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[2] The home page of the website should contain the generic European flag and the FP7 logo which are available in electronic format at the Europa website (logo of the European flag: http://europa.eu/abc/symbols/emblem/index_en.htm logo of the 7th FP: http://ec.europa.eu/research/fp7/index_en.cfm?pg=logos). The area of activity of the project should also be mentioned.

Final publishable summary report

Executive summary

CIT-PART comparatively studied the use and impact of participatory technology assessment (PTA) and expert based technology assessment (TA) in science and technology policy in several EU Member States and organizations such as Austria (AT), Denmark (DK), Great Britain (GB), Italy (IT), Latvia (LV), The Netherlands (NL), Sweden (SE), the European Commission (EC), the OECD, Canada (CA), Switzerland (CH) and The Holy See (VA).

The main research questions were:

- To what extent was TA and PTA used?
- Which factors facilitated and constrained PTA?
- What was the impact of TA and PTA on policy-making?
- How can PTA increase citizen participation on decision-making?

CIT-PART studied these questions by taking xenotransplantation policies in the 1990s and early 2000s as an example. Xenotransplantation involves the transplantation of cells, tissues and organs from animals to humans. It is representative of many contemporary technologies in the sense that it is a complex problem, possibly with huge potential benefits, on the one hand, but also risks and ethical challenges on the other. It is therefore potentially controversial in public.

The CIT-PART consortium identified a great variety between the cases:

- Diversity of xenotransplantation policies ranging from permissive (most often), to restrictive and wait and see
- There was a great diversity of framing, but organ shortage and risk often dominated discussion
- Expert advice dominated policy development
- Experts and civil servants were critical actors in policy development, particularly on the level of influential international organisations
- In general the public had a weak role.
- There was little direct but a variety of broader impact of PTA exercises
- However, also impact of expert TA varied
- A number of facilitating and constraining factors could be identified

Based on research results CIT-PART formulated several recommendations:

- Use of PTA should be increased
- Citizen involvement should be at the heart of framing.
- Broad framing should be allowed for
- PTA needs an addressee in policy-making
- PTA should be embedded in institutions to allow for learning
- Existing participatory traditions and practices should be built on
- International examples to identify and overcome factors constraining PTA can provide valuable lessons
- Impact should be planned
- PTA needs time which should be allowed for

Summary description of project context and objectives

Objective of the research

CIT-PART comparatively studied the use and impact of participatory technology assessment (PTA) and expert based technology assessment (TA) in science and technology policy in several EU Member States and organizations such as Austria (AT), Denmark (DK), Great Britain (GB), Italy (IT), Latvia (LV), The Netherlands (NL), Sweden (SE), the European Commission (EC), the OECD, Canada (CA), Switzerland (CH) and The Holy See (VA).

In contrast to existing comparative studies on PTA, CIT-PART compared the use and impact of TA and PTA in the context of the same technology.

The main questions were:

- To what extent was TA and PTA used?
- Which factors facilitated and constrained PTA?
- What was the impact of TA and PTA on policy-making?
- How can PTA increase citizen participation on decision-making?

CIT-PART studied these questions by taking xenotransplantation policies in the 1990s and early 2000s as an example. Xenotransplantation involves the transplantation of cells, tissues and organs from animals to humans. It is representative of many contemporary technologies in the sense that it is a complex problem, possibly with huge potential benefits, on the one hand, but also risks and ethical challenges on the other. It is therefore potentially controversial in public.

Work performed

In addition to wide-ranging analysis of literature and policy-documents, 135 in-depth interviews were carried out at the national and international level with policy-makers, experts, stakeholders and representatives of NGOs involved in TA and PTA

CIT-PART included three phases:

1. Mapping the field including (a) analysis of democracy theory in order to obtain models and instruments of democratic participation, (b) overview on policies on xenotransplantation and the procedures upon which they were based as well as on public attitudes towards xenotransplantation, (c) classification of xenotransplantation policies.

2. Case studies. In-depth case studies of xenotransplantation policies, as well as the use of TA and PTA therein, of selected countries and international organisations.

3. Comparative Analysis.

Main results achieved

Diversity of policies

In the early 2000s, a diversity of xenotransplantation policies existed across Europe. They ranged from a wait and see position, in which no particular policies were formulated (AT), to permissive

ones, which allowed clinical trials following approval by responsible authorities (EC, IT, LV, OECD, CH, GB, VA), to formal and informal moratoria on clinical trials (CA, DK, NL, SE).

Expert advice dominates

Expert TA dominated policy advice on xenotransplantation policies. Only a small minority of governments commissioned PTA to involve the public (CA, CH, NL). In some cases, academics initiated participatory exercises (AT, EC, and GB). These had no direct impact on decision-making in xenotransplantation policies.

Experts and civil servants are critical actors

In almost all of our cases, civil servants and experts were "the" critical actors in policy development. Elected politicians only contributed to policy making in a few countries (CA, CH, DK; NL, SE). Despite the fact that reports repeatedly mentioned ethical issues as critical, ethicists – either in the form of national ethics committees or single experts involved in TA and PTA - played a lesser role and only became strongly involved in a few cases (UK, CA, and VA). NGOs also became involved in only a few countries (GB, CA, CH, and NL). Particularly animal welfare organisations faced difficulties to participate. In some cases, there was almost no public involvement beyond information being made public (AT, IT, LV, VA, OECD). By contrast, industry and science were able to considerably contribute as stakeholders to policy development. Citizens only became actively involved in xenotransplantation policies in a minority of countries (CA, CH, and NL).

Diversity of framing, but organ shortage and risk often dominate

First, xenotransplantation was not a controversial topic or the subject of hot debate in all cases.

- In two countries there was no debate at all (AT, LV).
- In most cases xenotransplantation did not give rise to serious conflicts and was handled as "business as usual" (DK, EC, VA, IT, OECD, SE).
- In two countries a situation of managed tension arose (NL, CH).
- However, in Canada and Great Britain, xenotransplantation was discussed in the context of a serious crisis of trust in government regulation.

Second, framing of xenotransplantation as a topic was contingent on and varied between cases.

- In most countries the topics of organ shortage and risk dominated the discussion.
- In some cases xenotransplantation was discussed in the context of national economic competitiveness (CH, EC, GB, LV, OECD, and SE).
- Less frequently ethical issues (CA, CH, SE, and VA) and animal welfare (CH, EC, NL, and VA) were critical and they became significant topics only in a few cases.
- In two cases trust in government (CA, GB) became critical.
- In one country xenotransplantation gave rise to struggles for competencies between parliament and government (NL).

Weak role of the public

The public was mostly involved in the weakest possible form, i.e. through surveys (in all cases except CH, LV, OECD, and VA). Additionally, with the exception of AT, almost all countries informed the public in one way or another. This was done to varying degrees, ranging from full-blown information campaigns (CA, CH, NL, SE) to simply publishing reports online (EC, DK, IT, OECD, VA). In a few cases the public was consulted. The intensity of consultation varied and was found to be very strong in some cases (CA, CH, GB, SE), strong in others (SE), or rather weak (EC, OECD). Again, the public was only involved in PTA exercises in CA, CH and NL.

Little direct but a variety of broader impact of PTA

Although policy-makers approved - in all the cases in which PTA was carried out - of both the PTA itself and its results, no unambiguous direct impact of these exercises could be established.

- In the Netherlands, the results of the PTA were available only after xenotransplantation policies were adopted and the organizers of the PTA did not have concrete plans for feeding them into policy-making. As it turned out, PTA results and official xenotransplantation policies were congruent.

- The same was true for Switzerland, where there was again an agreement between PTA results and government policies, which were determined before the end of the participatory exercise.

- In the Canadian case, it was hard to pinpoint a direct impact of the consultation exercise because the government did not make an official statement on its xenotransplantation policies and, in accordance with the public consultations' opinion, thereafter no clinical trials were carried out.

However, adopting a perspective on impact assessment that goes beyond the mere handing over of a final report, all three PTAs had an impact on the development of xenotransplantation regulation. The PTAs contributed to creating public awareness of the issue and to a (re)configuration of the relationship between relevant actor groups. PTAs also played a part in the definition of xenotransplantation as an issue by legitimizing and giving authority to claims made and to actor positions in the debate and regulatory procedures. In all three cases, PTA exercises were by and large considered legitimate and meaningful ways to gain knowledge and to involve the public in a debate about science and technology policy.

Varied impact of TA as well

Difficulties in the integration of findings from assessment studies into policy-making are not restricted to PTA. Expert TA also faced difficulties in directly impacting the regulation process. While in three of our cases, the TA exercises had a strong impact on policy-making (DK, GB, and OECD); in another two cases direct impact was weaker or at best 'mixed' (EC, VA). However, in three cases there was no direct impact on policy-making at all (IT, LV, SE). Important factors that co-determined a study's impact were:

- The kind of institution in which an advisory body is located;

- Its mandate as advisory or regulatory body;

- The extent to which its connection to policy-making was institutionalised, and

- Its reputation as a competent and independent organisation.

Moreover, the technical development of the policy issue and its framing in political and broader public debate played a role.

Facilitating Factors

- Existing traditions that PTA can build on, i.e. commissions involving participatory elements, adult education, direct democracy, consultation;
- Existing practices of accountability and openness;
- Coordination with responsible policy-making authorities and departments;
- Combinations of various methods (e.g., surveys, emails, plays, consensus conferences);
- Involvement of the wider social and political context in the organisation of PTA and dissemination of its results;
- Involvement of antagonistic groups in the PTA.

