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INFORMATION AND ATTITUDES: Consulting the public about biomedical science

A report published by the Wellcome Trust
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Cover image: Colour-enhanced electron micrograph of Adenovirus particles, used as a vector for gene therapy.
David Gregory and Debbie Marshall

1. Beyond the ballot box

In 1999 the Wellcome Trust funded the National Centre for Social Research to design a study of what people thought about gene therapy. The study aimed to produce data on lay attitudes towards genetic technology. But it also looked in detail at what kind of information and discussion people found helpful and, in particular, on whether any of this was likely to alter their views. So as well as yielding specific information about attitudes to one particular novel biomedical technology, it offered useful data about methods of deliberation, consultation and public engagement¹.

Most agree that decision making in a democratic society should take account of public attitudes, and that elections alone can be a poor way of gauging the public's views on a range of issues.

The media frequently report opinion poll findings on a whole range of topics. But while polls are an important part of our social conversation, they have their limitations. They may not lend themselves to complex topics, or to questions that people do not know much about. And they are, at best, snapshots. They do not give any indication of how views may develop after a little discussion.

New issues with a strong scientific content sometimes seem particularly unsuited to the one-shot interview technique used for a typical opinion poll. Novelty usually means unfamiliarity, so responses are likely to be either 'don't know' or attitudes contrived in the moment, not reflecting much thought. Technical details are hard to get hold of quickly, or to compress into questions that can be used in a standard interview.

In the last ten to fifteen years, increasing efforts to consult lay people about scientific issues have seen trials of a range of new methods. They usually involve talking to a smaller group of participants than is reached by a typical opinion poll, but in considerably more detail. They often include offering information or discussion to the group to help people make sense of the questions. And there may be a second or third meeting to allow time for reflection and for digesting all of the new information.

All of these things can produce valuable results, particularly when put alongside a broader opinion survey along more traditional lines. But there is still much scope for new experiments, and for detailed examination of how they work. The study examined here was done in 1999–2000, but the results should still be of use to those interested in setting up public information campaigns and consultations. A separate summary report² gives an overview of the results of the study, and of some of the factors that can affect attitudes. This report looks at the methods and processes used in the study; it focuses

¹ A large-scale study on attitudes to genomics in the UK is underway at the University of Surrey. It also incorporates a baseline survey, information provision, group discussions and other experiences that may alter participants' views. It is due to be completed in 2006.

² Wellcome Trust. 2005. What do People Think about Gene Therapy?
See www.wellcome.ac.uk/knowledgecentre/reports/.

both on ways of providing information and on their possible effects on knowledge and attitudes. To know what weight to put on these results, it is useful to give some details of what the researchers did, and what they found. For a more selective overall assessment, see sections 7 and 8 at the end.

2. Ask, then ask again...

The first stage of the project involved a baseline national survey. Face-to-face interviews were conducted with 696 adults nationwide. But for some of those, this was only the start of a lengthy four-stage process.

