

Public engagement in genetics: a review of current practice in the UK

A report for NOWGEN

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1 Introduction

In the past few years many organisations and public services have been responding to the growing interest in 'engaging' the public more directly in order to address sensitive areas of scientific and technological policy (see for instance POST, 2001, 2002). Health professionals have always been aware of a need to address their patients concerns and to consult them about services that affect them personally but, also, it is becoming clear that issues raised by modern scientific and medical innovations, particularly in the emerging applications of genetics, go beyond individual concerns of patients and service users. It is now widely accepted that there needs to be recognition that these developments take place against a background of wider social values and ethical judgements that affects our society as a whole and in which we participate at many levels both as individuals and as citizens. Developments in genetics have begun to create new interfaces between health practitioners and the public, to change the way we practice medicine and even to change the way we understand health and illness (Webster 2002). These developments occur within a political and social context and raise new sets of ethical and challenges that need to be thought about in different ways. The new genetic technologies now have wider implications for the public than individual concerns about informed consent and individual risk assessment. For instance, they introduce social and ethical concerns about inequality, discrimination, privacy, and commercial ownership and about whether professionals, policy makers and regulators can be trusted to address these concerns.

This study has been undertaken for the North West Genetics Knowledge Park as a review of public engagement activities in the field of medical genetics in the UK. An important aspect of the study is that it takes a broad and critical view of the notion of public engagement, that is, in unpacking and clarifying the meanings attached to 'the public' and to the roles of processes now referred to as 'public engagement'. For instance, we are all members of the public and it is obvious that there is a whole range of ways in which we identify ourselves in that capacity – from individual consumers of goods and services to politically and civically active members of society. Equally, we engage, or are engaged, in a whole variety of ways and at various levels for many purposes. The terms of engagement the expected outputs and the impacts are many and varied. If asked how and why they 'engage' with the public, health professionals might answer in different ways dependent upon their role, as general practitioners, specialists, counsellors, managers, economists or policy makers. The boundaries between professional interactions with colleagues and interactions with 'the public' are also often blurred. It is important, therefore, to place the full range of public engagement practices in a clearer context, to map out where they are located and to understand what they might be expected to achieve.

To set the terms of reference, in the hope of putting this in perspective, and since it is a baseline survey, this review of public engagement also takes a very broad view of the relationship between 'genetic knowledge', 'the public' and 'engagement'. It is important to begin by reflecting on how the notion of public engagement sits within the overall NOWGEN project. The seven strategic objectives outlined in the NOWGEN Project Plan (NOWGEN, 2003) provide a clear set of goals designed to promote a genetic knowledge enterprise for economic development and to improve understandings of genetics and genetic services. It will be argued in this review that current understandings of the role of public engagement cut right across (or have direct relevance to) these objectives. Improvement of genetic services, education and understanding of genetics, development

of national policy and economic development all require understanding of, and input by, the public. Thus, although 'user' engagement is a key topic for theme number four, the issue of public engagement is equally relevant in the evaluation of genetic based health care (theme one), as a topic for professional education (theme two) and as an ethical, legal and social dimension of genetics.

It is worthwhile to reflect on where these objectives fit within a broader framework of health policy and arrangement of social services generally. It is important to stand back in this way since there is a wider context of meaning in which the various sectors of the public encounter these health issues. In other areas of science and technology policy a similar understanding, or reflection about this wider context has been found to be crucial. A good illustration is provide by the post hoc realisation that the negative public perceptions of GM technologies were based not so much on the genetic technology as such but on a range of other factors: on the context in which it was introduced¹, lack of confidence in government (given their poor performance in the past) to regulate its introduction, and the lack of genuine dialogue about its public benefit and purpose. In new areas such as this it has been realised that the scientific innovation behind new products and services needs still, to some extent, to be influenced in an accountable way by a sensitivity and commitment to, public needs. For instance, in terms of health policies, this commitment has recently been articulated in various dictates by the government². But has this new commitment got to grips with the full range of social and ethical issues underlying current developments in science and medicine and if not where is the gap in understanding the problem?

One way to look at this is as a shift in the balance of power towards 'users'. For instance, the former Health Minister Alan Milburn in a recent interview on the BBC 4 Today programme (2.03.04) talked about the new political agenda for health (post Wanless). Milburn argued that to achieve improvements in health, as well as health services, you have to involve users. In order to achieve a sustainable improvement in the nation's health, he emphasised the need to enlist the support and involvement of communities. He also said that it is no longer possible to run services by dictates from the top down and that there needed to be less emphasis on top-down targets. In order to achieve more accountability downwards and outwards we need to ask for the views of patients and parents. Milburn also mentioned the principle of 'subsidiarity' and described it as 'decisions made at the lowest possible levels – not so much 'off the peg' as 'bespoke' service provision'. He put a strong emphasis on there being a role for the public in negotiating what counts as public benefit if health providers are to produce science led services that address people's real needs. Crucially, however, there is a danger in this popular shift, which is that it naturally directs attention to those situations where health service providers most often encounter the public i.e. in clinics, wards etc.. Yet the public is present – in a less visible way in the many other, and 'upstream' contexts of health provision such as biotechnology policy, medical research, health economics and such like, where assumptions about the future of medicine and the health service are being made on behalf of UK citizens. If public engagement is to be taken seriously these are also important contexts that need to be taken into account.

The purpose of this review is to map out the various areas of activity in public engagement within the emerging field of new genetic health technologies. A whole range of activities and innovative methods of public engagement are considered but the aim is

¹ The patronising and dismissive body language of institutional science.

² The recent review of the NHS, published in 2002 (Wanless 2002) recommended greater engagement, by health professionals, with the public. In June 2003 a white Paper on genetics ('Our Inheritance: our future' www.doh.gov.uk/genetics/whitepaper.htm) emphasised the role of the Human Genetics Commission in engaging the public.

to offer an interpretive frame, a way of understanding how these practices are being used and evaluated – rather than a ‘toolkit’. This is an important point. There is no simple way to understand public engagement and no simple answer to successful practice. I hope it will become clear that it is a continual learning process.

What is being called for is a more reflexive practice. This suggests that there is a need to reflect on the complex relationships between ethics, science and governance at all levels of engagement from the laboratory and the clinic to the parliamentary policy forum. Toolkits are useful, but only in so far as they are theoretically informed and applied in the right context. Above all, reflexive practice incorporates learning at both the individual and at the collective levels and requires a better appreciation of uncertainty and of how complex the issues are. A ‘reflexive practitioner’³ is engaged in that iterative ‘moral learning’⁴ process within a culture of reflexive practice.

In order to engage with that learning process, what follows is first of all a brief look at the past and then a set of open ended questions that ask what we currently mean by public engagement in this area and how we might evaluate the process. The review also includes a look at a whole range of new approaches and initiatives designed to engage with or consult the public about genetics.

³ The notion of a ‘reflective practitioner’ comes from Argyris and Schon and – although it could be debated that reflective practice is not quite the same thing as reflexive practice – it is argued that, as a practitioner you have to be constantly aware of the assumptions you make and the power you hold. But this is also a never ending self- reflection and recognition of why you are engaging and of how you might be influencing the process.

⁴ Wynne per comm

2 From public deficit to public dialogue: a brief history

The policy-charged notion of public engagement has entered common discourse only recently⁵. This following section outlines a brief history of how our current understanding of 'public engagement' between professional science and the public has evolved in the last twenty years as it moved towards a more democratic and deliberative approach to communicating science and medicine.

The early 1980s, against a background of falling economic budgets for scientific research and public concern about the state of the environment brought about by increasing awareness of the impact of industrial pollution and nuclear contamination (Gregory and Miller, 1998), marked a cooling off of the post-war enchantment with science and the 'white heat of technology'. In 1985 the Royal Society responded to this state of affairs by calling for scientists to pay more attention to science communication and by initiating a report (Bodmer 1985). This report, entitled 'Public Understanding of Science' and subsequently referred to as the 'Bodmer Report' led to the creation of a 'public understanding of science' (PUS) movement and the setting up of COPUS (the Committee On the Public Understanding of Science) whose remit was to promote a wide range of initiatives devoted specifically to increasing public awareness, knowledge and appreciation of science.

The growth of these PUS initiatives was largely driven by the belief that the public needed to know more about science and that failure to understand in a particular way was a failure of comprehension that needed to be addressed by education. It was also believed that increased knowledge and 'correct' understanding would promote a better appreciation of modern science and technology. However, the notion of science communication as a movement to create a better public understanding of science led to criticisms that this reinforced a number of stereotypes of a monolithic 'science' and an undifferentiated and ignorant 'public' (see for example Wynne 1991, Irwin and Wynne 1995, Irwin 1995). This 'deficit' model of the public was criticised on the grounds that it presented a one dimensional, uni-directional model of science communication in which the public were portrayed as lacking in the necessary (scientific) knowledge to fully appreciate the wonders (and safety) of modern technology. It has subsequently been argued that people's understanding of science is more complex than that and, far from being an incapacity to grasp the 'facts' of the matter, arises from a context-dependent understanding of the ways in which knowledge is encountered in different circumstances (Wynne, 1995). Furthermore, the claim that increasing levels of scientific literacy would result in increased public acceptance and confidence in science has not been upheld by the evidence of repeated surveys of public opinion.

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 not only uneasy but: 'in a critical phase!' (House of Lords, 2000: 11) The report suggested that in the last twenty years the handling of scientific issues such as BSE and GM foods has been accompanied by a marked change in attitude of the British public towards institutions and science based policy actors to the extent that there is now a crisis of confidence in some areas of science governance. The report also highlighted a need to build stronger links between professional scientists, the lay public and other communities through greater openness and engagement.

⁵ See for instance how Wellcome Trust Analysis 'Getting Engaged' describes the use of this terminology in terms of how social research into public opinion has been used to inform and shape recent projects in biomedical science (Hurren, 2003).

In the aftermath of their investigation, the authors of the House of Lords report recommended that there needed to be a move towards greater integration (listening to the public), although the report did not go on to suggest how that might be achieved. Subsequently, the Parliamentary Office of Science and Technology (POST) was asked to keep the government informed about developments in public consultation and dialogue on science-related issues (POST, 2001). The subsequent report, published by POST - 'Open Channels' - refers to a shift from a deficit model to a democratic engagement model (POST 2001:4). Other projects, to encourage a more dialogical approach to science communication, have also arisen as a direct result of the House of Lords report: this includes a set of practical guidelines – developed for the Research Councils UK and the Office of Science and Technology - intended to integrate dialogue with the public more fully into science-based policy (PSP, 2002). Patrick Jenkin aptly summed up the aim of these guidelines in the foreword to the report:

Perhaps our single most important message was that aiming at 'the public understanding of science' was no longer enough to engage today's more sceptical and less deferential public. The phrase has a condescending, even demeaning tone which, far from engaging the public in debate, tends to turn people off. In its place, we called for a new mood of dialogue: 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" was how one of our witnesses put it. (Lord Jenkin of Roding in the preface to Research Councils UK, 2002)

So, since 1985, it appears that the science community and government have undergone an attitudinal change in their attempt to balance the public's understanding of science with a more highly attuned understanding of the public on their own part i.e. understanding and really hearing what the public are saying is more than just collecting expressed attitudes, preferences opinions etc. it is about creating an atmosphere for understanding often unspoken or unconscious concerns. This requires an emphasis on two-way interaction between professionals and the public, integrity and intelligence on the part of the professional to listen to what is being said and to deliberate about a range of possible options and the ability to interpret the response.