Constraining Factors

- When a topic is not perceived as political at all because it is only framed as a scientific issue - excluding or postponing e.g. questions of collective risk, ethics, human rights, politics and economics - or considered as a matter of individual choice;
- Case-by-case decision-making on individual clinical trials, which undermine an understanding of xenotransplantation as a fundamentally political issue;
- When the public does not consider itself to be a legitimate actor vis-à-vis policy-makers and experts;
- Traditions of paternalism, neo-corporatism and a strong and exclusive links between elites from science and the civil service that exclude the public;
- Lack of infrastructure and funding.

Description of the main S&T results/foregrounds

Introduction

Citizens, policy makers and social scientists often call for citizen participation to make policies simultaneously more effective and democratic. This claim has been made vigorously in science and technology policy, as shown by new biotechnologies and nuclear energy for example.

During the past two decades, many countries have therefore witnessed the introduction of Participatory Technology Assessment (PTA) exercises in science and technology policy. In contrast to expert based Technology Assessment (TA), PTAs are procedures where lay citizens systematically discuss the pro- and contra arguments of certain technologies. While most people would probably agree that such forums of debate have inherent democratic merits and a democratizing potential, important questions remain about their actual impacts on policymaking. Impact could be PTA's Achilles heel for reaping the democratizing potentials of enhanced citizen participation.

The CIT-PART project studied the use and impact of PTA and expert based TA comparatively in several EU Member States (Austria, Denmark, Italy, Latvia, Netherlands, Sweden, the United Kingdom), the European Commission, the OECD, Canada, Switzerland and The Holy See (in this report designated with the more commonly used name the Vatican), and addressed the following research questions:

- To what extent and in what context were citizen participation exercises applied in the case of xenotransplantation across Europe?
- What were the factors that facilitated or limited citizen participation in complex decision-making processes? And to what extent did cultural differences account for variation across countries in this respect?
- What in actual fact was the impact of PTA as one approach to promote citizen involvement on decision-making processes? In which way were PTA processes more or less effective with regard to their impact on decision-making compared with expert based TA?
- What can we learn about the complex relation between lay-peoples' and experts' views and expertise in TA and PTA?
- How can PTA increase citizens' influence on decision making? What are ways to improve the impact of citizen participation on policy-making on national and EU levels? Did citizen involvement increase the democratic legitimacy of policy decisions?

CIT-PART addressed these questions through analysing the reactions of various political systems to the challenge of xenotransplantation.

Xenotransplantation stands for the transplantation of animal organs, tissues or cells into humans. Xenotransplantation is highly controversial: Its advocates perceive it as a promising technology since it could address the shortage of human transplants, but its opponents insist that it involves many risks, most prominently infection from animals to humans, as well as ethical questions about appropriate human-animal relations and economic priorities in the health care sector.

The CIT-PART project assumes that the impact of citizen participation on decision-making is not only dependent on the quality of the PTA process itself but on practices of policy-making in which

PTA is embedded. Following from this theoretical approach the project applied qualitative methods of empirical research such as in-depth interviews and document analysis.

Before taking a closer look at the findings of CIT-PART, let us first consider the two issues that are at the heart of this project: Technology Assessment (TA) and Participatory Technology Assessment (PTA) on the one hand, and xenotransplantation on the other. Let us first address (P)TA: what is it and why it is it worth organizing?

Technology Assessment and Participation

Since the 1970s, controversies about the physical risks and social impacts of science and technology have given rise to TA in many countries. TA as a scientific counseling tool aims at broadening the knowledge base of political decision making through comprehensive analysis of socio economic conditions and of possible social, economic and ecological consequences of new technologies. The underlying rationale is that scientific expertise may improve political decisions. Its proponents initially saw TA as an opportunity to add rationality to policy-making by "speaking truth to power".

Proceeding from this assumption, the US Office of Technology Assessment's method inspired by the ideal of objective, unbiased, scientific counselling on policy advice was exemplary for many other TA organisations.

Over time, this expert oriented approach drew criticism on both normative and pragmatic grounds (Hansen 2010; Joss/Torgersen 2002: 157):

- Insights into the limited scope of technocratic TA approaches to offer solutions were sobering; so were the findings on the actual impact of TA studies, which did not reach the high levels of expectation placed on them.

- In general, doubts arose more about the assumption implicit in TA that firm scientific knowledge about future developments is obtainable, and that authoritative advice on policy decisions can be given.

- The conviction that technological innovation could solve the problems of industrial society was challenged.

- Research carried out in the field of the 'social studies of science' showed that technology is socially constructed and hence can be influenced at the stage of construction; this inspired all sorts of new varieties of TA aimed at influencing technologists and scientists rather than policy-makers.

- The insights into the socially constructed nature of technology also inspired and enforced a less analytical, more political criticism. The assumed objectiveness of the expert's view was demystified in the context of the rise of social movements in the 1970s, such as: the anti-nuclear movement, the environmental movement, and the second wave of feminism as, so to speak, a bias-in-disguise. 'Objective' expert knowledge was exposed for carrying the mark of the money on its production.

This type of criticism led to a call for a 'democratisation' of knowledge and the ways in which it was applied in the production of artefacts and decisions (Liberatore/Funtowicz 2003). Among the developments this set forth were attempts at a broadening of the basis for decision-making on science

and technology. This ambition was at the heart of the methodological innovation in TA to include citizens, laypeople and – later on – patients in assessment schemes.

Advocates of PTA typically invoke these lines of argument. On the one hand, PTA has the advantage of taking into account the knowledge and values of laypeople that are normally factored out of experts' discussions. These concern the definition of problems and issues to be investigated, the inclusion of local knowledge, the identification of chances and risks involved in a given technology, and the elaboration of innovative solutions. Thus, participation is claimed to increase the analytical depth of TA. On the other hand, the inclusion of affected persons may also improve acceptance of decisions on technology policy (Commission of the European Communities 2001) and help to create arenas where negotiations over competing demands and an elaboration of solutions can take place. PTA procedures are arrangements where not only knowledge, but also legitimacy and trust can be created.

Thus, PTAs are arrangements by which "experts and laypersons, decision makers and affected persons, opponents and advocates, all together try to reach a reasoned decision on whether or not a controversial new technology should be introduced, and if so, how it would have to be regulated" (Bora/van den Daele 1997). Many authors perceive PTA – as with TA as a tool for policy advice, but some see its scope as wider, embracing "decision-making" too (Joss/Durant 1995: 290).

The past fifteen to twenty years have witnessed the development of a wide variety of methods and participatory designs. After years of experimenting with PTAs, the assessment of their impact is now considered a key concern of PTA

research (Abels 2007; Loeber et al. 2011). The CIT-PART project addressed the question of use and impact of TA and PTA from an internationally comparative perspective, focusing on a highly sensitive policy issue. To allow for a comparison of how policy on such an issue is advised and informed, a salient issue was selected that provoked to various degrees decision-making in all countries selected: xenotransplantation.

What is Xenotransplantation and Why Does it Pose a Problem for Policy Making?

Xenotransplantation is the transplantation of cells, tissues, or organs from one species to another (Council of Europe 2003). It is a medical intervention, the scientific basis and practical application of which are the subject of on-going worldwide research. As with many technological and scientific advances in medicine, xenotransplantation holds the promise to cure diseases, but it also entails risks and ethical problems (Engels 2002; Schicktanz 2002; Sykes et al. 2003). Xenotransplantation was presented by its advocates as a solution to reduce the shortage of implantable organs, cells and tissues observed in many countries (OECD 1999). Therefore it would, if made available, contribute to saving lives. For that to happen, numerous immunological and physiological obstacles have to be tackled (Beckmann et al. 2000). Among these obstacles is the risk that known or unknown viruses from the so called "source animals" could infect the human recipient and possibly spread to the population at large, thus causing, in the worst case, epidemics of yet unknown diseases (e.g. Butler 1998).

Some of the basic ethical questions connected with xenotransplantation discussed worldwide include:

- Taking into account religious beliefs and/or ethical convictions; is it acceptable to use animals as "sources" of organs, cells, or tissues for human beings?

- Under which conditions is it permissible?

- Would it be tolerable to limit the individual freedom of patients and of their relatives in order to control the risk of infection, e.g. by quarantine, life-long monitoring?

- By whom and in what way could informed consent be given for xenotransplantation?

- What role do arguments based on animal ethics play with respect to the required genetic modification, cloning, breeding and keeping of "source animals"?

- Does xenotransplantation imply a "transgression" over the barrier between species and how is this to be evaluated? What effect would xenotransplantation have on the patients' identities (e.g. Hansson 2011)?

- What are the potential effects of a large-scale implementation of xenotransplantation on public healthcare spending? Is this acceptable, given national and international inequality?

We selected xenotransplantation as a vehicle for studying how and why decision-making on such a salient topic is advised and informed, and the effects of including citizens in such an analytic process, for several reasons:

- Firstly, as mentioned above, xenotransplantation research involves – as many contested modern innovations in science and technology do – questions of risk, uncertainty and ethics.

- Secondly, in the late 1990s and early 2000s many national governments and international organisations had to formulate within a relatively short period of time policies concerning the medical risks and ethical questions posed by xenotransplantation research. Policy makers in different countries and international organisations had to deal with the scientific, social and ethical questions posed by xenotransplantation.

- Thirdly, policy-makers addressed these questions differently with regards to process, as well as content. To support their policies some governments solely involved experts, some also included stakeholders, some tried to represent the interests of the public by including elected politicians, whilst others also asked ordinary citizens. In addition different governments took different policies towards xenotransplantation.

