Projektbericht

Final Report

Increasing Public Involvement in Debates on Ethical Questions of Xenotransplantation

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Bemerkungen

This final report reflects the author's views. The European Community is not liable for any use that may be made of the information contained in this report.

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Foreword

This report presents the results of the research project "Increasing Public Involvement in Debates on Ethical Questions of Xenotransplantation" (XENO) funded by the European Commission DG XII Project Number: HPRP-CT-2001-00013.This report is based the project deliverables (Gronke 2002, Griessler/Bogner 2003a, Griessler/Leuthold/Littig 2003b, Hüsing 2004, Santos/ Muñoz 2003a, Santos/Muñoz/Ponce/Dordoni 2003b, Zimmer/Gronke/Hüsing 2003), which are available on the project web site http://space.ihs.ac.at/departments/soc/xeno-pta.

The project partners[1] want to thank the European Commission for its generous financial support and all interview partners and participants in the Neo-Socratic Dialogues for their friendly cooperation, which made this experimental project possible.

This report starts with an executive summary. Chapter 1 introduces into the project and presents the project goals and the research design. Chapter 2 is dedicated to a short summary of the state of the art of xenotransplantation. Chapter 3 presents the different background for the Neo-Socratic Dialogue in Austria, Germany and Spain by describing the xenotransplantation debate in the three countries. Chapter 4 describes the method of the Neo-Socratic Dialogue, the organisation of the dialogue, the evaluation methods as well as the participants of the dialogue. Chapter 5 analyses the process of the dialogue, describes the participants' assessment of the group and the problems that arose during the dialogues. Chapter 6 is dedicated to the participants' assessment of the dialogue. The concluding chapter 7 addresses the question whether XENO reached its objectives and ends with a general assessment of the project. The appendix presents the dissemination activities within the project, a list of interview partners in Austria and Spain, references to the literature as well as a summory on xenotransplantation regulation in EU countries (European Commission 2001).

[1] The following partner organisations co-operated in the XENO project: Institute for Advanced Studies (IHS), Vienna, Austria (as co-ordinator); Free University Berlin (FUB), Berlin, Germany; Fraunhofer Institute for System and Innovation Research (FhG-ISI), Karlsruhe, Germany; Consejo National de Investigaciones Cientificas (CSIC), Madrid, Spain.

0 Executive Summary

0.1 Objectives

Xenotransplantation is the transplantation of living cells, tissues and organs across species borders. Like many developments in modern science and technology, xenotransplantation is associated with new risks and raises a number of major ethical problems. It could help to solve the shortage of organs from human donors and save the lives of many patients waiting for transplantation, but there is also a serious risk that viruses causing animal diseases might cross the species barrier and spread in human populations. Ethical problems connected with xenotransplantation touch upon questions such as individual benefit versus collective risk, informed consent, equal access and just allocation of organs, the relationship between man and animal/nature and, last but not least, animal rights. EU member states vary considerably with respect to public awareness and discussion of these problems. While some countries formed expert commissions to investigate the problems of xenotransplantation, many other countries have yet to address the issue. Apart from the lack of a well-developed public debate on the ethical issues raised by xenotransplantation, basic and still unresolved questions in many modern societies are: Who could legitimately discuss and resolve ethical problems of science and technology? In which way can these questions be debated and resolved; what decision-making procedures could legitimately be used to resolve ethical problems? It was the main objective of the XENO project to introduce and evaluate a method for resolving ethical issues – the Neo-Socratic Dialogue (NSD) – with respect to a specific debate about technological risks in modern societies.

0.2 State of the art in Xenotransplantation

Although xenotransplantation research has been conducted for several decades, a number of scientific-technical obstacles will have to be removed before xenotransplantation is ready for application in clinical practice. Those obstacles concern control of xenograft rejection, physiology, infection risks, genetic modification of source animals (pigs), identity, psychological impact and also survival and quality of post-transplantation life.

Xenotransplantation can only be successful if the following prerequisites are fulfilled:

- availability of enough suitable organs
- equal access to xenotransplants for all patients in need of an organ
- the xenotransplant function must be at least equivalent to any allotransplant function.

At present, it is an open question whether it will be possible to supply all needed organs via xenotransplantation. Possibly, only certain organs (e.g. hearts) will be provided in this way, while the shortage of other needed organs (e. g. liver, lung) is unlikely to be resolved by xenotransplantation. This raises two questions:

- whether resource allocation to xenotransplantation is justified if it constitutes only a partial solution to the organ shortage problem;

- how resources should be allocated between xenotransplantation and alternative forms of treatment.

At present, it is obvious that xenotransplantation will be at least as expensive as allotransplantation, so it will be a relatively expensive, high-tech option. We do not know today whether and how equal access to either allo- or xenotransplantation can be guaranteed, and what consequences widespread use of transplantation would have regarding resource allocation within individual national health care systems and at the supranational level.

For the foreseeable future it is most unlikely that xenotransplants will function as effectively as allotransplants. This is due to four unsolved scientific-technical problems (rejection, physiology, psychology, infection).

The state of the art in these areas can be summarised as follows:

Xenograft rejection is more vigorous and complex, and it differs from allograft rejection. By using organs of source animals that have been "humanised" (through expression of human complement regulatory proteins), the current maximum life-supporting xenograft survival time in non-human primates is 78 days (kidney), 39 days (heart) and 8 days (liver). Overcoming additional rejection mechanisms would require the introduction of further genetic modifications into the source animals, cloning of source animals, intensive medical immuno-suppression in the xenograft recipients, and possibly also tolerance induction in xenograft recipients.

Our present knowledge regarding the **physiological aspects of xenotransplantation** is still very incomplete. Despite this limited knowledge, most probably, physiology is the crucial stumbling block in progress towards clinical xenotransplantation trials. Crucial differences in the composition and viscosity of porcine and human blood suggest that the microperfusion of all xenogeneic organs will be severely compromised in human recipients, leading to reduced blood flow, blood stasis and thrombosis, even in the absence of rejection. The assessment of other physiological (in)compatibilities is organ-specific. The xenotransplantation of porcine **hearts** appears to be least susceptible to major physiological incompatibility problems, but lethal disrhythmias due to anatomical differences in the intrinsic innervation of the heart would still have to be overcome. In **kidneys**, differences in the renal handling of creatinine, urea and electrolytes such as calcium and phosphate require further research in long-term experiments. It is unlikely that xenografted **livers** will function properly in human recipients due to the complexity of their metabolic, hormonal and regulatory functions. Xenotransplantation of **lungs** seems to be least advanced among all solid organs, and it is likely that the postural change from the supine position in the donor pig to the upright position in the human recipient will significantly compromise the lung function.

Risk of infection. Xenotransplantation bears the risk that xenograft recipients may be infected by known source-animal pathogens, and that previously unknown pathogens might emerge that could endanger the health of patients, contact persons and of the general population. The risk of infection

due to porcine endogenous retroviruses (PERV) has been extensively investigated in recent years. This group of viruses has been thoroughly characterised on the molecular level, and their infection behaviour in vitro has also been investigated. At present, there is no evidence for PERV infection of humans in vivo, and good in vivo animal models to address this question further are still lacking. Measures for the prevention and control of infection events have been discussed and developed for PERVs and for known pathogens present in pigs. They comprise the breeding and housing of specific pathogen-free source animals, the development of highly sensitive and specific detection methods for infectious agents, the implementation of monitoring measures aiming at early detection of any infection events and the prevention of transmission; furthermore, the development of drugs for the control of infectious agents, or the development of vaccines. Appropriate regulations are being discussed at supranational and national levels. In recent years, the establishment of regulatory oversight and compliance with existing guidelines and standards has markedly reduced the risk of xenotransplantation-introduced infection – at least in some countries - compared with the unregulated situation in 1995. Altogether, these advances allow greater confidence in the reasonableness of proceeding with limited clinical trials, provided those trials are accompanied by appropriate safeguards and provided there is some reasonable basis for expectations that the participants will benefit .

In analogy to allotransplantation it is likely that xenotransplantation will have **unintended impacts on mental state, identity and personality**. These effects will probably not be directly attributable to the effects of the xenograft, but rather to the patients' different psychological ability to cope with the transplanted organ. In allotransplantation, the ease of coping correlates with the recipients' individual concepts of their own bodies.

To sum up, at the present state of the art, it is unlikely that a patient would benefit from solid organ xenotransplantation; only prolongation of life for a number of days without improvement in the quality of life seems achievable. Therefore, general consensus has emerged in the last few years that, at present, the possible benefit is not greater than individual and collective risks, and that consequently solid-organ xenotransplantation should not be performed at present.

In the medium term, bridging the waiting time until an allotransplant becomes available seems possible, at least for hearts. But if xenografts can only be used as bridges to allotransplantation, this form of xenotransplantation will probably aggravate the existing problems of human organ shortage and human organ allocation.

0.3 Xenotransplantation debates in Austria, Germany and Spain

The Neo-Socratic Dialogues on ethical problems of xenotransplantation took place against a different background in each of the participating countries:

In Germany, long expert debates about xenotransplantation had previously taken place, while in Austria and Spain there had not been any significant discussion of this topic either among experts or by the general public.

The German debate consisted of four distinct clusters, i.e. the transplantation medicine/ natural

science cluster, the ELSA cluster, the NGO cluster, and the policymakers cluster. The transplantation medicine/ natural science cluster was the most influential one, setting the agenda in politics and in the media. The ELSA and the NGO clusters were more marginal. In Austria and Spain transplantation surgeons had the greatest influence in the still undeveloped xenotransplantation debate.

Among the three countries investigated, Germany was the only country with significant xenotransplantation research. There are several research clusters in Germany, co-operating nationally and internationally. In Spain, only one research group is active in xenotransplantation, while in Austria no direct xenotransplantation research is taking place.

Novartis, the world's leading company active in xenotransplantation research, is a major actor in the national health markets of all three countries. Novartis is funding xenotransplantation research in Germany, and is supporting transplantation surgery in all three countries (by sponsoring symposia etc.). In our country sample, Novartis appears either as an important overt or latent actor in the xenotransplantation debate.

Germany is the only country with strong research on the ethical, legal and social aspects (ELSA) of xenotransplantation. This line of research, however, has only limited influence on xenotransplantation research in the narrower sense as well as on public debates. There is no such research in Austria and Spain.

At the political level there is little activity in all three countries. Germany, again, is the country with most political action: there have been parliamentary inquiries and a parliamentary technology assessment. The German government keeps a "wait and see" position on xenotransplantation, it is waiting for international regulations by WHO, OECD and the Council or Europe. Austrian politics is not active in xenotransplantation, apart from participation in international regulatory bodies and the formulation of preliminary ideas about xenotransplantation regulation by public bodies. In Spain, there is no xenotransplantation activity at the political level, but the Spanish authorities did not observe the Council of Europe's moratorium.

In Germany, different actors have published a number of advisory studies on xenotransplantation. In Austria, there are none, and there is only one in Spain.

In all three countries the print media pay little attention to xenotransplantation (in contrast, e.g., to stem cell research). Xenotransplantation reports mainly appear in quality newspapers and are therefore unlikely to reach a broad public. One may proceed from the assumption that in all three countries the general public is not informed about xenotransplantation, about its potential benefits and risks, and about the ethical problems connected with it. The media mostly present xenotransplantation as a challenging solution for organ shortage and they concentrate on technical xenotransplantation problems. The risk of infection is presented as the main problem, but this problem is not viewed as an ethical one (individual benefit versus public risk). In general, the media hardly refer to ethical problems. Animal welfare, though only of secondary importance, is discussed as an ethical problem in Germany and Austria. In Spain, the problem of animal welfare is attributed even less importance than in Austria and Germany.

In all three countries, scientists determine the xenotransplantation debate in the media. Other actors, such as NGOs (patient organisations, animal welfare groups), do exist, but are not present in the public or expert debate. Critical views about xenotransplantation and about how to resolve organ shortage do exist, but they are not taken up and multiplied by media. This is particularly true for Germany with its complex ELSA research scene on xenotransplantation. Particularly animal welfare advocates are excluded from public debate.

There are no recent data about public attitudes towards xenotransplantation. In Germany and Spain, people generally express a positive attitude towards transplantation, and this might also be the case in Austria. The somewhat outdated information presented in *Eurobarometer* shows a positive attitude towards xenotransplantation among Spaniards, more scepticism in Germany and, particularly, scepticism in Austria. However, these statements may be misleading, given that the public is poorly informed about xenotransplantation, that there has not been any intensive public debate on the respective benefits and risks, or on the ethics of xenotransplantation. Results from a German citizen's forum suggest that more information about the benefits/risks and ethics of xenotransplantation might lower acceptance. In summary, the public does not seem to be well prepared for judging xenotransplantation.

0.4 Neo-Socratic Dialogue

Usually, NSD is preceded by the formulation of a fundamental question that is applied to a specific decision situation, or rather, to a complex of decision situations. During NSD, a group of dialogue partners tries to obtain consensual insights regarding this fundamental (ethical) question through common reflection based on personal experience accessible to all dialogue partners. The basic idea of NSD is to give participants the opportunity to clarify their fundamental assumptions in a rational way. The main goal is that participants will communicate about the normative framework of general practices and basic ideas, so as to ascertain their validity.

After formulation of a general, broad question focusing on a general problem in a specific situation of challenge (in the context of xenotransplantation this question was "What risk to take?), the dialogue is to concretised, first, by looking at some specific situation of personal experience (an everyday example) and then by considering the example giver's personal judgement. The dialogue group examines this judgement, first to analyse and differentiate it, then to correct or to reformulate it (if necessary). Finally, the group must find more general rules and principles as (commonly accepted) general reasons or general conditions for the validity of the conclusion process and of the judgement. These general rules and principles must then be applied to the current situation of challenge. A facilitator supports the exchange of reasoned arguments in the group through behaviour-oriented, methodological and structural interventions. The facilitator does not support the dialogue process by any personal contributions to the content of the argumentation. The participants are encouraged to accept and to adhere to several characteristics of the NSD attitude, e.g. taking time to think, listening to each other, explaining one's opinion, not thinking against each other but joint thinking, making room for new thinking, not being fixed on producing solutions but looking for basic reasons, criteria, principles and values of a possible solution.

In total, six NSDs were carried out in three countries between October 2002 and February 2003. The Austrian NSDs took place in October and November 2003, the Spanish and German ones in January and February 2003.

0.5 Participants

A total of 55 persons participated in the six NSDs. In Austria and Germany, there were 18 participants; in Spain the number was 19. With the exception of politicians and animal welfare organisations in Spain, and of patient representatives in Germany, it was generally possible to involve representatives of all relevant xenotransplantation stakeholders. Thus, the NSDs brought together an adequate mix of relevant persons from research, patient organisations, policy-making bodies as well as relevant NGOs. Looking at their professional or private links with xenotransplantation, 47% of the participants came from research, 13% were patients or patient representatives and 9% came from NGOs. Additional participants came form public administration, churches, media, insurance, and industry.

In general, in all NSDs, there was a male majority. In total, about two-thirds of the participants were male (64%) and one-third was female (35%). The women's share was highest in Spain (42%) and lowest in Germany (28%). In Austria, their share was 33%.

Not surprisingly, because of the selection criteria for participants, a majority of 71% of the participants felt that they were either very closely or moderately connected with xenotransplantation.

Altogether, the participants thought that they were well informed about xenotransplantation. 35% percent of them stated that they were perfectly informed, 44% that they were sufficiently informed and 22% that they were somewhat informed. None of them said that they were not at all informed about xenotransplantation.

There were significant differences between the three countries with regard to the participants' overall attitude towards xenotransplantation. The German participants were most critical in our three-country sample, with relative shares of 29% agreement, 12% undecided and 58% disagreement. By contrast, the Spanish participants were most positive: 84% of the NSD participants were in favour of xenotransplantation, 5% were undecided and only 11% were against xenotransplantation as future treatment. In Austria, 50% of the participants strongly agreed or tended towards agreement that xenotransplantation is a desirable future treatment, 28% were undecided and 22% tended towards disagreement or totally disagreed with this statement.

Comparing Austria, Germany and Spain, the three countries differed in the individual dialogues both with respect to the participants' connection with the topic and their level of information and opinions about xenotransplantation. On average, the German participants were most strongly related, best informed and most sceptical. The Austrian participants took a middle position regarding their relatedness to xenotransplantation, their information level about and their attitude towards xenotransplantation, being less sceptical than the German participants. The Spanish participants were almost unanimously optimistic about xenotransplantation, but on average least related to and informed about the topic.

The participants had very high expectations about what could be termed dialogue quality, i.e. about the NSD method as a different form of discussion, as an egalitarian dialogue among all participants, in an open, relaxed atmosphere (96% agreed), an exciting discussion about important topics. Only a minority had special expectations about content-oriented aspects of the dialogue, e.g. receiving new information about xenotransplantation, getting a clear answer how to handle the problem of xenotransplantation, achieving consensus on the subject of xenotransplantation, changing their own attitude towards xenotransplantation.

0.6 Process

As requested, nearly all participants gave short descriptions of risk situations in which they had personally been involved. Two of the chosen examples concerned risky car driving. In one case the example was about speeding to get to an important private rendezvous (A1), in the other case it was driving to fulfil the important social obligation of attending a funeral in spite of being too sleepy to drive (SP1). D2 was also somewhat related to car driving, i.e. taking the risk to help another driver in a potentially dangerous situation (because the situation could also have turned out to be an ambush). The example in A2 was risky advice given to a farmer about de-horning cattle in free range husbandry. The cattle later injured the farmer. Participants in D1 selected the risky decision to go on a sailing trip in bad weather. The SP2 group selected taking the risk of working in a dangerous laboratory with insufficient safety standards because of better career opportunities.

The major theme in the NSDs was the concept of risk and how it should be dealt with. But during the dialogues several sub-themes emerged that were closely linked to the main topic and needed clarification before the main question could be answered. In many cases, these sub-themes represented a kind of hidden precondition or motivating factor for the risky situation itself. Such sub-themes, which are also relevant in the case of xenotransplantation, were: When are we obliged to help in an emergency situation, what are the limits to this obligation? Which risks should one take if one must help someone? Which precautionary measures must one take? What is sufficient expertise to deal with a situation adequately? What does *"the right to pursue individual happiness"* mean? What role does ideology play in judging a situation? To what extent must one respect authority? When is it necessary to fulfil a strict social norm and what are the limits to such an obligation? What is the proper balance between taking a risk and pursuing one's career?

In all dialogues, the acceptability of risk was conceptualised as relationship between risks, damage, or disadvantage on the one hand and benefit on the other hand. In two dialogues (SP2, A2) participants also used the probability of occurrence (of the risk) as an argument.

In all examples presented, the potential personal benefit to the example giver was high, as with xenograft recipients in xenotransplantation. The probability of occurrence of various risks was considered to be high in one case, low or unclear, respectively, in two cases, and non-existent in one case. Despite the fact that the examples chosen in the dialogues were very heterogeneous, there seemed to be a common line of argument regarding the handling of risk. If one compares the general assumptions backing judgement, there was a tendency to assign greater weight to the benefit side of the risk concept and less to the danger side. In all NSDs, participants appeared to be quite cautious in

the sense that they tolerated high risk only if they could clearly expect high benefit.

The participants' statements became much more diverse when the results of the dialogues were applied to xenotransplantation. Discussion focussed on different problems such as the problem of risk evaluation, distributive justice at the national and global levels, discontinuation criteria for research, the quality of those criteria (health care costs, protection of animal welfare), as well as the necessity of prevention measures and alternatives to xenotransplantation. This diversity of topics might be explained by the participants' differing knowledge and involvement regarding xenotransplantation. In all dialogues, there was not enough time for the application of discussion results to xenotransplantation. But given the time limit, there still seems to be the problem that consensus on rather general assumptions becomes fragile when applied to concrete problems.

Problems that arose in the dialogues concerned shortage of time; in some groups, difficult group dynamics; and in one group, participants' acceptance of the NSD method. The main problem, which arose in almost all dialogues, concerned the transfer of basic ethical principles deducted by the participants from their everyday examples to the topic of xenotransplantation. Changes in the design of the dialogue (more time, additional methods, more expert input, embedding in technology assessment) would be necessary to improve transfer of NSD results to a chosen controversial topic.

0.7 Assessment

From a general perspective, the participants assessed NSD very positively. 86% of them said that their expectations were met. They also marked the event rather positively by school grades: 29% assigned an excellent, 56% a fair, 10% a satisfactory, 4% a sufficient and only 2% a failure mark. In addition, a large majority of the participants was willing to recommend NSD to interested colleagues; 62% would recommend NSD and 31% would recommend it with certain reservations. A share of 74% agreed that the results were useful in their professional or voluntary environments (15% very useful, 59% useful). The question whether the NSD method was considered useful received an affirmative answer by 82% of the participants (20% very useful, 62% rather useful).

In a three-country comparison, the German and Spanish participants' expectations were met more often than those of the Austrian ones. The German participants also evaluated NSD more favourably than the Spanish and particularly the Austrian participants. The Spanish respondents were most willing to recommend NSD to interested colleagues, followed by the German participants and, as always, with a considerable gap, by the Austrians. The Spanish participants evaluated the usefulness of results most positively, followed by the Germans and, at a considerable distance, by the Austrians. The three countries were closer to each other in their evaluations of the NSD method. German participants were most positive, followed closely by the Spaniards and the Austrians.

There were considerable differences among the six dialogues with respect to the aspects of general NSD assessment. Certain aspects were evaluated most favourably by the German dialogue participants, i.e. met expectations, school grades and recommendations to colleagues. With respect to the categories usefulness of the method and usefulness of results, the first Austrian dialogue received

the best evaluation. However, looking at all categories, the second Austrian dialogue was evaluated most negatively.

Second, there were differences between dialogues within each country. Looking at all categories, i.e. met expectations, school grades, recommendation to colleagues, usefulness of results and method, the participants in the Austrian dialogue A1 were more positive in their evaluation than those in the second dialogue, A2. The same was true for D1 and D2, as well as SP2 and SP1, respectively.

We did not find any significant differences between groups with differing closeness to xenotransplantation, information levels, attitude towards xenotransplantation and gender. Neither did we observe significant differences between scientists/physicians and other participants, or participants who had previously participated in some xenotransplantation discussion and others who had not done so. However, our sample did reveal the following differences:

- Participants who were a very closely related to xenotransplantation evaluated NSD more positively than others (except concerning usefulness of the NSD method).

- Perfectly informed participants were most positive in their evaluations across all items compared with less well-informed participants (except concerning usefulness of the NSD method).

- Advocates of xenotransplantation were slightly more positive with regard to met expectations and usefulness of the method, opponents were a little more positive with regard to results, school grades and recommendation.

- Scientists/physicians were more positive about the event than people with other professions or occupations (except concerning the evaluation of results).

- Participants in previous xenotransplantation discussions were a little more positive about their met expectations, whereas participants without such an experience were slightly more positive regarding the following aspects: usefulness of results, usefulness of the method, school grades, recommendation to other colleagues.

- Women evaluated the event more favourably than men along all items.

The evaluation of particular features of the process and outcome aspects of NSD showed diverse results:

First, the attempt to acquaint stakeholders in xenotransplantation with NSD as a new instrument was clearly successful. 96% of the participants agreed that they became acquainted with NSD and with a different form of discussion, respectively.

Second, the participants agreed very much that they experienced certain features regarding qualitative aspects of discussion: 98% agreed that they experienced an egalitarian dialogue; 96% stated that the dialogue created a relaxed atmosphere conducive to exchange of views; 93% said they came to know other people and learned something about their points of view; 91% experienced that other

participants had an interest in the topic; 89% experienced a high-quality discussion and got to know other people and their points of view; 80% agreed that they had experienced a clearly structured discussion, that other participants had listened to them and had tried to understand them, that NSD had given them time and opportunity to consider an ethical problem.

Third, a number of other qualitative aspects of discussion also received very high agreement by the participants, but less unanimously than the qualities mentioned above: 72% experienced that other participants referred to their arguments; 78% that they came to understand other participants' points of view; 70% experienced an exciting discussion on the subject; 65% that NSD created tolerance towards other persons' points of view and 65% that NSD helped to improve their communicative skills.

Fourth, dialogue aspects related to xenotransplantation as a topic received agreement by a minority of the participants only. 38% said that NSD clarified their own standpoint; 31% that NSD provided new insights into xenotransplantation; 30% that NSD resulted in consensus on the subject of xenotransplantation; 27% thought that NSD provided new information about xenotransplantation; and 22% that it gave a clear answer on how to deal with the problem of xenotransplantation. Only 19% of the participants agreed that NSD enabled them to convince others about their own point of view . Compared with the other items, the smallest share of participants (15%) experienced change in their personal attitude towards ethical problems of xenotransplantation.

0.7.1 Change in attitude

In general, only very few participants changed their mind about xenotransplantation during or after NSD. Only 13% of the respondents agreed with they statement that they changed their attitude towards xenotransplantation. There was a significant difference between Austria, Germany and Spain in this respect. In Germany, none of the participants changed their mind about xenotransplantation, in Austria this share was 6%, but in Spain it was 32%. Also, the differences among different NSD groups were significant. In three groups, none of the participants changed their standpoints towards xenotransplantation. However, in A1 and SP1 13% changed their mind and in SP2 46% did so. Another significant difference was between persons who had participated in a xenotransplantation discussion before and those who had not. Persons with no previous xenotransplantation discussion experience changed their mind significantly more often than persons without (27% versus none). There were also other non-significant differences between different groups in our sample. With the exception of "moderately related" participants, people who were less closely related to xenotransplantation changed their mind more often than those who were more closely connected (very closely related 11%, moderately related 10%, hardly related 17%, not at all related 33%). Also, less informed persons changed their mind more often than better-informed ones (perfectly informed 5%, sufficiently informed 13%, somewhat informed 25%). Advocates of xenotransplantation changed their mind about it more often than opponents or undecided persons (20% versus 8% versus none); scientists changed their mind slightly more often than others (15% versus 10%), women a little more often than men (16% versus 11%).

Clearly, more participants, namely 23 participants or 42%, changed their opinion about other participants than about xenotransplantation. In the German dialogues, the share of people who

changed their attitude towards others was highest (67%), followed by Austria with 33% and Spain with 26%. Furthermore, the share of xenotransplantation opponents who changed their mind about other participants was much higher (83%) than that of advocates (33%) and of undecided persons (25%).

But there were also other differences between groups. In the German dialogues, the share of participants who changed their mind was highest (67% each). In the Austrian dialogue A1 this share was 50% while in the Spanish dialogue SP1 it was 38%. The Austrian dialogue A2 and the Spanish dialogue SP2 had the lowest shares of persons who changed their opinion about others, with 18% and 20%, respectively. By contrast, there was not much difference between participants with different closeness to xenotransplantation. The fact that people who were not at all related to xenotransplantation did not change their opinion seems plausible, since they probably had no opinion about it before NSD. There were only small differences between groups with different information levels about xenotransplantation. 47% of the perfectly informed participants changed their opinion. This share was 38% in the sufficiently informed and 42% in the somewhat informed. The share of scientists who changed their opinion about other participants was only slightly higher than in non-scientists (46% versus 38%). This was also the case with people who had or had not previously participated in other xenotransplantation discussions (45% versus 38%).

0.8 Conclusions

To what extent did XENO reach the goals formulated at the start of the project?

0.8.1 Raising the relevant actors' and the general public's awareness for the ethics of xenotransplantation

In summary, we can say that we succeeded in involving actors relevant for xenotransplantation in our project. Altogether, we recruited 55 relevant xenotransplantation stakeholders in Austria, Germany and Spain for six Neo-Socratic Dialogues dedicated to ethical problems of xenotransplantation. The positive assessments of NSD as a communication tool and the participants' willingness to recommend NSD to interested colleagues reflect their satisfaction with the NSD method. Our results show that NSD is a communication method suitable to make ethical principles underlying the arguments used by xenotransplantation supporters and xenotransplantation opponents more transparent and plausible to the respective opposite side. However, NSD is an inappropriate method for discourse processes involving a large number of participants and a high degree of publicity. NSD is a method that must take place in a protected space, as one participant put it, and it will only work in small groups. But it is possible to include key persons who will act as multipliers and introduce NSD results to their own and/or to other organisations, as well as to the general public. In our project, we also attempted to involve representatives of stakeholder groups that are normally excluded from decision-making processes on technologies, e.g. patient representatives and animal welfare groups.

0.8.2 To discuss the ethics of xenotransplantation

With respect to the question whether it was possible to discuss the ethics of xenotransplantation, we

suggest, for analytical reasons, to distinguish between process- and content-related aspects in particular dialogues.

Looking at process-related aspects, NSD received very positive evaluations by the participants. The evaluation showed that NSD was particularly helpful in creating an open and clear structure for discussing the ethical basis of xenotransplantation. In such a framework, NSD can be fruitful for dissolving deadlocked debates and confrontations, making debates more objective and uninfluenced by emotions and prejudices, as well as becoming sensitive to and capable of intellectually grasping basic ethical principles, values and interests.

Compared with the very good results regarding process-related aspects, the participants evaluated content-related items less favourably. This less favourable assessment was due to several factors. First, in most dialogues, it was not possible to complete the transfer of basic principles derived from discussing an everyday example to the topic of xenotransplantation. The project results clearly show that more time is needed for the transfer phase. Moreover, as could be observed in the first Austrian dialogue, more specific expert input is needed to address detailed questions arising in the transfer phase. The low assessment of content-related aspects of NSD might also be connected with the high level of expertise regarding xenotransplantation within the groups. The evaluation showed that participants with differing information levels about xenotransplantation assessed content-related items differently. Somewhat informed people received new insights about the issue of xenotransplantation more often, and received new information more often, than perfectly or sufficiently informed participants. These results indicate that NSD is also useful for conveying information to less informed persons.

0.8.3 Clarification of various actors' responsibilities regarding the ethics of xenotransplantation

The first step in clarifying the responsibilities of various actors is the acknowledgement that such a responsibility exists. This is indicated by a person's willingness to participate in a discussion devoted to the ethics of xenotransplantation, such as NSD. Although it was difficult to recruit all stakeholders that had been contacted originally, eventually a sufficiently large number of relevant stakeholders were ready to participate in XENO, to discuss ethical problems of xenotransplantation. We asked the participants a number of questions intended to clarify the actors' responsibilities. One of them was whether the respondents thought that NSD contributed to a clarification of their standpoint. Another question was whether they considered the results of NSD as useful for their work. Although a considerable share of participants agreed that they clarified their own standpoint to some extent and that the results were useful for their work, the evaluation results clearly show that there is room for improvement regarding content-related aspects of the dialogues.

0.8.4 To inform decision-makers about the ethical basis and consequences of xenotransplantation

In order to inform decision-makers about the ethical basis and consequences of xenotransplantation, we pursued a two-way strategy. On the one hand, we informed them directly, since some NSD

participants were in influential positions regarding xenotransplantation in their respective fields of activity. They will also be informed about final results.

Since transfer of NSD results to the topic of xenotransplantation was achieved only partially in most dialogues, we changed our dissemination strategy somewhat, focusing on dissemination to the respective actors in xenotransplantation as well as in science and technology. This dissemination process will continue after the formal conclusion of the project (see appendix for a list of presentations given so far).

0.8.5 Consensual policy options regarding ethical problems of xenotransplantation

As reflected by this report, consensual policy options could only be defined in very general terms. The principles agreed upon only provided a weak kind of orientation. More time would have been needed to transfer the derived basic principles to the multifaceted problem of xenotransplantation.

0.8.6 Improvement of the respective actors' communication patterns and their capability of coping with ethical questions arising from modern science and technology

The participants had relatively high expectations regarding communication when they agreed to take part in NSD. They hoped that NSD would enable a different kind of discussion, differing from the usual confrontational forms. The participants also expected to learn how to communicate with other people, especially with opponents, and to improve their personal communicative patterns and capabilities.

After the respective dialogues, the majority stated that they had been able to improve their capabilities regarding interpersonal communication. More detailed analysis showed that the participants had experienced dialogues that were egalitarian for all participants, that enabled participants to listen to their dialogue partners, to refer to other participants' arguments, to understand other persons' opinions, and to tolerate other opinions.

The participants learned to question their own as well as other participants' positions. It was thus possible, through NSD, to improve the communicative patterns and capabilities of actors in the field, helping them to cope with ethical questions arising from modern science and technology. Using one specific everyday example, they were able to discuss it without prejudices in an atmosphere of trust.

1 Objectives

1.1 The ethics of xenotransplantation as a decision-making problem

Xenotransplantation, or animal-to-human transplantation is the transplantation of living cells, tissues and organs across species borders. Xenotransplantation is based on several medical and scientific advances, in particular: (a) progress in transgenics and immunology enabling the production of genetically modified animal organs that are more compatible with the human immune system, and (b) improvements in regulating the human immune response. Xenotransplantation, like many developments in modern science and technology, is associated with new risks (Bonß 1995) and raises a number of major ethical problems. Although xenotransplantation could help to solve the shortage of organs from human donors and thus save the lives of many patients waiting for transplantation, there is a serious risk that viruses causing animal diseases might cross the species barrier and spread in human populations (Guenzburg/ Salmons 2000).

Ethical questions of xenotransplantation still to be resolved include: Is it acceptable, in principle, for reasons of religious belief, cultural values and animal welfare, to use animals in order to provide organs and tissues for transplantation into human beings? Which animals could be used (primates or non-primates)? Is it acceptable to save the life of an individual while putting at risk health care professionals, relatives and the general population? Is it acceptable to restrict the individual freedom[2] of xenograft recipients in order to protect public health? Is it acceptable to neglect alternative approaches to relieving the donor organ shortage[3] and to invest limited research resources into a technology whose success is highly uncertain?

The EU member states vary considerably with respect to public awareness and discussion of xenotransplantation (Council of Europe 2000, European Commission 2001, see also Appendix). While some countries formed expert commissions to investigate the problems of xenotransplantation and have started to issue related guidelines, e.g. for the UK (Advisory Group 1996), for the Netherlands (Gezondheidsraad 1998) and for Germany (Petermann/ Sauter 1999), many other countries have yet to address xenotransplantation (Council of Europe 2000).

Apart from the lack of a well-developed public debate on the ethical issues raised by xenotransplantation, basic and still unresolved questions in many modern societies are: Who could legitimately discuss and resolve ethical problems of science and technology? Would it be sufficient to rely on professional bio-ethics experts only, or do we need a broader ethical debate also involving other actors in the field, including the concerned general public? (e.g. Chadwick 1999) Furthermore, if broad public discourse on ethical problems raised by modern science and technology is both necessary and desirable, one would have to find out in which way these questions could be debated

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[2] Proposed measures include e.g. long-term or even lifelong monitoring and quarantine not only affecting the patients themselves but also their relatives and persons in close contact with them (Petermann/ Sauter 1999).

