

WHAT DO PEOPLE THINK ABOUT GENE THERAPY?

A report published by the Wellcome Trust
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Cover image: Colour-enhanced image of the Sendai virus. It is being investigated as a vector for gene therapy in diseases such as cystic fibrosis.
University of Edinburgh

1. Introduction

New biomedical technologies are usually complex and unfamiliar, especially when they have not yet been developed for widespread use. This is definitely the case with gene therapy, which has made it difficult to get a clear idea of what public attitudes to altering human genes might be. In 1999, the National Centre for Social Research (NatCen) began a major study for the Wellcome Trust that set a new benchmark for understanding what people in the UK thought about gene therapy, and how their attitudes were formed.

The research was primarily concerned with building upon existing models of social research to develop more rigorous models of public consultation. It assessed the impact of innovative stimuli intended to encourage and support debate about the social and ethical issues raised by scientific developments. By combining both quantitative and qualitative approaches in a panel study, it attempted to offer both breadth and depth of understanding in relation to public attitudes towards gene therapy.

The study began with a detailed survey of opinion. It then moved on to a series of follow-up inquiries designed to shed light on what kind of information or process may affect attitudes. That is, it went beyond survey methodology to provide people with more information, and allowed participants to discuss a range of different possible uses of genetic techniques.

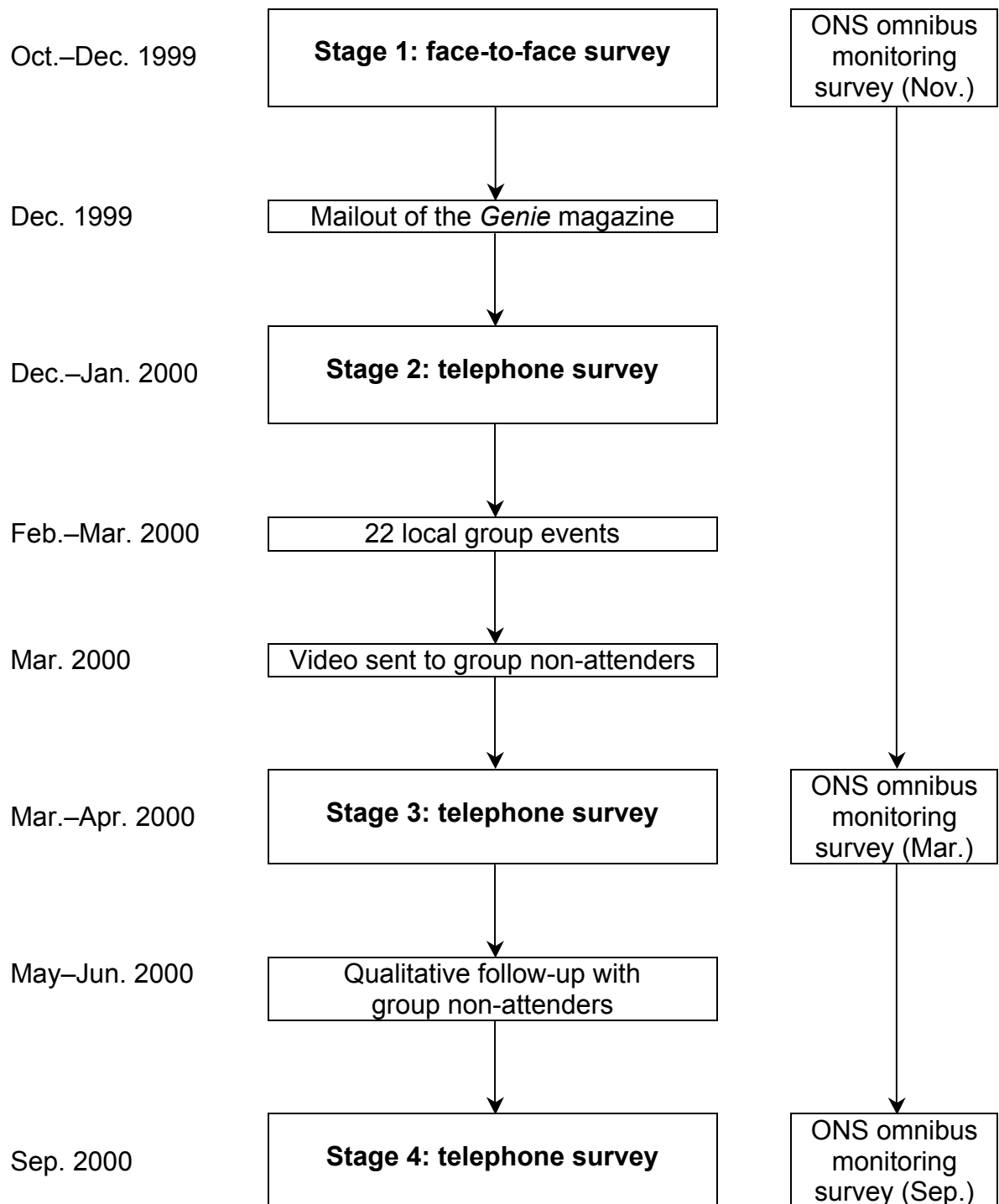
This summary report presents some of the findings of the study. As the results of the initial survey are a few years old now, it also compares them with some less detailed surveys that have been conducted in the UK, the USA and Australia. The fact that those are broadly in line with the more elaborate study carried out by NatCen suggests that their results remain important to take into account in discussion of the development and regulation of gene therapy. The report then gives some details of the later stages of the study, and of what was found about the effects of providing additional information and discussion of the issues.