In order to learn from this diversity, as said, we developed a comparative research design including countries in Europe and North America as well as some of the most important international organisations operating in this field. Thus, in contrast to most impact studies, which centre on the concept of PTA, the CIT-PART project took as a point of departure an ethically sensitive and technically complex technological issue, rather than participatory experimentation per se. Putting the emphasis on substance rather than on procedure as a common denominator between cases meant that the question about reasons that further facilitate or restrict public engagement could be raised and systematically answered. It implied too that the number of cases, which included elements of PTA or a full PTA, might be low.

Results

Advocates of Participatory Technology Assessment (PTA) claim that this approach to public engagement could improve the quality of decision-making in science and technology policy, enhance citizen involvement in complex policy issues and increase the public acceptance of decisions made. Yet, more often than not, even in cases of technically and ethically highly complex issues, policy-makers do not opt for such a form of public engagement. Instead, policy-makers make use of expert-

led Technology Assessments, or refrain from commissioning any specific technology-oriented policy analysis at all. The question is why? To what extent is PTA or TA applied? What explains the choices made, what are the experiences of using either, and what is their impact on policy-making? Extensive research on PTA has provided a comprehensive overview of PTA methods and the use and impact of PTA. However, characteristically, such research compares cases in which different PTA methodologies are used to investigate different technologies. In addition, TA is seldom included in such studies and there are hardly any studies analysing how PTA processes are incorporated into policy-making. The CIT-PART project addressed these research gaps. Comparing different countries and international organisations, it focused on how one particular policy problem, the issue of xenotransplantation, was approached. Centre stage was the PTA or TA procedures that were initiated to support policy-making processes. Thus the CIT-PART project was set to find out what factors facilitated and restricted the use of, and impact of citizen participation on decision-making.

Xenotransplantation as a policy issue

A first, striking, observation was the sheer variety of ways in which the cases under investigation dealt with xenotransplantation. While in principle the issue could be addressed uniformly in all cases given its technological aspects, the risks involved and its potential benefits, huge differences were observable in how the issue was approached between countries, and how it was regulated. From the variation in policy response that we found in our cases we conclude that context specific national and historic factors to a large extent co-determine the choice for including a (P)TA arrangement in the policy preparation process. Culture plays a significant role in science and technology policy-making. The CIT-PART project thus empirically underscored the contention of Science and Technology Studies literature that a problem is not ‘given’ but is contingent on the way an issue is perceived in a certain setting, and is subject to particular framings. Framings cum circumstances can either provoke discussions or not, and can render some issue controversial or not. We found that the ways xenotransplantation was perceived and treated depended significantly on the way it was framed, and on previous experiences in a country. In Canada for instance the issue was considered potentially socially explosive, another potential test of the trustworthiness of a government that had recently been hit by a scandal over HIV-infected blood, while in Austria xenotransplantation was not identified as a policy problem at all. The xenotransplantation issue was framed in various ways. Whereas organ shortage and risks – mainly of cross-species infection – were dominant frames in almost all of our cases, ethics and animal welfare were only important in a minority of them. In some cases, business interests provided an important framing. International organisations in particular, which influenced xenotransplantation policy development significantly, dealt with xenotransplantation mostly within a strict framing of sound science, evading – though recognizing – ethical, social and political implications. Only a minority of cases, among them Canada, Switzerland, the Netherlands, Sweden, the UK and the Vatican discussed the ethics of xenotransplantation thoroughly. In other words, we observe that framing was a decisive, basically contingent factor. The way the issue was framed in a nation or organisation was highly dependent on a country’s or international organisation’s previous experiences and history, and, in the case of international organisation, its mandate.

Xenotransplantation regulation

Not just the framing of xenotransplantation and the intensity of (public) discussions differed between countries. A second observation was that the way the topic was translated in public policy and regulation varied (Tallacchini 2011). Our international comparison showed a diversity of xenotransplantation policies. Most countries and international organisations decided upon permissive policies, but in a minority of cases countries opted for a de facto or de jure moratorium. One country, Austria, took a ‘wait-and-see’ position.

Technology Assessment on xenotransplantation

A third observation concerns the forms of policy analysis used to channel (societal and expert) discussions to inform the policy decisions made. Expert TA turned out to be the dominant way to deal with xenotransplantation. Most countries and international organisations, which were influential in international xenotransplantation policy development, applied expert TA only. This group included the OECD, Sweden, the Vatican and the EC scientific advisory system. International organisations played an important role in the dissemination of technical information on xenotransplantation. Networking by and through international institutions such as the Council of Europe, the WHO, the OECD and at an EU level provided civil servants with knowledge on the issue. An interesting observation we identified was that in most policy efforts of international organisations, experts who advocated xenotransplantation were dominant, whereas positions opposing xenotransplantation were weakly represented. We found that this potentially created a dangerous in-group thinking effect, especially since the same studies and reports were used as authoritative sources of information in policy processes throughout Europe. Dissenting views were thus already put in a disadvantaged position at the very onset of policy dialogues and public debates on the topic. The staging of PTA remained a minority in xenotransplantation policy-making. Only three countries in our large sample carried out a PTA (Canada, the Netherlands and Switzerland). The reasons why PTA was set up in these three countries varied, as did the way it was organised. As concerns the reasons why some countries opted for a PTA: The federal department Health Canada decided for a broad consultation strategy which included expert TA and public consultation. This decision was made for various reasons: a) there was uncertainty about the promises and risks of xenotransplantation, b) it was assumed that applications for clinical trials were imminent, which Health Canada was legally bound to address within a short period of time, and c) there were concerns over a previous scandal (see above) which had undermined the government's regulatory credibility. The Dutch case revealed a different set of reasons. In the Netherlands, the responsible minister, while herself initially in favour of a permissive policy on xenotransplantation, answered demands for a public debate by Parliament with an initiative for public consultation. A PTA was then organised to stimulate debate but also notably to inform the public on the issue of xenotransplantation; a new episode in what was seemingly becoming a tradition of broad societal debates on life-science issues in the Netherlands. In Switzerland, it was TA-Swiss, a TA organisation then linked to Swiss Parliament that initiated a PTA. Reasons for doing so included the international developments, namely forecasts that clinical trials in xenotransplantation would be imminent and promised a huge economic market, and because a NGO criticising xenotransplantation triggered a public discussion on the topic in this country which had already reached Parliament. In addition to these three instances of PTA in policy-making on the issue of xenotransplantation, there were a variety of Technology Assessment exercises that sat on a sliding scale between 'full-blown' formal public engagement and mere expert advice. In the UK, TA exercises were expert-led but also involved invited stakeholder discussions. Furthermore, in Canada, the Netherlands and Switzerland the PTAs were staged alongside expert TAs of various kinds. Academics in some other countries and at EC level took initiatives to experiment with PTA on xenotransplantation, yet did not link these efforts to policy-making.

Actor group involvement: the 'social map' of xeno-debate

In keeping with the framing of the issue and the intensity of the debate, varied the range of actors that got involved in discussions on xenotransplantation and its regulation. In most cases, civil servants interacted not only with researchers, physicians and other experts, but also with patient organisations, animal welfare organisations, ethicists and the lay public at large so as to inform political judgement and decision-making. Yet the group of actors that was most intensely involved in the preparation of policy on xenotransplantation in almost all cases was the civil service. They served

as a bridge between engaged politicians, knowledge providers, and in those cases where there was a PTA initiated. Another actor group heavily involved were scientists and physicians. They operated in multiple roles, acting not only as neutral experts, but also as spokespersons for patients and representatives of their own and the industry's interest (see also Gottweis 1998). Together with civil servants they formed the core of an international epistemic community, which met on repeating occasions to discuss the regulation of xenotransplantation in different forums such as the Council of Europe, the OECD, and the WHO but also on national level. The strong involvement of the two groups and the formation of an epistemic community that started to share policy ideas contributed to a dominant technocratic framing in discussions on xenotransplantation policies. In contrast to civil servants and scientists, ethicists were less strongly involved in TA, with the exception of Canada, Sweden, the UK and the Vatican. In Denmark, Italy, the Netherlands and Switzerland they contributed less strongly to the debate. Ethicists played only a minor role in the OECD and none in EU advisory bodies. In general, systematic investigation into ethical arguments was therefore less frequent, despite the fact that documents repeatedly emphasised its significance given the characteristics of the issue of xenotransplantation. Early documents on the ethics of xenotransplantation prepared by the Nuffield Council of Bioethics (1996) and the British Advisory Group on the Ethics of Xenotransplantation (1997) therefore often became important points of reference to various regulatory bodies on a national and international level, which were used to legitimate xenotransplantation research.

Only in a minority of cases politicians, i.e. members of parliament and ministers, got involved in xenotransplantation policies (Canada, Denmark, Netherland, Sweden, and Switzerland). NGOs were involved in some TA and PTA exercises (UK, Canada, Switzerland, and Netherlands), however, in many cases they did not participate, either because they were excluded or they themselves decided not to engage in the debate. Although many TA documents demanded public debate, actual and direct citizen involvement was an exception. As has been said, only in Canada, the Netherlands and Switzerland were citizens strongly involved in PTA exercises. Thus, xenotransplantation policies remained primarily the domain of policymakers and experts. Of the many ways in which the public may be involved in policy development, polling can be seen as the most passive. This was most often used. In addition, in most countries, though with different intensity, the public was informed about xenotransplantation. As already mentioned, public consultation and discussion, which gives citizens the most active role, was only carried out in a minority of countries.

