

*Review of public engagement in the
development and oversight of
emerging technologies
(‘science and society’)*

by Janet Salisbury and Barbara Nicholas

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1 Science and society

1.1 Introduction

The development on public policy on issues such as human cloning, embryo research and the use of genetically modified organisms provides the Australian scientists and government agencies the opportunity to build on international experience with public and stakeholder consultations, and to develop a program of consultation that genuinely engages the community and helps to increase understanding and trust among scientists, policy makers and the general public.

This review of international initiatives to promote public engagement in the development and oversight of emerging scientific technologies has been prepared to assist people who are involved in policy development in these areas. It builds upon the experience of the authors in assisting government agencies collate information, analyse public submissions and develop policies on issues such as animal-to-human transplantation, assisted reproductive technology and embryo research. Our research strategy is described in Appendix 1.

The review is in four sections:

Section 1 provides an overview of the way that public perceptions of emerging technologies have changed over the past 20 years, the response of governments and the emergence of science communication as a profession, and the subsequent change in orientation from education to engagement.

Section 2 tracks initiatives for public engagement in science in a number of overseas countries and in Australia.

Section 3 reviews the academic literature on the public engagement in science from 2000–05.

Section 4 provides practical advice for planning a public consultation.

1.2 Public perceptions of science

The rapid pace of biomedical science over the past 20–30 years has been accompanied by increasing levels of concern among the general public, fuelled by controversies such as radioactive waste, bovine spongiform encephalopathy (BSE, or ‘mad cow’ disease), mobile phones and genetically modified (GM) food. In addition, some emerging biotechnologies challenge our core values about who we are and how we want our society to be.

As these tensions emerged in the 1990s (particularly in the UK after the BSE disaster), governments allocated large-scale public spending to programs of public science education (science centres, festivals, education programs, TV and radio shows, media presentation of all kinds) and the profession of science communication was launched. These initiatives, referred to as ‘public understanding of science’ (or PUS), were based on a ‘deficit’ model of science communication — or a belief that public sympathy for science would be increased if people knew more about it. Despite all the activity, however, by 2000, public mistrust of science was deepening.

Faced with this worsening situation, especially with respect to GM food, in 2000 the UK government commissioned the House of Lords Select Committee on Science and Technology to conduct an inquiry. The report of the inquiry, *Science and Society*, marked a turning point in science communication worldwide (UK House of Lords Select Committee on Science and Technology, 2000).

A key finding of the inquiry was that educational activities were no longer enough to engage a more sceptical and less deferential public. Instead, the report recommended the need for a dialogue, where those seeking to promote science also listen to the concerns of the public, particularly when ethical questions arise. The following key issues were identified in the report:

- The perceived purpose of science is crucial to the public response.
- People question all authority, including scientific authority.
- People place more trust in science that is seen as ‘independent’.
- A culture of governmental and institutional secrecy in the United Kingdom invites suspicion.
- Some issues currently treated by decision makers as scientific issues involve many other factors besides science. Framing the problem in a way that excludes moral, social, ethical and other concerns invites hostility.
- What the public finds acceptable often fails to correspond with the objective risks as understood by science. This may relate to the degree to which individuals feel in control and able to make their own choices.
- A variety of values underlie people’s attitudes to science. Bringing these values into the debate and reconciling them are significant challenges for the policy maker.

The *Science in Society* report was followed by a plethora of activity and other reports from the UK. In one study by the Office of Science and Technology and the Wellcome Trust (2000), people were asked about their overall attitude towards science, about the benefits versus the harms, and about the control of science. The study concluded that the public:

- are interested in science but concerned about harmful effects
- are sceptical of political motives and the government’s ability to enforce regulations
- want scientists to listen more to what ordinary people think.

In the same year, the UK Department of Trade and Industry (2000) published a White Paper — *Excellence and Opportunity: A Science Innovation Policy for the 21st Century*. The paper praised the scientists who take part in expert scientific advisory committees but, in line with the findings of the *Science and Society* report, noted:

...science is too important to be left only to scientists. Their knowledge and their assessment of risks is only one dimension of the challenge for society. When science raises profound ethical and social issues, the whole of society needs to take part in the debate.

Since these reports, there has been a considerable activity in the UK, European Union, and elsewhere to promote the recommendations of the Science in Society report and many approaches for public engagement in active debate and dialogue have been discussed and trialled. These are discussed further in Section 2 of this review.

The dialogue, or public engagement in science (PES), model aims to stimulate and inform debate and include the community in a decision-making process that takes account of the opinions, expertise and values of all parties. The difference between the deficit model and the dialogue model is shown in Table 1.

Table 1 Comparison of deficit and dialogue models of science communication

	PUS (deficit model)	PES* (dialogue model)
Aims	To increase public sympathy for science by telling people more about science	To stimulate and inform debate and to increase public awareness of science processes
Methods	One-way — tells people about science	Two-way — encourages feedback and debate
Scope	Narrow — considers issues within narrow scientific paradigm	Broad — considers science issues within social context that allows values and feelings to be included in discussion
Starting position	Science is good (people just need to understand it better)	Open minded (different parties may come with different viewpoints but process seeks consensus)
Benefits and risks	Benefits highlighted by the overall enthusiasm of the science presenter and/or funding imperatives and/or bias for positive results	Allows benefits to be presented realistically, and risks and uncertainties admitted
Fears	Not expressed	Expressed
Ownerships	Exclusive (technology is owned by scientists)	Inclusive (technology is owned by the community)

*In Australia, the term ‘public awareness of science’(PAS) is also been used

Source: Janet Salisbury (presentation to an Australian Health Ethics Committee conference, 2002)

1.3 Developing public policy

When is a dialogue between scientists and the public most likely to happen? One place when representatives of different community stakeholder groups come together to discuss emerging technologies is at the ‘science-policy interface’ — that is, when decisions are made about (a) what research to support and (b) what new technologies to accept into society, and in what ways.

