

CHAPTER 1

ADAPTA EXECUTIVE SUMMARY

This is the final report of the European research project called ADAPTA, *Assessing Debate and Participatory Technology Assessment*, of the FP4-Biotechnology programme (ELSA). This study has been performed between September 1998 and November 2000.

The ADAPTA project aims at providing a better understanding of the role of structured participatory processes (such as pTA) in the area of biotechnology in Europe. The research does not focus on such structured processes *per se*, but it gives a comprehensive analysis of the interactions between such events and wider public debate in various institutional and political contexts. The research also analyses the interactions between these various forms of public participation (formal and informal) and the policy process in the area of biotechnology.

Six countries have been studied by national teams: Denmark, France, Germany, Portugal, The Netherlands, and the United Kingdom. Three fields of observation have been chosen: urban transport, genetically modified organisms in food and agriculture and genetic testing. In total, 17 case studies have been carried out to assess those interactions. The urban transport debate cases have been used to test the field research methodology. This report is focused on the analysis and comparison of 12 cases on the use of GMOs in agriculture and food on the one hand and on the use of genetic testing for human health on the other hand.

An International Workshop has been held in October 2000¹, as part of the ADAPTA project dissemination process. This Users' Workshop was designed as the final step of the research process. Our objective was double: to see if participants' experience and researchers' findings fitted together and to provoke a discussion on some key questions in order to improve the final report.

1 - 1. THE ANALYTICAL FRAMEWORK

The necessity of public participation in technology assessment is currently widely acknowledged by policy makers, key institutions as well as many scholars. Such a recognition reflects the failure of current forms of policy making and the need for new types of interactions between science, technology and society. Indeed, in the last fifteen years, the issue of participatory Technology Assessment (pTA) has been given prominence by many institutions and actors. This has resulted in a number of experiments unevenly distributed amongst countries and a quite significant corpus of literature in social sciences and political sciences.

However, the questions of broader interactions between pTA and Public Debate (PD) are seldom analysed. Previous approaches mainly focus on the internal properties of pTA and on the impact of these events on policy process. But since the notion of *public debate* is not really defined, the analysis of the interactions between pTA, the policy process and public debate are generally rather sketchy. These interactions are the main focus of the ADapTA project .

¹ Users' Workshop of Adapta project: Public debate and participation in science and technology policy assessment: Public scrutiny of public decision making under scientific uncertainty and controversy". Brussels, October 9th and 10th, 2001.

We identify different forms of public consultation or participation in science and technology policy making:

- **Formal dialogue processes or arrangements** : some of them involve lay people participation and are organised under specific rules by technology boards (like the Danish Board of Technology in Denmark, the Rathenau Institute in the Netherlands or OPESCT in France). In our project , most of those institutionalised participatory exercises are consensus conferences and citizen juries or panels which can be considered as participatory technology assessment events (pTA). Other formal arrangements do not involve lay people and are rather expert discourses or expert debates (even when they include NGOs representatives).
- **Informal or non-institutionalised actors' interventions** such as direct action, public protests, consumer boycott...which may precede, follow or be parallel to the organisation of formal events. They include less clearly defined, less formal (sometimes less well focused) activities which go on in civil society, extra-institutionally, as parts of processes which are forms of social or public technology assessment.

We propose an “arena framework” which allows to consider through the same analytical perspective public debate, technological trajectories and pTA. In this perspective, pTA differs from other formal dialogue processes (such as legal processes, parliamentary debates, ...) since debate is not anchored within one single arena, but it entails interactions between different arenas. Thus, there is a similarity between pTA and other forms of dialogue and confrontations which favour trans-arena interactions (such as direct action, public protests,...). Of course there are obvious differences: pTA is organised and framed by an initiator; whereas informal dialogue or confrontation erupts as a the result of mobilisation of social movements and it implies more or less mobilised actors which claim to act as spoke persons of parts of the society (consumers, the “public”, the environment, farmers, future generations, patients,...).

HOWEVER, PTA AND INFORMAL DIALOGUE/CONFRONTATION PROCESSES HAVE A COMMON EFFECT SINCE THEY FIRE UP OR INTENSIFY INTERACTIONS BETWEEN SPECIALISED ARENAS THUS ALLOWING A WIDE RANGE OF WORLD VIEWS TO BE EXPRESSED AND/OR TAKEN INTO ACCOUNT IN TECHNOLOGY ASSESSMENT.