Incorporation of (P)TA in the policy process: impact

A fifth observation concerns the way in which TAs and PTAs were included in processes of xenotransplantation regulation, and the extent to which they impacted on these. We found that, in general, open political systems were more likely to integrate public engagement exercises such as PTAs. Yet it is not enough simply to suggest institutionalising public engagement exercises as a suitable way forward. Our findings show that the mere fact that such exercises were carried out did not mean that they had a clear effect on the regulation of the new technology. This was the case in all three countries in which a PTA was staged. Though policy-makers in all the cases in which PTA was carried out approved of the PTA and its results, we could not to establish an unambiguous direct impact of these exercises. In the Netherlands, the results of the PTA were available only after xenotransplantation policies were adopted and the organizers of the PTA did not have concrete plans for feeding them into policy-making. As it turned out, PTA results and official xenotransplantation policies were congruent. The same was true for Switzerland. Again there was an agreement between PTA results and government policies, which were decided before the end of the participatory exercise. In the Canadian case, it was hard to pinpoint a direct impact of the consultation exercise because the government did not make an official statement on its xenotransplantation policies, and, in accordance with the public consultations' opinion, thereafter no clinical trials were carried out.

However, adopting a broader framework for analysing impact as developed in the CIT-PART project, the PTAs can all be argued to have had an impact on the development of xenotransplantation regulation. The PTAs contributed to creating a public to the issue, to a (re)configuration of the relationship between relevant actor groups, to the definition of xenotransplantation as an issue and to a (de) certification of claims made, and of actor positions in the debate and regulatory procedures. In all three cases, PTA exercises were considered legitimate and meaningful ways to gain knowledge and to involve the public in a debate about science and technology policy.

PTA exercises also turned out to be helpful in including opposing views on an issue (e.g. animal-rights). This was effective in Canada and Switzerland but only partly successful in the Netherlands, where a small group of animal welfare activists fundamentally opposed to xenotransplantation literally remained on the margin of public consultation events. However, experiences with TA on xenotransplantation at European level and in the UK showed that the exclusion of antagonistic NGOs can have negative consequences. Necessary conditions for including opposing interest groups are: a real willingness on the side of democratic institutions to include representatives of dissenting interest groups and to accommodate their views up to a point, instead of shutting them out; and a willingness on the side of interest groups to reach a compromise. Yet, we recognize that some groups may prefer to use the public arena outside of an institutional forum – through media or street protests – to make their case.

The case studies revealed that difficulties in the integration of findings from assessment studies in policy-making is not a problem restricted to PTA. Expert TA also had some difficulties to directly impact the regulation process. While in three of our cases, the TA exercises had a strong impact on policy-making, in another two, direct impact was weaker, or 'mixed' at best. However, in three cases there was no direct impact on policy-making at all. Important factors that co-determined a study's impact were: a) the institutional locus of the advisory body, b) its mandate as advisory or regulatory body, c) the extent to which its connection to policy making was institutionalised, and d) its reputation as a competent and independent organisation. Moreover, the technical development of the policy issue and the issue's framing in political and broader public debate played a role.

Citizen participation in technically and ethically sensitive policy issues

To sum up, the CIT-PART project showed that in spite of a strong call for citizen engagement (in circles of experts and professionals, rather than among the public), the extent to which citizens were actually engaged in processes of debating and regulating xenotransplantation was very limited. Initiatives to that end were strongly contingent on context-specific national and historical developments, and were influenced by the way the issue of xenotransplantation was initially framed in expert reports prepared by international organisations and 'first mover' countries, as primarily a technical problem.

More generally, as regards the question whether PTA would inevitably lead to a restrictive policy, our analysis showed that two of the three political systems that made use of participatory instruments featured restrictive regulations on the risky new technology xenotransplantation. Equally, not all countries and international organisations that favoured expert advice ended up with permissive regulations. The CIT-PART project thus gives evidence of the perhaps counterintuitive observation that the involvement of the public does not necessarily lead to a 'Not-In-My-Backyard' sentiment resulting in a no introduction of the (new) technologies discussed, nor that a concentration on expert advice in decision-making makes acceptance of a new policy more likely.

As concerns some questions of gender, our study showed that women were more equally represented in advisory bodies and as participants in citizen forums and public discussion than in expert TA.

There was more awareness towards the composition of such bodies in PTA than in TA arrangements. PTA therefore has the potential to further the cause of women in discussion, consultation and decision-making in science and technology policy.

Our research also showed a number of factors which can restrict citizen participation.

- The case of Latvia showed that a topic has to be perceived as political to be meaningfully addressed by participatory practices. Citizen participation simply does not make sense as long as xenotransplantation is exclusively perceived as a matter of individual choice about a medical treatment made by a single patient and his/her physician, rather than a political issue concerning society at large. Understood as a matter of individual choice, questions of collective risks, ethics and human rights are bracketed out of the discussion. This observation has far-reaching implications. It draws attention to the need to frame an issue as a matter of political judgement rather than (or in addition to) individual (medical) choice in early (international) reports that mark the beginning of processes of policy-making regulation. The xenotransplantation case studied in the CIT-PART project shows that the predominantly technical framings of the authoritative reports of the OECD and the WHO, among others, impacted the way the issue was picked up and understood on the national level. Furthermore, on the national level, decisions on individual clinical trials made by expert commissions on a case-by-case basis also undermined an understanding of xenotransplantation as a fundamentally political issue. As the case of Latvia and Austria showed in order to give the notion of 'citizen participation' any meaning, the public has to see itself as a legitimate actor vis-à-vis policy makers and experts in discussing some issue. A lax attitude among the public is reinforced by policy makers' and experts' attitude of what one may call the paternalism of adopting

Also traditions of neo-corporatism in which strong interest groups dominate policy-making and exclude direct citizen involvement (Sweden, Austria) can hinder PTA.

This is also true for the strong and exclusive link between elites from science and civil service observed, e. g, in the OECD. Adopting such deficit models, as was the case to various degrees in our cases (Austria, Latvia, Sweden, Vatican, and even in the staging of a full PTA in the Netherlands), implies denying the public a legitimate voice. Yet, what CIT-PART also shows is that a PTA often presents a first occasion for people to encounter an issue, and as such is instrumental in creating a public for the issue in the first place. Awareness of that role, in addition to an acknowledgement that this does not necessarily imply the attitudes associated with the deficit model may help set the stage for proper public engagement.

- As already mentioned, framing turned out to be a critical issue in citizen participation. Who is allowed to determine what framing counts as legitimate in a (P)TA setting? In several cases TA only allowed for downstream-oriented and strictly scientific framing with an emphasis on "sound science" and risk evaluation. It sometimes explicitly excluded a broader framing by social, ethical, economic and political questions. Scientific commissions who subscribed to a strict scientific paradigm sometimes delegated these questions to ethics commission, which in fact rarely convened. Often it was solely experts and policy-makers who framed the topic and controlled access to TA, while the public was left out or, as was sometimes the case in Sweden, was considered represented by experts and elected politicians. The PTA examples of Canada, the Netherlands and Switzerland showed that broader and up-stream framing was possible, overcoming a narrow scientific framing and downstream orientation.

- In addition, in some countries such as Austria, Latvia and Italy the lack of organizational structures and funding for PTA badly impeded the potentiality of citizen engagement.

The cases studied in the CIT-PART project revealed a number of elements in existing TA and PTA exercises which might facilitate public involvement.

- In several cases countries could build on existing traditions and practices of citizen involvement in policy-making. This includes the Canadian tradition of including individuals and groups in Royal Commissions; Denmark, though it did not use PTA in xenotransplantation, in many other cases has a strong tradition of adult education; in the Netherlands a tradition of policy negotiation exists (the so-called Polder Model), which puts consultation at the heart of policy preparation and formulation. This idea is also present in the country's approach to PTA, where the tradition of stakeholder consultation is broadened to include the wider public; Switzerland, finally, has a strong tradition of direct democracy. It was obvious in our cases that countries lacking such traditions of citizen participation did not consider PTA or attach meaning to the notion of citizen engagement.

- In order to get to a broad framing of the issue and to involve citizens in as many ways possible, it is necessary to apply a multiplicity of methods. The Canadian PTA is a good example in this case. In a representative and an open model, a number of different methods were applied to encourage public consultation and public participation.

- Xenotransplantation is a multidisciplinary research field, which involves scientific areas such as surgery, physiology, immunology, genetics, infectious diseases, and veterinary medicine and therefore it also crosscuts policy fields and departmental responsibilities. This poses a particular challenge to TA and PTA. Canada provides a good example of how to deal with this challenge. Recognizing that xenotransplantation was a crosscutting and interdepartmental issue which concerned human health, animal issues and ethics, Health Canada took particular care to create interdepartmental coordination and to embed a new instrument for public consultation in its organisation. PTA was meticulously planned and later evaluated. The overall positive evaluations of PTA and its prior embedding in the organisation enabled long-term institutional learning which established public consultation as a routine tool in a ministry (Einsiedel et al. 2011). Together with Switzerland (Griessler 2011), Canada is a good example of how to adapt the Danish consensus conference model successfully (Klüver 2002) in another country.

- Transparency and accountability are important challenges for TA and PTA. In this respect we can learn both from cases of TA and PTA. In Switzerland the organisation actually carrying out PTA was selected after an international open call for tender. This contrasts with some examples where recruitment was based on opaque political nomination or self-selection by personal acquaintances and on unclear selection criteria. The advisory system at EC level that dealt with xenotransplantation is another example of good practice in this case. In the aftermath of the BSE scandal it developed routines of recruitment and committee work that contribute to accountability (Griessler et al. 2012a). This includes the recruitment of members after an open call for expressions of interests and the publication of selection criteria. Moreover there are established working routines such as regularly demanding declarations of conflicts of interest, publication of agendas, meetings, reports, and public consultation. Though there is always room for further improvement, these routines established in EC scientific advisory bodies might serve as examples to increase accountability (Griessler et al. 2012a). Openness is another important element in PTA. The British UKXIRA's approach of

holding its annual meeting in public (Brown/Beynon-Jones 2011) might provide an example for the increasing accountability of advisory bodies.

