least concerned about unforeseen consequences and risks, believing that science is all powerful. The term “Nature” was described as cared for, friendly and fragile; the British also rated it highly as being “untouched by human beings” , unchanging and unstoppable.
  - Most trust was held in science, doctors, teachers and environmental groups; least trust was for politicians, journalists and company representatives.
  - Xenotransplantation and gene therapy (for obesity; no examples for medical purposes given) were discussed. Long term consequences were a concern for both, and working class children were less likely to agree with research. Empathy for humans, rather than the organ-donor animal, increased with age. Gene therapy for obesity was viewed reasonably well; 40% were in favour of it and 50% of these would take the therapy themselves, although there was strong opinion that it would be better to lose weight naturally.
  - There was a strong feeling that the body was sacred and unique, and not to be tampered with in any way. Taking pills with genes in (gene therapy) was seen as unnatural as it involved manipulation of genes; only 2% argued that genes are naturally occurring, and not a drug.
- Work done with young people showed confusion about the nature of biotechnology (Gunter *et al*, University of Sheffield, 1998). It was mostly associated with food processing, although some made comments on Dolly and the mouse with a grafted ear

and few knew why this research had been performed. Some knowledge of biotechnology was remembered from GCSE level (30% sited school as the main information source for biotechnology, compared to 5% for the rest of the population).

- Most people thought that it should be the Government who regulated biotechnology. The fears of biotechnology – that it's unnatural and may lead to human cloning – are generally outweighed by the benefits. Money is thought to be the main driving force behind biotechnology, but the best justification for biotech is curing diseases.
- The structured approach to science at school, as opposed to the less structured approach in the real world may account for the confusion about science that sets in in adulthood (Hutton N, PUS 5, 1995).
- Teachers in Ireland (Michael *et al*, PUS 6, 1997) find it hard to convey the ethical issues of biotechnology into science lesson plans, which have to be predominantly based on facts. The pupils are enthusiastic about biotechnology, more so than other areas of biology, and find it more relevant to their lives. Eugenics is still a concern.
- The younger teenagers (14 -16 year olds) showed more “risk-taking” attitudes with regards to genetics, and more abstract concerns than the older teenagers (17 –19 year olds), who were more prudent and had more concerns relating to everyday life. This change would seem to reflect changes in maturity with age, rather than generational differences (Stratford *et al*, BSA, 1999).
- Generational differences observed in this study included greater knowledge of genetics and a more liberal attitude to sexuality.
- Work done young people's attitudes to the new genetics explored a lot of areas (Lewis, 1996):
  - Half of those asked couldn't define a function of DNA or genes and there was confusion as to their location: although 75% knew that they were present everywhere in the human body, the remainder thought that they were only present in certain places, specifically the reproductive organs. It was unclear as to whether bacteria and viruses contained genetic material. The main view of genetic material was that it determined an individual's characteristics and individuality, although mention was made of the social uses of material, eg. DNA testing.
  - DNA testing, genetic engineering, cloning and genetic fingerprinting were the most widely heard of applications of the new genetics; gene therapy and the Human Genome Project were the least heard of. The main news source for such things was the media, although popular tv programmes and films were also mentioned (eg. The X-Files, Jurassic Park, Star Trek, Red Dwarf). The role of DNA testing in the OJ Simpson trial was also mentioned. Genetic engineering is principally thought of as a mechanism, rather than a purpose.
  - Cloning is seen as copying things, yet 16% describe it as reproductive techniques, confusing it with such techniques as in vitro fertilisation. Genetic engineering is most associated with agriculture and medicine, and again is confused with reproduction.

- Discussions were held about cystic fibrosis (CF). The concepts behind CF, gene therapy for it and the chances of inheritance were well understood. Confusion was evident about inheritance and phenotype expression of a recessive gene. Termination of pregnancy and the accuracy of prenatal screening were discussed. Strong polarised views were held about whether prenatal screening should be used in this case: the majority thought that if the foetus was shown to have CF, the pregnancy still shouldn't be terminated.
- Knowledge of issue and attitudes in biotechnology were tested. There was awareness that taking genes from an animal isn't a painful process, and that to separate these genes requires "special laboratory reagents" due to their size.
- There was confusion over the information encoded by these genes though; the children were unsure about the genetic differences between plants and animals, and confused about the genetic cause of transgenic sheep able to produce human insulin.
- General attitudes to GE are: things are as they are for a reason so shouldn't be tampered with; tampering with genes is wrong; all organisms are not equal; animals shouldn't be used for human benefit; it is only acceptable to make changes to an organism if the organism's consent is gained.

## Views of ethnic minorities

- Very little work has been done in the UK on the views of ethnic minorities towards genetic information.
- The most recent British Social Attitudes survey (Stratford *et al*, 1999) examined the differences between (as self-defined within closed boundaries) whites, blacks and Asians over a number of issues:
  - The main differences come over attitude towards abortion and prenatal testing, with blacks most opposed and whites most in favour.
  - Blacks are more restrictive and less enthusiastic than whites and Asians about the possibility of altering human genes. Asians, although the most enthusiastic are also cautious.
- Work done for the MRC about genetic databases (Cragg Ross Davison, 2000) also examined race differences with respect to viewpoint. They also conducted focus groups with religious leaders from a number of backgrounds (see below):
  - African leaders raised concerns about identification, immigration, anonymity, consent and the apparent focus of the database on 'white' diseases. The link between blood samples and HIV was off-putting.
  - Pakistani Muslim leaders thought that Muslims would be unwilling to donate samples for anyone outside the community. The need to show respect for the dead was brought up.
  - The Hindu leader believed that many Hindus have little faith in medicine, even though they feel medical research to be important.
  - African-Caribbean leaders thought mental health and HIV were particular problems in the community. Genetics was seen as unfamiliar and frightening. Practical difficulties were anticipated, as many African-Caribbeans aren't registered with their GP.
- This work however is not the result of direct quantitative questions to a large number of people, or even discussion within a focus group; it is the opinion of single (usually) men speaking to represent a community, rather than the voice of the community itself.
- Work has been done in other countries on the views of ethnic minorities; in particular, the views of African-Americans and Hispanics in the USA, and of Maoris in New Zealand. However, these views are not representative of, or relevant to those of ethnic minorities in the UK, and so have not been analysed further.

