

Session 3 Science, policy and people

Giskin Day

Sir Aaron Klug, speaking in 2000 as President of the Royal Society, said,

'Dialogue is about science's licence to practice. Science is, necessarily, run by scientists but it ultimately society that allows science to go ahead and we need to make sure that it goes on doing so. So we need input from non-experts to make sure that we are aware of the boundaries of our licence.'

Policy-making is essentially a boundary-setting exercise. Therefore, in order to realise Klug's pro-dialogue stance – which resonates with a wider call for a democratisation of decision-making activities – public involvement in policy becomes imperative.

The mantle of responsibility of the policy-maker is not borne lightly. Decisions made about the regulation of science and technology, priorities for investment, and standards setting, all have material consequences for both science and society. The drivers for policy have always been a complex combination of politics, economics and ideology, but it is fair to say that, in the UK at least, the watchwords 'transparency' and 'accountability' have heralded a renewed focus on the *process* by which policies are formulated.

The factors that underpin this shift in emphasis are embedded in a complex matrix of issues, many of which have their roots in a restructuring of traditional, and never entirely separable, areas of endeavour. Wilsdon and Willis (2004) point to the break down of divisions between academia, commerce and politics as contributing to a climate in which science no longer has an automatic claim to authority. Science has been implicated in a number of controversies, such as Bovine Spongiform Encephalopathy (BSE), the measles, mumps and rubella (MMR) vaccine and genetic modification (GM), and these have exposed weaknesses in the application of expert knowledge to problems that are suffused with politics and economics. A reliance on big business to fund innovation has fuelled scepticism from some scientists and non-scientists about the motivations of scientists. The image of the altruistic scientist working for the good of humanity is incompatible, in the imaginations of at least some members of the public (others might celebrate these developments), with the gleaming hi-tech environment of the modern laboratory, in which fame and fortune beckon to those who can come up with the latest breakthrough.

Much of cutting-edge, twenty-first century science involves using technology to manipulate living processes. These ethically fraught areas of research hold out the promise of great benefits, but they also carry risks which are difficult to anticipate and control. It is legitimate, therefore, to ask questions about how, and if, this research should proceed, and whether, as a society, we are comfortable about the direction in which science is heading. A prominent means of giving scientists a 'licence to practice' is to promote organised initiatives under the banner of 'public engagement with science'. This article examines some of the trends associated with this movement and encourages you to look critically at examples of engagement activities in the UK.

A more nuanced understanding of risk

Sociological research into the perception of risk has given us an insight into the shortcomings of number-crunching as a basis for policy making. Statistical probabilities and traditional risk-benefit analyses tell only part of the story. It is now appreciated that contextual factors that defy quantification place parameters

around what people are prepared to recognise as acceptable risk. These are often rather loosely termed 'values'. This does represent a real change from the past in which 'rational thinking' involved rejecting any so-called subjective factors in favour of ostensibly objective calculations of probabilities and perceived economic outcomes. It is now appreciated, although not by everyone, that decisions involving values, be they moral, cultural or (a)religious, are not necessarily inferior to those based purely on risk–benefit analyses. To the contrary, the taking into account of values is seen as more realistic and beneficial to robust decision making. However, given that values are usually deeply personal, consensus may be harder to reach – and impossible in some cases. This poses a seemingly intractable problem for policy making, adding further layers of complexity to issues that rarely had a single resolution in the first place.

For policies to receive broad public support, they must be seen as being fair. If technological innovation causes risks and benefits to be inequitably distributed (in other words, some people benefit while others are disadvantaged), policy can serve as a corrective, putting guidelines in place to encourage maximum benefit to society as a whole. On what basis are decisions about the public good made, and how is scientific evidence integrated with other less-tangible agendas?

Activity 1

In 2006, there was considerable outcry over a decision by the National Institute for Health and Clinical Excellence (NICE) to limit the use of some drugs to treat early dementia as their benefits could not be conclusively scientifically established. You can read more about the controversy, and find links to other information, here: <http://news.bbc.co.uk/1/hi/health/7129623.stm>.

NICE is charged with a deceptively simple remit: allocate health-care resources in England and Wales based on evidence-based assessment; in other words, establish which drugs offer the best value for money. It uses the 'quality-adjusted life-year' (QALY) as a measure to assess treatments by their effect on both length and quality of life. Cost per QALY allows NICE to compare value for money across populations and age-groups. On the face of it, this process seems an eminently rational way of addressing the problem of prioritising spending for greatest benefit.

