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## **Visions and Versions of Governing Biomedicine: Narratives on Power Structures, Decision-making and Public Participation in the Field of Biomedical Technology in the Austrian Context**

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**ABSTRACT** In recent years, governance and public participation have developed into key notions within both policy discourse and academic analysis. While there is much discussion on developing new modes of governance and public participation, little empirical attention is paid to the public's perception of models, possibilities and limits of participation and governance. Building on focus group data collected in Austria within the framework of a European project, this paper explores lay people's visions and versions of government, governance and participation for two biomedical technologies: post-natal genetic testing and organ transplantation. Building on this analysis, we show that people situate their assessments of public participation against the background of rather complex lay models of the governance and government of the respective technology. Because these models are very different for the two technologies, participation also had very different connotations, which were deeply intertwined with each socio-technical system. Building on these findings we argue for a more technology-sensitive approach to public participation.

**Keywords** biomedicine, governance, public participation, technology

## Visions and Versions of Governing Biomedicine:

### Narratives on Power Structures, Decision- making and Public Participation in the Field of Biomedical Technology in the Austrian Context

*Ulrike Felt, Maximilian Fochler, Astrid Mager and Peter Winkler*

In recent years, governance and public participation have developed into key notions both for policy discourse and academic analysis. Scientific and technological development is one policy segment that has been particularly touched by these changes. Public controversies over technologies such as genetically modified organisms (GMOs), or a major crisis such as the one surrounding bovine spongiform encephalitis (BSE), have hinted at the fragile nature of public trust in how scientific and technological developments have been handled. There are many examples that illustrate these shifts.

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The White Paper on Governance, published 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. The foundation of the Centre for Public Engagement with Science and Technology by the American Association for the Advancement of Science (AAAS)<sup>1</sup> is an example of the institutionalization of these policies in the academic sphere.

The explicit objective in many of these policy discourses is to 'bring science closer to citizens' (European Commission, 2002: 7), in order to 'provide a space for scrutiny and informed debate on important issues of public concern' (European Commission, 2002: 17), or to address 'not only the inherent benefits, but also the limits, perils and pitfalls' of science (Leshner, 2003: 977). Indeed, the European Commission's White Paper on Governance (2001: 10) clearly outlines the need for more 'participation throughout the policy chain – from conception to implementation. Improved participation is likely to create more confidence in the end result and in the institutions which deliver policies.' It also makes a clear plea that 'legitimacy today depends on involvement and participation' and calls for new forms of governance to replace 'the linear model of dispensing policies from above' (p. 11).

In most of these policy papers, but also in much of the academic analysis, participation in governance is seen as an answer to the shortcomings of top-down techno-scientific approaches. Thus, an analysis is carried out as to which governance models may/should be developed and how public participation is/should be implemented, but little attention is paid to the public's perception of models, possibilities and limits of participation and governance. Governance and participation are also 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.

This paper uses focus group data collected within the framework of a European project to critically question these basic assumptions and analyse in detail the perceptions and images that citizens have of government, governance and public participation. The focus group discussions, and our analysis of them, concerned two biomedical technologies: organ transplantation and post-natal genetic testing. Our study takes up one of the most central arguments in critical Public Understanding of Science research: that the positions taken by lay people are much more complex than any top-down vision ever seems to recognize. As has been shown by previous STS studies, lay understandings of techno sciences are shaped by situated perspectives as well as institutional contexts.<sup>2</sup> Many STS studies have discussed situated understandings of biomedical issues by demonstrating the importance of different relations, such as personal affectedness, to the subject in question.<sup>3</sup> While such studies are highly relevant to our empirical orientation, in this paper we expand the focus to a less prominent issue in STS discussions: lay political theories (Michael, 2002) and their relations to public conceptions of socio-technical systems.

How do people perceive participation and governance in a socio-technical system? What are their different visions and versions of how

technologies are embedded in society, and of how active or passive they allow themselves to be towards such technological systems? How do they perceive the prevailing power structures, what potential do they see in participating and where do they find the limitations? These questions were featured in our focus group discussions and are addressed in this paper. We begin by discussing the relation between the concepts of government and governance, and follow with reflections on citizens' participation in techno-scientific decision-making. After discussing our research design, we will briefly characterize organ transplantation and post-natal genetic testing. This will lead us to the core of the paper, the detailed analysis of the focus group data.

Our discussion examines the extent to which technology makes any difference for participants' visions and versions of government, governance and public participation. We conclude by arguing for a more technology-sensitive approach to public participation and governance.

### From Government to Governance?

Governance has become a buzzword in much recent political and academic discourse. As with many popular analytical concepts, the use of the term varies widely between authors and disciplines. Studies have shown that a large number of competing definitions for the concept can be identified (Jordan et al., 2005). It is not our aim in this paper to join this discussion or even to add another 'definition' to those that have been advanced. It is sufficient for our purposes to identify elements of the governance concept that constitute a kind of 'baseline agreement' (Stoker, 1998).

One of these baselines is that governance describes a change in the meaning of government (Rhodes, 1996). While the terms 'governance' and 'government' have for a long time been used synonymously in ordinary as well as scientific usage, the recent discourse about governance situates both terms at opposing extremes, as two 'heuristic "poles" on a continuum of different governing types' (Jordan et al., 2005: 492). 'Government' is used to denote a traditional mode of ordering society, where power rests in the hands of formal public institutions and the state. In this mode, steering is accomplished through centralized means of exercising power, such as laws and regulations.

In contrast, 'governance' refers to new constellations of power that go beyond the structures, rules and processes of classical government. 'Governance' often involves non-governmental actors in policy-relevant decision-making, which means that the boundaries between public and private sectors are increasingly blurred. With the involvement of these new actors in policy-making, decision-making constellations shift from the top-down model that is characteristic of 'government' to network-shaped structures that exemplify 'governance' (Stoker, 1998). The framing of policy issues and the processes of regulation and implementation are increasingly de-centralized in this model of ordering society. Thus, 'governance' may be seen as a new mode of distributing power and regulatory competences.

The emergence of governance is often argumentatively linked to a decline in the ability of central governments to effectively steer society and

the failure of traditional decision-making structures. The reasons for this failure range from challenges posed by processes of globalization, to a displacement of power from the nation state to supranational organizations such as the European Union. However, the empirical basis for the shift from government to governance is often criticized as being rather weak (Jordan et al., 2005). Key empirical questions about the relationship between governance and government and the identity of new actors and their role in these processes remain open.

