

Xenotransplantation: Risk Identities and the Human/Nonhuman interface

Research sponsored by the Economic and Social Research Council

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This project sets out to explore how risk is understood and managed by different groups of people. Xenotransplantation (XT), the use of nonhuman tissues and organs in human transplantation, illustrates many of the questions and difficulties presented by modern healthcare technology. In particular, XT raises special issues about the changing relationships between humans and other species resulting from new biotechnological innovations.

The research team commenced their work in January 2000 and will conclude in the summer of 2003. This briefing paper offers a very short overview of the progress made in undertaking the research. It is aimed at all those with whom we have had contact so far and is therefore written with both specialist and non-specialist audiences in mind.

Fieldwork

As intended, the project has successfully completed three main fieldwork undertakings.

Literature review

First, the opening months of the project were concerned with collecting as much written material as possible and providing a list of these items on the project website. Materials included natural and social science documents, contributions from moral philosophy, regulatory documents, news items and general commentary. Company documents and industry reports were also archived. The purpose of this exercise was to provide a broad appreciation of the many developments and varied perspectives that together make up the social and technical world of xenotransplantation.

Interviews

Second, in depth interviews were conducted with 25 individuals who have been variously involved in contributing to discussions about the technology. These were drawn from a wide range of backgrounds including research groups (immunology, virology, surgery), regulatory bodies, the media, non-government organisations (animal

welfare and patient advocacy organisations) and policy makers. At present, some of these interviewees are being approached again to offer their views on changes that have taken place since they were first interviewed.

Discussion Groups

Finally, discussion groups were organised where participants could comment on the wide range of issues raised by xenotransplantation. Various briefing documents and visual/textual prompts were used to stimulate conversation about illness, health, transplantation and the use of animals in research. Participants were selected for the range of views that they might bring to the discussion. Five groups were formed from patient support organisations where people had experienced long-term illness or who had supported members of their family through illness. Another four groups were formed from various local community organisations, including nursery workers, sports clubs and students. Each of the discussions lasted two hours and groups met twice, allowing them a period of time between the first and second meeting to think about issues raised at their first meeting.

Analysis and first publications

A number of themes have emerged as particularly significant throughout the research and some are summarised here. Analysis of the interviews and the discussion groups is now in progress and the themes below are important points for consideration. Some of this work has now been published and complete abstracts are available on the project website. Copies of papers can be obtained from the publishers concerned or by contacting the project administrator, Gillian Robinson (see contact details below).

Hope, Promise and Expectations

One of the most important themes to emerge during the research has centred on differences in the expectations people have of medical research. For clinical research groups, expectations are an important way of attracting interest and investment. Likewise, patient groups often latch on to or encourage these expectations in the hope that research will eventually alleviate suffering. But many research fields today have encountered long-standing difficulties in achieving their initial objectives. Interview and discussion groups responses have prompted us to consider how patient organisations, researchers and policy makers respond to these changes in expectations. We have had to take into account differences in the time frames of expectations and differing degrees of uncertainty across groups.

Brown, N. & Michael, M. (2002) A Sociology of Expectations: Retrospecting Prospects and Prospecting Retrospects, *Technology Analysis and Strategic Development*, in press.

Transparency and access to information

Access to information is an important consideration in any debate where people may have very different views about science and technology. Various controversies in science have encouraged many organisations to become more transparent and focus greater attention on communicating with those outside their organisations or institutions. Likewise, openness is always constrained to some extent by legal, commercial and personal factors. Our analysis shows that transparency is often only successful (for example, in creating more trust) where relationships are already stable. When relations are characterised by a lack of trust, then gestures of openness and access to information are usually interpreted sceptically.

Brown, N. & Michael, M. (2002) From Authority to Authenticity: The Performance of Transparency in Biotechnology, *Health, Risk and Society*, in press.

Nik Brown and Michael, M. (2001) Transgenics, Uncertainty and Public Credibility. *Transgenic Research*, 10, 4, 279-293.

Human / nonhuman boundaries

Clearly, xenotransplantation raises quite special questions about the way in which the relationships between species are currently undergoing change as a consequence of biotechnological innovation. But how these changes are interpreted differs dramatically according to variations in different people's experience and background. These backgrounds might be disciplinary or professional, as for example differences between the views of immunologists and virologists, or cardiac surgeons and neurologists. Or they might be related to experiences of illness and wellness, as illustrated by discussion groups convened with local sports clubs and patient support organisations. These differences are a source of ongoing consideration for us in the analysis stage of the project.

Michael, M. (2001) Technoscientific Bespoking: Animals, Publics and The New Genetics, *New Genetics and Society*, 20, 3, 205-224

Nik Brown and Michael, M. (2001) Switching Between Science and Culture in Transpecies Transplantation. *Science, Technology and Human Values*, 26, 1, 3-22

Michael, M. (2002). Animals, publics and identities: uncertainty, ambivalence and policy making. In H. Von Troil (Ed). *Transgenic Animals in Medicine*. Report of the seminar, 8-10 October 2000 (p.4). European Federation of Biotechnology/Task Group on Public Perceptions of Biotechnology.

Brown, N (2002) Containing Contradictions: Debating Nature, Controversy and Biotechnology, forthcoming in Peter Glasner (ed) *Reconfiguring Nature: Issues and Debates in the New Genetics*, Ashgate.

Contributing to the project

The research team would like to encourage ongoing input into the findings of the project and the discussion it has been able to foster, particularly from people who have participated as interviewees or discussion group

members. Please visit the project website where you will find more information on our work and also have the opportunity to have your comments posted on the webpage (see below).

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