Now read Jonathan Michaels' article, 'Improving NICE's social value judgements' in *British Medical Journal* (2006, **332**, pp. 48–50).

(<http://www.bmj.com/cgi/reprint/332/7532/48?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=NICE+value&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT>)

Michaels flags up a number of shortcomings and benefits of the cost–utility mechanism. Which 'values' are identified by Michaels as confounding NICE's approach?

Part of NICE's response to criticism has been to undertake a public consultation on exactly the types of issues articulated by Michaels (and others). You can read the consultation document here

(<http://www.nice.org.uk/aboutnice/howwework/socialvaluejudgements/SVJconsultation.jsp?domedia=1&mid=8B4C7211-19B9-E0B5-D43EC713540B6AB4>) and participate in the consultation by submitting any comments you may have (the consultation ends on 7 March 2008).

Ultimately, NICE represents something of a throwback to a policy-making process made as 'objective' (and some would say 'reductionist') as possible. However, making public the principles by which decisions are arrived at (and emphasising

the findings of their 'Citizens Council'), NICE aims to make the process more 'open' and 'transparent', both of which are important conduits for increasing levels of 'trust'.

Apparent in the NICE controversy is the vociferousness, and influence, of patient groups. The identification of stakeholders is an important part of modern policy making, which leads to the next trend identifiable in inclusive science policy-making: the role of 'expert' is no longer conferred only on scientists.

Towards a more inclusive definition of 'expertise'

Experts in matters relating to science and technology have traditionally been viewed as those with special training and a degree of recognition in a particular field. A seminal study was carried out by Brian Wynne (1995) on the communication (or, more accurately, the lack of it) between scientists advising Cumbrian hill farmers on the likely effects of the fallout from the 1986 Chernobyl nuclear accident. Wynne found that the scientists' unwillingness to acknowledge 'local' expertise – on matters such as sheep feeding patterns and soil conditions – had a long-lasting, highly damaging effect on management of the crisis. Farmers' expertise went unacknowledged, and there was little means of challenging the perceived automatic authority of scientists to command the knowledge base. Scientists were perceived as arrogant and unwilling to appreciate that science could not be separated from its local context. In the Cumbrian example, clearly a more inclusive concept of expertise was warranted.

When users of technologies or patient voices are involved in policy-forming committees, they often bring to the table an experiential expertise that can contribute substantively to debate. Contributing to this trend is the increased accessibility of academic knowledge on the internet. Laypeople are able to acquire academic expertise (a 'body of knowledge') far more easily than ever before. It is experiential knowledge, which one cannot acquire through accessing research, that is now at a premium.

The picture becomes murkier when 'lay' voices specifically are called for, i.e. a role is defined by a deliberate *lack* of expertise. Sarah Dyer (2004) has been prominent in questioning the conceptualisation of lay members as independent from experts. She found that lay members were often interested in participating in local research ethics committees because they were retired or career-break health professionals. Their considerable formal expertise and experience made their 'lay' status seem rather dubious. Similarly, 'expert' members were frequently called upon to evaluate research that fell outside their specific competencies.

The inclusion of lay voices is habitually justified on the basis that it demonstrates openness in decision-making, confers legitimacy on decisions, ensures probity and provides oversight, and safeguards public interest by bringing in views of people who have neither professional self-interest nor commercial links to industry (Hogg and Williamson, 2002). Based on these rationalisations, lay representation on policy committees is open to accusations of tokenism and political correctness because the mere presence of a lay representative, rather than any input they may make, is assumed to serve as some sort of guarantee of non-partisanship. In reality, lay representatives may well bring a range of competencies to the table, and 'experts' draw on life experience rather than professional competence to provide input to policy. The lay–expert dichotomy is a somewhat fallacious distinction in this scenario.

So how, then, do we make provision for public input into policy making that transcends a purely procedural function? Engagement activities that give a substantive voice to laypeople may be a credible alternative to committees in which unrealistic roles are conferred on individuals.

