

Biomedicine as a Socio-cultural and Ethical Challenge: Final Points to Consider and Recommendations for European and National Policy Makers and European Research

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Preface

This document is the result of research and discussion by members of the European Research Project “Challenges of Biomedicine – Socio-cultural Contexts, European Governance and Bioethics”. It presents proposals on the basis of interdisciplinary socio-empirical research and ethical reasoning on attitudes of European citizens (lay people and patients), taking into account their moral opinions, cultural experiences and expectations about participatory issues and governance in the field of biomedicine (predictive genetic testing and organ transplantation).

The focus of our research project was threefold: a) the role of identity and body-concepts in public attitudes towards biomedicine, b) public attitudes towards and experience with the role of participation and governance in biopolitics, and c) the dealing with the variety and diversity of values and moral opinions within a medical-cultural framework.

The points to consider aim at assisting future activities of European and national policy makers to engage the public in a broader debate in ethical, social and cultural issues on biomedicine. Additionally, they should also prove useful to European and national research policies and agendas at the interdisciplinary intersection of social and ethical studies of science and medicine.

The recommendations and points to consider provided here are understood as conclusions from broad, comparative research to inform existing and future decision making processes on how European citizens’ attitudes toward the social and ethical dimension of medicine should be considered in an adequate and respectful way.

Objectives

The objective of our considerations is to establish a broader awareness for cultural embeddings of science and medicine and, additionally, lay peoples’ and patients’ needs for information and participation. Hereby we want to increase sensitivity for recent problems in biomedical practise and European science and research policy. Hence, our considerations touch upon different levels of policy making: the macro level of European policy, the meso-level of national health policy or education of professionals and the micro-level of physician-patient-relationship in health care institutions. With respect to intensive research on local

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phenomena, problems and contexts, we also address the local level of biomedical practise and public discourse. The purpose of interdisciplinary research is to provide new insights and to establish new methods. Therefore, we also address problems and considerations about how to intensify interdisciplinary research at the intersection of science and society within the European research area. We distinguish the following dimensions:

(1) European Policy Level

- European harmonisation and diversity of cultures
- Citizen participation and governance
- European research policy

(2) Health Care Policy Level

(3) Local Policy Level: Recognising Problem Areas in National Policy and Infrastructures

- Austria
- Cyprus
- Germany
- Latvia
- The Netherlands
- United Kingdom

1. European Policy Level

a. European Harmonisation and Diversity of Cultures

One way to understand the European Union is to describe it as a project of harmonisation, both in technological as well as in social and political terms (Barry 2001). From the very beginning of the European project, the vision of one economic and thus technological Europe may be analysed as accompanying, but also as an important means and motor of social and political integration. Harmonisation implies the reduction of national differences that seem to hinder the process of 'growing together' as well as the quest for and definition of common ways of coming to terms with the current and future challenges to governing, as for example in the area of science and technology and especially biomedicine. This in turn means the creation of European actors and identities, such as *the* European Commission, *the* European Group on Ethics, or *the* European public to be represented in European Citizen conferences. It may be argued that these are processes and attempts of the construction of a European technological society, or a European techno-political culture.

But this picture seems to be not complex enough for an adequate understanding of the developments in Europe. The challenge of technological developments in a growing Europe and in the context of globalization has a much deeper impact on the self-understanding and identity of European citizens, nation states and Europe as a whole. Value differences can not be overcome by formulating an overlapping consensus, but are in need of much deeper reflection on the interrelationship between technology, personal identity, culture and morality. Our research strongly challenges the position that technology is independent from its cultural context, and that harmonisation thus may be a smooth process. Rather, our argument is that

much of European political and scientific discussion lacks a deeper understanding of the intricate ways in which technology and its respective cultural/ national context are connected. Thus there has been limited attention given to what the 'costs' and obstacles may be of harmonising the governance of biomedical technologies across Europe.

Rec. 1: The harmonisation of Europe should be re-thought while the richness of the large diversity as well as shared communalities of techno-political cultures should be acknowledged

Our research shows the fundamentally different ways biomedical technologies are inscribed into society. Though quite similar basic challenges posed by the technologies were perceived, such as the danger of genetic discrimination or an unfair allocation of organs, the way they were addressed was very different. The respective technologies have been inscribed into and become blended with technopolitical culture in the different national contexts (Felt, Fochler & Winkler, to be subm.). The processes of this inscription are to be understood as the central mechanism of coming to term with new technologies which intrude as deeply into individual and collective lives as biomedical technologies do.

Altogether, the EU-level of policy-making was rarely or only indirectly mentioned by our respondents. They primarily refer to the national level when it comes to issues of collective decision making and regulation of biomedicine and research. Also the impact of the supranational level of EU-politics and EU-policies was not very present. In other words, individual attitudes towards biomedicine relate foremost to regulations and regulatory 'traditions' at the nation-state level. Respondents are considering 'local', directly experienced regulations and implementations of biomedical applications and they refer to local discussions and discourses. Interestingly, respondents' accounts show how the perceived moral heterogeneity and normative plurality in single nation states is considered as already highly problematic. Overall, there is an awareness (or scepticism) that simple consensus about ethical problems (e.g. end-of-life-definitions, relationship of individual vs. collective rights etc.) will not be achievable. However, most respondents feel that this is the price to be paid in a democratic, pluralistic society. The EU-level of policy making is under this perspective rather adding to this heterogeneity and puzzling complexity. This is even the case in new member-countries like Cyprus and Latvia: while EU-membership is appreciated as a sign as well as a guarantor of social and political modernity, there is a clear nostalgia for earlier times of an alleged normative homogeneity: EU-harmonisation is perceived as a kind of loss in biopolitical sovereignty.

The regulation of bioethical and biopolitical issues on the EU-level has to take cultural, normative differences into account in a more systematic fashion in order to avoid feelings of biopolitical domination. Especially if it comes to different notions of individuality or different relations of individual and family – e.g. if countries like Germany or Cyprus are compared –, regulatory instruments concerning bioethical issues should be implemented in a context-sensitive way. Thus, to understand public attitudes towards biomedicine, one has to take into account a country's history, tradition and pictures of medicine. Different nations are thus more or less sensitive towards what is seen as a 'bioethical problem' and what not. Abuse, instrumentalisation and ideology in the medical system, as prominent in Nazi Germany, or rather recent scandals such as the contaminated blood affair in France or the handling of the BSE crisis in Great Britain mark historical events which have left a trace in the public representation of medicine. Citizens use them as references to judge biomedical developments and especially the way medicine is linked with economy or politics. Therefore,

it is important to recognise such a collective memory. In this context, the image of biomedicine in the media may also turn to be very useful to understand cultural differences in the perception of technological changes. Such kind of future research will allow a better understanding of opinion changes, public hopes and fears generated by such techniques and their representation in the media.

Rec. 2: Civic and citizen epistemologies should be recognized

It has become common to speak of modern societies as 'knowledge societies'. This also implies that knowledge as a resource, but also as a form of legitimating political action, has become central to the political process. However, all too often in this discourse, knowledge is on the one hand implicitly equated to scientific knowledge, and other forms of knowledge existing in society are not taken into consideration. On the other hand knowledge is often taken to be independent of its cultural context, ignoring the large differences in how knowledge is assessed and used in different political cultures (Jasanoff 2005).

Our research shows that the way people refer to knowledge, which different forms of knowledge they delineate, and how they assess its legitimacy as well as its political implications, varies strongly between national political cultures, technological context as well as with regard to their affectedness by the respective technology (Felt & Fochler, to be subm. A). Policy needs to be attentive to the different forms of knowledge present in a society and the way citizens assess them, if it is not to face the danger of public rejection of policies based on a reductive understanding of public knowledge.