While in the academic literature the concept of governance is used to conceptualize an empirical shift in the modes of ordering society, the use of the term in the political arena often carries a normative connotation. The involvement of new actors and the implementation of new mechanisms of governance are explicitly called for to address pressing problems of the current situation of government. In a White Paper on Governance, the European Commission (2001) calls for new methods of policy-making in response to a perceived crisis in governance. It mentions two dimensions of this crisis: a 'perceived inability of the Union to act effectively' (European Commission, 2001: 7) on problems such as unemployment or food safety, and a growing sense of distrust in existing political institutions. Traditional political means of steering and regulation are seen as ineffective and to be supplemented by new mechanisms such as 'co-regulation' that involve non-governmental actors 'upstream' in the policy process. More importantly, however, the crisis is linked to difficulties in the political relationship between the European Union and its citizens. Increasing distrust and disinterest in traditional political institutions are seen as the main obstacles to be overcome, and a 'reinforced culture of consultation and dialogue' (European Commission, 2001: 16) is seen as the answer to this dilemma. In this conceptualization of governance, 'citizens' and 'civil society' should be more actively included in the policy-making process, even though it remains unclear exactly who is to be involved and who will speak in the name of society.

### **Public Participation: From Experiment to Best Practice?**

The increasing emphasis on creating a dialogue between science, science policy and society in the European policy sphere has created a demand for ways to enact these new forms of governance and has spawned a number of experiments in participatory engagement with science and technology. These experiments draw on European traditions of participatory events both in policy and academic spheres. We use the term 'participatory events' to denote methods that attempt to incorporate public representatives in the discussion of and the decision-making about technoscientific issues.

Although it is difficult to pinpoint an exact point of departure for the history of public participation in science and technology in Europe,<sup>4</sup> the first consensus conference held in 1987 in Denmark is a reasonable starting point. The Danish model of the consensus conference is considered a paradigmatic example of public participation in technoscience. The process

involves giving a group of lay citizens a broad topic; the group then defines a specific question to be addressed in the conference. During the conference, the citizens select and question experts on the chosen topic. The lay panel drafts a statement documenting the opinion of the group, and this statement is often directed towards policy-makers. The consensus conference model developed by the Danish Board of Technology was taken up in the mid 1990s by other European countries, such as Great Britain and the Netherlands. Since then, a large number of European countries have imported the model. European countries have also experimented with new methods of public participation, and the scope of methods available has been broadened significantly. In Austria, which may be described as a late-comer concerning public participation in science and technology in Europe (Grabner et al., 2002; Felt et al., 2006), a number of experiments have taken place, including a citizen conference. Most of the recent events focused on genomics and society, especially in the medical domain, but their impact on public discussion in Austria has been limited due to a lack of media coverage.

The growing attention given to public participation has created an attendant increase in discussions about best practices. Considerable time has been devoted in science studies writing on participatory designs to finding common definitions and standards for evaluating participatory events (Rowe & Frewer, 2004). In light of the fact that several exports of the standardized package of the consensus conference to other European national contexts have failed, a framework for evaluation seems both necessary and legitimate. Such a reductive framework, however, is ill-equipped to contribute to an understanding of these failures, as it does not take the cultural situatedness of participatory mechanisms into account. Experiences in transferring the consensus conference model to other national contexts such as Austria or France have shown that the assumptions concerning the relation between science, the public and the policy sphere implicit in the standardized package may not apply in all European contexts (Felt et al., 2006).

The importance of cultural context has been amply demonstrated in the case of public understanding of science activities (Felt, 2003), and we argue that different (national) cultural contexts must be taken into account when transferring participatory mechanisms from one nation to another. In other words, the models and conceptualizations of governance built into the design of the participatory exercise must be compatible with the existing models of governance in the national (and local) context. This approach suggests that efforts to determine best practices and benchmarking criteria for public participation at the European level (European Commission, 2002) may not be successful.

## Voicing and Silencing Citizens

Participatory methods can also be read as ‘technologies of community’ (Rose, 1999; Irwin, 2001), in the sense that they create contingent representations of the public in the policy process. Michael and Brown (2005) have

argued that these designs ‘make’ citizens through ‘formalized mechanisms of voicing’. Assumptions about who may legitimately speak in the name of society are built into participatory designs, and the ‘construed publics’ of different designs vary widely.<sup>5</sup>

We have argued that these assumptions are often implemented in a top-down way, without taking into account whether they fit the views of the lay people who are expected to ‘participate’. In some cases, participants may reject the model of political representation built into the design. This was the case with the first Austrian consensus conference, where the participants did not perceive themselves as being in a legitimate position to decide on the issue discussed (Grabner et al., 2002). This example suggests that citizens are not only ‘made’, but that they also may resist the ideas of governance imposed on them.

While the role of the public is important both in European policy and the STS discourse on governance (Hagendijk et al., 2005; Jasanoff, 2005), relatively few studies have addressed the public’s perception of the processes of governance and of the actors involved. Michael and Brown (2005) have examined public self-representations in the area of xenotransplantation. Based on focus group data, they show a wide range of representations of science and the public in lay people’s accounts that ‘do not necessarily follow common notions of the divide between science and society’ (Michael & Brown, 2005: 55). Their work suggests that the public’s perception of central categories relevant to the concept of governance may be quite nuanced and context-sensitive.

## Tracing Perceptions and Imaginations of Government, Governance and Public Participation

### *Starting Hypothesis*

In this paper, we explore the complexity of public perceptions of processes of governance and the possibilities and limits of public participation for two selected biomedical technologies. We offer two preliminary working hypotheses. First, we assume that whether participants are affected by the technology or not will make a difference. Second, we state the thesis that technology makes a difference. So far, very little attention has been paid to the relation between the participatory method and the particular issue or technology to be discussed. This may be seen as surprising in so far as studies of public perception of technologies have shown that the political issues may be assessed quite differently depending on the technology (Grove-White et al., 2000).

### *Setting and Method*

This paper is based on research carried out within the scope of the transdisciplinary European project ‘Challenges of Biomedicine: Socio-cultural Contexts, European Governance and Bioethics (CoB)’,<sup>6</sup> involving ten partner

institutions in eight European countries.<sup>7</sup> The main aim of this project is to obtain a better understanding of how biomedical technologies are perceived in the public sphere, what role cultural values/backgrounds play, and to what extent previous experiences matter when people position themselves towards such technologies.