## **Public attitudes in other countries**

### **Knowledge and attitudes to science**

- A literature review of work done in New Zealand (NZ) and the USA in 1998 (Capper *et al*) showed high levels of public interest and low levels of public understanding; very few thought that they could participate in science discussions. Positive opinion of science drops as children start secondary school.
- Questionnaires done by this team in NZ of teachers and students showed lots of interest in new scientific discoveries, especially those in medicine. Low awareness of science is seen, with teachers being more informed on medical and environmental discoveries and students being more informed on space exploration. Medicine and environmental science had the most attentiveness.
- Between 1990-1997 knowledge of, and attitudes towards science rose hugely in the USA and NZ.
- (USA, Miller *et al*) There was an increase in knowledge of scientific enquiry and in interest in current issues, but no change in attentiveness of medical and scientific issues. Only 3% felt that genetic engineering was the most important scientific discovery of the past 10 years, with fluctuations in the benefit/harm ratio. Despite (or maybe because) of increased knowledge of science, there is increased belief that science education is inadequate. There are more relaxed attitudes towards the scientific profession. There is more belief in science, and stronger views that scientists should have more freedom.

### **Information sources and trust**

- US students were given articles to read using the “blueprint”(deterministic) and “lottery” (nondeterministic) metaphors about genetics. The messages in the articles didn’t override individual beliefs about genetics, with genetics being understood as “probabilistic” rather than certain, showing awareness of genes only playing a partial role in generating phenotype. The “blueprint” metaphor was preferred to the “lottery” metaphor. It was implied that it should be possible to frame public messages about genetics in a way that encourages non-discriminatory and nondeterministic viewpoints. The range of opinions gained was due to the audience research performed; it would have been harder to get this with a survey.

### **Knowledge and understanding of biotechnology, genetics and inheritance**

- 37% of NZ questioned (1998, Capper *et al*) had some understanding of DNA. 47% didn’t understand the concept of scientific enquiry, although understanding was generally 5 times higher than the USA. UK, NZ and USA showed similar levels of awareness of scientific issues, although the USA had lower knowledge of vocabulary.

- (Singer, 1993, USA) (NB. Jurassic Park was released in 1993) 41% were able to define DNA correctly (open questions) which decreased with age. 59% knew that DNA regulates inherited characteristics. The older generation knew less of biomedical concepts and also personal health.
- (Australia, 1994, Schibeci et al). Performed in the aftermath of the introduction of the FlavrSavr™ tomato to consumers. Most were familiar with biotechnology, citing the media as the main, but not trusted source. The science behind GM food is fine, but the applications are not always good, and the idea of “altering nature” is bad.
- (Canada, 1994, Sheehy et al) Although there was a 90% acceptance of the general principle of patents, there was only 24% support for the patenting of higher life forms. 54% thinking that patents on human genes were unacceptable if they would lead to the eventual commercialisation of the human body. There was high (84%) familiarity for genetic testing for disease, and 70% considered themselves well informed of the public issues.
- (USA, 1998, Singer et al) There were increases (1995-97) from those having heard nothing about genetic testing. There was an increase in those thinking that genetic engineering leads to more harm than good. There is only minority support for altering genes to improve IQ or physical characteristics. Opposition to cloning in the USA has risen since Dolly the sheep, and there is more opposition to human than animal cloning. Only religion seems to play a major role in defining attitudes in this study.
- (Japan, NZ, USA, Europe; Macer, 1992) Japanese awareness of genetic manipulation of human cells was higher than of NZ, but had lower acceptance of this than NZ and the US (this survey was shortly after the first human trials of gene therapy). It was deemed unacceptable because of playing God/interfering with nature (more public view than that of the scientists; scientists more concerned with control of technique). NZ and Japan benefit:risk ratios are similar (41% say b>r) but the Japanese have higher risk perception, especially teachers and the public. Major benefit is medical intervention; although the question was worded to imply “national benefits” the answers focussed around “world benefits”. Views were similar to Europeans. The risks were more varied than the benefits, although “eugenics” wasn’t as common as European answers. Risk reasons were similar to unacceptability reasons, but with more worries about human health.
- Both Japan (93%) and NZ (86%) think that social issues surrounding biotechnology should be taught in schools.

## **Insurance and employment**

- (USA, Geller *et al*, 1992) Half of respondents with a genetic condition (and their parents) asked had experienced genetic discrimination from insurers, clinics, adoption agencies, armed services, employers, blood banks and educational institutions. All discriminators showed little understanding that carrying an “at risk” gene doesn’t imply 100% likelihood of developing that disease. Great psychological distress was evident in these people as a result of their condition, even before testing was carried out. Genetic discrimination was avoided by getting private insurance, taking anonymous genetic tests that insurance companies couldn’t obtain, avoiding testing where genetic information would be used against them, and outright lying on forms
- (USA, Singer E, 1990) 85% felt that employers didn’t have the right to genetically test their employees, and 89% felt that employers don’t have the right refuse employment to someone on the basis of their genetic tests.
- (USA, Singer *et al*, 1998) Fears of privacy are unchanged over time – 60% are very concerned about making results of genetic tests available to employers and insurers, yet acknowledge that test results shouldn’t be kept strictly personal. The questions asked here focused on the information as medical rather than genetics (ie. information-like blood samples, but more so).

## **Prenatal/ genetic screening and termination**

- (USA, Singer E, 1990) The majority thought that genetic screening did more good than harm, and would have a partner tested, even if the condition couldn’t be cured. A near-equal amount thought that these tests should and shouldn’t be compulsory, and 42% didn’t think that a genetic condition was a suitable reason for termination.
- 51% would undergo testing to determine if they were likely to develop a disease later in life. There was misunderstanding about the nature of genetic/prenatal screening – a third thought that it was able to correct syndromes such as Down’s etc. White men and black women were more in favour of termination if testing indicated a genetic condition. Younger people and better educated people were more in favour of genetic testing. (No questions asked about testing simply for genes)
- The majority would take a test to detect a curable genetic disease, with the minority taking a test to detect an incurable genetic disease and both increase over time. 75% would undergo testing to see if they are a carrier, with 54% interested in gene alteration to avoid transmitting such a disease.
- There were no changes in those willing to undergo prenatal testing (66%, 1986-96) or to allow gene therapy for a child (90%). But 90% reject the idea of gene therapy on themselves. There is a small increase in those rejecting termination if testing indicates a genetic condition.
- There was more acceptance in the US and Japan for gene therapy for children, rather than for personal use. No correlation for opinion with any other factors. There was an increase in approval of gene therapy since 1985, with 75% support.