Rec. 3: The search for common values and overlapping consensus is in need of deeper reflections about impacts of medicine and technology on culture and identity

The response of European citizens towards biomedical technologies and social and ethical aspects has shown that the perception and evaluation of these technologies is influenced by a variety of concepts of the body, images of the body, gender and religious perspectives. Debating about organ transplantation and genetic testing, we confronted them with technologies that are influencing their concepts of personal and cultural identity in different respects. Some people were perceiving the body as a kind of machine where exchange of organs is easy to integrate while others were influenced by a intimate relationship to specific parts of their body (Schweda and Schicktanz, under review; den Dikken, to be subm.). It was often difficult to grasp to what extent religious convictions are influencing the perception of those technologies. Nevertheless, it became obvious that especially for religious people, independent of kind of religion, their concept of personal identity was at stake when referring to the importance of their believe for their evaluation of technologies. The ideas and images of a healthy body are to some extent influencing the demand for new technologies, but they are for sure influencing the perception of technologies. An important step in an adequate discussion of new biotechnologies is to describe the different ways in which the forming of identity is interrelated with different social and cultural factors. Value differences are in this context not differences in convictions between members of different countries or nations, but national and cultural contexts constitute a context in which identities are formed and the values of individuals and groups have to be interpreted against the background of this complex process of the formation of values. Each approach of a simple harmonization of values and explication of an overlap of different values will fail to understand the context of our evaluative frameworks in technology perception (Rehmann-Sutter, Düwell and Mieth 2006).

Rec. 4: Ethical discourses should be understood as mutual learning process instead of static mapping of recent values

Discourses about the moral evaluation of new technologies are presupposing first of all a methodology for interpreting the values that are influencing our technology perception and the ways identities are formed in the process of technological developments. The aim of this discourse can not be an explanation of overlaps between current values for several reasons. First of all, a policy that is based on an overlap between values would conceptualise values as 'static'. Such an approach is necessarily not capable of understanding values as interrelationships between different areas of our conviction, social, political and technological changes and our moral attitudes towards those factors. Secondly, to rely on an overlap between values of national states would presuppose that national values are uniform and stable and would not encourage discourse and development of a European self understanding of moral convictions. A learning process in Europe, however, should not be conceptualized as a harmonization of European values but as a process of learning and development. Such a process requires a twofold procedure: first a theory of the interpretatory schemes in evaluating new technologies, second a discourse about the justification of our evaluative schemes. A learning process concerning moral evaluation of technologies presupposes that the values at stake are discussed in an open process of justification of our moral expectations. The guiding question should not be what are existing overlaps of values but what are the necessary prerequisites in order to enable European citizens to actively participate in the guidance and developments of technology policy.

Rec. 5: Bioethics in Europe needs multilayer empowerment on decision making instead of ensuring informed consent procedures

From an ethical point of view, the question arises as to by which central values the process of technology policy and implementation is guided (Beyleveld, Brownsword 2001). In the centre of moral conviction, we find the idea of the unalienable rights of each individual and the inherent worth of each human being. The urgent question arises as to what prerequisites for an adequate protection of this inherent worth of the individual are needed in this dynamic process of technological development. It seems quite clear that new technologies have a deep impact on the way the individual perceives and values him- or herself. The current developments, however, are giving rise to the question whether the old instruments of moral protection are still sufficient for the challenges of biomedicine. The fast development of new technologies can hardly be regulated in an adequate way if we only protect 'informed consent' in individual decision making. In the light of the inherent worth of the individual it rather seems necessary to ask for an empowerment of European citizens for an active role in the development of the technologies. The task of enabling European citizens for participation in technology policy seems to presuppose a much deeper reflection of the potential of European institutions to develop their own discourses on technology policy. These discourses will fail right from the beginning if they are only conceptualized as activities to increase the public understanding of science. The aim should be the active empowerment of citizens in a common learning process in dealing with new technological opportunities.

b. Citizen Participation and Governance

In recent years, public participation has developed into a key notion in the discourse on the governance of science and technology. The White Paper on Governance by the European Commission (2001) and the Science and Society Action Plan (European Commission, 2002) can be cited as key policy statements on these issues. Improved participation is expected to create more confidence in the technoscientific outcomes and in the institutions which deliver policies.

For many respondents in our focus groups and interviews, participation is a highly relevant factor in modern democracies. However, their viewpoints regarding 'participation' tend to be much more nuanced than the 'official' uses of the concept in recent political debates about governance in the field of science and technology in many European countries suggest: Contrasting both levels, important and partially subaltern imaginaries of citizenship, statehood, and subjectivity are revealed, as are notions of solidarity, altruism and social cohesion that are building-blocks of lay-persons' political and social practices in the countries under review. These imaginaries are often *implicit* or *tacit* elements of a 'cultural grammar' informing decisions, values, and everyday practices of citizens in a not apparent and culturally highly specific way. This has a number of theoretical as well as methodological consequences.

Rec. 6: The concept of participation is in need for differentiation

One significant result of the project is the broad spectrum of *different forms* and *modi* of participation respondents alluded to. Variation refers here not only to the different local contexts and cultural ideas of participation. In addition to conventional, rather limited understandings of participation as pursuing political interests via memberships in parties or interest groups, many of our respondents mention other forms of participation, especially participation through sustainable commitment in patient groups, as activists and campaigners or through active participation in clinical research.

One key problem is the conflation of terms. For example: public versus patient or involvement versus participation. What exactly do we mean? Do we want an 'new' expert (Badcott 2005)? Patients are members of the public (unless they are health tourists in which case they could be considered to be members of a different 'public'). Most members of the public are patients in as much as they are registered with a family doctor and will have been a patient in the past even if they have not been a patient in a hospital, or are not currently being treated for an illness. A patient may have a level of expertise in their own disease, but may not be able to comment on services for other diseases, and also may not be able to be objective in rationing decisions between one healthcare service and another. One of the problems of direct participation is that individuals who wish to participate have some driving issue – yet good participation requires a measure of distance and impartiality. All of these problems are often used as excuses for not involving the public. Altogether, the term 'participation' seems to be used in a very broad sense, and the related understandings and meanings need more systematic consideration and differentiation – otherwise participation and its broad application and usage in policy, everyday as academic discourse runs at risk of becoming a mere "plastic word" (Pörkensen 1989).

Rec 7: Participation should not be seen as ,standard recipe' solution, because it is not unconditionally welcomed by citizens

Participation in governance is seen as an answer to the shortcomings of top-down technoscientific approaches. However, as citizen participation becomes a standard policy discourse, it often seems to become a 'standard recipe' which is deployed in any technoscientific setting and cultural surrounding without any consideration of the respective context. Participation is thus in the danger of becoming a mere ritual, an empty rhetoric (Irwin 2006), or even a new form of "tyranny" (Cooke and Kothari 2002) as it is implemented in a top-down way without reflecting on whether the expected participants will share the political visions enacted in these models or even the baseline assumption that an increase in public participation would be desirable.

Our research shows that citizens have quite complex and often intuitive understandings of the governance of the technologies discussed in our project (Felt et al. 2008). As they situate their position towards public participation in the context of these understandings, they do not unconditionally welcome public participation. Rather, in a number of cases, participation in its 'standard form' was seen as either undesirable, unrealistic or counterproductive. Engaging with these public meanings seems of key importance if the involvement of the public as a strategy to build more socially robust policies is to be successful.