2. The stages of the study

The face-to-face baseline survey was conducted between October and December 1999. Those who agreed to take part were then asked to participate in follow-up telephone interviews at several points over the course of the study. These were: to see if they had read a special magazine sent to them about gene therapy (the *Genie*), and with what effect; to assess the results of day-long discursive workshops; and to see if their attitudes were the same some months later. These results were compared with key questions placed on the quarterly national omnibus survey conducted by the Office for National Statistics (ONS).

The full plan for the study is set out in figure 1 below.

Figure 1: Timing of study stages



The numbers of participants reduced between each stage, and the composition of the sample also changed. So the results from each stage are not directly comparable. Nevertheless, they do give some useful indication of the effects of the additional information and discussion on participants' attitudes.

3. Key findings

Some key findings of the initial survey were:

- Public attitudes towards gene therapy were complex. The initial survey used several carefully developed scenarios, concerning somatic, germline and *in utero* therapies and possible applications: life-threatening conditions, those regarded as non-medical, and improvements (scenarios included heart disease, cystic fibrosis, baldness and boosting memory in healthy subjects).
- Attitudes towards the acceptability of altering genes varied a great deal from one scenario to another. The research showed that people do make distinctions between medical and non-medical applications, and between somatic, germline and *in utero* gene therapy. While the majority are comfortable with the idea of somatic therapy for serious illness (for instance, 82% would allow somatic gene therapy to treat heart disease), only two-thirds (64%) would support germline therapy for this, and *in utero* therapy commanded even less support (49%).
- Awareness of and knowledge about gene therapy were both fairly low.
- Few participants knew anything about the existing regulatory system: 15% of the sample were aware that the UK permits experiments altering genes in somatic but not reproductive cells.
- Most participants were found to be optimistic about progress in gene therapy research. Seven out of ten believed that gene therapy could already treat some or many diseases and six in ten think that gene therapy treatments for heart disease will exist within five to ten years.

Subsequent stages of the study found that:

- Reading the gene therapy magazine had little effect on attitudes, although it appeared to increase both knowledge and reassurance about the existing regulatory framework.
- More participants watched the video than read the magazine, but with similar effects on attitudes.
- The most powerful effects on attitudes stemmed from the combined video and extended group discussions. After these events, the smaller number of people involved demonstrated: more knowledge of

regulations and trust in their adequacy; more trust in scientists; and more enthusiasm about genetic research in general and fewer doubts about its future uses. However, they also showed reduced support for gene therapy for non-medical reasons.

- The final follow-up interview showed that these more powerful changes in this smaller group were lasting. Attitudes among the general population, as measured by the ONS omnibus survey, remained broadly unchanged.