Activity 2

One of the most innovative initiatives has been 'Nanojury UK' which set out to present a non-specialist perspective on nanotechnology, in the interests of 'broader democratic control over the development and global regulation of new technologies'. Explore the Nanojury website (<http://www.nanojury.org.uk/index.html>), looking particularly at the sections on 'perspectives' and 'the future'. Note down what you perceive to be the strengths and weaknesses of this method of consultation. How might you characterise the relationship between laypeople and experts in this context?

You may wish to compare this initiative with others in the government's programme of engagement in nanotechnologies, available here (<http://www.berr.gov.uk/files/file27705.pdf>).

Although the Nanojury exercise has not had a measurable impact on policy, at least not yet (2008), it clearly had a transformative effect on some of the lay participants, who joined 'Right to be heard' (<http://www.ncl.ac.uk/peals/dialogues/r2bh.htm>) which advocates for participatory processes as a means of addressing what are perceived to be social injustices.

Representation

One of the criticisms levelled at deliberative methods such as policy committees and citizens' juries is that only a small number of participants are involved. The outcomes of these activities are sometimes viewed as less legitimate because they do not statistically represent 'the public'. Proponents such as Tom Wakeford (2002) argue, however, that the process of deliberation allows conclusions over what are often complex issues to be of greater validity when compared to the instantaneous reactions of citizens delivered by closed questioning ('yes' or 'no') during opinion polls.

Scientists and policy makers are understandably worried about knee-jerk, precautionary reactions to new technologies, where the risks may appear disproportionate to the benefits until the underlying science is explained. And the process of democratising science is fraught with the same types of problems that face any other enterprise in search of a mandate: which voices should count? Should those that are interested enough in the issue to participate in consultation exercises (i.e. what marketers might call 'attentives' and 'activists') have a greater say, or should a poll of a statistically representative sample of the public – necessarily a rather blunt instrument – provide a firmer basis for lay input into policy?

Activity 3

The Human Fertilisation and Embryology Authority (HFEA) has run a number of public consultations involving a variety of participatory methods. In 2007 a public consultation was held on the ethical and social implications of creating human/animal embryos in research. The consultation involved a public meeting, a written consultation exercise with responses gathered via an online questionnaire, and an opinion poll. There was also a deliberative consultation, in which 12 groups met in different parts of the country. Participants were told about different types of human–animal embryos and the science behind them, and initial reactions were gathered. Half of these participants, chosen at random, were then

invited to attend a workshop in which expert speakers were involved and the issues were debated.

Read the report on the consultation *Hybrids and Chimeras* (http://www.hfea.gov.uk/docs/Hybrids_Report.pdf) and note the different profiles of respondents for the types of consultation.

The opinions from the different types of consultation are given different weightings in the HFEA's final decision. Consider the reasons given in the report for prioritising some of the results over others. Do you agree with the conclusions reached about how to incorporate the consultation into policy? Can you identify flaws in the way the consultation was set up which led to certain of the results being discounted?

You may wish to read the consultation document produced by the HFEA to explain the background to the proposed research (http://www.hfea.gov.uk/docs/HFEA_Final.pdf).

Upstream engagement

One of the highest profile public engagement exercises, was *GM Nation?*, a multi-tiered, national consultation on the growing of genetically modified crops. The results of the public consultation had no appreciable effect on policy, much to the chagrin of at least some of those involved. One of the many criticisms leveled at the consultation was that it took place too late to be able to influence the trajectory of a technology to which government and industry were perceived to already be irrevocably committed. A corrective to this has been a newfound enthusiasm for 'upstream engagement' in which the consultation process takes place in advance of decisions being made about development (see Wilsdon and Willis; 2004; Stilgoe, 2007 for discussion).

Upstream engagement faces a particular challenge in providing an evidence base with which to inform decision making. If technologies are not yet developed, a great deal of uncertainty must surround potential applications or possible risks. It becomes difficult to distinguish between information and speculation.

Activity 4

The Sciencehorizons programme ran from January to July 2007, under the auspices of the Horizon-Scanning Centre within what was then the Office of Science and Innovation (OSI).¹ It consisted of a three-part process, involving a deliberative panel, facilitated public events and small group discussions based on a number of scenarios set in 2025.

Choose a theme here (<http://www.sciencehorizons.org.uk/interactive.asp>) and look at the materials provided to stimulate discussion and the questions asked on the response form. Does the design of the consultation deliver the type of information that could usefully inform policy making?