Doubts were sometimes expressed by our respondents either with respect to the participation of a *general* public or with respect to the participation of patients. Accordingly, two central motifs for scepticism against an unreflective widening of participatory instruments have to be taken into account: an imagined deficit in information on part of the *general public*, and an imagined bias in information of *specific publics*, namely patient-organisations, who are expected to pursue mainly their self-interests. The first perspective relies on an understanding that is dominant in European policy discourse: the "information deficit" model of science communication (cf. Felt et al. 2007). Our respondents tend to be influenced by this 'official' view of the public as 'lacking' knowledge, information, and education to make informed, ethical choices facing difficult choices. More important, what respondents quite normatively refer to as 'informed participation' consists of more than the notion of information but an idea of participation based on a broad notion of competence that can be based on scientific or *professional knowledge* as well as on personal *experience*. In this sense, other forms of knowledge, e.g. patient's self-knowledge, a profound experience in dealing with life-world problems etc. are included in these understandings of expertise (see also above). This wide notion of experience applied by our respondents is easily compatible with perspectives of an anthropology of knowledge. At issue here – and this is the second point – is the question of representativeness. While patients are usually seen by our respondents as highly competent and knowing in respect of their health conditions, whose expertise-by-experience should increasingly be taken into account by policy-makers, the participation of patients also causes concern and critical examination. The role of patients in the decision making process is welcomed as an antidote to one-sided industrial or expert influence; resulting in a less flawed policy – however, not an ideal one. According to our respondents, an ideal system would maximise the *collective benefit* and accordingly will not come into being by simply 'adding' individual interests.

On the basis of our empirical material, however, we see a more foundational problem with participatory instruments as they are applied recently: There is a constant danger of grounding the legitimacy of political claims on 'affectedness', understood as an allegedly 'authentic' bodily experience and suffering. More precisely, in patient's (and sometimes layperson's)

accounts, 'experience' becomes a resource for making claims more authoritative. This problem is even more pressing when patient groups are closely collaborating with pharmaceutical industry or other stakeholders in the medical system - a problematic many of our respondents are aware of.

Rec. 8: Context matters – The differences of technology and political culture should be taken into account

Very often in the practice of putting citizen participation into practice, 'best practice' examples such as the 'consensus conference model' are deployed with little consideration of the concrete context of the local political culture and the cultural embedding of the technological issue to be discussed (Felt, Fochler & Müller 2006). However, our research shows that public expectations towards participation as well as the imaginations of its role in a governance of technology vary strongly in the context of different political cultures (Felt & Fochler to be subm. B), but also between different technological settings within one political culture (Felt et al. 2008).

Therefore, it is important to consider the various representations of citizens' participation according to countries. In some countries citizens do not necessarily wish to take part directly in the decision-making process on technical or biomedical subjects, they only want to raise their voice about their opinion. In others, direct participation is part of the traditions and it is claimed to be a right. Especially the fact that citizens judge participation very differently according to the actors associated with and the challenges raised by the governance of a specific technology is new to the academic literature and raises important implications for the practice of participatory politics (Felt et al. 2008). This especially puts into question the practice to define and adhere to standardized 'best practice' examples. Rather, a variety of different engagement structures, involving different actors, moderation procedures, and empowerment efforts are needed to address the complexity of issues at stake. In this respect, context-sensitivity seems more important than benchmarking. Thus, Public participation and governance issues draw increasing attention both within EU science policy and research agenda following that policy.

At the same time critical research of public and participation issues is needed, thus contributing to the development of participatory practices from their different cultural contexts. Here, a more refined distinction between participation in the information process, the deliberation process or the decision making process could be helpful in research and policy. Moreover, any comparative perspective on participatory practices in European countries has to take the intense history of entanglements or transfers of knowledge, artefacts, social forms (i.e. institutions like bioethics committees, patient-organisations, etc.), or citizens' expectations between nation-states into account. While the historiography of these entanglements is a research question in its own right, (Werner and Zimmermann 2002; Conrad and Randeria 2002) European harmonising practices pose a new challenge for research in the social sciences and the humanities: harmonisation – understood as the intensification of transfers and transactions in Europe –, has multiple and diverse effects in different European countries due to their historical, political, cultural and socio-economic specificities. (Barry 2001) Even if new participatory regimes might be implemented in European countries in an identical manner, they will have quite different *meanings* in a post-colonial society like the Republic of Cyprus, in a post-socialist country like Latvia or in an "old" democracy like Sweden.

c. European Research Policy

Rec. 9: Strengthening qualitative comparative research in Europe is in need of specific financial support and structural conditions

Analyzing *opinions* alone is not sufficient to reveal the *hidden, culturally specific orientations* that ultimately inform perspectives, practices and values European citizens develop regarding the “challenges of biomedicine”. In order to complement the rich quantitative data amassed by comparative survey-instruments such as the Eurobarometer surveys, methodological approaches have to be developed that make possible a deeper understanding of citizens’ attitudes and values on the basis of qualitative data about actual practices. A comparative perspective based on qualitative data (e.g. biographical narratives, highly subjectivist accounts, observational data of health practices) is theoretically, methodologically and logistically extremely sophisticated and has to take rather diffuse contexts into account – a highly diverse landscape of institutional, legal, and cultural settings, historically different collective experiences and culturally specific imaginaries of statehood, citizenship, solidarity etc. (Gingrich/Fox 2002; Hannerz 1998; Herzfeld 2001)

An essential part of the projects’ research was to engage the qualitative data collected in national focus groups and interviews in a cross-cultural comparative perspective. To do qualitative social research in highly diverse socio-cultural contexts in order to produce comparable data requires intensive exchanges between researchers. This is all the more true for the collective comparative work and the involved procedural, methodological and theoretical integration of independent local research teams, partly from different disciplines. First of all, such comparative endeavours require an intensive exchange throughout the research process by all of the involved partners. Regular computer-based communication can supplement but not replace needs of close face-to-face interaction. While the allocated money for project-meetings and workshops was adequate, there were no funds available to facilitate collaborative modes of fieldwork that would have allowed a more nuanced comparative perspective.

The experience of the Challenges of Biomedicine project provides important points to be considered in future planning and funding of qualitative research. We hope to have shown the value of this type of research within the framework of the European Union. The projects combination of focus group data and selective ethnographic interviews worked very well. Topics, impressions, and arguments of the focus groups could be re-introduced and clarified in the interviews. While the focus group allowed learning more about the social exchange, negotiation, positioning of individual preferences in a social or semi-public setting, the more intimate setting of the interviews made it possible for thoughts and argumentations to evolve in a more biographical mode and thus allowed discerning in a much more detailed way individual patterns of perception and reflection. However, the typical FP6 social science project architecture involving a rather large group of partners “covering” diverse European backgrounds is at odds with the necessities of this type of research, under the condition of limited budgets. Any true comparative analysis requires more than simply adding the viewpoints of local experts; in contrast, any comparative analysis requires *deep knowledge* about the respective socio-cultural contexts where the empirical material originates. Due to the financial cuts in the application procedure, however, there were no resources for giving national researchers involved in the production and interpretation of qualitative data the chance to learn about the other contexts and sites of data collection.

Developing good qualitative comparison entails intense face-to-face interactions between the participating researchers, which is currently constrained both by project size and limited amounts of travel money. Further, it seems often to be overlooked that it is not only the production of qualitative data, but also and foremost its context-sensitive interpretation, which is time- and thus cost-intensive. More focussed project endeavours seem needed to do this kind of research, equipped with ample travel and personal resources to adequately address the methodological challenges of comparative qualitative research.