The development of science and science policies in biomedical areas is complex. To use the emerging technologies wisely, society must weigh up benefits, assess risks and make decisions about what is acceptable and what is not. Regulatory agencies around the world have struggled to find a path that allows the ethical development of appropriate new technologies while maintaining public confidence.

Some key stakeholders in this process are:

- researchers (including both those undertaking basic research such as biochemistry, microbiology, and immunology, and those involved in applied research such as clinical trials)

- practitioners (such as GPs, medical specialists, dentists, physiotherapists and so on, who want to use the new technologies)
- science funders (both public funders, such as the National Health and Medical Research Council (NHMRC), and private funders, such as biotech and pharma companies)
- health consumers (that is those people who have medical conditions that could potentially be treated using the new technologies)
- Special interest groups
- The general public
- Regulators (that is, government decision makers).

Key issues for consideration:

- ethical issues relating to the new technology
- how well it works
- how safe it is
- its cost effectiveness compared to other technologies and its socioeconomic impact.

Consideration of these issues is affected by timescales as it can take many years for a piece of scientific research to be translated into a recognisable result (usually around 10 years). Governments operate in a three-year cycle and the media and public tend to operate in the 'here and now'.

Through the political and government decision-making processes, the regulators have to balance all these inputs and considerations to develop the most appropriate policies and regulations. This is a very difficult job and would be greatly helped by strong input from an involved public rather than a standoff with a distrustful and antagonistic community.

However, most of the stakeholders who have input into the discussion may have little experience of what it would be like to actually make the decision when they are in a situation where there have to address opposing views or find consensus. When people are placed in this situation, they are often surprised by how hard it is. This was illustrated anecdotally in a series of public workshops held in the UK. Participants were split up into small workgroups to discuss different bioscience topics. The consultants running the workshops reported that when one participant suggested that things were getting difficult for his particular workgroup, another remarked that this must be what it was like in 'real life' (The Wellcome Trust 1998).

1.4 Conclusions

Overall, the following conclusions have clearly emerged as a result of the 'science and society' debate and subsequent activities:

- Public understanding of science per se does not increase sympathy for new technologies.
- Denial of risks and uncertainties, or exaggeration of benefits, undermines the credibility of science.
- Ethical values need to be explored within a broad social, rather than narrow scientific, context.
- Awareness of scientific methods and limitations encourages realistic expectations.

- Genuine dialogue would build public ownership of science and develop trust in scientists and regulators.

For scientists there are undoubtedly dangers in consulting the public — a genuine dialogue means that both sides need to start the discussion with some willingness to change; there is no right and wrong. However, the frustrations of short-term losses and slow-downs in some areas may be more than offset by the long-term benefits of a supportive public.

However, the public may be sceptical about public engagement if it appears to be a token process that allows them to express their views without any clarity about how this will influence the ultimate decision-making process. This highlights the need for careful planning of objectives and management of expectations (see Section 4).

2 Public/stakeholder consultation in the development of science policy — international review

2.1 Introduction

In democratic societies, there is a tradition of consultation as policies are developed. This tends to follow well-established methods — advertisements in newspaper, calls for submissions, public meetings, and select committee hearings. Where there are particular challenges, governments may form expert panels and/or increase the knowledge base for experts and politicians by funding research.

However, the limitations of these approaches have been recognised in a number of jurisdictions, where new political pressures have emerged in response to developments in science (see Section 1). Political pressures have been prompted by public concerns about safety (eg genetic modification) and/or concerns about the social, economic or ethical implications of emerging technologies. This has led to public demands for greater influence in decision making around emerging technologies. Some countries have responded to this with a political (and funding) commitment to increased public involvement in decision making and the development of innovative strategies to engage people in the decision-making process through dialogue.

This section provides a brief overview of activities in the area of public and/or stakeholder consultation about bioscience issues in some key countries identified in the review.

2.2 United Kingdom

After the publication of the House of Lords inquiry, *Science and Society*, in 2000, there was a great deal of activity in science communication programs to reorient activities from a public understanding and education focus (deficit) to a genuine public engagement (dialogue) focus. However, despite much discussion about the need for this, progress was slow.

Before the publication of the report, there had already been activities involving public consultation, such as a 1999–2000 consultation on preimplantation genetic diagnosis (HFEA 2000). However, these activities, while eliciting public opinion, did not bring together stakeholders in a dialogue situation.

The study of attitudes to science by the Office of Science and Technology (OST) and the Wellcome Trust (2000; see Section 1), included a review of the way information about science issues was communicated to the general public. This confirmed that most activities provided facts about science rather than highlighting the ethical and policy issues raised by the science. It concluded that at a national level there was a lack of a framework within which people can access information about new science, and (importantly) assess and judge it for its importance. Finally, the report identified a number of attitudinal clusters from ‘confident believers’ to those with greater concerns. These characteristics were affected by age, gender and socioeconomic class and indicate that science communication activities need to target a number of ‘publics’.

In 2002 a further report, *Dialogue with the Public: Practical Guidelines*, was published by the Research Councils UK and the OST, in an attempt to fill the gap left by the *Science and Society* report about how a public dialogue approach could actually be managed. This much more practical guide set out the following steps:

- Setting objectives. These need to be clear, measurable and agreed by partners/funders of the event(s). Desired outcomes should also be identified, such as targets for the number of people or stakeholders that the activity engages, the number positively influenced etc.
- Understanding audiences. The next step is to identify who needs to be involved (different 'publics') and what their needs are.
- Attracting audiences. This step involves identifying and contacting the people identified as the target audience and ensuring that the event is organised to allow their attendance and participation.
- Encouraging dialogue within traditional formats. With careful planning, opportunities for dialogue can be included in many traditional formats of science communication events (eg by allowing time for two-way exchanges at public talks and meetings, subdividing participants to allow more opportunities for discussion).
- Identifying appropriate techniques to facilitate dialogue. There are many methods available to promote dialogue (such as interactive meetings, deliberative polls, citizens' juries, consensus conferences, web discussions, written consultations). Which to use depends very much on the objectives and the audience, and requires very careful planning.
- Evaluation of the project against objectives.

