

Participatory Governance and Institutional Innovation

The New Politics of Life

introduction

Institutional Change and Politics of Life

politics of life

New Frontiers in Governance

governing uncertainty

From Risk to Uncertainty

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Reworking Contemporary Governance

science and participation

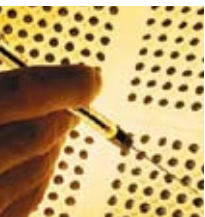
Beyond the Dichotomy of Experts and Citizens

from logos to pathos?

The Rise of "Ethics"

conclusion and recommendations

Towards the Governance of Life



Summary Report of the PAGANINI Project
Participatory Governance and Institutional Innovation:
The New Politics of Life

The PAGANINI Project

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Participatory Governance
and Institutional Innovation
The New Politics of Life

Summary Report of the PAGANINI Project

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PAGANINI

GM Food



Participatory

Nature Conservation

Governance and



Nuclear Energy

Institutional



Genetic Testing

Innovation

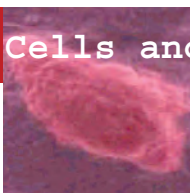
Political Theory

The New Politics

BSE and Food Scares

of Life

Stem Cells and Cloning



The PAGANINI Project/The PAGANINI Team

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The PAGANINI Project

FOCUSSING ON SELECTED KEY AREAS of the 6th European Union (EU) Framework Programme for Research and Technology, PAGANINI investigated the ways in which participatory practices contribute to problem-solving in a number of highly contentious fields of EU governance. PAGANINI looked at a particular dynamic cluster of policy areas concerned with what is called here the “politics of life”: medicine, health, food, energy, and the environment.

“Politics of life” refers to dimensions of life that are only to a limited extent under human control, or else where the public has good reasons to suspect that there are serious limitations to socio-political control and steering. Also, “politics of life” areas are strongly connected to normative, moral and value-based factors, such as a sense of responsibility towards non-human nature, future generations and/or one’s own body. In these areas, traditional mechanisms of governance appear to limit the efficiency and effectiveness of policy making and, as a result, much institutional experimentation has been taking place.

The overall objectives of the PAGANINI project were:

- ▶ 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 contribute to institutional re-design in the emerging European “Politics of Life”.

Starting in 2004, the PAGANINI project was concluded with a conference held in Vienna, on June 11-12, 2007. This booklet provides a summary of the main results and findings of the project.



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Introduction

Institutional Change and Politics of Life

OVER THE PAST DECADE, there has been a clearly visible shift in governance in Europe. Areas of administration and governance that were previously the exclusive domain of technical experts and of meetings behind closed doors are being opened up to public scrutiny and participation. Increasingly, government agencies are arranging for opportunities to interact with lay persons on what appear to be highly technical questions vis-a-vis regulation. Some researchers even see emerging new forms of participation by citizens in governance as a major trend in democratic societies at the beginning of the 21st century.

Legal systems in various countries have long relied on juries of laymen; now, one could argue, a somewhat similar approach is being tested by the legislative branch in the form of participation by citizens in deliberating difficult regulatory issues. This participation has taken many forms: government agencies have experimented with the Internet to make policy information available to a large number of citizens early in the policy process. New ways to consult with the public have been proposed and tested. Citizen conferences have been held in numerous locations and on a variety of topics. Equally important, such events have been widely reported on by specialized journals as well as by the general press.

The motivation behind these experiments with citizen participation has been varied. In some cases highly publicized events (such as the British BSE crisis) have triggered such experiments in participation, while in other instances (such as the threat of global warming) the sheer enormity and scale of future risks or the exorbitant cost of regulation simply defy traditional approaches toward regulation.

What distinguishes these new forms of participation from earlier cases of participation is the often very general, wide-spread, far-reaching, abstract, highly technical, and yet value-laden nature of the issues at stake. Equally, citizens are now highly knowledgeable about the issues at hand at a much earlier stage, are being increasingly informed about uncertainties at play in these issues and, in addition, are invited to form their opinions beyond a simple dichotomy of “compliance” or “rejection” which, in earlier participatory arrangements, were often the only options available.

For example, the consultation with the “public” may not be about whether to build a dam project in a certain location, but about the way how human life is defined; when it

starts; and how it should be protected. Not all areas of regulation have been equally subject to experiments with participation. For example, decisions about the safety of pharmaceutical products are still made mostly by committees of technical experts. But even in as arcane a technical fields as drug regulation and safety, there are increasing efforts to consult with the public, as numerous recent examples—from new vaccine programs to the regulation of biological products in health care—amply illustrate.

The PAGANINI Project: Participation and Institutional Innovation in Politics of Life

Some critics of these new arrangements and of new forms of participation in government have argued that arranged, or staged, forms of participation—such as citizen conferences—are little more than public rituals for display without any real significance to government or democracy. Others are more optimistic and have pointed to experiments in participation as a new means to replace technocratic styles of regulation and governance with more democratic arrangements.

The main goal of the PAGANINI project was to gain an understanding of the sheer variety of new forms of participations that have developed in Politics of Life domains, spanning the conventionally defined, formal participatory arrangements as well as institutionally less articulate new practices of governance. An important underlying hypothesis of the project was that, when approaching policy making from a conventional perspective, many of these new forms of participation easily escape the eye, since they do not always fit the conventional model of participation (*e.g.* participation in the form of referendums or citizen surveys). The PAGANINI project explored both formal and informal manifestations of participation, in order to locate them within wider struggles over legitimacy in a political field disrupted by what is termed here the Politics of Life.

Thus, PAGANINI was not simply a study on the formalized, government-led exercises in participation that have come into being over the past decade. As an interdisciplinary social science research project, the objective in PAGANINI was to observe participation and institutional transformation *in practice* and *in situ*. Most importantly, the project did not start with a working hypothesis or a research focus on any particular form of participation, but rather intended to understand participation as it was actually being carried out in the areas selected for investigation. The goal of the PAGANINI project was to study, through a series of detailed empirical case studies, the reality of participation and changes in contemporary governance. Further, it was also an explicit goal of the project to *study participatory practices in a wider cultural, scientific, and political context* and to investigate how long-term political or cultural changes impact upon participatory practices.

Already in the early phase of the project, it became clear that formal, arranged types of participation are but one case of a rich spectrum of modes of participation, most of which arise spontaneously and often make use of existing institutions in creative and

often surprising ways. It quickly emerged that participation is a highly diverse phenomenon and a reflection of the shift away from a modernist, technocratic style of governance in Europe. Participation, in this view, is about the creation of new political spaces that supplement, and in some cases may even replace, classical forms of participation and/or representation by elections, political representation, or scientific expertise.

“Politics of Life”: A Window to Survey Critical Changes in Democratic Societies in Europe Today

For investigating emerging patterns of participation and institutional transformation in policy making, areas of politics were chosen that relate intimately to our own bodies and thus are close to, and of relevance to all of us (see BOX 1).

Box 1: The PAGANINI Case Studies Covered in this Booklet

- ▶ **DEFINING HUMAN LIFE: HUMAN EMBRYONIC STEM CELL RESEARCH BETWEEN POLITICS AND ETHICS.** In this work package the conflict about human embryonic stem cell research and therapeutic cloning was studied. The focus was on Austria, Germany, the United Kingdom, Italy, at the EU and international level, and against the background of the situation in the United States and Israel.
- ▶ **GOVERNING UNCERTAINTY: ACTIVE CIVIC PARTICIPATION AND NEW FORMS OF GOVERNANCE CONCERNING GENETIC TESTING.** Here the social controversy pertaining to genetic testing and the effects of said controversy on the emergence of new forms of civic participation in Germany, Austria, the UK and at the EU-level was investigated.
- ▶ **BUILDING TRUST THROUGH PUBLIC PARTICIPATION: LEARNING FROM CONFLICTS OVER THE IMPLEMENTATION OF THE HABITATS DIRECTIVE.** This work package focused on the dynamics of the implementation of European conservation policy with a focus on the protection of endangered animal species (Habitats Directive, Article 12), specifically on two model species, the flying squirrel (*Pteromys volans*) in Finland and the loggerhead sea turtle (*Caretta caretta*) in Greece.
- ▶ **LEARNING AFTER THE EVENT: ASSESSING THE INSTITUTIONAL ROLE OF CIVIC PARTICIPATION AFTER FOOD SCANDALS AND FOOD SCARES.** This work package addressed changing patterns in governance with regard to food safety after the outbreak of BSE, the bovine variant of the brain affliction “spongiform encephalopathy” in the Netherlands, Germany, the UK, and at the EU-level.
- ▶ **GM CROPS AND FOOD: THE ROLE OF PARTICIPATION IN A TECHNO-SCIENTIFIC CONTROVERSY.** This work package examined the role played by public participation in the regulation of agricultural biotechnology in Europe, with a focus on GM Food regulation in the UK, Greece, and at the European level.

Within the PAGANINI project, these areas of politics were termed the Politics of Life.

During the last decades of the 20th century, concerns about the environment and nature became an important cause that triggered political reform and the creation of new political constituencies, such as new parties or non-governmental organizations. Further, over the past two decades, many important political controversies in Western democracies have centred around topics that relate to life as such. For example, advances in human biomedical research (in conjunction with the human genome project or new discoveries on the early stages of life) not only have profound and far-reaching practical implications for health care provisioning, but also affect our perceptions of what are considered the most basic human rights or values. The term Politics of Life was used to indicate this shift from concerns over the manipulation of an “external” nature to broader concerns over the manipulation of life in all its forms, human and non-human, and the distinctive challenges this poses for the practice of governance.

Examples of Politics of Life domains include all of the PAGANINI case studies, such as genetic testing, reproductive medicine and stem cell research or issues such as food safety after the BSE outbreak in the United Kingdom.

Politics of Life domains were chosen since, as per the initial hypothesis of the project, they provide *exemplary cases to study present changes in governance and regulation in democratic societies*. The findings of our case studies have largely confirmed this hypothesis as well as the key assumptions of our undertaking, given below:

- ▶ Classical modernist models (such as political representation) as well as technocratic models of governance (expert committees) are often found to be inadequate in Politics of Life domains.
- ▶ The reference to scientific facts alone no longer provides for a robust basis of regulation in Politics of Life domains.
- ▶ In politics of life domains the dichotomy of reason (*logos*) versus emotions (*pathos*) becomes untenable.

Politics of Life

New Frontiers in Governance

SINCE THE 1960s, environment and environmental issues have emerged as crucial issues on the political agenda. In numerous countries in Europe, environmental concerns even led to the formation of new political parties such as the Green Party in Germany. Environmental concerns were a clear response to the perception that increasing destruction of the external environment was occurring through rapid industrialization. It is arguable, at the beginning of the 21st century, that with the vast expansion of the biomedical research enterprise, (human) life itself has turned into an object of manipulation by economic, social, and political forces.

The notion of the “Politics of Life” refers 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 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 have revealed themselves as problematic and, as a result, much institutional experimentation has been taking place. The “new” Politics of Life of the 21st century hence concerns those issues with respect to life—in both its somatic and environmental interpretations and their associated constructions of human identity, self-hood, and individual and collective responsibility—for which modernist forms of governance are no longer viable. In other words, life-political issues in late modernity *tend to expose the built-in tensions and implicit assumptions underlying modern governance* and call into question actual, concrete practices of government in an often acute fashion.

Politics of Life, therefore, in our definition is not simply about the regulation of biomedical research. Rather, in our usage the term includes environmental politics as well as many other areas of politics that relate to the manipulation of material that once lived (such as food regulations). The term was used since the empirical research undertaken within the PAGANINI project indicated that there is indeed a similarity in areas of regulation as distinct as conservation and genetic testing, or stem cell policy and food safety control.

Governing Life: The Limitations of “Modernist” Approaches

Politics of Life questions are not entirely new. By some measure, governments have dealt with Politics of Life domains for over a century. Still, over the past two decades we have witnessed in Europe a powerful series of events that have brought Politics of Life issues to the forefront of regulatory interest. In many of the cases studied within the PAGANINI project, highly visible events—from spectacular scientific discoveries to near-catastrophic events such as the BSE crisis—have been important triggers to put Politics of Life issues on the broader political stage.

