

The Science Communication Conference
22nd – 23rd May 2003

Session 3 – Different Perspectives

Chair: **Professor Robert Worcester, Chair of MORI:**

Tor Lezmore Assistant Director Nuffield Council on bioethics - Who should the Nuffield Council on Bioethics consult and why?

I'm going to talk about the Nuffield Council and how it does public consultations.

Firstly, I need to say that the Council's role is not primarily one of public consultation or public education, but to advise policy makers on ethical issues raised by advances in biology and medicine. However, public education is reflected in our terms of reference. The Council is an independent body funded by the Nuffield Foundation and the Medical Research Council and the Wellcome Trust which was established in 1991. We have published papers on the following topics [See slide]. We published the final three on the list last year, and this year we are planning to publish a short paper on GM crops to follow up our previous publication and a report on Pharmacogenetics which I will say more about shortly.

The Council convenes Working Parties to look at the issues that it wants to study. The working parties include various council members but there are also external people representing a range of expertise relevant to whatever the question is that's being addressed. The Working Party then meets between 5 and 15 times, over a period of anywhere from 6 months to 2 years.

We also have fact finding meetings which is like a kind of evidence gathering session with experts we wish to ask about specific things in detail. We commission papers from experts when we need substantial reviews, of technical areas of science in particular, and we also have a public consultation period for almost all of our reports, which is what I am going to talk about now.

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The final element of the process is that we peer review all our publications as well.

The aim of our consultations is not to get a representative view of what people think about topics. We aren't set up to do in-depth proper quantitative research, nor do we have the funds to commission such research. So we make use of existing surveys and polls that have been carried out but we don't commission that kind of work or engage in focus groups ourselves.

However, our consultations do give people an opportunity to contribute to our reports while we are still thinking about what we are going to say, rather than just criticising them afterwards. And it also is a good way of getting extra information and factual detail submitted to the Working Party which we might not have come across otherwise.

So the target audience is primarily the first two of those listed [see slide]: organisations or institutions and academics. We also hope that we will receive responses from the lay public, and we do, depending on the topic, but they are in the great minority, which I will show in a bit more detail later on.

The Secretariat and the Working Party read all the consultation responses thoroughly and then discuss interesting issues that arise. We also occasionally quote from them the reports and will normally produce a summary of the responses, while acknowledging that they are not representative of the wider population, in an annex to a report.

The consultations themselves involve written consultation papers of varying lengths which we send out to people and organisations we think might be interested. People then also write in and ask us for copies or download them from the website. We attempt to obtain media coverage of the consultation process, although of course it's much easier to get coverage of our final recommendations. We allow three months for people to respond to the consultations.

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I will run through, a couple of case studies. Genetics and Human Behaviour is a report we published last year. The year before that we'd had a public consultation on the topic. We sent out 1,400 copies, and 1,500 were downloaded from the web (although one must always regard web viewing figures with some scepticism as you can't be sure exactly what they are measuring).

We got quite a lot of media coverage of varying quality. The consultation was about genetic influences on normal behavioural traits like intelligence, personality and anti-social behaviour, but the headline in the Daily Mail was a photo of Myra Hindley and the headline 'Innocent because of her genes?', and underneath, in smaller type 'Will we one day see headlines like this?'. To which the answer was clearly 'Yes'.

Despite getting the most media coverage for any of our consultations to date we had 110 responses. This sounds quite small, but is fairly standard for a written public consultation documents of the type organisations like the Council produce. This slide shows a breakdown of where they came from, mainly from organisations and academics and then 27 from, as far as we could tell, 'lay' people.

The next case study is about pharmacogenetics, which we are publishing in September. This is a fairly short project and we had the consultation period over Christmas. This is a more specialist topic and we asked fairly technical questions about the impact on research and development and clinical practice of genetic tests which predict response to medicines. Genes and behaviour is slightly more 'public friendly' in the sense that people are more likely to have an opinion on whether or not it's okay to have designer babies than they are about whether the costs of medicines is likely to go up if pharmacogenetics isn't incorporated into clinical trials. We mailed the consultation paper to 400 people, and 3,000 copies were downloaded. (The huge increase in our

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download figures has happened in the past year because we circulated a CD of all our publications with Nature and since then the number of visitors to our website has gone up hugely). We had various articles based on the consultation document published in specialist journals. We also had an event organised by the BA which discussed the consultation document, and was then written up as a response, which was excellent.

This pie chart shows the breakdown of the responses [see slide]. It's predominantly academics, professional bodies and people involved in the area, with only 2 lay individuals out of 84 responses. We a fantastically multi-national response: 15 countries including two responses from Ecuador.

As I said, the consultations have a relatively low response rate. Whether that's to do with the way they are publicised or the way we write them is difficult to say, although I suspect that the style and content of the papers is a barrier. The Department of Health has just published a summary of its responses to its consultation on Human Bodies, Human Choices, which is an extremely policy-relevant and topical consultation. They had only 280 responses, but the consultation document itself was over 200 pages long. There was a short version, but even so, I don't think it is surprising that so few of the population submitted responses.

As I said, we don't expect our consultations to provide quantitative data. We realise the responses aren't representative and that the responses are usually from those with an existing interest in the subject. It is a challenge to produce documents which everyone can read, but which don't compromise our insistence on accuracy and comprehensiveness.

One hypothesis about how to get more responses from a consultation of the kind that we do, would be to pick the most controversial topic you could think of. Later this year we will publish a consultation document on research involving animals, including genetically modified animals. This is our newest Working Party, and is due to publish its report in 2005. We are currently trying

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to explore better ways, and different ways of carrying out a public consultation within our budgetary constraints. As well as having a written document we are going to produce a shorter document with fewer questions. We are going to have an online facility for people to submit responses that way rather than having to write them out and send them back, and we are going to explore various options to do with consulting with young people through Science Centres.

That is the end of my presentation, but I would like to say that we are always interested in hearing suggestions for how we could consult more effectively. Thank you.