This new perspective will lead us to closely analyse the issue of the objectives (how do such processes emerge as a solution to a given problem) and of their appropriation by the social actors (how stakeholders and actors engaged in the debate integrate the results of the formal exercise or informal process?). This analytical frame is important in order to capture the way in which public debate and/or structured processes may influence the rhythm and the direction of socio-technological trajectories.

1 - 2. THE FIELD RESEARCH METHODOLOGY

The field research methodology gave emphasis to two dimensions: the articulation between the case studies and their national context and the comparative dimension.

The forms of public participation are strongly embedded in national contexts. What we call national context is a mix of factors which include social context (socio-demographic features, associative movement, professional associations,...), institutional setting, and political culture (openness of decision process, tradition of participation, interactions of science and policy and boundary work). National context conditions both the dynamics of public debate and the forms of public participation in technology assessment, including the design and functions of formal dialogue arrangements.

Therefore, these arrangements should not be considered as singular events, but should be analysed in a more holistic way.

According to political culture and to various political science traditions, the normative value attributed to public debate is viewed in quite different ways:

- Traditional forms of political representation (as parliamentary) can be considered as the mean through which general interest can be pursued and public opinion enlightened. In such a perspective, public debate has traditionally be understood as in need of "management" or "prevention", since it is seen to conflict with or threaten these traditional forms of representation.
- On the other hand, public protest and direct actions may be considered as a beneficial addition to democratic systems through which the capture of policy making by bureaucracy and political elites may be counter-balanced.
- In Nordic countries, institutionalised participatory processes are considered as the main forms of public debate and normal features of democratic systems based on participation and consensus building. In this perspective, public expressions of dissent are not always seen as positive signals of the running of democracy, but rather as a failure of a system which is unable to propose accepted/acceptable solutions.

As a European research network, we had to take benefit from a reflexive stance which may feed the analysis. Therefore, we ought to take advantage of the variety of the situations and of our own perception (or misperception) of these differences. In this perspective, it was meaningful to observe that in some countries it was very difficult to find many formal dialogue arrangements or any pTA (say in Portugal) or that in other cases, the national research team considered that formal arrangements had to be considered in relation with various forms of direct action which trigger public debate, etc.

This underlines the relevance of the comparative analysis. The processes of development of public debate and the emerging of the many forms of public participation may tell a lot on or need to be understood in the national context. Therefore, the analysis of the links between national context and the design of the formal dialogue arrangements and its roles or effects on the policy process has been central.

1 - 3. COMPARING THE FORMS OF DEBATE ON GMOS IN THE VARIOUS COUNTRIES

Six case studies from the different countries are presented in the report and compared on the interactions between public debate, public participation and policy process on the GM Food issue.

1 - 3.1. The specific actors' constellation

Unlike other major technological innovations (e.g. nuclear power), food production and distribution involves numerous and diverse actors throughout the food chain: farmers, seed companies, food manufacturers and distributors, biotechnology firms, research scientists... Each of these groups have their own vested interests and their own specific relationship with citizens and consumers. Furthermore, food products are something that citizens are in contact with everyday and about which they have some - relative - direct choice. Citizens have therefore been able to influence decisions about GM food through their behaviour as consumers and voters as well as through their role as environmental activists.

These specific features of the GM food issues may explain the intensity of public debate and the frequent initiatives which aim to broaden public participation.

1 - 3.2. Public debate and public participation on GMOs

Since 1996, a wide public controversy on the use of GMOs for agriculture and food production has developed in various European countries. This controversy has resulted in a severe reaction against government policies and ag'biotech companies strategies and it has had profound influences on the policy process at EU as well as national level.

