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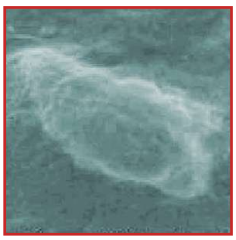

Participatory Governance and Institutional Innovation [PAGANINI]
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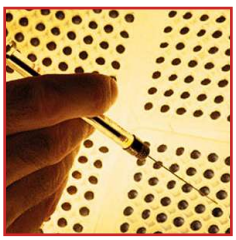
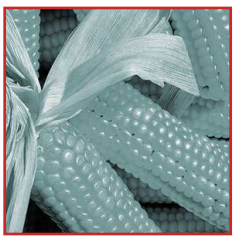
Work Package 3_The Governance of Genetic Testing

A NON-ANTAGONISTIC SETTING, "AUTHENTIC PUBLICS" AND MOMENTS OF UNEASE





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6th EU Framework Programme for Research and Technology

Participatory Governance and Institutional Innovation [PAGANINI]
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WORK PACKAGE 3 _ THE GOVERNANCE OF GENETIC TESTING

A NON-ANTAGONISTIC SETTING, "AUTHENTIC PUBLICS" AND MOMENTS OF UNEASE

Susanne Schultz, Kathrin Braun, Erich Griessler

The Paganini Project

Focussing on selected key areas of the 6th EU Framework Programme for Research and Technology, PAGANINI investigates the ways in which participatory practices contribute to problem solving in a number of highly contentious fields of EU governance. PAGANINI looks at a particular dynamic cluster of policy areas concerned with what we call "the politics of life": medicine, health, food, energy, and environment.

Under "politics of life" we refer to dimensions of life that are only to a limited extent under human control - or where the public has good reasons to suspect that there are serious limitations to socio-political control and steering. At the same time, "politics of life" areas are strongly connected to normative, moral and value-based factors, such as a sense of responsibility towards the non-human nature, future generations and/or one's own body. In these areas traditional mechanisms of governance can be seen to hamper policymaking and much institutional experimentation has been taking place.

The overall objective of the proposed research is

- to analyse how fields of governance related to the "politics of life" constitute a new and particular challenge for citizen participation and the generation of active trust
- to illuminate how citizens' participation in key areas of European research and technology policy that are connected to the "politics of life" can be made more effective and appropriate,
- to investigate the changing role of civic participation in the context of multi-level governance in the European Union,
- to contribute to institutional re-design in a the emerging European "politics of life".

Work package 3 – Genetic Testing

Work package 3 set out:

1. to investigate the effects of social controversy in the issue area of genetic testing on the emergence of new forms of civic participation in Denmark, Germany, Austria, the UK and on the EU-level and

2. to analyse the mechanisms and rationales underlying these new forms as well as their effects. The goal is to increase our understanding of the effects of institutional crisis in the sphere of "politics of life" on the development of new forms of participatory governance.

This report

This report is the final report of work package 3.

Table of Contents

1. Introduction

"But the problem is that the critique has become an integral part of all the talking about human genetics. All research programs are promoting that you produce critical thoughts on them. (…) Under the umbrella of democracy and participation the contradictions become a little bit wiped out, smoothed and softened. In my opinion the reason for existence of these bodies is basically to keep the talk alive, to continuously keep things in the consciousness." (Interview 26-3 2006)

This case study discusses the recent and current transformations of the politics of genetic testing. It refers to three quite different applications of genetic testing in the area of health politics:

- the practice of prenatal genetic diagnosis (PND) which by now has become a routine practice in antenatal care,
- the practice of pre-implantation genetic diagnosis (PGD) which is still prohibited in some countries and still very controversial in the countries under study, and
- the field of genetic testing for diagnostic and prognostic purposes in health care, related to the paradigm of a "predictive", "pre-symptomatic" medicine.

The study focuses on Austria, Germany, UK, and at the European level, which are characterized by quite different discourses on human genetics, different institutional settings, different (participatory) governance arrangements, and different transformations of discourses, institutions and governance arrangements over time. These arrangements range from a "permissive" and highly reflexive advisory system in the UK marked by pragmatic approaches and by a quite established and centralised public consultation scheme, which we will address in this report as "participatory governance arrangements", to a more restrictive system based on modern statecraft in Germany and Austria, where new participatory mechanism of citizens' participation are more disperse and marginalised by formal governance arrangements. The latter will be termed "participatory governance experiments" in this report.

Genetic testing as the most established application of human genetics is still a domain where national regulatory systems are comparatively dominant whereas in other fields of biotechnology such as "green" biotechnologies or stem cell research the supranational level is rather important. Within the EU institutional framework, health policy is not among the policy areas the EU has responsibility for but is still under the authority of national regulation and sovereignty. However, there are multiple indirect ways how EU policies are influencing the politics of genetic testing, for instance via research policies, or patent guidelines (Abels 2002). The Council of Europe with its Convention on Bioethics has also influenced the national debates on genetic testing in many ways. Moreover, there are various dimensions of the development of genetic testing that transgress national competences: Patients, tests, specimens, and related data are crossing national borders without regulation: There is a tendency towards treatment "tourism", especially in the case of PGD, an "internationalisation" of genetic tests due to an international network of laboratories (OECD 2005), and the international supply of commercial tests via the internet.

Genetic testing in the last decade, unlike most of the other areas of the politics of life studied by the Paganini project, is not a field marked by strong moments of rupture or dense dislocatory moments. It has not been characterised by strong controversial settings (as was the case with green biotechnologies), scandalous accidents (as in the case of nuclear energy) or strong crises of scientific frames (as in the case of BSE). Transformations of governance in the area of genetic testing have taken place in a context characterized by creeping changes and a simultaneous coexistence of different governance arrangements, discursive frames, and political subjectivities. Generally, the governance of genetic testing is based on an increasing public acceptance of human genetics as normal part of health care and health research (cf. narratives, chapter 3). There are strong indicators that Western European societies already have passed a process of "geneticisation", a concept which we will discuss in chapter 2. The supposed determination of human health and behaviour by genes has become deeply rooted in popular knowledge, although "scientific uncertainties" are increasing (Fox 1999). This has not always been the case. On the contrary, there had been strong social movements against "genetic engineering" in the 1980s when feminist and disability rights groups have developed a techno-sceptical discourse towards genetic testing. Some of the elements of this discourse, namely the metaphor of designer babies and the critique of genetic testing as a new form of eugenics, are still circulating today. Asides to these elements, conservative and pro life concerns referring to the status of the human embryo and to intervention in human nature underlie and frame debates on genetic testing today. These discursive heritages and frames are the ongoing reference points of certain

moments of public unease and concern expressed in the debates on "designer babies" or on the continuity of "eugenics".

However, and this is one important result of our study, today this unease does not take the form of acute public protest or opposition but is rather expressed within a pluralist, non-antagonistic setting where these oppositional arguments are not dominant, yet, nevertheless, vaguely and subliminally present. By "non-antagonistic setting" we mean a situation that is not characterized by an adversarial confrontation of two opposing "camps", in this case a pro and a contra genetic technology "camp", taking diametrically opposed views on the issue, each striving at defeating the other and making it politically insignificant. In today's constellation, techno-sceptic arguments have been disconnected from an antagonistic pro and contra constellation. They are circulating in a much more fragmented, sophisticated, professionalised, normalised, post-euphoric and post-catastrophic debate - which is nevertheless a broad and vivid debate, a debate, whose focus has shifted toward the daily applications of technologies and daily experiences with genetic testing.

The challenge for this work package was to understand the simultaneity of a non-antagonistic setting on the one hand, marked by the *absence* of antagonist conflict, and a "discourse intensification" on the other hand, incited and fuelled by participatory governance arrangements in different sites and settings – sometimes directly channelled from "above" by government-sponsored consultation processes or consensus conferences, sometimes more disperse, connected to academic social or cultural research or to NGO-activities.

Another specificity of genetic testing, distinguishing it to some extend from other issue areas within the politics of life, is that the perception and problematization of danger, risk, or uncertainty does not so much refer to unknown consequences of human intervention in biology or nature. It is not so much an irreversible or inappropriate interference into nature which makes genetic testing problematic in the view of its critiques. Genetic tests as diagnostic devices are not problematised as being risky because they would form invasive technologies, although repro-genetics are linked to very invasive procedures such as in vitro fertilisation (IVF) or amniocentesis. Also, there is still the promise of using genetic diagnostics for purposes of gene therapy, which would be a technology of intervening into the "nature" of people, in the future. Yet, what takes the centre stage in the perception of risks, dangers, or uncertainties with respect

to genetic testing is not so much its invasive character as the issue of potential social implications caused by its proliferation in society.

A third difference, for example in comparison to stem cell research, is that genetic testing has become a routine practice already in the area of PND and has lost the character of "science fiction technology", although in the realm of "pre-symptomatic medicine" widespread genetic screening practices are still "dreams of the future". Today, genetic testing has become a practice nearly everybody has come in touch with or knows someone – especially someone female – who has used it. The motivations, interests, or pressures upon individuals to use these technologies and – in neoliberal health care settings – the idea of exercising individual self-steering and individual self-responsibility via genetic testing have become an important element of the debate.

For all these reasons, in this case study we focus and reflect on the double dimension of "life" when we talk about "politics of life": the dimension of *zoe* and the dimension of *bios*. This double dimension of "life" refers to Aristotle and the fact that the ancient Greeks had no single word for "life", as Agamben has reminded us (Agamben 1998: 1), but these two different terms of *zoe* and *bios*. *Zoe* refers to what we call today the "biological" dimension of life which humans share with other living beings, whereas *bios* refers to the life you live as a social being, a citizen. The term "life" today can refer to both dimensions, however, in the context of the "life sciences" and the surrounding debates about it "life" tends to mean mostly *zoe*. As regards genetic testing, we hold, this would be too narrow a perspective. Genetic testing, in fact, today is at least as concerned with *bios* as with *zoe*, without, however that the two dimensions could be reduced to one another or have become "indistinguishable", as Agamben suggests. On the one hand, genes as artefacts entering politics stand for the idea of an "essence of life", of the ultimate "elements of life" in the sense of biological life (*zoe*). On the other hand – and this is one of our research results –the dimension of governing one's life in the sense of "*bios*", of lived individual life, of biography has become more and more important under conditions of a geneticised idea of the self. Genetic testing is increasingly linked to ideas of self-responsibility, life style, perceptions of a good body and good health and linked to an increasing discourse production on individual motivations and the social embedding of the motivations to use or not use tests and to handle their outcome. The increasing importance of *bios* in the field of genetic testing in turn has to do with a paradigm shift in genetics away from the "single gene hypothesis" to a more systemic focus on the interrelations between genes, genetic and epigenetic factors,

and genetic factors and the social environment and life style of a person. To the extend that the functions and the effects of "genes" are understood as expressions of multiple interactions between elements and subsystems some of which belong to *zoe* whereas others belong to *bios*, the study of *bios* is getting more and more significant to the study of human genetics.

What does all this imply for the relationship between risk and uncertainty? First of all, we need to emphasise that in our context we are not observing a linear transformation from risk regimes to regimes of uncertainty, but a change of these concepts themselves and their relation to one another. Second, in our context the term uncertainty does not refer to the uncertainty of scientific knowledge only (Jasanoff 2005; Wynne 2002), but also to the uncertainties of the governance of genetic testing, the uncertainty of economic prospects of the biotech industry (cf. chapter 2) and the uncertainty that we call the "uncertainty of the bios".

The idea of risk remains key within genetic knowledge production. In the context of genetic testing, "risk" refers to an individualised translation of statistical correlations within populations into individual probabilities of future illness or having "defect children". The idea of risk therefore is permanently present as an indispensable epistemological element of knowledge production in the area of genetic testing. However, the dimension of the emotional, psychological, and social embedding of (possible) test results more and more moves from the margins to the centre of the knowledge production and governance of genetic testing. The question whether and how consumers and health markets respond to genetic tests, and to what extent a pre-symptomatic and individualised medicine on the basis of genetic tests will establish, is one of the uncertainties that are increasingly becoming the focus and the main challenge for governance – we could call this an "uncertainty of the bios". This uncertainty increasingly incites reflections which in turn are present in the newer governance schemes. Therefore, we are observing a change from governance schemes in the 1980s that were based on the idea that experts can predict and evaluate the benefits and risks of genetic engineering for the society as a whole (as euphoric or apocalyptical settings of science fiction) to a situation where risk evaluations are handed over to the individuals while at the same time governance schemes are increasingly referring to "ethical aspects" of genetic testing – allowing a more pluralist conceptualisation of positions, values, and motivations toward these technological practices. In this sense the "ethicisation" of politics has a contextualising dimension. On the other hand, in the context of "regulatory ethics" we also observe a de-contextualising process of separating scientific facts from social concerns framed as "ethical". The process of "ethicisation" in the

context of regulatory politics also serves as a political/juridical tool to make unruly conflicts and concerns negotiable in terms of "brokerage". In the second part of chapter 4 on "politics of life" we will, however, show that these frames limiting and channelling the discourse on genetic testing not always take hold. There are still frames that consider the implications of genetic testing for the social order as a whole and transgress the fragmenting effects of ethicisation – as for example the concerns about the eugenic implications of genetic testing or about the possibility to create "designer babies". Their incompatibility with the dominant features of current governance schemes might explain why there are considerable efforts to limit, channel, and discredit such perspectives.

In comparison to the 1980s, the current discursive frames to govern genetic testing display a tendency to debate human genetics within a "post-euphoric" or "post-catastrophic"[1] setting. The reductionist idea of single genes directly determining certain traits of the body or the behaviour of a person have been challenged by more complex approaches studying the interplay between genes, cells, and the environment (cf. chapter 2). In this context the specificity of human genetics itself in comparison to other forms of medical or biological scientific knowledge is at stake. In chapter 4 on "politics of life" we will therefore address debates on "genetic exceptionalism", the specificity of "genetic discrimination", and also on the continuities or discontinuities of the eugenics frame within the new settings. The transformations of "politics of time" are important in this context and will be considered in three dimensions – as separation of past and present, in the context of "post-euphoric" or "post-catastrophic" scenarios, and in the context of new forms of "colonisation of the future".

How do (participatory) governance arrangements or experiments react to and also produce/incite the situation of a "non-antagonistic" pluralism of positions, multiple dimensions of uncertainty and double dimensions of life politics concerning the three areas of genetic testing under research? We approach this question in chapter 5. First, we examine institutional ambiguities in a twofold sense. Generally, there is an institutional ambiguity between the mechanisms of modern statecraft and newer governance schemes. The mechanisms of modern statecraft are firmly at place in large parts of regulatory decision-making and with respect to the

[1] The term post-catastrophism was introduced by Jahn/Wehling to describe the change in ecological discourses from the apocalyptical concerns of the 1980s to the promises of regulating and governing environmental problems since the 1990s. (Jahn & Wehling 1998: 81)

"hard issues" – such as research and patent policies, or the regulation of the health care system. These issue areas are often not influenced by newer governance schemes and are also marginalised by the discursive frames that actively influence the way how to publicly debate genetic testing. Second, there are mechanisms of professional self-regulation in research but also in medical care where guidelines of medical associations are the main regulatory force, for example, in the case of PND. This system of self-regulation in science and medicine is not really affected by newer governance schemes either.

Hence, one instance of institutional ambiguity we find in the area of genetic testing concerns the separation of new forms of governance from governance schemes dominated by either professional self-regulation or classical modern state power. A second level of institutional ambiguities is to be found *within* the new settings, that is within the sites where participatory governance plays a role and where "publics" and forms of problematisation of genetic testing are incited, activated, and constructed in a complex and also heterogeneous way. To study this type of ambiguities, we focus on micro-political settings, on specific examples of participatory governance arrangements or experiments: In the UK we focus on the Human Genetics Commission (HGC), in Germany on the internet forum www.1000fragen.de and the Youth Conference "The next GENEration" in May 2006 in Leipzig. However, we also take into account other participatory experiments such as a dialogue project at EU level or a consensus conference in Austria.

In this context, the dimension of performativity is crucial. In chapter 5 we will show which scenarios, which ways to communicate, and which political subjectivities are performed in the concrete settings of participatory governance practices. Thereby, we want to understand, how the "politics of life", which we have analysed in a more discourse analytical sense in the previous chapter 4, are *practiced* – both in the sense of being performed and of being exercised - and are *mise en scène*. Here, we study the frames and forms of problematising "life", but also the sites and scenarios in which they are performed, and the specific constructions of publics and political subjectivities that are addressed within these scenarios (Hajer & Versteeg 2005; Loeber et al. 2005).

In our work package, the dimension of discourse intensification in a situation of a non-antagonistic setting, the permanent activation of debates and participatory mechanisms without a driving force of an underlying conflict are of special interest. We will show that practices of

"performing participation" are constructing publics and political subjectivities in a messy way: On the one hand there is a heterogeneous setting of technologies to construct different "publics" – especially elaborated in the UK case: "Abstract publics" (constructed via opinion polls), "pure publics", that is formerly "ignorant" but then "informed" and "educated publics" (constructed, for example, via citizen juries), "expert publics" (a way especially "stakeholders" are categorised), and "affected publics". These different participatory technologies are linked to a changing landscape of political subjects considered relevant for the debate: Generally, we are observing a trend towards two poles. On the one hand, there is an increasing limitation of what is considered a "affected public" – reduced to people with personal experiences with problematic "genetic conditions" and leaving out older "affected subjects" rooted in social movements such as feminist or disability movements. On the other hand, there is a preference to perform abstract publics as "citizens" or "lay people", conceptualised as ignorant but nevertheless capable of being educated and providing ethically valid evaluations and opinions.

In chapter 6 we will connect the two analytical parts of our research, the focus on the *discursive* setting of politics of life and the focus on *performative* dimensions of participatory governance. We will add general remarks and caveats about the current challenges of participatory governance in this sphere of current politics of life.

Admittedly, the structure of this report requires some patience from the reader interested in the research results. Before analysing the specific PAGANINI questions and approaches it is necessary to expose and connect different historical, political, economic, and scientific events and transformations – in order to make our analysis transparent and base it in our empirical research results. Therefore, we will start the report in chapter 2 with an introduction into the techno- and econoscapes of genetic testing, the changing scientific knowledge production and technological practices of genetic testing, and the social visions and economic projects in which they are embedded. In chapter 3 we will try to order the politics of genetic testing in regard to the three fields, PND, PGD, and "predictive" medicine, as narratives, covering the time span from the 1980s through today.

2. Governing genetic testing: scientific and economic uncertainties, and dimensions of geneticisation

The social imaginary of genetic testing – once linked to science fiction imaginations such as the "total surveillance state", the "*gläserner Bürger*" (vitreous citizen), or "designer babies" (Franklin 2006) –, has changed in the last decades as genetic testing has turned into a widely accepted normal element of medical research and health care – above all in the area of ante-natal care. Nevertheless, the expansive possibilities of human genetics still evoke concerns and unease – some present from the beginning, some more oriented on the concrete applications of genetic testing in the context of health care, biotech research and industry as they have so far developed.

In the following we will map the scientific and economic landscape of current genetic testing practices, its links to the knowledge economy, knowledge production, and social visions packaged within, as well as the connected production of subjectivities. We will briefly discuss the scientific uncertainties evoked by an increasing complexity of models in human genetics or "post-genomics", the economic uncertainties a biotech-industry faces that is based on diagnostics without adequate therapeutic equivalents, and the psychosocial uncertainties inherent in the promotion of individual self-steering based on risk calculations and probabilities.

We will first introduce the definitions of genetic testing and current technologies of testing and discuss the underlying scientific knowledge production and changing social visions based thereon. Second, we focus on the institutionalisation of genetic testing in health care systems and move on to the "econoscapes" of genetic testing, thereby linking it to research policies and its interconnections with the biotech-industry and the production of "biovalue".[2]

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[2] Catherine Waldby describes the term 'biovalue' as *"a simultaneous surplus of vitality and profit, where the reformulation of in vitro life translates into patentable entities (cell lines, GMOs, gene sequences, SNPs) which attract venture capital, and eventually, it is hoped, into globally marketable diagnostics or therapies"* (Waldby 2005).

2. 1. Genetic testing: complex definitions, techniques and applications

The definition of genetic testing itself is contested. The range of medical practices, to which the term "genetic testing" supposedly refers, is a discursive element we need to contextualise in our research (Kegley 2000). While some definitions limit genetic testing to the direct analysis of DNA (deoxyribonucleic acid) sequences by molecular genetic techniques, the tests that ascribe genetic characteristics to individuals are much more complex and include tests on chromosomes, proteins and other biochemical markers (Hopkins & Nightingale 2004: 142). If defined even more broadly, "genetic testing" may also include the deduction of a "genetic condition" from certain physical features or from information about the family history of disease (Human Genetics Commission 2002b: 11).

Currently this uncertainty concerning the exact definition of genetic testing is articulated in two different interpretations. Some critiques of "genetic exceptionalism" claim that DNA-analysis is not fundamentally different from other diagnostic procedures. They argue that it is the diagnostic outcome concerning a "genetic condition" that is relevant and not the diagnostic technique or procedure employed to achieve such a result. Others, in contrast, opt for an extended definition of genetic testing. The purpose of this latter approach is to cover a broad range of possible forms of genetic discrimination and thus cover a broader range of practices, whether based on DNA analysis or other methods, by potential protective measures against "genetic discrimination" (see below).

Hence, genetic testing is a complex and heterogeneous set of technologies, applications, and purposes (Bayertz et al. 2001). In the following we focus on those forms of genetic testing that are integrated in medical practices and linked to changing ideas of corporality, health, disability, and disease (Kay 2000). We thus leave out forensic applications of genetic testing (criminological testing) and applications for identification purposes (e.g., paternity tests) and instead concentrate on three main fields of genetic testing in health care which have dominated the respective political debates in the last decades: First, pre-natal genetic diagnosis (PND), second, pre-implantation genetic diagnosis (PGD), and third, the field often summarised as "predictive medicine", referring to post-natal testing to predict the expression of potential future "genetic conditions".

The first two applications pertain to the field of "reproductive genetics" aiming at the prediction of genetic characteristics of future children. Pre-natal genetic testing refers to various non-

invasive and invasive testing practices in order test the embryo or foetus in the context of ante-natal care, that is involving the pregnant woman (see below). Pre-implantation genetic diagnosis (PGD), in contrast, is applied on an embryo created through in vitro fertilisation (IVF). PGD means to remove one of its cells in order to test its genetic characteristics before either implanting the embryo in the woman's uterus or discarding it. It should be noted that another type of analysis has recently emerged, which is known as "polar body biopsy". It involves the genetic analysis of the oocytes' polar bodies and allows to test the oocytes' DNA in the process of fertilisation before the emergence of "toti-potent" cells, thereby avoiding to test what is already considered an embryo, like in PGD (Nationaler Ethikrat 2004b).

The third application of genetic testing under study here refers to tests that are summarised as "predictive medicine". These are tests that predict future "late onset" inherited diseases or diagnose an increased probability or risk of getting ill by diseases some of which have only recently been conceptualised as being genetically conditioned. This transformation of diagnosis involves a transformation of the concept of disease itself by creating new perceptions of "still healthy" or "healthy ill" patients. There is also a broad field of practices to diagnose already manifest health conditions by genetic testing; yet, the social visions, promises, uncertainties, and political debates associated with "predictive" or "pre-symptomatic" medicine are the public energy field we are interested in. Therefore, we will confine our attention to this dimension of "post-natal" testing.

The techniques to analyse chromosomes and DNA sequences have developed over time. In the early 1960s cytogenetic techniques entered into widespread clinical use in order to detect chromosomal alterations – such as the maybe most "emblematic" condition through today, the Down's Syndrome. In the mid-1980s it became medical practice to test "single gene disorders" with clear patterns of inheritance using molecular genetic techniques (as for example Chorea-Huntington or cystic fibrosis). These so-called "high penetrance" conditions only included those with a very high probability to be "expressed" early or later in life or – in the case of recessive inheritance patterns – to be passed to children. In the light of such new possibilities it became standard routine in gynaecologic practice in a lot of industrialised countries to test such conditions by use of amniocentesis and chorionic villus sampling. Amniocentesis is normally performed between the 15th and 17th week of pregnancy. Through a needle into the uterus of the pregnant woman the physician collects amniotic fluid containing cells of the foetus. Chorionic villus sampling is performed earlier between the 10th and 12th week of pregnancy. A sample of

the chorionic villi, small projections making up part of the placenta, is taken through the cervix of the abdominal wall.

These invasive testing practices imply a certain risk themselves – for example a 0.5 to 1% risk of suffering a miscarriage in the case of amniocentesis. Starting at the age of 35 this risk is calculated statistically minor to the possibility of a "positive" test result – a cynical argument in favour of establishing screening procedures for women of that age group (Bartram 2005; Nippert 2005b). Invasive testing practices are normally prepared by pre-selecting techniques, which are interpreted as "sieving technologies" by Barbara Duden (Duden 1996) because they integrate a wide range of women into risk assessment. An older "sieving technique" leading to very uncertain results is a blood test executed between the 15th and 18th week of pregnancy (German: Triple Test, English: MoM-Test – Multiples of Median), testing the concentration of three hormones in the blood of the pregnant woman. MoM-testing has been increasingly questioned because of high false rates, both negative and positive (Samerski 2002). Therefore, there this pre-selective method is increasingly replaced by the rapidly expanding technique to scan the embryo via ultrasound. This scan is performed in the 11th or 12th week, assessing the nuchal translucency thickness in order to identify a higher risk of chromosomal "abnormalities". Nevertheless, this screening procedure yields, again, high rates of false negative and positive results (for example 20% false negatives) (Nippert 2005b).

While PND has become a routine practice, PGD is still a rather rare procedure (see below), yet important for our research as an "interface between reproduction and genetics" (Fukuyama 2002). PGD is a practice that links various concerns and topics in the current debates on politics of life. PGD consists of the extraction of one cell from a four to ten-cell stage embryo. Whether the cell at that stage still has the ability to develop into an entire embryo is contested. The fact that in order to perform PGD a "pool" of embryos are deliberately created only some of which are meant to be transferred to the uterus whereas those deemed "defect" or "superfluous" are destroyed or stored for research purposes is the main reason why PGD is considered to be prohibited by the German Embryo Protection Act of 1990 which bans the destruction of human embryos altogether. PGD as such, however, is not explicitly mentioned in the text of the Act. Another concern is that PGD could be performed on cells that are actually still "toti-potent", that is able to develop into an embryo and eventually a fetus – a reason why the artificiality of this cell and the question whether it is toti- or pluri-potent have become politicised. The status of the embryo is a frame that sets the basis to connect the discussion of

debates on PGD on the one hand and post-PND abortion on the other hand. The comparability results from the question whether an embryo or foetus can be discarded or aborted after specific genetic test results. Against this de-contextualised perspective on the entity of the embryo feminists have emphasised the difference between the situation of a pregnant women and the laboratory setting of PGD.

The increasing complexity of genetic testing is due to the expanding range of health conditions researched by human genetics and translated into testing practices. Human genetics research is steadily increasing the number of diseases or "impairments" ascribed to genetic factors – currently calculated as more than 10,000 (OMIM 2006). Whereas initially only monogenetic diseases were tested for, in the 1990s tests on genetic conditions became available that are described as "low penetrance". They are linked to such "genetic diseases" that are constructed as being caused by multiple, interacting factors rather than a single gene, based on the idea of an interaction between genetic and environmental or lifestyle factors. This type of genetic testing on genetic risk factors is the result of the expansion of human genetics research to cover nearly all most common diseases (in industrialised countries), as for example heart disease, diabetes, Alzheimer, and cancer (Hopkins & Nightingale 2004). Typical for this new field of "multi-factorial genetic conditions" is the high uncertainty of test results with respect to the question whether one person will in fact develop or not develop the respective disease in the future. Tests on "low penetrance" genetic factors provide unclear, uncertain diagnostic information on risks thereby leading to the problem of falsely positive or falsely negative diagnosis.

The innovation in this respect that has gained most public attention is the supply of genetic tests on familial breast cancer since the mid-1990s (Lemke 2003; Wagenmann 2003/2004). The tests on alterations in the BRCA 1 and 2 genes, which have been conceptualised as the familial breast cancer genes, are linked to a lot of uncertainties: First, they are only relevant to specific types of breast cancer, which make up less than 10 percent of all cases. Second, the probability of a woman with a positive test result to actually develop this type of cancer in the course of her life has been calculated with an increasingly less ratio and is currently estimated at less than 70 percent. Third, test results do not reveal when a disease will break out and how the disease will develop. Fourth, a negative test result does not imply that a woman will not still develop a different type of breast cancer during her life (Lemke 2003; Wagenmann 2003/2004).

Until now genetic testing has been the only application of human genetics in actual medical practice (leaving aside its indirect use in genetic engineering of pharmaceutical products). The promises of gene therapy, although having been promoted by a lot of research projects, have not resulted in applicable therapies yet. Maybe this is one reason why in recent years there has been an increasing investment in the idea that genetic testing can be developed and expanded to predict individual susceptibilities to specific drugs and medical treatments. The idea of this field of research and applications, called pharmacogenetics (cf. GeneWatch UK 2003a), is to detect genetic characteristics that are linked to the degree of individual sensitivity or insensitivity to a drug, to allergic reactions, or to side effects. Pharmacogenetics are currently at the top of the publicly presented possible future applications of human genetics and of genetic testing. The Department of Health of the UK in 2003 promised in its report "Our Inheritance, Our Future":

"The greatest impact of genetics on healthcare in the shorter term is likely to come from pharmacogenetics (…) likely to become available within the next five years" (Department of Health 2003: 14).

Until today, the molecular analysis of DNA sequences requires complex laboratory techniques that are time and money consuming. For the diagnosis of several "genetic conditions" a comprehensive search for a mutation by screening hundreds of possible mutations is required. An OECD study on "Quality Assurance and Proficiency Testing for Molecular Genetic Testing" in 18 countries explains:

"Many molecular genetic tests designed to determine if specific mutations are present start with the amplification of specific segments of the genome by the Polymerase chain reaction (PCR) followed by mutation detection using a direct or indirect method. More comprehensive analysis of genes, particularly when the precise underlying mutation is unknown, is accomplished by sequence analysis (…) Laboratories use a wide range of approaches for mutation analysis and a majority develop and use reagents for these procedures produced in-house (81%) while only 14% are indicating they rely entirely on commercial test kit systems. Thus, most genetic tests are provided as services by laboratories that develop, assemble and perform their own tests" (OECD 2005: 6).

Until today, these technological limitations of DNA testing impede a lot of screening projects of larger populations because they are too cost and time consuming. However, most observers of genetic testing technologies suppose that in the next decade these limitations will be transgressed by the development of DNA-Chip technologies. That would make genetic testing a lot cheaper and easier to apply (Schwerin 2002). The connection of molecular genetics with computer technologies will allow a drastic acceleration of sample evaluation and a high amount

of simultaneously tested DNA segments (Deutscher Bundestag 2000; Schwerin 2002; Zerres 1999).

2.2. (Post)Genomics? Scientific uncertainties and epidemiological self-evidence

On which knowledge about "life", which concepts of "life" are the practices of genetic testing based? In order to understand the transformations in the governance of genetic testing, we hold, we have to look at the continuities and discontinuities of the gene paradigm as it has evolved since James Watson and Francis Crick established the model of DNA as a double helix in 1953 to describe the structure of long chains of nucleotides containing deoxyribonucleic acid as "chemical of life" (Fox-Keller 2002; Kay 2000; Nelkin & Lindee 1995; Lock 2005). In the following years human genetics evolved around the idea later called the "deterministic model", which deduces complex processes of organic systems from the simplest elements, the single genes. Van Dyck has noted that this approach also helps to construct an image of the geneticist as hero conquering new land– framing human genetics as permanent story of "discoveries" (Dyck 1998). The idea that one gene generally determines one aspect of the human phenotype or of human behaviour is a linear model starting from the smallest element following it upwards until complex characteristics of the organism can be framed (Conrad 1999; Köchy 2003). This "bottom-up" approach dominated the various efforts of mapping the DNA sequences during the last century (Kevles & Hood 1993).

In the last decade various developments in human genetics research have contributed to shattering this model by introducing ever more complexities – but without completely giving up either the idea of a cause-effect relationship between genotype and phenotype or the informational model assuming that the genome contains the "programme" for life (Fox-Keller 2001). Researchers started to analyse the DNA sequences in relation to mRNA synthesis, to the regulation of proteins, to the interaction with other genes, to its cellular environment, and generally to the question at what time genes are expressed, activated, or inactivated. These are all aspects of a research trend away from focusing on isolated genes toward a research sometimes summarised as "epigenetics" or – referring to the protein expression, "proteomics", or more generally "post-genomics" (Rheinfelder 2003). The disciplinary boundaries between developmental biology and molecular biology have become blurred (Fox-Keller 2002) when

human genetics thus started to conceptualise genes less and less in isolation and instead rather in their interaction with other genes and with factors of the organic environment (cf. Duden & Zimmermann 2000).

One important event that has strengthened this critique of simple determinist models was the publication of the Human Genome Project. The Project had resulted in a (nearly) complete sequencing of the human genome in 2000 (or at least what was later called a "working edition"). The result of this sequencing project was a total number of only 20,000 to 25,000 genes (International Human Genome Sequencing Consortium 2004), much less than had been estimated before – further eroding the hypothesis of all human characteristics being reducible to certain individual genes. In addition, researchers found out that what had been termed "junk DNA" and what makes up about 98% of the DNA probably plays a decisive role in steering the development of an organism (Lock 2005: 47).