## **Current and future research**

*Although research in this area is presumably being carried out, no feedback has been received as to the nature or timing of this work. There are many research opportunities in this area, including more in-depth work on genetic databases, the nature of genetic information and the question of identity.*

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### **Research done by other groups**

- No feedback has been received from those carrying our research in this area. Any information known about this would be gratefully received.

### **Potential work**

#### **Areas**

- As mentioned, there has only been one in depth study performed about genetic databases in the UK, performed as a series of focus groups and interviews. Further work in this area, particularly in a quantitative manner, would be useful to establish more solid opinions.
- Very little work has been done to establish the views of ethnic minorities on many issues surrounding genetics and biotechnology. Given the size of the People's Panel, it should be possible to perform a large enough study which would be indicative of proportional representation of ethnic minorities within the UK whilst giving statistically significant results.
- Knowledge of science and genetics does seem to be improving. Yet many studies don't distinguish between self-defined knowledge and actual knowledge, as circumscribed by closed and open questions. It would be interesting to see if there is a correlation between the two.
- No-one has yet investigated how the public actually (ie. as open question) defines genes or genetic information.
- All of the work discussed in this report was carried out before July 2000, when the news of the mapping of the human genome was made public. The increased prominence of the project has obviously increased public awareness of the potential of the new genetics, and influenced opinions. As such, views expressed from the work studied in this report will not reflect the probable change in public opinion that has occurred in the past few months. It would therefore be valuable to determine the public reaction to news of the human genome project, and their change in awareness and knowledge.

## **Techniques**

- As members of the HGC are well aware, there are benefits and pitfalls to every method of social science investigation.
- Closed question surveys give solid statistical quantitative answers and media-friendly headline, yet do not provide more in-depth knowledge or analysis. Moreover, the answers given are more “off the cuff” and less reliable than open questions, as interviewees may feel forced to choose a given answer rather than admit lack of knowledge.
- Open questions give broader and more accurate answers, but are harder to quantify. There are also more likely to be “don’t know” answers with this type of question, particularly when the participant is pressured for time.
- Discussions are valuable for establishing a wide-range of in-depth opinions, but by their nature cannot give quantitative answers. It is also possible for one very opinionated group member to drive the views of the discussion away from how it might otherwise have been.
- In this vein, some women who have taken part in this type of research have reported to be intimidated by some of the men in their groups (Wellcome. 1997). This may be due to simple male “machismo”, and results in women being less forthcoming and honest as they might otherwise have been.
- A research tool that may be useful for measuring public opinion of low salience issues is the deliberative opinion poll, whereby several hundred participants undertake a day or weekend of exposure to lectures, materials and workshops about the chosen subject matter. Questionnaires are distributed to determine attitudes at the beginning and end of the session, and the resulting data giving an idea of how the issue will be received by the general public when it becomes high profile.
- The techniques chosen are a matter for the HGC, and should be discussed with due care.

**Georgina Voss  
September 2000**

## ASSOCIATION OF BRITISH INSURERS

### ABI Citizen's Jury

**Aim:** To investigate the public's opinion about insurance companies, genetic testing and genetic data.

**Country and Sector:** UK – Genetic data.

**Groups surveyed:** Genetic data. Genetic testing. Insurance companies.

**Year:** 1997

**Number and Type of Respondents:** 14 adults, age 18-77.

**Method:** Citizen's jury – discussion, questionnaires and talks over 4 days.

**Performed by:** Institute for Public Policy Research (IPPR) for the ABI.

**Presented:** Published as report by the IPPR, 1997.

## BLOCH *et al*

Predictive Testing for Huntington's Disease in Canada: The Experience of Those Receiving an Increased Risk

**Aim:** To follow the experience of adults receiving HD testing.

**Country and Sector:** Canada – HD, Genetic Testing.

**Groups surveyed:** HD, Genetic Testing, Genetic Counselling.

**Year:** 1991

**Number and Type of Respondents:** 4 adults.

**Method:** Follow the subjects experience of being tested for HD, both before and after the event.

**Performed by:** Bloch M, Adam S, Wiggin S, Huggins M and Hayden M.

**Presented:** "American Journal of Medical Genetics" 42 (1992) pp 499-507

## BREAKWELL *et al*

Gender, parental and peer influences upon scientific attitudes and activities

**Aim:** To examine how far gender differences during adolescence in attitudes towards science at school and in society, and involvement in scientific activities are mediated by parental and peer influences.

**Country and Sector:** Britain – Science, taught science.

**Groups surveyed:** Attitudes towards science. Extracurricular scientific activity. Liking and self-reported performance in school science. Scientific peers. Peer youth culture. Parent/ child sharing of activities. Mother and father support of science. Parental support. Parents "liberalism". Social class.

**Year:** 1992

**Number and Type of Respondents:** 391 pupils from state sector schools. Age–11-14.

**Method:** Questionnaires.

**Performed by:** Breakwell G and Beardsell G.

**Presented:** "Public Understanding of Science" 1 (1992), pp 183-197.

## CAPPER

### Science and Technology Attitudes and Performance: A brief literature review

**Aim:** To review literature on public attitudes to and awareness of science and technology, and the performance of school students in science and technology subjects.

**Country and Sector:** USA and New Zealand – Science and Technology.

**Groups surveyed:** Public interest and understanding of science. Content and direction of science education.

**Year:** 1998

**Number and Type of Respondents:** Literature review.

**Method:** Literature review.

**Performed by:** Capper P

**Presented:** Report published by Ministry of Research, Science and Technology

## CAPPER *et al*

### Science and Technology Interest, Understanding and Attitudes in the New Zealand Community

**Aim:** To investigate interest and understanding of science and technology.

**Country and Sector:** New Zealand – Science and Technology.

**Groups surveyed:** Public interest and understanding of science. Sources of scientific information. Attitudes towards science and technology policy. Risks and benefits.