One of the most important findings of the PAGANINI project was, that through re-defining participation and through involving citizens in early stages of deliberations on assessing the significance and potential of scientific advances, and by making processes of political judgement and decision making transparent, representative or technocratic approaches of governance can be redesigned into adequate arrangements for dealing with Politics of Life. In other words, Politics of Life domains have become an important locus for *institutional innovation* in governance.

Politics of Life issues are often associated with new scientific knowledge, especially new technologies that interfere with life as such. That revolutionary new scientific findings—and their technological implications—challenge existing approaches to government is not new. Nuclear energy is a case in point. Still, the pervasiveness and extensive implications that some of the new challenges in Politics of Life domains pose with regards to society, the fundamentals of our legal systems, and basic values, may well be a novel quality. Considerations about biomedical research and society are several decades old, yet even the most seasoned experts were struck by the worldwide reception of the announcement of the first cloned mammal (see BOX 2).

Box 2: Dealing with New Realities

Case Study Overview Cloning and Stem Cell Research

An instance of a key event in the field of embryonic stem cell and cloning research was the announcement of the birth of Dolly the sheep in March 1997. The announcement led to intense discussion and soul-searching. It was met with shock and horror in many countries. It also incited regulatory activities, both on the level of the countries under study, as well as on the level of numerous international organizations such as the United Nations, the European Union and the Council of Europe. What rendered things complicated and unruly, however, was that Dolly was not universally damned as a nightmare. The birth of Dolly the sheep also generated a lot of excitement over the potential benefits of the technology that helped to give birth to the globe’s first cloned mammal. Dolly proved that somatic cell nuclear transfer (SCNT) did indeed work, thus demonstrating that an adult cell could be “reprogrammed” and go “back in time”. A somatic cell that fulfills a very specific function could give rise to an embryo and, progressively, to a foetus. Some scientists and policy-makers argued that while this technology should not be used for human reproductive purposes, the technol-

ogy as such should have nevertheless its place in the range of permissible practices. SCNT, so the argument went, could be used to generate cell lines that are perfectly compatible with patients. The combination of human embryonic stem (hES) cells and cloning technology gave shape to a whole set of new medical-therapeutic expectations that promised to offer unprecedented possibilities for dealing with serious ailments and diseases for many of which there existed no alternative treatments. However, while some framed these prospects as unprecedented opportunities, others regarded them as the crossing of “fundamental moral boundaries” and as the beginning of a public-health nightmare.

It was also observed that patterns of controversy and political participation change as new technologies become more broadly available throughout society. This is hardly surprising, since the diffusion rate of a new technology is, in itself, an important measure for the social acceptance of a new technology. As a new technology becomes pervasive, patterns of debate and participation shift. To start with, debates turn more technical in content as the participants in the debates become more informed and knowledgeable. Similarly, policy processes adapt as well and acquire a more long-term orientation. This is what has happened in the case of genetic testing, where controversies have shifted from at times violent struggles over principles—and the fate of the entire field of genetic testing—towards more targeted debates on specific issues or risks associated with certain techniques or approaches (see BOX 3).

Box 3: Integrating New Technologies into the Fabric of Society Case Study Overview Genetic Testing

Contrary to the cloning debate, the issue area of genetic testing has rather been characterized by a de-escalation of public controversy and public unrest within the past two decades. Still, there are important differences between different fields of controversy concerning genetic testing. Pre-natal diagnosis (PND) has become a widely accepted practice in antenatal care in the countries under study and has ceased being a controversy demanding prohibition. Even many critics of PND and selective abortions choose to not challenge the regulatory frame of PND, mainly because this would in all likelihood entail a re-opening of the abortion controversy, which they do not want. While matters of concern remain, including the issue of late term abortions or the question of which kind of counselling should be provided, these issues do not really stir public unrest or public debate. The situation is somewhat different concerning pre-implantation genetic diagnosis (PGD). In contrast to PND which is mainly governed by professional self-regulation, the question on how to properly regulate PGD has given rise to public debate. This debate was most intensive and controversial in Germany, but to some extent also took place in Austria and the UK. The intensity of this public debate has nothing to do with the availability of PGD which is still a relatively rare practice. On the contrary, there is an inverse relation between the availability of a practice and the intensity of debate about it; the more common a practice gets, the less controversial public debate there is. Rather, PGD, as an interview partner put it, “pushes some very sensitive buttons

of some individuals, on both sides”, evoking anxieties about “designer babies”, the status of the embryo, and the health of future children. The PGD debates were especially intense during the millennium change and accompanied by the establishment of new advisory bodies or new bioethics councils. In recent years, however, the public debate about PGD has calmed down as well.

In many cases, Politics of Life domains not only pose new questions but have such a profound impact on the regulatory scene that the result is a reorganization of government—or a complete re-writing of major laws or regulations. In all case studies a significant impact of public debates on policies or institutional arrangements could be observed, even if the end-results were quite varied among policy domains and countries. In some cases—such as food safety after BSE—the result was a complete reworking of regulatory approaches across several domains and the creation of a whole new government agency (see BOX 4); in other cases they were much more modest.

Box 4: When Regulatory Institutions Turn Inadequate Case Study Overview BSE

It was not so much the first clinical signs of BSE in cows in the UK in 1986 that came to upset standing practices of risk control, but the concern that the disease might afflict humans. In 1995, public concern proved justified when three young people died from what was apparently a new human variant of the brain inflection Creutzfeldt-Jacob Disease (nvCJD). Public turmoil in Britain arose when on March 20th 1996, UK Health Secretary Dorrel publicly announced the likelihood of a link between the cattle disease and the newly found variant of the human equivalent. These developments had a strong impact in various policy fields, among them trade and internal relations within the EU. The same year, the EU imposed a ban on the export of British beef, forcing Germany to replace the unilateral ban it had set in place as a first reaction to the British veterinary problems. The assertion that BSE was a zoönosis, that is, an animal disease that may affect humans, strongly disrupted the institutional organisation of both policy areas affected: agriculture on the one hand, and public health on the other. Both fields had been organised largely in relative isolation from one another. The historical institutional design was characteristically divided into a series of arrangements set up to deal with agricultural production and veterinary care on the one hand, and a set of arrangements for dealing with human health on the other. This separation was among the reasons that the human risks involved in BSE went unnoticed for a long time. The landslide that BSE set in motion once it was identified as a zoönosis included more than mere organisational rearrangements. BSE cut through the classificatory schemes that modernist institutions use to routinely separate the realm of the animal from that of the human. BSE presented a clear and unavoidable incentive to re-consider the boundaries between the two spheres. As a result, the institutional arrangements for governing the public consequences of food production and consumption themselves became the object of political conflict, which culminated particularly in a re-designing of food safety regulatory settings. In particular the newly designed arrangements in the UK, where food safety has been made the responsibility

of an independent governmental body (the Food Standards Agency), offers an interesting and promising example of how administrators, scientists and citizens jointly can be engaged in risk assessment and risk management in a meaningful way.”

Because of their broad nature and broad impact, Politics of Life issues can also lead to an immense and unprecedented loss of trust in public institutions and established practices in regulation and government. Starkly contrasting policy objectives—precaution versus economic growth and support for new industries—can contribute significantly to this loss of trust. This is what appears to have happened in the case of GM food in Europe (Box 5). This loss of trust, in turn, is what has led agencies to experiment with new strategies of participation and new ways to re-gain trust, with rather mixed success.

Box 5: Trust through Participation

Case Study Overview Genetically Modified Crops and Food

When in 1996 the first GM crops came to the European market, they soon became the centre of contention. This contention was considerably fuelled through the announcement by the UK government in March 1996 that a probable link had been established between the human brain disease vCJD (variant Creutzfeldt-Jakob Disease) and BSE, after years of assurances by government scientific advisers, politicians and the industry that “British beef is safe to eat”. Following this admission in 1996, public trust in the regulatory and scientific advice system along with the food and agriculture industries plummeted. The years 1996—1999 became a period of serious crisis for the existing European regulatory regime which had been established by the Deliberate Release Directive (DRD, 1990/220). By the end of 1998, the crisis of legitimacy for those trying to promote GM agri-food in Europe had become critical. An institutional void around the governance of GM crops had become visible to all. The 1990/220 DRD had attempted to govern the release of GM crops as a separate and distinct category. However, it had provided no machinery for post-market regulation, assuming that its responsibility ended once the new varieties were released into the fields or supermarkets. Yet now retailers found themselves on the frontline of a new cultural and political battle that threatened their sensitive and elaborate system of negotiations with consumer consciousness, based upon trading with symbols of naturalness, purity and health. Within this meltdown of public trust proliferated a growing series of improvised measures, ranging from national bans by EU member states to boycotts by powerful supermarket chains. Activists arrested for sabotaging GM test fields would escape punishment, with the courts’ refusal to convict them demonstrating the wider lack of cultural legitimacy of the GM project. This political, cultural, epistemic and regulatory logjam intensified in the following years. In October 1998, Greece invoked Art. 16 of Directive 1990/220 in order to ban previously authorized GMO from its territories. In June 1999 five EU member states—Denmark, France, Greece, Italy and Luxembourg—successfully proposed a de-facto moratorium on any new Part C consents to the European Environment Council. The motion at Council said that, given concerns about risk, the specificity of

European ecosystems, and the need to restore the confidence of public opinion and the market, the Commission should suspend new authorisations until it had strengthened and widened its risk assessment procedures and put in place a system allowing the complete traceability of GMOs and products derived from them. Thus the last two GM crops given Part C Consents in 1998—AgroEvo/Aventis/Bayer's HR Maize (T25, import only), and Monsanto's bt resistant maize (MON 810, import and cultivation)—were to be the last under the old directive 90/220. In addition the countries of Austria, Belgium, Finland, Germany, Netherlands, Spain and Sweden stated they would take a "thoroughly precautionary approach" in dealing with marketing applications, urging the Commission to make proposals for the traceability and labelling regulations as soon as possible. Hence, what we see in the case of the GMO conflict is less the dislocatory power of a certain identifiable event, or a series of events, but an institutional void created by the clash of two contradictory imperatives built into the European Union's original GMO regulatory framework of the 1990 DRD: On the one hand there was an imperative to foster a climate of innovation and economic growth, on the other hand there was an imperative to address the precautionary concerns around the potential impact of these innovations on health and the environment. Thus, while being committed to the free movement of GMOs within European space, the DRD created a special regulatory category of the GMO, with each variety needing to go through a process of approval before gaining admission within EU territory.

Finally, very nature of Politics of Life issues often creates conflicts and a need for adjustment at a multitude of levels, which opens up numerous opportunities for participation. Conservation policy is a case in point (BOX 6). Even modest successes in conservation only become possible through extensive and far-reaching coordination among many players and contrasting policy objectives at various levels, from local to international, creating numerous opportunities for participation.

Box 6: Exercises in Coordination **Case Study Overview Conservation Policy**

Two model endangered species were investigated, the flying squirrel (*Pteromys volans*) in Finland and the loggerhead turtle (*Caretta caretta*) in Greece. The aim of conservation management according to the EU Habitats Directive is to integrate the strict protection of the species with the ongoing activities of forestry and tourist services. The conflict between these imperatives in both countries increased in the late 1990s. In the latter case, although failure of implementation tied to the local economy had been visible since the late seventies, conflicts over the implementation of presidential decrees and land use restrictions intensified due to conservationist pressures to protect the sandy nesting beaches on Zakynthos which attracted both tourists and loggerhead turtles. Matters became worse in 1985, when the conservationists and the relevant NGOs suddenly appeared on the island, attempting to impose measures and restrictions without discussing them with the local people and explaining their motives. In addition to the problem of competing imperatives, conservation policy is characterized by

a conflict between multilevel governance and local implementation. One could speak of an “implementation ambiguity” here. What makes a successful conservation policy difficult, among other things, is that the deterioration of biodiversity is caused by various activities in sectors of production, transport and energy that deal with land use management – that is, basically, all sectors. This is also implied by the ambitious coverage of the EC Biodiversity Strategy. The EU Commission however lacks competence in the field of land management, which has caused a gap between capability and expectation. The conservation policy of the EU is affected by the following heavy historical burden: originally, the member states were reluctant to give the Commission competence in matters that extend to land use management which, on the other hand, is a necessary condition of any conservation policy worth the name. It was the international normative pressure which broke this dead-lock. The member states, on the other hand, are poorly equipped to respond adequately to the tasks defined by the Habitats Directive. The point is, however, that conservation policy has to be context-specific in detail; it cannot be successfully implemented without taking local circumstances into account. In the case of the Habitats Directive, in order to successfully implement the law which has been adopted on the European level, interactions between three different levels are required—the local, regional, and EU level.