Margaret Lock concludes: *"The result is that gene fetishism, never embraced wholeheartedly by all the scientists involved (…), is now clearly on the wane among many (perhaps the majority of) experts, and this decline is hastened by the undeniable fact that genomic "deliverables" are as yet few and far between. Only one new drug the development of which was based on information obtained from genomics has been marketed in 2003 (…)."* (Lock 2005:48)

New approaches in biology such as developmental system theory deliberately turn away from genetic determinism, arguing that epigenetic should be recognized as the effects of dynamic interactions among many variables with numerous possible outcomes. Genes, within this theoretical framework, form only one factor among many (Lock 2005).

Nevertheless, the main investment of human genetics research today is not invested in such systemic approaches either, but in epidemiological studies and in the search for so-called biomarkers. Thereby, human genetics research is compensating the problems it still has on the level of theoretical models and systematic research, as well as the increasing uncertainties concerning the relationship between genotype and phenotype.

Biomarkers are thought to be precursors of a specific disease under investigation long before any symptoms are recognized (Lock 2005: 52). Detecting such biomarkers, who may for instance indicate an increased probability to development Alzheimer´s disease or other complex

conditions, involves extensive monitoring of thousands of healthy people for signs that may or may not be significant predictors for future disease (Lock 2005: 55).

Epidemiological strategies study statistical correlations between certain genetic characteristics and certain diseases or "conditions" in a certain population by trying to identify so-called risk factors. Risk factors as such do not necessarily *cause* a certain disease but rather indicate an increased probability. To take the example of late onset Alzheimer again, risk factors may include a wide variety of variables such as age, gender, education, family history, Down syndrom, head trauma, and, among other factors, a certain genetic variation (Lock 2005: 55). The correlations between such factors can then be translated into individual risks and attributed to an individual body as its "genetic disposition". Therefore it is mainly epidemiological and "association studies", as Martin calls them, that are increasingly relevant – especially as regards the search for genetic factors of multi-factorial diseases, *"where there is no clear pattern on inheritance"* (Martin 2001: 163). This research is a "data-driven research" highly dependent on the development of processing huge amounts of data, of bio-informatics, requiring high amounts of centralised data and DNA-samples in order to result in relevant risk calculations (Köchy 2003; Rheinfelder 2003). It is this research that is the main attractive, pragmatic site of intervention for biotech industry promising concrete results in the form of risk calculations for specific diseases.

In short, investigating multi-factorial diseases requires a large scale involvement of *healthy* people, people who do not or not yet have developed the disease under study. Research on complex, multi-factorial diseases thus is dependent on the participation of huge numbers of people, providing data which may or may not be useful to study a certain disease. The same holds true, as Anne Kerr notes, for developing and making use of biobanks as a research strategy (Kerr 2003a). We will argue that actually this "need for participation" in genetic research, due the "eclipse" (Lock) of the single gene paradigm, forms a main element in the context of the increasing emphasis on civic participation in science – society deliberations (see chapter 5).

Meanwhile, the pretensions of "post-genomics" or of complex conceptualisations of multi-factorial diseases do not correspond to the development of theoretical and not even of adequate statistical models (Interview 26-3 2006) – and there are very little concrete research projects directly addressing the interplay between environmental and genetic factors (cf. www.ngfn.de; Lock 2005). Köchy explains that processing big amounts of data still remains the main "proof for scientific excellence", but that today there are strong "deficits in the synthesis above all in

the level of theoretical reflection" (Köchy 2003: 16). Hence, although there is a trend towards integral systemic approaches to combine molecular with cellular, histological with organic, and biomolecular with social research, this systemic approach is not being translated into concrete research and theoretical models (Rheinfelder 2003).

This dominance of data-driven epidemiological research in current human genetics makes clear that scientific uncertainties concerning the genotype-phenotype relationship are compensated by the alleged self-evidence of epidemiologic risk calculations. Observers of these developments express little doubt that the results of this research – for example being able to link a 15 percent increased risk of heart disease to a certain gene as a statistical correlation – will be the relevant kind of knowledge production for future health politics and the basis of a further expansion of genetic testing practices (Interviews 14-3 2006; 5-3, 2006).

The concept of life based on the idea of the human genome as a "book of life" has therefore not been altogether de-legitimised by new scientific uncertainties. Rather, there is the idea of a more and more complex grammar of reading and interpreting this text or programme (Jacob 2002; Kay 2000) in the context of systemic or multi-factorial models. Life is thereby conceptualised not simply as biological essence but as systemic totality of interactions between biological essences and statistically de-contextualised " environmental", "psychological" or "social" factors – as a systemic imagination without a suggestion of how to decipher it in the near future.

However, in popular presentations of human genetics the systemic paradigm coexists with the deterministic idea of a gene for this and another gene for that. The deterministic model persists in research projects on genetic links to emotional, psychological or behavioural attributes[3], e.g., homosexuality, nicotine addiction, alcoholism, obesity, schizophrenia, depression, or loneliness (Gen-Ethischer Informationsdienst 2003/2004: 29; Gen-Ethischer Informationsdienst 2004/2005: 37; Gen-Ethischer Informationsdienst 2005: 33; Gen-Ethischer Informationsdienst 2005/2006: 38).

[3] For example in February 1995 the Ciba Foundation organised a "Symposium of Genetics of Criminal and Antisocial Behaviour" in London together with the main shareholder of the British pharmaceutical enterprise Wellcome, the Wellcome Centre for Medical Science (cf. Bock & Goode 1996).

2.3. Dimensions of geneticisation

Which social visions underlie the scientific agenda of human genetics (Shapin and Schaffer 1985)? And how has science on the other hand influenced social ideas of the body, corporality, and disease? How is it itself shaped by such visions or more concretely by current economic and political projects?

Some authors have proposed that we are experiencing a "geneticisation" of society (Koch 1993; Lippmann 1991; 1998), referring not only to medical practices but also to expanding knowledge patterns in daily life that establish a "genetic essence" of human beings and stabilise ideas of inheritance and biological determination of one's features – and futures. Genes as an essence of life have unquestionably become an artefact entering daily life. They are certainly linked to ideas of minor or higher values or qualities of life and connected to markers of social hierarchies, ideas which are reverberating albeit not repeating ideas of eugenics and Social Darwinism.

However, two remarks need to be made in favour of a cautious interpretation of "geneticisation". Firstly, it would be overhasty to assume a general hegemony of geneticisation in the societies under study. We have to keep in mind that the social realities of practicing genetic testing and the sites where these practices are performed are heterogeneous and disperse. They range from routine procedures such as PND to the project of "predictive medicine", which basically remains a project for the future and, if realised, is performed above all in pilot screening programs and clinical experiments (see below). The expansion of these practices still remains uncertain; postulating "predictive medicine" as an already self-evident future constitutes a problematic "politics of time", which we will address further below. Here, the "uncertainty of the bios" comes into play*:* The future of genetic testing depends on its appropriation by individual consumers, clients of health care systems or patients accepting the label of being genetically "at risk" or being affected by a "genetic condition". Although in the case of PND there is certainly a broad acceptance, this is not necessarily the case for future applications of predictive genetic testing, given the gap between diagnostic and therapeutic possibilities. Furthermore, it is unclear how the free market for life style tests (for example for the susceptibility to nicotine addiction, for dietary advice etc.) will develop. Until now the experiences are limited to pilot experiments. The future of genetic testing depends highly on consumer behaviour, the change of health, body and risk perceptions and the spread of individual strategies to acquire knowledge and control about one´s individual "genetic risk". This

explains in part the generally increasing sensitivity for the contingent behaviours, motivations, or concerns of individuals or groups as (potential) users/consumers of genetic testing that more and more permeates the governance of genetic testing beyond the concern about the education and trust with respect to "pure" scientific knowledge.

Second, when talking about "geneticisation" we need to take into account the change of knowledge regimes on genes as mentioned before. Authors from governmentality studies (Lemke 2000; Rose 2001; 2007) have emphasised that we do not simply deal with a biologisation of the social through genetic reductionism or genetic determinism today. This argument does not suffice to understand the expanding of the "Alltagsgen" (every day's gene) (Duden 2001) into current visions of health and the body. These scholars explain the attractiveness of individual risk calculation in the context of a neoliberal programmatic subjectivity that implies the norm to continuously, actively, responsibly and autonomously manage one´s own health care (Heath et al. 2004; Lemke 2004; Rose & Novas 2003).

It is exactly the uncertainty prior to doing a test on monogenetic diseases, and even more so the uncertainty of risk calculations resulting from tests in the case of multi-factorial diseases that can contribute to the idea that individuals can develop active and autonomous strategies, whether, under what conditions, and when to do a test or not. Especially in the case of tests for multi-factorial diseases, the uncertain and merely probabilistic character of test results may incite the development of individual strategies of self-care in order to reduce one´s individual risk to develop the disease through preventive measures or changes in individual life style. In this context, new uncertainties, new responsibilities, and also new forms of social pressure on the individual bring about a need to make decisions on how to individually access and manage this risk information and how to cope with it (Lemke 2004; Polzer n.d.). However, individual self-technologies, strategies of self-care, individual responsibility and "autonomous" decisions and reproductive choices are embedded in institutional settings which should not be overlooked or underestimated. In the following we will offer some remarks on how these new subjectivities and paradoxes of hereditary destiny und individual responsibility are institutionalised in health care systems and genetic counselling.

2.4. Genetic testing and counselling in health care systems

Genetic testing in the countries under study is mainly practiced and institutionalised within the health care systems where it has expanded in the recent decades – above all in the context of PND. In the beginning, genetic testing in Germany, Austria and the UK was embedded in specialised disciplines and isolated segments of health care and used to be governed by human geneticists and their counselling services – above all in human genetic institutes of universities and hospitals.

The establishment of these specialised segments in the broader health care system took its time. In Germany, for example, only in 1993 the medical specialist for human genetics has been recognised as a medical specialisation among others (Deutscher Bundestag 2000: 22). In the last decade public health genetics have been promoted (Petersen 2003; World Health Organisation 2002) as a normal and important part of the national health systems in general, thus "geneticising" the systems and building stronger linkages between public services, human genetics research, and the development of genetic tests by private research and biotech-firms.

In the following we will show that the process of normalisation and de-specialisation of human genetics within health care systems is heterogeneous. While laboratories still need complex technologies especially in the area of molecular (not cytogenetic) testing, genetic counselling and the supply with tests – especially in PND – has become de-specialised and routinised. In general, there are tendencies of privatisation in all different areas of genetic testing under study.

The internationalisation of complex laboratory networks as a challenge for multi-level governance

In the last decades, the amount of laboratories offering cytogenetic and molecular testing procedures has increased enormously. In Germany, the Journal Medizinische Genetik (not exhaustively) counted 27 laboratories in 1991 – nearly exclusively within Universities – compared to 104 laboratories in 1999 of which 32 were in private hands (Medizinische Genetik 1999). In Austria, laboratories that carry out predictive genetic tests on humans have to be

licensed according to § 68 of the gene technology law. According to the Ministry of Health and Women in July 2006 53 laboratories had such a license.[4]

Most genetic tests performed by laboratories today remain cytogenetic tests of chromosomal structures with a minor, albeit increasing, percentage of molecular DNA analysis.[5] At an international level, molecular genetic analyses have increased in 18 OECD countries from 874,608 samples in 2000 to 1,401,536 samples in 2002 (OECD 2005: 5). Generally, cytogenetic tests and those molecular tests that are more common and based on stable technologies (for example tests for cystic fibrosis, fragile X syndrome, genetic hemachromatosis) have become increasingly privatised and commercialised, while more complex tests remain largely integrated into public hospitals and/or university research (OECD 2005; Samerski 2002). This still high level of centralisation and specialisation of laboratories could change in the context of DNA chip technology which would enable the passing of molecular genetic testing from human geneticists to general practitioners and non-human genetic experts (Deutscher Bundestag 2000; Zerres 1999).

There are differences in how these services of laboratories are integrated into the respective national health care system and who will be the gatekeepers who organise access to the tests. While in Germany patients can acquire genetic testing directly from the laboratories and the process of privatisation of services is particularly high,[6] in Austria the intermediaries are physicians, and in the UK regional genetic centres are heterogeneously organising the access to genetic testing (Human Genetics Commission 2004; OECD 2005).

Laboratories in general are specialising on certain tests so that no laboratory can offer all existing tests. Therefore there is an increasing interchange of specimens also across national borders. The OECD study speaks of this increasing circulation of tests, human samples, and related data as "internationalisation" of testing and interprets it as a challenge for multi-level governance because there is nor transparency or regulation with respect to quality standards (for example under which criteria potential tests are ready to move from the research phase to a clinical

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[4] http://www.bmgf.gv.at/cms/site/attachments/8/9/5/CH0256/CMS1087982873584/__68_genanalyse-einrichtungen_03_06.pdf, 20.10.2006

[5] In 1991 5,792 DNA-diagnostics were performed in Germany, whereas 1997 there already were 13,436 persons tested (Nippert 1997 quoted in Deutscher Bundestag 2000: 24).

[6] This high level of privatisation has to do with the German health care system being based on the state insurance reimbursement system, which works with private doctors within the public health care system (OECD 2005: 9).

laboratory setting), data protection, and informed consent concerning the samples crossing borders and being mostly collected and stored by the laboratories for an indefinite time (OECD 2005). For example, over a third of all laboratories surveyed which conduct the especially sensitive pre-symptomatic or predisposition testing do not have any confidentiality policy (OECD 2005).

PND: routine practice, precarious counselling and effects of privatisation

While laboratories in molecular genetic testing mostly remain specialised and centralised entities, offering the test to clients as well as counselling before and after applying it, especially in the area of PND, is no longer restricted to specialised segments of professional expertise in human geneticists but more and more performed by general practitioners, since in reproductive genetics these tests have become integrated into the normal routine of gynaecological practice. This process of de-specialisation has given reason to conflicts and competition between professional human geneticists and general practitioners (Harper 1995). In Germany, for instance, there is the general trend that *"with an increasing amount of tests offered and an increasing demand the offer shifts from human genetic institutions of universities to practicing physicians because of reasons of capacity alone"* (Deutscher Bundestag 2000; cf. Schmidtke et al. 2005). The percentage of invasive PND (amniocentesis and chorionic villus sampling) performed by private practitioners, for example, has increased in Germany from 56% in 1991 to 76,7% in 1997 (Deutscher Bundestag 2000): 22). The trend of de-specialisation can also be observed in the UK and in Austria, while both differ from the German health care system in that in the UK and in Austria genetic testing is directly integrated into public health care (OECD 2005).

The routinisation of PND has led to a situation where the boundary of human genetics being only of interest to specific persons, families, and couples affected by family histories of monogenetic diseases has been exceeded by far. Access to genetic testing has been expanded to virtually all pregnant women who are considered somehow "at risk" – above all because of the "age indication". In Germany, for example, pregnant women have at first been categorised as being "at risk" when aged over 38, then when over 35 years old; but the number of so-called "psychological" indications for prenatal genetic diagnosis, irrespective of the woman´s age, has increased, too (Samerski 2002). Eva Schindele calculated as early as in the late 1980s that in

Germany up to 80% of all pregnant women were classified as belonging to some form of risk group and accordingly being offered some screening procedure or other (Schindele 1990: 37).

In the UK, 30,000 amniocenteses and 8,000 chorionic villus sampling tests were performed in 2003 (as reference: in 2003 there were 700,000 births in the UK) (Human Genetics Commission 2004: 8). In Germany, the estimated current percentage is even higher with 130,000 invasive tests per year (Nippert 2005b) In 2001 in Germany, the chromosomes of more than 10% of all babies born have been tested (Spitzenverbände der Krankenkassen 2005). In a survey for Austria, Czypionka and others (2006: 237 ff.) found out that the number of chorionic villus sampling increased significantly from 1995 (118 tests) to 2004 (648). The number of karyotyping of amniotic fluid in the same period remained relatively constant from 1996 to 1999 (ca. 870 tests), decreased in the next two years to 643 tests and increased again in 2004 to 749 test. The survey, however, does not cover all Austrian labs that carry out genetic testing. To put this numbers in perspectives, according to Statistics Austrian 78.190 babies were born alive in Austria in 2005. [7] According to Wiesner (2006: 174) a trend exists in Austria, that invasive methods of PND are used to a lesser extent, while the number of non-invasive methods would sharply increase and gain routine character.

As already mentioned, invasive tests such as amniocentesis and chorionic villus sampling are normally preceded by pre-selective procedures. In Germany this trend is fostered by the privatisation of health care services. The first trimester ultrasound scan is not covered by the health insurance system but rather has to be paid for by the clients as an extraordinary service, and the effect of this expansion of "IGeL" (individual health services) is that the application of this "sieving" technique has expanded as source of extra-income for gynaecologists during the last years (Braun, A. 2005; Nippert 2005a).

The routinisation of PND is embedded in practices of counselling before and after the testing procedure – albeit in a precarious way: In the UK, there is a very heterogeneous situation of counselling across health authorities (Wald et al. 1998) depending *"on priorities of local providers and clinicians with an interest in particular screening technologies"* (Kerr 2004), and observers generally criticise a lack of adequate counselling (Williams et al. 2002).

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[7] http://www.statistik.at/statistische_uebersichten/deutsch/pdf/k14t_4.pdf, 20.10.2006

In Germany, the coverage of counselling is also very low. According to a study of Nippert, Neitzel, und Schmidtke, only in 20% of PND diagnostics any human genetic counselling is provided, mostly only after the communication of a specific test result. Only in 10% of the cases the study found counselling after a pre-selective result and before an invasive testing procedure (Nippert 2005a), although the German Society for Human Genetics (Deutsche Gesellschaft für Humangenetik) and the Maternity Guidelines (Mutterschafts-Richtlinien) recommend counselling at least before invasive testing procedures (Bundesausschuss der Ärzte und Krankenkassen 2003; Samerski 2002).

Another limitation of counselling is that after invasive prenatal tests there often is very little time between the communication of the test result and the abortion. In 81% of the cases pregnancy is terminated within 10 days after the information about a "positive" test result (Nippert 2005b) so that a lot of women decide in a traumatised moment without sufficient time for reflection (Rohde 2005). Even less established than human genetic counselling is the possibility of psychosocial counselling before and after PND, an option preferred by feminist networks and offered by NGOs and welfare organisations (Interview 5-3, 2006). However, gynaecologists generally do not inform women about these possibilities (Braun, A. 2005; Rohde 2005).

The concept of counselling as institutionalised in these (precarious) offers of psychosocial or genetic counselling has changed in the last years. More and more the idea of individual self-steering has taken ground. While in the beginning genetic counselling was conceptualised as an advise given by an expert to the ignorant patient, in the 1990s the model of a *"non-directive process of communication between consulter and client"* (Deutscher Bundestag 2000: 21)[8] or as *"psychologically embedded interactive information"* took ground (Samerski 2002: 46; cf. Reif & Baitsch 1986). Techno-sceptical voices expound the problem that there is an *"increasing pressure to apply existing PND possibilities"* and that in the context of increasingly sophisticated ultrasound scans it becomes increasingly difficult to ensure the *"right not to know"* (Rohde 2005). For the UK, the Human Genetics Commission acknowledges:

"It has been shown that midwives and ultrasonographers may offer screening in such a routine manner that it becomes a default option, rather than a considered choice." (Human Genetics Commission 2006: 12).

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[8] The dilemma of "non-directive" is expounded by the statement of the German Ministry of Health's Advisory Board on Ethics in 2000: "*The patients should not be patronised but neither should they be denied advice*" (Ethik-Beirat beim Bundesministerium für Gesundheit 2000).

Samerski explains that PND results force women into a situation of decision-making "*between the devil and the deep blue sea*" (Samerski 2002), because the only active decision, the only "therapeutical" solution[9] is abortion – a situation where the practice of *"tentative pregnancy"* (Rothman 1992) has become hegemonic. For example, in both Germany and the UK today more than 85 percent of women recur to an abortion after the diagnosis of Down's syndrome, and even more after the diagnosis of neural tube defects (e.g., Spina bifida) (Nippert 2005b; People Science & Policy 2005: 23).

While PND has become a routine practice in antenatal care, PGD remains a comparably rare practice. In our country cases it has only been allowed in the UK where between 2002 and 2003 8 clinics conducted 155 PGD cycles (Human Fertilisation and Embryology Authority 2005a).[10] The biggest clinic in the UK, the Guy's and St. Thomas NHS Foundation Trust, for example, conducted 330 cycles of PGD from 1997 to 2005 resulting in 85 babies out of 60 deliveries (Lashwood 2006). The "success rate" of PGD is quite low: An international survey of the European Society of Human Reproduction and Embryology estimates that only 14% of couples undergoing PGD actually become parents (Sermon et al. 2001). The level of privatisation of these services is quite high. In the mentioned UK clinic only 60% of the couples are funded by the NHS while the others privately pay about 5000 GBP for one cycle (Lashwood 2006). At the European level the fact that national regulations are very different from one another has led to a so-called "reproductive tourism" from countries prohibiting to countries allowing PGD – thus constituting another challenge for European politics when the aim is to homogenise health care and make multi-level governance consistent (Blyth & Farrand 2005).

There are two types of PGD: the one excluding a certain genetic condition, while the other – also called Pre-implantation Genetic Screening (PGS) – is done in order to enhance the success rate of IVF for women who already had a number of "failed fertility cycles" or "IVF failures". Via PGS, those embryos with the most potential to develop are selected and transferred to the woman´s uterus (Sermon et al. 2001). Alison Lashwood, a nurse working at the already mentioned large PGD clinic in the UK, explains: *"That aspect is very big business in the UK"* (Lashwood 2006).

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[9] There are rare exceptions for therapeutic possibilities – for example medicinal treatment of the mother in the case of heart rhythm disorders of the foetus or blood transfusion in the case of incompatibility of rhesus factors.
[10] Meanwhile the number of clinics licensed to do PGD has been expanding permanently to 12 clinics in 2004 (Human Genetics Commission 2004).

The rare but nevertheless expanding practices of PGD and PGS lead us to the dimension of econoscapes of human genetics – as PGD and PGS need to also be situated in the context of the interests of scientific research to get access to eggs and embryos. This becomes especially important when we consider the trend to interpret PGD (where not prohibited by law) as an exchangeable technique with PND. PGD and PGS make it possible to extend the application of IVF beyond the "treatment of infertility". Their promotion might thus broaden the couples using IVF in order to pre-select embryos and thereby has the potential to increase the production of surplus embryos accessible for research. In this sense, the contexture of PGD is also embryonic stem cell research, as work package 2 explores.

2.5 Econoscapes of genetic testing: linkages between health care, human genetics research, and biotech industry

The access to surplus embryos for research is only one indirect aspect in the "econoscapes" of genetic testing regarding the triangle of health care system, human genetics research, and biotech industry. The increasing interconnection between genetic diagnosis as intrinsic part of the public health care system, as means and as result of private and public human genetics research, as product of biotech-firms and pharmaceutical industry, and as product of public or private laboratories needs to be taken into account as the context of our research. Generally, the analysis of the governance of genetic testing needs to consider the interrelation between the commercialisation and privatisation in health care, neoliberal programmatic subjectivities and norms of self-management, and the potential of genetic testing to individualise risk profiles and, as in pharmacogenomics, medical treatment itself (Mykitiuk 2002; Petersen 2003; Sexton 2006). However, until today there have been few studies analysing the connection between neoliberal health care policies and human genetics and the existing ones are not based on empirical investigations into the application of genetic testing in "predictive medicine" but rather on speculative considerations, e.g. on "colonising the future" (Sexton 2006; Shalev 2006). By the term "colonization of the future", technosceptical approaches indicate and reflect that their prognostics about the future might be based on the hypothesis of a continuous expansion of the use of genetic testing. This unproven hypothesis thereby is a "colonising" scenario of the future that influences the current debate on probable political challenges.

Similarly, the debate on the use of genetic testing by insurance companies and employers is to a large degree based on future scenarios rather than on empirical investigation. As we will show in our narrative analysis there are already cases of employers demanding genetic test results from their employees, and private insurance companies are currently paying a lot of attention to the future possibilities of checking health risks through genetic testing. Yet, the fact that insurance companies are prompted to sign moratorium agreements concerning the use of genetic tests indicates that the "econoscape" of genetic testing is to a large extend based on expectations about future developments in this area (Interviews 14-3 2006, 5-3 2006). However, this may change drastically with the development of DNA chip technology.

When looking at the current econoscapes of genetic testing we have to focus, first, on the public health care system as the main market of genetic testing, second, on the interrelation between private and public human genetics research and the research interests into samples collected by biobanks, laboratories, and screening programs, third, on the development of patenting, and, fourth, on the uncertain economic prospects of biotech-firms.

Public health systems as main market for genetic testing:

Biotech and pharmaceutical firms are dependent on public health care systems because these still form the main market for genetic tests. In Europe, we do not yet have a significant "free market" for commercial tests as in the United States (Parthasarathy 2005). Hopkins and Nightingale show for the UK that nearly all tests are marketed through the channels of the NHS, while the marketing of direct over-the counter tests often failed because it led to a lot of public controversies and scandals (Hopkins & Nightingale 2004; see also Martin and Frost 2003). For example, in the early 1990s, in the UK a cystic fibrosis test, marketed directly to the public, led to a lot of critique (House of Commons Science and Technology Committee 1995). In 2002, the project of The Body Shop and the UK company Sciona selling a genetic test in Body Shop stores as basis for dietary advice was quickly abandoned after a lot of protest (GeneWatch UK 2003c). More recently, there have been protests against a genetic test offered via internet that promised to diagnose nicotine addiction, marketed by g_Nostics Ltd., a "spin out" company from Oxford University (GeneWatch UK 2005).

Nevertheless, there are sporadic examples of commercial tests – above all by firms with strong linkages to academics. Their main interest is to market their research results – and less to actually actively develop stable markets for private clients of these tests. For example, in Germany there was the case of the enterprise DiaGen announcing a series of tests for disease predispositions – ranging from obesity, Alzheimer, osteoporosis, rheumatic diseases heart problems to diverse cancer risks diagnostics.[11] Another example is the biotech enterprise Adnagen, a spin-off of the "Fraunhofer Institut für Grenzflächen und Bioverfahrentstechnik" in Stuttgart together with the Institute for Microbiology of Hannover. Adnagen offers pharmacogenetic tests to detect "normal or rapid drug metabolisers" and the "susceptibility for environmental chemicals" and other "environmentally caused diseases" (Deutscher Bundestag 2000: 29, cf. www.adnagen.com).

A lot of directly commercialised test are offered via the internet – an international market without any regulatory control. It is often quoted as a challenge for international governance mechanisms. However, in the last years there has been no evidence that the European markets for tests would expand dramatically as a market beyond the health care systems.

Generally, the trend is not to totally disconnect the market for genetic testing from the established medical system but to stay articulated at least for the part of counselling and possible treatments after the test (Parthasarathy 2005). Even more, until now the main form of marketing the tests remains directly through the public health care system. One important example of this way of commercialisation of tests is the case of Myriad Genetics, the firm that holds the patent for the tests for BRCA1 and BRCA2 familial breast cancer genes (Institut Curie 2005). It is obvious that the promotion of screening procedures within the public health care system have to be analysed as a very important future market for the commercial suppliers of genetic testing. In the case of the first larger genetic screening project in Germany, the screening of hemachromatosis performed by the medical insurance company Kaufmännische Krankenkasse, for example, observers have suggested to analyse the commercial interests of the supplier of the

[11] Legally, only the cancer diagnostics could be challenged by an investigation of the Medical Association (Ärztekammer) of North-Rhine-Westphalia (Deutscher Bundestag 2000: 28).

test involved in this project. For obviously the necessity of this test is highly contested within the scientific community.[12]

Public and private research interests in genetic testing as basis for access to DNA samples

Moreover, public and private research interests form part of the econoscapes of human genetic testing. The expansion of genetic testing practices is directly linked to research interests in the sense of access to genetic data produced by screening procedures. Furthermore, the expansion of genetic testing practices is necessary to legitimise human genetics research agendas in general and to stabilise the promises that investment in research will translate into the exploitation of "biovalue" in the future (Waldby 2000; Waldby 2005).

The interrelationship between health care, research, and commercial interests is based on "hybrid" networks of research involving public and private, academic, and patient-oriented actors. The connection between public research and biotech firms increases with more and more academics founding spin-off firms and patenting gene sequences for future commercial interests (Martin 2001). There is also a "hybridisation" of research with new networks integrating public funding and research, biotech firms, and organisations of people with specific "genetic conditions". For example, the German project "Kompetenznetzwerke" (networks of competence), which has been built up by the Ministry for Education and Research since 1999, is systematically integrating patient groups and biotech-firms into its research (www.kompetenznetze-medizin.de). Also the Genetic Interest Group in the UK, a relevant lobby organisation for genetic research, is not only a representation of self-help groups, but also a hybrid network of commercial and public research (www.gig.org.uk/members.htm; cf. Lemke 2004).

"Association" and epidemiological research on genetic risk factors, on which the development of genetic testing relies, depend on access to large collections of tissues, blood, or DNA-samples. Hence, the current boom of new biobank projects forms another important context of

[12] Steindor shows that first, the predictability of the test is not very high: The tested HFE-gene mutation is only one genetic defect attributed to hemacromatosis. Second, only between one and fifty percent of those with a homozygotic HFE-mutation will really develop the disease during their life. Third, the diagnosis of the disease is easily performed through routine blood tests when there are manifest symptoms of the disease (Steindor 2005).

the regulation of genetic testing (GeneWatch UK 2001a; Gottweis 2005; Nationaler Ethikrat 2002). Some biobank projects are building up new population-based collections (Gen-Ethischer Informationsdienst 2004/2005), for example the Biobank Project in the UK with its objective to collect half a million DNA samples in the whole population of Great Britain (www.ukbiobank.ac.uk), or on a smaller scale, the project Popgen in Germany that collects material from a regional population in Schleswig Holstein (Görlitzer 2004/2005; Wagenmann 2004/2005).

However, most research until now has depended on already existing collections within the public health care systems. For example, in Germany the already mentioned government project to build up networks of competence is investing into the integration and systematisation of existing samples of clinics and research projects focusing on certain diseases. The highly controversial biobank project in Iceland, organised by the Biotech-firm DeCode, is also based on already existing collections of samples in the Icelandic public health care system. Therefore, the current debate on genetic testing and screening is intrinsically linked to issues of confidentiality of data and informed consent concerning test results and DNA-samples resulting from the testing procedures (Feuerlein 2003/2004b; Nationaler Ethikrat 2002; Steindor 2005). Considering the great importance the public health systems' collections have for public and private research, it is easily understandable why access and use of genetic information is intrinsically linked to the debates on regulating genetic testing (Gen-Ethischer Informationsdienst 2004/2005; Human Genetics Commission 2002a; Nationaler Ethikrat 2004a). Generally, there is little resistance within public health care systems against enabling such access. Furthermore, as already mentioned in the context of laboratories, the politics of laboratories are inconsistent with respect to the confidentiality of data or informed consent – and pose a challenge for governance of data protection and research policies: They often do not clarify whether they open their collections to research (OECD 2005).

Patenting

Patenting and its regulation are another important aspect of the "econoscapes" of human genetics. The possibility to patent DNA sequences has been a highly contested political issue since the 1990s, when the European Union's patent guidelines were debated and confronted by campaigns such as "no patent on life". Nevertheless, in 1998 the European Parliament adopted

these guidelines (Directive 98/44/EC) followed by the UK government in 2000, and in a more restrictive version by the German parliament in 2004.

Again, we need to distinguish between the direct perspective on patenting the respective genetic tests themselves, and the implications of patenting genetic data in a broader sense for policies surrounding genetic testing. According to Hopkins and Nightingale, using intellectual property rights in the marketing of tests is not a very widespread practice because public health systems are the main market of testing (Hopkins & Nightingale 2004). The most famous case is the already mentioned case of Myriad Genetics which patented the genes BRCA1 and 2 linked to breast cancer. This patent, with the license fees it implicates, has raised the cost for a single test, for example, in Germany from 1500 Euro to 5000 Euro (Institute Curie 2005).[13] Despite of the relative reluctance to introduce patents on genetic tests until now, the recent OECD study observes an increasing availability of patents on genetic tests and *"evidence that some genetic testing service providers are withdrawing some patented tests from the 'menu' they make available"* (OECD 2005: 11). A study of Schissel et al. shows that patents on tests themselves have negative impacts on access, cost, and quality of tests (Schissel et. al. 1999; referred to in OECD 2002: 69).

However, more important in this context than the direct patenting of genetic testing procedures is the more general background that patenting human gene sequences is in fact a common practice in human genetics research. This background is important when considering the motivations for doing broader screening procedures and storing samples from tests. The journal Science estimated in October 2005 that 4,382 of 23,688 genes registered by the National Centre for Biotechnological Information were patented in the United States alone, 63% of them by private companies. Various genes are covered not only by one but by various patents (Jensen & Murray 2005).

The interest of health and research ministries to promote human genetics by spreading genetic testing in the health care system and thereby emphasising this type of medical knowledge needs to be linked to the economic promises of a growing biotech-industry, which is securing its future markets and possibilities by patenting genes. That is why laboratories and screening projects, as for example Popgen, are usually not explicitly abandoning the right to derive patent

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[13] Another example is the patent on the gene linked to Chorea Huntington. In March 2003 the General Hospital Corporation (USA) gained the patent (EP 614977) and hence the right to license all applications of this gene in diagnostics and therapeutic products (cf. www.1000fragen.de/dialog/diskussion/pate.php?gid=68).

rights as possible outcome of research conducted on their collected samples (Feuerlein 2003/2004a; Wagenmann 2004/2005).