- As can be seen from our study, the creation of impact on the regulatory process is a particular challenge to TA and PTA. The Swiss TA and PTA on xenotransplantation provide good examples how to make an effort to embed such exercises in the wider social and political context in order to increase direct impact on policymaking. TA-Swiss involved the Ministry as co-organizer and member of the advisory boards that accompanied the studies. It presented the results both to Parliament, the Ministry and to the general public at a press conference. • Involving antagonistic groups in PTA and TA is also a particular challenge. Again TA-Swiss provided an example how to involve groups critical of xenotransplantation fruitfully into TA and PTA by including them in advisory boards and involving them as experts and informant NGOs (Griessler 2011).

- The division between natural sciences on the one hand and social sciences, humanities and ethics on the other is a particular challenge to both TA and PTA. In our cases there were several examples of how successfully to address and partly overcome this division. In Sweden natural scientists and social scientists started to collaborate in research projects that also investigated the meaning of xenotransplantation for patients and the social dimension of xenotransplantation (Hansson/Lundin 2011). The methodology used in the Pontifical Academy for Life, in which scientists and ethicist discussed questions of science and ethics was highly appreciated by interviewees (Griessler et al. 2012b). This example might need further investigation in order to remedy the obvious lack of ethical considerations in many of the TA studies.

The potential impact and main dissemination activities and exploitation of results

Recommendations for citizen participation in complex and knowledge intensive policy areas

1. PTA was carried out only in a minority of cases in regulating xenotransplantation, and had little direct impact on it. Still, when assessed in terms of the process-oriented impact assessment framework developed in the CIT-PART project, PTA can be considered a success, given its numerous positive effects in creating and stimulating public debate. It is recommendable therefore that the use of PTA should be increased, particularly in expert international bodies and in the EU advisory system, which despite their high significance for international policy development tend to frame discussions of technologies purely in terms of sound science.

2. International expert bodies are advised to increase awareness of how their work may impact the way an issue is framed in (national) policy-making processes. In addition to the many mechanisms that increase accountability, the encouragement to include citizens in processes of analysis, judgement and even decision-making should be more than just an appendix to the recommendations. Only if the idea of civic engagement is at the heart of a body's framing of the issue may it further help public involvement on a countrywide level.

3. CIT-PART shows that a PTA often presents a first exposure of people to a particular issue. The instrumental role of PTA in creating a public in relation to the issue should not be confused with, or understood per se in terms of the deficit model. The deficit model implies denying the public a legitimate voice. A perspective on reaching out to an audience to create a public implies setting the stage for genuine civic engagement in political judgement. The

theatre play included in the Dutch PTA setting, based on a British play, which toured schools and other young people's meeting places, presents a good example of how to establish such an involvement practically. However, the case of Denmark revealed that in some cases it might not be useful to plead for a PTA, because, depending on a country's history, culture and specific setting, the topic is considered benign, uncontroversial or untimely, or only relevant in too distant a future.

4. Allow for a broad framing that not only considers "sound science" but also allows for social, political, economic and ethical questions raised by stakeholders and the public.

5. Try to embed PTA as much as possible in an organisation to increase its impact and instigate institutional learning. Most topics in science and technology policy present issues that cut across institutional borders. Take into account departmental specialisation, which might be connected to departmental fragmentation and struggles. Work against organisational fragmentation by involving responsible authorities, agencies and departments in order to increase the impact of PTA later on.

6. Build on existing participatory traditions and practices.

7. Take also into consideration factors that might hinder PTA such as closeness of policy-making, closely knit policy communities, paternalism, expert orientation, lack of accountability, transparency and openness, lack of open public debate and active mass media. Learn from and improve existing international examples that worked to overcome these obstacles. There are good examples not only in PTA but also in TA for critical elements such as transparency, openness, accountability, embedding, diversity of methods, involvement of antagonistic groups, overcoming the division between the different cultures of science, opening of framing, improving timing, and enhancing direct impact.

8. Think about how to increase direct impact on policy-making but also on broader terms of impact in the public debate.

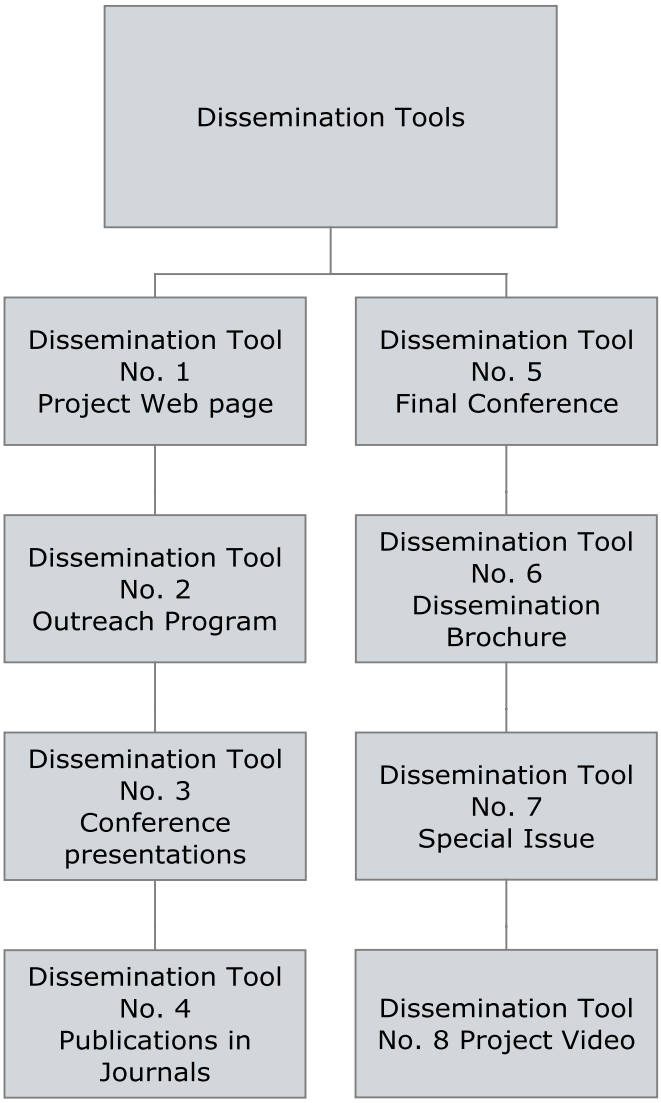
9. Timing turned out to be a problem in two cases of PTA, i.e. the result of PTA came shortly or long after a political decision was made. Only in Canada was it stated that no decision would be made until the PTA was finished. Several cases showed that regulators felt a certain urgency to arrive at policies, which were produced by the promises of xenotransplantation research that clinical trials would be imminent (Beynon-Jones/Brown 2011). However, predictions that clinical application was 'just around the corner', it turned out, were unrealistic. Participatory experiments need time. Policymakers therefore should consider not answering the pressure produced by promises from science and industry too promptly, and allow sufficient time to stimulate proper civic engagement in procedures for political judgement on issues such as xenotransplantation, which touch on the very basics of our understanding of public health, medical choice, collective safety and human identity.

- For researchers of public engagement in science and technology policy, it is recommendable not to take formal arrangements for public debate as a point of departure in designing research. As the CIT-PART project shows, wider perspectives of how science and technology policy unfolds, for instance by taking a particular issue as a starting point in the analysis, shed light on subtle and complex conditions under which civic engagement is stimulated or hampered in today's networked arenas for public policy-making. The address of the project public website, if applicable as well as relevant contact details.

Dissemination activities

The CIT-PART project strongly emphasized dissemination activities. So far, 41 various disseminative activities have been carried out by consortium members to inform researchers, policy-makers, stakeholders and the public about the project, its objectives and results. Dissemination activities involved a number of instruments as is depicted in Figure 1.

Figure 1: Dissemination Tools



Project web-page

The objective of the website (www.cit-part.at) according to contract was: (1) "To present the project, its objectives and its result (including results and presentations of the final conference) to "an" interested public. (2) To stimulate public debate on the issues raised by the project and the project results." (Annex I: 70).

The task of designing and maintaining the website was subcontracted to Christine Baumgartner. It was planned to launch the project website in February 2009. The website actually went online on

14/4/2009. Since then it has been continuously updated. This will continue after the life time of the project, particularly regarding dissemination activities as well as publications originating from the CIT-PART project.

Currently the websites includes information on objectives, results (downloads of final report, policy brief, project reports, case studies, articles), partners, researchers, events, video and contacts.

Outreach programme

The outreach programme shall inform interested users in policy-making, academia, NGO and the public about the project and its results. One of the main tools for accomplishing this goal was the final conference and the dissemination brochure of which 650 copies have been printed and sent out in September 2012 at national and international level to organisations and individuals interested in xenotransplantation as well as TA and PTA.

Conference presentations

Conference presentations addressed different audiences in academics and policy-making. Within academics several disciplines were particularly addressed by conference presentations.

One important addressee in the research community was **Science and Technology Studies** (STS):

- A main dissemination activity in this respect was the organisation of Track 31: "Practicing Public Engagement in Controversial Science and Technology" at the Conference of the European Association for the Study of Science and Technology (EASST) from 2 – 4 September 2010. The track was organised by Nik Brown, Edna Einsiedel, Erich Griessler and Susanne Lundin. Drawing more than 40 proposals, the call for abstracts was highly successful. Finally the conveners were able to accept 30 papers, seven of which by CIT-PART consortium members.

