

CHAPTER 3

PROJECT RESULTS: PRESENTATION OF THE CASE STUDIES

3 - 1. INTRODUCTION TO CASE STUDIES

A major characteristic of the Adapta project is the possibility to compare the ways the interactions between public debate, formal dialogue arrangements and policy processes develop in the countries in the fields of genetically modified food and the use of genetic testing.

In some countries, there are formal dialogue arrangements to be examined and in other countries there are not. This disparity is *per se* an object of our analysis.

In the countries where formal dialogue arrangements could be observed, the local research team was the main responsible for the choice of the case, according to some common criteria as:

- relevance of the case on the debated issues,
- press coverage,
- political importance,
- uniqueness of the case.

The main actors of those events (participating or not participating) have been interviewed. Their words and rationales, in their diversity, weighted a lot on the analysis.

To analyse the cases, all the partners have adopted the same questionnaire and the same analytical guideline. Even with those precautions, the focus of the cases may have differed according to the national research teams skills, knowledge, understanding of the issues. Another important difficulty needs to be pointed out: some case studies happened some years ago and it has been sometimes difficult to find key actors and to make them remember what happened in that time. So this time distance may have introduced some biases: the story may have been partially forgotten or re-written. However, all those elements are good to be taken into account.

We present in this chapter a synthesis of those cases.

The reader can find the complete version of the cases in the national reports (in annex). In those national reports, the case studies concerning urban public transport debate are also presented.

3 - 2. GM FOOD CASE STUDIES

3 - 2.1. GMOs- ID CARD- France

1 – the public debate	
What are the issues at stake?	<p>The actors mobilised on the GMOs controversy do not frame the GMO issue in the same way:</p> <ul style="list-style-type: none"> ◆ <i>food safety</i> : right to be informed, right to choice genetically modified food or not (issue framed mainly by consumers) : importance of questions raised on antibiotic resistance gene; controversies on labelling ◆ <i>environmental problems</i> (mainly gene flows) : importance of questions raised by gene flows in the case of rape seed and sugar beet (issue framed mainly by environmental groups) ◆ <i>economic problems</i> : genetic power, globalisation, dependence of farmers, choice of a model for agriculture ;"agriculture paysanne" or mass- productive agriculture (issue framed by Farmers Unions and Greenpeace) ◆ <i>issue of science and expertise</i> : independence of experts, limits of sound science, precautionary approaches
Did they change in the last 5 years?	<p>The main stakes in the public debate were per se the same, partisans and opponents did exchange many arguments on the nature of the risks, their control and the interest of these techniques. But there were changes in the nature of the public debate and in the responses of the government to the mobilisation.</p> <p>1. <i>Change in the nature of the public debate</i> : broadening of the space of mobilisation, increasing importance of concerns, emphasis on uncertainty and on labelling. The campaign on "Mal bouffe" which was developed in 99 provided a link between the various frames : food safety, environmental adverse effects and choice of agricultural model. The hardening of the movement against GMOs led the opponents to GMOs to establish a black list of GMOs products and make a destruction campaign of transgenics plants.</p> <p>After the controversy on the Terminator the questions relating to the economic organization (concentration of firms, appropriation of living being) became more and more topical</p> <p>2. <i>governmental response</i> : emphasis on bio-vigilance (creation of the committee of bio-vigilance), partial moratorium, change in the composition of the CGB, the main experts' committee for GMOs, which was over represented by biomolecular scientists, organisation of a PTA, the "Conférence de Citoyens", leading position in favour of the suspension of authorisation for GMOs at the European Council of the Environment....</p>
Who are the main Actors of the debate?	<p>1. The mobilisation space:</p> <ul style="list-style-type: none"> ◆ The first circle of mobilisation <p>-Greenpeace and Confederation paysanne (a farmer trade union) had a key role in the launching of the controversy. The Confederation paysanne was the main actor to frame and link the problems.</p> <p>-The other associations of environmental protection, which are federated principally by "Acting for the Environment"¹ and including Ecoropa, "Nature France and Environment" claimed a general moratorium about transgenic plants too but were more follower. However they could rely on their strong militant structure in order to develop decentralised actions: use of their influence on school canteens, mobilisation around the problems of lack of transparency in information about cultivation GMOs tests.</p>

¹ Greenpeace was member of "Agir pour l'Environnement" too

	<p>-The actors of this first circle tried to mobilise and heighten public awareness thanks to legal action (they deposited an appeal to Council of State, which led to suspend the decree of authorisation for cultivation corn Bt 176 in September 1998) and thanks to illegal action of seeds destruction.</p> <p>"Nature France and Environment" and Ecoropa refused to participate in the PTA.</p> <p>◆The second circle of mobilisation</p> <p>- The consumers' associations reject the illegal actions, but they are sensitive to the concerns, which had justified actions of Environmental and Farmers' NGOs. They assert a greater control of the food safety and the possibility of reliable information and free choice of products.</p> <p>-After the PTA the consumers associations became the allies of a firm distribution Carrefour and the FNSEA for a reflection about the setting up of a non –GMOs food chain. The FNSEA, the first farmer trade union in France, being located in a modernistic tradition had evil to play a role on the scene occupied by the Confederation Paysanne. It participates in the debate by reflecting about the setting up of a non- GMOs food chain.</p> <p>◆ radical but minority opposition to GMOs. The Association " Some enemies of the best of the transgenic world" denounces the origin of the technological totalitarianism, which consists in " substituting technical solutions for choices of a political nature ". Within this framework, the debate in its view can only be trapped and manipulated. It did not participate in the PTA.</p> <p>2. Actors, who are not in the space of mobilisation but who participate in the public debate in trying to react to the mobilisation:</p> <p>- The agro-food firms like Novartis, Monsanto, have tried to support the GMOs by different communication campaigns. Novartis took part to the PTA.</p> <p>- The government. But it was not homogenous, because some issues brought into conflict the Ministry for Environment and the Ministry of Agriculture, which support different causes. Then the Prime Minister had to be the arbiter. The government contributed to launch a controversy and a strong mobilisation because of its successive contradictory decisions concerning GMOs.</p> <p>-The Green political. They criticised the decisions of the government, because these one would violate the principle of precaution and would carry the mark of a lack of democracy. But they have a limited role in the mobilisation because of their participation in the government.</p> <p>3. The media play a key role in being the relay of the mobilisation. They largely cover the topics.</p>
2 – The PTA	
When did it happen?	<p>The PTA did happen in June 1998. The government Jospin had decided in the same time, on the 5 February 1998 to authorise the cultivation of GM maize and to organise a PTA about GMOs. This PTA was one of the measure announced by the government as a way to improve transparency for the public.</p> <p>The PTA was organised at a time when public debate was going on, when actors like consumers associations, associations for the protection of environment, mobilised and when the media reported a lot the mobilisation.</p>
Who organised it?	<p>The idea of a PTA was launched by the government but it was organised by the OPECST, Parliamentary Office for Scientific and Technological choices, which had to assure the independence and neutrality in the debate. For the Office, this PTA was led within the framework of the study of his President Jean-Yves LE DEAUT, which comprised a study during which the rapporteur auditioned 250 people, a public audition, an internet forum and the PTA itself.</p>
What was the core question?	<p>The conference was aimed at contributing to a definition of the acceptable risks standards as regards to GMOs. That's why several aspects were dealt with and the</p>