The work presented in this paper is based on focus group discussions<sup>8</sup> on organ transplantation and post-natal genetic testing. In total, five 2-hour focus group discussions<sup>9</sup> were carried out in Vienna, Austria. As affectedness (personal experience with organ transplantation or genetic testing) was expected by the project team to be a key factor in individuals' attitudes towards the technology, each biotechnology was discussed in separate groups of either affected or non-affected ('lay') participants. In total, there was one affected and one lay group on organ transplantation, and one affected and two lay groups on genetic testing. A broad definition of affectedness was used as a selection criterion: experience with the technology as a patient or a person closely linked to a patient.<sup>10</sup> Non-affectedness was defined as having no contact with the technology on a personal or kinship level. Special emphasis was placed on obtaining a balanced group composition with regard to gender, age, religious background and education. The size of the focus groups ranged from seven to ten people. Participants were recruited by mailing flyers to private households in Viennese districts inhabited by people from different social backgrounds. Further, specific institutions, such as self-help groups, clinics, general practitioners and religious institutions were targeted.

Research team members acted as facilitators for the focus groups. A set of open questions were used to guide the discussion of the respective technology from a level of general individual perception, through scenarios in which participants were asked to discuss ethically controversial aspects, to a concluding reflection of possible alternatives for political steering, public information and participation. All discussions were fully transcribed and analysed with the qualitative research software ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, <[www.atlas.com](http://www.atlas.com)>), along a gradually revised and refined set of codes based on grounded theory methodology.

### *Organ Transplantation and Genetic Testing: Two Very Different Technologies*

These two technologies<sup>11</sup> were chosen for the project because they represent very diverse ways of thinking and doing medicine, and raise quite different ethical issues.

The basic rationales for the technologies, and also the way the body is conceptualized in their construction and performance, differ fundamentally. Transplantation medicine is a paradigmatic example of the conception of the body as a 'machine' consisting of discrete elements with specific functions. The metaphor of mechanistic replacement remains dominant in media debates<sup>12</sup> and popular beliefs (Sanner, 2002). In contrast, post-natal genetic testing is associated with information technology metaphors. These metaphors liken the



body to a medium carrying information – a specific genetic code that may be mapped and read by medicine (Keller, 1992; Kay, 2000).

These different ways of conceptualizing the body affect the medical encounter between technology and the individual. In organ transplantation, the individual is both the focus and frame of reference for medical diagnosis and intervention. A test to determine genetic risks, in contrast, can only be interpreted by referring to population-based data. The test result thus does not directly reveal anything about the healthy or unhealthy status of the person tested, but reveals only the person's risk of developing an illness based on his or her membership of a genetically defined risk collective (Rabinow, 1996). The two technologies thus mark the oft-cited shift from case-based individual treatment to population-based medicine (Armstrong, 2002).

Organ transplantation and genetic testing may also be described as technologies that alter basic socio-cultural categories such as death and illness. Following the first transplantations of vital organs, the legal definition of death was changed from heart death to brain death in many countries to ensure a legal basis for the implementation of this new technology. Genetic testing in turn blurs the boundaries between health and illness. People who are 'genetically at risk' for certain disorders are often conceptualized as neither healthy nor ill, but as something in between (Novas & Rose, 2000).

Within Austria, there are further differences between the two technologies concerning organization, legal regulation and public discussion. In the case of organ transplantation, the roles, duties and hierarchies of the institutions involved are clear-cut. Potential donors are reported to regional transplantation centres, which organize the allocation and distribution of organs. Austria is a member of the European organization, Eurotransplant. Most of the organs are distributed nationally, in order to minimize the time between organ removal and implantation (Hohmann, 2003). However, they may also be distributed to recipients in other member countries. In contrast to this centralized system, the infrastructure for genetic testing is more complex and de-centralized. While in organ transplantation the institutions involved in the system are strictly defined and limited, genetic testing can be carried out by any institution holding a licence. This makes the 'market' of genetic testing quite complex and lacking transparency. Since genetic testing is generally not covered by the Austrian health insurance scheme, the tests are treated as 'goods' on the healthcare market.

The respective clarity and complexity of the two technological systems correspond to their legal regulation. Organ transplantation involving dead donors is not covered by a distinct transplantation law. Instead, it is referenced in a single paragraph as part of the general hospital law.<sup>13</sup> Genetic testing, in contrast, is regulated by a specific law on genetics that is approximately 80 paragraphs long. Although the gene technology law also covers agricultural use of genetics, the different treatment that the two medical technologies receive from a legal perspective is significant. The brevity of the legal regulations on Austrian organ donation seems astonishing in light of the potentially controversial nature of the procedure. This regulation,

which is known as the ‘objection solution’,<sup>14</sup> dictates that each person on Austrian territory is automatically considered an organ donor, unless there is knowledge that the person made an explicit, prior objection to being one. Furthermore, there is no obligation for the state to inform citizens of the legal situation (Hohmann, 2003), as there is in Belgium, for example. Since the state follows a ‘politics of discretion’, significant parts of the Austrian population remain uninformed of the regulation. It might be speculated that the low number of people who have registered their names on the objection list is a consequence of this politics<sup>15</sup> – which may be described as quite successful, in so far as Austria is among the countries in Europe with the highest rate of organ donations per capita.

Although the ‘objection solution’ may be seen as a potential source of conflict, it has never been the subject of a public controversy, not least because the Austrian media supports the ‘politics of discretion’. Organ transplantation is framed as a national success story by the extensive description of the achievements of the ‘world-class’ transplantation practitioners, while controversial aspects are neglected. In contrast, genetic testing is much more controversial in the Austrian media, particularly in terms of data protection and possible genetic discrimination. Furthermore, success stories comparable to spectacular organ transplantations are lacking in the field of genetics, especially since treatments such as gene therapy are still far from being realized.

### *Structure of the Empirical Analysis*

In what follows, we analyse the concepts of governance, government and participation that were implicitly or explicitly discussed in the focus groups. We aim to identify ‘lay political theories’ (Michael, 2002) implicit in the participants’ discussions of the socio-technical systems. Hence, our empirical analysis is structured along three lines:

1. The initial focus is on the participants’ assessments of the *governmental regulatory structures* of the respective biomedical technology and the role of the individual citizen within these structures.
2. The second focus draws on the participants’ thoughts concerning the role and influence of new non-political actors on the evolution of the technologies – in other words, their perceptions *of / governance / with regard to the technology* discussed.
3. The final focus is on participants’ reflections on *possibilities of public participation in the governance* of the technology.

