

Public Consultation in Bioethics. What's the Point of Asking the Public When They Have Neither Scientific Nor Ethical Expertise?

Mairi Levitt^{1,2}

With the rapid development of genetic research and applications in health care there is some agreement among funding and regulatory bodies that the public(s) need to be equipped to deal with the choices that the new technologies will offer them, although this does not necessarily include a role for the public in influencing their development and regulation. This paper considers the methods and purpose of public consultations in the area of genetics including large-scale surveys of opinion, consensus conferences and focus groups. Consultation has been undertaken to enable the researchers/policy makers to see what the public do not know and plan more public education to make up the deficiency, to check on areas of concern so that public education can be used to address them or to gain a public mandate for a planned policy. An alternative and more recent approach is to find out what the public(s) do know and understand and to see how experts can learn from them in order to get a fuller view of technology in use.

KEY WORDS: bioethics; genetics; public consultation; public understanding of science; research methods.

WHY CONSULT THE PUBLIC?

The impetus for writing this paper was attendance at a meeting for a European bioethics project where most participants were philosophers and medical scientists.³ The view was expressed that there was not much point in public consultation

¹Centre for Professional Ethics, University of Central Lancashire, Preston, England.

²Correspondence should be directed to Mairi Levitt, Centre for Professional Ethics, University of Central Lancashire, Preston PR1 2HE, United Kingdom; e-mail malevitt@uclan.ac.uk.

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about ethical issues in science and technology. The scientists agreed that the public are ignorant about science and that they need more information presented in a clear and simple way. The philosophers' accepted this and talked about the need for science to present the facts while they (the ethicists) highlight and discuss the ethical issues. For them finding out what people think is not furthering ethical research which, instead, aims to clarify what ought to be done. However, scientific "facts" were seen as relevant background. Sarah Franklin comments on the contrast made (in the area of cloning) between "scientific descriptions [which] are presented as the neutral, factual and objective basis that constitutes a shared, undisputed territory" (Franklin, 1999, p. 112) and, public attitudes, which are seen as subjective, perceptual, and emotional responses not theoretically grounded nor based on systematic observation. This may seem an impossibly naïve understanding of science but can be found in official reports from advisory committees in the area of genetics, as well as in textbooks (Marteau and Richards, 1996).

Recent Consultations in Genetics

Even those who do not see any value in asking the public have noticed that there is enthusiasm among advisory and funding bodies for seeking public opinion on new research developments and applications. Alongside the practice of inviting responses from interested organisations and individuals, these bodies are commissioning their own market research on the "lay" public. Recent examples in the UK have been the Wellcome Trust and Medical Research Council qualitative research linked to their proposals for a human gene bank and the Human Genetics Commission using a market research company (MORI) to conduct a "People's Panel Quantitative Study" on public attitudes to human genetic information (Wellcome Trust/MRC, 2000; HGC, 2001). The European Union has funded numerous projects involving public consultation, other recent studies have been supported by the Academy of Finland and by the German Ministry for Education, Science, Research and Technology (Chadwick et al, 1998; Jallinoja and Aro, 1999; Hampel and Renn, 2000). Some funding bodies are even demanding an empirical element in the bioethical research they support (Wilkie, 1998). Just looking at recent examples of public consultation on biotechnology, methods range from large scale surveys of opinion and knowledge using structured questionnaires (Durant, 1998; Stratford et al, 1999) through Citizen's juries and consensus conferences (based on the model developed in the Netherlands and Denmark, WISHC, 1998; Science Museum, 1994), interviews, web based consultations (Science Museum, BBC Gene Stories) and focus groups (Grove-White et al, 1997; Wellcome, 1998; Kerr et al, 1998).