The amplitude of the reaction has been much higher in countries like France and UK which are traditionally characterised by elitist and (in the case of France) technocratic mode of policy decision making processes. On the other hand, in countries like Denmark and the Netherlands –and Germany to a lesser extent-, where participation in technology assessment is embedded in the national political culture, GM food –and more broadly genetic engineering- has been a major area where pTA has been organised in order to launch and foster public debate

The public controversies and the new experiences which take place in various European countries may be considered as genuine social experiments on new forms of governance of socio-technical innovation. Nevertheless, this cannot be taken for granted since in various countries, political elites and interest groups are not necessarily receptive to this new forms of deliberation. Furthermore, these broad social experiments were fuelled by a specific problem, namely: the failure of the introduction of GM food in Europe. However, GM food controversy may be interpreted as the reaction against a technocratic mode of governance of innovation. Social mobilisation was fuelled by the inability of the institutional system to respond adequately to peoples' concerns and it is also a reaction against a process of technological innovation which has failed in integrating peoples' interests and in taking account their values.

The characterisation of public debate on GM Food shows that sharp differences between countries exist in terms of the temporal evolution of the public debate as well as in terms of framing and space of mobilisation. We suggest that one of the main factors explaining differences in the dynamics of public debate lays on the degree of openness of the policy process.

From a different perspective, we can see that different factors favour an international dissemination of the public debate and tend to erase national differences in the recent period: (i) the transnational dimension of the GM food issue, because of agricultural trade, EU and international regulations and also actors (Companies as well as some NGOs) who have global strategies; (ii) the very low degree of openness of the GM socio-technical network .

In this context, beyond their diversity, formal dialogue exercises have a double face. On the one hand, they are quite satisfactory in terms of free deliberation; they may foster trans-arena interactions and help to articulate different "world views". On the other hand, they have a limited impact on the public debate and differentiated effects on the policy process according to countries.

In four countries out of six, Denmark, France, Germany and UK, the formal dialogue events we examined were structured around lay citizens which play a central role in the assessment process:

- the consensus conference in Denmark, organised by the Danish Board of Technology in Spring 1999 focused on the understanding of the population's continued scepticism about GMO food;
- the Citizens Conference in France, organised in June 1998 by OPESCT, Parliamentary Office for Scientific and Technological Choices;

- the Buergerforum in Germany, initiated in July 1995 by the Land of Baden-Wuerttemberg;
- the Citizen Foresight in UK, organised by an NGO (The Genetic Forum) in conjunction with an academic institution, in 1998.

Three of them (Denmark, France and UK) can be considered as participatory technology assessment exercises. They involve lay people and deal with public opinion: they aim at better assessing public opinion in this controversial area (what are the key issues at stake? What are the main conflicts? ...). The expected benefits of this formula relies on the possibility to involve an *informed public* in a deliberative process. Lay people who have not vested interests are selected precisely because they only represent nothing but themselves. Also, they do not have any expert knowledge. That's why the pTA exercise includes a phase of training where panel members receive basic information on the subject which aims at showing the state of the art, the state of the unknown and the areas of controversies. With such a training, lay citizens are supposed to *represent an informed public*, independent from specific vested interests.

In the two other countries, the cases which have been studied are not participatory exercises.

- In Portugal, no real participatory event has been identified, despite the emerging of many formal dialogue arrangements involving mainly experts, policy makers and a few NGOs. The issue of public participation in science and technology is quite new in Portugal. The authoritarian regime that ruled Portugal from 1926 to 1974 has been quite unfavourable to public participation in general, and to the institutionalisation of pTA events in particular.
- The Dutch case cannot be considered as a "participatory exercise" *stricto sensu* since it does not involve lay people. The *informal consultation* which took place from 1991 to 1998 is the result of an initiative of a manager at Unilever which formed an informal group of stakeholders and public interest groups, in close connection with the major Consumers Association (Consumentenbond)². This case was chosen as this kind of informal, nonofficial meeting is considered typical for Dutch civic society ("Poldermodel"). It is a "people network" (note a network of organisations) building trans-arena relations between economic actors and consumer, environmentalist organisations.

1 - 3.3. Lessons from this comparative analysis of the GM food case studies

Relations between public debate and formal arrangements

- When public debate has already developed, the possibility to influence it through formal dialogue arrangements (as pTA) is often limited.
- It is possible to better inform the policy process through "materialisation of the public opinion" and involvement of lay people. However, the re-appropriation of this result is limited in a situation where the actors strategize and contribute to the public-isation of the issues at stake.
- The analysis suggests that the pre-emptive effect only observed in the Dutch case is not related to any possibility to channel or preclude the debate; this effect is rather conditioned by the influence of the exercise on the policy process.