[3] Alternatives would include measures to increase the number of human donors; prevention and improved therapy of diseases leading to organ failure; development of artificial and bio-artificial organs as well as therapeutic cloning (Petermann/ Sauter 1999).

and resolved; what decision-making procedures could legitimately be used to resolve ethical problems. So far, a number of approaches to Participatory Technology Assessment (Hennen 1999, Joss 1999) such as citizen's juries (Stewart et al. 1994), focus groups (Hörning 1999) and consensus conferences (Joss/ Durant 1995), have been applied to foster public discussion about emerging technologies.

The overall aim of the XENO project was to introduce and evaluate a well-established method for resolving ethical issues – the Neo-Socratic Dialogue (NSD) – to a specific debate about technological risks in modern societies.[4]

1.2 Goals

The interdisciplinary XENO project had the following interrelated objectives:

1. To raise public awareness and to involve the general public of selected EU member countries in the debate about ethical questions of xenotransplantation.

2. To develop and evaluate by cross-country comparison a new mechanism of public debate in order to reveal the ethical foundations and consequences of xenotransplantation in Austria, Germany and Spain.

3. The Neo-Socratic Dialogue on xenotransplantation had the following aims:

    a. to raise the awareness and sensitivity for ethical problems connected with xenotransplantation in the actors of this field and also in the interested/concerned general public;

    b. to reveal the ethical basis and consequences of xenotransplantation ("ethical impact assessment");

    c. to clarify responsibilities of researchers, policy makers, economic actors and citizens with respect to ethical questions of xenotransplantation;

    d. to inform decision makers about the ethical basis and consequences of xenotransplantation;

    e. to improve the communication patterns and capabilities of actors in the field with respect to the resolution of ethical questions arising in modern science and technology;

    f. to create material for qualitative analysis of different cultural, regulative and socio-economic contexts affecting attitudes towards xenotransplantation.

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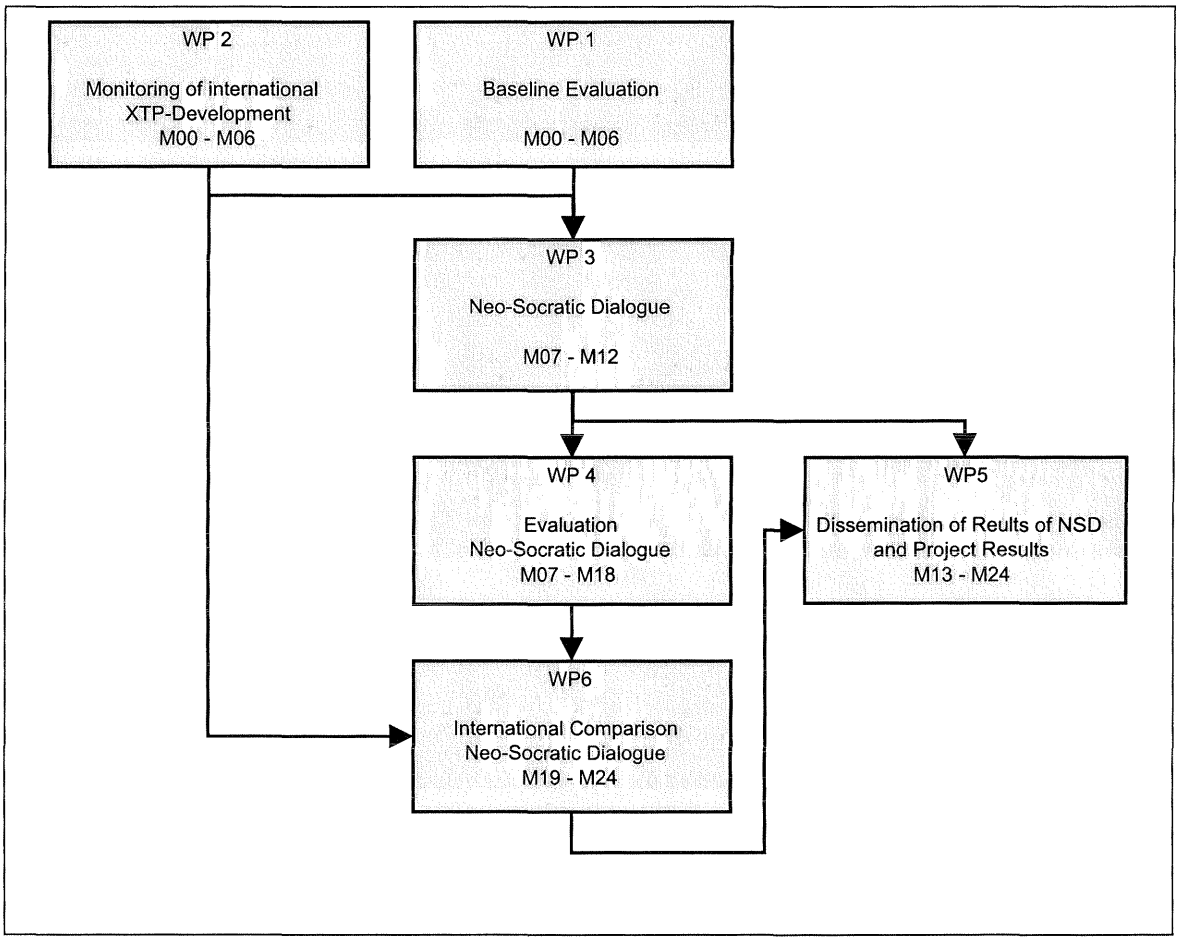
[4] NSD goes back to Socratic Dialogue developed by Leonard Nelson in the 1920s (Nelson 1922, 1965).

1.3 Research design

The diagram below summarises the research plan developed for the XENO project (Figure 1).

Figure 1: Research Design of XENO

EMBED



The project started with Work Package 1, the Baseline Evaluation, in which the "evaluators" analysed the xenotransplantation debates in Austria, Germany and Spain and identified potential participants in Neo-Socratic Dialogues.

As xenotransplantation is a rapidly developing field, it was possible that some of the Baseline Evaluation would become outdated due to changes occurring in the course of the project. Also, the emergence of national xenotransplantation programmes and policies could only be reasonably judged against the background of relevant international developments. Thus, Work Package 2 was dedicated to monitoring and analysing the development of xenotransplantation internationally. In this work package we surveyed major scientific and commercial developments, ethical debates, public policies and regulations, as well as the development of alternatives to xenotransplantation.

Work Package 3 was dedicated to actual NSDs on xenotransplantation in Austria, Germany and Spain. In the preparatory phase to the Dialogues, Horst Gronke compiled a methodological guidebook. Decisions who should be invited to participate in the Dialogues and which questions were suitable for NSD relied on the Baseline Evaluation and on discussions among evaluators and facilitators during the second project workshop. The facilitators organised the NSDs in co-operation with the evaluators. Two NSDs with expert/stakeholders and members of the general public were organised in each of the three countries. The goal of the NSDs was to discuss the ethical implications of xenotransplantation and to elaborate and substantiate recommendations with respect to the ethical acceptability of xenotransplantation. The goal of the Dialogues, however, was not only to work out recommendations but, simultaneously, also to create discursive space for social learning. The NSDs should enable participants to weigh the ethical aspects of xenotransplantation and to learn (e.g. to perceive the other actors' perspectives, to uncover their personal basic assumptions). For this purpose, NSD participants had to be relieved of any immediate pressure for action, they had to be removed from their daily routines and their fixed viewpoints. Social learning is easier to accomplish in small rather than in large groups. Thus, the number of participants in the NSDs was restricted, ranging between 8 and 12 persons.[5]

In Work Package 4, the evaluators evaluated the input, process, output and "resonance" of the Dialogues. The evaluators conducted one survey at the beginning of the Dialogues and two waves of follow-up interviews.

Work Package 5 was dedicated to the dissemination of research results to relevant actors, to the general public, to relevant international organisations, as well as to the scientific community. The NSDs themselves already constituted a dissemination instrument since alliances between actors tend to be formed through them. Naturally, the dissemination phase will not stop with the end of the project but will continue beyond the official closing date of the project.

In Work Package 6, each responsible evaluator compared and analysed differences and similarities between the national NSD evaluation reports. This work package was the basis for preparing the final report.

The XENO was not only a research project but also an intervention in this field of activities, i.e. the researchers were purposefully involved in this field in order to change it. The project was based on a number of ex-ante normative postulates postulates, as outlined in the project proposal. The explicit demands were that:

1. concerned citizens, i.e. stakeholders and the interested general public

2. should discuss the ethical aspects of xenotransplantation

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[5] It is a common and well-known argument in PTA research that PTA cannot accomplish "representativeness" in the sense that "participants reflect the relative weight of interests, views, arguments and groups in society" (Klüver et al 2000). Like other PTA approaches, XENO does not aim at "representativeness" in this sense, but at "balance" among actors. XENO attempts "to involve people from all 'relevant' groups (arguments, viewpoints, interests and other background variables)" (ibid.).

3. systematically

4. and that this discussion should have an impact on decision making.

Such an approach blurs the boundaries between researcher, evaluator and activist, in the sense that the researcher is not separated from the research object. In order to control this blend of roles, we tried to separate the roles of activist and researcher as much as possible by assigning these roles to different people within the research project.

In Austria, Erich Griessler and Alexander Bogner (IHS) performed the baseline evaluation. Beate Littig facilitated the NSDs and also observed one NSD each in Germany and in Spain. The Austrian evaluation team included Erich Griessler and Margit Leuthold. Margit Leuthold, who was not present during the Dialogues, conducted the interviews.

In Germany, Bärbel Hüsing and René Zimmer (FhG-ISI) carried out the baseline evaluation and organised the NSD. Horst Gronke was the facilitator of the two German Dialogues. Bärbel Hüsing and Renè Zimmer who were present at the Dialogues but did not participate in the discussions evaluated the Dialogues.

In Spain, Emilio Muñoz and David Santos (CSIC) were responsible for the analysis of the Spanish xenotransplantation debate. They also organised the Spanish Dialogues, which were moderated by Paolo Dordoni. The Spanish evaluation group consisted of Emilio Muñoz, David Santos and Gloria Ponce. Again, the evaluators were present at the Dialogues but did not participate in the discussions.

2 State of the art[6]

2.1 Definition and promises of xenotransplantation

Xenotransplantation is the transplantation of living cells, tissues and organs across species borders (Beckmann et al. 2000, Hüsing et al. 1998, Hüsing et al. 2001). In the context of this paper, xenotransplantation is understood as the transplantation of animal organs, mostly from pigs as source animals, to humans, with the aim of treating diseases due to the irreversible loss of organ, tissue, or cell functions.

If animal organs could be transplanted successfully into humans, xenotransplantation could help to solve of many problems of today's transplantation surgery. It could have the following advantages:

1. "Infinite" supply of organs according to organ demand. The most severe problem of today's transplantation surgery is that the demand for donor organs is significantly higher than the number of donated human organs. Since animals as organ source could be bred according to graft demand, xenogenic organs could be supplied to every patient in need of organ transplantation. This could have the following desirable consequences:
    - saving the lives of patients who would otherwise die while waiting for an organ,
    - improving the organ recipient's quality of life,
    - no further need for waiting lists,
    - reduced psychological stress for patients and their families,
    - no further demand for the sale of human organs.
2. Organ allocation solely based on medical criteria.
3. Planned surgical procedures. Organ transplantations could be planned beforehand and would no longer be emergency procedures. This could have the following desirable consequences:
    - improved clinical outcome,
    - reduced stress for patients, their families and the medical staff involved.
4. Fewer problems connected with the brain death concept. The ethical and legal problems associated with the brain death concept and also psychological stress for relatives and medical staff could be reduced.

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[6] This chapter has been taken in part from the XENO project report by B. Hüsing (Hüsing, Bärbel, Monitoring of International Developments in Xenotransplantation, Fraunhofer Institute for Systems and Innovation Research, Karlsruhe, 2004).

These advantages could be realised within the established system of transplantation surgery. Xenotransplantation therefore seems to be an option neatly fitting into the existing transplantation system and "only" requiring a change in the organ source. Especially if the xenotransplantation of cells and tissues is considered, it offers the potential for expansion of transplantation medicine to the treatment of diseases and disorders outside the traditional field of surgery (e. g. Parkinson's disease, diabetes).

Although xenotransplantation research has been conducted for several decades, a number of scientific-technical obstacles will have to be removed before xenotransplantation is ready for application in clinical practice. Those obstacles concern:

- Control of xenograft rejection
- Physiology
- Infection risks
- Genetic modification of source animals (pigs)
- Identity, psychological impact
- Survival and quality of post-transplantation life.

2.2 State of the art

This section summarises how realistic expectations are that xenotransplantation will achieve its aims.[7] Xenotransplantation can only be successful if the following prerequisites are fulfilled:

- availability of organs that are in short supply
- equal access to xenotransplants for all patients in need of an organ
- the xenotransplant function must be at least equivalent to any allotransplant function.

At present, it is an open question whether xenotransplantation will supply all required organs. It is more likely that only certain organs (e. g. hearts) can be provided through xenotransplantation, and that solutions for the shortage of other organs (e. g. liver, lung) are unlikely to come from xenotransplantation. This raises two questions:

- Whether resource allocation to xenotransplantation is justified if it only provides a partial solution to the organ shortage problem.

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[7] For a more detailed description c.f. the XENO project report. Hüsing, Bärbel, Monitoring of International Developments in Xenotransplantation, Fraunhofer Institute for Systems and Innovation Research, Karlsruhe, 2004

- How resources should be allocated between xenotransplantation and alternative forms of treatment.

At present, it is obvious that xenotransplantation will be at least as expensive as allotransplantation, and will thus be a relatively expensive, high-tech option. We do not know today whether and how equal access to either allo- or xenotransplantation can be guaranteed, and what consequences widespread use of transplantation would have on just resource allocation within individual national health care systems as well as at supranational level.

For the foreseeable future it is most unlikely that xenotransplants will function as effectively as allotransplants. This is due to four unsolved scientific-technical problems (rejection, physiology, psychology, infection).

The state of the art in these areas can be summarised as follows:

Xenograft rejection is more vigorous and complex, and it differs from allograft rejection. By using organs of source animals that have been "humanized" (through expression of human complement regulatory proteins), currently the maximum life-supporting xenograft survival in non-human primates is 78 days (kidney), 39 days (heart), and 8 days (liver). Overcoming additional rejection mechanisms would require the introduction of further genetic modifications into the source animals, cloning of source animals, intensive medical immuno-suppression in the xenograft recipients, possibly also tolerance induction in xenograft recipients.

Our present knowledge regarding the **physiological aspects of xenotransplantation** is still very incomplete. Despite this limited knowledge, most probably, physiology is the crucial stumbling block in progress towards clinical xenotransplantation trials. Crucial differences in the composition and viscosity of porcine and human blood suggest that the microperfusion of all xenogeneic organs will be severely compromised in human recipients, leading to reduced blood flow, blood stasis and thrombosis, even in the absence of rejection. The assessment of other physiological (in)compatibilities is organ-specific. The xenotransplantation of porcine **hearts** appears to be the least susceptible to major physiological incompatibility problems, but lethal disrhythmias due to anatomical differences in the intrinsic innervation of the heart still have to be overcome. In **kidneys**, differences in the renal handling of creatinine, urea, and electrolytes such as calcium and phosphate require further research in long-term experiments. It is unlikely that xenografted **livers** will function properly in the human recipient due to the complexity of their metabolic, hormonal and regulatory functions. The xenotransplantation of **lungs** seems to be the least advanced of all solid organs, and it is likely that the postural change from the supine position in the donor pig to the upright position in the human recipient will significantly compromise the lung function.

Risk of infection. Xenotransplantation bears the risk that xenograft recipients may be infected by known source animal pathogens, and that previously unknown pathogens may emerge which might be a health hazard to patients, contact persons and the general population. The risk of infection due to porcine endogenous retroviruses (PERV) has been extensively investigated in recent years. This group of viruses has been thoroughly characterised on the molecular level, and also their infection behaviour in vitro has been investigated. Up to now, no evidence for PERV infection of humans in vivo

has been obtained, but good in vivo animal models are still lacking to address this question further. Measures for the prevention and control of infection events have been discussed and developed for PERVs and for known pathogens present in pigs; they comprise the breeding and housing of specific pathogen-free source animals, the development of highly sensitive and specific detection methods for the infectious agents, the implementation of monitoring measures aiming at early detection of any infection events and the prevention of transmission; furthermore, the development of drugs for the control of the infectious agents, or the development of vaccines. Appropriate regulations are being discussed at supranational and national levels. In recent years, the establishment of regulatory oversight and compliance with existing guidelines and standards has markedly reduced the risk of xenotransplantation-introduced infection – at least in several countries - compared with the unregulated situation in 1995. Altogether, these advances allow greater confidence in the reasonableness of proceeding with limited clinical trials, provided those trials are accompanied by appropriate safeguards and provided there is some reasonable basis for expectations that participants will benefit.

In analogy to allotransplantation, it can be assumed that xenotransplantation may have **unintended impacts on mental state, identity and personality**. These effects will probably not be directly attributable to the effects of the xenograft, but rather to the patients' different psychological ability to cope with the transplanted organ. In allotransplantation, the ease of coping correlates with the recipients' type of "concept of one's own body".

To sum up, at the present state of the art, it is unlikely that a patient would benefit from solid organ xenotransplantation; only prolongation of life for a number of days without improvement in the quality of life seems achievable. Therefore, general consensus has emerged in the last few years that, at present, the possible benefit is not greater than the individual and collective risks, and that consequently no solid organ xenotransplantation should be performed at present.

In the medium term, bridging the waiting time until an allotransplant becomes available seems possible, at least for hearts. But if xenografts can only be used as bridges to allotransplantation, this form of xenotransplantation will probably aggravate the existing problems of human organ shortage and human organ allocation.

2.3 Ethical questions of xenotransplantation

The following table provides a short overview on ethical problems of xenotransplantation.

Table 1: Overview on ethical problems of xenotransplantation

Risk of infection	How can individual advantage and collective risk be balanced against each other? How can the right of patients to stop receiving treatment at any time be balanced against the necessity of lifelong surveillance and precautionary measures?
Risks for patients	How can patients' informed consent be guaranteed? What balance should be established between the health of individual patients,

	scientific progress and commercial interests? Which pre-clinical research results ought to be present before the first xenotransplantation into a human being can take place? Who should be involved in such a decision?
Equal access, allocation	How can patients' equal access to both xenotransplantation and allotransplantation be guaranteed? If allotransplantation has better clinical results than xenotransplantation, which criteria guide organ allocation?
Costs / benefits	How can the respective economic costs and benefits be shared equitably between the public and the private sector? To what extent should the economy's private and public sectors, respectively, be involved in R & D of xenotransplantation?
Relationship man - animal	When animals are "humanised" and when animal organs are implanted into human beings, does this constitute a transgression of "natural" boundaries? What are the effects on identity and psyche?
Animal rights	Is it ethically justified to use animals for xenotransplantation? In general? Under certain circumstances? Must we distinguish between certain animal species? What consequences does xenotransplantation have on the relationship between men and animals?

3 Comparison of Xenotransplantation Debates

3.1 Goals

The objective of analysing the state of xenotransplantation discussions in Austria, Germany and Spain was to characterise the intensity, content and actors of (potential) xenotransplantation debates in the three countries. Moreover, the so-called baseline evaluation was to identify participants for the Neo-Socratic Dialogue (NSD), analyse their position towards xenotransplantation and identify issues for the NSDs on xenotransplantation that we were planning.

In this chapter we describe, first, the methods we used in the baseline evaluation. We continue with a comparison of the number of organ donations in the three countries, followed by a description of xenotransplantation research activities in Austria, Germany and Spain. Moreover, we compare research activities with respect to *ethical, legal and social aspects* (ELSA) of xenotransplantation and we describe xenotransplantation activities in industry, politics, the media, NGOs, as well as public attitudes towards xenotransplantation.

3.2 Methods

The methods we used for the baseline evaluation were content analysis of newspapers, magazines and policy papers, review of literature and reports, secondary analysis of opinion polls and interviews with active and latent stakeholders.

Our initial approach in media analysis was to select daily newspapers and weekly magazines in all three countries and to look for articles referring to xenotransplantation. For that purpose the research teams in Austria, Germany and Spain used keywords such as "xenotransplantation", "organ transplantation AND pig", "transplantation AND animal organ". The period of analysis was January 1995 to March 2002 for Spain and Austria, and January 1995 to July 2002 for Germany.

Given specific features of the print media sector in each country, we had to use slightly different criteria for the selection of samples in each country. In Austria, a small country with a media market of manageable size, it was possible to look at all quality papers, tabloids and weekly magazines that are covered by the Austrian Press Agency's online research option. Thus we covered almost all Austrian print media. However, in the two large countries Germany and Spain, total media coverage was impossible. Thus we had to make a selection. In Germany, the FhG-ISI selected three daily quality papers available all over Germany, one tabloid and two weekly magazines. In Spain, the CSIC team, because of absence of tabloids in Spain, selected four daily quality papers and two popular science magazines. Table 2 summarises the print media we selected in all three countries, their type, circulation number and political orientation. For Austria, Table 2 presents data on the print media, with most xenotransplantation articles.

Table 2: Print media in Austria, Germany and Spain selected for analysis

Country	Name of print medium	Type of print medium	Circulation	Remarks
Austria[8]	Der Standard	Daily newspaper	67.400	centre-left
	Salzburger Nachrichten	Daily newspaper	74.400	liberal
	Kurier	Daily newspaper	171.800	conservative (tabloid)
	Kleine Zeitung	Daily newspaper	258.300	conservative (tabloid)
	Presse	Daily newspaper	77.200	conservative
Germany	Frankfurter Allgemeine Zeitung	Daily newspaper	400.600	liberal, formerly conservative
	Süddeutsche Zeitung (SZ)	Daily newspaper	418.900	liberal
	Tageszeitung (taz)	Daily newspaper	63.700	left
	Bild-Zeitung	Daily tabloid	4.264.800	populist
	Spiegel	Weekly magazine	1.010.300	left-liberal
	Focus	Weekly magazine	733.800	right-liberal
Spain	El Pais	Daily newspaper	433.600	center-left
	El Mundo	Daily newspaper	312.400	center-right
	ABC	Daily newspaper	279.000	conservative
	La Vanguardia	Daily newspaper	191.700	center
	Muy Interesante	Popular science magazine	283.700	
	Quo	Popular science magazine	160.000	

(Source: Griessler/Bogner 2004, Hüsing/Zimmer 2003, Santos/Muñoz 2003)

[8] Sold daily copies (mean) in 2003: downloaded from http://www.oeak.at on 5.4.2004.

Similar to newspaper analysis, literature review also faced different situations in the three countries. In Germany, a wealth of literature on ELSA of xenotransplantation existed already (de Wit 2001, Jungeboldt 2002, Quante 1998, Quante/Jungeboldt 1998, Quante/Vieth 2001, Schicktanz 2001, 2000a and 2000b, Schlitt 1999). There were also several Technology Assessment (TA) studies available, that had been carried out by various institutions (Bayertz et al. 1998, Beckmann et al. 2000, Hüsing et al. 1998, Hüsing/Schicktanz 2000, Hüsing et al. 2001, Sauter 2001, Sauter/Petermann 1999a and 1999b). In addition, several official documents dealt with xenotransplantation, originating from government sources (Bundesregierung 1997 and 2001, Kiper et al. 1997), the parliament (Deutscher Bundestag 1999 and 2000, Heinrich et al. 2000) and Bavarian authorities (Dürr et al. 2001, Maget et al. 2000, Münzel et al. 1998, Staatsministerium für Unterricht, Kultus, Wissenschaft und Kunst 1997). Furthermore, there were several position papers by the Federal Association of Physicians (Bundesärztekammer 2000, Wissenschaftlicher Beirat der Bundesärztekammer 1998, 1999a and 1999b), the Protestant Church (Kirchenamt der Evangelischen Kirche in Deutschland 1998) and a NGO with close ties to the Lutheran Church (Haniel et al. 1999). Moreover, in 2001 a citizen's forum was organized with German pupils (Haniel 2002). In contrast, there was significantly less literature on xenotransplantation and related activities in Spain (Alonso 2000, Diaz 2001, Romeo-Casabona et al. 2002, Sociedad Espanola de Biotecnologica 2002, Ministerio des Sanidad y Consumo 1999) and practically none in Austria. Thus, in those two countries, we had to rely more heavily on interviews with various active or latent xenotransplantation stakeholders.

In order to get in-depth information about the xenotransplantation debate in Austria and Spain, researchers from IHS and CSIC conducted 34 and 18 interviews, respectively, with active or latent stakeholders in the development and practice of xenotransplantation in their countries. In contrast the German FhG-ISI team did not have to carry out additional interviews but had ample information about the German xenotransplantation debate from existing literature and interviews with German xenotransplantation stakeholders they had collected for previous research projects.[9]

In international perspective there is little information about attitudes towards xenotransplantation (National Kidney Foundation 1997; Arundell et al. 1997; Ward 1997; Mohacsi et al. 1997; Coffman et al. 1998; Julvez et al. 1999; Sanner 2001b; Sanner 2001a; Omnell Persson et al. 2001). SHOULD BE UPDATED! This is also true for our three-country sample. In Germany several surveys have been conducted in recent years on public acceptance of organ transplantation (c.f. Hüsing Zimmer 2003: 66 ff)[10]. Also data on the Spanish situation were available (Santos/ Muñoz 2003: 35), but for Austria we could not find quantitative data on this issue. The only available data about public acceptance of xenotransplantation for all three countries was a rather old Eurobarometer (Durant et al. 1998). No Austrian or Spanish surveys exist on patients' attitudes towards xenotransplantation but there was one

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[9] Technology Assessment Xenotransplantation (commissioned by the Swiss Science Council, Programme Technology Assessment, Bern, Switzerland; 1997-1998; Hüsing et al. 1998).

State of the Art of R&D Activities and Trends in the Field of Xenotransplantation of Organs (commissioned by the Office of Technology Assessment at the German Parliament, Bonn/Berlin, Germany 1998-1999, Hüsing et al. 2000).

Technology Assessment Cellular Xenotransplantation (commissioned by the Center for Technology Assessment TA-SWISS at the Swiss Science and Technology Council, Bern, Switzerland, 1999-2001, Hüsing et al. 2001).

[10] forsa, Gesellschaft für Sozialforschung und statistische Analysen mbH, Berlin in 2001; Institut für Demoskopie Allesnbach in 1991, 1991 and 2000, Akademie für Technikfolgenabschätzung in Baden-Würtemberg, Stuttgart in cooperation with ZUMA and INRA Deutschland (Zwick/ Renn 1998) in 1998, EMNID-Insitut Bielefeld in 1997 and 1998.

German survey about patients on transplantation waiting lists and their attitudes towards xenotransplantation (Schlitt 1999).

3.3 Organ transplantation and organ donations by human donors

The numbers of organ donations vary considerably between Austria, Germany and Spain. Table 3 provides the total number of donations and the relative number per million inhabitants in several selected countries.

Table 3: Number of donations and donation per million inhabitants in selected countries

Country	Number of donations	Donation per million inhabitants
Spain	1.409	33.68
Latvia	56	24.35
Austria	195	24.25
Portugal	217	21.70
Belgium	223	21.65
USA	6.183	21.50
R. Ireland	80	21.05
Estonia	29	20.71
France	1.198	20.00
Italy	1.019	18.10
Slovenia Rep.	35	17.50
Finland	89	17.12
Hungary	167	16.70
Malta	6	15.00
United Kingdom	765	12.96
Denmark	73	12.81
Poland	490	12.69
The Netherlands	202	12.62
Germany	1.001	12.18
Sweden	98	11.01
Cyprus	7	10.77
Australia	206	10.62
Croatia	41	9.36
Lithuania	26	7.88
Luxemburg	3	7.50
Slovak Rep.	37	6.98
Greece	65	5.91

(Source: Organizacion Nacional de Transplantes; retrieved March, 25th 2004.
http://www.msc.es/Diseno/informacionProfesional/profesional_trasplantes_e.htm)

Table 3 shows Spain as leading country in the sample measured by number of donations per million inhabitants and Austria as third. Germany is somewhat in a middle position but has far less donations relative to its population than Austria and Spain. A more detailed look at heart transplantations, a topic of particular interest in organ xenotransplantation, shows that the lack of human hearts for transplantation seems much more severe in Germany than in Austria and Spain. The number of donors per million inhabitants was lowest in Germany. Germany was also the country with the longest waiting list for heart transplantation and with the highest number of people admitted to the waiting list. Germany was also the country among the three, with the highest number of people dying while on the

waiting list (Table 4).

Table 4: Selected figures on heart transplantation in Austria, Germany and Spain (2002)

	Austria	Germany	Spain
Total number of donors	72	395	310
Number of donors per million inhabintants	8.96	4.81	7.41
Patients admitted to the waiting list during 2002	103	622	423
Patients awaiting for a transplant by 2002 31st Dec.	39	359	96
Patients dead while on the waiting list during 2002	17	131	35

(Source: Organizacion Nacional de Transplantes; retrieved March, 25th 2004.
http://www.msc.es/Diseno/informacionProfesional/profesional_trasplantes_e.htm)

3.4 Xenotransplantation Research in Medicine and the Natural Sciences

Xenotransplantation research activities in the natural sciences and medicine differ significantly between Austria, Germany and Spain. In Austria we did not identify direct xenotransplantation research. Prof. Guenzburg from the Institute of Virology, a virologist at the Veterinary University of Vienna, is studying retroviruses in gene-therapy and participated as an expert in a German TA study (Beckmann et al. 2002). Also Prof. Brem from the Institute of Livestock Breeding and Genetics at the Veterinary University of Vienna participated in this TA study. He is active in research on genetic modification of donor animals, but conducts his research in Germany. Prof. Wekerle at the Vienna General Hospital is doing research on immunology and transplantation.

In Spain, a research group at La Coruna is studying the problem of graft rejection following the hyper-acute phase in a pig-baboon-model (Santos/ Muñoz 2003: 47). In brief, the position of these researchers is that xenotransplantation might offer great benefits for patients by reducing organ shortage, reducing waiting lists and reducing deterioration effects on patients due to organ failure immediately after xenotransplantation intervention.

In contrast to Austria and Spain, a significant number of German researchers are carrying out xenotransplantation research. Several institutes are studying transplantation, genetically modified animals, islet cell xenotransplantation transplantation and infection risks (Hüsing Zimmer 2003: 42 ff.). Table 5 summarises German research institutes and their xenotransplantation activities.

Table 5: German research institutes and their xenotransplantation activities

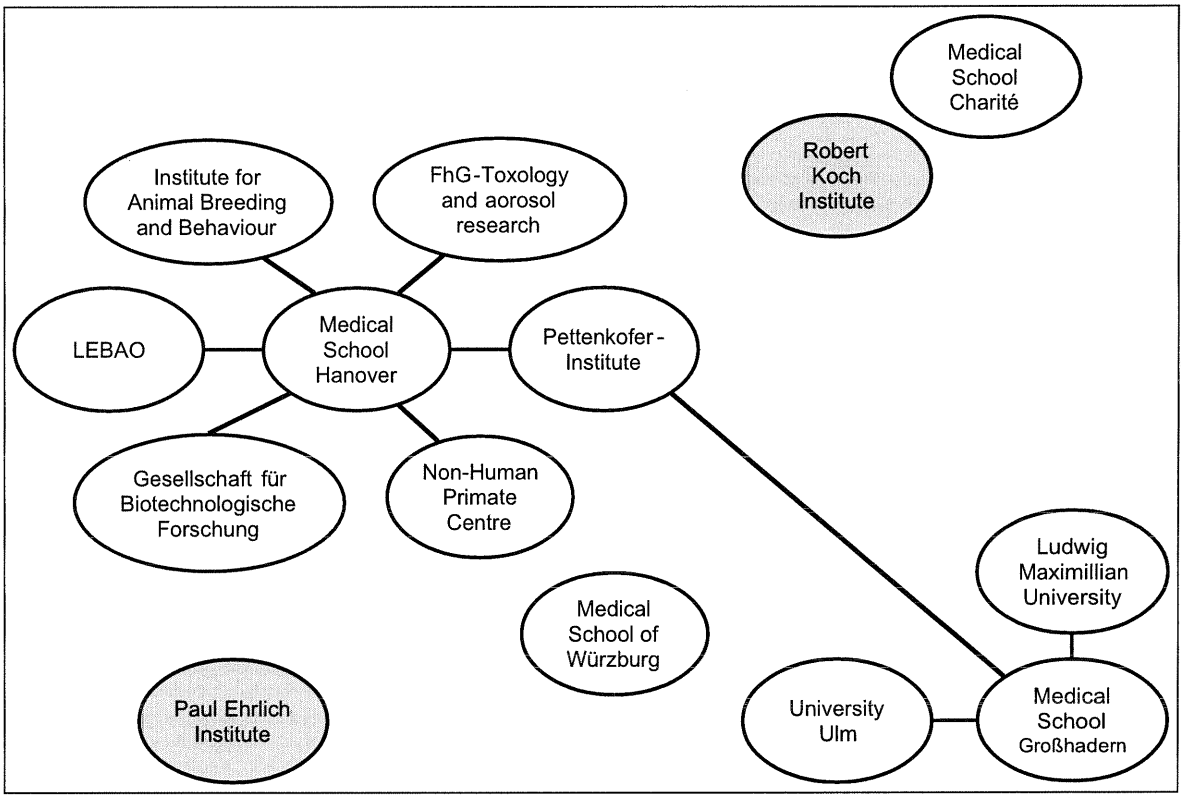
Research institute	Topic
Medical School Hanover	Transplantation surgery, xenotransplantation (rodent, dog and non-human primate model) immunology, virology
Institute for Animal Breeding and Animal Behaviour (Hanover)	Genetic engineering of livestock
Gesellschaft für Biotechnologische Forschung (Braunschweig)	Genes and vectors
Leibniz Research Laboratory for Biotechnology and Artificial Organs (LEBAO, Hanover)	xenotransplantation risk of infection
Non-Human Primate Centre (Göttingen)	Husbandry of non-human primates, immunology
Fraunhofer Institut für Toxologie und Aerosolforschung (Hanover)	Immunology
Pettenkofer Institute (Munich)	xenotransplantation risk of infection
Institute for Surgical Research, Medical School of Großhadern (Munich)	Rejection, physiology, experiments with organs from transgenic pigs, non-human primates
Ludwig Maximilian University, Chair for Molecular Livestock Breeding and Livestock Genetics (Munich)	Transgenic source animals
University Ulm, Department of thoracic and vascular surgery (Ulm)	Transplantation surgery, immunology
Medical School Charité, Clinic of General, Visceral and Transplantation Surgery (Berlin)	Transplantation surgery, liver transplantation, extracorporal liver support systems
Medical School of Würzburg, University Hospital of Surgery, Experimental Transplantation Immunology (Würzburg)	Pig islet cells for therapy of diabetes, pig rodent models
Robert Koch Institut (Berlin)	xenotransplantation risk of infection (porcine circoviridae and herpersviridae)
Paul Ehrlich Institut (Langen)	xenotransplantation risk of infection (PERVs)

(Compiled from Hüsing/Zimmer 2003: 42ff.)