Relationship Between Knowledge and Attitudes

One encouragement to public consultation has been the concern among researchers, the medical profession and governments about public disquiet and even

opposition to genetic research. It might be assumed that there is a causal relationship between knowledge and attitudes, that more knowledge makes people more accepting of scientific innovations. But the relationship is not so simple. Those opposed to some applications of biotechnology can provide evidence that on the contrary more knowledge will make people more distrustful. Both may be right because the number of don't knows decreases with increasing knowledge so both those optimistic and pessimistic about biotechnology could increase (Eurobarometer, 1996, p. 29). The Eurobarometer, which is a structured questionnaire survey comparing attitudes across EU countries, also found that those who were the most ignorant tended to be the least concerned. A study which gave an overview of surveys found that knowledge of biotechnology has increased overall but support has declined (Voss, 2000, p. 9). For example, in the Eurobarometer 1999 there has been a fall in the percentage agreeing that "biotechnology/genetic engineering will improve our lives" (ibid, p. 10). Taking an example from a qualitative study, the Wellcome Trust funded focus groups on cloning, as people learned more about cloning they had more arguments against it (Wellcome, 1998, p. 6). In this research information on the science of cloning was supplied by Wellcome Trust staff. The public may be forced to be either for or against biotechnological applications by consultations that allow only "yes" or "no" responses to complex questions (BBC, 2002). However, given the chance the public distinguish between different applications, will accept higher risk for some applications than others and can discuss the ethical, legal and social problems. "The public" is, of course, made up of diverse groups with different perspectives and interests and should not be romanticised as the voice of truth and morality. However, it will be argued in this paper that these "publics" do have an important place in debate about genetic applications.

TWO MODELS OF PUBLIC CONSULTATION

Some of those seeking public opinions would agree with the view that the public are ignorant about science and unqualified to comment on ethical issues. Their purpose in consulting the public is to identify the gaps in their knowledge and understanding in order to devise public education programmes to remedy the deficits. After such a programme the public may be ready to participate in decision-making about scientific research and applications from a position of knowledge. In this paper this approach is called Model 1.

The first model takes natural science research as its ideal type. The researcher, whether scientist, social scientist or philosopher, has the role of the expert. S/he is to be a rational observer of the research subjects and remain objective and detached from those being studied. The researcher constructs hypotheses derived from a theory, devises the research instrument to test them and controls the way in which the research is carried out in order to prevent extraneous factors

MODEL 1	MODEL 2
Theoretical background	
Positivism	Interactionism
Natural science model of research	Verstehen- empathetic understanding
The researcher	
Expert	A learner
Neutral, detached, uninvolved	Involved
View of research subjects	
The public	Diverse publics
Ignorant or non-expert	A resource with relevant expertise
Methods of data collection	
Standardised, structured methods	Unstructured, “open” methods
Setting controlled by the researcher	Natural settings
Focus on objective, measurable aspects of the topic	Participants shape the focus
Nature of responses controlled	Free responses
Separation of fact and value	“Facts” depend on their context
Analysis	
Standardised	No predetermined categories
Statistical analysis	Analysis is a creative process
Summaries and comparisons	Rich data using respondents’ own language
Aims	
To test causal propositions	Findings emerge from the data
To produce facts	To produce insights
Results which are valid and reliable	Results which promote understanding

influencing the results. Model 1 research is most likely to be carried out by expert scientists or geneticists with a deficit model of public understanding of science. The view of the public embodied in this model makes it less likely that the aim of the consultation is actually to involve them in decision-making.

In the second model while it is recognised that the public may not have scientific expertise, this does not prevent them from having other forms of expertise which should be drawn upon by policy-makers. Model 2 is based on a Weberian model in which people’s own understandings of the topic are the starting point and theory is grounded in these understandings. The purpose of the research is to uncover what the public knows and think about scientific developments and

applications. The researcher is involved in the subject of study as a learner, who is learning about someone else's culture and experiences. The researcher does not know the answers in advance and is prepared to be surprised by the findings. As far as possible research is carried out in natural settings rather than settings controlled by the researcher because people will not behave naturally or reveal their attitudes and feelings unless they feel comfortable. The aim of consulting the public is to find out what the participants think is important and what they feel. Theory is grounded in, that is, emerges from, the data. The researcher is seeking to understand the participants' point of view and analyse the data in order to present the themes which came up in the language in which they were expressed.

In the first model the public is a resource to test hypotheses, so the researcher will choose methods which give maximum control to the experts who devise and use them and the least opportunity for "off the agenda" responses. Standardised structured questionnaires with closed questions fulfil these criteria as do official records (census data, doctors' notes). In model 1 the reason why the public is consulted is typically to test their knowledge, based on what the experts think they ought to know, and to test their attitudes on particular applications which interest the funding body. Two examples are the Eurobarometer which measures knowledge and attitudes across Europe on a wide range of biotechnological applications and the Human Genetics Commission's survey on views about the storage and use of human genetic information (Eurobarometer, 1996; Human Genetics Commission, 2001). Both used structured questionnaires on relatively large populations. Any survey testing knowledge with closed question will be able to use the results to argue for increased education. Those looking at particular applications may want to see whether the time is right for research or an application to go ahead. For example, what would public reaction be to the establishment of a population based DNA data bank or to children born from donated sperm knowing the identity of their genetic father?