The idea of reflexive practice, mentioned earlier, emerges here as a culture of practice which is more reflexive about its own assumptions, including problem definitions and what is taken for granted by that professional culture and including its assumptions about those outside of the culture (including the public). The reflexive practitioner would be the professional who is able to balance their desire to communicate their own valuable expertise with a more humble and meaningful interaction with the public. What has been called for is an attitude change within practice to match the House of Lords recommendations.

3. Clarifying the notions of Public Engagement

There is no doubt that there is ambiguity about the meaning of public engagement and it is also the case that it has several distinct, if overlapping, possible roles within an institutional setting although they are usually combined under a single title 'public engagement' or 'public dialogue'. For instance, since the publication of the House of Lords report on Science and Society the term 'engagement' is often used interchangeably with other terms like 'dialogue' and 'consultation'. The main point is that different processes are used for substantively different **purposes**. So, rather than trying to pin down specific definitions, this section looks at the various notions of public engagement that are being used in practice with a view to unpacking and clarifying the contexts of use. Whilst there are no agreed definition⁶, the following clarification has been offered in the Research Councils UK practical guidelines suggesting that:

'Engagement is stimulating interest in science and generally raising awareness of science and the issues it raises among the public.' (Interaction being characterised as two-way and informal).

'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.' (Interaction being portrayed as informal and multi-way as, for example, in television and radio programmes and web based discussion sites).

'Consultation, that is consulting the public on issues, 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.' (The interaction implied being two-way and formally instigated for a policy outcome). (Research Councils UK, 2002: 41-42).

The definitions given above suggest that there are at least three ways to understand the interactions between professional experts and the public. But, whilst it may be helpful to reflect on how these terms are used to denote different forms of interaction it would be a mistake to try to capture them in such a definitive way. I have already made the point that public engagement is a term that can be interpreted in many ways. However, it might be more useful to focus on the **terms** of engagement by asking the following questions: which publics? In what capacity? what manner of engagement? and, perhaps most significantly of all, engagement to what end?

Publics: which publics?

A clearer understanding of public engagement begins with the realisation that the public is not one homogenous entity. There is a range of categories for sub-dividing 'the public' into various 'publics' and, naturally these categories are not mutually exclusive. Traditionally, sociologists divide people up by gender, class and ethnicity and age and 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 new genetics. Emily Martin (1989) has argued that it is crucial to understand

⁶ 'Engagement' is used for this review following the Nowgen Project Plan 2003

how knowledge is encountered, and under what circumstances, when interpreting women's understandings and attitudes to fertility and pre-implantation genetic diagnosis (PGD). Similarly, in the case of ethnicity, Peter Glasner has made the point that: 'ethnic minorities with specific single gene inherited disorders such as thalassaemia or sickle cell anaemia are also very focused on the issues' (Glasner 2001:44). Other well defined groups of the public for whom genetics is particularly important are those with specific conditions, and their relatives. But age is also a factor since children, for instance, do not have the same level of agency as adults and may be affected by health issues in different ways.

Another way to ask the question (which publics?) is to ask in what capacity are people being engaged. For example, as individuals people are often addressed (by market research methods) as consumers or as individual 'users' of services (cf. Royle et al 2001 and see, also, Boote, Telford and Cooper 2002, Shickle et al 2003). They may also be asked, as individuals, for their informed consent to participate in medical research. But at the same time these individuals are not being addressed as members of wider social groups (which share other concerns), although that may also be part of their identity⁷. We might, on the other hand, be aware of the need to engage with representatives of groups of people such as carers, long-term users of services, members of organisations representing consumer's interests, as patient pressure groups or disability groups. Or, given the pressing need to address health budgets we might need to engage a more amorphous public - in choosing between economic options - as 'tax payers' or collectively as 'citizens'.

The idea, that we (practitioners) assume, or 'frame' our interactions with the public in particular ways is a complex one that requires more explanation. Anne Kerr (2002), for instance, has outlined the ways in which professional discourses (i.e. taken for granted ways of talking and writing) about genetic citizenship tend to frame it in terms of the public obligation to act as citizens, with shared responsibility in promoting the 'public's good' eg. by donating to biobanks and by participating in research, or as political subjects interested in building democratic and sustainable health outcomes. Professionals, on the other hand are assigned the entitlement to dictate the terms of the engagement. Kerr points out that these taken for granted ways of talking can affect our understanding about terms of engagement when public's entitlements are narrowly expressed as citizen-consumers of already existing services (Kerr, 2000).

Overall, then it appears that public understanding of science needs to be balanced by a much more nuanced understanding of the public, by the other parties to the engagement – the professional experts. Problems often arise when the need for this level of reflection is overlooked and when assumptions are made. A number of sociologists have highlighted how implicit discourses are often used so naturally and unreflexively, as operating assumptions about the public, that they frame out alternative understandings of issues (see for instance, Michael 1998, Irwin 2001 and Kerr 2002). Public benefit is one such term that is often used, alongside a 'discourse of great promise' that implies an unreflexive certainty about scientific progress, a unitary public and a non-negotiable concept of benefit. So, we need to ask; what are the operating assumptions about the public and what gets framed out of these discourses? For instance, do individual autonomy, democratic accountability and scientific uncertainty get overlooked?

⁷ To really hammer home this point – think of the complex identity of someone who is an Asian woman with a single gene disorder, a parent of an autistic child, and who is also living in a socially deprived area.

Engagement: how?

I have already discussed the general trend towards a more iterative and consultative mode of engagement, and made the point that professional-public interaction can occur at many levels and for many purposes. Current approaches to engagement, dialogue and consultation all now emphasise the idea of a two-way interaction and deliberation between professionals and the public, based on the exchange of information and views about a particular subject (in this case the subject is broadly defined as genetics).

In the healthcare setting many practitioners are advocating the use of deliberative and inclusionary processes (DIPS) as the best way to engage the public (Coote and Lenaghan, 1997, Mclver, 1998, Lenaghan, 1999). The reason for this is that:

‘Complex decision making processes...require a more informed citizenry that has weighed the evidence on the issue, discussed and debated potential decision options and arrived at a mutually agreed upon decision or at least one by which all parties can abide. An active, engaged citizen (rather than the passive recipient of information) is the prescription of the day.’(Abelson et.al., 2003:240)

The concept of deliberation arises from the political ideal of a growing trend towards participatory democracy - as opposed to a representative democracy – as an antidote to the current ‘democratic deficit’. John Dryzek argues that the key to democracy is deliberation, as a new style of governance to address the democratic deficit based on active citizenship and promoting empowerment, accountability and capacity building (Dryzek, 2000). Dryzek’s argument about deliberative democracy relates to the degree to which democratic governance is substantive and engaged rather than symbolic (see Dryzek, 2000). Deliberative modes of engagement imply that there is an opportunity for all parties to negotiate and to re-evaluate their position, if necessary, during the process of social interaction. Deliberation also implies there will be a range of perspectives or views to be considered.

Inclusion is a factor in the engagement process insofar as the process is expected to include a wider range of participants. This is in contrast with many traditional consultation processes that have tended to consult only professional experts and representatives of the usual pressure groups (commonly referred to as ‘the usual suspects’). Power is at issue here and the democratic principles of social inclusion require that all those *affected* by a decision should be given an opportunity to take part (including traditionally excluded minorities).

It can be seen from the diagram below how different processes, defined by the extent to which they are deliberative and informed, address different publics in different ways: for instance, citizens’ juries and consensus conferences, which are informed and highly deliberative, are designed to engage people as citizens, in contrast with large scale surveys that would be more effectively utilised to address individuals in their capacity as consumers of goods and services.

Fig 1 : Approaches to Public Consultation

	Informed	Uninformed
Deliberated	Citizens’ Juries Deliberative Panels	Focus groups
Undeliberated	Questionnaire with written information	Large scale postal surveys

(Source: Dowswell et al 1997)

In summary, given the wide range of interpretations of public engagement, it is worth emphasising that whatever the notion of the public or the mode of engagement the terms of engagement and the desired outcomes should be theoretically informed and meaningful i.e. have the power to influence a decision. It is also worth noting that engagement processes are normally associated with learning (for both professionals and the public) and that they are part of an iterative process in which understandings develop. So, in addition to being a one-off process, public engagement is part of an ongoing social process.

4 Why engage the public?

It is already clear from the preceding sections that there is a convergence of activity around public participation amongst public policy makers and academics and that it is generally accepted that new developments in science raise far-reaching ethical and social issues about which a wider of publics needs to get involved at various levels and for various reasons. These reasons range from the ideals of participatory democracy and social accountability and sustainable health technologies to more pragmatic ones based on the need for popular acceptance and support for policy agendas and new service options (Rowe 2004). However, there is often a lack of clarity or perhaps, to put it more bluntly, a lack of honesty and reflection about the real purpose of the engagement and the objectives. Clearly defined objectives will not only increase the prospect of their being achieved, but are also a factor in making the process accountable by giving clear signals to participants and, ultimately, the initial objectives will provide a framework for evaluation of the engagement process (see section 6). The following section looks at the range of purposes and goals of public engagement.

Democracy and social accountability

To begin with these participatory initiatives reflect a realisation that science has increasingly become more 'embedded in' and therefore must be more accountable to society at large (Nowotny et.al., 2001, Jasanoff, 2002). Nowotny et. al. (2001) suggest the concept of 'socially robust knowledge' as a solution to the current fallibility of science in the face of declining public confidence. These wider democratic goals are also highlighted by the Parliamentary Office of Science and Technology (POST, 2001) when they refer to: 'setting goals' such as: strengthening the democratic purpose, increasing trust and building mutual understanding .

Shaping new health technologies

In a similar vein, Andrew Webster has pointed out that rapid developments in health technologies demand more of people, as active participants, in the mobilisation of these technologies at their very early stage of development in order to stabilise socially robust and sustainable technologies (Webster 2002). That means involving people in a social process of *shaping* the technology in question, or a particular vision of future healthcare (see here Hedgecoe and Martin, 2003). It could also mean getting people involved in interpreting findings or to take part in 'extended peer review' about the results of research and development and what the future implications are (Funtowicz and Ravetz, 1992.)⁸.

Engaging in policy formulation

Similarly there is now a move towards involving people in establishing a robust regulatory framework. For example, the core remit of government agencies such as the Human Genetics Commission is to recognise the importance of the substantive role of public consultation in their activities. This move has arisen because there is recognition that the inevitable risks and unforeseen consequences of new health technologies require negotiation, and not just by bioethics experts. Rather, it is maintained that there is a pressing need for more attention to be given to the complex relationship between ethics, science and governance. Kelly (2003), for instance, suggests that public bioethics bodies can often operate effectively as 'border guards' - both in protecting an unwarranted status for the science, and in maintaining a distinction between science and its ethical

⁸ See also, for example, Box 6.3 on the subject of behavioural genetics which outlines the importance of an informed and extended 'conversation' about the issues raised by research in this area.

consequences (see also Wynne 2001). So, as I have pointed out already, there is a role for public engagement in the governance of both the science and the ethical frameworks. Sarah Franklin (1999) has made this point too, in arguing that the inequality between scientific expertise and 'lay' knowledge is brought out in the separation of official authoritative reports about new health technologies from the debatable matter of how to govern them - effectively re-configuring the boundary between science and its social (or public) context.

So far, there have been a range of policy issues that the public have been involved in (see section 6) notably about cloning, genetic testing and genetic databases.

Improving health services

Patients and the representatives of groups of health users have always been involved, to some extent in consultations about the delivery of services to patients. 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 (see appendix 2).

It has also been suggested that the quality of medical research is likely to improve if 'consumers' are involved in the research process (Royle et al 2001 see also the research carried out by Consumers in NHS Research⁹). Many patient groups are now bringing their own experiences to bear and are taking an interest in influencing how research is carried out and in directing research in particular ways. For instance, the Alzheimer's Society, which is 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 (see Box 4.1).