In the same year, the British Association (BA) published *Science in Society* to provide further advice to government on how to progress the public dialogue agenda (BA 2002). This report formed the basis of an implementation plan by OST (OST 2002), which resulted in a call for applications from science communication organisations for government-sponsored programs to promote public engagement activities.

Under the new framework set up by OST, in 2002 a public engagement process to discuss genetic modification of food crops was funded by government. This project — called *GM Nation?* — ran parallel to a review of the science behind genetic modification and a study into the costs and benefits associated with the growing of genetically modified crops.¹ The public engagement process, overseen by a government-appointed steering board, included:

- initial workshops at a 'grassroots level' to frame the issues
- public meetings around the country
- qualitative research conducted to give in-depth insight into the views of members of the general public on GM issues.

The report of this major initiative was released in September 2003 (DTI 2003). The key findings confirmed that people in the UK are generally uneasy about GM crops (and these feelings are intensified when they find out more about them). They also have little support for

¹http://www.gmnation.org.uk/ut_17/index.htm

early commercialisation, mistrust government and multinational companies, have a broad desire to know more and for further research, and have a special concern for developing countries. Overall, however, people welcomed and valued the debate.

The process was evaluated by an independent team (Horlick-Jones et al 2004). The evaluators were broadly supportive of the initiative in terms of its innovation and relevance, as well as the enjoyable nature of the events themselves. However, they criticised its timing (too rushed) and implementation (under-resourced), which meant that the project fell short of its objectives of engaging a wide cross-section of the community in a truly deliberative way.

The Wellcome Institute² and the British Council³ also fund extensive programs to further the science and society agenda, each recognising the importance of cultural dimensions of science. The British Council promotes a form of science discussion forum in both the UK and overseas (including Australia), called ‘Cafe Scientifique’ (or ‘Cafe Scientific’ in Australia), to engage the wider public. These informal sessions can be run in any public venue such as a cafe, club or pub and involve a moderator, some experts and the public in discussion of a topical science issue.⁴

In 2002–03, the Human Fertilisation and Embryology Authority ran a consultation on options for the regulation of sex selection through preimplantation genetic diagnosis and other methods (such as sperm sorting). Unlike the earlier consultation on PGD, this project included focus groups, a written consultation and a national opinion poll (HEFA 2003). The findings of the opinion poll — that the public were against allowing sex selection for family balancing — were strikingly different from expert opinion. The government ruled in line with public opinion.

A common barrier to dialogue between scientists and the public, or between other groups, is the language used to describe the issues. If the language used does not mean the same to all participants, a dialogue will be hard to maintain. A recent initiative of the BA has been a project called *Finding Common Language* in which members of the public are involved in helping to frame how a new area of research can be communicated outside the scientific arena (BA 2004). Through workshops with members of the public on the issue of emerging research area of ‘cognitive systems’ (neuroscience/computer science), this project identified language, stories and frames of reference that can be used to stimulate mature public discussions.

Finally, in 2004, the UK Council of Science and Technology commissioned RAND Europe to assess how public consultation can be fed into policy debates. RAND analysed four previous public consultations in the UK and surveyed the organisers and respondents to the consultations. One of the main findings of this study was that clarity of purpose, good management of expectations and consideration of likely outputs (including how the results of the consultation will influence policy) are important for effective consultation. The authors also warned of ‘consultation fatigue’ and stressed the importance of evaluation (Wooding et al 2005).

²http://www.wellcome.ac.uk/doc_WTD003250.html

³<http://www.britishcouncil.org/science-society.htm>

⁴<http://www.britishcouncil.org/science-society-cafesci.htm>; <http://www.cafescientific.com.au/>

2.3 United States

In the United States, the major public discussions around science and society have focused on reproductive technology and research with embryos. These discussions are highly politicised (and frequently reliant on the activities of nongovernment organisations (NGOs), and lobby groups to sponsor wider discussions⁵) and/or referred to ‘experts’ for advice or recommendations. For example, a number of bioethics councils have been established, the most recent being the President’s Bioethics Council,⁶ which has offered advice on a range of developments in biotechnology. This council has not sought to engage directly with the general public.

While there have been some discussions in the literature on the possible usefulness in the United States of other models of public consultation (for example, Allspaw 2004), there is little evidence of systematic attempts by government to widen the public debate using initiatives that are additional to the traditional political processes for influencing government. Promotion of public understanding of emerging technologies has been via public funding of research, for example, into the ethical, legal and social implications of genetics.⁷

2.4 Canada

Canada first committed itself to extensive stakeholder engagement around the development of its legislation on reproductive technology. In 1989, a government-appointed Royal Commission on reproductive technologies undertook research and public meetings, resulting in 1993 in a substantial report that captured public views, *Proceed with Care* (Royal Commission on New Reproductive Technologies 1993).

The Canadian government later developed its Canadian Biotechnology Strategy in 1998, and the following year established the Canadian Biotechnology Advisory Committee (CBAC), whose role includes ‘[e]ngaging the people of Canada in the dialogue and providing them with accurate information’. The CBAC processes for developing advice have embraced the idea of public engagement with recent development of a ‘Dialogue Tool’ for discussion of GM foods (CBAC 2004). The tool is in matrix form, with visual components intended to aid understanding and dialogue. The tool is designed to plot a real or hypothetical situation on the matrix so concepts can be grasped, different perspectives aired and the dialogue progress charted. In the first pass, participants create issue profiles under each ‘consideration area’ for the policy issue under consideration. On a second pass, they begin to consider the issue in terms of its ‘acceptability’ or ‘supportability’.