² This model of "informal consultation" is not a Dutch monopoly. Various experiences taking place in other countries, including France, could be quoted. The Dutch specificity lies in the strength and influence of such consultation in the Netherlands.

Relations between public participation and policy making

- In many countries, the pressure of social actors' direct intervention on the policy making has a leading influence on the structuring of the interactions between arenas and actors of the arenas.
- The possibility to implement early formal dialogue processes is related to a political culture of openness and of public participation in policy process.
- Structured participatory processes enable the integration of a diversity of world views without strong polarisation of the positions. They may have a very important –although not traceable- function within the policy process through a better understanding of people's concerns and interests. Therefore, they should not be viewed as an isolated exercise but as a part of an overall effort towards wider public participation.

1 - 3.4. Comparing the forms of debate on the use of genetic testing

An early policy framing

Most of the selected countries present a framework characterised by a double dimension made of :

- active science and technology policies aiming at promoting biotechnologies,
- implementation of a legislative frame for defining and controlling the conditions of development of genetic engineering applications to human health. This legal framing is twofold: one dimension is the regulation and control of research and its applications; the second dimension is the implementation of advisory instruments to advise, steer and monitor new developments.

Quite early (since mid'80s) public authorities have implemented legal and regulatory frames for controlling genetic research and its applications. Simultaneously, bioethics committees and advisory bodies have been set up by those legal initiatives to emit signals to policy makers and the public that social and ethical concerns have to be taken into account.

Portugal could be an exception where public policies aiming at the promotion of biotechnologies remain quite modest and specific and consistent regulatory framework for human genetics still does not exist.

The actors' configuration

The driving mobilising actors are patients' associations, geneticists and medical doctors. They are mainly in favour of the development and large dissemination of genetic tests, considered as a *point de passage* for gene therapy of genetic disorders and diseases. The mobilisation of those actors is focused towards the formation of an actors' network and the building of joint strategies.

Active drivers as patients' associations representing genetic disorders exposed groups of population, are involved in the consolidation of the socio-technical trajectory: how could patients' associations be opposed to genetic testing and gene therapy as THE solutions? Their major strategy is to enrol and elaborate common platforms and programmes with researchers and medical professionals, with the kind support of drug industry, public authorities and insurance companies (in The Netherlands). In this context biotech and drug industries remain absent of the debate. However, they are mediators in that they work with researchers, they fund (partly) research, and they may sponsor patients' organisations for establishing genetic testing as obligatory point de passage of gene therapy. But there is clearly no *Monsanto* of genetic testing or gene therapy, being a catalyst for support or opposition.

By opposition to patients' organisations, smaller patients' organisations, disabilities and women movement (in Germany), civil right groups, concerned scientists associations (in France) position themselves in the fields of citizenship and the right for all to health insurance, work or personal genetic data protection. They consider social discrimination and eugenics to be serious issues and risks related to the generalisation of genetic testing. They are also engaged in a process of alliance building in the different countries, as in France or the UK.

Public debate and public participation on genetic testing

The spaces of construction of such a strategy are mainly expert arenas, hybrid fora, but also formal dialogue arrangements (in Germany and The Netherlands). Those hybrid fora involve very different kinds of actors for this joint objective, which is the promotion of the development of gene therapy and genetic testing for medical purposes. So, they promote and multiply interventions for pushing joint strategies. And their participation in formal dialogue arrangements could be considered as a part of this enrolling process.

Civil society actors like associations (NGOs or charities) lead to the constitution of hybrid fora, considered as spaces of deliberation and articulation between actors from different arenas. This important characteristic helps to understand the enclosure of the debates in spaces like arenas and hybrid fora.

On the six countries, only four have hosted formal dialogue arrangements on genetic testing or genetic research:

- Denmark: The Danish Board of Technology of the Danish Parliament organised a consensus conference on human genetic research in 1989 and on gene therapy in 1996;
- Germany: From 1991 to 1998, three (1991, 1993, 1998) discourse meetings took place in Bonn, organised by human geneticists of the Institute of Human Genetics of the University of Bonn and associations of patients concerned with inherited and congenital disorders; a consensus conference will take place in Dresden in 2001;
- The Netherlands: In 1994, the Platform for Science and Ethics organised its first event with a consensus conference "to stimulate knowledge and the forming of opinion with regard to hereditary research";
- UK: In November 1997 the Welsh Institute of Health and Social Care carried out a Citizens' Jury with the following question: "What conditions should be fulfilled before genetic testing for susceptibility to common diseases becomes widely available on the NHS?"