Our analytical approach for each of these three foci will be to trace the implicit set of assumptions about the ‘ordering’ of each socio-technical system. Both the focus groups on organ transplantation and on genetic testing were lively and contentious. In analysing the material, we realized that basic assumptions concerning the ‘political ordering’ of the respective socio-technical system seemed to be shared between affected and non-affected

groups. Thus, the divide in perceptions of government, governance and participation was to be found between the two technologies, rather than along the affected/non-affected dimension, as might have been expected from the STS literature on public uptake and involvement. Groups that discussed one technology seemed to share implicit 'paradigms' about government, governance and participation, although they evaluated them differently. Hence, we present our analysis of the three key concepts by contrasting the two technologies rather than the affected versus non-affected groups.

We conceptualize the participants' narratives as both perceptions and imaginations. While doing so, we stress that we read participants' accounts as active constructions consisting of inseparably interwoven 'perceptions' or 'versions', and more speculative 'imaginings' or 'visions' of the technology. Analytically separating 'actual' experiences from extrapolations based on these experiences is impossible in a focus group setting.

### *Perceptions and Imaginations of Government*

In the group discussions on *organ transplantation*, participants described the Austrian nation state as a centralized, powerful, sovereign and autonomous actor. This conceptualization of the state is reflected in a central topic of discussion within the organ transplantation focus groups: the relationship of the individual and the state, or more concretely, how far the sovereign state and its laws are allowed to intervene in the individual's life and personal rights. This question was mainly discussed in relation to the Austrian 'objection solution' and the concomitant 'politics of discretion'. Most participants, except for those directly affected, were unaware of the current Austrian regulation. After the facilitator introduced the regulation in the group discussion, two opposing argumentative positions could be identified.

Some strongly supported the current legal regulation, because they saw the state as acting 'reasonably'. This discursive coupling of the autonomy of the state and its rationality can be seen in statements such as one made by a young medical student commenting about the 'objection solution':<sup>16</sup>

**P5m:** ... that we are fortunately in a situation in Austria, where the law is actually very much based on reason in some way, even if this is explained in terms of history, and this was not a decision made by Austrians. ... (OTaff: 75)<sup>17</sup>

Speakers supporting this position portrayed the state as a legitimate political actor, a 'caring' state that carries out regulatory practices that ensure a high donation rate and thus 'saves lives'. In their view, the current regulation follows a benevolent logic by serving the collective good of its citizens, even when they do not know what is best for them. According to this logic, the 'rational' regulation should be prioritized over the individual right to freely decide for oneself:

**P5m:** ... I also find, not only for one's personal decision but in respect to the decision of an entire state. I believe indeed, we are in the fortunate

situation to also consider individual cases, e.g. if someone still decides against it, as we have many organs in Austria. But in respect to legislation and the general decision of a state I definitely believe that one should prioritize rational considerations over religious or any other notions. (OTaff: 175)

Unlike this speaker, some participants were critical of the current regulative practice and questioned its legality, especially of the way it seemed to violate the fundamental civil right of self-determination. The current regulation was even termed as a ‘state of lawlessness’ (P13f OTlay: 299) by one especially upset participant. This position is rooted in the conviction that it is legally wrong for a state to overrule the rights of a brain dead person, especially the right of corporal integrity, without that person’s prior consent. An example of this position was expressed by a young bookseller in a lay focus group:

**P18f:** ... The human being has indeed his own will and should decide during his lifetime what he would like to do thereafter. That the state is saying, if there is no response available, then we will remove the organs – I don’t believe that this is right and also not ethical. Now he is assuming a position that he should not have. Because I believe, the state is not allowed to rule about the person. ... (OTlay: 139)

Though they did not question the effectiveness of the current regulation for ‘saving lives’, speakers supporting a similar position strongly contested the moral legitimacy of the means used to achieve this goal, as expressed by a participant describing himself as an ‘active catholic’:

**P11m:** ... He [the brain dead person] still has his rights, his human rights. He still has his dignity, his human dignity and I cannot simply take it away from him, based only on the assumption: I could save another person with it. I cannot play off people against each other. ... (OTlay: 37)

In this quote, the current regulation’s implicit preference for a collectivistic logic to the individual right of self-determination is regarded as illegitimate. Thus the current governmental practice is perceived as a highly problematic and paternalistic restriction of those rights, rather than as an act of a ‘caring state’.

Nonetheless, both conceptualizations – the caring and the paternalistic state – share a view of the Austrian state as the central political actor that should decide on and implement regulations to serve the public need, and towards which the individual citizen has to define its position. The means through which this should be accomplished are the subject of conflict. However, in developing their arguments, both sides referred to law as a central form for negotiating the possibilities and limits of the sovereign state.

In addition to discussing the relationship between the individual citizen and the state, participants also debated the relationship between the state and ‘the public’ in general. Participants shared the perception that the exclusion of the public (because of a lack of information) plays a crucial role in the current regulative practice, as the lack of awareness of the public

ensures high 'donation' rates. Those in favour of the government's policy discussed the lack of publicly available information as a necessary precaution to defend 'reasonable' governmental regulation against a public that they characterized as irrational and unable to understand the logic of the current regulation. Those opposed to the government's policy regarded the lack of public information as an extension of governmental paternalism.

While group discussions of organ transplantation conceptualized the state as a central and sovereign actor, the discussions of *genetic testing* presented fundamentally different views of classical government structures. In the discussions, the 'state' as one single central actor was often completely absent. The term 'state' was not mentioned even once in any of the three focus groups, while it was frequently used in discussing organ transplantation; the participants used terms such as 'politics' or 'the politicians' when referring to the actors of government. However the term 'politics' was far from being a mere synonym for the 'state', since it carried very different connotations. It was seen as an assemblage of actors (individuals and institutionalized collectives), which ideally would be capable of acting independently and according to its own rationale. Yet in the case of genetic testing it was mainly characterized as only to be understood by taking into account the interests and logics of 'external' actors who influence it.