Common Issues in Politics of Life Domains

Based on the observations from the PAGANINI case studies, a number of important characteristics of Politics of Life domains were identified, and the basic assumptions for the empirical research were refined. The following chapters will discuss these basic propositions in more detail.

- ▶ To start with, existing institutional arrangements of political participation and representation (what we have, somewhat simplistically, termed the “classical modernist model”) are often found to be inadequate or, at least, in need of significant re-adjustment when confronted with Politics of Life domains. Such re-adjustments typically happen only as part of a reaction to a profound crisis, and often lead to important institutional innovations, as is illustrated by the creation of the Food Standards Agency (FSA) as a new, more open type of regulatory agency in the United Kingdom.
- ▶ Further, in many Politics of Life domains, the calculation of risks and benefits becomes protracted and often even impossible. The link between BSE and variant Creutzfeld-Jakob disease (vCJD) is a case in point. Despite a Nobel prize for the proponent of the prion hypothesis, the true long-term risk of vCJD caused by the consumption of BSE-infected food products remains a matter of speculation. Only a few years ago, risk estimates ranged from tens of cases to hundreds of thousands of cases. In other words, uncertainty can no more be reduced to calculable risk, but rather government agencies need to find novel ways to deal with uncertainty in a

responsible way.

- ▶ Participation in Politics of Life domains is both crucial and pervasive and takes place through many mechanisms. There is rarely one dominant form of participation, but rather participation via many different forms, from “arranged” participation in the form of public deliberations on a given topic by concerned citizens or the inclusion of citizens in expert or advisory committees, to spontaneous and informal political participation that can even take on the form of a public “happening.”
- ▶ Scientific research, still often deemed an impartial input into political deliberations, becomes an important locus for participation through what could be termed “participatory knowledge production”. What this somewhat ill-conceived term expresses is that scientific research as a process can turn by itself into a mechanism of political participation by interested citizens. This form of participation can have immensely powerful effects, both on the kind of research that is performed and on the political significance of the research that is performed. Examples include the increasing inclusion of consumer representatives in expert committees or the empowering role of patient organizations in medical research. No cases were found where participatory knowledge production had a *negative* impact on the validity of research findings.
- ▶ Finally, arguments about values, ethics, and ethical behaviour—as opposed to economic or political interests or disinterested, scientific facts —have today become a crucial component of policy deliberations in Politics of Life domains. While this fact is widely known, its effects remain poorly understood. This inclusion of ethos and pathos is the reflection of the reduced credibility of classical modernist institutions in Politics of Life domains. Discourses about ethics have replaced both more principled ways to argue inspired by religious doctrine and the idea of science as an impartial form of knowledge.

Governing Uncertainty

From Risk to Uncertainty

UNCERTAINTY HAS MANY DIFFERENT FACES, some of which manifest in each of our case studies. What do we mean by uncertainty? Uncertainty is best defined in relation and contrast to “risk”. The concept of risk implies that one has instruments and criteria to diagnose, measure, and calculate the possibility of harm or peril of a specific action or event, and then balance this against its potential “benefits” and eventually make an informed decision on the basis of such calculations. Framing events as risks does certainly present a challenge to governance. Yet it also provides possibilities to politically and technically deal with them, for instance in terms of a procedure or an accepted institutional framework for making matters governable.

Calculations of costs and benefits—whether implicit or explicit—continue to form the basis of many existing regulations. As critics have pointed out, in a real-world political setting, the analysis of costs and benefits is never perfect, and influenced by numerous factors. No legislator would push for a new regulation if he or she cannot explain its benefits to his or her constituents. A formal incorporation of cost benefit analysis as an economic technique in a regulatory framework is rare enough; implicitly, however, there is always a perception of risks and benefits present.

Also, since any cost-benefit analysis involves *per definition* a valuation, and since in practice information about costs and benefits is never perfect, an assessment of risks and benefits is always an approximation. Our case studies indicate that traditional models for cost-benefit analysis often simply break down or turn out as grossly inadequate in Politics of Life areas. What is more, these models are often linked to institutions or particular regulatory frameworks that are equally found to be inadequate.

In many of the PAGANINI case studies there were no instruments or criteria available to calculate risks and, thereby, make issues governable, either because such instruments were altogether missing or because they were themselves politically contested. This typically happens when there is a lack of agreed-upon (scientific) knowledge as regards the prospects, implications, and effects of a new technology or of a regulatory initiative. And even in case such scientific evidence is available, there often exist no fixed and uncontested criteria how to measure, calculate or evaluate implications and effects. If that happens, the “rules of the game” are put up for discussion, along with the very issues that the game is about.

There are various reasons why risks become difficult to calculate. In the case studies, several instances of uncertainty were identified:

- ▶ Scientific uncertainty: when regulatory or political questions can no longer be answered in a practical fashion through research.
- ▶ Uncertainty about the very objects of regulation: when the objects of regulation are themselves unstable.
- ▶ Uncertainty about the impact or application potential or benefits of a new technology or uncertainty that is caused by the diffusion of a new technology.
- ▶ Political and organizational uncertainty: when the political or organizational context of regulation is so complex that no clear expectation about the future is possible any longer.

In what follows, the above instances of uncertainty will be discussed further with reference to the PAGANINI case studies.

Scientific Uncertainty

In the classic “trans-science” situation that Alvin Weinberger described several decades ago, either the investments needed to produce scientific insights to respond to a given regulatory question with some certainty are too high, or the results cannot be produced in time, or else, such knowledge is simply not available. The reaction by the British government to the issue of BSE is a case in point: while the questions were well known, and regulatory frameworks were well established, a lack of scientific evidence was used as an excuse to postpone any regulatory action (BOX 7).

Box 7: Scientific Uncertainty and Political Inaction Case Study BSE and vCJD

Looking at the issue area of BSE, it appears that it was in particular the focus on scientific certainty as a requirement and rationale for governmental action that kept the British government from acting swiftly in the face of potential risks to human health. When officials of the Ministry of Agriculture in the UK in later 1986 were first informed about a new disease among cows and the albeit vague and seemingly unlikely possibility that this disease might affect humans, they did not share this information and concern with the Department of Health (DoH). A lack of scientific evidence kept them from doing so. In a related yet slightly different reading of the events, respondents indicate that the lack of scientific certainty functioned as an excuse for policy-makers not to act: “And I remember so well, when the whole issue of BSE began [here in the UK] (...) they always used to say there is no scientific evidence that this disease can pass to humans, our scientists (...) And that was their protection they thought that if there was

no scientific evidence, then they could afford to ignore it". In December 1984, a British farmer contacted a vet as he worried over one of his cows. The problem seemed to spread to other cows, and there was no response to treatment. After losing 9 of his cows, the farmer sent the 10th victim to a local ministerial laboratory, from which the cow's head was sent to the Central Veterinary Laboratory (CVL) in Weybridge. The pathologist on duty that day was "excited" to find indications of spongiform encephalopathy in the material under her microscope (tiny holes in stained sections of the brain). The supervising senior pathologist who later had a look at the material in contrast did not make a connection with scrapie, and he put the observed anomalies down as resulting from "toxic poisoning".

Uncertainty about the Objects of Regulation

Especially in biomedical research, uncertainty about the future of a new technology is sometimes linked to yet another form of uncertainty and instability that is well exemplified in many of the PAGANINI case studies: uncertainty about the very objects of regulation.

If we talk about stem cells, or prions, what are we really talking about? How is this object defined? Is it defined in a fashion that can withstand legal and political scrutiny? Is the definition stable? Often in biomedical regulation, the definition of the objects of regulation is *unstable* and regulators need to find ways to deal with these constantly shifting objects (BOX 8).

Box 8: Uncertain Objects: What is a Stem Cell? Case Study Stem Cells Research

What is a stem cell? Remarkably, this question cannot be answered easily. Stem cells cannot be reliably morphologically identified; neither do scientists agree on a set of molecular biomarkers that signal the presence of a stem cell. Even the most powerful microscope cannot help to set stem cells apart from other types of cells, and scientists neither know, let alone agree, on the expression of what set of genes marks a cell's "stemness". In the absence of other agreed-upon criteria, scientists rely on functional definitions of stem cells, that is, they define stem cells through what they are doing and producing. Bio-functionally speaking, then, a stem cell is a cell that is not yet differentiated and that has the potential to undergo divisions to form other, more specialized cells that will perform specific functions in human bodies. Hence, stem cells are less specific and less differentiated than other cells. Secondly, stem cells divide in a way that sets them apart from other cells within our bodies. Rather than symmetrically, they divide asymmetrically, giving rise to both a more specialized progeny cell and to an identical stem cell at the same time. Stem cells have hence the capacity to self-renew for an indefinite period of times.

In the case of human embryonic stem cell and cloning research, it is found that actors

struggle with a lack of uncontested “facts” about the future prospects of this field of research. There are hopes and expectations and some progress has been made concerning the establishment and maintenance of embryonic stem (ES) cell lines.

But the field is still very much in the state of an early “science in the making” that is characterized by struggles over the meaning of shared and agreed-upon terms and concepts. The proliferation of uncertainty and scientific controversies that characterizes human embryonic stem cell and cloning research, however, is not unique to this field of research, but indeed a characteristic of any newly-emerging field of research. What nevertheless renders the uncertainty surrounding stem cell research special is that the struggle for “stem cell facts” remains burdened by political struggles over the meaning of “life” in the 21st century. Scientific controversies are translated into political conflicts and *vice versa* political conflicts are being recast as scientific ones.

Uncertainty Associated with the Diffusion of a New Technology

Scientific uncertainty can also take on another, slightly different form. In the case of new biomedical technologies, from genetic testing to stem cells, what is often unknown is the technical application potential and thus the potential real-world impact of a new finding. Especially in the biomedical area, the time lag between a novel finding and its application is significant. There are few new insights that make it into the clinic in less than a decade.

Since regulation in the biomedical field has already reached the research laboratory—in the past a location that regulators rarely considered—the uncertainty associated with the potential future impact of a new technology is significant not only for entrepreneurs, but also for regulators. Should certain research techniques in stem cell biology be controlled, or banned, even if they may eventually lead to revolutionary new therapies?

And, once put in practice, novel techniques may come with their own uncertainties that cannot be easily resolved, as the case of genetic testing illustrates. Genetic testing is also a case in point of demonstrating that an increase of knowledge does not *per se* imply a reduction of uncertainty. But, very rarely do genetic test results provide positive knowledge about one’s future health status. Only in the case of so-called monogenetic diseases such as Huntington’s disease will the test provide a 100% certainty that the person will develop the disease at some point in life. Monogenetic diseases, however, are rare. The vast majority of conditions with a genetic component are so-called multifactorial diseases or disorders, meaning that they are related to different types of factors such as epigenetic factors, genetic factors and the social environment and life style of a person.

This type of genetic testing on genetic risk factors is the result of the expansion of human genetics research to cover nearly all common diseases in industrialised countries, including notably heart disease, diabetes, Alzheimer, and cancer.

Box 9: Uncertainty Associated with a New Technology **Case Study Breast Cancer Diagnostics**

One of the genetic tests that has gained most public attention in recent years is a test for familial breast cancer available since the mid-1990s. Tests on alterations in the BRCA 1 and 2 genes, known as the familial breast cancer genes, are linked to numerous uncertainties. First, they are only relevant to specific types of breast cancer, which make up less than 10 percent of all breast cancer 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 smaller 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. Consequences that might be drawn from a “positive” test result range from preventive health care and regular physical examinations to breast amputation.