- Erich Griessler presented his paper "Expertise and politics - Negotiating the future of xenotransplantation in (participatory) technology assessment procedures" at the conference: "Governing futures. Imagining, Negotiating and Taming Emerging Technosciences", Vienna (22 – 24 September 2011)

The consortium also addressed the **xenotransplantation research** community by participating in the "Berlin Symposium Xenotransplantation" at the Robert Koch Institute, Berlin on 10 June 2011. Participants in this Symposium were xenotransplantation researchers from Germany, Belgium and New Zealand who presented their recent research results. Erich Griessler presented the interim results of the CIT-PART project in his paper, "Xenotransplantation as policy problem. Comparing public debate and policies in an international perspective". The abstract of this paper was published in the important xenotransplantation journal "Xenotransplantation. In this way the xenotransplantation community was widely informed about the project.

Another target group were **political scientists**. Members of the consortiums presented papers to this audience at several occasions:

- Anne Loeber and Agnes Allansdottir organized and chaired a panel at the 2011 ECPR conference in Reykjavik. Within the 'Argumentative Turn revisited' stream organised by Prof. H. Gottweis of the University of Vienna and Prof. F. Fischer of Rutger's University. The panel dubbed "Rethinking the deliberative turn in policy analysis: Critical reflections

from empirical work in STS" featured three contributions by consortium members in addition to two papers by authors not connected to CIT-PART on related themes (25 – 27 August 2011).

- Peter Biegelbauer, Erich Griessler and Anne Loeber presented their paper „Politik, Verwaltung, Wissen und komplexe Entscheidungen" at the „Tagung der DVPW-Sektion ‚Policy-Analyse und Verwaltungswissenschaft' zum Thema: ‚Wissen und Expertise in Politik und Verwaltung'" at the „Deutsches Forschungsinstitut für öffentliche Verwaltung" in Speyer, (10 – 11 November 2011).

- Peter Biegelbauer and Janus Hansen presented their paper „Democratic Theory and Citizen Participation: Democracy models in the evaluation of public participation in science and technology" at the ÖFG Research Conference: "representative democracy - the democratic deficit - institutional reform to enhance democratic performance" organized by the Österreichische Forschungsgemeinschaft, Wien (25 – 26 November 2011).

Another research community addressed in dissemination activities was the **TA and PTA**.CIT-PART members presented several papers to this target group:

- Erich Griessler presented the paper "Partizipative Technologiefolgenabschätzung und "politische Kultur". Ein Vergleich der Schweiz und Österreichs" at the TA'11 Conference „Partizipation in Technikfragen - Legitime Hoffnung oder bloße Illusion?" at the Institut für Technikfolgenabschätzung, Vienna (20 June 2011).

- On 17 October 2011 Peter Biegelbauer gave a lecture at the Institut für Technikfolgenabschätzung und Systemanalyse (ITAS), Karlsruhe titled „Von der Theorie für die Praxis oder von der Praxis für die Theorie lernen? Die Beurteilung von (partizipativer) Technikfolgenabschätzung in umstrittenen Fällen von Wissenschaft und Technologie".

Another target group addressed in the project were **sociologists**:

- Erich Griessler, Peter Biegelbauer presented their paper "Participatory technology assessment and political culture. An international comparison of the case of xenotransplantation" at the 10th Conference of the European Sociological Association, Geneva (7 – 10 September 2011). At the same conference Janus Hansen presented his contribution "QCA as an answer to the methodological challenges of evaluating public participation across contexts?".

- Erich Griessler contributed to the "Offenes Panel Technik und Wissenschaftssoziologie, Sektion für Technik- und Wissenschaftssoziologie der Österreichischen Gesellschaft für Soziologie" his paper "Citizen participation in highly contested policy areas in international comparison - The case of xenotransplantation" (29 September 2011, Innsbruck).

Several papers were addressed at **anthropologists**:

- Aivita Putnina contributed the paper "Consuming biotechnology products: the relations between humans and nature when eating and repairing bodies" during the 2010 American Anthropological Association Annual Meeting: "Circulation" in New Orleans, USA, 17 – 21 November 2010.

- Aivita Putniņa presented her paper “Bodies and biotechnologies: relating bodies and their new parts to the world” in Soderton University, Sweden at the seminar “The Body as Gift, Resource and Commodity”, 5 May 2011.

- Jekaterina Kalēja (together with Z.Linde, I.Mileiko) presented a paper „Exploring medical biotechnologies in post-soviet Latvia” during the conference „(Bio)Medicine as culture in post-socialist Europe” in Prague, Czech republic, on 10 – 11 June 2011.

- Kristofer Hansson presented ”Studying medical transgressions through policy processes: a methodological discussion” on ”The 32nd Nordic Ethnology and Folklore Conference 2012”, University of Bergen (June 18 - 21).

Publications in journals

Another main dissemination activity was publications in scientific journals and edited volumes. So far twelve articles have been published, another two three have already been accepted and several other articles are in the stage of planning. The articles address different target groups such as

- Anthropology (“Kulturstudier”,“Soderton Studies in Practical Knowledge”)

- Political Science (“Der Moderne Staat”)

- Public Health (“Health; Risk and Society”, “Social Science and Medicine”)

- STS community, policy makers and researchers and practitioners in TA and PTA (“Science and Public Policy”, “Poiesis and Practice”)

- Xenotransplantation Research (“Xenotransplantation”)

Final conference

The final conference “Decision-Making on Complex and Sensitive Issues - A Case for Citizen Participation? Experiences with Xenotransplantation” took place as planned on 12 June 2012 at the “Wien Haus” in Brussels. The aim of this workshop was to present the project results to researchers and policy makers and to discuss them with this target group. The workshop was well attended with 30 participants.

Dissemination brochure

Another main dissemination instrument was a dissemination brochure of 140 pages, which was designed by Elisabeth Marek. Its first edition of 50 copies was presented at the final conference. Feedback from conference participants was included whenever possible in the second edition of 600 copies. Distribution of the brochure to researchers, policy-makers and stakeholders already started in August 2012 and will continue in the next weeks.

Special issue in “Science and Public Policy”

Another main output of the project was the special issue in the peer reviewed journal “Science and Public Policy” which was published, as planned, in October 2011. The Special issue includes seven peer reviewed articles by consortium members.

Project video

The objective of the video was the "presentation of project results to a lay public" (Annex I: 72). The project videos are aiming at introducing an interested public in the projects objectives and research areas.

The task of designing a website was subcontracted to Christina Lammer, MedArt/somafilm, Austria, (www.corporealities.org). For that purpose she participated in project workshops in Vienna (2009), Trento (2010) and Copenhagen (2011). On these occasions she videoed part of the meetings and discussions. She also did interviews with individual researchers of the CIT-PART teams as well as with a transplantation surgeon and a transplantation patient.

Based on this material she produced a total of 19 short video clips which can be watched at, and downloaded from the CIT-PART project website http://www.cit-part.at/video.php and are also available on YouTube for a broader audience.

It was originally planned to publish the videos in June 2012. Accordingly the main videos were presented at the final CIT-PART workshop in Brussels (12 June 2012) and put on the website.

Policy brief

An additional dissemination activity not foreseen in Annex I was the production of a Policy Brief. From 15 – 16 December 2011 Erich Griessler participated in Brussels in a Communication Master Class organized by the SCOOP Project. This Master Class turned out extremely valuable for inspiring new dissemination activities. Based on the lessons learned, Erich Griessler produced a 10 pages policy brief which was presented at the final conference and can be downloaded from the project website.

Media contacts

Finally consortium members made contact with media to inform the public about the project.

- An article about the main research results based on an interview with Erich Griessler will be published on the SCOOP website in September 2012 (http://www.scoopproject.org.uk/).
- The text of a press release about project activities in Latvia and results was submitted to the Department of the Higher Education, Science and Innovation, Ministry of Education of the Republic of Latvia.
- Susanne Lundin had several media contacts: Vetenskapsradion (Swedish Science Radio), 2010-07-15; Vetenskapsradion (Swedish Science Radio), 2011-04-15; Människor och Tro, (Swedish Science Radio), 2011-03-25; Västvärldens jakt på hälsa (West's quest for health), Seminar at Almedalen, http://en.wikipedia.org/wiki/Almedalen, The Swedish Research Council Formas, 2011-06-04
- Nik Brown published the article "What is human? What is animal? And what of the biology in between? The Guardian, 25 July 2011 available at: www.guardian.co.uk/profile/nik-brown

Academic teaching

Results of the CIT-PART project were also included in academic teaching of the consortium members.

Edna Einsiedel: Xenotransplantation: social-ethical and policy considerations—used as case study in a course on Science, technology and society (STAS 343), Fall, 2011.

Aivita Puntina: Two lectures (27 April 2011; 16 April 2012) and two seminars (25 May 2011; 23 April 2012) on topic "Biotechnologies and Society" were organised and conducted for the first year bachelor level students in Social and Cultural Anthropology as a part of the study course "Anthropological Research in the Baltic Region".

Aivita Putnina: The study course "Biotechnologies and Society" (3 ECT; course code Antr5012) for master level students in Social and Cultural Anthropology was developed in 2011 and conducted during autumn semester (08 September 2011 –27 October 2011). Lectures, seminars and exercises and tests in electronic environment were held within this course.

Anne Loeber: First-year introductory course on policy and governance from a political science perspective (Propaedeuse Inleiding Bestuur en beleid), University of Amsterdam, department of Political Science.

Anne Loeber: Introductory course to the MA trajectory on Policy and Governance in the Master Political Science (Master Specialisatiemodule Bestuur en beleid), University of Amsterdam.