Biotech-industry as a vulnerable project

To emphasise economic and commercial research interests as background of the promotion of genetic testing through the channels of public health systems does not mean denying the crisis moments of this industry. The trend of the 1990s, when there was a boom of biotech-firms which then merged into huge pharmaceutical and agrochemical corporations, has reverted since the change of the millennium and today we rather see a trend to decartelise the agro- and pharmaceutical sectors (GeneWatch UK 2002, 2003c, 2004b). Partly this trend might be interpreted as reaction to the increasing public mistrust concerning especially green biotechnologies and GM Food production (see work package 6). The future of genetic testing markets is by no means certain, on the contrary public mistrust in general, but also the increasing gap between diagnosis and therapy generate a certain sense of crisis. There is no imminent prospect of new therapies surfacing that correspond to genetic tests, and there has been a certain backlash in the "economies of hope" due to various scandals in gene therapy projects in the recent years. One of these scandals occurred in 2002 when a French gene therapy project led to two children developing leukaemia. Subsequently, critiques demanded more restriction and higher degrees of control of such experiments (Pollack 2003). Some years before in 1999, the death of eighteen year old Jesse Gelsinger as a human subject in a gene therapy trial had already caused a major crisis of public trust in medical trials and gene therapy in the US (http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetherapy.shtml).

An indicator of such crisis is further the fact that biotech enterprises today often undertake "risk evaluations" before they market gene tests, trying to measure public mistrust in order to not cause scandals. For example, Hopkins and Nightingale explain the preference of genetic test producers not to market tests directly but mainly through the NHS as expression of such a risk avoiding strategy (Hopkins & Nightingale 2004).

Despite the enormous problems in scientific knowledge production there are strong economic reasons for research to continue the "genohype" as genomics is still a terrain with high capital inflows and high state (on both national and European Union level) investment. However, the

future of these investments and the future of biotech industries are uncertain and contingent on the development of corresponding therapies and on the broad acceptance and implementation of individualised and "pre-symptomatic" medicine in future health care systems or privatised services. Therefore, the "colonisation of the future", the production of future health care scenarios has itself become an important part of the governance of genetic testing (see "politics of time" in chapter 4).

3. Narrative Topographies

How to tell the story of the politics of genetic testing when there is a lack of strong dislocatory moments or disruptive events in which change culminates and can be studied in a focused way? How present an account of rather creeping changes and simultaneous heterogeneous settings?

This heterogeneity concerns national settings, the different applications of genetic testing and different sites of governance. Comparative studies on the biotechnology regimes in different countries already have pointed out that there is a strong difference between the governance arrangements of biotechnologies in Germany and Austria, where regulatory state-led governance schemes are strong – and civil society organisations are operating rather separately from the state. In the UK, this separation is less clear – the flexible governance scheme of arm's length bodies integrates, centralises, and channels the efforts of civil society organisations to a greater degree (Dryzek et al. 2003). Jasanoff concludes that in the UK policies are more flexible, oriented on the "process", while German policies are more governed by "program", by more categorical lines (Jasanoff 2005). However, the following narrative has not been written as a national comparison in a strict sense, because commonalities and differences are cross-cutting national borders and also depend on the different applications of genetic testing (PND, PGD, or predictive medicine) and sites of governance. We will stress commonalities, but point out differences whenever necessary – which is especially relevant for the regulation of PGD. We will approach the construction of narratives in the following way.

First, we subdivide the time scale into three historical phases concerning the governance of genetic testing and identify general changes between them: the 1980s, the 1990s, the millennium

change (with some more dense developments concerning PGD and new governance arrangements in Germany and the UK) and current policies.

The second subdivision concerns the different areas of genetic testing we are studying: PND, PGD and "predictive medicine". We begin the narrative with the 1980s general debate on "genetic engineering" considering all three topics combined. Following this, we will subdivide the narrative with respect to three different settings in order to account for the specialisation and segmentation of debates.

The intensity of political debates, the regulatory schemes and the public energy fields with respect to these three different research topics have shifted over time. Therefore, we start the specific narratives in the 1990s with the governance of PND (and add remarks on its developments until today), because this was an important phase of routinisation and transformation of political approaches toward PND. Then we continue with the millennium change and the developments of the public energy field concerning PGD, because in this period PGD was subject of dense political discussions which in part generated institutional reforms too. Finally we conclude our synchronic/diachronic mix of narratives with the governance of "predictive medicine" because of the expanding political discourse regarding its regulation that has developed in recent years.

These stories, however, are not neatly separated because the different debates overlap. The question of whether and how the processes we study are embedded in a "geneticisation" of health and body politics, of knowledge production on "life", binds all the stories together.

At the same time, the way of telling the story has been a contested political issue itself. For example, some stories present the development of PND and PGD as inseparably linked to one another, emphasising the common dimension of selection and excluding "genetic disorders" in the process of procreation, while other stories would clearly separate them.

There are also a lot of overlapping dimensions in the three narratives with respect to regulatory events or formal governance arrangements, insofar as they concern the whole map of politics on human genetics. For example the reform of the advisory system in 1999 in the UK has affected all the political debates on human genetics. To some extent that was also true for the debate on a proposed law on genetic diagnosis in Germany in 2004 (although centred in "post-natal" testing) (Bundesministerium für Gesundheit und Soziales 2004).

This overlapping of our three stories on genetic testing can also be observed in our micro-political approaches to those exemplary participatory governance arrangements or participatory governance experiments we have studied more intensely and will emphasise on in the narrative regarding various aspects:

In the UK we focused the empirical research on the Human Genetics Commission (HGC), a new advisory body established in 1999 and linked to the Department of Health. The HGC has made strong efforts to promote elements of participatory governance in the last years by conducting consultations, citizen juries, and opinion polls bundling the debates on genetic testing. More specifically, we concentrate our analysis on its consultation process on repro-genetics, and its resulting "Making Babies"-report (Human Genetics Commission 2004; Human Genetics Commission 2006). This report was published in the same week when researcher Susanne Schultz interviewed members of the HGC and representatives of NGOs in London in the end of January 2006.

In Germany, we picked two experiments of participatory governance which are much more disconnected from the state than in the UK, but represent new practices of "Bürgerbeteiligung" (citizen participation – public engagement). We refer to the internet forum on bioethics called 1000fragen.de organised by the Aktion Mensch since 2002, a big welfare NGO for disabled people. This has been a very visible public relations campaign and is particularly accessible for research because of its transparency through the website (www.1000fragen.de).

Second, we analyse a youth conference on genetic testing in Leipzig called "Die nächste GENeration" (the next GENEration) in which Susanne Schultz participated on the 19th of May 2006 (www.gen-diskussion.de). This has given us the opportunity to use the methodology of participative observation and to develop insights into a project that was evoking deliberation and constructing a specific political subject, the "youth" as an abstract, lay public.

In Austria we focus on the citizen conference "genetic data: from where, whereto, what for?" (BürgerInnenkonferenz "Genetische Daten: woher, wohin, wozu?"), which was organised by the Austrian Council for Research and Technology development, an advisory body to the government, in Vienna in June 2003.

3.1. 1980s protest against "genetic engineering" benefit/risk assessment and new regulatory arrangements

We begin our narrative with a general picture of the 1980s policies setting towards genetic testing. The 1980s were marked on the one hand by public protest against "genetic engineering", influenced by social movements of that time, on the other hand by the establishment of technology assessment regimes. These regimes were based on the idea that above all scientific and legal, but also – as a beginning trend – philosophical experts could manage these new challenges. Their task was to elaborate a balanced analysis of benefits and risks in order to evaluate the impact of genetic engineering for society as a whole and for its larger future prospects.

Until the end of the 1980s and beginning 1990s these risk-and-benefits-frameworks contributed to the establishment of highly country-specific regulatory frameworks that have influenced the governance of genetic testing through today. They vary extremely and range from a pragmatic, flexible case by case management in the UK to a combination of professional self-regulation and statutory law as dominant regulatory instruments in Austria and Germany.

In the 1980s the contemporary, but even more so the potential future implications of human genetics became a subject of heated political debates ignited by social movements. Basically, the debates in the 1980s had a more general focus compared to today's specialised agendas (Interview 27-3 2005). They addressed the future potentialities of human genetic engineering and oppositional movements evoked apocalyptical negative utopias and scenarios ("brave new world", "total surveillance state", "production of human beings" etc.) oftentimes based on deterministic ideas about the implications of technological change for society (Kontos 1985; Schultz 1996). These debates focused mainly on the field of reproductive technologies. The birth of the first "test-tube baby" Louise Brown in the UK in 1978 (Steptoe & Edwards 1978) and the increasing possibilities of PND provoked concerns about the contents and consequences of human genetic counselling and about abortion practices following PND. In the UK, pro-life movements connected their protest against the new technologies with their moral objections against abortion. In the following, we will show the different governance schemes resulting from these different social conflict settings on genetic engineering in the countries studied.

In Germany, in the 1980s a broad range of feminist groups and organisations of disabled people centred their actions on a radical critique of reproductive technologies and genetic engineering (Bradish et al. 1989; Die Grünen im Bundestag 1985). The main frame within which feminist groups presented their arguments could be termed an "oppression frame", including the argument that women were made victims of medicalisation and that the capacities of the female body were being dis-appropriated by (male) medical experts who sought access to and control over procreation and the uterus, human eggs and embryos. But also anti-eugenic and anti-capitalist positions developed in this context. They were pushed forward above all by organisations of disabled people, especially by the radical movement which called itself the "movement of cripples".[14] These groups regarded PND and selective abortion as a modern form of eugenics and the new possibilities of genetic testing as an instrument to serve as utilitarian strategies for capitalist purposes, that is to enhance the "quality" of the future labour force or of the national population.

The issue of abortion after PND caused some dissent between the feminist movement and the disabled people´s movement. Positions ranged from the feminist claim that women have the right of self-determination, meaning the right to abortion, when pregnant with a disabled child up to rigorous anti-abortion pro-life positions within the movement of disabled people. But inside these movements a position promoted by some disabled feminist women evolved that sought to combine women's right to self-determination with an anti-eugenic critique of selective practices such as PND (Degener & Köbsell 1992). Militant movements engaged in these issues as well. The feminist guerrilla group Rote Zora invaded laboratories and published papers about biotechnological research projects, which they had seized in their assaults (Bürobert et al. 1996: 99; Rote Zora 1989). These radical movements had a considerable political impact in that they were a starting point for the German debates on reprogenetics and biomedicine. They remain influential as being embedded in social movements that were the historical background of several NGOs[15], experts, and social researchers until today.

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[14] The journal "Randschau" and its predecessors ("Krüppelzeitung", "Luftpumpe") are an interesting source when studying this movement (www.martinseidler.privat.t-online.de/randschau.htm).

[15] Gen-Archiv Essen, Bioskop, Gen-ethisches Netzwerk, Aktion Mensch, Institut Mensch, Ethik und Wissenschaft, Netzwerk gegen Selektion in der Pränataldiagnostik and other institutions and organisations were founded in continuity of these movements or need to be analysed against the background of these movements.

In these years the issue of human genetic engineering gave rise to a new type of institutions, namely advisory bodies on ethics (Damm 2004; Wildfeuer 1993). In 1984, the "Benda [16] Commission" named after its chair, Ernst Benda, was established in order to advice policymakers on ethical and legal questions of IVF, gene therapy and embryo transfer. The Commission published a report in 1985 (Bundesminister für Forschung und Technologie 1985) [17]. In 1987 a Parliamentary Study Commission (Enquete-Kommission), which is a commission composed one half each by parliamentarians and experts, was established on "risks and benefits of genetic technology", thereby expressing the dominant frame at that time, namely the "risks and benefits" frame (Enquetekommission Chancen und Risiken der Gentechnologie 1987). These commissions worked on the basis of a frame that was different from that of the social movements in that the former referred to the idea that positive and harmful consequences of the new technologies for society as a whole could be evaluated and balanced, thus arriving at an optimum middle course.[18] One of the consequences of these processes was the establishment of the Office for Technology Assessment (Büro für Technikfolgenabschätzung) in the German Parliament in 1990. Also, in 1990 the first important legal act setting the regulatory frame for reproductive technologies and indirectly for repro-genetics was passed in Germany, the Embryo Protection Act (Embryonenschutzgesetz), still in place through today. It provides penalties for the artificial fertilisation of an egg cell for other purposes than causing a pregnancy of the woman who the egg cell was taken from. Further, it prohibits any "consumptive" research on human embryos, thereby indirectly prohibiting PGD through today.

In Austria, similarly, no explicit regulation for PGD developed in these years. Neither the reproductive medicine law (1992) (Fortpflanzungsmedizingesetz) nor the gene technology law (1994) regulate PGD explicitly. However, jurists agree that reproductive medicine law implicitly prohibits PGD in most cases because its § 9 states that the examination of developable cells, sperms or human eggs, respectively, is only allowed if examination and treatment are necessary

[16] Chairman was the ex-president of the German Constitutional Court, Ernst Benda.
[17] The commission was an inter-ministerial working group of the Ministry for Research and Technology and the Ministry of Justice.
[18] The Benda Commission evaluated prenatal diagnosis on the positive side as an enhancement to the protection of health and life and as a possibility of preparing therapies for newborns, but on the negative side as a technology that could contribute to the discrimination of disabled people or could develop into a problematic routine practice (Wildfeuer 1993).

to bring about pregnancy. However, since polar body does not serve conception, this ban does not cover polar body biopsy. In addition, no consensus exists between jurists about the coverage of the ban, in particular with regards to the clause "to bring about pregnancy". Some jurists argue that the law has to interpreted as a total ban of PGD, others that PGD is allowed and a third group thinks that PGD might be allowed if the test focuses on genetic anomalies that inhibit pregnancy. However, one has to bear in mind that PGD is only allowed in cases of in-vitro-Fertilisation and the reproductive medicine law strictly constricts the relevant techniques to the treatment of infertility. Thus it is prohibited to carry out IVF for the only reason to conduct PGD without an indication to circumvent infertility. Breach of the law is considered as petty offence and penalised with a fine of € 36.000. (Bioethikkommission beim Bundeskanzleramt 2004: 19ff).

In the UK, a controversial debate on the issue of reproductive technologies and human genetics evolved in the mid 1980s – however leading to the establishment of a very different, less restrictive and more flexible regulatory regime which is also in place through today. In 1982, the UK government authorised a Committee of Inquiry into Human Fertilisation and Embryology, headed by the moral philosopher Baroness Mary Warnock, whose remit it was to develop a proposal for the regulation of assisted reproductive technologies. The Committee comprised scientific, religious, legal experts and lay members. The task of the inquiry committee was *"to consider recent and potential developments"*, *"safeguards"*, and *"social, ethical and legal implications"* (Ziegler 2004: 66).

In 1984, the committee published the Warnock Report which recommended the controlled and restricted permission of various aspects of assisted reproduction technologies (Eser et al. 1990: 389).[19] The Warnock committee had been established in the context of struggles in society over abortion and the pressure by conservative anti-abortion movements. Alfred Moore interprets it as a conscious reframing of reprogenetics issues, replacing the idea of grounding legal regulation on a "common morality". Instead, it proposed a deliberative regime in order to keep regulatory possibilities open and flexible (Moore 2006). In the beginning, the Warnock Report was extremely contested (Mulkay 1997; Ziegler 2004: 68). Researchers opposed any intervention into their freedom of research and in 1986 established a "Voluntary Licensing Agency", thereby

[19] There was no consensus in the committee. Three members voted against embryo research and four against the production of embryos for research.

opting for self-regulative mechanisms, whereas the majority in the parliament and in the public rejected the recommendations of the Warnock Report as being too permissive. A conservative lobby worked out the proposal of the Unborn Children (Protection) Bill (Eser et al. 1990: 393), which was confirmed by Parliament in the first reading, but then after delay did not pass. Similar to the German and Austrian legislation the Unborn Children (Protection) Bill would have made it an offence to fertilise an egg cell outside the womb unless it was destined for implantation to a woman and permission had been given by the Health Secretary. This bill, thereby, would also have prohibited PGD. But in the years after the Warnock Report, parliamentarian and public opinion changed. One important event in this context was the worldwide first successful pregnancy after PGD in the UK in 1989. During that time, the British Medical Journal euphorically evaluated: *"The antenatal diagnosis of foetal defects is perhaps the greatest advance in perinatal medicine for generations"* (quoted in Farrant 1985: 96). Ziegler comments that the promise that genetic screening of embryos will eventually lead to advances in gene therapy was also an important argument which influenced the public towards taking a more permissive attitude (Ziegler 2004: 73).

By the end of the 1980s, after the experience of the Unborn Children (Protection) Bill, researchers too supported the recommendations of the Warnock committee. In 1989, in a White Paper the Health Ministry suggested future legislation that would follow the recommendations, opting for an independent licensing agency and thereby against professional self-regulation as well as against direct state control (Eser et al. 1990: 394) Also the Catholic Bishops Joint Committee on Bio-Ethical Issues favoured this form of regulation and a majority in the Anglican and Methodist Church accepted the definition of embryos as being "pre-embryo" until the 14th day from conception as recommended by the Warnock report (Ziegler 2004: 72). These recommendations became the law when the Human Fertilisation and Embryology Act (HFEAct) was passed in 1990.[20] It constituted the Human Fertilisation and Embryology Authority (HFEA) as a body established in1991, which licenses and controls clinics offering reproductive technologies. The HFEA also has the authority to make decisions on a case to case basis when it comes to controversial practices such as exercising PGD for purposes of sex selection or the generation of a so-called saviour sibling.

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[20] Documented at http://www.opsi.gov.uk/acts/acts1990/Ukpga_19900037_en_1.htm.

The cases of the UK, Austria, and Germany show that in the 1980s heterogeneous regulatory practices developed in Europe. In Germany and Austria, PGD was indirectly prohibited, while in the UK a sophisticated case by case regulation was established based on a new regulatory body. But there is less contrast, if we consider the developments in the case of PND.

3.2. PND: Changing perceptions in the context of normalisation

The following narrative on PND, starting in the 1990s, deals with the main field of "normalisation" and routinisation of genetic testing and the changing frames to explain and politically problematise the expanded application of prenatal genetic tests. The debates about PND are characterized by three main features:

First, over time the attention paid to the modalities of individual decision-making by pregnant women has increased; their motives to use genetic tests, the institutional pressures on them, their need for counselling, and more profoundly the subjectivities developing in this context became increasingly important. This aspect will be fundamental for our analysis of changing concepts of "life" as we will further explore in chapter 4. Second, the concern about genetic testing as a selection practice by which the birth of people with "genetic disorders" can be avoided, thereby reintroducing eugenic ideas and practices, never quite disappears but persists through today. Third, the issues of abortion and the status of the embryo continue to be an important concern too. The regulatory framework developed and transformed above all in the 1990s. In recent years, the more formal aspects of governance remained generally stable whereas the area of participatory governance exercises formed an area of dynamic development. Generally, the increasing routinisation of PND was not directly embedded in legal regulations, but in a system of professional self-regulatory practices within the health care system, which holds true for all countries under study here.

Germany

In Germany, the so-called maternity guidelines (Mutterschaftsrichtlinien), issued by a common committee by physicians and health insurance companies, recommend how to deal with PND tests and with counselling before and after doing the test (Bundesausschuss der Ärzte und Krankenkassen 2003). This commission also determines for which tests, how often and in which

cases the costs are covered by the health insurances. The application of PND, and in particular of amniocentesis, expanded enormously during the 1990s, a development that correlates with the increase in the varieties of tests the health insurances covered as well as the expanding indications for applying prenatal testing. In 1987, the commission issued that the costs of an amniocentesis would be covered for pregnant women age 35 and older; but in 1997 this barrier was dismissed too so that any pregnant woman who feels anxious about the genetic condition of her fetus has access to amniocentesis without having to pay for it (Enquete-Kommission Recht und Ethik der modernen Medizin 2002: 152-179). Genetic testing during pregnancy as well as abortion after PND became a routine, as already described in chapter 2. This process of normalisation was accompanied by a change in focus concerning the debates and controversies on PND in the 1990s. In the 1980s, techno-sceptical voices had been addressing pregnant women mostly as victims of institutions, medical experts, and research. This changed during the 1990s when it became clear that pregnant women were actively and voluntarily using both PND as well as the new methods of assisted reproduction such as IVF. Their complex motivations to do so began to interest social researchers (e.g., Fränznick & Wieners 1996) and also became the subject of a broader public debate. In this context, the call for a prohibition of PND started to lose ground in feminist debates and also to some extent within the disabled people's movements (Interview 27-3 2005).[21] At the same time, the intermediate political position to support women's right to abortion while opposing selection through PND was developed further by some groups, in particular by the Network against Selection in Prenatal Diagnosis in Germany (Netzwerk gegen Selektion in der Pränataldiagnostik) which was founded in 1995 (www.netzwerk-praenataldiagnostik.de).

A revision of abortion law in the 1990s in Germany contributed in a specific unintended way to the process of normalization and routinization of PND and ensuing abortions. After German unification, abortion law had to be renegotiated since there had been huge differences between the abortion laws in the two German states before. One of the outcomes was that the critique on eugenic aspects of abortion practices in the context of PND was incorporated into the new abortion law in that it did not include the previous "embryo-pathological" indication for abortion anymore. This indication had allowed abortions up to the 22nd week of pregnancy if the

[21] This discursive change, for example, becomes obvious in the form how people deliberated in the 1000fragen.de internet forum. Only 22 percent of the contributions on PND, PGD, and "desired children" ("Wunschkinder") consisted of a resolute statement (Waldschmidt et al. 2006).

fetus had been diagnosed as genetically or otherwise "defect". In contrast, abortions for other reasons had been legal only up to the 12th week of pregnancy. The legislators considered this difference to be discriminatory and abolished it. The unintended consequence, however, was that selective abortions continued to take place but were now subsumed under the category "medical indication". In case of a medical indication, meaning that the life or the health of the mother is endangered by the pregnancy, an abortion can be not only exempt from punishment but legal and the woman does not have to undergo counselling, in contrast to cases in which she is seeking an abortion due to "social distress". In addition, there is no time limit for performing an abortion falling into this category. Women having learned that their fetus was diagnosed as genetically defect would thus get access to a legal abortion even in the second or third trimester of pregnancy, provided they argue that having a disabled child would endanger their mental health. This soon became a wide-spread practice. In the end of the 1990s, the conservative parties CDU and CSU started several attempts to restrict the practice of late-term abortions and organisations of and for disabled people issued position papers criticizing this practice (Lebenshilfe 1999).

Another influential juridical event that further contributed to the pervasiveness of PND was a decision by the German Constitutional Court in 1997 on "wrongful birth". The Court sided with the parents of a disabled child who claimed that their gynaecologist had not counselled them adequately about the options of prenatal diagnosis – by which they could have avoided the birth of the child. The gynaecologist was sentenced to pay alimony for the child (Riedel 2003). In order to protect themselves against such law suites, gynaecologists now have to recommend prenatal genetic testing at any rate.

UK

In the UK, there has been no dramatic change in the legal regulation of PND during the 1990s. The UK's Abortion Act had been established as early as 1967 and allows abortion up to the 24th week of pregnancy – and without time limit if the woman's life is at risk or if *"there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously*

handicapped" (quoted from: Human Genetics Commission 2006)[22]. Hence, it did not establish limitations for the practice of PND combined with abortion. Furthermore, PND has expanded gradually culminating recently in the announcement of the Department of Health (DoH) to screen all pregnant women for the Down's syndrome (Department of Health 2003: 42).

During the 1990s, a set of new advisory bodies emerged with relevance to genetic testing. Generally, the bioethical approach to the issue of human genetics was strengthened in 1991 by the foundation of the Nuffield Council on Bioethics. Although it was founded by private charity foundations (the Nuffield Trust and the Welcome Trust) and not formally embedded in the state, this Council has since functioned as an institutional equivalent to the national ethics councils in other countries (Moore 2006; Jasanoff 2005: 171-202; Fuchs 2005: 32). As early as in 1993 it published its report "Genetic Screening: Ethical Issues" (Nuffields Council on Bioethics 1993) discussing *"benefits and disadvantages of screening programmes - for individuals, families and society in general"* (ibid: 87) – and debated the *"general risk of a stigma of attaching or being attached for those being perceived as genetically disadvantaged"* (ibid: iv). The report recommended a balanced assessment for "society in general" and flexible regulations at the same time, because *"no-one can lay down fixed and immutable guidelines for the future of genetic screening",* thus aiming at keeping the door open for future screening programs. Further, it proposed "ethical" criteria for a legitimate application of PND, such as adequate counselling, confidentiality, and informed consent.

This approach of regulatory flexibility towards human genetics was further developed in the Science and Technology Committee's report "Human Genetics: The Science and its Consequences" in 1995 (House of Commons Science and Technology Committee 1995). It proposed the construction of new advisory bodies to establish regulatory mechanisms for various dimensions of human genetics.

However, the pro life movement re-gained momentum during the 1990s too. In 1994, Comment on Reproductive Ethics (CORE) was founded in order to promote the conservative pro life opposition towards reproductive technologies, engaging especially against abortion after PND and the liberal UK regulation of PGD (Interview 22-3 2006). It aims "*to facilitate informed*

[22] The Abortion Act does not apply for Northern Ireland, where abortion is still illegal.

and balanced debate" and explains *"the absolute respect for the human embryo"* as *"a principal tenet"* (www.corethics.org).

In the movement of disabled people during the 1990s diverging positions evolved: While some radical groups continued to campaign against Nazi-eugenics, the British Council of Disabled People (BCODP), for example, developed a more moderate position, criticising further investment into PND rather than PND in general (Shakespeare 1999). Paradigmatic for these changes is the example of Tom Shakespeare, an important activist of the movement, who changed his position from a vehement critique of eugenics in the context of PND to a much more moderate position in favour of a dialogue between disabled people, people using PND, and human geneticists (Schneider 2002).

In Austria PND is a common practice of antenatal care; little disputed in the public and the media. PND in general is governed by standards of "good medical practice" only (Wieser 2006: 166) and no special legal regulation exists. Thus PND is legally allowed within the general frame of medical treatment (especially information and consent). Pre-natal predictive *genetic* testing, however, is covered by the Gene Technology Act (Bioethikkommission 2004: 71). The Austrian penal code, which came into effect in 1975, constitutes a general prohibition of abortion (§ 96 (3)), but at the same time defines several important exceptions from punishment: firstly, if the intervention is carried out within a three months' period after the beginning of pregnancy (§ 97 (1) 1); secondly, even after this period, in cases of medical, eugenic or ethical indication (§ 97 (1) 2).

Public concerns about PND in recent years

In recent years, PND has turned into a widely accepted practice in the countries under study and stopped being a dense public energy field. Even critics of PND and selective abortions do not dare to challenge the regulatory frame of PND fundamentally. For Germany, one interview partner, a long standing activist and researcher in this field, explains that one reason for critics not to debate the regulatory framework of PND was that they wanted to avoid the risk of challenging existing abortion law:

"Since the new regulation on abortion the topic has been sort of dead: Nobody dares to touch it, to demand a new juridical regulation of PND, because that would mean to re-open the exasperating discussion of abortion" (Interview 27-3 2005).

Nevertheless, there have been dispersed moments and spaces where the debate on PND continued to circulate, be it in expert circles or in participatory experiments. Generally, we can identify three main concerns dominating these enduring debates: the quality of counselling, pro-life motivated debates on late-term abortion, and an ongoing broader public unease toward the eugenic or selective implications of PND.

One recurrent point of discussion is how counselling services in the context of PND should be improved. We suggest that the interest in counselling practices can be understood in the context of the expanding knowledge production about the modalities of individual decision-making concerning PND. As we explained in chapter 2, the expansion of PND services has not always been accompanied by a corresponding expansion of counselling services (see chapter 2). For this reason, the feminist network Reprokult in Germany focused their efforts on the question of counselling when the proposed law on genetic diagnosis was negotiated (but not approved) in 2004 and 2005. Through political lobby work they achieved that the obligation of gynaecological practitioners to inform pregnant women about the possibilities of psychosocial counselling before consenting to PND (Interview 5-3 2006) was established in the law proposal – which, except for this point, did not place a lot of emphasis on the issue of PND, however (Wagenmann 2005). The Parliamentary Study Commission on Ethics and Law of Modern Medicine also contributed to that debate. While their main focus at the time was not on repro-genetics (see below with respect to PGD), the Commission nevertheless organised a hearing in 2005, troubled by the increasing privatisation of PND as privately paid extra service. Further, the youth conference in Leipzig in May 2006 intensively discussed the question of adequate counselling. Various youth groups dealt with PND by questioning the problematic psychosocial situation of pregnant women confronted with the possibilities of PND, and the catalogue of demands that the young people set up called for a *"comprehensive counselling before and after every genetic test"* (www.gen-diskussion.de). Likewise, in the UK context the Consultation Paper on reproductive decision-making emphasised questions around the models and quality of counselling as one of the main issues for public dialogue (Human Genetics Commission 2004: 29).

While these debates on counselling mostly circulated in expert-oriented debates and participatory experiments, the issue of late term abortion also received some attention by the media in the last years. It is connected to PND insofar as abortion after amniocentesis often takes place late in pregnancy. Since neonatal care has improved the survival rates of premature infants considerably, some of these "aborted" fetuses (abortion at this point of time means induced labour) would have a chance for survival if they were taken care of. Responding to this situation, the new German government included the promise to regulate late-term abortion in its 2005 coalition contract. In the UK, in 2006 a MORI opinion poll reintroduced the issue to a broader political debate (Campbell & Hinsliff 2006).

In recent years the question of late-term abortion received some attention also in Austria. The discussion however remained in small circles of experts[23] and activists and ended soon in the usual tracks of the Austrian abortion debate (Griessler/Hadolt 2006).

These uprising problematisations of late-term abortions have been interpreted by some as attempts by pro-lifers to revitalize the anti-abortion debate (Interviews 5-3 2006, 14-3 2006, 26-3 2006). One interview partner from the *Institut Mensch, Ethik, Wissenschaft* (IMEW) in Berlin explains that the different approaches – the conservative attack on abortion in the context of PND and late-term abortion on the one hand and the call for psychosocial counselling before and after PND on the other– reflect the difference of critiques toward PND very clearly:

"That is the conflict between those debating critically the issue of PND. The question is: where is the right moment to intervene. Feminist positions have always emphasised that the supply with genetic tests is the critical point, because here the pressures to decide are becoming effective. Those who want to protect the unborn life are intervening at the moment of abortion. In my view this is the central contradiction in the current political development: There is the offer [of PND services] *that is suggesting that it pertains to a responsible decision not to have a disabled child – and than they judge women morally when they abort – that is too simple."* (Interview 5-3, 2006)

[23] See, e.g., a symposium in Salzburg in 2006 on late term abortion.
http://www.virgil.at/de/bildungszentrum/1044556130/1141283565/, 20.10.2006

The third ongoing concern keeping the debate on PND alive without directly calling for regulatory reforms is the ongoing diffuse public unease regarding the selective dimension of PND. Certainly, today the commitment to individual bodily autonomy is nearly a hegemonic position (except for pro-life groups) and the call to ban genetic counselling and genetic testing altogether, as many groups had demanded in the 1980s, has lost ground since. Nevertheless, various participatory governance experiments in the last years have shown that on a different level, concerns about eugenic practices or eugenic social developments persist.

For example, in Germany a Consensus Conference on Genetic Diagnosis was initiated by the Ministry of Education and Research and organised by the Hygiene Museum Dresden in 2001 (Deutsches Hygienemuseum Dresden 2002). The organizers invited 19 citizens, selected through a random process, to deliberate on various aspects of genetic testing during a course of several days. With regard to PND, the 19 participating citizens came to the following conclusion: *"We are extremely concerned that PND has expanded so much in the last years"*. Further, they criticised the untenable promise of getting "healthy" children and the social pressure on women *"to deliver a quality product"* (Schicktanz & Naumann 2003: 89).

These concerns became even more salient in the internet forum 1000fragen.de organised by Aktion Mensch, a huge organization for and by people with disabilities, which revealed that there is a pervasive range of concerns and fears in the public. The 1000fragen campaign basically collected questions from citizens about reprogenetics and biomedicine in a very broad sense. These questions were published on the internet and some of them in an advertisement campaign by Aktion Mensch. In a second round, prominent figures from the public sphere such as public intellectuals, actors, politicians and others were asked to comment on these questions with their comments being published too. Most of the 8,500 questions collected from citizens referred to the topic of the "(im)perfect human being" – and a lot of references were made to the issue of "selection", linking genetic testing practices to social tendencies of eugenics (Aktion Mensch 2003; Waldschmidt et al. 2006).

Again, during the youth conference in Leipzig, a recurrent topic concerning PND was that genetic testing might imply the idea of human beings being considered a "Fehlkonstruktion" (mis-construction). Posters were developed with slogans such as: *"With or without handicap, it doesn't matter to us"* or *"You are special, for how much longer"* or *"GENug GENormt"* (enough with standardisation).