Box 4.1. Quality Research in Dementia

(This information was taken from personal communication and from the QRD website www.qrd.alzheimers.org.uk)

The Alzheimer's Society, through their research grants programme, called Quality Research in Dementia (QRD) is committed to involving consumers in influencing not only care practice and health and social policy for the people who suffer from dementia and their carers and families but also the direction of basic research. The Alzheimer's Society has won an award for excellence in public involvement from the Guardian newspaper and the Institute for Public Policy Research (IPPR) in recognition of their way of working that has broken down the traditional divide between patients and doctors and put users at the heart of decision making. Research priorities for the QRD programme include not only the biomedical science but also alternative and complementary therapies and care regimes. The programme is also unique in recognising the carer as an extension of the patient.

The National Institute for Clinical Excellence (NICE) has taken this a step further in setting up a Citizens' Council to discover what the wider public think about the treatments and care people can expect of the NHS. Within the context of NICE guidelines, which are to improve clinical and cost effectiveness, the citizens' council has been set up to provide much needed input into the wider context of social values within which these costs and benefits have to be negotiated (for further information about the NICE Citizens' Council see Box 4.2)

Box 4.2 The NICE Citizens' Council

⁹ See the Conres website at www.conres.co.uk

(The following explanation of the role of the Citizens' Council was taken from a presentation, by Ela Pathak-Sen Project Manager, given to the BA Science Communication Conference May 2004. For further information see www.nice.org.uk or contact ela.pathak-sen@nice.nhs.uk)

The Citizens' Council was set up in 2002 to help NICE to decide whether or not treatments are clinically and cost effective and what pathways of care should be recommended. In addition to the advice given by experts, it was felt that what was missing was a wider social perspective – 'a view from the public'. This has been seen as: 'an experiment in deliberative democracy' and, because it is so difficult to take a set of well defined guidelines of good practice 'off the shelf' it is also seen as an example of 'learning by doing'.

The Council is made up of thirty members of the public recruited from all walks of life. Meetings are held in public and are facilitated by an independent research organisation Vision 21 (see appendix 2)

Consultation/counselling

The traditional general practice doctor-patient consultation based on one-to-one interaction in the surgery has stood the test of time built up a legacy of trust and underlies most people's encounters with the health service and with their overall positive attitude to medical science. This is an extremely important interface between the public and the health service. Nevertheless, genetic counselling is a special area of one-to-one consultation practice. Studies have been carried out to look at all the issues around counselling and to inform the move towards non-directive counselling. (Clarke et.al. 1995, Petersen, 1999). New understandings refer to 'psycho education' (Biesecker and Peters 2001). It is worth quoting the words of the Association of Genetic Nurses and Counsellors to illustrate how this special relationship is portrayed. The AGNC suggests that:

'Genetic counselling may change the client's quality of life. Quality of life may change positively or negatively. Positive change requires not only provision of factual information but also:

- *the formation of good relationships between the client and the counsellor*
- *enabling the client to place factual genetic information into the family context*
- *facilitating the client to integrate lay knowledge with factual information.'* (AGNC, 2004)¹⁰

The emphasis is clearly on establishing good relationships and facilitating an exchange of information. Crucially, genetic counselling is portrayed here as non-directive i.e. not coercive. However, many people now argue that the idea that doctors and nurses are non-directive is a 'myth' (Marteau et. al. 1993, 1994, Kerr and Shakespeare, 2002). The problem is that counselling, between a health professional and a patient – usually about genetic testing - takes place against a background, or a wider framework of health policies and strategies that are not value neutral. In this sense non-directive counselling, about whether or not to take a test, does not leave the patient with a free choice because choices are limited by social circumstances (i.e. whether there are therapies or disability services available). Kerr and Shakespeare (2002) have argued, for instance, that pre-natal testing creates difficult dilemmas for the parent of an unborn child that may be diagnosed with a severe genetic disorder – particularly when no cure exists.

Box 4.3 Could genetic counselling lead to eugenics?

The issues around counselling for patients undergoing pre-natal genetic testing have given rise to a debate about whether this process could be, indirectly, coercive and thus seen as a form of eugenics. It is suggested that, despite the fact that race is no longer the issue, the eugenics ideal survives. In this new situation the biological, or genetic, quality of human populations has now become the target. as the ability to screen out undesirable

¹⁰ <http://www.agnc.co.uk/>

genetic traits (such as Down's Syndrome and Cystic Fibrosis and dwarfism) move us closer to the ideal of perfect health. Disabled people claim that a key issue is that this trend reflects an increasing tendency to see disability as essentially a medical problem – that can be solved by termination of the pregnancy. This is very much in line with trends in medicine generally, and supported by wider health strategies, that have narrowed the treatment of people onto the pathology of disease. Prenatal genetic testing can be seen as the logical extension of this process. Disabled people, and others, have called for a societal debate about broadening the treatment of disability and illness to include the removal of current social barriers in transport, mainstream education, employment and other public services. (see also the British Council Of Disabled People <http://www.bcodp.org.uk/> appendix 2)

Education

As I outlined earlier, in explaining the context for the move towards a more participatory approach to science, technology and health, public engagement is often equated quite simply with education and better communication (for instance in a Public Understanding of Science agenda) in order to address a 'deficit' in understanding on the part of the public. However, any misunderstanding about the wider range of objectives does not diminish the importance of education as one of the goals of public engagement. 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 selling services and products the 'market research' model is alive and well in 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'

It has also been suggested, and the language of many public engagement activities seems to support this, that a common and very pragmatic reason for 'engaging the public' may be about increasing public acceptance and enlisting popular support for policies and decisions that have already been decided.

In summary, a clear understanding of the purpose of engagement and clearly defined objectives not only increases the chance of their being achieved but also helps to define the criteria for evaluation and gives a well defined accountability framework for participants. As Ela Pathak-Sen put it when she explained why the public were asked to take part in the NICE Citizens' Council:

Its very important to be able to define your expectations right at the beginning ... Everything we looked at pointed to being clear about one's expectations and about being clear about the question one wanted answers to.

Nevertheless, as so often is the case, it is not always clear what those questions are in advance:

The one overriding lesson is that you have to learn to change your expectations and be flexible around the process. The process cannot be set in tablets of stone.

(Ela Pathak-Sen Session 5 'Real Life Tales: The Voice of the Citizen' The BA Science Communication Conference 24th – 25th May 2004)

5 Methods of Public Engagement

This section reviews the various methods of public engagement. The point has been made that methods of engagement are chosen to address a particular sector of the public and for a particular purpose i.e. consumer surveys, consultation with users, input into policy etc. It is vital that methods are designed to address a well articulated goal or purpose and the initial questions to ask might be: why am I, or my organisation doing this? and what do I/we want to achieve?. However, in seeking to determine the optimal mode(s) of engagement, the choice is by no means straightforward because there are many cross-cutting issues to consider, such as the cost of the exercise, the timing, who to involve and how best to inform the process. All of these factors will also have a role in determining the legitimacy and in deciding whether the exercise has been a success or failure (see section 6). Furthermore, and this is a point I made earlier about not claiming to provide a 'toolkit', it is crucially important to note that this section does not aim to provide guidance on 'correct methods'. Methods can only be correct in so far as they address a relevant issue in a meaningful way – which may be very specific (like 'what colour would you like the consulting room wallpaper?') or very general (like 'how can we promote deliberative democracy?'). Public engagement cannot be reduced to a formulaic method. Much more important than method is the requirement for a relationship of mutual trust and an intelligent, reflexive and learning attitude on the part of those who commission and carry out public engagement processes.

Table 5.1 provides an overview for those who require a rough idea of the range of methods available. Further explanation, and a number of case studies, is also included in this section

Key issues in determining the legitimacy of a process are framing, representativeness, timing and scale and, lastly, power relations - both within the process and in the ability of any process of engagement to affect outcomes.

Framing of the issue, to be debated, discussed, consulted about etc., is perhaps the most important aspect of a legitimate process. Sheila Jasanoff emphasises how important it is to consider, and if necessary re-consider, the initial framing of public engagement and scientific policy issues because: '*if a problem is framed too narrowly, too broadly, or wrongly, the solution will suffer from the same defects* (Jasanoff, 2003: 240). In the case study outlining a 'deliberative mapping approach' (Box 5.1) the point is made that the framing of the issue can be placed in question too.

Representation. The issue of representation arises in all but one-to-one methods of engagement, where individuals can clearly be seen to 'represent' themselves (although even in this case one might surmise that a person might be illegitimately posing as an 'expert'). Participants can be 'representative in different ways. Different types of representation include: quantitative and statistically representative samples (used in surveys) for demographic, political or geographic purposes; or participants who represent target groups in a more qualitative way. Given the problem of trying to represent particular views (we all have very complex and cross-cutting identities), sampling is sometimes carried out to be 'inclusive' of a wide diversity of views rather than representative of wider populations.

Timing and Scale. Selecting a method of engagement to fit in at an appropriate stage in a decision making process can also enhance the legitimacy of the process. For instance, the notion of 'decide, announce, defend', where a decision has been made before any wider participation is introduced, is well known. It is also important to consider whether a

particular method is appropriate for the scale of the issue i.e. local user engagement or debate about national policy.

The relative **power** of the participants involved in an engagement process is a constant over-riding factor. People are often reluctant to accept the legitimacy of a process when they are sceptical about what potential influence and practical meaning it might have. For instance, do people have any power to influence or deflect a process of social change or technological innovation that, like a juggernaut, is already in motion and travelling towards a pre-destined outcome?

Table 5.1 Methods of Public Engagement

Method	Used for	Type of engagement	Numbers of people involved	Cost
Surveys	Quantitative market research Public attitudes	Usually uninformed, via 'closed' questions.	500 – 10,000 numbers dictated by the requirement to sample a 'representative' quota.	Varies. Can be very expensive to gain access to a representative group
Deliberative polls	A model of direct democracy to debate a policy issue	Polling re-convened after deliberative input and debate	500-1,000 numbers dictated by the requirement to engage a demographically representative group	Expensive (up to £200,000)
Focus groups	Qualitative market research Public perceptions about issues requiring lived experience or context	Qualitative, focused discussion (normally uninformed, but can be reconvened after information is supplied and deliberative input)	6- 10 people	Relatively inexpensive (depending on recruitment method and level of interpretation required)
Citizen juries	Public input into local government policy issues and environmental, medical or science based issues.	Informed deliberation	12-20 people	Relatively expensive (over £25,000)
Citizen panels	Standing panels often used by local authorities and public agencies for ongoing service consultations.	Informed. Can be used for either qualitative or quantitative consultation	20- 5,000 people	Variable, depending on time-scale and numbers involved
Consensus conferences	Used to debate scientific issues of national importance	Informed deliberation	16 –20 people	Expensive (over £100,000)
Delphi or Multi-criteria mapping	Used to consider complex and negotiable issues	An iterative semi-deliberative process based on a series of questionnaires		
Internet consultation	Now used for a wide range of consultations	Informed but not very interactive	Open ended	Variable. Can be relatively inexpensive
Individual meetings/consultations			1 to 1	
Exhibitions	Information dissemination/education	Can be interactive or non-interactive displays	Open ended	Relatively inexpensive
Theatre performance	Education, raising awareness, cultural event	Performance can be informed and participative	Open ended	Relatively expensive
Web discussions			Open ended for anyone with internet access	
Public debates		Discursive/deliberative	Varies, depending on the medium of communication eg. face-to face, TV, internet,	
Informal public discourse				

Sources of information: (Policy Studies Institute, 1998, Audit Commission, 1999, POST, 2001,2002, People, Science and Policy, 2002)

How have these methods been used in practice?