The two consensus conferences in Denmark have been undertaken by an actor from the political arena: the Danish Board of Technology, linked to the Danish Parliament. Their focus was quite broad : human genetic research (1989) and gene therapy (1996) in Denmark. The actors' configuration is quite different in the Netherlands : the consensus conference has been organised by a set of actors from different arenas: Rathenau Institute and Health Council with the support of VSOP (patients' associations' umbrella).

In Denmark, debate in specialised arenas is sufficient for stimulating the organisation of a formal dialogue arrangement like pTA. It is seen as a sign of an upcoming debate or a sign for opening up a debate, which pTA can help doing. In the Netherlands, the Consensus Conference was organised before the possible expiration of the moratorium in 1995 which provoked then reactions from HIV patients' associations. The Danish and Dutch pTA exercises present some similarities in their format and organisation: the Danish and the Dutch consensus conferences, with lay panel declarations at the end of the pTA.

The two other events are the so called discourse meetings in Germany and the Welsh citizens' jury in UK. In the German case, there was no final declaration and in the British case, the organisers wrote the final report. In Germany and the UK, instigators are actors involved in the development of genetic research, the Institute of Human Geneticists of Bonn University, or in the development of genetic testing use, the Welsh Institute of Health and Social Care in UK.

A common point to the German, British and Dutch cases is their focused orientation:

- Common grounds between patients associations and human geneticists in Germany and hereditary research in the Netherlands
- The British exercise was on genetic testing within an acceptability perspective (“conditions to be fulfilled before genetic testing to be available in the NHS?”).

In France, no formal dialogue arrangement organised at national level has been analysed. The debate is driven by the legislative activity: adoption of the bioethics laws in 1994 and their revision in 2001 or 2002, with a lot of discussions between experts and policy makers channelled by the technology board (OPESCT) of the French Assemblée nationale. There are more and more demands of discussions and debates about human biotechnology issues like cloning and genetic testing. Cities, universities, hospitals and associations already develop some informal debates between lay public and professionals in order to broaden the debate and diffuse the information.

In Portugal, there have been no participatory initiatives. Some space for public participation in decisions concerning the uses of human genetics may be opened by interventions in public health and require the convergence of State agencies, researchers, clinicians and local populations.

A direct outcome of the 1989 Danish Consensus conference on human genetic research has been the Parliamentary debate resulting in 1996 Law on genetic testing and screening. An interesting consequence of the learning process generated by those exercises is that most of the time new projects of institutionalised debate emerged with the ambition of replicating the same process, considered as positive, in other contexts or having a more focused scope for the next exercises. So the shift is from questions and discussions on human genetic research towards predictive medicine, as field of application.

Lessons learnt from the comparative analysis of the genetic testing case studies

Relations between public debate and formal arrangements

- The rigorous legislation of some countries like Germany or Denmark has influence on the agendas by transforming some questions into non-issues. Early formal dialogue processes in Denmark or Germany may have anticipated on the issues, provoked a debate and avoided polarisation of positions. This means that we may have a quite broad debate without acute polarisation or controversy.
- The French case shows that the channelling of the dialogue between experts, ethicists and policy makers into the parliament under the authority of OPESCT (the French technology board) also contributed to early policy decisions.

The importance of concerned groups

- In all countries, actors from civil society like patients' groups, civil right associations or churches intervene in the public debate by building new spaces for networking and joint strategy elaboration, that we have called hybrid fora. Such a process has a decisive influence on the channelling of the public debate at a trans-arena level and on the policy making.