Rec. 10: Cross-disciplinary research in social science and ethics need dense expert exchange and time for mutual learning

Bringing diverse disciplines together to research social and ethical issues can be incredibly fruitful and rewarding. The experience of the Challenges of Biomedicine project provides further important points to be considered in planning and funding research on issues of values and European development, which might bring together people from different disciplinary backgrounds – in our case ethics and social sciences. We do perceive a value of this type of cooperative research within the framework of the European Union, however see that the budgetary and time constraints do not really allow for sufficiently dense exchange and learning opportunities. As for good qualitative comparison, interdisciplinary work entails intense face-to-face interactions between the participating researchers. Thus it seems central that within FP7 research the budget size for such projects should reflect the challenges this research poses.

Interdisciplinary research can sometimes be hindered by interdisciplinary rivalry, especially where one discipline perceives that their research and methodologies are less valued than the other. Thus rather than endeavouring to understand the strengths and weaknesses of each approach, to take the best from each or to triangulate findings, more adversarial stances can be taken up. Language used within disciplines can be a significant barrier. Some disciplines use terms that have a specific meaning. Care must be taken to avoid misunderstandings in communication if researchers use a term in different disciplinary senses, while the other understands the term in their 'disciplinary' context. There is a general problem that professional groups like to use jargon, sometimes without realising it. Terms, acronyms, reference to authors and their theories can be used as a short hand. Sometimes such jargon is used as a form of machismo as a way of establishing individual or professional status.

In the field of cross disciplinary studies, ethics and social science studies could be seen as a special case. The advantage of our enterprise was the high variety of disciplinary backgrounds: moral philosophers, theologians, bioethicists, anthropologists and social scientists worked together. This allows us some general considerations: Having various limitations and hurdles in mind, coming from the theory and practise of each discipline, we believe that such a co-operation could be very fruitful and even necessary for European ELSA Research and studies of 'science and society'. Topics such as trust, participation and the meaning of the body – to name but a few examples – are crucial for both disciplines, but theoretically, ethics/moral philosophy is concerned with the conceptual clarification and the justification of norms, while social science is concerned with empirical description, reconstruction and theoretical analysis (Düwell 2005). Nevertheless, both refer to human behaviour and value systems. Many authors understand applied ethics and bioethics itself as an interdisciplinary field in which descriptive statements are linked to prescriptive statements. As applied ethics, according to some philosophical traditions, wants to have an impact on

practise, it is in need of practical import. Nevertheless, there is an ongoing debate in bioethics to which amount and rating bioethics itself could be reduced to empirical or descriptive studies (Birnbacher 1999; Borry et al. 2005) – the self-understanding of modern ethics as a reflective discipline would take a critical stance to such a reductive approach. Social science itself encompasses various strands of empirical and theoretical approaches. The plurality in theory and methods between quantitative, qualitative or anthropological approaches are a challenge not only for cross-disciplinary research in the field of social science, but also between social science and ethics. Social science seems to be in need of normative considerations where it wants to have an impact on practice, too (Hacking 1999). In practice, it is necessary to define needs and requirements of each discipline for other disciplines in the beginning. Without the sensitivity and awareness of the limits of the own disciplinary background, such a cooperation will have no surplus value other than the serial addition of disciplinary results. This attitude should be promoted as early as possible in the education programmes. Additionally, it seems necessary to allow fruitful process of mutual learning of how the own and the others' discipline are respectively built upon descriptive, normative, practical and theoretical assumptions.

Rec. 11: Research on gender issues in the medical system should be enforced on the qualitative and quantitative level

The ideas of women liberation and gender equality are essential elements of international and national law on human rights and individual freedom and were officially made central aims of the EU policy with the concept of gender mainstreaming in the *Amsterdam Treaty* (1997). Against this background, the role and status of women in the medical and health care system and its cultural background conditions clearly need further scientific investigation and political consideration. According to the academic literature, gender related issues refer to the question about how opinions, behaviours and therapies in the biomedical field are divided and constructed along gender/sex differences and vice versa: how gender differences are manifested by values, behaviours and therapy. While more research is done in the field of reproductive medicine, cosmetic surgery or medical intervention on sexual identities, there is low information level on gender issues in other fields of biomedicine

In our investigated fields of medicine, organ transplantation and genetic testing, gender studies are a challenge insofar as they are very often only implicitly a topic of discussion. Most lay people, patients and professionals are not aware of gender differences in accepting, rejecting or discussing biomedicine. On the other hand it is documented that there are significant gender differences in organ donation, especially in living organ donation in many European countries such as Germany, Austria, Belgium, Switzerland, Netherlands. According to the literature, the typical living donor has been described as a 35-49 years old female. In comparison, the typical recipient is male. For example, in Germany, more women donate kidneys to their husbands and brothers than vice versa. Significantly fewer fathers and significantly more mothers donate to their children than one would expect from the epidemiological data. Also in Sweden, among students (age 15-18), female students were more often in favour of donating their organs after death than male students. They also reported feelings of discomfort about the thought of donation (78%) more often than did male students (65%). Nevertheless, there is a lack in recent quantitative data for many other European countries on how often women and men donate and receive an organ. Moreover, qualitative research is needed to explore why women donate organs more often and how this is influenced by socio-economic structures, information policies or values. The Latvian case

analysis, for example, shows that donation is closely linked to breadwinning male and caring female roles in family. In a situation of high social insecurity, the number of living donations is extremely low. Temporary disability of the donor and risk of further complications leading to disability are the main factors why recipients refuse to accept living donations. Disability of any member of the family and especially that of the male breadwinner lessens the chances of the family to survive. Thus gender factors directly influence access to and use of the technologies.

Nevertheless, gender disparity raises different serious ethical and practical questions to European health care systems and whether they guarantee equal access for all patients. It would be necessary to increase the awareness and sensitivity of health care professionals who eventually have a gate keeper position in health care decision making processes.

2. Health Care Policy Level

Rec. 12: Informal forms of knowledge should be recognized

Our recommendations relate to the better account of informal forms of knowledge provided by patients and affected people. This informal knowledge includes personal knowledge, experience of having gone through the disease and medical procedures, symbolic and family values, professional forms of knowledge, information coming from the internet or originating from the media in general. The importance of a trusting relationship with medical professionals is essential (O'Neill 2002) as it allows the patient to lean on persons who have the necessary skills to face the disease. However, this relationship is often deemed asymmetrical by nature as the professionals are perceived as being more powerful than the patient. The data we collected show that public acceptance of biomedicine is more likely when there is a symmetrical relationship between the patient and the medical professional. In this scope, acknowledging informal forms of knowledge and their importance should be encouraged. Therefore, it is important that medical professionals learn to take into account these forms of knowledge and how to consider them as an opportunity to learn something on the disease. This could be part of a shared decision making process in which both scientific information and knowledge originating from experience by professionals and patients are shared. Furthermore, it would allow an improvement in the transmission of medical knowledge, since people suffering from the disease and the general public would then be in a position to make such knowledge their own and give it a meaning. Such a process of giving meaning can be facilitated at patient-doctor conferences and also, in a more generalised way, at various discussion forums where medical world and 'lay' world are confronted.

Rec. 13: Self-help groups and patients associations should be engaged as mediators between individual patients and professionals

Information gathered in the course of our focus groups shows that associations play – and should play – a fundamental role in the relation between patient, medicine and disease. This can be explained by the fact that affected people give them significant respect and trust, as members of these associations have generally gone through the same problems, the same constraints, and therefore share with them a common knowledge and a common experience. Thus in some fields, and more particularly organ transplants, associations compensate for the lack of "humanity" displayed by the medical system and denounced by patients, offering care before and after the person's transplant operation. This type of action could be supported and spread around.