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)¹¹. 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 and 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.

(Fishkin, et.al. 2000)

Focus groups or group discussions can provide rich and detailed qualitative data about people's perceptions, experiences and understandings of an issue (see for instance Barbour and Kitinger 1999). 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 etc.). e.g. Wellcome Trust focus groups on cloning

Citizen juries

The concept of the citizens' jury was developed in the mid-1990s, from models used in Germany and America. The methodology is quite specific in that a group of citizens (12-24) are recruited to be inclusive of 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 (Coote and Lenaghan 1997). 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 and 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, the jury's recommendations.

Citizen panels combine the need to provide information on a complex issue with the need to deliberate. Unlike citizen 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 for 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. (see, for instance, the NICE Citizen Council Box 4.2)

¹¹ For information about how surveys are used in the health service see, for instance, the Picker Institute (www.pickereurope.org)

Consensus Conferences

The idea was originally developed in Denmark, where there is a long tradition of social democracy and public debate in all areas of public policy. So far only two consensus conferences have been carried out in the UK (one on plant biotechnology and another to discuss the issue of nuclear waste disposal) (for an evaluation of consensus conferences see Joss and Durant, 1995). However, the idea of consensus building has been used by an independent group, the Environment Council, to help groups with opposing views to work together and create dialogues.

Multi-criteria mapping is an appraisal process that emphasises diversity in knowledge input and exchange by combining expert and citizen assessment in an iterative and auditable framework. A useful development of M-C mapping, from the original decision technique of multi-criteria utility analysis, is that the framing of what the issue is can be placed in question too, as part of a deliberative process. Deliberative mapping (as it is called) can enable some re-definition of what the 'issue' is. It is claimed that DM: 'offers a practical means to inform technical policy decisions in a robust and accountable fashion. It shows that quantitative and qualitative appraisal techniques and individual and group-based methods can work together effectively as part of a deliberative and inclusive process.' (Burgess et. al 2003: 8).

Box 5.1 Appraising options for addressing the 'Kidney Gap'

<http://www.deliberative-mapping.org>

A recent two year project was carried out by Jacquie Burgess, Gail Davies and Andy Stirling (funded by Wellcome Trust) to develop an innovative method for public engagement in the biosciences based on deliberative mapping. The aims of the project were to: examine how far scientific, expert driven risk assessment techniques could be reconciled with deliberative public engagement and to develop and test the method as an approach to evaluating a complex medical issue such as 'how best to reduce or close the kidney gap'¹². It appears that the options for addressing this crucial health service problem range from the possibility of developing highly technical innovations such as stem cell therapies and xenotransplantation to much more practical solutions such as changes in donation practices and to improved health education. It is suggested that, with such wide ranging, multi-disciplinary and complex policy options to choose from, there is real value in approaches to public engagement which emphasise mutual learning between a whole variety of experts, patients, users and the general public. This method combined open ended interviews, a series of citizen panels, quantitative scoring and a stakeholder workshop. It also produced a number of outputs including feasibility options, ethical evaluation and economic considerations. The process was complex and protracted but at the end all of the participants (including the experts) felt that they had learned a lot and all expressed a strong sense of 'ownership' of the problem.

Internet consultation/debates

Interactive web sites are becoming a popular way of involving potentially large numbers of people in interactive 'survey style' consultation and in discussion groups. Access can be open or restricted to selected participants. The use of the internet considered to be particularly suitable for young people, and for educational purposes (where IT facilities are easily accessible). It should be noted that this method could exclude some sectors of the community - for instance elderly people and those without IT skills or access to a

¹² The problem is associated with a shortage of donor kidneys for transplantation

computer. However, the Internet is increasingly being made more available in libraries and public places and its use could be facilitated by an advisor.

Psci-com

Public debates (Café Scientifique network)

The 'Cafe 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. According to the network organisers there is an overall commitment to promoting public engagement with science and to making science accountable and this should not be used as a forum for promoting science i.e. 'a shop window' for science.

Dialogue

The Research Council UK's guidelines for dialogue with the public (2002) suggests that dialogue need not be limited to face to face conversations and that it is just as feasible to conduct a dialogue using other media of communication. Its also possible to think in terms of many possible forms of interaction: one-to-one, one-to-many, many-to-many etc. e.g. Royal Society Dialogues.

Other methods include exhibitions and theatre/dance events.

6 The role of public engagement in new genetic health technologies

The following section highlights some of the key issues that have been addressed by public engagement and consultation exercises and looks at the purpose and function of a range of those activities. It is worth noting how those concerns were defined and the extent to which these engagement processes have been (or will be) able to influence the development of the technology, or its technological trajectory by analysing the terms of the engagement and the role of the participants in the 'mobilisation of the technology' (Webster 2002).

Cloning

The vision of human cloning is the stuff of science fiction and so, with the prospect and then the reality of animal cloning in 1997 the public debate happened early on in the new genetics revolution. In 1997 Dolly the sheep demonstrated to the world a successful animal cloning by nuclear transfer - derived from an adult somatic cell (Wilmut et al. 1997). This scientific breakthrough brought up a whole range of issues for wider discussion and debate including: the safety of the process or the risk posed to the cloned animals (subsequently humans); issues about consent and whether people could trust the scientific and regulatory institutions to act responsibly; and a whole range of more esoteric issues about whether we want to allow our human identities to be compromised.

Box 6.1 Public perspectives on Human Cloning

In 1998 the Wellcome Trust commissioned qualitative research to provide, as they put it: 'input from members of the public not usually consulted about such issues' (Wellcome 1998: 6). The consultation, to explore public attitudes and opinions to human cloning in depth and to explore the factors that influence these, used group discussions and interviews. It was designed to feed into a wider consultation being carried out for the Human Genetics Advisory Commission (HGAC, now HGC) in collaboration with the Human Fertilisation and Embryology Authority (HFEA). In an attempt to address a perennial problem of consulting people about a scientific subject about which they know very little, the method was adapted to find out whether people's views changed once they had been given some technical information about cloning and been given time to consider this information. Individual interviews also allowed for unique insights and by a combination of methods to give greater insights.

Sarah Franklin (1999) referred to this particular consultation process about cloning as offering a benchmark example of public engagement. It responded to a paradox because, unlike normal consultation that begins with a presentation of the scientific facts, the Wellcome research challenged the stability of scientific facts in that Dolly's birth was counterfactual. The design of the process, by adapting the well established focus group method to allow for more iterative and deliberative discussions to take place, gave participants an opportunity to learn something about the science of cloning. What was interesting was the finding that public acceptance of cloning was not enhanced by more scientific knowledge, quite the reverse: 'as participants' awareness increased so did their apprehension' (Wellcome 1998). Franklin makes the point that this public engagement process was unusual at the time for its ability to address uncertainty and to interpret public responses sensitively and appropriately.

Genetics testing

Genetic tests are the most widely used of all genetic health technologies. They provide many points of contact and modes of engagement between professionals and the public,

through medical research and participation in research, through specialist and general practice, in negotiating regulation and between the pharmaceutical industry and the public. The wider implications of genetic tests include the fact that they lead to new clinical practices and new understanding of health and illness. There is a need, therefore, for reflexive practice and concern to distance the 'new genetics' from older eugenic practices that were associated with coercion.

A key area is the genetics clinic where specialist genetics counsellors 'engage' with people who are contemplating, or have had, a test to see if they have a genetic disorder. As I mentioned earlier, test are usually accompanied by 'non-directive' genetic counselling (Clarke, 1991). The overall goal of counselling is to ensure that a person is prepared to make an informed decision about testing, having carefully thought through the full implications of the test. Counselling is designed to raise issues and address questions that might not previously been considered. It should be noted that these considerations are particularly important when effective therapy or treatment for the genetic condition is not available. However, where these disorders can be inherited, a wider network of family is also implicated and the earlier commentary on counselling raised the question about the overall influence of society's attitude to disability and health service agendas that may, effectively discriminate against people who do not accept those agendas. As I have already pointed out, many people argue that patients do not have the free choice they appear to be offered, for instance when a test reveals that a pregnancy may result in the birth of a disabled child.

Tests are carried out for three ranges of conditions: inherited disorders e.g. cystic fibrosis and Huntingdon's disease; chromosomal abnormalities, such as Down's Syndrome; and complex multi-factorial disorders that are caused by a combination of genetic and environmental factors, such as heart disease and cancer. Testing can occur at various stages, from pre-natal testing for chromosomal disorders to post natal testing of children and adults (including potential carriers and paternity testing).

An increasing number of genetic conditions can now be tested for and commercial interest is high, particularly in the development and marketing of testing kits. Some companies are also beginning to market testing services directly to the public, raising concern about the lack of counselling provided in this situation. A key issue about commercial involvement in genetic testing is related to the patenting of tests and the degree of control this gives the company over the information offered by the health services.

Charities representing people with genetic diseases have traditionally been very closely involved in genetic testing. They are involved in a number of ways, as research participants, as consultants and as advocates or lobbyists in promoting new technologies. Disability groups have also been active in campaigning to raise awareness of the possibility that coercion is still a factor that needs to be addressed in genetic testing, particularly for pre-natal testing and pre-implantation genetic diagnosis (see Box.4.3 above) but, to a lesser extent in pre-symptomatic testing and screening.

Genetic testing - public engagement/consultation activities:

Association of British Insurers ABI (1997)

A citizen jury was consulted on insurers genetics code of practice - organised by the Institute for Public Policy Research in partnership with Opinion Leader Research.

<http://www.abi.org.uk/>

WIHSC Citizens' jury on genetic testing for common disorders (1997) (evaluated by Glasner and Dunkerley)

Genetics and reproductive decision making amongst older teenagers
Rachel Iredale of the Genomics Policy Unit is being funded by the Wellcome Trust to conduct a Citizen's Jury with young people aged 16-19 years across Wales on the topic of 'Genetics and Reproductive Decision Making'. This project is being run in conjunction with collaborators from the Wales Gene Park and Techniquest and will be held in Cardiff in September 2004.

People Science & Policy Ltd (PSP)

Qualitative consultation on 'The supply of genetic tests direct to the public'.
The HGC commissioned (PSP) to undertake eight focus groups to provide lay perspectives on the issue to augment the views of interested groups and individuals that responded to the HGC's consultation.

http://www.peoplescienceandpolicy.com/supply_of_genetic_tests_to_public.html

HGC has consulted on the following genetic testing issues

- Genetic Testing and Employment
- Genetics and Reproductive Decision Making
- Genetics Profiling at Birth
- Genetic Testing and Insurance
- Preimplantation Genetic Diagnosis
- Paternity Testing Services (forthcoming)

<http://www.hgc.gov.uk/topics.htm>

Royal Society

'Talk to Us' – an internet discussion site to provide channels for the public to communicate with each other and the Royal Society on a wide range of issues related to the impact of science and technology on society, including the question:

'Would you want a genetic test to tell you if you're at risk of developing a disease?'

<http://www.royalsoc.ac.uk/templates/talkingpoints/discussions/Forum.cfm?ForumID=23>

Stem cells

The debate about stem cell research is gaining momentum, as the possibility of effective therapies gets closer to reality. The debate usually hangs on the source of the cells: stem cells are the precursors (or blue-print cells) of other cells in the body and they are classified, according to their source as being derived from either embryonic or adult cells. Overall, debates have been framed in the following way:

- whether the source of the concerns are about the source of the cells or about the technology i.e. does it matter where the cells came from?
- the creation and manipulation of human embryos for research.
- the use of spare or 'discarded' embryos
- whether people who are undergoing fertility treatment should be asked for their individual informed consent to donate spare embryos
- the commercial patenting of therapies based on naturally occurring substances donated for public benefit research

The most recent topic for debate and consultation is the setting up of a national stem cell bank.