In recent years, xenotransplantation (animal-to-human transplantation) has also been the focus of efforts in Canada to consult the public over a controversial technology requiring some government oversight. Public consultation on this topic was led by The Canadian Public Health Association, which used both an ‘open model’ (website survey, mail-in survey, emails and letters, public forums), and a ‘representative model’ (citizen forums and follow-up telephone surveys). Their range of techniques provided a robust range of views, and in the citizen forums, a more sophisticated engagement with various views was possible than is

⁵See, for example, <http://www.publicconversations.org/pcp/index.asp>, which offers resources for communities keen to talk about difficult issues; and <http://www.dnapolicy.org/> for the Genetics and Public Policy Center which is an independent centre funded by a charitable trust.

⁶<http://www.bioethics.gov/>

⁷http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml

usually the case with traditional one-way consultation (CPHA 2001, 2002). After the consultation, the Canadian government imposed a moratorium on clinical trials of xenotransplantation in Canada.

The process was regarded as having been successful by communications experts (Einsiedel 2002) but has been criticised by some experts in the transplantation field for overemphasising negative aspects of the technology with insufficient opportunity for feedback from experts in the field (Wright 2004).

2.5 New Zealand

In New Zealand there have been a number of initiatives to involve the public in discussions of emerging (bio)technologies. A significant political driver of these initiatives has been developments in plant biotechnology but the conversations have widened from there to include other technologies. Initiatives have included:

- ‘Talking technology’ conferences on plant biotechnology, with the first held in 1996 and a follow up in 1999. These were funded by a range of government departments, NGOs and businesses.
- Formation of the Independent Biotechnology Advisory Council appointed by government — replaced in 2000 with the Royal Commission on Genetic Modification (RCGM), which reported in July 2001. The public were involved in the Commission activities through public submissions and public meetings throughout the country (both initially through scoping meetings and later public meetings). In addition to general open invitation events, provision was made for specific input from Maori and youth. Survey research was also commissioned on public views.
- Toi te Taiao: the Bioethics Council was established in 2002 as a ministerial advisory body following the RCGM, and required, among other things, to ‘promote and participate in public dialogue on cultural, ethical and spiritual dimensions of biotechnology’. It has run two major dialogue projects — one on the use of human genes in other organisms (Toi te Taiao: the Bioethics Council 2004) and the other (still running) on xenotransplantation.⁸ These projects have included public ‘dialogue’ events with various cross-sections of the community, and an on-line discussion forum.
- The Ministry of Research Science and Technology has funded research on methods for public dialogue. This has covered areas of biotechnology, landcare and water decisions.⁹

These initiatives are additional to the more conventional public consultations processes that have taken place in the development of both guidelines and new legislation to cover reproductive technology, and the review of other science-related legislation.

2.6 Europe

Europe offers some examples of the most long-standing initiatives to involve the public in emerging biotechnologies. Some countries have concentrated on ‘experts’ to inform

⁸ <http://www.bioethics.org.nz>

⁹ <http://www.morst.govt.nz/?CHANNEL=DIALOGUE&PAGE=Dialogue+between+science+and+the+community>

government, but others have made systematic attempts to develop public understandings of science, and yet others to provide channels for public views to influence decision making.

Denmark led the way by using participatory models of public consultation with the establishment of the Technology Board (later Danish Board of Technology) in 1986 to promote ongoing discussion of technology.¹⁰ They have developed a range of methods to use in this work, including consensus conferences, development space, and future panels (Anderson and Jaeger 2002).

Other European countries have taken initiatives that also seek to increase the influence of the public. For example, the Swiss have explored various methods for public dialogue within the context of technology assessment.¹¹ as have the Norwegians, who specifically aim to ‘strengthen the voice of lay people’.¹²

At the European governance level, the Commission of European Communities noted in its 2002 report, *Life Sciences and Biotechnology — a Strategy for Europe*, that:

Life sciences should continue to be accompanied and guided by societal dialogue, which should be ‘inclusive, comprehensive, well informed and structured. (Commission of European Communities (2002).

There have been collaborations within Europe to strengthen understanding of the use of Participatory Technology Assessment (see for example ‘The EUROPTA Project’ (European Participatory Technology Assessment), which involved people from Denmark, Germany, Austria, Holland, and Great Britain.)¹³ There have also been some significant reports that have shaped more recent thinking around the science/society interface, a notable one being *Public Perceptions of Agricultural Biotechnologies in Europe* (Marris et al 2002).

2.7 Australia

Australian public consultations on biotechnologies have centred around genetically modified organisms (GMOs) and, more extensively, some health technologies, such as xenotransplantation.

As regulatory arrangements have been put in place or amended to take account of these new technologies (such as establishment of the Office of the Gene Technology Regulator), the ‘traditional’ strategies of public consultation have been used, with calls for written submissions, and some limited use of public meetings and select committees.

In 1999, Australia held a consensus conference on GM foods at Old Parliament House.¹⁴ A group of lay volunteers received briefing papers, heard talks and were able to question experts. They were then asked to produce a report with recommendations. The resulting report, while having some errors of technical detail, was clear in its intent and similar to other reports prepared with public input elsewhere. Many were amazed that a lay group could produce such a report but some stakeholders were disappointed the report did not come to the conclusions they had hoped for and immediately sought explanations for this result. The

¹⁰<http://www.tekno.dk/subpage.php3?page=forside.php3&language=uk>

¹¹<http://www.ta-swiss.ch/framesets/projects-e.htm#publiforum>

¹²<http://www.teknologiradet.no/html/454.htm>

¹³<http://www.tekno.dk/subpage.php3?article=345&language=uk&category=11&toppic=kategori11>

¹⁴http://www.csiro.au/pubgenesite/eval_rep.htm#es

process was evaluated by an independent evaluator who found it to have met its objectives and to be an effective tool for public participation.