Patients can also have a role in guiding the prioritisation of research questions, as bearers of knowledge based on experience. There are a number of ways in which they can influence the direction of research. The first model is the one established in France in the Nineties, in the context of AIDS research. Associations are represented in decisional committees attached to research agencies by members who are trained in scientific issues. This allows patients' interests to be promoted and an influence on orientations and research policies to be developed. However, this model remains imperfect as it essentially turns to scientific knowledge (and, therefore, neglects knowledge acquired through experience). In a second model, more widespread in Europe, associations commission the research or make decisions about which applications from researchers and doctors to fund. In this model the funding of research is part of the core activities of the association, and it seeks charitable contributions to fund the research. The origin and the purpose of biomedical research is

therefore the patient (Rabeharisoa and Callon 1999). This model should be supported and spread out as it allows genuine continuity between the world of research, biomedicine and persons who live with the disease.

Rec. 14: Participatory elements in the health care sector should be strengthened and expanded

The WHO declaration on the promotion of patients' rights in Europe (1994) stresses the individual rights of patients, but also claims that "[p]atients have a collective right to some form of representation at each level of the health care system" (§ 5.2.). And the Council of Europe (2000) issued recommendations „on the development of structures for citizen and patient participation in the decision-making process affecting health care“. However, while informed consent procedures have been widely established to protect and guarantee individual patients' rights to have a say in their own medical treatment, collective patients' rights for participation in political decision making processes in the health care sector are hardly institutionalized, yet (see Hart 2001). Hence, participatory procedures in this field often rather have the character of single, sporadic events with experimental character.

When it comes to the question of what role ‚participation‘ should play in decision making, policy development, or democratic processes, the respondents in our focus groups and interviews clearly expressed their view that participation is conditional for a modern, plural democracy. More precisely, the participation of patients in political decision-making or that their specific interests are taken into account in the political sphere is seen as a crucial element of modern systems of governance in the health care sector. In this context, the aspect of being affected turned out to play a crucial role in almost all group discussions. ‚Being affected‘, a concept not only applied to patients, themselves, but also to their closer surroundings, was perceived as a specific status by affected *and* lay people (see Schicktanz, Schweda and Franzen 2007): It was supposed to generate an epistemic authority based on experiential and embodied forms of knowledge often rated higher than expert knowledge and was linked to specific moral and political rights and responsibilities. Although these ideas were also critically discussed in the focus groups and definitely need further consideration and investigation, each of them might constitute claims for participation, be it in the name of maximising the competence of decision making or the congruence between those deciding and those concerned.

If affected peoples' role is to be strengthened not only on the level of protecting individual autonomy, but also of establishing collective participation, patients and their relatives should be represented on a regular basis, through the means of associations, in decisional, scientific and ethics committees. They should not only be encouraged to participate in their therapeutic process but also to partake in the decision making process as a group with direct experiences with specific illnesses and genuine interests assisting health professionals and decision makers, such as politicians and authorities, to better understand what might be good for the patients. So, instead of having a top-down approach of what is beneficial for patients, a mixed approach of top-down and bottom-up could be adopted constructing a more balanced relationship between patients and health professionals in the decision making process. This could be achieved if selected individuals, possibly from patient groups, are appointed to be part of committees and meetings among the decision makers. However, traditions and participation practices may have spread across the ‚old‘ Europe, but need to be transferred in culturally sensitive ways to the ‚new‘ countries still building their democratic practices. Here, better impact can be reached by uniting and formulating common interests

between NGOs at EU level. International cooperation both allows strengthening the capacity for public participation and brings the changes in understanding the concepts of public and governance. This strategy has already proved to be successful, e.g. in the case of Latvia.

Rec. 15: Public information policies should not be built upon the idea of public's deficit of information but on public's demand for information

The overall complaint that the public lacks information about biomedicine leads us to recommend that the public should be provided with more information and to rethink whether current information is well adapted to the needs of the public. Especially in the case of organ transplantation people seem to wish more practical, medical and technical information.

Educational programs could be a format in which such information can be given in a structural form.

These recommendations bring us to raise the issue of information, which may easily be perceived in the studies we undertook. Using the word 'information', we do not mean some unilateral transmission of messages, but rather the elaboration of information taking into account actual questions raised by the public and feed-back data. In brief, information should be divided into modules more often. This issue is raised on two levels: information aimed at the general public and information aimed at affected people.

In the scope of a first step, it would be important to establish an inventory of the requests for information as voiced by people. The idea would be to identify the public's questions and perceptions and, above all, the implications these questions can bear on the representation of the medical world and associated technologies. Therefore, such inventory may not be limited to a mere survey carried out through the means of some questionnaire or Eurobarometer, but rather with focus groups or citizens' conferences. Data collected in the scope of our focus groups are already giving some indications.

Rec. 16: Ensuring the right not to know should be based on the right to refuse modern medicine and to refuse personal support/donations.

The fact that affected people refuse either a treatment or some medical innovation or organ donation is typically explained with the assumption that they do not understand scientific, technological or institutional ins and outs. Yet our fieldwork shows that there is no dichotomy whereby ignorance and knowledge would exclude one another, indeed there are rather various forms of more or less 'active' ignorance (Michael 1996). This observation leads us to take into account the idea that citizens do not necessarily want to know everything on the disease, its course of development, surgical operations and technical issues. Taking into account such forms of decided non-knowledge on an individual basis would allow better dialogue between, on the one hand, doctor and patient and, on the other hand, biomedicine and society generally.

In the field of genetic testing, persons potentially concerned by a genetic disease may prefer not to know and refuse to undergo testing or to know the outcome of such tests. Reasons given to justify such refusal are varied in nature and it is important to protect this right "not to know", all the more since some of the tests available nowadays do not allow a diagnosis of whatever disease but merely indicate probability. Respecting this right not to know is also a way of facilitating the acceptance of a technology yet contested. More sensitivity and transparency towards verbal manipulation and communication strategies.

In the scope of organs donation, refusals or the fact that people do not want to take a decision may be related to a variety of acceptable reasons, there may even be a will not to

know, as such knowledge would affect a personal balance, for instance. Indeed, taking a decision about organ donation calls for a reflection on one's own death or the death of close relatives. Yet, many citizens do not wish to be confronted with such reflection. In this scope, information is simply not received as it is ignored, consciously or unconsciously. This type of attitude should be taken into account, otherwise information on organ donation would make people feel guilty and, therefore, reinforce refusals. Another point shows that the differences in national standards as regards means of acceptance or refusal, as well as the criteria to establish brain death are making the public understanding of transplants more difficult. Whereas in Germany, the issue of brain death has been widely discussed in the public arena, it has never raised any reaction in France. Therefore, it would be important to harmonise both criteria and means of refusal or acceptance, and to spread communication about these issues (while taking into account national differences). Work on the vocabulary used (words, metaphors, discursive registers...) is of prime importance in this instance. Similarly, French focus groups have shown that the notion of anonymous donation remains highly ambiguous within the general public. On the contrary, we observe that there is a desire to give the donated organ to a loved one or someone the donor knows. This point highlights a fairly typical communication problem: it is not enough to communicate about a word, simply stating that it is something basically "good".

Rec. 17: Information policies should avoid stigmatisation of patients and disabled people and stress the individual

Any communication endeavour involving a disease may lead to the stigmatisation of people who suffer from it. One concern identified by patients and affected persons in our focus groups was that an individual could be reduced to his pathology or to the results of his genetic tests. The person is no longer considered outside the state of his health. It seems that in the case of severe genetic diseases, this danger has not been totally avoided. This may be due to several factors like for instance not clarifying the status of the person bearing the disease (this is still surrounded by myths and taboos), the difficulty in understanding insurance principles and employment law rights relating to these patients. All this leads to a situation where the secret is maintained by affected people as they fear for their job or their insurance policies, and it facilitates stigmatising.

