



## Xenotransplantation: Risk Identities and the Human/Nonhuman Interface

### KEY FINDINGS

The core aim of the research was to investigate how risk identities emerged in relation to xenotransplantation innovation. Four key themes were addressed:

- Risk and Expert Disciplinary Boundary Change: how different scientific specialisms characterised the relationship between host and donor species;
- Science/Culture and Embodied Risk Identities: the role of distinctions between science and culture;
- The Temporal Dynamics of Risk Identities: how views of risk involved understanding of the future and change over time;
- Models of Risk Governance and Regulation: how regulatory governance encompasses issues of expertise, culture and time.

- Different views on xenotransplantation related to disciplinary specialism but perceptions of the viability of xenotransplantation also reflected other factors. As such, a model was developed for better understanding how expectations about the viability of an innovation will predictably vary. Two key parameters were identified: whether technologies are relatively established, and relative closeness to, and involvement in, the innovation process itself.
- Attempts by advocates to make their decision-making transparent are faced with the problem of 'meta-risk', the risks that arise in risk deliberation itself, particularly in respect to the credibility of decision-makers. Resolving this 'meta-risk' can involve claims to authenticity (rather than authority) through the 'performance of suffering'.
- The use, by advocates of metaphors such as 'meat' that aim to diffuse the 'strangeness' of xenotransplantation were problematised by lay persons who, in our focus groups, revealed 'meat' to have fluid and contradictory meanings, thus threatening the credibility of the source of the analogy.
- Expectations about the future of xenotransplantation varied systematically between lay, advocacy, critical and regulatory actors. Importantly, in contrast to advocates who stressed a singular future, patient groups tended to argue for many future possibilities, but also were against the premature announcement of futures.

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## Risk and Expert Disciplinary Boundary Change

As expected we found that different views on xenotransplantation were expressed depending on the disciplinary specialism (eg virologists were more negative than immunologists about the potential viability of the technology), but rather than xenotransplantation being another occasion for disciplinary differentiation, specialists' engagement with other disciplines was more complex and highly interactive. Indeed, our focus upon the differentiation between disciplines proved inadequate on two counts. Firstly, perceptions of the viability of innovations like xenotransplantation reflect proximity to the multidisciplinary point of innovation and an awareness of the 'maturity' of the research field (see below). Secondly, risk perception is shaped not by disciplinary boundaries but by boundaries marking more heterogeneous collectives that include scientific expertise, regulatory regimes, publics and ethics (see below).

## Science/Culture and Embodied Risk Identities

Analysis of interviews and other data (for example, TV programmes and press releases) has suggested that there is emerging a new form of justification for decisions available to expert advocates. Spokespersons who try to make their decision-making (on risk, for example) transparent are, because their decisions can never be fully transparent, faced with the problem of 'meta-risk' in which further risks to their own credibility are generated. Resolving this 'meta-risk' involves, we suggest, a 'performance of suffering' in which spokespersons display that they have considered and *agonised over* as many disparate viewpoints as is possible in reaching their decision. Underlying this performance is a rhetoric that takes the following form: 'As a decision-maker, I have dealt with such disparate positions that it has caused me great suffering. What more can you expect me to do? I have

incorporated as many different viewpoints as is bearable. Is that not inclusive, open and transparent enough?' We suggest that this rhetoric - this move from *authority to authenticity* - draws on a series of contemporary conditions including the rise of the 'audit society' and the entrenchment of confessional culture. Decisions, rather than being justified by the patterned use of scientific and cultural discourses, increasingly draw on such broader rhetorics. This analysis can serve as a basis for a more systematic scrutiny of the pronouncements of technoscientific spokespersons across a range of controversial areas.

Another finding relates to contrasts in the use of 'meat' as a motif in coming to understand, and judge the value of, xenotransplantation. Various advocates have drawn ethical parallels between eating a ham sandwich and xenotransplantation. This sort of comparison is meant to diffuse the 'strangeness' that is associated with xenotransplantation. Common as this motif was in the talk of our public focus groups, 'meat' turned out to have fluid and contradictory meanings. For example, while meat's supposed 'natural-ness' was used to justify xenotransplantation, lay people also problematised it: for example, the 'making of meat' was itself artificial and eating meat was a matter of choice. This suggests, amongst other things, that simple parallels drawn between strange innovations and a familiar analogies readily unravel threatening the credibility of the source of the analogy.

## The Temporal Dynamics of Risk Identities

In examining expert respondents' uses of 'future expectations' (which are crucial to the dynamism of innovation processes), we have developed a model for better understanding how expectations will predictably vary. Two key parameters were identified. Firstly, expectations seemed to vary according to the degree to which particular technologies and the institutional

relations of which they are a part are either relatively established or newly emergent. Secondly, expectations were related to relative closeness to, and involvement in, the innovation process itself. Thus, those most closely associated with an innovation tended to be more wary of positive predictions than those further away (say, interested in application). At the same time, this was conditioned by the extent to which the innovation was seen to fit into other stable research programmes and institutional arrangements. A key implication of this analysis for the management of innovation is that experts' recall of previous expectations should be treated circumspectly in the assessment of the promise of current initiatives.