	<p>view was not to reach a definitive consensus about GMOs.</p> <p>It was divided in 5 round tables:</p> <p>-Medical risks-Environmental risks- Information of the consumer- Legal questions-The regulation of relations of conflicts - The complex interests around GMOs.</p>
How was it organised	<p>The model chosen was the Danish model with some adaptation.</p> <p>The PTA was called citizens conference and not consensus conference, which left more flexibility in the use of the text for all the actors because the difference of opinions were underlined.</p> <p>The steering committee included 7 experts and no representative of associations.</p> <p>No device of evaluation was made after the conference.</p> <p>A pool institute selected the members of the panel.</p> <p>According to the standard method of Consensus conference two working week ends were organised for the formation of the lay people. The conference lasted two days, divided in 5 round tables.</p> <p>During the night of the second day the panel had to write the final declaration and gave it to the government and the parliament after the press conference.</p>
3 - Interactions PTA/ Public Debate	
<p>Is PTA as an answer to the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>The choice of a PTA was determined by urgency of the situation, by the pressure of public opinion in this controversy and by the pressure of USA. All actors agree to say that this PTA was as an answer to the very polarised and mediatized public debate.</p>
<p>Did PTA amplify the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>The Ministries of Agriculture and of Environment thought the PTA was a way to stimulate the debate in France and on behalf of people who have not extreme positions.</p> <p>The actors, institutional, NGOs, scientists think it was favourable to channel and stimulate the debate partly because the PTA was an event favourable to meetings between different stakeholders. Moreover the representative of NGOs and associations of environment and people from INRA think that the PTA allowed producing an internal debate in their own organisation.</p>
<p>Did PTA contribute to modify the content of the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>In the view of organizer the PTA was to clarify the public opinion, while launching a debate on “healthy” bases.</p> <p>The key actors recognized the quality of debates, which were developed during the conference but underlined the lack of re-appropriation of the conference by the government and by the parliament. It was as if the PTA concluded the public participation, the exchanges between the political power and the public. The actors think that impacts on the content of the public debate should be evaluated like impacts on public decisions too. And on that point they were not satisfied. In summary the confining of the exercise, its outcomes in an simply annex of an other report, its institutional defensive characteristic and the possible ambiguity of its objectives had prevented, since the announcement of this PTA, any transformation in the nature of the public debate.</p>

3 - 2.2. GMO ID CARD – Germany

1 – the public debate	
What are the issues at stake?	<p>In the agro-food sector the first products such as herbicide resistant plants like soybeans or maize have entered the market stage, which are also available in the EU. However, opinion polls, studies, and campaigns showed that the consumer acceptance of genetically engineered food and agro-products in general was low and seems to decline since the cloning of the sheep "Dolly" and the broader entrance of genetically modified food products into the market.</p>

Did they change in the last 5 years?	In the last five years genetically modified food has been introduced into the market. Primarily the debate is carried out on the mode labelling of genetically modified food. However, risk analysis as the studies of Pusztai were discussed in the public in Germany but did not gain the same importance as the discussion on genetically modified food in the past.
Who are the main Actors of the debate?	The positions between people favouring and rejecting biotechnology differed extremely. Communication between the two parties was hardly possible. The group rejecting biotechnology was constituted from consumer protection associations, interest groups for ecological agriculture, associations for environment protection and the "Öko-Institute" in Freiburg (a private research institution that carries out studies on the ecological impact of new technologies). The fraction favouring biotechnology was less organised and present in the public. It was formed mainly from scientists, few companies such as Monsanto, and politics. The industry with few exceptions such as UniLever did not join the PD at all. However, especially Monsanto followed an aggressive PR-strategy that enhanced the conflict between biotechnology supporters and biotechnology opponents.
What are the main topics of the controversies?	Topics discussed were applications in medicine, agriculture, food technology and environmental biotechnology. The discussion was dominated by the analysis of risks and uncertainties of this technology concerning application in agriculture and food processing in particular. In this context, a big campaign "Essen aus dem Genlabor? Natürlich nicht" (Food from genetic engineering laboratories? Of course not) was initiated in which information material was published which mainly stressed the risk of genetic engineering. Due to the lack of other information material the brochures published in this campaign have been relatively widespread, often using public consumer information services for distribution.
2 – The PTA	
When did it happen?	The BUERGERFORUM took place in July 1995.
Who organised it?	The BUERGERFORUM was part of a project initiated by the state of Baden-Wuerttemberg to evaluate the potentials of biotechnology and genetic engineering. The organising institution was the Center of Technology Assessment in Baden-Wuerttemberg.
What was the core question?	The BUERGERFORUM dealt with the aspects of biotechnology and genetic engineering in the field of agriculture and food. The main topics were: Identification of conflicts of aims due to the introduction of genetic engineering, risk discussion at the example of release of transgenic plants and discussion on economic importance of genetic engineering.
How was it organised?	In the BUERGERFORUM 200 representatives of the general public were chosen randomly in three towns of Baden-Wuerttemberg in order to discuss specific topics dealing with the applications of genetic engineering in food production with experts for four days. After the discussion rounds the citizens were asked to decide on selected questions in this field in order to get assessment of genetic engineering applications by informed people. The organisation of the BUERGERFORUM was based on the theoretical background of the "Planungszelle" (planning cell) invented by the University of Wuppertal by P.C. Dienel in 1975. This method had been proven to be an efficient tool for pTA/PD in various cases.
3 – Interactions PTA/public debate	
Is PTA as an answer to the public debate? Who says yes and why? Who says no and why?	Yes. The controversial debate on the application of genetic engineering in agriculture and food industry was one of the factors which lead public institutions to initiate and finance (p)TA activities in this field.
Did PTA amplify the public debate? Who says yes and why?	Overall the impact of the BUERGERFORUM on PD on genetic engineering issues in Germany seems to be rather small. It is very difficult to identify any direct links to policy actions.

Who says no and why?	
Did PTA contribute to modify the content of the public debate?	No. The BUERGERFORUM did not influence the contents of the public debate.
Who says yes and why?	
Who says no and why?	

3 - 2.3. GMO ID CARD – The Netherland

1 – the public debate	
What are the issues at stake?	<p>Freedom of choice to consumers, the possibility to avoid food made with the help of genetic modification.</p> <p>Issues: what food should be labelled, only foodstuffs containing genetically modified elements (in the end products or all foodstuffs made with genetic modification? The choice is to label on the basis of the chemical composition of the end product or on the basis of the way of production.</p> <p>The possibility to keep streams of gmo raw materials (maize, soy etc) separated, from non gmo raw material.</p> <p>Do citizens/ consumers want the inserted qualities in crops: herbicide resistance, pesticide resistance Is there consumer demand for g.m. crops?</p> <p>environmental risks and human health risks</p>
Did they change in the last 5 years?	<p>The issues themselves did not change. But the accents and standpoints and insights changed</p> <p>Consumers who want to consume gmo free can only do so if streams of raw materials are kept separated and when the administration and labelling of the gmo foodstuffs is done in an accurated way.</p> <p>The standpoint changed from labelling on the basis of chemic composition toward labelling on the basis of production procedure.(This is a change in the state of the art and a change for strategic reasons)</p> <p>Now separation of streams of materials is being considered (power shift)</p> <p>This demand question is still there, but is all the time overshadowed by risk discussions. (risk discussion predominate over desirability discussions)</p> <p>the discussion on health risk predominates that on environmental risks.</p>
Who are the main Actors of the debate?	<p>Industry (Science on the background)</p> <p>Consumer organisations</p> <p>Environmental organisations</p>
What are the main topics of the controversies?	<p>To introduce gmo food (soy and maize), to apply gene technology and be open about it</p> <p>To communicate about gmo food in a neutral/ balanced way</p>
2 – The PTA	
When did it happen?	<p>1991-1998: there were informal consultations (meetings) a few times a year.</p> <p>In other words: the consultations started before the introduction of gmo foodstuffs in Europe and before European legislation on biotech food.</p> <p>It finished after the formulation of European legislation based on the composition principle.</p>
Who organised it?	<p>Unilever organised it together with the consumer society and the foundation consumer and biotechnology. Alternating Unilever and the Consumer Society</p>

