Expectations in transplant innovation
26th Feb 2003
Council Rooms, Medical Research Council

Overview of workshop discussion

Introduction

The seminar was designed to bring together a range of stakeholders to discuss some recent social scientific findings concerning the role of expectations in transplant innovation. Two papers based on current research were presented:

- Xenotransplantation: risk identities and the human nonhuman interface (supported by the Economic and Social Research Council) – Mike Michael & Nik Brown

- Deliberative Mapping: citizens and specialists informing decisions on organ transplant options (supported by the Wellcome Trust) – Jacquie Burgess, Gail Davis, Malcolm Eames, Suzanne Williamson, Andy Stirling and Sue Meyer

Dr Paul Martin (University of Nottingham) as discussant explored some of the broader issues relating to the function of expectations in wider biomedical innovation.

Prof. Andrew Webster (York University) provided the concluding remarks.

The session generated a lively and interesting discussion. What follows is a summary of some of the key points that emerged in the course of the afternoon, and, as means to stimulating further discussion, a bullet point listing of core issues.

Xenotransplantation - Nik Brown

Nik Brown's paper illustrated some of the ways in which participants from a number of constituencies envisioned the expectations surrounding xenotransplantation. He noted that expectations about biomedical innovation are usually more optimistic for those 'furthest away' (in time and space) from the source of innovation (laboratory science, etc).

For example, while some lab bench scientists were highly uncertain about the prospects of a transplant innovation technology such as xenotransplantation or stem cells, other professionals (surgeons, etc) were often far more positive about the future of the technology. Members of the public who had no investment in xenotranplantation were also rather positive about these developments, though were surprised when some of the risks were raised. Other members of the public with an interest in these innovations, specifically patients with Parkinson's disease, were circumspect in their expectations, being highly sensitive to and critical of premature announcements of success.

This variation was analysed with the aid of a heuristic model – the 'trough of certainty'. Accordingly, actors close to the *point* of innovation were very aware of its uncertainties, as indeed were those opposed to the technology or committed to other technologies. Potential users were altogether more certain – that is, they are located in the trough of certainty. However, obviously this varies, such that the bell shape of the trough becomes constricted and over time fewer and fewer groups are confident about the prospects of an innovation. For example, accumulated experience of disappointment that came with premature announcements of success meant that potential users such as Parkinson's disease patients had learnt not to hold great expectations, even about relatively new innovations like stem cell applications. This raised the question that perhaps some form of quality control for expectations was needed, or certainly some way of building uncertainty into discussions about technological innovation.

In discussion the following key points emerged:

- That much of respondents' discourse tended to focus on the technical – whether an innovation was technically feasible. More social futures around issues of species change, animal welfare and social identity were not articulated. It was suggested that possibly this lack of attention to the social dimension of the expectations reflected the trust in regulatory processes – the social had been absorbed by the 'powers' that be, leaving only technical feasibility as the unknown factor in expectation.
- The fact that patients were reticent about their expectations and in fact didn't want to know about innovations unless relatively imminent was unexpected. This was a reaction to the overstatement of expectations found in the press (and the fact that press releases were in actuality directed at a small constituency including potential backers, but actually reached much broader publics). However, over-expectation is also productive in mobilising research, not least in government where initiatives were driven by hot topics and imminent breakthroughs. The discussion suggested that, generally, patients' expectations often vacillated (flip-flopped) – sometimes they were highly expectant, at other times highly sceptical.
- The notion of 'trough of certainty' and its changing shape over time suggested that there might be particular moments when technological innovation would be more acceptable or credible. It would be interesting to see what lessons could be learnt in identifying or predicting those moments where particular constituencies were especially 'certain' and thus open to more productive dialogue.