German research institutes are involved in national and international cooperation. It is possible to identify several German xenotransplantation research clusters, which are located around Hanover, Munich, Würzburg and Berlin (Figure 2).

German xenotransplantation researchers meet in various scientific forums for formal and informal information exchange, such as the "Section Xenotransplantation of the German Transplantation Society" (Deutsche Transplantationsgesellschaft, DGT), the "Commission Xenotransplantation", which is part of the "Scientific Advisory Board of the DGT," the "German Working Group Xenotransplantation (DAX)" (Deutsche Arbeitsgemeinschaft Xenotransplantation) and the annual "Symposium on Innovative Organ Replacement". Also the "Society for Virology" is dealing with the topic of xenotransplantation and has published a position paper (Hüsing/ Zimmer 3002: 45 ff.).

Figure 2: Xenotransplantation-Research Cooperation in Germany



(Compiled from Hüsing/Zimmer 2003: 42ff., shaded institutes are working in the field of virology)

In brief, the common view in Germany with respect to xenotransplantation research is that xenotransplantation is acceptable in general but should not be practised yet. In the future, xenotransplantation should be controlled via certain prerequisites. In the future, appropriate safety measures and precautions should be developed in order to minimize infection risk for the patient and the general population (e.g. archives of xenotransplant source animal and recipient tissues, registries of xenotransplant recipients, xenotransplant review boards, advisory or supervisory bodies). The individual benefit for xenograft recipients and for the general population must be balanced. Non-human primates should not be used as donor animals, but only in research, as models for humans. Further research is needed on the functionality of xenografts and on microbiological safety. Moreover, it is necessary to develop harmonized international guidelines and regulations for xenotransplantation (Hüsing/ Zimmer: 47).

3.5 Industry

Novartis plays a leading role in international xenotransplantation research and regulation:

"Since the beginning of the 1990s, Novartis through its daughter companies and cooperation partners has been one of the main drivers of xenotransplantation development and its most important sponsor. It holds the largest herd of genetically engineered pigs as source animals and has research co-operations with the leading xenotransplantation researchers worldwide. Due to its initially monopolistic role regarding transgenic source animals, through its allocation policy distributing transgenic pigs only exclusively to selected research groups, Novartis had considerable influence which research groups

were able to carry out relevant, publishable xenotransplantation research. Moreover, the company has considerable influence on the shaping and harmonization of the legal framework of xenotransplantation: by announcing its will to carry out clinical xenotransplantation in the near future in the middle 1990s, it challenged the administration to act; it presented experimental and epidemiological evidence on the risk of infection associated with xenotransplantation (Onions et al. 1998; Paradis et al. 1999) and is present in all relevant negotiations (De Wit 2001: 239 ff.), where Novartis (...) establishes its way to handle xenotransplantation as a standard and as a benchmark for its competitors(e.g. regarding animal housing, screening for pathogens in pigs and humans, monitoring of patients after transplantation)" (Hüsing/ Zimmer 2003: 53ff.)

In Germany Novartis is "an important sponsor of symposia, meetings and congresses in transplantation medicine and also gives significant financial support to project in transplantation and xenotransplantation research. It has established close contacts to academic groups and makes use of their expertise both in allo- and xenotransplantation. Moreover, it was essential both for Novartis and Paul Ehrlich Institute/ Robert Koch Institute to cooperate because Novartis could give the RKI/PEI researchers the required ready access to research materials, and at the same time the company gained access to the administration which is in charge of oversight and control of xenotransplantation" (Hüsing/ Zimmer 2003: 54).

In Austria, Novartis holds a similar position with respect to allotransplantation as in Germany.

3.6 Parliament and government

Up to now, Austrian politics and public administration have almost not been active with respect to xenotransplantation. There has been no discussion in parliament on xenotransplantation and no government position exists. The ministries responsible for executing relevant regulations, such as the Austrian Pharmaceutical Act and the Austrian Gene Technology Act, are informed about xenotransplantation and are involved in the debate in international bodies such as WHO, the Council of Europe and OECD, but they have not formulated any official position so far.

So far the Spanish Government has no new legal and/ or regulatory framework for xenotransplantation under preparation (European Commission 2001: 28). However, it is remarkable that Spanish authorities decided not to follow the Council of Europe's recommendation for a moratorium on xenotransplantation research. According to the chairman of the Spanish Permanent National Transplant Commission, the Spanish decision not to follow the recommendation was based on the argument that the US would continue their research even if Europe stopped its xenotransplantation activities, and on the claim that the recommended moratorium had been based on political arguments and not on scientific reasons (Santos/ Muñoz 2003: 15ff.).

Germany was the country in our sample with most xenotransplantation activities at the political level. In parliament, the Green Party made a minor interpellation about xenotransplantation in 1997, asking the then conservative-liberal government about its activities in and perspective on xenotransplantation. In its reply the government perceived xenotransplantation as potential medical treatment in the future, but considered clinical xenotransplantation as unjustified for the moment. It believed that genetic

modification of animals for xenotransplantation would be justified and thought that xenotransplantation would not impair the identity of humans. It regarded the existing legal framework as sufficient and estimated the federal funds for xenotransplantation research with € 300.000 per year (Hüsing/ Zimmer 2003: 55). In September 2000, deputies of the Liberal Party in the Bundestag asked the Social-Democrat/Green Party coalition government in a major interpellation about its xenotransplantation position and activities. The answer of the Federal Ministry of Health on behalf of the Federal Government was quite similar to the one given by the former conservative-liberal Government in 1997 (Hüsing/ Zimmer 2003: 58).

In January 1998 the Parliamentary Committee for Education, Science, Research and Technology Assessment commissioned the Office of Technology Assessment of the German *Bundestag* (parliament) with a comparative overview on existing TA-studies on xenotransplantation. In summer 1998 the scope of this study was widened to a state of the art report on organ xenotransplantation, a review on the ethical debate of xenotransplantation and a literature analysis on the legal situation in Germany. All four studies were published, submitted and approved by the contractor in 1999. The Parliamentary Committee for Education, Science, Research and Technology Assessment discussed the report in 2000 in depth and asked the Enquete Commission "Law and Ethics in Modern Medicine" to deal with xenotransplantation. Although the Commission was planning to deal with xenotransplantation it did not have time to do so (Hüsing/ Zimmer 2003: 55 ff.).

The German Bundestag also discussed the recommendation of the Council of Europe, which called for a moratorium. The implementation of a xenotransplantation moratorium in Germany is still pending.

In public administration the Ministry for Education and Research is responsible for xenotransplantation research, the Ministry of Health for clinical application and the prevention and management of potential infection risks. The Ministry of Justice is responsible for legal aspects of xenotransplantation. These ministries give low priority to xenotransplantation and have delegated their seats in national and international committees to individual scientists in the biomedical/natural science cluster (Hüsing/ Zimmer 2003: 58).

3.7 Advisory Bodies and Position Papers

In Austria, no paper of a national advisory body exists about xenotransplantation. In Spain, the Sub-commission of the National Transplant Commission produced Recommendations for the regulation of Xenotransplantation activities.

As Table 6 shows, several bodies in Germany have produced official papers on xenotransplantation.

Table 6: Summary of selected German xenotransplantation position papers from various actors

Institution	Position	Reference
German Medical Association (Bundesärztekammer) xenotransplantation Working Group of the Scientific Advisory Board	xenotransplantation is supported in general. Clinical xenotransplantation procedures should not be performed yet until more information on risks and benefits is available.	Wissenschaftlicher Beirat der Bundesärztekammer 1999b
Society for Virology	At the present time, xenotransplantation cannot be considered as an ethically unproblematic alternative to the therapeutic application of human embryonic stem cells. Intensive research is required to reach functionality of xenografts and microbiological safety	Gesellschaft für Virologie 2002
European Academy for the Study of the Consequences of Scientific and Technological Advances Bad Neuenahr-Wahrweiler GmbH	Cautious and stepwise approach towards clinical xenotransplantation under strictly controlled conditions is recommended. Moreover, strict supervision of xenotransplantation procedures is recommended. Public discussion should be carried out. (Beckmann et al. 2000)	Beckmann et al. 2000
Church Office of the Evangelical Church in Germany, Secretariat of the German Bishops' Conference	Different positions towards xenotransplantation can be taken and are all well founded by arguments. xenotransplantation is only one of several options to solve the problem of organ shortage. Dealing with this problem must comprise the search for and inclusion of alternatives, other options than xenotransplantation. This research has to orient itself on saving human lives, the dignity of man and respect for animals.	Kirchenamt der Evangelischen Kirche in Deutschland et al. 1998
Institute Technology-Theology-Natural Science	No fundamental ethical objections against xenotransplantation. Research should be supported. Clinical application is rejected for ethical reasons because of uncertainties regarding functionality; compatibility, infection risks and alternative options have not been fully researched. Regulations should be initiated based on interdisciplinary xenotransplantation expert committee.	Haniel et al. 1999

(Compiled from Hüsing/ Zimmer 2003)

3.8 Research on ethical, legal and social aspects of xenotransplantation

In Austria we did not find much research in ELSA of xenotransplantation. Lapka et al. conducted a survey on the acceptance of xenotransplantation by heart transplantation patients (2001) in 1999. And Prat published an article on xenotransplantation from an ethics perspective (Prat 2001).

Also in Spain there is no research on ELSA of xenotransplantation. The main issues raised during the interviews with Spanish bioethics specialists were public health risks, alternatives needed to solve organ shortages and animal rights. The interviewees considered infection risk as the main technical problem of xenotransplantation. More information about the potential infection risks from animals to humans should be an absolute prerequisite for clinical practice of xenotransplantation. They did not think that continuous monitoring would restrict the patient's individual freedom. Monitoring of private life of xenograft recipients would be the cost to be paid for the improvement of their quality of life. They also supported the use of animals for research and as source animals, provided that all relevant international conventions and laws would be respected. Research on xenotransplantation should be promoted without forgetting alternatives, e.g. stem cell research, which in their opinion would not pose an ethical problem (Santos/ Muñoz 2003: 43).

In contrast to Austria and Spain, Germany has a vivid research scene on ELSA of xenotransplantation. This ELSA cluster is dealing with xenotransplantation from the perspective of ethics, philosophy, law and an inclusive technology assessment, which involves the above-mentioned aspects in its assessment (Hüsing/ Zimmer 2003: 47 ff.). The ELSA cluster, which is often critical about xenotransplantation, raises issues that the transplantation medicine/ natural science cluster does not deal with. The transplantation medicine/natural science cluster focused on pragmatic solutions to xenotransplantation problems arising from clinical application, stressing the benefit to individual patients. In contrast, the ELSA cluster extended the debate and raised a number of issues not covered by the natural scientists, e.g. acceptability of xenotransplantation as such and in comparison to alternatives, animal welfare, psychology/identity, benefits and risks to the general public, allocation problems on the individual, national and international levels, normative questions in law, questions of life and death, the relationship between man and his own body and between man and animals, alternatives to xenotransplantation, social networks in which xenotransplantation evolves, historical and cultural backgrounds of organ transplantation. Some of the actors of the ELSA cluster adopted a problem-driven instead a technology-driven approach (Hüsing/ Zimmer: 47). Table 7 summarises people, institutions and topics of the German ELSA cluster.

Table 7: Overview of the German xenotransplantation ELSA Cluster

Institution	Person	Topic
Eberhad Karls University (Tübingen) Chair for Ethics and Life Science	Prof. Engels, Dr. Schicktanz	Ethics of xenotransplantation
University of Hamburg Research Group "Technology Assessment of Modern Biotechnology in Medicine/ Neurobiology)	Prof. Kollek, Dr. de Wit	Social and ethical controversies of biomedicine
European Academy for the Study of Consequences of Scientific and Technological Advance Bad Neuenahr-Ahrweiler	Prof. Beckmann	Technology Assessment
FhG-ISI	Dr. Hüsing	Technology Assessment
Institute Technology - Theology - Natural Science	Prof. Haniel	Interdisciplinary dialogue on ethical problems in technology and natural science
Philosophical Seminar of the University of Münster argos Institute Münster	Dr. Quante	Ethics of xenotransplantation
University of Göttingen, Institute of Ethnology at	Dr. Hauser-Schäuble	Cultural dimension of organ transplantation and reproductive medicine
University of Göttingen ,Chair of Criminal Law and Criminal Trial Law	Dr. Schreiber, Dr. Jungeboldt	Bioethics and biolaw
University of Lüneburg, Institute for Jurisprudence	Prof. Simon	Ethical, social, economical and legal aspects of xenotransplantation

(Compiled from Hüsing/Zimmer 2003: 42ff.)

3.9 Patients

Because xenotransplantation is rather far from clinical application it is not a matter of high priority for German patients organisations. Nevertheless, representatives of German patient organisations keep informed about xenotransplantation (Hüsing/ Zimmer: 75). In 1998, Schlitt et al. (1999) carried out an survey on German patients waiting for transplantation.

"It was the aim of this study in Germany to analyse the attitudes of patients toward transplantation of xenogeneic organs and evaluate factors influencing these attitudes. Attitudes toward xenogeneic compared with allogeneic organ grafts were evaluated by means of detailed questionnaires in 1,049 patients in Germany, who either had received transplants (n=722) or were on the waiting list for various organ grafts (n=327). Answers were correlated to demographic data as well as to the physical and mental conditions of the patients. The survey indicates that 77 % of patients would accept xenografts while 7 % would refuse them if results of xenotransplantation were comparable with those of allotransplantation, 16 % were undecided. If xenotransplantation were associated with increased risks due to more intensive medication 58 % would still basically accept xenografts. Acceptance of xenografts was significantly higher in patients who had received transplants and among males. Age, religion, waiting time, and type of organ were not found to influence acceptance rates. Xenografts were thought to be associated with considerable or severe emotional stress by 23 % of patients, versus 3 % for allografts. The pig was the preferred donor animal, and gene therapeutic manipulation for improvement of results would be accepted by 84 %. Major concerns for the patients were inadequate graft function/increased risk of rejection (60 %), risk of disease transmission (52 %),

emotional concerns (24 %) and animal-rights concerns (15 %). The authors conclude from the results of this survey that the potential acceptance rate of xenografts would be quite high, with a more positive attitude in transplanted patients than in waiting-list patients. Interestingly, patients waiting for a life-saving organ (heart, lung) were especially sceptical in comparison to already transplanted patients. Major concerns about xenotransplantation currently are functional inferiority and transmission of diseases (Schlitt et al. 1999)." (Hüsing/ Zimmer 2003: 76).

Similar to Germany, Austrian patient representatives are not involved in the xenotransplantation debate, but in our interviews were positive about this technology. This result is in line with the findings of Lapka et al. (2001), who did in 1999 a survey on 100 heart transplant patients in the Vienna general hospital and their attitude towards xenotransplantation. According to this study 2/3 of the patients could imagine very well to receive a xenograft and more than 80% would accept xenotransplantation.

Spanish patient representatives demanded more public information about xenotransplantation research. They criticized researchers for not showing a clear will to communicate information in an understandable way to the public. Television, which should be a major instrument to inform the public, should pay more attention to xenotransplantation. The patient representatives considered stem cell research as more promising than xenotransplantation and thought that the infection risk would be the major hurdle to clinical application of xenotransplantation. Until this risk was not sufficiently assessed, individual benefits would have to be sacrificed on behalf of public health. The patient representatives thought, *"animals should be used as support for human welfare, since the right to health is more important than animal rights, though it is important to avoid unnecessary suffering to them and to provide good conditions for animal living"* (Santos/ Muñoz 2003: 41).

3.10 NGOs

The situation of animal welfare and the attitudes of environment protection NGOs are similar in Austria and Germany. They are very critical about xenotransplantation, but are not involved in the xenotransplantation debate. This may be due to their limited financial and personal resources and their engagement in other campaigns, but certainly also a lack of interest by the media may be responsible for the marginal importance of these groups.

Animal rights have an even lower priority in the Spanish "xenotransplantation debate". One indicator for this is that in Spanish xenotransplantation articles only three interviewees dealt with the issue of animal welfare (Santos/ Muñoz 2003: 51). The interviewed Spanish animal rights activists considered information about biotechnology in Spain as poor and biased. The debate focussed on benefits and needs, accompanied by a strategy of intentionally hiding the potential problems such as eventual pandemics and animal suffering. The living conditions of donor animals, in particular baboons, would be far from their natural habitat and would involve animal suffering. They interviewees also felt it unacceptable to distinguish between donor animals, in the case of xenotransplantation between pigs and non-human primates. All animal activists interviewed considered research on stem cells as interesting possibility to breed custom-made organs but thought that stem cell research would be blocked for of extra-scientific reasons. They thought, that the costs, risks for public health and animal

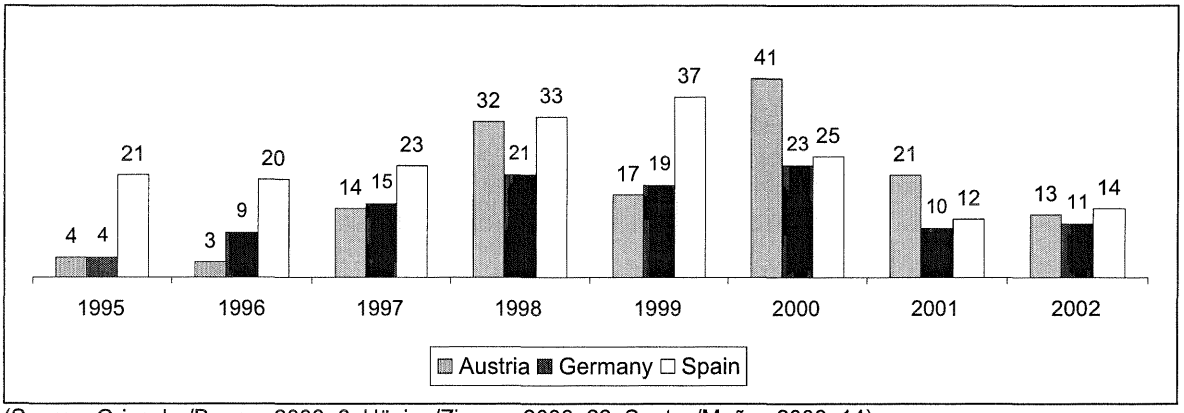
suffering involved in xenotransplantation research exceed the benefits of this technology (Santos/ Muñoz 2003: 41ff.).

In Germany the Evangelic Churches and the Catholic Church together produced a paper on xenotransplantation (Kirchenamt der Evangelischen Kirche in Deutschland; Sekretariat der Deutschen Bischofskonferenz 1998). In Austria no such an official paper exists, but in the media the Catholic Church takes a positive stance towards xenotransplantation.

3.11 Media

To get an idea about the media reports on xenotransplantation in Austria, Germany and Spain we looked at articles published between 1995 and 2002 in selected print media (Table 8). Please keep in mind that the total numbers in the three countries are not comparable because of different sizes of samples (Austria all print media covered by Austrian Press Agency on-line recherché, papers, Germany and Spain 6 papers each).

Table 8: Number of articles in Austria, Germany and Spain in selected print media (1995-2002)



(Source: Griessler/Bogner 2003: 6, Hüsing/Zimmer 2003: 22; Santos/Muñoz 2003: 14).

Between the year 1995 and 2000, print media in all three countries reported about xenotransplantation to some extent. Although the total numbers of articles are not comparable due to differences in country size and media market structure, which made adjustments in the selection of samples in the three countries necessary, it was possible to discern certain common patterns in Austria, Germany and Spain.

One common feature was the relatively low coverage of xenotransplantation in the selected media. In order to put xenotransplantation into perspective we also looked in selected samples for the term "stem cell" (singular and plural). The quantity of articles on this issue by far exceeded the number of xenotransplantation reports in all three countries. Thus, it is sound to conclude that in all three countries xenotransplantation was of marginal interest for print media. It must be added, however, that the number of articles does not say anything about their length, content and quality.

In comparison with Spanish newspapers and magazines Austrian and German media reported about

xenotransplantation rather late. In both countries there was only little reporting from 1995 to 1997. Austrian papers published 21 xenotransplantation articles in this period (14% of all Austrian articles) and German papers 28 articles (25% of the German total). By contrast, Spanish papers carried 64 xenotransplantation reports in the same time span, i.e. 35% of all Spanish xenotransplantation articles.

Another common feature was a certain "boom" of xenotransplantation reports: The period from 1998 to 2000 was the one with increased xenotransplantation reporting in all three countries. But 2001 was the year with most of articles per year in Austria and Germany, whereas in Spain this was the case in 1999. The year 2001 again showed a decline in articles in all three countries.

Quality papers had a primary role in all three countries regarding xenotransplantation information. This is a truism for Spain, where no tabloids exist. But also the two Spanish popular science magazines investigated had little xenotransplantation coverage. In Germany and Austria, xenotransplantation reporting was highly concentrated in quality papers.

3.11.1 Austria

Xenotransplantation is not at all a prominent issue in Austrian media so far. It is only dealt with in short news items and not in the form of long reports. It is not a topic on front pages and it is particularly not debated in the politics sections of newspapers, but rather in the science, health and medicine as well as local news section of papers (Griessler/ Bogner 2003: 9). The media document primarily the scientific development of xenotransplantation, but do not debate the issue in depth. Basically, Austrian media present xenotransplantation in two respects: first, xenotransplantation as a logical but technically challenging response to organ shortage; second, xenotransplantation in the context of cloning and stem cell research, as a gene-technological alternative in transplantation medicine. In both contexts it is not easy to raise the ethics of xenotransplantation: In the first case it is hard to question xenotransplantation because it is presented as continuation of a successful and already accepted transplantation practice. In the latter case the ethics of stem cell research are discussed and they are different from the ethics of xenotransplantation (Griessler/ Bogner 2003: 15f f.).

It cannot be said that Austrian newspapers totally omit the ethics of xenotransplantation, though allusions to ethical questions refer to animal rights and the creation of chimera rather incidentally, which are aspects that have been debated for a long time in other contexts. Sometimes, articles vaguely hint at the existence of *"ethical limits"* to research. Sometimes they simply point out that ethical questions do exist. However, Austrian media neither develop the ethical aspect of animal rights and welfare systematically nor do they discuss these issues in depth. The press concentrates primarily on technical aspects of xenotransplantation and discusses primarily technical/scientific solutions or „scientific problems". Infrequently raised ethical issues of xenotransplantation concern animal rights and social values that would be affected by xenotransplantation as well as stringent protective measures. Since Austrian media predominantly discuss medical and epidemiological risks, XPT appears as acceptable in principle, but - at the moment – as a not yet well-mastered technology. (Griessler/ Bogner: 24). Austrian media debate is clearly dominated by scientists and physicians (Griessler/ Bogner: 27).

3.11.2 Germany

The selected German media placed xenotransplantation most often in the science/medicine section (47% of all xenotransplantation articles), the politics (14%) and features section (11%, Hüsing/ Zimmer 2003: 23 ff.). Usually, articles in the science/medicine sections of the media presented xenotransplantation as a challenging problem, and as a most probably feasible medical-scientific development.

Articles are most often concerned with the technical-scientific feasibility of xenotransplantation (49 of 112 articles), its benefits and risks (22 articles), donor organ shortage (15 articles), regulatory problems (12 articles) and impact on fundamental societal values (10 articles).

The issues most often raised in the articles are scientific-technical obstacles to xenotransplantation (in 68 of 112 articles or 61 %). Among these the ones most often discussed are infection risk (54 of 68 articles mentioning obstacles) and xenograft rejection (35 articles). 27 articles discuss state-of-the-art xenotransplantation, 20 address immune-suppression and 6 physiological incompatibilities (Hüsing/ Zimmer 2003: 37).

Benefits of xenotransplantation are another important issue, addressed in 66 of the 112 articles (59%). The most important benefit, deducing from the number of references, is "xenotransplantation as a solution to donor organ shortage". 56 of the 66 articles addressing the benefits of xenotransplantation mention this assumption. 13 of the articles mentioning the benefits of xenotransplantation for patients address improving patients' quality of life, 5 saving patients' life, and 8 articles other topics.

Another important issue covered by German newspapers and magazines is the use and manipulation of source animals. 61 of the 112 articles address this issue (54%).

49 of the 112 xenotransplantation articles refer to societal questions (44%), which mainly relate to public acceptance (25 articles), economic questions and costs (18 articles), regulatory initiatives and present state of regulation (16 and 10 articles respectively). Only few of these articles refer to acceptance of the use of animals (3 articles) and religious issues (2 articles).

Alternatives to xenotransplantation are not often addressed in 8 of the 112 xenotransplantation articles (7%).

Ethical questions are raised in 50 of the 112 German xenotransplantation articles (45%). 33 of these articles deal with risks, and 16 articles with animal welfare. 8 deal with patients' rights and 6 with cultural values and equal access. Only 2 articles deal with economics and 1 article with regulation.

An absolute majority of the articles were balanced in their opinion about xenotransplantation (57%), roughly a quarter had negative attitude towards xenotransplantation (24%) and about one-fifth was positive about xenotransplantation (19%). However, a comparison between the periods 1995-1998 and 1999-2000 shows a decrease of positive articles (27% to 13%) and an increase of balanced (51% to 62%) and negative articles (22% to 25%, Hüsing/ Zimmer 2003: 40 ff).

The Media coverage is clearly dominated by scientists and physicians (57%), followed by companies (13%), the media themselves (9%), and representatives of (federal) agencies (8%). All other actors (13%), e.g. patients, churches, the general public, financial services or animal activists are only represented in two or three articles (Hüsing/ Zimmer 2003: 83ff.).

3.11.3 Spain

With 89%, the reporting type "news item" was the most frequent type of article in Spanish print media. This figure suggests that the media do not attach great importance to that topic, because these articles do not express the media's specific points of view (Santos/ Muñoz 2003: 16). The six subjects most often dealt with were: genetic engineering to overcome hyper-acute rejection (21% of all articles); xenotransplantation as a means to overcome organ shortage (17%), xenotransplantation as benefit to patients' quality of life (9%), genetic manipulation of animals (9%), present state of the art (7%) and regulatory initiatives (7%).

23% of the documents did not raise the ethics of xenotransplantation, but 77% did, though not very intensely. Information about the ethics of xenotransplantation relate to the infection risk (37% of all articles), to values (19%, mostly about crossing the boundaries between species) and animal welfare (10%).

The actors most often quoted in articles are scientists (71%) working either in public research organisations (44%) or for industry (27%). Politicians are the second group of actors (15%), often appearing in the papers in the context of regulatory initiatives, e.g. the Council of Europe's moratorium or British xenotransplantation regulations. NGOs, particularly animal welfare organisations, are almost completely absent in the papers; only 3 documents quote animal welfarist. In summary, xenotransplantation coverage in the Spanish press concentrated on scientific issues and paid little attention to socio-political, ethical or economic aspects. In general the press was rather positive about xenotransplantation; 58% of all articles were mainly positive, 26% neutral and 16% negative (Santos/ Muñoz 2003: 14 ff.)

3.12 Public Attitude

3.12.1 Austria

In General there is little recent information about the public attitude towards xenotransplantation in the three countries. For Austria we did not find any surveys on people's opinions about transplantation in general and xenotransplantation in particular besides the Eurobarometer of 1996. However, interviews with stakeholders vaguely indicate that the acceptance of transplantation might possibly be higher in Austria than in other European countries. Interview partners give some historical reasons for this assumption. Already in the 18th century empress Maria Theresia decreed that all patients who died in hospital had to have a post mortem. Several interview partners think that this regulation contributed to a different attitude towards the dead body and organ donation.

3.12.2 Germany

The "Deutsche Gesellschaft für Humanes Sterben" contracted two surveys in 1997 and 1998, which showed that the majority of Germans consider organ transplantation as a good and right treatment.[11] In 1997 84% of the respondents said that organ transplantation was a "good idea, the right thing", in 1998 the respective number was 74%. Another study carried out in Baden-Würtemberg in 1998 showed, that 67% of the population supported organ-transplantation, but only 21% genetic engineering, a method necessary for xenotransplantation.[12] A more recent survey[13] carried out in 2001 showed, that organ transplantation was considered as positive by 82% of the Germans, but that only 32% of them have thought about this question intensively so far. This survey also showed that 67% of the population in principle agrees with an explantation of their organs after death, but only 12% of the population had an organ donor card or, the other way round, 87% did not have it. This is important, since in Germany, in contrast to Austria the transplantation law assumes a refusal to organ transplantation unless the deceased person held a so-called organ donor card. Thus the willingness of the population to donate organs directly affects the number of donations (Hüsing/ Zimmer 2003: 64 ff.)

With regard to xenotransplantation, a survey carried out in 2000 showed that only 8% of the Germans considered it a good thing to receive an animal heart, e.g. pig or baboon, in case of organ damage or disease.[14] In contrast to the healthy population's reluctance, a German survey of patients on transplantation waiting lists showed that 58% of them would accept xenografts even if they were inferior to allografts, and 77% would accept them if they were equal to allografts (Schlitt et al. 1999).

3.12.3 Spain

A Spanish survey[15] carried out in 1996 showed that 97% of the people interviewed thought that transplantation has contributed to improving the quality of life. 81% wanted more successful research in all aspects related to transplantation though xenotransplantation was not suggested in the interview. This positive attitude towards transplantation could be connected to the successful work of the Spanish transplantation organization (Santos/ Muñoz 2003: 35)

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[11] The questions was: "Do you think that organ transplantation is a good idea and the right thing, or are you against organ transplantation". Respondents came from all over Germany, the number of the sample was not available.

[12] The study was commissioned by the Landesforschungsbeirat of Baden-Würtemberg and carried out by the Akademie für Technikfolgenabschätzung in Baden-Würtemberg in cooperation with ZUMA and INRA Deutschland (Zwick/ Renn 1998). The survey covered the population of Baden-Würtemberg. The wording of the question was: "What do you think about the following technologies?"

[13] The study was commissioned by the Bundeszentrale für gesundheitliche Aufklärung and carried out by forsa, Gesellschaft für Sozialforschung und statistische Analysen mbH. The sample of this poll was 3,254 persons from all over Germany over 14 years. The wording of the questions was: "Which view do you take of organ donation?"; "Have you already gone into the issue of organ donation intensively, or have dealt with it only little or not at all?".

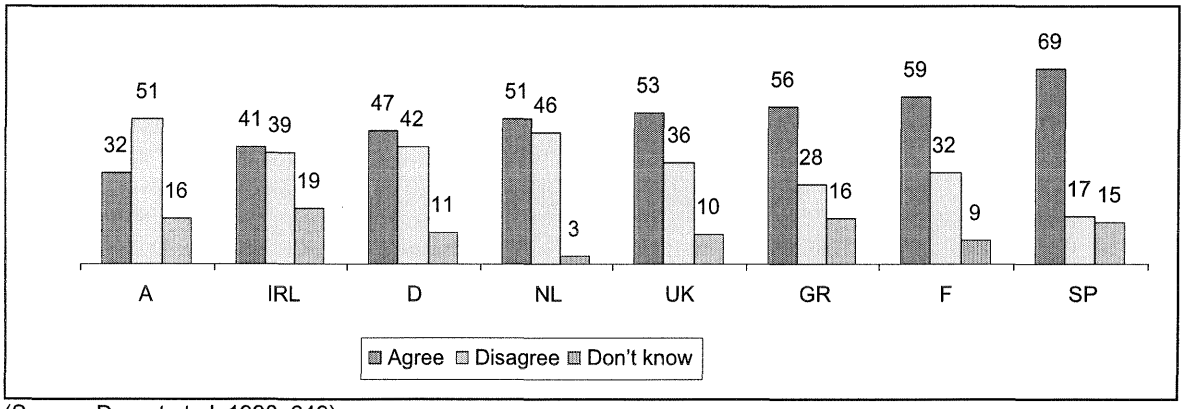
[14] The wording of the question was: "Assuming you were suffering from severe heart disease and are in need of a new heart. If you could choose, what from this list would you like most, what would you take".

[15] La imagen social de las nuevas tecnologias biológicas en Espana" (Social perception of new biological technologies in Spain), Atienza, Julián and Luján, José Luis. Survey No. 2213, 1996, CIS, Madrid, www.cis.es. The sample was 2730 people aged 16 to 64 years.

3.12.4 Eurobarometer (1996)

Public opinion about xenotransplantation differs clearly between the three countries; Austria and Germany being on one side of the range and Spain on the other side. While a large majority of the Spanish population consider xenotransplantation as useful for society (69%), the Austrian population is at the opposite end of the sample (32%, Figure 3). This pattern also is visible in the questions whether xenotransplantation is morally acceptable (Spain: 47% agreement, Austria 24% agreement, Figure 5) and whether society should encourage xenotransplantation (Spain: 53% agreement, Austria 26% agreement, Figure 6). The German population is a bit more positive about xenotransplantation than the Austrian population, but still much more negative than the Spanish (47% agreement on the usefulness for society, 32% agreement, that society should encourage xenotransplantation, 28% agreement, that xenotransplantation is morally acceptable). The public in all three countries, however, holds more or less the same opinion about the risk of xenotransplantation. In Germany 55% consider xenotransplantation as risky, in Spain 53% and in Austria 46% (Figure 4)

Figure 3: Is xenotransplantation useful for Society?[16]

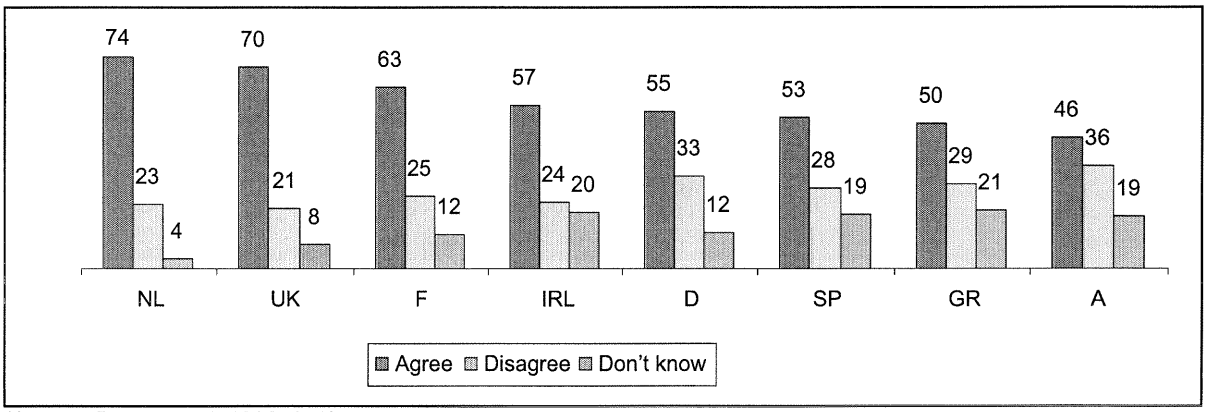


(Source: Durant et al. 1998: 249)

Interestingly enough, however, in contrast to this disapproval, the proportion of Austrians who consider xenotransplantation as risky is smaller than in other European countries (43%, cf. Diagram 6).