Another conspicuous feature of the recent PND debates is the increasing reaction to these concerns, aiming to channel, control, and discredit the ongoing public unease towards PND. A sphere of strong reaction is academic social research. There are a lot of attempts to challenge and question the interpretation that PND forms the continuation of eugenics. Rose and Rabinow, for instance, emphasize the differences between the "old biopolitics" and the "new biopolitics" we see today. They refer to the voluntary character of PND today and insist that these practices today do not refer to the quality of a national population or even less to "race" (Rabinow & Rose 2003, see chapter 4). There are a lot of studies emphasising the complexity of individual motivations and reasons to undergo genetic testing (e.g., Heath et al. 2004; van den Daele 2005; see chapter 4). Also, in the last years we can observe strong efforts within the advisory system in the UK to discredit the analysis of current applications of genetic diagnosis as a continuity of eugenic traditions. Interestingly, for example, the predominant focus of the consultation leading to the "Making Babies"-report was directed at the question of persisting eugenics with the aim formulated by the HGC *"to debunk some of the myths in this area"* (Human Genetics Commission 2004: 19). This consultation process was linked to the recent commitment of the Department of Health to expand screening for Down's syndrome to all women, irrespective of age (Department of Health 2003), against which there had been some protest (GeneWatch UK 2004a).

3.3. PGD: a public energy field around the millennium change: regulatory changes and new participatory governance experiments

In contrast to PND which is mainly governed by professional self-regulation – and by the paradigm of guided individual self-steering –, the governance of PGD is linked to an intense debate on the role of modern statecraft and new forms of formal governance arrangements. PGD can in all cases be interpreted as an experimental field with – at some historical moments – strong controversial energy flows, as a public energy field that could be linked to the establishment of new advisory bodies or new bioethics councils around the millennium change. Hence, the debates on PGD became the occasion of further establishing and institutionalising the process of "ethicisation" of the debate on human genetics and reproductive technologies (see chapter 4). However, the forms of governance established in the different countries have been quite heterogeneous. In Austria and Germany, due to the existing the ban on PGD which had been established in the beginning 1990s the debate focussed on the question of whether or

not to legalise PGD at all and on the pros and cons of such deregulation. In the UK, in contrast, the application of PGD was governed by a flexible case-by-case mode of decision-making employed by the HFEA and public debate was much more pragmatically oriented. In this context, debates did not revolve around the general acceptability of PGD but focused on specific conditions and situations of its application – allowing a gradual shift of boundaries toward an ever more permissive regulation.

Pre-implantation genetic diagnosis is the most controversial practice among the three applications of genetic testing under study here. The intensity of this public energy field, however, is not related to the width of current applications of these practices, which in fact are still quite rare (chapter 2). Rather, as an interviewee put it, *"it pushes some very sensitive buttons of some individuals, on both sides"* (Interview 13-3 2006). These debates have involved a lot of actors, media, formal governance institutions, and NGOs in the last years and (with the exception of Austria) went beyond expert circles – evoking controversies as well on the topic of "designer babies" (or "Baby nach Katalog" – baby selection from a catalogue) as on the status of the embryo. The PGD debates were especially dense around the millennium change and linked to a change in formal governance arrangements:

Around the millennium change in Germany, PGD formed a field of controversial debate and controversial institutionalisation of expertise and counter-expertise within formal governance arrangements (Braun, K. 2005, Braun & Herrmann 2001). The debate was initiated by the Bundesärztekammer (Federal Medical Association), which in 1999 published draft guidelines recommending the legalisation of PGD in certain cases and the establishment of certain governance procedures to process these cases (Bundesärztekammer 2000). This lead the newly elected government of Social Democrats and Greens and its Minister of Health, Andrea Fischer (The Greens), to react by proposing a new law on reproductive medicine that should clarify the matter. The intention of Minister Fischer was clearly to incorporate a legal ban on PGD into the prospective law on reproductive medicine. Fischer, however, took an unusual way, not just drafting a law but initiating a huge public deliberation process on the matters at stake first. She convened a huge symposium with some hundreds of experts from different disciplines and professions, not only physicians and scientists, but also midwives, counsellors, social workers and so on, among them many critics of PND and PGD, such as the Network against Selection in Prenatal Diagnosis and feminist experts with a background in the movements against reproductive and genetic technologies. In addition, she appointed feminist and other techno-

sceptic critics to her newly constituted Advisory Board on Ethics. Some representatives of this new type of NGO experts[24] also became members of the newly established Parliamentary Study Commission "Enquete-Kommission Recht und Ethik in der modernen Medizin", an advisory commission composed one half each by parliamentarians and experts, which published its position about PND and PGD in 2002 (Deutscher Bundestag 2002). The commission confirmed the existing restrictions of the Embryo Protection Act and voted in its majority against the legalisation of PGD. In this context, the reaction of the German Chancellor, Gerhard Schröder, to establish the National Ethics Council (NEC-Nationaler Ethikrat) as a "counter project" to the Parliamentary Study Commission (Bogner et al. 2006) in 2001 was highly contested in the German public (Braun, K. 2005). Unlike the Parliamentary Study Commission the National Ethics Council was mostly composed of supporters of biotechnological research and development. In regard to PGD it did not achieve an internal consensus but published an ambiguous position in 2003 (Nationaler Ethikrat 2003). For a short time, the discussion in the media framed the conflict as an expression of a crisis of expertise, making it very clear that the evaluation of these issues depended on the different interests and different political backgrounds of different experts rather than on a "neutral" or "impartial" ethical expertise.

These formal governance arrangements in the context of a new government opened a window of opportunity for questions of new direct and indirect forms of discrimination and social pressure via genetic testing, originating from the feminist and anti-eugenic social movements, to enter expert discourse. The broader public and media debate on the issue of PGD was quite different as it focussed not so much on questions of discrimination and social pressure but more strongly on the status of the embryo. The debate was largely framed as a controversy between advocates of medical progress and economic competitiveness, such as Chancellor Schröder, and conservatives seeing the embryo as a human being from the moment of conception. Meanwhile, gender issues and concerns by feminist groups about the social implications of PND, PGD or embryonic stem cell research for women were increasingly marginalised in this debate (Braun 2007; Braun & Hermann 2001: 23).

[24] They founded a feminist expert network called "Reprokult" (www.reprokult.de).

After the intense debate during and shortly after the millennium change which resulted in a stand-off situation, the debate on PGD lost momentum. The next Parliamentary Study Commission (called "Enquete-Kommission Ethik und Recht der modernen Medizin") turned to other bioethical issues – and neither did the National Ethics Council consider PGD of priority any more. Only indirectly there was a push toward the issue by legitimising the genetic diagnosis of oocytes in 2004. The National Ethics Council published its recommendation in 2004, concluding that the genetic diagnosis of the egg during the process of fertilisation is not to be considered restricted by the Embryo Protection Act and thereby opted for its unrestricted application (Nationaler Ethikrat 2004b).

This situation might change soon. In July 2006 the new German government proclaimed the replacement of the National Ethics Council by a new German Ethics Council, at the same time not re-establishing the Parliamentary Study Commission. As the Minster for Education and Research announced this new body will review the issue of PGD (Bundesministerium für Bildung und Forschung 2006).[25]

Austria is a case against PAGANINI's primary assumption that politics of life challenges and transforms traditional ways of public involvement in policymaking. The Austrian discussion can be characterized as an elite debate with little participation of the general public and the media. In general the politics of PGD, PND and postnatal genetic testing follow for the most part the usual patterns of Austrian of policy making, that means it is concentrated in ministries, marked by elite participation, and consensus orientation.

Most preparatory work for legislation as regards content is done within the responsible ministries, that is the Federal Ministries for Health and Women (Bundesministerium für Gesundheit und Frauen, in the following BMGF), the Federal Ministry for Justice (Justizministerium, in the following BMJ) and the Federal Ministry for Education, Science and Culture (Bundesministerium für Bildung, Wissenschaft und Kultur, in the following BMBWK). Civil servants do the preparatory work but the ministers' directives are decisive.

[25] Oppositional parliamentarians protested against this expert-oriented ethics frame because there is no bioethics institution left for their direct participation (Hampel 2006).

The National Council and its individual representatives - as in most policy areas in Austria - play only a minor role in political debate and decision-making, despite their formal final legislative responsibility (Müller 2006).

There is also little political controversy about genetic testing in public (Felt 2003: 16), however, due to the past abortion controversy of the early 1970s which ended in a fragile, but permanent compromise, politics of PGD are characterised by the threat of potentially heavy conflicts and therefore by a practical deadlock (Grießler 2006).

Party lines are less than homogenous in the area of PGD. Up to now (autumn 2006) a pro-restriction that includes, e.g., Federal Chancellor Wolfgang Schüssel, Science Minister Elisabeth Gehrer and Representative Franz-Josef Huainigg dominated the governing Austrian People's Party (Österreichische Volkspartei, ÖVP). But there is also a permissive ÖVP wing existing that includes, e.g., Economics Minister Martin Bartenstein, Minister for Health and Women Maria Rauch-Kallat, and the representative and party speaker for science Gertrude Brinek. Both opposition parties, the Austrian Social Democratic Party (Sozialdemokratische Partei Österreichs, SPÖ) and the Green Party (Die Grünen) take a more permissive stand towards PGD than the dominant wing within the governing ÖVP.

An elite of scientific experts (e.g, human geneticists, genetic researchers) and physicians play an important role within advisory boards and expert commissions such as the gene technology commission (Gentechnikkommission [26]) at the BMGF and the bioethics commission (Bioethikkommission) at the Federal Chancellery (Bundeskanzleramt)[27]. But also a handful of catholic and protestant theologians as well as secular philosophers are important elite actors in governmental commissions and public debate as well. So far expert advice stemming from these commissions was extremely important because it informed or at least legitimated government proposals and decisions on genetic testing. Traditional or new expert commissions such as the relatively recent bioethics commission and the more than 10 years old gene technology commission remedy legitimation deficits.

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[26] http://www.bmgf.gv.at/cms/site/attachments/7/7/8/CH0260/CMS1085581033386/original-liste_gtk__2005-2009_.pdf, 20.10.2006

[27] http://www.bka.gv.at/DesktopDefault.aspx?TabID=3455, 20.10.2006

The officials of the Catholic Church, which take a very restrictive position, are rather influential particularly via their connection to the restrictive wing within the ÖVP. NGOs such disabilities groups and moderate catholic pro-life activists play a significant role, yet uninvited by elite circles, at times upsetting policy makers and blocking a permissive regulation of PGD. These groups cooperate loosely, e.g. within the working group "Ethics commission FOR the Austrian Federal Government"28 (Ethikkommission FÜR die österreichische Bundesregierung), and try to gain access to the policy arena.

The governance of "red biotechnology" from above included also in Austria - similar to the German case - the establishment of a new national Bioethics Commission (Bioethikkommission, Brede 2005). This commission, established in 2001, advises the Federal Chancellor from an ethical perspective in all social, scientific and legal questions, which stem from the scientific development of human medicine and human biology. The commissions' tasks include in particular: First, to inform society about important discoveries of human medicine and human biology and the ethical questions that are related to these discoveries. Furthermore, the commission shall promote discussion in society about these questions. Second, the commission ought to report practical recommendations. Third, it shall suggest the necessary legal measures and, forth, prepare reports for particular questions. The commission includes not less than 15 and not more than 25 experts from human medicine (gynaecology, psychiatry, oncology, pathology), molecular biology and genetics, law, sociology, philosophy and theology.

The legitimacy of the expert committee did not remain uncontested. Partly challenging the Bioethics Commission, the City of Vienna installed a bioethics committee of its own.[29] In addition, as already mentioned, a group of representatives from disabilities groups and moderate pro-life activists formed the platform "Ethics Commission FOR the Austrian Federal Government" ("Ethikkommission FÜR die Österreichische Bundesregierung") because governmental officials, who did not consider them as "experts", denied these activists access to the official Bioethics Commission. It is therefore the aim of the alternative Ethics Commission to complement the opinion of the expert oriented Bioethics Committee and to provide an additional opinion from lay people who are actually affected by biotechnology.

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[28] http://www.service4u.at/ethikkommission/index2.html, 20.10.2006.
[29] called Beirat für Bio- und Medizinethik; cf. http://www.wien.gv.at/vtx/vtx-rk-xlink?SEITE=020021129020.

PGD, in contrast to PND, is a controversial topic in Austria. However, the general public is little involved and the debate is limited to expert circles. Experts of medical law assume, as already mentioned, that the Austrian reproductive medicine law from 1992 prohibits implicitly PGD in almost all cases but does not cover polar body diagnosis. In recent years there have been efforts from expert geneticists and physicians to ease the legal restrictions placed on PGD. In 2004 a governmental advisory committee of experts recommended to loosen the law and to allow PGD in a small number of cases (BMGF 2005). Also a majority opinion of the official Bioethics Commission recommended to loosen the rigorous regulation of PGD in some cases (Bioethikkommission beim Bundeskanzleramt 2004). However, coordinated efforts of self-help groups of disabled and moderate pro-life activists stopped these attempts. Thus, "bottom up" participation of unruly and excluded stakeholders turned out to be extremely influential in this case. However, these marginalized groups used traditional forms of political campaigning and networking to gain access in the policy-making arena they were initially excluded from.

In the UK, the debate on PGD began when the first fertility clinics started offering PGD in 1989. In the end of the 1990s this debate was institutionalised by establishing two advisory committees following the recommendations of the 1995 report of the House of Commons Science and Technology Committee (House of Commons Science and Technology Committee 1995). The Advisory Committee on Genetic Testing, established in 1996, and the Advisory Working Group on Pre-Implantation Genetic Diagnosis, a sub-commission of the HFEA, established in 1997, started a debate on the rules and criteria in regard to licensing PGD (Human Fertilisation and Embryology Authority and Advisory Committee on Genetic Testing 1999). Then HFEA-chairwoman Deech explained their efforts, expressing that she wanted to avoid PGD *"for any social, physical or psychological characteristics… that are not associated with serious, often life threatening medical disorders"* (Ziegler 2004: 86). This position remained stable within HFEA politics for a long time. Nevertheless we will show that it was open to a lot of different interpretations concerning the question of which conditions could be interpreted as "serious", according to which criteria and who would be authorised to define them.

When in 1999, the advisory system on biotechnologies in the UK was reformed, following an initiative of the Cabinet Office and the Office of Science and Technology (Cabinet Office & Office of Science and Technology 1999), the system of advisory bodies was assigned the function not only to react to existing debates but also to initiate debates. The explicit aim of this reform was to expand the mandate of the advisory system so that it would go beyond merely

reacting to concrete cases of technological development and beyond the expertise of specialised technocratic bodies. The idea was to develop a more encompassing "strategic framework" and to guide public debate on human genetics and make it more *"forward-looking for so rapidly developing a technology"* (Cabinet Office & Office of Science and Technology 1999: ii). The background of this reform was above all the uprising public unrest regarding GM crops and food (see work package 6; Interview 14-3 2006). Nevertheless, the reform also changed the governance arrangements for "red" biotechnologies, and, while preserving the statutory body of the HFEA in regard to assisted reproduction, in addition to it the Human Genetics Commission as meta-regulatory body on the social, ethical, and legal implications of human genetics was created (Cabinet Office & Office of Science and Technology 1999). The Human Genetics Commission absorbed the former Advisory Committee on Genetic Testing and took over the consultation project on PGD that had already been started (Advisory Committee on Genetic Testing 2000). In 2001, HFEA and HGC published the outcomes from this consultation together with the HFEA's and HGC's recommendations on the issue (Human Fertilisation and Embryology Authority & Human Genetics Commission 2001). They had consulted stakeholder organisations as well as the broader public. The background to this event had not been a big controversial debate about PGD in general, but rather the question, in which cases following which criteria the HFEA should license its application. It turned out that the majority of respondents accepted the existing practice of the HFEA of *"licensing clinics to perform PGD for a limited number of specific serious inherited conditions, including sex linked disorders and chromosome abnormalities"* (Human Fertilisation and Embryology Authority & Human Genetics Commission 2001: 12). Restrictions should be placed on the use of PGD *"to prevent it being used for frivolous or 'social' reasons, or for eugenic purposes"* (ibid.: 12). Also, the majority opted in favour of using PGD only for *"highly predictive serious disorders, not complex genetic components"* (ibid.: 20).

While these opinions, according to the report, were supported by the majority of those consulted, the consultation report also admitted the existence of some controversial issues. One was the question of tissue typing or so-called "saviour siblings" (Bionews 2005b). Tissue typing is done by Human Leukocyte Antigen Typing which allows to determine whether the tissue of the embryo matches with that of an ill family member, in most cases that of an existing sibling. That is why this use of PGD is also known to the public as selecting a "saviour sibling". The advisory bodies recommended further consultations on this issue (Human Fertilisation and Embryology Authority & Human Genetics Commission 2001: 6). Another controversial issue concerned the use of PGD to test for late-onset genetic diseases such as Huntington's Disease.

On this question, the report only suggests rather ambiguously that this *"should be one of a number of factors but not an overriding factor, whether PGD should be offered"* (ibid.: 19).

Nevertheless, in the following years the HFEA *did* license uses of PGD the majority of respondents in this consultation had not approved. The most controversial case, leading to a sophisticated juridical, political, and media debate in the following years, was the license for "tissue typing."

Unlike it had announced previously, the HFEA did not conduct another consultation but allowed tissue typing in the case of the Hashimi family. However, it later rejected such use in the case of the Whitaker family. The main rationale was that the disease of Zain Hashimi, which was thalassemia, is considered a genetic disorder which meant that the embryo who would function as a "saviour sibling" would have to betested for the gene him- or herself, as well as for the tissue compatibility. In the case of Charlie Whitaker who suffered from the Diamond-Blackfan, a non-genetic disease, the embryo who would serve as a "saviour sibling" for Charlie would not be screened for this genetic condition (Wasserman 2003). The pro life NGO CORE took legal action against the decision in the Hashimi case, arguing that third party interests should not be a justification for the use of PGD; however, after initial success before the High Court, in the end it lost the case (Ziegler 2004: 90).

Later the HFEA also allowed cases similar to the Whitaker case. The HFEA justified its policy change by pointing to a shift in priorities: While in the beginning the (small) risk for the prospective "saviour sibling" to be born with a genetic disorder was considered more important, later the HFEA in a more "contextual" way regarded the "welfare of the family" and their right to "reproductive choice" to be of higher priority (Mills 2006).

The "saviour sibling" debate is one example of policy shifts regarding PGD that are not backed by consultation processes. Another contested case which marks a policy shift refers to the licensing of PGD in order to test for a form of eye cancer that is considered to be caused by genetic factors in 2005 (Bionews 2005a). The family in question already had one child with this "genetic condition" who had already been treated and had survived the disease. In this case, the HFEA *did* start a consultation process on this specific question – yet only *after* having issued the license (Human Fertilisation and Embryology Authority 2005b). Another specific consultation referred to sex selection – resulting in a refusal of sex selection related to non-medical reasons, but an acceptance of PND and PGD for sex-linked inherited "disorders" such as Duchenne

muscular dystrophy which predominantly affects boys (Human Fertilisation and Embryology Authority 2003).

These policy shifts concerned the criteria for applying PGD that were linked to the specific condition tested. Another mechanism for keeping the licensing system rather flexible has been the interpretation of the general requirement established by the HFEA that the "genetic disorder" tested for has to be "serious" in order to justify the application of PGD. HFEA did not establish a set of fixed criteria as regards which conditions were deemed "serious" and which were or not. Instead, the HFEA leaves this decision to case by case decision-making, taking the subjective assessments of the persons involved into account. Hence, the document that presents the outcomes of the consultation explicitly declares that: *"The seriousness of a condition should be a matter for discussion between the people seeking treatment and the clinical team."* (Human Fertilisation and Embryology Authority & Human Genetics Commission 2001). This mechanism shows that the governance of genetic testing, here, is directly linked to the motivations and the social situation of couples and families seeking genetic testing. Hence, the production of knowledge on what these motivations and situations are is required and the processes of regulation are, at least indirectly, linked to processes of such knowledge production. In a similar vein, a proposal that referred to recommendations from some disability rights organisations suggested to integrate *"the testimony of families and individuals about the full range of experiences of living with the condition"* into the decision-making process about PGD (Human Fertilisation and Embryology Authority & Human Genetics Commission 2001: 8).

The flexibility in decision-making on PGD was also supported by the argument that *"PGD should be consistent with the use of PND"* (Human Fertilisation and Embryology Authority & Human Genetics Commission 2001: 6). This argument also reappeared in the consultation paper "Choosing the future: Genetics and reproductive decision making" (Human Genetics Commission 2004), which was prepared by the HGC for the "Making Babies" report. One of the key points it made was that the policies on PGD should be consistent with the guidelines and practices governing the application of PND. The consultation paper recommended to make both practices coherent in the sense that disorders or "defects" considered to be a reason for aborting a foetus should also be considered a possible reason for using PGD (Human Genetics Commission 2004). Such a policy would extend the scope of applications of PGD considerably. The document also establishes a direct link between PGD and the argument of reproductive choice, thereby assuming that there is no relevant difference between the situation of a woman

who is already pregnant but does not want to be and the situation of a couple and their doctors to deliberately create embryos via IVF that they know might eventually be destroyed.[30]

One of the explicit purposes of the "Making Babies" consultation process was – like in the case of PND and the eugenics frame – to discredit the concern that PGD will lead to the production of "designer babies". The Making Babies-report explains:

"The anxiety that PGD lies at the top of a slippery slope leading to the possibility of a wide range of potential enhancements, such as intelligence or beauty is misplaced" (Human Genetics Commission 2006).

The delegation of decision-making to an authority, here the HFEA, and the case to case modus of regulation were not uncontested within government circles. The Science and Technology Committee of the House of Commons, for example, harshly criticised the arbitrariness of decision-making and argued in favour of a re-establishment of modern statecraft (Secretary of State for Health 2005). On the occasion of the government's initiative of 2004 to review the HFEAct itself (Department of Health 2005), the Science and Technology Committee assessed the HFEA's work as being "clearly unsatisfactory" (Secretary of State for Health 2005: 18) and objected in particular to what it saw as an inconsistency and arbitrariness of case-by-case decisions. It argued, for example, that the differentiated decision-making procedure of the HFEA that approves PGD for some genetic conditions but restricts it for others would make no sense. It argued in favour of a more general permission for PGD, refuting anxieties about the creation of "designer babies":

"PGD is limited in that it can only be used to screen out disorders and thus it cannot be used to create 'designer babies'. We see no reason why a regulatory framework should seek to determine which disorders can be screened out using PGD" (Secretary of State for Health 2005: 18).

This review process of the HFEAct may point to a crisis of the advisory system in the UK itself, challenging it from both sides, from claims to professional self-regulation on the one hand and the call for more general legal regulations and norms on the other.

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[30] In Germany, this point played a certain role in the 2000/01 debate and was made mainly by feminist groups but also by other actors such as the then Minister for Justice, Herta Daeubler-Gmelin.

However, this critique was not strong enough to fundamentally challenge the system of arm's length bodies. What is more important in order to explain the reform process that may result in the dissolution of the HFEA in the next years is a shift in how reproductive technologies are framed within the system of arm's length bodies. It is planned that the HFEA will merge with the new Human Tissue Authority established by the Human Tissue Act in 2004 (see www.dh.gov.uk; Wallace 2006). This integration of reproductive technologies and, more specifically PGD, into the HTA framework can be interpreted as a shift away from locating PGD within the framework of procreation. Instead, in the new institutional arrangement embryos, sperms, eggs, or toti-potent cells, blood, or bone marrow are equally framed as "tissue"; thus entities whose origin is actually quite different are all subsumed in one and the same category. This re-framing shows that the research perspective is getting more dominant in relation to reproduction, as research is mainly interested in tissue as research material (Interview 10-3 2006). Insofar, the integration of the HFEA into the HTA would be another step of normalising PGD and other aspects of reproductive technologies.

3.4. "Predictive medicine": deregulated practices and incipient intents of regulation

The landscape of regulations regarding "post-natal" medical genetic testing is also quite heterogeneous. While there is no comprehensive legislation on genetic testing in Germany and the UK, Austria has a Genetic Engineering Act (Gentechnikgesetz) prohibiting the use of genetic test results by insurers and employers. In recent legislation a ban on non-consensual genetic testing within the UK Human Tissue Act came into effect the 1st of September 2006. But its scope is rather limited and it installs a lot of caveats with respect to medical purposes and criminal investigations (Williams 2006). On the whole, the field is characterized by non-regulation or deregulation. New practices of using genetic testing for the prediction of future disease, or the probability thereof, but also for insurance or employment purposes are starting to proliferate – without a consistent regulation of these practices.

Scientific uncertainties concerning the validity of test results, as well as the contested concept of genetic testing, and the view of genetic data as referring to the most personal level of the

individual, to the core of her or his personality, all complicate the establishment of coherent legal frameworks. To make things more complicated, oftentimes powerful interests seeking to get access to genetic data may play an influential but not always visible role. Participatory processes and arrangements often confine the issue to the question of individual rights, consent, confidentiality, data protection, and counselling without addressing powerful research and economic interests at stake.

"Post-natal" genetic testing had already been a controversial issue in the 1980s in a discourse that also addressed future potentialities of human genetic engineering and negative utopias as for example the fear that these technological developments would result in a totalitarian surveillance of citizens and a qualitative selection of workers by gene checking. These fears were a reason why the Commission of the European Union in 1988 had to rename their project for research on the human genome. The initial title of "predictive medicine" was revised due to massive protest by the EU-Parliament who discerned a eugenic framing at work here (Abels 2002).

In Germany, in the 1990s the issue of genetic testing was addressed, albeit not as a salient question, by the campaign against the Bioethics Convention of the Council of Europe. People with disabilities organizations, religious organisations, anti-eugenic groups, civil rights groups and other groups protested against the proposed article on genetic testing (Art. 17) of the initial proposal and its possible negative impact on the rights of people affected by genetic disorders. Critics held that the language of this article did not restrict genetic testing at all as it would allow for requiring genetics tests from people for a broad range of reasons such as for *"health care purposes or scientific research"* but also *"outside the health field"* when *"overriding interests"* were concerned (Braun 2000b: 234).[31]

In the UK, during the 1990s the newly established ethical advisory bodies were already tackling the question of how to regulate genetic testing, though still to a limited extent. The 1993 paper of the Nuffield Council on Ethics already proposed a flexible policy regarding genetic testing and opposed general legal restriction or regulations placed on these medical practices (Nuffields Council on Bioethics 1993). In 1997, the Advisory Committee on Genetic Testing (ACGT)

[31] The scepticism towards abuse of genetic information still became visible in a statement by the Advisory Board on Ethics of the Green Ministry of Health in 2000 (Ethik-Beirat beim Bundesministerium für Gesundheit 2000). The statement integrated a strong "socio-ethical" approach against the "social risks" for disabled people and proposed restrictive conditions for research on genetic data and opposed the use of genetic data by insurers or employers.

developed a first Code of Practice opting for a *"voluntary system of compliance and monitoring"* for test suppliers (Advisory Committee on Genetic Testing 1997). However, this code was later criticised as *"ill-designed"* by the HGC (Human Genetics Commission 2002b): The code referred only to over-the-counter tests supplied directly to the public and covered only certain tests on inherited dominant and x-linked disorders and on late onset genetic disorders.[32] Hence it left out life style oriented tests or risk calculating tests referring to "multi-factorial" diseases.

It has only been in recent years that medical genetic testing has entered the political agenda in a much more intense, complex, and sophisticated way, a process that is partly due to the expanded range of "genetic diseases" tested for or likely to be tested for in the future and in the build-up of biobanks, as introduced in chapter 2. Debates have evolved on ethical and legal questions of regulating genetic testing procedures. Nearly inseparable from this, there is an intensified debate on the access to and the management of individual genetic information.

In the UK, as has been the case with PGD, the debate was initiated from above after the reorganisation of the advisory system on biotechnologies and the establishment of the HGC in 1999 had taken place. By organising various consultations on these topics the HGC followed the idea behind the reorganisation of the advisory system of a "strategic framework". One of the consultations that the HGC initiated after its constitution was a repetition of the consultation process on commercially supplied tests, a consultation which did not result in a clear recommendation for legal restrictions or regulations (Human Genetics Commission 2003). But the biggest consultation effort made by the HGC was on genetic testing and data protection, titled "Whose Hands on your Genes" and addressing the general question of how to regulate genetic information. It started as early as 1999 (Human Genetics Commission 2000). The consultation process integrated a mix of stakeholder responses, a people's panel, and a consultative panel and thereby interpellated different types of political subjectivities and different forms of publics it considered to be relevant. The evaluation of this consultation process by the HGC was published under the title "Inside Information" in 2002 (Human Genetics Commission 2002a). It touched a much wider range of issues related to genetic data than previous consultations – such as family relationships, paternity testing, consent,

[32] This limited orientation reflected the public debate on the marketing of a test for cystic fibrosis in the early 1990s, which the STC had vehemently criticised in its 1995 statement (House of Commons Science and Technology Committee 1995).

confidentiality, protection of genetic information in medical practice, research, insurance, employment, and criminal investigations. In a lot of respects the recommendations of the HGC remained rather ambiguous, although clearly favouring the individual's right to personal genetic data protection. For example, the report opted for a differentiated approach to the sensitivity of data (Human Genetics Commission 2002a: 4). Concerning the possible disclosure of data it declared:

"Disclosure of sensitive personal genetic information without consent may be justified in rare cases where a patient refuses to consent to such disclosure but the benefit to other family members or the wider public substantially outweighs the need to respect confidentiality" (Human Genetics Commission 2002a: 10).

At least the Department of Health seemed to consider this statement as a legitimate basis not to promote a more cautious approach to data protection within medical care and research, but to foster the expansion of human genetics services within health care. One year later it published a White Paper which above all opted for the expansion of human genetics, genetic testing, screening, and counselling within the NHS, called "Our Inheritance, Our Future. Realising the potential of genetics in the NHS" (Department of Health 2003). The document announced the investment of an additional 50 Million GBP in the NHS to further develop the integration of human genetics into health care services. And it proposed a general screening for a broad range of genetic conditions with newborns (Department of Health 2003: 43), a proposal that provoked astonishment in the expert communities and later also became a topic for consultation (Interview 13-3 2006; Human Genetics Commission 2005).

In Germany, there have been various statements on the topic of genetic testing and on genetic data and biobanks, issued by the National Ethics Council and the Parliamentary Study Commission (Deutscher Bundestag 2002; Nationaler Ethikrat 2004a; Nationaler Ethikrat 2005). This mainly expert-based debate opened up to some extent when in October 2004 the Government drafted a new law on genetic testing (Bundesministerium für Gesundheit und Soziales 2004). The draft caused an intense public debate and numerous NGOs set up position papers on the issue.[33] The media mainly focused on the issue of paternity tests, above all on the question whether the mother's consent should be required. A broader public debate also

[33] Gen-Ethisches Netzwerk 2003;Netzwerk gegen Selektion durch Pränataldiagnostik 2004.

addressed the right of employers and the insurance industry to demand genetic test results. The law proposal was quite restrictive in this respect, although in the first draft version it had some loopholes (for example with respect to public servants). Less observed by the public was a much more "liberal" or market- and research-oriented aspect within the proposal referring to access to genetic data for research (Wagenmann 2005).[34]

Until today the process did not result in passing the law – not only because of the early end of the coalition government of the Social Democrats and Green Party in autumn 2005. Apart from the public controversy on paternity testing, one important obstacle was the contradiction between the claim of individual data protection and the claim of the security apparatus to have access to medical data collections (Averesch 2005).

One interview partner from the NGO Gen-Ethisches Netzwerk explains:

"It won't be possible to solve the problem legally (…) There are too many different interests involved which they cannot abandon. One, for example, is the confidentiality of research with respect to the data collections. (…) The confidentiality of research would make research much more comfortable, with an easier access to the test persons. On the other hand there is no protection for biobanks against confiscation on reasons of criminal prosecution or danger in delay. The police can always justify that they need access to the data and the state will not desist of this right. In my view it is an impossible task to regulate these contradictions" (Interview 26-3 2006).

Another obstacle is the question of how exactly to define genetic testing – and how to differentiate information resulting from genetic tests (see chapter 2) from other kinds of health information. Nevertheless, the Green Party, now in opposition, is currently starting a new initiative and has announced to present a new draft in autumn of 2006.

At the Leipzig youth conference in May 2006 this stalemated situation was a critical point of debate. The adolescents had been called to produce a catalogue of their demands with respect to the legal regulation of genetic information - only to learn that such regulation was not really promoted by politics. In the end of the conference, they were upset about the disinterest of

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[34] This position substantially differs from the suggestions of the Advisory Board on Ethics of the Green Ministry of Health on predictive genetic testing in 2000: It still generally opposes the use of tissue samples, taken for other medical purposes, or for genome analysis (Ethik-Beirat beim Bundesministerium für Gesundheit 2000: 15).

journalists and policy makers in the outcome of the allegedly participatory process – and about the permanent delay of legislative efforts.

In Austria, public involvement apart from the usual mechanisms of representative democracy was almost absent in the regulation of post-natal genetic testing. One exception was the citizen conference on genetic data "Genetic Data: From Where, Whereto, What For?" (BürgerInnenkonferenz "Genetische Daten: woher, wohin, wozu?"), which was organised in 2003 (Felt 2003).The event was commissioned by the Austrian Council for Research and Technology Development (Rat für Forschung und Technologieentwicklung) within its public relation campaign "Innovatives Österreich". The citizen conference was designed after the Danish model by the PR-agency "communication matters" (Bogner 2004, Menasse 2004). The primary aim of the conference was to raise public awareness for science and technology and not to take any decision at all. "Communication matters", the organisers, consider this event as an attempt of institutional innovation, however, their efforts to place the consensus conference appropriately in the Austrian decision-making mechanisms completely failed and the conference remained disconnected from actual policymaking. The most influential politicians in this area either completely rejected or neglected the consensus conference. Other politicians, such as Representatives of the National Council simply did not notice the event.

Despite the absence of a manifest public controversy the issue of genetic testing is still a challenge to government. However, it is not the general public but an elite of policy makers, experts and stakeholders who perceive a particular deficit of legitimacy.