Organizational Complexity and Political Uncertainty

In yet another pattern encountered in the PAGANINI case studies, the technical or scientific complexity of a given question prevents a simple answer. This appears to have been the case with the European Habitats Directive. Interestingly, such situations appear to often go hand in hand with yet another form of uncertainty. This uncertainty is political in nature and often occurs in a regulatory context where there is no one agency involved, but many agencies at different levels—from regional to international—and where there is a large gap between the interests of the various groups involved in a political process.

Over the past few years, environmental conservation in Europe has shifted from a focus on single species in a given territory toward a much more comprehensive approach. As the following case study illustrates, this has also increased the amount of uncertainty, both political and scientific, that agencies face. Efforts to reduce this uncertainty through additional investments in scientific research have only been partially successful (Box 10).

Box 10: Dealing with Organizational and Political Uncertainty **Case Study Nature Conservations**

The conflict on the implementation of the European Union’s Habitats Directive in the case of the flying squirrel in Finland and the loggerhead sea turtle in Greece cannot be properly understood without the background of an increasing cultural awareness of uncertainty. The character of nature conservation has undergone a profound change from *target-specific* to *comprehensive* conservation. Increasing awareness that human modification of nature on the global scale brings about an increasing threat of an extinction avalanche is the main driver behind this shift. Traditionally, the goals of nature conservation were either specified protected species or areas set aside from all productive activities as

nature reserves. Species and areas remain focal points in conservation, but the shift to comprehensive conservation means that conservation needs are framed in a new way: on the one hand, what is protected and why is defined through systematic, comprehensive assessment and classification, for instance through Red Data Lists of endangered species, and on the other hand, the ecological context of protected species and areas is emphasized. The latter aspect is quite natural: the viability of species populations depends on the continuous suitability of the ecological context in which they live, and protected areas are greatly influenced by what happens in their surroundings. Both “sustainable development” and “biodiversity preservation” have arisen as normative ideals and a response to this awareness of uncertainty in the context of this shift towards comprehensive conservation. In the 1980s, “biodiversity” was conceived as an umbrella term that gives a comprehensive description of contemporary conservation concerns. This shift towards comprehensive conservation, while a response to the growing awareness of uncertainty on the one hand, brings about a new series of uncertainties itself which pose new, unexpected governance challenges for public administrations on all levels of government. Conservation management is torn between the two conflicting imperatives: On one hand, the strict protection of the endangered species; the ongoing activities of forestry and tourist services on the other. In addition, comprehensive protection relies on a considerable amount of knowledge about complex and ever-changing circumstances, such as the size of the existing populations of the species and recent population trends of that species. The situation is further complicated when the potential impact of conservation measures on the livelihood of local people is taken into account, or when the potential impact of prospective construction projects is to be assessed. In short; the more complex, dynamic and future-oriented conservation policy becomes, the more it depends on knowledge which, however, will never be able to produce scientific certainties about each and every possible development. The shift from the comparatively one-dimensional target-related approach to the more complex comprehensive approach in conservation practices is intrinsically linked to the need for new and more participatory forms of knowledge production, the “ethicization” of conservation policies, and issues of trust.

Governance Despite Uncertainty

The absence of common criteria to calculate future risks and benefits does not, of course, dismiss the need for political action in the present. On the contrary, Politics of Life areas seem to be characterized by a strongly perceived need for political action, and often for urgent action. Governance cannot be postponed to the day when science will have provided sufficient, reliable and uncontested evidence and a consensus on normative criteria for appropriate action will have evolved in society. This pressure for action is linked to and partly caused by another salient feature of Politics of Life areas. In Politics of Life areas, the very objects of governance have “a life of their own”: they are constantly evolving, altering, increasing or decreasing, and manifesting themselves differently over time. Phenomena of life are inherently *dynamic*, which makes them particularly unruly and unpredictable and poses specific challenges to governance, not least the challenge

to govern the future manifestations and implications of these objects, as to yet unknown and never completely predictable. Governance, in the Politics of Life area, largely means governing despite uncertainty, as the future is unforeseeable and unpredictable and rather consists of an endless multiplicity of possible futures. The envisioning—or not—of such futures in this context has political implications and thus is a political act in itself.

Box 11: Governance Despite Persisting Scientific Uncertainty Case Study BSE and Food Scares

In the UK, where the concern over BSE was strongly cast in terms of a distrust in the state's capacity to handle the potential risks, much more so than in Germany or the Netherlands, there was a perceived need to act in view of public health in spite of a lack of scientific evidence. Yet how to act could not be based on scientific knowledge because scientific analyses of the situation were themselves contested. Existing control measures to guarantee food safety were designed to detect and fight bacteria and viruses. The problem with BSE was that these measures would not work in the case of prions. New "rules of the game" in food safety regulation in general and about how to deal with the risks associated with prion-infected animals and their carcasses in particular had to be created *simultaneously* with the development of scientific insight into what was happening.

The GMO case (see Box 12) somewhat resembles the situation with BSE (Box 11) in the sense that the key regulatory issues could not be reduced to technical questions, or answered in some form through scientific research.

Box 12: Negotiating Uncertainty and Risk Case Study GM Crops and Food

Similarly, scientific uncertainty concerning the potential health effects and environmental effects of genetically modified plants and their products by the EU regulatory framework implied the need to step beyond given regulatory instruments. The controversy on GM-food that exploded in the EU and many member states in the late 1990s was largely a controversy about the question whether GM-food should adequately be framed as a matter of *risk* to the environment or the health of consumers, or whether GM plants and their products were a matter of *uncertainty* in that their potential effects remained so complex that nobody would be able to foresee, calculate, or contain them. Before the first GM crops and foods arrived into global markets and ecosystems in the mid 1990s, the European Union had already established its regulatory framework around the Deliberate Release Directive (DRD, 1990/220). This regulatory framework was based upon expert scientific advice about possible harm to health or the environment and required each member state to establish a "competent authority" (CA) which would handle such decisions. The EU to some extent recognized the condition of uncertainty concerning GM-food when, in the DRD 1990, it explicitly acknowledged the unique nature of GMO's and their potential risks: "[L]iving organisms, whether released into the environment in large or small amounts for experimental purposes or as commercial products, may

reproduce in the environment and cross national frontiers thereby affecting other member states; [and] the effects of such releases on the environment may be irreversible." The EU adopted a regulatory framework that was inherently more precautionary than that adopted by the US. Unlike the US, the EU considered the novelty of the genetic modification process to still contain important areas of scientific uncertainty and potential risk, with GMOs being a special category that required its own unique regulatory framework. This led the EU to base its GMO regulatory system upon the *process* behind the products while the US approach was based upon the simple regulation of the end *products* alone. Thus, the EU regulatory framework can be viewed as a *hybrid* offspring of a technocratic risk culture on the one hand, assuming that regulations and new authorities (the CAs), based on scientific expert advice being able to control the risks implied in this technology, and a culture of uncertainty on the other, recognizing the unprecedented novelty of the technology and the potential irreversibility of its consequences. This hybrid regulatory approach produced a series of hybrid governance responses to the political controversy on GM-food.

How have governments and agencies dealt with uncertainty that can no longer be reduced to calculable risk? The PAGANINI case studies provide a number of answers. In pragmatic terms, the initial response to a regulatory issue that defies a simple calculation of risk includes a broad array of measures, sometimes deployed simultaneously, and which range from increased funding for new scientific studies to the creation of an entire new regulatory framework. But, most importantly, when faced with uncertainty, *other* means to legitimacy become prominent. The PAGANINI case studies point to three strategies that appear to be increasingly important and which will be discussed in the following chapters:

- ▶ Public participation by various actors in the polity process through formal or informal means.
- ▶ The repositioning of scientific research as a means to *enable participation*, rather than closed, technocratic discourses.
- ▶ Finally, the rise to prominence of entirely different registers, notably discourses about ethics and even sentiments.

Participation

Reworking Contemporary Governance

IN THE FACE OF UNCERTAINTY, and often crisis, public participation has increasingly become a preferred strategy by policy makers wanting to build public support for a new policy or regulatory measure. In fact, the term “public participation” over the past few years has come to signify just such planned types of consultation with the public. This was also the notion embraced by the PAGANINI project at the outset. The project started from the hypothesis that “in the domain of life-political issues, the notions of participation and governance seem to have become intermingled to an unusual extent”; in other words, participation was largely defined as state-driven.

The evidence from the empirical research undertaken within the PAGANINI project tells a very different story. While evidence has been found for formalized, planned, state-driven participation in most of the case studies under question, empirical data suggest that such exercises in participation, often highly visible and well-delineated, constitute only a small fraction of the various activities that can count as participation. In the light of these findings, the very notion of participation needs to be rethought. In order to re-appreciate the resilience and vitality of democracy an understanding of “participation” and “public involvement” should not be limited to state-driven initiatives.

Participation and Pluralist Governance

The case studies within the PAGANINI project point essentially to four patterns of participation:

- ▶ Informal participation in its various forms, relying on conventional means such as mass media, PR, political lobbying, and even non-conventional forms of participation, sometimes at or beyond the border of what is strictly legal (as in the case of crop thrashing at the height of the GMO debate in various European countries). This is the most common form of participation.
- ▶ State-driven and planned exercises in participation and public involvement. These include, among others, consensus conferences and various other schemes that provide for opportunities by citizens to voice their opinions.

- ▶ Innovative forms of participation that centre around increased accountability and transparency of processes of political judgement. In contrast to the above forms of participation, here citizens are not, or not initially, actively taking part in the deliberations (and thus given a “voice”). Rather, through such schemes citizens are enabled to better monitor and thus evaluate what others discuss and decide on their behalf (and are thus provided with “eyes”). This democratisation of administrative and political oversight (as, for instance, through the web-casts of the FSA board meetings) enables “bystanders” to turn into veritable “citizens” and, eventually, to become involved and participate, if they choose to do so.
- ▶ Participation through the creation of new political spaces—here, participants creatively use existing organizations or institutions as forums for political participation, as in the case of the Farm Scale Evaluations or Seed List Hearings in the debate on GM crops and food in Great Britain.

Some of the most surprising and most forceful articulations of the will to participate in and contribute to a given policy issue were observed in this last category. Examples of this last type of participation are given below (BOX 14). Several case studies also pointed to an interesting, and very effective version of this third category of participatory governance that will be discussed in the next chapter: participation in the area of scientific advice and expertise.

These three patterns of participation also relate to distinct “publics” or, at least, visions of the “public”: state-driven initiatives are often oriented towards “pure” or “affected publics”, while spontaneous participation is often related to “engaged” or “concerned publics”.

The empirical cases investigated within the PAGANINI project suggest that government actors appear to prefer “pure publics” or “affected publics” to “engaged publics”. Considerable scepticism was found towards “engaged publics”, and this is especially true for some policy areas (such as GM crops and food regulation). The position of a representative of a political group, an NGO, or an interest group, in short of somebody taking a “partisan” position, was frequently depicted in a rather negative fashion, for example as a “minority of highly vociferous groups”, as a “small set of people”, or as a “self-selecting sample”.

Yet “publics” are always actively assembled. There is a heterogeneous set of technologies used to aggregate different “publics”: “abstract publics” (constructed via opinion polls), “pure publics”, that are formerly “ignorant” but then “informed” and “educated publics” (constructed, for example, via citizen juries), “expert publics” (a way “stakeholders” are often categorised), and “concerned publics”. These different participatory technologies are linked to a changing landscape of political subjects considered relevant for the debate.

There also appear to be increasing limitations, in some Politics of Life areas, on what is considered a “concerned public”—the definition being reduced to people with personal experiences of problematic “genetic conditions”, but excluding “concerned publics”

rooted in social movements such as the feminist or disability movements. By contrast, recent organizational reforms that have led to an increase in transparency in the area of food safety control are genuinely innovative when it comes to “participation”. Rather than acting as a gate-keeper granting or withholding pre-defined publics access to the political arena, here the state allows individuals to themselves choose their moment, and subject area, for becoming politically active.

Informal and Spontaneous Participation

Judging from the case studies undertaken within the PAGANINI project, informal and spontaneous participation is pervasive in Politics of Life domains. Informal and spontaneous participation can take many forms—from grassroots politics to quasi-illegal activism. By and large, the case studies in the PAGANINI project suggest that informal participation in its “conventional” form often employs means that are fairly conventional—such as lobbying, the mass media, or advertisement campaigns. At the same time, it was also found that concerned citizens have cleverly used public spaces that were not initially designed for public participation—ranging from village halls to supermarkets—to cater for attention to their cause.