	preceded? The meetings.
What was the core question?	How to introduce gmo food without risks and troubles. How to introduce gmo food in an open and honest way?
How was it organised?	Informal meetings of a few hours/ half a day took place 4-6 times a year, during 5-6 years. Often there was a presentation of a standpoint followed by a discussion. There was hardly any or no decision making. Alternatingly Unilever and the Consumer Society presided over the meeting. Minutes were sent to the participants and to some externals (Government). Once there was a press conference on an agreement on labelling and the provision and exchange of information.
3 – Interactions PTA/public debate	
Is PTA as an answer to the public debate? Who says yes and why? Who says no and why?	This pTA was not a direct reaction to a public debate, but it may be considered a response from Unilever to an attempt from the side of the Consumer Society to mobilise consumers on biotech. This is the view of Unilever. As a researcher I state that there was no unrest among consumers at that time; there was only a thread of unrest.
Did PTA amplify the public debate? Who says yes and why? Who says no and why?	Not really, that means nobody said that the informal meetings intensified public discussion. In 1996 when the gmo maize and soy was introduced and the environmental organisation left the meetings the discussion inside that environmental organisation enlarged. The board of that environmental umbrella organisation wrote a position paper about it. (so the pTA stimulated some debate inside organisations)
Did PTA contribute to modify the content of the public debate? Who says yes and why? Who says no and why?	General opinion: No says. It changed decision making slightly: e.g. industry decided to avoid antibiotic resistance (says the industry) Outsiders from environmental organisations (Green peace, analyst /reporter) says that the pTA made the discussion less polarised and critical. :

3 - 2.4. GMO ID CARD – Denmark

1 – The public debate	
What are the issues at stake?	(NB. While this case study analyses the development of public debate about gene technology and GM food throughout the 1980s and 1990s, the following focuses on the latest phase, from 1996 onwards.) At the centre of public debate was the question of how to deal with the issue of GM foodstuffs. This was prompted by the arrival of GM food products (soya bean, later corn) on the Danish market. The introduction of these products was made possible because of related European Commission approval. However, in Denmark there was a great deal of resistance to GM food, which manifested itself in the outbreak of a public controversy, which a group of Danish academics described as “probably the most intense debate since biotechnology became an issue of public interest”. A large proportion of the population was said (as evidenced by several opinion polls) to reject GM food and insist on clear product labelling. In short, the issue was how to tackle the <i>problem</i> of GM foodstuffs, which for some meant how to ban GM food, and for others how to regulate it effectively and ensure proper consumer choice. There were also associations in the public debate with related topics, such as the wider issue of how to achieve sustainable agriculture, and the issue of cloning (in connection with ‘Dolly the sheep’).
Did they change in the last 5 years?	There was a considerable change in the intensity and nature of public debate between the period before the introduction of GM foodstuffs and the period thereafter. While the period before was described as relatively quiet and uncontroversial, the arrival of GM soya led to a sea change in public debate. There was significantly increased media reporting, different actors got directly involved in public debate (sometimes

	<p>using ‘public opinion’ as justification for their action/viewpoints).</p> <p>The issue changed in the sense that GM food presented itself as something real (rather than abstract), a concrete application of modern biotechnology that had entered everyday life, forcing politicians/public authorities into action.</p>
Who are the main Actors of the debate?	<p>The Danish Parliament and government reacted quite swiftly to the changing public debate, by agreeing for example on GM food labelling guidelines before the European Commission negotiations on the novel food directive came to conclusion in 1997. There was considerable concern amongst Danish politicians (from across the party-political spectrum) about the speed with which GM food had become an issue in public debate.</p> <p>NGOs, and especially Greenpeace, were an important driving force of the public debate and political action. They managed to influence the debate in a way which they had found difficult to do prior to 1996.</p> <p>Food processors and food retailers started to take more notice of public debate and reacted, for example, by declaring GM-free policy implementations.</p> <p>Industry was still largely in favour of GM food, although there apparently was some tension rising between the agricultural and the pharmaceutical ‘wings’ within the Danish Association of Biotechnology Industries (the pharmaceutical companies were concerned about the unprecedented public scepticism, which could possibly undermine the future of gene technology in the human domain).</p> <p>The media were an important actor, as they amplified and channelled the debate taking place in the various public sphere arenas. Last, but not least, the public itself was an important actor, albeit a more passive and elusive one, as represented by public opinion polls and media reporting.</p>
What are the main topics of the controversies?	<p>They included, amongst other things:</p> <ul style="list-style-type: none"> Environmental risks; Risk to human health; How to deal with uncertainty; Separation of GM-free/GM food products; (lack of) labelling, especially in relation to processed food; Industry-driven development (as opposed to public sector-driven); Imposition of European Union regulation on Denmark; Ethical concerns.
2 – The PTA	
When did it happen?	<p>In spring 1999, a consensus conference was held on the issue of GM food. It had originally been planned for 1998, but was moved back for organisational reasons. A couple of interviewees (including the organisers) thought the conference might have been more timely, had it been held earlier. Others, however, thought that it was timely, as public debate about GM food had not really abated in 1999.</p>
Who organised it?	<p>The conference was organised, as usual, by the Danish Board of Technology, the national technology assessment organisation set up by the Danish Parliament. A planning group, existing of external experts, supported the Board in its task.</p>
What was the core question?	<p>According to the Board of Technology, “the backdrop for the conference is the population’s continued scepticism about genetically modified foods. Why does this scepticism persevere and how are we to relate to GM foods now that they are gaining ground on the shelves of Danish supermarkets?”</p>
How was it organised?	<p>The conference followed the Board of Technology’s well-established methodological procedure. This includes, at its centre, a panel of lay people/citizens who are charged with assessing the issue at stake. They do so by first informing themselves about the issue, then formulating questions for debate at the public, four-day conference, and inviting different kinds of experts to discuss their questions. Following this information provision and exchange of views, the lay panel evaluate the issue amongst themselves, as a result of which they produce a written report which is</p>

	<p>published and sent to Members of Parliament and anyone interested in the panel's views and recommendations.</p> <p>The citizen panel came up with ten core questions, ranging from queries about environmental risk, safeguarding consumer choice, to ethical considerations. They invited 13 experts, including several scientists, NGO representatives, an ethicist, an industry representative and a policy expert. The media and members of the general public were invited to follow the proceedings. The lay panel report provides answers to their questions as well as specific recommendations, which were highlighted in an overall summary.</p>
3 – Interactions PTA/public debate	
<p>Is PTA as an answer to the public debate? Who says yes and why? Who says no and why?</p>	<p>Clearly, this consensus conference was a reaction to the increased public debate about GM food. (N.B. The role of some of the other consensus conferences has been to stimulate, rather than to react to, public debate.)</p> <p>The conference reflected public debate in that the 'two sides' – those in favour of GM food and relatively lax regulation, and those in favour of a ban/moratorium on GM food, or at least stringent regulation – were present. However, the conference centred upon the citizen panel's investigation and assessment. The panel recommended, amongst other things, strict regulation of GM food by public authorities, proper consumer choice and an ethical evaluation as part of the authorisation process.</p>
<p>Did PTA amplify the public debate? Who says yes and why? Who says no and why?</p>	<p>Not substantially.</p> <p>The conference was well attended. One interviewee (a NGO representative) said that 'everyone involved was there'. Politicians were interested in the lay panel's report. Most interviewees regarded the conference as useful. What the analysis also shows is that for the majority of participants, the conference acted more as a 'space for self-reflexion' than an amplifier of public debate. It allowed those involved in the political and public debate to get a more concrete, 'materialised' understanding of the phenomenon of 'public opinion'.</p>
<p>Did PTA contribute to modify the content of the public debate? Who says yes and why? Who says no and why?</p>	<p>This is difficult to assess, but on the basis of the available evidence the answer is 'no'. However, several actors (on the expert panel and in the audience) said that the lay panel report helped them gain a better understanding of lay people's treatment of the issue, as a result of which they refined their arguments/strategies.</p>