Background to the UK Stem Cell Bank: In September 2002 the Medical Research Council and the Biotechnology and Biological Sciences Research Council announced funding to establish a UK Stem Cell Bank. The Bank has been charged with providing ethically-sourced, quality-controlled adult, fetal and embryonic stem cell lines for research and for the development of therapies.. It will be hosted by the National Institute for Biological Standards and Control (NIBSC).

Stem cells – public engagement/consultation activities:

Medical research Council MRC

'Draft Code of Practice for the use of Human Stem Cell Lines'

A formal written consultation (8 April 2004 - 28 May 2004). The Steering Committee invites all organisations, centres and individuals who may use this Code, or have an interest in it, to comment. Comments welcomed from any source.

http://www.mrc.ac.uk/prn/index/public-interest/public-consultation/public-stem-cell-consultation/public-use_of_stem_cell_lines.htm

People Science and Policy

'Consultation on Public Attitudes to Stem Cell Research and the National Stem Cell Bank'

The objective of this consultation was to understand the views of the public and in order to inform the communication activities of the MRC and the Bank, mainly with those likely to be asked to donate stem cells but also with the wider public.

http://www.peoplescienceandpolicy.com/national_stem_cell_bank.html

Genetic databases

Medical research has always relied to some extent on collected and stored data. But, as opposed to the traditional patient-centred identification of inherited disease patterns and symptoms that were undertaken in the clinical setting by clinical geneticists, it appears that the current research need for databases has arisen out of a new phase of functional genomics and the need for large statistical samples of population based data. This new technological trajectory is also seen as a natural progression of the human genome mapping project. For instance, in announcing the forthcoming UK Biobank project, the Director of the Wellcome Trust - Mike Dexter - has put it this way: 'The UK Biobank is a natural progression of the [Wellcome] Trust's involvement in the Human Genome Project'

There are now a large number of publicly funded and private sector databases under construction in Europe and throughout the world.

The debates have been framed in the following way:

- ownership – who should 'own' the databases (private or public ownership)?
- how to maintain confidentiality and the security of the personal data
- who should have third party access – including external agencies like the police.
- whether it is possible to obtain fully informed individual consent of the donors
- the potential for discrimination, by employers and insurance companies, based on the data analysis.
- the regulation of access and use of the database
- the overall social acceptability of the research which may arise from the use of the data.

The UK Biobank, mentioned above is being presented as the world's largest national genetic database for studying the role of nature and nurture in health and disease. 500,000 people in the UK, aged between 45 and 69 will be asked to participate by contributing DNA samples, lifestyle information and access to their medical histories. The project is being funded by the Wellcome Trust, the Medical research Council and the Department of Health. Prior to launching the biobank there was a certain amount of proactive research to understand public concerns about the implications for future healthcare, in order to react to those concerns? The Human Genetics Commission has also a consultation.

In addition to these formal processes of consultation, there has been an ongoing debate, amongst scientists, pressure groups and other interested parties, about whether UK Biobank is a scientific project or a resource and about whether there has been sufficient discussion about the benefits of such an expensive and risky project. In 2002 the House of Commons Select Committee on Science and technology interrogated the Biobank

fundings and criticised the project as being 'politically motivated'. An NGO pressure group, GeneWatch UK and the Consumers Association have criticised the UK Biobank's funders (DoH, MRC and Wellcome) for the lack of public engagement (as a public and Parliamentary debate) in debating the possible social, ethical and legal implications of this particular approach to healthcare (eg. prediction and individual genetic risk assessment) which, they claim is being driven by commercial motives such as patenting and privatisation agendas, rather than public benefit.

Genetic databases - public engagement activities:

Wellcome/MRC

'Public perceptions of the collection of human biological samples'

In 2000, as a first step in the continuing public consultation about the proposed UK Biobank (then known as the UK Population Biomedical Collection), the Wellcome Trust and the Medical Research Council (MRC) commissioned qualitative research to start to explore the views of the public and particular interest groups. An independent research group - Cragg Ross Dawson - was commissioned to consult with an initial cross-section of the public across the UK, with religious and community leaders, and with spokespeople for organizations with a special interest in the issues surrounding genetics research. The report was published in September 2000.

<http://www.wellcome.ac.uk>

Human Genetics Commission

'Public attitudes to human genetic information'

In March 2001, HGC conducted a MORI survey to investigate public attitudes to human genetic information as part of a wider (2002) consultation which resulted in the report 'Inside Information'

<http://www.hgc.gov.uk/topics.htm#ddna>

People, Science and Policy

'The UK Biobank - A Question of Trust'

The Wellcome Trust (WT) and the Medical Research Council (MRC) commissioned People Science & Policy Ltd to conduct a public consultation about the ethical and management issues surrounding the proposed Biobank UK project

Box 6.3 UK Biobank: A question of trust?

(Carried out by PSP for Wellcome/MRC 2002 - evaluated by Kerr, (2002))

This public consultation, according to Kerr, appeared to be reactive rather than proactive i.e. the report suggests where the barriers to participation are and appeared to make recommendations about how to surmount these obstacles. The consultation objectives stressed the need for citizen involvement in the forthcoming biobank but the analysis of the responses commented on the levels of inertia that would need to be overcome. It is pointed out that this 'consultation', far from being conducted as an opportunity for dialogue in order to improve the database set-up and technical systems, was directed towards finding out how to get people to accept and participate. As such it could be regarded as 'ad hoc'.

Pharmacogenetics

Pharmacogenetics or, (since the advent of functional genomics) pharmacogenetics, is the study of the way in which an individual's genetic makeup can influence drug metabolism and hence their response to drug treatment (see Snedden, 2000, Webster et al 2001). Hedgecoe et.al present it as the first clinical application of the HGP, the ultimate goal of

pharmacogenomics being to make use of an individual genetic profile of the patient in diagnostic assessment and drug treatment.

'It therefore appears that the construction of a bioethics discourse around pharmacogenetics is mainly being shaped by researchers advocating the development of the technology and is closely tied to the creation of scientific and commercial expectations' (Hedgecoe and Martin 2003: 351)

Pharmacogenetics - public engagement/consultation:

Nuffield Council

A public consultation was held between November 2002 and February 2003. During this time more than 70 responses were received from 15 countries. Respondents included academics, representatives from industry, general practitioners, members of LRECs, patient groups and other professional organisations.

<http://www.nuffieldbioethics.org/pharmacogenetics/public.asp>

Xenotransplantation

The demand for human tissue and organs for transplantation has become more acute recently due to a widening gap in the availability of donor organs. This is due to a number of factors including the improvements in techniques but fewer organs available. This widening gap has led to renewed interest in the use of non-human tissue and organs (xenotransplantation).

The key issues have been framed in the following way:

- Social pressure not to risk the development of these techniques set against pressure, by patients and patient groups who are desperate to seek remedies
- Uncertainties about the science and the longer term consequences.
- Psychological effects and psycho-cultural distaste about implantation with non-human tissue and cells.
- Animal welfare
- High numbers of experimental primates required by the research.

Xenotransplantation - public engagement/consultation activities:

Science and Technology Policy Research (University of Sussex)

'Appraising options for addressing the 'kidney gap'

A 'Deliberative Mapping' project to pilot an innovative public consultation process with the case of xenotransplantation and organ failure.

<http://www.deliberative-mapping.org>

Behavioural genetics.

The debates surrounding research into behavioural genetics are mainly about the concern not to over-emphasise genetic factors, or to 'medicalise' what many people would see as social problems, especially characteristics that many people would see as part of human diversity that are accepted by society, such as homosexuality.

It has been suggested that since experts do not agree about how to interpret the results there should be wider, or 'extended peer review' by the public. (see Box 6.4 below)

Box 6.4 Hastings Centre 'A Big Conversation'

Source: Parens, E (2004) Genetic differences and Human Identities: on why talking about behavioural genetics is important and difficult. Special supplement to *The Hastings Centre Report*. Hastings Centre

The project aimed to produce 'tools' for public conversation. This included both the conceptual tools needed to talk productively and to interpret the range of viewpoints, and the communication and dissemination products. It also involved bringing together scientists and non-scientists to discuss what the science means (rather than just the

implications). Some disagreements may, in part, have been due to the fact that the scientists came from different disciplines but there was also debate, within the discipline of behavioural genetics both about the meaning of the findings and the prospect of molecular approaches. The greatest obstacle is the preference for simple answers and exaggeration of the significance of the findings

Behavioural genetics- public engagement/consultation activities:

Nuffield Council on Bioethics

A public consultation was held between March and July 2001. During this time 110 responses were received from a wide range of interested individuals and organisations.

<http://www.nuffieldbioethics.org/behaviouralgenetics/index.asp>

7. Is it possible to evaluate PE exercises?

The evaluation of participatory methods of public engagement has traditionally been guided by a set of criteria against which the actual process could be assessed, typically on the basis of fairness and competence (Renn et al, 1995). These first and most comprehensive attempts to provide a framework for evaluation were based on Habermas' normative theory of ideal speech and communicative competence. However, since the concept of public engagement is so complex and value laden and the range of participatory methods varies so widely in method and expected purpose, establishing an overall framework for evaluation is problematic and there are no widely agreed criteria for judging the success or failure of a process.

It is useful to start by defining the goals of a public engagement, even before any assessment of the process. Most guidelines for good practice emphasise the need for clearly defined objectives, where possible, agreed by all the participants at the outset, that can then be evaluated and lessons learned (Audit Commission, 1999, POST 2001, 2002). Sherry Arnstein's (1969) 'ladder of participation' offers a normative evaluation of participatory processes in terms of levels of empowerment or citizen control in which it is assumed that citizen control is the desired end of the process. Arnstein's ladder depicts the stages whereby power can be delegated to a wider community of participants and invites practitioners to move up the ladder if they wish to demonstrate good practice. But, it is clear from examples of public engagement practices already discussed that consultation and participation can happen at a number of levels and for a number of purposes. A process must be designed to be fit for purpose and thus it is not always possible, or desirable, to delegate complete ownership and responsibility to participants.

Rowe et. al. (2000, 2004) offer a 'more lenient' definition of the concept of participation based on 'active information provision' (Rowe et. al. 2004: 117) towards a desired goal such as influencing a decision or a future policy. They suggest that it is useful to distinguish between public 'participation' and 'communication', whereby communication is often seen as a process of aligning public views with those of the experts and addressing a knowledge 'deficit' in order to encourage acceptance, whereas participation implies a more two-way process involving the soliciting of public (or lay) knowledge. In a recent article they revised their original nine evaluation criteria based on acceptance and process. They suggest that all but one of the criteria can be scored. Other scholars have questioned the scoring system and maintain that more work still needs to be done to unpack the notion of effectiveness and to establish generalisable principles (Abelson et.al. 2003). In the meantime they argue that: '*clear thinking about why you want to consult, with whom and about what will take participation practitioners at least part of the way.*' (Abelson et.al. 2003: 249)

Many people still argue that the engagement process, like any other relationship, cannot be separated from the wider factors influencing all parties to the process. It is very hard to say what factors influence people or how long it takes for those factors to make an impact on people's decisions. Nevertheless, given the increasing level of investment, in time and general expense, of participation exercises, there is increasing pressure to justify the investment to sponsors and participants and to learn from the process and to share the learning with others. Criteria for assessment can be broadly divided into those associated with process and those for evaluating the outcomes.