For example, a key problem anticipated in all groups on genetic testing was the potential for discrimination on the basis of genetic information. When the facilitator asked the affected focus group how this problem could be prevented, the participants identified governmental actors as in principle carrying the responsibility to solve this problem:

**P19m:** This is a sensitive topic and it can only be solved by politics. And it will for sure not be solved in our favour.

[P25f and P20m simultaneously]

**P25f:** Laws could be ... [simultaneously]

**P20m:** We won't be able to influence that. Only during elections and they don't do what we want anyway. [simultaneously]

**P24m:** Politics are shaped by economic interests, not by an interest in the human being. (GTaff: 652ff.)

Politics, in this excerpt and in many other discussions, does not follow its own rationale and make autonomous decisions. Instead, it is continually shaped and influenced by other forces, but not necessarily in the interest of ordinary citizens. Its capacity to solve problems in the interest of its citizens has been undermined by a plethora of different, in many cases labelled as economic, interests. Government as regulatory actor is perceived as being captive of such interests.

Thus, implicitly central governmental actors are conceptualized as either too weak to be able to legally prevent genetic discrimination, or as unwilling to do so because it serves the interests of actors they are more indebted to than to their own citizens, as the discussants stress in a number

of statements. They base this opinion not on any special feature of genetic data evoked in the discussion, but on the state's inability (or unwillingness) to prevent other kinds of structural discrimination in the labour market. For example, participants in the lay groups pointed to gender-related discrimination, while people in the 'affected' groups drew analogies with the ineffectiveness and even the counter-effectiveness of current disability regulations, as one senior representative of a cancer self-help group did:

**P19m:** ... Because a future employer isn't very likely to hire you if you are disabled up to 80%. Even if you couldn't tell just by the way you look. And it is the same with genetic testing. ... (GTaff: 105)

As in the organ transplantation focus groups, individual rights were thus in the centre of discussion. In both cases the state was criticized for not sufficiently protecting individual rights. However, in the discussions on organ transplantation, the state was described as actively reducing individual autonomy in favour of collective interests. The state was thus seen as violating these very rights, but in principle able to guarantee them. In genetic testing, governmental actors were conceptualized as unable or unwilling to protect these rights in the first place, and were not expected to take any action that would establish any regulation in the interest of its citizens. Rather, responsibility was seen as 'outsourced' to the individual citizen. He or she becomes responsible for 'knowing his/her genetic future' and acting accordingly to prevent illnesses and the costs that may arise for society. This was expressed in the following exchange between a general practitioner and a representative of a self-help-group:

**P21f:** It is already here. Acceptance for one's own decision is not given in society. ... It is my own fault if I don't make use of tests. If I make use of tests, then I will have problems with my private insurance or with a loan that I want to get from the bank.

**P19m:** It's also the following: [simultaneously] last year on the occasion of a 10-year-anniversary of cancer aid Vienna, Mrs Federal Minister stood on stage saying: Cancer is preventable. [some are laughing.] And this is the next step: it is your own fault.

**P21f:** It's your own fault, why didn't you prevent it?

**P19m:** And that's a very dangerous statement. (GTaff: 157ff.)

The perceived pressure to know one's genetic predispositions and the responsibly to act on the basis of this knowledge was also seen as part of a shift in the equilibrium of rights and obligations between the sick individual and society. Instead of illness (and similarly disability) being an 'accident' for which the individual is not responsible, preventing illness is increasingly seen as a personal responsibility.

While there was consensus concerning the diagnosis that responsibility is outsourced to the individual, there was no agreement on whether this should be seen merely as a burden or also as an opportunity both in terms of improving the individual health status, but also of contributing to a

responsible dealing with a healthcare system under financial pressure. A senior citizen affected by prostate cancer expressed the latter by stating:

**P20m:** ... Well, I believe it is also a responsibility towards the healthcare system, because the sooner the treatment is begun, the cheaper it is most likely. ... (GTaff: 99)

In the narrative of the few speakers supporting this position, the individual citizen is expected to take responsibility to compensate for the lack of agency of governmental actors.

### *Perceptions and Imaginations of Governance*

Which views of governance were discerned in our material on *organ transplantation*? Since the discussions and debates within the groups were dominated by a conceptualization of the state as a dominant and central actor, the 'mode of ordering organ transplantation' in Austria presumed by the participants resembles classical conceptions of government rather than new modes of governance. When participants' statements focused on networks of governance, though, they referenced or implicated other actors active in the governance of organ transplantation. They mentioned institutions close to the state, including the healthcare system itself, as well as self-help-groups and the medical profession. In contrast to participants in the groups on genetic testing, however, they did not mention 'non-medical' actors, such as players from the economy or the scientific community, as being part of the network of governance. The actors mentioned were also ascribed hardly any interests or rationales of their own, but were characterized as 'silent supporters' of the current regulatory practice. The positions taken by individual participants towards these 'silent supporters' depended on whether they accepted the legitimacy of the current regulation. For example, since the Austrian regulation depends on the diagnosis of brain death, participants opposing the current regulation questioned brain death as the only possible definition of death, as well as the authority of the medical profession to make that diagnosis. One participant even argued that physicians are 'probably not able to deal with ethical questions' and thus should not be allowed to make the decision to determine death:

**P11m:** I don't want to leave this question up to physicians, because physicians unfortunately tend to reduce the human being to organs, this is simply in their professional routine. ... (OTlay: 355)

In this quote, the medical diagnosis is not a neutral arbiter capable of pronouncing when an individual is dead both physically and socially and therefore loses his or her personal rights. Rather, it is described as a rationale that supports the existing system. It is not capable of adding any legitimacy to a practice that is already seen as unjustified.

The public is the only actor in the narratives on organ transplantation that is described as a qualitatively different type of 'silent supporter'. It is

conceptualized as ‘silently’ supporting the system – an actor that becomes a ‘present absence’ (Law, 2004) in the governance of organ transplantation. Still, there was a strong notion, especially among those in favour of the current regulation, that this absence is not the same as being powerless. In a sense, the system depends on the ‘discretion’ of this seemingly powerless actor. This was very well expressed by a young woman who received a lung transplant:

**P3f:** I, as someone who is affected, would not want it to change. Well, the system that has been built up, the transplant system seems to function very very well, particularly in Vienna. ... I would also worry – if that is discussed in public – that many people actually think about it and rather register themselves really in the objection list; and that we then actually, just like it is in Germany, have to wait much longer for an organ. ... I would rather fear – precisely, as you have said – if people who are not very familiar with it, all of a sudden join in the discussion. And their thoughts appear to be rather emotional and not based on one’s own experience and on being affected. (OTaff: 570)

This participant attributes the power to change the system to the public, but for the worse. If this ‘sleeping giant’ awoke and became aware of the current regulation, the regulation would probably have to be altered and the efficiency of the system would be diminished. In this storyline, the state is no longer absolutely sovereign, but is sovereign only on the condition of the public’s silence.