In 1998, the Austrian government faced the civic initiative on gene technology. The initiative was extremely critical about "green biotechnology" and demanded a very restrictive governmental policy. This civic initiative on gene technology ("Gentechnikvolksbegehren") became one of the most successful civic initiatives in Austrian history. This act of civic participation traumatised politicians and civil servants who want to promote in research and development for economic growth. We propose to look at the "Gentechnikvolksbegehren" together with the abortion debate in the 1970s as one of the main "dislocatory events" of life politics in the area of genetic testing in Austria. Both were very emotional controversies, characterised by seemingly irreconcilable cleavages within society and followed by a political deadlock (Grießler 2005).

One response of politicians and policy makers to this experience of public rejection of biotechnology was to initiate and support the foundation of the "Plattform Gentechnik und Wir" (now "Dialog<>Gentechnik"), a platform of scientific societies that should defend the cause of biotechnology by giving science a voice in public debate.

The lesson from the "Gentechnikvolksbegehren", trying to seek a dialogue with a presumably sceptical public about the benefits of life science in order to create acceptance is also present in a strategy paper of the Austrian Council for the development of life science in Austria, that emphasises the importance of entering into dialogue with scepticisms in order to gain broad acceptance in society for life science (RFT 2004: 10).

Thus the challenge for policy makers in this area is to raise positive awareness for the life sciences by increasing acceptance for "red" and thus avoiding the disaster of "green biotechnology" in the late 1990s. In the case of "green biotechnology" the controversy came rather late, was very emotional and led into a deadlock. Some actors perceive public participation events as one strategy within this general goal. However, they are confronted with the problem that they search and address a public that hardly becomes visible and shows up in the events they are staging together with social scientists and PR-agencies - such as scientific cafés, consensus conferences and days of dialogue -, as can be seen in the small numbers of participation and media response.

However, there are also civil servants and researcher who perceive participatory events differently and want to connect them to decision making on different levels.

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However, there are also civil servants and researcher who perceive participatory events differently and want to connect them to decision making on different levels.

At the European level the Commission of the European Union also initiated a debate on the issue of genetic testing – without offering any concrete regulatory influence on projects concretely at stake (Interview 3-3, 2006). In May 2004, it organised a conference on genetic diagnosis in Brussels, the "European Stakeholders' and Citizens' Conference on 25 Recommendations by the European Commission's Expert Group" (European Commission 2004b). As the title already demonstrates, the conference limited the opportunities of intervention for the invited guests to submitting comments on the recommendations on *"ethical, social and legal aspects of human genetic testing in research and healthcare applications"* (European

Commission 2004a) that had been pre-elaborated by experts before. These recommendations in general did not propose clear regulatory mechanisms, but information, dialogue, and the consideration of certain questions. It introduced discursive mechanisms of differentiation such as the claim to avoid "genetic exceptionalism" – opting for the integration of regulation of genetic testing into the existing health care regulations and the claim to avoid "unfair discrimination" – a term that leaves the door open to "fair" discrimination – for example in the case of risk calculations of the insurance industry. The expert group who had formulated these recommendations consisted mainly of representatives of pharmaceutical enterprises, complemented by some academic scholars and patient organisations: The expert group also designed an Action Plan for further activities that should promote public dialogue and establish an "education network" especially for programs directed at school students (Feyerabend 2004/2005). What becomes obvious in the EU efforts of dialogue is that it privileges the speaking position of patient organisations – apart from direct scientific and pharmaceutical lobby groups (see chapter 5).

As we have already mentioned, the efforts of participatory and advisory processes initiated from above through diverse mechanisms have not resulted in specific legal regulations on genetic testing referring to "predictive medicine". In the following we will summarise the main issues at stake, the frames of debates, and the governance mechanisms on the different topics involved.

A very prominent debate in politics and the media has been the debate on regulating the use of genetic test results by insurance companies and employers.

The topic of genetic testing and insurances was widely debated in the UK during the "Whose Hands on Your Genes" consultation and was also promoted by the government in the context of election campaigns. In 2001, the British government and the Association of British Insurers signed a moratorium whereby the insurance industry committed itself to not demand or use genetic test results in the next years, with the exception of life insurances exceeding a certain financial limit (Association of British Insurers 2001; Gesamtverband der Deutschen Versicherer 2001). There are different interpretations within the expert community in the UK how to interpret the influence of the HGC on this moratorium: Some members of the HGC consider it a success of its consultation efforts (Interview 20-3 2006). However, one observer mentions that the HGC was still working on its report on the insurance question when the negotiations between the insurance industry and government had already developed:

"There was a rush to have a policy agreement. So they rushed their report ahead of their schedule. Then they did a moratorium. But the real political forces that created that moratorium were the government and the insurance industry" (Interview 14-3 2006).

This impression is supported by the fact that the moratorium was again prolonged in 2005 without any dialogue procedure on the part of the HGC. One commercial law expert within the HGC explains:

"I wasn't thinking that the moratorium was extended by the government and the insurance industry without us knowing about it, we agreed to the first one, but I was very much in the view that we should have used that in the interim time, I as a lawyer saw it as an interim injunction, you know you get a preliminary injunction, basically it maintains the status quo and in the meanwhile you sort out what to do about it" (Interview 20-3 2006).

In the same year, in Germany the insurance industry also declared a moratorium committing itself not to demand genetic testing results except for contracts exceeding a financial limit of 250,000 Euro (Gesamtverband der Deutschen Versicherer 2001).

Generally, the moratoriums should be interpreted as means of a "politics of time" as they delayed regulatory decision-making to the future. They form a concession by the insurance industry to public concerns in a moment when genetic tests results are still too rare and too uncertain to be economically relevant. Most test results give insufficiently clear prognostic information on life prospects so that insurance companies cannot efficiently calculate with them (Interview 13-3 2006). Also, representatives of insurance companies themselves point to the uncertainty of genetic test results in order to delude public concerns. For example, Achim Regenauer, chief medical expert of the Insurance Company Münchner Rückversicherung, puzzled the adolescents at the youth conference in Leipzig by emphasising that the insurance industry until then was not interested in using genetic tests. [35] Oppositional voices express concern that this situation could change dramatically as soon as DNA chip technology results in broader genetic risk assessment strategies within health care (Interviews 5-3 2006, 14-3 2006, 26-3 2006).

[35] At the same time, he is an important lobbyist against a general legal restriction of insurance companies using genetic tests (cf. Will 2005).

The situation is similar concerning the question of whether employers should be allowed to demand genetic test results from employees. One member of the Human Genetics Commission explains:

"I think there is much more to come because even a lot of scientists made very sweeping statements with mapping the human genome, and I think one begins to understand, how poorly determinant it is, really. (…) We have and we will do more about how poorly predictive tests, even for something like Huntington disease, predicts, you can't predict 100 percent, and so it might be long after someone's employment career, so how limited, of what limited usefulness most of these tests are. (…) So very few employers are using very few tests, so that is an implicit acknowledgement of how limited their usefulness is, which is an implicit acknowledgement of the failure of genetic determinism, so the knowledge is out there but it is not very well articulated" (Interview 6-3, 2006).

However, there has been an intense public debate in recent years on this question. In Germany, it took place in the context of the law proposal. It proposed to generally prohibit employers from demanding access to genetic data, but provided exceptions, for example for public servants (Staeck 2004). In the UK, the debate has been incited by the Inside Information report in 2002 and prior to that also by an early consultation of the Human Genetics Advisory Committee. This predecessor of the HGC, one of the specific advisory committees of the 1990s, had proposed a legal restriction of the use of genetic test results by employers (HGAC 1999). The UK government, however, reacted by proposing exceptions such as in the case of *"susceptibility of specific features of a working environment"* (Department of Health 2000). Until now there is no regulation and no clear legal requisite to restrict the employers' demand of genetic test results (GeneWatch UK 2003b).

Although making genetic tests a precondition for employment still appears to be a science fiction scenario, there have already been some spectacular cases that caught international attention: One was the case of a teacher in Germany who was, in order to be employed as public servant, obliged by the school authority to do a genetic test because of cases of Chorea Huntington in her family. The teacher sued the school authority, refusing their demand, and the courts sided with her (Tolmein 2004). This case has further promoted public concern and unease as massively expressed in participatory governance experiments such as the 1000Fragen.de internet forum or the youth conference in Leipzig.

The proponents of permitting, albeit in a regulated way, the use of genetic tests for employment purposes above all question the "genetic exceptionalism" frame, that is they denied that genetic

information is essentially different from other health information. They opt for a differentiated evaluation of genetic test results as part of normal prognostics in health care. For example, the National Ethics Council in Germany published a statement in 2005 on "predictive health information in employment examinations". It argued against a specific regulation on genetic testing and instead opted for a regulation consistent with other diagnostic methods, thereby proposing a more permissive regulation in favour of using certain predictive diagnostic test results in employment (Nationaler Ethikrat 2005). However, opponents of the use of genetic test results in employment are also increasingly confronted with the question of how to define genetic tests and the specificity of genetic discrimination – in the context of scientific uncertainties. We will further address this issue in chapter 4.

In contrast to the debate on regulating genetic testing in insurance and employment, which is mainly directed to future possibilities, the question of access to genetic data is, as mentioned, already highly relevant for current human genetics research. As we exposed in chapter 2, currently biobanks are being newly established or coordinated and centralised on the basis of existing collections. There is an increasing orientation of human genetics research towards epidemiological research today. This is why research is dependent on the access to large samples of blood, tissue, and large data bases on individual health biographies and life styles.

The debate on how to govern access to such data is mainly framed as a debate about the individual rights of the donors up to now. The confidentiality of data and procedures to gain the informed consent of the donors when using genetic data for research is an issue for an expanding expert discourse. The proposed law in Germany – following the recommendations of the National Ethics Council (Nationaler Ethikrat 2004a) – suggested only a very general, blank consent for using personal genetic data and material for research. Moreover, it established exceptions, for example, in the case of already collected materials. NGOs reacted to this proposal by pointing out the problem of anonymisation and pseudonymisation in genetic research. They proposed more restrictive regulations regarding data confidentiality and consenting procedures (Wagenmann 2005). The feminist expert network Reprokult proposed complex requirements for informed consent that could be read as an obstructive strategy – because putting it into practice would make research projects very difficult to perform (Reprokult 2004).

In the UK, the debate was connected to the establishment of the UK Biobank. There have been a lot of objections to its establishment by different experts – ranging from issues of scientific consistency of this form of data collection (Barbour 2003) to ethical issues and the lack of safeguards concerning confidentiality and informed consent which were established only later in response to fierce criticism (e.g., Interview 6-3, 2006). In the beginning, the UK Biobank project had no clear criteria how to guarantee informed consent and data protection. Nevertheless, the mainstream position of the advisory system was the following: Because donors would participate voluntarily in the project and because the Biobank had meanwhile established its own ethical governance arrangement they saw no need for the HGC to further follow up this large experiment of genetic data collection by organising participatory deliberative processes in the future (Interview 20-3 2006).

Generally – and as a result of these evaluations – the media and the broader public did not pay a lot of attention to this aspect of genetic testing although access to genetic data is economically quite relevant for current human genetics and so are the prospects of the biotech industries. In contrast to the insurance and employment issue, this topic generally did not transcend the boundaries of the expert community.

There have been other expert-based debates with respect to genetic testing in "predictive medicine", for instance on the question how to handle the samples existing in laboratories and internationalised via the exchange of samples beyond national borders (OECD 2005), or on how to regulate screening projects within health care systems and how to use the resulting data (GeneWatch UK 2004a; Steindor 2005).

Another important issue linked to the access to data is the question of patenting. Patents are a key mechanism to secure "biovalue" generated in human genetics research. Thus, the issue of patenting has been an important public energy field, in particular when it came to implementing the European patent guidelines as mentioned in chapter 2. Nevertheless, the participatory governance arrangements and experiments we have studied did not promote active deliberation on the issue of patenting. Patenting was a rather neglected issue within these arrangements and experiments compared to other topics. HGC members justified this abstinence either with the argument that patenting was too complicated an issue for public debate or that it was not the competence of the HGC to debate such issues (e.g., Interview 20-3 2006).

Among NGOs both in the UK and in Germany, interestingly, the debate on access to genetic data led to a renewed interest in the Bioethics Convention of the Council of Europe. This is because the Convention in its revised version had established the restriction of genetic testing only for health purposes. Currently, in the UK, NGOs call for a ratification of the Convention referring to these restrictions (GeneWatch UK 2003b). In Germany, in contrast to the former rejection of the Convention, there are now also some voices from the techno-sceptic community who are debating whether to ratify the Convention in order to use its restrictive impact on genetic testing (Deutscher Bundestag 2005).

4. Politics of life: ethicisation, governing the bios, and strategies to discredit concerns about the future social order

Is it possible to draw conclusions about a common specificity of "politics of life" if we consider the heterogeneity of the narratives on PND, PGD and "predictive medicine" and the different (participatory) governance arrangements and experiments in the different country settings? To what extent and how have the relationships between scientific facts and social order, risk and uncertainty, "bios" and "zoe", "genes" and "environment" changed over the time period studied? What concept(s) of "life" are becoming central in current strategies of governance, which approaches and frames structure the politics of genetic testing?

In the following chapter we will approach the politics of genetic testing as "politics of life" from a discourse analytical perspective, for we will focus on shifting frames, concepts, processes of discursive dislocation and (re-)ordering. In chapter 5 we will then connect the results of this chapter with a view on the performative dimensions of these processes by investigating the sites, institutions, political subjects, and forms of communication by which these discursive practices are staged and exercised.

We will approach the dimension of "politics of life" from two angles. First, we will consider the process of "ethicisation" and its various dimensions. By ethicisation we refer to the currently hegemonic approach to deal with human genetics by framing it within a language of ethics (4.1).

However, in the second part we will address some subliminal and diffuse concerns about the consequences of genetic testing for the social order – and the strategies to govern these concerns (4.2).

Our analysis concludes that the phenomenon of "ethicisation" is not completely new compared to the approaches of the 1980s. In the 1980s, technology assessment already focused on social and also already "ethical" implications of genetic testing. The difference is rather that in the 1980s an expert-based balancing of risks and benefits focused on the future *social* risks of genetic testing for society as a whole, while the newer perspective operates with a more fragmented, individualised, and versatile reference system. In the following, we will take a closer look at this policy of acknowledging and protecting different values, approaches, and contingent situations in the political discourse in order to understand the production of the "non-antagonistic" setting we are interested in.

In the second part of this chapter, we look at public concerns that nevertheless refer to the future social order as a whole. These concerns do not constitute dense "public energy fields" in the sense of culminating or condensing in conflictive settings, however. Rather what we find here is subliminal, diffuse, and dispersed unease or concern. In this context, we will analyse the politics that still recur to the frame of "eugenics" or "selection". And we will also show that participatory governance arrangements and experiments today invest into governing these concerns. One of the strategies is to simply discredit these concerns as unrealistic feelings, another to postulate a new phase of biopolitics separated from the past. Hence, the transformation of the "politics of time" is an important element of these intents of reordering. They are transforming the temporal perspectives in which the debate is embedded.

4.1. Dimensions of ethicisation

"We have set out general principles to promote the use of genetic information in a fair and ethical way." (Human Genetics Commission 2002a: 6)

A powerful arrangement to control the "politics of life", to establish boundaries as well as specific relationships between the social and the scientific – and at the same time to order the social in a specific way – is the process of "ethicisation" (Braun et al. 2001; Lettow 2004). We

have shown in the narrative that bioethics has been institutionalised by the proliferation of different types of ethical advisory bodies in policy-making in the 1990s. The deliberation on "ethical aspects" of genetic testing has become the main frame for public engagement. This process of "ethicisation" constitutes certain forms of problematisation, certain discursive frames, which structure and limit the talk on genetic testing. In the literature, this transformation is often linked to the shift away from the risk-oriented model of technology assessment in the 1980s and beginning 1990s (cf. Beck 1986; Wynne 2002). This former model centred on the evaluation and the "balancing" of future benefits and risks of the new biotechnologies. The transformation towards ethics is usually explained as the acknowledgement by official politics that problematic effects of technological change could not be reduced to calculable risks and therefore could not be dealt with by scientific experts only.[36]

Looking at the institutional setting, the change from the risk model to the ethical model of governance also proves true for genetic testing. Nevertheless, in the case of genetic testing the change concerning the patterns of problematisation was not as abrupt as the above hypothesis might suggest. Throughout the 1980s, we see an overlap between the risks frame and the ethics frame for a while. The Benda Report of 1985 in Germany and more explicitly the Warnock Report of 1984 in the UK already focused on "ethical aspects" of human genetics (cf. Herrmann 2006; Moore 2006). Note also that the transformation did not start from a risk-model referring to the calculation of physical safety or danger, as it was the case in many other areas of the politics of life. "Risk" within the debate on genetic testing in the 1980s already meant a social risk, for example the risk to create a hostile climate against disabled people or the risk to neglect social causes of health problems (see Bundesminister für Forschung und Technologie 1985; Enquetekommission Chancen und Risiken der Gentechnologie 1987).

Therefore, we can better conceptualise the change as a crisis of the idea that experts can evaluate the dangers of genetic testing for society as a whole. Instead we see an increasing recognition of a broader plurality of risk perceptions and forms of evaluating risks. For this plurality ethics became more and more hegemonic as the all-encompassing framework for problematisation and the privileged technique of negotiation. Another transformation that occurred is that the ethics frame has been gradually accepted by actors, such as feminist groups, activists of the disability

[36] Regarding the critique of the risk paradigm in technology assessment see Wynne 2002.

rights movement, who, in the beginning of the debate had vehemently criticised the ethics frame for promoting a utilitarian approach. Such rejection of the ethics frame was, for instance, at the heart of the protests against Peter Singer, a radical protagonist of a utilitarian bioethics, in Germany (Bogner 2000; Braun 2000a). In recent years, organisations of disabled people have started to refer to the ethics frame and even accepted the term "bioethics" which before had been strongly equated with a utilitarian approach in ethics, such as the approach of Peter Singer. The NGO Aktion Mensch, for instance, established the internet forum 1000fragen.de on questions about "bioethics" and in Berlin stakeholder organisations of disabled people founded the "Institut Mensch, Ethik und Wissenschaft" (Institute Human Being, Ethics and Science). In the UK the disability rights network BCODP developed a training pack on Disability and Bioethics (BCODP 2006), and in Austria, techno-sceptical NGOs also referred to the ethics frame by setting up the Ethics Commission for the Austrian Government in 2001 as a response to the constitution of the official Bioethics Commission (http://www.service4u.at/ethikkommission/index2.html). However, it has to be added that involvement into the debate about ethics is only a minor within a vast range of campaigning activities of Austrian disability groups.

The process of ethicisation has complex and sometimes contradictory implications. In the following we will first focus on the institutionalisation of ethics as regulatory ethics. We will address some of the main features and implications of ethicisation, namely the persisting mechanism to separate "scientific facts" from ethical evaluation and to present "scientific facts" as the unquestionable basis of deliberation and the de-contextualizing effect of the ethics frame (4.1.1.). Another main feature of the ethics frame is its ability to function as a mechanism of "ethical brokerage" through refining and inventing concepts and thus facilitating negotiation (4.1.2.). And third, we will address the dimension of life style ethics as a phenomenon of ethicization, indicating the dimension of daily individualised ethics referring to experience-based knowledge about the modalities of individual decision-making on genetic testing (4.1.3). Life style ethics as a phenomenon can be seen in the context of the "bios-orientation" of genetic testing is also increasingly shaping current politics of genetic testing. Further, it explains the increasing reference to empathy and emotionality within the political talk (4.1.4). The critique that the ethics frame has de-contextualising effects has to be modified with regard to the phenomenon of life style ethics. In fact, in a sense, there is a growing interest in the social and psychological context of individual decision-making concerning genetic testing today. An aspect common to all these characteristics is the claim that the only legitimate discourse is the one that

acknowledges the authenticity of the interlocutors and the legitimacy of different values and personal experiences. This aspect contributes to a process of "apoliticisation" in the sense that it delegitimises the fundamental critique of certain political positions (cf. Braun 2006; Herrmann 2006; Moore 2006).

4.1.1. Deliberating on cases of life

Framing the public debate on genetic testing as an ethical debate has resulted in emphasising certain issues while de-contextualising or ignoring others (Herrmann 2003; Lettow 2004; Waldschmidt 2002). Bioethics is embedded in different philosophical traditions, a fact which establishes tensions within the field itself. On the one hand, a dominant approach is utilitarianism; another, mainly in the German and Austrian context, is the deontological approach strongly referring to the Kantian idea of human dignity. These approaches to bioethics constitute certain important controversies as, for example, those on the hierarchy between freedom of research and human dignity, a question central to debates on discrimination of disabled people or eugenics.

However, the tableau of ethics, structured by the dominant approaches, also impedes certain forms of politicisation, for it generally tends to frame problems of biotechnologies in a de-contextualised, abstract way, presenting them as comparable "cases of life" (Herrmann 1999). The ethics frame pushes to the fore questions such as those about the beginning and the end of life, about the essence of being human, or about the status of the embryo. Renee Fox summarises the meta-themes of bioethics as:

"issues concerning life and death and human personhood, their definition and meaning, beginning and end, the virtues, limits and dangers of vigorously intervening in the human condition to alleviate suffering, improve the quality of existence, and maintain life" (Fox 1999).

However, the ethics frame tends to marginalise other issues such as questions about the character of scientific knowledge production. Usually, scientific knowledge functions as an allegedly objective basis for ethical reflections. Also problems in regard to distributive justice as, for example, the involvement of economic interests in human genetic research, the issue of

patenting, the marketing of tests as well as the development of health care systems are heavily neglected if not excluded by bioethics (cf. Callahan 1994).

Another tendency of de-contextualisation via the ethics frame is linked to reproductive genetics: The ethics frame features the embryo as the main discoursive figure of reprogenetics debate in focussing heavily on the question of its legal and moral status. The embryo appears as an isolated entity whose status can allegedly be discussed without referring to the pregnant women or even the difference between embryos *in vitro* or *in vivo*. Thereby, the practice of abortion and the destruction of an embryo produced in vitro are constructed as equal practices that accordingly have to be treated alike by ethics and the law. This framing marginalises a feminist perspective that seeks to promote a relational view on genetics, reproductive medicine, pregnancy and abortion, seeing them as practices that take place within a broader social, cultural and institutional context that is shaped not least by gender relations rather than discussing the abstract status of entities such as embryos, human eggs, or gene sequences. (Graumann & Schneider 2003; Wiesemann 2003).

What does the process of ethicisation mean for the reordering of the politics of life? One implication of ethicisation is the separation of "scientific facts" from ethical deliberation. This operation becomes quite visible when we look at the performative aspect of participatory governance experiments. Usually, the first step is that the organizers offer a dossier or some presentation by experts on the issue to the public respectively the participants. It is presented as the compilation of the most relevant scientific facts about the issue participants will have to know in order to be able to deliberate about the ethical aspects of the issue. In a second step the participants are asked to deliberate on the ethical (and only secondarily on "social" and "juridical") aspects of such "objective" scientific and technological settings. That is, we see a traditional "facts first" approach here. Furthermore, the main objects of deliberation about ethics are not social relations as such but the de-contextualised "cases of life", the entities of laboratories, which put certain definitions of biological life or aspects of "zoe", such as the status of the embryo, the definition of the beginning and end of life, the genetic make-up of an individual etc. at the centre of deliberation.

4.1.2. Ethical brokerage and the creation of new scientific artefacts

The ethics frame allows and organises the pluralistic coexistence of different and oftentimes contrary values and opinions on these "cases of life". It demands that pluralist "personal" or "intimate" convictions and values have to be recognised and respected in any case. In situations where there is no perception of an urgent need for governance or coherent regulation it is comparatively unproblematic to maintain this pluralistic setting. Bogner et al. explain:

"The function of the ethics expertise is not the production of definite decision knowledge, but rather the constitutions of the necessity of politics as an independent field of action" (Bogner et al. 2006).

However, this setting becomes problematic when regulatory efforts are under way and powerful interests emerge seeking to influence the policy process and its juridical outcome. In such situations, regulatory ethics demonstrates another of its functions, namely to provide mechanisms to facilitate decision-making, negotiation and the production of comprises.

For example, in the case of the debates on PGD in Germany, the ethics frame organised a radical opposition between the embryo as a human being here and as tissue there, and thus established apparently non-negotiable positions. However, this setting, as Brian Salter has shown for bioethics at the EU, can also be transformed and transferred into a situation of "ethical brokerage", where intermediate positions and criteria are established to open the field for political negotiation and trade-off (Salter 2005). With "brokerage" we mean the permanent creativity in the governance of genetic testing to develop ever new criteria of differentiation. These criteria establish intermediate positions between conflictive viewpoints suggesting the possibility of compromise in situations where at first glance positions seem non-negotiable.

In the UK, "ethical brokerage" is inscribed into the system of arm's length bodies itself, as the statutory licensing body HFEA allows a step by step transformation of regulatory principles in its case by case decision making.[37] The consultations and public debates on PGD during the last years, which did not focus on the general approval or disapproval of PGD, are a case in point of

[37] Not only the form of negotiating cases but also the concepts introduced by the Warnock report and the HFEAct show the production of intermediate concepts which open the field for political solutions. For example the "special status" of the embryo as neither human nor tissue, or the concept of the "pre-embryo" until 14 days of existence (cf. Moore 2006; Mulkay 1997).

an ethical brokerage setting. We have observed an increasing sophistication of the criteria how to judge specific applications of PGD. Criteria such as the "seriousness" of a condition, "third party interests" (in the case of tissue typing), "health purposes" vs. "frivolous or 'social' reasons", "late-onset" vs. "early onset" disorders, "low penetrance" vs. "high penetrance genetic conditions", as well as the "viability" of the embryo have entered the debate thus causing an explosion of ever refined and differentiated criteria and subcategories to facilitate negotiation and decision-making.

Within public debate, we can observe the mechanism of ethical brokerage too, for instance in the debates on how to offer which types of genetic testing, under which quality control and through which channels of services. Also, the debates on possible procedures to acquire informed consent to research on individual genetic material, as it is now becoming rampant in the context of the establishment of biobanks, is another field where a "criteria differentiation explosion" has taken place.

Ethical brokerage, therefore, creates a strategic situation in which the attention is shifted away from the fundamental questions of whether society is in need of such technologies at all and if so for what purposes, towards a universe of negotiable gradual criteria. Despite this expansion of discourse the ethics frame at the same time restricts discourse in that a lot of political problems and issues are not addressed within this frame. Yet, it creates the basis for a permanent renegotiation of issues at stake, for "slippery slope" situations or "salami slicing" as one disability rights activist describes it (Interview 11-3 2006). The effect of ethical brokerage is to deepen the public´s knowledge on very specific situations in genetic testing and to have this knowledge permanently circulating, an effect that leads to a normalisation of situations which in fact are very rare medical cases.

From a techno-sceptical point of view, the strategy of continuously shifting the boundaries between what is ethically acceptable and what is not, might appear arbitrary and creating a "slippery slope" (Interviews 9-3 2006, 22-3 2006). Nevertheless, the complicated and multiple criteria of (ethical) brokerage provide a set of sophisticated arguments that are meant to generate trust in the consistency, transparency, and justice of compromises despite of the instability of the negotiated technological applications. For us, this discursive productivity in the governance of genetic testing is key in order to understand the current transformations in the "politics of life": The permanent introduction of new artefacts or new scientific criteria and parameters in

order to "ethically" negotiate them, tends to question the boundary between scientific facts and ethical values – which at the same time is and paradoxically remains – the fundament of ethicisation.

There are several examples for the expansion of "scientific facts" or the deliberation on "biological life" or "zoe" at the centre of the ethics frames – translating scientific uncertainties into a certain ethical relativism.

In Germany, for example, in the context of PGD, proponents of deregulating this practice recurred to a redefinition of the cell extracted from the embryo to test its genetic "quality". In order to by-pass the Embryo Protection Act, the point was made that at a certain stage of embryonic development the extracted cell is no longer totipotent (and can develop into an entire embryo) but only "pluripotent" (Hillebrand et al. 2006). Thus, it would not count as an embryo according to the Embryo Protection Act. The differentiation between "totipotent" and "pluripotent" cells thus became one of the central questions, a question, however, that could – theoretically- be determined by scientists only, not by lawmakers or the general public. The newly revised ethical criteria were thus directly depending on scientific know how.

Another case of redefining the stakes is the discursive and political strategy to debunk "genetic exceptionalism". This strategy, pronounced by proponents of fostering R&D policies in human genetics and deregulating governance schemes, is based on the reordering of categories by questioning a broad definition of "genetic testing". First, this strategy replaces the generic concept of "genetic testing" by more complex and sophisticated criteria (see chapter 2). For instance, during the youth conference in Leipzig, Prof. Dr. Peter Propping, the director of the Institute for Human Genetics in Bonn, discredited the catalogue of demands pronounced by the adolescents as being incoherent because they did not clarify their definition of genetic testing. Second, the strategy is to question that there is a relevant difference between genetic diagnostic procedures and other medical diagnostic methods. This strategy aims at discrediting any specialised regulations of genetic testing and proposes to subsume genetic testing under the existing regulations for the use and marketing of medical devices. In that vein, the National Ethics Council in Germany intended to frame the predictive dimension of genetic testing as similar to other predictive diagnostic procedures. Also in the Human Genetics Commission "genetic exceptionalism" is an established concept from which part of the Commission members distance themselves. One HGC member declares:

"I am questioning the extent to which ethics in genetics is so very different from ethics in health care generally, because there is a point to which having this genetic exceptionalism. If you look for example genetic data, well it really is just about health care data, it is part of your health record, and so separating out genetic data, starts to get very difficult." (Interview 20-3 2006).

In this context the term "genetic discrimination" – a strategically important element within the critique of using genetic tests in the insurance business and employment – has also become a contested issue (GeneWatch UK 2001b; Lemke 2005; Stockter 2004/2005). One issue concerns the question on the basis of which diagnostic procedure a person is "discriminated" against: Is he or she discriminated on the basis of a DNA test or simply on the basis of the analysis of the "phenotype", which is linked to a "genetic disease"? Second, the level of probabilities is at stake, the predictive value of a diagnostic procedure and also the "seriousness" of the condition predicted – a lot of levels of differentiation. These categories of differentiation are based on the increasing scientific uncertainties themselves, produced by epidemiological knowledge and the focus on "multi-factorial" diseases (chapter 2).

Today, mostly the proponents and not the critics of genetic testing emphasise the scientific uncertainty of the knowledge produced by predictive genetic tests, especially by the tests for multifactorial disorders, arguing that the information a test provides has only a probabilistic character and does not foretell a predetermined future but rather offers a range of options to the user. Thus, proponents contest the assertion that the knowledge produced by genetic tests is more personal – and accordingly more sensitive – than other information about the individual. Opponents, on the other hand, are under pressure to shift the parameters of their critique and to move towards more ambiguous constellations of arguments – in order to react to these discoursive strategies of genetics' new modesty. Techno-sceptical NGOs like the German GenEthic Network argue for example that the current self-representation of scientific expertise is ambivalent because there is still some form of genetic reductionism at work today, manifesting itself in the fact that huge resources in health research are still concentrated on research based on the reductionist genetic paradigm[38] or –- despite of recent insights into the complexity of gene-gene and gene – environment interactions – on the idea of a single genetic factor causing a

[38] In the UK, the 2004 Treasury's Report confirmed this critique by concluding an imbalance in medical research funding, with too much emphasis on genetics. (Wanless 2004)

particular diseases (cf. Interview 26-3 2006). Some of the NGOs oppose the argument that the capacities of human genetics research are limited and that accordingly its risk and dangers are being exaggerated. One interview partner from Human Genetics Alert in the UK argues that techno-sceptic positions should not underestimate the seriousness and scope of individual genetic risk assessment and the articulated possibilities of genetic discrimination in the future (Interview 14-3 2006).

This ambiguous positioning of techno-sceptic arguments also affects the term "genetic discrimination": While most NGOs cling to the term as an important oppositional frame, the problem of defining remains. Generally, the argumentative strategy is to opt for the broadest possible concept of genetic testing – including for example all diagnostics that ascribe some disease or impairment to genetic factors, whether it is deduced from the family history or from phenotype analysing (e.g., Reprokult 2004, Gen-ethisches Netzwerk 2003). Another strategy chosen by techno-sceptics is to distinguish between "direct genetic discrimination", referring to the use of genetic test results by employers or the insurance industry, and "indirect genetic discrimination", which would comprise more diffuse effects such as a hostile attitude towards disabled or ill people in society (Interview 5-3, 2006). However, these strategic reflections carry the prize of assimilating oppositional strategies to practices of "ethical brokerage". One German disability rights activist – when asked whether the term "genetic discrimination" would indirectly contribute to a stabilization of genetic determinism as a way of thought by emphasising the "genetic" quality of certain conditions – answered:

"Those debates – I would say very simply – are meta-debates. They can move within circles that have time and energy for those considerations. (…) We don't have time for these meta-debates. And they don't get to the point. The point is that to reduce a group of people to one common characteristic, say Down's Syndrome, that does not say anything about them" (Interview 11-3 2006).

4.1.3. Life style ethics as individual management of uncertainties: "bios-oriented" governance of genetic testing

"The lines are crossed at different stages of severity in the disorder or disability. People's attitudes to severe mental impairment are often different from their approach to physical impairment. Decisions are often linked to whether the family could cope with the demands of a child with such problems, the impact it would have on other children, or on the carers. Something few outsiders can gauge accurately" (Kennedy 2006).