Patients are demanding a more global and more subtle vision. If single identities were represented and more taken into account by members of the medical community, a symmetrical trusting relationship could be facilitated. De-stigmatising communication aimed at the general public will necessarily go through recognition of the complex identity of the person who has to "live with it". Such communication should clearly state that the disease, or suspicion of disease, is indeed an element of the person's identity, but that the person affected by the disease deals with this and has a personality and a personal life that may not be reduced to the disease. It might be instructive to educate or inform people about the use of less stigmatizing descriptions of diseases, which would absolve the person of blame and distance the disease from the self. For example, terms or labels such as diabetics, nephropaths, cardiopaths and so on, work as contexts of constructing personal identities rather than as imaging conditions within bodies. These labels may conjure up images that portray a person as problematic in all aspects of his or her social life. While descriptions such as "people with diabetes" or "people with renal failure" are increasingly used among health professionals it seems that this is not the case among lay and affected people. One instrument of education could be the introduction of biomedical as well as psycho-social

approaches to diseases in the school curriculum in order to: (a) help build a society of social solidarity and mutual understanding, (b) realize that human beings are mortal and that there are many diseases which they may suffer from throughout their lives. This disease-socialization would likely help people being in the position of the other and societies deal with the issue of stigmatisation and discrimination, (c) establish the importance of the well-informed and active lay and affected people in the decision making process so as to image participation in these issues as “natural”, Encourage lay people to be involved in several civil society organizations or patient groups where they could contribute and better understand the managing means of diseases, being in a constant contact with patients and realize that all people may develop diseases. This would further contribute to de-stigmatising patients. Campaigns by medical charities, patients association or research programmes, often emphasise the suffering or disability associated with a particular disease. The aim of this is to stimulate an emotional response from citizens to contribute money to the ‘good cause’. This type of communication operation tends to reinforce patients’ stigmatisation rather than facilitate their integration in society. Without denying the importance of such specific approaches, a manner of more sustained raising of awareness would allow not only a respect for the human complexity of people who have to live with it, but it would also highlight the existence of such pathologies and the research studies conducted on them. These pathologies would then lose their exceptional nature. It is important to consider health and disease not so much in some binary manner but to realize that intermediary states do exist. The notion of “a person living with it” (it being a transplant or a positive genetic test) or that of “affected person” is indeed fundamental when taking into account an individual both from the medical perspective or with regards to his integration in society. Such notions help in better taking into account the patients’ physical and psychological reality (transplants or genetic tests). A person can feel in good health although genetic tests will tend to include him in the perspective of a disease, even if this person suffers no symptom: they change our vision of what health represents, not in a positive way though, as they can generate the feeling or the fear to be sick despite having no symptom or pain. Even if a test turns out to be negative, the very fact that a person did that test may unbalance the individual in question, especially when the person has doubts as to reliability or where results are not absolutely definite.

Rec. 18: Bioethics and public policies should acknowledge the variety of body concepts and anthropological premises in bioethical arguments and biopolitical efforts

Ethical discussions, political decisions and legal regulations concerning medicine and health care often implicitly involve ‘thick’, anthropologically loaded concepts of and premises about human nature, the body, personal well-being, health and disease etc. On the one hand, these anthropological concepts and premises can vary strongly within and between different cultural contexts, as discussions about the brain death criterion or the commodification of the human body in the context of tissue banking or organ transplantation (see Schweda and Schicktanz, under review) show. On the other hand, their role still does not seem to be sufficiently considered in clinical practice, ethical debates and political decision making processes. Instead, modern medicine and health care systems in western industrial countries rather tend to focus on the ‘curing’ of malfunctioning organs and pay little attention to personal, cultural and social factors.

However, a purely mechanistic and objectivistic vision of the body can be counter-productive for accepting both disease and medicine. Thus, for instance, the body runs the risk of being considered solely as a set of organs, made up of spare parts that may be detached and changed. As for genetic tests, they can give an impression of physical determinism, as if the body was programmed. People can have difficulties adopting such representations when they concern their own body or the body of beloved relatives, but conflict with the manner in which they live their disease, the vision they have of their own body and meanings to which they are attached. Therefore, governments should not only rely on clinical studies that indicate the therapeutic or managing capacities of medicine, but also on social studies in order to unpack the possible impact on individuals and social relations and both improve medical practice and consult the users in such a way as to make medication friendlier and more controllable. Physicians are trained to manage pathological bodily conditions and should therefore be supported by other specialists and patients. Psychologists, anthropologists and sociologists may respectively take care of the psychological impact of chronic diseases, the personal socio-historical background in understanding diseases and the illness experiences and new directions in the organization and implementation of the health care system.

When it comes to legal regulation of medicine and health care, the factual diversity of human self-understandings and world views poses a particular challenge to modern states: If – and insofar as – they understand themselves as liberal communities, they have to consider ways of tolerating this plurality without at the same time abandoning basic ethical principles or game rules of society – a problem which recurs in an even more challenging form on the EU-level. This is particularly clear when regulations involve the human body. Thus, with regard to organ donation, the *Council of Europe* declared in 2002 that “[i]n facilitating the transplantation of organs and tissues in the interest of patients in Europe, there is a need to protect individual rights and freedoms and to prevent the commercialisation of parts of the human body”. And a year later, the *European Parliament* discussed an initiative of the Greek presidency to prohibit any organ trafficking on the EU-level. However, the plan was suspended pending further investigation of the concrete situation (see European Parliament 2003). At the same time, a certain erosion of this political and legal consensus has taken place in ethical and legal discourse during the last decade. Our research indicates that a great variety of body concepts is existent among the European public and interwoven with their moral attitudes to transplantation medicine and organ donation in complex ways – although none of our participants favoured financial profit for organ donation (see Schweda and Schicktanz, under review). There seem to be different ways of dealing with such a plurality which need further consideration: An ‘*anthropologically informed*’ ethics or policy which assumes that the body either resists or is suited for commodification seems to claim authoritative insights into the nature of the human being and its corporeal existence. Irrespective of the epistemological question how these insights could be won and justified, it would be of interest to see how such a position deals with the non-informed, ignorant or uninterested lay person who simply insists on its own views on the body and the self. In modern, liberal democracies, there seems to be no way of imposing body concepts on those who simply do not accept them. Because of these difficulties, the *liberal tradition* tries to get rid of all substantial anthropological or metaphysical assumptions in order to found and justify a neutral moral and legal framework for the peaceful coexistence of the plurality of world views. In this spirit of tolerance, however, the liberalists have to be careful not to privilege a

particular world view, themselves, e.g. specific conceptions of nature, self and body implied in modern naturalistic science.

Rec. 19: A more patient adequate communication should avoid simple one-side rhetorics of science, progress and innovation.

Some one-sided discourse on progress or changes aiming at promoting any type of technical progress tends to discredit any refusal of new technologies, whereas such refusals (for instance of genetic testing) may perfectly be justified. Yet this discourse is the one often adopted at the moment by European nations.

Furthermore, all technical progress in biomedicine (development of genetic testing) does not necessarily translate into therapeutic progress. It is important to differentiate between mere progress in knowledge or technique and actual progress in therapies. For instance, genetic tests are perceived as being liable to spoil the life of those who undertake them. Especially where what they “predict” is serious and incurable, or where they predict things which are not definite. They introduce doubt as to the future on a daily basis. This is all the more difficult when there is no treatment. This is the reason why it is so important to be careful when using tests giving results that are not definite or those relating to pathologies which may not be treated at the moment (Huntington’s chorea, etc).