3 - 2.5. GMO ID CARD – Portugal

1 – the public debate	
<p>What are the issues at stake?</p>	<p><u>Scientific</u> controversies between scientists about the risks and benefits of GMOs on environment and human health. Scientists are divided which may contribute to puzzle the public opinion</p> <p><u>Political</u> lack of a clear strategy about the policy to follow regarding the import of genetic food.</p> <p><u>Social</u> role of NGOs taking the lead of opposing to GMO imports. Episodic references on the media hardly succeeds in mobilising the public attention.</p>
<p>Did they change in the last 5 years?</p>	<p>In 1997 Greenpeace promoted a demonstration in Lisbon harbour against the disembark of GMO's. It was this event that most contributed to sensitive the public opinion turning the GMO in an issue.</p> <p>In the late 1998 the Government created an Interministerial group of experts to advice about GMO issue.</p> <p>In February 1999 two varieties of transgenic corns were authorised.</p> <p>In November 1999 a coalition of Portuguese NGO's pleaded for a moratorium, and in</p>

	December the sales authorisation was suspended. In January 2000 the GMO issue was debated in the Parliament.
Who are the main Actors of the debate?	The government, namely at the level of the Ministry of Agriculture, whose policy zigzagged between extremes. In February 99 two varieties of transgenic corns were authorised only to be suspended in December of the same year. Economic agents, such as Monsanto, Novartis and Agrevo, who pleaded about the benefits of GMO's and minimized the risks. QUERCUS who succeeded in mobilizing a number of other NGO's in claiming for a moratorium. The scientists acting in individual terms rather than reflecting a consensual position of their community.
What are the main topics of the controversies?	Uncertainty about eventual risks and benefits of GMO's for health and environment. Controversy about the feasibility of labelling and desirable criteria levels to apply. Lack of information and very low scientific literacy by the general public. Lack of clear rules and strategies underlying the process of decisions making.
2 – The PTA	
When did it happen?	No PTA in the Portuguese context
Who organised it?	
What was the core question?	
How was it organised?	
3 – Interactions PTA/public debate	
Is PTA as an answer to the public debate? Who says yes and why? Who says no and why?	
Did PTA amplify the public debate? Who says yes and why? Who says no and why?	
Did PTA contribute to modify the content of the public debate? Who says yes and why? Who says no and why?	

3 - 3. GENETIC TESTING CASE STUDIES

3 - 3.1. Genetic testing in Denmark

1 – the public debate	
What are the issues at stake?	There have been different, sometimes overlapping, arenas of public debate about genetic testing. Generally, however, these arenas have been rather limited in terms of their public outreach and have been characterised by the participation of a relatively small number of actors. Genetic testing has been debated in relation to a variety of areas of application: <ul style="list-style-type: none"> • Reproductive medicine (IVF treatment, ‘designer babies’);

	<ul style="list-style-type: none"> • Predictive medicine (ante- and post natal testing); • Curative medicine (such as in connection with gene therapy); • Abortion (late abortions on ground of genetic disorder); • Employment; • Insurance; • Law and order (DNA-fingerprinting in forensic science, genetic screening). <p>Across these areas, questions of ethics, human rights and societal values have been an important part of the discussion.</p>
<p>Did they change in the last 5 years?</p>	<p>Generally, there has not been as much of a change in relation to genetic testing as there has been in relation to other areas of gene technology (especially food biotechnology) for the following three related reasons:</p> <ul style="list-style-type: none"> • Within the existing arenas of public debate, there has been an ongoing discussion of these issues for quite some time (for example, genetic testing in reproductive medicine has been debated since the early 1980s; genetic testing in relation to employment and insurance were addressed by Parliament and government in the early to mid 1990s); • In many cases genetic testing has not (yet) manifested itself quite as directly and forcefully in everyday life and at societal level (it is usually discussed within specific arenas, and often still rather hypothetically); • The debates within the more ‘specialised’ arenas have not spilled over into a more substantive general public debate. <p>At more specific levels, there have been certain changes which are partly due to new developments, and partly due to policy-making. For example, in 1997 a guideline was published listing the genetic disorders that justify abortions beyond the 20th week. As a result, over 100 permissions for late abortions were granted in a two-year period, leading one newspaper article to declare (February 2000): “genetic test gives right to abortion”. Another example is DNA-fingerprinting, which moved centre-stage in law and order in recent years when a murder conviction was reached on the sole basis of DNA profiling. And in the area of employment and insurance, legislation prohibiting the use of genetic tests was passed in the Danish Parliament in 1996.</p>
<p>Who are the main Actors of the debate?</p>	<p>The actor network is largely ‘personalised’ in the sense that it is mainly individual, concerned actors who drive the debate. This is partly because of the relatively small number of directly concerned people – such as in the case of specific patient organisations or groups representing handicapped people – and partly because of the strong ethical-moral dimension of genetic testing that engage people at a personal level. Within certain sectors, for example the medical sector, there are often several actors representing different points of views. Only the pharmaceutical industry was referred to by several interviewees as a major actor more or less speaking with one voice.</p> <p>A strong institutional voice is the Danish Parliament which over the years has taken quite an active role in regulating genetic testing and influencing related public debate. The Ethics Council and the Board of Technology have been important players in the debate.</p> <p>The actors include:</p> <ul style="list-style-type: none"> • Geneticists (researchers and clinicians); • Ethicists, philosophers (university-based); • Social commentators • Patients organisations (such as cystic fibrosis, chorea huntingdon); • Organisations representing handicapped people; • Pro-life/pro-choice groups; • Pharmaceutical industry (such as NovoNordisk); • Medical profession (midwives, GPs, laboratory technicians); • Scientific and ethical committees (7); • Danish Ethics Council; • Danish Board of Technology;