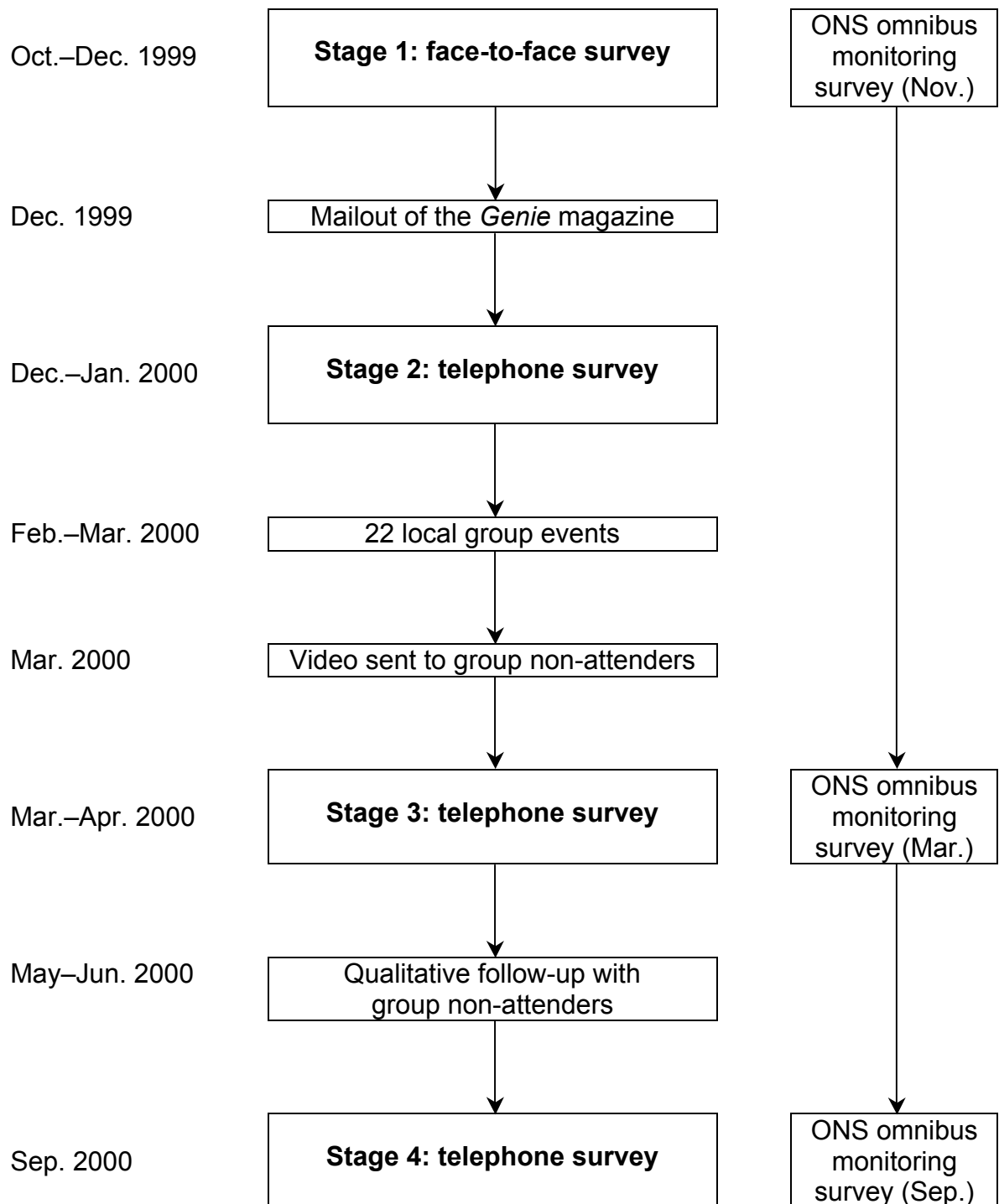
The research team sent everyone they had interviewed a copy of a specially written magazine about the scientific, ethical, social and legal aspects of gene therapy (the *Genie*). Then they contacted all of them again and asked them to agree to another 25-minute interview, conducted by telephone.

A few weeks later, the researchers invited each of the 696 to one of a series of 22 group events, as near to where they lived as possible. These lasted a full day, and between them covered the whole country. Now the focus was on another way of conveying information about the topic: a custom-made video, which everyone watched and then talked about in a moderated discussion. Naturally, some people did not come to the meetings, so they got a copy of the video through the post instead. There was another round of follow-up telephone interviews after this, as well as separate interviews with some of the people who chose not to come to the meeting to try to find out why.

Finally, everyone who had seen the video, whether in a group or at home, was asked for one last, slightly shorter interview six months later to see if their views had changed in any way since the viewing. This was now ten months after the original baseline survey, so the researchers also checked for general shifts in attitudes among the wider population. This was achieved using the omnibus survey conducted quarterly by the Office for National Statistics (ONS).

The stages of the study, and their timing, are set out in figure 1 below.

Figure 1: Timing of study stages



3. Today, my view is...

The 696 participants who took part in the initial survey had a variety of attitudes towards gene therapy. But how might these attitudes change over time? And do the different ways of trying to help people get better informed have any particular effect?

One striking feature of the results of the later parts of the study, aside from the effects of providing additional information, is that individual views were not particularly stable. This is not the same as saying that if two polls are run some time apart then overall attitudes may not look rather similar. But underneath the similarities there can be a lot going on. The aggregated statistics may record small or even non-existent shifts in attitudes even though many individual respondents are changing their position. But these individual shifts of view will only show up in the totals if more people move in one direction on an issue than move the opposite way.