Anne Loeber: MA Research project on conflict resolution and governance, with an emphasis on knowledge-intensive policy controversies, in the English-taught Master Conflict Resolution and Governance, University of Amsterdam

Susanne Lundin: Aktuell forskning inom etnologi VT 2011 presentationer (Current research in ethnology), Dept of Arts & Cultural Sciences, Lund University, 2012-04-01

Susanne Lundin: MACA (Master of applied cultural analyses), Lund University, 2011-09-15

Use and dissemination of foreground

A plan for use and dissemination of foreground (including socio-economic impact and target groups for the results of the research) shall be established at the end of the project. It should, where appropriate, be an update of the initial plan in Annex I for use and dissemination of foreground and be consistent with the report on societal implications on the use and dissemination of foreground (section 4.3 – H).

The plan should consist of:

- Section A

This section should describe the dissemination measures, including any scientific publications relating to foreground. **Its content will be made available in the public domain** thus demonstrating the added-value and positive impact of the project on the European Union.

- Section B

This section should specify the exploitable foreground and provide the plans for exploitation. All these data can be public or confidential; the report must clearly mark non-publishable (confidential) parts that will be treated as such by the Commission. Information under Section B that is not marked as confidential **will be made available in the public domain** thus demonstrating the added-value and positive impact of the project on the European Union.

Section A (public)

This section includes two templates

- Template A1: List of all scientific (peer reviewed) publications relating to the foreground of the project.
- Template A2: List of all dissemination activities (publications, conferences, workshops, web sites/applications, press releases, flyers, articles published in the popular press, videos, media briefings, presentations, exhibitions, thesis, interviews, films, TV clips, posters).

These tables are cumulative, which means that they should always show all publications and activities from the beginning until after the end of the project. Updates are possible at any time.

template A1: list of scientific (peer reviewed) publications, starting with the most important ones

NO.	Title	Main author	Title of the periodical or the series	Number, date or frequency	Publisher	Place of publication	Year of publication	Relevant pages	Permanent identifiers[3] (if available)	Is/Will open access[4] provided to this publication?
1	*Citizen participation in technically and ethically sensitive*	Erich Griessler	Science and Public Policy	38/8	Beach Tree Publishing	Guildford	2011	583-588		Yes

[3] A permanent identifier should be a persistent link to the published version full text if open access or abstract if article is pay per view) or to the final manuscript accepted for publication (link to article in repository).

[4] Open Access is defined as free of charge access for anyone via Internet. Please answer "yes" if the open access to the publication is already established and also if the embargo period for open access is not yet over but you intend to establish open access afterwards.

	policy issues									
2	*Democratic theory and citizen participation: democracy models in the evaluation of public participation in science and technology*	Peter Biegelbauer	Science and Public Policy	38/8	Beach Tree Publishing	Guildford	2011	589-597		Yes
2	*Democratic theory and citizen participation: democracy models in the evaluation of public participation in science and technology*	Anne Loeber	Science and Public Policy	38/8	Beach Tree Publishing	Guildford	2011	598-608		Yes
4	Assessing the impacts of citizen participation in science governance: exploring new roads in comparative analysis	Janus Hansen	Science and Public Policy	38/8	Beach Tree Publishing	Guildford	2011	609-617		Yes
5	Cultures, contexts and commitments in the governance of controversial technologies: US, UK and Canadian publics and xenotransplantation policy development	Edna Einsiedel	Science and Public Policy	38/8	Beach Tree Publishing	Guildford	2011	619-628		Yes
6	Framing the public: the policy process around	Kristofer	Science and Public	38/8	Beach Tree	Guildford	2011	629-637		Yes

	xenotransplantation in Latvia and Sweden 1970-2004	Hansson	Policy		Publishing					
7	Time, timing and narrative at the interface between UK technoscience and policy	Sian M Beynon-Jones	Science and Public Policy	38/8	Beach Tree Publishing	Guildford	2011	6389-648		Yes
8	The reconfigured body. Human–animal relations in xenotransplantation	Kristofer Hansson	Kulturstudier	2	Södertörns högskola		2011	142-156		Yes
9	Xenotransplantation as policy problem: Comparing publicdebate and policies in an international perspective	Erich Griessler	Xenotransplantation	19	John Wiley & sons	Singapore	2012	142-156		No
10	The Relations between the Body and Its Parts: Accommodating Stem cell, Gene, tissue, and Organ Transplantation Technologies in Latvia.	Aivita Putnina	Södertörn Studies in Practical Knowledge		Södertörns högskola	Huddinge	2012	80-102		Yes
11	Institutional policy learning and public consultation: the xenotransplantation	Mavis Jones	Social Science and Medicine	73/5	Elsevier		2011	655-662		No

	experience									
12	Reflex Regulation: an anatomy of promissory science governance	Nik Brown	Health, Risk and Society	14,/3	Routledge			2012		No

template A2: list of dissemination activities								
NO.	Type of activities[5]	Main leader	Title	Date	Place	Type of audience[6]	Size of audience	Countries addressed
2								
3								

[5] A drop down list allows choosing the dissemination activity: publications, conferences, workshops, web, press releases, flyers, articles published in the popular press, videos, media briefings, presentations, exhibitions, thesis, interviews, films, TV clips, posters, Other.

[6] A drop down list allows choosing the type of public: Scientific Community (higher education, Research), Industry, Civil Society, Policy makers, Medias ('multiple choices' is possible.

Section B (Confidential[7] or public: confidential information to be marked clearly)

Part B1

The applications for patents, trademarks, registered designs, etc. shall be listed according to the template B1 provided hereafter.

The list should, specify at least one unique identifier e.g. European Patent application reference. For patent applications, only if applicable, contributions to standards should be specified. This table is cumulative, which means that it should always show all applications from the beginning until after the end of the project.

Template B1: List of applications for patents, trademarks, registered designs, etc.

[7] Note to be confused with the "EU CONFIDENTIAL" classification for some security research projects.

Type of IP Rights[8]:	Confidential Click on YES/NO	Foreseen embargo date dd/mm/yyyy	Application reference(s) (e.g. EP123456)	Subject or title of application	Applicant (s) (as on the application)

[8] A drop down list allows choosing the type of IP rights: Patents, Trademarks, Registered designs, Utility models, Others.

Part B2

Please complete the table hereafter:

Type of Exploitable Foreground[9]	Description of exploitable foreground	Confidential Click on YES/NO	Foreseen embargo date dd/mm/yyyy	Exploitable product(s) or measure(s)	Sector(s) of application[10]	Timetable, commercial or any other use	Patents or other IPR exploitation (licences)	Owner & Other Beneficiary(s) involved
	Ex: New superconductive Nb-Ti alloy			MRI equipment	1. Medical 2. Industrial inspection	2008 2010	A materials patent is planned for 2006	Beneficiary X (owner) Beneficiary Y, Beneficiary Z, Poss. licensing to equipment manuf. ABC

[19] A drop down list allows choosing the type of foreground: General advancement of knowledge, Commercial exploitation of R&D results, Exploitation of R&D results via standards, exploitation of results through EU policies, exploitation of results through (social) innovation.

[10] A drop down list allows choosing the type sector (NACE nomenclature) : http://ec.europa.eu/competition/mergers/cases/index/nace_all.html

Type of Exploitable Foreground[9]	Description of exploitable foreground	Confidential Click on YES/NO	Foreseen embargo date dd/mm/yyyy	Exploitable product(s) or measure(s)	Sector(s) of application[10]	Timetable, commercial or any other use	Patents or other IPR exploitation (licences)	Owner & Other Beneficiary(s) involved

In addition to the table, please provide a text to explain the exploitable foreground, in particular:

- Its purpose
- How the foreground might be exploited, when and by whom
- IPR exploitable measures taken or intended
- Further research necessary, if any
- Potential/expected impact (quantify where possible)

Report on societal implications

Replies to the following questions will assist the Commission to obtain statistics and indicators on societal and socio-economic issues addressed by projects. The questions are arranged in a number of key themes. As well as producing certain statistics, the replies will also help identify those projects that have shown a real engagement with wider societal issues, and thereby identify interesting approaches to these issues and best practices. The replies for individual projects will not be made public.

A General Information (completed automatically when Grant Agreement number is entered.

Grant Agreement Number:	
Title of Project:	
Name and Title of Coordinator:	

B Ethics

1. Did your project undergo an Ethics Review (and/or Screening)? • If Yes: have you described the progress of compliance with the relevant Ethics Review/Screening Requirements in the frame of the periodic/final project reports? Special Reminder: the progress of compliance with the Ethics Review/Screening Requirements should be described in the Period/Final Project Reports under the Section 3.2.2 *'Work Progress and Achievements'*	0Yes 0No
2. Please indicate whether your project involved any of the following issues (tick box) :	YES
Research on Humans	
• Did the project involve children?	
• Did the project involve patients?	

• Did the project involve persons not able to give consent?	
• Did the project involve adult healthy volunteers?	
• Did the project involve Human genetic material?	
• Did the project involve Human biological samples?	
• Did the project involve Human data collection?	
Research on Human embryo/foetus	
• Did the project involve Human Embryos?	
• Did the project involve Human Foetal Tissue / Cells?	
• Did the project involve Human Embryonic Stem Cells (hESCs)?	
• Did the project on human Embryonic Stem Cells involve cells in culture?	
• Did the project on human Embryonic Stem Cells involve the derivation of cells from Embryos?	
Privacy	
• Did the project involve processing of genetic information or personal data (eg. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction)?	
• Did the project involve tracking the location or observation of people?	
Research on Animals	
• Did the project involve research on animals?	
• Were those animals transgenic small laboratory animals?	
• Were those animals transgenic farm animals?	
• Were those animals cloned farm animals?	
• Were those animals non-human primates?	
Research Involving Developing Countries	
• Did the project involve the use of local resources (genetic, animal, plant etc)?	
• Was the project of benefit to local community (capacity building, access to healthcare, education etc)?	
Dual Use	

• Research having direct military use	0 Yes 0 No
• Research having the potential for terrorist abuse	

C Workforce Statistics

3. Workforce statistics for the project: Please indicate in the table below the number of people who worked on the project (on a headcount basis).