The *Gene Technology Act 2000* makes provision to consult the community on specific applications for use of GMOs, and to pay attention to ethical dimensions of the technology. A consultation committee and ethics committee have therefore been established under this legislation.

In the health area, the *National Health and Medical Research Council Act 1992* requires the NHMRC to undertake public consultation:

...to the extent that it is practicable to do so, the Council should adopt a policy of public consultation in relation to individual and public health matters being considered by it from time to time.

NHMRC has fulfilled this requirement through traditional approaches (that is, publication of a draft report or discussion paper by an expert group convened for the purpose, call for written submissions from either the whole public or a targeted group of stakeholders, revision of report to take account of submissions received).

When the issue for consultation has included the development of regulatory recommendations, the process must include two rounds of consultations. A wide range of topics have been reviewed in this way and many practice guidelines or regulatory recommendations have been developed. However, in reality these consultations often attract relatively few submissions, mainly from key stakeholders. The history and overall approach of the NHMRC to public consultation has been reviewed in more detail by Thomson (2003).

In recent years, two important consultations have led to some slightly more innovative approaches. In 2001–03, the Australian Health Ethics Committee (a principal committee of NHMRC) took part in a joint consultation with the Australian Law Reform Commission on the protection of genetic information.¹⁵ Although the central themes of the inquiry were ethical standards, privacy protection and protection against unlawful discrimination, the final report examines the impact of the ‘new genetics’ across a wide range of social and professional contexts. The consultation involved the following activities to engage different groups, or ‘publics’:

- individual consultations with selected people to identify and clarify issues
- review of issues by an expert committee
- preparation and public release of an ‘Issues Paper’ with detailed description of the issues
- advertisements/call for submissions
- public meetings and meetings with key people who had made submissions or were otherwise identified
- preparation and public release of a detailed ‘Discussion Paper’ quoting from responses received and responding to issues raised
- advertisements/call for submissions
- public meetings and meetings with key people who had made submissions

¹⁵ <http://www.alrc.gov.au/inquiries/title/alrc96/>

- preparation of final report and recommendations of commission (*Essentially Yours — the Protection of Human Genetic Information in Australia*), a 2-volume 1200-page document with 144 recommendations for reform, which was tabled in parliament in May 2003
- consideration by the Australian Government and by the many other bodies to whom the recommendations are addressed.

Overall, there were 15 open forums around Australia, more than 200 meetings with interested parties in Australia and overseas, and 300 written submissions. In the course of the extensive community consultation effort, the inquiry found significant optimism in Australia about the promised benefits of genetic science for improved diagnostics and therapies (Weisbrot and Breen 2003). However, there is also an underlying anxiety about the rapid pace of change and the capacity of our institutions to regulate science effectively in the public interest. Thus, the centrepiece of the recommendations is the establishment of a standing Human Genetics Commission of Australia (HGCA). The role of the HGCA would be to provide independent, high-level, technical and strategic advice to Australian governments, industry and the community generally about current and emerging issues in human genetics, and to provide a consultative mechanism for the development of policy statements and national guidelines in this area.

This process required considerable resources and time to run, but the final report has been widely praised.

Building on the experience of the joint AHEC/ALRC inquiry, AHEC took the step of expanding the usual NHMRC approach to consultation for its public consultation on whether Australia should allow clinical trials of animal-to-human transplantation (xenotransplantation), which had already started.¹⁶ This process therefore ‘evolved’ rather than being thoroughly planned from the outset. It ultimately included the following steps:

- review of issues by an expert committee (Xenotransplantation Working Group)
- preparation and public release of a ‘Discussion Paper’ with detailed description of the scientific and ethical issues, and proposed draft guidelines for regulation of clinical xenotransplantation research should it be allowed to proceed (*Draft Guidelines and Discussion Paper on Xenotransplantation*)
- advertisements/call for submissions (approximately 100 submissions received)
- small public discussion meetings (not facilitated) in several capital cities and one targeted meeting with some key stakeholders
- preparation and public release of a detailed ‘Response Paper’ quoting from responses received, responding to issues raised and providing additional information (*Animal-to-Human Transplantation: How Should Australia Proceed?*)
- preparation and public release of a plain-English community guide to animal-to-human transplantation.
- advertisements/call for submissions (approximately 300 submissions received, including some ‘proforma’ campaign submissions and a number from school children; a petition was also received)
- larger facilitated public meetings in capital cities
- preparation of final report with advice from the working group to NHMRC Council

¹⁶ <http://www.nhmrc.gov.au/ethics/human/issues/xeno/index.htm>

- consideration by NHMRC and decision to impose an immediate moratorium on animal organ transplants and a request for further scientific risk assessment of other types of transplants
- further consideration by NHMRC Council of risk assessment and decision to impose a moratorium of all clinical xenotransplantation research.

Neither the ALRC/AHEC inquiry or the public consultation on xenotransplantation were formally evaluated. In his review, Thomson (2003) concluded that NHMRC consultations based predominantly on public submissions to technical documents with some open public meetings no longer meet best practice as it is being developed overseas and may not reflect contemporary democratic values and processes. As a way forward, he recommended a move towards more carefully planned processes of citizen participation, such as those described in the series of publications prepared by the Citizens and Civics Unit, Western Australian Government.¹⁷ See Section 4 for further information.

¹⁷ <http://www.citizenscape.wa.gov.au/index.cfm?fuseaction=ccu.publications#publications>

3 Review of the academic literature

3.1 Introduction

As discussed in Sections 1 and 2, the explosion of possibilities in bioscience in the last decade has prompted considerable public debate and discussion. Initial optimism about the technologies has been tempered by concerns with the associated biological risks, economic impacts, and social and ethical implications. Governments' various agendas have been in tension with one another, as they seek to both promote biotechnology, and regulate it, and the role of science in policy has been questioned in some jurisdictions — how can science inform government policy (which may be critical of science, or have particular political agendas) when the scientific community is also keen to gain government support for research?