Beyond the aspects of regulatory ethics discussed so far, we have detected another aspect of ethical governance within our narratives. It is linked to the expansion of knowledge production about what we can call the "bios-aspect" of genetic testing. We have observed a discursive explosion about the contingent social, cultural, psychological etc. modalities of individual decision-making on genetic testing or the subjectivities developing (and also required) in the context of a "geneticised" paradigm of individualised health care. This discursive explosion is linked to the notion of individual self-steering, to the *"micro-choices for individuals that the biomedical powers force on them"* (Callahan 1994).

The increasing interest in the question how individuals handle uncertain and complex social situations in the context of increasing possibilities of genetic testing is linked to the scientific uncertainties produced within epidemiological knowledge on "multi-factorial" diseases. Governmentality studies scholars have analysed the construction of subjectivities linked to the new paradigm of genetic self-governance (Lemke 2004; Polzer n.d.; Rose & Novas 2003). They emphasise that the allegedly unchangeable destiny a genetic test result supposedly reveals is but one element of truth production involved in genetic testing. Opposed to this, the uncertainty of risk calculations and the paradigm of "multi-factorial" diseases, paradoxically, also foster the "responsibilization" (Rose 1999: 74) of the individual.. Responsible behaviour is seen as something to be activated in order to minimise risk by compensating the influence of negative genetic factors through decreasing other risk factors such as smoking, unhealthy nutrition etc. and counterbalancing the "bad" genes by a "good" life style (exercise, dietary measures), or psychosocial factors (seeing a therapist, having a more optimistic outlook on life etc.). Further, it implies preventive health care and measures – ranging from regular physical examinations to – in the case of breast cancer – breast amputation. This neoliberal paradigm of individual self-responsibility implies the integration of other forms of knowledge about health or social and environmental factors of diseases – beyond genetics. But the paradigm still concentrates on the

individual, its agency, and its responsibility. Hence, it is not directed toward broader projects of social change, for example to improve environmental conditions or conditions of work in order to prevent disease. This is another reason why we consider the term "bios-orientation" adequate to describe this form of knowledge production, for it centres on the biography and the individual relationship to the own body and health.

The new forms of expertise about the modalities of individual decision-making develop in different contexts:

First, there is a field of research dedicated to complement "hard" scientific research on "red bio-technologies" by producing sociological, cultural, or psychosocial analyses of the social embedding of genetic testing. This research is interested in the effects of the application of genetic testing. It studies the promises and future projections that shape the understanding of kinship, health care, corporality, or disease. Moreover, this kind of research is interested in the strategies individuals develop to handle often contradictory social norms, expectations, and desires (Knecht 2005; van den Daele 2005; Rapp 2000: for a critical overview see Kerr 2004, 84-102).

Second, this type of knowledge on the "bios-aspect" of genetic testing is also produced within the more practical context of counselling, guided by ever more sophisticated "non-directive" and "communicative" counselling concepts (Samerski 2002; Vieth 2004). For example, Alison Lashwood, consultant nurse at the biggest UK PGD clinic, explains that counselling is a rather therapeutic, comprehensive communication that by far exceeds the aspect of conveying information about the medical procedures and the risks at stake:

"We spend a lot of time discussing PGD with couples before they undertake it. And the things we want to talk to them about it: What is the background, what has happened previously, so that we can understand where they are coming from, why they might be asking for this and why they think, PGD may help them" (Lashwood, 2006).

Third, this knowledge production also takes place within participatory governance experiments. At the youth conference in Leipzig, the youth groups emphasised the need for reflecting on what would be the best practices of counselling. A considerable part of the catalogue of demands the young people developed referred to the adequate ways to address the fears, concerns, and needs of women confronted with the possibility of PND. Thus, not the practices of genetic testing and its social implications themselves were the major issues of negotiation at

the youth conference, but the modalities of counselling, informing, and addressing fears or enhancing individual choices.

In the UK case, we have shown that the specific and contingent individual social and psychological situation of a "family" or "a couple",[39] requesting PGD are in fact the main criteria for evaluating the "seriousness" of a condition and thus for deciding about approval or disapproval of their demand. Again the consultant nurse Lashwood explains:

"The severity of a condition, the conception of this, may vary tremendously from family to family. It is not enough just looking at a situation of a child with a genetic disorder without looking at that within the context of the family, the family experience, what has happened before, how many children this couple have" (Lashwood, 2006).

Hence, scientific facts about genetic disorders are viewed and evaluated in the context of personal experience, subjective perspectives and feelings (Interview 17-3 2006).[40] When the HFEA refuses to set up a catalogue of genetic disorders considered as "serious" enough to justify the use of PGD, it argues in a similar vein. In this paradigm, scientific facts such as in this case genetic data form merely one element in within a complex composed of different types of factors and their interrelationships. This systemic paradigm does not allow for any kind of long-term, stable boundaries or regulations based on fixed categories but only for a rather flexible case to case decision-making. It thus shows an inherent tendency of expanding the application of such practices.

Last but not least, the increasing interest in the contingent "bios-aspect" of genetic testing, in the specific social and emotional conditions of people using or not using genetic tests, is also expressed in the constitution of a new political subject involved. We will discuss this political subjectivity further in chapter 5 and characterize it as the "individual expert of its own lived genetic disorder". The interest, for example, of the HGC to establish a Consultative Panel of 100 persons being affected by "genetic disorders" was to get into contact with people who are

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[39] In the UK, the policy discourse is very family- or couple-oriented and much less oriented toward the individual woman than for example in Germany.

[40] One interview partner, a disability rights activist, reports a similar but authoritarian version of this practice: He remembers a human geneticist counselling couples for PND who explained to him that she would recommend couples to meet with families with the same specific genetic condition as diagnosed for the pregnant woman before doing an abortion – and that she would organise the contact with families that have problems for those women she evaluates as not capable of having a disabled child and organise meetings with more "successful" families for those she would recommend to have the child (Interview 11-3 2006).

considered experts of their own lived genetic condition: They are of interest because they have the expertise to speak about the individual, yet socially embedded experiences of living with a certain condition in a certain social context, about the emotional circumstances of being confronted with the possibility of a test, about the family situation when having a disabled child etc.

4.1.4. Empathy in order to gain "bios-related" expertise about genetic testing

By taking into account this explosion of knowledge production on the "bios-aspect" of genetic testing we can understand and interpret the increasing reference to empathy and emotional conditions inscribed in the new forms of governance regarding genetic testing. We would argue that the interest in the emotional situation of the individual, couple, or family situation, in which a genetic test is relevant, is not only an effect of media sensationalism. It is not just a strategy to provide striking arguments in favour of medical or technological innovations, although it may be that too. Sensationalism is in fact involved, when, for example, a telecast about a family applying PGD for a "saviour sibling" was presented to the youth conference of the HGC in Wales (an element of the "Making Babies" consultation process). One interview partner from the pro life NGO CORE who was present at the conference remembers that she had no chance to argue against the emotional impressions incited by this feature:

"They showed a television programme which lasted nearly an hour of a couple who was trying to have a baby and so it was just endless pictures of the sick child and how dramatic it was. It was impossible to compete with that. My feeling afterwards was: you don't move into discussing big ethical issues after you have watched a hair-tracking programme on television" (Interview 22-3 2006).

Yet, on a more profound level, the role of empathy in the current governance of genetic testing in our view is related to the urge to know more about and thereby to better govern the individual "ethics" of using genetic tests (Heath et al. 2004). It is embedded in the efforts to steer the individual "economies of hope" (Brown 2006) linked to genetic testing and to the therapeutic promises of human genetics research.

For example, one interview partner from the Genetic Interest Group (GIG) in the UK explains, in a rather cynical way, how the GIG "governs" the hopes of their members by developing a

sophisticated "politics of time": He explains that a five years interval is useful when you want to generate hopes about prospective successes of human genetics in developing new therapies for certain genetic conditions. This time period would be short enough to maintain hope alive at the moment of making the promise and long enough for people to have forgotten about the promise once the five years are over and no therapy has shown up (Interview 13-3 2006).

The increasing interest in the emotions involved in the use of genetic tests therefore is directed at a more permeating knowledge relevant for gaining public support, not just at an occasionally instrumental knowledge. That might be the reason why stories of individual cases are circulating within the expert communities; they might be interesting not only for strictly medical reasons. Rather, they are metaphors everybody is familiar with. At times, such stories do not even refer to concrete "cases" but to hypothetical constellations. There is the example of the story about the deaf community, a case referred to in nearly each of our interviews in the UK and circulating widely in the debate (Interviews 6-3 2006, 9-3 2006 and 17-3 2006; Brecher 2006; Mills 2006). The story is about the possibility that the people from the deaf community could demand to use PGD in order to select an embryo with a specific form of inherited deafness. By this means, so the story goes, the couple could make sure that their child will be like them and just like they want it to be: deaf. The story attracted a considerable amount of attention; it was evoked again and again, mainly in order to illustrate the potential troubling consequences a technology such as PGD might have.

But there has been no such case in the UK. The story refers to a merely hypothetical setting, originally incited by an article about a deaf lesbian couple in the US who had looked for a sperm donor with a certain genetic condition linked to deafness (Spriggs 2002). Yet, the story is circulating as a means to incite empathy as well as reflections about a complicated and interesting issue to argue about. It is presented as an ethical dilemma, constituted by the value of reproductive autonomy on the one hand and the "welfare of the child"-principle as established by the HFEAct, on the other.

Another example of the power of stories would be story of "the Hashimis" or "the Whitakers", both families who have become enormously famous because they requested PGD for the purpose of "tissue typing". These stories are about "suffering", the need for making hard choices, but also about the need for the expert community to show empathy towards such individual cases.

The intensified interest in the "bios-aspect" of genetic testing, in the individual strategies to handle genetic testing emotionally, but also rationally and practically, has to be interpreted in the context of the economic vulnerability of the biotech industry and its uncertain future (see chapter 2). Only if (private or public) health care really adopts the paradigm of "pre-symptomatic" medicine and only if the demand steadily increases, genetic tests and human genetics research in general will be able to expand beyond repro-genetics and beyond the rather small group of clients as patients with monogenetic diseases. And only then – with genetic testing as the forefront of possible other future applications of human genetics and as basis for access to samples and data – the research industry can continue.

4.2. Governing the submerged unease on social implications of genetic testing

In the following, we will confront the process of ethicisation with another aspect of the politics of life as observed in our narrative: The analysis of the process of ethicisation has shown, that – in summary – both pluralist value systems at the level of regulatory ethics and the importance of the "bios" at the level of individualised ethics contribute to the "non-antagonistic setting" in the politics of genetic testing. They establish the general claim of bioethics that values and personal experiences are "authentic" and need to be respected and not to be challenged within politics. At a symposium on the politics of bioethics in Seattle various participants analysed the function of bioethics within politics in its dynamic to depoliticise or "apoliticise" (Braun 2006) the debate on biotechnologies. Ethical policy advice does normally not provide definitive solutions to political governance problems (Herrmann 2006). Rather, ethics contributes to framing the issues in a way that precludes questioning the "authentic" experiences and the values of others. Therefore, *"the ethics frame implies a tendency to avoid or at least mitigate controversial fights over substantial positions"* (Braun 2006). Further, it has established fragmented and plural sites for the evaluation of the social consequences of genetic testing, thereby avoiding a perspective on the consequences of genetic testing for social order as a whole.

Nevertheless, we have shown in the narrative that certain moments of diffuse unease about genetic testing remain that in a certain manner transcend the ethics frame of coexisting, fragmented, plural, "authentic" values and experiences. There is a persistence of discursive elements and forms of problematisation in the current "politics of life" that still refer to the implications of genetic testing to the social order as a whole – thereby transcending the

fragmenting ethics frame. While we hold that today's politics of genetic testing is not a field of major conflicts or disruptive moments, these frames are interesting subliminal moments of dislocations and of unstable interpretations. In chapter 4.2.1., we will briefly introduce the character of these concerns, and then focus on strategies of current participatory governance arrangements and experiments to govern them (4.2.1). Further, we will focus on the question which changes in the "politics of time" are linked to these strategies – which we will address in subchapter 4.3.

4.2.1. Eugenics and "designer babies" as disturbing approaches

There are two major discursive elements still circulating within participatory governance arrangements. They resume the existing public unease about the normalising tendencies of genetic testing and its implications for the future social order: the critique of eugenic motives and backgrounds – in Germany rather pronounced as the critique of the "selective" bias of genetic testing, on the one hand, and the metaphor of "designer babies" or "babies by catalogue", on the other hand.

These two discursive elements differ in origin, and in the sites from which they are emanating: The reference to eugenics is embedded in the history of technosceptical social movements and NGOs. Today, it is above all disability rights and "pro life" activists who recur to these elements (e.g., Interviews 9-3 2006, 14-3 2006, 22-3 2006). However, its scope exceeds these circles and sites by far. The participatory governance experiment 1.000fragen.de demonstrated this very clearly: An overview over the questions formulated in the internet forum shows that there is a pervading range of concerns and fears, linking genetic testing practices to social tendencies of eugenics (Aktion Mensch 2003). A research project about 1000fragen.de at the University of Cologne evaluated the campaign and concluded that the topic of "(im)perfect humans" (Der (im)perfekte Mensch) was the favoured topic followed by the topic "PGD, PND, and planned children" (Waldschmidt et al. 2006). Within the category "PGD, PND and planned children" questions addressing these concerns were so abundant that two subcategories on "eugenics" (ibid.: 49-51) and "selection" (ibid 117-131) were established.

Whereas the concern about eugenics is formulated mostly by organised groups or NGOs, the metaphor of "designer babies" or "baby by catalogue" is more diffusely originating in media

discourses and images (Interview 5-3 2006). However, it could also be found within the 1000fragen.de campaign. At the 1000fragen.de internet forum questions such as "Designer Babies – the best for the child?" addressed that concern (www.1000fragen.de: question7360). There have also been a lot of connected questions such as *"Does disability start with the wrong hair colour"* or *"What, if my child wants optimised parents?"*, two questions which were selected as representative for the poster series. At the youth conference in Leipzig a group designed a poster with the title *"baby from catalogue"*; another group integrated *"no baby from catalogue"* in its list of demands.

How to describe the character of these more diffuse public concerns that in the last years have not culminated in broader conflictive settings? Maybe the explanation of one researcher interviewed, interpreting the character of the discourse evoked by the 1000fragen.de experiment, is enlightening in understanding at which level of "public knowledge" these concerns are situated. The persistence of references to selective practices and eugenics occurs within a sphere that she describes as commonplace knowledge directed to the public (Interview 27-3 2005). This means that this knowledge directed to the public (in the sense of social visions) differs from the perspective of individuals towards individual decision-making on health and reproduction, a perspective of choice or self-determination widely accepted at the same time (with the exception of pro life groups). It is exactly this perspective which challenges the current politics of life – maybe a reason why it is addressed extensively and even evoked by the participatory governance arrangements we studied – although there was no necessity to pacify concrete conflicts or even reorder moments of disruption.

4.2.2. Strategies to "debunk myths" and to reduce political positions to "false" emotions

In our narratives we have identified various sites where discursive strategies developed to evoke and deal with this broader but diffuse public unease towards genetic testing. A site where this could be observed very clearly is the consultation process in the UK, with the "Making Babies" report as its result. In the consultation paper there was an explicit reference to those concerns and to the necessity to "debunk" and divert them (Human Genetics Commission 2004). But this effort was also present in the other participatory endeavours, for example when a jury at the

youth conference in Leipzig evaluated the best media and art products created during that process. It deemed certain films or posters presented by young people to be "exaggerated" or "one-sided" and negative, or emphasised that possibilities of genetic engineering were "overestimated". Efforts to "debunk myths" and especially to normalise PGD against these concerns have also been obvious in the academic setting of a symposium on "Designer Babies" at Middlesex University, in which researcher Susanne Schultz participated in February 2006. [41]

The 1000fragen.de project differed from the other examples insofar that it was a more open space, more sympathetic for these concerns, allowing them to circulate without developing explicit counter-strategies; after all the NGO Aktion Mensch as an organisation for disabled people is more grounded in these concerns. Nevertheless, there have been experts invited to discuss some of the questions at the forum and some of these experts used this space to discredit some of those concerns.

One strategy, for example, to argue against the accusation formulated by disability rights organisations that PGD or PND would discriminate people with disabilities, was to differentiate between the individual decision and the social discrimination of a group. The dossier about PGD at 1000fragen.de for example explains:

"A lot of associations and groups of disabled people explain that PGD has a discriminatory character. However, it would be wrong to state that the personal decision of a couple to use PGD amounts to a discrimination of the group of people with disabilities" (www.1000fragen.de/hintergruende/dossiers/).

In a similar vein, the HGC Making Babies report recommends policy measures to compensate the potentially discriminating effects of PND and thus to solve the problem:

"We suggest that a strong programme of research aimed at better treatments for genetic conditions, coupled with availability of appropriate services for those with genetic conditions, is the best means of addressing some of the ethical objections to prenatal screening" (Human Genetics Commission 2006: 35).

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[41] Symposium: "Ethical and Legal Issues at the Beginning of Life: Debating 'Designer Babies'" Middlesex University, 2.2.2006. London.

The public deficit to understand the "bios-orientation" of genetic testing

"Obviously there has been a lot of talk here but also in America and across Europe about designer babies, the ethics of that. But what the commission always strongly say in their meetings, but perhaps haven't said in a report before, is that actually a lot of this is fantasy, that the science just doesn't match the tabloid of public perception of what is possible, that it is just not possible, and we can't conceive of a time in the near future that it would be possible to have any child you want" (Interview 4-3, 2006).

In general, concerns about the return of eugenics via genetic testing often refer to the "feelings" or "emotions" of disabled people that could be offended by preventing the birth of people like them. The counterstrategy, in turn, responds that these feelings have to be taken seriously, but that they are nevertheless misled (e.g., van den Daele 2005: 226). Here the respect for feelings and emotions and the high regard for authenticity shows some limitations. The strategies to debunk concerns about eugenics and "designer babies" stem from the classical deficit model of public understanding of science: They declare that public fears are unfounded and irrational because they are not grounded in real facts, not based on real developments but on "myths" and in they get declassified as being emotional in a pejorative sense. In the case of PGD the argument normally is that it had nothing to do with the concept of "designer babies" for there are no practices and also no technological possibilities to select "blue eyes" or "intelligence" (e.g., Interview 17-3 2006). This rhetoric also refers to the indication that PGD was not about positive eugenics (in the sense of deliberately producing a higher "quality" baby) but merely constituted a "dis-selective" strategy to exclude embryos with certain negative characteristics (e.g., Interview 10-3 2006).

However, these arguments about the scientific incorrectness of public fears, which are a typical gesture of the old deficit model are now embedded in a different type of argumentation. The discursive investment not only and even not primarily aims to identify the lack of understanding as a lack of "objective" or scientific knowledge. Above all it discredits evaluations of the motives and reasons why people use or not use PGD or PND as "false": We would argue that this is a prevailing dimension in the present governance of genetic testing and recurs to the expanded knowledge production on the "bios-aspect" of genetic testing.

For example, the typical argumentative strategy in favour of PGD and against the "designer babies" paradigm is to explain that the procedure of IVF and PGD is very arduous and harmful for the patients, that often the treatments do not result in a pregnancy, and that patients only

undergo the procedure when they are faced with extremely burdensome experiences in their families and extreme situations of suffering. Here again, we see the new modesty assumed by proponents of genetic technology. Interestingly, this argumentative strategy partly refers to arguments (once) formulated by critical feminists protesting against the harmful procedures of hormone treatment and IVF.

For example, one commission member of HFEA explains:

"My view is that eugenics isn't a very helpful word because it has such negative overtones for very good reasons, and I think what we mean by PGD isn't eugenics in any sense, as I would understand it. I suppose, really important to remember with PGD is that it is very, very rare, it is very difficult to do, it is very expensive and is really stressful for the patients, and the people who go through have nasty, nasty conditions in their families, they are not doing that for some sort of breeding superchildren, they have generally had children who have died of horrible diseases or who have horrible diseases and they don't want their next child to suffer. And I can't see that as eugenics, I see that as parents doing everything they can to avoid their children suffering" (Interview 10-3 2006).

In the last years, this argument also surfaced, as a disability rights activist observes, in more expert oriented panels where academic experts try to discredit the positions of technosceptical NGO representatives by referring to empirical studies about the motivations of people using PND:

"There are various academics who intent to prove by scientific arguments that PND does not have a discriminatory factor; what is ridiculous because it very simply has this factor, but they try to prove contrary with strange empirical studies" (Interview 11-3 2006).

For example, Wolfgang van den Daele, a social researcher very present in public discourse in Germany as a member of the former National Ethics Council and, for example, also as participant of the youth conference in Leipzig, has published recent empirical research results about the consequences of PND for disabled people. He concludes that there is no empirical proof that the expanding practice of PND is embedded in an increasing discrimination of disabled people within the German society. He argues that from the individual perspective of a woman having an abortion after PND it is *"obvious that the judgement to be 'not desired' is a judgement against the disability as characteristic and not against the disabled as a person"* (van den Daele 2005: 228).

Generally, this reference to empirical knowledge about the motives of people using PND or PGD, the reference to the "bios-aspect" of genetic testing distracts attention from the fact that abortion after PND, or PGD is a selective practice based on normative approaches towards the "quality" of genetic or bodily characteristics of future persons.

Eugenics beyond state coercion?

Connected to the emphasis on the motives why women or couples choose to use PGD or PND is the general argument that the decisions to use PGD or PND are voluntary and part of individual reproductive choice and freedom – and, therefore, have nothing to do with the tradition of eugenics. The effort to distance the analysis of genetic testing practices and its contextures from the tradition of eugenics is also present in social science research on "biopolitics" (Rabinow & Rose 2003). The main argument is, that today's developments could not be interpreted as eugenics,[42] because they are no longer state-governed, coercive, and directed to a national or racial body.

This arguments shows that the definition of eugenics itself is a contested terrain in this "public energy field" – although the question of definition mostly is not addressed directly.

The efforts to accuse anti-eugenic positions of ignoring the voluntary character of current selective practices within reproduction attempt to marginalise the concerns of those who consider the new "individualised" or "normalised" forms of eugenics a nevertheless problematic development relevant for deliberation and political debate.

Especially in the UK, the strategy to debunk the term eugenics as a wrong perspective on politics of genetic testing is currently very present. Techno-sceptic pro life organisations and disability rights activists refer to historical eugenics when they criticise practices of genetic testing. They argue that even in the absence of state coercion, individualised or "laissez-faire" eugenics nevertheless constitutes a practice of eugenic selection (Interview 14-3 2006). Or, secondly, they interpret current practices of repro-genetics as nevertheless indirectly state-led or

[42] There are exceptions: For example STC declares in its statement on the review of the HFEAct that it has no problem to positively refer to the term: *"If ensuring that your child is less likely to face a debilitating disease in the course of their life can be termed eugenics, we have no problem with its use"* (Secretary of State for Health 2005).

institutionally controlled. For they question the possibilities of voluntary decision-making or self-determination for individual patients within these settings (Interviews 9-3 2006, 22-3 2006).

4.3. Reordering the politics of time

The strategy to discredit the argument of a continuum between historic eugenics and genetic testing is linked to a specific "politics of time". In the following we will look at the relation between the politics of life and the politics of time in the field of genetic testing. Three aspects are important here: first, the separation of past and present, second, different approaches towards the future in terms of different time horizons (near – far) on the one hand and different degrees of predictability on the other (uncertain and "realistic" vs. predictable and extreme), and third, the contents of the different approaches to the future and their changes over time.

4.3.1. Separating past and present

One element within the strategies to discredit those who see a continuity of between historic eugenics and PND and PGD is to draw a clear line between the past and the present and to emphasise discontinuities (Kerr 2004, 15ff.). In some respect the point made by Rose and Rabinow (Rose 2001; Rabinow & Rose 2003) that we are currently experiencing a new form of biopolitics supports this strategy. Anne Kerr, in contrast, argues that recent research (and we would add: recent governance too) is oriented towards patient autonomy, lay people, genetic citizenship, and the separation between the past and the present, while there is a tendency to neglect continuities, the power of experts and professions, and the institutional control of genetic testing by health care systems (cf. Kerr 2003, 2004). In regard to the question of eugenics and the politics of time, there was a telling conflict within the Human Genetics Commission between the utilitarian hardliner John Harris and other members of the commission. Insiders explain that the argument was about whether to include the topic of eugenics in the "Making Babies" report as the background for current politics of genetic testing. In the end, a reference to eugenics was included but only to historic eugenics without any discussion about potential continuities to the present (Human Genetics Commission 2006).

4.3.2. Post-catastrophic/post-euphoric realism

"You don't want to close the door on what is potentially good, but you don't want to rush ahead and do things before you are ready. So if at some point in the future there seems like a significant health gain to be had from doing it, then lets have the discussion then about the ethical and social consequences of doing it, but otherwise, if you do it now, then what you really do is guessing what is going to happen. And we have a very bad history of predicting where science will go" (Interview 13-3 2006).

Looking at the relation between the politics of life and the "politics of time" in our case study, we see a new "post-catastrophic" or "post-euphoric" realism emerging in recent years. Proponents of genetic testing today are incorporating techno-sceptic arguments into their evaluations of future scenarios. Additionally, we see a "new modesty" among proponents in that they emphasise the limited scope of human genetics' possibilities in the future. At least the expert community (less the media or public education projects on science) increasingly refers to the fact that human genetics have continuously revised their models during the last years turning away from models of genetic determinism towards more complex models, which, however, involve a considerable amount of scientific uncertainty (chapter 2). They thereby do not discredit human genetics research but rather consider science as being capable of self-reflection, modesty, and complexity. This integration of uncertainty about the future into (self-) presentation of human genetics also surfaces when HGC members reflect their limited possibilities to decide about future developments (see quotation above, interview 13-3 2006). One HGC commission member compares talking about regulatory decisions on future possible applications of genetic testing to *"crystal ball gazing"* when (Interview 20-3 2006). Similarly, the argument against "genetic exceptionalism" displays a post-euphoric but also post-catastrophic "realisms" in that it stresses the (so far) limited applicability of genetic tests for the insurance industry and employers and the uncertainty of genetic risk profiling – thereby normalizing genetic testing in framing it as just one way of acquiring – more or less reliable - information among others.

4.3.3. Colonising the future: exploitation of biovalue versus the administration of populations

"The workshop addressed the intersections between potential developments in biotechnology and current trends of commercialisation in health care systems. One of the major themes that emerged from the discussion was concern

about the subtle 'colonisation' of discourse on the future of health care by the pharmaceutical industry, which is highly invested in genetics research" (Summary of a workshop at the conference "European Biopolitics", Berlin 2006).

Despite this "new modesty" as regards predicting the future, some scenarios about the future *are* circulating and shaping the current governance of genetic testing. The debate on predictive medicine is essentially a debate on future scenarios. For up to now, the development of a predictive or "pre-symptomatic" medicine is limited to a few tests actually being on the market testing common "multi-factorial" diseases and not merely rare monogenetic conditions. Therefore, the current governance of genetic testing is permeated by future scenarios although with less apocalyptical or techno-euphoric elements. Rather, it is directed towards the economic possibilities and the scenarios the pharmaceutical and biotech industry promotes – such as the scenario of an individualised medicine and tailored drugs that would fit individual susceptibilities and risks. These future scenarios are linked to the success of health care concepts such as prevention, life style orientation, self responsibility, and also social differentiation of clients.

These changes in the politics of the future are also reflected by techno-sceptic NGOs. Recently, at a European workshop on biopolitics in Berlin,[43] NGOs debated whether they unconsciously have contributed and participated in this "colonisation of the future". Those NGOs asked themselves whether they had uncritically adopted pharmaceutical and human genetics research assertions about the development of future health care systems – without any evidence on the question of whether these projects will actually work and whether they will be integrated into future health care systems or will only develop in niches of privatised services (Sexton 2006; Shalev 2006).

Hence, proponents as well as critics have changed their politics of time towards less forward-looking utopian or dystopian scenarios and increased their scepticism towards the possibilities of anticipating scientific and technological transformations in human genetics.

However, there are a lot of differences in which frames are used in order to (more cautiously) approach nearer future scenarios. Especially, there is a certain tension between an economic

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[43] Conference: European Biopolitics. Connecting Civil Society - Implementing Basic Values, 17-19 March 2006. Heinrich Böll Stiftung Berlin.

frame and a more state-oriented frame, which is important for the contested perspective on eugenics.

There is a trend in current social research projects – and also in the debates within formal governance institutions – to focus on the economic prospects of biotech or pharmaceutical industries. This perspective is interested in the increasing networks of research and industries seeking to exploit "biovalue" (e.g., Gottweis 2005; Rose 2006; Rabinow & Rose 2003).

While the (nation) state plays a minor role in these analyses and scenarios, some voices continue to link these developments to the question of the role of the state and the dimension of administration of populations, a dimension neglected or even negated within mainstream social research approaches (van den Daele 2005: 219). Especially in the context of the privatisation of health care systems they alert that strategies of cost-efficiency and commercialisation can be linked to strategies of population management. They argue that strategies to reduce costs by reducing the amount of "ill" or "disabled" children or strategies to delegate the responsibility for preventing future diseases to the individuals show continuities to the historical background of eugenics and have administrative state-oriented dimensions. One interview partner from the pro-life organisation CORE, for example, mentions a text in the British Medical Journal, in which the economic benefits of a general screening of pregnant women for Down's syndrome are calculated (Gilbert et al. 2001).[44] One interview partner from the German NGO Gen-Ethisches Netzwerk explains that in her view a eugenic perspective is present when administrative and economic projects come together in order to manage the quality of a population as has been the case in her view in recent attempts to establish the discipline of public health genetics in Germany (Interview 26-3 2006).

These different frames to evaluate the futures of genetic testing are connected to the question whether more systemic or more fragmented perspectives on the social implications of genetic testing should be adopted. The economic frame suggests a more fragmented type of analysis by looking at different projects to exploit biovalue and different interests of "consumers" and "providers" within complex sets of research interests and potential products of human genetics. In contrast, the focus on population management highlights a strategic setting or even "state

[44] In Copenhagen there has been a proposal to screen all pregnant women in order to detect cases of Down's syndrome, openly basing their case on the reduction of public expenses for disabled children (Dahl 2003).

project" that, if not in terms of intentions but in terms of effects implies eugenic features– and is impregnating the future social order with hierarchical norms about the quality of human bodies and populations.

5. Performing participation: multiple publics and new political subjectivities

"I am sure that the aim [of creating the Human Genetics Commission] *is to prevent all the trouble that they had with GMOs (…) But there hasn't been a really large public movement in the area of human genetics, so we can't test whether that commission would have an effect."* (Interview 14-3 2006)

As work package 1 has elaborated theoretically, the shifts in the politics of life in recent decades took place within concrete more or less institutionalised procedures, within specific sites, setting the scene for specific forms of communication and constituting specific "publics" and specific political subjectivities. It is this performative dimension of the governance of genetic testing we will stress in this chapter, by analysing the concrete new models of participatory governance arrangements or experiments that we have selected for observation in more detail.

For our work package the perspective on performativity is particularly illuminative, because the new governance schemes did not develop within strong conflict settings but are – at least in the UK – part of a "strategic framework" developed by the government to promote public deliberation. Hence, they need to be analysed as the production of a "public energy field" that is initiated, shaped and steered "from above". Hence, we can see that the forms of political problematisation and the subjectivities circulating within these settings are not only "mise en scène" but even evoked within performative practices. In the following, we will approach the concept of performative practices also in the sense of practicing, or exercising – the new governance arrangements are a place to exercise new ways to talk, act, and think about genetic testing and to establish these forms by continuously repeating and inciting them.

In the UK, we have observed the establishment of a flexible, expanding advisory system including lay people participation, public consultations, people's panels, citizen juries, focus

groups, and consultative panels. In contrast, at the European Union level there have only been isolated dialogue processes, strictly regulated and limited by pre-formulated recommendations. In Germany and Austria we have observed a more state-centred system of parliamentary study commissions and the National Ethics Council (or future German Ethics Council) in Germany, or the Bioethics Commission in Austria. They integrate experts and some stakeholder representatives, while participatory governance experiments such as consensus conferences and other participative projects have rarely been embedded within these formal governance arrangements. Jasanoff discerns different styles of governance of biotechnologies in Germany and the UK, distinguishing between state-led "programmatic regulation" in Germany, and regulation focused on the process in the UK (Jasanoff 2005). However, as regards Germany, the picture would be incomplete without taking into account a rather strong tradition of protest movements and a vital civil society in the sense of Dryzek and others (Dryzek et al. 2003). In Germany, the separation between the sphere of civil society and what is going on there on the one hand and the state and its formal governance arrangements on the other is deeper and more significant than in the UK. In Germany and Austria, formal governance arrangements are more insulated against public engagement practices. One reason for this separation might be that in Germany today's "involved publics" are still perceived as being successors of the rather oppositional, in part radical protest movements in the 1980s.