Type of Position	Number of Women	Number of Men
Scientific Coordinator		
Work package leaders		
Experienced researchers (i.e. PhD holders)		
PhD Students		
Other		

4. How many additional researchers (in companies and universities) were recruited specifically for this project?	
Of which, indicate the number of men:	

D Gender Aspects

5.	Did you carry out specific Gender Equality Actions under the project?	○	Yes
		○	No

6. Which of the following actions did you carry out and how effective were they?

	Not at all effective				Very effective
❑ Design and implement an equal opportunity policy	○	○	○	○	○
❑ Set targets to achieve a gender balance in the workforce	○	○	○	○	○
❑ Organise conferences and workshops on gender	○	○	○	○	○
❑ Actions to improve work-life balance	○	○	○	○	○

○ Other:

7. Was there a gender dimension associated with the research content – i.e. wherever people were the focus of the research as, for example, consumers, users, patients or in trials, was the issue of gender considered and addressed?

○ Yes- please specify

○ No

E Synergies with Science Education

8. Did your project involve working with students and/or school pupils (e.g. open days, participation in science festivals and events, prizes/competitions or joint projects)?

○ Yes- please specify

○ No

9. Did the project generate any science education material (e.g. kits, websites, explanatory booklets, DVDs)?

○ Yes- please specify

○ No

F Interdisciplinarity

10. Which disciplines (see list below) are involved in your project?

○ Main discipline[11]:

○ Associated discipline[11]:

○ Associated discipline[11]:

G Engaging with Civil society and policy makers

11a	Did your project engage with societal actors beyond the research community? *(if 'No', go to Question 14)*	○ ○	Yes No

11b If yes, did you engage with citizens (citizens' panels / juries) or organised civil society (NGOs, patients' groups etc.)?

○ No

○ Yes- in determining what research should be performed

○ Yes - in implementing the research

○ Yes, in communicating /disseminating / using the results of the project

11c	**In doing so, did your project involve actors whose role is mainly to organise the dialogue with citizens and organised civil society (e.g. professional mediator; communication company, science museums)?**	○ ○	Yes No

12. Did you engage with government / public bodies or policy makers (including international organisations)

○ No

[11] Insert number from list below (Frascati Manual).

- ○ Yes- in framing the research agenda
- ○ Yes - in implementing the research agenda
- ○ Yes, in communicating /disseminating / using the results of the project

13a Will the project generate outputs (expertise or scientific advice) which could be used by policy makers?

- ○ Yes – as a **primary** objective (please indicate areas below- multiple answers possible)
- ○ Yes – as a **secondary** objective (please indicate areas below - multiple answer possible)
- ○ No

13b If Yes, in which fields?

Agriculture		Energy		Human rights	
Audiovisual and Media		Enlargement		Information Society	
Budget		Enterprise		Institutional affairs	
Competition		Environment		Internal Market	
Consumers		External Relations		Justice, freedom and security	
Culture		External Trade		Public Health	
Customs		Fisheries and Maritime Affairs		Regional Policy	
Development Economic and Monetary Affairs		Food Safety		Research and Innovation	
Education, Training, Youth		Foreign and Security Policy		Space	
Employment and Social Affairs		Fraud		Taxation	
		Humanitarian aid		Transport	

13c If Yes, at which level?

- ○ Local / regional levels
- ○ National level
- ○ European level
- ○ International level

H Use and dissemination

14. How many Articles were published/accepted for publication in peer-reviewed journals?	
To how many of these is open access[12] provided?	
How many of these are published in open access journals?	
How many of these are published in open repositories?	
To how many of these is open access not provided?	
Please check all applicable reasons for not providing open access:	
❑ publisher's licensing agreement would not permit publishing in a repository ❑ no suitable repository available ❑ no suitable open access journal available ❑ no funds available to publish in an open access journal ❑ lack of time and resources **❑ lack of information on open access** **❑ other[13]: ……**	
15. How many new patent applications ('priority filings') have been made? ("Technologically unique": multiple applications for the same invention in different jurisdictions should be counted as just one application of grant).	

[12] Open Access is defined as free of charge access for anyone via Internet.

[13] For instance: classification for security project.

16. Indicate how many of the following Intellectual Property Rights were applied for (give number in each box).	**Trademark**	
	Registered design	
	Other	
17. How many spin-off companies were created / are planned as a direct result of the project?		
Indicate the approximate number of additional jobs in these companies:		

18. Please indicate whether your project has a potential impact on employment, in comparison with the situation before your project:

❑	Increase in employment, or	❑	In small & medium-sized enterprises
❑	Safeguard employment, or	❑	In large companies
❑	Decrease in employment,	❑	None of the above / not relevant to the project
❑	Difficult to estimate / not possible to quantify		

19. For your project partnership please estimate the employment effect resulting directly from your participation in Full Time Equivalent (*FTE = one person working fulltime for a year*) jobs:	Indicate figure:
Difficult to estimate / not possible to quantify	❑

I Media and Communication to the general public

20. As part of the project, were any of the beneficiaries professionals in communication or media relations?

○ Yes ○ No

21. As part of the project, have any beneficiaries received professional media / communication training / advice to improve communication with the general public?

○ Yes ○ No

22 Which of the following have been used to communicate information about your project to the general public, or have resulted from your project?

❑	Press Release	❑	Coverage in specialist press
❑	Media briefing	❑	Coverage in general (non-specialist) press
❑	TV coverage / report	❑	Coverage in national press
❑	Radio coverage / report	❑	Coverage in international press
❑	Brochures /posters / flyers	❑	Website for the general public / internet
❑	DVD /Film /Multimedia	❑	Event targeting general public (festival, conference, exhibition, science café)

23 In which languages are the information products for the general public produced?

❑	Language of the coordinator	❑	English
❑	Other language(s)		

***Question F-10*:** Classification of Scientific Disciplines according to the Frascati Manual 2002 (Proposed Standard Practice for Surveys on Research and Experimental Development, OECD 2002):

FIELDS OF SCIENCE AND TECHNOLOGY

1. NATURAL SCIENCES

1.1 Mathematics and computer sciences [mathematics and other allied fields: computer sciences and other allied subjects (software development only; hardware development should be classified in the engineering fields)]

1.2 Physical sciences (astronomy and space sciences, physics and other allied subjects)

1.3 Chemical sciences (chemistry, other allied subjects)

1.4 Earth and related environmental sciences (geology, geophysics, mineralogy, physical geography and other geosciences, meteorology and other atmospheric sciences including climatic research, oceanography, vulcanology, palaeoecology, other allied sciences)

1.5 Biological sciences (biology, botany, bacteriology, microbiology, zoology, entomology, genetics, biochemistry, biophysics, other allied sciences, excluding clinical and veterinary sciences)

2 ENGINEERING AND TECHNOLOGY

2.1 Civil engineering (architecture engineering, building science and engineering, construction engineering, municipal and structural engineering and other allied subjects)

2.2 Electrical engineering, electronics [electrical engineering, electronics, communication engineering and systems, computer engineering (hardware only) and other allied subjects]

2.3. Other engineering sciences (such as chemical, aeronautical and space, mechanical, metallurgical and materials engineering, and their specialised subdivisions; forest products; applied sciences such as geodesy, industrial chemistry, etc.; the science and technology of food production; specialised technologies of interdisciplinary fields, e.g. systems analysis, metallurgy, mining, textile technology and other applied subjects)

3. MEDICAL SCIENCES

3.1 Basic medicine (anatomy, cytology, physiology, genetics, pharmacy, pharmacology, toxicology, immunology and immunohaematology, clinical chemistry, clinical microbiology, pathology)

3.2 Clinical medicine (anaesthesiology, paediatrics, obstetrics and gynaecology, internal medicine, surgery, dentistry, neurology, psychiatry, radiology, therapeutics, otorhinolaryngology, ophthalmology)

3.3 Health sciences (public health services, social medicine, hygiene, nursing, epidemiology)

4. AGRICULTURAL SCIENCES

4.1 Agriculture, forestry, fisheries and allied sciences (agronomy, animal husbandry, fisheries, forestry, horticulture, other allied subjects)

4.2 Veterinary medicine

5. SOCIAL SCIENCES

5.1 Psychology

5.2 Economics

5.3 Educational sciences (education and training and other allied subjects)

5.4 Other social sciences [anthropology (social and cultural) and ethnology, demography, geography (human, economic and social), town and country planning, management, law, linguistics, political sciences, sociology, organisation and methods, miscellaneous social sciences and interdisciplinary , methodological and historical S1T activities relating to subjects in this group. Physical anthropology, physical geography and psychophysiology should normally be classified with the natural sciences].

6. HUMANITIES

6.1 History (history, prehistory and history, together with auxiliary historical disciplines such as archaeology, numismatics, palaeography, genealogy, etc.)

6.2 Languages and literature (ancient and modern)

6.3 Other humanities [philosophy (including the history of science and technology) arts, history of art, art criticism, painting, sculpture, musicology, dramatic art excluding artistic "research" of any kind, religion, theology, other fields and subjects pertaining to the humanities, methodological, historical and other S1T activities relating to the subjects in this group]