What these forms of participation have in common is they are not state-initiated but rather emerge from within civil society. Participants in these informal exercises in participation have not been “invited” by government institutions nor have they been selected by any organizers; to the contrary, actors are self-selected here or “self-appointed” and as such usually have entered the debate from a “partisan” point of view, promoting their respective views. Consequently, participation or public involvement often takes place at unexpectedly politicized sites, is civil society-led rather than state-led, tends to be of an antagonistic nature, and is characterized by adversarial arguments and struggles. We can term the types of publics emerging at such sites “engaged publics” or “issue publics”. These “publics” are not stable and may evolve over time, as the case of genetic testing illustrates.

Box 13: Participation Over Time: Two Decades of Genetic Testing Case Study Genetic Testing

In this case study, the height of public unrest and public controversy was in the 1980s when the possible future implications of human genetics became a subject of heated political debates ignited by social movements. These movements evoked apocalyptic scenarios (“brave new world”, “total surveillance state”, “production of human beings” etc.) often based on deterministic ideas about the implications of technological change for society. In Germany a broad range of feminist groups and organisations of disabled people articulated criticism towards reproductive technologies and genetic engineering. The main frame applied by feminist groups could be termed an “oppression frame”, portraying women as victims of increasing “medicalisation” and alienation by (male) medi-

cal experts and scientists who wanted to get access to and control over procreation and the uterus, human eggs and embryos. Anti-eugenic and anti-capitalist positions also developed in this context, pushed forward by the radical movement of disabled people, who called themselves the “movement of cripples”. They saw genetic testing, PND and selective abortion as a modern form of eugenics and an instrument to enhance the “quality” of the future labour force or of the national population. Militant activists like the feminist guerrilla group Rote Zora invaded laboratories in Germany and published research papers which they had seized in their assaults. In the UK, pro-life movements connected their protest against the new technologies with their moral objections against abortion. All in all, in comparison to the mid and late 1980s, the years after the millennium change are rather characterized by a non-antagonistic constellation. By “non-antagonistic constellation” it is meant a situation not characterized by the confrontation of two opposing “camps”, one opposed to and the other in favour of genetic technology, each striving at defeating the respective other “camp”. To be sure, a lot of unease about “designer babies” or “a new form of eugenics” still exists, but it is a rather subliminal. Techno-sceptic arguments are circulating within a post-euphoric and post-apocalyptic debate that is much more fragmented, sophisticated, professionalized, and normalised; it is a debate whose focus has shifted from fundamental “yes or no” questions to more pragmatic questions such as how to properly organize counselling. Interestingly, in this case study the absence of fierce antagonist conflict is paired with a “discourse intensification” and a number of participatory governance arrangements and experiments such as consultation processes, consensus conferences, or youth conferences.

Then again, one can distinguish a form of civic interaction where the supposed separation of “science” and “politics”, “matters of fact” and “matters of concern” (B. Latour) has been undermined. For example, National Seed List hearings in the UK had unexpectedly turned into forums for informal participation. These hearings had originally not been designed to make political statements or political decisions but to gather “facts”, but unexpectedly turned into newly politicised spaces where the debate about “facts” mingled with political arguments. These hearings formed newly politicised spaces, but they were not the only ones. The Farm Scale Evaluations (FSEs), which had originally been designed by the UK government in order to take the heat out of the GMO debate, are another interesting example of a public space that suddenly became politicized.

Box 14: Participation in GM Food: Farm Scale Evaluations Case Study GM Crops and Food

The concept of the farm scale evaluations came into being when in 1998 the industry formed a strategy and in June launched SCIMAC (Supply Chain Initiative on Modified Agricultural Crops), which advocates the managed and regulated introduction of GM Crops, allegedly in co-existence with conventional and organic agriculture, and supports the labelling of GM products for the consumer. On 5 November 1998, the government announced a voluntary agreement with SCIMAC for a moratorium on commercial GM plantings and a programme of

Farm Scale Evaluations (FSEs) of four GM crops, which would be compared with non-GM crops for their effects on wildlife biodiversity. In this scenario the limited commercial planting of the herbicide resistant GM crops would go ahead, but this would be accompanied by farmscale evaluation of this process for ecological effects, such as the effect of the different herbicide regimes on agricultural biodiversity. However, by 1999 it was being emphasised that these were non-commercial trials, and therefore “purely scientific”. The environment minister clarified the position by announcing a further deal with SCIMAC in November 1999 agreeing that no commercial cultivation would go ahead until another three years of the trials. Thus the FSEs were born as commercial scale trials, but sanctified as pure “science”. These birthmarks raised further scepticism amongst critics in the NGOs and media that behind the scientific and precautionary rhetoric the FSEs were merely a way of further moving the GM project towards a goal of mass commercial release. However, following the development of this strategy public hostility continued to grow, with the FSEs providing a new focus for opposition and concern. Before the FSEs, GM had been an abstract issue; the field trials made them concrete and located. Hence, the FSEs also opened up new political spaces for informal participation concerning the issue.

Formalized Consultation: A New Technique of Governance

In contrast to informal, spontaneous participation where concerned citizens or groups pro-actively engage with the government, or even “occupy” novel political spaces, there is by now a long history of formal consultation initiated by governments. Over the past few years, such planned exercises in participation have almost become synonymous with the term participatory governance, which illustrates their importance in governance debates in recent years. Still, the case studies within the PAGANINI project clearly illustrate that planned participation accounts at best for a small percentage of all activities that can be classified as participatory governance. The GM Dialogue in the UK is an exemplary case for a complex, extensive exercise in “participatory governance” as a form of formal, state driven participation.

Box 15: Large Scale Planned Participation: The GM Dialogue Case Study GM Crops and Food

The design and trajectory of the GM Dialogue in the UK is instructive with respect to the chances, limits and ambivalences of participatory governance arrangements. In May 2002 the government announced that there should be a “national dialogue” on GM issues that would be separated into three different strands—a review of the science of GM, a study of its economic feasibility, and a public debate. Preparation for these began in late 2002, with the main processes running through 2003. The public debate “GM Nation” was the largest and most visible formal participatory governance arrangement in the GM controversy in the UK. A Steering Board was established and a membership

appointed that included both a leading figure from the Five Year Freeze anti-GM coalition as well as from the industry body the "Agricultural Biotechnology Council" (ABC). When the steering body had to appoint a contractor in September 2002 that would actually implement the debate, it found it had little choice, and for reasons of budgetary and time constraints had to appoint a government agency, the Central Office of Information. The decision evoked concerns among some members suspecting that it might compromise public confidence in the independence of the exercise from the government. Time constraints would continue to shape GM Nation and diminish it in the eyes of its critics. The process was criticised by NGO's and by academics. Also questions were raised about the government's stance toward the outcomes of the debate. Eventually the Secretary of State granted an extension of the time period so that it would "allow for the expected publication of the first results of the farm-scale evaluations". A series of nine "Foundation Workshops" were held during November 2002 in a series of towns to give the public the opportunity to frame the questions for the debate. At this stage, a contrast between a conception of "the general public" versus another category of the "actively involved" emerged, categories that would become significant in the subsequent reception and interpretation of the debates outcomes by various parties. Eight of the workshops involved members of the general public, representing four broad stages in life and two broad socioeconomic groups. However, the Norwich workshop, for purposes of comparison, comprised participants who were "actively involved" in GM, half of them supporters and half opponents. From these foundation workshops, each of which had 18-20 participants meeting for three hours, the subcontractor charged with this task identified six overlapping principle threads for the debate (food, choice, information needs, uncertainty and trust, ethics, and the targets and intended trajectory of GM technology). This report was then distilled into a series of tools for public engagement and participation. The public debate itself was launched on 3 June 2003 with a press briefing, and the first of the six Tier 1 meetings which were facilitated round-table discussions based on stimulus materials. The rest of the Tier 1 events took place in different cities over the next ten days, attended in total by over 1,000 people. An estimated total of around 40 Tier 2 regional and county-level meetings took place between 16 June and 18 July, more varied in form, including expert witnesses and debates around a motion. Another estimated 629 local Tier 3 meetings were largely organized by town councils and civil society groups for which the "toolkit" was made available. At each meeting in every tier feedback forms were made available so the participants could express further views. According to the Steering Board: "Over 4,500 individual requests for materials were received by GM Nation. As a result 20,000 workbooks, 6,000 CD-Roms, over 1,000 videos and more than 70,000 feedback forms were sent to members of the general public and interested parties. In addition, the contents of the workbook was available on the GM Nation website, along with the feedback form, which was available to complete between 3 June and 18 July 2003. During this period over 27,000 unique visitors to the website were recorded. (...) In total 36,557 completed questionnaires were received by 18 July 2003 and were included in this analysis. Of these, 18,771 were submitted in hard copy, and 17,786 were submitted on the website." In contrast to the public meetings where the participants were self-selected, the Steering Board also commissioned a series of "narrow but deep" focus group discussions in June and July 2003 to act as a "control". Ten different groups were convened

with a total of 77 participants, chosen to be broadly representative of the general public, and selected to have no immediate connection or interest in the issue. Each group met twice over a two week period.

While the size, strategic objectives, and actual means to implement such large consultations differ, there is a number of characteristics that appears to be shared by many of the formal consultation exercises undertaken so far:

- ▶ Formal consultation typically aims at a “representative public” of disinterested individuals that have not been deeply involved in a given issue or question. This is not without problems. Idealized publics do not exist *per se*, but need to be created in the most pragmatic sense of the term. A more problematic issue is that if citizens are uninformed about a given issue they also need to be educated, which is never a trivial matter.
- ▶ Exercises in formalized or controlled consultation—in the form of citizen workshops or consensus conferences—are often outcontracted by government agencies to external organisations or companies; there is “work to be done” and there is perhaps always an element of “engineering” and “manipulation” in such exercises.
- ▶ There probably exists a trade-off between generic forms of public participation (that can be applied in any policy field) and more specialized mechanisms of participatory governance that are, more or less, limited to a single issue. While the latter will provide quick results in a singular case, more generic approaches using public consultation—once well established—are likely to provide more sustainable results in the long run.
- ▶ Exercises in formal consultation typically come with a clear, strategic agenda. It is often only when all other, less costly and also less risky approaches to governance have failed, or are likely to fail, that agencies start to convene exercises in participation. In some cases, these formal consultations were set up in order to replace spontaneous participation and, thus, obtain better control over the outcome of participation. This appears to have been the case with GM Nation.

Despite their various shortcomings, exercises in formal, government-led participation have become a well-established approach toward participatory governance. Over time, the areas of policy making where governments or institutions of the European Union make use of formal arrangements for participatory governance are likely to increase. Yet again, the case studies undertaken within the PAGANINI project suggest that it is hardly possible to replace the various types of spontaneous participation that exist in a pluralist society by state-driven exercises in participation only, and this is especially true in an early phase of regulation where “concerned publics” do often play an important function.

Rather than *replacing* manifestations of spontaneous participation, the case study on food safety demonstrates that mechanisms of participatory democracy can be designed in a way that the state can benefit from spontaneous participation by, first of all, supporting and enabling them (e.g. through heightened transparency), and secondly, by *building upon the momentum* of stakeholder-initiated participation (e.g. this is what the Dutch government does when it cooperates with farmer-led designs for promoting a more sustainable agriculture). These kinds of state-citizen interaction are of relevance notably in regard to the production of knowledge in the early phases of regulation. This issue will be addressed in the next chapter.

Science and Participation

Beyond the Dichotomy of Experts and Citizens

IN POPULAR VIEWS OF REGULATION science often takes the form of a black box device that miraculously provides answers to administrators and government officials; answers that help in settling disputes and that provide “closure” of protracted debates; answers that have an aura of impartiality that is beyond the interests of stakeholders. This black box portrait of science as it is used in governance sometimes conceals the most particular point about science: science is, first of all, a shared understanding of nature and of life. Scientific knowledge is strictly limited to those facts and interpretations that are shared by at least a fraction of a designated community.