**Year:** 1998

**Number and Type of Respondents:** I) Parents and teachers of 9-11 year old. Ii) 6<sup>th</sup>/7<sup>th</sup> year students (in last formal year of education). Iii) New-entrant college of education students..

**Method:** Questionnaires.

**Performed by:** Capper P and Bullard T

**Presented:** Report published by Ministry of Research, Science and Technology

## CHADWICK *et al*

### Cultural and Social Objections to Biotechnology: Analysis of the arguments with special reference to the views of young people

**Aim:** To study the attitudes of young people to biotechnology.

**Country and Sector:** Finland, Germany, Spain, UK - Biotechnology

**Groups surveyed:** Concern. Use of science and technology. Attitudes to experts. Environmental uses of biotechnology.

**Year:** 1996

**Number and Type of Respondents:** 1. 600 11-18 year olds (238 from UK); all social classes and mixed ethnic backgrounds.

**Method:** 1. Literature review. 2. Questionnaires: open/closed questions + reading material.

**Performed by:** Chadwick R, Levitt M, Whitelegg M, Lealy D, Hayg H, Hayry M and Lushof J

**Presented:** Published as report by University of Central Lancashire for European Commission.

## CONDIT

How the public interprets genetics: non-deterministic and non-discriminatory interpretations of the “blueprint” metaphor

**Aim:** To assess public interpretations of popular discourse about genetics.

**Country and Sector:** US – genetics.

**Groups surveyed:** Conceptions of genes depending on source material read. Deterministic and non-discriminatory views of genes. “blueprint” vs “lottery” metaphor. Influence by media.

**Year:** 1995

**Number and Type of Respondents:** 137 undergraduate students at a south-western US university.

**Method:** Subjects asked closed questions, given article about genetics to read - 50% articles used “blueprint” metaphor, 50% used “lottery metaphor” – then asked open-ended questions.

**Performed by:** Condit CM

**Presented:** “Public Understanding of Science” 8 (1999), pp169-180.

## CRAGG ROSS DAVIDSON

Qualitative research to explore public perceptions of human biological samples

**Aim:** To explore public perceptions of the use of databases of human biological samples.

**Country and Sector:** UK

**Groups surveyed:**

**Year:** 2000

**Number and Type of Respondents:** 16 general public. 6 community leaders. 7 religious leaders. 14 disease specific groups. 5 special interest groups. 8 primary healthcare professionals.

**Method:** Depth interviews. Group discussions.

**Performed by:** Cragg Ross Davidson (MRC/Wellcome)

**Presented:** Published by Cragg Ross Davidson.

## CRAUFORD *et al*

### Uptake of Presymptomatic Predictive Testing for Huntington’s Disease

**Aim:** To determine the uptake of presymptomatic HD testing in a community

**Country and Sector:** UK – Genetics, HD

**Groups surveyed:** Presymptomatic genetic testing – attitudes and effects.

**Year:** 1989

**Number and Type of Respondents:** 201 adults (110 at risk of HD).

**Method:** Offering predictive HD testing and monitoring uptake.

**Performed by:** Crauford D, Dodge A, Kersin-Storror L and Harris R

**Presented:** “The Lancet” September 9<sup>th</sup>, 1989, pp 603-605

## **CUNNINGHAM-BURLEY *et al***

### **The Social and Cultural Impact of the New Genetics**

**Aim:** To explore attitudes, beliefs, understanding and cultural values to genetics, and to identify and analyse the coverage given to genetics in the printed media.

**Country and Sector:** UK – Genetics

**Groups surveyed:** Press coverage. Ethics. General knowledge of genetics. Genetic testing, inheritance and prenatal screening.

**Year:** 1998

**Number and Type of Respondents:** I) General public – no direct experience of genetics or genetic screening. II) Some experience of genetic-related illness or behaviour. III) Direct experience of genetic health concern. IV) 16 science journalists.

**Method:** Focus groups. Interviews. Literature search.

**Performed by:** Cunningham-Burley S, Amos A and Kerr A.

**Presented:** Report published by University of Edinburgh/ESRC

## **DAVISON *et al***

### **Problematic Publics: A Critical Review of Surveys of Public Attitudes to Biotechnology**

**Aim:** Discussion of public surveys to biotechnology, their problems and alternative approaches.

**Country and Sector:** USA, UK, Netherlands, Europe, Ireland, Japan, New Zealand, Canada, Denmark (and others).

**Groups surveyed:** Public attitudes to biotechnology. Construct of opinion polls. Construct of "Public Discourse". Development of better surveys and better understanding.

**Year:** 1997

**Number and Type of Respondents:** Literature review.

**Method:** Analysis of previous surveys.

**Performed by:** Davison A, Barns I and Schibeci R

**Presented:** "Science, Technology and Human Values" 22:3(Summer 1997) ,pp 317-348

## **DURANT *et al***

### **The Human Genome Project and the British Public**

**Aim:** To analyse public understanding of the new genetics and the Human Genome Project with reference to the media.

**Country and Sector:** UK -Genetics

**Groups surveyed:** Genetics – Understanding, attitudes, knowledge.

**Year:** 1993

**Number and Type of Respondents:** General public of Greater London; 12 focus groups.

**Method:** Focus group discussions. Literature search – current media coverage.

**Performed by:** Durant J, Hansen A, Bauer M and Gosling A

**Presented:** Published as report to the European Commission, London

## **DURANT *et al***

### **Public understanding of science in Britain: the role of medicine in the popular representation of science**

**Aim:** To explore public interest in, attitudes towards and public understanding of science.

**Country and Sector:** Britain - science.

**Groups surveyed:** Scientific knowledge. Understanding processes of scientific inquiry. Scientific status of different disciplines. Prominence of medical science.