	<ul style="list-style-type: none"> • Parliament.
What are the main topics of the controversies?	<p>At the centre of debate has not so much been genetic testing <i>per se</i>, but the purpose and repercussions of using this technique. This includes both questions of fundamental nature – such as what this new technology means for the understanding of mankind, disease and being ‘normal’ – and questions of practical nature – such as what effect genetic testing will have in the areas of insurance and privacy.</p> <p>The specific topics vary from area to area. Pre-natal diagnosis poses different questions to post-natal genetic testing. And genetic testing of individuals (for medical purposes) poses different questions to genetic screening of (sections of) the population. Then there are also overlaps with other more recently developed techniques, such as gene therapy and xenotransplantation.</p> <p>As mentioned above, ethical questions have played an important role in the debate about genetic testing, both within the specialist arenas and the wider public.</p>
2 – The formal dialogue arrangements (among them PTA)	
When did it happen?	<p>It should be noted that this case study does not analyse one particular pTA initiative, but tries to compare different approaches to what may be called ‘participatory technology assessment’, with special emphasis on the treatment of ethical questions.</p> <p>The following ‘pTA’ initiatives (directly or indirectly) dealt with genetic testing:</p> <ol style="list-style-type: none"> 1) The consensus conferences on human genome mapping (1989) and gene therapy (1995); 2) The Ethics Council’s public debate on foetal diagnosis (1997) and school debate about cloning (1998); 3) The BioTik expert group (1997-1999).
Who organised it?	<ol style="list-style-type: none"> 1) The consensus conferences were held by the Danish Board of Technology, the national technology assessment organisation. The Board of Technology has become widely known as instigator of innovative technology assessment schemes, including scenario workshops, voting conferences and future search conferences. 2) The Danish Ethics Council, a sister organisation of the Board of Technology set up in the late 1980s, focuses on ethical issues relating to scientific-medical research and technological applications in the human domain. One of its core objectives (besides advising government/Parliament) is to stimulate public debate, which it tries to accomplish mainly in the form of public hearings/conferences and individual contributions by Council members. It has not been as methodologically innovative as the Board of Technology. 3) The BioTik expert group was set up as a non-statutory, <i>ad hoc</i> advisory body by the Ministry of Trade and Industry with the aim of providing ethical guidelines for the assessment of gene technology. Apart from giving advice to government, the idea behind the BioTik initiative was to stimulate a broad public debate in Denmark (and beyond) about the ethics of gene technology.
What was the core question?	<ol style="list-style-type: none"> 1) <u>Consensus conference on human genome mapping</u> (1989): the core question was “how will we use the increased knowledge about human genes?”. The reason for holding the conference were the international efforts to map the human genome (HUGO) and the related discussion within the European Commission as to whether the European Community ought to support this research actively. At the time, this posed the following question (according to the Board of Technology): “how will this information be applied, for example in relation to pre-natal diagnosis, screening of the adult population, crime-solving and on the labour market?” The citizens’ panel made a number of specific recommendations, such as a ban on genetic testing for employment and insurance purposes. It also called on a wider public debate, including a discussion of the ethics underlying human genetics research and development. <p><u>Consensus conference on gene therapy</u> (1995): genetic testing was discussed in relation to the key issue of gene therapy. The citizens’ panel emphasised, in one of the eight key questions, the importance of providing sufficient information</p>

	<p>about the results of genetic testing to patients. It also stressed the importance of non-discrimination on the ground of genetic profiling.</p> <p>2) <u>Ethics Council hearings/public debates</u>: there have been separate conferences/hearings on, amongst other things, pre-natal genetic testing (1997) and ethical problems related to genetic screening (pending). The latter was requested by the Ministry of Health.</p> <p>3) <u>BioTik expert group</u>: the aim was to “prepare a discussion paper intended as a foundation for a comprehensive debate on biotechnology and genetic engineering”. The group was asked to come up with ethical criteria/guidelines for the evaluation of genetic engineering. The group gave the following rationale: “the idea behind the formulation of ethical guidelines can thus be said to be twofold – on one hand to identify reasonable and ethically acceptable uses, and on the other hand to set limits for the use of genetic engineering.</p>
How was it organised?	<p>1) The consensus conferences each had at its centre a panel of lay people who were in charge of setting the agenda (by drafting the conference questions and selecting experts) and evaluating the proceedings (by leading the discussion with the experts, assessing the received information amongst themselves and subsequently publishing a report at the end of the four-day public event).</p> <p>2) The Ethics Council has so far used four forms of stimulating public debate: (i) publication of its reports; press releases; (ii) public hearings/conferences; (iii) public appearances by individual Council members; (iv) an initiative targeted at schools, encouraging school classes to write essays, the best of which were published in a broad-sheet newspaper.</p> <p>3) The BioTik initiative was set up as an expert committee, including scientists, a sociologist, philosophers, a health care specialist and a technology assessment expert were appointed in a non-institutional, individual capacity. The committee held several hearings, to which the ‘two sides’ were invited to give evidence. No wider public event/hearing was organised.</p>
3 – Interactions formal dialogue arrangement /public debate	
<p>Is pTA as an answer to the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>The answer is partly ‘yes’ and partly ‘no’. The pTA activities described in this case study represent a reaction to public debate in a wider, indirect sense: both the Council of Ethics and the Board of Technology were set up in the late 1980s in response to growing public and political debate about gene technology; their activities have aimed at taking up issues treated in public debate. And the BioTik expert group was set up in the aftermath of the 1996- public controversy about GMO food. However, neither of the pTA activities represent direct, immediate reactions to public debate. In the case of the Board of Technology’s two consensus conference and the Ethics Council’s hearings, these acted rather as a means of translating the debate taking place within specialised arenas (the scientific community, policy-makers etc) into a wider public discourse. In other words, they served to stimulate public debate (in addition to advising politicians). Likewise, the BioTik report was intended by the Ministry of Trade and Industry as an input into ‘comprehensive public debate’.</p>
<p>Did pTA amplify the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>The level of amplification of individual pTAs is difficult to determine, as public debate is typically the result of diverse inputs and complex dynamics.</p> <p>The 1989 consensus conference inspired a parliamentary motion by several MPs to introduce new legislation regulating genetic testing in employment and insurance (the new enactment was eventually passed in Parliament in 1996). The extent to which the conference influenced public debate is unclear. The 1995 consensus conference resulted in average media coverage (around 100 press articles). A pre- and post-conference public opinion survey suggested that respondents had read/heard more about gene therapy after the conference. How much this was due to the effect of the consensus conference and related media reporting could not be determined. The amplification effect of the Ethics Council’s public hearing activities is difficult to determine, too. No significant direct/visible impact on public debate was reported. No information is available about the possible influence of the BioTik report on public debate.</p>

<p>Did PTA contribute to modify the content of the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>This is difficult to determine (see above). What can be said is that the aforementioned pTA activities influenced the debate within the policy-and decision-making community. The BioTik report, for example, was considered by government, as a result of which government made a declaration to Parliament. The 1989 consensus conference was discussed in related Parliamentary proceedings. Insofar as public policy-making and related political debate influence public debate, the aforementioned pTA activities may have brought about certain changes in public debate. However, this would only be as part of a many factors influencing the course of public debate.</p>
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3 - 3.2. Genetic testing in France

1 – the public debate	
<p>What are the issues at stake?</p>	<p>1. The main issue with regards to predictive genetics research is insurance problems and risk of discrimination for the employment, which become concrete when predictive tests can determine the future health status of someone.</p> <ul style="list-style-type: none"> - Insurers can refuse to insure someone, who knows he will develop a non curable disease. Patients 's associations on the contrary fear the risk of non insurability. - The employers do not use the genetic testing for the selection of candidates to a job but want to keep open the application for the future. The workers trade unions and some physicians in the "médecine du travail"⁽¹⁾ fear the social discrimination. <p>In 1994 a law about bioethics was voted, which bans the use of genetic testing for social purposes and authorises its use for medical and scientific purposes. This law should have been reviewed in 1999, but the review has some delays. Despite of the legal banning, the issue of the future practices in social fields concerning genetic testing is at stake.</p> <p>2. A more general issue, which is linked to the controversy about researches on embryos, is the risk of eugenics. This is a more ethical issue, which worries some religious representatives, some professionals in genetics and medical areas and the general public. This issue at stake has become much more important and stigmatized since the controversy about the researches on human embryos.</p>
<p>Did they change in the last 5 years?</p>	<p>Although genetic tests can affect everyone, there is no large debate going on among the general public. People have a good idea of genetic testing when the technique is used in medical sector as a health tool. 2 short overflowing of the debate happened in the last 5 years, and showed that the large public is very suspicious of the use of genetic testing in social fields.</p> <p>The issues are still the same :</p> <ul style="list-style-type: none"> ◆The insurance firms have renewed in 1999 their moratorium signed firstly in 1994 about the non-use of genetic testing for insurance contracts, but some associations of patients fear the future practices of insurers. In a recent report aimed at preparing the review of bioethics laws, the Council of State said for example that, he found coherent, that a subscriber could not hide the result of a genetic test to the insurers, if he had made it voluntary before the signing of his contract. <p>Moreover a short overflowing of the debate about genetic testing for employment selection happened in 1997 :</p> <ul style="list-style-type: none"> ◆The INRS, the National Institute for Researches about safety at work, was reproached by workers' trade unions and "médecins du travail"² for its research programme in predictive medicine at work. This controversy was ended by a view of the CCNE, the French National Committee of Ethic, in favour of the INRS. But at present an association, the GEL, is mobilising and is enrolling physicians of industrial medicine in order to persuade the government to reinforce the legislative purview concerning the banning of genetics discrimination in social fields.