Read the summary of the results here (http://www.sciencehorizons.org.uk/resources/sciencehorizons_summary_report).

¹ The OSI has become the Government Office of Science, which now sits within the Department for Innovation Universities and Skills.

[pdf](#)). If you were charged with proposing policy on the theme you chose, how might the findings inform your decisions?

Conclusions

In this short article we have looked at a small selection of some of the many public engagement activities being undertaken across the UK that aim to inform science policy. What emerges from these examples, is that policy makers are enthusiastic about the process of public engagement, but are sometimes less enamoured of the results. Where multiple strands of consultation have been offered, almost invariably, the findings of deliberative groups, in which experts have a chance to engage in dialogue with participants, are given more weight than consultations involving large-scale public surveys or activities in which laypeople are given control of the framing of the terms of debate. Deliberative consultation tends to yield recommendations that are less precautionary. Cynics might say that proponents of new technologies have the opportunity to persuade lay participants of benefits and provide reassurance about risks. Criticisms of this ilk are countered by claims that participants in deliberative groups are better 'informed' than consultations which merely require an opinion or 'pit' experts against lay people in the semi-adversarial environment of a citizens' jury.

For public participation in science policy to be successful, it must address the contradiction at the heart of the democratising impulse. Lay participation as a response to public mistrust of experts is predicated on a wider spectrum of voices being fed into policy making in order to lend it legitimacy. Yet, consensus is often sought by these processes precisely because policies cannot be ambivalent or inclusive of all points of view. They must set clear frameworks, boundaries and procedures for scientific research. But as Dyer (2004) argues: 'To invest lay members with this kind of representative power assumes a moral consensus that is difficult to argue for in Britain today' (p. 43). She points out that lay participation is all very well as a response to perceived or actual public mistrust of experts, but enthusiasm for pluralism (what might be thought of as an emphasis on diversity) of our age is part of what has led to the legitimisation crisis in the first place. It is paradoxical, she says, that the response of lay involvement in decision making, should assume the very condition of moral consensus that contributed to the problem.

On a less philosophical level, public engagement activities are time-consuming and expensive. The UK currently lacks formal mechanisms of feeding the results of public engagement into policy. Reports are regularly presented to government, but it is difficult to link their findings to any obvious impact on policy making. The entire public engagement movement therefore risks being branded as meaningless unless there is clear evidence that results count.

Few would disagree that meaningful public engagement is an ideologically sound response to the changing conditions in which scientists now conduct research. The challenge remains to find innovative ways of putting this into practice. Anyone for a debate?

References

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- Hogg, C. and Williamson, C. (2001). Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees, *Health Expectations*, **4**, pp. 2–9.

Klug, A. (2000). Address of the President, Sir Aaron Klug, O.M., P.R.S. Given at the Anniversary Meeting on 30 November 2000, *Notes and Records of the Royal Society of London*, **55**(1) (Jan., 2001), pp. 165–177.

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Wakeford, T. (2002). Citizens juries: a radical alternative for social research, *Social Research Update* **37**. (Guildford: University of Surrey).

Wilsdon, J. and Willis, R. (2004). *See through science: why public engagement needs to move upstream*. (London: DEMOS).

Wynne, B. (1995). Misunderstood Misunderstandings: Social Identities and Public Uptake of Science, in Wynne, B. and Irwin, A. (eds.) *Misunderstanding science*. (Cambridge: Cambridge University Press).

Suggestions for further reading

Stilgoe, J. (2007). *Nanodialogues: Experiments in public engagement with science*. (London: DEMOS). Available at:
<http://www.demos.co.uk/publications/nanodialogues>.

This pamphlet presents the findings of the *Nanodialogues*. The *Nanodialogues* were a series of experiments in upstream public engagement with a range of partners working in different contexts.

Wilsdon, J. and Willis, R. (2004). *See through science: why public engagement needs to move upstream*. (London: DEMOS). Available at:
<http://www.demos.co.uk/publications/paddlingupstream>.

This pamphlet explores the ways in which citizens can expose to public scrutiny the assumptions, values and visions that drive science. In so doing, it provides a rationale for moving public engagement upstream as novel science innovations begin to emerge, then continuing these deliberations downstream.