4. Knowledge, interest and outlook

Before looking at what people thought about altering genes, it is useful to know a little about their general interest in and attitudes towards genetics. These survey results are based on face-to-face interviews with a representative sample of just under 700 adults across the UK in late 1999. As other surveys have found, most had heard of genetically modified foods and cloning, but awareness of gene therapy was quite a bit lower. Asked if they had heard about “curing diseases through genetics” within the last month, only 41% said yes. This figure fell to 31% among readers of tabloid newspapers, but stood at 64% for broadsheet readers. In line with this, most people (79 %) reported that they received little or no information about genetics. Nor was genetics in general a topic of conversation. About half of the sample had not discussed it with anyone else in the past year. A simple genetic knowledge quiz suggested that most people had a little basic knowledge of genetic facts, but more often resorted to ‘don’t know’ when asked more detailed questions. See table 1 below for more details.

Table 1: The genetic knowledge quiz

Percentage giving each answer (correct answers in bold)

Statement	True	False	Don't know
Identical twins have the same genes	65	17	18
Whether a couple have a boy or a girl depends on the woman's genes	15	64	21
Half your genes come from your mother and half from your father	61	19	20
Down's syndrome is an inherited disease	22	58	20
Children look like their parents because they have the same type of red blood cells	15	58	26
Most cells in our body contain a copy of all our genes	57	7	36
There are test tube babies who grew entirely outside the mother's body	31	47	23
Genes of all living things on earth are made up of different combinations of only 4 or 5 chemical building blocks	28	12	61
We have around 150 000 different chromosomes, which contain our genes	31	13	56

Not surprisingly, then, beliefs about the current state of gene therapy tended to be inaccurate. More than half of the sample (60%) thought that some diseases could already be treated by altering genes. There is little evidence that this is the case today (2005) and there was certainly none in 1999. Some people (8%) already believed that many diseases were treatable.

The survey also probed people's general attitudes towards science. The results again show an encouraging consistency with other studies. Most people (79%) agreed that science makes our lives healthier, easier and more comfortable, but half still felt that it makes things change too fast – a feeling more prevalent among older interviewees. Those aged over 55 were also twice as likely as younger people to think that modern science does more harm than good, with more than 20% agreeing with this statement.

5. Gene therapy: in general

In addition to considering the acceptability of gene therapy in a range of different circumstances, respondents were also asked a set of general questions about genetic research and gene therapy. Their answers at this level already indicate some ambivalence about the idea of altering genes. A large majority thought that genetic treatments could reduce human suffering, and that research would do more good than harm. However, just as many people also agreed with the suggestion that it would be better to cure illness in other ways. And more than a quarter felt that we should never interfere with

people's genes, and it would be better not to find out how to do it (see table 2 below).

Table 2: Attitudes to genetic research and treatments

Percentage agreeing with each statement

Positive:	
Genetic treatments for illness will do a lot to reduce human suffering	76
In the end, research into human genes will do more to help us than to harm us	68
People worry too much about the risks of changing human genes	43
Negative:	
It is better to try to cure illness without changing people's genes	74
Changing a person's genes is too risky, whatever the benefits might be	49
We should never interfere with people's genes	31
It would be better if we did not know how to change people's genes at all	28
Changing genes should be forbidden as it is tampering with nature	26
Scientists should not look for genetic cures, because the world will become too overpopulated	20

How does this translate into responses to specific proposals for altering genes?

6. Gene therapy: where and when?

Most previous attempts to find out what people think about altering human genes stopped at general questions, and did not elucidate what was meant by gene therapy. An important feature of this survey was that it was more detailed in approach. After the first set of questions, the interviewers moved on to inquiries about a collection of carefully worded scenarios in which genetic alteration might play a part. They were designed to bring out a number of differences between potential uses of new genetic technology.

For example, genes might be altered in somatic (body) cells, to help a single individual who already has a disease, or is at risk of getting it. Or genes might be changed in reproductive cells (germline therapy), in a way which would be passed on to someone's children. Many countries already distinguish between these two categories of gene therapy in their regulations. A third category was also included here: altering fetal genes in the womb (*in utero* therapy). See box 1 below for example questions.

Aside from which cells are targeted, and when, the possible applications also vary. The researchers wanted to distinguish between life-threatening conditions, those normally regarded as non-medical, and actual improvements. Specifically, they asked about heart disease, the genetic

disease cystic fibrosis, baldness, and the possibility of improving memory in healthy subjects.