In the following, we will not so much present a systematic comparative study about the nationally specific forms of governance but rather highlight the different ways in which new participatory governance arrangements or experiments dislocate and reorder "politics of life". In our narrative we have described the absence of strong controversies and the coexistence of a plurality of different positions which do not collide with one another but stand side by side. Within this non-antagonistic setting critique is not invisible but is able to circulate in the various channels of fragmented debates. We want to show that the procedures and sites of deliberation that we will analyse in the following are effectively organising this situation. They do so by multiplying different forms of "publics" and political subjectivities, and by stimulating the debate and even the circulation of techno-sceptical or oppositional arguments. However, these performative practices guarantee that the discourses of problematisation circulate in fragmented and specialised ways, regulated by new and differentiated forms of expertise. We therefore suggest that, although the participatory governance experiments at the EU level, in Austria and Germany are much more isolated, disperse, and disconnected from the centres of political power, they nevertheless might contribute to a similar "strategic constellation". The term

"strategic constellation" refers to the interpretation of strategy by Michel Foucault and thus does not refer to actors intentionally promoting and planning these strategies (Foucault 1983). This concept also takes into account that this strategic constellation might not be completely established and that there is no linear development toward its completion.

We will approach the performative dimensions of the current new governance schemes in the field of genetic testing in the following way: We start with a twofold approach to "institutional ambiguities", one concerning the boundaries between what is inside and what is outside of these participatory practices, the other concerning institutional ambiguities within those practices: Therefore, first, in 5.1 we have to point out the limited scope and influence of participatory governance arrangements within existing power relationships of human genetics. We can discern different dimensions of limitation here. Second, in 5.2., we will analyse in more depth the institutional ambiguities within these new schemes of governance – especially the multiplicity of different "publics" constituted by these participatory procedures and the paradoxical democratic pretensions of citizen juries or consensus conferences. In this subchapter we will at first focus on the case of the Human Genetics Commission in the UK, because of its explicit complex strategic framework. Afterwards we will compare these findings with the more disperse settings in Germany and Austria. In a third step (5.3.), we will take a closer look at two privileged political subjectivities staged within the new settings: the figure of the patient or the personally affected individual as "individual experts of the lived genetic condition", and the "genetic citizen", connected to the idea of "genetic solidarity or altruism".

5.1. Institutional Ambiguities 1: the boundaries of new participatory governance practices

"One general thing I would say about the Human Genetics Commission that actually whenever there is a concrete policy issue to decide, it gets marginalised. For example on all which has to do with reproduction, it is basically the HFEA that takes policy decision, in the area of genetic screening, you have a genetic screening committee etc." (Interview 14-3 2006).

In the course of the presented narrative of genetic testing our case study has made a general observation on the changing "politics of life": There has been a change in governance away from pure technocratic and expert-based models of policy advice toward – albeit often

piecemeal or comprising pilot elements only – participatory, deliberative, consultative, or dialogue approaches. As Jones and Salter have shown in a discourse analysis of the European and UK governmental documents on human genetics policies, there is a growing emphasis on "transparency" and "openness" as criteria for a good regulatory practice (Jones & Salter 2003). For Germany, Herrmann identifies the beginning of a third phase of bioethics policy characterized by dialogue and participation of "basically everybody" (Herrmann 2006).

These new elements, nevertheless, coexist with regulatory principles based on experts, stakeholders, or even on formal state institutions only. Anne Kerr has analysed this ambiguity with respect to human genetics as a simultaneously centrifugal and centralist tendency of governance (Kerr 2003). Braun has suggested the coexistence of an "expert model", a "stakeholder model", and a "republican model" in the governance of human biotechnologies (Braun 2002). [45] Moreover, several studies suggest that these coexisting or combined governance models are not combinations governed by equitable forces, but that there is a persisting nucleus of insiders, allotted expertise, and professional and scientific/technological self-regulation. This nucleus is not seriously questioned by the new forms of governance. Rather, it is merely complemented, and uses mechanisms of closure and control towards new governance elements in times of public contestation of certain technological developments (Herrmann 2005; Kerr 2003). The new forms of participatory, dialogue oriented governance techniques are often situated at the periphery of the policy arena, while technocratic, professional, and modern-statecraft forms of governance still dominate the politics of genetic testing in a lot of ways. This proves to be especially true when examining the "end product" of political, regulatory decision making (Interview 3-3, 2006). Regarding their influence and connection to "modern state-craft" and to the technocratic and professional nucleus of power in human genetics, we need to take into account the following limitations:

First of all, the impact of the new participatory elements on political decision-making and on the control over the development of research and the regulation of genetic testing is rather limited. In the UK, the advisory system which organised public engagement procedures has a mainly non-statutory character – with the exception of the HFEA and its right to license individual procedures in reproductive technologies. There is no guarantee that government policies or

[45] Similarly: Jones & Salter 2003.

parliamentarians will consider the advisory system's recommendations in their decisions (Jones & Salter 2003; Martin 2001) – and often, when the HGC claimed to have had such influence, insiders questioned the commission's real impact on government action (see, for example, the insurance moratorium). Moreover, consultations, forums, and panels as forms of direct involvement of "the public" or of stakeholder organisations are dependent on their translation into policy recommendations by the advisory committees, which are not obliged to follow the outcomes of these participatory processes (see below).

In Germany and Austria, even more so, new forms of participatory governance have not even been established in a consistent way. As mentioned before, traditional institutions of modern statecraft such as parliamentary study commissions with its mix of parliamentarians and experts and the National Ethics Council (based on experts and stakeholders) or, as planned by the current government, the German Ethics Council, dominate the governance arrangements. And consensus conferences or other models of public engagement have been disperse and marginalised from political decision making.

Moreover, there are various mechanisms to exclude certain issues from deliberation within these participatory spaces: In our narrative we have already pointed out that a lot of "hard" issues in the politics of genetic testing are negotiated and decided while ignoring the new promises of dialogue, transparency, and public engagement. At the symposium on European biopolitics in Berlin, UK participants pointed out the "elephant in the corner" neglected by new participatory forms of governance. For example, the UK Human Genetics Commission has no mandate to debate research policies and has only marginally touched the topic of patent law, claiming that both were not a topic for the ethical and social aspects of human genetics. It also withdraws from involvement as soon as other institutions – as recently the UK Biobank project – establish their own ethical governance schemes (Interview 20-3 2006). The 1999 review of the biotechnology framework already alluded to this possibility to exclude certain issues from consultation when it declared that *"in future, the public will have* […] *the opportunity (where appropriate) to comment"* (Cabinet Office & Office of Science and Technology 1999).

There also is a limitation in regard to the time frame: At which stage of technological development are participatory elements introduced? We can observe that in all national contexts most dialogue and consultation processes on genetic testing have been established when genetic testing practices were implemented and applied for the first time – in the sense of cutting-edge

science – for example genetic testing on "multi-factorial" conditions now and PGD during the millennium change. This focus keeps both already established practices and research and development phases of genetic testing out of the debate (Jones & Salter 2003).

Another limitation concerns the impact of possible outcomes of participatory governance practices. Governments or decision-making authorities oftentimes choose not to respond to controversial outcomes of for instance consultation processes by simply delaying the political decisions. This became obvious, for example, in how the HFEA and the HGC handled the vote on PGD for tissue typing. Also the fact that in Germany PGD was removed from the political agenda when the controversies during the millennium change did not result in public acceptance for more permissive regulations could be interpreted as a delay strategy that avoided a formal legal regulation of the issue at a time when large parts of the public remained opposed to PGD.

Beyond these more direct limitations to participatory deliberation there are also inherent limitations set by the discursive frame of ethicisation: firstly, insofar as regulatory ethics has a de-contextualising effect on defining what is considered an issue worthy of discussion, and secondly, insofar as the ethics frame discredits substantial political controversies by referring to the plurality and personal status of differing values.

5.1.1. Governance through professional self-regulation

The new participatory governance arrangements are not only limited in their relationship to formal regulatory state-led decisions, to modern statecraft. Our narrative has shown that there are also important sites of governance of genetic testing not covered by state-based regulatory procedures. These sites consist of, on the one hand, governance through professional self-regulation; and, on the other hand, the spaces left to individual decision-making backed by the paradigm of individual self-steering and linked to professional self-regulation by the policies and codes for counselling.

Practices of professional self-regulation are not only prevalent in scientific research and in the commercial sector but also in the public health care system. PND, which in quantitative terms is the most wide-spread practice of genetic testing, is regulated mainly by guidelines of medical associations. Also, in Germany it is physicians who "rule" whether the health of a pregnant

woman is endangered by the "defect" fetus she is pregnant with. Decision-making about abortions after PND in general and about late-term abortions too is exercised by the medical profession. For the UK, Martin concludes that the strongest governance institutions for human genetics in health care are medical bodies such as the Royal Colleges and the British Medical Association. He also shows that often their guidelines and codices are more influential and often do not follow the recommendations of the non-statutory advisory system but rather collide with them (Martin 2001).

In this context it is interesting that internal professional governance procedures in health care are often left out from consultation processes. For example, it is illustrative that the first consultations on genetic testing performed by the new advisory system in the UK referred to over-the-counter-tests only, leaving out tests delivered within the NHS and thus via the medical profession. In Germany, there haven't been any influential public initiatives to influence practices of late-term abortion through medical guidelines either (Interview 27-3 2005). Neither did the debate on the proposed law on genetic testing in 2004 and 2005 focus on PND, although some feminist experts engaged in revising some of the formulations in the draft.

5.1.2. Governance by individual self-steering as background of de- or non-regulation

Beyond these different sites of governance, we also need to take into account the persisting space of practices of genetic testing not regulated at all – as is the case for commercially supplied tests (with the exception of Austria). The paradigm of individual or consumer choice and individual self-steering is another general boundary. It is promoting recommendations and codes of practices rather than legal regulations. In the case of the proposed law for genetic testing in Germany it became clear that there is much opposition to regulate this space at all (in particular in the case of paternity tests). In the UK, the paradigm of individual choice has also prevented the advisory system from proposing clear forms of regulation in a lot of areas and cases. For example, the consultation on over-the-counter-tests resulted in a limited scope of recommendations of codes of practice to be voluntarily implemented by the biotech industry itself. Hence, the paradigms of reproductive or patient autonomy, consumer choice, and individual responsibility for health care are themselves an important obstacle against the

influence of more collective, consensual decision-making, and, in this sense, participatory governance mechanisms.

The paradigms of counselling, privacy, confidentiality, and informed consent strengthen the scope of individual decision-making and protect it against collective decision-making, whether participatory or not. Therefore, these individualistic paradigms in a sense limit the scope and influence of participatory governance too.

5.2. Institutional ambiguities 2: within the new governance arrangements

"The government is also very aware how difficult and controversial these areas are and actually quite happy to have the commission [HGC] *feeling its way and supporting. They have such a mess in almost every other area of society, I think they are well off leaving this alone."* (Interview 6-3 2006).

"Since the HGC was established it has been quite successful in terms of promoting rational discussion of the issues. (….) there was no forum within which it was possible to have a measured debate. Discussion of the issues tended to be more sort of shouting from fixed viewpoints, so as they were, and hoping to convince whoever, the government the public, about the validity of your views simply by the force with which you expressed it. Human Genetics Advisory Commission moderated that and then the Human Genetics Commission I think improved even better" (Interview 13-3 2006).

After having emphasized the limitations of new participatory governance arrangements or experiments, we will concentrate on the internal rationalities and the ambiguous constellations within participatory governance arrangements or experiments in the area of genetic testing.

In the beginning we will focus on the advisory system in the UK with its complex but nevertheless centralised system of different forms of consultation and public engagement – and integrate some observations about other national settings with respect to the different "publics" constituted. Also, we will at the end of this subchapter comment on the differences between Austrian, German, and EU settings.

5.2.1. Flashing out heterogeneous "publics"

"The commission [HGC] *is much more concerned to work, ensuring that it flashes out the viewpoints that exist around an issue. That is why in a sense there are multiple ways in which you can input to the commission"* (Interview 13-3 2006).

"We did not count how many organisations and individuals argued one point as against another. (…) Instead we were interested in understanding and considering the variety of views. Each conclusion and recommendation is taken on its own merit" (Human Genetics Commission 2006).

First, institutional ambiguity within the participatory governance arrangement of the UK means that the HGC and also the HFEA apply heterogeneous methods to organise consultation and public engagement, with a diversity of procedures to stage different forms of political subjects:

- the "abstract public" constituted by opinion polls,
- the "pure public", the ignorant public, eventually being converted through the process of citizen juries and focus groups into the "informed" or "educated" public,
- the "partisan public", namely the stakeholders who are given a voice in the consultation paper responses, and
- "affected publics" constituted by individuals who are directly or indirectly affected by a certain genetic condition or disorder, as we see for instance in the constitution of a patients panel.

In the UK, this huge discourse machinery seems to work quite well in centralising and channelling a broad range of the political debates on genetic testing. Also techno-sceptic, oppositional NGOs feel generally obliged to respond to consultation papers, although they rather view this as an "arduous task" absorbing a lot of work without having much impact (Interviews 14-3 2006, 22-3 2006).

The effect of this arrangement of methods, actors, and viewpoints staged by the advisory system could be interpreted as performing the complexity, fragmentation, contingency, and uncertainty of political stakes and thereby contributing to the versatile, non-antagonistic setting we have introduced at the beginning. At the same time the highly appraised claim of the advisory system to produce consensual recommendations organises this complex landscape of opinions and actors in such a way that it draws a line between positions that are still inside and other that are

outside of a "measured debate" (Interview 13-3 2006), excluding the latter for being extremist or fundamentalist positions.[46]

How is the construction of different types of "publics" integrated into the governance of genetic testing? How do these constructions shape the advisory system's decision making and how have they regulated the public debate? There are various answers, which hold, as we would argue, different momentum:

Certainly, there are cases in which the results of participatory consultation processes are quite obvious, when the opinion or concern articulated via these procedures appears quite clear and quite unanimous. In these cases, for example, in the consultation on sex selection, when the vast majority of responses expressed strong objections against using sex selection for "family balancing", the advisory system here functioned as a mode to react to this more or less homogeneous public concerns. In this case the consultation process led to a clear recommendation respecting the concerns. It even resulted in a clear vote against liberal utilitarian representatives within in the HGC or also against the STC who had voted in favour of the right to select the sex of one´s future child via PGD (Bionews 2006a; Moore 2006).

Within the general situation of very few conflicts on genetic testing, the main function of the advisory system, nevertheless, is not to directly react to public concerns. It is rather an instrument to proactively incite and steer public discourse on genetic testing prior to the emergence of antagonistic constellations. Even more, it not only anticipates public concerns but even more actively initiates a productive discourse machinery influencing and shaping the future hegemonic discourse on genetic testing.

Hence, one interview partner from the techno-sceptic NGO Human Genetics Alert concludes that the main function of the HGC is not to be an early warning system for oppositional and conflictive arguments and movements. Rather, he interprets it as a discourse machine *"directed toward policy formation organisations and NGOs and think tanks"* (Interview 14-3 2006). However, this analysis again misses the point in regard to the political subjects constituted and privileged in this process. The privileged subjects in the UK case are not NGOs or representatives of older

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[46] The claim of a measured debate is connected to the bioethics frame that focuses on *"conciliatory, moderate regulation as the antidote to extremism of the right or left"* (Callahan 1994).

forms of expertise and think tanks but other forms of "publics" and – coming along with them – also new forms of experts, staged in these processes. In the following we will analyse this new construction and constellation of "publics" in regard to their function within the advisory system.

The analysis of primary documents and interviews with HGC and HFEA members makes very clear that the main function, which these advisory bodies ascribe to consultation processes and public engagement, is not the function of acquiring representative inputs that could provide a basis for the democratic legitimacy of policies. Rather theses procedures are conceptualised as combined instruments to flash out the political landscape of opinions and as a tool to produce sophisticated arguments within a "measured debate" on the specific topics deliberated. Then, – this is the other direction of the deliberative process – the collected arguments are filtered and packed in order to return them into public discourse by allowing them to circulate in order to foster and animate discourse while keeping its flow within a certain realm.

The idea of having a "measured debate" is also supported institutionally by the way the HGC's and HFEA's membership and speaking positions are constructed. Although the commissions are composed of an interdisciplinary group representing different forms of expertise and professional or social groups, the idea is that their recommendations do not result from their role as representatives but from independent individual evaluations, opinions, and value systems. The HFEA, for example, bases the appointment of its members by the UK Health Ministers on the "Nolan" principles, demanding that: *"Members are selected not as representatives of any particular group or organisation, but because of their personal knowledge and expertise."*[47]

Furthermore, the interviewees explained that the main purpose of consulting the public was not to learn about the quantitative distribution of opinions, to investigate the representative opinions of democratic majorities, but rather to "flash out" all arguments (Interview 13-3 2006), to get the maximum range of views to inform their own individual (and then consensual group) decision making. The speaking position of the HFEA and HGC members fits into the ethics frame in demanding that decisions within this frame are value decisions and as such personal judgements or *"decisions on a matter of conscience"* (Bogner et al. 2006).

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[47] Quoted from the HFEA webpage (http://www.hfea.gov.uk/main.htm).

One HFEA manager explains that even the instrument of opinion polls was not interesting to the HFEA as a "quantitative" method in a strict statistical sense but only as a method to compare the scope of arguments resulting from a poll with the scope of responses to the consultation paper (Interview 17-3 2006). Thus, the quantitative dimension is of minor relevance in "opinion polls" – when compared to the aim of fishing for complex arguments by calling for consultation papers. This fact already demonstrates that within the consultation policies of the HGC and the HFEA there is a hierarchy of priorities attributed to the different methods, and hence to the different "publics" constituted.

5.2.2. Hierarchies of publics – and new experts

"Abstract publics" constituted by opinion polls

"So you have to be quite careful with polling and sort of justify why you come to a different conclusion. But I sort of rationalised it in my mind, that it is not unlike the way in which a court or a judge weighs evidence, you know some evidence is more persuasive because it is nearer, or because it is more relevant, or because it is more recent, or because you like the witness better, you trust the witness better" (Interview 20-3 2006).

In the interviews, HGC and HFEA members expressed a general scepticism toward the method of opinion polls (e.g., Interview 10-3 2006). One manager of the HFEA, for example, explains: "*Of course, the disadvantage of the opinion poll is that people involved in it are not involved"* (Interview 17-3 2006). This is the classical deficit model argument against polls: the public is not informed enough to give adequate, thoughtful answers without being coached first. (Interviews 10-3 2006, 20-3 2006).

Interestingly, in the interviews especially those actors who are considered extremists within the UK human genetics debate and who are located outside a "measured debate" by the advisory system – and therefore not represented within it– are referring to quantitative methods such as polls as possible form of participation: For example, the interview partner from the pro life organisation CORE calls for a strengthening of representative democratic methods such as opinion polls (Interview 22-3 2006).

Stakeholders as experts, not representatives

However, not only opinion polls, but also the classic stakeholder-oriented responses to consultation papers tend to be discredited by the advisory bodies when it comes to appreciating the political subjects staged thereby. Subsuming very different social, political, lobby, or interest groups under the category of "stakeholders" already demonstrates that the specific interests, programs, power resources, etc. of these groups, organisations, enterprises, or NGOs do not matter so much here. The possible speaking position of representing specific interest groups is not even mentioned in the interviews – a further hint at the fact that it is not substantial controversy that structures the constitution of publics.

The main interest of the UK advisory bodies in "stakeholders" – and this becomes very obvious in the interviews – is that they dignify the deep insight into complex arguments allowing their "harvest" through consultation. They recur to "stakeholders" as experts of political discourse, of producing the most complex variety of arguments. In contrast, they discredit the speaking position of the stakeholder as a representative (of an oppositional NGOs, a political lobby, an interest group, an association, etc.), arguing that they are a *"minority of highly vociferous groups"* (Interview 20-3 2006), a *"small set of people"* (Interview 6-3 2006), a *"self-selecting sample"* (Interview 17-3 2006), that is not at all democratically legitimated.

This quality of being experts in order to provide a tableau of complex arguments differs from and extends the older expertise function of NGOs, of being addressed as "counter-experts". This role was still visible, for example, during the conflict between the Parliamentary Study Commission in Germany, being dominated by "counter-experts" in comparison with the different set of experts within the National Ethics Council. In the UK, this pro- and contra structure is not operative within the participatory governance frameworks. Bogner et al. explain the role of stakeholders as experts in the following way: *"Civil society actors do not act as pressure groups but rather operate as organisers of a public discourse, consciously keeping it open"* (Bogner et al. 2006).

In contrast to the scepticism toward "opinion polls" and this "abstract uninvolved public", on the one hand, "stakeholder" participation as representatives of groups, on the other hand, the interviewees celebrated two models as more adequate methods of public engagement: citizen juries or focus groups – constituting "pure publics" to be converted into "informed" citizens undergoing a process of education – and panels of "affected" publics.

The affected public

In chapter 4 we have mentioned the role of the Consultative Panel (consisting of 100 individuals living themselves or having family members with a "genetic disorder") to organise an empathetic relationship with commission members. The Consultative Panel is organised as a space for informal personal communication and contact and thus has a directly performative dimension. The HGC members explain that being able to personally talk with the consultative panel members in small table groups during a meeting was a most helpful experience in order to prepare the "Making Babies" report (Human Genetics Commission 2006).

One of the commission members remembers:

"Another consultation we had I think that was very valuable, there is a group of people with genetic disabilities who are consulted on a regular basis.(…) They spent a whole day sitting in meetings in open discussions in a big room you know in a table like this and they did have a chance to really go deeply into things (…) Somehow the fact that you met face to face with people who were involved was helpful. I am sure that where people did have strong points, these would have been repeated and remembered by the commission" (Interview 1-3, 2006).

We will have a closer look on the role of these "affected publics" when we examine the new political subjectivities staged in the participatory practices in subchapter 5.3.

The pure public: Citizen juries as privileged form of consultation

"They specifically wanted to take people who probably know nothing or very little about the use of genetic information, apart from what they see on television, and to spend two or three days with them and have real expert witnesses and educate them about the issues involved, and then ask them, after these few days, how they feel about it. Just to get a flavour (…) They want a measure of how people would feel, when they are ignorant of the issue and when they are completely educated" (Interview 4-3 2006).

The other participatory method preferred by HGC members is the deliberative process by citizen juries and focus groups, educating participants and pointing out the change of their view and attitudes during the process. This strategy is based on a specific idea of democracy, emphasising the change of attitudes and viewpoints through participatory mechanisms instead of looking for channels to communicate already existing preferences and opinions. This idea, however, leads to a paradoxical imperative: there is the aim to, on the one hand, avoid to manipulate participants but also to, on the other hand, foster a process of opinion

(trans)formation. The dilemma inherent in the concept of citizen juries is a motor for the permanent enhancement of methods. In a sense the dilemma is equivalent to the dilemma of non-directive counselling. The idea is to give "non-directive" balanced information on biotechnologies in order to strengthen the autonomy of the participants and their possibilities to develop their deliberation in an unbiased way. However, when it is presupposed that the procedure itself will actually change opinions in a substantive way, there always remains the temptation for the organisers of such events to select and evaluate the informative or educative inputs given by experts or via dossiers, etc. in regard to the expected output. Therefore citizen juries or consensus conferences provide many opportunities for manipulation and also the setting for a propaganda competition between the experts invited and presented whenever they have conflicting viewpoints (Interviews 11-3 2006, 22-3 2006).

A transformed deficit model of public understanding

To a certain extent the practice to inform and educate people before giving them the authority to deliberate on a certain topic is linked to the old "deficit model of public understanding": This model implies that technocratic experts, who are authorised to evaluate benefits and risks of technologies, should instruct a public, which is constructed as a passive absorber of information, in order to make it "understand" scientific and technological developments, on the assumption that such understanding will lead to an increase in trust and not to an increase in scepticism (see Irwin 2006). The separation between science as objective pre-information and pre-condition of deliberation and deliberation itself is not questioned within this process. We have already emphasised this separation in its discursive dimension as one effect of "ethicisation" in chapter 4. It is performed in citizen juries, consensus conferences, or focus groups through the separation between scientific pre-information (by experts, dossiers, etc.) and the deliberative process on ethical (and social) aspects itself.

This old, very instrumental version of the "deficit model", for example, appears in the Human Genetics Commission's report "Inside Information" when it justifies its work as follows: *"We want to ensure that the exciting prospects for genetic research will not be impeded by public anxiety"* (Human Genetics Commission 2002a: 3). In the Department of Health report "Our Inheritance, Our Future", following the Inside Information report in 2003, the deficit model is also prevalent, albeit combined with other paradigms such as openness and transparency (Jones & Salter 2003). In the chapter "Ensuring public confidence" it explains:

"Realising the full benefits of human genetics will require public acceptance and public confidence. Fundamental to this is greater public understanding of genetics. The government is committed to ensuring openness and transparency in genetic policy making. We want to engage in a genuine dialogue on genetics issues" (Department of Health 2003: 10).

Nevertheless, we suggest that what we see here is not simply the old deficit model. There is something new. We have shown in chapter 4 that the focus in these processes is shifting from "objective" scientific facts towards a more contingent and contextualised presentation of genetic testing integrating its application, the empathetic attitudes toward "affected" people, user's motivations and fears etc.

New expertise – lay experts of the bios and the process

"I conceive an expertise quite on the top of the things and also a dominance of the experts; the more official bodies were founded the more there is a professionalisation and expert-orientation in the discourses. Therefore, there is no crisis of expertise in the sense that experts are retreating, but one type of expert is replaced by another" (Interview 27-3 2005).

The shift toward knowledge production on the bios-aspect of genetic testing is further combined with the effects of a differentiation of expertise within these processes (and not its crisis as some analyses have elaborated) (cf. Interview 27-3 2005). First, this means that social science and cultural studies or theologians – sometimes academics recruited from NGOs or other civil society organisations – are becoming more relevant in the education on "ethical" or "social" aspects of genetic testing.[48] Second, there is a new (meta-level) expertise within these participatory practices that is not directly an expertise on scientific facts, but on the process of deliberation, on organising these processes, an expertise based on the work of political science, pedagogic and participation experts. It is also contributing to some new forms of "deficits" in the non-expert communities. The upcoming of "deliberation experts" indicates an ambivalent situation. There is the more and more acknowledged claim that scientific experts do not represent an objective, neutral position relevant for society as a whole and that there are

[48] *"Each exponent of a discipline – the physician, the lawyer, the sociologist can maintain the status of an expert for a certain stock of knowledge"* (Bogner et al. 2006).

specialised plural perspectives on biotechnologies. Nevertheless, these plural perspectives have to be governed and managed by the new set of experts; experts who no longer directly refer to substantial scientific truth but to the process of deliberation and to their expertise in organising and managing it. They are experts of the process. By legitimising their expertise not by science itself but by negotiating science debates, they also add to the stabilisation of a new "reflexive" model of expertise, which can be organised as a deficit model all the same, in this sense: People need to be instructed in order to understand that the new forms of governance and deliberation governed by the new experts are legitimate and adequate for debating genetic testing.

5.2.3. Germany and Austria: disconnected participatory governance experiments

The UK advisory system fundamentally differs from the German and Austrian situation. More than the UK situation, the German governance situation concerning the politics of genetic testing lacks a strategic centre of debate because of the persistence of a stakeholder and expert oriented system of modern statecraft and disconnected experiments of heterogeneous forms of public engagement. For example, a researcher of the IMEW and former member of the Parliamentary Study Commission, observes that politicians generally are not interested in the outcomes and even less in the procedures of consensus conferences and are much more relying on expert and stakeholder knowledge production (Interview 5-3 2006). This also proved true at the Leipzig youth conference. Although it was a large national consultation project patronised and financed by the BMBF (Ministry of Education and Research), no politician from federal parliament, government, or the political parties was disposed to participate in the central event of this process.

Despite this uncoupling of participatory governance experiments from formal governance, we need to emphasise some similarities with respect to the broader and also internal discursive and performative effects of these more isolated experiments within the national settings of politics of genetic testing.

First of all, the isolated practices of participatory governance experiments in Germany and Austria add additional speaking positions to the broader discourse on genetic testing – contributing to the map of fragmented and plural publics. Thereby, they foster and connect the development of new forms of expertise of the process and expertise on the bios-aspect of

genetic testing. If we look at the expert community invited to the 1000fragen.de experiment (2002-4), the Leipzig youth conference (2006) or the Dresden consensus conference (2001), we can observe a knowledge community on genetic testing present in the different places – composed by NGO experts, human geneticists, and social science and participation experts.

The new subjects performed in these events, that is "lay" citizens involved in a process of education and deliberation, contribute knowledge on "authentic" and "experienced based" ethical values to the expert debates within media and formal governance settings. They can thereby contribute to a policy model that substitutes conflictive political positions by plural ethical positions and knowledge on the contingency of the bios-aspect of genetic testing.

In considering the German experiments we need to distinguish between different performative settings within which this production of publics happens.

The Dresden Consensus Conference on genetic diagnosis was an elaborated and long-planned "serious" consensus conference – above all serving as a reference point and model for the participating expert community itself – while having little impact on formal policy (Fraunhofer Institut für Systemtechnik und Innovationsforschung 2002; Schicktanz & Naumann 2003). It was initiated by the BMBF (Federal Ministry for Education and Research) and located in the "Hygiene-Museum" as a cultural and academic place which guaranteed a certain appearance independent from direct political decision-making.

The youth conference in Leipzig was also initiated from above, from the same Ministry, and also had difficulties to find a link to formal politics. In contrast to the Dresden conference, however, it demonstrated less elaborated participatory techniques and displayed some effects of the paradoxes of this procedure– in its pitfalls, failures, and also Freudian slips: The construction of the youth as a homogeneous social group and as a "pure" public – in the sense of citizens of the future – hindered the conference in discussing and deliberating on the obviously quite controversial and heterogeneous positions presented by different youth groups. Addressing the youth as an amorphous mass was further emphasised in various situations. At some moments during the conference the participants were not even addressed by their first-names when speaking in panels, but only presented as "pure" public of young people, while "experts" were presented with full titles and curricula.

This disinterest in different political positions and backgrounds of the youth groups was just the prelude to the last act of the conference, the elaboration and presentation of a common "catalogue of demands". This procedure was rather manipulative – the group of young people did not elaborate the catalogue themselves but more or less only consented to demands pre-formulated by the organisers of the conference. Generally, the bias in differentiating between renowned experts invited and ignorant young people was not really levelled in this conference. In the end of the process it led to a feeling of disregard and useless effort from those young people who had invested a lot of time in studying and elaborating their projects without having the feeling to have influenced political decision-making through this process. This feeling was further reinforced by some experts on the panels who emphasised that the outcome of the conference, the catalogue of demands was nothing new and would not have any effect on politics or media. Some Freudian slips by the organisers were also quite telling: one speaker spoke of disinviting ("ausladen") the young people instead of inviting ("einladen") them, another even more puzzling moment was a panel which was inaugurated without inviting the young participants to their chairs at the podium. These gestures can be evaluated as expression of an antidemocratic expert-centred political culture in Germany. But beyond this aspect, we would add that it also revealed the somehow empty speaking position of "the youth" keeping them from entering political debate – by, on the one hand, giving them the authority to be an "authentic voice" but, on the other hand, evaluating their concrete interventions as expression of the ignorant public that has to be submitted to revision and refinement by qualified experts.

The 1000fragen.de project of Aktion Mensch differed from these consensus conferences initiated by the government and executed by academic or cultural institutions. It was not initiated by a government initiative but by a large NGO involved in welfare politics for disabled people. The campaign was much more visible publicly than the consensus conferences because it included a broad poster and media campaign. Its major aim was not to set up a catalogue of "the public's" recommendations or demands for purposes of policy advice (although a publication with the questions collected was presented to politicians), but to offer an internet platform in order to facilitate discussion without the pressure of decision-making ("Austausch ohne Entscheidungsdruck") (Aktion Mensch 2003: 11). As we have mentioned in chapter 4, this civil-society-led rather than state- or expert-led arrangement enabled some unease and concern about the implications of genetic technology for the social order as a whole to circulate more freely within this project than in others. A research project at the University of Cologne which evaluated the internet forum speaks of a process of "socialisation" of the issues at stake that

took place here (Waldschmidt et al. 2006). However, there are also aspects of the 1000fragen.de project, identified by this research project that point to effects of ethicisation in that the discourse established via the internet forum legitimates itself not through reference to scientific facts, but through reference to experience.

The interim report of the research project explains:

"First results of the systematic coding focused on the knowledge type 'experience-based knowledge' reveal that not only expert knowledge, but also experience-based knowledge are able to produce powerful speaker positions – powerful in that the ensuing discussion threads concur with the argumentation pattern of the experience-based knowledge (…) The greatest legitimation is ascribed to personal experience" (Waldschmidt et al. 2006).

Similarly, the organisers praised the internet forum for the special "authenticity" of the contributions gathered here (Aktion Mensch 2003: 12). The research project considers expert knowledge and experience-based knowledge as competing forms of knowledge within the field of bioethics. However, as has been argued in chapter 4, we consider scientific knowledge production and "authenticity" of experiences not to be two antithetical types of knowledge in the field of genetic testing but rather two necessary elements, both referred to by expert communities and governance arrangements, within the new systemic type of knowledge production which characterized genetic testing today.

The performance of authentic and lay people's speaking positions based on experience are the basis of two political subjectivities which are clearly privileged in the UK case, but have also proliferated through the more disconnected participatory governance experiments at the EU level, in Austria, and in Germany. In the following, we will concentrate on these two speaking positions: Individual experts of lived genetic conditions and ignorant, albeit ethically capable, citizens as new political subjectivities emphasised by the new forms of governance.

5.3. New political subjectivities within participatory practices

"Various ideal types inform this model [of genetic governance]*: an educated public, consenting patients and tissue donors, centralised regulatory agencies, a community of experts who debate and discuss the ethics of their work, and a responsible and innovative industry, in need of nurturance"* (Kerr 2003: 123).

If we look at the main political subjects addressed by participatory governance arrangements from above in recent years, we can observe a certain trend towards two poles, which correlate with the methods of public engagement privileged by the HGC, namely the Consultative Panel, and the citizen juries.