**Year:** 1992

**Number and Type of Respondents:** 2000 adults. General public. Age - 18+.

**Method:** Interviews.

**Performed by:** Durant J, Evans G and Thomas G.

**Presented:** "Public Understanding of Science" 1, (1992) pp161-181

## **EUROPEAN COMMISSION**

### **The Europeans and modern biotechnology: EUROBAROMETER 46.1**

**Aim:** To understand current European understanding and attitudes to biotechnology.

**Country and Sector:** Europe (12 member states) – split ballot of 50% 'biotechnology' and 50% 'genetic engineering'.

**Groups surveyed:** Science and technology optimism. Knowledge of biotechnology. Perception of nature/nurture. Regulation of biotechnology and trust.

**Year:** 1996

**Number and Type of Respondents:** 15, 900 general public (1,000 – UK).

**Method:** Interviews. Questionnaires.

**Performed by:** European Commission.

**Presented:** Published report.

## **EVANS *et al***

### **The relationship between knowledge and attitudes in the public understanding of science in Britain**

**Aim:** To explore the relationship between understanding of science and levels of support for science.

**Country and Sector:** Britain – Science.

**Groups surveyed:** Knowledge of science. Interest in science. Support for science, scientific activities and scientists. Distinction between science in general and scientific research. Public spending on science.

**Year:** 1988

**Number and Type of Respondents:** 2009 adults.

**Method:** See Durant J, Evans G and Thomas G "The Public Understanding of Science" Nature 340 (1989), pp 11-14

**Performed by:** Evans G and Durant J

**Presented:** "Public Understanding of Science" 4 (1995), pp57-74

## **FREWER *et al***

### **Reactions to information about genetic engineering: impact of source characteristics, perceived personal relevance, and persuasiveness**

**Aim:** To investigate the impact of source factors (trust) and the perceived personal relevance of information, including the persuasiveness of the information, on attitudes towards genetic engineering

**Country and Sector:** UK – Genetic Engineering.

**Groups surveyed:** Trust in information about genetic engineering in food production. Impact of perceived risk immediacy and persuasive content.

**Year:** 1999

**Number and Type of Respondents:** i) Selection of persuasive messages - 26 members of general public, 11 male, 15 female (mean age - 32.9) ii) Interaction of messages – 160 members of general public, 96 male, 64 female (mean age – 42)

**Method:** Selection of persuasive/non-persuasive statements. Applications of these statements in questionnaire.

**Performed by:** Frewer LJ, Howard C, Hedderley D and Shepherd R

**Presented:** "Public Understanding of Science" 8 (1999), pp 35-50.

## **FREWER *et al***

Ethical Concerns and Risk Perceptions Associated With Different Applications of Genetic Engineering: Interrelationships With The Perceived Need For Regulation Of The Technology

**Aim:** To compare public attitudes towards genetic engineering for two different applications (food production vs medicine), with respect to risk, benefit and control.

**Country and Sector:** UK – Genetic engineering

**Groups surveyed:** Genetic engineering in food production and medicine. Control, risk and benefits.

**Year:** 1995

**Number and Type of Respondents:** 180 adults, age 46 ± 14.6 years. General public.

**Method:** Questionnaire.

**Performed by:** Frewer LJ and Shepherd R

**Presented:** "Agriculture and Human Values" Winter 1995, pp 48-57

## **FREWER *et al***

Attributing information to different sources: effects on the perceived qualities of information, on the perceived relevance of information, and on attitude formation

**Aim:** To examine differences in information quality, subsequent trust in information sources and impact on risk attitudes.

**Country and Sector:** UK – News sources on genetic information

**Groups surveyed:** Perceived quality of information. Perceived source of bias. Attitudes and trust..

**Year:** 1994

**Number and Type of Respondents:** 150 adults (age 19-70, mean 42.8). General public.

**Method:** Questionnaires.

**Performed by:** Frewer LJ and Shepherd R

**Presented:** "Public Understanding of Science" 3 (1994), pp 385-401

## **FREWER *et al***

### **Public Concerns in the United Kingdom about General and Specific Applications of Genetic Engineering: Risk, Benefit, and Ethics**

**Aim:** To determine what terminology is used to distinguish between various applications of genetic engineering in food-related, agricultural and medical backgrounds.

**Country and Sector:** UK - Genetics

**Groups surveyed:** Applications of genetic engineering; attitudes towards such applications.

**Year:** 1992

**Number and Type of Respondents:** Study 1) 25 adults. Mean age -  $47.5 \pm 18.2$  years. General public. Study 2) 25 adults. Mean age -  $45.7 \pm 16.25$  years. General public.

**Method:** Repertory grid interview

**Performed by:** Frewer L, Howard C and Shepherd R.

**Presented:** "Science, Technology and Human Values" 22:1 (Winter 1997), pp 98-124

## **GELLER *et al***

Individual, Family and Societal Dimensions of Genetic Discrimination: A Case Study Analysis

**Aim:** To investigate genetic discrimination as a result of genetic screening.

**Country and Sector:** USA – Genetics.

**Groups surveyed:** Discrimination, inc. insurers, employers etc.

**Year:** 1992-3

**Number and Type of Respondents:** 917 individuals either at risk, or parents of children at risk, of developing genetic conditions (eg. Huntingdon's).

**Method:** Questionnaires: open/closed questions. Interviews.

**Performed by:** Geller LN, Alper JS, Billings PR, Barash CI, Beckwith J and Natowicz MR.

**Presented:** "Science and Engineering Ethics" (1996) 2, pp 71-88

## **GUNTER *et al***

### **Development of a Strategy to Promote the Public's Understanding of Biotechnology**

**Aim:** To investigate the public's awareness, knowledge, perceptions, attitude and orientations towards biotechnology.

**Country and Sector:** UK - Biotechnology

**Groups surveyed:** Awareness of biotechnology. Perceived risks, concerns and orientations. Information sources about biotechnology. Young people. Scientists and Journalists.

**Year:** 1998

**Number and Type of Respondents:**

**Method:** Focus groups. Interviews.

**Performed by:** Gunter B, Beyleveld D and Kinderler J (Sheffield University)

**Presented:** Report published by the University of Sheffield..o

## HAGEDORN *et al*

Issues in agriculture and environmental biotechnology: identifying and comparing biotechnology issues from public opinion surveys, the popular press and technical/regulatory sources

**Aim:** To identify issues of public concern over agricultural and environmental biotechnology from various sources.

**Country and Sector:** USA - Agricultural and environmental biotechnology.

**Groups surveyed:** Biotechnology issues – comparison, fears. Source of information about biotechnology. Frequency of news about biotechnology. Perceptions of biotechnology.

