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## A Review of Public Engagement with Genetics





# A Review of Public Engagement with Genetics

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This digest has been adapted by Mairi Levitt, Deputy Director of CESAGen – Centre for the Economic and Social Aspects of Genomics – at Lancaster University, from *Public Engagement in Genetics: a review of current practice in the UK* by Sue Weldon for Nowgen. The full text, with examples of public engagement activities and references, is available on the Nowgen website.




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## Introduction

Health professionals have long been aware of a need to address patients' concerns and to consult them about services that affect them as individuals. But it is clear that issues raised by scientific and medical innovations, particularly in the field of genetics, go beyond individual concerns of patients and service users. These are developments that affect our society as a whole. As well as concerns about individual consent and risk, there are social and ethical concerns about inequality, discrimination, privacy and commercial ownership, and about whether professionals, policy makers and regulators can be trusted to address them.

**Nowgen's overall aim** is to create an international centre of excellence for the application of genetic knowledge to improve human health and well-being. Improvement of genetics services, education and understanding of genetics, as well as the development of national policy and economic development, require public input. If health providers are to produce science-led services addressing people's real needs, then the public have a role in negotiating what counts as public benefit. This implies consulting the public as users and their involvement 'upstream', where health provision is debated and where assumptions about the future of medicine and the health service are being made on their behalf.



extent to which they were able to include an appropriate diversity of views, the *quality of the deliberation* rather than numbers and an evaluation of the *information or knowledge transfer*.


Looking at outcomes, a public engagement process should contribute to both organisers' and participants' learning. It is desirable for a process to afford some degree of *civic agency*, which implies that the process affects change: anything from a contribution to making a decision to a better-designed or more cost-effective service.



## From public deficit to public dialogue

The growth of public understanding of science (PUS) initiatives in the 1980s was largely driven by the belief that the public needed to know more about science. In this 'deficit' model, the public lack the necessary (scientific) knowledge to fully appreciate the wonders (and safety) of modern technology. It has since been argued that people's understanding of science is more complex than that. Far from being incapable of grasping the 'facts', people have important expertise based on context, location and experience. In addition, public surveys show that there is no simple link between increased scientific knowledge and increased public acceptance - and confidence - in science.

By 2000, a report published by the UK House of Lords Select Committee on Science and Technology was suggesting that society's relationship with science was "in a critical phase". The handling of scientific issues such as BSE and GM foods has been accompanied by a marked change in the attitude of the British public to the extent that there is now a crisis of confidence in some areas of science governance. The report highlighted a need to build stronger links between professional scientists, the lay public and other communities through greater openness and engagement. Research Councils UK and the Office of Science and Technology published a set of practical guidelines intended to integrate dialogue with the public more fully into science-based policy:



“...instead of the one, top-down process of seeking to increase people’s understanding of science, there has to be a two-way dialogue, where those seeking to communicate the wonders of their science also listen to the concerns of the public. Dialogue requires ears as well as voices”... (RCUK, 2002)


## Clarifying the notions of public engagement

Research Councils UK have offered the following definitions:

“Engagement is stimulating interest in science and generally raising awareness of science and the issues it raises among the public.”

“Dialogue is generating debate and interaction between individuals and groups, and creating a climate where people discuss scientific issues in a way in which they discuss other issues of public and social policy.”

“Consultation must contribute to, and feed into, some decision-making process. This is because ‘consultation’ means ‘to seek advice from; to take counsel’, which in turn means ‘to talk or think over what is to be done’ and implies an interaction of views and a shifting of positions as each party comes to understand the perspective of the other....Non – ‘experts’ often raise questions ‘experts’ overlook and contribute ideas drawn from different backgrounds and experiences.” (RCUK, 2002: 41-42).



## Is it possible to evaluate public engagement exercises?


There are no widely agreed criteria for judging the success or failure of a process. Most guidelines for good practice emphasise the need for clearly defined objectives, where possible agreed by all the participants at the outset.

This will enable the exercise to be evaluated against these objectives. But there may be changes to these objectives during the process itself, as learning occurs. Other issues are how long to wait to assess the possible impacts of the exercise, and how to deal with indirect and cumulative effects.