In the second model, research methods are as open as possible in order to allow participants to speak or write in their own words and so to raise their own concerns rather than respond to those of the researcher. Typical methods for public consultations are in-depth interviews, questionnaires with open-ended questions, focus groups and workshops, the use of personal records and diaries. Researchers are most likely to be social scientists with a view of science as a social and cultural product. However, these methods can be used to conduct a study which is rooted in the deficit model of the public. A citizen's jury or consensus conference may be organised on the rhetoric of public participation but in fact have input and discussion structured by scientific experts which makes it difficult for the public to raise their own concerns. At the UK Plant Biotechnology Consensus conference an expert witness stated that the task of ACRE, the Advisory Committee on Releases into the Environment, should be focussed on the capacity of GMOs to do harm and should not deal with the broader issues. To do that would allow "idiosyncracies to influence and undermine their objectivity" (Barns, 1996, p. 204). This centred

the public debate around the technical assessment of risk and benefit in which the witnesses had expert knowledge. Observers commented that it was difficult for the public to widen the debate to look at what happens in practice, when genetic technology is actually used, or to ask broader ethical and social questions (Barns, 1996; Purdue, 1999).

If the aim in consulting the public is to show that more public education is needed then one method is to ask specific questions, keeping the focus in the researchers'/funding bodies' area of expertise. The Eurobarometer is an EU wide survey of 15,900 people, age 15 and over, interviewed by market researchers in their own homes. The question below is reproduced from the 1996 survey, which was repeated with three additional questions in the 1999 report (Eurobarometer, 1996; 1998). The expected answers and percentages giving them follow each question.

"The following question was asked in a bid to measure the Europeans' understanding of biotechnology objectively":

"Here are some statements. For each of them, please tell me whether you think it is true or false. If you don't know, say so, and we will go on to the next statement."

- a) There are bacteria that live from waste water (*TRUE*) 83% correct
- b) Ordinary tomatoes do not contain genes, whereas genetically engineered tomatoes do (*FALSE*) 35% correct, 35% DK
- c) Cloning living things produces exactly identical offspring (*TRUE*) 46% correct, 35% DK
- d) If people eat genetically modified fruit, their genes could also become modified (*FALSE*) 48% correct
- e) Viruses can be contaminated by bacteria (*FALSE*) 19% correct, 48% wrong, 33%DK
- f) Yeast for brewing contains living organisms (*TRUE*) 68% correct
- g) During the first few months of pregnancy, it is possible to detect whether a child will have [Down's syndrome, trisomy, mongolism- CHOOSE THE ONE OR TWO TERMS APPROPRIATE TO THE COUNTRY] (*TRUE*) 81% correct
- h) Genetically modified animals are always larger than ordinary animals (*FALSE*) 36% correct
- i) More than half of human genes are identical to those of chimpanzees (*TRUE*) 51% correct, 35% DK
- j) It is impossible to transfer animals genes to plants (*FALSE*) 27% correct, 44% DK

(Eurobarometer 1996, p. 24)

When asked straightforward factual questions a proportion of the public are bound to choose the wrong answer but these ten questions illustrate the problem of "facts" in the area of biotechnology. First, those giving the wrong answer may in fact have more knowledge on the topic than those giving the right answer. For example, those agreeing with statement (h) may have read about cloned animals being larger than their genetic parents or genetically modified salmon being bigger than other salmon. Those who gave a "wrong" answer to (c) may have known about mitochondrial DNA or be thinking of the environmental factors which would affect a clone in utero or post-natally. Second, an incorrect answer may be a product of a general attitude, for example, a fear of GM food (statement d) and perhaps a connection with reports of other foods which can affect people bodies in a strange