We have termed the model of governance described in the discussions on organ transplantation a ‘governance of discretion’. Discretion in this case carries a double meaning. On the one hand, a ‘governance of discretion’ denotes a system in which most actions are at the discretion of a central actor, referred to in the literature as ‘discretionary governance’ (Hagendijk et al., 2005). Thus this model of governance is strongly related to the concept of government. On the other hand, this governmental structure can also be thought of as conditionally sovereign, its sovereignty and success depending on the discretion and silence of the seemingly most powerless actor – the public.

In summary, only a few references or allusions to ‘governance’ are evident in the discussions on organ transplantation, even though the public is assumed to have an important role in the governance perspective. Both the participants opposing and those supporting the current regulation viewed organ transplantation as a stable, centralized system with clearly identifiable elements. Even though they understood that the government depends on the public’s discretion, participants did not broach the question of whether the state as the central actor is capable of ordering and regulating the way organ transplantation is done in Austria. Possible misuse or corruption was hardly mentioned, and if so then in reference to other nations, such as China. Instead, controversy in the focus groups concerned the means through which the ordering is done, specifically by keeping large parts of the public uninformed and taking organs without prior consent.

In contrast to the groups on organ transplantation, the groups on *genetic testing* paid little attention to government as a mode of ordering.



Instead, they conceptualized the state as merely one of many players active in shaping genetic testing and its social implementation. The other actors included the pharmaceutical industry, insurance companies, employers, patent holders and scientists. The mode of governance implied in the discussions on genetic testing is not an ordered and stable network with clearly discernible actors; rather, it is a chaotic and fluid system in which each actor tries to enrol others, as well as the technology itself, to share its rationale and serve its interests.

**P33m:** I ask myself what is behind these genetic tests, because, well, I wouldn't put that past anyone, neither the pharmaceutical industry nor some physicians that the only intention to develop and manufacture genetic tests in the first place, is altruism or any other idealistic good. ... But I suspect tangible material and economic interests. And I ask myself whether that's to be desired? Whether that is to be desired that a society invests funds by public and private organs so that a handful of elite scientists are able to make a name for themselves, are awarded Nobel prizes or any other thing and a few corporations make profit. ... (GTLay1: 769)

This participant describes two main actors as controlling the development and implementation of genetic testing: 'corporations' and 'elite scientists'. Neither of these actors is interested in the collective good, but instead serves own interests by seeking to increase profit or personal reputation. While other actors and motivations also are mentioned, economic motivations are most frequently cited. The strength attributed to the role of economic actors in governing genetic testing provides a reason for doubting the government's capacity to regulate and protect genetic data.

As evident in the quotation, participants expressed a negative view of such dominance by powerful economic interests. Only one participant, who advocated a 'liberal' position concerning the outsourcing of responsibility from the state to the individual, countered such criticisms by saying that economic interests are not necessarily negative:

**P26m:** I believe – because you have addressed the pharmaceutical industry – well they actually want to make profit with it. Well, I still have a little of a rural influence, and I don't know any farmer, who would do his job based on altruism, but he wants to live off it and that's his right. And the pharmaceutical industry. Well I don't want to somehow defame them more than they are. And on the other hand I am grateful to everyone, who gives me the opportunity, as aforementioned, to decide beforehand. I don't have to do it, but today, thank god, we are able to choose between many options of treatment. (GtLay2: 791)

In this excerpt, the speaker views profit as a reasonable motivation for pharmaceutical companies, no less than for farmers and other economic actors. Using classical economic reasoning, this participant also strongly separates production driven by economic interest from consumption, which offers users choices.

As in the case of organ transplantation, participants' views of governance imply that the public holds an important but special position in a

fluid and rapidly changing system: the public is an important ally for corporate actors and scientists, as a minimum of tacit public approval and consumer support is necessary to further their interests. Though viewed as an important actor, the public was treated differently from the other actors involved: the public did not follow its own interests or try to enrol other actors; rather, public opinion was easily manipulated and highly malleable:

**P39m:** It is indeed important how such an opinion arises. It's pretty clear, if a firm invests billions in producing such a test, it will also make sure that the public will have the opinion that that's a good thing. They will do advertisements; they will order studies that prove without any doubt, that it is good for us. As they are expecting profit, one can't even imagine, how much return something like that brings. There are opinion leaders and all of us are all depending; I mean we are influenced from different sides. And no matter how educated you are, I mean, we are all influenced from the outside. (GtLay2: 1159)

In summary, the governance of genetic testing was presented in our focus groups as a confused system of multiple actors that was difficult for the public to comprehend. They assumed that the development of genetic testing was driven by economic interests, which used publicity to obscure the risks, dangers and possible misuses of the technology from the public. It is interesting to note that by stating this the focus group participants set themselves apart from the 'general public', which does not recognize the true driving force behind genetic testing – while they do. In contrast to the groups that discussed organ transplantation, participants treated genetic testing to be difficult to predict, monitor and regulate. The complexity of the system is not the only reason for this difference, however: the participants seemed to view genetic testing as a novel and untested technology, unlike organ transplantation, which was perceived as more established. They also cited the fact that genetic testing produces data that can travel quickly and may be reproduced and used in unexpected places. This danger was often related through telling small anecdotes or jokes:

**P33m:** Well, I don't know what happens with such data. I am worried enough, when I think my preventive check up could lead to some data ending up at the health insurance agency, even though I don't really want that. And if some, I don't know, some clerical assistant will get my files by chance thinking: Oh my God, he lives next to me or ...

**P27f:** What, he wants to marry my daughter and is affected by that? [laughing] Coincidences have always occurred. (GTLay1: 935ff.)

Thus, while organ transplantation was described as an ordered socio-technical system, genetic testing was conceptualized and discussed as a complicated, confusing and difficult to localize system associated with high levels of social and technical uncertainty.