² "Médecins du travail" : doctors, who carry out the annual examination, required by law, of a company's employees

<p>Who are the main Actors of the debate?</p>	<p>The main actors in the debate are the experts/adviser committees firstly, the insurance firms, the workers' trade unions, the media, the INRS exceptionally and the GEL, which is an association of physicians and genetic researchers fighting against the eugenics by genetics selection. :</p> <ul style="list-style-type: none"> ◆The experts' committees are principally: the National Consultative Committee for Ethics (CCNE), the OPECST (Parliamentary Office for Scientific and Technological choices), the Council of State, which give advices to the Parliament and government as regards to the review of the bioethics laws. The main change during these last 5 years is probably the place of the CCNE in the debate. Before 1994 the CCNE was in charge of promoting public debate, in particular about ethic, societal problems linked to the medical and scientific progresses. But since 1994 the CCNE' mission was more focused on advising government as regards ethic problems and risks of science and public policy. It is considered in France as the wise men committee, which has a very strong moral authority on debates like this one about genetic testing. ◆The patients' associations have a weak visibility on the public scene because on the one hand they support the development of genetic testing in the medical sector but on the other hand they fear the social consequences of a large use in employment and insurance fields. ◆Insurance companies argue, that genetic testing is not interesting now because of the lack of relevance in the technique and they have signed the moratorium for 5 another years, but they fear the process of self selection and would be favourable to a flexibility of the law implementation. They ask for a concrete debate, where geneticists, insurers and jurists could think together about this topic and find acceptable solutions. ◆The State did not stimulate the self-regulation among actors and has reinforced a legislative framing in order to limit the use of genetic testing. It has authorised the genetic testing in medical and research fields but has banned it for social purposes. ◆The medical sector (hospitals and clinical genetic centres) does not take part to the debate. They are waiting for the implementation of all the decrees. Only the medical professionals, who work in "médecine du travail" try to mobilise against the risk of social discrimination. The National Council of Doctors and the National Academy of Medicine take part to the debate in specialised areas in collaboration with the government and have made reports about the evaluation of the bioethics laws. ◆The media are passive on the public scene. They report to the public on the different stakes of genetic testing : <p>They draw the attention on the delay of the law, on the progress of the technology, on the risk of eugenics and social discrimination but wait for events.</p>
<p>What are the main topics of the controversies?</p>	<p>The main topics of the controversies are the risk of social discrimination in insurance and employment areas and the relevance of the genetic testing. The subject hardly reaches the general public. The risk of eugenics and the pre-implantatory diagnosis are subjected to controversy too but are linked to a larger debate, which is the status of human embryos.</p>
<p>2 – The formal dialogue arrangements (among them PTA)</p>	
	<ul style="list-style-type: none"> ◆There was no national or large Pta activity organised around this topic. But we attended in January a local workshop organised by an association of formation for practitioners, whose objective was to make 20 practitioners aware of the issues of genetic testing, which were progressively touching them in their daily professional activities. The view of the organisers was to make the physicians define a stand about this problem and make them participate in a debate. One professor of ethic and a geneticist were invited in order to help these people in their reflection. The day was divided in two parts. During the morning 4 limited workshops were organised on different topics and during the afternoon the organisers focused on a general brainstorming and conclusions. But the participants have not taken a stand and admitted, that they considered genetic testing only as a supplementary health tool, that they had to use and they were waiting for top instructions about the good use of this tool. This attempt of local Pta was perceived as a failing attempt by the organiser of this event. It had no impacts on public debate. ◆There are at present in France more and more demands of discussions and debates

	<p>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.</p> <p>◆The interviewed people feared the risk of political manipulation of the public by the politicians, when was asked them to give their view about the opportunity of a PtA about genetic testing. The problem of ethical and political complexity of the topic was often underlined but a majority of people admitted, that citizens could be able to discuss technical problems and choices of society. But it seems that in the view of these people a PTA would be too premature, because the topic is not mature, the public is not mature too, as if a debate with citizens would be possible only by emotion and by following a trigger.</p>
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3 - 3.3. Genetic Testing in Germany

1 – the public debate	
What are the issues at stake?	<p>1. Genetic testing methods give the possibility to test embryos for genetic defects. If the embryo is affected by inherited and congenital disorders a woman can have an abortion (negative eugenics). In future also positive eugenics will be possible. It means to select embryos according to characteristics wished-for by the parents.</p> <p>2. Several of associations of patients concerned with inherited disorders reject vehement genetic testing. The patients argue that if there would have been PID or PND and abortion some decades ago than they would not exist. That is why they feel restricted in their own right of living although they feel it is a life worth living.</p> <p>3. There are also important non-medical aspects like the use of genetic information through insurers and employers. On the one hand there is the hope to improve the provision in industrial medicine. Also insurers can develop a better risk assessment for policy holders. But on the other hand there is the danger of selection and discrimination of employees or policy holders or with specific genetic characteristics.</p>
Did they change in the last 5 years?	Genetic testing became a highly controversial issue in the German public debate in the last 5 years. The debate culminated in 2000. The debates became necessary because of the various new possibilities in diagnosis and therapy based on genetic engineering.
Who are the main Actors of the debate?	Different actors from politics, science, medicine, patients' and women's associations were involved in the debates. Key actors were the German government, the federal states, human geneticists, several patients' associations, the medical practice, the pharmaceutical industry and the press. Communication processes have begun between representatives of human genetics, patients' associations or the pharmaceutical industry. Also, the German government tries to solve the problems in the field of genetic testing in a co-operative approach. However, there are often clear boundaries between people or groups who support genetic testing and those who refuse this new method. Astonishingly, the German insurance agencies have kept very much in the background of the debate until now.
What are the main topics of the controversies?	The following topics related to genetic testing were hotly debated by the German public: the Bioethical Convention of the Council of Europe, the German Enquete Commission Bioethics, the controversial statements of the philosophers Peter Singer and Peter Sloterdijk and the ethicist Dieter Birnbacher, the very late abortion, the preimplantation diagnosis and the decoding of the human genome. These debates mainly focus on the ethical problems, the conditions and risks that have arisen in society because of the use of genetic testing, not on the technology production or genetic research itself. Another important central thread in all debates is the National Socialist history of Germany when hundreds of thousands of people with inherited and congenital disorders were forcibly sterilised or killed. This seems to be the reason for the very emotional and controversial public debate about genetic testing in Germany.