way i.e., if soya beans which people eat can mimic the effects of human sex hormones then perhaps GM food can modify genes. A third point is whether the information is relevant and useful for the public to know. Statement (g), on prenatal screening, provides useful information for non-scientists and had a high proportion of correct answers. If the sample had selected those for whom the information is most relevant, women of child-bearing age, the proportion would probably have been even higher. Finally, how useful is a score for knowledge when different surveys have different correct answers? A “wrong” answer for the Eurobarometer statement (c) was a correct answer in another survey, which illustrates the problem of isolating scientific “facts” in this area. For the Eurobarometer statement (c), “cloning living things produces exactly identical offspring,” is true, whereas in a German report on a public survey it was stated that “a majority of 62% *wrongly assume* that cloning produces completely identical beings” (my emphasis) (Pfister et al., 2000, p. 301). It is clear that true/false answers to these statements are not particularly helpful as a measure of knowledge about biotechnology without further information.

Closed Questions

Closed questions are useful for gathering information provided, firstly, that those asked know the answer and are likely to answer truthfully, or that they are prepared to say if they do not know. Secondly, the questions must be unambiguous and the responses offered to people be mutually exclusive and exhaustive. Once the questions move beyond gathering basic personal information or general attitudes to an area of biotechnology, closed questions become less useful.

Moving away from structured responses reduces the control researchers have over the respondents and the results of their consultation. In a schools’ programme which provided teaching materials on ethical issues in science, the evaluation found that some science teachers did not like discussing ethics in the classroom because “you never know what they are going to say” (Ratcliffe, c.1997). A recent Wellcome Trust survey found that ethical issues in science were more likely to be discussed in school by humanities rather than science teachers (Wellcome Trust, 2001). In a study on risk in genetics a theme that emerged in focus groups was “where do you draw the line” in genetic research and the use of genetic technology (Kerr et al, 1998). An exercise on “drawing the line” using cards with different diseases/conditions showed the difficulty people found in establishing firm distinctions between medical and non-medical conditions and defining seriousness. This was not because the public were ignorant but because they wanted to bring in the social and cultural context, including social pressures and individual situations. Whereas it was easy to make distinctions at the extremes the groups found there were “gray areas” in the middle ground. Survey methods with closed questions suppress ambiguity whereas focus groups are less predictable and raise complex issues. While the data from focus groups cannot be used to make firm

recommendations on where to draw the line, Kerr et al argued that boundaries between autonomy and responsibility, medical and non-medical genetics which are reinforced in policy documents, are unpacked and challenged in lay accounts (Kerr et al., 1998, p. 130f).

THE IGNORANT PUBLIC

In interviews with scientists and clinicians working in the new genetics in the UK, Kerr et al found that they saw the public as ignorant about the new genetics and criticised “media sensationalism” (Kerr et al., 1997, p. 291). They blamed the media for exaggerating both positive and negative implications and argued the need for objective and factual scientific knowledge as an antidote. The professional scientists interviewed in this study saw science as an objective uncovering of “facts” about nature and demarcated scientific “facts” from their social and ethical consequences.

All the interviewees saw the public as ill informed about the new genetics. For the most part the public were characterised as a homogeneous group and interviewees showed no appreciation of the way in which relevancy shapes people’s uptake and interpretation of information about the new genetics. It was argued that the public lack essential knowledge of the “basic” science and mathematics underpinning the new genetics and need to be better educated, particularly at school, about the “facts” of the new genetics (Kerr et al., 1997, p. 291).

These scientists assumed that society and culture lag behind technological change and have to catch up. This seems to imply that technological change is independent of social conditions and makes it less interesting to ask people for their attitudes. The geneticists interviewed saw a clear separation between good and bad science. Bad science, in particular eugenics, is science which has been influenced by social factors and is an abuse of neutral empirical knowledge. For them it is society that is responsible for the way the new genetics is used and abused, although those interviewed were prominent on bodies advising the government about applications and making recommendations about genetic regulation. In this way these scientists separated context from content. Content requires scientific knowledge so cannot be questioned by the general public. However, in model 2 consultations the public ask questions about control, regulation and ownership of science and accountability. In questioning the validity of scientific knowledge, content as well as context, there is a recognition that scientific facts cannot be separated from the way they are produced. Finally, the geneticists were keen to provide “neutral” advice about the social applications of research which might affect their own practice (Kerr et al., 1997, p. 299).