**Year:** 1997

**Number and Type of Respondents:** Literature search.

**Method:** Frequency index based on content analysis used to rank biotechnology issues in public opinion surveys, the popular press and technical/regulatory sources.

**Performed by:** Hagedorn C and Allender-Hagedorn S

**Presented:** "Public Understanding of Science" 6 (1997), 233-245

## HCC-De Facto

### Dolly research Shows High Public Awareness and Understanding

**Aim:** To determine awareness and understanding of Dolly the sheep in various sectors of society

**Country and Sector:** UK - Cloning

**Groups surveyed:** Awareness of Dolly. Understanding of cloning. Commercial awareness. Attitudes towards biotechnology.

**Year:** 1998

**Number and Type of Respondents:** 1018 general public. 24 members of biotechnology/pharmaceutical industry. 10 biotechnology investors. 9 science journalists.

**Method:** Phone questionnaire

**Performed by:** HCC-De Facto.

**Presented:** to 3<sup>rd</sup> European Biotechnology Symposium in Glasgow, 1998.

## HUTTON

### Interactions between the formal UK school science curriculum and the public understanding of science

**Aim:** To examine the features relevant to the public understanding of science and science education in UK schools.

**Country and Sector:** UK - Science

**Groups surveyed:** Aim of science education in schools. Science coverage in the media; relevance of science topics and comparisons with the National Curriculum.

**Year:** 1996

**Number and Type of Respondents:** Literature search.

**Method:** Comparison between science in public domain of newspapers and that included in formal education.

**Performed by:** Hutton N

**Presented:** "Public Understanding of Science" 5 (1995), pp 41-53

## IMPERIAL COLLEGE/LSE

### Public approach to science under the microscope

**Aim:** To understand public understanding of science.

**Country and Sector:** UK – science.

**Groups surveyed:** Understanding of science and genetics.

**Year:** 1997

**Number and Type of Respondents:** General public – 2500 adults.

**Method:** Phone questionnaire?

**Performed by:** Imperial College/ LSE (Nuffield foundation/ OST)

**Presented:** Published by Imperial College.

## INRA

### Eurobarometer 52.1: The Europeans and Biotechnology

**Aim:** To better understand European's attitudes to various problems concerned with biotechnology.

**Country and Sector:** Belgium, Denmark, Old Lander, Germany, New Lander, Greece, Spain, France, Ireland, Italy, Luxembourg, Netherlands, Austria, Portugal, Finland, Sweden, United Kingdom – Biotechnology and genetics.

**Groups surveyed:** Impact of technologies on life. Modern biotechnology and its implications. Knowledge of biotechnology. Perceptions of applications of biotechnology. Ethics of animal cloning and biotechnology. Attitudes and action towards application of biotechnology. Attitudes towards groups involved in biotechnology: media, industry, ethics committees, consumer organisations, environmental pressure groups, government, food safety groups, farmers, churches, doctors. Trust of information sources of biotechnology. Discussion of biotechnology.

**Year:** 1999

**Number and Type of Respondents:** 16,082 people – average 1,000/country. General population. Age – 15+.

**Method:** Face-to-face interview with closed questionnaires.

**Performed by:** INRA (Europe)

**Presented:** Report published by European Commission.

## KENWARD

### Science stays up the poll

**Aim:** To explore the public's opinion on science and technology

**Country and Sector:** UK – Science and Technology

**Groups surveyed:** Effects of science and technology. Public spending. British science. Politics and science. Control of science.

**Year:** 1989

**Number and Type of Respondents:** 2009 adults. General public.

**Method:** Questionnaire – closed questions.

**Performed by:** Kenward M (reporter)/ Gallup

**Presented:** "New Scientist" 16<sup>th</sup> December 1989, pp 57-61.

## LEMKOW

### Public Attitudes to Genetic Engineering: Some European Perspectives

**Aim:** To investigate and contrast European attitudes to various areas of biotechnology.

**Country and Sector:** UK, France, Germany, Spain – Biotechnology

**Groups surveyed:** Biotechnology; knowledge and attitudes. Future research.

**Year:** 1992

**Number and Type of Respondents:** 1. "Informed public" (but not professionals) 2. Representatives of pressure groups and interested parties.

**Method:** 1. Focus groups (1 x male, 1 x female) of 7-9 people. 2. Workshops.

**Performed by:** Lemkow L

**Presented:** Published by the European Foundation for the Improvement of Living and Working Conditions.

## LEWIS

### Young people's understanding of, and attitudes to, "The new genetics"

**Aim:** To investigate young people's attitudes to "the new genetics" in the context of school science education.

**Country and Sector:** UK – Science and genetics.

**Groups surveyed:** Understanding of: Basic genetics, DNA technology, Genetics of cells, prenatal screening, individual screening, attitudes.

**Year:** 1996

**Number and Type of Respondents:** 743 young people: 84% 16-17 year olds, 16% 14-15 year olds.

**Method:** Written probes and discussion packs.

**Performed by:** Lewis and Leach

**Presented:** Published as working paper by Learning in Science research group.

## MACER

### Public Acceptance of Human Gene Therapy and Perceptions of Human Genetic Manipulation

**Aim:** To investigate public attitudes and knowledge towards gene therapy and gene manipulation

**Country and Sector:** Japan, (comparison with US, Europe, NZ) - Genetics

**Groups surveyed:** Awareness of genetic manipulation and attitudes. Acceptance of gene therapy. Genetic engineering and the curriculum.

**Year:** 1994

**Number and Type of Respondents:** 228 high school biology teachers, 551 general public, 555 scientists, 728 academics.

**Method:** Questionnaire – open and closed questions.

**Performed by:** Macer D

**Presented:** "Human Gene Therapy" 3, pp 511-18

## MARTIN

### Attitudes of selected public groups in the UK to biotechnology

**Aim:** To study attitudes of people with an interest in biotechnology.

**Country and Sector:** UK - Biotechnology

**Groups surveyed:** Knowledge of biotechnology. Attitudes towards genetic information.

**Year:** 1992

**Number and Type of Respondents:** 1. 47 research students. 2. 195 living near GM research station. 3. 199 living near GMO release site. 4. 105 environmental biotechnologists. 5. 176 employees of biotechnology company. 6. 200 Friends of the Earth members. 7. 97 university green group members. 8. 70 general public.