This is evident in the second wave of interviews in this study, a few weeks after participants had received their copy of the *Genie*, the magazine sent to all the sample. Ignoring any influence the magazine may have had for the moment, one thing that stands out is that between one-third and one-half of the sample shifted their views on most of the issues in between the two interviews. However, this impression of volatility disappears from the overall figures because for many of the possible uses of gene therapy roughly the same proportion of participants became more favourable towards the technology as became less favourable.

For example, almost half of the sample changed their attitudes about somatic therapy for heart disease between the first and second sets of interviews, but as approximately the same number became more permissive as became more restrictive, overall there was only a small move in a permissive direction. For similar reasons, although about a third of respondents changed their views about somatic therapy for cystic fibrosis, this change did not register overall. This effect is worth bearing in mind when considering the effects of the information offered to participants in this study. For the rest of the results, though, we consider only the overall changes.

4. The *Genie* out of the bottle

A main point of the later stages of the work was to discover what could help people to develop their views of a novel topic such as gene therapy. There are at least two big problems with any attempt to investigate this in a rigorous way. One is that the researchers have to keep asking the same participants to do things, and some inevitably drop out. This makes it harder to get strictly comparable results, as the make-up of the group under study keeps changing. The other problem is that a group involved in such a study may alter their attitudes over time just because the first lot of questions set them thinking. This makes it harder to judge the effects of anything else they may do.

Both problems appear in the results of the next phase of the study. This was the simplest effort to lead people deeper into the subject. As we have said, everyone who was interviewed at the outset got a copy of the magazine, the *Genie*. This was carefully put together to be an easy read, and covered the possible uses of gene therapy and its risks, benefits and regulation. The results suggest that it was pitched at the right level – most participants who read it read the whole thing, and found it easy to understand (the magazine had been pre-tested prior to final drafting).

That did not mean, though, that the magazine was particularly effective in changing attitudes. This is partly because it was only read by about a third of the people who received it. That fraction is based on the roughly two-thirds of the original sample who took part in the second phase of interviews. There is no way of knowing, of course, if those who read the magazine were more likely to get involved in that round of telephone interviewing, but it seems prudent to regard that one-third reach as a maximum. Of the rest, half of the sample merely glanced at it and 17 per cent did not look at it at all. There was also a significant difference between age groups here. The youngest subset, 18–34-year-olds, were less than half as likely to have read the magazine as the over-65s.

What effect did the magazine have on those who did read through it? Not a lot, overall. There were some changes in attitude between the two interviews (comparing just the results from those who took part in both). The group as a whole appeared to have become more positive about genetic technology. On specific applications, there were some small shifts that at first sight seemed linked to reading the magazine. There was a slight reduction in support for altering genes for non-medical reasons, for example, and a general fall in enthusiasm for altering reproductive cells.

However, a closer look, and some more refined statistical analysis of all the variables involved, suggested that these changes were as likely to be due to simply thinking things over since the first interview as to actually reading the magazine. The *Genie* did seem to contribute to participants' knowing more about how gene therapy was regulated, and this made them happier about the adequacy of the regulations. But this was the only effect that appeared directly attributable to reading the magazine.

In addition, as indicated at the beginning of this section, it is hard to judge whether these results are generally applicable because the sample may have been biased. Reading the magazine may have appealed more to people who were more interested in genetics, for example.

5. I haven't read the book, but I've seen the film

It is good to test the effectiveness of posting out printed information, as this approach is often the first thing that occurs to people who want to help some target group get better informed about a new topic. It is not, of course, cost-free, but it is relatively cheap and easy to do. Alas, on this evidence, it is not likely to be terribly effective. What else is there to try? Perhaps a different medium would work better. One group of participants in this study (those who did not come to one of the group meetings) shed some light on this. They were sent a specially made video through the post, and then asked to participate in another interview.

Around half of the interviewees at this stage had watched the video (including those who saw it at a group meeting). They mostly rated it highly, though some found it was biased in favour of gene therapy. Distinguishing specific effects is particularly hard here because video viewers had already received the magazine. However, as with the magazine, there was some evidence that participants who watched it knew more about the regulations afterwards, and were more likely to find them adequate. And it seemed to discourage support for gene therapy for non-medical conditions such as baldness. Otherwise, neither knowledge gains nor shifts in attitudes were especially marked after seeing the video, although participants appreciated the chance to watch instead of reading.