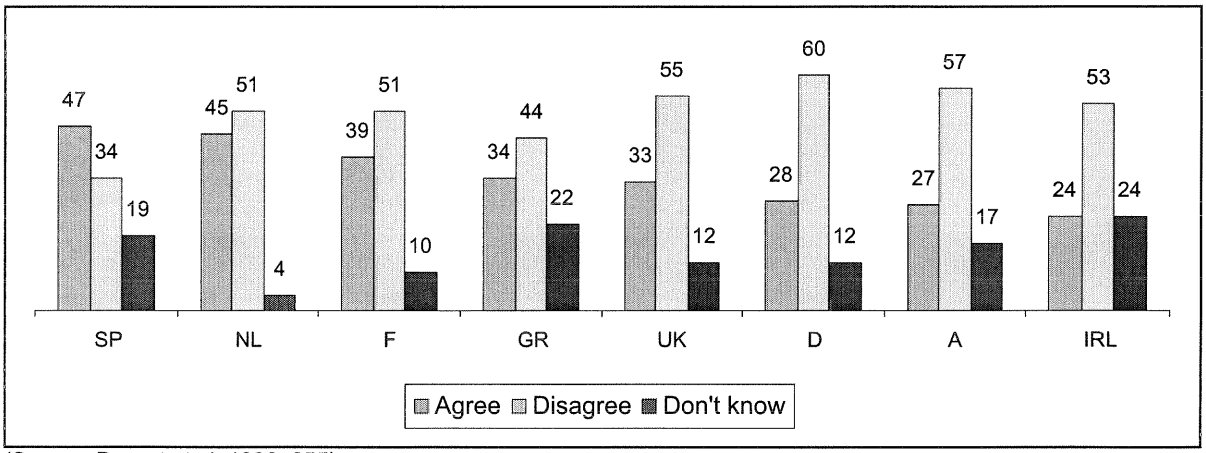
[16] Question: Do you definitely agree, tend to agree, tend to disagree or definitely disagree that it is useful for society to introduce human genes into animals to produce organs for human transplants, such as into pigs for human heart transplants?

Figure 4: Is xenotransplantation risky?[17]



(Source: Durant et al. 1998: 252)

Figure 5: Is xenotransplantation morally acceptable? [18]

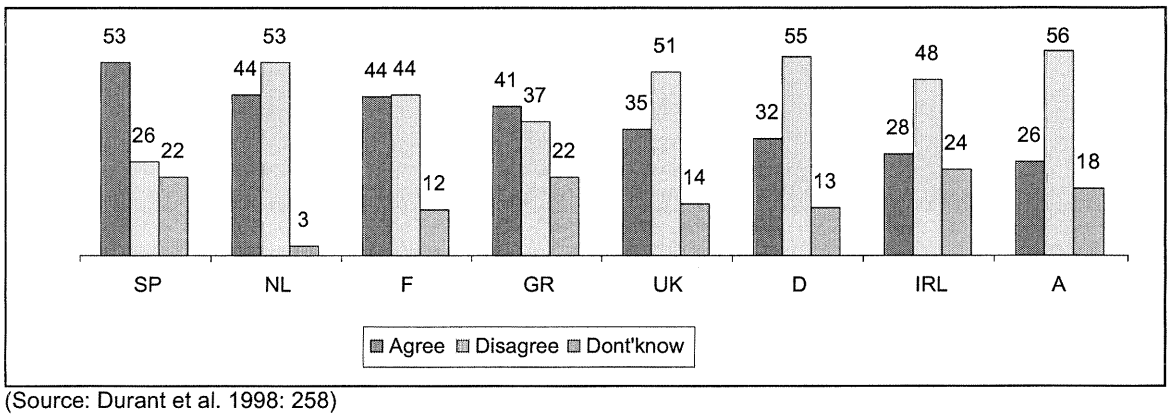


(Source: Durant et al. 1998: 255)

[17] Question: Do you definitely agree, tend to agree, tend to disagree or definitely disagree that it is risky to introduce human genes into animals to produce organs for human transplants, such as into pigs for human heart transplants?

[18] Question: Do you definitely agree, tend to agree, tend to disagree or definitely disagree that it is morally acceptable to introduce human genes into animals to produce organs for human transplants, such as into pigs for human heart transplants?

Figure 6: Should Society Encourage xenotransplantation?[19]



(Source: Durant et al. 1998: 258)

Santos and Muñoz (2003: 37) question the reliability of these rather old data, given the fact that the respondents might know only little about xenotransplantation. They warn that opinion polls in which the interviewees are not well informed about the issues addressed must be treated with caution. This warning is supported by results from a German exercise in participatory technology assessment, which showed intensified scepticism towards xenotransplantation after thorough information on the issue. In November 2000, the Technology-Theology-Natural Science Institute carried out a citizen's forum about xenotransplantation with 60 pupils and students. The citizen forum used a structure similar to consensus conferences, in which laypeople form an informed opinion on a topic after intensive consultation with experts from the field.

"At the beginning of the forum, 75 % of the lay participants said they would agree to receive an animal organ in case of failure of their own organ. An even larger share supported research on xenotransplantation. After the three-day forum, the share of those willing to receive an animal organ had dropped to 26 %, and hardly 40 % still supported research on xenotransplantation. This increase in negative attitudes towards xenotransplantation was explained by the fact that in the beginning of the event, participants felt ill informed on the details of xenotransplantation, but learned during the forum of the unsolved questions in xenotransplantation (e. g. rejection, physiological compatibility between donor and recipient, risks of infection). These unsolved questions were given as reasons for the more negative or sceptical attitudes after the forum (Anonymous 2000; Haniel 2002). This result is in line with findings from other projects on attitudes towards biotechnological innovations which showed that more information does not "automatically" lead to larger acceptance of the innovation, but to a more decided and differentiated opinion (e. g. Zimmer 2002; Hampel 1999, p. 33ff., Hüsing/Zimmer 2003: 74).

[19] Question: Do you definitely agree, tend to agree, tend to disagree or definitely disagree that society should be encouraged to introduce human genes into animals to produce organs for human transplants, such as into pigs for human heart transplants?

3.13 Configuration of xenotransplantation debate in Austria, Germany & Spain

3.13.1 Austria

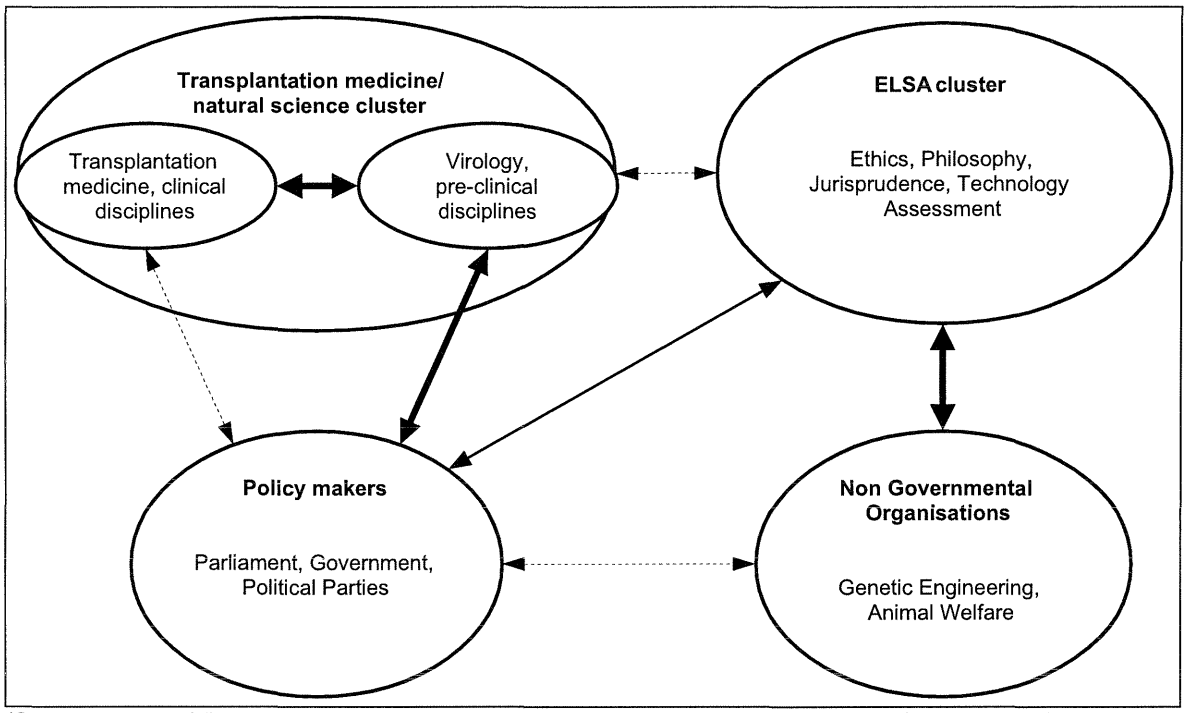
There is definitely no public debate on xenotransplantation in Austria. The media cover xenotransplantation only very little and only few latent actors are aware of the issue (Griessler/ Bogner 2003: 5 ff.). No national ethics committee or similar body has provided an opinion on xenotransplantation (European Commission 2001: 4). There has also not been any structured public debate on xenotransplantation up to now. Furthermore, until today, none of the latent stakeholders in xenotransplantation (research, transplantation surgeons, patient groups, animal welfare groups, politics, industry, private and public health insurance) have raised the issue in Austria.

Reports on xenotransplantation in the print media - apart from that there is no public forum on xenotransplantation - are clearly dominated by transplantation surgeons and physicians. If there is any discussion on the ethics of xenotransplantation in the media, it is dominated by positions of the Catholic Church. Secular ethical positions are almost non-existent in the media. Neither are positions of animal rights activists. In exceptional cases, physicians raise questions of animal rights. Social scientists are not present in the debate, as well. One reason for the dominance of transplantation surgeons in the Austrian xenotransplantation discourse, and for the exclusion of other latent actors might lie in the very lack of controversy on this issue. The discourse focuses on transplantation medicine, and xenotransplantation is a logical step on this trajectory. One of the most striking features is the complete absence of animal welfare groups and environmentalists, which differs from their deep involvement in the debate on genetically modified organisms. Also, patient self-help groups are absent from the debate. Since the Austrian xenotransplantation discourse is in an embryonic state there are no explicit coalitions between actors, but there are surely latent coalitions, e.g. between surgeons, patient self-help groups and pharmaceutical industry on the one side, and animal welfare groups and dissenting natural science and humanities researchers on the other side.

3.13.2 Germany

In contrast to Austria, Germany has a much more complex, active and multi-faceted xenotransplantation debate that involves different actors from medicine and natural sciences, humanities, policy makers from parliament, parties and government, as well as NGOs in four distinctive clusters (Figure 7).

Figure 7: Coalitions in the German xenotransplantation arena



(Source. Hüsing/Zimmer 2003: 85, the thickness of lines indicates the strength of cooperation)

Hüsing/ Zimmer (2003: 84 ff.) distinguish four clusters:

The transplantation medicine/ natural science cluster includes the most influential actors and consists mainly of two kinds of actors: (1) scientists and physicians working in transplantation medicine and clinical disciplines and (2) scientists in virology and pre-clinical disciplines. This cluster evolved over time in a difficult and long formation process by settling previously antagonistic views about the infection risk involved in xenotransplantation (Hüsing/ Zimmer 85ff.). At present, this cluster has the strongest impact on the public debate and it sets the agenda in the German xenotransplantation debate. It presents xenotransplantation as a technology-driven solution to the problems of transplantation.

In contrast to the biomedicine/natural science cluster, the ELSA cluster is by far less influential. It has less impact on public media and agenda setting. By contrast, it has strong links to NGOs, but those are again not very strong and do not participate in the xenotransplantation debate. The ELSA cluster also has limited influence on policy makers, e.g. by TA studies. Despite regular contact during workshops and symposia, the relationship between the transplantation medicine/ natural science cluster and the ELSA cluster is still problematic and mainly antagonistic. The transplantation/ natural science cluster accepted only a few individuals from the ELSA cluster as equals and adopted to a limited extent certain thematic and methodological contributions by the latter (c.f. Hüsing/ Zimmer 2003: 87)

German ministries have so far delegated their participation in international bodies to certain committees and individual scientists from the biomedical/ natural science clusters. The ministries have privileged access to government-owned virology institutes (Paul Ehrlich Institute, Robert Koch

Institute), which are part of the transplantation and natural science cluster, but also maintain some contact with the ELSA cluster.

NGOs cooperate strongly with the ELSA cluster but have no contact with the transplantation medicine/ natural science cluster.

3.13.3 Spain

In Spain, too, there is no substantive public debate on xenotransplantation (Muñoz/Santos 2003: 54 and 55), but it is possible to identify three groups: (1) scientists and (2) patients, who are favouring xenotransplantation and (3) animal rights activists opposing xenotransplantation.

3.14 Summary

Table 9 recapitulates the main findings of the baseline evaluation in a short overview.

Table 9: Summary of xenotransplantation debates in Austria, Germany and Spain

	Austria	Germany	Spain
XTP debate	No debate	Debate restricted to experts	No debate
XTP research	No direct xenotransplantation research. Several individual researchers in xenotransplantation-relevant fields. Transplantation surgeons keep informed about xenotransplantation development	Several xenotransplantation research clusters	One research group
Research in ELSA	No activity	Significant activity	Little activity
Industry	Novartis is an important player in transplantation research	Novartis is partly funding German xenotransplantation research	Novartis is partly funding Spanish xenotransplantation research
Parliament	No activity	Little activity: minor and major interpellations, TA-study on xenotransplantation. No call for legislation	No activity
Government	Topic with low priority. Some, not specified, considerations at ministerial expert level about adapting relevant laws to xenotransplantation. Relevant ministries keep informed, e.g. by participation in international bodies	Topic with medium priority. Wait and see position regarding xenotransplantation legislation. Few projects funded by the government. Delegation of influence in international bodies to xenotransplantation researchers	No activity, but did not observe the Council of Europe's moratorium
Advisory bodies	No activities	TA study for the German *Bundestag* (TAB); Society of Virologists, Federal Chamber of Physicians	Recommendations by the xenotransplantation Subcommittee of the National Transplantation Organisation
Media	Little media coverage (e.g. in comparison to stem cell research)	Little media coverage (e.g. in comparison to stem cell research)	Little media coverage (e.g. in comparison to stem cell research)
Patients	Positive (not involved)	Positive (not involved)	Positive (not involved)
NGOs	No activity	Churches: formed a task group (position paper), offer workshops, position paper. Other NGOs: few activities	No activity
Public Attitude	Negative	Negative	Positive

4 Neo-Socratic Dialogues on the ethics of xenotransplantation[20]

This section describes firstly, the method of the Neo-Socratic Dialogue; secondly, the organisation of the actual Dialogues on xenotransplantation in Austria, Germany and Spain; thirdly, the evaluation methods used to assess the input, process and output of this exercise; and finally the participants of the Dialogues.

4.1 Description of the Neo-Socratic Dialogue method

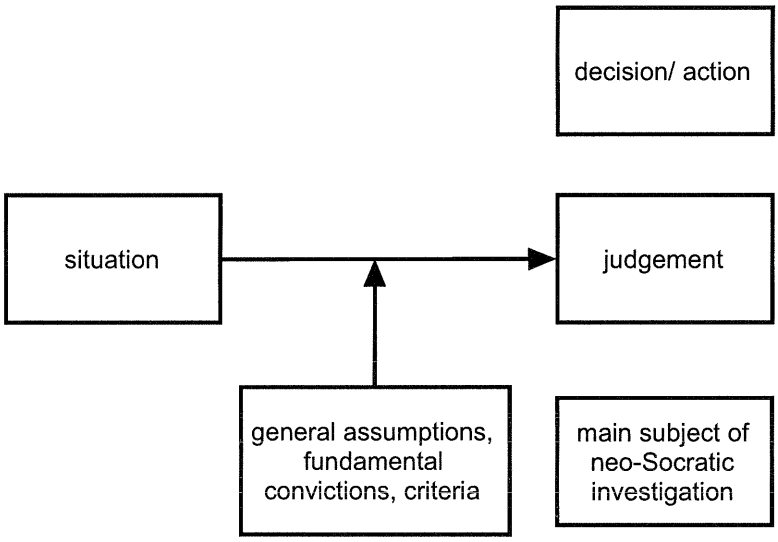
Usually, NSD is preceded by the formulation of a fundamental question that is applied to a specific decision situation, or rather, to a complex of decision situations (like research in the field of xenotransplantation). In our case, this was the question "What risk to take?". During the NSD, a group of dialogue partners tries to obtain consensual insights regarding this fundamental (ethical) question through common reflection based on personal experience accessible to all dialogue partners.

The basic idea of NSD is to give participants the opportunity to clarify their fundamental assumptions in a rational way. The main goal is to communicate about the normative frame of general practices and basic ideas in order to ascertain their validity.

This philosophically based method adopts elements of the traditional Socratic Dialogue also used by Plato. It integrates those elements, forming a model concept of inter-subjective communication corresponding to the challenges of a democratic society. NSD seems to be very suitable for the clarification of public debates on scientific or technological projects. But one should keep in mind that NSD is not a suitable means for solving any specific current problem, rather, it helps to make general values and principles explicit, to exchange them, to state them more precisely and to demonstrate that they exist. For visualising the structure of the argumentation process in a NSD we used two models. The first one symbolises the logical relations of the argumentation (Figure 8).

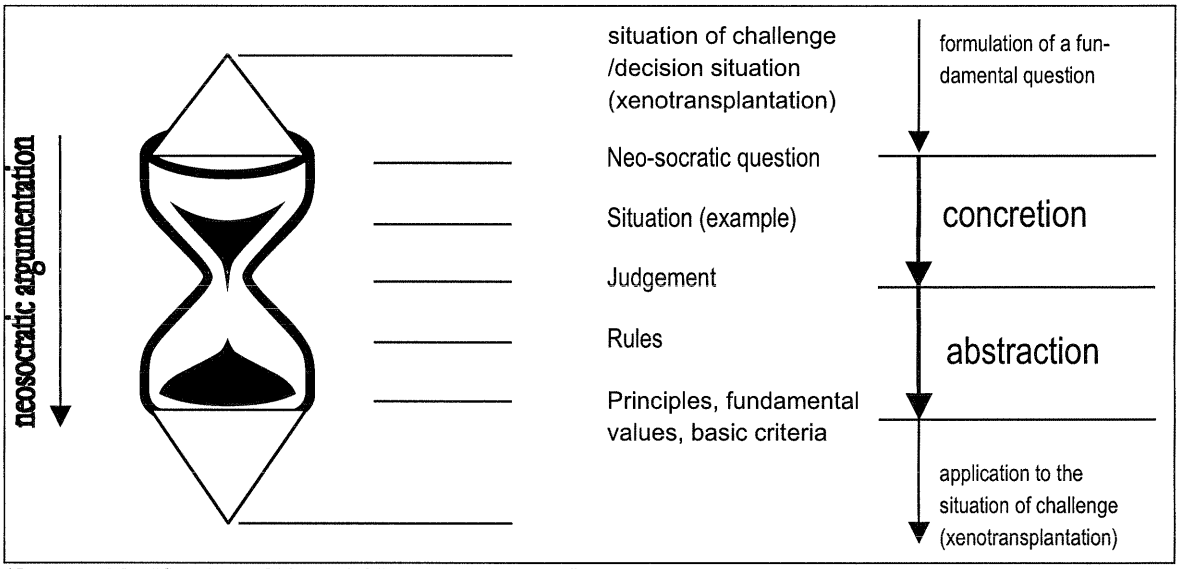
[20] This section is partly based Horst Gronke's contribution to Zimmer et al. 2003: 17 ff.

Figure 8: Argumentation process during NSD



Starting from the relevant aspects of the situation (as concrete premises) you make a judgement (as the conclusion) how to act in this situation. Then you look for reasons (general premises) to justify this conclusion. The second model used to clarify the NSD process is called the "hourglass model" (Figure 9).

Figure 9: Structure of the argumentation process in a NSD



(Source: Modification of Kessels' "hourglass model", Kessels 1997 and 2001: 205)

After formulation of a general, broad question focusing on a general problem in a specific situation of challenge, the dialogue is to be concretised, first, to a specific situation of personal experience (example) and then to the judgement of the example giver. Then the dialogue group examines this judgement, first to analyse and differentiate it, then to correct or to reformulate it (if necessary). Finally, the group has to find more general rules and principles as general reasons or general conditions

(which are commonly accepted) for the validity of the conclusion process and of the judgement. These general rules and principles are then to be applied to the current situation of challenge.

A facilitator supports the exchange of reasoned arguments in the group by behaviour-oriented, methodological and structural interventions. She or he notes on a flipchart the essential aspects of the argumentation. The facilitator does not support the dialogue process by his or her own contributions to the content of the argumentation.

The participants are encouraged to accept and to adhere to seven characteristics of the NSD attitude (c.f. Table 10)

Table 10: Seven characteristics of NSD

1. Take time to think! NSD strives for deep insights. It requires an unhurried step-by-step procedure.
2. Listen to each other! Ask! Put yourself in other peoples' place. Look at the world with the eyes of those who are involved or concerned.
3. Explain your opinions. Make yourself understood by explaining your thoughts on the basis of concrete experience.
4. In NSD, you judge and decide with regard to a concrete example, but this is only an intermediate stage. The real aims of NSD are: to create deeper understanding, to appreciate the opinions of the other dialogue partners, to identify agreement and disagreement.
5. Don't think against each other (yes but). Reflecting together, investigate the subject; take up the arguments of your dialogue partners (yes and).
6. Don't be fixed on solutions. Look for the basic reasons, criteria, principles and values of a possible solution.
7. Look for a constructive balance between criticism and self-criticism; express only your own ideas, be open to the ideas of the others. Make room for new thinking. Leave something of your old thinking behind.

The characteristics of a favourable dialogue attitude having been explained, the participants received an outline how NSD would proceed the next day. The schedule included seven phases. It was announced that depending on possible time pressure, some of these phases would be shortened.

4.1.1 The seven phases of NSD

The dialogue deals with situations in which NSD participants are significantly involved. It must be about a problem situation related to the initial question.

1. Give a short description of your experience. (all participants)

   a. What happened? (facts, situation)

   b. What did I do? (action)

   c. What meaning did the situation have for you personally? (emotion, inner experience)

   d. What is your answer to the initial questions shown by your concrete action?

      (judgement: "in this situation it was suitable to take the risk ... because ...")

2. Choose one of the described situations as an example for the following dialogue (all participants):
   a. What is the link between the situation and the initial question?

   b. Is there a specific situation for a limited time?

   c. Is the example accessible to others?

   d. Does the example contain suitable starting points for the argumentation?

3. Give a detailed description of the example situation (the example giver):

   a. Situation: Who was actively involved? Who was concerned? What were your emotions in this situation? Which needs and interests were at play? What was the conflict about? Who was responsible? Whom was he or she answerable to?

   b. Action: Which alternative actions did you see? What consequences did you think about? Which alternative action did you choose? How and when did you decide?

4. Judgement: The action was justified because ... (the example giver)

   Here: It was (not) justified to take the risk ... because ...

5. Questions concerning information and understanding (all participants)

6. The others put themselves in the place of the example giver (all participants):

   a. What meaning does the situation have for you in this perspective? (emotion, inner experience)

   b. What would you do in this situation? (action)

   c. How do you justify your supposed action? (judgement)

7. Inquiry into general assumptions (all participants):

a. Which fundamental convictions are supporting the judgements?

b. What is the logical status of these convictions? (values, norms, criteria, principles, rules, conceptions about man, world views, strategies, ...)

c. Is there any consensus?

d. What is still open to dispute?

e. Which questions should be asked to clarify the controversial issues?

At the end of the dialogue, the participants are given the opportunity to apply the dialogue results to xenotransplantation: What risk to take or not to take in xenotransplantation research and its possible applications?

4.2 Organisation of the Dialogues

In total, we carried out six NSDs in the three countries between October 2002 and February 2003. The Austrian NSDs took place in October and November 2003, the Spanish and German ones in January and February 2003.

The German NSDs were dedicated to the question "What risk to take?" because the different risks inherent in xenotransplantation were a key issue in the European xenotransplantation debate, as discourse analysis had shown. In Austria and Spain, the participants modified the question a little, to: "What risk are we allowed to take?" and "What risk should we take?" respectively. In Spain and Austria the participants have been explicitly asked to agree on one common question for the dialogue. In the discussion about what question to take, the participants modified our preliminary question 'What risk to take'?' to 'What risk are we allowed to take?' They decided to take the second, more open, formulation representing a more cautious approach towards the risks of xenotransplantation. By contrast, the question 'What risk do we have to take?', which was also considered, appeared to be much more narrowly defined: it implies that risks have to be taken without further deliberation. The Spanish version of the question "What risk should we take?" is a more moderate formulation of the latter, which implies that risks have to be taken and cannot be avoided.

There was an introductory evening meeting the day before actual start of the NSDs. It introduced participants to the structure and goals of the project; they were informed about the chances and risks of xenotransplantation (including the results of the Baseline Evaluation) and were instructed about the theory and practice of NSD. Another purpose of those preliminary instructions was to get the participants into the right frame of mind, i.e. the right dialogical attitude, and to inform them about the planned course of the NSD.

With their invitations, the participants had received a description of the key features of NSD. The facilitator summarised this description once again in the introductory evening session and gave some additional information about appropriate behaviour during NSD and about its planned course. At the

end of the evening the moderator asked the participants to think overnight about an everyday example they had experienced themselves, which included the element of risk.

The actual NSDs on the next day took about six hours, divided into four sessions of about one and a half hours each. The NSDs started with the collection of personally experienced situations that were related to the general question of the dialogue. It was the dialogue group's task to reveal and to prove the more general assumptions that are behind the example giver's decision and, if possible, to arrive at consensus about them. The final hour of the dialogue was reserved for applying the dialogue findings to xenotransplantation.

4.3 Evaluation methods

We used several evaluation tools to assess the input, process, output and impact of the NSDs. First, the evaluators of the research team were present as observers during the NSDs. The evaluators, however, did not contribute to the discussion but merely watched the Dialogue. Second, we taped the dialogues, which provided one basis for our evaluation of the content and process of the NSDs. Third; we did two rounds of surveys, one at the beginning and another one at the end of each NSD.[21] In the first round we asked the participants about their motivation to take part in the NSDs. We also asked them to assess the intensity of their connection with xenotransplantation, their level of information about the topic, and to evaluate several ethical issues with respect to xenotransplantation. Moreover, we asked for some statistical data such as profession, age and gender. This questionnaire was based on the expert interviews we had conducted in the baseline evaluation. In the second round of the survey, we wanted to know about the participants' experiences with the NSD. We also asked the participants to assess the group, the moderator, the process and the results of the NSDs. Furthermore, we asked them to assess the usefulness of the outcome of the NSD, and of this method in general, for their work. Finally, several weeks after the NSDs, we conducted telephone interviews with 50 of the 55 participants.

4.4 Participants

This section will deal with the personal composition of the Dialogues. We will discuss the participants' relationship with the topic, assess their level of information and attitude towards xenotransplantation in general, as well as their specific attitude towards ethical problems of xenotransplantation. Moreover, we will describe the participants' motivations and expectations.

4.4.1 Was it possible to enrol all relevant actors for NSD?

A total of 55 people participated in the six NSDs. In Austria and Germany, there were 18 participants, in Spain the number was 19. With the exception of politicians and animal welfare organisations in Spain, and of patient representatives in Germany, it was generally possible to involve representatives

[21] The questionnaires were formulated in German and then translated into Spanish. The English version presented in this report was not used for our empirical research.

of all relevant xenotransplantation stakeholders. Thus, the NSDs brought together an adequate mix of relevant persons from research, patient organisations, policy-making bodies as well as relevant NGOs. Looking at their professional or private links with xenotransplantation, 47% of the participants came from research, 13% were patients or patient representatives and 9% came from NGOs. Additional participants came form public administration, churches, media, insurance, industry and other organizations.

In Austria, NSD participants consisted of two researchers (virology, immunology), one transplantation surgeon, three representatives of patient self-help groups and patient attorneys, two patients, three representatives of NGOs (two members of animal welfare groups, one member of an organisation advocating alternatives to animal testing), two civil servants from relevant ministries, one Green Party member of parliament, as well as one person each from an insurance company, Austrian Radio (Ö1), a private company and the Austrian Ecumenical Council. People's self-definition was not clear-cut, so there were several overlaps in definition: the participating politician was also physician and researcher, likewise one NGO representative was also a physician and researcher, two of the researchers considered themselves also as physicians, and one of the civil servants also as a researcher.

The German NSDs involved two transplantation surgeons, one expert for allograft logistics, four scientist, one politician from the Social Democratic Party and the Green Party each, a member of the office of the German National Ethics Council, one civil servant each from the Federal Ministry of Health and the Federal Ministry of Justice, one member of the Office of Technology Assessment at the German Parliament, two representatives of animal rights groups, a retired pastor, a lawyer and a journalist. Group composition in the participants of Dialogue 1 (D1) and Dialogue 2 (D2) differed somewhat, i.e. many physicians and scientists were present in D1, whereas in D2 there were more representatives of NGOs, churches and the media (Zimmer et al. 2003: 3).

The Spanish NSDs included three professionals in the field of xenotransplantation and transplantation (xenotransplantation researcher, transplantation surgeons), two patients, one journalist and fourteen persons interested in biotechnology from several perspectives, such as industry, consulting, law, ethics, public perception, training, public communication as well as one person with special interest in NSD. Despite invitation, members of animal welfare organisations did not participate because of lack of time. Neither did representatives of political parties participate in the Spanish NSD in a significant way. Although members of the conservative Popular Party and of the Socialist Party had been invited, only the socialist party member participated, for one half-day (Santos et al. 2003b: 10 ff).

4.4.2 What did the participants think about xenotransplantation?

Not surprisingly because of the selection criteria for participants, a majority of 71% of the participants felt that they were either very closely or moderately connected with xenotransplantation (Table 11).

Table 11: Participants' relation to xenotransplantation by country (% and mean)[22]

	Very closely related	Moderately related	Hardly related	Not at all related	Total	Mean
All countries	34,5	36,4	21,8	5,6	100	1,98
Austria	29,4	47,1	17,6	5,9	100	2,0
Germany	55,6	33,3	11,1	0	100	1,56
Spain	21,1	31,6	36,8	10,5	100	2,37

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Altogether, 35% of all participants said that they were very closely related with xenotransplantation and another 36% that they were moderately connected with the topic. 22% said that they were hardly related and only 5% said they were not at all related to xenotransplantation. The participants' connection was strongest in Germany and weakest in Spain.

But there were also differences between the individual Dialogues (Table 12).

Table 12: Participants' relation to xenotransplantation by NSD (% and mean)

	Very closely related	Moderately related	Hardly related	Not at all related	Total	Mean
All NSDs	34,5	36,4	21,8	5,6	100	1,98
A1	42,9	42,9	14,3	0	100	1,71
A2	20,0	50,0	20,0	10,0	100	2,20
D1	77,80	22,2	0	0	100	1,22
D2	33,3	44,4	22,2	0	100	1,89
SP1	25,0	12,5	50,0	12,5	100	2,50
SP2	18,2	45,5	27,3	9,1	100	2,27

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

In Austria the participants of A1 felt a stronger connection to xenotransplantation than the participants of A2, in Germany this was the case for D1 and in Spain for SP2. In D1 participants felt the strongest relation to xenotransplantation, whereas participants of A2 felt the least connection.

What did the participants know about xenotransplantation? Were they well informed about the topic or were they going to discuss an issue they knew only little about? In order to find out we asked the participants to assess their level of information about xenotransplantation. Table 13 provides the results of this assessment by countries.

[22] How closely related is the subject of xenotransplantation to your professional or voluntary activity?

Table 13: Participants' assessment of their information about xenotransplantation by country (% and mean)[23]

	Perfectly informed	Sufficiently informed	Somewhat informed	Not at all informed	Total	Mean
All NSDs	34,5	43,6	21,8	0	100	1,87
Austria	27,8	55,6	16,7	0	100	1,89
Germany	44,4	55,6	0	0	100	1,56
Spain	31,6	21,1	47,4	0	100	2,16

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Altogether the participants considered themselves as well informed about xenotransplantation. 35% percent of them stated that they were perfectly informed, 44% that they were sufficiently informed and 22% that they were somewhat informed. None of them stated that they were not at all informed about xenotransplantation. Again, there were differences between Austria, Germany and Spain. In Germany the share of perfectly or sufficiently informed participants was 100% and in Austria 83%, but in Spain only 52%.

A comparison within countries shows that the participants in A1 were slightly better informed than in A2; in Spain participants in SP2 were better informed than those in SP1 (Table 14).

Table 14: Participants' assessment of their information about xenotransplantation by NSD (% and mean)

	Perfectly informed	Sufficiently informed	Somewhat informed	Not at all informed	Total	Mean
All NSDs	34,5	43,6	21,8	0	100	1,87
A1	25,0	50,0	25,0	0	100	2,00
A2	30,0	60,0	10,0	0	100	1,80
D1	44,4	55,6	0	0	100	1,56
D2	44,4	55,6	0	0	100	1,56
SP1	25,0	12,5	62,5	0	100	2,38
SP2	36,4	27,3	34,4	0	100	2,00

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 15 summarises the participants' overall attitude towards xenotransplantation by country. There were significant differences between the three countries. In Austria 50% of the participants strongly agreed or tended towards agreement that xenotransplantation is a desirable future treatment, 28% were undecided and 22% tended towards disagreement or totally disagreed on this statement. The German participants were the most critical ones in our three-country sample and the proportion was 29% agreement, 12% undecided and 58% disagreement. By contrast, the Spanish participants were

[23] How well informed are you about the subject of xenotransplantation?

the most positive. 84% of the participants were in favour of xenotransplantation, 5% were undecided and only 11% were against xenotransplantation as future treatment.