Box 1: Sample questions about types of gene therapy

Somatic

Heart disease can happen when a person's arteries get clogged up and not enough blood gets to the heart. This can cause pain and disability and may lead to a heart attack. Eating healthier food, not smoking, and taking regular exercise can reduce the risk of getting heart disease. People with heart disease may need to take drugs or have major surgery.

I'd like you to think of someone in their **20s** who has **serious heart disease**. Suppose it was discovered that changing some of their genes by giving them an injection could help treat their heart disease. These new genes would **not** be passed onto any children they might later have.

Do you think this should be allowed or not allowed?

Germline

Now, what if the new genes **were** passed onto their future children, to give **them** less chance of getting serious heart disease in their 20s? Do you think this should be allowed or not allowed?

In utero

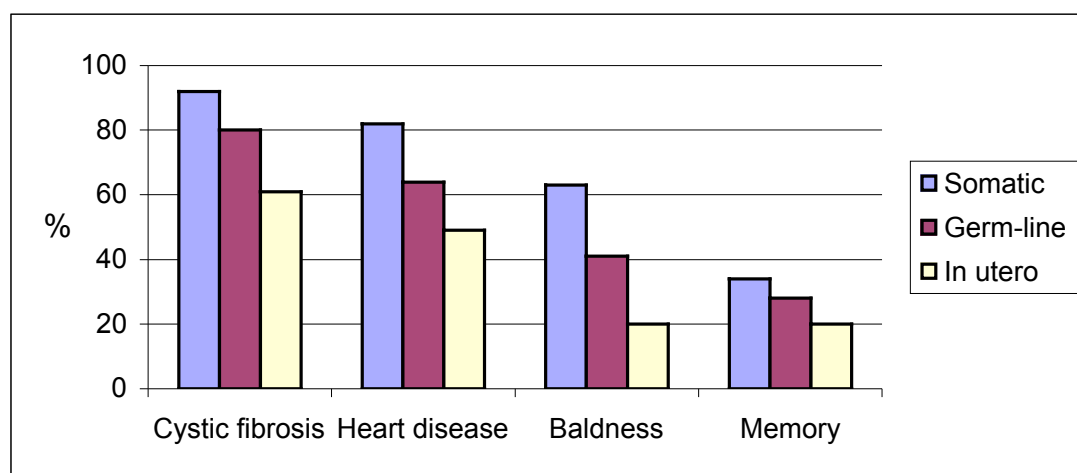
Now suppose a person's genes could be changed before they were born – by treatment while still in their mother's womb – to give them less chance of getting serious heart disease in their 20s. The new genes would not be passed onto any children they later have. Do you think this should be allowed or not allowed?

The results were intriguingly varied. When the target condition was a serious illness and only body cells were affected, the vast majority would agree to genetic alteration: 92% for cystic fibrosis and 82% for heart disease. A two-thirds majority (63%) would even allow changing genes to overcome baldness. But far fewer – only 34% – would approve of this approach to improving memory.

If the change was proposed to affect reproductive cells, so that the person's children would be spared disease, keep their hair or have better memories, approval fell. But three-quarters of the sample still felt that this would be acceptable for cystic fibrosis, and just under two-thirds for heart disease. In each case, altering genes in the womb was the least acceptable option. The idea of operating on unborn babies clearly increased any doubts people already had about genetic procedures.

Figure 2: Approval rates for gene therapy applications

Percentage support for use of different types of gene therapy for different conditions



7. Complex attitudes confirmed

This picture of attitudes to different types of gene therapy is partly confirmed by other surveys carried out since 1999 in Britain and elsewhere. All show strong support for the idea of gene alteration – even germline alteration – to prevent or cure disease. At the same time, there is general wariness about the possibility of gene alteration for non-medical use.

In the UK, for example, a national MORI survey in 2000 commissioned by the medical charity Action Research found that “74% of the public agrees that gene therapy is acceptable if tightly controlled”. A later MORI poll for the Medical Research Council, in 2003, indicated that 40% of people thought that the applications of DNA knowledge of most benefit to society were gene therapy and the ability to understand and predict inherited diseases. And a qualitative study in Wales in 2002 found significant support for germline therapy for cystic fibrosis¹.