These issues have become particularly acute in relation to genetically modified organisms, but also arise in issues associated with reproductive and genetic technologies, and xenotransplantation.

This section briefly reviews the academic literature over the period 2000-05, and reports on:

- reflections on the place of the citizen in science policy
- issues to be considered when designing a consultative or deliberative exercise
- some recent examples of public engagement in areas of science and technology.

The search strategy used is described in Appendix 1 and involved searches in MEDLINE and individual searches of specific journals. Articles with an emphasis on the process of public engagement in science policy development have been included. Time constraints have meant that, although the most significant articles have been retrieved. In addition, we recognise that there is a considerable literature within the social science disciplines that we have not included in this review. The following discussion should therefore be regarded as only an introduction to this broad subject.

The literature from 2000 builds on and extends the discussions of the 1990s. Some of the literature is highly theoretical (eg Hamlett 2003, Elam and Berttilsson 2003) while other papers are more pragmatic (eg Braun 2002, Moore and Breithaupt 2000) or merely descriptive (eg Gaskell et al 2000). Debates about genetically modified food have dominated the literature, but attention is now shifting to other technologies where regulation is seen to be necessary (eg xenotransplantation and genetic testing).

3.2 Emergence of the science citizen

Policy responses to biotechnologies have changed over time from acceptance of self-regulation by science, to a more active role for government (Cantley 2004). In addition, there has been an increasing call from the public for science policy decisions to pay more attention to the concerns of the wider public. While this call has been particularly acute in countries that have had particular crises in science policy to contend with (such as the BSE scare in the UK), it is a call that is also heard elsewhere as other political and cultural changes contribute to changing understandings of authority (including that of science), and to various models of the democratic citizen.

Following the increasing rejection in the late 1990s of the ‘deficit’ model of public engagement with science (which assumes that more and better understanding of the science will resolve the policy difficulties and political resistances to particular technologies), there is a continuing reflection on how the public, or democratic citizens, can participate in science policy decisions.

This has included questioning the underlying assumptions about what forms of knowledge are relevant, what model of democratic citizen is appropriate, who should be involved in deliberations, and what mechanisms and processes are most appropriate. Policy makers must make decisions, but who should be involved, and how? Clearly, expertise is required (scientific but also on occasion ethical and legal), yet given that policy and regulatory decisions require more than technical considerations, how should the wider public or democratic citizen be involved? And at what stage in the decision-making process — in constructing or framing the issues; in providing information about their views; in interpreting the significance of technical knowledge; and/or in shaping political responses? And using what mechanisms? (Hamlett 2003, Goven 2003, Irwin 2001, Elam and Bertilsson 2003).

In parallel with the political move to explore various forms of participatory democracy, there has also been an increasing use of bioethics advisory bodies to advise government, or charged to develop a consensus response. Kelly (2003) offered a discussion of the role of ethics committees as ‘boundary organisations’ where competing claims to authority in science policy can be negotiated, and Dzur and Levin (2004) explored the extent to which the public are able to be involved or their issues considered when the conversations of an ethics commission function at the expert level.

Alongside these discussions about political decision making is a parallel concern with ‘science communication’. Writing in this area reflects the tension between two models of science communication — science communication whose primary aim is to enhance public understanding of science (the ‘deficit’ model) (Norlin 2004), and science communication that emphasises two-way communication, and the enhancement of dialogue and public engagement (Winter 2004, Hails and Kinderlerer 2003, Arntzen et al 2003). There have also been critiques of media reporting of public debates in biotechnology (Dixon 2003) and analysis of the debate as played out in the media (Neresini 2000). Wachelder (2003) reported on Dutch Science Shops, an initiative dating from the 1970s, which provides a link between science and other social actors. Their development and shape has changed over time in response to institutional support and political context.

3.3 Issues to consider in designing public engagement

When choosing or designing methods for public engagement, there are both conceptual and practical considerations to take into account if one's method is to achieve what one intended.

Irwin (2001) identified a range of issues to consider in planning a consultation exercise. What institutional and political constraints and negotiation is one working with? What is the agenda and whose questions (those of the policy makers or those of the public) are being asked? Is the agenda led by the citizens, or is its purpose to inform policy that is already shaped in some way? What outputs are likely to be seen as useful? What time frames are involved? Is the engagement structured as a research project (to get information for the decision makers, or is it an exercise in democracy and citizen participation)? Similar issues were raised by Goven (2003), Hamlett (2003), Dietrich and Schibeci (2003), and Elam and Bertilsson (2003).

Rowe and Frewer's (2005) typology for public engagement mechanisms offered three concepts of engagement or public participation:

- Public *communication* — in which the citizen is a passive recipient of information.
- Public *consultation* — in which information also flows to the sponsors of the engagement from the public.
- Public *participation*. — in which to the public is involved in a two-way dialogue.

The choice of *method* of public engagement is huge and needs to be matched to the purpose of the engagement, and the role for the public in decision-making.

3.4 Some recent examples

Genetically modified food continues to be a focus of reports of surveys on public attitudes to technologies (Bucchi and Neresini 2004, Gaskell et al 2000, Morris and Adley 2001, Dietrich and Schibeci 2003) and attempts at public engagement. For instance, Barbagallo and Nelson (2005) noted the structure of the UK *GM Nation?* experiment in public engagement. This included nine foundation workshops; a three-tier program of debate (six national and regional conferences, smaller county-level meetings, and local meetings); a research component to go deeper into selected issues (‘narrow-but-deep’); official stimuli material; and a website where people could post comments and read about the progress of the debate.

Morris and Adley (2001) described the Irish consultation in developing its policy in GM food. After a call for submissions, they allowed for a two-day consultation debate, with a panel of stakeholder representatives (industry, science and NGOs) picked from those who responded to an advertised call for submissions. These partook in debate sessions chaired by an independent panel. There were severe problems ending in a boycott of the final day by most NGO/pressure groups.