Deliberative Mapping - Gail Davis, Malcolm Eames, Suzanne Williamson

Deliberative Mapping was outlined as an approach to public consultation in the assessment of technology. Integrating citizens' and specialists' appraisals, it is an inclusive process that involves both deliberative and quantitative dimensions, aims for rigour and transparency, and encourages social learning between lay people and experts. Importantly, it is oriented toward the mapping of diversity that highlights uncertainty. In the analysis of experts' assessments of organ (kidney) transplant options, xenotransplantation and embryonic stem cell technologies fared particularly badly; improved transplant services and encouraging healthier living were the favoured options.

Similar results emerged for the citizens' panels, though there were noticeable gender differences. Thus, one women's panel were most negative toward both embryonic and adult stem cell and xenotransplantation technologies, they were most positive toward improved transplant services and encouraging healthier living. Men's panels displayed similar patterns but there was more tolerance for the innovative technological options of embryonic stem cell and xenotransplantation. These evaluations were based largely on technical criteria such as viability, risk, value and availability. Social criteria such as would these developments offend people's were somewhat less important.

It was suggested that gender differences in citizen assessments (which were largely technically framed) reflected diverging views of the impact of long-term high-risk technologies. For women, investment in these options detracted from the immediate needs of the here and now. As such, this was a more socio-political evaluation about how investments in technological options operated (zero-sum?). For men, such long-term high-risk technologies were an investment into the future: options were kept open. However, overarching all of these assessments was a fatalistic view that these options would be pursued by somebody somewhere.

In the discussion, the following points were particularly prominent:

- In the sessions that brought specialists and citizen panellists together, the latter were readily able to challenge the former. However, in terms of social learning, the specialists appeared to have learnt from other specialists rather than from citizens.
- It was again noted that citizens tended to evaluate the options in terms a technological frame (viability, risk etc) while social considerations were less important. It was suggested that this might be due to the fact that social dimensions were already assumed – that these were taken into account by citizen-respondents.

- There was some concern over the salience of transplant options as a topic for deliberation. A parallel was drawn with road safety: transplant options, and xenotransplantation, had the same generally low priority of road safety and thus that the citizen engagement with this topic was rather artificial. It was suggested that these topics were important in the context of risk migration – that risks about one area migrated into another area (eg GMOs into xenotransplantation). As such the risks attaching to xenotransplantation and embryonic stem cells were both indicative of broader risks and could serve to index risks in other areas.

Expectations in Wider Biomedical Innovation - Paul Martin

Expectations are not peripheral in the context of biomedical innovation but absolutely central to it. They serve in the mobilization of resources, winning support and testing scenarios. Expectations thus create the future in the present and can be found in, for example:

- scientific literature & the design of experiments and trials
- firm strategies and investment decisions
- social concerns and ethical debates.

In the case of gene therapy, there was over-expectation about its feasibility: the expectations of patient and regulatory constituencies were raised only to be dashed when efficacy could not be demonstrated and risks around the use of retroviral vectors were realised. This is one particular cycle of expectation and disappointment, but these cycles will vary across cases.

How could the harm done to gene therapy be avoided? Assess expectations by:

a. evaluating how realistic expectations are
b. checking on the means by which expectations are monitored
c. examining the values that are embedded within expectations.

The discussion featured the following points:

- Cycles of expectation and disappointment were highly variable. The furore around a new innovation might fade over time so that it returns with less fanfare and quietly becomes established (eg allotransplantation, IVF, vaccination).
- Expectations of interest (e.g. patients) groups are important and serve in setting research agendas. There is a balance to be had between the diffuse anxieties of general publics and the intense needs and concerns if specific users. This raised the issue of the nature of the citizen.
- To pursue the idea of managing expectations, it was necessary to ask who did the managing and what levels of expectation, uncertainty, wisdom, hope and so on would be 'correct'. While it might not be possible to specify or reach a consensus about such levels, it was possible to engage in the process of reviewing, deliberating and consulting over the context of uncertainty: that uncertainty, contingency etc were always part and parcel of innovation and decision-making had to accommodate these.
- It was suggested that it might the case that sometimes institutions (eg the government) do not need to engage in such consultation processes, especially when expectations were particularly vibrant and able to mobilise resources especially effectively. One way of overcoming the dangers of this was through a process of horizon scanning – being attuned to the possibilities of things going wrong (or going better than expected) and modulating the rate of technological development accordingly.