What is peculiar about science, and what distinguishes science, is the process by which facts are shared and accredited. These processes of sharing and certifying facts about the nature of life are highly fragile and far from perfect. Also, it is known that in many areas of science used in regulation these processes of sharing and certification have been altered to suit the special needs of regulators and policy makers who need timely, clear-cut conclusions that can feed into a political process (rather than an open ended debate that can go either way).

What is peculiar about Politics of Life domains (and, so the underlying hypothesis of the PAGANINI project, will become increasingly common in other areas as well) is that both the reference to science *and* participation are crucial. The PAGANINI case studies also provide some evidence that there are indeed new linkages between scientific expertise and democratic participation. Not only do many organizations now rely on some form of research (large NGOs typically hire their own scientists and even sponsor research projects), but there are also increasing opportunities for participation in the scientific research enterprise. It is especially in this respect that the Politics of Life is almost a sort of laboratory for the future of democratic governance.

The Role of Science in Politics of Life Domains

In all cases studied, Politics of Life domains are heavily linked to the scientific enterprise. Not only does scientific research often play an important role in the creation of

new questions for regulators, but science itself is at the very centre of regulation and political debate in many Politics of Life domains. Stem cells and genetics testing are but two examples where advances in scientific research have created an entirely new spectrum of questions for regulators and policy makers. The research enterprise is heavily involved in the debate in Politics of Life domains: nature conservation is no more possible without an extensive body of scientific research and the same is true for all other areas of regulation that were investigated.

Another characteristic of Politics of Life domains is that scientific knowledge, while crucial, is often simply not enough to provide closure in a given debate. At the same time, the very nature of scientific knowledge in Politics of Life domains is changing in a fundamental way. So far, the argumentation has been limited mostly to political participation. In numerous cases it has been shown that political participation occurs across an entire spectrum of arrangements, from informal, spontaneous participation that creatively re-uses existing organization or institutions for political purposes, to formalized exercises in participation planned and implemented by government organizations in a way not too different from juries in the legal system of some countries.

Evidence from the case studies points to yet another level of participation where political participation mixes with the scientific research enterprise. In fact, it is one of the conclusions of this project that participation in knowledge production is one of the most surprising, but also powerful forms of participation that take place in many Politics of Life domains.

Who Participates in Knowledge Production?

Talking about “knowledge” poses many fine semantic problems. We talk about “knowledge production” as if “knowledge” were a durable good, produced in some arcane, remote factory. We assume that “knowledge” is made in scientific laboratories. An unbiased observer in a scientific laboratory does not find “knowledge” but only a multitude of data, drawings, or publications. What we refer to as “knowledge” is data, drawings, or interpretations that are shared among a sufficiently large group of people; and not only shared, but also agreed upon and certified. Knowledge is thus by definition never produced by a single individual, whatever his qualities might be; rather it is always collective, shared, and mutually confirmed.

Participation in knowledge production can happen in many ways. Like governments, various societal groups can, of course, influence scientific research simply by the distribution of funding to specific thematic areas that otherwise might have been neglected. Companies, industry groups, NGOs, patient organizations, and even individuals have funded scientific research in a broad array of topics, typically with specific political objectives in mind, and often in a way not too different from the funding of research by regulatory agencies. While some of the actors that fund scientific research may be new—such as environmental organization or patient groups—participation in research

through funding is well understood. Some government organizations have even established informal rules or guidelines on how to deal with scientific research funded by stakeholders.

Other forms of participation in research relevant to politics are much less well understood. Patients may participate in publicly funded research through donating blood or other cells or tissues, a form of participation that is often crucial in biomedical research and through which certain groups can influence research in a very powerful way. In other areas, citizens may participate in research actively through the collection of data (as in the case of conservation—see BOX 16). In yet other cases, citizens or concerned groups may participate in validating research results or else engage in new forms of scientific critique or surveillance.

Box 16: Participation in Knowledge Production Case Study Nature Conservation

Participatory knowledge production forms part of the method of implementing conservation policies. Protection of both the flying squirrel (*Pteromys volans*) and the loggerhead turtle (*Caretta caretta*) have given rise to specific knowledge practices, such as assessing the total population size, as well as activities that require more specialized skills—such as surveying the squirrels, and monitoring the nesting cycle of the turtles. Semi-professional nature surveyors who specialize on squirrel surveys develop specific embodied working practices, while volunteers participate in the monitoring work at the nesting beaches of the turtles. In the case of the squirrels, the extremely secretive habits of the flying squirrel set considerable challenges to the skills of surveyors. The new nature surveyors were usually biologists by education, hired by planning and consultant offices, municipalities or governmental agencies. Some larger cities such as Tampere have had suitable people among their own staff. After specific training, an increasing number of forestry professionals have learned to command the surveying methodology. Personal, local and embodied experience plays a big role in surveying animals such as the flying squirrels. The embodied style of collecting ecological data by the surveyors is based on a special kind of human-animal relationship. The surveyors are trained in surveying flying squirrels using the behaviour and habits of the animals as cues; by experiencing and learning weak signals and different combinations of them; by working in different areas; and in particular by learning the contexts of droppings which are variable but also have invariants which the surveyors are able to sense and record. In the case of the turtles, volunteers have an essential role in guarding and monitoring the nesting beaches. One could argue that knowledge needs concerning the conservation of *Caretta caretta* are not a complex issue since tracking the animal's nesting behaviour is a clearly visible process, while the applications and use of the knowledge have been major issues when discussing the protection of this species. For both the squirrels and the turtles, the need to get reliable records on the location of the breeding sites and resting places of the animals has given rise to new knowledge practices. In the case of the squirrels, a semi-professional group of surveyors was in charge of the data collection; in the case of the turtles, NGO volunteers produce a huge amount of the knowledge needed to implement conservation policies. Knowledge production takes place

not in the lab or in the office but out in the forests and on the beaches where it is done by a mixture of scientists; non-scientists; prospective, but not-yet scientists (students); professionals; semi-professionals; and volunteers.

Participation in knowledge production is often related to specific interests (parents of patients who donate eggs for stem cell research) or concerns (volunteers helping to survey wild animals). But this is not always true. There are also cases where knowledge production and scientific research that very likely will benefit only a limited group of people with certain diseases relies heavily on a much broader group of volunteers (Box 17).

Box 17: Participation in Research: Multifactorial Diseases Case Study Genetic Testing

Knowledge production in the field of genetic testing relies on “involving the public” too, albeit in a different way. The vast share of research and development concerning genetic testing is done in the sector of multi-factorial diseases, not on monogenetic diseases. Research into the genetic aspect of multi-factorial diseases, both through epidemiological studies and the search for biomarkers, however, 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.

Participation in knowledge production is not limited to “stakeholder publics”. In fact, one could speculate that there are broader social changes in highly educated, egalitarian societies that have lead to an increase in participation in knowledge production. While on one side scientific enterprises become ever more specialized, it is equally true that scientific and technical research has become ever more prevalent. There is no domain of daily life that is not touched by the scientific research enterprise or by technical change. Thus, the opportunities for participation are continually increasing.

From Knowledge Production to Political Participation

How does participation at the level of knowledge production relate to political participation? The case studies provide a few initial answers to this important question. Notably, there are cases where existing forums that were once the domain of technical decision-making have turned into a locus for both participation in knowledge production and political participation. The practice of inviting a consumer representative as full member in a scientific committee advising the British government on scientific aspects of food safety issues is a case in point. In many of these cases, participation in knowledge

production actually turns into powerful forms of political participation, as the case of the Seed List hearings illustrates (Box 18).

Box 18: From Participation to Politics Case Study GM Crops and Food

Taking a closer look at the GM-food controversy, one finds that participatory knowledge production took place to some extent in National Seed List Hearings held in 2000 and 2002 over the GM HR Maize variety Chardon LL (T25). These hearings formed not only newly politicised arenas of political participation but also were places of participatory knowledge production. In fact, they provided an opportunity for a participatory intrusion that commented on, challenged and changed the science itself; these hearings can be characterized as a hybrid space in which participatory knowledge production was a powerful act of political participation. Following an early EEC directive (70/457/EEC), the sale of a new variety of seed was prohibited unless it was included in the EEC Common Catalogue and National List. This was originally aimed at securing minimum standards of seed quality. The legislation predates the GM controversy and applies to all varieties, not just GM ones. Under this directive, statutory tests and trials are required to demonstrate that new varieties are “distinct, uniform and stable” (DUC), have “value for cultivation and use” (VCU) and represent an improvement on existing listed varieties. Seed listing constituted the last stage in the regulatory process and follows the granting of marketing consent under the GM Deliberate Release Directive (DRD) 1990/220. In March 2000, the addition of the genetically modified product Chardon LL T25 Maize was proposed to the UK National List, marking the final part of legislative clearance for that variety. This gave another alarm signal to those opposed to GM plants: Despite the commercial moratorium during the farm scale evaluations (FSEs), the introduction of the technology was still moving forward with government approval.

Various other cases where the boundaries between knowledge production and political participation are blurred have been analyzed within the PAGANINI project. However, there is some indication that these moments are a temporary stage in a political process. Once a stable and robust consensus has been reached, a re-separation takes place and science and political representation become clearly delineated worlds again.

New Criteria: Social and Political Robustness

Perhaps the most powerful effects of participation by citizens or publics in knowledge production relates to the “robustness” of scientific knowledge in a political environment or public forums (H. Nowotny). The notion of social or political robustness of knowledge (and regulations that are, at least partially, based upon knowledge) adds a new dimension to assessing the societal significance of scientific knowledge. It is important to note here that knowledge that is social and political *robust* is a subset of scientific

knowledge, since it is both scientifically valid and socially and politically accepted.

In Politics of Life domains, debates on regulation increasingly take place in public, rather than within the confined spaces of an expert committee. This opens up scientific knowledge production to new forms of scrutiny and critique, and in some cases, participation in knowledge production turns into a powerful form of political representation. This does not mean that knowledge production itself simply degrades into a political farce where science becomes replaced by politics. Rather, social and political robustness is typically a more restricted criterion than scientific validity. Knowledge that is scientifically unchallenged is not necessarily also socially and politically robust, while social and political robustness builds upon scientific validity.

From Logos to Pathos?

The Rise of Ethics

ONE OF THE MOST STRIKING RESULTS from the empirical case studies was the extent to which arguments about “what should be done” and “what ought to be” have invaded political and rhetoric debates in Politics of Life domains. Discourses about ethics were first institutionalized within expert committees, and following a classical modernist paradigm of policy making. However, the PAGANINI case studies also suggest the rise, over the past few years, of ethos/ethics as well as pathos as rhetorical strategies (rather than fields of expertise). What follows is a brief summary of the rise of discourses on values and sentiments in Politics of Life domains.

The Experience with Bioethics

While its history goes back to the Nürnberg trials and the Helsinki declaration, bioethics as a field of study and as a form of political discourse has gained prominence in most industrialized countries at least since the 1980s, following the discovery of recombinant DNA research in the 1970s and the first debates on how to regulate this new, revolutionary technology.

Since then, bioethics has become a well established academic discipline with its own research centres, journals, and research funding schemes. Bioethics has also found its way into government by way of “ethics” committees, typically staffed by an interdisciplinary mix of experts from a variety of disciplines, including bioethics (BOX 19).