Also, although communicating the results of positive tests is ruled by a very sophisticated protocol at the moment, it is also important to rule over the communication of negative testing. Finally, three recommendations may be suggested regarding this excessive promotion of progress:

First, the fact that people may refuse something new should not merely be ignored or despised, but should be taken into account. Likewise, it would be appropriate to show more respect towards free will. Finally, pressure exerted either consciously or unconsciously by medical bodies in order to encourage a patient to undergo a test which he does not really want to do should be motivated by the case’s degree of seriousness.

The requirement for a more humane medicine often comes up, particularly in the field of genetics as it seems to be somewhat separate from traditional medicine, cold, distant, dehumanised and where the relationships between patient and doctor, patient and institution are reduced to a minimum. Adding a human aspect to genetics could be going through some enhanced link between the local doctor, the general practitioner and the geneticist, in order to consider the patient within his entire life, therapeutically, really, and not merely through his genetic profile. There is an expressed wish not to reduce everything to mere genetics: some room should be left to “traditional medicine” (cf. symptoms screening, e.g. manual breast cancer screening) to which the public is attached. Such more traditional medicine is also considered as really efficient as it is actually curing diseases (whereas genetics is not considered to be curing anything). The discourse promoting ‘innovation’ (like testing ...), should also take into account this medicine which may be ‘older’ but which has also proved its value and benefits from a good public image.

National Policy Level: Recognising Problem Areas in National Policy and Infrastructures

Austria

Ulrike Felt, Maximilian Fochler

Governance built on public uninformedness is fragile

The Austrian focus groups reveal that in some areas of Austrian technology policy, current regulations may be built on fragile foundations (Felt et al. 2008). In the field of organ transplantation, large parts of the public are unaware of the current regulation which allows the removal of organs of any deceased person on Austrian territory after brain-death has been declared, if there is no explicit prior objection. In the group discussions, as participants became aware of the regulation, a vivid controversy arose as a large number of participants felt patronised by this practice and hence strongly expressed their distrust in this regulation. However, it was not the objection solution as such which was subject of critique. Generally it was seen as a good means to assure that sufficient organs are available to help people in need. Much more, it was the fact that the public is kept uninformed which gave rise to their protest. Hence our research provides strong arguments for more public information and discussion of organ transplantation regulation and practice in order to build a stable relation.

Technology as an ,alien' issue – Missing cultural reference points

In the case of Austria, we have seen that participants seem to lack cultural frameworks or clear reference points to come to terms with a particular technology and to assess if they could trust governance in a particular technological setting (Felt, Fochler & Winkler to be subm.). Compared to other national settings, participants found it quite hard to develop a vocabulary to discuss the two biomedical technologies and to clearly express the problems they implicitly perceived with regard to these very technologies. In our opinion, this is strongly linked to the very scarce public discourse in Austria both on technology in general as well as on issues of technology policy in particular. In contrast to contexts such as France, technology is in Austria hardly seen as a part of culture, but often rather as its antithesis; hence public engagement initiatives which raise the issue in which ways also Austrian culture is intrinsically linked to technology and which open discussions on the societal impacts of technology seem needed.

Cyprus

Costas Constantinou

Information and counselling of chronically ill patients should be improved

Patients who suffer from chronic diseases lose control over their body and social life and experience feelings of uncertainty. They look for ways to regain control over their body and restore psycho-social integrity. Therefore, therapeutic procedures should incorporate careful counselling sessions for patients that pay particular attention to patients' preconceptions as well as other aspects in their psycho-social environment. Also, if patients request, the therapeutic process should encompass information sessions in which patients would be informed in detail about the nature of a disease, its progress and management, the therapeutic stages and their implications, side-effects of medications etc. Common procedures for all patients and the involvement of external quality control committees should

be established, which would ensure a fair implementation of clearly defined criteria (e.g. waiting list). When people are put on an equal basis, feelings of injustice and thoughts of breaking the rules may not accrue. Patients with similar health conditions are suggested to be brought together – upon their consent – to socialize and exchange ideas. This would help them realize that they are not unique within the context of their community and would thus abnegate any feelings of deviant behaviour. This is a way to perceive diseases as a “normal” onset in people’s life. Furthermore, they would have the opportunity to help each other and participate in social events as well as discussions about the causes and therapies of their diseases.

Physicians should take into account patients’ ambivalent perceptions and expectations

On the one hand, patients criticize physicians and, on the other, they heavily rely on them for both counselling and treatment. Against this background, physicians are recommended to attend information and training sessions about patients’ perceptions, worries, psycho-social and bodily disruption. They should pay particular attention to patients’ perceptions and attitudes and work together for the most appropriate therapeutic procedure. Having talked with the patients, they are recommended to apply the most appropriate counselling strategy so as to inform patients in a smoother way. Being in a constant dialogue, patients would have the opportunity to be better informed about the causes of their diseases and the therapeutic means, and would thus feel that they acquire control of their body and disease, which would contribute to better compliance and ameliorating psychological state.

Germany

Silke Schicktanz, Mark Schweda

Recent strategies to increase the number of donor organs are in need for reconsideration

A central concern of the German policy debate on organ transplantation is the mismatch between the supply and demand of donor organs and the attempt to raise their total amount. This was one of the main motives of the Transplantation Law (1997) and many public information campaigns and constitutes both, an important touchstone for their evaluation and a legitimacy basis for recent, far reaching proposals, e.g. the plea for financial incentives (see e.g. Breyer et al. 2006) or for an objection solution (see *National Ethics Council* 2007). However, in the light of our findings, the premises of these strategies need reconsideration: The participants in our lay focus groups did not seem to be unaware of the problem of ‘organ scarcity’ or their possibilities to help, nor did they appear to be selfish or attracted by financial benefits (see Schweda and Schicktanz [in process]). Instead, one of the main factors impairing their motivation to donate seemed to be a lack of information on the political and organisational aspects of the transplantation system. Not being able to exclude inefficiency, wastage, injustice or even abuse in the system nurtured distrust and was a reason for reluctance to donate. Therefore, stimulating the public’s readiness to donate might not so much require changes to the system as such, but rather an increase in its publicity and transparency.

Genetic testing is discussed in the context of an erosion of the German welfare state

In the German focus groups, the erosion of the present welfare state and its solidarity-based health care system constituted an important reference point in many discussions of the risks and potentials of biomedical technologies. Current political reforms and cuts in the social security and health care system and the accompanying media coverage may contribute to this picture. In the discussions, biotechnological developments were frequently linked to this trend as one of its driving forces and manifestations. Especially with respect to genetic testing, the fear was expressed that it could prepare the ground for or advance the evolution of a two-tier medical system by shifting the responsibility for health care from the state respectively society to the individual, thus making the quality of medical care dependent on its access to and management of diagnostic and preventive options. The impression that genetic testing intensifies social insecurities and inequalities seems to be additionally reinforced through the risk of genetic discrimination by insurance companies or employers. A clear regulation that provides legal certainty, especially with respect to data security in the context of insurance and employment law, is still lacking (a draft being in abeyance since 2004), although it could be pivotal to reduce some of these fears.