6. Immersion for a day

The final effort to help participants develop their views in this study combined a set of ways of involving people in further discussion. So it was more complex to carry out and to analyse.

This time, researchers went back again to all the original 696 participants in the baseline survey and invited them to a small meeting to talk through some of the issues. For those who came, there were five ways in which they could get new information:

- from each other, drawing on their thoughts, reasoning and experience
- by watching the specially prepared 15-minute video
- by reading (or re-reading) the *Genie* magazine during the meeting
- by calling the telephone inquiry service Science Line, whose staff were on standby to help
- from the moderator, who had a list of answers to frequently answered questions about gene therapy.

This was obviously a richly supported discussion, though there was no access to, for example, live experts, other printed materials or the internet – things that could also be tried but that would have complicated the analysis still further. The group meetings lasted a whole day. The participants responded to a series of scenarios involving different applications of gene therapy, as well as to the other materials on offer and to each other's ideas and views.

These scenarios, like the questions in other parts of the study, covered a range of different possible contexts for gene therapy – from life-threatening conditions to baldness and attempts to increase intelligence. The scenarios are summarised in table 1 below.

Table 1: Proposed gene therapy scenarios

Subject	Condition	Risks/prognosis	Proposed treatment
Anita and Ronnie, in their twenties	Carriers of cystic fibrosis	1 in 4 chance baby will have cystic fibrosis	Germline gene therapy; change Ronnie's sperm cells to stop him carrying cystic fibrosis
Rita, 52	Cancer of the colon. Has had surgery and chemotherapy	With treatments, 50–50 chance of being alive in 2 years	Gene therapy to treat her cancer
Bernard, 68	Arthritis – takes tablets to reduce pain and inflammation and cannot walk for more than 10 minutes	Cannot be cured and over time can result in permanent damage	Gene therapy to treat his arthritis
Paul, 27	Clinically depressed for last 14 years. Takes anti-depressants and sees a psychotherapist every week		Gene therapy to treat his depression
Robert, 34	Going bald and feels really self-conscious	Will be completely bald in 3 years	Gene therapy to treat hair loss; hair can be replaced using hair transplants, wigs or treatment
Louise, 23	Struggling with her work and wants to improve her memory		Gene therapy originally developed for Alzheimer's disease might improve memory
Claire, 32	Pregnant with her first child and has been told her baby has severe form of alpha-thalassemia	No treatment: babies usually miscarry or die soon after birth	<i>In utero</i> gene therapy (with a small risk that the changes would be passed on to future generations)

The resulting discussions were wide-ranging, and across the 22 groups they covered many different aspects of the possible uses of genetic alteration.

This was undoubtedly useful for refining ideas about particular scenarios. For example, the group responses went further than the survey data in showing that participants' views on the suitability of gene therapy could depend on the severity of the condition it was being used to treat, the impact the gene therapy was expected to have, whether other treatments were thought to be available, the possible long-term consequences of the therapy, the age of the patient, and the cost to the NHS.

As these more involved discussions unfolded, they did have an effect. The post-group interviews showed that those who took part were likely to have changed their minds on a number of topics, and that these changes were largely a result of what they learned over the course of the day. Again, the largest shifts were in favour of some of the medical gene therapy scenarios, but also against non-medical uses.

A final round of interviews some months later showed that where there had been changes in knowledge or attitudes after any of the earlier stages (magazine, video or group), they tended to persist – comparison with the ONS omnibus data reassured the researchers that the shifts in the original survey group were not a reflection of changes in the general population.

7. It's good to talk

There is an enormous amount of data in the full report of the study, along with detailed samples of the discussion in the groups and reflections on the methods the researchers used. Although this was as elaborate as any research ever carried out on consultative methods, there were plenty of angles that could not be covered. There are also limits on the conclusions about what action had what effect, because the groups at each interview stage changed composition, and it was not possible to include a 'control' group, who got no more information about the topic aside from what they might encounter in everyday life.