### *Perceptions and Imaginations of Public Participation*

Towards the end of the focus group discussions, participants were asked about the possibilities and limits for public participation in technological governance. In both the groups on organ transplantation and the groups on genetic testing, participants reflected on the chances and limits of public participation and drew conclusions based on the previously discussed visions of governance and government.

In the case of *organ transplantation*, participants concluded that the public has an important function in the socio-technical system through the very fact of its exclusion. Accordingly, the public's lack of awareness of the current regulation ensures the smooth running and success of the 'Austrian approach' to organ transplantation, and this works to the advantage of the dominant actors who are held partially responsible for not informing or misinforming the public.

Consequently, the possibility of public participation was seen as especially provocative for the organ transplantation groups. Participants in those groups assumed that the sovereign space of action reserved for the Austrian state in this system depended upon the public's exclusion, and so procedures enhancing participation might endanger the existing social order. This notion was shared within all groups that discussed organ transplantation, but since they disagreed about the legitimacy of the present regulation (specifically the 'objection solution'), they also differed on whether this would be desirable. Participants defending the rationality of the current system viewed public participation as unnecessary and the current regulation as fully satisfactory. This view was expressed by a medical student who was generally in favour of the consensus conference model, but argued differently for the particular case of organ transplantation:

**P5m:** And I believe the model is very, very reasonable. I only believe that for organ transplantation this is actually not necessary for the moment, as we have a law that actually everyone is somehow very satisfied with, yes. And if this should not be the case anymore, then this will probably be brought up within the political discussion, and then this entire democratic decision procedure is getting off the ground and there are elections, and so forth, but for the moment, I don't believe this is actually necessary, yes, to question anything. (OTaff: 568)

Accordingly, questioning the current regulation by enhancing public participation is unnecessary and potentially dangerous. This view was especially prevalent among members of the 'affected' groups, who argued that participation and discussion should be restricted to those who are either affected and therefore 'know the system' or are experts such as physicians or scientists. The wider public was described as either being too emotional or uninformed to join the discussion.

This position was strongly opposed by others who questioned the legitimacy of the current regulation. In their line of argumentation, the success of the system should not be used as an argument to cancel a basic right in a democratic society – the right of public participation in important political

decisions. The following exchange between two participants from the lay group exemplifies this conflict:

**P15m:** [Discussion on regulating organ removal in the hospital] You cannot always sort out this by way of popular discussion with the public, because people have very weird thoughts. Let's ask the people first e.g., if genetically unaltered tomatoes do still contain genes. 35% of all people will say: Organic tomatoes don't have genes. People are simply not ...

**P11m:** The question is not whether people are so ignorant or have different opinions, but that is a removal of organs, it is a political decision. And with such an important question it should be found by way of a public discussion and, I believe, not hidden in a chamber. (OTlay: 385ff.)

While the groups that discussed organ transplantation viewed public participation as having potential for changing the current system, the groups on genetic testing expressed nearly the opposite opinion. They saw public participation as futile in a system where the power of central political actors is extremely reduced and other actors have taken up the main roles. While the participants generally advocated public participation in governance, they also agreed that the voice of the public would remain largely unheard, given the chaotic nature of the current socio-technical system and the limited role that politics plays in it. Interestingly, though the discussants bemoaned the loss of classical participation mechanisms, they did not take up the idea that there might be other political mechanisms, such as consumer protests. Instead of envisioning other 'uninvited' forms for voicing public opinion, they seemed nostalgically to long for a strong state that would 'listen' to the voice of the public.

Furthermore, they viewed public participation as futile, not only because it had lost its main addressee, but also because the basic democratic rationale underlying the idea of public participation seemed to have lost importance compared with other competing rationales. They portrayed economic interests and rationales as largely displacing political considerations. This was exemplified by a discussion of ethics commissions in a lay focus group. In the discussion, ethics commissions were considered to be an important deliberative forum by the participants, which could include actors representing different groups and sectors of society. When the discussion turned to how a decision might be produced in such a setting, a retired person, using the dissent in the focus groups as her point of reference, questioned whether it would be possible to formulate a consensual statement.

**P27f:** Will it be done democratically? [by voting; authors' comment] There are six who are saying: yes, now everyone has to get genetic testing – and for two it is too much to ask for; or how will that take place?

**P30f:** There will be an economic consensus.

...

**P27f:** Yes, exactly, there will be economic experts, economic lobbyists are very competent within the EU [European Union]. (GtLay1: 1185ff.)

In this exchange, a democratic decision-making mechanism is presented as inherently weaker than a consensus dominated by economic rationales and interests.

As noted earlier, participants also characterized public opinion as highly manipulable by dominant economic actors. Consequently, they viewed participation not only as futile, but also as a sham and ‘waste of money’:

**P30f:** And, I mean, we all know ourselves, if surveys are conducted how it is dealt with it. They are initiated with a lot of money, conducted and pocketed – it will indeed, it will not even be ignored. [some are laughing]

**P26m:** ... The information that I am provided with shapes my opinion, because I am no specialist or because I am not an expert. And therefore I am incredibly easy to be manipulated ... And those are stories, where I am saying: If we allow for a broad public to have a say, and then they may be manipulated again with a lot of money ... – it is actually wasted money. (GtLay1: 1161ff.)

Some focus group members viewed public participation not only as futile, but also as potentially dangerous, since it would lend legitimacy to the non-democratic interests that manipulated it.

### **Conclusion: Technology Makes a Difference**

The findings from our study provide insight into the way citizens conceptualize three key-notions: government, governance and participation. Their views may complement and refine those expressed in current academic debates, but they also offer starting points to re-think the way governance and participation are ‘implemented’ and ‘practised’ in techno-scientific settings.

Our analysis indicated that the type of technology discussed was crucial for the positions expressed in the groups, rather than whether or not participants were affected by the technology. While there were differences between the affected and lay groups, even opposing arguments shared the same frameworks of reference for governance. For example, the affected and lay groups on organ transplantation expressed very different normative assessments of the role of the state in the governance of organ transplantation, but they shared the assumption that the state was a strong central actor. This differed completely from the groups on genetic testing, all of which assigned government only a minor role. Therefore, the specific features of the technologies and the participants’ perceptions of them seemed to play an important role in developing visions of government, governance and public participation.