Latvia²

Aivita Putnina

Organizing participation as a trust building mechanism

In Latvia, patients and patient organisations have a comparatively weak role in decision-making processes. First, Latvian society trusts science and scientists, which is reflected in the distribution of authority and knowledge in the case of the new biotechnologies. Second, civil society and public participation is still a new practice and patients are undereducated in basic principles of health care and science governance. Cooperation with patient NGOs from neighbouring Scandinavia proved to be a crucial step for setting foundations for patient NGO movement. However, much should be done strengthening the capacity of patient NGOs both in terms of quality of interest lobbying and securing financial basis. Patient NGOs emerge not only in the situation of economic insecurity hindering citizens and especially those chronically ill invest time in participatory activities. They also occur in the landscape with strong professional doctor and scientists organisations having considerable experience effectively lobbying interests and possessing administrative resources for these activities. The public and governance in its democratic sense is missing from Latvian public debate on biotechnologies. Scientists, doctors and politicians play the main role in defining the policy agenda and they see normative regulations as means to replace transparency and accountability of the policy process in the area. At the same time, decline in trust and support to biotechnologies can be observed. The CoB case study shows that high trust in science still influences the positive attitude towards the technologies in general but has a negative impact on behaviour when reacting to the situation with the technologies in particular. Insofar failure in trust towards technologies can be explained by individual factors towards science will remain intact and only behaviour as adaptation to particular situation will change. The development of both biotechnologies – organ transplantation and human genome project is threatened, as it requires the active participation of donors. Participation without granting access to decision-making will further corrupt eroding trust relationship between the public

² In Latvia, no focus groups or interviews were conducted within the framework of the project.

and the technologies. Public participation traditions, accountability and transparency of should emerge as a factor balancing trust towards the technologies.

Biotechnological developments produce new forms of affectedness

New technologies erode previously set borders of affectedness and non-affectedness. This poses threats for the development and application of the biotechnologies not only in terms of participatory practices defining the groups of affected persons but also conceptualising affectedness in the light of the new technologies. For example, participation in genome project allows defining affectedness in a much broader sense as presently occurring illness. The Latvian case study shows that patients are not willing/prepared to share this new definition of illness and chose not to use and not to know about. The new technologies can be applied only under the condition that health and illness definitions change. Otherwise the new knowledge and costs invested in producing it might prove being ineffective if potentially affected people would refuse to know and utilise it. Involving non-affected people according to the traditional definitions of illness in decision-making process and treatment developments will be a challenge that is posed already now, e.g. in case of public support for organ donation. Gender factor in organ donation reflects gender-based inequality and economic security. The low number of live donors depends on the lack of real social security provisions for the donors during the donation and virtually no social security in case the donation brings risks to health. Donation brings risks of losing job and damaging health which in the situation of economic instability threaten families to a greater degree than the lack of donors. Men are especially vulnerable group as they still are main breadwinners and their health condition and job are the main guaranty for survival of the family, especially when one member of the family is already affected and already draws additional resources from the family.

The importance of reciprocal relationships

Organ donation and gene donation set a particular relationship based on gift economy. The morality of gift depends on situation and mutuality of transaction that cannot be normatively regulated. Therefore, trust building as an active mechanism of establishing mutuality should be stressed. Latvian case study shows that reliance on solely normative regulations erodes trust. At the same time mutuality, significance of personal relationship, long experience of cooperation and responsible attitude towards partners in organ procurement allow building long-term trust relationship that become an effective mechanism for regulating the reporting for organ procurement. Similarly, despite the presumed consent regulation and very low public knowledge of this regulation the high number of potential donors does not play a crucial role in receiving formal consent for donation. Rather conversations and respect paid to relatives of the post-mortem donor become the main source for consent. Donation produces new kinds of obligations and responsibilities that might seem irrelevant from a normative point of view but are essential from the point of gift economy – organ transplantation produces “kinship” between recipients of the same donor kidneys, making them “siblings” (term that is used by patients); establishes imagined relationship between the donor and recipient, and relatives of the deceased donor and recipient. All these relationships are essential forms of engagement that should be taken into account considering the building of trust.

The Netherlands

Annika den Dikken, Marcus Düwell

Information policy concerning organ donation in need of revision

All Dutch focus group participants recognize a lack of information concerning each issue of biomedicine. They wish to receive more information about the questions they will be confronted with, the procedures and the technical aspect. In case of genetic testing, the participants wish more information for those who need to consider genetic testing; about procedures and (ethical) questions that relate to the test. They also wish more information for the general public. Informing the public could raise understanding for people who have a hereditary disease in the family, whereas they now find people judging too easily. In the case of organ transplantation, all participants think there is a lack of information. For years, the government and several associations have tried to increase the number of organ donors by informing the public. Our results raise the question whether the information that has been given served the needs of the public. The emphasis of most actions was on the positive effect of transplantation for the recipient, showing that people's lives are saved or improved in quality. The group participants do not question that at all, but the persons who explicitly refuse registration as a donor mention that they do not have enough information about the procedures of organ removal. They fear that they will be declared brain dead too easily and that their relatives cannot say goodbye in a way that is good for them.

Information and medical care in need of standardisation

The participants view government as the most responsible actor in the regulation of biomedicine. The most important reason for that seems to be that it can introduce laws and rules that are general, so that information reaches all citizens and differences between hospitals can disappear. However, many participants are not content with the way the Dutch government copes with biomedicine. This can be related to a general lack of trust in the government that has been discussed in the media during the last few years. The affected people acknowledge their own possibilities and responsibilities towards the public. Many of them already participate in educational programs of the associations related to organ transplantation or genetic diseases. However, they do not think that is the ideal situation, because they could never reach everybody. Many organisational issues surrounding biomedicine, like the offering of information and in the context of genetic testing some procedural issues or matters of service (genetic counsellors) now seem to depend on personal or institutional initiatives. On the one hand this leads to the lack of information people complain about. On the other it causes fundamental differences in how people are guided in their confrontations with biomedicine. We would recommend further research to see whether there are ways to standardize the information about biomedicine presented to the public. Furthermore, especially in the case of genetic testing it is important to recognize that affected people notice that they are treated very differently in different hospitals. Further research is necessary to find out whether general standards can be formalized, covering medical aspects, but also reflection about guidance on the psychological, emotional, interpersonal and ethical aspects people are confronted with.

United Kingdom³

Darren Shickle

The role of patients in the health care system is changing

In Britain, there has been a change from patients being passive recipients of health care to consumers of health care. Patients used to be deferential to doctors and grateful for the care that they received. Now they are expected to have more control over the care they receive and take responsibility for their health accordingly. This has been associated with the introduction to an internal market within the NHS, with publicly funded hospitals competing for patients. However, while a customer in a shop or some other service is able to form some judgement of quality of product/service, this is much more difficult in the health sector as health interventions are much more complex, require different/deeper knowledge bases and the stakes involved of making wrong choices are much more serious. With the increasing presentation of the citizen as a consumer of social goods, there has also been increasing use of the term 'social marketing' and advertising techniques are being used to achieve behavioural and attitudinal changes amongst the public e.g. within health promotion.

Public and patient involvement in decision making is seen as deficient and impeding

Under current UK Government policy, there is no statutory requirement to consult with patients and the public on major changes. Previously, NHS bodies were required to consult with independent Community Health Councils funded by the government if they wanted to make significant changes to services. This lack of an independent statutory body is a weakness in the UK – linked to public perceptions of trust. Public consultation is often perceived as a bureaucratic hurdle. It tends to be done late in the planning process after decisions are made and when it would be difficult to change plans. Most 'ordinary people' will be unaware that a consultation is taking place. Those who respond tend to be professionals or organised lobby groups with particular agenda, which follow the debate and hence know when consultations have been launched. Consultation methods are not developed to maximise input. It is therefore not surprising that responses to public consultation are poor. However, public bodies see this as public apathy, and reasons for not investing too much time or money in consultation. This is a vicious circle, as it leads to poorer response in the future if the public perceive as a waste of their time if their views are not taken seriously. There is concern that government is more interested in protecting the interests of commercial sector and organisations than in looking out for the interests of the ordinary citizen. Historically, a key challenge has been characterised as one of representation versus representativeness. Representation should be meaningful, supported and of equal value, with clear lines of accountability. The agenda should be transparent to all. Proxy involvement should be valued equally with individual engagement.

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³ In the United Kingdom, no focus groups or interviews were conducted within the framework of the project.

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