Box 19: The Rise of Bioethics in Governance: Ethics as Expertise Case Studies Genetic Testing, Cloning and Stem Cell Research

In the areas of genetic testing and embryonic stem cell research, one observes the establishment of a series of new institutions, from the 1980s onwards, that were charged to advise the government on how to regulate new biomedical technologies on the one hand and how to meet public concerns and public unease on the other. The emergence and proliferation of *bioethics advisory bodies* at the government level is the most conspicuous phenomenon of institutional innovation in the area of genetic testing and embryonic stem cell research. What

one also witnesses is a change from expert-based governance schemes in the 1980s, largely based on a “risks and benefits” framing, to governance schemes that increasingly refer to “ethical implications”. In part, this “ethical turn” is accompanied by the integration of lay people, citizens, social scientists, and ethicists. On the EU level, the EGE (European Group on Ethics in Science and New Technologies) which had started in 1991 as the “Group of Advisers to the European Commission on the Ethical Implications of Biotechnology” (GAEIB) plays a certain role in EU stem cell policy. In Germany, a series of new expert bodies were established between the mid 1980s and 1990 that were designed to give policy advice on biomedicine and biotechnology, including issues of genetic testing. These new expert bodies include the “Benda Commission” (named after its chair Ernst Benda), established in 1984 order to advise policy makers on ethical and legal questions of IVF, gene therapy and embryo transfer; the “Parliamentarian Study Commission on Risks and Benefits of Genetic Technology” (*Enquetekommission Chancen und Risiken der Gentechnologie*), a commission established in 1987 and composed one half each by parliamentarians and experts; and the Office for Technology Assessment (*Büro für Technikfolgenabschätzung*) in the German Parliament, established in 1990. Although these commissions and bodies already referred to “ethics”, “ethical implication” or “ethical issues”, the main concern of debates on genetic testing was still on risks and benefits. In 2001, Chancellor Schröder set up the National Ethics Council (*Nationaler Ethikrat*), exactly at the time when the legalization of importing hES cell lines was being discussed in Germany. Barely six months after its creation, it issued a recommendation in favour of allowing the import of hES cell lines. With the National Ethics Council, debates now started to shift towards ethical considerations on fostering (or limiting) the development of new technologies, such as stem cells. A similar shift in the debate on biotechnology towards ethical imperatives can also be observed elsewhere. For example, in a deliberate attempt to build trust, Bill Clinton asked the National Bioethics Advisory Commission (NBAC) in 1998 to review of the medical and ethical issues associated with human stem cell research.

Interestingly, the rise of bioethics in government largely followed a technocratic model: bioethics was institutionalized through expert committees, with the only exception that these committees now included “experts” whose expertise was not in science or technology, but in philosophy, the social sciences, and quite frequently, also theology. But, while ethics was at first a minor consideration within scientific expert committees, ethical questions increasingly turned into the focus of debates. Ethics, by some measure, turned into a new way to speak about new technologies, to build trust in governance, and to fashion politically stable compromises in governance.

Political Credibility: A Shift from Logos towards Ethos/Pathos?

The PAGANINI case studies suggest that discourses on ethics and sentiments have

gained prominence in many Politics of Life domains well beyond the narrow field of ethics expertise in government. Faced with scientific and political uncertainty, the rhetoric of ethics and of “what should be done”, as well as discourses of sentimental attachment (to an embryo or to a rare species) have come to play an important function in many Politics of Life domains.

Box 20: Ethos and Pathos in Debates on Stem Cells
Case Study Genetic Testing, Cloning and Stem Cell Research

Emotions have played a crucial role throughout the countries discussed in this report. Emotions came into the field of stem cell governance along two central axes: first, stem cell research is about doing research with early embryos. The question whether this research with early embryos is acceptable has been key to the debates, not only in the sense of ethical acceptability, but also emotional acceptability. Decisions about the manipulation and use of human cells derived from early embryos or gained through the creation of early embryos are not necessarily based only on philosophical expertise, but typically are grounded in a mixture of sentiment and logical reasoning. Second, the potential of stem cell research to heal dreadful and often deadly diseases has an emotional power on its own that transcends not only the logical arguments, but also ethical and religious principles as well. Just as it is with trust and ethos, emotional language can be used in support of stem cell research, or in its critique. Life science governance in the field of stem cell research was not only shaped through emotions, but also through the deliberate mobilization of emotional language and the space that emotions were given in the regulatory process. Emotional language and articulation was particularly prominent in the United States and in the United Kingdom in various policy settings from campaigns to the parliament/Congress. While in the US emotional language quickly led to polarization, in the UK the display of emotions together with the creation of trust in institutions created a political space where a topic as delicate and intimate as stem cell research could be debated without polarization. At the same time, in Germany significant efforts were made to keep emotions out of the stem cell debate and to let the quest for the German ethos determine the style of the discussion. The exchange between the German president, the German chancellor, and the German parliament dominated the discussion, and few attempts were made to connect the top decision-makers with the various groups of stake-holders.

from logos to pathos?

What is the role of arguments on ethics or emotions in Politics of Life domains? Dominant currents in discourse ethics would suggest that moral problems can be solved in a *rational* and *cognitive* way. Further, there seems to be a tendency in policy analysis to confine reasoning to deliberative and judicial reasoning, as opposed to merely manipulative, negative rhetoric: only the former is thought of as genuine argumentation while the latter is mere propaganda. The PAGANINI case studies suggest, to the contrary, that ethos and pathos—important strategies in classical Greek rhetoric—can and do play an important role in participatory governance. While the rise of ethics in governance—and the ethicization of policy debates—also poses many questions and, as the

US debate on stem cell research illustrates, can also lead to stalemates in a debate that become very difficult to resolve, arguments on ethics and sentiments have an important positive effect, especially in Politics of Life areas.

Several aspects are important with respect to the rise of discourses on ethics and sentiments in Politics of Life domains. First, it implies that “matters of fact” can no longer be separated from “matters of concern”. In Politics of Life domains, “facts” have direct moral and political consequences. There are barely any “neutral facts” which can be “established” without this very act being itself a politically relevant decision. Secondly, the rise of ethical discourse displays the practical character of the issues at stake and the strongly perceived need for action, even in the absence of scientific certainty, and the practical orientation of actors who ask themselves what they should or should not do.

From Pathos to Participation

There is yet another interesting implication of the increasing prominence of ethics with respect to Politics of Life issues: in areas where talk about ethics or morality prevails, people tend to take a first-person stance on the issue at stake. The questions asked include notably the following: What are we supposed to do? What shall we do next? What is the right thing for *me* to do here? In other words, if moral or ethical arguments in an issue area or a governance problem become pre-eminent, actors relate the issue to themselves and their actions and thus take a *participant's point of view*. They now assume that it does matter to some extent what they personally believe and act in regards to the issue and do not assume that it is the exclusive responsibility of others, be it experts or policy-makers, to shoulder the entire burden of decision. In other words, the public becomes a *concerned public*.

Conclusions and Recommendations

Towards the Governance of Life

A BASIC ASSUMPTION of the PAGANINI project was that established practices of governance in Europe (the “classic modernist” approach) are largely inadequate to deal with the challenges to regulatory regimes posed by Politics of Life domains. The case studies undertaken within the PAGANINI project provide ample evidence on this point. But, also, existing institutions and approaches have proved both remarkably resilient and increasingly flexible. Innovative new organisations such as the UK Food Standards Agency (FSA) are designed to embrace new, transparent, and reflexive approaches to governance while maintaining at the same time a sound scientific basis for food safety regulation.

A key insight from PAGANINI is that in contemporary governance, there is *no single, preferred approach* that can be deployed across many policy domains. In contemporary governance scientific advice coexists with public participation, and scientific rationality coexists with discourses on ethics or sentiments. In Politics of Life domains, policies that solely rely on a technocratic model of scientific advice or on approaches that only mobilize formal exercises in public participation rarely lead to optimal outcomes and frequently fail to win broader acceptance. More realistically, government agencies will need to define flexible, open approaches to governance that combine a variety of practices, from classical scientific advice or regulatory science, to formal participation or the strategic use of various spontaneous forums and informal participation by a variety of actors.

Public participation in Politics of Life domains is not simply a miraculous mechanism that can replace scientific facts; on the contrary, public participation often happens in reference to science. The case studies undertaken within the PAGANINI project clearly show that often the most crucial work to be done is reconnecting these various actors in new and innovative ways. Evidence has been found that the very categories used to classify actors—be they scientists, experts, consumers, activists, politicians, or administrators—are not as stable or clear-cut as it may appear. Political imagination is called upon to translate this insight into novel governance practice.

It was further shown that the types of discourse that are pertinent and that can instil legitimacy in Politics of Life domains have equally multiplied. In addition to logos, ethos and pathos have become frequently deployed discursive strategies in Politics of Life domains. In other words, in such domains we can see an increasing salience of dis-

courses that are grounded not so much in facts as in ethics and/or sentiments. Again, what is most remarkable about Politics of Life domains is that these discursive strategies, or “discourse worlds,” coexist with existing ones, notably scientific rationality and legal reasoning.

Governing despite Uncertainty

Uncertainty—rather than risk—is perhaps the main common feature of all Politics of Life domains. In an administrative or governance context, uncertainty differs significantly from risk. While risks can be calculated, and balanced against benefits, uncertainty is not calculable. Uncertainty can have many sources and can be scientific, technical, organizational, or political in nature.

The absence of common criteria to calculate future risks and benefits does of course not dismiss the need for political action in the present. On the contrary, Politics of Life areas seem to be characterized by a strongly perceived need for political action, oftentimes for urgent action. Governance and regulation cannot be postponed to the day when science will have provided sufficient, reliable, and uncontested evidence and when a consensus on normative criteria for appropriate action will have evolved in society. This pressure for action is linked to, and partly caused by, another salient feature of Politics of Life areas: the very objects of governance are constantly evolving, altering, increasing or decreasing in numbers, and appearing in different manifestation over time.

Phenomena of life thus are inherently dynamic—which makes them particularly unruly and unpredictable. It also poses specific challenges to governance, not least the challenge to govern the as yet unknown, and never completely predictable, future manifestations and implications of these objects. Governance, in Politics of Life domains, is mostly about governing the future (as is the case in all areas of governance), but this future is unforeseeable and unpredictable; there is, in fact, a multiplicity of possible futures. The envisioning of such futures has political implications and, thus, is a political act *per se*. Whether one investigates the case of stem cells and stem cell lines, and the prospects of therapies derived from them; or monogenetic or multi-factorial diseases and the prospects of genetics based diagnosis and therapy; or genetically modified plants and their future environmental or health impacts; or “unruly” threats like BSE and vCJD; or endangered species and biodiversity, it is found that prognosis *is* politics: envisioning certain possible futures, at the expense of others. Drawing conclusions from these visions forms an essential part of the struggle over meaning and, as such, of any kind of politics.

Governing the future is fundamentally related to the act of building scenarios of the future, but such scenarios are not normatively neutral and never solely derived from the extrapolation of “objective” scientific data. In Politics of Life domains, the assumptions buried under specific constructions of the future are not likely to be left buried for long, but themselves become the object of contestation and debate.

Participatory Governance: Engaging with a Multitude of Publics—Rebuilding Institutions

The case studies indicate that “participation”—in its many forms—is a key to successful governance in Politics of Life domains in Europe. At the outset, the PAGANINI project started from the hypothesis that “in the domain of life-political issues, the notions of participation and governance seem to have become intermingled to an unusual extent”. Empirical research pointed to a more complex reality—and to the need to rethink the very concept of participation and of participatory governance. Perhaps most importantly, “participation” and “public involvement” cannot and must not be confined to formal, state-initiated arrangements.

As the case of GMO politics in Greece and the UK demonstrates, participation can take the form of democratic grassroots politics by NGOs or consumer groups, who are seeking to make their case heard in public and who exercise pressure on the government through a multitude of democratic means, including lobbying and the mass media. Such groups have even used advertisement campaigns, as the 1000frage.de campaign on biomedicine in Germany demonstrates. We can speak here of *conventional informal participation*.

In the case study on GM plants, another form of informal and spontaneous participation could be observed. This form of participation was often related to the creation of new political spaces, meaning spaces that had originally not been designated as arenas of direct civic participation in politics such as supermarkets or farmers’ fields, or equally village halls, Magistrates and Crown Courts. Public involvement or participation often remain fairly conventional, but there is also ample evidence for unconventional, informal participation, for instance in the form of “crop-trashing”. Then again, one can distinguish a special form of civic participation, e.g. the case of the National Seed List hearings, that clearly undermined the supposed separation of “science” and “politics”, “matters of fact” and “matters of concern”. These hearings had originally been designed to gather “facts” and had not been designed to make political statements or political decisions, but unexpectedly turned into newly politicized spaces where the debate about “facts” mingled with political arguments. Political participation happens here as participation in knowledge production.