Still, bearing in mind these caveats, if one looks at the main numbers and the kinds of comment that participants made, there are some useful practical lessons. These do not add up to a recipe for what to do to achieve public engagement, but they do offer some pointers to the strengths and limitations of different methods.

The thing that comes across most clearly is that it is hard to get people's attention. There are plenty of things in life to worry about, and we all get through the day by ignoring most of them, most of the time. In this case, gene therapy was not a topic that many participants were particularly interested in. In fact, the research team found it quite hard to recruit participants even for the first round of interviews. No doubt this reluctance was because some of them did not care to be put on the spot about a subject they felt they would not know enough about to answer questions. But there was certainly little in the way of a ready-made audience for a debate about genetic intervention. In line with this, the interview sample shrank throughout this long study, from 696 at the beginning, to under 500 at the second stage, and under 400 by the end.

Not surprisingly, the simplest strategy for developing attitudes – just giving people information – was not brilliantly successful. Reading a magazine, or even watching a video, appealed most to those who were already interested, who knew the most, or who had some special motivation such as experience

of genetic disease in their family. It was less likely to make much of an impression on the rest.

Given this, producing material that was read or viewed by a third of those who had it (the magazine) or viewed by half of them (the video) was no mean feat. The reactions were mainly favourable, although the occasional criticism for lack of balance showed that such media items need to be prepared very carefully, and pilot tested, before they are put out.

While these materials can, of course, be used more than once if the same issue suddenly attracts a lot of attention, a single distribution will not achieve a huge amount. In a culture where effective media campaigns repeat simple messages many times in different formats, the solution will not be a one-off approach. It was encouraging, though, that there was a measurable increase in interest among those who stuck with this study: they said they would be more likely to watch a future TV programme on the subject, for example. So perhaps a limited information campaign can expect to benefit from a modest media multiplier effect in the longer term.

What of other, more demanding options? Aside from giving more information, the group meetings offered things that a magazine or a video cannot provide: deliberation and intense interaction. From the comments made, the reaction was overwhelmingly positive. Whatever they may have felt about gene therapy, those who attended thought that this way of discussing the issues was definitely a good thing.

Participants liked that there was information available in different forms, enjoyed the discussions and felt they had learned a lot. Some would have liked a more expert adviser on hand as well as the magazine, video and telephone help. There seemed to be two things about the day they valued especially highly. One was the fact that there was time to explore several different aspects of an issue. Many intuitively felt the gene therapy scenarios were too complex for them to be happy with the simple 'yes' or 'no' that opinion-poll questions tend to invite. Their first thought tended to be that 'it all depends', and this was a chance to think through exactly what that meant. The other thing they liked was that they heard other people's views, and the reasoning behind these. In sum, it's good to talk.

But despite this very positive impression of the meetings, one fact counts against them: it was very hard to get people to attend. The research plan originally estimated that 60 per cent of the original survey group would attend a discussion. In the end, only 17 per cent participated. The reasons were mixed, but lack of time and a disinclination to expose themselves to a discussion of a complex issue among a crowd of strangers were both key factors reducing attendance. Some, of course, were just tired with the study by this time, which takes us back to the level of interest in the topic in the first place.

8. A public engagement cocktail?

So the overall picture, as one might expect, is one of compromises and trade-offs. It will always be easier to reach people with an existing interest than the mass of the population, and for complex issues the interested group may be quite small. There is no magic formula for reaching the rest. Sending out information has its place, but it only seems likely to make a big impression if it is part of a longer-term campaign or is timed to coincide with a period of sustained media coverage.

The discussion group is clearly very useful for those who take part, but needs careful organisation, and benefits from being led by experienced moderators. As an aid to consultation, it is also very helpful in getting a more detailed picture of the kinds of consideration that influence people's thinking on an issue. But its reach is obviously limited compared with the mediums of print or video.

In the end, it seems clear that serious efforts at public engagement are likely to employ a mixed strategy – the various methods of addressing the public are not mutually exclusive. An ideal prescription might be to harness the greater reach of print or video to the more nuanced treatment that can emerge in group discussions. At the least, such a discussion can inform preparation of an article, a pamphlet or a video. More elaborately, some parts of the discussion could actually be incorporated directly in a cleverly produced publication. The cost of the longer production process this implies may be a deterrent, but the advantages of hybrid approaches should compensate for any extra investment.