The project also explored the contrast between the expectations of lay, advocacy, critical and regulatory actors. Several discourses were identified. Unsurprisingly, advocates of xenotransplantation assumed a better future, and critics assumed either worse or alternative futures. Regulators by comparison were concerned much more with the process of getting to whatever future lay ahead. Patients tended to argue for many future possibilities, but also were against the premature announcement of futures (which was dispiriting). Finally, 'disinterested publics' tended to have a typically underdeveloped sense of the future or else regarded the future as inevitable (and usually belonging to someone else). Over and above the identification of these discourses, we have tried to understand them as reflecting an interest in particular arrangements of humans, animals, discourses, technologies, and institutions. For example, patients' embrace of multiple futures does not necessarily make them the allies of those interested in xenotransplantation as some felt this had, like many other initiatives, been prematurely publicised.

## Models of Risk Governance and Regulation

Over the course of the research, and on the basis of a number of observations at meetings, and preliminary analysis of interview data, we have developed a new framework for the analysis of scientific governance. Instead of seeing it in terms of, for example, the oppositions between science and lay, governance seemed to be conducted through the interactions of collective actors incorporating advocates and spokespersons, scientists and regulators, media, social scientists and lay publics. That is to say, political dialogue was between these loose configurations (technically, 'ethno-epistemic assemblages'). This framework has also illuminated the way that attempts at rendering science policy development more transparent, participatory and deliberative produces what he have called above the problem of meta-risk. The attempted solution often entails a 'performance of suffering' - 'all who could be canvassed have been; what more is possible?' However, this performance makes such democratizing processes spectacles to be *consumed* by observing publics. This clearly has major implications for notions of 'governance' and 'citizenship' which potentially become conflated with 'spectacle' and 'consumer'.

In addition, the research itself can be regarded as contributing to the process of scientific governance insofar as, in the focus groups, it institutes a setting for deliberation and participation. Reflecting on the research process itself, some of the underpinning assumptions about scientific citizenship that informed the present research were explored (eg tacit reliance on an expectation of scientific literacy). It was found that patient groups, possibly because of existing political practices, tended not to discuss xenotransplantation issue with others. In contrast, 'disinterested' publics did engage with discussion, thereby, in some small measure, enacting a version of scientific citizenship.



## About the Project

In pursuing the core objective of investigating how risk identities emerged in relation to xenotransplantation innovation a range of methods were used.

In Phase 1 the team embarked on a comprehensive literature review and 'network mapping'. Accordingly, the opening months were devoted to generating a bibliographic database of relevant secondary sources using a range of search tools (Medline, Clinical Trials databases, patent databases, Ingenta, etc). Materials included: press releases and investment reports; humanities, social and natural science publications; parliamentary proceedings; regulatory and advisory reports; popular media; television and radio documentary transcripts. These materials were assigned to an electronic data archive (Atlas ti) for coding. This greatly assisted in the identification of key interview respondents and formulation of the interview schedule/aide memoir.

Phase 2 entailed interviews with key respondents, notably 25 semi-structured interviews were conducted with individuals in research (immunology, virology, surgery), attached to regulatory bodies, in the media or associated with non-government organizations (animal welfare and patient advocacy organisations). Interviews usually took at least an hour. A standard qualitative interview schedule was used to guide discussions. Though two interviews with each respondent were designed into the initial project, in the context of the dramatic scaling down of the xenotransplantation initiative in UK, it was decided to review the 'state of play' through a small number of follow up interviews with key respondents.

In the final phase, focus group discussions with patient and non-patient participants were conducted.

11 focus groups were recruited and sessions conducted twice with each focus group. Recruitment took place within the York area, and serious consideration was given to reflecting as wide a range of demographic and social variation as possible. Group types were deliberately structured to facilitate a methodologically desired dynamic - male-only groups, women-only groups, patient and non-patient groups, covering an age range of over 57 years in all (25 years within 4 groups). In light of the topic area, it was decided that the key comparative dimension would be 'interest' whether there was a direct benefit to be derived from xenotransplantation for self or close relatives. As such five groups were formed from patient support organisations and six groups from various local community organisations, including sports clubs, colleges and nursery school workers. In the first session, a series of visual and textual word prompts were presented in order to examine how xenotransplantation was understood. At the end of this session, participants were provided with briefing materials to examine prior to the next session.

Each focus group was convened for two separate two-hour sessions. Two week intervals were chosen to allow participants sufficient time to think about issues raised, and to review briefing material given, in the first session. In the second session, a series of biographical vignettes were used these were fictional but plausible character sketches with which to engender discussion. After transcription, ATLAS-ti was used to aid analysis, not least because it could incorporate visual materials which were used as prompts in the focus groups.

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