The latest major UK survey of knowledge about and attitudes towards genetics was carried out between June and September 2003 as part of a large-scale Economic and Social Research Council-funded study. The study also included extensive follow-up work using interviews, focus groups and other methods, but only the basic survey results have been published to date. This national survey of 3500 people involved gene therapy questions on the annual British Social Attitudes Survey – run by the National Centre for Social Research (NatCen) – some of which had been used in previous rounds of that

¹ See, respectively: www.mori.com/polls/2000/action.shtml; www.mori.com/polls/2003/mrc.shtml; and Iredale R, Dolan G, McDonald K, Kirk M. Public attitudes to human gene therapy: a pilot study in Wales. *Community Genetics* 2003;6(3):139–46.

survey, allowing an assessment of the extent to which attitudes are changing over time. It found that 81% thought that genetic alteration should “definitely or probably be allowed” to reduce someone’s chances of getting breast cancer. More than half were also willing to permit it to make someone less aggressive or violent. The percentages were much lower for making someone heterosexual rather than homosexual (18%) or determining the sex of an unborn baby (15%). Very similar responses to this question were recorded in 1998 and 2000, although the percentage approving of the idea of gene alteration to help prevent breast cancer rose from 72% in both of those years to the 81% figure of 2003².

Other surveys from abroad yield more similarities to the findings from the NatCen study. A nationwide telephone survey in the USA in 2002 for the Genetics and Public Policy Centre at Johns Hopkins University found that opinions about genetic engineering to avoid disease and to create desirable traits almost mirrored one another. Disease avoidance prompted 59% approval and 34% disapproval. Use of genetic techniques to promote desirable traits such as strength, intelligence or attractiveness, on the other hand, was disapproved of by 76% of this sample, and approved by only 20%³.

Like the detailed British survey, this study also found that knowledge of gene therapy was pretty sketchy, with 23% of people believing that it was already possible to prevent a genetic disease using genetic engineering. And, again as in the UK, approval for efforts to deal with disease extended to germline alteration. In fact that 59% approval figure was in response to the question: would you approve or disapprove if parents were offered a way to change their own genes in order to prevent their children from having a genetic disease?

Finally, a nationwide survey of attitudes to biotechnology in Australia in 2003, the latest in a series, found that 71% believed that gene therapy would “improve our way of life”⁴. And, similar to the UK figure, 21% of people in the USA believed that gene therapy was already doing so. Another 24% thought it would bring improvements within five years, and 28% in 10 years. If this indicates some kind of approval, then one must also take into account that 33% of those asked thought that gene therapy was already making things worse.

Those Australian findings seem harder to interpret than answers to questions that probe approval directly. But taken together, these later surveys suggest that the results of the NatCen study are a snapshot of public opinion in Britain that has not been superseded, and that is broadly similar to results in other

² For details, see Park A, Curtice J, Thomson K et al (eds). British Social Attitudes: The 21st report. London: Sage; 2004.

³ Genetics and Public Policy Center, Johns Hopkins University. 2002. Attitudes about Reproductive Genetics. See www.dnapolicy.org/research/reproductiveGenetics.jhtml.

⁴ Millward Brown Australia, for Biotechnology Australia. 2003. Biotechnology Public Awareness Survey: Final report. See www.biotechnology.gov.au/index.cfm?event=object.showContent&objectID=F76C3B54-BCD6-81AC-165EA28AFE8D57AD.

countries. It also appears that this study remains the best one conducted so far for those who want an in-depth look at attitudes and factors that affect them.

8. What influences attitudes to gene therapy?

The detailed results of the survey conducted by NatCen can be analysed to give some indications about the sorts of personal characteristic that may affect people's views of gene therapy. Both education, and knowledge of gene therapy, for example, seemed to have some effect. Some other studies have indicated that knowing more about it may make people more likely to support gene therapy. The results here suggested that it is not as simple as that. For instance, while knowing more about genetics went along with higher approval of somatic gene therapy for serious illnesses such as cystic fibrosis, the more knowledgeable were somewhat less likely to support germline alteration.