**Method:** Interviews and questionnaires.

**Performed by:** Martin S and Tait J.

**Presented:** in "Biotechnology in Public" Durant J (ed).

## MICHAEL

### Teaching biotechnology: identity in the context of ignorance and knowledgeability

**Aim:** To analyse teachers' views on biotechnology and the teaching of it.

**Country and Sector:** Republic of Ireland - Biotechnology

**Groups surveyed:** Knowledge and understanding of biotechnology. Issues (ethical, risk) of biotechnology; presenting these issues in the classroom. Teaching biotechnology. Issues raised by the performance of school lab experiments, re: scientific uncertainty.

**Year:** 1997

**Number and Type of Respondents:** 16 secondary school teachers (15 biology, 1 religion). 3:5 male:female.

**Method:** Workshops.

**Performed by:** Michael M, Grinyer A and Turner J.

**Presented:** "Public Understanding of Science" 6 (1997), pp 1-17

## MICHIE *et al*

### A comparison of public and professionals' attitudes towards genetic developments

**Aim:** To assess the attitudes of the general public and three professional groups to genetic development, genetic testing in pregnancy and decision-making about availability.

**Country and Sector:** UK – Genetics.

**Groups surveyed:** Attitudes to new genetic discoveries. Genetic testing in pregnancy and the consequences. Decision making and control of genetic testing.

**Year:** 1995

**Number and Type of Respondents:** 973 general public, age 18-45. 59 geneticists. 44 obstetricians. 46 medical ethicists.

**Method:** Questionnaire.

**Performed by:** Michie S, Drake H, Bobrow M and Marteau T/ Gallup

**Presented:** "Public Understanding of Science" 4 (1995), pp 243-253

**MILLER *et al***

## **Public Attitudes Toward Science and Technology**

**Aim:** Comparison of national attitudes to science and issues involving science from 1979 to 1990.

**Country and Sector:** USA - Science

**Groups surveyed:** Understanding of science. Information acquisition. Issue attentiveness. Attitudes toward science – general and specific controversies. Political attitudes.

**Year:** 1979 – 1990.

**Number and Type of Respondents:** General public.

**Method:** Telephone interviews. In-depth interviews.

**Performed by:** Miller JD, Pifer LK and Ressmeyer TJ/ National Science Foundation.

**Presented:** Published report – International Centre for the Advancement of Scientific Literacy.

## **MORI/ OST**

### **The Public Consultation on Developments in the Biosciences**

**Aim:** To examine the general public's attitudes to wider implications of recent developments in the biosciences.

**Country and Sector:** UK - Biosciences

**Groups surveyed:** Awareness. Issues.

**Year:** 1998-9

**Number and Type of Respondents:** 123 members of "People's Panel" and 2200 members of general public.

**Method:** Workshops. Interviews.

**Performed by:** MORI

**Presented:** Published by Office of Science and Technology

## **PIFER**

### **Public Understanding of Basic Biomedical Concepts**

**Aim:** To investigate the public understanding of basic biomedical concepts

**Country and Sector:** USA - Biomedicine

**Groups surveyed:** Understanding of various types of biomedicine.

**Year:** 1993

**Number and Type of Respondents:** General public

**Method:** Interviews

**Performed by:** Pifer LK/ National Science Foundation/ National Institute of Health

**Presented:** Published report by the International Center for the Advancement of Scientific Literacy

## RADAR

### Genes are us? Attitudes to Genetics and Disability

**Aim:** To investigate the attitudes of non-disabled and disabled people with respect to the new genetics and future research.

**Country and Sector:** UK – Genetics and disability.

**Groups surveyed:** Genetics and regulation. Genetic discrimination. Cloning. Employers and Insurance. Abortion.

**Year:** 1999

**Number and Type of Respondents:** 452 members of RADAR member groups; 57% disabled, 71% female. 44% non-religious, 43% Christian. Most respondents in 40-70 age group. 96% white, 2% Asian.

**Method:** Questionnaire with closed and open questions, prefaced by information about topics.

**Performed by:** RADAR (Royal Association for Disability and Rehabilitation)

**Presented:** Published by RADAR

## SCHIBECI *et al*

### Public attitudes to gene technology: the case of MacGregor's<sup>®</sup> tomato

**Aim:** To report the perceptions of four "interested publics" (ie. members of a group that are not experts in the field but have an interest because of the membership of their group) about the Flavr Savr<sup>™</sup>/ MacGregor's<sup>®</sup> tomato.

**Country and Sector:** Australia – Genetic Engineering

**Groups surveyed:** Understanding of biotechnology. Awareness of commercial biotechnology. Business, ethical and political implications of biotechnology. Regulation of genetic engineering. Health and environmental considerations.

**Year:** 1994

**Number and Type of Respondents:** 60 adults: 19 biotechnology students, 18 "science and society" programme students, 14 members of conservation organisation.

**Method:** Interview involving computer-based information package.

**Performed by:** Schibeci R, Barns I, Kennealy S and Davison A

**Presented:** "Public Understanding of Science" 6 (1997), pp 167-183

## SCOTINFORM LTD

### Public awareness of science in Scotland

**Aim:** To establish the general public's attitude to and awareness of science and scientists; to ascertain which current scientific issues are of concern to the public and to look at attitudes toward future scientific breakthroughs.

**Country and Sector:** Scotland – Science.

**Groups surveyed:** Health and wellbeing. Environment. Imaginative breakthroughs. Attitudes towards science and scientists. 20<sup>th</sup> century achievements. Future scientific advances. Living scientists. Awareness of science festival.

**Year:** 1990

**Number and Type of Respondents:** 1000 members of general public. Age –16+ (slight weighting towards younger age group). 509:491 male:female.

**Method:** Questionnaire.

**Performed by:** Scotinform Ltd

**Presented:** Report published by Scotinform, 1991.

## THE SCOTTISH OFFICE

### Turning the Light on Science: A review of public understanding of science and technology in Scotland

**Aim:** To clarify how the general public perceive science and technology, identify how science and technology are promoted in the education system and encourage debate on taking positive responses forward in Scotland.