Table 15: Overall attitude towards xenotransplantation by country (% and mean)[24]

	I strongly agree	I tend towards agreement	I am undecided	I tend towards disagreement	I totally disagree	Total	Mean
All countries	18,5	37,0	14,8	18,5	11,1	100	2,67
Austria	27,8	22,2	27,8	16,7	5,6	100	2,50
Germany	5,9	23,5	11,8	29,4	29,4	100	3,53
Spain	21,1	63,2	5,3	10,5	0	100	2,05

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Again there were also differences between NSDs within one country. The participants of A1, D1 and SP1 were more strongly in favour of xenotransplantation than the participants of A2, D1 and SP2, respectively (Table 16). Participants in D1 were most sceptical and participants in SP2 least sceptical about xenotransplantation.

Table 16: Overall attitude towards xenotransplantation by NSD (% and mean)

	I strongly agree	I tend towards agreement	I am undecided	I tend towards disagreement	I totally disagree	Total	Mean
All NSDs	18,5	37,0	14,8	18,5	11,1	100	2,67
A1	25,0	25,0	25,0	12,5	12,5	100	2,63
A2	30,0	20,0	30,0	20,0	0	100	2,40
D1	12,5	25,0	12,5	25,0	25,0	100	3,25
D2	0	22,2	11,1	33,3	33,3	100	3,78
SP1	12,5	62,5	0	25,0	0	100	2,38
SP2	27,3	63,3	9,1	0	0	100	1,82

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

In order to find out about participants' attitudes towards specifically ethical problems of xenotransplantation, we asked them about the extent to which they agreed with certain statements favouring or opposing xenotransplantation, respectively? (Table 17 and Table 18)

[24] How far do you agree with the following statement? Overall, I think xenotransplantation is a desirable future form of treatment.

Table 17: Attitudes towards arguments in favour of xenotransplantation (means of all NSDs, per country and NSD)[25]

I think xenotransplantation is ethically desirable because: ...	Total	A	D	SP	A1	A2	D1	D2	SP1	SP2
xenotransplantation may remove the present organ shortage	2	2	3	2	2	2	2	3	2	
xenotransplantation may save human lives and improve patients' quality of life	2	2	2	2	2	2	2	3	2	
Physicians' obligation to cure individual patients is more important than a potential infection risk for the population	4	3	4	3	3	3	3	4	4	
There is no fundamental difference between using animals for food or as organ donors	2	2	2	2	3	2	2	3	2	
xenotransplantation could reduce the basis for organ trade	2	2	3	2	3	2	4	4	2	

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

The argument pro xenotransplantation that met with most agreement by the participants was that xenotransplantation could save human lives and could improve patients' quality of life. In total, 66% of all participants from all three countries supported this argument, 31% disagreed and 3% were undecided. Also, the arguments that xenotransplantation could remove the present shortage of human organs (62% pro, 35% against and 4% undecided) as well that there is no fundamental difference between using animals as food and organ donors (55% pro, 40% against, 5% undecided) met a majority's approval. 50% of the participants thought that xenotransplantation could reduce the need demand for organ trade, but 46% did not and 4% were undecided. The participants were most sceptical about the statement that a physician's obligation to cure individual patients is more important than a potential infection risk for the population. Only 17% agreed with this statement, while 79% did not and 4% were undecided. A comparison of mean values by country shows differences between the Austrian, German and Spanish participants. The Spanish participants were most optimistic about xenotransplantation across all statements, whereas the German participants were most sceptical. A further comparison of NSDs within each country also showed differences in assessments.

[25] How strongly do you agree or disagree, respectively, with the following statements? I think xenotransplantation is ethically desirable because: ... The range was: I strongly agree, I tend towards agreement, I tend towards disagreement, I totally disagree, I am undecided.

Table 18: Attitudes with respect to arguments against xenotransplantation (means all NSDs, per country and NSD)[26]

I think xenotransplantation is ethically undesirable or desirable because:	Total	A	D	SP	A1	A2	D1	D2	S1	S2
One cannot exclude transmission of infections from donor animals to patients, or, in the worst case, transmission to the general population	2,80	2,7	2,6	3,0	2,5	3,0	2,8	2,4	3,4	2,7
It might be necessary to restrict patients' basic freedoms (e.g. quarantine) to minimise the danger of diseases being transmitted from donor animals to patients, or the general population	3,33	3,0	2,8	4,1	2,5	3,4	2,9	2,8	3,4	3,2
xenotransplantation reduces animals to nothing but an organ source	3,98	3,8	3,7	4,4	3,4	4,1	3,8	3,7	3,4	3,6
Breeding, raising and utilizing donor animals is incompatible with established criteria of humane animal husbandry	3,46	3,4	3,3	3,7	3,0	3,7	3,2	3,3	3,1	3,5
xenotransplantation transcends the species boundary between animals and man	3,45	3,4	3,2	3,7	3,4	3,5	3,2	3,1	3,0	4,1
xenotransplantation channels scarce financial resources into high tech medicine, to potential detriment of basic general health care	3,55	3,7	2,9	4,0	3,4	4,0	3,2	2,6	3,1	3,4
xenotransplantation uses up financial resources within developed countries, thus withholding them from basic health care in the Third World	3,55	3,8	3,3	3,5	3,5	4,1	3,8	2,8	3,3	3,0
xenotransplantation patients might experience psychological problems having to live with animal organs inside their own body.	3,36	3,3	3,6	3,3	3,1	3,4	3,0	4,1	3,0	2,6
Animals must be genetically modified in order to make their organs suitable for transplantation to humans	3,16	3,6	3,1	2,9	3,5	3,7	3,2	2,9	1,9	3,3
The possibility of xenotransplantation would reduce people's willingness to donate organs even more	3,04	2,8	3,0	3,3	2,4	3,1	3,0	3,0	2,6	2,7

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Only a minority of the participants supported arguments critical of xenotransplantation. The argument against xenotransplantation that received most overall approval was the claim of infection risks (49% agreement, 11% undecided and 40% disagreement). 45% of the participants disapproved of xenotransplantation because it would involve genetic modification of donor animals (4% undecided, 51% approval). 38% of the participants objected to xenotransplantation because they thought it might necessitate the restriction of basic freedoms due to necessary monitoring of patients and of their relatives (56% did not object and 6% were undecided). Only a small minority of participants thought that arguments relating to animals would apply to xenotransplantation. 33% disapproved of xenotransplantation because it would transcend the boundaries between humans and animals (13% undecided, 54% approval); 26% took a stance against xenotransplantation because it would be incompatible with established criteria of humane animal husbandry (13% undecided, 61% approval) and only 18% were against xenotransplantation because it would reduce animals to being nothing but

[26] How strongly do you agree or disagree, respectively, with the following statements? I think xenotransplantation is ethically undesirable or desirable because:

organ donors (82% approval). Arguments against xenotransplantation having to do with proper resource allocation in the health sector on a national and global level met the approval of about one-third of the participants. 31% of the participants were sceptical about xenotransplantation because it would tie up national financial resources to the disadvantage of basic health care (4% undecided, 65% disapproval) and the same share took a stance against xenotransplantation because of money being tied up in top medicine and therefore unavailable for basic health care in the Third World (7% undecided, 62% disapproval). Another 33% disapproved of xenotransplantation because they thought it might cause psychological problems for patients (5% undecided, 62% disapproval).

Looking at differences between the three countries, the Spanish participants were least sceptical, except with respect to global justice in the allocation of health funds, potential psychological problems of patients and genetic modification of donor animals.

By contrast, the German participants were most sceptical among the three countries regarding all items, except potential psychological problems for patients, genetic modification of donor animals and the potentially negative influence on people's willingness to donate organs.

The Austrian participants were mostly less sceptical than the German ones, but also much less positive than the Spaniards. The only exceptions concerned most sceptical assessments regarding the impact of xenotransplantation on resource allocation between top medicine and primary health care, and regarding genetic modification of donor animals. Austrian participants were least sceptical in their assessment of the impact of xenotransplantation on donation of human organs.

Once more, there were not only differences between countries, but also within them. In Austria, participants in group A1 were more in favour of xenotransplantation than the members of group A2. Similarly, in Germany the participants of D1 were more in favour of xenotransplantation than the participants in D2. Also, in the Spanish case, there were several differences between SP1 and SP2 but no clear trend could be observed.

4.4.3 Gender and age

In general, in all NSDs, there was a male majority. In total, ca. two-thirds of the participants were male (64%) and one-third was female (35%). The women's share was highest in Spain (42%) and lowest in Germany (28%). In Austria, their share was 33%.

The total average age of Austrian participants was 46 years (standard deviation: 9.9), of German participants were younger with an average of 42 years (standard deviation 9.3) and the Spanish participants on average youngest with 36 years (standard deviation 10.5).

4.4.4 What were the participants' motivations for participation in NSD?

In the Austrian Dialogue, the participants were generally motivated to take part in NSD for several reasons. Some participants were interested in xenotransplantation itself, others wanted to develop their expertise or wanted to act as stakeholders. Furthermore, some group members were interested

in dealing with an ethical question, or interested in the NSD method and in conducting a public discussion on the issue (Griessler et al. 2003b: 11ff.). In the German NSD, three kinds of motivations were important for stakeholders to participate in the dialogue: first, many participants were interested in the method of NSD, in its strengths and weaknesses; second, several participants' motivation came from wanting to take part in an ethical debate; and, third, some persons named their interest in xenotransplantation as important motivation to take part in such an exercise (Zimmer et al. 2003: 11). In the Spanish NSD, most of the participants attended the meeting out of two motivations: interest in xenotransplantation and interest in the method of NSD (Santos et al. 2003: 21).

4.4.5 What were the participants' expectations for the NSD?

In order to find out about the participants' expectations, we asked them to assess 22 statements that we derived from the baseline interviews. We asked the participants to rate their expectations in a range from "1 = very high expectation" to "5 = no expectation". We classified these expectations into four fuzzy groups of "topics of xenotransplantation", "Method of NSD", "qualities of the Dialogue" and "personal rewards from the Dialogue".

The participants had very high expectations about, what could be termed the quality of the Dialogue and expectations about the method, i.e. to get acquainted with the NSD (93% agreed) and a different form of discussion (89% agreed), an egalitarian dialogue among all participants (89% agreed), to meet other people and learn something about their points of view (98% agreed), an open, relaxed atmosphere (96% agreed), an exciting discussion about important topics (86% agreed), to take part in a high quality discussion (80% agreed), a clearly structured discussion (75% agreed), interest in the subject from other participants (89% agreed), to improve my understanding of the other participants' point of view (89% agreed), new insights into the ethics of xenotransplantation (87% agreed).

A large majority expected application of results (65% agreed), greater tolerance for my personal views (63% agreed), to have time and possibility for reflection on a specific ethical problem (61% agreed), to improve my communicative skills (62% agreed) and clarification of my own point of view (50%).

A minority of participants expected new information about xenotransplantation (47% agreed), that other participants will listen to me and try to understand me (41%), a clear answer how to handle the problem of xenotransplantation (35% agreed), consensus on the subject of xenotransplantation (22% agreed), that other participants will refer to the arguments I presented (32%), to convince other people of my own point of view (13% agreed), changes in my attitude towards xenotransplantation (11% agreed).

Table 19: Participants' expectations (by mean)[27]I

Personally, I am expecting	Total	A	D	SP	A1	A2	D1	D2	SP1	SP2
To get acquainted with the NSD	1									
An egalitarian dialogue among all participants	1									
Meet other people & learn something about their view points	1									
To get acquainted with a different form of discussion	1									
An open, relaxed atmosphere	1									
Interest in the subject also from other participants	1								2	
An exciting discussion about important topics	1							2		
To improve my understanding of the other participants' point of view	1					2				
New insights into the ethics of xenotransplantation	1						2			
To take part in a high quality discussion	1				2		2		2	2
A clearly structured discussion	1						2	2	2	
Greater tolerance for my personal views	2				2	3	2	2	2	2
To have time and possibility for reflection on a specific ethical problem	2				2	2	2		2	2
That other Dialogue participants will listen to me and will try to understand me	2				2	3	2		2	3
That other participants will refer to the arguments I presented	2				2	3	2	2	3	3
To improve my communicative skills	2				2	2		2	2	2
Clarification of my own point of view	2				3	2	3	2	2	2
New information on XTP	2				2	2	4		2	2
To convince other people of my own point of view	3				3	3	3	3	3	3
Consensus on the subject of xenotransplantation	3				3	3	3	4	2	2
A clear answer how to handle the problem of xenotransplantation	3				3	3	3	3	2	2
Changes in my attitude towards xenotransplantation	3				3	3	3	3	3	3
Application of results					2	2	2	2	2	

[27] As participant in the NSD on ethical aspects of xenotransplantation you will have had personal expectations regarding this event. How strongly do you agree with the following expectations? 1 = I agree very much, 2 = I tend to agree, 3 = I am undecided, 4 = I tend to disagree, 5 = I do not agree at all

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

"The results reflect the situation in the xenotransplantation debate: in general the relevant actors are interested in communication with other actors in order to understand them better and get to know better their arguments and positions. Because of their own experiences in former debates they hop to find in the NSD a better communication tool different from the common practice, which renders possible understanding and rational dialogue. Due to the same experience the participants have only very low expectations regarding the issue of xenotransplantation. They "know" that it is extremely unrealistic to change one's own opinion because auf new insights or to reach a consensus on xenotransplantation" (Zimmer et al. 2003: 5)."

5 The dialogue process

In this section, we will analyse the six dialogues comparatively and describe how the participants evaluated the dialogue moderators. We will then turn to the assessment of the NSD groups by their respective members. The section concludes with a discussion of problems arising during NSD dialogues.

5.1 Comparative description of the dialogues

Table 20 summarises the examples chosen during all dialogues, characterising them by their content: whether they were taken from the private or the professional sphere; which relevant sub-themes of the dialogue were used in the chosen examples; whether the examples expressed responsibility on the part of the example givers for other persons; also, the example giver's personal judgement, as well as that of the other participants, about the ethics of the respective action chosen by the group; perception or awareness of risk; expected benefits of the chosen action; perceived probability of risk; general assumptions of the group which backing its judgement; and , lastly, application of the group's results to the case of xenotransplantation.

5.1.1 Examples

As requested, nearly all participants gave short descriptions of risk situations in which they had personally been involved.

Most of the chosen examples came from the participants' private sphere, only three from the example-givers' professional experience. In principle, it does not matter from which sphere the examples are taken, as long as chosen examples are comprehensible for all dialogue participants. If this is not the case, the example is not suitable for the dialogue. Private examples can be advantageous because they bring the discussion to a more personal level. This can stimulate a more open discussion. On the other hand, private examples can be judged as being rather trivial compared with the problem at stake. This may make people sceptical about the NSD method in general.

Generally, the process of example selection is a first analytical phase in NSD during which examples are compared and typologies are created. Analogies are recognised, differences stressed. In our particular case, the choice of the examples was guided by their connection with xenotransplantation (analogies and differences). For example, the group considered cases where the expected benefit would be very high (if the risk was taken), like in xenotransplantation, e.g. save people's lives could be saved; or the discussion was about potential harm that would only affect the example giver or concrete other people, whereas in the case of xenotransplantation an epidemic could concern the entire population. Both during the initial phase of NSD and during the later stages, participants repeatedly referred to xenotransplantation.

Table 20: Comparative description of chosen examples

	A1	A2	D1	D2	SP1	SP2
Content	Risky car-driving (high speed)	Consulting a farmer on dehorning cattle	Sailing trip with pupils under bad weather conditions	Help in a potential emergency situation	Risky car driving (being exhausted)	Insufficient safety standards in a laboratory
Sphere	Private	Professional	Professional	Private	Private	Professional
Subtthemes of NSD	Pursuit of individual happiness	Animal's rights as an ideology. Lack of professional experience	Importance of respect for the teacher, lack of professional experience	Obligation to help someone in a (potential) emergency situation	Obligation to fulfil a social norm, e.g. attending a friend's funeral	Importance of a professional career, little professional experience
Responsibility for others involved?	Not perceived	Yes, but in conflict with the image of being an animal rights activist	Yes, but in conflict with personal interests	Yes, for the person who might be in danger	Yes, but not in the foreground	Yes, but personal interests in the foreground
Judgement by the example-giver: the described (risky) behaviour was:	Wrong	Wrong	Wrong	Right	Right	Right
Judgement by the other participants (relative to example-giver)	Mixed	Agreement	Agreement after additional information	Agreement	Agreement	Agreement
Perception/ awareness of risk	None. Rather spontaneous action	Yes. Neglect of an inner warning voice that one should act differently.	Yes. Low probability of occurrence of risk.	Yes. Mainly personal reputation at stake.	Yes	Yes, risk seems controllable
Expected benefit(s)	High personal benefit for the example giver	High personal benefit for the example giver	High personal benefit for the example giver. Giving pupils fun	Possible high benefit for others	High personal and social benefit	High personal benefit
Perceived probability of risk	Not perceived	High	Low	Not clear	Not clear	Low
General assumptions backing the judgement	"The relationship between potential harm and expected benefit must be clearly positive on the side of benefit."	"Among several options the selected alternative must be the one providing optimal benefit at acceptable risk."	"A qualitatively high risk is permissible only if the expected benefit is high." "The decision taken must be comprehensible for others, and one must accept responsibility for its consequences even many years later."	The group formulated a general norm expressing the obligation to minimise risk as much as possible: "If someone needs help then I am obliged to help." ("I must help if it is reasonable for myself and others.")	"We should not run risks, even if only a limited number of persons is affected, if a particular risk is potentially very dangerous".	"It is permissible to run risks if reasonable knowledge about those risks exists and if the relationship between risk and benefit clearly favours individual and collective benefit."

	A1	A2	D1	D2	SP1	SP2
Application of results to the case of xenotransplantation	Participants applied the 'general rule' to three selected risks of xenotransplantation: The risk of infectious epidemics. (How to deal with uncertainty and lack of secure knowledge.) Risk of a totally instrumental society-nature relationship. (Problem of animal rights. The benefit of animals must also be considered .) Risk of neglecting basic medical care in favour of high-tech medicine. (Problem of distributive justice.)	The dialogue did not reach this stage.	Xenotransplantation research inivolves a high risk of serious negative consequences (e.g. infection) Expected benefits are high (saving lives) Discontinuation criteria must be defined before the start or continuation of research One must consider the point of no return, i.e. the point when unintended side-effects become irreversible Exceeding a limit of tolerable costs might be one discontinuation criterion If animals are regarded as belong to the range of affected beings, then the discontinuation point of the project must brought forward alternatives to xenotransplantation research must be considered One must think not about emergency equipment only but also about adequate prevention means	The main goal of research must be to help other people The risks of people indirectly affected by research, and by the application of such research, must be considered The perspective of distributive justice must be considered in a suitable way (with regard to the living conditions in the "Third World") Other beings concerned by research, i.e., the animals used, must be taken into account The persons being affected by such research but deriving no direct benefit from it must be identified True Moral action and speech are necessary Other less risky alternatives are to be intensively thought about	Three factors must be taken into account: the probability of a specific risk, the seriousness of this risk and the control of the different various results How to evaluate the probability of a particular risk, its seriousness and the possibility of controlling alternative outcomes of the decision taken? One of the main problems to be faced is knowledge about the probability of risk, i.e., to quantify the probability of an outcome of some concrete action. If this probability is known, decision-makers have more information helping them to take the right decision	In the case of xenotransplantation neither do we know neither the probability of possible problems nor their seriousness. This makes the case of xenografts more uncertain. How should one deal with this uncertainty?

Two of the chosen examples concerned risky car driving. In one case, the example was about speeding to get to an important private rendezvous (A1), in the other case it was driving to fulfil the important social obligation of attending a funeral in spite of being sleepy (SP1). D2 was also somewhat related to car driving, i.e. taking the risk to help another driver in a potentially dangerous situation (because the situation could also have turned out to be an ambush). The example in A2 was risky advice given to a farmer about de-horning cattle on a pasture. The cattle later injured the farmer. Participants in D1 selected the risky decision to go on a sailing trip in bad weather. The SP2 group selected taking the risk of working in a dangerous laboratory with insufficient safety standards because of better career opportunities.

5.1.2 Sub-themes

The major theme in the NSDs was the concept of risk and how it should be dealt with. During the dialogues, several sub-themes emerged that were closely linked to the main topic and needed clarification before the main question could be answered. In many cases, these sub-themes represented a kind of hidden precondition or motivating factor for the risky situation itself.

In D2, the example-giver felt obliged to help another person in a potential emergency situation, which meant putting herself at risk in that situation. The dialogue then revolved about clarifying the obligation to help someone in an emergency situation, as well as limits to this obligation. This sub-theme included questions like: Which risks should one take if one must help someone? Which precautionary measures must one take? These questions are also relevant to xenotransplantation.

Other sub-themes in dialogues concerned the question of sufficient expertise to deal with a situation adequately (A2, D2, SP2), the right to pursue individual happiness (A1), the role of ideology in judging a situation (A2), respect for authority (D1), the obligation to fulfil a strict social norm (SP1) and the importance of pursuing one's career (SP2).

5.1.3 Presence of responsibility for others

In all dialogues except A1, the example-givers stated that they felt responsible for other people in their respective action. This responsibility was either due to professional duty (A2, D1) or felt to be a personal obligation (D2, SP1, SP2). What varied was individual perception of responsibility. In some cases, the example-givers were strongly aware of their responsibility towards other people, in others the perception of responsibility was mixed with other interests or thoughts. There was a clear link between perception of responsibility and xenotransplantation, i.e. responsibility towards patients and their relatives, the responsibility for oneself and for the entire population.

5.1.4 Judgement by the example-giver

In NSDs, the starting points for the argumentation phase are the example-givers' personal judgements about their own behaviour. Example-givers may express agreement with their former actions or decisions, they may disagree with them, or be ambivalent about them. Clarity of judgement by the example-giver is an advantage. A clearly taken position (be it negative or positive) is usually accompanied by clear reasons for or against this position. In all dialogues, a clearly stated position helped the other participants to refer to the respective judgement.[28]

5.1.5 Judgement of other participants

Since in NSD orientation towards consensus is a regulative influence, the judgements and reasons expressed by the other NSD group members reveal the heterogeneity or homogeneity of the respective group. Also, the other group members' positions constitute important information for the facilitator and for the group as a whole when it has to decide how to proceed. For reasons of group dynamics, if available discussion time is limited, it is useful to initially concentrate on common reasons while not neglecting dissent. In our dialogues, agreement with the example-givers' judgements was quite high in nearly all cases. What varied were the reasons given for the respective judgements, which provided sufficient incentives for vivid discussion.

5.1.6 Perception of risk

In all dialogues, the acceptability of risk was conceptualised as relationship between risks, damage, or disadvantage on the one hand and benefit on the other hand. In two dialogues (SP2, A2) participants also used the probability of occurrence (of the risk) as an argument.[29]

In all examples presented, the potential personal benefit to the example giver was high, as with xenograft recipients in xenotransplantation. The probability of occurrence of various risks, i.e. of causing a car accident, causing injury to a farmer, causing a sailing accident, letting down a person in need of help, or being infected by AIDS because of lax safety standards, was considered to be high in one case, low or unclear, respectively, in two cases, and non-existent in one case.

Despite the fact that the examples chosen in the dialogues were very heterogeneous, there seems to be a common line of argumentation regarding the handling of risk. If one compares the general assumptions backing judgement, there is a tendency to assign greater weight to the benefit side of the

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[28] Difficulties arise in dialogues where the example-givers are ambivalent and keep changing their positions. This did not happen in our dialogues.

[29] In the sociological discussion of risk and risk-taking society, the concept of risk follows the modern idea of risk or risky action as calculated (human) action striving to maximise benefit and to minimise damage (e.g. Bonß 1995). This conception of risk originated in the 13th century accompanying the development of overseas trade.

risk concept and less to the danger side. In all NSDs, participants appeared to be quite cautious in the sense that they tolerated high risk only if they could clearly expect high benefit.

5.1.7 Transfer to xenotransplantation

The participants' statements became much more diverse when the results of the dialogues were applied to xenotransplantation. Discussion focussed on different problems:

A2 as well as SP1 and SP2 dealt with the problem of risk evaluation (probability of occurrence, seriousness).

A1 and D2 dealt with the question of distributive justice at the national and global levels, given restricted financial resources.

D1 dealt with discontinuation criteria for research, i.e. with the point when unintended consequences of xenotransplantation research might become irreversible. They looked at the quality of those criteria (cost, animal welfare) and of necessary prevention measures.

D1 and D2 stressed the importance of thinking about alternatives to xenotransplantation.

This diversity of topics, which emerged in the transfer phase, might be explained by the diverse knowledge and involvement of the participants regarding xenotransplantation. In all dialogues there was not enough time for the application of discussion results to xenotransplantation. But given the time limit, there still seems to be the problem that the consensus on rather general assumptions becomes fragile when applied to concrete problems. This difficulty cannot be handled by NSD. For this kind of decision-making other methods are needed.

5.1.8 Consequences for the debate about (the ethics of) xenotransplantation

Comparing the NSDs with regard to their xenotransplantation-related outcomes, they seem to be rather heterogeneous. Every group came up with special considerations how to deal with xenotransplantation, which measures should be taken, which questions should be elaborated. In the end, more questions were raised than answered. This heterogeneity can be partly explained by time constraints regarding the transfer phase of NSD results to xenotransplantation. The experience of time restrictions was mentioned by many participants. Given the complexity of ethical problems raised by xenotransplantation, participants became aware that they cannot be resolved in a few minutes. Having been well prepared for ethical debates by their NSDs, many participants wished to have more time to deal explicitly with xenotransplantation. Thus, further projects/experiments with NSD should foresee much more time (an entire workshop) for discussing the technology at stake. NSD can raise

participants' sensitivity regarding ethical issues and argumentation but, by definition, it does not aim at concrete decision-making. NSD aims at norms and principles able to back up decisions.

5.2 Assessment of the moderation

In order to find out whether the NSDs were managed efficiently, we asked the participants to assess the moderators' intervention. In general, the participants appreciated the moderation and the moderators highly in all three countries. 96% of the participants agreed very much or tended towards agreement that they were content with the moderation (Table 21).

Table 21: Assessment of the moderator by country (% and mean)[30]

	I agree very much	I tend towards agreement	I tend towards disagreement	I disagree	Total	Mean
All countries	67,3	27,3	3,6	0	100	1,35
Austria	64,7	23,5	11,8	0	100	1,47
Germany	83,3	16,7	0	0	100	1,17
Spain	57,9	42,1	0	0	100	1,42

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

A country comparison of these very positive results by their mean values shows that the moderators were evaluated most favourable in Germany and a little less favourably in Spain and Austria. A closer look at the mean values of individual NSD again reveals differences (Table 22). The NSDs A1 and D1 were evaluated most favourably, whereas the dialogues SP1 and A2 were evaluated least positively. The participants of A1 evaluated the moderator more positively than the ones in A2. The same is true, but to a lesser extent, for SP2 and SP1.

[30] Overall, I was satisfied with the moderation (1= I agree very much, 2 = I tend towards agreement, 3 = I tend towards disagreement, 4 = I disagree).

Table 22: Assessment of the moderator by NSD (% and mean)

	I agree very much	I tend towards agreement	I tend towards disagreement	I disagree	Total	Mean
All NSDs	67,3	27,3	3,6	0	100	1,35
A1	100,0	0	0	0	100	1,00
A2	40,0	40,0	20,0	0	100	1,80
D1	100	0	0	0	100	1,00
D2	66,7	33,3	0	0	100	1,33
SP1	25,0	75,0	0	0	100	1,75
SP2	81,8	18,2	0	0	100	1,18

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

In order to find out more specifically about the moderators' performance we asked the participants to evaluate their moderation in detail (Table 23) and regarding certain characteristics (Table 24).

Table 23: Assessment of the moderation (means)[31]

The moderator:	Total	A	D	SP	A1	A2	D1	D2	SP1	SP2
integrated all points of view well	1,26	1,19	1,28	1,32	1,14	1,22	1,2	1,3	1,50	1,18
kept the sessions well focused on the subject at hand	1,60	2,13	1,33	1,42	1,29	2,78	1,2	1,4	1,75	1,18
involved all participants in the dialogue	1,33	1,29	1,33	1,37	1,14	1,40	1,3	1,3	1,75	1,09
kept on top of the situation	1,35	1,53	1,17	1,37	1,00	1,90	1,1	1,2	1,63	1,18
stimulated an atmosphere favourable to discussion	1,31	1,41	1,17	1,37	1,14	1,60	1,1	1,2	1,63	1,18
summarised points made very well	1,48	1,53	1,56	1,37	1,29	1,70	1,7	1,4	1,38	1,36
kept the discussion focused on essentials	1,87	2,35	1,50	1,79	1,57	2,90	1,4	1,6	2,00	1,64
reacted adequately to conflicts	1,50	1,33	1,44	1,68	1,00	1,50	1,4	1,5	1,75	1,64
influenced the way in which the discussion evolved too much	3,24	3,47	3,44	2,84	3,57	3,40	3,6	3,3	3,00	2,73

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

All participants thought that the moderator integrated all points of view well and 98% thought that the respective moderator had involved all participants (98% agreement). 96% of the participants agreed that the moderators kept the sessions well focused on the subject at hand, that they stimulated an atmosphere favourable to discussion, summarised the points made very well and reacted to conflicts

[31] To what extent do you agree with the following statements about the moderation? (1 = I agree very much, 2 = I tend towards agreement, 3 = I tend towards disagreement, 4 = I disagree)

adequately. 94% thought that they kept on top of the situation. Only 13% thought that the moderator had influenced the way in which the discussion evolved too strongly. Among those very favourable assessments, the least favourable evaluation regarding interventions by moderators concerned keeping the discussion focused on essentials, with 81% agreement.

However, there are significant differences between countries with regard to the issues "kept the sessions well focussed on the subject at hand", "kept on top of the situation", and "kept the discussion focussed on essentials".

There were differences between the NSDs in each country. In Austria, A1 was evaluated more favourably than A2 across all items. This was also the case in Spain (SP2 evaluated better than SP1) and with only two exceptions also in Germany (D1 evaluated better than D2). The differences between individual dialogues were also significant regarding the items "kept the sessions well focussed on the subject at hand", "kept on top of the situation", and "kept the discussion focussed on essentials".

Table 24: Assessment of the moderator[32]

The moderator was:	Total	A	D	SP	A1	A2	D1	D2	SP1	SP2
Well prepared	1,19	1,24	1,06	1,26	1,00	1,40	1,0	1,1	1,38	1,18
Competent with respect to the subject discussed	1,31	1,29	1,22	1,42	1,00	1,50	1,1	1,3	1,50	1,36
Patient	1,26	1,24	1,17	1,37	1,14	1,30	1,1	1,2	1,37	1,55
Self-assured	1,41	1,59	1,28	1,37	1,29	1,80	1,2	1,3	1,25	1,45
Neutral	1,39	1,41	1,28	1,47	1,29	1,50	1,1	1,4	1,50	1,45
Fair	1,30	1,24	1,22	1,42	1,14	1,30	1,1	1,3	1,50	1,36
Keen	1,24	1,24	1,17	1,32	1,00	1,40	1,1	1,2	1,38	1,27
Charming	1,25	1,35	1,18	1,21	1,00	1,60	1,1	1,3	1,25	1,18
Dominant	3,47	3,56	3,67	3,21	3,86	3,33	3,9	3,4	3,50	3,00

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

All participants agreed very much or tended towards agreement that the respective moderators were well prepared, competent with respect to the subject discussed, patient, neutral, fair and keen. 96% agreed very much or tended towards agreement that they were self-assured, 98% that they were charming. 92% disagreed or tended towards disagreement that their moderator was dominant.

[32] To what extent do you agree with the following statements about the moderation? (1 = I agree very much, 2 = I tend towards agreement, 3 = I tend towards disagreement, 4 = I disagree)

5.3 Participant' assessment of the group

In general, the participants described their respective NSD groups rather favourably (Table 25). In the three countries, nearly all participants agreed or tended towards agreement with the statement that they had been satisfied with their group. But there were differences between countries. Participants in Germany were most satisfied with their group, followed by Spain and Austria.

Table 25: Overall assessment of the group by country (% and mean)[33]

	I agree	I tend towards agreement	I tend towards dis-agreement	I disagree	Total	Mean
Austria	58,8	35,3	5,9	0	100	1,47
Germany	70,7	29,4	0	0	100	1,29
Spain	57,9	42,1	0	0	0	1,42

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

There were also differences between the individual groups. Participants in the German dialogue D2 evaluated their group most favourably, followed by the second Spanish dialogue and by the first Austrian dialogue. Again there were differences between dialogues in individual countries, particularly between A1 and A2, as well as SP2 and SP1.

Table 26: Overall assessment of the group by NSD (% and mean)

	I agree	I tend towards agreement	I tend towards disagreement	I disagree	Total	Mean
A1	71,4	28,6	0	0	100	1,29
A2	50,0	40,0	10,0		100	1,60
D1	62,5	37,5	0	0	100	1,38
D2	77,7	22,2	0	0	100	1,22
SP1	37,5	62,5	0	0	100	1,63
SP2	72,7	27,3	0	0	100	1,27

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

All participants agreed that their respective groups had particularly positive qualities. The groups allowed everybody to speak (86% agreed very much, 14% tended towards agreement), they fostered

[33] To what extent do you agree with the following statement? Overall, I was content with this group (1 = I agree, 2 = I tend towards agreement, 3 = I tend towards disagreement, 4 = I disagree)

a friendly atmosphere (82% agreed very much, 18% tended towards agreement), and they admitted the expression of dissenting opinions (64% agreed very much, 36% tended towards agreement).

In addition, but less strongly, almost all participants thought that the group had co-operated well (64% agreed very much, 35% tended towards agreement, 2% tended towards disagreement), had concentrated on the set topic (60% agreed very much, 35% tended towards agreement, 5% tended towards disagreement), had concentrated on the task (56% agreed very much, 36% tended towards agreement, 7% tended towards disagreement), participants had been able to follow well (47% agreed very much, 44% tended towards agreement, 9% tended towards disagreement), and that a dialogue of high quality had been maintained (36% agreed very much, 53% tended towards agreement, 11% tended towards disagreement). In almost three-quarters of the groups participants expressed the opinion that the group had achieved results with which they were content (29% agreement, 44% tending towards agreement, 20% tending towards disagreement).