As experience of methods of public engagement increases, more evaluations of initiatives are being reported (Rowe 2000, 2004, 2004a), and it is becoming possible to make comparisons between initiatives. Einsiedel et al (2001) compared the use of consensus conferences on food biotechnology in Denmark, Canada and Australia and Goven (2003) provided a critique of the consensus conferences on food biotechnology in New Zealand in the late 1990s. Such comparisons allow identification of similarities and differences, and the linkage of these to contextual issues in each country. In Australia and Canada recruitment for the conferences was via advertising and then interview, leading to selection of 14 lay participants. The Denmark Board of Technology recruited by letter from a randomly selected pool of adults. Einsiedel and Eastlick (2000) discussed the Canadian experience in more detail.

However, areas of biotechnology other than genetic modification are also the focus of initiatives in public engagement (eg xenotransplantation and protection of human genetic information).

In their enquiry, *The Protection of Human Genetic Information*, the Australian Law Reform Commission took the view that one objective was to promote community education and debate about the technologies involved, and that this was not an area to be left to experts, industry, professional or interest groups. In addition to providing information, they planned public forums and targeted meetings with a range of professional, interest and community groups (Weisbrot 2003).

In Canada in 2000, the Public Health Association (CPHA) was contracted to conduct a public consultation on xenotransplantation. This project used four tools: a general population survey of 1519 randomly selected people; a survey mailed to ‘stakeholders’; a web-based survey; and six regional forums using a citizens’ jury model. The forums took the form of 20 randomly selected people spending a weekend together, with presentations from transplant recipients and experts, questioning, and discussion. Einsiedel (2002) systematically assessed

the effectiveness of the forums, considering the institutional arrangements, process, representativeness, accessibility to resources, deliberation, and outcome criteria of learning, participant satisfaction, extension of public information and debate, and policy influence. Wright (2004) offered some critiques of the CPHA's interpretation of the fora results, and Allspaw (2004) reflects on how the Canadian model could be useful in the US situation. (When read alongside other literature that predominantly comes from the European context, this paper provides an illustration of the effect of the political context on how engagement with the public is understood.)

4 Planning a public/stakeholder consultation

4.1 Introduction

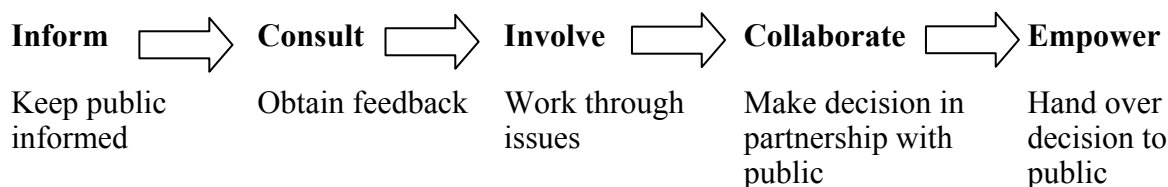
In the light of the increased interest in developing a more meaningful dialogue between scientists/ policy makers and the broader community, several guides have been prepared to bring together the available information on citizen participation from other disciplines, as well as from the existing experience with science and technology, particularly biotechnology. Some of these have already been mentioned in Section 2 of this review but for the purposes of this section, I have selected two publications prepared by the Citizens and Civics Unit, Western Australian Government:¹⁸

- *Consulting Citizens: A Resource Guide* — guidelines for government agencies undertaking consultation. The guide was developed in a consultative manner drawing on the experience and input of people from government departments, nongovernment agencies and the community. In particular a public forum on consultation practice was held in 2001.
- *Consulting Citizens: Planning for Success* — a planner for public participation programs that are appropriate to issues and objectives.

While these guides have not been prepared specifically for developing and running public consultation programs for science and technology issues, the advice provided is readily transferable to science issues and accords well with the evaluation comments already emerging from the public engagement in science activities described in Section 2 of this review. The advice in these guides is also similar to the process described by the Research Councils UK and Office of Science and Technology (2002) in their publication, *Dialogue with the Public: Practical Guidelines* (see Section 2.2), and by the New Zealand Ministry of Agriculture and Forestry in *Guidelines for Effective Stakeholder Consultation*.

4.2 Planning

The guides outline the reasons why public participation is important and provides some guiding principles for engaging citizens (commitment, maintenance of citizen's rights, clarity of purpose, timeliness, objectivity, resource use, coordination, accountability, and evaluation). It describes a spectrum of involvement of the public in decision making from being kept informed to making the decision, on the following spectrum:



The failure of many consultations can be traced back to lack of clarity about why the consultation was being held. Before starting a consultation, it is therefore important to carefully consider the purpose of the consultation and other important parameters.

¹⁸ <http://www.citizenscape.wa.gov.au/index.cfm?fuseaction=ccu.publications#publications>

Checklist of issues to consider:

- Why are we planning a public participation exercise for this issue?
- Are the parameters of the issue clearly defined and able to be articulated to all who will participate?
- Are we clear about what is negotiable and what is not?
- What are the impetus and drivers of the issue and of the consultation?
- What do we hope to achieve through public participation?
- What is the decision being made?
- Who will make the decision?
- What will be done with the information gathered?
- How much influence will the public have on the final decision and what role will they play in the decision-making process?

Identify the issue

It is important for all involved to understand the issue under consideration. This can involve a preliminary stage of public participation to identify the issue. The issue should be identified from the perspective of both the consulters and of the critical stakeholders. This may require consideration of:

- drivers (eg legislation drafting, use of technology)
- history (factors relevant to the development of the issue)
- values/ideology (eg social impact, safety, cost).

Consideration of these factors provides a ‘frame’ for the issue and, in the case of science and technology discussions, ensures that the frame includes social values and feelings as well as the scientific imperative.