2 – The formal dialogue arrangements (among them PTA)	
When did it happen?	<p>Three discourse meetings took place in Bonn between 1991 and 1998.</p> <p>The first discourse took place between the 29th of November and the 1st of December 1991 in Bonn and had as a headline "Discourse between patients' associations and human geneticists – expectations and fears".</p> <p>The second discourse took place between the 12th and the 14th of September in 1993 in Bad Herrenalb and had as a motto "From dialogue to common action – attempt to take stock of common aims".</p> <p>The third discourse took place between the 11th and the 13th of December in 1998 in Bonn.</p>
Who organised it?	The first nation-wide expert discussion in the field of genetic testing in Germany was organised by human geneticists and associations of patients concerned with inherited and congenital disorders in 1991. The head of the Institute of Human Genetics of the University of Bonn Prof. Klaus Zerres tried to get a large selection of patients' associations and human geneticists together at a round table.
What was the core question?	<p>The lectures of the first discourse meeting covered the following three fields: Description of the daily work in human genetic institutes and human genetic advice centres, description of different inherited and congenital disorders and sociopolitical risks of new biomedical technologies, e.g. the use of prenatal diagnostics for selection of worthy and unworthy life.</p> <p>The main subjects of the second discourse meeting were: Diagnostics of heterozygotes, predictive genetic testing and prenatal diagnostic as screening.</p> <p>The lectures of the third discourse meeting covered the following fields: Actual developments in genetic testing, experts, lay people, politics – rules for human genetic praxis, take out a patent for genes – chances for handicapped people? and the orphan drug legislation.</p>
How was it organised?	It was a kind of assessment of a newly developed technology through experts who worked in hereditary research, genetic testing, diagnostics and counselling. The activities were orientated on the model of the Netherlands, where there is a powerful umbrella organisation of associations of patients' concerned with inherited and congenital disorders and human geneticists which have a large influence on politics.
3 – Interactions formal dialogue arrangement/public debate	
<p>Is it as an answer to the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>No. Starting point was not an overheated public debate but a PhD thesis about the attitudes of patients' associations and genetic support groups to human genetics at the Institute of Human Genetics of the University of Bonn. The head of this institute, Prof. Klaus Zerres, got to know the attitudes of patients' associations and genetic support groups think about human genetics. The results of the PhD thesis demonstrate that there is firstly a very high uncertainty among patients' associations. Second, there is a very great difference in the attitude of the individual patients' associations toward human geneticists. And third, there was no networking between patients' associations. Every association pursued only its own aims.</p>
<p>Did it amplify the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>The influence from participatory technology assessment on public debate is also very low. One of the most important indirect impact is that patients' association and human geneticists get into conversation. So at both sides a lot of problems and prejudices could be reduced. But there were also indirect impacts on political decision making. For example some of the discourse participants are members of the "Ethical Advisory Board" of the Ministry of Health. And the discourses were important events for network building between the different actors in the field of genetic testing.</p>
<p>Did it contribute to modify the content of the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>No. The three discourse meeting did not influence the contents of the public debate.</p>

3 - 3.4. Genetic testing in the Netherlands

1 – the public debate	
What are the issues at stake?	<p>The main issue with regard to predictive genetic research is insurance problems which arise when predictions about someone's future health status can be made. Insurance companies cannot insure a person when he knows he is going to get a certain (non treatable) disease. Further, they fear self-selection. Patients' organisations on the other hand, say that everyone has a right to be insured and they fear a growing number of non-insurables with the growing number of predictions coming up.</p> <p>An important issue among the general public, is the establishment of an ethical minimum. This is a more philosophical issue</p> <p>Further, handicapped people emphasis their future position in society and their right to live. They feel pushed aside by the promises scientists make consensus conference about preventing all handicaps.</p>
Did they change in the last 5 years?	<p>1 .No, the issue is still the same. Patient's organisations still fear the possibility of non-insurability. However, nowadays there is more collaboration between patient' organisations and insurance companies (and other actors, such as industry as well). In the last 5 years a network has been established in which the actors together are trying to develop policy with regard to genetic tests and the way they should be embedded in society.</p> <p>In 1995, the Rathenau Institute (Dutch institute for Technology Assessment) changed the subject of their activities with regard to predictive testing, from Predictive Genetic Research to Predictive Medicine. By changing the name, they tried to broaden the subject.</p> <p>Although genetic tests can affect everyone, there is no discussion going on among the general public. As far as people know about tests, they are seen as good and useful techniques for preventing grief. Articles about genetic issues are only published as scientific news.</p>
Who are the main Actors of the debate?	<p>The main actors in the debate are patients' organisations, insurance companies, industry and government.</p> <p>VSOP, the largest patients' organisation of the Netherlands. They see predictive genetic research as a good technique but only when it is used in a correct way. The results of a test should not be used to exclude people from social provisions.</p> <p>Insurance Companies. They are constantly making clear that they cannot insure everyone. Further they fear self-selection</p> <p>Government. The Dutch Government stimulates self regulation among the actors involved. Only when necessary the Government interferes.</p> <p>Industry, since 1997. By joining the network, they try to increase public acceptance on biotechnology.</p> <p>The medical sector (hospitals and Clinical Genetic Centres) do not take part in the debate</p>
What are the main topics of the controversies?	<p>Apart from the insurance problems, there have not been any controversies on genetic tests. The subject has not reached the general public.</p>
2 – The formal dialogue arrangements (among them PTA)	
When did it happen?	<p>The pTA activity of this case study took place in February 1995. Preparations already started in 1994.</p> <p>The conference took place at a time when social organisations (mostly the VSOP and the Council for Handicapped People) were considering the consequences of human genetics, but no public debate was going on.</p> <p>The field of biotechnology was (and still is) moving. It was foreseen that with the HUGO-project lots of information would become available soon which would have</p>

	<p>great impact on peoples lives.</p> <p>Further, the moratorium on hereditary research was about to expire and the solution was yet unknown.</p>
Who organised it?	The conference was organised by the Platform of Science and Ethics (PWE). This Platform was established in 1994 and is an official forum for organising debates on science, technology and ethics. In 1995 the platform became a part of the Rathenau Institute, the Dutch Institute for technology Assessment. The consensus conference was the first activity of the Platform.
What was the core question?	The main question dealt with in the conference, was ‘predictive human genetics, where will it lead us?’. There was not one core question. Several aspect with regard to this question were discussed, such as insurance problems, gene technology and ethics.
How was it organised?	<p>The design of the pTA was that of a consensus conference (CC) as often used in Denmark. The Dutch call it a Public Debate.</p> <p>The pTA was organised according to the standard method of a consensus conference with some additions. The year before the conference five preparatory workshops among experts of several organisations had been organised. During these meetings, several experts met for the first time and from this moment, a network began to develop. These workshops are extra in addition to the regular CC set up.</p> <p>According to the standard CC set up two working weekends were organised for the lay panel. The conference itself lasted three days. The first two days experts answered the questions of the lay panel and the audience. The audience consisted predominantly of interest groups. The last day the lay panel presented the final declaration discussed it and handed it to a member of Parliament.</p>
3 – Interactions formal dialogue arrangement (PTA)/public debate	
<p>Is it an answer to the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	As mentioned before, several developments were going on at the time of the conference such as the expiration of the moratorium, insurance problems and the HUGO-project. So, one can say that the pTA was organised as an answer to these developments. All actors (VSOP, Government and Insurance companies) confirm this hypothesis of timing.
<p>Did it amplify the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>According to all actors, the pTA had hardly any effect on the public debate. The aim was to include general public and thereby amplify the debate, but this did not happen. The general public and media were not reached and therefore no real debate started.</p> <p>However, because of the rather broad preparation phase of the conference, lots of actors met for the first time. The network science and the rest of society that nowadays exists can be seen as a result of the conference (and its preparations).</p>
<p>Did it contribute to modify the content of the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>Before the conference the issue was about insurance problems. During the conference an attempt was made to broaden the subject (primarily in the direction of ethics) by choosing several themes (of which insurance’s was just one of the five themes). However, after the conference it seems that the discussion is narrowed again to insurance problems.</p>