Criteria for evaluation of process:

Process based evaluations state the criteria for a successful process, such as:

Representativeness (see also section 4) Did the process engage with the targeted group or with a representative sample of the population? When the views of large

numbers of people are required, such as in community or wider public consultation, questions are often raised about whether engagement processes involving only small number of people (e.g. focus groups and citizen panels) can 'represent' those views. However, although large quantitative surveys aim to base their findings on statistically representative samples of the population, qualitative methods do not make this particular claim based on numbers but, rather, on **inclusiveness** i.e. the extent to which they were able to include an appropriate diversity of views and the **quality of the deliberation**. Evaluation of the quality of deliberation involves assessing the features of the process – and these might require facilitation – such as timing and an opportunity to question the informants or to challenge the information/knowledge transfer. Here again, evaluation of **the information or knowledge transfer** relates to a number of aspects of the process, including selection of informants (or witnesses) based on their 'expertise', presentation of a number of viewpoints and foregrounding of such things as uncertainty, unpredictability (or even ignorance). All of these features can be evaluated as the criteria for a successful process.

Criteria for the evaluation of outcomes

The evaluation criteria to assess the outcomes of a process are similarly wide-ranging, and often contested (the goal of consensus is a good example). However, almost everyone would agree that it is important that there should be some **contribution to learning** by both the organisers and the participants as an outcome of a public engagement process and, equally, that it is desirable in principle for a process to afford some degree of **civic agency**. However, it could also be argued that this latter outcome would not be achieved unless the process **affects change**: the change being anything from a contribution in making a decision, a better designed or more cost-effective service, to a situation in which more people benefit or fewer suffer.

Overall, it is important to be able to determine whether the engagement exercise has been 'legitimate' (for example in terms of fairness, method and timing and participation POST 2001:9). Many engagement exercises, without this seal of legitimacy, have been regarded as 'tokenistic' (see, for instance, the Welsh Citizens' jury described below).

Since the precise criteria for evaluation of public engagement practices are so ill-defined, and since not all techniques provide successful outcomes, it may be more useful to learn from actual experience. The Wellcome Trust have supported six projects exploring novel methods of public engagement (see Levitt et.al. below) and their new 'Engaging Science' grants (2002-) aim to provide feedback from completed projects in order to help others to learn from their experience. The two case studies below illustrate different ways of evaluating processes of engagement.

How is evaluation carried out in practice?

The first case study, about a novel process based on a media consultation, illustrates how the public engagement **process** was evaluated:

Box 7.1 Gene Week. A novel way of consulting the public

Source: Levitt, M., Weiner, K., and Goodacre, J., submitted to Public Understanding of Science (2003)

The consultation carried out by Mairi Levitt and Kate Weiner was funded through a Wellcome Trust programme promoting projects that aimed to develop and evaluate novel methods of consulting people about genetic issues. The evaluation of this project focuses primarily on the actual process – since it was designed to pilot a new method, rather than to affect any specific policy process. The aim of the Gene Week project was to consult a wide range of people about the ethical and social issues of a number of genetic technologies (including genetic testing, pre-implantation genetic diagnosis, cloning, biobanks and xenotransplantation). Gene Week was novel in that it used a local

newspaper (with an average circulation of 57,000 people) to disseminate the information – one issue for each day of the week - in the form of a one-page news-spread and a feedback form. It was designed to be both a quantitative and a qualitative approach, with a combination of large scale circulation and open-ended questions. In this way the process aimed to address a large number of people, particularly people who would not normally read about genetic issues, in an open and accessible manner. Open-ended feedback was invited in response to the articles.

Evaluation of the process was based on four main criteria:

The level of deliberation – the method was not specifically designed to be deliberative, but it did have deliberative elements

The approach to information – which was carefully designed to be accessible and balanced, rather than media 'hype'.

The selection of participants – in that the project aimed to reach large numbers of people but could not determine the level of response or claim to be statistically representative of any demographic population.

Framing of the issues – the newspaper articles deliberately maintained an open framing of the issues, by emphasising uncertainty and ethical choice. To this extent it attempted to minimise the framing by not setting a hard-line agenda. In addition, the consultation invited, and received, contextual responses.

A final criterion for evaluation of the process was *the degree of influence*, if any, of the process. The organisers made it quite clear that this consultation had not been designed to input into any specific policy decisions. The aim was to learn more about the process. However, they did maintain that it was very successful in highlighting the issues for a new audience (through 5,000 words published in a local newspaper that had previously not covered anything about these genetic issues). It would be very difficult to evaluate the impact that might have had on people who read about the issues but did not respond to the consultation.

The second case study, about the first citizens' jury to address a genetic policy issue, illustrates how the **outcomes** of a public engagement process were evaluated by two independent academics:

Box 7.2 A Welsh Citizens' Jury

Sources: Dunkerley and Glasner, (1998), Glasner, (2001)

In 1997 the Welsh Institute for Health and Social Care carried out the first citizens' jury designed to address the following question:

'What conditions should be fulfilled before genetic testing for people susceptible to common diseases becomes available on the National health service?'

This was a complex process and every effort was made to follow guidelines for conducting a citizens' jury. An independent evaluation, by David Dunkerley and Peter Glasner suggested that, to some extent, a citizen jury process of this nature sits uneasily in the context of national policy formulation. In the first place the outcome, in the form of recommendations, had nowhere to go because it had never been formally 'plugged in' to the policy process (although it was presented to the Advisory Commission on Human Genetics – a forerunner to the Human Genetics Commission). In the second place they pointed to a number of issues concerning the process that would affect legitimacy; it had not included the views of ethnic minorities and disabled people and the process appeared to favour the expert testimony of the professional experts rather than the lay witnesses. Finally, Glasner has argued that institutional processes such as citizen juries can be counter-productive to the overall goal of promoting active citizenship because they are effectively tokenistic, and in that way act as 'technologies of legitimation' (Glasner 2001:44)

8 Discussion

With an explicit commitment to the 'reflexive' learning points I'm trying to make, and the argument that this is an iterative review I'm leaving discussion points and ways forward open until it has been fully circulated and I have received critical feedback. This is just a start.

Self –reflexivity and learning.

The review points to a general consensus about the need to be clear about goals and about where public engagement fits in – at what level and for what purpose. Are the aims clearly defined and have practitioners thought about what is being left out? We need to be more attuned to our assumptions or projections of the public and their apparent needs. Being clear about what is taken for granted (assumed) in engagement practices. For instance, it is often assumed that 'the public' is some homogenous mass and belongs to some other 'tribe', rather than the society we all live and work in. It is also assumed that the participants in engagement processes are free agents, but they may be limited by structural constraints. For example, in genetic counselling it is assumed that genetic knowledge will be helpful for everyone in the same way and that non-directive counselling is always possible.

There is an associated problem of reliance on language and information exchange and of not being aware of tacit knowledge (for instance experiential and intuitive knowledge) and non-linguistic factors (hospitals and clinics can be intimidating and people can feel pressured). This is a general point but this might be particularly significant for disabled people or people from other cultures. Disability groups argue that health agendas based on genetics services have excluded their needs.

Reflexive practice belongs within a learning institution and is less about information and knowledge inputs and more about self-reflexivity. The reflexive practitioner is more aware of these things and able to adopt a flexible attitude that is open to feedback and learning.

Who frames the issues? (instrumental vs moral learning)

How can we let people in to give some input into deciding the goals of the research (as QRD have done)? Rather than opening up the issues to the public, are we just creating new categories of expertise? For instance we see in the separation of the science from the ethical issues (a form of boundary work) public engagement is only invited in informing 'subjective' ethical issues eg UK Biobank (Wynne 2001, Weldon, 2004). This is a particular framing of the terms of engagement dictated by experts who define and defend the boundaries. Kelly (2003) also talks about the continued use of bioethics bodies as a strategy for engaging public concerns while protecting the autonomy of science. Is it possible to reflect on, and work across, those boundaries?

Is genetics the only frame of reference?

Genetic determinism – a 'hard' determinism wherein genetics determines future predictions about the health (or illness), ability (or disability), behaviour (or mis-behaviour), of the nation would be unsustainable and unacceptable. A softer determinism suggests that our health futures will be determined, to some extent, by these new technologies and that it is important that they be governed in a democratic way. This is particularly important because the terms of engagement are changing, to the extent that patients are being asked to make healthcare choices based on risk and probability rather than certain cause of illness (Nelkin and Lindee 1995, Clark 1995). The new terms of engagement are based on 'active participation' (see also Kerr)

Restoration of trust

Restoration of public trust is a key concern for professionals, but can trust be managed in an instrumental way? Is this how trusting relationships are created? As Pathak-Sen explained in talking about the NICE citizen panel, participatory decision making should not be reduced to formulaic methods but should be built on mutual respect and carried out as a dynamic relationship.

The politics of public participation

Is the institutionalisation of public participation a new way of enrolling the public, of disciplining them by appearing to listen to them but only doing so on the institution's or practitioner's own terms. For instance the consultation entitled 'A Question of Trust' was criticised as being an exercise directed towards engineering acceptance (Levidow refers to some participatory processes as 'technologising democracy', i.e. rather than democratising technology)

Why at this point in time?

Why, at this point in time, do we have this overarching demand (across all institutions) for public engagement? Organisations are facing new demands: new technologies, health scares, financial pressures etc. and corresponding demands from patients and from society for more informed and balanced debates and some sort of purchase on our future health agendas. Medical science is an area that has always been characterised by risk and uncertainty, but since it is becoming more and more dominated by biomedical and genetic models of illness and disease there is concern that it may be overstating the degree of scientific control (Webster 2002). Are the scientific projects – on pharmacogenetics and behavioural genetics for instance – carrying over-optimistic messages about prediction and control? Is this being put across by industry and the media – but maybe not by scientists (who sometimes disagree with one another anyway). In one sense this is a case of health agendas being defined before needs are identified or treatment available (note it has been a criticism of health services that the treatment/drugs are looking for patients but this is one step up where a knowledge discipline is defining a future that does not yet exist. It has been suggested (Wynne)¹³ that one problem with the new move to public dialogue and user engagement is that, although the public is given the role of stating a need or preference in relation to genetic technologies and services, there are a number of ways in which they are not fully informed. In the first place they are unable to see, or understand, what is on offer. In the second place what appears to be on offer is blindly optimistic (therapies and cures). Thus the dialogue is either somewhat stilted, and therefore empty, or based on over-optimistic predictions that fail to live up to the promises. There is an implication here that we need to develop more 'realistic' dialogues in which some of these concerns are addressed.