Table 27: Assessment of group activities[34]

The Group:	Mean									
	Total	A	D	SP	A1	A2	D1	D2	SP1	SP2
allowed everybody to speak	1	1	1	1	1	1	1	1	1	1
developed a friendly atmosphere	1	1	1	1	1	1	1	1	1	1
admitted the expression of dissenting opinions	1	1	1	1	1	1	1	1	1	1
co-operated well	1	1	1	1	1	1	1	1	1	1
concentrated on the set topic	1	1	1	1	1	2	1	1	1	1
concentrated on the task	1	1	1	1	1	1	1	1	1	1
was able to follow well	1	1	1	1	1	2	1	1	1	1
maintained a dialogue of high quality	1	1	1	1	1	2	1	1	2	1
achieved results with which I am content	2	2	1	1	2	3	1	2	2	1

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

[34] How strongly do you agree or disagree, respectively, with the following statements? (1 = I agree, 2 = I tend towards agreement, 3 = I tend towards disagreement, 4 = I disagree)

The participants described the group as fair (84% agreed very much, 15% tended towards agreement, 2% tended towards disagreement), open (77% agreed very much, 22% tended towards agreement, 2% tended towards disagreement), keen (69% agreed very much, 21% tended towards agreement), competent (61% agreed very much, 39 tended towards agreement), well composed (40% agreed very much, 49% tended towards agreement, 11% tended towards disagreement).

Table 28: Assessment of group characteristics

	Mean									
The group was	Total	A	D	SP	A1	A2	D1	D2	SP1	SP2
Fair	1	1	1	1	1	1	1	1	1	1
Open	1	1	1	1	1	1	1	1	1	1
Keen	1	1	1	1	1	1	1	1	1	1
Competent	1	1	1	1	1	1	1	1	1	1
well-composed	1	1	1	1	1	1	1	1	2	1

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

The group members described each other as co-operative (100% agreement), tolerant (100% agreement), charming (100% agreement), equal (97% agreement). None of the participants considered the group as aggressive.

5.4 Problems arising during the dialogues

5.4.1 Shortage of time

It is not a straightforward task to make participants spend an evening and a day on deliberations about ethical problems of science and technology. The organisers of the Austrian and the Spanish dialogues experienced some difficulties to recruit the appropriate number of persons for NSD (Griessler et al. 2003: 6, Santos et al. 2003: 52). Also, in the second German dialogue, two participants cancelled because of lack of time (Zimmer et al. 203: 3). Although the organisers finally succeeded in assembling a sufficiently large and heterogeneous group of people, many stakeholders had problems to fit the dialogue into their agendas and some of them cancelled. One reason for this may have been that many stakeholders considered xenotransplantation as something far from clinical application and thus not a very pressing societal problem. Lack of time was also one reason why, in all three countries, a small number of the participants had to leave earlier or stayed for a certain period of time only. Although the total number of those persons was negligible, their departure nevertheless caused a minor disruption of the process, with which the participants had to cope.

On the other hand, there were participants in all dialogues who criticised the lack of time, having been asked to transfer the results of NSD to the issue of xenotransplantation in the span of one and a half days (Santos et al. 2003: 53). In the Austrian dialogues several participants would have liked more time to discuss ethical problems of xenotransplantation more exhaustively; the available time did not seem sufficient. The difficulty of finding enough competent and concerned persons with sufficient time for NSD, the problem of early leavers on the one hand and demand for more discussion time on the other hand, underline the time dilemma when discussing the ethics of science and technology.

5.4.2 Group dynamics

It became obvious that the individual dialogues varied considerably in their dynamics. Whereas in A1 conversation was quite fluent, this was a problem in A2. The questionnaires give some indications supporting this thesis. Group A2 was a bit more sceptical about the moderator's success in involving all participants in the dialogue (mean 1,40 versus 1,14) and stimulating an atmosphere favourable for discussion (1,14 versus 1,60, Table 23). Moreover, overall, group A2 was more sceptical (1,60 versus 1,29, Table 25), particularly about a friendly atmosphere (1,13, versus 1,60) and co-operation in the group (1,70 versus 1,13, Table 26).

No such differences were reported about the two German dialogues and participants' assessment of their moderator was quite similar between the two groups. Overall group assessment was a little better in the second dialogue (1,22 versus 1,38) and specific items such as “allowed everybody to speak” and “developed an friendly atmosphere” were equally assessed to have been excellent (1,2, 1,1, respectively).

The Spanish dialogues varied regarding fluency of exchange, SP1 being more difficult than SP2. In the first Spanish dialogue *"the dialogue between participants did not start off smoothly. Some persons were reluctant to show their own point of view at the beginning of the session" (Santos et al. 2003b: 54).* The first dialogue developed a less friendly atmosphere than the second one (Santos et al. 2003: 55). Some participants criticised that certain stretches of the dialogue had been too slow. The moderator could have put less effort in animating participants to express their opinion (Santos et al. 2003b: 70). The second group found it easier to comment on ethical aspects. The facilitator also had an easier task in making them express ideas (Santos et al. 2003b: 53).

If we look at our survey results about the moderators’ and the groups’ characteristics, the participants in SP1 thought less often that the moderator involved all participants in the dialogue (1,75 versus 1,09) and that he stimulated an atmosphere favourable to discussion (1,63 versus 1,18). Participants in the first Spanish dialogue, overall, were also less satisfied with the group (1,63 versus 1,27); in particular, they stated less often that the group admitted the expression of dissenting opinions (1,63 versus 1,27). On the other hand , there were only small differences between the two groups regarding the items “allowed everybody to speak” (1,13, versus 1,00), “developed a friendly atmosphere” (1,13 versus

1,00) and “co-operated well” (1,63 versus 1,45). Regarding all those items, the participants in SP1 were more sceptical than their colleagues in SP2.

Santos et al. suggest that these differences may have been due to the composition of the two groups. They called the first group "positivist". In the second group there was a majority of persons who were better informed about and more interested in ethical aspects of xenotransplantation (Santos et al. 2003: 53). On average, the participants in SP1 were less well informed than in SP2. In SP1 there were two highly informed participants about xenotransplantation, who also had a strong connection with xenotransplantation. The rest of the participants mostly had less connection with xenotransplantation (1 medium, 4 minor, 1 none) and were considerably less well informed (1 person fairly informed, 5 little informed). This asymmetry in knowledge and connection with xenotransplantation might have hampered the discussion. In the second Spanish dialogue the distribution of knowledge and relatedness to the topic was more even, so the participants did not feel uncomfortable when expressing their opinions (Santos et al. 2003b: 57).

5.4.3 Acceptance of NSD

In A1 and A2 a problem occurred, which did not arise in Germany and Spain. In A1 one person and in A2 several participants did not accept the concept of the NSD and they wanted instead an expert oriented risk assessment (Griessler et al. 2003: 21 ff.). This conflict differed in intensity and consequences for the outcome in the two Austrian dialogues. In A1 the person who disapproved of the NSD articulated the criticism after the dialogue in the interview and did not profoundly influence the course of events. The person also left earlier because of other obligations. By contrast, in A2 it was the most active part of the group that was critical of the NSD. They voiced their critique during the last quarter of the dialogue and the discussion of the method of the NSD dominated the dialogue thereafter. This course of discussion also inhibited the transfer from the general rule worked out in the NSD to the topic of xenotransplantation. Points of critique on the NSD were, that the NSD would be *"too time consuming"* and, as one participant put it not *"goal oriented"*. This participant advocated an expert approach, which would deal with each problem of xenotransplantation separately. Decisions should be made after having listened to two experts. However, such a "goal oriented" approach in our opinion only applies existing opinions on decision problems and fails to probe the principles and rules that are the bases for such opinions. It also does not question the validity of these assumptions and cannot be called in our opinion a discussion of ethics.

5.4.4 Transfer

The main problem of the dialogues, which occurred in almost all dialogues, was the transfer of the basic ethical principles that the participants deducted from the every day example to the topic of xenotransplantation.

In the first Austrian Dialogue first steps were successfully made to transfer the general rules agreed upon to problems of xenotransplantation (Griessler et al. 2003: 18 ff.). However, it turned out that more time and expert input would be necessary to complete this transfer phase. In the second Austrian dialogue the transfer phase was not started because a principal discussion about the method of the NSD developed.

Also the German dialogues faced problems in the transfer of the results. In neither of the two German dialogues this step was completely finished and the participants' expectations on this point were not met (Zimmer et al. 2003: 34).*"Unfortunately, for this step only one hour was left. In this short time the participants could only start the transfer. But concrete results how to deal with ethical problems of xenotransplantation was one of the main reasons for many participants to take part in the NSD. So after the NSD many participants were disappointed with the NSD in this respect, namely, the results on xenotransplantation. Interestingly, they didn't blame the method but the lack of time. The participants were very optimistic that consent would be possible with this method on some topics or at least consent on the fact dissent exists in certain issues." (Zimmer et al. 2003: 38).*

Also the Spanish participants requested more time for the last phase of the dialogues in order to enable the drawing of conclusion related to the specific case of xenotransplantation (Santos et al. 2003b: 52 ff.).

5.4.5 Conflict in content

Conflicting views, especially on ethical questions, are by definition a constituent part of controversies about science and technology. As stated in chapter 4.4.2 above, conflicting standpoints were also present in our NSDs, particularly in Austria and Germany, but they did not obstruct the dialogues and were dealt with rather productively in the NSDs in the three countries.

In A1, a patient, a physician and an animal welfarist anticipated sharp controversy about xenotransplantation in the evening before the start of their NSD. They became involved in an intensive debate about xenotransplantation, but at the end of the next day the group applied the general rule it had agreed upon regarding the three problematic issues of xenotransplantation and was thus able to arrive at a provisional and implicit agreement about these topics (Griessler et al. 2003: 18 ff.). Although in A1, concluding from the questionnaires, latent conflict still existed in the group between advocates and those critical of xenotransplantation, this difference of opinion was not debated in the dialogue. This might have been a weakness of this dialogue: Some participants who thought that people were not emotionally involved in the discussion or did not articulate their standpoint concerning xenotransplantation also criticised this lack of controversy.

In Germany conflicting views about xenotransplantation also existed in the groups but, similarly, this did not result in personal conflict between participants. The participants said that the dialogue did not incite a sterile pro or contra discussion (Zimmer et al. 2003: 27).

It was a characteristic of both NSD "that the groups developed more and more into teams (...) There was consensus in the group that the possibility of getting to know each other and the ethical motivation of the other participant resulted in increasing acceptance of the other's position (...) A particular characteristic was that both groups developed into teams and the participants co-operated for a common inquiry into ethical principles relevant to the problems of xenotransplantation. The interactions between participants were very friendly despite the well-known differences in their opinions about xenotransplantation (Zimmer et al. 2003: 33).

Participants also said that, unlike in unfruitful, sterile discussions, they came to know their counterparts and learned to understand them better. All participants seemed to have become more humane after the event:

"The 'counterpart' was more congenial as I had experienced him/her in former events; Finally it was the first time that I got to know the 'counterpart' in person; It was possible to understand the other participant's position and this resulted in higher acceptance of those positions; Even if we have different opinions, we recognised that we use the same basic ethical principles" (Zimmer et al. 2003: 45).

"People from different professions with different opinions about xenotransplantation were able to reach agreement about basic ethical rules without having to be afraid to lose their face" (Zimmer et al. 2003: 27).

The Spanish evaluation team did not mention conflicts on content as a problem in the dialogues, either. However, different from Austria and Germany all Spanish participants except three were in favour of xenotransplantation. Some Spanish participants described their experience in the dialogue as follows:

"There was a great variety of opinions and individuals, what has made us to get more rich as human beings. At the end we achieved a constructive result on some key points with the involvement of all" (Santos et al. 2003b: 70).

"The dialogue allowed a very good working atmosphere in search of a consensus by means of an open and flexible attitude of all members" (Santos et al. 2003b: 70).

"Ideas were expressed with freedom, nobody felt being attacked personally. Active participation was higher than expected and the number of participants seemed suitable (Santos et al. 2003b: 70)".

6 Assessment

We evaluated NSD results in the following way:

First, for a general assessment of the dialogues, participants were asked several questions, i.e., whether their expectations were met and whether they would recommend NSD to interested colleagues. We also asked participants to assign school grades to their particular dialogues. In addition, we inquired whether participants considered the NSD results useful for their professional or voluntary activities. Finally, we wanted to know to which extent participants considered the NSD method to be useful in dealing with the ethical aspects of xenotransplantation in their professional or voluntary environment.

Second, in another set of questions, we wanted to find out more specifically about the participants' experiences with the NSD method of discussing the ethics of xenotransplantation. In this section, we wanted to learn more about different qualitative aspects of the dialogues about xenotransplantation and their specific outcomes.

Third, we wanted to know whether the participants thought that NSD contributed to change in their attitude towards xenotransplantation or towards other participants.

Finally, we asked participants to assess their NSD group and the group members. These questions aimed at the activities and qualities of the group.

6.1 General assessment

6.1.1 Fulfilled expectations

NSD met the participants' expectations to a large degree. In total, 86% of them said that their expectations were met (Table 29).

In detail, 27% thought that their expectations were surpassed, 38% that they were met and 20% that they were more or less met. Only 7% said that their expectations were hardly met or not at all met, respectively.

Table 29: Met expectations by countries (% and mean)[35]

	Surpassed	Met	Met more or less	Hardly met	Not met at all	Total	Mean
Austria	27,8	22,2	11,1	16,7	22,2	100	2,83
Germany	33,3	50,0	11,1	5,6	0	100	1,89
Spain	21,1	42,1	36,8	0	0	100	2,16
All countries	27,3	38,3	20,0	7,3	7,3	100	2,29

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

A three-country comparison shows significant differences between the three countries.[36] The expectations of German participants were met most often, whereas the Austrian participants' expectations were met least often. The mean of the Spanish participants shows a middle position. In detail, 33% of the participants in Germany said that their expectations were surpassed, 50% that they were met, 11% that they were more or less met and only 6% that they were hardly met. In Spain this ratio was 21% surpassed, 42% met and 37% more or less met. In Austria the evaluation was least favourable in our sample of countries. Although there was an overall positive majority - 28% thought that their expectations were surpassed, 22% that they were met and 11% that they were more or less met - there was also a rather strong minority of altogether 39% who said that their expectations were not met.

The relatively poor Austrian result is due to the second Austrian dialogue (A2) in which 30% of the participants declared that NSD had hardly or not at all met their expectations, respectively (Table 2). Generally, individual dialogues varied significantly across and within countries regarding assessment.[37] Above all, there were large differences between individual dialogues. D1 is the most favourably evaluated dialogue with respect to met expectations: 89% of the participants said that their expectations were surpassed or met. At the other end of the scale, A2 is the least favourably evaluated NSD: 60% of the participants said that their expectations were hardly or not at all met. But there are also differences within countries. In all three countries, one of the two dialogues was evaluated more favourably. Comparing the mean values, A1 was evaluated more favourable than A2 (mean 1,88 versus 3,60), D1 more positively than D2 (1,44 versus 2,33) and SP1 more positively than SP2 (1,82 versus 2,63).

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[35] Please state to what extent your expectations regarding NSD have been met or disappointed, respectively. My expectations were: 1 = surpassed, 2 = met, 3 = met more or less, 4 = hardly met, 5 = not at all met.

[36] 0,002 Pearson qui-square if the categories surpassed, met and more or less met as well as hardly met and not at all met are computed.

[37] 0,001 Pearson qui-square if the categories surpassed, met and more or less met as well as hardly met and not at all met are computed.

Table 2: Met expectations by dialogues (% and mean)

	Surpassed	Met	Met more or less	Hardly met	Not met at all	Total	Mean
A1	50,0	37,5	0	0	12,5	100	1,88
A2	10,0	10,0	20,0	30,0	30,0	100	3,60
D1	66,7	22,2	11,1	0	0	100	1,44
D2	0	77,8	11,1	11,1	0	100	2,33
SP1	0	37,5	62,5	0	0	100	2,63
SP2	36,4	45,5	18,2	0	0	100	1,82
All NSDs	27,3	38,2	20,0	7,3	7,3	100	2,29

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

6.1.2 School grades

We also asked the participants to assign school grades to their dialogues. For this, we used the grading scheme common in Austrian schools. This scheme ranges from 1 = excellent to 2 = fair, 3 = satisfactory, 4 = sufficient to 5 = failure (Table 3).

Table 3: School grades by country (% and mean)[38]

	Excellent	Fair	Satisfactory	Sufficient	Failure	Total	Mean
Austria	26,7	40,0	13,3	13,3	6,7	100	2,33
Germany	38,9	55,6	5,6	0	0	100	1,67
Spain	21,1	68,4	10,5	0	0	100	1,89
All countries	28,8	55,8	9,6	3,8	1,9	100	1,94

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

In general, participants assigned rather favourable marks to the NSDs. The total mean across all three countries was 1,94, which is close to "fair". In detail, 29% of the participants assigned the mark excellent, 56% assigned fair, 10% satisfactory, 4% sufficient and only 2% assigned the failure mark.

The German participants evaluated the NSDs most favourably, followed by the Spanish and Austrians. The German and Spanish mean values are positioned between "excellent" and "fair", and the Austrian ones between "fair" and "satisfactory". In detail, 39% of the German participants evaluated the dialogue as excellent, 56% as fair and 5% as satisfactory. 21% of the Spanish participants considered NSD to be excellent, 68% thought it was fair and 11% marked it as satisfactory. In Austria, 27%

[38] Overall, I grade the event as follows: 1 = excellent, 2 = fair, 3 = satisfactory, 4 = sufficient, 5 =failure

evaluated the dialogue as excellent, 40% as fair, 13% as satisfactory, but also 13% marked it sufficient and 7% as failure.

The evaluation by school grades varied significantly across individual dialogues (Pearson chi-square 0,027). Again D1 was evaluated most and A2 least favourably. Again, A1 was evaluated more favourable than A2, D1 better than D2 and SP 2 better than SP1, respectively (Table 4).

Table 4: School grades by NSD (% and mean)

	Excellent	Fair	Satisfactory	Sufficient	Failure	Total	Mean
A1	57,1	42,9	0	0	0	100	1,43
A2	0	37,5	25,0	25,0	12,5	100	3,13
D1	55,6	44,4	0	0	0	100	1,4
D2	22,2	66,7	11,1	0	0	100	1,9
SP1	0	75,0	25,0	0	0	100	2,25
SP2	36,4	63,6	0	0	0	0	1,64
All NSDs	28,8	55,8	9,6	3,8	1,9	100	1,94

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

6.1.3 Willingness to recommend NSD to a colleague

We also asked participants whether they would recommend this kind of event to a colleague (Table 5). We considered this to be a rather strict criterion, since we assumed that the recommendation would connect the recommended event with the recommending person's reputation. In other words, the recommending person's reputation was put at stake.

Table 5: Recommendation of NSD by country (% and mean)[39]

	I would recommend it	I would recommend it with certain reservations	I would tend not to recommend it	I would not recommend it at all	Total	Mean
Austria	38,9	38,9	16,7	5,6	100	1,89
Germany	66,7	33,3	0	0	100	1,33
Spain	78,9	21,1	0	0	100	1,21
All countries	61,8	30,9	5,5	1,8	100	1,47

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

[39] How strongly would you recommend participation in this kind of event to interested colleagues? 1 = I would recommend it, 2 = I would recommend it with certain reservations, 3 = I would tend not to recommend it, 4 = I would not recommend it at all.

The participants were generally very willing to recommend NSD to interested colleagues. 62% said they would recommend NSD and an additional 31% said they would recommend it with certain reservations. Only 5% of the participants tended not to recommend it and 2% said that they would not recommend it at all. Spain was the country with the greatest number of participants willing to recommend NSD, followed by Germany. Again, Austria was the country with the least favourable results, due to the relatively sceptical attitude of participants in A2 (Table 6, 0,012 Pearson qui-square).

Table 6: Recommendation of NSD by NSD (% and mean)

	I would recommend it	I would recommend it with certain reservations	I would tend not to recommend it	I would not recommend it at all	Total	Mean
A1	75,0	12,5	0	12,5	100	1,50
A2	10,0	60,0	30,0	0	100	2,20
D1	77,8	22,2	0	0	100	1,2
D2	55,6	44,4	0	0	100	1,4
SP1	62,5	37,5	0	0	100	1,38
SP2	90,9	9,1	0	0	100	1,09
All NSDs	61,8	30,9	5,5	1,8	100	1,47

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

SP 2 was the dialogue evaluated most positively and A2 the one assessed least favourably. There were also differences within countries. A1, D1 and SP2 were evaluated more positively than A2, D2 and SP1, respectively.

6.1.4 Usefulness of NSD results in the participants' environments

We asked participants to what extent they thought the dialogue results were useful in their professional and voluntary environments (Table 7).

Table 7: Usefulness of results by country (% and means)[40]

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Austria	17,6	35,3	11,8	35,3	100	2,65
Germany	11,1	66,7	16,7	5,6	100	2,17
Spain	15,8	73,7	10,5	0	100	1,95
All countries	14,8	59,3	13,0	13,0	100	2,24

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

In total, 74% of the participants agreed that the results were useful in their professional or voluntary environments, including 15% of the participants who stated that the results were very useful, and 59% that they were useful. 13% of the participants stated that the results were rather not useful and another 13% that they were not useful in their professional or voluntary environments.

There were significant differences (0,040 Pearson chi-square) among the three countries. Spain was most positive about results: 16% of the NSD participants said that the results of the dialogue were very useful, 74% that they were useful and 10% that they were rather not useful. In Germany 11% thought that the results were useful and another 67% that they were rather useful, but also 17% considered the results to be rather not useful and 5% not useful. In Austria only 17% of the participants thought the results were useful and another 35% that they were rather useful. But 12% considered the results as rather not useful and 35% as not useful at all. These relatively poor Austrian results are again due to obvious differences between A1 and A2, since the negative evaluations came entirely from A2 (Table 30).

Table 30: Usefulness of results by NSD (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
A1	42,9	57,1	0	0	100	1,57
A2	0	20,0	20,0	60,0	100	3,40
D1	22,2	66,7	11,1	0	100	1,9
D2	0	66,7	22,2	11,1	100	2,4
SP1	0	87,5	12,5	0	100	2,13
SP2	27,3	63,6	9,1	0	100	1,82
All NSDs	14,8	59,3	13,0	13,0	100	2,24

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

[40] Having participated in Neo-Socratic Dialogues about xenotransplantation, please indicate to what extent NSD results have been useful in your professional environment: 1 = very useful, 2 = quite useful, 4 = rather not useful, 5 = not at all useful.

SP2 was the dialogue with the highest number of participants thinking that its results were very or rather useful, while A2 was the dialogue with the strongest expression of scepticism. The participants in A1, D1 and SP2 were more positive in their assessment than their colleagues in A2, D1 and SP2, respectively. The relationship between NSD and assessment of usefulness of results was significant (0,001 Pearson chi-square).

Two weeks after the NSDs, the FhG-ISI team asked the participants in the German NSDs whether they considered their results as useful.[41] The interviews showed that satisfaction with the results dropped with different intensity regarding the two dialogues. Immediately after D1, two persons said that they considered the results as very useful and six as rather useful, whereas only one said they were rather not useful. Two weeks later, none of the D1 respondents considered the results as very useful, two considered them as rather useful, but five as rather not useful and one person as not useful. One participant explained his decreasing satisfaction as follows: *"My expectations were fulfilled directly after the NSD. I had the feeling that it was a good dialogue. But after the event I became frustrated more and more because I didn't know if the method really worked" (Zimmer et al. 2003: 34).*

Dialogue D2 did not show such a marked drop in the assessment of the usefulness of results. Immediately after the dialogue, six persons said the results were rather useful, two stated they were rather not useful and one person said that they were not useful. Two weeks later, four people thought that the results were rather useful and four people said they were rather not useful.

In contrast to NSD results, the NSD method as such did not experience such a drop over an interval of two weeks. Immediately after D1, three participants considered the method as very useful, four as rather useful and two as not useful. Two weeks later, two participants said they could imagine using the NSD method for their work, two could rather imagine it and three could not imagine it. In D2, the respective shares were: one very useful, seven rather useful and one rather not useful immediately after the event; compared with three persons who could well imagine, four who could rather imagine and one who could rather not imagine it two weeks later (Zimmer et al. 2003: 46ff.).

6.1.5 Usefulness of the method

We wanted to know whether the participants considered the NSD method adequate for discussing xenotransplantation in their professional or voluntary environments (Table 31).

[41] For this wave of interviews the FhG-ISI team interviewed 8 of the 9 persons who had participated in each German Dialogue.

Table 31: Usefulness of the method by country (% and mean)[42]

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Austria	27,8	38,9	11,1	22,2	100	2,28
Germany	22,2	61,1	16,7	0	100	1,94
Spain	10,5	84,2	5,3	0	100	1,95
All countries	20,0	61,8	10,9	7,3	100	2,05

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

In total, a large majority of 82% gave a positive answer to this question, including 20% who considered the method as very useful and 62% who evaluated it as quite useful. However, 11% thought that the method was rather not useful and another 7% that it was not useful at all.

The mean values of German and Spanish participants were quite close in their rather positive assessment. In Germany, 22% of the participants thought the NSD method was very useful for discussing controversial problems of science and technology, 61% evaluated it as rather useful and 17% as rather not useful. In Spain, this ratio was 11% very useful, 84% rather useful, and 5% rather not useful. In Austria, the share of sceptical participants was highest compared with the other two countries. But still 28% of the Austrian participants considered the method as very useful and 39% as rather useful. In total, one-third was pessimistic about the method (11% rather not useful and 22% not useful).

The Austrian participants in A1 were most positive about the method across all dialogues, whereas their colleagues in A2 were most sceptical (Table 32). Again, participants in D1 and SP2 were more positive in their assessment than participants in D2 and SP2, respectively.

[42] To what extent has participation in NSD been useful to you in your professional or voluntary activities with respect to resolving ethical questions connected with xenotransplantation? 1 = very useful, 2 = quite useful, 4 = rather not useful, 5 = not at all useful

Table 32: Usefulness of the method by NSD in %

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
A1	50,0	37,5	0	12,5	100	1,75
A2	10,0	40,0	20,0	30,0	100	2,50
D1	33,3	44,4	22,2	0	100	1,9
D2	11,1	77,8	11,1	0	100	2,0
SP1	0	87,5	12,5	0	100	2,13
SP2	18,2	81,8	0	0	100	1,82
All NSDs	20,0	61,8	10,9	7,3	100	2,05

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)T

6.1.6 Which factors might have influenced the evaluation of the outcome?

We already saw that country and individual dialogues had an influence on the evaluation of several features of NSD. We wondered whether any other factors might have influenced the outcome in a similar way. In order to clarify this question we looked at the relationship between outcome of individual dialogues and degree of relatedness to the topic of xenotransplantation, but also at level of information, attitude towards xenotransplantation, and the characteristics of participants, grouping them into scientists and non-scientists, persons with previous experience of discussion on xenotransplantation as well as, finally, gender. In the following section we will discuss these variables one by one.

6.1.6.1 Strength of relatedness to xenotransplantation

Which influence did the perceived closeness of participants have on their evaluation of NSD? Did participants who felt to be closely related to the topic evaluate NSD more positively than persons who felt less related, or vice versa? In order to answer this question, we looked at the relationship between strength of relatedness to xenotransplantation and met expectations (Table 33), school grades (Table 34), recommendation (Table 35), usefulness of results (Table 36) and usefulness of the method (Table 37).

On the whole, there were clear differences between different groups of participants, differentiated according to their closeness to the topic of xenotransplantation.

Participants very closely related to xenotransplantation (i.e. 35% of all participants) evaluated the event most favourably (with the exception of the usefulness of the method): 42% of the very closely related participants said that their expectations were surpassed and 47% that they were met; 42% marked the event as excellent and 53% as fair; all of them would recommend the event to a colleague

(74% very much, 26% with certain reservations); 26% considered the results as very and another 69% as quite useful, while 32% considered the method as very and another 53% as quite useful.

Participants who felt to be hardly related to xenotransplantation were second in their assessment of the event, with the exception of met expectations (third position) and usefulness of the method (most positive evaluation). In total, 22% of the participants felt to be hardly related to the topic. 50% of those persons said that their expectations were surpassed or met; 36% each marked the event as excellent or fair, all of them would recommend the event to a colleague (67% very much); 67% considered the results as quite useful and all of them thought the method was useful (17% very useful, 83% quite useful).

Participants who felt to be moderately related to xenotransplantation, i.e. 37% of all participants, evaluated the event as less favourable than those with a close relationship and little relationship. The only exception was the item "met expectations", where persons with moderate relationship to xenotransplantation gave NSD the second best evaluation (60% surpassed and met).

Altogether three people (6 % of all participants) who felt no relatedness to xenotransplantation were least satisfied with the event, as expressed by met expectations (67% more or less met, 33% not at all met), school grades (67% fair, 33% sufficient), recommendation (67% with reservation, 33% tend not to recommend it), usefulness of results (67% quite useful, 33% not at all useful), and usefulness of the method (33% each quite useful, rather not useful, not at all useful).

Table 33: Met expectations by relatedness to xenotransplantation (% and mean)

	Surpassed	Met	Met more or less	Hardly met	Not met at all	Total	Mean
Very closely related	42,1	47,4	10,5	0	0	100	1,68
Moderately related	25,0	35,0	15,0	10,0	15,0	100	2,55
Hardly related	8,3	41,7	33,3	16,7	0	100	2,58
Not at all related	0	0	66,7	0	33,3	100	3,67
All participants	27,3	38,2	20,0	7,3	7,3	100	2,29

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 34: School grades by relatedness to xenotransplantation (% and mean)

	Excellent	Fair	Satisfactory	Sufficient	Failure	Total	Mean
Very closely related	42,1	52,6	5,3	0	0	100	1,63
Moderately related	11,1	72,2	5,6	5,6	5,6	100	2,22
Hardly related	36,4	36,4	27,3	0	0	100	1,91
Not at all related	0	66,7	0	33,3	0	100	2,67
All participants	28,8	55,8	9,6	3,8	1,9	100	1,94

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 35: Recommendation by relatedness to xenotransplantation (% and mean)

	I would recommend it very much	I would recommend it with certain reservations	I would tend not to recommend it	I would not recommend it at all	Total	Mean
Very closely related	73,7	26,3	0	0	100	1,26
Moderately related	60,0	25,0	10,0	5,0	100	1,60
Hardly related	66,7	33,3	0	0	100	1,33
Not at all related	0	66,7	33,3	0	100	2,33
All participants	61,8	30,9	5,5	1,8	100	1,47

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 36: Usefulness of results by relatedness to xenotransplantation (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Very closely related	26,3	57,9	5,3	10,5	100	2,0
Moderately related	0	68,4	10,5	21,1	100	2,53
Hardly related	25,0	41,7	33,3	0	100	2,08
Not at all related	0	66,7	0	33,3	100	2,67
All participants	14,8	59,3	13,0	13,0	100	2,24

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 37: Usefulness of method by relatedness to xenotransplantation

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Very closely related	31,6	52,6	15,8	0	100	1,84
Moderately related	10,0	65,0	10,0	15,0	100	2,30
Hardly related	16,7	83,3	0	0	100	1,83
Not at all related	0	33,3	33,3	33,3	100	3,00
All participants	20,0	61,8	10,9	7,3	100	2,05

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

6.1.6.2 Level of information

Did participants who were better informed than others evaluate NSD differently? In other words, is there a connection between personal knowledge about xenotransplantation and a person's evaluation of the NSD event? We again looked at met expectations (Table 38), school grades (Table 39), recommendation (Table 40), usefulness of results (Table 41), and usefulness of the method (Table 42).

In general, we did not find any statistically significant differences between groups with different levels of information about xenotransplantation, but in our sample there still were considerable differences between them:

Perfectly informed participants (i.e. 34% of all participants) were more positive about the event than less informed participants with respect to all our general NSD evaluation questions except one.

Of the perfectly informed participants, 37% said that their expectations were surpassed and 42% that they were met (mean = 1,89). Sufficiently informed and somewhat informed participants were also quite positive about the event, but clearly to a lesser degree. 21% of the sufficiently informed persons said that their expectations were surpassed and another 46% that they were met (mean = 2,46) and 25% of the somewhat informed respondents stated that their expectations were surpassed and 17% that they were met (mean = 2,58).

Looking at the school grades, perfectly informed persons again assessed NSD most favourably. 32% of them marked the event as excellent and 63% as fair (mean = 1,79). The sufficiently and somewhat informed participants were also quite positive about the dialogues, but again to a lesser extent. 32% of the sufficiently informed respondents said that NSD was excellent, 46% that it was fair and 14% that it was satisfactory. But there were also 4% who assigned sufficient and failure marks, respectively, to the dialogue (mean = 2,05). The group of somewhat informed participants showed the smallest share of excellent marks (18%). 63% of the somewhat informed persons marked the event as fair and 18% as satisfactory.

64% of the perfectly informed participants would recommend NSD very much to an interested colleague and another 37% would do so with certain reservations (mean = 1,37). In the group of sufficiently informed participants the share of strong recommendation almost equals that of the perfectly informed persons, but in the latter group the share of recommendation with reservations is smaller (25%) and there are also 13% who would tend not to recommend the dialogue to an interested colleague (mean = 1,50). In the group of somewhat informed participants 58% would recommend NSD very much and 33% would recommend it, but there are also 8% who would not recommend it at all (mean = 1,58).

The group who was most positive about the results of NSD was the one consisting of somewhat informed persons. 18% of them considered the results as useful for their work and another 82% as somewhat useful (mean = 1,82). Perfectly informed participants were more sceptical. 16% considered the results as very useful and 58% as quite useful, but 10% also considered them as rather not useful and 16% as not useful at all (mean = 2,26). The sufficiently informed were the most sceptical ones among the three groups. 13% of them considered the results as very useful and 50% as quite useful, but 21% thought that the results were rather not useful and 17% that they were not useful at all (mean = 2,42).

Assessment of the method again reveals perfectly informed persons as the most positive participants. 26% of them considered the method as very useful and 68% as quite useful (mean = 1,79). In the group of somewhat informed participants the share of strong agreement and agreement with the method is less strong, with 17% and 67%, respectively. Moreover, there are also 8% each who consider the method as rather not useful and not useful, respectively (mean = 2,08). The least positive participants were the sufficiently informed ones. This group had the highest share of participants who considered the method as rather not useful (17%) and not useful at all (12%, mean = 2,25).