On the one hand, the group of people considered to be directly affected by genetic testing is narrowed down to people who have personal experiences with genetic testing, such as people who have a certain "genetic disorders" or have a family member who has, or people confronted with the possibility to do a test or women/couples prompted to make decisions in regard to PGD and PND. If we look at the European dialogue projects and the influence of the Consultative and Patients Panel as well as the Genetic Interest Group in the UK, we can see here the promotion of patients and patient organisation to fill in this speaking position.

Another type of addressees of new participatory governance arrangements are the "pure" (ignorant) citizens, the lay people who not yet hold any specific views on the issue and do not form part of a political or interest group active in this field. This "pure" public is called upon in many consultation processes and consensus conferences, oftentimes constructed as forming the opposite of or counterweight to another group build of experts, scientists, or politicians (Edwards 2002).

The trend towards referring to or establishing these two authorised speaking positions is certainly not absolute. Yet, it contributes to a shifting of power relations in the field of speaking positions. For example, by emphasising that patients are the ones "truly" affected by genetic testing, the claims of social groups who see their lives as actually or potentially affected by the practice of genetic testing too, albeit not necessarily in a medical but rather in a social and cultural way (such as the feminist or the disabled movement) are delegitimated and not accepted as a legitimate speaking position. In the UK case we have shown that the speaking position available to these latter groups is rather the position of "stakeholders" and even they are not so much invited to participate as representatives of group interests or as empathetic dialogue

partners but mostly as a resource of knowledge in that they help organizers to flash out the complex landscape of possible arguments.

5.3.1. The "authentic public" or the experts of embodied experience

"There was a certain amount of engineering involved [in constituting the Consultative Panel], *because they wanted a range of experiences as wide as possible. So people were asked what the genetic condition was, were they affected directly or were they looking after someone, or were they someone who had a condition run in the family and they didn't know if they were affected yet, so that kind of thing. It was to get as broad a picture as possible, and then so there was a little bit of engineering I think, because they would get a lot of people with a certain genetic condition and not so many with another, and they wanted to balance"* (Interview 4-3 2006).

This new type of political subjectivity staged by new participatory governance arrangements is more clearly discernible in the UK than in the other countries we looked at in our work package. The HGC's Consultative Panel is a case in point here. The subject celebrated here is the individual confronted with the diagnosis of a specific "genetic condition" (of him-/herself or of a family member). The panel consists of 100 individuals with "genetic disorders" or who have family members with such a disorder. They are explicitly not selected as representatives of certain disability or patient organisations nor as individuals with a specific professional or political background but as individuals as 'pure' as possible, as individuals affected by a specific genetic health condition. One of our interview partners within the HGC makes it clear that people from political organisations or "lobbyists" of the disabled community are not tolerated as members of the Consultative Panel so that the expertise required, the speaking position established is that of experts of being personally affected by a medical condition, either by suffering from it or by caring for someone who suffers from it (Interview 4-3, 2006), their speaking position thus is framed and allocated in medical terms and on the basis of a medical model of disease and disability.

However, participants are framed not as passive patients but as active individual experts in their own right. They are addressed as experts knowing about social, familial, and health care situations as well as about the research progress and the symptoms, diagnostics, and therapies of their specific "impairment". This speaking position is equipped with a special authority, the authority of authenticity which grants its incumbent and his or her views a highly regarded and

virtually unquestionable status. Nevertheless, as an expert position it is rather fragile insofar as this expertise is based on the individual situation only, the situation of being affected – thus not on broader social settings or political positions. This expertise is integrated, as demonstrated in chapter 4, into the advisory system by settings supposed to generate empathy with those who are considered truly affected – in this medicalised sense - when for example HGC members celebrate their meetings with the Consultative Panel's members in small groups for giving them the opportunity to get very close to "these people" and being emotionally moved by this experience.

This expertise, on the one hand, constitutes a shift away from the supposedly objective, universal scientific type of expert knowledge about "genetic disorders", traditionally provided by medical experts and scientists. On the other hand, the speaking position of the "affected public", at least if constructed in medical terms - strongly differs from what disability rights activists propose – namely a speaking position based on a social model of disability. The social model of disability interprets disability not just as a physical condition but as socially constructed in that it is society that disables people through labelling, reducing them to this one characteristic only, through stigmatisation, or denying access to public goods. It connects disability to other civil rights movements and political struggles against all forms of segregation, discrimination, and exclusion of people on the basis of certain characteristics – a position which the HGC discredits as undesired lobbyism within the Consultative Panel.

Nevertheless, the borders between these two political subjectivities are not always clear. The possibility to speak as an expert of certain social situations and lived experiences and not only as an expert about certain "matters of facts", established only through scientific knowledge, is offered by both speaking positions. The organisational borders between both positions are not always clear, either. Nevertheless, the position of the Genetic Interest Group (GIG) in the UK, in favour of and actively promoting human genetic research and genetic testing on the one hand, and older types of disability rights organisations such as the BCODP or Disability Awareness in Action on the other, opposing what they see as the eugenic contexture of genetic testing, are extremely opposed to each other (Interviews 13-3 2006, 9-3 2006). The power relationship between both speaking positions in the current governance setting of genetic testing is not easy to define and has been analysed in rather different ways by our interview partners. Among HGC members we interviewed, we found both positions from the BCOCP and from the GIG as

commission members, but the HGC clearly frames the Consultative Panel as a space for the representation of bodily affected patients.

In Germany, pro-human genetics research and self help groups are not as visible and influential as in the UK and there is no centralised political lobby group equivalent to the Genetic Interest Group. As we have shown in the narrative, there nevertheless is a rather disperse network of patient and research cooperation with similar attitudes. Its formal cohesion is organised by the Federal Association of Self Help Groups (BAGS) that however does not articulate a similarly accentuated political lobby position like the Genetic Interest Group.

One disability rights activist we interviewed held that until now the lobbyist background of some patient organisations financed by pharmaceutical or biotech industry has remained quite obvious (for example in the EU context). They have not yet achieved a hegemonic speaking position in its own right (Interview 11-3 2006). As other commentators state with regard to the German situation: Although the patients' speaking position has become more visible in the last decade, there has also been an increasing acceptance of disability organisations with a more pronounced disability rights background within the political realm (Interview 5-3 2006). Insofar the balance of speaking positions is not developing in a linear manner, but has different focuses and sites of power and resources within different national settings.

Moreover, the expertise on one own individual "genetic disorder" in itself presents an ambiguous frame between representing "bios" and "zoe", between a medicalised body and the social embedding of disease: It does allow bringing in knowledge on a lived condition by non-medical experts and as not primarily medical expert knowledge. Nevertheless, it is closely linked to a predominantly genetic framing of disability. This form of biologisation becomes quite evident in the positive reference to "genetic diversity". This concept, supposedly critical of genetic testing, circulates within the UK context (not in Germany): It could be endangering the future, so the argument goes, to limit the genetic diversity of mankind by eliminating certain genes through selective abortion or PGD. Such biologisation of human diversity as biodiversity (which in turn is linked to evolutionist models) shows that all the expansion of contingent and individualised knowledge on "lived conditions" has its limit in the subtext of an extremely medicalised knowledge pushing back the social model of disability.

The understanding of mankind as a gene pool is also important for analysing the second speaking positions "mise en scène" in the new forms of governance of genetic testing:

5.3.2. Lay citizens and genetic solidarity

"Genetic solidarity: We spent two years trying to sort out what we meant by it, and we did come up with these principles genetic solidarity and genetic altruism, all this sort of things: you know, we are all citizens of the world, we share the same DNA" (Interview 20-3 2006).

The other political subjectivity addressed by the new governance arrangements is that of the ignorant but nevertheless ethically capable citizens; a subjectivity performed in citizen juries or consensus conferences. It is also evoked in youth conferences addressing the youth as the citizens of the future.

As mentioned before, the staging of "lay people" as a performative effect of consensus or citizen conferences contributes to a non-antagonistic setting. Like the affected individuals with an authentic experience, lay people are also constructed as authentic speaking position of the public – as a site of neutral reflection of information and input given to them within those processes.

First, we need to distinguish what is meant by lay people within different settings. Within the advisory system of the UK, `lay´ simply means non-scientific in the sense of not being a researcher (or entrepreneurs) within the biosciences. Thus, in the HGC and the HFEA journalists or lawyers also count as lay people. Within the public understanding of science debate, this perception is linked to the idea of a division between scientists representing science and lay people representing society. This frame proves less relevant in the other national settings. Therefore, in the following we will concentrate on the speaking position that refers to lay people in the sense of "pure", ignorant citizens as evoked in the participatory governance arrangements or experiments in all country settings.

Recalling the concerns we have addressed in the second part of chapter 4 on the "politics of life", the speaking position of neutral citizens could be a space for republican deliberation on the implications of genetic testing for the social order as a whole – as they are expressed for example in the concerns on eugenics and designer babies. However, the idea of pure citizens is linked, at least in the UK, to "discursive currencies" (Jones & Salter 2003) such as "genetic solidarity", "genetic altruism", and – a more academic discourse – "genetic citizenship". These

concepts are based not on debating broader social processes but rather on the ideas of duties and obligations for citizens as individuals.

"Genetic citizenship" is a term which, on the one hand, refers to an individualised perspective of rights: the right to participate, to have access to information, to non-discrimination, to counselling, to consumer choice, etc. The frame "genetic citizenship", on the other hand, also establishes duties of citizens: the duty to donate tissue samples or blood, to consent to research, or to inform family members about certain test results (Petersen 2003).

The HGC frames these obligations in the concept of "genetic solidarity" or "altruism" – explaining them in its report "Inside information" as follows:

"Genetic knowledge may bring people into a special relationship with one another. We lead our lives as members of large and small communities and we have certain duties to other members of these communities. … Sharing our genetic information can give rise to opportunities to help other people and for other people to help us and we have a common interest in the benefits that medically-based genetic research may bring. We have, therefore, set out a concept of genetic solidarity and altruism. *This supports the idea that, although nobody should feel pushed into taking part in genetic research, when they make this decision people should be aware that by taking part they might help those suffering from disease"* (Human Genetics Commission 2002a: 6; accentuation in the original).

HGC further explains genetic solidarity and altruism:

"We all share the same basic human genome, although there are individual variations which distinguish us from other people. Most of our genetic characteristics will be present in others. This sharing of our genetic constitution not only gives rise to opportunities to help others but it also highlights our common interest in the fruits of medically-based genetic research" (Human Genetics Commission 2002a: 18).

Hence, the Human Genetics Commission frames the reason why genetics should be an issue for all citizens by pointing at the idea of a common DNA we all share; this common DNA is the reason why everybody should be participating in the debate. This explains why in the view of utilitarian liberal John Harris, member of the HGC, everybody should feel the "moral duty" to give samples of his or her DNA to the UK Biobank project (Bionews 2006b). In contrast, other HGC members refer to the concept in arguing that everybody should oppose genetic

discrimination and should accept the right of disabled people not to know about their genetic characteristics (Interviews 1-3 2006, 6-3, 2006).

Similarly, the concept "genetic literacy", which was introduced by the British Medical Association (British Medical Association 1998; Jennings 2004), is based on the assumption that genetic knowledge is essential to people and to society. However, the idea of a duty of citizens to be informed about human genetics neglects the fact that truth claims in human genetics themselves are highly contested and that different concepts of life are intermingled within the current governance schemes of genetic testing.

Although these concepts are contested in the way we mentioned with regards to genetic solidarity, the paradigms of "genetic solidarity" or "genetic altruism" as "overarching principles" (Human Genetics Commission 2006: 10) display a certain form of geneticisation as they put "genes" and the relation of people to "their genes" at the centre of social relations and political engagement. It is simply assumed here that "bio-sociality", as Nikolas Rose has called it, (Rose 2001), is a reality and not just a contested discourse. The genetic paradigm and its truth claims lie at the heart of metaphors such as "genetic solidarity" or "genetic altruism" but also of "genetic citizenship", "genetic diversity" or "genetic literacy", assuming that "the genes" are the essence of a person, of a group, and of humanity and that therefore the way to deal with genetic information is essential for society.

This geneticised way of framing citizenship and solidarity is less visible in the German or Austrian case, or at least not publicly stabilised by terms such as genetic solidarity or genetic diversity. Nevertheless, there are various tendencies pointing in the same direction, beyond the proliferation of self help groups linked to medicalised identity politics. The first population-based biobank project in Northern Germany, popgen, addresses the same type of altruism and solidarity as it calls on people to help future generations by participating in the collection of DNA samples (Görlitzer 2004/2005).

There also is a strong impetus, a strong obligation towards "genetic literacy", present in participatory experiments and projects of public education from above (for example the Year of Life Sciences propagated by the BMBF in 2001). Also, we find the idea, albeit not the term of "genetic literacy", in the design of the Leipzig Youth Conference at work in the form of genetic truth claims and the claim that everybody should get an education about human genetics. The Leipzig youth conference included a first phase in which participants received an education

about human genetics as a prerequisite for further deliberation without that the contested character of this knowledge was addressed in any way.

6. Conclusions: Politics of genetic testing – non-antagonistic, fragmented, and systemic

6.1. PND, PGD, and "predictive medicine": different stories to tell

Are there some cross-cutting, general results about the new politics of life and new participatory governance arrangements within the current politics of genetic testing? On the basis of our case study the answer at first sight would be 'no', while a second glance yields the answer 'yes'.

Concerning the politics of life, we have found that there are different stories to tell depending on whether one looks at PND, PGD, or genetic testing within "predictive medicine": The public energy field around PND has been established beyond strong formal regulatory mechanisms, beyond the judicial power of modern statecraft, while PGD is still a contested issue at the heart of debates on how to formally regulate genetic testing. Concerning "predictive medicine", we found that the politics of time are of especial importance.

- **PND** is a field where professional self-regulation and the paradigm of individual self-steering have become the major governance schemes – within a context of routinisation and normalisation. Codes and guidelines or medical associations are the main regulatory mechanisms – and the paradigm of individual reproductive choice guided by counselling has become hegemonic. Hence the former strong pros and contras about selective abortions have been mitigated by a frame centred on the complex motivations and concerns of the pregnant woman or the couple deciding about PND. In the consequence, there have been few dense political conflicts around PND in the last years, while there is a persisting but subliminal public unease about it.
- In contrast, **PGD** is a field where different formal governance arrangements have dominantly shaped policy-making and the forms of deliberation. We have discerned a temporary but dense conflict in Germany around the millennium change about whether or not to ease the restrictions of the Embryo Protection Act – or its interpretation – in

order to legalise PGD. In the UK, PGD constitutes a major "public energy field", too, but in a different manner. In contrast to Germany, regulation does not take the form of criminal law but of an intense flexible and sophisticated decision-making process on a case by case basis – with the HFEA as a prototype for the UK arm's length bodies system.

- **"Predictive medicine"**, finally, is still widely characterised by non-regulation and incipient forms of regulation (in the form of moratoriums, law proposals, and very recent legislations). Debates in this issue area centre on the questions how to regulate at all. The debate is highly dependent on different projections about future scenarios of genetic testing within health care – and is thereby a debate on different "colonisations" of the future. It is the field where politics of time and interpretative strategies about the specificity or non-specificity of human genetics have became especially important for governance strategies.

6.2. Introduction into common features

Despite these strong differences in the issues at stake and country settings under study, we have found a number of common features, which are visible only at second glance. These features relate to political settings, strategic constellations, changes in political subjectivities, the transformation of frames, and the performative dimension. We can summarise them by the following keywords:

A non-antagonistic setting: The current governance of genetic testing can be analysed as governance via a "non-antagonistic setting". Compared to former periods, in recent years we have noted the absence of an antagonistic conflict constellation and of dense dislocatory processes. Interestingly, this does not mean that public discourse runs dry. On the contrary, we see an ever more active discourse machinery permanently inciting and regulating debates in which techno-sceptical arguments against the expansion of genetic testing practices are circulating, but are detached from the idea of fundamental political conflict.

Diversification and fragmentation: This non-antagonistic constellation is partly due to the enormous diversification and fragmentation among different coexisting forms of expertise, sites

of negotiation and deliberation, political subjectivities, publics, and increasingly detailed issue constructions.

Ethicisation: On the other hand, we find a process of ethicisation in the sense of an increasingly prevailing ethics frame stretching across this diversity of coexisting sites, problems, publics, and subjectivities and organising the different debates. The process of ethicisation contributes to the non-antagonistic character of the political setting, privileging certain topics and political subjectivities while marginalising others. We can distinguish between regulatory ethics and life style ethics. Life-style ethics have incited an enormous knowledge production on what we call the **bios-aspect** of the governance of genetic testing. This knowledge production addresses the motivations, desires, concerns, anxieties, and decision-making and coping strategies of individuals who are confronted with the possibilities of genetic testing.

Post-euphoric and **post-catastrophic narratives:** We have found the politics of time to be a key aspect in understanding the specificities of the current governance of genetic testing. With respect to the politics of time, we note that current politics of genetic testing are framed in less far-sighted prognostics – no matter whether the prognosis is derived from a techno-sceptical or from a techno-optimistic viewpoint. Expectations towards genetic testing in general are rather based on concrete experiences and economic and scientific uncertainties are taken into account. Post-euphoric respectively post-catastrophic narratives have superseded the big stories of all encompassing solutions, on the one hand, and scenarios of a horrendously geneticised society, on the other hand.

Subliminal public unease: The above listed keywords describe a hegemonic setting. However, we have also elaborated that there is a subliminal public unease which is disturbing, albeit not confronting this hegemonic setting by referring to the frame of eugenics and the metaphor of designer babies.

These results arise from the focus on the participatory governance of genetic testing, as marked by more coherent and centralised arrangements in the case of the UK and more disperse and disconnected experiments in the cases of Germany, Austria, and the European Union. Before further explicating them, we need to highlight once again that the participatory practices are clearly limited with respect to scope and political influence. The participatory arrangements we have looked at in our case study exercised little influence on formal political decision-making.

Generally, "hard" issues of considerable economic interest, such as national research policies or patenting, tend to be absent from the agenda of participatory governance arrangements.

6.3. Dimensions of ethicisation

In chapter 4, when discussing the discursive dimensions of the current governance of genetic testing, we have emphasised that the non-antagonistic constellation in the debates on genetic testing partly results from a process of ethicisation – a process with at least three dimensions.

We distinguish between regulatory ethics and life style ethics. Regulatory ethics is established via expert commissions or advisory bodies whose task it is to study the ethical implications of certain contested practices and technologies such as genetic testing with respect to possible or necessary regulation. Regulatory ethics is the use of ethics-as-expertise in science policy-making. Applying regulatory ethics implies framing the issues at stake in the language of ethics, which in turn implies a tendency towards a non-antagonistic constellation. One mechanism of ethicisation in this sense, which we can discern, for example, in the debate on PGD in Germany, is framing the issue in terms of "ethical dilemmas" which as such appear to be pre-given and unquestionable. The dilemmatic structure of the issue demands a relativist acknowledgement of different values and opinions within a frame of dialogue (Moore 2006). Moore (2006) and Braun (2006) argue that regulatory ethics serves less in creating a consensus but rather help to *"move the struggle from politics"*.

Regulatory ethics, as we have shown in our case study, sometimes also organises processes of negotiation, of "ethical brokerage". This proves to be especially true when there is a need for formal governance to find compromises and develop coherence in political and juridical terms. The case of PGD in the UK can be considered a prototype of such processes within which there is an enormous productivity of new differentiated artefacts, new intermediate concepts in order to find coherent solutions – such as debating who can how assess the "seriousness" of a condition, what happens with "late-onset" and "low-penetrance" genetic conditions, etc. Moreover, these intermediate concepts allow for gradually shifting the boundaries of what is

allowed and what is prohibited – for example gradually allowing PGD first for a few restricted and then for more cases of tissue typing, or also allowing PGD for risk of an inherited cancer.

Life style ethics, on the other hand, is intrinsically linked to the neoliberal paradigm of individual self-steering and self-care. Concerning genetic testing, life style ethics manifests itself in a knowledge production dealing with what we call the "bios-orientation" of genetic testing. Here, we see a sophisticated knowledge production about the motivations, desires, fears, hopes, and anxieties of individuals using genetic testing, considering to use genetic testing or being confronted with family members who use or consider to use genetic testing. This knowledge production focuses on the pressures these individuals are exposed to as well as their scope of action and the social, cultural, and psychological conditions under which they take decisions. This experience based knowledge contextualises the scientific dimensions of genetic testing – however in an individualistic, consumerist way. We have argued that the increasing interest in the bios-aspects of genetic testing explains the increasing significance ascribed to emotionality and empathy within the governance of genetic testing, establishing the perception of an unquestionable authenticity of those who are "really" affected by or in need of genetic testing.

6.4. Anticipatory governance strategies and authentic subjects

In the issue area of genetic testing, as our case study shows, discursive frames, narratives, and participatory arrangements are inseparable from performative practices. Discursive frames are staged within specific sites of negotiation and by specific forms of communication, and they are bound to specific political subjects constituted within these practices. We have shown that this is especially relevant for our case. Within a non-antagonistic setting, as we have found in this issue area, participatory governance arrangements or experiments are oftentimes rather *producing* concerns than responding to existent conflicts or debates. In the case of the Human Genetics Commission we have shown that it explicitly established an anticipatory strategy in order to incite and channel discourses on human genetics even *before* controversial issues would appear. In this case, we can speak of a government-induced public energy field. Hence, the current governance of genetic testing not only responds to or transforms but actively constitutes public energy fields.

In our case study, the practices of participation and the problems and subjects staged in this context constitute a fragmented and heterogeneous landscape. We can distinguish between different types of publics staged:

- The "abstract public" as addressed by opinion polls,
- the "pure public", made up of "ignorant but ethically capable" individuals as addressed by consensus conferences, youth conferences and citizen juries
- stakeholder publics as experts of complex political arguments addressed within consultation processes,
- "affected publics" as representatives of people affected individually by certain genetic disorders and/or genetic testing.

Within this plurality of publics, we have shown that the ethics frame especially strengthens two kinds of political subjectivities, two speaking positions: on the one hand, the figure of the abstract citizen or lay person – who constitute the "pure public" – and, on the other hand, the "affected public" made up by patients as individual experts of being personally affected by a certain genetic condition. Both constitute an "authentic" speaking position either based on personal values or experiences. "Authenticity" seems to form a new type of qualification for a privileged position in processes of dialogue and deliberation, one specifically promoted by the ethics frame. We can interpret the focus that many participatory governance arrangements in the area of genetic testing put on the "affected" and the "pure public" as part of a process of apoliticisation in the sense that political struggle is discredited or at least mitigated. "Authentic" subjectivities are positioned against older models of speaking position such as lobby or interest groups or social groups in the sense of Iris M. Young, constituted along lines of social difference. For example, current participatory governance regimes marginalise the speaking position of disabled people as a social group, that is as a group constituted via socially discriminated people and not via specific "genetic conditions". Or they neglect women as a social group positioned within specific gender regimes in society and not as individual consumers of genetic testing.

6.5. Scientific and economic uncertainties as basis for a systemic approach

Which scientific truth production has fostered these models of governance?

We have shown that there is an increasing attention for scientific uncertainties within the hegemonic setting of governance. The crisis of genetic determinism has not resulted in the rejection of the gene paradigm altogether but rather in its transformation. On the one hand, the increasing importance of epidemiological knowledge production has resulted in statistical foundations of probabilities and risk factors for "low penetrance" genetic conditions; on the other hand, systemic models of the interrelation between environmental, organic, and genetic factors have become the dominant paradigm. Epidemiological and more complex approaches in human genetics have transformed but not abolished the process of geneticisation already deeply rooted in popular knowledge.

The systemic approach, that is the idea that individual health can be understood as the result of multiple interacting factors, such as life style, environment, genes, and processes occurring in the cell, the proteins, or the larger organism, implies an increasing significance of what we have called the "bios-orientation" of genetic testing. We can understand the new focus on life style ethics in the light of a twofold uncertainty: On the one hand, life styles form an important element within the new systemic paradigm of human genetics which produces knowledge about a bundle of factors and their interactions rather than about a single gene and its expressions. Hence, life styles are of enormous interest for research into multi-factorial genetic diseases. Knowledge about life styles, life style decisions, and life style ethics thus is required to increase the production of (more) reliable diagnostic or prognostic instruments – if not therapies – and to thus reduce scientific uncertainty in the area of human genetics. At the same time, the focus on life style ethics can, on the other hand, be understood in the context of economic uncertainty, namely the uncertainty regarding the establishment of a genetics-based "pre-symptomatic" medicine within the health care systems and regarding the question of whether the market for genetic testing will actually expand in the near future. In the absence of gene therapies and the uncertainty concerning "low penetrance" risk factors, the production of "biovalue" in this field depends on individuals actively requesting and applying genetic knowledge. In this context, the motivations, fears, anxieties, and hopes surrounding both genetic disorders and genetic tests as such need to be governed adequately in order to reduce and handle economic uncertainties. Hence, the focus on "bios" has not replaced the focus on "zoe" in hu-

man genetics, nor have "bios" and "zoe" become undistinguishable, as Agamben holds, nor can social and individual identities necessarily be reduced to "somatic identities" as Rose argues, but rather does the systemic approach integrate and produce knowledge about both zoe and bios and the different modes of their interrelations without collapsing the distinction or reducing one to the other.

The systemic model with its privileged position for the "bios", that is for life styles and life style decisions, thereby also stabilises the gene paradigm, albeit in a modified form. The gene paradigm, that is the assumption that knowledge about the "genetic makeup" is the key to predict, preserve or improve individual health, remains the unquestioned reference point of the systemic approach. We have shown that the gene paradigm also forms the foundational basis of new paradigms of governance such as "genetic solidarity", "genetic citizenship" or "genetic diversity" which all frame political concepts with reference to the gene paradigm.

6.6. Disturbing effects of the frame of eugenics and the designer babies metaphor

In this context, it becomes clear that the recent focus on the "bios", for instance on emotions and on the social context of individual decision-making, as such does not pose a serious challenge to the dominant model of genetic governance. In fact, it is contrary to de-contextualising trends within regulatory ethics and within the older genetic determinism, but it introduces social contingency in a consumerist way without questioning the gene paradigm as an integral part of a systemic approach. Other frames and metaphors seem to be more unruly and disturbing, as we can see from the increasing discursive investments into the delegitimisation of the frame of eugenics and the metaphor of designer babies. However, these investments have occurred with a certain time-lag; they did not come up when debates about eugenics and designer babies had been embedded in ongoing political conflicts. It is against the background of the dominant non-antagonistic and ethicised setting that the eugenics frame or the metaphor of designer babies becomes unruly and provokes delegitimising efforts in that they question the benefit of genetic testing for the social order as a whole. These discoursive elements principally question the basis of genetic knowledge as knowledge based in the differentiation of social groups and transgress a setting of pluralist values by emphasising the negative and hierarchical consequences for society as a whole.

Hence, these discourses take an implicitly macro-political and antagonistic approach in the sense that they imply a substantial opposition between a "right" and "wrong" way for society to go. Such a substantial and macro-political opposition can not be represented within the current systemic, non-antagonistic governance scheme. In addition, the eugenics frame and the metaphor of designer babies deviate from the medium-term time frame characteristic of post-euphoric and post-catastrophic perspectives in that they imply a more farsighted look onto an envisaged future.

The strategy to discredit selective abortions and PGD as eugenic practices does not fit into the dominant ethics frame. While the dominant ethics frame always claims to respect the authentic emotions of those who are personally affected by a genetic disorder, it is questioning the relevance of personal authenticity and affectedness in the moment when eugenics is addressed. Eugenics is not addressed by people with disabilities who speak from the speaking position of individuals defined by their medical condition but from the speaking position of a social or political group. The efforts to delegitimise the eugenics frame as being erroneous and irrational shows that here the old deficit model of public understanding that has discredited techno-sceptical arguments as emotional and false – supposedly overcome within new governance schemes – is still in place. Despite all references to empathy and emotionality, there is a clear tendency to re-establish the talk on rationality and scientific knowledge (integrating social research on the role of the bios in genetic testing) in order to discredit these broader and more fundamental questions about the social meaning of genetic testing.

Within fragmented landscapes of multiple speaking positions, issues, expertises, and problems, it is difficult to propose general political strategies in order to improve participation and political transparency within the political decision-making on genetic testing. However, one message of our case study might be that there should be a greater attention to these disturbing effects of a subliminal public unease. This attention could be a starting point in order to overcome the effects of apoliticisation and of a non-antagonistic setting organised by ethical governance. There are other messages implied by our results that have to do with the problems of ethicisation. For example, there should be strategies to counteract the effects of marginalising "hard" political and economic issues from participatory deliberation on human genetics. And there should be the possibility to reengage with a general critique of geneticisation, politicising scientific and economic uncertainties in ways that should transcend the mutual reference

systems of reinforcing individualising perspectives and the gene paradigm within a systemic approach.

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7.2. Interviews

Interview 1-3: Member of the HGC, London, UK, February, 2, 2006.

Interview 2-3: Austrian Academy of Science, Institute for Technology Assessment, Vienna, Austria, June, 28, 2006.

Interview 3-3: Member of the European Parliament, Green Party, telephone interview Berlin-Strasbourg, France, April, 4, 2006.

Interview 4-3: Secretary of the HGC, London, UK, February, 2, 2006.

Interview 5-3: Institut Mensch, Ethik, Wissenschaft, Berlin, Germany, March, 31, 2006.

Interview 6-3: Member of the HGC, London, UK, February, 2, 2006.

Interview 7-3: Geneticist, Medical University Vienna, Univ.-Klinik für Frauenheilkunde, Vienna, Austria, September, 20, 2005.

Interview 8-3: Member of Parliament, Austrian Peoples Party, Vienna, Austria, August, 21, 2006.

Interview 9- 3: Disability Awareness in Action, telephone interview Berlin-UK, March, 6, 2006.

Interview 10-3: Member of the HFEA, London, UK, January, 31, 2006.

Interview 11-3: Initiative Selbstbestimmt Leben, Berlin, Germany, March, 20, 2006.

Interview 12-3: Aktion Leben Österreich, Vienna, Austria, September, 5, 2006.

Interview 13-3: Genetic Interest Group, HGC, London, UK, January, 31, 2006.

Interview 14-3: Human Genetics Alert, London, UK, February, 2, 2006.

Interview 15-3: Aktion Leben Österreich, Vienna, Austria, July, 3, 2006.

Interview 16-3: Public Relations Agency "communication matters", Vienna, Austria September, 6, 2006.

Interview 17-3: Manager of the HFEA, London, UK, February, 2, 2006.

Interview 18-3: University of Vienna, Institute for Political Sciences, Vienna, Austria, June, 28, 2006.

Interview 19-3: Austrian Council for Research and Technology Development, Vienna, Austria, September, 6, 2006.

Interview 20-3: Member of the HGC (until 2005), London, UK, January, 28, 2006.

Interivew 21-3: Ethikkommission FÜR die österreichische Bundesregierung, Vienna, Austria, August, 21, 2006.

Interview 22-3: CORE, telephone interview Berlin-London, UK, March, 14, 2006.

Interview 23-3: Aktion Leben Österreich, Vienna, UK, July, 3, 2006.

Interview 24-3: University of Vienna, Institut für Bildungswissenschaft, Sonder- und Heilpädagogik, Vienna, August, 30, 2006.

Interview 25-3: Science-Center-Networks, former team member of "dialog<>gentechnik", Vienna, Austria, June, 29, 2006.

Interview 26-3: Gen-Ethisches Netzwerk, Berlin, February 15, 2006.

Interview 27-3: Heilpädagogische Fakultät der Universität Köln, Research Project on 1000fragen.de September, 9, 2005.

7.3. Conferences/Meetings/Workshops (taped or taken notes)

"Forum Biopolitik" Bundeskoordination Internationalismus (BUKO), 5-9.May 2005, Hamburg; (notes).

"Partizipation und Biopolitik", Veranstaltung des Nationaler Ethikrats, 18 May 2005, Berlin (notes).

"Patented New World", Internationale Fachtagung, Heinrich-Böll-Stiftung, 2-3 June 2005, Berlin (notes).

"Ethical and Legal Issues at the Beginning of Life: Debating 'Designer Babies'", Symposium: at Middlesex University, School of Health and Social Sciences, 2 February 2006 London (taped and partly transcribed).

"European Biopolitics. Connecting Civil Society – Implementing Basic Values", 17-19 March 2005, Heinrich Böll Stiftung (taped) – and on http://www.boell.de/en/04_thema/4205.html.

Youth Conference "Die nächste GENeration", Gewandhaus Leipzig, 19 May 2006 (www.gen-diskussion.de).

8. Acronyms

ACGT:	Advisory Committee on Genetic Testing
BCODP:	British Council of Disabled People
CORE:	Comment on Reproductive Ethics
DAA:	Disability Awareness in Action
EU:	European Union
GIG:	Genetic Interest Group
GMOs:	Genetically Modified Organisms
HFEA:	Human Fertilisation and Embryology Authority
HFEAct:	Human Fertilisation and Embryology Act
HGA	Human Genetics Alert
HGAC:	Human Genetics Advisory Committee
HGC:	Human Genetics Commission
HTA	Human Tissue Act
IMEW:	Institut Mensch Ethik Wissenschaft Berlin
NHS:	National Health Service
OST:	Office for Science and Technology
PGD:	Pre-implantation genetic diagnosis
PGS:	Pre-implantation Genetic Screening
PND:	Prenatal genetic diagnosis
STC:	Science and Technology Committee
TAB:	Büro für Technikfolgenabschätzung (Office for Technology Assessment)