What these forms of participation have in common is they are not state-initiated but rather emerge from within civil society. Participants in these informal exercises in participation have not been “invited” by government institutions nor have they been selected by any organizers; to the contrary, actors are self-selected here or “self-appointed” and as such usually have entered the debate from a “partisan” point of view, promoting their respective views. Consequently, participation or public involvement often takes place at unexpectedly politicized sites, is civil society-led rather than state-led, tends to be of an antagonistic nature, and is characterized by adversarial arguments and struggles. We can term the types of publics emerging at such sites “engaged publics” or “issue publics”.

In the case studies, a number of formal participatory arrangements were encountered, mainly in the case studies of genetic testing and GMOs. Both academic and po-

litical discourses on enhancing “civic participation” or strengthening “participatory governance” usually refer to such formal arrangements which are typically understood as a means to democratize policy-making and re-create trust, particularly in highly contested policy areas. After a careful analysis of these formal participatory arrangements within the broader context of other forms of political participation and governance practices, however, it is clear that formal civic participation has its own implications that require careful consideration.

In contrast to the antagonistic nature of civil society-led participation, *formal* participatory governance arrangements are typically set up by state institutions, and often precisely in order to counter, and mediate, this adversarial type of public involvement. One of the most extensive experiments in participatory governance, GM Nation, for instance, was set up in response, and as an alternative, to informal participation at National Seed List hearings.

Formal, state-initiated participatory arrangements, as the case studies on GM plants and genetic testing show, are often swayed by the desire to achieve balanced representation among participants, to mirror the “general public”. They are composed of individual participants who take no particular interest in the respective issue and possibly or who are as yet “unspoiled” by partisan views and supposedly open “rational” education, as in the case of the youth conferences that were analyzed. The construction of such “pure publics” thus may provide an alternative to existing “engaged publics” or “issue publics”.

However, as all case studies have shown, the design of any formal participatory arrangement involves a considerable amount of “engineering”, including practical arrangements seeking to invite a “representative”, disinterested, “pure” public. But there is no such thing as “the public” that is waiting to be called up. Formal participatory arrangements are inevitably linked to a process of active construction that involves activities of goal-setting, selection, decision-making, agenda setting—and includes the decision to prioritize the “pure public” at the expense of “engaged publics”. The objectives, ideas, priorities, and selection criteria that inform the construction of those “publics” need to be made transparent.

Organizers of such formal exercises in participation and participatory governance should be aware that there is no “pure public”; and that inviting non-state actors as participants inevitably involves political decisions and actions that take place within a specific political context and that have political implications. Alternatively, arrangements may be designed that allow for better “self-selection” of potential publics by improving the transparency of processes of political judgement and decision making.

The PAGANINI case studies suggest there is a clear and urgent need for more *reflexivity about the construction of these “publics” in participatory arrangements*. In particular, the linkages built with “engaged publics” appear crucial. But, even “engaged publics” need to be selected, constituted, and recruited into a participatory governance arrangement. One crucial lesson from the PAGANINI project is that relevant “publics” are both an input and a pre-condition for participatory governance and the result of par-

ticipatory governance; they are not simply pre-existing entities that are just there, but entities that are actively *shaped* by the very processes of participatory governance.

Recommendations: Participation, Institutional Innovation, and the Governance of Life

The focus within the PAGANINI project was on participation in Politics of Life domains and how Politics of Life domains problematise existing forms of political decision making and participation. Within the case studies undertaken over the course of the project, the goal was to observe political participation and participatory democracy: to trace how regulatory questions turn into issues that are more broadly debated; to examine how novel spaces for political debate are created, often in unseemly places; to demonstrate how they multiply through institutional innovations; to study how, in some areas of political decision making, notions of risk or benefit as something that is calculable are giving way to radical uncertainty; to investigate the emergence of specific types of discourse within the political sphere termed “ethical” and that often also refer to sentiments, rather than rational argumentation or economic calculus; and finally, to research how knowledge used in decision making is created in an increasingly open process that includes not only scientists but a variety of participants.

When analyzing the PAGANINI case studies, “modernist” techniques of governance were contrasted with contemporary participatory approaches to governance. Interestingly enough, the PAGANINI case studies do not suggest a complete shift from one model of governance to another one. Rather, the empirical findings of the project suggest that modernist techniques of governance have proved fairly resilient and, in many cases, have adapted well to the new realities of Politics of Life domains. As a result, different approaches and paradigms of governance will often coexist. Ethics committees, an adaptation of technical expert committees to the domain of values, are a case in point. Ethics committees are more reminiscent of technocratic, elitist forms of governance and have little to do with broader participation. Still, ethics committees can open up debates and make them visible to a broader audience; they can become mechanisms to enable wider participation in governance. And even scientific advisory committees can turn into forums for public participation, as the British food safety case shows. Thus, in practice, elitist, technocratic forms of governance often coexist with more open and democratic approaches to governance.

In the PAGANINI case studies, one observes a picture of participation that is both more nuanced and more complex than many studies or commentaries on participation and the democratization of technocratic decision making would suggest. Participation has indeed multiplied; participation has also become a new buzzword within government, especially in Europe. Partly this may well be a reflection of the fundamentally weak mechanisms of political representation at the European level and an increasingly urgent need, within the organizations and agencies of the European Union, to engage more and more directly with their citizens. From the PAGANINI case studies it is clear

that participation is hardly a simple, quick fix that can be applied in any instance where the model of technocratic decision making has failed.

Citizen and consensus conferences are but one mode of consultation and, so the case studies seem to suggest, certainly not the most common. Tribunals of “disinterested citizens” who agree to follow certain idealized rules of discourse, are at best an extreme of artificially engineered participation that simply does not do justice to the numerous modes of participation in regulatory policy that have emerged over the past few decades. Any government agency dealing with Politics of Life domains should make it as their first task to understand, in as much detail as possible, the various “publics” that are related to any given regulatory question.

Beyond this insight, are there any normative conclusions emerging from this project? What lessons are to be drawn from the PAGANINI case studies for those in public administrations or in political positions who need to make decisions now? In what follows, some insights that would seem to emerge from the case studies are provided. The goal is to provide practical suggestions on how, in Politics of Life domains, administrators or government officials can successfully devise processes of participatory decision making and participation that are likely to yield outcomes that are durable, scientifically sound, and socially robust.

1. Participatory democracy, both arranged and spontaneous, has become an essential instrument of governance in Politics of Life domains in Europe

In all cases studies within the PAGANINI project participatory democracy and participatory governance have become a crucial instrument to re-build trust in European government. While participatory governance is by now a well-established and legitimate mechanisms of governance, efforts to further strengthen mechanisms of participatory governance and participatory governance in Politics of Life domains are clearly warranted. However, it was also found that participation and participatory governance is by no means limited to state-led efforts only. Such formal or arranged participation was encountered in a number of cases studies within PAGANINI. There can be no doubt that formal participation, whatever form it may take, is by now a political reality. Still, the empirical findings also suggest that formal participation is typically only one mechanism of participation among others. Furthermore, the complete substitution of informal or spontaneous participation as opposed to formal or “invited participation” almost never seems to succeed. At best, formal participation is an additional mechanisms that may add to, or complement, other mechanisms of participation. Government agencies may also use formal participation as a means to limit the impact of other mechanisms of participation. But, not a single case was found where a full substitution of in-

formal participation by a formally arranged and supervised exercise was successful. Thus, our conclusion that government agencies should look at formal mechanisms as an additional and supplementary mechanism of participation, rather than as a substitute for forms of participation that may appear less easy to control. Finally, formal mechanisms of participation come with their own limitations, inherent dynamics, and uncertainty.

2. Acknowledge the fundamental uncertainty of Politics of Life domains

Uncertainty is a fundamental feature in Politics of Life domains. While classical techniques of governance and administration aim at reducing uncertainty to calculable and quantifiable “risks” or “benefits”, in Politics of Life domains this is often not possible. The case studies within the PAGANINI project suggest that, for governments, it would often be the best strategy to acknowledge this fact at the outset. While this has happened to a certain extent under policies that are based on the “precautionary principle”, it is important to note here that uncertainty in Politics of Life domains is much broader, and also includes uncertainty about the very objects of regulation and governance, or uncertainty about the benefits of a novel technology (and not just uncertainty about its risks).

3. Find ways to account for the instability over time inherent in Politics of Life domains

In the Politics of Life, nothing is stable. The objects of regulation often change over time, as does the scientific knowledge relevant to political decisions, or the composition of interested publics. For example, the creation of a new scientific object, such as the discovery of a novel gene, can have a multitude of societal and political implications and may lead to the formation of entirely new social groups or new stakeholder publics, as the case of the breast cancer genes BRCA 1 and BRCA 2 has demonstrated. Government agencies would be well advised to find arrangements that, to the extent possible, acknowledge this inherent instability in Politics of Life domains. What this really means, in political or legal terms, will depend on the specific case. In Politics of Life issues, government would best adhere to approaches to regulation that allow for quick changes or that remain entirely informal. In fact, such arrangements may turn out as problematic since political compromises in Politics of Life domains often are “tested” in more thorough ways than is the case for many other areas of politics. Still, there is good indication that formal approaches to regulation in Politics of Life areas will be most successful if they acknowledge the inherent instability of the very ingredients of these regulations—starting with issues deemed problematic, to relevant scientific knowledge, or the composition of the concerned publics.

4. Focus on the societal robustness, in addition to the scientific credibility or regulatory coherence of new policies or regulations

In Politics of Life domains, questions, relevant expertise, and the composition of concerned publics may vary over time. Yet, at the same time, political decisions do need to be remarkably robust. Political governance in Politics of Life domains that is not socially robust stands little chance of political success. Social robustness is typically more important than scientific credibility in the narrow sense. It is also more important than regulatory coherence. Note, however, that social robustness is not, in any sense, a direct substitute for scientific credibility—rather, social robustness is a more stringent standard. Socially robust knowledge is simply a *subset* of scientific knowledge. A political compromise that is socially robust is, by definition, also scientifically credible. Yet, scientific credibility is only one facet of social robustness—only a fraction of the knowledge produced by scientists at any given point in time will also satisfy the criteria of social robustness.

5. Develop an empirically rich understanding of the various types of publics involved in Politics of Life domains

The case studies undertaken within the PAGANINI project clearly suggest that participation in Politics of Life domains is extremely rich, highly varied, and often happening in surprising locations and under circumstances that nobody would have predicted. For political actors there are simply no mechanisms to predict what form participation will actually take. Still, the empirical evidence suggests that, for political actors, an important step toward societal robustness is to develop an empirically rich, well informed, and in-depth understanding of the various types of “publics” that are related to a given Politics of Life domain at any point in time.

6. Acknowledge ethics and emotions as legitimate, and complementary, forms of political discourse about Politics of Life issues

In all case studies the surge in importance of ethical discourses was broadly documented. In ethical and moral discourses scientific knowledge as basis for normative action has been partially replaced by considerations of values, concern, and what is deemed as “right” or “wrong”. At the same time, a strongly emotional language characterizes many of the discussions in areas such as stem cell research or on GM Food. Government agencies would often do good to acknowledge that values and even sentiments about a given question are a legitimate form of political discourse—rather than simply ignore those who use such arguments. This is certainly not to suggest that, in Politics of Life

domains, government organizations or the European Union should base their regulatory decisions mainly on arguments about values and emotions rather than facts. But creating legitimate political spaces for articulating concerns, values, moral positions, anxieties and hopes might increasingly become a precondition for successful governance in the domain of the Politics of Life.

7. Early, proactive, and coherent efforts toward political participation are more likely to yield success than half-hearted, delayed and contradictory approaches

From a governance perspective, it is key in the Politics of Life arenas to develop an early, proactive and coherent effort to deal with new challenges as opposed to half-hearted, delayed, and contradictory approaches. Here, the interaction with the various publics and an open understanding of participation form central elements. Time tends to be essential in many Politics of Life fields. Neither can trust be generated *ad-hoc*, nor can political institutions be rebuilt quickly on demand. Trust in the quality of highly contentious political decisions must be created pro-actively through a variety of discursive and institutional mechanisms, reforms, designs and strategies. Only through acknowledging the special character of Politics of Life domains will governments be able to face up to the multitude of currents and future challenges in this domain in Europe.

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THIS DOCUMENT is based on the following reports prepared within the framework of the PAGANINI project. All documents and work package reports are available in electronic format on the PAGANINI project web site at www.paganini-project.net

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