Table 38: Expectations met by level of information (% and mean)

	surpassed	met	met more or less	hardly met	not met at all	Total	Mean
Perfectly informed	36,8	42,1	15,8	5,3	0	100	1,89
Sufficiently informed	20,8	45,8	12,5	8,3	12,5	100	2,46
Somewhat informed	25,0	16,7	41,7	8,3	8,3	100	2,58
All participants	27,3	38,2	20,0	7,3	7,3	100	2,29

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 39: School grades by level of information (% and mean)

	Excellent	Fair	Satisfactory	Sufficient	Failure	Total	Mean
Perfectly informed	31,6	63,2	0	5,3	0	100	1,79
Sufficiently informed	31,8	45,5	13,6	4,5	4,5	100	2,05
Somewhat informed	18,2	63,6	18,2	0	0	100	2,00
All participants	28,8	55,8	9,6	3,8	1,9	100	1,94

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 40: Recommendation of NSD by level of information (% and mean)

	I would recommend it very much	I would recommend it with certain reservations	I would tend not to recommend it	I would not recommend it at all	Total	Mean
Perfectly informed	63,2	36,8	0	0	100	1,37
Sufficiently informed	62,5	25,0	12,5	0	100	1,50
Somewhat informed	58,3	33,3	0	8,3	100	1,58
All participants	61,8	30,9	5,5	1,8	100	1,47

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 41: Usefulness of results by level of information (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Perfectly informed	15,8	57,9	10,5	15,8	100	2,26
Sufficiently informed	12,5	50,0	20,8	16,7	100	2,42
Somewhat informed	18,2	81,8	0	0	100	1,82
All participants	14,8	59,3	13,0	13,0	100	2,24

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 42: Usefulness of method by level of information (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Perfectly informed	26,3	68,4	5,3	0	100	1,79
Sufficiently informed	16,7	54,2	16,7	12,5	100	2,25
Somewhat informed	16,7	66,7	8,3	8,3	100	2,08
All participants	20,0	61,8	10,9	7,3	100	2,05

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

6.1.6.3 Advocates and Opponents

Did advocates and opponents of xenotransplantation, and people who were undecided about this technology, assess NSD equally? Were opponents or advocates more in favour of the event?

In total, 56% of the participants advocated xenotransplantation, 22% were against this technique and 22% were undecided. Looking at the general evaluation of NSD under the perspective of advocates or opponents of xenotransplantation, there were no big differences between these two groups. Advocates of xenotransplantation evaluated met expectations (mean 2,10 versus 2,25) and usefulness of the method (mean 1,93 versus 2,00) slightly more positive than the opponents. By contrast, opponents were more positive with regard to NSD results (mean 2,00 versus 2,07), school grades (mean 1,64 versus 1,90) and recommendation (1,25 versus 1,40) than advocates.

On the other hand, there were remarkable differences between persons with declared positions in favour of xenotransplantation and undecided participants. In all items of general evaluation, the undecided ones were more critical than persons who took a pro or contra position towards xenotransplantation.

Table 43: Met expectations by attitude towards xenotransplantation (% and mean)

	Surpassed	Met	Met more or less	Hardly met	Not met at all	Total	Mean
Pro	26,7	46,7	20,0	3,3	3,3	100	2,10
Undecided	16,7	25,0	33,3	0,0	25,0	100	2,92
Contra	33,3	33,3	8,3	25,0	0,0	100	2,25
All participants	27,3	38,2	20,0	7,3	7,3	100	2,29

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 44: School grades by attitude towards xenotransplantation (% and mean)

	Excellent	Fair	Satisfactory	Sufficient	Failure	Total	Mean
Pro	30,0	60,0	3,3	3,3	3,3	100	1,90
Undecided	0	60,0	30,0	10,0	0	100	2,50
Contra	45,5	45,5	9,1	0	0	100	1,64
All participants	28,8	55,8	9,6	3,8	1,9	100	1,94

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 45: Recommendation of NSD by attitude towards xenotransplantation (% and mean)

	I would recommend it	I would recommend it with certain reservations	I would tend not to recommend it	I would not recommend it at all	Total	Mean
Pro	63,3	33,3	3,3	0	100	1,40
Undecided	50,0	25,0	16,7	8,3	100	1,83
Contra	75,0	25,0	0	0	100	1,25
All participants	61,8	30,9	5,5	1,8	100	1,47

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 46: Usefulness of results by attitude towards xenotransplantation (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Pro	20,0	63,3	6,7	10,0	100	2,07
Undecided	0	36,4	27,3	36,4	100	3,00
Contra	16,7	66,7	16,7	0	100	2,00
All participants	14,8	59,3	13,0	13,0	100	2,24

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 47: Usefulness of method by attitude towards xenotransplantation (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Pro	23,3	63,3	10,0	3,3	100	1,93
Undecided	16,7	50,0	8,3	25,0	100	2,42
Contra	16,7	66,7	16,7	0	100	2,00
All participants	20,0	61,8	10,9	7,3	100	2,05

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

6.1.6.4 Scientists /non-scientists

Were scientists or physicians more critical of NSD than other participants, or were they, perhaps, more positive than the rest of their group?

47% of all participants indicated scientist or physician as their primary profession. This group was more positive about the event than participants with other primary professions, with one exception, i.e. evaluation of NSD results. 77% of the scientist/physician group said that their expectations were surpassed or met (mean 2,00), 96% rated the event as excellent or fair (mean 1,77), 96% recommended the event (mean 1,38) and 85% considered the method as useful (mean 1,92).

In comparison, only 52% of the other participants said that their expectations were met (mean 2,55), 83% of them rated the event as excellent or fair (with lower numbers in both categories, mean 2,12). Moreover, slightly fewer people recommended the event to a colleague (mean 1,55) and considered the method useful (mean 2,17).

Table 48: Expectations met by scientists/ others (% and mean)

	Surpassed	Met	Met more or less	Hardly met	Not met at all	Total	Mean
Scientists (physicians)	30,8	46,2	19,2	0	3,8	100	2,00
Others	24,1	31,0	20,7	13,8	10,3	100	2,55
All participants	27,3	38,2	20,0	7,3	7,3	100	2,29

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 49: School grades by scientists/ others (% and mean)

	Excellent	Fair	Satisfactory	Sufficient	Failure	Total	Mean
Scientists (physicians)	34,6	61,5	0	0	3,8	100	1,77
Others	23,1	50,0	19,2	7,7	0	100	2,12
All participants	28,8	55,8	9,6	3,8	1,9	100	1,94

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 50: Recommendation by scientists/ others (% and mean)

	I would recommend it	I would recommend it with certain reservations	I would tend not to recommend it	I would not recommend it at all	Total	Mean
Scientists (physicians)	65,4	30,8	3,8	0	100	1,38
Others	58,6	31,0	6,9	3,4	100	1,55
All participants	61,8	30,9	5,5	1,8	100	1,47

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 51: Usefulness of results by scientists/ others (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Scientists (physicians)	15,4	53,8	19,2	11,5	100	2,27
Others	14,3	64,3	7,1	14,3	100	2,21
All participants	14,8	59,3	13,0	13,0	100	2,24

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 52: Usefulness of method by scientists/ other (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Scientists (physicians)	26,9	57,7	11,5	3,8	100	1,92
Others	13,8	65,5	10,3	10,3	100	2,17
All participants	20,0	61,8	10,9	7,3	100	2,05

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

6.1.6.5 Previous event on xenotransplantation

Did people who had previously participated in a discussion on xenotransplantation assess the event differently from participants who had not?

In total, 53% of the participants had previously been involved in discussions about xenotransplantation while 47% had not discussed the subject before. In general, there were no significant differences between those two groups. Looking at the mean values, previous participants in discussion on xenotransplantation were slightly more positive about their met expectations (2,24 versus 2,35), whereas participants without such an experience were slightly more positive in the following aspects: usefulness of results (2,08 versus 2,39), usefulness of the method (1,96 versus 2,14), school grades (1,92 versus 1,92), and recommendation to other colleagues (1,38 versus 1,55).

Table 53: Expectation met by previous participation in a xenotransplantation discussion (% and mean)

	Surpassed	Met	Met more or less	Hardly met	Not met at all	Total	Mean
Yes	27,6	41,4	17,2	6,9	6,9	100	2,24
No	26,9	34,6	23,1	7,7	7,7	100	2,35
All participants	27,3	38,2	20,0	7,3	7,3	100	2,29

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 54: School grades by previous participation in a xenotransplantation discussion (% and mean)

	Excellent	Fair	Satisfactory	Sufficient	Failure	Total	Mean
Yes	28,6	57,1	7,1	3,6	3,6	100	1,96
No	29,2	54,2	12,5	4,2	0	100	1,92
All participants	28,8	55,8	9,6	3,8	1,9	100	1,94

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 55: Recommendations by previous participation in a xenotransplantation discussion (% and mean)

	I would recommend it very much	I would recommend it with certain reservations	I would tend not to recommend it	I would not recommend it at all	Total	Mean
Yes	55,2	37,9	3,4	3,4	100	1,55
No	69,2	23,1	7,7	0	100	1,38
All participants	61,8	30,9	5,5	1,8	100	1,47

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 56: Usefulness of results by previous participation in a xenotransplantation discussion (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Yes	7,1	60,7	17,9	14,3	100	2,39
No	23,1	57,7	7,7	11,5	100	2,08
All participants	14,8	59,3	13,0	13,0	100	2,24

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 57: Usefulness of method by previous participation in a xenotransplantation discussion (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Yes	17,2	58,6	17,2	6,9	100	2,14
No	23,1	65,4	3,8	7,7	100	1,96
All participants	20,0	61,8	10,9	7,3	100	2,05

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

6.1.6.6 Gender

64% of the participants were men and 34% women. Did men evaluate the event differently from women? In general, this question can be answered with "yes". Women evaluated the event more favourably than men along the items met expectations (mean 1,89 versus 2,43), school grades (1,84

versus 2,00), recommendation of NSD (1,16 versus 1,57), usefulness of results (2,00 versus 2,37) and usefulness of the method (1,95 versus 2,06).

Table 58: Expectations met by gender (% and mean)

	Surpassed	Met	Met more or less	Hardly met	Not met at all	Total	Mean
Male	22,9	40,0	17,1	11,4	8,6	100	2,43
Female	36,8	36,8	26,3	0	0	100	1,89
All participants	27,3	38,2	20,0	7,3	7,3	100	2,29

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 59: School grades by gender (% and mean)

	Excellent	Fair	Satisfactory	Sufficient	Failure	Total	Mean
Male	27,3	57,6	6,1	6,1	3,0	100	2,00
Female	31,6	52,6	15,8	0	0	100	1,84
All participants	28,8	55,8	9,6	3,8	1,9	100	1,94

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 60: Recommendation of NSD by gender (% and mean)

	I would recommend it very much	I would recommend it with certain reservations	I would tend not to recommend it	I would not recommend it at all	Total	Mean
Male	51,4	40,0	8,6	0	100	1,57
Female	84,2	15,8	0	0	100	1,16
All participants	61,8	30,9	5,5	1,8	100	1,47

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 61: Usefulness of results by gender (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	Mean
Male	11,4	57,1	14,3	17,1	100	2,37
Female	21,1	63,2	10,5	5,3	100	2,00
All participants	14,8	59,3	13,0	13,0	100	2,24

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 62: Usefulness of the method by gender (% and mean)

	Very useful	Quite useful	Rather not useful	Not at all useful	Total	
Male	20,0	62,9	8,6	8,6	100	2,06
Female	21,1	63,2	15,8	0	100	1,95
All participants	20,0	61,8	10,9	7,3	100	2,05

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

6.2 Which experiences did the participants have?

Beside general evaluation of the dialogues via the methods presented in the previous sections, we also wanted to find out about certain details of the participants' experiences. Table 63 provides a comparison of the respective answers by their mean values.

6.2.1 Outcomes of the dialogue which met with strong agreement

The survey results demonstrate, above all, that we succeeded in getting participants acquainted with NSD as a different form of discussion. 96% of the participants agreed that they became acquainted with NSD, and a different form of discussion, respectively. The mean values of these questions were rather close (1,23 and 1,25).

The participants also agreed very strongly that they experienced certain qualitative aspects of discussion, such as an open atmosphere, equality, mutual understanding, interest, mutual learning, clear structure, listening and time for reflection. 98% of the participants agreed that they had experienced an egalitarian dialogue (mean 1,24); 96% said that NSD created a relaxed atmosphere conducive to an exchange of views (mean 1,31); 93% said that they had become acquainted with other people and had learned something about their points of view (mean 1,56); 91% experienced that other participants also took an interest in the topic (mean 1,53); 89% said that they had experienced high-quality discussion (mean 1,76) and had come to know other people and their points of view. 80% of the participants agreed with the following statements: they experienced a clearly structured discussion (mean 1,81), they felt that other participants were listening to them and trying to understand them (mean 1,83), and they felt that NSD gave them time and possibility to consider an ethical problem (mean 1,85).

Table 63: Which experiences did the participants have?[43]

	Total	A	D	SP	A1	A2	D1	D2	SP1	SP2
to get acquainted with a different form of discussion	1.23	1.39	1.17	1.21	1.25	1.50	1.0	1.3	1.38	1.09
enabled egalitarian dialogue among all participants	1.24	1.50	1.11	1.11	1.38	1.60	1.2	1.0	1.13	1.09
acquainted me with the method of NSD	1.25	1.50	1.17	1.05	1.17	1.70	1.2	1.1	1.13	1.00
created a relaxed atmosphere conducive to an exchange of views	1.31	1.50	1.06	1.37	1.31	1.80	1.1	1.0	1.75	1.09
showed me that other persons were also interested in this subject	1.53	1.69	1.28	1.63	1.14	2.11	1.2	1.3	1.63	1.64
acquainted me with other people and their points of view	1.56	2.06	1.50	1.16	1.38	2.60	1.3	1.7	1.13	1.18
to take part in a high quality discussion	1.76	1.83	1.61	1.84	1.75	1.90	1.6	1.7	2.13	1.64
enabled a clearly structured discussion	1.81	2.12	1.50	1.84	1.43	2.60	1.3	1.7	2.38	1.45
created a situation in which other participants listened to me and tried to understand me	1.83	2.35	1.44	1.74	2.00	2.60	1.6	1.3	1.75	1.73
gave me time and possibility to consider an ethical problem	1.85	2.22	1.67	1.68	1.87	2.50	1.8	1.6	1.50	1.82
enabled other participants to refer to my arguments	2.04	2.29	1.61	2.21	2.14	2.40	1.7	1.6	2.25	2.18
helped me to understand other participants' point of view better	2.06	2.65	1.89	1.68	1.71	3.30	1.9	1.9	1.75	1.96
resulted in exciting discussions on the subject	2.07	2.35	2.00	1.89	1.29	3.10	1.8	2.2	2.38	1.55
brought tolerance towards my views	2.09	2.41	2.33	1.58	2.00	2.70	2.6	2.1	1.58	1.64
helped me to develop my personal communicative skills	2.24	2.71	2.22	1.84	2.00	3.20	1.9	2.6	1.88	1.82
has clarified my own standpoint	3.13	3.72	3.06	2.63	2.50	4.70	3.2	2.9	2.63	2.64
enabled me to convince others of my own point of view	3.15	3.06	3.39	3.00	2.86	3.20	3.4	3.3	2.88	3.09
has given me new insights about the subject of xenotransplantation	3.20	3.44	3.89	2.32	2.88	3.90	4.2	3.5	2.50	2.18
resulted in a consensus on the subject of xenotransplantation	3.45	4.00	4.06	2.42	2.86	4.80	4.2	3.9	2.50	2.36
has given a clear answer on how to deal with the problem of xenotransplantation	3.45	3.67	3.94	2.79	2.88	4.30	3.7	4.2	3.00	2.64

[43] You are now asked to evaluate the NSD on ethical problems connected with xenotransplantation. To what extent do you agree with the following statements? (1= I agree very much; 5 = I do not agree at all).

	Total	A	D	SP	A1	A2	D1	D2	SP1	SP2
provided me with new information about xenotransplantation	3.67	3.83	4.61	2.63	3.25	4.30	4.7	4.6	2.38	2.82
has made me change my attitude towards ethical problems of xenotransplantation	3.84	4.33	4.17	3.05	3.88	4.70	4.3	4.0	3.82	2.82

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

The responses to these questions show a diversity of assessments.

6.2.2 Outcomes of NSD that met with high agreement

The general evaluation also shows that further qualitative aspects of discussion were also positively noted by the participants, but less strongly than the qualities discussed above. 72% of the participants experienced that other participants referred to their own arguments (mean 1,83); 78% that they came to understand other participants' points of view (mean 2,06). 70% experienced an exciting discussion on the subject (mean 2,07); 65% that NSD created tolerance towards other persons' points of view (2,09) and 65% that NSD helped to improve their communicative skills (2,24).

6.2.3 Outcomes of NSD that met with low agreement

Beside the clearly positive results with regard to presentation of the method and qualitative aspects of discussion, personal experiences related to the content of xenotransplantation clearly met with fewer acceptances. The high cumulative percentages of these items are misleading because they add all the intensities of agreement to one value. Therefore we also present the mean value, which can range between the value 1 and 5.

- 60% of the participants said that the NSD clarified their personal standpoint. This high cumulative figure includes 9% who agreed very much to this statement, 29% who agreed and 22% who tended towards agreement (mean 3,13).

- 70% of the participants agreed that the NSD enabled them to convince others about their own point of view. This figure includes 18% who agreed and a large share of 52% who tended towards agreement, mean 3,15.

- For 58% of the participants the NSD provided new insights into xenotransplantation. 16% agreed very much on this statement, 14% agreed and 27% tended towards agreement (mean 3,20).

- 51% of the respondents said that NSD resulted in consensus on the subject of xenotransplantation. The share of people who agreed very much on this statement was very small with 4%. 26% agreed on this statement and 21% tended towards agreement (mean 3,45).

- For another 51% of the participants the NSD gave a clear answer on how to deal with the problem of xenotransplantation (11 very much agreement, 11% agreement, 29% tend towards agreement, mean 3,45).

- Only for a small part of 36% of the participants the NSD provided new information about xenotransplantation (11% very much agreement, 16% agreement, 9% tend towards agreement, mean 3,67).

- 35% experienced a change in their personal attitude towards ethical problems of xenotransplantation (4% very much agreement, 11% agreement, 20% tend towards agreement, mean 3,84).

6.2.4 Differences in outcomes of NSD meeting low agreement

The survey results revealed the following interesting differences with respect to outcomes of NSD that had met with low agreement by the participants.

6.2.4.1 Has clarified my own standpoint

Overall, 60% of the respondents thought that NSD contributed to a clarification of their standpoint. In detail, 9% agreed very much, 29% agreed, and 22% tended towards agreement; the mean was 3,13.

However, there were significant differences between Austria, Germany and Spain with regard to this question. 79% of the Spanish participants agreed that NSD contributed to a clarification of their standpoint, and 67% of the German participants also expressed agreement. In Austria, however, only 33% of the respondents agreed with this statement. The Pearson chi-square showed a significance of 0,014.

There were also significant differences between individual groups (Pearson chi-square 0,001). In four groups of our sample more than 70% of the participants agreed that they had experienced a clarification of their standpoint (SP1 72%, A1 75%, D2 78% SP1 88%), but in one group the share of persons having experienced clarification of their standpoint was much lower (D1: 56%) and in another group none of the participants reported such clarification (A2).

In the group of respondents who discussed xenotransplantation for the first time during NSD, the share of persons who experienced a clarification of their standpoint was higher than in the group of persons who had previously discussed this topic (73% versus 48%). This difference, however, was not significant.

There were also no significant differences between groups differentiated by closeness to xenotransplantation, or by gender, or by attitude towards xenotransplantation.

Neither was there any significant difference between groups of perfectly, sufficiently and somewhat informed participants. But the share of somewhat informed persons who clarified their standpoint through NSD was clearly higher than the shares of perfectly and sufficiently informed persons (83% compared with 63% and 46%, respectively).

The relative share of persons who clarified their standpoint was higher in the group of scientists, but this difference was not significant (69% versus (52%).

6.2.4.2 Has given me new insights about the subject of xenotransplantation

58% of the respondents agreed with the statement that they had received new insights into the issue of xenotransplantation (16% agreed very much, 15% agreed and another 27% tended towards agreement, mean 3,20).

There were significant differences with respect to new insights into the issue of xenotransplantation among the three participating countries and also between different dialogues, as well as with respect to previous participation in xenotransplantation discussions, relatedness to xenotransplantation and attitude towards xenotransplantation.

Whereas in Spain 79% of the participants thought that they had received new insights into xenotransplantation, in Austria the respective share was only 56% and in Germany 39% (Pearson chi-square 0,046).

Again, there were differences between individual dialogues. In half of the dialogues a large majority of participants thought they had received new insights into xenotransplantation (A1 88%, SP1 82%, SP 75%), whereas in the other half of the dialogues only a minority held this opinion (D2 44%, D1 33%, A2 30%, Pearson chi-square 0,028).

Persons without previous xenotransplantation discussion experience stated significantly more often (77%) than others (41%) that they had received new insights into this subject (Pearson chi-square 0,008).

The relation between connection to xenotransplantation and new insights does not reveal a clear trend. On the one hand, 83% of those with little and 67% of those with no connection to the topic stated that they had received new insights. On the other hand, also 63% of the closely xenotransplantation-related participants agreed that they had received new insights. In the group with medium relatedness to xenotransplantation, only 35% agreed that they had received new insights into this subject.

The share of people who had gained new insights into the topic was also higher in the group of somewhat informed participants (75%) than among sufficiently informed NSD participants (54%) and perfectly informed (53%) participants.

There were no big differences between advocates of and opponents to xenotransplantation (70% versus 68%), but distinctive differences between those two groups and undecided persons (25%, Pearson chi-square 0,023). Scientists/ physicians said less often than others that they had gained new insights (50% versus 65%).

6.2.4.3 Resulted in consensus on the subject of xenotransplantation

51% of the participants agreed with the statement that NSD resulted in consensus about xenotransplantation (4% agreed very much, 26% agreement, 21% tended towards agreement, 19% tended towards disagreement, 30% agreed not at all, mean 3,45).

With regard to reaching consensus, the results showed significant differences between the three countries (0,001) and different groups.

In Spain, 84% of the participants agreed that they had reached consensus to some extent, whereas the respective share was 35% in Austria and 29% in Germany.

There were also significant differences between groups. In three groups, more than 80% of the participants said that they had reached consensus to some extent (A1 86%, SP1 82%, SP2 82%), whereas in the remaining groups the respective share was much lower (A2 0%, D1 22% and D2 38%).

Participants without previous experience in xenotransplantation discussions were also significantly more positive about achieved consensus (65%) than those who had previously participated in such discussions (37%, 0,039 Pearson qui-square).

Relatedness to xenotransplantation did not significantly influence the assessment of consensus achieved. Neither did personal level of information, but the relative share of persons who thought that consensus was reached was much higher in somewhat informed participants (82%) than in sufficiently and perfectly informed ones (46% and 39%, respectively).

Women were more positive about achieved consensus (68%) than men (41%), but this difference was not significant. There were also no significant differences between participants who were in favour of, opposed to, or undecided about xenotransplantation. However, the share of persons who said that consensus had been reached was larger in the pro-group (60%), than in the undecided (40%) and the contra group (42%). Likewise, there was no significant difference between scientists and other participants. Still, scientists were less positive about achieved consensus (40%) than others (61%).

6.2.4.4 Has given a clear answer on how to deal with the problem of xenotransplantation

51% of the participants agreed to some extent with the statement that NSD gave a clear answer on how to deal with the problem of xenotransplantation (11% agreed very much, 11% agreed, 29% tended towards agreement, 20% tended towards disagreement, 29% agreed not at all, mean 3,45).

Participants in Austria, Germany and Spain differed significantly (0,039 Pearson chi-square) in answering the question whether NSD gave a clear answer on how to deal with the problem xenotransplantation. In Germany, only 33% of the participants agreed with this statement, in Austria the share was 44%, while in Spain the respective share was much higher with 74%.

There were also significant differences between the groups (0,037 Pearson chi-square). The share of participants who thought that a clear answer had been given on how to deal with xenotransplantation was low in three groups (A1 20%, D1 and D2 33%, each) and high in the remaining groups (75% in A1 and SP2, 72% in SP1).

The share of persons who agreed about provision of a clear answer to the problem was higher among persons who had previously participated in a xenotransplantation discussion (73%) than among persons who had not done so (48%). This difference was close to significance (0,054 Fischer's exact Test).

There was no significant difference between groups with different closeness to xenotransplantation, but people with medium relatedness to xenotransplantation agreed least often with the statement that they had received a clear answer (40%, versus 68% strong connection, 75% little connection, 67% no connection).

There was also no significant difference between groups with different levels of information about the topic, but in our sample the share of persons who said that they had received a clear answer on how to deal with xenotransplantation was higher in the group of somewhat informed participants (75%) than in the group of perfectly and sufficiently informed persons (42% and 47%, respectively).

There were no significant differences between men and women, as well as between scientists and others in our sample. However, advocates of xenotransplantation were more often of the opinion that they had reached a clear answer on to deal with xenotransplantation than opponents (25%) and undecided persons (33%, 0,011 Pearson chi-square).

6.2.4.5 Enabled me to convince others about my own point of view

Altogether 70% of the participants agreed to some extent that they had been able to convince other NSD participants about their own points of view. However, this share included 18% who agreed with

the statement and 52% who tended towards agreement, while 26% tended towards disagreement and 4% did not agree at all (mean 3,15).

There were significant differences between countries, different groups, participants who took part in previous xenotransplantation discussions or did not, groups with different knowledge, attitude or relatedness to xenotransplantation, as well as between men and women and different stakeholders.

In our sample, the share of participants who thought they had been able to convince other participants was highest in dialogue SP1 (88%), followed by the NSDs A1 (86%), A2 (70%) and D1 (68%). 61% of previous participants in xenotransplantation discussions agreed about having convinced the other NSD participants, while of those who had not previously discussed xenotransplantation 81% agreed that they had convinced the others. 68% of persons very closely related to xenotransplantation thought that they had been able to convince the other NSD group members. The respective share among those with moderate xenotransplantation relatedness was 63%, 83% among those with little xenotransplantation relatedness and 100% among those with no xenotransplantation relatedness. 90 % of persons having little information about xenotransplantation thought that they had convinced other participants, whereas 74% of the perfectly informed ones and 58% of the sufficiently informed ones held this opinion. The share of men who thought they had convinced other people was lower than the respective women's share (69% versus 74%).

6.2.4.6 Provided me with new information about xenotransplantation

36% of the participants agreed to some extent that NSD brought them new information about xenotransplantation (11% agreed very much, 16% agreed, 9% tended towards agreement, 22% tended towards disagreement, 42% agreed not at all; mean 3,67).

There were significant differences with regard to provision of new information between countries (Pearson qui-square 0,004) and groups (Pearson qui-square 0,004). In Germany, only 11% of NSD participants said that they had received new information. In Austria, 33% of the participants said they had gained new information, but in Spain the respective share was much higher with 63%. In half of all dialogues, a majority of participants said that they had received new information (SP1 75%, A1 63% and SP2 55%), whereas in the other half this was almost not the case (A2 10%, D1 and D2 11% each).

There were also significant differences with regard to previous participation in xenotransplantation discussions (0,000 Pearson qui-square). 62% of persons without previous participation in xenotransplantation discussion said they received new information, whereas in the group with previous xenotransplantation discussion experience the respective share was only 14%.

Moreover, there were significant differences regarding relatedness to xenotransplantation (0,020 Pearson chi-square). 15% of persons with moderate relatedness to xenotransplantation said that they

received new information. The respective share was 37% in those with strong xenotransplantation relatedness and 67% each with little or no relatedness to the topic.

Likewise there was a significant difference with regard to level of information (0,007 Pearson chi-square). 75% of persons with little information about xenotransplantation said they had received new information about the subject of xenotransplantation, whereas the respective share was 26% and 25% among perfectly and sufficiently informed participants, respectively. There were no significant differences with regard to gender, different attitudes towards xenotransplantation and scientists/ others.

6.2.4.7 Has made me change my attitude towards ethical problems of xenotransplantation

Only 35% of the participants said that they changed their attitude towards ethical problems of xenotransplantation (4% agreed very much, 11% agreed, 20% tended towards agreement, 20% tended towards disagreement and 29% disagreed, mean 3,84).

The countries represented in our sample differed significantly with regard to changes in attitude towards xenotransplantation (0,03 Pearson chi-square). Whereas in Spain 58% of the participants agreed that they had changed their attitude towards xenotransplantation, this applied to only 22% of the Austrian and German participants, respectively.

There were no significant differences between groups regarding change in attitude towards xenotransplantation, but the two Spanish groups had higher shares of persons who had changed their attitude (SP1 50%, SP2 64%) than all the other groups in Austria and Germany (A1 38%, D1 and D2 22% each, A2 10% agreement).

There were significant differences between persons who had previously participated in a xenotransplantation discussion and those who had not (0,004 Pearson chi-square). Whereas 54% of those who had not taken part in an xenotransplantation discussion before agreed that their attitude had changed, the respective share was only 17% among the ones without previous xenotransplantation discussion experience.

Notably, somewhat informed participants changed their attitudes significantly (0,049 Pearson chi-square) more often (58%) than sufficiently informed ones (38%) and perfectly informed ones (16%). There was no significant difference between scientists and others, men and women, and persons with differing attitudes towards xenotransplantation and differing connection with this topic. However, in our sample, advocates of xenotransplantation changed their attitude more often (43%) than undecided persons and opponents (25% each).

6.3 Changes in attitude

6.3.1 Attitude towards xenotransplantation

A total of seven persons, or 13% of all NSD participants, said that they changed their attitude towards xenotransplantation; while the large majority of 48 participants, or 87%, said that their attitude did not change through NSD.

There were significant differences between the three countries in this respect (Pearson chi-square 0,008). In Austria, only one person, or 6% of the participants, changed his or her mind about xenotransplantation and in Germany no such change happened.

By contrast, in Spain, six persons or 32% of the participants did change their opinion about xenotransplantation during or after NSD (Table 64). In the first dialogue one person changed his/her mind about xenotransplantation, becoming more positive of xenotransplantation. In the second dialogue participants who changed their mind stated, said e.g.: NSD had helped them to formulate a judgement, that it enlarged their knowledge base and helped to look at xenotransplantation from one's own beliefs, that it provided more and richer information with more perspectives, that technical experts could not be the ones to take risky decisions. One participant said, that s/he started to look at xenotransplantation as a global problem (Santos et al. 2003b: 83).

There were also significant differences between different NSD groups (0,012 Pearson chi-square). Whereas in the two German NSDs and in the second Austrian dialogue none of the participants changed their standpoint, 13% of the participants in A1 and SP1 did do so. The share of people changing their opinion about xenotransplantation was particularly high in the second Spanish dialogue (46%, Table 65). People who had participated in a xenotransplantation discussion before changed their mind significantly less often than people who had not (Pearson chi-square 0,03, Table 66).

Table 67 shows that with the exception of "moderately related" persons, the share of people who changed their mind about xenotransplantation increased with decreasing closeness to the topic. Also, groups with different information level differed with regard to changes in opinion. In general, persons with little information changed their mind more often (Table 68). Participants in favour of xenotransplantation changed their mind about it more often than xenotransplantation opponents or undecided persons (Table 69), scientists changed their mind slightly more often than others (Table 70), women a little more often than men (Table 71). But none of these differences were significant.

Table 64: Change of attitude towards xenotransplantation by country in %[44]

	Change	Did not change	Total
Austria	5,6	94,4	100
Germany	0	100	100
Spain	31,6	68,4	100
All countries	12,7	87,3	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 65: Change of attitude towards xenotransplantation by NSD in %

	Change	Did not change	Total
A1	12,5	87,5	100
A2	0	100	100
D1	0	100	100
D2	0	100	100
SP1	12,5	87,5	100
SP2	45,5	54,5	100
All NSDs	12,7	87,3	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 66: Change of attitude towards xenotransplantation by previous participation in xenotransplantation discussions in %

	Change	Did not change	Total
Yes	0	100	100
No	26,9	73,1	100
All participants	12,7	87,3	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

[44] Participation in this NSD has changed my attitude towards and opinion on xenotransplantation (yes, no)

Table 67: Change of attitude towards xenotransplantation by relatedness to xenotransplantation in %

	Change	Did not change	Total
Very closely related	10,5	89,5	100
Moderately related	10,0	90,0	100
Hardly related	16,7	83,3	100
Not at all related	33,3	66,7	100
All participants	13,0	87,0	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 68: Change of attitude towards xenotransplantation by level of information in %

	Change	Did not change	Total
Perfectly informed	5,3	94,7	100
Sufficiently informed	12,5	87,5	100
Somewhat informed	25,0	75,0	100
All participants	12,7	87,3	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 69: Change of attitude towards xenotransplantation by attitude towards xenotransplantation in %

	Change	Did not change	Total
Pro	20,0	80,0	100
Undecided	0	100,0	100
Contra	8,3	91,7	100
All participants	13,0	87,0	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 70: Change of attitude towards xenotransplantation by scientists/ others in %

	Change	Did not change	Total
Scientists (physicians)	15,4	84,6	100
Others	10,3	89,7	100
All participants	12,7	87,3	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 71: Change of attitude towards xenotransplantation by gender in %

	Change	Did not change	Total
Male	11,4	88,6	100
Female	15,8	84,2	100
All participants	12,7	87,3	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

6.3.2 Other participants

In contrast to changes of opinion regarding xenotransplantation, many more people changed their opinion about other participants. Altogether, 23 of the participants, or 42%, changed their attitude towards and opinion about other participants.

By countries, Germany was the country where most participants changed their mind about other group members (67%), followed by Austria with only one-third of participants, and Spain with slightly more than one-quarter of the participants.

The share of persons who changed their opinion about others was much larger among those who were opposed to xenotransplantation at the start of the dialogues (83%) than among xenotransplantation advocates (33%), or undecided persons (25%).

The NSDs differed with regard to changes in attitude towards other participants. In the German dialogues D1 and D2, 67% of the participants changed their opinion about other group members, while in A1 this share was 50%, and in SP1 38%. The Austrian dialogue A2 and the Spanish dialogue SP2 had the lowest shares of participants changing their opinion about others, with 18% and 20%, respectively.

By contrast, there was not much difference between participants with differing closeness to xenotransplantation. The fact that people who were not at all related to xenotransplantation did not change their opinion seems plausible, since they probably had no opinion about others before NSD.

There were also only small differences between groups with differing levels of information about xenotransplantation. 47% of perfectly informed persons changed their opinion. The respective share among sufficiently informed ones was 38% and 42% among the somewhat informed ones. The share of scientists who changed their opinion about other participants was only slightly higher than that of non-scientists (46% versus 38%). This was also the case with people who had previously participated in xenotransplantation discussions (45% versus 38%).