The issues at stake

- In Denmark, France, Germany and The Netherlands, the debate on predictive medicine is quite active and visible. For reproductive medicine, Germany seems to have a long and permanent debate, due to its past; in Denmark, there has been a long debate about reproductive medicine, which helped to trigger the whole debate about gene technology in the political-regulatory and wider public arenas. Risks of discrimination are on the agendas in Denmark, France, while in Germany, while in the Netherlands, the United Kingdom and Portugal it is not so much the case.
- On ethics, Denmark and Germany are more active than the others. In all countries, ethicists and social scientists underline risks such as eugenics induced by the use of prenatal diagnosis, social discrimination at work and health insurance against individuals presenting genetic predisposition to diseases.
- The weakness of actors or actors' mobilisation in countries like Portugal do not mean that pointed questions are not issues, but mean that it is difficult for those issues to emerge as problems at arena and even more at public sphere level.

1 - 3.5. Overall conclusions

The claim for public participation in science and technology policy assessment

In all countries, there is a clear public pressure for participating in the assessment of technology. This pressure may be seen as a social answer to the closeness of policy systems unable to provide acceptable solutions. Then, the demand for public participation is a reaction of society to the growing distrust towards policy making and science. In another perspective, the expressions of public participation can be seen as a positive signal for policy systems where enlightenment and empowerment of The public are or should be key values of democracy. This first result should be carefully taken into account by European institutions as it concerns also the ways European institutions interact or should interact with society when elaborating and assessing science and technology policies.

The forms of public participation differ a lot according to national socio-political cultures and policy systems

The forms of public participation in science and technology assessment are very diverse: They may be formal and informal. The formal forms are structured as formal dialogue arrangements (among them are the participatory technology assessment exercises, pTA) while the informal forms result from social actors' direct intervention in the public debate.

The national socio-political culture and policy system are two key variables weighting a lot on the forms and expressions of public participation (formal and informal) in technology assessment. The possibility to organise early formal dialogue arrangements is related to the culture of openness of policy process. Therefore formal public participation should not be viewed as an isolated (one-off) event, isolated exercise but as a part of an overall effort towards wider public participation.

The forms of public participation differ also according to the field we examine: overflowing for the GM food debate and channelling for genetic testing use debate

The European analysis on GM food debates shows that in some countries, society mobilisation has taken place to stop the GM “juggernaut”. When public debate has already developed on such a direct way, the potential influence of late formal dialogue arrangements as pTA is often limited . The re-appropriation of the results is limited in a situation where the actors strategize and "publicise" the issues at stake.

The genetic testing European comparison reveals that in all countries, actors from civil society like patients' groups, civil right associations or churches intervene in the public debate by utilising new spaces for networking and joint strategy elaboration, that we have called hybrid fora. Such a process has a decisive influence on the public debate by channelling or transmitting it at a trans-arena level. The building of an actor network joining patients' groups, geneticists, medical doctors and industry to disseminate as fast as possible the use of genetic tests, as a necessary "point de passage" for gene therapy, is for now the dominant structuring factor.

Issues at stake and expertise

A significant difference between the GM food cases and genetic testing cases is on the way uncertainty is managed when dealing with the possible consequences of GMO's and their release in the environment and their consumption, and in using tests, with uncertain reliability on the outcomes. For GMOs, the strong scientific controversy involves "official"experts and counter-experts mobilised by NGOs, and scientists from public research institutions: this scientific controversy points out uncertainty of knowledge and potential risks for environment and health. "Experts disagree". In most genetic testing cases, the absence of scientific controversy about the technology prevents a "crystallisation" of fears and anxiety about genetic testing. There is no visibility of a controversy between scientists about the core and the safety of the genetic testing. The debate is rather directed towards embryo status questioning, predictive and reproductive medicine issues or human rights concerning discrimination risks or genetic data protection.

Individual choices and society interests: a potential conflict revealed by the genetic testing cases?

The genetic testing examples raise a serious question if human biotechnology development depends on concerned groups: How society common interests can be taken into account? How other issues than gene therapy can be put on public agenda? There is an important boundary here between individual choices and concerns (i.e testing in clinics for specific disorders) and the more general (public collective) social concerns about data collections and national screening. It would be more likely for issues related to testing associated with insurance or with workplace conditions, or with the construction of DNA databases (like in Iceland) , to screen the population for a range of multi-factoral conditions, to turn into issues for public debate. Then, genetic testing could be seen as impacting citizens in an even more profound way than, say, GM food: in the right of all to health insurance, work and privacy, ie issues concerning civil liberties.