**Country and Sector:** Scotland – Science and technology

**Groups surveyed:** Perceptions of science and technology. School issues of science and technology. Young people. Government initiatives.

**Year:** 1994

**Number and Type of Respondents:** Literature review.

**Method:** Literature review and case studies

**Performed by:** The Scottish Office

**Presented:** Report published by the Scottish Office.

## SHEEHY *et al*

### Consumers and Biotechnology: A synopsis of Survey and Focus Groups Research

**Aim:** To investigate the work done on opinions of Canadian to public-based biotechnology.

**Country and Sector:** Canada - Biotechnology

**Groups surveyed:** Biotechnology. Knowledge and attitudes.

**Year:** 1998

**Number and Type of Respondents:** Literature review

**Method:** Literature review

**Performed by:** Sheehy H, Legault M and Ireland D.

**Presented:** "Journal of Consumer Policy" 21 (1998), pp 359-386

## SINGER

### Public attitudes towards genetic testing

**Aim:** To measure public attitudes toward genetic testing.

**Country and Sector:** USA – Genetics.

**Groups surveyed:** Prenatal testing. Abortion. Sex determination.

**Year:** 1990

**Number and Type of Respondents:** General public, age 18+.

**Method:** Phone questionnaire.

**Performed by:** Singer E/ Gallup

**Presented:** "Population Research and Policy Review" 10 (1991), pp 235-255

## SINGER

The Polls – Trends: Genetic Testing, Engineering, and Therapy; Awareness and Attitudes

**Aim:** To document changes in public awareness, beliefs and attitudes to some of the issues raised by genetic technology.

**Country and Sector:** USA - Genetics

**Groups surveyed:** Awareness of genetic screening/testing and engineering. Attitudes towards Genetic Screening/Testing and Engineering, Therapy and Engineering. Willingness to undergo testing or therapy. Willingness to have foetus/children undergo testing or therapy. Attitudes towards abortion in case of genetic disease or defect. Privacy concerns. Nature vs nurture. Cloning: animal and human.

**Year:** 1998

**Number and Type of Respondents:** Literature Review

**Method:** Comparing attitudes from surveys conducted over time

**Performed by:** Singer E, Corning A and Lamias M

**Presented:** "Public Opinion Quarterly" 62 (1998), pp 633-664

## SPARKS

### Gene Technology, Food Production, and Public Opinion: a UK Study

**Aim:** To assess perceptions gene technology among the UK public.

**Country and Sector:** UK- Biotechnology

**Groups surveyed:** Biotechnology. Attitudes towards genetic engineering. Risks, implications and benefits. Trust in groups associated with genetic engineering.

**Year:** 1994

**Number and Type of Respondents:** 6000 members of general public targeted.

**Method:** Questionnaire.

**Performed by:** Sparks P, Shepherd R and Frewer LJ

**Presented:** "Agriculture and Human Values" Winter 1994, pp19-28

## STRATFORD

### Tailoring genes

**Aim:** To investigate British social attitudes.

**Country and Sector:** UK - Genetics

**Groups surveyed:** Prenatal genetic testing. Privacy – access to genetic records. Altering human genes. Religion and age.

**Year:** 1999

**Number and Type of Respondents:** 4800 general public.

**Method:** Questionnaire: closed questions.

**Performed by:** Stratford N, Marteau T and Bobrow M.

**Presented:** in "British Social Attitudes: the 16th Report", (1999), Jowell R *et al.*

## TYLER

### Presymptomatic Testing for Huntingdon's Disease in Wales 1987-90

**Aim:** To investigate the issues involved in HD presymptomatic testing programmes.

**Country and Sector:** Wales – HD, Genetic Testing

**Groups surveyed:** Attitudes and responses to genetic testing.

**Year:** 1987-90

**Number and Type of Respondents:** 238 adults at 50% HD risk.

**Method:** Study of ongoing HD testing programme.

**Performed by:** Tyler A, Morris M, Lazarou L, Meredith L, Myring L and Harper P

**Presented:** "British Journal of Psychiatry" (1992), 161 pp481-488

## WELLCOME

### Public Perspectives on Human Cloning

**Aim:** Explore public perspectives on human cloning.

**Country and Sector:** England – cloning.

**Groups surveyed:** Ethical issues;. Own genetic identity;. Instrumentalisation; Experimental human beings. Natural/ unnatural;. Understanding;

**Year:** 1998

**Number and Type of Respondents:** 79 adults – 10 focus groups: B, C1, C2 & D (social grade grouping), lesbians, women who had lost a young child, pregnant women, women with difficulty conceiving, grandparents, women in their late 30s and early 40s with no children; opposite-sex couples. Age 25 – 55+

**Method:** Group discussions and reconvened group discussions (single sex); partner paired depth interviews and reconvened partner paired depth interviews (opposite sex).

**Performed by:** The Wellcome Trust / NOP Family and The Research Business International

**Presented:** Report published by The Wellcome Trust.

## WELLCOME

### The People Decide

**Aim:** To increase public awareness of genetic research and the issues involved.

**Country and Sector:** UK - Genetics

**Groups surveyed:** Knowledge of genetics

**Year:** 1997

**Number and Type of Respondents:** Greater London general public - 425 adults (16+). 79% White, 6% Black, 8% Asian, 7% other

**Method:** Discussions

**Performed by:** Wellcome Trust

**Presented:** Published by Wellcome Trust

**WOOD-ROBINSON *et al***

**Young people's understanding of the nature of genetic information in the cells of an organism**

**Aim:** Investigating the understanding of cell genetics by 15-16 year olds

**Country and Sector:** UK - Genetics

**Groups surveyed:** Nature of genetic information. Transfer of genetic information. Scientific logic.

**Year:** 1997

**Number and Type of Respondents:** 35 pupils at comprehensive schools in West Yorkshire. Age 15-16 years. Mixed ability.

**Method:** Discussion group.

**Performed by:** Wood-Robinson C, Lewis J, Leach J and Driver R. (Leeds University)

**Presented:** at European Science Education Research Association conference, Rome 1997.