Table 72: Change of attitude towards other participants by country in %[45]

	Change	Did not change	Missing value	Total
Austria	33,3	61,1	5,6	100
Germany	66,7	27,8	5,6	100
Spain	26,3	73,7	0	100
All countries	41,8	54,5	3,6	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 73: Change of attitude towards other participants by NSD in %

	Change	Did not change	Missing value	Total
A1	50,0	37,5	12,5	100
A2	20,0	80,0	0	100
D1	67,7	33,3	0	100
D2	67,7	22,2	11,1	100
SP1	37,5	62,5	0	100
SP2	18,2	81,8	0	100
All NSDs	41,8	54,5	3,6	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 74: Change of attitude towards other participants by relatedness to xenotransplantation in %

	Change	Did not change	Missing value	Total
Very closely related	42,1	57,9	0	100
Moderately related	45,0	45,0	10,0	100
Hardly related	41,7	58,3	0	100
Not at all related	0	100	0	100
All participants	40,7	55,6	3,7	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

[45] Participation in this NSD has changed my attitude towards and opinion on other participants. (yes, no)

Table 75: Change of attitude towards other participants by level of information in %

	Change	Did not change	Missing value	Total
Perfectly informed	47,4	52,6	0	100
Sufficiently informed	37,5	58,3	4,2	100
Somewhat informed	41,7	50,0	8,3	100
All participants	41,8	54,5	3,6	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 76: Change of attitude towards other participants by attitude towards xenotransplantation in %

	Change	Did not change	Missing value	Total
Pro	33,3	66,7	0	100
Undecided	25,0	58,3	16,7	100
Contra	83,3	16,7	0	100
All participants	42,6	53,7	3,7	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 77: Change of attitude towards other participants by scientists/ others in %

	Change	Did not change	Missing value	Total
Scientists (physicians)	46,2	53,8	0	100
Others	37,9	55,2	6,9	100
All participants	41,8	54,5	3,6	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 78: Change of attitude towards other participants by previous participation in xenotransplantation discussions in %

	Change	Did not change	Missing value	Total
Yes	44,8	48,3	6,9	100
No	38,5	61,5	0	100
All participants	41,8	54,5	3,6	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

Table 79: Change of attitude towards other participants by gender in %

	Change	Did not change	Missing value	Total
Male	45,7	54,3	0	100
Female	36,8	57,9	5,3	100
All participants	41,8	54,5	3,6	100

(Sources: IHS-Survey 2003, CSIC 2003, FhG-ISI 2003)

7 Conclusions

In this section we will return to the beginning of this report and to the initial goals of our project.

7.1 Raising awareness for the ethics of xenotransplantation

With XENO we attempted to raise the relevant actors' and the general public's awareness for ethical problems involved in xenotransplantation. To answer the question whether we were able to reach our goals, we will, first, discuss the relevant actors' involvement; secondly, we will deal with the participants' general assessment of the dialogues and, lastly, we will address the question to which extent it was possible to involve the general public in the project.

7.1.1 Involvement of actors

In summary, we can say that we succeeded in involving relevant actors with respect to xenotransplantation in our project. Altogether, we engaged 55 relevant xenotransplantation stakeholders in Austria, Germany and Spain in six Neo-Socratic Dialogues to deal with the ethical problems of xenotransplantation. Particularly in Germany, with its characteristic separation between the natural science cluster and the ELSA cluster, it was possible to bring together relevant actors from both clusters. The NSD participants included relevant persons from research, patient organisations, policy-makers and relevant NGOs (e.g. churches, animal welfare groups). Most of the participants were perfectly or sufficiently informed about xenotransplantation and, in general, felt to be strongly or moderately connected with the topic. Their motivation to participate mainly came from their interest in xenotransplantation, in the NSD method and in a debate on ethical problems of xenotransplantation.

The dialogues involved people with diverging opinions about xenotransplantation. Altogether, 55% of the participants approved of xenotransplantation, 15% were undecided and 30% disapproved of xenotransplantation. The arguments in favour of xenotransplantation most often confirmed by the participants were improvement of patients' quality of life (66% approval), solution to organ shortage (62% approval), and removing the reasons for organ trade (50% approval). Arguments against xenotransplantation met the approval of a minority of participants only. Strongest approval of such arguments was expressed regarding infection risk (49% approval), genetic modification of donor animals (45%), and potential restriction of civil rights (38%). Animal welfare arguments against xenotransplantation were important for only a small minority. Contra arguments relating to national or international allocation problems in health financing, too, were only considered valid by a 1/3 minority. The same was true for potential psychological problems experienced by xenograft recipients.

Contrasting these overall figures, Austria, Germany and Spain, as well as the individual dialogues, differed with regard to the participants' connection with the topic, their level of information and opinions about xenotransplantation. On average, the German participants were the most strongly related,

informed and sceptical ones. The Austrian participants took a middle position regarding their relatedness to xenotransplantation, their information level and their attitude towards xenotransplantation, being less sceptical than the German participants. The Spanish participants were almost unanimously optimistic about xenotransplantation, but on average least related to and informed about the topic.

7.1.2 General assessment of the event by the participants

Looking at the overall figures, the participants evaluated NSD very positively.

- 86% said that their expectations were either surpassed, met or rather met.
- 29% marked the Dialogue as excellent, 56% as fair and 9% as satisfactory.
- 62% would recommend NSD, and an additional 31% would recommend NSD with certain reservations.
- 74% agreed that the results were useful for their professional or voluntary environment, including 15% of the participants who said that the results were very useful, 59% that they were useful.
- Finally a great majority of 82% agreed that the NSD method would be useful in their professional or voluntary activities with respect to resolving ethical questions connected with xenotransplantation. This share includes 20% who considered the method as very useful and 62% who evaluated the method as rather useful.

A comparative look at Austria, Germany and Spain shows differences between the three countries: The German participants stated most often that their expectations were met; they marked the NSDs most favourably; were second in their willingness to recommend NSD and in their appreciation of the usefulness of NSD results; they were first in their positive assessment of the usefulness of the NSD method of discussing xenotransplantation problems in their work environment. The Spanish participants took a middle position in all these respects, with the exception of usefulness of results. The Austrian participants were positioned at the other end of the scale in our sample of three countries: in Austria the highest share of participants stated that their expectations were not met; the Austrian participants marked NSD less favourably than was the case in the other two countries, and the Austrians evaluated NSD results and the NSD method less positively than their Spanish and German colleagues. These more negative results are primarily due to the more sceptical average evaluation of the second Austrian dialogue.

The positive assessments of NSD as communication tool as well as the participants' willingness to recommend NSD to interested colleagues reflect the participants' satisfaction. Our results show that NSD is a suitable communication method to make ethical principles underlying the arguments of

xenotransplantation supporters and xenotransplantation opponents more transparent and plausible to the respective opposite side.

7.1.3 Involvement of the general public

If we understand public debate on ethical problems connected with xenotransplantation exclusively as a form of discussion with a big audience conducted over a short period of time, then clearly our project was a failure. However, by contrast, we suggest to define "public debate" as all formal and informal, intended and unintended communication about an issue occurring on different levels of society (e.g. expert discourse, politics, mass media, everyday conversations), in different forums (e.g. conferences, workshops, NSDs, citizen conferences, round tables) and with differing numbers of participants (Zimmer et al. 2003: 49).

Following this definition, NSD is not appropriate for each discussion forum on each level. Because of its need for small groups and its slow process, NSD is an inappropriate method for discourse processes involving a large number of participants and a high degree of publicity. NSD is a method that must take place within a protected area, as one participant put it; and it will only work in small groups. But it is possible to include key especially persons, who will act as multipliers, introducing NSD results to their own and/or to other organisations, as well as to the general public. In our project, we also attempted to involve representatives of stakeholder groups that are normally excluded from decision-making processes on technologies, e.g. patient representatives and animal welfare groups.

7.2 To discuss the ethics of xenotransplantation

With respect to the question whether it was possible to discuss the ethics of xenotransplantation, we suggest, for analytical reasons, to distinguish between process- and content-related aspects in particular dialogues.

7.2.1 Process-related issues

Looking at process-related aspects, NSD received very positive evaluations by its participants. All participants said that they became acquainted with NSD and with a different form of discussion. Moreover, all participants agreed that they experienced an egalitarian dialogue, a relaxed atmosphere conducive to an exchange of views. More than 95% of the respondents experienced other participants' interest in the topic, a high-quality and clearly structured discussion, and that other participants referred to their arguments. 96% of the respondents had the feeling that the other participants listened to them and tried to understand them. More than 90% thought that NSD created tolerance towards other people's points of view; that they met other people and learned something about their points of view; that they had time and the possibility to consider an ethical problem. 85% of the participants stated that they had an exciting discussion on the subject.

The evaluation showed that NSD was particularly helpful in creating an open and clear structure for discussing the ethical basis of xenotransplantation. In such a framework, NSD can be fruitful for: dissolving deadlocked debates and confrontations, making a debate more objective and uninfluenced by emotions and prejudices, becoming sensitive to and capable of intellectually grasping basic ethical principles, values and interests. A participant said: *"NSD is a good possibility for bringing contrary positions into a constructive dialogue"* (Zimmer et al. 2003: 49).

7.2.2 Content-related issues

Compared with the very good results regarding process-related aspects, the participants evaluated content-related items less favourably. Still, 58% of them stated that NSD had given them new insights into xenotransplantation. But this cumulative percentage includes only 16% who agreed very much, 14% who agreed and a large share of 27% who tended towards agreement (mean 3,20). A comparatively small share of 36% thought that the dialogue provided new information about xenotransplantation (11% very much agreement, 16% agreement, 9% tended towards agreement, mean 3,67).

This less favourable assessment was caused by several factors. First, it was not possible in most of the dialogues to complete the transfer of the basic principle derived from the dialogue on the everyday example to the topic of xenotransplantation. This was, in most cases, due to shortage of time (Griessler et al. 2003a, Zimmer et al. 2003, Santos et al 2003b). However, in the second Austrian dialogue this transfer was not accomplished because of strong resistance by leading group members against the NSD method (Griessler et al. 2003a). The project results clearly show that more time is necessary for the transfer phase. Moreover, as could be seen in the first Austrian dialogue, more specific expert input is necessary to address the detailed questions that might arise in the transfer phase (e.g. health economics).

The low assessment of content-related aspects of NSD might also be connected with the high level of expertise regarding xenotransplantation within the groups. The evaluation showed that participants with different information levels about xenotransplantation assessed content-related items differently. Somewhat informed people received new insights about the issue of xenotransplantation more often, and received new information more often, than perfectly or sufficiently informed participants. These results indicate that NSD is also useful for conveying information to less informed participants.

7.3 Clarification of various actors' responsibilities regarding the ethics of xenotransplantation

The first step in clarifying various actors' responsibilities is acknowledgement of such a responsibility. This is revealed by their willingness to participate in a discussion devoted to the ethics of xenotransplantation, such as NSD. Although we had certain problems in recruiting all stakeholders

originally contacted, eventually a sufficiently large number of relevant stakeholders were ready to participate in XENO and to discuss ethical problems of xenotransplantation.

We asked the participants a number of questions intended to clarify the responsibilities of the actors. One of them was whether the respondents thought that NSD contributed to a clarification of their standpoint. 60% agreed with this statement, including 9% who agreed very much, 29% who agreed and 22% who tended towards agreement (mean 3,13). In Spain and Germany the share of agreement was higher than average (79% and 67%, respectively), but in Austria the share of persons who clarified their standpoint was particularly low (33%). In four groups the share of persons who reported a clarification of their standpoint ranged between 70% and 88%, but in one group this share was lower with 56% and in one group zero. People who had not participated in any xenotransplantation discussion before taking part in NSD, as well as respondents who were only somewhat informed about the topic, clarified their standpoint more often than others.

Only 35% of the participants experienced a change in their personal attitude towards ethical problems of xenotransplantation (4% very much agreement, 11% agreement, 20% tended towards agreement, mean 3,84). The share of people who changed their mind about xenotransplantation was highest in Spain (58% versus 22% in Austria and Germany). Participants without experience in xenotransplantation changed their mind more often than others (54% versus 17%). The same was true form somewhat informed participants (43% versus 25%).

Clarification of responsibilities also implies that the results of NSD were useful for the participants' professional activities. Almost three quarters of the participants agreed that the results were useful in their professional or voluntary environments (74%), including 15% of the participants who said that the results were very useful, 59% that they were useful. This share was particularly high in Spain and Germany, but not in Austria (the second Austrian dialogue being the exception to the relatively positive results).

Although a considerable share of participants agreed that they clarified their standpoint to some extent and thought that the results were useful for their work, the evaluation results clearly show that there is room for improvement regarding content-related aspects of the dialogues.

7.4 To inform decision makers about the ethical basis and consequences of xenotransplantation

In order to inform decision makers about the ethical basis and consequences of xenotransplantation, we pursued a two-way strategy. On the one hand, we informed decision makers directly, as some NSD participants were in influential positions regarding xenotransplantation in their respective fields of activity. They will be informed about the final results.

Since transfer of NSD results to the topic of xenotransplantation was achieved only partially in most dialogues, we changed our dissemination strategy somewhat, focusing on dissemination to the respective actors in xenotransplantation, as well as in science and technology. This dissemination process will also continue after the formal conclusion of the project. A list of presentations given so far can be found in the appendix.

7.5 Consensual policy options regarding ethical problems of xenotransplantation

As reflected by this report, consensual policy options could only be defined in very general terms. The principles agreed upon give orientation in a weak manner only. More time would have been needed to transfer the derived basic principles to the multifaceted problem of xenotransplantation.

51% of the respondents said that NSD resulted in consensus on the subject of xenotransplantation. The share of people who agreed very much with this statement was very small with 4%. 26% agreed with this statement and 21% tended towards agreement (mean 3,45). Clearly, the share of people who thought that consensus was reached was much higher in Spain with 84%, because there were almost no opponents of xenotransplantation in Spain. In Austria and Germany the share was much lower with 35% and 29%, respectively. But there was also the first Austrian dialogue, in which 86% of the participants thought that consensus was reached. Participants without previous experience in xenotransplantation discussions were more positive about consensus reached than participants who did have such experience. The same was true for somewhat informed participants.

For another 51% of the participants, NSD gave a clear answer on how to deal with the problem of xenotransplantation (11% very much agreement, 11% agreement, 29% tended towards agreement, mean 3,45). Again, in Spain, where participants agreed almost unanimously on xenotransplantation, almost three quarters of the respondents agreed that they received a clear answer. In Germany and Austria this share was distinctly smaller (33% and 44%, respectively). But there was also the first Austrian dialogue in which 75% of the participants thought that they received a clear answer. Again, persons without previous xenotransplantation discussion experience (73%), and somewhat informed participants (75%) were more positive than others.

7.6 Improvement of communication patterns and capability of coping with ethical questions arising from modern science and technology

The participants had relatively high expectations regarding communication when they agreed to take part in NSD. They hoped that NSD would enable a different kind of discussion, differing from the usual confrontational forms. The participants also expected to learn how to communicate with other people, especially with opponents, and to improve their personal communicative patterns and capabilities.

After the respective dialogues, the majority stated that they had been able to improve their capabilities regarding interpersonal communication. More detailed analysis showed that the participants had experienced a dialogue that was egalitarian for all participants, enabled them to listen to their dialogue partners, to refer to other participants' arguments, to understand other persons' opinions, and to tolerate other opinions

The participants also learned to question their own positions as well as other participants' positions. It was thus possible, through NSD, to improve the communicative patterns and capabilities of actors in the field, helping them to cope with ethical questions arising from modern science and technology. Using one specific everyday example, they were able to discuss it without prejudices in a trustful atmosphere. Additionally, some participants stated that they intended to incorporate some NSD elements into their everyday practice.

7.7 Final conclusions

The project succeeded in bringing together relevant, informed and concerned actors regarding xenotransplantation, for a dialogue on the ethical problems connected with this technology. Advocates, opponents as well as undecided persons participated in the dialogues. In retrospect, it turned out not to be a matter of course to make participants spend an evening plus a whole day on deliberations about ethics. Thus, there was a certain paradox concerning available time: on the one hand, several participants wished to have had more time for discussing the respective issues exhaustively and seriously, but on the other hand we also learned that it is hard to find persons willing to discuss a certain moral issue for as much as one evening plus one day.

The evaluation results allow the conclusion that NSD is a suitable instrument for discussions among stakeholders about ethical problems of xenotransplantation, and that NSD will probably also be suitable for dialogues about other controversial technologies. Overall, the participants assessed the project very favourably. They were very positive in their evaluations about the respective groups, about the moderation, as well as about process-related aspects. They were less positive about content-related aspects of the debate, mainly because transfer of the dialogue method to the topic of xenotransplantation was accomplished only partially.

As the respondents' overall assessment clearly shows, in principle NSD is appropriate to facilitate discussion among experts and laypersons about ethical aspects of modern science and technology. The use of NSD can be very fruitful, especially if rigid opposing fronts have already formed or are likely to form because the issue is very controversial. By extracting ethical principles from everyday examples and not from the controversial technology itself, open-minded discussion among stakeholders with differing opinions is possible. Therefore, NSD is able to function as a confidence-building measure.

The particular strength of the NSD method lies in interpersonal communication. Through collective discussion of an everyday example, the participants came to know their opponents in a new manner. The NSD participants experienced that it was possible to discuss something in a rational way and to arrive at common ethical principles. After participation in NSD, ethical principles were no longer abstract, but extracted from experiences that everyone had had in their everyday lives. Ethical principles deduced from one's own personal experience are likely to have a greater impact on action than those one simply reads about in a textbook.

Another important characteristic of NSD is that stakeholders or experts are forced to think in the way common citizens do. Normally, experts immediately begin discussing an issue against the background of their specific expert cultures. In NSD, they have to take a personal stand on general moral principles. They have to find out on which ethical principles their personal decisions or actions are normally based.

In this project, for the first time, the NSD method was extended by an additional step. The attempt was made to transfer or apply the extracted ethical principles to a specific technology, in this case, xenotransplantation. This attempt was successful to a limited extent only. Nevertheless, such transfer seems to be possible and reasonable. The fact that this step could not be completed in most of the dialogues must be attributed to lack of time. Transfer of ethical principles to xenotransplantation would require a full day in addition.

In order to establish the right balance between NSD and transfer to the issue of xenotransplantation, one would need enough time for expert input (e.g. on immunology, health economics, patient rights, animal breeding and husbandry respecting the needs of different species). In this sense, the project was both too ambitious and not ambitious enough at the same time. It tuned out that we need discussion both on "hard facts" and on "ethical questions". The focus on "ethical questions" proved to be too narrow. Embedding NSD in an overall technology assessment exercise could perhaps solve this problem.

Our project also showed that one single NSD is not sufficient to deal with a subject like xenotransplantation. The ethical principles extracted from the discussed everyday examples turned out to be insufficient to cover a topic as complex and controversial as xenotransplantation in general. Other important concerns (e. g. animal rights) would have to be extracted from everyday examples in future NSDs. In this way, the participants could gradually develop a range of principles they personally consider important in analysing ethical problems connected with xenotransplantation.

The evaluation showed clearly that some dialogues worked better than the others. Further research would be needed to find out what was responsible for those differences. One factor, surely, is group composition, e.g. whether there is strong knowledge asymmetry among participants. Moreover, NSD depends on the participants' acceptance of the method and on certain personal qualities in them. NSD participants must have certain personal qualities and skills. It requires what one could call "open-mindedness" by the participants, i.e. willingness to reveal and to evaluate their own standpoints and

values on the basis of their own experiences, and not according to "textbook" theories. Furthermore, the participants must be willing to answer ethical questions on their own account, and not by transferring responsibility to some anonymous authority such as "human society". This is totally different from the usual conception of professional expertise and not a "natural" process. Acceptance of the NSD method by the participants is indispensable. In our project, some participants did not accept the basic idea of NSD. Instead, they called for expert-oriented risk assessment, which was not the goal of our project. It is important to stress that NSD on the ethics of xenotransplantation is not a discussion on risk assessment, but a dialogue on ethical questions and problems involved in xenotransplantation. Therefore, it is necessary to start the NSD process with a short introduction on general ethical questions, e.g. *"What distinguishes ethical questions from knowledge questions and where are the differences in approaching them?"* This information is necessary since participants will not be familiar with NSD. If the basic principles of NSD are not clarified at the start, participants may get the feeling that they are being manipulated, that they are "guinea pigs" in some "sociological experiment"; they will then obstruct the dialogue by withdrawing personally, or by causing lengthy meta-discussions. NSD cannot provide instant ready-made solutions to ethical questions. Rather, it may lead on to fundamental questions about values that are usually not considered in everyday life. Ethical problems of this kind that surfaced during our dialogues were, for example: How much suffering is part of "normal" life? What does global and inter-generation equality and justice mean with respect to allocation of health expenditures? In this way, NSD can generate more questions than answers.

Just as with other new methods of participatory technology assessment, representativeness of the participants for the general population is a weak point. In our experiment, we did not attempt to choose the participants at random, rather, we tried to get at least one representative for each stakeholder group, since the restricted number of participants necessary for direct face-to-face communication strongly limits representativeness anyway.

Like other methods of participatory technology assessment, the legitimacy of such an exercise and its connection with political decision-making is not direct and unclear. Also, in our experiment, dissemination of NSD results in the participants' respective institutions was unsystematic and was left to the participants' own initiative. In future, it will be necessary to find ways of integrating NSDs in existing institutions.

8 Appendix

8.1 Dissemination activities

All reports are available on the project web site http://space.ihs.ac.at/departments/soc/xeno-pta.

8.1.1 Austria

The Austrian team presented papers on the following conferences:

„TA'02: Technikgestaltung im 21. Jahrhundert" at the Austrian Academy of Science, on May 27th 2002. Socratic Dialogue as a New Means of Participatory Technology Assessment? The case of Xenotransplantation"

International Summer Academy on Technology Studies: Technology and the Public, Inter-University Research Centre for Technology, Work and Culture, (IFZ/IFF) Graz, Deutschlandberg/Austria on July 8th 2002. „Socratic Dialogue as a New Means of Participatory Technology Assessment? The Case of Xenotransplantation"

Conference: "Ethics and Socratic Dialogue in Civic Society", organised by the Society for the Furtherance of Critical Philosophy (SFCP)/ Politisch-Philosophische Akademie (PPA). Birmingham, July, 29th 2002. "Socratic Dialogue in Civil Society. The Case of Xenotransplantation". This article has also been placed on the website of the Pantaneto Forum http://www.pantaneto.co.uk. The Pantaneto Forum aims to promote debate on how scientists communicate, with particular emphasis on how such communication can be improved through education and a better philosophical understanding of science.

Presentation on a XENO-workshop on February 22nd 2003 to the Department of Philosophy at Osaka University. "Socratic Dialogue as a New Means of Participatory Technology Assessment? The case of Xenotransplantation"

ECPR Joint Session, Edinburgh, March, 28th until April, 2nd 2003. "Multiple 'institutional voids'. Experimenting with the Neo-Socratic Dialogue for discussing the ethics of xenotransplantation"

11th Congress on Alternative to Animal Testing, Linz, September 19th until 21st Together with Franz P. Gruber (Zürich) we organized a workshop on Xenotransplantation. The Workshop included the presentation of papers from Heinrich W. Grosse (Hannover) on "Xenotransplantation aus ethisch-theologischer Sicht, Silke Schicktanz (Berlin) on "ethische Fragen der Xenotransplantation unter besonderer Berücksichtigung von tierethischen Aspekten and Beate Littig, Erich Grießler

„Xenotransplantation im Gespräch. Der neosokratische Dialog als Instrument für partizipatives Technology Assessment"

The Unifying Aspects of Cultures, Vienna, 7. – 9.11.2003, Sektion sozialverträgliche Wissenschaftskulturen. Erich Grießler/ Beate Littig: Partizipative Experimente in „institutionller Leere": neookratische Dialoge zu ethischen Fragen der Xenotransplantation.

"Wissenschaft und Technik des Lebens". Tagung der Sektion Wissenschafts- und Technikforschung in der Detuschen Gesellschaft für Soziologie in Kooperation mit dem Kulturwissenschaftlichen Institut der Humboldt-Universität zu Berlin. January, 9th to 10th and "Das Verbindende der Kulturen", Sektion "Sozialverträgliche Wissenschaftskulturen", Wien, November, 7th to 9 th.

Workshop for the Clinical Communication and a international comparative research on the policy of bioethics. Osaka University, Graduate School of Letters, February 23th to March 4th 2004.

Results of the Austrian case have been published in:

Griessler, E./ Littig, B. (2003): "Participatory Technology Assessment of Xenotransplantation: Experimenting with the Neo-Socratic Dialogue" Practical philosophy 6/2

Further publications of project results are planned.

8.1.2 Germany

The FhG-ISI team presented the project in the following forms:

Presentation of the XENO project in a debate club organised by the protestant church: Hüsing, Bärbel: Xenotransplantation – Gentechnisch veränderte Schweine als Organspender? Denk-Bar der Evangelischen Erwachsenenbildung, Karlsruhe, April 3, 2003

Presentation of the XENO project in a secondary school science club, specialising on genetic engineering: Hüsing, Bärbel, Xenotransplantation – Tiere als "Ersatzteillager"? Themenabend Xenotransplantation, Graf Eberhard-Gymnasium Bad Urach, June 20, 2003

Presentation of the XENO project in a university lecture on technology assessment: Hüsing, Bärbel: Xenotransplantation – Tiere als Organlieferanten für den Menschen? Ringvorlesung Technikfolgenabschätzung SS 2003, Universität Stuttgart, Stuttgart, June 24,2003

Presentation and podium discussion: Zimmer, René: The Neo-Socratic Dialogue as a New Instrument of the Public Understanding of Science. 2nd International Science & Society Conference „Research on the human being", Luzern, Switzerland, February 6-7, 2004

A project description was posted under the address: http://www.isi.fhg.de/bt/projekte/2a-e-sb-eu-xt.htm in February 2002 and was updated regularly. The web page was linked to the XENO project homepage, produced by the project co-ordinator.

The following project reports were published as Fraunhofer ISI reports. These reports are widely distributed among the interested scientific community, are made available through public libraries and are listed in several literature data bases. Moreover, the reports were made available as free pdf downloads via the project home page.

Hüsing, Bärbel (2003): Increasing Public Involvement in Debates on Ethical Questions of Xenotransplantation. Baseline Evaluation: Monitoring of International Developments in Xenotransplantation. Karlsruhe: Fraunhofer ISI

Hüsing, Bärbel; Zimmer, René (2003): Increasing Public Involvement in Debates on Ethical Questions of Xenotransplantation. Baseline Evaluation, National Report Germany. Karlsruhe: Fraunhofer ISI

René Zimmer, Horst Gronke, Bärbel Hüsing (2003): Evaluation of the Neo-Socratic Dialogues in Germany" as Fraunhofer ISI report

Additionally the project XENO was entered into the research project database FORIS.

8.1.3 Spain

The members of the Spanish team have been working in some activities that contributed to the dissemination of the results of the XENO project. These activities are essentially addressed to a knowledgeable public as scientists, clinicians, bioethicists, social scientists, scholars on biotechnology courses, etc. The CSIC team presented the project at the following seminars and conferences.

David Santos, *"Xenotransplantation: analysis of press contents", Seminar: "Los desafíos de la biotecnología en el mundo actual"*, Cátedra Miguel Sánchez Mazas, 12 de diciembre de 2002, Universidad del País Vasco, Vitoria-Gasteiz.

David Santos and Marta Plaza, *"Biotecnología, sociedad y opinión pública",* Máster en Ciencia, Tecnología y Sociedad, 16 de septiembre de 2003, Universidad de Salamanca, Salamanca.

David Santos and Marta Plaza, "Percepción social de la transgénesis, xenotrasplante y clonación animal", Seminar: "Transgénesis, clonación animal y xenotrasplante: aspectos científicos, éticos y jurídicos", Cátedra Interuniversitaria Fundación BBVA - Diputación Foral de Bizkaia de Derecho y Genoma Humano Universidad de Deusto, 24 y 25 de noviembre de 2003, Universidad del País Vasco/EHU, Bilbao.

The Spanish team published the following papers:

"Xenotrasplante y debate ético: un proyecto europeo", David Santos y Emilio Muñoz, Alcer, número 122, julio, agosto, septiembre, 2002, Madrid.

"Xenotransplantation, ethical issues of a challenging biomedical development", Emilio Muñoz y David Santos, Business Briefing Global Healthcare 2003, mayo 2003, Londres.

David Santos y Paolo Dordoni: "Opinión pública y debate ético-social sobre un reto de la biotecnología: los xenotrasplantes". Sistema: Opinión pública y biotecnología, Editorial Sistema, marzo 2004, Madrid.

8.2 Interview partners in Austria

Interviewed Person	Affiliation
Mr. Horst Achaz	Gesellschaft Nierentransplantierter und Dialysepatienten Österreichs
Univ.-Prof. DDr. Gottfried Brem	Institut für Tierzucht u. Genetik, Veterinärmedizinische Univ. Wien
Dr. Robert Buchacher	Profil
Dr. Walter Dohr	Wiener Patientenanwaltschaft
Mrs. Christine Ecker DGKP	Österreichischer Gesundheits- und Krankenpflegeverband
Mr. Andreas Feiertag	Der Standard
DI Reinhard Geßl	Freiland-Verband für ökologisch-tiergerechte Nutztierhaltung und gesunde Ernährung
Dr. Peter Eichler	Uniqua Personenversicherungs AG
Mag. Edith Freundorfer	AKH Wien
Mr. Fabian Friedrich	Vier Pfoten
Dkfm. Erhard P. Geisler	Pharmig
Mag. Dr. Marion Gmach	BMSG
Univ.-Prof. Dr. Kurt Grünewald	Die Grünen
Univ. Prof. Dr.Dr. Walter H. Günzburg	Institut für Virologie Veterinärmedizinische Universität Wien
Dr. Walther Helpersdorfer	Österreichische Ärztekammer
Dr. Gertrud Kalchschmid	Patientenvertretung der Tiroler Landeskrankenanstalten
Frau Elisabeth Kanert	Gesellschaft Nierentransplantierter und Dialysepatienten Österreichs
Univ.-Prof. Dr. Klaus Klaushofer	Hanuschkrankenhaus
Dr. Hans Kurz	BMSG
Dr. Jürgen M. Langenbach	Der Standard
Univ.-Prof. Dr. Günter Lorenz	Universität Innsbruck
Mag. Stephan Mildschuh	ÖBIG-Transplant
Univ.-Prof. Dr. Ferdinand Mühlbacher	AKH Wien

Mag. Markus Pasterk	BMBWK
Mag. Friederike Preschern	ÖBIG-Transplant
Univ.-Prof. Dr. Walter Pfaller	Universität Innsbruck
Dr. Erwin Rasinger	Österreichische Volkspartei
Dr. Wolfgang Schnitzel	Novartis
Dr. Eveline Schütz	Österreichischer Rundfunk
Mag. Renate Skledar	Patientenombudsfrau
Erzbischof Metropolit Michael Staikos	Ökumenischer Rat der Kirchen in Österreich
Mag. Erika Tuppy	Ökumenischer Rat der Kirchen in Österreich
Univ.-Prof. Dr. Ina Wagner	TU Wien, Institut für Gestaltungs- und Wirkungsforschung
Univ.-Prof. Dr. Thomas Wekerle	Institut für Chirurgie, Universität Wien

8.3 Interview partners in Spain

Name	Affiliation
Antonio Alonso	President of the Heart Transplanted Patients Association.
Manuel Arias	Kidney transplantation surgeon, Hospital Marqués de Valdecilla, Santander.
Victoria Camps	Professor of Moral and Political Philosophy, Universidad Autónoma de Barcelona. Expert in Bioethics.
Manuel Carrasco	Manager of "Fondo de Investigaciones Sanitarias", Ministry of Health.
María Casado	Doctor of Law, Universidad de Barcelona. Director of the Bioethics and Law Observatory.
José Antonio García	President of the Kidney Transplanted Patients Association.
Óscar Horta	Degree of Philosophy, Universidad Autónoma de Madrid. Representative of "Alternativa para la liberación animal", an animal rights activist association.
Nicolás Jouvé	Professor of Genetics, Universidad de Alcalá. This person was proposed by the Episcopal Conference.
Pablo de Lora	Professor of Law, Universidad Autónoma de Madrid. Animal rights activist.
Rafael Máñez	Responsable for the Transplants Unit, Hospital Juan Canalejo, A Coruña. Researcher on xenotransplantation.
Rafael Matesanz	Former president of the National Transplants Organization and former chairman of the Spanish Permanent National Transplant Comission.
Blanca Miranda	President of the National Transplants Organization, Ministry of Health.
Marcelo Palacios	President-founder of the International Society of Bioethcis, former member of the Spanish Parliament (1982-1996) and member of the Parliamentary Assembly of the Council of Europe (1986-1996).
Carlos Prieto	Kidney transplantation surgeon, Hospital Doce de Octubre, Madrid.
Nuria Ramírez	Journalist of the Society and Health Section, ABC.
Jorge Riechmann	Degree of Law. Representative of "Instituto sindical de trabajo, ambiente y salud", dependent on the CC.OO trade union. Animal rights activist.
Carlos Romeo Casabona	Professor of Penal Law, Universidad del País Vasco. Expert in Bioethics and author of several articles and literature about xenotransplantation.
Malén Ruiz de Elvira	Journalist of the Society and Health Section, El País.

The German FhG-ISI team did not have to carry out additional interviews but had ample information about the German xenotransplantation debate from existing literature and interviews with German xenotransplantation stakeholders they had collected for previous research projects

8.4 Literature

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8.5 Survey Quality of Life (European Commission: 2001)

Table 80: Overview on opinion, public debates and changes of regulations on xenotransplantation in selected countries

	Opinion on XTP[46]	Public debate on XTP[47]	Change of regulation on XTP[48]
Austria	No	No	Under discussion (experts)
Belgium	No	No	No data
Denmark	Yes	Yes	Yes (moratorium)
Finland	No	No	No (follows moratorium)
France	Yes	Yes	No data
Germany	No	Yes	No data
Greece	No	No	No (there is a need felt)
Ireland	No data	No	No
Italy	Yes	No	No
Luxembourg	Is in planning	Planned after the opinion	Depends on opinion
The Netherlands	Yes	Yes	No
Portugal	No	No	No
Spain	Yes	No	No
Sweden	Yes	Yes	Probably yes
United Kingdom	Yes	No	Yes

In 8 countries there is an opinion and in 6 there is none. In 9 countries there is no debate and in 6 there is none. 7 have no changes planned, 3 countries there is no data, 3 countries are considering a change and 2 countries changed their law (moratorium and setting up an regulatory body).

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[46] Has your National Ethics Committee or similar body provided an opinion on xenotransplantation?
[47] Will (or has) a public debate take(n) place on xenotransplantation?
[48] Could you please indicate if any new legal and/or regulatory framework for xenotransplantation is under preparation?

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Projektbericht/Research Report

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