¹³ Per comm

9 Ways Forward

1. *Recognition of the role of public engagement in developing a reflexive and learning Knowledge Park.* Webster argues that opening up these new health technologies (opening the 'black bag') for more critical reflection may not necessarily be as destructive as it sounds because it makes for more robust medical technologies and clinical practice (Webster 2002). Involves putting PE at the centre of the knowledge enterprise and developing a reflexive and learning network.
2. *Recognition of the limitations of institutionalised participatory processes.*

Bibliography

- Abelson, J., Forest, P-G., Eyles, J., Smith, P., Martin, E and Gauvin, F-P. (2003) Deliberations about deliberative methods: issues in the design and evaluation of public participation processes. *Social Science and Medicine* 57 239-251. Elsevier Science
- Arnstein, S. (1971) A Ladder of Participation in the USA. *Journal of the Royal Town Planning Institute*. April 176-82
- Audit Commission (1999) *Listen Up! Effective community consultation*. Audit Commission: London
- Barbour, R. and Kitzinger, J. (eds.) (1999) *Developing Focus Group Research*. Sage: London
- Boote J, Telford, R and Cooper C (2002) Consumer involvement in health research: a review and research agenda. *Health Policy*. 61: 213-236
- Burgess, J., Davies, G. and Stirling, A (2003) *Deliberative Mapping: Appraising options for addressing the 'Kidney Gap'*. Executive Summary. UCL: London
- British Association (2002) *Science in Society: advice to the Office of Science and Technology from the BA*. The BA
- Clarke, A (1991) Is non-directive genetic counselling possible? *Lancet*. **338**. 998-1000
- Coote and Lenaghan, 1997 *Citizens' Juries: Theory into Practice*, IPPR, London
- Cragg Ross Dawson (2000) *Qualitative Research to Explore Public Perceptions of Human Biological Samples*. A report for The Wellcome Trust and Medical Research Council. London
- Department of Health (2003) *Our Inheritance: our future*
www.doh.gov.uk/genetics/whitepaper.htm
- Dickson, D (2000) Science and its public: the need for a 'Third Way', *Social Studies of Science*, 30 no.6 (2000): 917-23.
- Dowdswell T, Harrison S, Mort M and Lilford R (1997) *Health Panels: A Survey*, Nuffield Institute for Health, Leeds.
- Dryzek J (1994) *Discursive Democracy*, Cambridge University Press, Cambridge.
- Dunkerley, D and Glasner, P (1998) 'Empowering the public? Citizen's juries and the new genetic technologies', *Critical Public Health* 8 no.3 (181-192)
- Franklin, S. (1999) What we know and what we don't know about cloning and society. *New Genetics and Society* 18 (1) 111-120
- Funtowicz, S. and Ravetz, J. (1992) 'Three types of Risk assessment and the Emergence of Post Normal Science.' (in S. Krimsky and D. Golding eds.) *Social Theories of Risk*. 251-273 Praeger: New York.

Glasner, P. and Dunkerley, D. (1999) The new genetics, public involvement, and citizens' juries: a Welsh case study. *Health, Risk and Society* Vol. 1 (3) (pp 313-324) Taylor and Francis

Glasner, P. (2001) 'Rights or rituals? Why juries can do more harm than good. *Participatory Learning and Action Notes 40*: IIED

Haimes, E. and Wong-Barr, (2004) Levels and styles of participation in genetic databases: a case study of the North Cumbria Community Genetics Project. (In Tutton and Corrigan eds.) *Genetic Databases: socio-ethical issues in the collection and use of DNA*. Routledge: London

House of Lords Select Committee on Science and Technology. Session 1999-2000 3rd Report. *Science and Society* The Stationery Office: London

Harrison, S., and Mort, M., (1998) Which champions, which people? Public and user involvement in health care as a technology of legitimation. *Social Policy & Administration* 32 no.1: 60-70, p61.

Hedgecoe, A. and Martin, P. (2003) The Drugs don't work: expectations and the shaping of pharmacogenetics. *Social Studies of Science*. 33 (3) (327-364): Sage

House of Lords Select Committee Report on Science and Technology. Session 2000 –01 4th Report. *Human Genetic Databases: challenges and opportunities*. The Stationery Office: London

Human Genetics Commission (2001) *Public Attitudes to Human Genetic Information*. People's Panel Quantitative Study conducted for the HGC. London

Human Genetics Commission (2002) *Inside Information: Balancing interests in the use of personal genetic data*. A report by the HGC: London

Irwin, A. and Wynne, B. (eds) (1995) *Misunderstanding Science? The public reconstruction of Science and Technology*. Cambridge University Press: Cambridge

Irwin, A. (1995) *Citizen Science*. Routledge: London

Irwin, A. (2001) 'Framing the Scientific Citizen: science and democracy in the biosciences.' *Public Understanding of Science* 10 (1-18) Institute of Physics Publishing: London

Jasanoff, S (2002) technologies of Humility: citizen participation in governing science. *Minerva* 41 3

Joss, S. and Durant, J. (1995) *Public Participation in Science: the role of Consensus Conferences in Europe*. Science Museum: London

Joss, S. and Bellucci (2003) *Participatory Technology Assessment: European perspectives*. University of Westminster: London

Kelly, S. (2003) Public bioethics and publics: consensus, boundaries and participation in biomedical science policy. *Science, Technology and Human Values* 28 (3) (339-364)

Kerr, A., Cunningham-Burley, S. and Amos, A. (1998) Drawing the line: and analysis of lay people's discussions about the new human genetics. *Public Understanding of Science* 7 (113-133)

Kerr, A. and Shakespeare, T. (2002) *Genetic Politics: from eugenics to genome*. New Clarion Press: London

Kerr, A. (2002) Genetics and Citizenship: exploring transformations. *Critical Social Policy*

Lenaghan, J. (1999) Involving the public in rationing decisions. The experience of citizens' juries. *Health Policy* 49 (1-2) 45-61

Levitt, M., Weiner, K. and Goodacre, J. (2004) Stimulating public debate on the ethical and social issues raised by the new genetics' in S.Holm and M.E.Jonas (eds) *Engaging the World: the use of empirical research in bioethics and the regulation of biotechnology*. Amsterdam: IOS Press

Levitt, M. Weiner, K and Goodacre, J (forthcoming) 'Gene Week: A novel way of consulting the public' *Public Understanding of Science*.

Marinetti, M. (2003) Who Wants to be an Active Citizen? The politics and practice of community involvement. *Sociology* Vol. 37 (1) (pp103-120) Sage.

Marteau et. al. 1993, 1994

McIver, S.(1998) *Healthy debate? An independent evaluation of citizens' juries in health settings*. London; Kings Fund Publishing

Michael, M. (1998) Between citizen and consumer: multiplying the meanings of the "public understanding of science". *Public Understanding of Science* 7 (pp313-327) London

Martin, P. and Kaye, J. (2000) The use of large biological sample collections in genetics research: issues for public policy.' *New Genetics and Society* 19, 2: 165-91

Medical Research Council (2000) *Personal Information in Medical Research*. MRC

Michael, M ``Comprehension, apprehension, prehension; heterogeneity and the public understanding of science'' *Science, Technology, & Human Values*, 27, no.3 (2002): 357-378.

Nowotny, H., Scott, P. and Gibbons, M. (2001) *Re-thinking Science: knowledge and the public in an age of uncertainty*. Polity: Cambridge.

Nowotny, H. (2003) 'Dilemma of expertise: democratising expertise and socially robust knowledge'. In *Science and Public Policy*. Vol 30 No 3 (151-156) Beech Tree

Nuffield Council on Bioethics (2002) *Genetics and Human Behaviour: the ethical context*. Nuffield Council on Bioethics.

Parens, E. (2004) *Genetic Differences and Human Identities: on why talking about behavioural genetics is important and difficult*. A special supplement to the Hastings Centre report. Hastings Centre

Parliamentary Office of Science and Technology. (2001) *Open Channels: public dialogue in science and technology*. POST Report No. 153. POST:London.

Parliamentary Office of Science and Technology (POST). (2002) *The UK Biobank*. POST

Parliamentary Office of Science and Technology (2002) *Public Dialogue on Science and Technology*. POST Report No. 189. POST: London

People Science and Policy (2002) *Dialogue with the public: practical guidelines*. Research Councils UK

Petersen, A. (1999) Counselling the genetically 'at risk': a critique of 'non-directiveness'. *Health, Risk and Society*. 1 253-266.

Petersen, A and Bunton, R. (2002) *The New Genetics and the Public's Health*. Routledge; London and New York

Policy Studies Institute (1998) *Consulting the Public: guidelines and good practice*. London

Renn, O., Webler, T. and Wiedemann, P. (1995) *Fairness and Competence in Citizen Participation: Evaluating models for environmental discourse*. Kluwer Academic: London

Rowe, G. and Frewer, L (2000) "Public participation methods: a framework for evaluation", *Science, Technology & Human Values*, 25 no.1 (3-29).

Rowe, G., Marsh, R., and Frewer, L. (2004) Evaluation of a deliberative conference. *Science, Technology and Human Values* 28 (4) 513-537

Royle et al (2001) *Getting involved in research: a guide for consumers in NHS Support Unit*. Winchester

Snedden, R. (2000) The Challenge of Pharmacogenetics and Pharmacogenomics. In *New Genetics and Society*. Vol 19. No. 2. Taylor and Francis: London.

Sulston, J. and Ferry, G (2002) *The Common Thread: a story of science, politics, ethics and the Human Genome*. Transworld: London etc.

Turner, B. (2001) The Erosion of Citizenship. *British Journal of Sociology*. (pp189-209) Routledge.

Webster, A., Brown, N., Rappert, B., Martin, P., Frost, R. and Hedgecoe, A. (2001) *Human Genetics: an inventory of new and potential developments in human genetics and their possible uses*. Working document for the STOA panel. European Parliament.

Wanless, D. (2002) *Securing our future: taking a long-term view*. NHS.

Webster, A. (2002) Innovative Health Technologies and the Social: redefining health, medicine and the body. *Current Sociology* Vol 50 (3) Sage: London

Weldon, S. (2004) 'Public consent' or 'scientific citizenship'? What counts as public participation in population based DNA collections? (In Tutton, R and Corrigan, O eds.) *Genetic databases: Socio-ethical issues in the collection and use of DNA*. Routledge: London

Wellcome Trust (1998) *Public Perceptions on Human Cloning*. The Wellcome Trust.

Wellcome Trust, MRC (2000) *Qualitative Research to Explore Public Perceptions of Human Biological Samples*. The Wellcome Trust: London

Wellcome Trust, MRC. (2002) *Biobank UK: A Question of Trust: A consultation exploring and addressing questions of public trust*. A report conducted by People Science and Policy Ltd.

Wynne, B. (1991) Knowledges in Context. *Science, Technology and Human Values*. 16: 111-21

Wynne, B. (1995) The Public Understanding of Science. (In S. Jasanoff et.al eds) *Handbook of Science and Technology Studies*. Pp 361-88 Sage: CA

Wynne, B. (1996) Misunderstood misunderstandings: social identities and public uptake of science. in *Misunderstanding Science? The Public Reconstruction of Science and Technology* (eds. A. Irwin and B. Wynne) Cambridge University Press: Cambridge.

Wynne, B. (2001) Creating public alienation: expert cultures of risk and ethics on GMOs. *Science as Culture* 10:4.

Appendix 1

Who is doing what in PE?

The following institutions, non-government organisations and academic consultancies have been involved in public engagement activities relating to innovation and regulation of genetics

Association of the British Pharmaceutical Industry (ABPI)

A trade union association for approximately 100 drug companies, or producers of prescription medicines in the UK.

A wide range of publications published by the ABPI to inform the industry and the general public about.....

www.abpi.org.uk

Association of British Insurers

The Association of British Insurers is the trade association for the UK's insurance industry, representing around 400 companies

<http://www.abi.org.uk/>

British Association for the Advancement of Science BA

The BA is the UK's nationwide, open membership organisation dedicated to science communication. Their aim is to make science and its applications accessible to all. The BA also aims to promote openness about science in society and to engage and inspire people directly with science and technology and their implications. They run a number of programmes and events of interest to members of the public, scientists and people involved in communicating science. For example:

The X-change

At the x-change, people can share their opinions, knowledge and experience with others with an interest in current affairs.

Working lunches

This summer working lunches take place in Glasgow and Exeter

<http://www.the-ba.net>

BCODP The British Council of Disabled People

The British Council of Disabled People is the UK's national organisation of the worldwide Disabled People's Movement. They were set up in 1981 by disabled people to promote full participation in UK society, and they now represent 126 groups run by disabled people in the UK. Between them they have a total membership of around 350,000 disabled people. BDOP claims to offer all disabled people in the UK the chance to get involved directly in working to change our society. They also work at international level, particularly through membership of Disabled People's International, to support the capacity of disabled people to achieve greater civil rights and participation wherever they live.