Participants in the groups on organ transplantation drew on a widely disseminated story of success and progress, and assigned a dominant role to the state. They conceptualized organ transplantation as a system based on solidarity and a culture of exchange, with clearly discernible actors and structures. Potential risks involved in organ trade were seen as manageable through governmental regulation. The state was seen as a necessary central actor that assured the future of this field, even though criticism was raised particularly

by the non-affected participants with regard to the means by which this was done. Still, there was no fundamental disagreement that the field as such was working well and should continue to do so. From a governance perspective, the focus groups on organ transplantation expressed strong awareness that the current system depends on the discretion and 'silent support' of an excluded public. A change in public participation – shifting the public from silent support to more active involvement – might thus endanger the organization of organ transplantation in Austria.

The dynamics were quite different in the discussions of genetic testing. Accounts and narratives on this technology were mainly built around problems, and there were few clear success stories. Genetic testing was linked to monetary interests, potential discrimination, unclear power structures and unknown dangers. The socio-technical system was described as complex and difficult to grasp. Even the affected group, whose members often stressed the usefulness and importance of testing, qualified their statements with criticisms and doubts about the consequences of this new type of knowledge. The state was virtually absent from discussions, and its regulatory role could best be described as weak and steered by a changing set of actors who mainly worked in the service of economic interests. Thus, the dominant model of governance was based on the co-existence of competing rationales, with political logics being relegated to marginal status. Hopes for public participation were thought to be illusory, in the sense that such participation would have little potential impact without help from a central powerful political actor. Democratic participatory structures were seen as weak counterparts to powerful economic players, and focus group members feared that participatory structures might even lend legitimacy to the vested interests of the corporations that manipulated those structures.

Focus group members' perceptions and imaginations of government, governance and participation were complex and diverse. Such diversity challenges the idea that citizens see public participation per se as a desirable form of governance. Instead, participation was given very different meanings that were deeply intertwined with visions and versions of governance and government of specific socio-technical systems. Our material shows strong evidence that lay political theories must be seen as complex and multi-layered, just as STS scholars have demonstrated for lay understandings of technoscience.

Exploring these lay theories in relation to technoscience opens up a line of research questions to develop in further work. More detailed case studies would add to a deeper understanding of how different groups of people relate their visions and versions of governance and public participation to their perceptions and imaginations of specific kinds of technology. A comparative analysis of the relationship between lay political theories and the perception of technology across different political systems and cultures also may contribute to debates on the limits and possibilities of public participation across national borders in the European Union and elsewhere.

To conclude, we offer some thoughts on implications these findings may have for carrying out exercises in public participation. As outlined

earlier, two difficult-to-reconcile positions co-exist in the political and academic debate: one is that policy-makers should build upon standardized and transferable models of governance and participation, while the other stresses that policy-makers should take into account critical analysis that underscore the complexity of situated perspectives and local political cultures. Our findings point to a further issue that renders the idea of standardized ‘best practice’ designs and evaluation criteria even more problematic: Governance structures and participatory exercises in technoscientific decision making must also consider the specific features of the technologies involved and the lay political theories associated with them. As we have shown, people’s views on governance and participation vary fundamentally with the different technologies involved – even in rather closely related fields. Hence, in order to make citizen participation possible, it is important to take account of these differences. This implies the need to consider different engagement structures, involving different actors, moderation procedures and empowerment efforts.

## Notes

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1. <[www.aaas.org/programs/centers/pe/](http://www.aaas.org/programs/centers/pe/)>
2. See Wynne (1992) as a ‘classic’ representing an important tradition of STS writing in this domain.
3. For example, Epstein (1996) as an example of many other contributions.
4. For an overview of public participation methods in Europe see Joss & Bellucci (2002).
5. These arguments concerning the formation of ‘the public’ through participatory technologies link to the broader concept of governmentality (Foucault 1991 [1979]; Rose, 1999), which focuses on the processes by which political actors such as ‘the public’ are discursively formed. This discursive rendering takes place in policy documents, participatory designs and studies such as ours.
6. Funded by the European Commission under the 6th framework programme, ‘Science and Society’, Contract No. SAS6-CT-2003-510238.
7. The other partner institutions are from Cyprus, France, Germany, Latvia, the Netherlands, Sweden and the UK (<[www.cob-europe.org](http://www.cob-europe.org)>).
8. In addition, qualitative in-depth interviews were carried out in some participating countries.
9. For details concerning focus group methods see Bloor et al. (2001).
10. For example, the affected group for organ transplantation consisted of several persons who had received transplants, several relatives of receivers and one relative of a ‘dead donor’, as well as a physician formerly involved in organ transplantation. The group for genetic testing mainly was made up by people who had had a genetic test, or were related to a person who had taken a test. A number of different diseases were represented, including breast and prostate cancer as well as Crohn’s disease.

11. We take a broad view of technoscientific developments, looking at not only their technical features, but also the social and political contexts in which they are embedded. We do not conceptualize technology and society as two distinct entities, but as co-constructing each other and we understand both organ transplantation and genetic testing as socio-technical networks having both technical and social aspects inscribed in the structure of the system (Latour, 1991).
12. Philippe Chavot, Ulrike Felt and Anne Masseran (2001) have analysed how organ transplantation is framed in the French media with a specific focus on audiovisual formats.
13. Organ transplantation involving living donors is not regulated at all in Austrian law.
14. Our use of the term 'objection solution', instead of 'objection regulation', is based on the direct translation of the German term, *Widerspruchslösung*.
15. The objection may be deposited in a central registry called *Widerspruchsregister* at the Austrian Health Institute (ÖBIG).
16. Quotes are used for exemplifying our argument. If a number of quotes in a section are taken from one specific focus group and only a minor part from another, this does not necessarily mean that the argument was more strongly present in the former. It only means that the statements made in the former group concerning this issue were more 'quotable'. Speaker codes consist of a unique speaker number (Px) and the sex of the participant: for example, P11m stands for the male participant number 11. Focus Groups are identified as 'GT' for genetic testing or 'OT' for organ transplantation, and as 'aff' for the affected and 'lay' for the non-affected group. The two lay focus groups on genetic testing are indicated as GtLay1 and GtLay2.
17. The translations of the quotes into English were made by a native English speaker, though in a way that preserves as much as possible of the German word order. We have refrained from changing them into a stylistically more correct English on purpose, because to do so in many instances would have meant to shift implicit and explicit meanings.

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