These dimensions become more important the more weight is given to the cultural change agenda (as distinct from more immediate and more instrumental objectives). Most evaluations of public engagement or participation in issues involving science simply do not address these questions.

It is useful to distinguish participation from communication. Whilst ‘communication’ may mean experts imparting their knowledge and understanding of the issues, which the public are encouraged to accept, participation implies a more two-way process involving the soliciting of public/lay knowledge.

The criteria for a successful process would include assessing its *representativeness*. Does the process engage with the targeted group or with a representative sample of the population? For those using qualitative methods, representativeness would be based on *inclusiveness* i.e. the



**Internet consultation/debates.** Interactive websites are becoming a popular way of involving potentially large numbers of people, especially young adults. Access can be open or restricted to selected participants. While this method excludes those without IT skills or the necessary access, the internet is increasingly being made more available in libraries and public places, and its use could be facilitated by an advisor.

**Public debates - Café Scientifique network.** The *Café Scientifique* network was set up as a public forum for debating the latest ideas in science and technology in an informal setting. Meetings have taken place in cafes, bars, restaurants and even theatres, but always outside a traditional academic context. There is an overall commitment to promoting public engagement with science and to making science accountable, rather than simply promoting science.

**Dialogue.** Dialogue need not be limited to face-to-face conversations. It is just as feasible to conduct a dialogue using other media.




## Publics: which publics?

The public is not an homogenous entity. Pertinent divisions might be along lines of age, sex, socio-economic class and ethnicity, among others. An understanding of these differences is clearly significant for public engagement in genetics. For instance, women's understandings of the issues are particularly pertinent in relation to genetic testing, since currently many programmes target pregnant women.

People are engaged in different capacities: for example, as individual consumers of a service or when asked for individual informed consent to participate in medical research. People are engaged as representatives of groups, such as carers, long-term users of services, patient pressure groups or disability groups. Or, given the pressing need to address health budgets, the public are engaged as 'tax payers' or 'citizens'. Any individual will, of course, belong to more than one category.

Current approaches to engagement, dialogue and consultation now emphasise the idea of a two-way interaction and deliberation between professionals and the public, based on the exchange of information and views. In the healthcare setting, many practitioners are advocating the use of deliberative and inclusive processes as the best way to engage the public. Deliberative modes of engagement imply that there is a range of views to be considered, and there will be an opportunity for all parties to negotiate and evaluate their position during the process. A process is inclusive to the extent that it includes a wide range of participants rather than 'the



usual suspects' - professional experts and representatives of pressure groups.

The democratic principles of social inclusion require that all those affected by a decision should be given an opportunity to take part. Citizens need to be involved, rather than simply receive information.

## What is the purpose of public engagement?

There are a range of goals for public engagement that are not mutually exclusive:

### ***Democracy and social accountability***


The recognition that science must be accountable to society at large in democratic societies.

### ***Shaping new health technologies***

If the aim is to shape health technologies, the public must be involved at a very early stage of development, reviewing the results of research and development, and its future implications.

### ***Engaging in policy formulation***

Government agencies such as the Human Genetics Commission have a remit to include public consultation in their activities.




***Citizens' panels.*** Unlike citizens' juries, which tend to address one issue or question, panels can be set up to address a number of issues requiring consultation. Panels can be large enough to allow for a representative sample or smaller to allow for more in-depth discussion. A standing panel, consisting of a demographically representative sample of 5,000 members of the public, was set up by MORI and Birmingham University for the Cabinet Office in 1998 and, subsequently, used as a government policy consultation tool for a number of issues, including a qualitative and quantitative public consultation about developments in the biosciences. The Wellcome Trust has also used a consultative panel on gene therapy.

***Consensus Conferences.*** This idea was originally developed in Denmark, where there is a long tradition of social debate in all areas of public policy. There have been consensus conferences in the UK on plant biotechnology and another to discuss the issue of nuclear waste disposal.

***Multi-criteria mapping.*** This is an appraisal process that combines expert and citizen assessment. A useful development, called deliberative mapping, includes questioning how the issue itself is framed, and eliciting values and priorities that would otherwise remain implicit, unexplored and, therefore, not open to scrutiny and negotiation.


***Theatre performance and events.*** This method can be used to aid consultation and dialogue, as well as in an educational context.