Engagement activities include lobbying, research and an internet based disability information forum.

<http://www.bcodp.org.uk/>

Department of Health

GeneWatchUK

GeneWatch UK is an NGO and was set up as a not-for-profit pressure group that monitors developments in genetic technologies. GeneWatch believes people should have a voice in whether or how these technologies are used and campaigns for safeguards for people, animals and the environment. They supply briefing information and work on all aspects of genetic technologies - from GM crops and foods to genetic testing of humans. Their involvement in public debate also includes parliamentary lobbying and acting as expert witnesses in citizen juries.

Briefing documents include:

Genetics and Predictive medicine: selling pills, ignoring causes (May 2002)

Pharmacogenetics: better, safer medicines? (July 2003)

Genetic testing in the workplace

<http://www.genewatch.org>

HGC

HGC was established following a comprehensive review in May 1999, about the time of the 'Great GM Debate'. The review, by the UK Government, of the regulatory advisory framework for biotechnology, concluded that the advisory framework, of which HGC is now a part, needed to: be more transparent, in order to gain public and professional confidence; be more streamlined, in order to avoid gaps, overlaps and fragmentation; ensure capacity to deal with rapid developments, and to take broad social and ethical issues fully into account.

The HGC Consultative Panel

The HGC has set up a Consultative Panel of people affected by a genetic disorder. The panel, made up of 106 people with direct experience of living with genetic disorders, acts as a sounding board for their reports and recommendations, as well as giving an insight into their concerns about genetic issues. They see the Panel as an important element of their public involvement strategy. They use the Panel to supplement their more traditional consultation via national organisations and patient groups.

The Panel includes people who have experience of single gene, chromosomal and multifactorial disorders, and of childhood and adult onset disorders. Some are affected themselves or are carriers and/or have experience as a parent of a child affected by a genetic disorder and/or caring for someone in their family who is affected. The Panel membership has a wide age range and includes people who live in England, Scotland, Wales and Northern Ireland. Membership is reviewed after three years to 'refresh' the panel with new input and ideas.

The HGC maintain that they want to hear from people directly affected by a genetic disorder so that they learn from people who know about the reality of living with a genetic disorder, their experience in deciding whether to take a genetic test and whether for example they have concerns about insurance and employment issues. The fact that the panel works primarily by correspondence allows people who cannot easily travel to meetings to join the Panel and means people can take part at times that suit them best and that fit in with other commitments.

HGC Consultations:

Whose Hands on your genes?

Genes Direct: ensuring the effective oversight of genetic tests provided directly to the public

Paternity testing services (later in 2004)

<http://www.hgc.gov.uk>

IPPR Institute for Public Policy Research

IPPR is 'think tank' charity whose purpose is to contribute to public involvement in a range of social, economic and political issues. They conduct interviews, focus groups, Citizens' Forums, Citizens' Juries, workshops and other deliberative events on a range of social and political issues. They also work with external organisations to help them engage with their stakeholders to develop new thinking and more effective ways of working.

National Health Service NHS

Service: Part of the plan to modernise the National Health Service¹⁴. is to give patients more say in their treatment and influence in the way the NHS works. This includes, for example, bringing citizens and patients into decision making at every level of service and provision and policy.

Research and development: The NHS R&D strategy is committed to involving members of the public in the work it undertakes - not as "subjects" of research, but as active participants. Members of the public have already played an important role in some areas of R&D in the NHS, but they maintain that there is room for improvement and have set up an initiative for involving consumers in research.

<http://www.invo.org.uk/>

NICE

The National Institute for Clinical Excellence works on behalf of the National Health Service and the people who use it. Although NICE decisions are based on evidence provided by clinicians, researchers and patient experts, they are set against a background of social values and judgments. It is therefore important to take into account what the public thinks about key issues that inform the development of guidance issued by NICE and the care that people can expect in the NHS.

For this reason the Institute set up a Citizens Council (which is similar to a citizens' panel) with 30 members drawn from all sections of the population, to have their say on wider issues. Council members reflect a cross section of age groups, social circumstances, ethnic backgrounds, regional differences and abilities. Their views and opinions provide a backdrop against which NICE and the independent Committees that advise it can develop their recommendations. The Citizen's Council brings the views of the public to NICE decision-making. The Council meets twice a year in 3-day sessions, and members deliberate on questions put to them by the Board of NICE. Meetings are open to the public.

<http://www.nice.org.uk>

The Nuffield Foundation

An independent charity whose funds are used to support projects designed to address social welfare or to advance education.

www.nuffieldfoundation.org

¹⁴ DoH (2000) The NHS Plan. A Plan for Investment. A Plan for Reform. July 2000

Nuffield Council on Bioethics

The Nuffield Council is an independent body established in 1991 by the Nuffield Foundation and is one of the major bodies considering bioethical issues in the UK. The Council claims that it plays a major role in contributing to policy making and to stimulating debate in bioethics. In considering a topic for investigation the Council establishes a multi-disciplinary group of experts and, in addition to this, will normally engage in a public consultation process.

Topics in medical genetics include:

- Genetic screening:ethical issues
- Human tissue: ethical and legal issues
- Animal-to-human transplants:the ethics of xenotransplantation
- Mental disorders and genetics: the ethical context
- Stem cell therapy:ethical issues
- The ethics of patenting DNA
- Genetics and human behaviour:the ethical context
- Pharmacogenetics: ethical issues

www.nuffieldbioethics.org

Office of Science and Technology (OST)

Within Government, responsibility for the Public Engagement with Science and Technology programme lies with a small team based in the Office of Science and Technology (OST). The Role of the Office of Science and Technology in Public Engagement. The SET community takes the lead in communicating the importance of their work and the career opportunities offered. Equally industry, with its requirements for a skilled workforce, has a strong interest in fostering a technically literate population. The objectives of the Public Engagement Team are to:

- increase public awareness of the role of science in society and everyday life;
- promote public engagement with and dialogue about science in society;
- inform policy-making and public engagement strategies by identifying public attitudes to science;
- and, increase the impact of public engagement and science communication activities in the UK by promoting and enabling collaboration, co-operation, networking and dissemination of best practice within the science communication community.

<http://www.dti.gov.uk/ostbusiness/puset>

Parliamentary Office of Science and Technology

POST was set up in the 1980s and, as the nearest thing we have to a UK office of technology assessment, is an office of the two Houses of Parliament (Commons and Lords). It provides independent analysis of public policy issues related to science and technology

http://www.parliament.uk/parliamentary_offices/post.cfm

People Science and Policy

People science and policy is an independent science policy consultancy that specialises in science and society issues. They specialise in the areas of public consultations on science related issues, public attitudes to science-based issues, governance of science,

science communication, education, employment and training in science-based organisations. New approaches to public consultation include reconvened group discussions, consultative panels, trade-off exercises and two-stage interviews. Recent consultations include:

<http://www.peoplescienceandpolicy.com>

Picker Institute

The Picker Institute was founded in the US 1987. The Picker Institute Europe is a UK-registered charity, which works with European health care providers to obtain feedback from patients and promote patient-centred care. Its stated mission is to improve the quality of health care through the patient's eyes by using a variety of survey methods, which evaluate quality of service and provide actionable feedback.

Picker Institute Europe runs the NHS Surveys Advice Centre for the national patient survey programme.

<http://www.pickereurope.org>.

Progress Educational Trust

The Progress Educational Trust is a charity with the following aims.

- To enhance the public understanding of human reproduction and genetics.
- To encourage both professional and public discussion of their social, legal and ethical implications.
- To facilitate effective lay involvement in policy making, regulation and monitoring of practice involving reproduction and genetics.
- To promote the need for further research in these areas of science and medicine.

Progress Educational Trust holds public forums on a number of official issues arising from assisted reproduction and genetics. It publishes a weekly e-mail news digest "Bio News", at www.bionews.org.uk which provides information and comment in assisted reproduction and human genetics; aimed at users with a general interest as well as professionals working in the area.

QRD

Quality Research in Dementia (QRD) is the award winning research grants programme of the Alzheimer's Society. Quality Research in Dementia influences the direction of basic scientific research, care practice, health and social policy for the benefit of people with dementia and their families.

Their research covers the effectiveness of drugs, therapies and care practices, and the health and social impact of dementia on carers and the community at large. The programme also funds and evaluates research on the basic science of dementias and contributes to the long-term search for prevention, treatments and cure.

<http://www.qrd.alzheimers.org.uk/>

Research Councils UK

Research Councils UK (RCUK) is a strategic partnership set up to champion science, engineering and technology supported by the seven UK Research Councils.

<http://www.rcuk.ac.uk/>

Eg

MRC

Consumer Liason Group to 'advise of ways of promoting effective and appropriate consumer involvement in MRC activities and to ensure MRC is aware of and able to respond to consumer interests and concerns about research.'(POST:32)

Draft Code of Practice for the use of Human Stem Cell Lines

The Steering Committee invites all organisations, centres and individuals who may use this Code, or have an interest in it, to comment.

<http://www.mrc.ac.uk/index/public-interest/public-consultation/public-stem-cell-consultation.htm>

ESRC

Consults 'users' of its research.

Funding programmes:

Participation and Democracy

Science and Society

Innovative Health Technologies

Royal Society

The Royal Society is the UK's independent academy of science. Dating back to 1660, it has About 1300 Fellows, 65 of whom are Nobel Laureates.

The RS has recently launched a new programme for 'Science in Society'

The programme was set up in response to concern that public confidence in certain areas of science was failing whilst general support for science remained high. These concerns were outlined in the House of Lord's Science and Society Report of February 2000 and have manifested themselves in various forms since. The programme is characterised by openness and by a commitment to a 'two-way dialogue between all sectors of society' in order to be responsive to public concerns and values'.

Aims to:

- Help restore confidence in science
- Find new and effective ways of communicating with the public
- Make sure the views of the public are heard in science policy

www.royalsoc.ac.uk/scienceinsociety

SETNET

The Science, Engineering, Technology and Mathematics Network (SETNET) is a UK-wide charity that promotes Science Technology Engineering and Mathematics (STEM) awareness, especially among young people.

<http://www.setnet.org.uk/>

The Kings Fund

An independent healthcare charity that aims to improve the provision of health and social care for people, especially in London. They work with a range of organisations in the health sector and beyond to celebrate health-related achievements, and to foster new ideas and best practice. These have included partnerships with GlaxoSmithKline to celebrate excellent community health projects. A recent King's Fund survey 'Public Attitudes to Public health Policy, conducted by research consultancy Opinion Leader Research (OLR), involved interviews with a representative sample of over 1,000 people across the UK. It was co-developed and funded by the Health Development Agency and supported by the Department of Health.

<http://www.kingsfund.org.uk/>

Vision 21

Vision 21 is a company specialising in research and community consultation to public bodies - from health authorities, through to housing associations. The company does not believe that an off-the-shelf market research programme can work just as well for a company selling soap as it does for a local authority developing its social services strategy, or a business trying to become more socially responsible. They maintain that their focus and vision comes from '**people not products**'. Vision 21 has undertaken to recruit and facilitate the NICE Citizens' Council.

<http://www.visiontwentyone.co.uk>

Wellcome Trust

A biomedical research charity. Invests in medical research and considers public engagement to be one of its main priorities. A key aim is to raise awareness of the medical, ethical and social implications of research and to promote dialogue between scientists, the public and policy makers.

www.wellcome.ac.uk