3 - 3.5. Genetic testing in Portugal

1- The public debate	
What are the issues at stake?	<p>Issues like privacy or possible discriminatory uses of genetic information have been mentioned, but are not central to the - limited - public uptake of the debate. Issues are being raised concerning the creation of a forensic database, but debate is still limited. Some legal scholars have have raised issues linked to the right to genetic heritage.</p> <p>The absence of a regulatory framework for genetic testing has not prevented it from being widespread and widely accessible, on a largely self-regulated basis, nor has it</p>

	been the cause of public debate. The same is true for the non-transposal of European directives or lack of ratification of international conventions.
Did they change in the last five years?	Most of the issues defined as in urgent need of debate and regulation in the 1989 parliamentary debate have not been dealt with. Some new issues have been raised by international developments related to cloning, stem-cell research, embryo research and cloning or the human genome draft, usually following media coverage. The recent announcement of the draft of the human genome was at the origin of several initiatives. But debate is generally confined, with some exceptions, to scientific and expert circles. The 1998 debate on the new law on legal abortion brought arguments against the law based on genetic determinism to public forums. It is possible that the announcement of a proposal for the creation of a forensic database containing DNA profiles of convicted individuals will foster some debate on issues of privacy and control of information.
Who are the main actors of the debate	<p>Government and Parliament are mostly silent about issues related to human genetics, After the parliamentary debate in 1989 leading to the creation, the following year, of the national Committee for Ethics in the Life Sciences, Government and Parliament have been silent on issues related to human genetics, apart from occasional, individual positions of members of Government or Parliament.</p> <p>Scientists and physicians have been active in discussing the scientific, ethical, social and legal issues related to human genetics, but the discussion was rarely brought to a wider public. Discussion has been extended to other experts, like social scientists, ethicists (most of them with a medical background) and legal scholars.</p> <p>The National Committee for Ethics in the Life Sciences had a largely reactive role to requests by the Government - in most of the cases not followed by legislative or regulatory initiatives. Its with positions were close to those of the Catholic church, and its influence on scientists was limited, being seen by the latter as too restrictive and too close to religious views.</p> <p>The media had an active role in relaying information on advances and breakthroughs in human genetics, mostly based on articles from Science or Nature, on press releases or accounts of press conferences. Television promoted public debates, with some space for participation of "lay" persons.</p> <p>Insurance companies and biotechnology and pharmaceutical companies have been conspicuously absent from debate.</p> <p>Local government (Aveiro), foundations like the Luso-American Foundation for Development, the British Council and scientific institutes have sponsored or organized public debates, with different degrees of outreach, but, with the exception of the latter, they have not been active in framing the issues</p>
2 - The formal dialogue arrangement (among them pTA)	
	There have been no pTA initiatives. Some space for public participation in decisions concerning the uses of human genetics may be opened by interventions in public health, and will require the convergence of State agencies, researchers, clinicians and local populations. One such experience, involving a program of screening for gastric diseases and identification of differential genetic susceptibility was carried out at the shipyards of Viana do Castelo, in Northern Portugal, but there have been, up to now, no similar initiatives.

3 - 3.6. Genetic testing in United Kingdom

1 – the public debate	
What are the issues at stake?	In human genetics the issues at stake are very different with different technological innovations i.e cloning, zenotransplantation, gene therapy and testing. It does depend on a specific technology, and how that technology is embedded in a sociological context. There is very little actual ‘public debate’ about genetic testing. Individuals have been affected and patient and disability groups represent special interests.

	<p>People have opinions about the NHS but are not close enough to the industry to feel affected by new technological developments.</p> <p>On genetic testing, so far the issues have been:</p> <ol style="list-style-type: none"> Eugenics. Will genetic testing for specific disorders, for which there is no treatment, lead to pressure to selectively abort the unborn child? How will knowledge about future disease, obtained from diagnostic genetic tests, be used by employers and by insurance companies? Could this lead to discrimination? Can the current regulatory framework control commercial interests, for instance in regulating commercially available tests and patenting of specific genetic tests? Will predicted changes in the NHS benefit patients?
Did they change in the last 5 years?	<p>Rapid advances in the Human Genome Project has meant that many new tests are becoming available. Moves from diagnostic testing for single gene disorders to debates about the significance of testing for susceptibility to multi-factoral common disorders has moved the debate from periphery to centre stage in the health service. Many more people will be affected.</p> <p>Changes in the State funded health service – towards integration of more commercial services – will increase the visibility of industry and commercial values. However, the traditional ‘gatekeeping’ relationship between the GP and the patient is still intact.</p> <p>Media coverage of human genetics is becoming more ‘investigative’.</p>
Who are the main Actors of the debate?	<p>National Health Service: which comprises health professionals such as policy makers, doctors in both primary care (GPs) and secondary care, clinical geneticists and nurse counsellors.</p> <p>Universities: medical researchers, ethicists, sociologists and policy analysts.</p> <p>Pharmaceutical companies: medical researchers, service managers</p> <p>Media: media coverage has gradually moved from the specialist science arenas to news reporting.</p> <p>Government: politicians, advisory bodies</p> <p>Interest groups: pro-genetics patient groups, disability groups</p>
What are the main topics of the controversies?	<p>Controversies have so far been confined to the main actors and have not spilled over into the public domain. Controversies have evident in various contexts:-</p> <ol style="list-style-type: none"> Commercial versus private interests competing for ownership of the Human Genome. Reorganisation within the NHS has resulted in some tension due to changing roles and re-classification of diseases. Disability rights groups (BCODP) versus pro-genetics lobby groups (Progress Educational Trust) on the subject of selective abortion and pre-implantation genetic testing.
2 – The foraml dialoguie arrangement (among them PTA)	
When did it happen?	<p>The Welsh Institute for Health and Social Care conducted a Citizens’ Jury between the 8th and 12th November 1997. Prior to that 7 focus groups were held between November 1996 and June 1997 to provide information to a steering group in order to frame the question for the jury to address.</p>
Who organised it?	<p>The jury was organised by the Welsh Institute for Health and Social Care, at the University of Glamorgan Pontypridd. A Steering Committee oversaw the whole process. The committee was selected to represent a broad range of expertise including a geneticist, doctor, health policy experts, a representative of a patient group and an expert in public participation.</p>
What was the core question?	<p>The question for the jury to address was: ‘What conditions should be fulfilled before genetic testing for susceptibility to common diseases becomes widely available on the NHS?’ The organisers make a point that criticism of other citizens’ juries had been that the core question is often imposed from the top. The idea of conducting focus groups to determine the question was to take a ‘bottom up’ approach. They</p>

	argue that the only pre-existing assumption was that it was going to be something to do with health – as opposed to employment or insurance.
How was it organised?	<p>The WIHSC Citizens’ Jury was organised as part of a programme of research, funded by the pharmaceutical company SmithKline Beecham, to examine the impact of human genetics on healthcare in the UK in order to help the NHS make optimal use of the new technology. The idea of a jury was taken from the notion, first initiated in Germany and the US, that this could be used as a means of enhancing public participation and critical appraisal of important public policy issues. The UK model was developed and overseen by the Institute of Public Policy Research.</p> <p>In the interests of transparency, the process was steered by a committee of experts. The question, for the jury to address, was developed out of focus groups.</p>
3 – Interactions formal dialogue arrangement /public debate	
<p>Is it an answer to the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>In this particular instance no. It was an experiment which aimed to promote greater public ‘awareness’ but the process was consensual and therefore not set up to generate a wider debate, either locally or in the media.</p> <p>This question really depends on how pTA is defined (see GMO case study). It is possible that other activities (which could loosely be described as pTA) have had more contribution to public debate.</p>
<p>Did it amplify the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>So far the main issues for debate have been confined to the impact of genetic testing on the health service, although disability groups have tried to influence the discussions to debate wider social issues. The WIHSC Citizen Jury discussed the impact of genetic testing on the health service and therefore made no contribution to an extended public debate.</p>
<p>Did it contribute to modify the content of the public debate?</p> <p>Who says yes and why?</p> <p>Who says no and why?</p>	<p>There is no evidence that the WIHSC Citizens’ Jury influenced wider public debate in any way although the organisers saw this an important opportunity to increase public awareness of the role of the new genetics in healthcare in Wales.</p>