In addition, it is important to consider the language that will be used in the consultation, because lack of a common language can be a significant barrier to effective communication. Therefore, some preliminary work may be required to identify where language problems might occur, and work with a representative group of potential participants to develop a common language to use (see also Section 2.2 for description of a British Association project on ‘common language’).

Finally, some consideration of any potential for controversy is helpful, especially for issues with significant impacts for some stakeholders or with a known history of controversy.

Having considered these issues, the Western Australian guide recommends writing a 1–2 sentence statement defining the decision or issue to be considered. If the issue is too large to be addressed within the time and resources available, it may need to be broken into smaller units.

Determine the objective

Ask ‘What do we want to achieve?’

Examples: develop policy, decide between options, gain consensus, discuss issues, resolve issues, provide information.

It is also vital to decide what, in the pursuit of the objective, is negotiable and what is not — that is, what aspects can be changed as a result of the consultation. These decisions have a significant affect on the level of participation sought.

The objective should be SMART:

- Specific
- Measurable
- Achievable
- Realistic
- Timely

Determine level of participation

There are numerous methods that can be used to engage the public. For example, the Citizen Science Toolbox, developed initially for consultations about environmental issues, has instructions for running more than 60 different community involvement activities, from public meetings to consensus conferences.¹⁹ However, the most suitable approach will depend on the level of participation required. Table 2 shows some the level of involvement for a range of activities.

¹⁹ <http://www.coastal.crc.org.au/toolbox/index.asp>

Table 2 Public participation spectrum

	Level 1 Inform Educate	Level 2 Gather Information	Level 3 Consult	Level 4 Involve	Level 5 Partner
High					
Citizen engagement					
Citizens' juries	•	•	•	•	•
Citizens' panels	•	•	•	•	•
Consensus conference	•	•	•	•	•
Deliberative opinion polling	•	•	•	•	•
Search conference	•	•	•	•	•
Study groups	•	•	•	•	•
Sustainable community development	•	•	•	•	•
Charrette	•	•	•	•	
Representative groups	•	•	•	•	
User panels	•	•	•	•	
Round tables	•	•	•	•	
Consultation					
Advisory committees	•	•	•		
Computer-assisted participation	•	•	•		
Interactive WWW/E-conference	•	•	•		
Online discussion groups	•	•	•		
Focus groups	•	•	•		
Workshops	•	•	•		
Community or public meetings	•	•			
Parliamentary committees	•	•			
People's panel	•	•			
Polling	•	•			
Public hearings	•	•			
Questionnaires and surveys	•	•			
Workshops	•	•			
User comments and complaints	•	•			
Communication					
Advertising	•				
Calls for submissions	•				
Fact sheets	•				
Exhibitions	•				
Information kits	•				
Mail-outs	•				
Media events	•				
Open days	•				
Press releases	•				
Low					
Site visits	•				

Adapted from Health Canada, 2000, Policy Toolkit for Public Involvement in Decision Making

Identify participants

The form of consultation is also influenced by who needs to be included:

Identify stakeholders:

- who is responsible for the issue?
- who might be affected by the issue?
- who are representatives of those likely to be affected?
- who can make a contribution?
- who is likely to mobilise for or against the issue
- whose absence will detract from the result?
- which government departments have an interest in the project?

Will consultation be only stakeholders or also involve the general public?

Stakeholders are representative groups. Stakeholder representatives may be required to put forward a set position. They may have little room to move or negotiate.)

Citizens are members of the public who are acting as deliberators. Their role is to debate and deliberate, considering the interests of the community above their own interests.

Methods

The Resource Guide includes a list of over 20 methods that can be used. The Science Citizen's Toolbox includes over 60 methods.

In the light of the international 'science in society' discussion (see Sections 1 and 2), a process that involves interactive dialogue between stakeholders would be the most effective (such as workshops, roundtables, online discussions etc).

Link objectives to an evaluation plan

Good evaluation brings benefits to both the organisers and those who have participated. Also, thinking about how to evaluate objectives helps to further clarify objectives.

Prepare a plan

The guide suggests writing a plan of the process decided upon.

Appendix 1 Search strategy

The review has been based on reports and information collected over the past five years in the course of the work of Biotext (science information consultants), attendance at national and international science communication meetings and personal discussions with personnel in Australia, Ireland, UK and New Zealand.

In addition, for the preparation of this report we have conducted a number of searches of the literature from 2000 – present (June 2005) as follows:

General websearch (Google)

Google was searched using combinations of the following search terms:

- public understanding science (or biotechnology)
- public engagement science (or biotechnology)
- public consultation science (or biotechnology)
- stakeholder consultation science (or biotechnology)
- science in society
- dialogue
- consensus conference
- science citizenship.

In each case, the number of hits was very high and so only the top few pages were examined in detail.

Searches also focused on specific countries known to have undertaken work in this area (eg UK, Canada, European Union countries, United States, New Zealand).

Hand searching of specific journals

Some journals known to include information relevant to this review were searched by hand from 2000–present (June 2005):

- *Public Understanding of Science*
- *Science, Technology and Human Values*
- *Current Opinions in Biotechnology*
- *Science Communication*.

Bioethics journals were not searched individually as the focus of these journals is on the ethical issues rather than on public consultation. Some relevant articles were picked up through the MEDLINE search (see below).

MEDLINE

MEDLINE was searched via PubMed for 2000–present (June 2005) using combinations of the following search terms:

“Public Opinion” (MeSH), “Attitudes to Health” (MeSH), dialogue, public consultation, stakeholder consultation, bioethics, biotechnology, GM.

Inclusions/exclusions

Only articles that were about the process of public or stakeholder consultation were included. Articles about public opinion per se, ethics or the technologies themselves were excluded.

Owing to the short timeframe available for this research, if the abstracts were not available for review and it was not obvious from the titles that articles included useful information about the *process* of public engagement in science issues, the articles were also excluded.

This review should therefore in no way be considered to be systematic.

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