Attitudes to science in general also mattered. People who had a generally optimistic view of science as a force for good were more likely to think that gene therapy was acceptable. However, this was not true across the board; optimists about science were less likely than others to like the idea of memory enhancement through genetic alteration.

A number of other factors were linked to attitudes to gene therapy. These included age, genetic interest, trust in science and scientists, and religion. Unlike some earlier surveys, the study picked up rather little in the way of differences between men and women.

The survey also found a close relationship between views about gene therapy and attitudes towards abortion, with those who are most opposed to abortion also being opposed to gene therapy. The researchers suggest that this is because both may be seen as interfering with natural processes. The researchers explored the extent to which *in utero* gene therapy might be considered as preferable to abortion in relation to an unborn child being confirmed to have cystic fibrosis. Despite the general lack of support for gene therapy *in utero*, most people (66%) still thought this would be preferable to abortion of the affected fetus.

Based on analysis of the data from the qualitative workshops, a number of factors were found to influence judgements about the acceptability of gene therapy. Overall, attitudes were underpinned by concerns relating to potential risks and consequences arising from the use of gene therapy.

Participants rationalised that the risks of gene therapy were worth taking in circumstances where they judged the condition to be serious, potentially life-threatening, or where the quality of life was felt to be very poor. In these cases, panel members sometimes even overcame their opposition to germline and *in utero* gene therapy, arguing that the associated risks were worth taking if it would prevent serious medical conditions being passed on, or developing.

For example, *in utero* gene therapy was sometimes positively viewed as an option for children who would be born with Down's syndrome, autism, alpha-thalassemia or cystic fibrosis. Where, however, participants did not perceive the case to be serious enough to risk the treatment – as, for example, in other medical applications and for cosmetic enhancements – they displayed their opposition to the use of any type of gene therapy.

Judgements were also dependent upon the degree of impact that gene therapy was likely to have on a particular condition. It was argued that the risks of gene therapy were worth taking if there was a real chance that it could bring relief and prevent the deterioration of a particular condition. In circumstances, however, where it was perceived that the treatment was likely to be of limited benefit because a condition had already progressed too far, for example following a heart attack, then it was sometimes argued that there would be little value in employing gene therapy.

While the consequences of the treatment influenced judgements about all applications of gene therapy, there was greater opposition where it was felt that there might be longer-term consequences, such as problems later in life or a mutation further down the germ line. Equally, the use of *in utero* therapy was opposed on the grounds that it was 'tampering with a fetus' during the developmental process and, as a consequence, might result in longer-term consequences for the child and its mother.

The nature of alternative treatments available sometimes had a bearing on judgements about somatic gene therapy. It seemed that gene therapy was more acceptable and worth risking in circumstances where there was perceived to be no existing treatment available. Equally, it was viewed more positively in circumstances where alternative treatments were perceived to be risky, to have a lower success rate, or to have debilitating side-effects (as in the case of chemotherapy). Conversely, where the alternative treatments were viewed as effective and relatively free of side-effects (such as counselling, psychotherapy and antidepressants for depression, or hair transplants or wigs for baldness), gene therapy was judged to be unacceptable.

The age of the patient sometimes seemed to affect judgements about gene therapy. In some cases it was argued that a high priority should be placed on using gene therapy to treat or prevent a serious medical condition in children and young people. In these circumstances, it seemed that the risks were sometimes worth taking because young people were at the beginning of their lives and therefore had more to lose. This view, however, did not seem to extend to *in utero* therapy – although there was insufficient opportunity within the workshops to explore this further.

The accuracy of the screening tests in predicting whether someone would develop a particular condition also affected whether respondents believed it was acceptable to use gene therapy or not. Given the concerns about the potential risks and consequences of gene therapy, there was less ease about

its use in cases where there was some doubt about whether a particular condition would develop.

The cost of the treatment was another factor that influenced judgements. The potential drain on NHS resources was raised primarily in connection with the use of gene therapy for non-medical applications. Thus, where people judged cosmetic enhancements as acceptable, they sometimes qualified this by stressing it should not be available on the NHS.