RISK

We can compare public consultation using the two different models by looking at the topic of risk. In model one research, assessing risk is a technical matter

relying on the development and quantification of accurate scientific information. An article by Ian Lloyd, who was chair of the UK Parliamentary Office of Science and Technology, sets out his objections to the idea that public opinion is a necessary part of risk assessment. He states that ordinary people do not understand risk analysis and probability. "We delegate decisions on major risks to them at our peril. 'Ethical values' are not a sufficient reason to circumscribe the advance of scientific knowledge. Our only real defence against disaster lies in delegating accountability to experts in the disciplines concerned" (Lloyd, 2000, p. 14f).

A model 1 type public consultation might ask the public to assess the risk of different activities, for example the number of deaths in a year, or to rank the risk of death from one activity compared with another (Royal Society, 1992, p. 99). The public will rank the risks incorrectly (*ibid*, p. 100). People do not perceive roads to be safer although there are fewer deaths than 70 years ago and the road accident death rate for children is less than half that of the 1920s. The objective measure of road safety is the casualty figures and the public's perception demonstrates their ignorance and irrationality. However if the aim of research is to understand the public's point of view and learn from them, as in model 2, then researchers might ask different generations of people to compare how they used the roads as children and how their children use the roads. In the 1920s children walked to school, played outside and were more often unaccompanied, and, there were far fewer cars. Now children's exposure to traffic is less and so casualty figures are down. Children are taken or, more likely, driven to school and allowed much less freedom outside the home. The objective measure of road safety by casualty figures does not take into account that people can modify their behaviour in response to their perception of risk.

Expert assessments are not neutral and objective but involve judgements. Brian Wynne writing about the way pesticide use in farming is assessed by scientific experts argues that experts make implicit assumptions. They assume that:

pesticides manufacturing process conditions never varied so as to produce dioxin and other toxic contaminants of the main product stream; drums of herbicide always arrived at the point of use with full instructions intact and intelligible; in spite of the inconvenience farmers and other users would comply with the stated conditions, such as correct solvents, proper spray nozzles, pressure valves and other equipment, correct weather conditions and full protective gear. As a model of the "real" social world and thus of the typical risk system, this was utterly naïve and incredible however good the laboratory science (Wynne quoted in Royal Society, 1992, p. 117).

Wynne's point is that objective and neutral assessment is not of much value for risk assessment. People will be using the technology in particular contexts so technical assessment of risk cannot be neutral about context. Assuming the aim is to assess consequences of employing a technology in the real world then a broad view of risk is needed and the people who will be using the technology concerned need to be involved in the assessment.

WHY CONSULT THE PUBLIC?

In the first model the public are consulted to see what they do not know, so that more public education can be devised to make up the deficiency, and to check on areas of concern so that public education can be used to address them. In the second model consultations enable the researchers to see what the public do know and understand and to see what experts can learn from them in order to get a fuller view of technology in use.

WHAT CAN PUBLIC CONSULTATION CONTRIBUTE TO BIOETHICS?

One answer is that public attitudes are not relevant because bioethics is about what ought to be the case, not what people think about it. Even if bioethicists could agree on the “ought” in specific applications of genetic technology, there is still the problem that if the “ought” does not connect with people’s own feelings, attitudes and experiences then it is unlikely to be realisable in practice. This is a problem if bioethicists want to contribute to public policy.

There is a tendency for ethicists who themselves use traditional methods of philosophical enquiry to take a respectful attitude to science, drawing on scientific evidence as “facts” to provide a necessary background to their own work while showing a lack of interest in the public. Ethicists have a vested interest in recognising scientific expertise and according it respect and expecting scientific experts and the medical profession to recognise and respect their ethical expertise. However, Dan Callahan suggests that bioethicists should “cause trouble now and then” (De Vries and Conrad, 1998, p. 245). He is not suggesting that bioethics should “cause trouble” for the sake of it, by, for example, opposing any application of genetic technology, but that they should beware of working only within the parameters set by those with particular interests. Public consultation is one way of raising wider issues by asking different kinds of questions but will not be taken seriously if ethicists separate science off from its applications or divorce ethics from the world in which people are living and making ethical choices. The importance of public consultations are summed up by Alastair Campbell, in a paper about consensus conferences in bioethics research, when he concludes that bioethics “needs to hear the diversity of voices in any modern society” and not assume too easily who are “the experts” (Campbell, 1995, p. 111).

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