**Focus groups or group discussions** can provide rich and detailed qualitative data about people's perceptions, experiences and understandings of an issue. Qualitative group discussions of this nature are not designed to be statistically representative of a population or to allow for measurements of numbers of people who believe one thing or another. Samples are best described as inclusive, as far as possible, of the views of a wide range of people (different ages, gender and social class) or of specific groups of people (working mothers, religious groups, patients).

**Citizens' juries.** The concept of the citizens' jury was developed in the mid-1990s, from models used in Germany and America. The methodology is specific in that a group of citizens (12- 24) is recruited to include a broad cross-section of society. The participants meet together over a period of time (3 to 5 days) to investigate, deliberate and make recommendations on a single policy issue. Citizens' juries require quite elaborate planning. Although the sponsoring body might choose the general theme of the issue, the specific framing could be open to negotiation, based on prior consultation. The process is normally overseen by a 'stakeholder panel', whose role it is to maintain a balanced input and to guarantee accountability. Given the level of investment, it is reasonable to suggest that they would normally only be commissioned by a body that was willing to listen to and had the power to act on a jury's recommendations.

### ***Improving health services***



The Department of Health requires each regional NHS Trust to provide feedback from patients about their experience of care, and this information is used in monitoring their performance. Regular patient surveys are carried out by the NHS and by independent consultants such as the Picker Institute.

### ***Improving medical research***

Would the quality of medical research improve if 'consumers' were involved in the research process? Many patient groups are bringing their own experiences to bear, taking an interest in influencing how research is carried out and in directing research in particular ways. For instance, the Alzheimer's Society, made up of people suffering from dementia and their carers, has set out to put users at the heart of decision-making, and this includes a significant role in directing the research process.

### ***Consultation/counselling***

The traditional GP doctor-patient consultation, based on one-to-one interaction in the surgery, has built up a legacy of trust. Genetic counselling is a special area of one-to-one consultation practice. The emphasis is clearly on establishing good relationships and facilitating an exchange of information. Crucially, genetic counselling is portrayed as non-directive. However, counselling between a health professional and a patient – including genetic testing – takes place against a background of health policies and strategies that are not value neutral.



## **Education**

Although public engagement has moved away from the idea that there is a 'deficit' in understanding on the part of the public, this does not eliminate the importance of education as one of its goals. Complex decision-making clearly requires a better educated and informed public, able to weigh up issues and to critically appraise the options.

## **Marketing to consumers**

In order to inform the commercial selling of health services and products, the 'market research' model is part of an increasingly privatised health service, where consumers have become the unit of engagement. Within the marketing vision of public engagement, there is a powerful commercial discourse of 'predict and cure' (or if cures are a little far on the horizon 'predict and provide an individual risk assessment').

## **Building trust, generating acceptance**

A pragmatic reason to engage the public is a recognition that the full benefits of genetics will not be realised without public 'acceptance'. The use of the word 'acceptance' in the Department of Health White Paper on genetics services, *Our Inheritance Our Future*, suggests that popular support is seen as important only for policies and decisions that have already been decided. A public engagement exercise conducted for this purpose may appear to listen to public concerns, but it does so only on the institution's or practitioner's own terms. It is not built on mutual respect and a willingness to learn on both sides. There is, then, a danger that public engagement could engender cynical reaction and disillusion, even when conducted sincerely.



## **Methods of public engagement**

Public engagement processes overall should allow participants to form and revise their views in discussion with others. In many cases, this might require a range of methods. It is not possible to devise *the* best method that would take care of public engagement in one event: each situation requires a differently-designed process, or set of engagement processes, and clarity of purpose.

**Large-scale surveys** are normally used to address large numbers of people about relatively straightforward issues with closed or tightly-framed questions (for instance, customer service feedback that requires yes/no answers). The results are relatively easy to collate and quantify. The questionnaire format does not allow for deliberation and does not give people an opportunity to weigh up alternative options. This may limit the opportunity for participants to respond to wider issues.

**Deliberative polling** is an appraisal technique designed to introduce a deliberative element into a traditional polling method. It often takes the form of a structured debate amongst different parties, with intervening votes on specific questions addressed in the discussion.