9. Attitudes to regulation

Agreeing that gene therapy might be acceptable does not indicate unconditional approval for all potential applications. There was a wide range of hopes and fears about what discoveries in genetics might bring, and although the hope generally outweighed the concern, many people (41%) reported having a mixture of the two. When it came to specifics, there were many worries, ranging from unethical experiments, side-effects and risks, to more diffuse concerns about 'playing God' or creating a 'master race'.

Not surprisingly, then, there were some strong views about who should be involved in regulation. Most thought the Government needed to be involved, but it was commonly felt that doctors and patients should have a say too. Scientists and researchers were also thought to have a role to play. However, there were two groups whom half or more did not want involved in the regulation of gene therapy: pharma companies and religious groups. Interestingly, religious people were more likely than others to believe that existing regulations were inadequate, a tendency shared by the more highly educated.

At the same time, most people actually knew little about how gene therapy is regulated now. Only 15% knew that the UK currently permits experiments altering genes in somatic but not reproductive cells. Such a low awareness of the existing regime, combined with a general disinclination to trust government and a wariness about some of the possibilities of gene therapy, suggests that this will be a difficult area for politicians and regulators to manage. It also invites the question of how best to improve people's knowledge of the issues, and what effect this might have on their attitudes.

10. Does more information change attitudes?

Finding out more about a new and potentially controversial subject is one factor among many that may influence a person's attitudes. Moreover, it is an open question as to how knowledge might influence the views people hold. The later stages of this study give some indication of what can happen in the case of gene therapy. As indicated in Section 3, both the specially prepared magazine and the video had some effect on knowledge for those prepared to read or watch, but the data show little effect on attitudes that can be attributed solely to the new information. One exception here was that participants

became better informed about the regulatory system. There was also a small shift towards trusting scientists to regulate themselves and not to conceal details of their work.

A more potent influence on attitudes (albeit for a smaller number of participants) was the extended group discussions. The information input here is difficult to specify because one of the things that those who took part were most enthusiastic about was the chance to talk to other people and hear their opinions and arguments. The effect here is due to the whole experience of the day, perhaps, rather than any particular part of it.

The group participants certainly felt that they became better informed. They reported knowing more about:

- how gene therapy works and what it might achieve
- the difference between somatic and germline therapy
- the different applications of gene therapy – medical and non-medical
- the regulation and control of gene therapy
- how far gene therapy has progressed.

Some also said that their participation might mean they would take a more active interest in the coverage of gene therapy in the future.

This increase in knowledge and awareness did go along with some shifts in attitude. Event participants became more enthusiastic about genetic research in general and less worried about its potential applications.

Those who attended the group events became more positive about the use of gene therapy to treat disease. A more positive attitude specifically among those who had participated in the group event can be seen in their responses to certain questions. They showed an increase of 12 percentage points in the proportion agreeing with the statement 'gene therapy will reduce human suffering', and an 11-point decrease in those agreeing that 'it is better to cure illness without changing human genes'. Agreement that 'we worry too much about the risks' increased by 13 points and there was a 12-point increase in disagreement that 'we should forbid gene changes as this is tampering with nature'.

Those who had attended the group event demonstrated a 26-point increase in knowledge that somatic gene therapy is allowed but germline therapy is not, from 14% to 40%. Opinions about who should influence decisions on gene therapy regulation also changed, suggesting that participation in a group event had shifted participants towards wanting influence spread more evenly between the various interest groups, rather than be dominated by scientists and the medical profession.

After attending the events and watching the video, participants did seem more reassured about the regulation of gene therapy. There was an 11-point increase in agreement that 'the rules are strict enough to protect us from associated dangers'.

This theme of reassurance is also evident when asked how far scientists should be trusted to regulate themselves. During the second interview, a majority of participants were in favour of restricting genetic research to that which is clearly related to detecting, preventing and curing disease. However, only those who attended a group event became more willing to trust scientists to do whatever research they choose (an increase of 19 points. Another indication that trust had increased is that the people who had attended the group event and those who had only seen the video both became less likely to believe that some genetic discoveries were being kept secret to avoid public outcry (a decrease of 10 and 9 percentage points respectively).

However, they became less likely to approve of germline gene therapy, even for serious medical conditions such as heart disease, and appreciably less supportive of any kind of gene therapy for non-medical reasons, such as baldness or for memory enhancement.