Concluding Remarks – Andrew Webster

Each of the papers had sought to better understand the problems presented in the relationships between innovation and expectations. Particularly, in respect to decision-making by policy makers (appropriate regulations), the market (wise investments) and consumers (who to trust).

These are far from being 'abstract' or rarefied concerns but, rather, affect the way in which people build expectations into the context of their biographies, especially at times of illness and crises. The accounts of Parkinson's disease patients in the first talk by Nik Brown were illustrative of this.

Likewise, uncertainties have differing values across a wide range of actors. These notions of position or location within the knowledge economy of expectations are useful here. Whilst distance from science and the source of innovative knowledge can lead to hype, it can also damage trust. That is, it can result in negative or alienated uncertainty about science. Similarly, closeness to scientific work, where uncertainties are very acute, can yield a positive uncertainty, that recognises the limitations of innovation. We need therefore to see a better connection between expert and lay experiences of uncertainty and encourage experimental innovators to be more frank about their uncertainties.

A number of participants had expressed the view that it would be useful to have some way of modelling expectation such that it might become easier to navigate the expectations world. A modelling of this kind might also be able to spot differences between areas of innovative research (stem cells, xenotransplantation, gene therapy). That is, there are important and uniquely distinct features to each of these areas (their regulation, cycles of investment and development, relevant user constituencies) which will have differing implications for the expectations associated with them.

This raises a further question for us about whether it is possible to arrive at some kind of quality assurance for the futures and expectations that we are continually exposed to.

Participants:

Richard Ashcroft	Senior Lecturer in Medical Ethics, Imperial College
Nik Brown	Deputy Director of the Science & Technology Studies Unity, Sociology, University of York
Anne-Marie Campbell	Secretariat to the United Kingdom Xenotransplantation Interim Regulatory Authority, Department of Health.
Peter Doyle	Senior Medical Officer to the Department of Health's Transplant Team
Gail Davies	Lecturer in Geography, UCL
Malcolm Eames	Research Fellow, Policy Studies Institute
Simon Festing	Director of the Association for Medical Research Charities
Alasdair Kent	Director, Genetics Interest Group
Natasha Lane	Scientific officer, Research animals division, RSPCA
Gareth Lloyd-Jones	Director of Research, Smith & Nephew
Paul Martin	Institute for the Study of Genetics, Biorisk and Society, University of Nottingham
Robert Meadowcroft	Director, Parkinson's Disease Society
Mike Michael	Head of Sociology, Goldsmith's College, University of London
Michael Reiss	Professor of Science Education, Institute of Education, University of London
Jacqui Russell	Parliamentary Office for Science and Technology
Andrew Webster	Professor in Sociology and Programme Director, Innovative Health Technologies Programme (ESRC), University of York
Suzanne Williamson	Geography, UCL

13.30 – 13.45 **Dr Mike Michael** (Sociology, University of London)
Introduction

13.45 – 14.30 **Dr Nik Brown** (Sociology, University of York)
ESRC research on xenotransplantation & risk (plus 20min discussion)

14.30 – 15.15 **Dr Gail Davies, Dr Suzanne Williamson** (Geography, UCL) and **Dr Malcolm Eames** (PSI) Wellcome Trust research on decision-making on organ transplant options (plus 20min discussion)

15.30 – 16.15 **Dr Paul Martin** (University of Nottingham)
Discussant: Expectations in biomedical innovation (plus 20min discussion)

16.15 – 16.30 **Prof. Andrew Webster** (Director of the Innovative Health Technologies Programme, ESRC) Concluding remarks

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